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Contents

Original Papers

Assessment of Wearable Device Adherence for Monitoring Physical Activity in Older Adults: Pilot Cohort Study (e60209)
Huitong Ding, Kristi Ho, Edward Searls, Spencer Low, Zexu Li, Salman Rahman, Sanskruti Madan, Akwaugo Igwe, Zachary Popp, Alexa Burk, Huanmei Wu, Ying Ding, Phillip Hwang, Ileana Anda-Duran, Vijaya Kolachalama, Katherine Gifford, Ludy Shih, Rhoda Au, Honghuang Lin. . . 1 1

Quantifying the Enhancement of Sarcopenic Skeletal Muscle Preservation Through a Hybrid Exercise Program: Randomized Controlled Trial (e58175)
Hongzhi Guo, Jianwei Cao, Shichun He, Meiqi Wei, Deyu Meng, Ichen Yu, Ziyi Wang, Xinyi Chang, Guang Yang, Ziheng Wang. 23

Digital Peer-Supported App Intervention to Promote Physical Activity Among Community-Dwelling Older Adults: Nonrandomized Controlled Trial (e56184)
Kento Tabira, Yuko Oguma, Shota Yoshihara, Megumi Shibuya, Manabu Nakamura, Natsue Doihara, Akihiro Hirata, Tomoki Manabe. 54

Exploring the Feasibility of Digital Voice Assistants for Delivery of a Home-Based Exercise Intervention in Older Adults With Obesity and Type 2 Diabetes Mellitus: Randomized Controlled Trial (e53064)
Costas Glavas, David Scott, Surbhi Sood, Elena George, Robin Daly, Eugene Gvozdenko, Barbora de Courten, Paul Jansons. 69

Development of a 12-Week Unsupervised Online Tai Chi Program for People With Hip and Knee Osteoarthritis: Mixed Methods Study (e55322)
Shiyi Zhu, Kim Bennell, Rana Hinman, Jenny Harrison, Alexander Kimp, Rachel Nelligan. 82

Designing Telemedicine for Older Adults With Multimorbidity: Content Analysis Study (e52031)
Nida Buawangpong, Kanokporn Pinyopornpanish, Suphawita Pliannuom, Nopakoon Nantsupawat, Nutchar Wiwatkunupakarn, Chaisiri Angkurawaranon, Wichuda Jiraporncharoen. 95

Internet-Based Social Activities and Cognitive Functioning 2 Years Later Among Middle-Aged and Older Adults: Prospective Cohort Study (e63907)
Sangha Jeon, Susan Charles. 108

Examining the Effect of Contactless Intergenerational Befriending Intervention on Social Isolation Among Older Adults and Students' Attitude Toward Companionship: Content Analysis (e47908)
Keya Sen, Nida Laheji, Zo Ramamonjiarivelo, Cecil Renick, Randall Osborne, Brad Beauvais. 121

Determinants of Implementing an Information and Communication Technology Tool for Social Interaction Among Older People: Qualitative Content Analysis of Social Services Personnel Perspectives (e43999)
Johanna Fritz, Petra von Heideken Wågert, Annelie Gusdal, Rose-Marie Johansson-Pajala, Caroline Eklund. 132

Perceptions Toward Telemedicine of Health Care Staff in Nursing Homes in Northern Germany: Cross-Sectional Study (e47072)
Pia Traulsen, Lisa Kitschke, Jost Steinhäuser. 146

Factors That Influence Successful Adoption of Real-Time Location Systems for Use in a Dementia Care Setting: Mixed Methods Study (e45978)
Lynn Haslam-Larmer, Alisa Grigorovich, Leia Shum, Andria Bianchi, Kristine Newman, Andrea Iaboni, Josephine McMurray. 155

Using the TrueLoo Smart Device to Record Toileting Sessions in Older Adults: Retrospective Validation and Acceptance Study (e50856)
Jordan Glenn, Parmoon Sarmadi, Paul Cristman, Gabrielle Kim, Ting-Hsuan Lin, Vikram Kashyap. 169

Efficacy of COMPAs, an App Designed to Support Communication Between Persons Living With Dementia in Long-Term Care Settings and Their Caregivers: Mixed Methods Implementation Study (e47565)
Ana Ansaldo, Michèle Masson-Trottier, Barbara Delacourt, Jade Dubuc, Catherine Dubé. 180

Factors Influencing Drug Prescribing for Patients With Hospitalization History in Circulatory Disease–Patient Severity, Composite Adherence, and Physician-Patient Relationship: Retrospective Cohort Study (e59234)
Tomoyuki Takura, Hiroyoshi Yokoi, Asao Honda. 203

Medication Self-Management for Home Care Users Receiving Multidose Drug Dispensing: Qualitative Interview Study (e57651)
Anette Josendal, Trine Bergmo. 221

Functional Monitoring of Patients With Knee Osteoarthritis Based on Multidimensional Wearable Plantar Pressure Features: Cross-Sectional Study (e58261)
Junan Xie, Shilin Li, Zhen Song, Lin Shu, Qing Zeng, Guozhi Huang, Yihuan Lin. 230

Development and Usability of an Advance Care Planning Website (My Voice) to Empower Patients With Heart Failure and Their Caregivers: Mixed Methods Study (e60117)
Chetna Malhotra, Alethea Yee, Chandrika Ramakrishnan, Sanam Kaurani, Ivy Chua, Joshua Lakin, David Sim, Iswaree Balakrishnan, Vera Ling, Huang Weiliang, Lee Ling, Kathryn Pollak. 249

Determinants of Successful Implementation of Assistive Technologies for Dementia: Exploratory Survey (e53640)
Henriëtte Van der Roest, Hannah Christie, Manuel Franco-Martin, Rose-Marie Dröes, Marjolein de Vugt, Franka Meiland. 266

How Time, Living Situation, and Stress Related to Technology Influence User Acceptance and Usability of a Socialization Service for Older Adults and Their Formal and Informal Caregivers: Six-Month Pilot Study (e54736)
Jasmine Pani, Letizia Lorusso, Lara Toccafondi, Grazia D'Onofrio, Filomena Ciccone, Sergio Russo, Francesco Giuliani, Daniele Sancarlo, Novella Calamida, Gianna Vignani, Tarmo Pihl, Erika Rovini, Filippo Cavallo, Laura Fiorini. 279

Digital Storytelling Intervention for Enhancing the Social Participation of People With Mild Cognitive Impairment: Co-Design and Usability Study (e54138)
Di Zhu, Abdullah Al Mahmud, Wei Liu. 329

Experiences of Older Adults, Physiotherapists, and Aged Care Staff in the TOP UP Telephysiotherapy Program: Interview Study of the TOP UP Interventions (e53010)
Rik Dawson, Heidi Gilchrist, Marina Pinheiro, Karn Nelson, Nina Bowes, Cathie Sherrington, Abby Haynes. 349

Acceptance of a Digital Assistant (Anne4Care) for Older Adult Immigrants Living With Dementia: Qualitative Descriptive Study (e50219)

Marloes Bults, Catharina van Leersum, Theodorus Olthuis, Egbert Siebrand, Zohrah Malik, Lili Liu, Antonio Miguel-Cruz, Jan Jukema, Marjolein den Ouden. 365

Technology Usability for People Living With Dementia: Concept Analysis (e51987)

Shao-Yun Chien, Oleg Zaslavsky, Clara Berridge. 376

A Voice-Activated Device Exercise and Social Engagement Program for Older Adult–Care Partner Dyads: Pilot Clinical Trial and Focus Group Study Evaluating the Feasibility, Use, and Estimated Functional Impact of EngAGE (e56502)

Megan Huisingh-Scheetz, Roscoe Nicholson III, Saira Shervani, Chelsea Smith, Margaret Danilovich, Laura Finch, Yadira Montoya, Louise Hawkley. 392

Decoding the Influence of eHealth on Autonomy, Competence, and Relatedness in Older Adults: Qualitative Analysis of Self-Determination Through the Motivational Technology Model (e56923)

Lynne Cotter, Dhavan Shah, Kaitlyn Brown, Marie-Louise Mares, Gina Landucci, Sydney Saunders, Darcie Johnston, Klaren Pe-Romashko, David Gustafson, Adam Maus, Kasey Thompson, David Gustafson. 405

Exploring How Older Adults Experience semAPP, a 360° Media–Based Tool for Memory Assessment: Qualitative Study (e56796)

Francesca Bruni, Valentina Mancuso, Jonathan Panigada, Marco Stramba-Badiale, Pietro Cipresso, Elisa Pedroli. 422

The Prevalence of Missing Incidents and Their Antecedents Among Older Adult MedicAlert Subscribers: Retrospective Descriptive Study (e58205)

Antonio Miguel-Cruz, Hector Perez, Yoojin Choi, Emily Rutledge, Christine Daum, Lili Liu. 458

Toward Safe and Confident Silver Drivers: Interview Study Investigating Older Adults' Driving Practices (e57402)

Sunyoung Kim, Phaneendra Sivangula. 474

Development of a Dementia Case Management Information System App: Mixed Methods Study (e56549)

Huei-Ling Huang, Yi-Ping Chao, Chun-Yu Kuo, Ya-Li Sung, Yea-Ing Shyu, Wen-Chuin Hsu. 487

Social Robots and Sensors for Enhanced Aging at Home: Mixed Methods Study With a Focus on Mobility and Socioeconomic Factors (e63092)

Roberto Vagnetti, Nicola Camp, Matthew Story, Khaoula Ait-Belaid, Suvobrata Mitra, Sally Fowler Davis, Helen Meese, Massimiliano Zecca, Alessandro Di Nuovo, Daniele Magistro. 501

Improving How Caregivers of People Living With Dementia Are Identified in the Electronic Health Record: Qualitative Study and Exploratory Chart Review (e59584)

Ariel Green, Cynthia Boyd, Rosalphie Rosado, Andrea Daddato, Kathy Gleason, Tobie Taylor McPhail, Marcela Blinka, Nancy Schoenborn, Jennifer Wolff, Elizabeth Bayliss, Rebecca Boxer. 561

An Evidence-Based IT Program With Chatbot to Support Caregiving and Clinical Care for People With Dementia: The CareHeroes Development and Usability Pilot (e57308)

Nicole Ruggiano, Ellen Brown, Peter Clarke, Vagelis Hristidis, Lisa Roberts, Carmen Framil Suarez, Sai Allala, Shannon Hurley, Chrystine Kopcsik, Jane Daquin, Hamilton Chevez, Raymond Chang-Lau, Marc Agronin, David Geldmacher. 571

Internet-Based Supportive Interventions for Family Caregivers of People With Dementia: Randomized Controlled Trial (e50847)

Yanhong Xie, Shanshan Shen, Caixia Liu, Hong Hong, Huilan Guan, Jingmei Zhang, Wanqi Yu. 584

mHealth Apps for Dementia Caregivers: Systematic Examination of Mobile Apps (e58517)

Ning Zou, Bo Xie, Daqing He, Robin Hilsabeck, Alyssa Aguirre. 596

Refining Cultural Adaptations of a Behavioral Intervention for Latino Caregivers of People Living With Dementia: Qualitative Interview Study in Washington State (e53671)

Celeste Garcia, Miriana Duran, Magaly Ramirez. 608

Expectation, Attitude, and Barriers to Receiving Telehomecare Among Caregivers of Homebound or Bedridden Older Adults: Qualitative Study (e48132)

Pansiree Onseng, Wichuda Jiraporncharoen, Sasiwimon Moonkayaow, Pimchai Veerasirikul, Nutchar Wiwatkunupakarn, Chaisiri Angkurawaranon, Kanokporn Pinyopornpanish. 621

A Web-Based Intervention Based on Acceptance and Commitment Therapy for Family Caregivers of People With Dementia: Mixed Methods Feasibility Study (e53489)

Golnaz. Atefi, Rosalia van Knippenberg, Sara Bartels, Andrés Losada-Baltar, María Márquez-González, Frans Verhey, Marjolein de Vugt. . .
6 3 2

The Olera.care Digital Caregiving Assistance Platform for Dementia Caregivers: Preliminary Evaluation Study (e55132)

Qiping Fan, Minh-Nguyet Hoang, Logan DuBose, Marcia Ory, Jeswin Vennatt, Diana Salha, Shinduk Lee, Tokunbo Falohun. 651

Digital Adoption by an Organization Supporting Informal Caregivers During COVID-19 Pandemic Showing Impact on Service Use, Organizational Performance, and Carers' Well-Being: Retrospective Population-Based Database Study With Embedded User Survey (e46414)

Ala Szczepura, Amir Khan, Deidre Wild, Sara Nelson, Sonja Woodhouse, Mark Collinson. 685

Sentiment Dynamics Among Informal Caregivers in Web-Based Alzheimer Communities: Systematic Analysis of Emotional Support and Interaction Patterns (e60050)

Congning Ni, Qingyuan Song, Qingxia Chen, Lijun Song, Patricia Commiskey, Lauren Stratton, Bradley Malin, Zhijun Yin. 701

The Implementation Outcomes and Population Impact of a Statewide IT Deployment for Family Caregivers: Mixed Methods Study (e63355)

Orly Tonkikh, Heather Young, Janice Bell, Jessica Famula, Robin Whitney, Jennifer Mongoven, Kathleen Kelly. 714

The CareVirtue Digital Journal for Family and Friend Caregivers of People Living With Alzheimer Disease and Related Dementias: Exploratory Topic Modeling and User Engagement Study (e67992)

Andrew Pickett, Danny Valdez, Lillian White, Priya Loganathar, Anna Linden, Justin Boutilier, Clover Caldwell, Christian Elliott, Matthew Zuraw, Nicole Werner. 731

Evaluating the Prognostic and Clinical Validity of the Fall Risk Score Derived From an AI-Based mHealth App for Fall Prevention: Retrospective Real-World Data Analysis (e55681)

Sónia Alves, Steffen Temme, Seyedamirhosein Motamedi, Marie Kura, Sebastian Weber, Johannes Zeichen, Wolfgang Pommer, André Baumgart. 747

Sleep Duration and Functional Disability Among Chinese Older Adults: Cross-Sectional Study (e53548)

Minjing Luo, Yue Dong, Bingbing Fan, Xinyue Zhang, Hao Liu, Changhao Liang, Hongguo Rong, Yutong Fei. 763

Factors Influencing Malnutrition Among Older Adult Residents in the Western Region of Saudi Arabia: Sex Differential Study (e55572)

Mai Ghabashi, Firas Azzeh. 777

Interrelationships Among Individual Factors, Family Factors, and Quality of Life in Older Chinese Adults: Cross-Sectional Study Using Structural Equation Modeling (e59818)

Yuting Wu, Cong Gong, Lifang Pi, Meixin Zheng, Weifang Liu, Yamei Wang. 789

Exploring the Perspectives of Older Adults Living With HIV on Virtual Care: Qualitative Study (e65730)
Kristina Kokorelias, Dean Valentine, Erica Dove, Paige Brown, Stuart McKinlay, Christine Sheppard, Hardeep Singh, Andrew Eaton, Laura Jamieson, Marina Wasilewski, Alice Zhabokritsky, Ashley Flanagan, Reham Abdelhalim, Rahel Zewude, Rabea Parpia, Sharon Walmsley, Luxey Sirisegaram. 821

Understanding Older Adults' Experiences With a Digital Health Platform in General Practice: Qualitative Interview Study (e59168)
Hanna Knotnerus, Hà Ngo, Otto Maarsingh, Vincent van Vugt. 832

Sociodigital Determinants of eHealth Literacy and Related Impact on Health Outcomes and eHealth Use in Korean Older Adults: Community-Based Cross-Sectional Survey (e56061)
Myat Kyaw, Myo Aung, Yuka Koyanagi, Saiyud Moolphate, Thin Aung, Hok Ma, Hocheol Lee, Hae-Kweun Nam, Eun Nam, Motoyuki Yuasa. . .
8 4 3

Adoption and Use of Telemedicine and Digital Health Services Among Older Adults in Light of the COVID-19 Pandemic: Repeated Cross-Sectional Analysis (e52317)
Motti Haimi, Ruslan Sergienko. 890

Experiences of a Community-Based Digital Intervention Among Older People Living in a Low-Income Neighborhood: Qualitative Study (e52292)
Si Lu, Sungwon Yoon, Wan Yee, Nerice Heng Wen Ngiam, Kennedy Ng, Lian Low. 911

Digital Literacy Training for Low-Income Older Adults Through Undergraduate Community-Engaged Learning: Single-Group Pretest-Posttest Study (e51675)
Lisa Miller, Rachel Callegari, Theresa Abah, Helen Fann. 924

Long-Term Adoption of Televisits in Nursing Homes During the COVID-19 Crisis and Following Up Into the Postpandemic Setting: Mixed Methods Study (e55471)
Tobias Martin, Sarah Veldeman, Heidrun Großmann, Paul Fuchs-Frohnhofen, Michael Czaplik, Andreas Follmann. 939

Exploring the Sociodemographic and Health-Related Determinants of Telehealth Use Among a Cohort of Older Australians During the COVID-19 Pandemic: Repeated Cross-Sectional Study (e58594)
Shanna Fealy, Suzanne McLaren, Claire Seaman, Melissa Nott, Donovan Jones, Pauletta Irwin, Patricia Logan, Rachel Rossiter, Simon McDonald. 959

Requirement Analysis of Different Variants of a Measurement and Training Station for Older Adults at Risk of Malnutrition and Reduced Mobility: Focus Group Study (e58714)
Lisa Happe, Marie Sgraja, Vincent Quinten, Mareike Förster, Rebecca Diekmann. 978

Internet Use and Higher-Level Functional Capacity Decline Suppression in Japanese Older Adults With Low Education: JAGES 2016-2019 Longitudinal Study (e53384)
Atsuko Tajika, Atsushi Nakagomi, Yasuhiro Miyaguni, Chie Koga, Katsunori Kondo, Toshiyuki Ojima. 990

Examining Whether Patient Portal and Video Visit Use Differs by Race and Ethnicity Among Older Adults in a US Integrated Health Care Delivery System: Cross-Sectional Electronic Health Record and Survey-Based Study (e63814)
Nancy Gordon, Chelsea Yin, Joan Lo. 1004

Nurses' and Nursing Assistants' Experiences With Teleconsultation in Small Rural Long-Term Care Facilities: Semistructured Interview Pilot Study (e65111)
Veronique Nabelsi, Marie Leclerc, Véronique Plouffe. 1020

Tailored Self-Management App to Support Older Adults With Cancer and Multimorbidity: Development and Usability Testing (e53163)
Sang-Wha Sien, Francis Kobekyaa, Martine Puts, Leanne Currie, Margaret Tompson, Penelope Hedges, Joanna McGrenere, Caroline Mariano, Kristen Haase. 1035

Remote Evidence-Based Programs for Health Promotion to Support Older Adults During the COVID-19 Pandemic and Beyond: Mixed Methods Outcome Evaluation (e52069)
Lesley Steinman, Kelly Chadwick, Erica Chavez Santos, Sruthi Sravanam, Selisha Johnson, Elspeth Rensema, Caitlin Mayotte, Paige Denison, Kate Lorig. 1051

Self-Explainable Graph Neural Network for Alzheimer Disease and Related Dementias Risk Prediction: Algorithm Development and Validation Study (e54748)
Xinyue Hu, Zenan Sun, Yi Nian, Yichen Wang, Yifang Dang, Fang Li, Jingna Feng, Evan Yu, Cui Tao. 1072

Exploring Older Adults' Perceptions of Using Digital Health Platforms for Self-Managing Musculoskeletal Health Conditions: Focus Group Study (e55693)
Sophie Clohessy, Christian Kempton, Kate Ryan, Peter Grinbergs, Mark Elliott. 1084

Perspectives and Experiences on eHealth Solutions for Coping With Chronic Pain: Qualitative Study Among Older People Living With Chronic Pain (e57196)
Annalisa De Lucia, Valeria Donisi, Ilenia Pasini, Enrico Polati, Lidia Del Piccolo, Vittorio Schweiger, Cinzia Perlini. 1098

Exploring the Linkages Among Chronic Illness, Substance Use, and COVID-19 Infection in Adults Aged 50 Years and Older: Retrospective Cross-Sectional Analysis of National Representative Data (e63024)
Suebsarn Ruksakulpiwat, Atsadaporn Niyomyart, Chontira Riangkam, Lalipat Phianhasin, Chitchanok Benjasirisan, Jon Adams. 1113

An eHealth Intervention to Improve Quality of Life, Socioemotional, and Health-Related Measures Among Older Adults With Multiple Chronic Conditions: Randomized Controlled Trial (e59588)
David Gustafson Sr, Marie-Louise Mares, Darcie Johnston, Olivia Vjorn, John Curtin, Gina Landucci, Klaren Pe-Romashko, David Gustafson Jr, Dhavan Shah. 1128

Age Variation Among US Adults’ Social Media Experiences and Beliefs About Who Is Responsible for Reducing Health-Related Falsehoods: Secondary Analysis of a National Survey (e56761)
Prathyusha Galinkala, Elise Atkinson, Celeste Campos-Castillo. 1149

The #SeePainMoreClearly Phase II Pain in Dementia Social Media Campaign: Implementation and Evaluation Study (e53025)
Louise Castillo, Vivian Tran, Mary Brachaniec, Christine Chambers, Kelly Chessie, Alec Couros, Andre LeRuyet, Charmayne LeRuyet, Lilian Thorpe, Jaime Williams, Sara Wheelwright, Thomas Hadjistavropoulos. 1182

Social Media Discourse Related to Caregiving for Older Adults Living With Alzheimer Disease and Related Dementias: Computational and Qualitative Study (e59294)
Andrew Pickett, Danny Valdez, Kelsey Sinclair, Wesley Kochell, Boone Fowler, Nicole Werner. 1201

Internet Use as a Moderator of the Relationship Between Personal Resources and Stress in Older Adults: Cross-Sectional Study (e52555)
Angélique Roquet, Paolo Martinelli, Charikleia Lampraki, Daniela Jopp. 1216

Barriers to and Facilitators of Older People’s Engagement With Web-Based Services: Qualitative Study of Adults Aged >75 Years (e46522)
Annemarie Money, Alex Hall, Danielle Harris, Charlotte Eost-Telling, Jane McDermott, Chris Todd. 1250

Online Cognitive Stimulation Therapy for Dementia in Brazil and India: Acceptability, Feasibility, and Lessons for Implementation (e55557)
Emily Fisher, Shreenila Venkatesan, Pedro Benevides, Elodie Bertrand, Paula Brum, Céline El Baou, Cleusa Ferri, Jane Fossey, Maria Jelen, Jerson Laks, Lisa Liu, Daniel Mograbi, Nirupama Natarajan, Renata Naylor, Despina Pantouli, Vaishnavi Ramanujam, Thara Rangaswamy, Raquel Santos de Carvalho, Charlotte Stoner, Sridhar Vaitheswaran, Aimee Spector. 1262

The Needs and Experiences of People With Early-Stage Dementia Using an Application for Cognitive and Physical Activation in Germany: Qualitative Study (e62689)

Melina Klein, Alexa von Bosse, Christophe Kunze. 1278

Baseline Smartphone App Survey Return in the Electronic Framingham Heart Study Offspring and Omni 1 Study: eCohort Study (e64636)

Jian Rong, Chathurangi Pathiravasan, Yuankai Zhang, Jamie Faro, Xuzhi Wang, Eric Schramm, Belinda Borrelli, Emelia Benjamin, Chunyu Liu, Joanne Murabito. 1285

Feasibility of Measuring Smartphone Accelerometry Data During a Weekly Instrumented Timed Up-and-Go Test After Emergency Department Discharge: Prospective Observational Cohort Study (e57601)

Brian Suffoletto, David Kim, Caitlin Toth, Waverly Mayer, Sean Glaister, Chris Cinkowski, Nick Ashenburg, Michelle Lin, Michael Losak. 1299

Performance Differences of a Touch-Based Serial Reaction Time Task in Healthy Older Participants and Older Participants With Cognitive Impairment on a Tablet: Experimental Study (e48265)

Christian Mychajliw, Heiko Holz, Nathalie Minuth, Kristina Dawidowsky, Gerhard Eschweiler, Florian Metzger, Franz Wortha. 1319

Smartwatch-Based Interventions for People With Dementia: User-Centered Design Approach (e50107)

Doreen Goerss, Stefanie Köhler, Eleonora Rong, Anna Temp, Ingo Kilimann, Gerald Bieber, Stefan Teipel. 1340

Examining Associations Between Smartphone Use and Clinical Severity in Frontotemporal Dementia: Proof-of-Concept Study (e52831)

Emily Paolillo, Kaitlin Casaletto, Annie Clark, Jack Taylor, Hilary Heuer, Amy Wise, Sreya Dhanam, Mark Sanderson-Cimino, Rowan Saloner, Joel Kramer, John Kornak, Walter Kremers, Leah Forsberg, Brian Appleby, Ece Bayram, Andrea Bozoki, Danielle Brushaber, R Darby, Gregory Day, Bradford Dickerson, Kimiko Domoto-Reilly, Fanny Elahi, Julie Fields, Nupur Ghoshal, Neill Graff-Radford, Matthew G H Hall, Lawrence Honig, Edward Huey, Maria Lapid, Irene Litvan, Ian Mackenzie, Joseph Masdeu, Mario Mendez, Carly Mester, Toji Miyagawa, Georges Naasan, Belen Pascual, Peter Pressman, Eliana Ramos, Katherine Rankin, Jessica Rexach, Julio Rojas, Lawren VandeVrede, Bonnie Wong, Zbigniew Wszolek, Bradley Boeve, Howard Rosen, Adam Boxer, Adam Staffaroni, ALLFTD Consortium. 1359

Optimizing Technology-Based Prompts for Supporting People Living With Dementia in Completing Activities of Daily Living at Home: Experimental Approach to Prompt Modality, Task Breakdown, and Attentional Support (e56055)

Madeleine Cannings, Ruth Brookman, Simon Parker, Leonard Hoon, Asuka Ono, Hiroaki Kawata, Hisashi Matsukawa, Celia Harris. 1376

Digital Storytelling for People With Cognitive Impairment Using Available Mobile Apps: Systematic Search in App Stores and Content Analysis (e64525)

Di Zhu, Abdullah Al Mahmud, Wei Liu, Dahua Wang. 1399

Comparison of the Burdens and Attitudes Between Standard and Web-Based Remote Programming for Deep Brain Stimulation in Parkinson Disease: Survey Study (e57503)

Xiaonan Wan, Zhengyu Lin, Chengcheng Duan, Zhitong Zeng, Chencheng Zhang, Dianyou Li. 1415

Predicting Adherence to Computer-Based Cognitive Training Programs Among Older Adults: Study of Domain Adaptation and Deep Learning (e53793)

Ankita Singh, Shayok Chakraborty, Zhe He, Yuanying Pang, Shenghao Zhang, Ronast Subedi, Mia Lustria, Neil Charness, Walter Boot. . . .
1 4 2 5

Developing a Life Story Intervention for Older Adults With Dementia or at Risk of Delirium Who Were Hospitalized: Multistage, Stakeholder-Engaged Co-Design Study (e59306)

Sarah Flessa, James Harrison, Roniela Turnigan, Megan Rathfon, Michael Chandler, Jay Newton-Small, Stephanie Rogers. 1477

Brief Video-Delivered Intervention to Reduce Anxiety and Improve Functioning in Older Veterans: Pilot Randomized Controlled Trial (e56959)

Christine Gould, Chalise Carlson, Julie Wetherell, Mary Goldstein, Lauren Anker, Sherry Beaudreau. 1500

Evaluating a Smart Textile Loneliness Monitoring System for Older People: Co-Design and Qualitative Focus Group Study (e57622)

Freya Probst, Jessica Rees, Zayna Aslam, Nikitia Mexia, Erika Molteni, Faith Matcham, Michela Antonelli, Anthea Tinker, Yu Shi, Sebastien Ourselin, Wei Liu. 1517

Development and Validation of an Explainable Machine Learning Model for Predicting Myocardial Injury After Noncardiac Surgery in Two Centers in China: Retrospective Study (e54872)

Chang Liu, Kai Zhang, Xiaodong Yang, Bingbing Meng, Jingsheng Lou, Yanhong Liu, Jiangbei Cao, Kexuan Liu, Weidong Mi, Hao Li. 1669

Expectations and Requirements of Surgical Staff for an AI-Supported Clinical Decision Support System for Older Patients: Qualitative Study (e57899)

Adriane Uihlein, Lisa Beissel, Anna Ajlani, Marcin Orzechowski, Christoph Leinert, Thomas Kocar, Carlos Pankratz, Konrad Schuetze, Florian Gebhard, Florian Steger, Marina Fotteler, Michael Denkinger. 1681

Social Media Programs for Outreach and Recruitment Supporting Aging and Alzheimer Disease and Related Dementias Research: Longitudinal Descriptive Study (e51520)

Anthony Teano, Ashley Scott, Cassandra Gipson, Marilyn Albert, Corinne Pettigrew. 1698

Automatic Spontaneous Speech Analysis for the Detection of Cognitive Functional Decline in Older Adults: Multilanguage Cross-Sectional Study (e50537)

Emilia Ambrosini, Chiara Giangregorio, Eugenio Lomurno, Sara Moccia, Marios Milis, Christos Loizou, Domenico Azzolino, Matteo Cesari, Manuel Cid Gala, Carmen Galán de Isla, Jonathan Gomez-Raja, Nunzio Borghese, Matteo Matteucci, Simona Ferrante. 1718

Using Existing Clinical Data to Measure Older Adult Inpatients' Frailty at Admission and Discharge: Hospital Patient Register Study (e54839)

Boris Wernli, Henk Verloo, Armin von Gunten, Filipa Pereira. 1735

Enhancing Frailty Assessments for Transcatheter Aortic Valve Replacement Patients Using Structured and Unstructured Data: Real-World Evidence Study (e58980)

Mamoun Mardini, Chen Bai, Anthony Bavry, Ahmed Zaghloul, R Anderson, Catherine Price, Mohammad Al-Ani. 1748

Determinants of Visual Impairment Among Chinese Middle-Aged and Older Adults: Risk Prediction Model Using Machine Learning Algorithms (e59810)

Lijun Mao, Zhen Yu, Luotao Lin, Manoj Sharma, Hualing Song, Hailei Zhao, Xianglong Xu. 1760

Developing Independent Living Support for Older Adults Using Internet of Things and AI-Based Systems: Co-Design Study (e54210)

Claire Timon, Emma Heffernan, Sophia Kilcullen, Louise Hopper, Hyowon Lee, Pamela Gallagher, Alan Smeaton, Kieran Moran, Pamela Hussey, Catriona Murphy. 1772

Promoting Personalized Reminiscence Among Cognitively Intact Older Adults Through an AI-Driven Interactive Multimodal Photo Album: Development and Usability Study (e49415)

Xin Wang, Juan Li, Tianyi Liang, Wordh Hasan, Kimia Zaman, Yang Du, Bo Xie, Cui Tao. 1800

Detection of Mild Cognitive Impairment From Non-Semantic, Acoustic Voice Features: The Framingham Heart Study (e55126)

Huitong Ding, Adrian Lister, Cody Karjadi, Rhoda Au, Honghuang Lin, Brian Bischoff, Phillip Hwang. 1814

Investigating Acoustic and Psycholinguistic Predictors of Cognitive Impairment in Older Adults: Modeling Study (e54655)

Varsha Badal, Jenna Reinen, Elizabeth Twamley, Ellen Lee, Robert Fellows, Erhan Bilal, Colin Depp. 1825

Extracting Critical Information from Unstructured Clinicians' Notes Data to Identify Dementia Severity Using a Rule-Based Approach: Feasibility Study (e57926)
Ravi Prakash, Matthew Dupre, Truls Østbye, Hanzhang Xu. 1842

Reviews

Characteristics and Range of Reviews About Technologies for Aging in Place: Scoping Review of Reviews (e50286)
Jenny Bergschöld, Mari Gunnes, Arne Eide, Eva Lassemo. 437

In-Home Positioning for Remote Home Health Monitoring in Older Adults: Systematic Review (e57320)
Andrew Chan, Joanne Cai, Linna Qian, Brendan Coutts, Steven Phan, Geoff Gregson, Michael Lipsett, Adriana Ríos Rincón. 520

Factors Affecting Clinician Readiness to Adopt Smart Home Technology for Remote Health Monitoring: Systematic Review (e64367)
Gordana Dermody, Daniel Wadsworth, Melissa Dunham, Courtney Glass, Roschelle Fritz. 536

The Use of Digital Technologies in the Promotion of Health Literacy and Empowerment of Informal Caregivers: Scoping Review (e54913)
Suzete Soares, Louíse Hoffmeister, Maria Fernandes, Adriana Henriques, Andreia Costa. 670

Markerless Motion Capture to Quantify Functional Performance in Neurodegeneration: Systematic Review (e52582)
Julian Jeyasingh-Jacob, Mark Crook-Rumsey, Harshvi Shah, Theresita Joseph, Subati Abulikemu, Sarah Daniels, David Sharp, Shlomi Haar.
1 4 6 0

The Implementation Success of Technology-Based Counseling in Dementia Care: Scoping Review (e51544)
Dorothee Bauernschmidt, Janina Wittmann, Julian Hirt, Gabriele Meyer, Anja Bieber. 1533

Patient and Public Involvement in Technology-Related Dementia Research: Scoping Review (e48292)
Pippa Kirby, Helen Lai, Sophie Horrocks, Matthew Harrison, Danielle Wilson, Sarah Daniels, Rafael Calvo, David Sharp, Caroline Alexander.
1 5 4 9

Strategies to Mitigate Age-Related Bias in Machine Learning: Scoping Review (e53564)
Charlene Chu, Simon Donato-Woodger, Shehroz Khan, Tianyu Shi, Kathleen Leslie, Samira Abbasgholizadeh-Rahimi, Rune Nyrup, Amanda Grenier. 1572

Adoption of Artificial Intelligence–Enabled Robots in Long-Term Care Homes by Health Care Providers: Scoping Review (e55257)
Karen Wong, Lillian Hung, Joey Wong, Juyoung Park, Hadil Alfares, Yong Zhao, Abdolhossein Mousavinejad, Albin Soni, Hui Zhao. 1586

Nursing Staff's Perspectives of Care Robots for Assisted Living Facilities: Systematic Literature Review (e58629)
Katie Trainum, Jiaying Liu, Elliott Hauser, Bo Xie. 1606

Exploring the Landscape of Standards and Guidelines in AgeTech Design and Development: Scoping Review and Thematic Analysis (e58196)
Shahabeddin Abhari, Josephine McMurray, Tanveer Randhawa, Gaya Bin Noon, Thokozani Hanjahanja-Phiri, Heather McNeil, Fiona Manning, Patricia Debergue, Jennifer Teague, Plinio Pelegrini Morita. 1618

Machine Learning Driven by Magnetic Resonance Imaging for the Classification of Alzheimer Disease Progression: Systematic Review and Meta-Analysis (e59370)
Gopi Battineni, Nalini Chintalapudi, Francesco Amenta. 1854

Viewpoint

The Best of Two Worlds to Promote Healthy Cognitive Aging: Definition and Classification Approach of Hybrid Physical Training Interventions (e56433)
Fabian Herold, Paula Theobald, Thomas Gronwald, Navin Kaushal, Liye Zou, Eling de Bruin, Louis Bherer, Notger Müller. 1649

Corrigenda and Addenda

Correction: Detecting Anomalies in Daily Activity Routines of Older Persons in Single Resident Smart Homes: Proof-of-Concept Study (e58394)
Zahraa Shahid, Saguna Saguna, Christer Åhlund. 1696

Assessment of Wearable Device Adherence for Monitoring Physical Activity in Older Adults: Pilot Cohort Study

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Abstract

Background: Physical activity has emerged as a modifiable behavioral factor to improve cognitive function. However, research on adherence to remote monitoring of physical activity in older adults is limited.

Objective: This study aimed to assess adherence to remote monitoring of physical activity in older adults within a pilot cohort from objective user data, providing insights for the scalability of such monitoring approaches in larger, more comprehensive future studies.

Methods: This study included 22 participants from the Boston University Alzheimer's Disease Research Center Clinical Core. These participants opted into wearing the Verisense watch as part of their everyday routine during 14-day intervals every 3 months. Eighteen continuous physical activity measures were assessed. Adherence was quantified daily and cumulatively across the follow-up period. The coefficient of variation was used as a key metric to assess data consistency across participants over multiple days. Day-to-day variability was estimated by calculating intraclass correlation coefficients using a 2-way random-effects model for the baseline, second, and third days.

Results: Adherence to the study on a daily basis outperformed cumulative adherence levels. The median proportion of adherence days (wearing time surpassed 90% of the day) stood at 92.1%, with an IQR spanning from 86.9% to 98.4%. However, at the cumulative level, 32% (7/22) of participants in this study exhibited lower adherence, with the device worn on fewer than 4 days within the requested initial 14-day period. Five physical activity measures have high variability for some participants. Consistent activity data for 4 physical activity measures might be attainable with just a 3-day period of device use.

Conclusions: This study revealed that while older adults generally showed high daily adherence to the wearable device, consistent usage across consecutive days proved difficult. These findings underline the effectiveness of wearables in monitoring physical activity in older populations and emphasize the ongoing necessity to simplify usage protocols and enhance user engagement to guarantee the collection of precise and comprehensive data.

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KEYWORDS

physical activity; remote monitoring; wearable device; adherence; older adults

Introduction

The global demographic shift toward an aging population has become a pressing concern, with an increasing number of individuals being affected by cognitive disorders [1]. However, the limited number of effective treatments for cognitive diseases such as Alzheimer disease and other forms of dementia underscores the importance of early detection and monitoring of cognitive decline [2]. Early detection not only facilitates timely intervention but also allows for the management and possibly slowing of the progression of cognitive decline. Therefore, identifying modifiable risk factors plays a critical role in cognitive intervention strategies [3]. Among these, physical activity has emerged as a significant factor closely linked to health across many domains, including cardiovascular health [4] and cognitive functioning [5]. It has been recognized as one of the 12 modifiable risk factors for dementia [6]. A growing body of research indicates that regular physical activity can mitigate the risk of cognitive decline and improve brain function among older adults [7,8]. Moreover, meta-analyses have shown an association between increased physical activity and a reduced risk of dementia [9-11]. Such findings highlight the potential of evaluating and monitoring physical activity levels in older adults to improve detection and intervention of cognitive decline. By accurately capturing participants' physical activity, actionable insights can be provided to inform lifestyle recommendations. This approach supports cognitive well-being and may help delay the onset of cognitive diseases.

Traditional in-clinic assessments of physical activity, however, are limited by their episodic nature, failing to consistently track an individual's activity patterns over time. Additionally, these assessments are susceptible to modifications in gait when individuals are aware they are being observed, a phenomenon known as the Hawthorne effect [12,13]. In contrast, remote monitoring technologies offer a promising solution by enabling continuous and unobtrusive tracking of physical activity outside of clinical settings. This approach provides a more comprehensive picture of an individual's physical activity patterns. This information is crucial for developing personalized interventions that are tailored specifically to the activity habits and needs of each participant. By identifying periods of inactivity or suboptimal activity levels, interventions can be more precisely targeted, thereby facilitating the effective implementation of strategies that are likely to be more engaging and beneficial for the individual. Therefore, our team has developed a pilot study using a participant-driven digital brain health platform [14], which incorporates wearable devices to collect physical activity data from participants. This initiative aims to facilitate comprehensive digital phenotyping of cognitive functions in the future.

However, monitoring physical activity continuously among older adults presents unique challenges, particularly concerning adherence issues [15]. Older adults may face physical, cognitive, or technological barriers that affect their consistent use of activity tracking devices [16]. These complexities require tailored approaches to ensure effective and sustained engagement in physical activity monitoring within this demographic. While some studies have focused on daily [17] and long-term [18] adherence to wearable devices, more studies that assess adherence metrics both daily and cumulatively throughout an entire study protocol could offer additional understanding of how older adults engage with these technologies. Additionally, this approach would be beneficial in exploring the consistency of the data collected, offering deeper insights into how consistently participants engage with the wearables over extended periods.

Therefore, this study aims to evaluate the adherence of wearable devices in remote monitoring of physical activity among older adults within a pilot study of digital brain health platform from the Boston University Alzheimer's Disease Research Center (BU ADRC). Our objective is to evaluate older adults' adherence at both daily and cumulative levels and the consistency of physical activity tracking and to explore preliminary strategies for optimizing study protocols, such as adjusting required wear durations. Our detailed examination of adherence patterns and device-specific data reliability aims to offer a unique addition to the collective understanding of wearable technology apps in aging populations.

Methods

Study Population

Participants from the Clinical Core of the BU ADRC were included in this study. The BU ADRC is one of around 33 ADRCs funded by the National Institute on Aging, sharing its findings with the National Alzheimer's Coordinating Center to advance collaborative Alzheimer disease research. The BU ADRC is located in the urban area of Boston, focusing on the older adult population within this community. Detailed information about the ADRC has been documented in a prior study [19]. In 2021, the BU ADRC introduced a digital brain health platform incorporating various digital tools for data collection, such as wearable devices for monitoring physical activity [14]. The cognitive status of participants was determined through comprehensive consensus conferences involving multiple disciplines [20]. Additional information about these diagnostic procedures can be found in the previous study [21].

Verisense Device

Verisense, developed by Shimmer Research Ltd, is a wrist-worn inertial measurement unit designed for tracking physical activity. This device integrates a tri-axial accelerometer and gyroscope, weighing 29.6 grams with dimensions of 35 mm × 43 mm × 12 mm, making it suitable for continuous wear on the wrist. With an IP55 resistance rating, the Verisense device is designed to be water-resistant and has protection against environmental contaminants and factors, safeguarding its functionality. Additionally, the device boasts a battery life of up to 6 months without the need for recharging, enhancing its usability for long-term monitoring. The sampling rate of the accelerometer of the Verisense device is 25 Hz. More description of Verisense can be found in a prior study [22]. Eighteen physical activity features (Table S1 in Multimedia Appendix 1), extracted using the GGIR software [23], were divided into 2 primary categories. The first category encompasses durations of various physical activities. These physical activities are classified by intensity levels from inactive to vigorous. The second category includes features related to acceleration, such as total acceleration during the most active 5 hours.

Study Procedure

Participants were presented with available technologies from a digital brain health platform that spanned different test instrument options from smartphone apps to wearable devices with the level of use commitment for each defined [14]. Depending on participant preference, the presentation of technologies took place remotely over videoconference or in person. For in-person study visits, the Verisense device was configured and given to the participant during the visit. For remote visits, or quarterly check-ins following an in-person visit, the device was configured at the study site and then shipped to participants. Using a participant-centric study design, participants opted into the technologies of their choice. They were given a 2-week assessment period to use their selected technologies and assessment periods were scheduled at quarterly intervals. Participants who opted into Verisense were instructed to wear the tracker continuously over the 14-day period within a quarter. During the 14-day use period, there was no need to recharge the device, and thus could seamlessly integrate this monitoring tool into their routine activities for a comprehensive capture of physical activity data. Participants returned devices after the 14-day period. Every 3 months, the device was mailed back to them, and participants were given a reminder about using their technologies at the start of their 14-day assessment period, at the midpoint, and at the end. The physical activity data was retrieved from the Verisense cloud-based portal. The duration of this study was from September 2021 to February 2023. More information about the study procedures can be found in a previous publication [14].

Statistical Analyses

Adherence metrics were derived from objective user data and analyzed daily, as well as cumulatively, for the first quarter of the 14-day follow-up period. First, daily adherence was evaluated by calculating the proportion of days where the daily wear rate surpassed predetermined thresholds relative to the total number of wear days. The thresholds denote the proportion of the days when participants wore the device. Given that participants maintain a high daily wear rate, we established thresholds of 90%, 95%, and 100% to differentiate levels of compliance throughout the day. Then, cumulative adherence was determined by assessing the overall proportion of days the device was worn (at least 8 hours a day [24]) during the requested 14-day period.

To assess the consistency of physical activity data across all participants over the entire study duration, we computed the within-person coefficient of variation (CV). This statistical parameter, defined as the ratio of the standard deviation to the mean of physical activity metrics, offers a uniform measure of data variability [25]. A lower CV value indicates greater consistency in the physical activity measure captured by the wearable devices.

We conducted a preliminary investigation to determine the potential for acquiring reliable physical activity data from participants within a shortened wear period. Specifically, we assessed the stability of physical activity measures through just 3 days of device use to increase the number of participants in the study samples. To measure the consistency of the data collected during these 3 consecutive wear days, including baseline, second, and third days between persons, the intraclass correlation coefficient (ICC) complemented by a 95% CI was calculated by a 2-way random-effects model [26].

Ethical Considerations

The institutional review board of the Boston University Medical Campus approved the procedures and protocols of this study (H 405 - 42). All participants provided written informed consent.

Results

Cohort Description

Our study included 22 participants from the BU ADRC (mean age 75, SD 7 years; 9/22, 41% women; an average of 16 years of education; Table 1). During the study period, 1 participant was diagnosed with non-amnestic, single-domain mild cognitive impairment. The distribution of each physical activity measure across 3 days, including 25th percentile, median, and 75th percentile values, is provided in Table S1 in Multimedia Appendix 1.

Table . Baseline demographics of the study participants (N=22).

Variable		Values
Age (years), mean (SD)		75 (7)
Gender, n (%)		
	Women	9 (41)
	Men	13 (59)
Years of education, mean (SD)		16 (2)
Race, n (%)		
	White	20 (91)
	Black or African American	2 (9)
Current marital status, n (%)		
	Married	16 (73)
	Divorced	5 (23)
	Never married	1 (4)
Level of independence, n (%)		
	Able to live independently	22 (100)
Living situation, n (%)		
	Lives alone	3 (14)
	Lives with spouse or partner	18 (82)
	Lives with relative or friend	1 (4)

Study Adherence

Adherence to the study on a daily basis outperformed cumulative adherence levels. The median proportion of days where wear time surpassed 90% of total wear days stood at 92.1%, with an IQR spanning from 86.9% to 98.4%. As the threshold for daily wear duration increased, adherence notably declined. For days achieving 100% wear time, the median proportion dropped to 86.8%, with an IQR between 83.4% and 95.6% (Table 2).

Table 3 represents participant-level daily adherence to device usage at different compliance thresholds. It is evident that 5 participants maintain high adherence rates even as the thresholds increase, the overall daily adherence rates of 82% (18/22) participants tend to decrease as the threshold for daily wear time increases. At the 90% threshold, most of the participants show a high percentage of daily adherence, with many participants nearing or achieving full daily adherence. However, as the threshold increased to 95% and 100%, the number of days meeting the daily adherence criteria decreased. Table 4 represents participant-level cumulative adherence with the total number of worn days within the required initial 14-day period for each participant. There are varying levels of compliance across participants. Where 59% (13/22) of participants demonstrated high compliance, wearing the device for 10 or more days within the first quarter of the 14-day period, 32% (7/22) of participants exhibited notably lower compliance, with the device worn on fewer than 4 days. We also presented the daily adherence of participants to device usage during the initial 14-day period in Figure S1 in Multimedia Appendix 1.

Table . Summary of study adherence statistics at the population level.

Adherence level		Median (IQR)
Daily		
	Proportion of days with a daily wear rate above 90% of total wear days	92.1 (86.9-98.4)
	Proportion of days with a daily wear rate above 95% of total wear days	89.6 (83.4-95.6)
	Proportion of days with 100% daily wear rate of total wear days	86.8 (79.3-92.4)
Cumulatively		
	Proportion of wear days during the initial 14-day follow-up period	71.4 (21.4-78.6)

Table . Participant adherence to the wearable device usage at varying daily compliance thresholds.

Participant ID	Total wear days, n	Adherence days, n		
		Threshold: 90% daily wear rate	Threshold: 95% daily wear rate	Threshold: 100% daily wear rate
1	25	24	24	24
2	12	12	10	10
3	46	46	45	44
4	43	36	36	34
5	66	65	64	61
6	34	31	30	29
7	56	48	47	42
8	28	22	22	22
9	72	66	64	64
10	52	51	49	45
11	21	19	16	14
12	13	9	9	8
13	16	16	16	15
14	15	12	12	12
15	31	28	28	27
16	13	12	12	12
17	38	35	35	34
18	15	14	14	14
19	12	12	12	10
20	33	33	33	32
21	25	23	22	22
22	18	15	14	14

Table . Participant adherence to the device usage at the cumulative level.

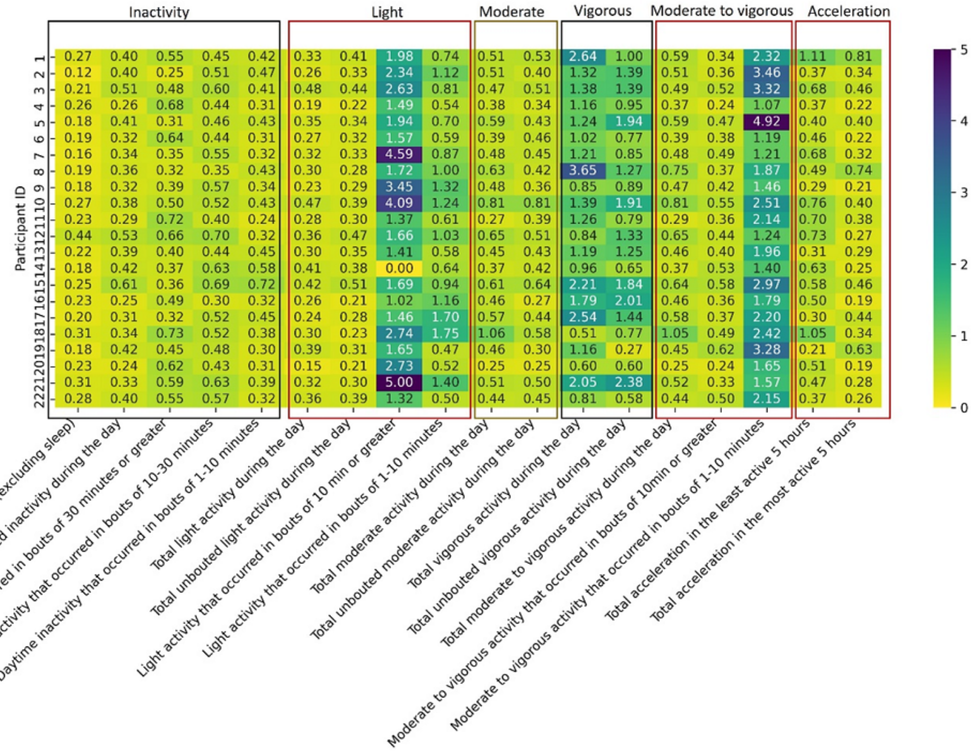
Participant ID	Days worn within the initial 14-day period, n
1	8
2	11
3	11
4	11
5	10
6	1
7	10
8	3
9	11
10	3
11	5
12	1
13	1
14	12
15	10
16	1
17	10
18	12
19	12
20	11
21	12
22	3

Data Consistency

Figure 1 displays the CV for different physical activity measures across participants. The vertical axis represents individual participants, with each row corresponding to 1 participant and their respective variability in physical activity measures. As shown by the heatmap, 4 physical activity measures—total vigorous activity during the day, light activity that occurred in bouts of 10 minutes or greater, moderate to vigorous activity that occurred in bouts of 1‑10 minutes, and moderate to vigorous activity that occurred in bouts of 10 minutes or greater—showed high variability (CV>1) for some participants, as evidenced by the darker shades in the respective columns. Conversely, other measures such as total inactivity time during the day displayed lower variability across participants, suggesting more consistency in those activity types.

Given that 32% (7/22) of participants wore the device for less than 4 days out of the initial required 14-day wear period, we conducted a preliminary investigation to determine if reliable data for specific physical activity measures could be obtained with just 3 days of wear. As shown in Table 5, four physical activity measures—total moderate activity during the day, total moderate to vigorous activity during the day, light activity that occurred in bouts of 1‑10 minutes, and daytime inactivity that occurred in bouts of 30 minutes or greater—demonstrated a moderate consistency with ICC greater than 0.5 over 3 wear days.

Figure 1. Variability of physical activity measures across participants. The vertical axis represents individual participants, with each row corresponding to 1 participant and their respective variability in physical activity measures. The coefficient of variation values are color coded, with darker shades indicating higher variability and lighter shades indicating lower variability.



	Inactivity					Light				Moderate		Vigorous		Moderate to vigorous			Acceleration	
Participant ID	Total inactivity time during the day (excluding sleep)	Total unbouted inactivity during the day	Daytime inactivity that occurred in bouts of 30 minutes or greater	Daytime inactivity that occurred in bouts of 10-30 minutes	Daytime inactivity that occurred in bouts of 1-10 minutes	Total light activity during the day	Total unbouted light activity during the day	Light activity that occurred in bouts of 10 min or greater	Light activity that occurred in bouts of 1-10 minutes	Total moderate activity during the day	Total unbouted moderate activity during the day	Total vigorous activity during the day	Total unbouted vigorous activity during the day	Total moderate to vigorous activity during the day	Moderate to vigorous activity that occurred in bouts of 10min or greater	Moderate to vigorous activity that occurred in bouts of 1-10 minutes	Total acceleration in the least active 5 hours	Total acceleration in the most active 5 hours
1	0.27	0.40	0.55	0.45	0.42	0.33	0.41	1.98	0.74	0.51	0.53	2.64	1.00	0.59	0.34	2.32	1.11	0.81
2	0.12	0.40	0.25	0.51	0.47	0.26	0.33	2.34	1.12	0.51	0.40	1.32	1.39	0.51	0.36	3.46	0.37	0.34
3	0.21	0.51	0.48	0.60	0.41	0.48	0.44	2.63	0.81	0.47	0.51	1.38	1.39	0.49	0.52	3.32	0.68	0.46
4	0.26	0.26	0.68	0.44	0.31	0.19	0.22	1.49	0.54	0.38	0.34	1.16	0.95	0.37	0.24	1.07	0.37	0.22
5	0.18	0.41	0.31	0.46	0.43	0.35	0.34	1.94	0.70	0.59	0.43	1.24	1.94	0.59	0.47	4.92	0.40	0.40
6	0.19	0.32	0.64	0.44	0.31	0.27	0.32	1.57	0.59	0.39	0.46	1.02	0.77	0.39	0.38	1.19	0.46	0.22
7	0.16	0.34	0.35	0.55	0.32	0.32	0.33	4.59	0.87	0.48	0.45	1.21	0.85	0.48	0.49	1.21	0.68	0.32
8	0.19	0.36	0.32	0.35	0.43	0.30	0.28	1.72	1.00	0.63	0.42	3.65	1.27	0.75	0.37	1.87	0.49	0.74
9	0.18	0.32	0.39	0.57	0.34	0.23	0.29	3.45	1.32	0.48	0.36	0.85	0.89	0.47	0.42	1.46	0.29	0.21
10	0.27	0.38	0.50	0.52	0.43	0.47	0.39	4.09	1.24	0.81	0.81	1.39	1.91	0.81	0.55	2.51	0.76	0.40
11	0.23	0.29	0.72	0.40	0.24	0.28	0.30	1.37	0.61	0.27	0.39	1.26	0.79	0.29	0.36	2.14	0.70	0.38
12	0.44	0.53	0.66	0.70	0.32	0.36	0.47	1.66	1.03	0.65	0.51	0.84	1.33	0.65	0.44	1.24	0.73	0.27
13	0.22	0.39	0.40	0.44	0.45	0.30	0.35	1.41	0.58	0.45	0.43	1.19	1.25	0.46	0.40	1.96	0.31	0.29
14	0.18	0.42	0.37	0.63	0.58	0.41	0.38	0.00	0.64	0.37	0.42	0.96	0.65	0.37	0.53	1.40	0.63	0.25
15	0.25	0.61	0.36	0.69	0.72	0.42	0.51	1.69	0.94	0.61	0.64	2.21	1.84	0.64	0.58	2.97	0.58	0.46
16	0.23	0.25	0.49	0.30	0.32	0.26	0.21	1.02	1.16	0.46	0.27	1.79	2.01	0.46	0.36	1.79	0.50	0.19
17	0.20	0.31	0.32	0.52	0.45	0.24	0.28	1.46	1.70	0.57	0.44	2.54	1.44	0.58	0.37	2.20	0.30	0.44
18	0.31	0.34	0.73	0.52	0.38	0.30	0.23	2.74	1.75	1.06	0.58	0.51	0.77	1.05	0.49	2.42	1.05	0.34
19	0.18	0.42	0.45	0.48	0.30	0.39	0.31	1.65	0.47	0.46	0.30	1.16	0.27	0.45	0.62	3.28	0.21	0.63
20	0.23	0.24	0.62	0.43	0.31	0.15	0.21	2.73	0.52	0.25	0.25	0.60	0.60	0.25	0.24	1.65	0.51	0.19
21	0.31	0.33	0.59	0.63	0.39	0.32	0.30	5.00	1.40	0.51	0.50	2.05	2.38	0.52	0.33	1.57	0.47	0.28
22	0.28	0.40	0.55	0.57	0.32	0.36	0.39	1.32	0.50	0.44	0.45	0.81	0.58	0.44	0.50	2.15	0.37	0.26

Table . Intraclass correlation coefficients of each physical activity measure for 2 different combinations of 3 wear days.

Physical activity measure		Baseline to day 2		Days 2 to 3	
		Values	*P* value	Values	*P* value
Inactivity (minutes), ICC[a] (95% CI)					
	Total inactivity time during the day (excluding sleep)	0.44 (0.05 to 0.72)	.02	0.47 (0.09 to 0.74)	.008
	Total unbouted inactivity during the day	−0.07 (-0.49 to 0.37)	.62	0.32 (−0.08 to 0.64)	.06
	Daytime inactivity that occurred in bouts of 30 minutes or greater	*0.58*[b] (0.21 to 0.80)	.002	*0.53* (0.17 to 0.77)	.003
	Daytime inactivity that occurred in bouts of 10 - 30 minutes	0.28 (−0.09 to 0.60)	.07	0.35 (−0.07 to 0.67)	.05
	Daytime inactivity that occurred in bouts of 1 - 10 minutes	−0.17 (−0.55 to 0.27)	.77	0.06 (−0.37 to 0.46)	.40
Light (minutes), ICC (95% CI)					
	Total light activity during the day	0.29 (−0.15 to 0.63)	.10	0.68 (0.37 to 0.85)	<.001
	Total unbouted light activity during the day	0.29 (−0.15 to 0.64)	.09	0.54 (0.17 to 0.78)	.003
	Light activity that occurred in bouts of 10 minutes or greater	−0.03 (−0.43 to 0.39)	.55	0.61 (0.27 to 0.82)	<.001
	Light activity that occurred in bouts of 1 - 10 minutes	*0.56* (0.18 to 0.79)	.003	*0.67* (0.37 to 0.85)	<.001
Moderate (minutes), ICC (95% CI)					
	Total moderate activity during the day	*0.55* (0.17 to 0.79)	.004	*0.61* (0.27 to 0.82)	<.001
	Total unbouted moderate activity during the day	0.49 (0.08 to 0.75)	.01	0.75 (0.48 to 0.89)	<.001
Vigorous (minutes), ICC (95% CI)					
	Total vigorous activity during the day	0.37 (−0.69 to 0.68)	.047	0.17 (−0.24 to 0.53)	.21
	Total unbouted vigorous activity during the day	0.84 (0.66 to 0.93)	<.001	−0.00 (−0.43 to 0.42)	.51
Moderate to vigorous (minutes), ICC (95% CI)					
	Total moderate to vigorous activity during the day	*0.55* (0.16 to 0.78)	.004	*0.60* (0.27 to 0.81)	<.001
	Moderate to vigorous activity that occurred in bouts of 10 minutes or greater	0.64 (0.30 to 0.83)	<.001	0.26 (−0.15 to 0.60)	.11
	Moderate to vigorous activity that occurred in bouts of 1 - 10 minutes	0.51 (0.11 to 0.76)	.008	0.46 (0.08 to 0.73)	.009
Acceleration, mg[c] (95% CI)					

Physical activity measure		Baseline to day 2		Days 2 to 3	
		Values	*P* value	Values	*P* value
	Total acceleration in the least active 5 hours	0.66 (0.34 to 0.84)	<.001	0.20 (−0.23 to 0.56)	.18
	Total acceleration in the most active 5 hours	0.49 (0.08 to 0.75)	.01	0.32 (−0.06 to 0.64)	.047

[a] ICC: intraclass correlation coefficient.

[b] Italic values represent ICC greater than 0.5 over 3 wear days.

[c] mg: milligee.

Discussion

Principal Findings

This study evaluated the adherence and consistency of remote monitoring physical activity among older adults. While adhering to a continuous 14-day device wear protocol posed challenges, the daily adherence levels were high, with many participants diligently following the usage guidelines. Furthermore, this study identified ICC values above 0.5 for certain physical activity measures, indicative of moderate reliability. While these results may not meet the highest standards for data stability, they demonstrate the feasibility of obtaining moderately reliable data with just 3 days of device wear. This insight supports the potential for shorter monitoring durations in future studies, which could reduce participant burden while still capturing consistent data.

Physical activity represents a modifiable behavioral factor with an association with enhanced outcomes across various health fields [27-29]. Yet, the deployment of physical activity interventions in clinical settings is not as prevalent as it could be [30]. Moreover, while participants may be encouraged or advised to increase their physical activity, healthcare professionals frequently face challenges in providing long-term follow-up [31]. This is particularly true for monitoring adherence to activity recommendations as outlined by the US Preventive Services Task Force [32]. Wearable technology presents an accessible approach to narrowing the divide between research and practical application in using physical activity as a preventive health strategy [33]. Especially, wrist-worn devices for monitoring physical activity are increasingly embraced by older adults [34]. The perspectives of older adults on activity trackers and their practical applications have been thoroughly documented, revealing generally high acceptability rates among this demographic [16]. However, whether older adults can strictly adhere to study protocols involving wearable devices still requires further investigation. In this study, participants are required to return the device after completing a 14-day wear period. This process assists in recalibrating the device and checking its functionality. Additionally, research indicated that the usage rates of wrist-worn devices decline over time after they are distributed to participants [35]. Therefore, returning the device acts as a reminder for participants, encouraging continued adherence to the usage protocol. While other reminder methods are available, this study opts for device return as the chosen strategy.

This study examined the adherence at both daily and cumulative levels. Overall, study adherence daily outperformed cumulative adherence levels. The median proportion of days where wear time surpassed 90% of total wear days stood at 92.1%, indicating that a substantial proportion of participants comply well with the device wear requirements at the daily level. However, ensuring near-perfect or perfect daily adherence remains a challenge, as seen in the decrease in adherence days at the strictest threshold of 100%. However, at the cumulative level, 32% (7/22) of participants in this study exhibited notably lower adherence, with the device worn on fewer than 4 days within the requested initial 14-day period. While 5 participants adhered to the protocol of recording their activity every 3 months, discrepancies were observed, with 5 participants having intervals of device use exceeding the 3-month interval. This variability signals that while some participants readily integrate the wearable devices into their daily routines, others face barriers that hinder consistent use. These barriers emphasize the necessity for adaptable and personalized approaches in encouraging sustained device usage. We also explored the implication of marital status, level of independence, and living situation on the study adherence. Three participants lived alone, two of which demonstrated relatively good adherence. We did not observe distinct patterns in adherence among participants with different marital statuses. Acknowledging and addressing these individual needs are pivotal in ensuring the efficacy of wearable technology as a tool for health monitoring in research settings.

Given that 32% (7/22) of participants wore the device for less than 4 days out of the requested 14-day wear period, we conducted a preliminary investigation to determine if some physical activity measures with moderate reliability (ICC bigger than 0.5) [36] could be obtained with just 3 days of wear. This investigation revealed that specific physical activity measures demonstrating moderate reliability, with ICC values greater than 0.5, can be reliably captured within this shorter timeframe. However, the overall reliability of these measures is not as strong as desired, suggesting that extended wear durations may still be necessary to ensure comprehensive data reliability across a broader range of physical activities. While this exploratory study suggests that shorter wear durations might reduce participant burden and enhance data collection efficiency for specific activities, it also highlights the need for careful result interpretation. Future research should prioritize enhancing the reliability of these measures before considering reduced monitoring durations to ensure that the data collected remains both robust and reliable. Our study employed the Verisense watch, a wearable technology that captures a comprehensive array of physical activity measures, offering a valuable data resource for further research into cognitive impairment. This pilot study not only assesses the adherence of older adults to a long-lasting, waterproof wearable device but also evaluates the consistency of detailed physical activity measures. As part of our ongoing digital brain health platform, we aim to integrate these physical activity insights with other modalities such as sleep and digital cognitive assessments to enhance our understanding of cognitive health. With an anticipated increase in sample size, we plan to provide a more complete digital phenotyping of cognition that leverages the combined strengths of various data types.

We recognized a few limitations in our study. First, the relatively small sample size makes this study serving primarily to offer preliminary insights at a pilot study level. Second, there is a potential for selection bias to influence the findings of this study. Specifically, within the digital brain health platform, participants are given the freedom to choose from various technologies according to their comfort and commitment levels. This choice means that participants who are more comfortable using the Verisense device might be more likely to participate in this study. Further research is also necessary to investigate the reasons behind the instances when the devices were taken off by participants. Third, investigating the impact of different wear time thresholds for defining worn days could be a valuable direction for future research, particularly in assessing device compliance and changes in physical activity measures. Fourth, the consistent inactivity observed in certain participants underscores the necessity for in-depth investigations into the potential health implications or obstacles preventing adherence, as well as the causes of activity variability. Future research should collect more comprehensive lifestyle and social determinant data to explain it.

Conclusion

In summary, this study revealed that while older adults generally showed high daily adherence to the wearable device, consistent usage across consecutive days proved difficult. The varied adherence rates highlight the importance of tailored strategies to improve commitment to the study. Additionally, our initial analysis suggests that stable data for specific activities can be achieved with as little as 3 days of device wear, opening the door to potentially shorter required wear times in subsequent studies. These findings underline the effectiveness of wearables in monitoring physical activity in older populations and emphasize the ongoing necessity to refine usage protocols and enhance user engagement to guarantee the collection of precise and comprehensive data.

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Data Availability

The datasets generated and analyzed for this study could be shared on reasonable request.

Conflicts of Interest

RA is a scientific advisor to Signant Health and Novo Nordisk, and a consultant to the Davos Alzheimer's Collaborative. VBK is on the scientific advisory board for Altoida Inc and serves as a consultant to AstraZeneca. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Multimedia Appendix 1
Supplementary table and figure.
[DOCX File, 162 KB - aging_v7i1e60209_app1.docx]

References

1. Pais R, Ruano L, Carvalho OP, Barros H. Global cognitive impairment prevalence and incidence in community dwelling older adults—a systematic review. Geriatrics (Basel) 2020 Oct 27;5(4):84. [doi: 10.3390/geriatrics5040084] [Medline: 33121002]
2. Zucchella C, Sinforiani E, Tamburin S, et al. The multidisciplinary approach to Alzheimer's disease and dementia: a narrative review of non-pharmacological treatment. Front Neurol 2018;9:1058. [doi: 10.3389/fneur.2018.01058] [Medline: 30619031]

3. Zhang XX, Tian Y, Wang ZT, Ma YH, Tan L, Yu JT. The epidemiology of Alzheimer’s disease modifiable risk factors and prevention. J Prev Alzheimers Dis 2021;8(3):313-321. [doi: 10.14283/jpad.2021.15] [Medline: 34101789]
4. Warburton DER, Bredin SSD. Health benefits of physical activity: a systematic review of current systematic reviews. Curr Opin Cardiol 2017 Sep;32(5):541-556. [doi: 10.1097/HCO.0000000000000437] [Medline: 28708630]
5. Dominguez LJ, Veronese N, Vernuccio L, et al. Nutrition, physical activity, and other lifestyle factors in the prevention of cognitive decline and dementia. Nutrients 2021 Nov 15;13(11):4080. [doi: 10.3390/nu13114080] [Medline: 34836334]
6. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 8;396(10248):413-446. [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
7. Biazus-Sehn LF, Schuch FB, Firth J, de Souza Stigger F. Effects of physical exercise on cognitive function of older adults with mild cognitive impairment: a systematic review and meta-analysis. Arch Gerontol Geriatr 2020;89:104048. [doi: 10.1016/j.archger.2020.104048] [Medline: 32460123]
8. Law CK, Lam FM, Chung RC, Pang MY. Physical exercise attenuates cognitive decline and reduces behavioural problems in people with mild cognitive impairment and dementia: a systematic review. J Physiother 2020 Jan;66(1):9-18. [doi: 10.1016/j.jphys.2019.11.014] [Medline: 31843427]
9. Hamer M, Chida Y. Physical activity and risk of neurodegenerative disease: a systematic review of prospective evidence. Psychol Med 2009 Jan;39(1):3-11. [doi: 10.1017/S0033291708003681] [Medline: 18570697]
10. Blondell SJ, Hammersley-Mather R, Veerman JL. Does physical activity prevent cognitive decline and dementia? A systematic review and meta-analysis of longitudinal studies. BMC Public Health 2014 May 27;14:1-12. [doi: 10.1186/1471-2458-14-510] [Medline: 24885250]
11. Guure CB, Ibrahim NA, Adam MB, Said SM. Impact of physical activity on cognitive decline, dementia, and its subtypes: meta-analysis of prospective studies. Biomed Res Int 2017;2017(1):9016924. [doi: 10.1155/2017/9016924] [Medline: 28271072]
12. McCambridge J, Witton J, Elbourne DR. Systematic review of the Hawthorne effect: new concepts are needed to study research participation effects. J Clin Epidemiol 2014 Mar;67(3):267-277. [doi: 10.1016/j.jclinepi.2013.08.015] [Medline: 24275499]
13. Czech MD, Psaltos D, Zhang H, et al. Age and environment-related differences in gait in healthy adults using wearables. NPJ Digit Med 2020;3(1):127. [doi: 10.1038/s41746-020-00334-y] [Medline: 33083562]
14. De Anda-Duran I, Hwang PH, Popp ZT, et al. Matching science to reality: how to deploy a participant-driven digital brain health platform. Front Dement 2023;2:1135451. [doi: 10.3389/frdem.2023.1135451]
15. Valenzuela T, Okubo Y, Woodbury A, Lord SR, Delbaere K. Adherence to technology-based exercise programs in older adults: a systematic review. J Geriatr Phys Ther 2018;41(1):49-61. [doi: 10.1519/JPT.0000000000000095] [Medline: 27362526]
16. Moore K, O’Shea E, Kenny L, et al. Older adults’ experiences with using wearable devices: qualitative systematic review and meta-synthesis. JMIR Mhealth Uhealth 2021 Jun 3;9(6):e23832. [doi: 10.2196/23832] [Medline: 34081020]
17. Paolillo EW, Lee SY, VandeBunte A, et al. Wearable use in an observational study among older adults: adherence, feasibility, and effects of clinicodemographic factors. Front Digit Health 2022;4:884208. [doi: 10.3389/fdgth.2022.884208] [Medline: 35754462]
18. Yingling LR, Mitchell V, Ayers CR, et al. Adherence with physical activity monitoring wearable devices in a community-based population: observations from the Washington, D.C., Cardiovascular Health and Needs Assessment. Transl Behav Med 2017 Dec;7(4):719-730. [doi: 10.1007/s13142-016-0454-0] [Medline: 28097627]
19. Frank B, Ally M, Brekke B, et al. Plasma p-tau181 shows stronger network association to Alzheimer’s disease dementia than neurofilament light and total tau. Alz Dement 2022 Aug;18(8):1523-1536. [doi: 10.1002/alz.12508] [Medline: 34854549]
20. Steenland K, Macneil J, Bartell S, Lah J. Analyses of diagnostic patterns at 30 Alzheimer’s disease centers in the US. Neuroepidemiology 2010;35(1):19-27. [doi: 10.1159/000302844] [Medline: 20357515]
21. Leoutsakos JMS, Forrester SN, Lyketsos C, Smith GS. Latent classes of neuropsychiatric symptoms in NACC controls and conversion to mild cognitive impairment or dementia. J Alzheimers Dis 2015;48(2):483-493. [doi: 10.3233/JAD-150421] [Medline: 26402012]
22. McDevitt B, Moore L, Akhtar N, Connolly J, Doherty R, Scott W. Validity of a novel research-grade physical activity and sleep monitor for continuous remote patient monitoring. Sensors (Basel) 2021 Mar 13;21(6):2034. [doi: 10.3390/s21062034] [Medline: 33805690]
23. Migueles JH, Rowlands AV, Huber F, Sabia S, van Hees VT. GGIR: a research community–driven open source R package for generating physical activity and sleep outcomes from multi-day raw accelerometer data. J Meas Phys Behav 2019;2(3):188-196. [doi: 10.1123/jmpb.2018-0063]
24. Evenson KR, Wen F, Metzger JS, Herring AH. Physical activity and sedentary behavior patterns using accelerometry from a national sample of United States adults. Int J Behav Nutr Phys Act 2015 Feb 15;12:20. [doi: 10.1186/s12966-015-0183-7] [Medline: 25889192]
25. Shechtman O. The coefficient of variation as an index of measurement reliability. In: Methods of Clinical Epidemiology: Springer; 2013:39-49.

26. Liljequist D, Elfving B, Roaldsen KS. Intraclass correlation: a discussion and demonstration of basic features. PLoS One 2019;14(7):e0219854. [doi: 10.1371/journal.pone.0219854] [Medline: 31329615]
27. Bauman AE, Sallis JF, Dzewaltowski DA, Owen N. Toward a better understanding of the influences on physical activity: the role of determinants, correlates, causal variables, mediators, moderators, and confounders. Am J Prev Med 2002 Aug;23(2 Suppl):5-14. [doi: 10.1016/s0749-3797(02)00469-5] [Medline: 12133733]
28. Chekroud SR, Gueorguieva R, Zheutlin AB, et al. Association between physical exercise and mental health in 1.2 million individuals in the USA between 2011 and 2015: a cross-sectional study. Lancet Psychiatry 2018 Sep;5(9):739-746. [doi: 10.1016/S2215-0366(18)30227-X] [Medline: 30099000]
29. Bouchard C, Blair SN, Haskell WL. Physical Activity and Health: Human Kinetics; 2012.
30. Koorts H, Eakin E, Estabrooks P, Timperio A, Salmon J, Bauman A. Implementation and scale up of population physical activity interventions for clinical and community settings: the PRACTIS guide. Int J Behav Nutr Phys Act 2018 Jun 8;15(1):51. [doi: 10.1186/s12966-018-0678-0] [Medline: 29884236]
31. Middleton KR, Anton SD, Perri MG. Long-term adherence to health behavior change. Am J Lifestyle Med 2013;7(6):395-404. [doi: 10.1177/1559827613488867] [Medline: 27547170]
32. Bleich SN. Updated USPSTF recommendations for behavioral counseling interventions: gaps, challenges, and opportunities. JAMA Intern Med 2022 Sep 1;182(9):901-903. [doi: 10.1001/jamainternmed.2022.2015] [Medline: 35881411]
33. Böhm B, Karwiese SD, Böhm H, Oberhoffer R. Effects of mobile health including wearable activity trackers to increase physical activity outcomes among healthy children and adolescents: systematic review. JMIR Mhealth Uhealth 2019 Apr 30;7(4):e8298. [doi: 10.2196/mhealth.8298] [Medline: 31038460]
34. Teixeira E, Fonseca H, Diniz-Sousa F, et al. Wearable devices for physical activity and healthcare monitoring in elderly people: a critical review. Geriatrics (Basel) 2021 Apr 7;6(2):38. [doi: 10.3390/geriatrics6020038] [Medline: 33917104]
35. McManus DD, Trinquart L, Benjamin EJ, et al. Design and preliminary findings from a new electronic cohort embedded in the Framingham Heart Study. J Med Internet Res 2019 Mar 1;21(3):e12143. [doi: 10.2196/12143] [Medline: 30821691]
36. Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. J Chiropr Med 2016 Jun;15(2):155-163. [doi: 10.1016/j.jcm.2016.02.012] [Medline: 27330520]

Abbreviations

BU ADRC: Boston University Alzheimer's Disease Research Center
CV: coefficient of variation
ICC: intraclass correlation coefficient

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Quantifying the Enhancement of Sarcopenic Skeletal Muscle Preservation Through a Hybrid Exercise Program: Randomized Controlled Trial

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Abstract

Background: Sarcopenia is characterized by the loss of skeletal muscle mass and muscle function with increasing age. The skeletal muscle mass of older people who endure sarcopenia may be improved via the practice of strength training and tai chi. However, it remains unclear if the hybridization of strength exercise training and traditional Chinese exercise will have a better effect.

Objective: We designed a strength training and tai chi exercise hybrid program to improve sarcopenia in older people. Moreover, explainable artificial intelligence was used to predict postintervention sarcopenic status and quantify the feature contribution.

Methods: To assess the influence of sarcopenia in the older people group, 93 participated as experimental participants in a 24-week randomized controlled trial and were randomized into 3 intervention groups, namely the tai chi exercise and strength training hybrid group (TCSG; n=33), the strength training group (STG; n=30), and the control group (n=30). Abdominal computed tomography was used to evaluate the skeletal muscle mass at the third lumbar (L3) vertebra. Analysis of demographic characteristics of participants at baseline used 1-way ANOVA and χ^2 tests, and repeated-measures ANOVA was used to analyze experimental data. In addition, 10 machine-learning classification models were used to calculate if these participants could reverse the degree of sarcopenia after the intervention.

Results: A significant interaction effect was found in skeletal muscle density at the L3 vertebra, skeletal muscle area at the L3 vertebra (L3 SMA), grip strength, muscle fat infiltration, and relative skeletal muscle mass index (all P values were <.05). Grip strength, relative skeletal muscle mass index, and L3 SMA were significantly improved after the intervention for participants in the TCSG and STG (all P values were <.05). After post hoc tests, we found that participants in the TCSG experienced a better effect on L3 SMA than those in the STG and participants in the control group. The LightGBM classification model had the greatest performance in accuracy (88.4%), recall score (74%), and F_1-score (76.1%).

Conclusions: The skeletal muscle area of older adults with sarcopenia may be improved by a hybrid exercise program composed of strength training and tai chi. In addition, we identified that the LightGBM classification model had the best performance to predict the reversion of sarcopenia.

Trial Registration: ClinicalTrials.gov NCT05694117; https://clinicaltrials.gov/study/NCT05694117

(JMIR Aging 2024;7:e58175) doi:10.2196/58175

KEYWORDS

sarcopenia; older adults; physical exercise program; explainable artificial intelligence; tai chi

Introduction

With the rapid development of medicine and technology, people are increasingly empowered to face life-threatening diseases, which has led to a prolonged human lifespan. However, this has also resulted in a higher prevalence of age-related illnesses. Further, 1 significant issue is the gradual decline in skeletal muscle function, particularly sarcopenia, which is the loss of strength, power, and muscle mass due to aging [1]. Sarcopenia is characterized by decreased muscle strength and impaired regeneration, with individuals potentially losing up to half of their skeletal muscle mass by the age of 80 years [2,3]. This decline is driven by interactions between systemic signaling and intrinsic muscle tissue mechanisms, leading to decreased protein synthesis and myofiber denervation. Additionally, the reduced regenerative potential of aging muscle cannot effectively regulate cell quality [4-6]. These pathological changes in the important part can seriously impact the quality of life and the ability to perform daily activities in older people [7-11]. Sarcopenia is also an objective indicator of cancer cachexia [12] and is associated with suboptimal surgical postoperative outcomes [13], lower survival [12,14], and toxic counteraction [15-17]. Mortality rates nearly double when sarcopenia is combined with inflammation [18]. Therefore, addressing the serious health issues of older people with sarcopenia is imperative.

Many approaches have been proposed to address the muscle loss associated with sarcopenia, including managing chronic low-grade systemic inflammation [19], leveraging the anabolic effects of insulinlike growth factor 1 (IGF-1) signaling [20], and increasing the intake of protein and vitamin D [7]. Correspondingly, hormones, anabolic drugs, and nutritional interventions have been explored for therapeutic applications. It is well established that lean body mass is critical to health, yet the effectiveness of protein interventions in increasing lean body mass remains inconsistent [21,22]. Notably, there is no positive impact on lean body mass or testosterone-induced anabolic responses when protein intake exceeds the recommended intake (0.8 g/kg/day for adults) [23,24]. While treatments such as myostatin antagonists and androgens are being developed and have garnered optimism [25], many commonly prescribed medications have unwanted side effects [25]. Consequently, the Food and Drug Administration has been cautious in approving drugs to treat sarcopenia and has yet to approve any such drug, emphasizing the importance of drug safety. Therefore, the treatment of sarcopenia requires consideration of alternative approaches.

Fortunately, exercise therapy has shown positive effects on older adults with sarcopenia [5]. Specifically, strength exercise training (SET) is regarded as the most effective intervention due to its ability to improve the activation of IGF-1, the Akt/mTOR, and Akt/FOXO3 pathways [26,27]. Additionally, several studies have shown that traditional Chinese exercise also has positive effects on muscle health. Over the last 15 years, 12 traditional Chinese exercise–based studies have been conducted [28-39], with 2 focusing on tai chi [37,38]. Tai chi, which combines physical exercise and respiration, has been shown to decrease fat mass and improve lower limb muscle strength. For example, Yang-style 24-form tai chi over 10 months decreased fat mass [38], while 8-style tai chi significantly improved lower limb muscle strength compared to a control group (CG) [37]. A cross-sectional study on 139 Italian older adults also found that tai chi practitioners had lower body fat content and higher muscle content in the trunk [40]. Altogether, tai chi has demonstrated positive effects on older individuals with sarcopenia. However, it remains unclear whether combining tai chi with SET can further enhance muscle growth and potentially reverse sarcopenia.

In recent years, the increasing interest in applying artificial intelligence (AI) in health care has extended to this field [41,42-44]. Among these applications, a model produced by an explainable AI (XAI) system is particularly noteworthy. This automated diagnostic platform enhances system understandability and trustworthiness through its human-interpreted, high-level learning capabilities. Consequently, this study developed an offline XAI model to forecast whether sarcopenia can be reversed and to boost its clinical applicability.

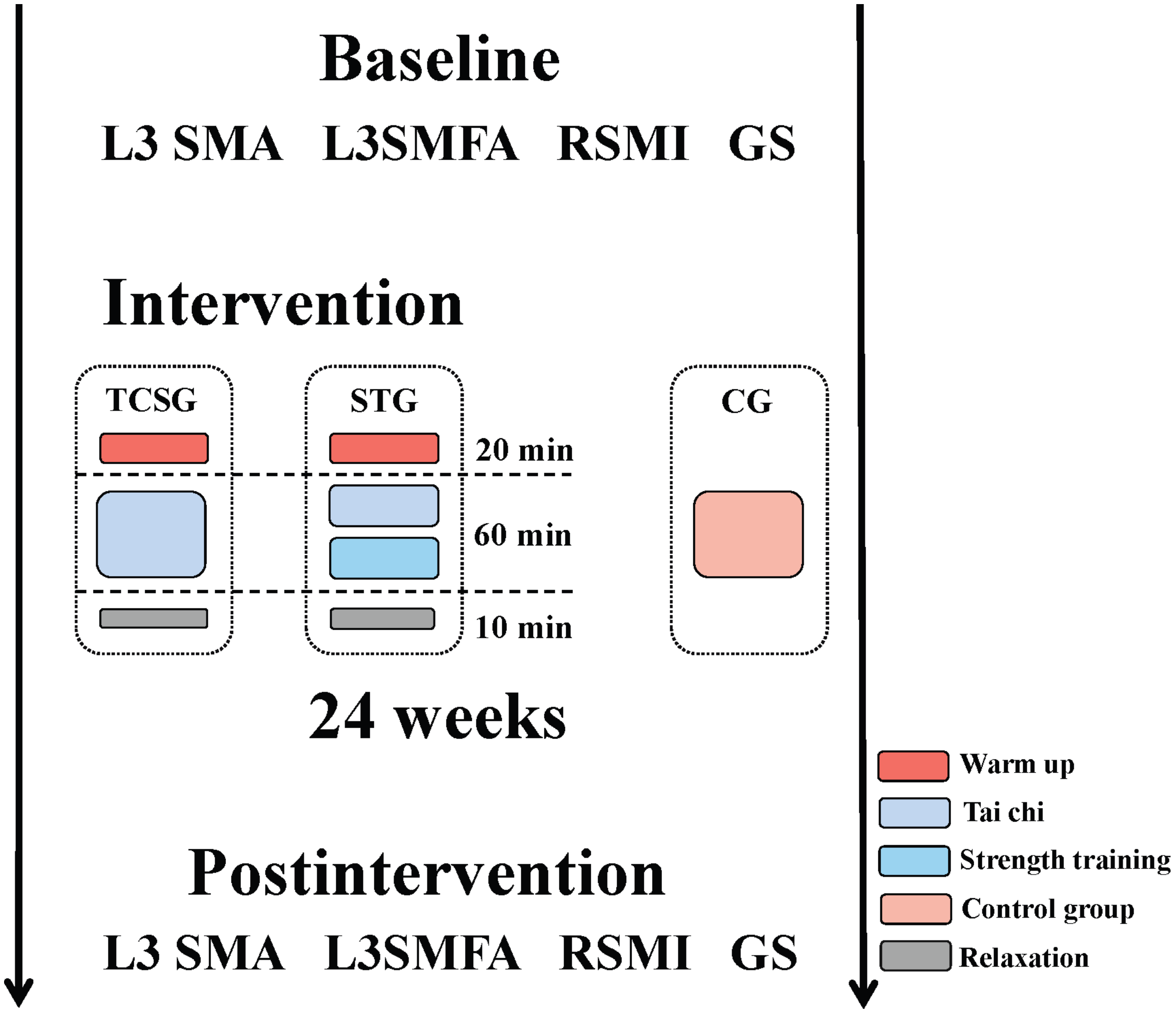
In summary, this study proposed a novel intervention method for older adults with sarcopenia, combining SET and tai chi. We discuss both the predictive and final effects on participants' sarcopenia state after 24 weeks of intervention. Based on initial physical ability, computed tomography (CT) scan findings, and 3 types of interventions, the effect was predicted using classic machine learning models. The final effect was quantified and visualized through CT scans. We hypothesized that the combined exercise intervention program of SET and tai chi will more effectively increase muscle mass and reverse sarcopenia than SET alone.

Methods

Research Experimental Program

This research was designed as a randomized controlled and double-blind trial with 3 different intervention groups: a tai chi exercise and strength training hybrid group (TCSG), a strength training group (STG), and a CG. This study was approved by the Ethics Committee of the Northeast Normal University (NC2019030702) and registered at ClinicalTrials.gov (NCT05694117). The random number table method was used to randomly assign participants to the 3 groups. CT provides precise estimates of muscle quality [45], and quantitative CT (QCT) can reveal the level of muscle edema and steatosis. It can also accurately analyze the form and structure of skeletal muscle by removing measurement errors caused by unstable CT readings [46]. Therefore, QCT scans were used to assess the area and density of skeletal muscle at the third lumbar (L3) in each group of participants at the imaging department of Baishan Central Hospital. The training was conducted 3 times a week for 90 minutes, for a total of 24 weeks of intervention from June 1, 2019, to December 30, 2019. The experimental protocol design is shown in Figure 1. During the experiment, each participant was requested to refrain from taking part in any other sort of physical exercise.

Figure 1. Experimental design flow chart. Participants were assigned to 1 of 3 intervention groups at random: the TCSG, the STG, or the CG. CG: control group; GS: grip strength; RSMI: relative skeletal muscle mass index; SMA: skeletal muscle area; SMFA: skeletal muscle intramuscular fat area; STG: strength training group; TCSG: tai chi exercise and strength training hybrid group.



Intervention

In total, 2 experimental groups and 1 CG were set for this trial. The intervention regimens included tai chi exercise hybrid strength training and strength training. The TCSG and the STG were the experimental groups. All participants in the experimental groups started with a 20-minute warm-up exercise and concluded with a 10-minute cool-down exercise. The following is a comprehensive outline of the intervention programs:

1. Tai chi exercise: The TCSG's tai chi training was structured into 2 cycles. The first cycle (weeks 1 - 12) focused on learning and consolidating basic tai chi movements, while the second cycle (weeks 13 - 24) aimed at improving and refining these movements. Each tai chi session lasted 30 minutes and included slow, flowing movements combined with deep breathing exercises to promote physical and mental relaxation.
2. Strength training: We designed a total of 5 strength training movements, 2 of which were for training the lower body muscles and 3 for training the upper body muscles. The movements to exercise the upper limb muscles were reverse grip curls, seated pull-downs, and bicep curls. The movements to train the muscle strength of the lower limbs were standing leg raises with an elastic band and supine leg lifts with an elastic band. Further, 1 training cycle lasted for 8 weeks, and the whole training had 3 cycles. In the first cycle, we trained with a light load but many repetitions (from 40% to 60% of 1 repetition maximum [RM] and 12 - 20 repetitions). A moderate-intensity load with a medium number of repetitions (60% - 80% of 1 RM and 5 - 12 repetitions) was used in the second cycle of training to further enhance the training load. To increase the participants' maximum muscular strength in the third cycle, we used a greater training load and fewer repetitions (70% - 85% of 1 RM and 5 - 8 repetitions). Participants in the STG performed 4 sets of each movement, while the TCSG completed 2 sets with a 2 to 3 minute rest between each set.
3. CG: Participants in the CG were provided with information on sarcopenia treatment and prevention, such as increasing protein intake and engaging in general physical activities.

Participants

We recruited volunteers from the Baishan Ciming Health Screening Center and the Health Screening Center of Baishan Central Hospital in Baishan, China, for this randomized controlled experiment. A form requesting informed permission was completed by each participant before the beginning of the trial. The screening process involved using the following inclusion and exclusion criteria to choose participants. Inclusion criteria: (1) patients between the ages of 60 - 75 years and (2) patients who meet the screening criteria for sarcopenia in Asia established by Asian Working Group for Sarcopenia (AWGS) 2016 [47]. Exclusion criteria: (1) participants taking medications that significantly impact musculoskeletal function, (2) participants enduring respiratory failure or other bodily problems, (3) participants with mental disorders or neurological disorders, and (4) patients who participate in other training programs on a regular basis. Prior research served as the basis for the calculation of the required sample size [48], which was at an α level of .01; we used 80% power and a 0.53 effect, and we assumed a 20% dropout rate. This resulted in a required sample size of 106 participants.

Assessment of Sarcopenia

The AWGS screening criteria [47] were used for each individual participant's evaluation. For a participant to be diagnosed with sarcopenia, they must satisfy each criterion listed below:

1. Grip strength: We used a Jamar Hydraulic Hand Dynamometer (SH5001, Saehan Corp, 2017) to measure participants' grip strength. Participants were instructed to maintain a natural standing posture during the duration of the test. They were also instructed to keep their wrists in a neutral position and their elbows completely extended [49]. The maximum value was retained after they were given 2 separate grip strength tests. The diagnostic boundary values for grip strength that met the screening criteria were <28 kg for males and <18 kg for females.
2. Physical performance: We assessed physical performance using the 6-meter gait speed recommended by AWGS 2016 [47]. Participants prepared behind the starting line, and when they heard the "start" command, they walked at normal speed toward the finish line, taking a few steps after walking across the finish line before stopping to avoid early deceleration [50]. Participants were considered to meet the criteria when their walking speed was less than 0.8 m/s.
3. Appendicular skeletal muscle mass (ASM): We used a multifrequency bioelectrical impedance analysis (Inbody S10 Biospace, Biospace Co Ltd) to measure the ASM. The screening criteria were satisfied by the men and women whose ASM was less than 7 kg/m^2 and less than 5.7 kg/m^2, respectively.

Assessment Methods for Skeletal Muscle and Fat

Overview

Further, 1 week prior to the beginning of the intervention and 1 week after it had concluded, we used a GE Revolution 256-row CT (General Electric Company, 2015) to measure the participants' abdomens. The scan was performed from the top of the diaphragm to the level of the umbilicus, and it was performed with the patient in a supine position with the hands raised flat over the head and the breath held at the end of a deep inspiration. The Gemstone Spectral Imaging scan used tube voltages ranging from 80 to 140 kVp (Peak kilovoltage), currents in the tubes that were intelligently regulated, a layer thickness of 5 millimeters, and a layer spacing of 5 millimeters. Immediately after the scanning process, the data and photos were saved in an automated manner in the workstation. The region of interest was manually defined at the L3 level using the X Section software on the GE ADW (version 4.7) workstation.

Measurement of Skeletal Muscle

Skeletal muscle density at the L3 vertebra (L3 SMD; Hounsfield units [HU]) and skeletal muscle area at the L3 vertebra (L3 SMA; cm^2) were measured using abdominal CT, with the HU range from −30 to 150 HU. This range provides the most realistic measurement of muscle and fat mass [51]. After a scan, an X Section software was used to manually outline the edges of the skeletal muscle tissue at this level, and the software automatically calculated the area of the corresponding tissue within the outlined area and the mean value of the CT.

Measurement Method for Skeletal Muscle Intramuscular Fat

Skeletal muscle intramuscular fat accumulates as the muscle mass decreases during the aging process [52]. At baseline and after the intervention, QCT was used to quantify the skeletal muscle intramuscular fat density at the L3 vertebra (L3 SMFD; HU), and the skeletal muscle intramuscular fat area at the L3 vertebra (L3 SMFA; cm^2). We used a range from −200 to 0 HU for the quantitatively measuring the fat threshold. After scanning, the X Section software was used again to manually outline the edges of the skeletal intermuscular fat at this level, and the software automatically calculated the area of corresponding tissue within the outlined area and the mean value of the CT.

Measurement Method for Relative Skeletal Muscle Mass Index

A relative skeletal muscle mass index (RSMI; kg/m^2) could be used to assess muscle growth [53]. The RSMI, which is represented as muscle mass per m^2 of the limbs, can be used to evaluate sarcopenia. Thus, RSMI was chosen as the main result indicator in the research and was evaluated using multifrequency bioelectrical impedance analysis.

Measurement Method for Muscle Fat Infiltration

According to research, muscle fat infiltration (MFI; %) will cause a reduction in muscle mass, producing muscular atrophy and leading to sarcopenia [54]. Therefore, we used the MFI as one of the observed indicators of the results as well. MFI was calculated by Equation 1:

(1)MFI=SMFA/(SMA+SMFA)\times 100

Measurement Method for Grip Strength

Grip strength is the most important criterion for diagnosing sarcopenia and a common indirect measure of total muscle strength [55]. Therefore, grip strength was selected as the primary observation and measured before and after the intervention. We used a Jamar Hydraulic Hand Dynamometer to measure grip strength of participants. Participants were instructed to maintain a natural standing posture during the duration of the test. They were also instructed to keep their wrists in a neutral position and their elbows completely extended [49]. The maximum value was retained after they were given 2 separate grip strength tests.

Data Analysis

In order to make the intervention runs as accurate as possible, we used a machine learning method to predict whether older people had sarcopenia after 24 weeks of intervention based on the participants' initial status before the intervention and the intervention protocol they received as features. The data used to train the model consisted of each participant's age, gender, and initial grip strength, RSMI, L3 SMA, and L3 SFMA as features and the presence or absence of sarcopenia after the intervention as a label. The performance of classification models was assessed per the F_1-score, precision, area under the curve (AUC), recall, and accuracy. These metrics were averaged across all validation or test sets during the repeated cross-validation process, with SD used to provide uncertainty estimates for these averages. Each model was trained 100 times individually using a 10-fold cross-validation. Hyperparameter tuning was performed using a grid search with cross-validation within each training fold to identify the optimal parameters for each model. For example, for the random forest (RF) model, we varied the number of trees (50 to 200), maximum depth (5 to 20), and minimum samples split (2 to 10). The best model was defined as the one with the highest average AUC across all folds. We also calculated the precision, recall, and F_1-score using a threshold of 0.5 for class predictions, ensuring consistency in performance evaluation. First, we trained 9 machine learning classification models using a k neighbors classifier [56], logistic regression (LR) [57], a gradient boosting classifier [58], linear discriminant analysis [59], an extra tree classifier [60], an RF classifier [61], a decision tree classifier [62], an XGBoost classifier [63], and a LightGBM classifier [64]. Then, the 3 best-performing models were selected for the stacking model in this dataset. The first layer consisted of the LightGBM, XGBoost, and RF classifiers. The second-level classifier, used to combine the outputs of these 3 models, was LR. In this research, a stacking technique was used in order to integrate numerous classifiers that were produced by various algorithms $L_1,...,L_n$ and applied to a singular dataset S. This dataset included instances of the type $S_i = (x_i, y_i)$, where x_i indicates the characteristic vectors and y_i indicates the classifications. In the beginning of this procedure, a group of base-level classifiers—C_1, C_2, and C_3, together with Ci = $L_n(S)$—were developed. Then, we had predictions for S_i, as per Equation 2:

(2)y^ik=Cki(xi)

The meta-level data were made up of several illustrations of the form ((y^i1,..., y^in), yi), in which features represent the output of the first-level classifier and categories are the appropriate labels for this sample.

The dataset was divided into 10 folds for cross-validation. Each model was trained on 9 folds and validated on the remaining fold, repeated 10 times for a total of 100 repetitions. For each fold, the model was trained and predictions were made on the validation fold. These predictions were saved. For each cross-validation run, the precision, recall, accuracy, and F_1-score were calculated. The means and SDs of these metrics over the 100 repetitions are reported in Table 1, providing an estimate of model performance and its variability. Predictions from all 100 cross-validation runs were aggregated to form a single prediction set. This aggregated prediction set was then used to generate the normalized confusion matrix presented in Figure 2, ensuring a comprehensive evaluation of the model's performance.

Table . Comparison of the performance of machine learning classification models. Performance metrics are reported as mean (SD), calculated over 100 repeats of 10-fold cross-validation.

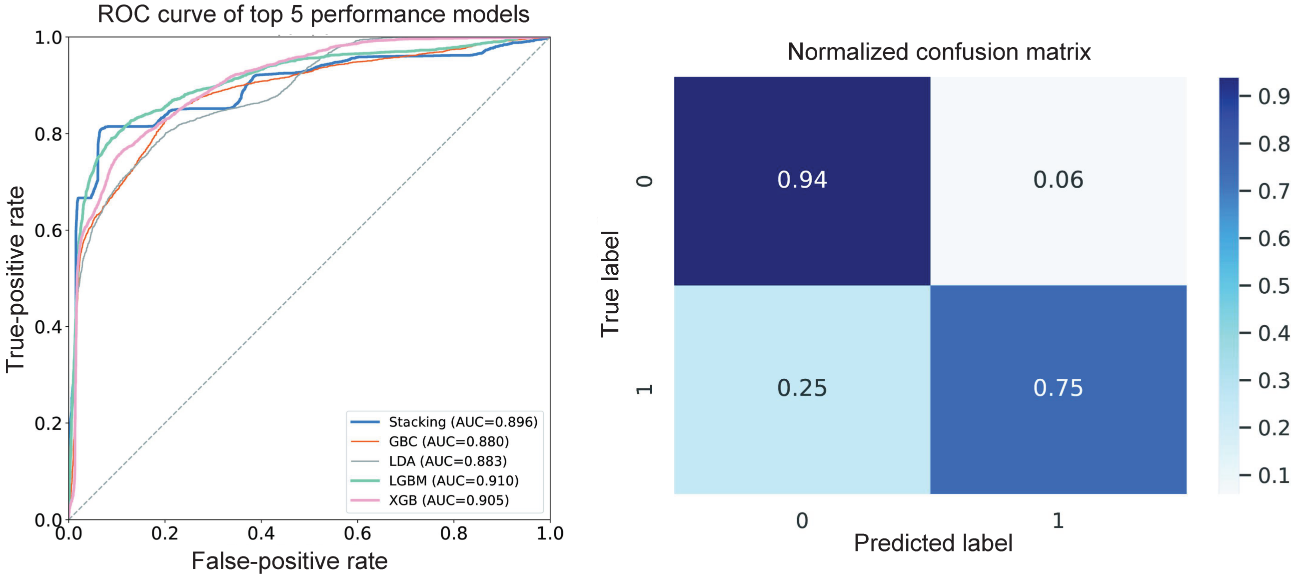
Models	Accuracy (%), mean (SD)	Precision (%), mean (SD)	Recall (%), mean (SD)	F_1-score (%), mean (SD)
KNN[a]	78.6 (1.9)	65.7 (5.9)	61.9 (5.2)	61.6 (4.2)
Decision tree	80.6 (2.5)	69.4 (6.7)	70.2 (5.7)	66.4 (5)
Logistic regression	82.8 (1.4)	75.9 (6.8)	60.6 (3.9)	63.6 (3.3)
Gradient boosting	83.5 (1.9)	76.5 (5.9)	67.1 (4.1)	67.9 (4.2)
LDA[b]	84.4 (1.6)	78 (4.9)	68 (3.4)	69.3 (3.7)
Extra tree	84.9 (1.8)	80.6 (7.1)	65.6 (4.8)	68.4 (4.9)
Random forest	85.5 (1.8)	81.7 (7.9)	60.3 (4.3)	65.7 (5.2)
XGBoost	85.8 (1.7)	81.4 (5.5)	68 (4)	71.2 (3.5)
Stacking	86.6 (2.6)	83.9 (5)[c]	67 (1.8)	71.3 (2.3)
LightGBM[c]	88.4 (2)[c]	83.9 (6.1)	74 (4.5)[c]	76.1 (5.1)[c]

[a] KNN: k neighbors classifier.

[b] LDA: linear discriminant analysis.

[c] The values indicate the best performance achieved by each model for the corresponding metric.

Figure 2. The results of the model’s performance to predict whether a participant is a patient with sarcopenia at second evaluation; the ROC curve of the top 5 models, and the confusion matrix of the LightGBM classifier model. (A) The top-5 performance models’ ROC curve; (B) normalized confusion matrix. AUC: area under the curve; GBC: gradient boosting classifier; LDA: linear discriminant analysis; LGBM: LightGBM classifier; ROC: receiver operating characteristic; XGB: XGBoost classifier.



(A) (B)

Moreover, the receiver operating characteristic curves for the top 5 models are shown in . The horizontal axis depicts false-positive rate, while the vertical axis depicts true-positive rate. A greater AUC indicates superior performance. The LightGBM classifier model had the highest AUC (0.910). The normalized confusion matrix offers a more perceptible view of the accuracy of each category’s predictions made by the model, while the prediction result confusion matrix clearly displays all model predictions, with the real labels in the horizontal direction and the outcomes predicted by the model in the vertical direction. It is clear from that the model showed great performance in predicting whether or not participants reversed sarcopenia after the intervention (94% and 75%, respectively).

In addition, we calculated SHAP (Shapley additive explanations) values, because it could assign an important value to each feature that represents the effect on the model prediction of including that feature [65]. Any machine learning model’s output can be interpreted using SHAP, a game-theoretic approach. The SHAP value quantifies the contribution of each feature to the model’s predictions, represented by Equation 3:

$$(3)\varphi j=\sum SF\subseteq F\ \{j\}|SF|!(|F|-|SF|-1)!|F|![fSF\cup\{j\}(xSF\cup\{j\})-fSF(xSF)]$$

in which S_F stands for all of the potential subsets that do not contain characteristic j, x stands for the values of the input characteristics, $|S_F|$ stands for the dimension of S_F, and j stands for a specific characteristic. To calculate this effect, 2 models, fSF∪j and fSF, were trained, conditioned on the presence or absence of feature j throughout the training process. This allows the contribution of each feature to be calculated. We used the SHAP TreeExplainer algorithm to identify important features that could accurately predict whether participants could reverse muscle loss after the intervention.

Statistical Analysis

All data analysis, statistical analysis, and visualization procedures for this study were completed using Python (version 3.7.1; Python Software Foundation) and SPSS (version 25.0; IBM Corp) software. Before performing ANOVA, data distribution was assessed using the Shapiro-Wilk test to check for normality, and Levene test was used to check for homoscedasticity. Nonnormally distributed data were log-transformed. Further, 1-way ANOVA and χ^2 tests were responsible for assessing baseline differences in demographic data among groups. Repeated-measures ANOVA was used to examine the impact of the 3 different intervention programs on the participants. Simple effects were used for the factors that had further interaction effects. The Bonferroni post hoc test was used to further investigate group differences when ANOVA indicated statistical significance. The Bonferroni post hoc test was chosen for its control of the family-wise error rate, making it suitable for pairwise comparisons. A *P* value of <.05 was used as the threshold for statistical significance

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of Northeast Normal University (approval NC2019030702). A written informed consent form was obtained from each participant. Measures were implemented to safeguard participants’ privacy during data analysis.

Results

Overview

A total of 164 individuals were recruited (Figure 3); however, only 106 (48 females and 58 males) were found to meet the inclusion and exclusion criteria. Finally, 93 (50 females and 43 males) participants finished the research. Dropping out of the training (n=8) and being unable to continue due to illness (n=5) were the reasons for not finishing the program. The demographic characteristics of the participants at baseline are summarized in Table 2.

Figure 3. CONSORT flow diagram. CG: control group; CONSORT: Consolidated Standards of Reporting Trials; STG: strength training group; TCSG: tai chi exercise and strength training hybrid group.

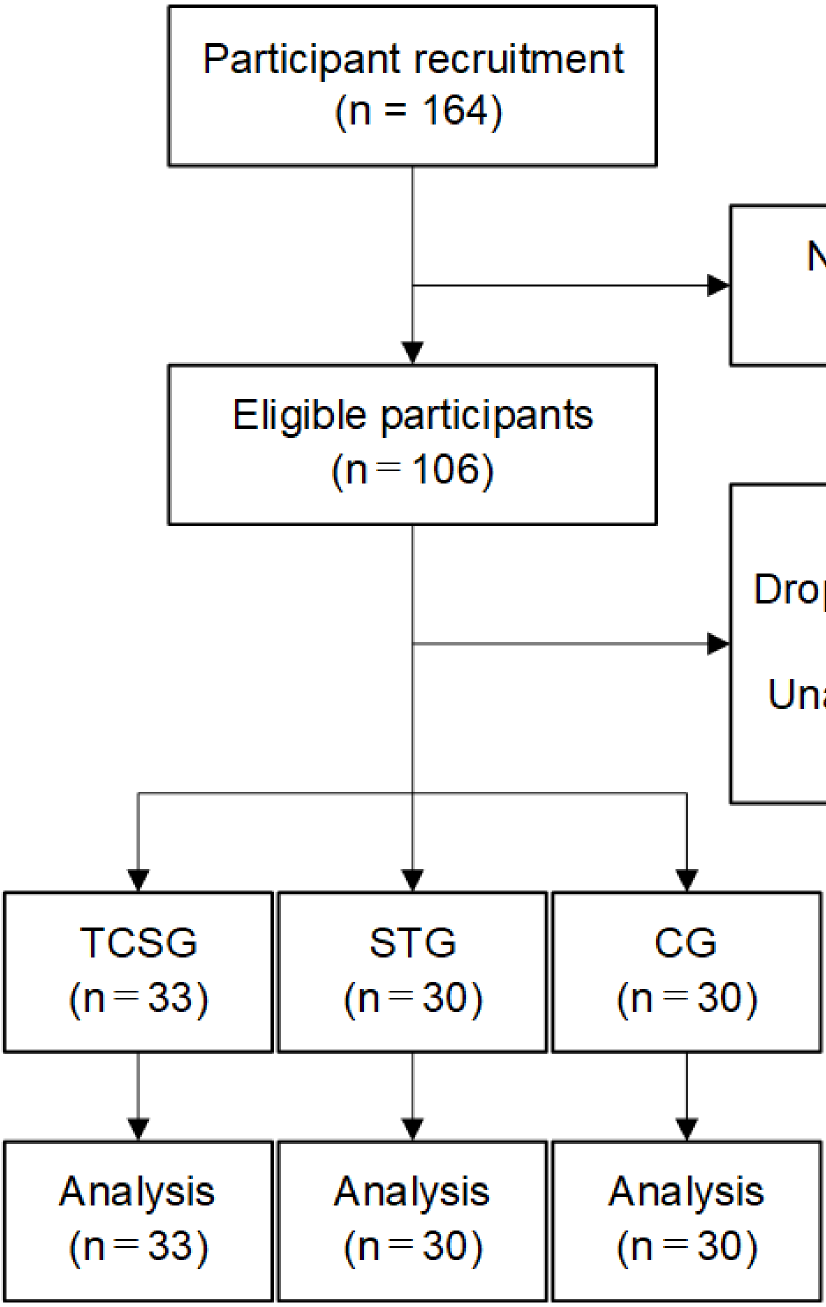


Table . Demographic features of the participants at baseline.

Items	TCSG[a] (n=33)	STG[b] (n=30)	CG[c] (n=30)	*P* value
Gender, n	male: 14; female: 19	male: 13; female: 17	male: 16; female: 14	.64
Age (years), mean (SD)	66.94 (4.42)	66.87 (3.84)	65.42 (3.97)	.34
BMI (kg/m^2), mean (SD)	23.23 (2.06)	22.8 (3.18)	21.93 (2.86)	.79

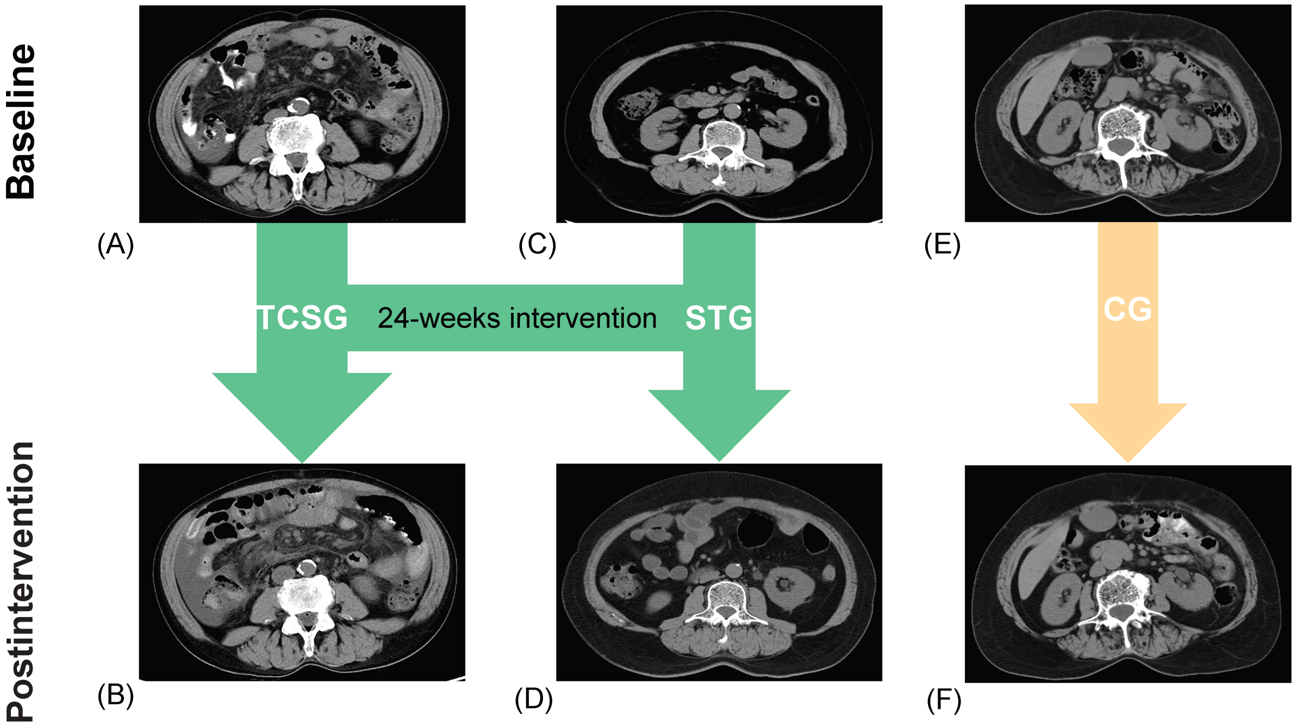
[a] TCSG: tai chi exercise and strength training hybrid group.

[b] STG: strength training group.

[c] CG: control group.

Further, a week after the experiment finished, we reassessed participants for sarcopenia. In the TCSG, we observed the reversal of sarcopenia in 15 (45.5%) participants, and in the STG, we observed the reversal of sarcopenia in 12 (40%) participants, for a total of 27 (29%) with reversal of sarcopenia. Expectedly, sarcopenia was not reversed in the CG participants. Furthermore, Figure 4 shows the QCT measurements of representative participants in each group before and after the intervention.

Figure 4. Shows the results of QCT scans of representative participants in each group before and after receiving the intervention. (A) Preintervention TCSG, (B) postintervention TCSG, (C) preintervention STG, (D) postintervention STG, (E) preintervention CG, and (F) postintervention CG. CG: control group; QCT: quantitative computed tomography; STG: strength training group; TCSG: tai chi exercise and strength training hybrid group.



Statistical Analysis Results

Figure 5 depicts the main results, and Table 3 presents results of repeated-measures ANOVA for each observation indicator. All variables did not differ between groups at baseline. It was found that grip strength (*P*=.008), RSMI (*P*=.002), L3 SMD (*P*<.001), L3 SMA (*P*=.005), and MFI (*P*=.008) had a statistically significant interaction effect. A significant improvement in grip strength, RSMI, L3 SMA, and L3 SMD was seen in the TCSG and STG at 24 weeks. There was a significant difference in postintervention L3 SMA in the TCSG compared to the STG and CG, as determined by a post hoc test. However, we did not find any significant interactions among L3 SMFA and L3 SMFD.

Figure 5. Violin plots of main results before and after the intervention for each group of participants. (A) RSMI; (B) L3 SMFA, (C) L3 SMA; and(D) grip strength. Violin plots show the distribution of the data, with the width of the plot indicating the density of data points at each value. Thex-axis represents the intervention groups (TCSG, STG, and CG), and the y-axis represents the measured outcomes (RSMI, L3 SMFA, L3 SMA, gripstrength). The green area represents the distribution of pretest values, and the orange area represents the distribution of posttest values. Individualpretest samples are marked by orange dots, and posttest samples are marked by red dots. CG: control group; RSMI: relative skeletal muscle massindex; SMA: skeletal muscle area; SMFA: skeletal muscle intramuscular fat area; STG: strength training group; TCSG: tai chi exercise and strengthtraining hybrid group.

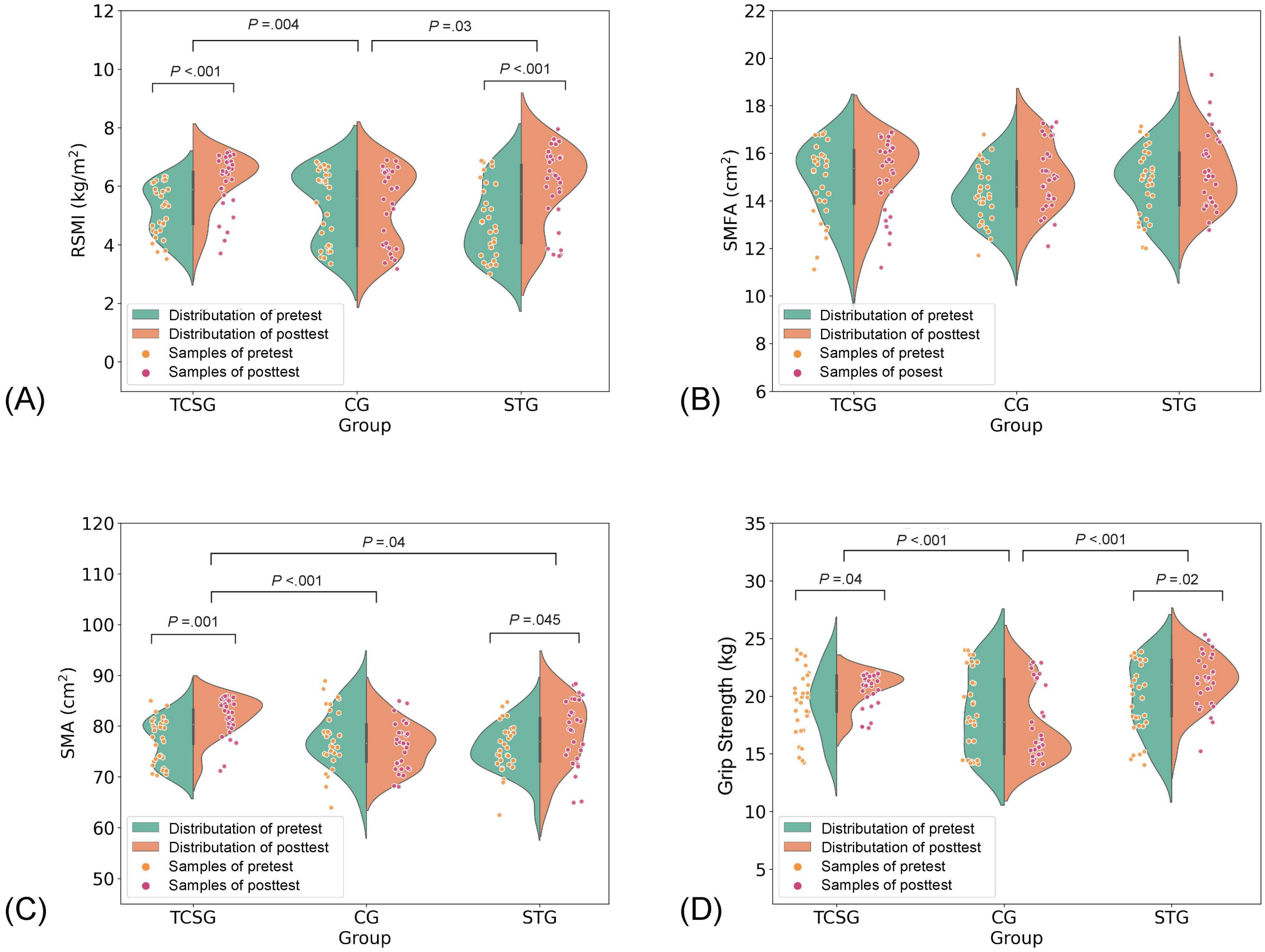


Table . Comparison of intervention effects between groups. Repeated-measures ANOVA analysis.

Parameters	TCSG[a] (n=33)		STG[b] (n=30)		CG[c] (n=30)		Group × time[d]
	Baseline	24 wk	Baseline	24 wk	Baseline	24 wk	*P* value
RSMI[e] (kg/m^2)	5.10 (0.91)	6.22 (0.93)[f,g]	4.84 (1.23)	6.05 (1.30)[f,g]	5.32 (1.21)	5.24 (1.28)[f]	.002
SMFA[h] (cm^2)	14.91 (1.59)	15.15 (1.49)	14.73 (1.43)	15.30 (1.58)	14.28 (1.24)	15.03 (1.39)	.38
SMA[i] (cm^2)	77.01 (4.42)	81.83 (3.83)[f,j]	75.79 (4.77)	78.64 (6.36)[f,k]	77.63 (5.81)	77.06 (4.53)[f]	.005
GS[l] (kg)	19.28 (2.75)	20.60 (1.50)[f,k]	19.73 (3.13)	21.35 (2.29)[f,k]	18.72 (3.48)	17.67 (3.10)[f]	.008
SMD[m] (Hounsfield units)	32.30 (1.84)	34.60 (1.98)[f,g]	32.64 (3.03)	34.72 (2.80)[f,g]	32.69 (3.72)	32.44 (3.31)[f]	<.001
SMFD[n] (Hounsfield units)	−65.14 (4.23)	−65.35 (3.73)	−64.01 (5.43)	−64.48 (4.71)	−64.21 (5.69)	−64.68 (6.11)	.76
MFI[o] (%)	16.23 (1.75)	15.61 (1.30)	16.30 (1.61)	16.35 (1.93)	15.60 (1.82)	16.52 (1.52)[k]	.008

[a] TCSG: tai chi exercise and strength training hybrid group.

[b] STG: strength training group.

[c] CG: control group.

[d] Analysis of two-way repeated measures ANOVA

[e] RSMI: relative skeletal muscle mass index.

[f] Significant difference among groups (*P*<.05).

[g] Significant difference within the group before and after intervention (*P*<.001).

[h] SMFA: skeletal muscle intramuscular fat area.

[i] SMA: skeletal muscle area.

[j] Significant difference within the group before and after intervention (*P*<.01).

[k] Significant difference within the group before and after intervention (*P*<.05).

[l] GS: grip strength.

[m] SMD: skeletal muscle density.

[n] SMFD: skeletal muscle intramuscular fat density.

[o] MFI: muscle fat infiltration.

Results of Machine Learning Model Classification

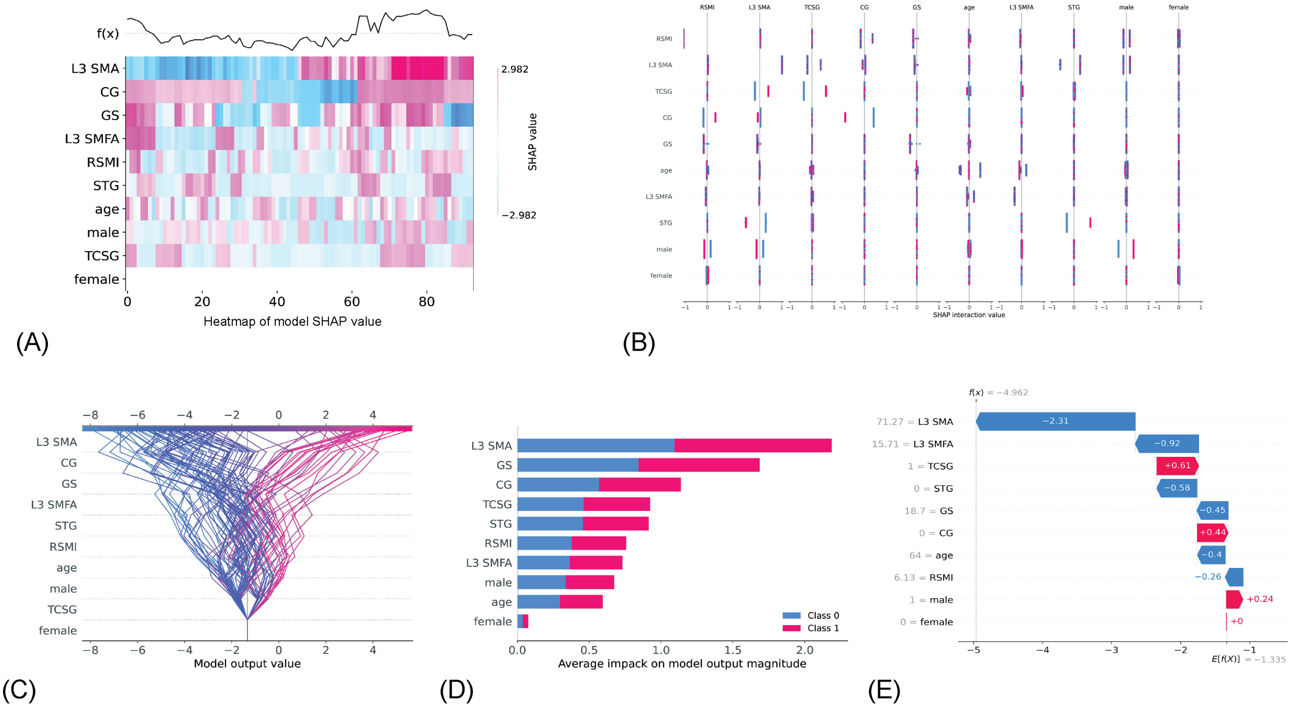
The average performance evaluation of the machine learning model after 100 rounds of training is shown in Table 1. We found that the LightGBM classification model exhibited the best performance in terms of average accuracy (88.4%, SD 2%), average recall (74%, SD 4.5%), and average F_1-score (76.1%, SD 5.3%). In addition, our stacking model with the first layer consisting of LightGBM classification model, XGBoost classification model, and RF classification model, and the second layer consisting of LR exhibited the best average precision (83.9%, SD 5%).

Moreover, the receiver operating characteristic curves for the top 5 models are shown in Figure 2A. The horizontal axis depicts false-positive rate, while the vertical axis depicts true-positive rate. A greater AUC indicates superior performance. The LightGBM classifier model had the highest AUC (0.910). The normalized confusion matrix offers a more perceptible view of the accuracy of each category's predictions made by the model, while the prediction result confusion matrix clearly displays all model predictions. This was with the real labels in the horizontal direction and the outcomes predicted by the model in the vertical direction. It is clear from Figure 2B that the model showed great performance in predicting whether or not participants reversed sarcopenia after the intervention.

Results of Feature Contribution

The SHAP values of features for contribution are presented in Figure 6. We used SHAP values specifically derived from the LightGBM model, as it demonstrated the best performance among all models. The feature's shape value indicates the degree to which the feature contributes to the overall model. The greatest contributions were shown in grip strength and L3 SMA across all variables. It is clear from Figure 6B that the characteristics may have an effect on one another. This implies that by evaluating all possible combinations of features, the optimal combination of features that would increase the performance of the model can be identified.

Figure 6. The SHAP values for each feature are shown in this plot. The various characteristics are shown along the y-axis. (A) Heat map plot: shows the SHAP values for each feature; the x-axis denotes the sample sequence; red denotes positive impacts and blue represents negative impacts; the degree of contribution is determined by the color shade. *f*(*x*) denotes the output of before activation function. (B) Interaction values plot: illustrates the connection that exists between the various features. (C) Decision plot: the influential features in deriving the model's output are shown. The features are listed on the y-axis in order of decreasing influence, while the x-axis reflects the model's output value. A line depicts the prediction for each observation. Each line crosses the x-axis at the predicted value for the relevant observation at the top of the figure. The SHAP values of each parameter are added to the base value of the model from the bottom to the top of the plot, illustrating how each feature affects the final prediction. Features moving rightward positively influence the model, while those moving leftward have a negative effect. (D) Bar plot: displays the average absolute SHAP values for each characteristic, with the x-axis indicating that L3 SMA has the greatest contribution of all the features. (E) Waterfall plot: illustrates the degree to which each feature in a single sample has an effect on the model. The x-axis indicates the SHAP value, with the expected value of the model output shown at the bottom. Each row illustrates how the contribution of each feature shifts the value from the expected model output to the prediction. This graph shows that the TR (intervention type) feature has the highest positive influence on model prediction performance, while the L3 SMA feature has the largest negative effect. CG: control group; GS: grip strength; RSMI: relative skeletal muscle mass index; SHAP: Shapley additive explanations; SMA: skeletal muscle area; SMFA: skeletal muscle intramuscular fat area; STG: strength training group; TCSG: tai chi exercise and strength training hybrid group; TR: intervention type.



Discussion

Principal Findings

This study suggests a novel hybrid training strategy for older individuals with sarcopenia that combines SET and tai chi. In addition, AI was used to foresee if the intervention in older adults will reverse their sarcopenia. The results of this study showed that at the end of the 24-week intervention, participants in both the TCSG and STG improved their grip strength, RSMI, and L3 SMA, albeit to varying degrees. In terms of L3 SMA, the TCSG outperformed the others and exhibited the most substantial improvement. The strongest results in reversion of sarcopenia, however, were seen with the hybrid exercise program combining the TCSG and STG. As well as this, we were among the first to use XAI to predict sarcopenia in a Chinese sample of older people with an average accuracy rate of 88.4% (SD 2%).

We revealed that older people with sarcopenia in the STG and TCSG showed improvements in hand grip strength, RSMI, L3 SMA, and L3 SMD after 24 weeks of intervention. In comparison to both the STG and CG, the L3 SMA of the patients in the TCSG significantly improved. In accordance with the present results, previous studies have demonstrated that SET intervention has the ability to reverse sarcopenia and improve physical health [66]. This result may be explained by the fact that the contraction of strength training's mechanical stress has a variety of positive consequences that increase intracellular protein accumulation net-positively, leading to the remodeling of the extracellular matrix and the growth of muscle fibers [67]. Specifically, SET stimulates PGC-1α expression in a working muscle, which could induce IGF-1 and suppress myostatin, leading to significant skeletal muscle growth [68], and IGF-1 expression increased, which might prevent atrophy and encourage hypertrophy; this might be a contributing factor to the amelioration of skeletal muscle area. Meanwhile, mechanical loading encourages the expression of growth hormone, as the growth hormone/IGF-1 axis and enhanced IGF-1 gene expression are thought to be the primary mechanisms by which growth hormone regulates postnatal bone development.

Perhaps the most important finding is that in terms of L3 SMA and RSMI, the TCSG considerably outperformed the STG after 24 weeks. These findings corroborate those of prior research suggesting that hybrid exercise may have a more potent effect on muscles [39,69-71]. Chinese traditional exercise, an assortment of low-intensity cardio mind-body exercises such as tai chi, Yijin Jing, Baduanjin, etc, has been used in China for centuries to both prevent and treat illness. As an aerobic training with low intensity, tai chi is commonly regarded as that it can improve physical condition, including improving endurance ability, increasing insulin sensitivity, and modulating fat metabolism. This impact is principally linked to the skeletal muscle's markedly increased mitochondrial volume and density. PGC-1α/FNDC5/UCP1 signaling pathway activation and PGC-1α overexpression are the 2 factors responsible for this increase [72]. This effect increases the amount and activity of mitochondrial enzymes while also increasing the rate of fat burning in muscles both at rest and during low-intensity exercise [73-76]. Another possible explanation for this is that the theoretical principles of traditional Chinese medicine are helpful in maintaining a calm and composed state of mind. They also help the body's innate self-regulatory or self-repair mechanisms to trigger and help the body to release endogenous neurohormones in a balanced manner [77,78]. Thus, the hybrid exercise training protocol of SET and tai chi had better performance and greater advantages than other intervention strategies.

Further, 1 unexpected finding was the extent to which neither the hybrid program nor SET could prevent intramuscular fat buildup. It is commonly known that as people age, their intramuscular fat content gradually increases [79,80]. The L3 level of the skeletal muscle intramuscular fat area showed a growing tendency in all 3 groups following the exercise intervention, but no statistical significance was identified. The findings of this study do not support the previous research finding that strength training and aerobic activity might assist older persons in avoiding age-related intramuscular fat accumulation [81]. This finding may be attributable to differences in the intensity and frequency of aerobic activity between studies.

The discovery that a total of 29% (n=27) of the participants were able to reverse their sarcopenia is perhaps the most clinically important finding. This included 40% (n=12) of the STG and 45.5% (n=15) of the TCSG. Our study links recovery from geriatric disease with a mixed exercise intervention, and the findings of this study could provide a new option for the treatment of sarcopenia and broadly support other research efforts in similar areas linking geriatric disease recovery to hybrid exercise [69,71].

Several limitations need to be noted regarding this study. First, given that there has been a wealth of research performed on the benefits of tai chi on skeletal muscle, we did not set up a distinct tai chi intervention group. Second, despite its effectiveness in enhancing the skeletal muscle area and RSMI in geriatric individuals with sarcopenia, the hybrid exercise program has limitations in terms of skeletal muscle intramuscular fat area. Third, we believe individual factors, such as the severity of sarcopenia and the activity habits of older people with sarcopenia, may influence the reversibility of sarcopenia. This study's sample size offers valuable insights, yet further validation in larger cohorts is recommended in alignment with the sample size guidelines proposed [82] for clinical prediction models prior to clinical implementation. By using initial sarcopenia in older individuals, reversal of sarcopenia, and interventions as foundational data, a more comprehensive system with diverse features may be developed in the future to provide specialized medical assistance to this patient population.

Conclusions

According to the results of our research, a combination exercise program consisting of SET and tai chi is capable of increasing muscle mass and reversing sarcopenia in older people effectively. In addition, the LightGBM classifier model performed better in determining if sarcopenia in older people can be reversed.

Acknowledgments

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Authors' Contributions

Data curation was handled by ZW, SH, and DM. Formal analysis was performed by ZW. Funding acquisition was carried out by GY. SH and MW was responsible for this study's investigation. ZW and DM aided in this study's methodology. MW and GY were involved in handling this study's resources. Supervision was done by GY. Writing of the original draft was worked on by HG, IY, XC, and JC. Review and editing of the writing was by HG, IY, XC, MW, ZW, and GY.

Conflicts of Interest

None declared.

Checklist 1
CONSORT-EHEALTH checklist (V 1.6.1).
[PDF File, 3216 KB - aging_v7i1e58175_app1.pdf]

References

1. Mielgo-Ayuso J, Fernández-Lázaro D. Sarcopenia, exercise and quality of life. Int J Environ Res Public Health 2021 May 13;18(10):5156. [doi: 10.3390/ijerph18105156] [Medline: 34067990]

2. Brooks SV, Faulkner JA. Skeletal muscle weakness in old age: underlying mechanisms. Med Sci Sports Exerc 1994 Apr;26(4):432-439. [Medline: 8201898]
3. Kim JW, Kim R, Choi H, Lee SJ, Bae GU. Understanding of sarcopenia: from definition to therapeutic strategies. Arch Pharm Res 2021 Oct;44:876-889. [doi: 10.1007/s12272-021-01349-z] [Medline: 34537916]
4. Yamakawa H, Kusumoto D, Hashimoto H, Yuasa S. Stem cell aging in skeletal muscle regeneration and disease. Int J Mol Sci 2020 Mar 6;21(5):1830. [doi: 10.3390/ijms21051830] [Medline: 32155842]
5. Aunan JR, Watson MM, Hagland HR, Søreide K. Molecular and biological hallmarks of ageing. Br J Surg 2016 Jan 15;103(2):e29-e46. [doi: 10.1002/bjs.10053]
6. Wu R, De Vito G, Delahunt E, Ditroilo M. Age-related changes in motor function (I). Mechanical and neuromuscular factors. Int J Sports Med 2020 Oct;41(11):709-719. [doi: 10.1055/a-1144-3408] [Medline: 32365388]
7. Greco EA, Pietschmann P, Migliaccio S. Osteoporosis and sarcopenia increase frailty syndrome in the elderly. Front Endocrinol 2019;10:255. [doi: 10.3389/fendo.2019.00255]
8. Bahat G, Tufan A, Tufan F, et al. Cut-off points to identify sarcopenia according to European Working Group on Sarcopenia in Older People (EWGSOP) definition. Clin Nutr 2016 Dec;35(6):1557-1563. [doi: 10.1016/j.clnu.2016.02.002] [Medline: 26922142]
9. Moore SA, Hrisos N, Errington L, et al. Exercise as a treatment for sarcopenia: an umbrella review of systematic review evidence. Physiotherapy 2020 Jun;107:189-201. [doi: 10.1016/j.physio.2019.08.005] [Medline: 32026819]
10. Peel NM, Kuys SS, Klein K. Gait speed as a measure in geriatric assessment in clinical settings: a systematic review. J Gerontol A Biol Sci Med Sci 2013 Jan;68(1):39-46. [doi: 10.1093/gerona/gls174] [Medline: 22923430]
11. Goates S, Du K, Arensberg MB, Gaillard T, Guralnik J, Pereira SL. Economic impact of hospitalizations in US adults with sarcopenia. J Frailty Aging 2019;8(2):93-99. [doi: 10.14283/jfa.2019.10] [Medline: 30997923]
12. Ubachs J, Ziemons J, Minis-Rutten IJG, et al. Sarcopenia and ovarian cancer survival: a systematic review and meta-analysis. J Cachexia Sarcopenia Muscle 2019 Dec;10(6):1165-1174. [doi: 10.1002/jcsm.12468] [Medline: 31389674]
13. van Vugt JLA, Levolger S, Coelen RJS, de Bruin RWF, IJzermans JNM. The impact of sarcopenia on survival and complications in surgical oncology: a review of the current literature. J Surg Oncol 2015 Nov;112(6):681-682. [doi: 10.1002/jso.24064] [Medline: 26488427]
14. Hopkins JJ, Reif RL, Bigam DL, Baracos VE, Eurich DT, Sawyer MB. The impact of muscle and adipose tissue on long-term survival in patients with stage I to III colorectal cancer. Dis Colon Rectum 2019 May;62(5):549-560. [doi: 10.1097/DCR.0000000000001352] [Medline: 30789442]
15. Cespedes Feliciano EM, Lee VS, Prado CM, et al. Muscle mass at the time of diagnosis of nonmetastatic colon cancer and early discontinuation of chemotherapy, delays, and dose reductions on adjuvant FOLFOX: the C-SCANS study. Cancer 2017 Dec 15;123(24):4868-4877. [doi: 10.1002/cncr.30950] [Medline: 28881381]
16. Huang X, Lv LN, Zhao Y, Li L, Zhu XD. Is skeletal muscle loss associated with chemoradiotherapy toxicity in nasopharyngeal carcinoma patients? A prospective study. Clin Nutr 2021 Jan;40(1):295-302. [doi: 10.1016/j.clnu.2020.05.020]
17. Vashi PG, Gorsuch K, Wan L, Hill D, Block C, Gupta D. Sarcopenia supersedes subjective global assessment as a predictor of survival in colorectal cancer. PLoS One 2019;14(6):e0218761. [doi: 10.1371/journal.pone.0218761] [Medline: 31220163]
18. Caan BJ, Cespedes Feliciano EM, Prado CM, et al. Association of muscle and adiposity measured by computed tomography with survival in patients with nonmetastatic breast cancer. JAMA Oncol 2018 Jun 1;4(6):798-804. [doi: 10.1001/jamaoncol.2018.0137] [Medline: 29621380]
19. Fulop T, Witkowski JM, Olivieri F, Larbi A. The integration of inflammaging in age-related diseases. Semin Immunol 2018 Dec;40:17-35. [doi: 10.1016/j.smim.2018.09.003] [Medline: 30287177]
20. Soerensen M, Dato S, Tan Q, et al. Human longevity and variation in GH/IGF-1/insulin signaling, DNA damage signaling and repair and pro/antioxidant pathway genes: cross sectional and longitudinal studies. Exp Gerontol 2012 May;47(5):379-387. [doi: 10.1016/j.exger.2012.02.010] [Medline: 22406557]
21. Ticinesi A, Nouvenne A, Cerundolo N, et al. Gut microbiota, muscle mass and function in aging: a focus on physical frailty and sarcopenia. Nutrients 2019 Jul 17;11(7):1633. [doi: 10.3390/nu11071633] [Medline: 31319564]
22. Fielding RA. Protein nutrition mediates lean body mass homeostasis in the aging warfighter. J Nutr 2013 Nov;143(11):1857S-1861S. [doi: 10.3945/jn.113.176768] [Medline: 24027178]
23. McLean RR, Shardell MD, Alley DE, et al. Criteria for clinically relevant weakness and low lean mass and their longitudinal association with incident mobility impairment and mortality: the foundation for the National Institutes of Health (FNIH) sarcopenia project. J Gerontol A Biol Sci Med Sci 2014 May;69(5):576-583. [doi: 10.1093/gerona/glu012] [Medline: 24737560]
24. Bhasin S, Apovian CM, Travison TG, et al. Design of a randomized trial to determine the optimum protein intake to preserve lean body mass and to optimize response to a promyogenic anabolic agent in older men with physical functional limitation. Contemp Clin Trials 2017 Jul;58:86-93. [doi: 10.1016/j.cct.2017.05.004] [Medline: 28483498]
25. Cao L, Morley JE. Sarcopenia is recognized as an independent condition by an International Classification of Disease, Tenth Revision, Clinical Modification (ICD-10-CM) code. J Am Med Dir Assoc 2016 Aug 1;17(8):675-677. [doi: 10.1016/j.jamda.2016.06.001] [Medline: 27470918]

26. Zeng Z, Liang J, Wu L, Zhang H, Lv J, Chen N. Exercise-induced autophagy suppresses sarcopenia through Akt/mTOR and Akt/FoxO3a signal pathways and AMPK-mediated mitochondrial quality control. Front Physiol 2020;11:583478. [doi: 10.3389/fphys.2020.583478] [Medline: 33224037]
27. Luo L, Lu AM, Wang Y, et al. Chronic resistance training activates autophagy and reduces apoptosis of muscle cells by modulating IGF-1 and its receptors, Akt/mTOR and Akt/FOXO3a signaling in aged rats. Exp Gerontol 2013 Apr;48(4):427-436. [doi: 10.1016/j.exger.2013.02.009] [Medline: 23419688]
28. Liu YC, Wang ZY, Fang L, et al. Effect of Yi Jin Jing on dynamic balance of patients with senile sarcopenia. J Hebei Tradit Chin Med Pharmacol 2014;29:9-11.
29. Zhu GF, Shen ZF, Shen QH, Jin YQ, Lou ZY. Effect of Yi Jin Jing (sinew-transforming Qigong exercises) on skeletal muscle strength in the elderly. J Acupunct Tuina Sci 2017 Dec;15(6):434-439. [doi: 10.1007/s11726-017-1041-8]
30. Jin DP, Jun XU, Zhao JZ, Ying HU, Wang DY. Effect of Yijinjing on daily living function and physical function of sarcopenia patients. Chin J Inform Tradit Chin Med 2011;18:14-16.
31. Liu YC, Yan JT, Wang ZY, et al. Influence of Yi Jin Jing on skeletal muscle contractile function in gerontism with sarcopenia. Acad J Shanghai Univ Tradit Chin Med 2016;30:42-45.
32. Yang J, Chen P. Clinical observation on the improvement of lower limb muscle strength and quality in elderly patients with sarcopenia by Tuina. Zhejiang J Tradit Chin Med 2016;51:753.
33. Fang L, Li Z, Tao X, Luo J. Clinical study on the effect of Yijinjing on the risk of fall in elderly patients with balance disorder. Chin J Rehabil Med 2020;35:319-323.
34. Gong L, Yan JT, Yc L, Fang L, Zhang H, Xu J. Effect of the tui na gongfu method Yi Jin Jing on isometric muscle strength in elderly patients with sarcopenia. Acad J Shanghai Univ Trad Chin Med 2011;25:55-58.
35. Zhao YJ, Zhang YM, Guo YH, Dou YL, Zhao J, He YX. Effect of tui na combined with resistance exercise on activities of daily living in patients with sarcopenia. Chin J Rehabil Med 2016;31:989-994.
36. Zhou SP, Zou Y, Sun XF, Xu QL. A study on the prevention of falls in elderly people with sarcopenia in Baduanjin. Sport Sci Technol 2020;41:27-58.
37. Zhou M, Peng N, Dai Q, Li HW, Shi RG, Huang W. Effect of tai chi on muscle strength of the lower extremities in the elderly. Chin J Integr Med 2016 Nov;22(11):861-866. [doi: 10.1007/s11655-015-2104-7] [Medline: 26015074]
38. Morawin B, Tylutka A, Chmielowiec J, Zembron-Lacny A. Circulating mediators of apoptosis and inflammation in aging; physical exercise intervention. Int J Environ Res Public Health 2021 Mar 19;18(6):3165. [doi: 10.3390/ijerph18063165] [Medline: 33808526]
39. Wei M, Meng D, Guo H, et al. Hybrid exercise program for sarcopenia in older adults: the effectiveness of explainable artificial intelligence-based clinical assistance in assessing skeletal muscle area. Int J Environ Res Public Health 2022 Aug 12;19(16):9952. [doi: 10.3390/ijerph19169952] [Medline: 36011588]
40. Stagi S, Doneddu A, Mulliri G, et al. Lower percentage of fat mass among tai chi chuan practitioners. Int J Environ Res Public Health 2020 Feb 14;17(4):1232. [doi: 10.3390/ijerph17041232] [Medline: 32075041]
41. Shirwaikar RD, Acharya U D, Makkithaya K, Surulivelrajan M, Srivastava S, Lewis U LES. Optimizing neural networks for medical data sets: a case study on neonatal apnea prediction. Artif Intell Med 2019 Jul;98:59-76. [doi: 10.1016/j.artmed.2019.07.008]
42. Vellido A. The importance of interpretability and visualization in machine learning for applications in medicine and health care. Neural Comput Applic 2019;32(24):18069-18083. [doi: 10.1007/s00521-019-04051-w]
43. Wang Z, Meng D, He S, et al. The effectiveness of a hybrid exercise program on the physical fitness of frail elderly. Int J Environ Res Public Health 2022 Sep 4;19(17):11063. [doi: 10.3390/ijerph191711063] [Medline: 36078781]
44. Yang G, He S, Meng D, et al. Body landmarks and genetic algorithm-based approach for non-contact detection of head forward posture among Chinese adolescents: revitalizing machine learning in medicine. BMC Med Inform Decis Mak 2023 Sep 11;23(1):179. [doi: 10.1186/s12911-023-02285-2] [Medline: 37697312]
45. Scott D. Sarcopenia in older adults. J Clin Med 2019 Nov 2;8(11):1844. [doi: 10.3390/jcm8111844] [Medline: 31684032]
46. Guerri S, Mercatelli D, Aparisi Gómez MP, et al. Quantitative imaging techniques for the assessment of osteoporosis and sarcopenia. Quant Imaging Med Surg 2018 Feb;8(1):60-85. [doi: 10.21037/qims.2018.01.05] [Medline: 29541624]
47. Chen LK, Lee WJ, Peng LN, et al. Recent advances in sarcopenia research in Asia: 2016 update from the Asian Working Group for Sarcopenia. J Am Med Dir Assoc 2016 Aug 1;17(8):767. [doi: 10.1016/j.jamda.2016.05.016] [Medline: 27372539]
48. Cadore EL, Casas-Herrero A, Zambom-Ferraresi F, et al. Multicomponent exercises including muscle power training enhance muscle mass, power output, and functional outcomes in institutionalized frail nonagenarians. Age (Dordr) 2014 Apr;36(2):773-785. [doi: 10.1007/s11357-013-9586-z] [Medline: 24030238]
49. Ha YC, Yoo JI, Park YJ, Lee CH, Park KS. Measurement of uncertainty using standardized protocol of hand grip strength measurement in patients with sarcopenia. J Bone Metab 2018 Nov;25(4):243-249. [doi: 10.11005/jbm.2018.25.4.243] [Medline: 30574469]
50. Cesari M, Kritchevsky SB, Penninx BWHJ, et al. Prognostic value of usual gait speed in well-functioning older people--results from the health, aging and body composition study. J Am Geriatr Soc 2005 Oct;53(10):1675-1680. [doi: 10.1111/j.1532-5415.2005.53501.x] [Medline: 16181165]

51. Prado CM, Lieffers JR, McCargar LJ, et al. Prevalence and clinical implications of sarcopenic obesity in patients with solid tumours of the respiratory and gastrointestinal tracts: a population-based study. Lancet Oncol 2008 Jul;9(7):629-635. [doi: 10.1016/S1470-2045(08)70153-0]
52. Yoshiko A, Hioki M, Kanehira N, et al. Three-dimensional comparison of intramuscular fat content between young and old adults. BMC Med Imaging 2017 Feb 10;17(1):12. [doi: 10.1186/s12880-017-0185-9] [Medline: 28183279]
53. Baumgartner RN, Koehler KM, Gallagher D, et al. Epidemiology of sarcopenia among the elderly in New Mexico. Am J Epidemiol 1998 Apr 15;147(8):755-763. [doi: 10.1093/oxfordjournals.aje.a009520]
54. Camastra S, Vitali A, Anselmino M, et al. Muscle and adipose tissue morphology, insulin sensitivity and beta-cell function in diabetic and nondiabetic obese patients: effects of bariatric surgery. Sci Rep 2017 Aug 21;7(1):9007. [doi: 10.1038/s41598-017-08444-6] [Medline: 28827671]
55. Porto JM, Nakaishi APM, Cangussu-Oliveira LM, Freire Júnior RC, Spilla SB, Abreu DCC. Relationship between grip strength and global muscle strength in community-dwelling older people. Arch Gerontol Geriatr 2019;82:273-278. [doi: 10.1016/j.archger.2019.03.005] [Medline: 30889410]
56. Cover T, Hart P. Nearest neighbor pattern classification. IEEE Trans Inform Theory 1967;13(1):21-27. [doi: 10.1109/TIT.1967.1053964]
57. Kumar R, Naik SM, Naik VD, Shiralli S, Sunil VG, Husain M. Predicting clicks: CTR estimation of advertisements using logistic regression classifier. Presented at: 2015 IEEE International Advance Computing Conference (IACC); Jun 12-13, 2015; Banglore, India p. 1134-1138. [doi: 10.1109/IADCC.2015.7154880]
58. Friedman JH. Greedy function approximation: a gradient boosting machine. Ann Statist 2001;29(5):1189-1232. [doi: 10.1214/aos/1013203451]
59. Szostak D, Walkowiak K, Wlodarczyk A. Short-term traffic forecasting in optical network using linear discriminant analysis machine learning classifier. Presented at: 2020 22nd International Conference on Transparent Optical Networks (ICTON); Jul 19-23, 2020; Bari, Italy p. 1-4. [doi: 10.1109/ICTON51198.2020.9203040]
60. Pedregosa F, Varoquaux G, Gramfort A, Michel V, Thirion B, Grisel O, et al. Scikit-learn: machine learning in Python. J Mach Learn Res 2011;12:2825-2830.
61. Breiman L. Random forests. Mach Learn 2001;45(1):5-32. [doi: 10.1023/A:1010933404324]
62. Linna L, Xuemin Z. Study of data mining algorithm based on decision tree. Presented at: 2010 International Conference on Computer Design and Applications; Jun 25-27, 2010; Qinhuangdao, China p. V1-155-V1-158. [doi: 10.1109/ICCDA.2010.5541172]
63. Chen T, Guestrin C. XGBoost: a scalable tree boosting system. Presented at: Proceedings of The 22nd ACM SIGKDD International Conference on Knowledge Discovery and Data Mining; Aug 13-17, 2016; San Francisco, CA p. 785-794. [doi: 10.1145/2939672.2939785]
64. Ke G, Meng Q, Finley T, Wang T, Chen W, Ma W, et al. LightGBM: a highly efficient gradient boosting decision tree. Presented at: NIPS’17: Proceedings of the 31st International Conference on Neural Information Processing System; Dec 4-9, 2017; Long Beach, CA p. 3149-3157 URL: https://papers.nips.cc/paper/2017/hash/6449f44a102fde848669bdd9eb6b76fa-Abstract.html [accessed 2024-11-04]
65. Lundberg S, Lee S. A unified approach to interpreting model predictions. Presented at: The 31st International Conference on Neural Information Processing Systems; Dec 4-9, 2017; Long Beach, CA p. 4768-4777 URL: https://proceedings.neurips.cc//paper/2017/file/8a20a8621978632d76c43dfd28b67767-Paper.pdf [accessed 2024-11-04]
66. Marini M, Sarchielli E, Brogi L, et al. Role of adapted physical activity to prevent the adverse effects of the sarcopenia. A pilot study. Ital J Anat Embryol 2008;113(4):217-225. [Medline: 19507462]
67. Bamman MM, Roberts BM, Adams GR. Molecular regulation of exercise-induced muscle fiber hypertrophy. Cold Spring Harb Perspect Med 2018 Jun 1;8(6):a029751. [doi: 10.1101/cshperspect.a029751] [Medline: 28490543]
68. Ruas JL, White JP, Rao RR, et al. A PGC-1α isoform induced by resistance training regulates skeletal muscle hypertrophy. Cell 2012 Dec 7;151(6):1319-1331. [doi: 10.1016/j.cell.2012.10.050] [Medline: 23217713]
69. Meng D, Guo H, Liang S, et al. Effectiveness of a hybrid exercise program on the physical abilities of frail elderly and explainable artificial-intelligence-based clinical assistance. Int J Environ Res Public Health 2022 Jun 7;19(12):6988. [doi: 10.3390/ijerph19126988] [Medline: 35742237]
70. Motl RW, Smith DC, Elliott J, Weikert M, Dlugonski D, Sosnoff JJ. Combined training improves walking mobility in persons with significant disability from multiple sclerosis: a pilot study. J Neurol Phys Ther 2012 Mar;36(1):32-37. [doi: 10.1097/NPT.0b013e3182477c92] [Medline: 22333922]
71. Wei M, He S, Meng D, Yang G, Wang Z. Hybrid exercise program enhances physical fitness and reverses frailty in older adults: insights and predictions from machine learning. J Nutr Health Aging 2023;27(10):894-902. [doi: 10.1007/s12603-023-1991-0] [Medline: 37960913]
72. Liu Y, Guo C, Liu S, Zhang S, Mao Y, Fang L. Eight weeks of high-intensity interval static strength training improves skeletal muscle atrophy and motor function in aged rats via the PGC-1α/FNDC5/UCP1 pathway. Clin Interv Aging 2021;16:811-821. [doi: 10.2147/CIA.S308893] [Medline: 34040358]
73. Hawley JA, Hargreaves M, Joyner MJ, Zierath JR. Integrative biology of exercise. Cell 2014 Nov 6;159(4):738-749. [doi: 10.1016/j.cell.2014.10.029] [Medline: 25417152]

74. San-Millán I, Brooks GA. Assessment of metabolic flexibility by means of measuring blood lactate, fat, and carbohydrate oxidation responses to exercise in professional endurance athletes and less-fit individuals. Sports Med 2018 Feb;48(2):467-479. [doi: 10.1007/s40279-017-0751-x] [Medline: 28623613]
75. Demontis F, Piccirillo R, Goldberg AL, Perrimon N. The influence of skeletal muscle on systemic aging and lifespan. Aging Cell 2013 Dec;12(6):943-949. [doi: 10.1111/acel.12126] [Medline: 23802635]
76. Lanza IR, Short DK, Short KR, et al. Endurance exercise as a countermeasure for aging. Diabetes 2008 Nov;57(11):2933-2942. [doi: 10.2337/db08-0349] [Medline: 18716044]
77. Luo C, Wen J, Sun W, et al. Effects of traditional Chinese exercise on cardiac rehabilitation after percutaneous coronary intervention: study protocol for network meta-analysis of randomised controlled trials. BMJ Open 2019 Feb 19;9(2):e023096. [doi: 10.1136/bmjopen-2018-023096] [Medline: 30782873]
78. Wang XQ, Pi YL, Chen PJ, et al. Traditional Chinese exercise for cardiovascular diseases: systematic review and meta-analysis of randomized controlled trials. J Am Heart Assoc 2016 Mar 9;5(3):e002562. [doi: 10.1161/JAHA.115.002562] [Medline: 26961239]
79. Wroblewski AP, Amati F, Smiley MA, Goodpaster B, Wright V. Chronic exercise preserves lean muscle mass in masters athletes. Phys Sportsmed 2011 Sep;39(3):172-178. [doi: 10.3810/psm.2011.09.1933] [Medline: 22030953]
80. Miljkovic I, Kuipers AL, Cvejkus R, et al. Myosteatosis increases with aging and is associated with incident diabetes in African ancestry men. Obesity (Silver Spring) 2016 Feb;24(2):476-482. [doi: 10.1002/oby.21328] [Medline: 26694517]
81. Bang E, Tanabe K, Yokoyama N, Chijiki S, Tsuruzono T, Kuno S. Effects of daily walking on intermuscular adipose tissue accumulation with age: a 5-year follow-up of participants in a lifestyle-based daily walking program. Eur J Appl Physiol 2018 Apr;118(4):785-793. [doi: 10.1007/s00421-018-3812-4] [Medline: 29380044]
82. Riley RD, Ensor J, Snell KIE, et al. Calculating the sample size required for developing a clinical prediction model. BMJ 2020 Mar 18;368:m441. [doi: 10.1136/bmj.m441] [Medline: 32188600]

Abbreviations

AI: artificial intelligence
ASM: appendicular skeletal muscle mass
AUC: area under the curve
AWGS: Asian Working Group for Sarcopenia
CG: control group
CT: computed tomography
HU: Hounsfield units
IGF-1: insulinlike growth factor 1
L3: third lumbar
L3 SMA: skeletal muscle area at the third lumbar vertebra
L3 SMD: skeletal muscle density at the third lumbar vertebra
L3 SMFA: skeletal muscle intramuscular fat area at the third lumbar vertebra
L3 SMFD: skeletal muscle intramuscular fat density at the third lumbar vertebra
LR: logistic regression
MFI: muscle fat infiltration
QCT: quantitative computed tomography
RF: random forest
RM: repetition maximum
RSMI: relative skeletal muscle mass index
SET: strength exercise training
SHAP: Shapley additive explanations
STG: strength training group
TCSG: tai chi exercise and strength training hybrid group
XAI: explainable artificial intelligence

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Characterizing Walking Behaviors in Aged Residential Care Using Accelerometry, With Comparison Across Care Levels, Cognitive Status, and Physical Function: Cross-Sectional Study

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Abstract

Background: Walking is important for maintaining physical and mental well-being in aged residential care (ARC). Walking behaviors are not well characterized in ARC due to inconsistencies in assessment methods and metrics as well as limited research regarding the impact of care environment, cognition, or physical function on these behaviors. It is recommended that walking behaviors in ARC are assessed using validated digital methods that can capture low volumes of walking activity.

Objective: This study aims to characterize and compare accelerometry-derived walking behaviors in ARC residents across different care levels, cognitive abilities, and physical capacities.

Methods: A total of 306 ARC residents were recruited from the Staying UpRight randomized controlled trial from 3 care levels: rest home (n=164), hospital (n=117), and dementia care (n=25). Participants' cognitive status was classified as mild (n=87), moderate (n=128), or severe impairment (n=61); physical function was classified as high-moderate (n=74) and low-very low (n=222) using the Montreal Cognitive Assessment and the Short Physical Performance Battery cutoff scores, respectively. To assess walking, participants wore an accelerometer (Axivity AX3; dimensions: 23×32.5×7.6 mm; weight: 11 g; sampling rate: 100 Hz; range: ±8 g; and memory: 512 MB) on their lower back for 7 days. Outcomes included volume (ie, daily time spent walking, steps, and bouts), pattern (ie, mean walking bout duration and alpha), and variability (of bout length) of walking. Analysis of covariance was used to assess differences in walking behaviors between groups categorized by level of care, cognition, or physical function while controlling for age and sex. Tukey honest significant difference tests for multiple comparisons were used to determine where significant differences occurred. The effect sizes of group differences were calculated using Hedges *g* (0.2-0.4: small, 0.5-0.7: medium, and 0.8: large).

Results: Dementia care residents showed greater volumes of walking ($P<.001$; Hedges g=1.0-2.0), with longer ($P<.001$; Hedges g=0.7-0.8), more variable (P=.008 vs hospital; $P<.001$ vs rest home; Hedges g=0.6-0.9) bouts compared to other care levels with a lower alpha score (vs hospital: $P<.001$; Hedges g=0.9, vs rest home: P=.004; Hedges g=0.8). Residents with severe cognitive impairment took longer ($P<.001$; Hedges g=0.5-0.6), more variable ($P<.001$; Hedges g=0.4-0.6) bouts, compared to those with mild and moderate cognitive impairment. Residents with low-very low physical function had lower walking volumes (total walk time and bouts per day: $P<.001$; steps per day: P=.005; Hedges g=0.4-0.5) and higher variability (P=.04; Hedges g=0.2) compared to those with high-moderate capacity.

Conclusions: ARC residents across different levels of care, cognition, and physical function demonstrate different walking behaviors. However, ARC residents often present with varying levels of both cognitive and physical abilities, reflecting their complex multimorbid nature, which should be considered in further work. This work has demonstrated the importance of considering a nuanced framework of digital outcomes relating to volume, pattern, and variability of walking behaviors among ARC residents.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12618001827224; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=376298&isReview=true

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KEYWORDS

residential aged care facility; cognitive dysfunction; mobility limitation; accelerometry; physical activity; aged residential care

Introduction

Physical mobility, such as walking, is a key predictor of health [1] and is considered a multifaceted experience that interconnects the physical, mental, social, and emotional needs of an individual with their sense of self [2,3]. Loss of physical mobility (eg, reduced volume of walking) is associated with increased safety risks (eg, falls), social withdrawal, and poorer well-being [4,5]. Supporting residents' physical mobility in aged residential care (ARC) can decelerate the progression of disabilities and dependency [6]. ARC refers to long-term full-time residential care, which provides multiple levels of care depending on an individual's needs. Other common terms for ARC include assisted living facilities, care homes, and nursing homes. It is recommended that all residents who can ambulate, regardless of cognitive abilities, should increase their activity levels to support their functional independence [7]. Continuous remote digital monitoring of mobility outcomes has been proposed as a method to objectively quantify changes in walking behaviors. This approach will inform the development of interventions aimed at better supporting mobility, which is a key factor in influencing well-being and function in the older population [2].

Accelerometers are the most common method to continuously assess walking behaviors in ARC residents [8], with outcomes relating to volume (eg, steps per day) and intensity (eg, moderate-vigorous physical activity) of walking activities most frequently reported. Based on the current literature, ARC residents primarily participate in low volumes of light-intensity walking and show little variation in their walking behaviors [8]. Based on prevailing gaps in the literature, current recommendations for the assessment of walking behaviors in ARC include the use of validated digital methods that can capture very low volumes of activity, using low cutoff thresholds (eg, any walking activity ≥3 steps), and derive standardized outcomes relating to volume (ie, the amount or duration of walking activity), pattern (ie, the distribution of walking activity across a time period), and variability (ie, changes in walking activities—either within-person or group activities—and over time) of walking behaviors [8,9].

Using this nuanced framework, we can consider how different attributes impact discrete walking behaviors. For example, we previously found that better physical function was associated with higher walking volumes in ARC residents in intermediate (ie, rest homes) and high-level (ie, hospitals) care, while surprisingly, moderate dementia, mild depression, and pain had no effect on walking volumes [10]. In contrast, people with mild cognitive impairment in the community show no differences in walking volumes compared to people who undergo normal aging, but they do demonstrate different patterns and greater variability in their walking behaviors [9]. By looking beyond the volume of walking activities to pattern and variability, we may garner information about people's routines and the time they spend indoors and outdoors (based on walking bout lengths) [8,9,11-14]; we can then examine the impact of cognitive and physical impairments on these behaviors [14]. This information can contribute toward the development of more holistic interventions to support mobility in ARC.

Notably, ARC residents are a complex multimorbid population with significant variation in cognitive and physical function, often reflected in the level of care provided. These heterogeneities are not reflected in the literature regarding walking behaviors, highlighting a clear gap [8,15,16]. For example, Mc Ardle et al's [8] review on the quantification of ambulatory activities in ARC reported that 26% of studies excluded people with cognitive impairment and only 17% explicitly characterized walking activities in people with cognitive impairment, despite a 65%-70% prevalence of cognitive impairment in ARC residents [17,18]. Additionally, no studies compared different levels of care. As such, Mc Ardle et al [8] recommended that we must characterize and compare the volumes, patterns, and variability of walking behaviors in ARC residents across different care levels, with different cognitive and physical abilities. By characterizing walking behaviors in a representative group of ambulatory ARC residents, we can gain a better understanding of physical mobility in ARC, which will inform future interventions and policies to promote walking activities and support mobility and function in ARC residents.

To address the highlighted gaps and recommendations, the primary aim of this study was to digitally characterize and compare walking behaviors across different levels of ARC using a validated and standardized framework, encompassing volume, pattern, and variability of walking. Secondary aims of this study were to characterize and compare walking behaviors in ARC residents according to their cognitive status and physical function.

Methods

Participants

Residents from 24 ARC facilities in New Zealand were recruited as part of the Staying UpRight randomized controlled trial (RCT), which evaluated an exercise intervention to reduce fall risk [19]. Only baseline data are included in this study. Participants were included if they were aged ≥65 years and mobile (ie, able to walk and transfer independently or with supervisory assistance). Participants were receiving one of the following levels of care: hospital-level care (24-hour care by, or under the supervision of, a nurse), rest home–level care (24-hour health-related care but not nursing care), or dementia-level care (rest-home level care in a secure environment to minimize the risks associated with dementia).

We excluded residents in psychogeriatric, respite, or palliative care; residents unable to undertake the assessment or the exercise intervention in the main RCT because they were acutely unwell (eg, gastroenteritis), or immobile (ie, unable to mobilize without 2-person assistance or bed bound) were also excluded.

Ethical Considerations

Participants who were able to give informed written consent did so before enrollment, and the facility clinical lead provided written consent for residents unable to provide their own informed consent because of cognitive impairment. The study was conducted according to the guidelines of the Declaration of Helsinki. Ethics approval was provided by the New Zealand Health and Disability Ethics Committee on October 31, 2018 (NZHDEC 18/NTB/151).

Clinical and Cognitive Outcomes

Demographic information for ARC residents included the following: age, sex, and years spent in the ARC facility. Physical function was measured using Short Physical Performance Battery (SPPB) [20] and the Timed Up and Go test [21]. Cognitive ability was assessed using the Montreal Cognitive Assessment (MoCA) [22].

Assessment of Walking Behaviors

ARC residents were asked to wear a small body-worn accelerometer (Axivity AX3; dimensions: 23×32.5×7.6 mm; weight: 11 g; sampling rate: 100 Hz; range: ±8 g; and memory: 512 MB) on the fifth lumber vertebra on the lower back. The accelerometer was affixed onto the skin using a double-sided hydrogel adhesive and a hypoallergenic plaster (Hypafix BSN Medical Limited). This particular protocol has been found to be feasible for multisite studies [23] in different aging cohorts [11,13,24]. Of particular note, algorithms used in this study for walking bout detection have been validated in ARC residents, with high accuracy for start and end time [25].

Participants were asked to wear the accelerometer continuously for 7 days, including in the shower and to bed. Once the assessment was complete, data were downloaded to a computer and processed via a validated analytical pipeline in MATLAB.

Data Processing and Walking Behavior Outcomes

Signals from the accelerometer were transformed to a horizontal-vertical co-ordinate system. Walking bouts were identified by filtering raw acceleration data using a second-order low-pass Butterworth two-pass digital filter, with a cutoff frequency of 17 Hz, and by applying selective thresholds on the vector magnitude and standard deviations of triaxial acceleration signals [11,23,26,27]. Once walking bouts were identified, for detecting steps, raw acceleration signals were filtered with low-pass, fourth-order Butterworth filter with cutoff frequency of 20 Hz. A Gaussian continuous wavelet transform of vertical acceleration was then applied to identify initial and final contacts, allowing the identification of steps. For each walking bout, total steps per bout and bout length were calculated. Sleep, lying, and sitting data were excluded based on the thresholds applied on the magnitude and standard of the accelerometry signal used to identify walking (eg, vertical acceleration, in a vertical position, needs to be −1 g and acceleration magnitude or standard needs to exceed these thresholds to be classified as walking). For sleep, the magnitude and standard of acceleration would be lower and the vertical acceleration would not be −1 g, so the position (orientation) excludes sleep, lying, or sitting.

A framework of walking behaviors was derived to remain consistent with previous literature [11,12,23,26], including volume, pattern, and variability of walking. Volume characteristics included total minutes spent walking as well as steps and bouts per day. Pattern characteristics included mean bout duration and alpha, which is derived by logarithmic transformation of bout density and length and is based on shape and power-law distribution [28,29]; alpha refers to the ratio of short to long walking bouts, which are scaled relative to an individual's shortest walking bout. A high alpha score indicates that an individual's total walking time is composed of proportionally shorter walking bouts compared to long walking bouts. Variability (S_2) refers to the variability of bout duration between walking bouts, estimating how much an individual's bout duration changes over the time period of data collection, and it was estimated using the maximum likelihood technique (previously described by Mc Ardle et al and Del Din [9,13]. The proportion of walking bouts taken in very short (<10 s), short (10-30 s), medium (30-60 s), and prolonged (>60 s) walks were calculated. These walking bout thresholds have been used commonly in other studies of a similar nature and provide contextual information regarding how walking takes place [13,30,31].

Considerations for Inclusion of Data

Given that most habitual walking takes place in <10-second bouts [13,32,33], we applied a minimum bout duration of 3 consecutive steps, and any period of rest that was ≥2.5 seconds was considered resting time [32]. Additionally, we included participants if they had ≥2 days of continuous walking activity data collected, as this is the minimum number of days required to reliably quantify our primary outcomes (ie, the volume of walking) across different care levels, based on Buckley et al [27].

Data Analysis

For demographic variables, chi-square tests and Fisher exact test were used to determine differences between groups for nominal variables, while one-way ANOVA was used to determine between-group differences for continuous variables; post hoc Tukey honest significant difference (HSD) tests determined where the differences lay.

Prior to statistical analysis relating to our primary and secondary aims, walking activity data were inspected visually using box plots, and outliers were identified. Separate analyses of covariance were used to assess differences in walking behaviors between groups categorized by level of care, cognition, or physical function while controlling for age and sex. Tukey HSD tests for multiple comparisons were used to determine where significant differences occurred. Sensitivity analysis was conducted by removing outliers more than 1.5 times above the third quartile or below the first quartile and by conducting the analysis of covariance and subsequent post hoc tests for each discrete grouping separately (eg, level of care, cognition, or physical function).

The effect size of group differences was calculated using the Hedges *g* formula to account for disparities between groups' sample sizes [34]. Effect sizes are interpreted as follows: 0.2-0.4:

small, 0.5-0.7: medium, and ≥0.8: large. Assumptions were evaluated (eg, normality of residuals) for all models, and statistical significance was defined as a $P<.05$.

Cognitive levels were assessed and categorized using MoCA cutoff scores, as follows: cognitively intact (MoCA ≥26), mild cognitive impairment (MoCA 18-25), moderate cognitive impairment (MoCA 10-17), and severe cognitive impairment (MoCA <10) [35]. Cognitively intact participants were excluded from the cognitive impairment severity analysis due to the small sample size but retained for illustrative purposes in Figures. Physical function levels were assessed and categorized using the SPPB cutoff scores, as follows: high-moderate function (SPPB 12-7) or low-very low function (SPPB <7) [36].

Results

Demographic Information

A total of 306 ARC residents were included in this analysis and were primarily grouped according to their level of care (Table 1). Figure 1 outlines reasons for exclusion and inclusion of participants for this secondary analysis from the Staying UpRight RCT. Hospital-level care residents had lower physical function compared to rest home–level care residents ($P=.01$) and took a longer time to complete the Timed Up and Go test compared to rest home–level ($P<.001$) and dementia-level ($P=.03$) residents. MoCA scores were significantly lower in dementia-level residents compared to rest home–level and hospital-level care residents ($P<.001$).

Table . Demographic information for participants categorized by levels of care. Italicized *P* values indicate significance.

Characteristics		Hospital (n=117)	Rest home (n=164)	Dementia care (n=25)	Overall *P* value[a]
Age (years; n=306), mean (SD)		84 (7)	84 (7)	81 (8)	.20
Sex (n=306), n (%)					.90
	Female	70 (60)	101 (62)	16 (64)	
	Male	47 (40)	63 (38)	9 (36)	
Years in facility[b] (n=304), mean (SD)		0.4 (0.2)	0.4 (0.2)	0.4 (0.1)	.60
SPPB[c] score (0-12; n=296), mean (SD)		4.3 (2.6)[d]	5.2 (2.6)[d]	4.1 (2.3)	*.008*
Physical function level [e] **(n=296), n (%)**					—[f]
	High physical function (SPPB 10-12)	5 (4.3)	9 (5.6)	0 (0)	
	Moderate physical function (SPPB 7-9)	19 (17)	38 (24)	3 (15)	
	Low physical function (SPPB 4-6)	37 (32)	70 (43)	8 (40)	
	Very low physical function (SPPB <4)	54 (47)	44 (27)	9 (45)	
	Unknown[g]	2	3	5	
TUG[h] (s; n=289), mean (SD)		37 (22)[d,i]	27 (15)[d]	25 (18)[i]	*<.001*
MoCA[j] score (0-30; n=285), mean (SD)		15 (6)[i]	15 (6)[k]	4 (6)[i,k]	*<.001*
Cognitive level [e] **(n=285), n (%)**					—
	Cognitively intact (MoCA ≥26)	5 (4.6)	4 (2.5)	0 (0)	
	Mild cognitive impairment (MoCA 18-25)	28 (26)	58 (36)	1 (5.6)	
	Moderate cognitive impairment (MoCA 10-17)	60 (56)	66 (42)	2 (11)	
	Severe cognitive impairment (MoCA <10)	15 (14)	31 (19)	15 (83)	
	Not tested[l]	9	5	7	
Days wearing the activity monitor (n=306), mean (SD)		6.5 (1)	6.4 (1)	6.3 (1)	.60

[a] One-way ANOVA, Pearson chi-square test, and Fisher exact test.

[b] For years in facility, 1 partcipant's data were missing from both the "hospital" and "rest home" groups.

[c] SPPB: Short Physical Performance Battery (2 participants in the "hospital" group, 3 participants in the "rest home" group, and 5 participants in the "dementia care" group were not tested for SPPB).

[d] Hospital vs rest home.

[e] Descriptive variable only (no statistical testing performed).

[f] Not applicable.

[g] "Unknown" indicates participant data missing in each group, so percentages are not applicable.

[h] TUG: Timed Up and Go (6 participants in the "hospital" group, 3 participants in the "rest home" group, and 8 participants in the "dementia care" group were not tested).

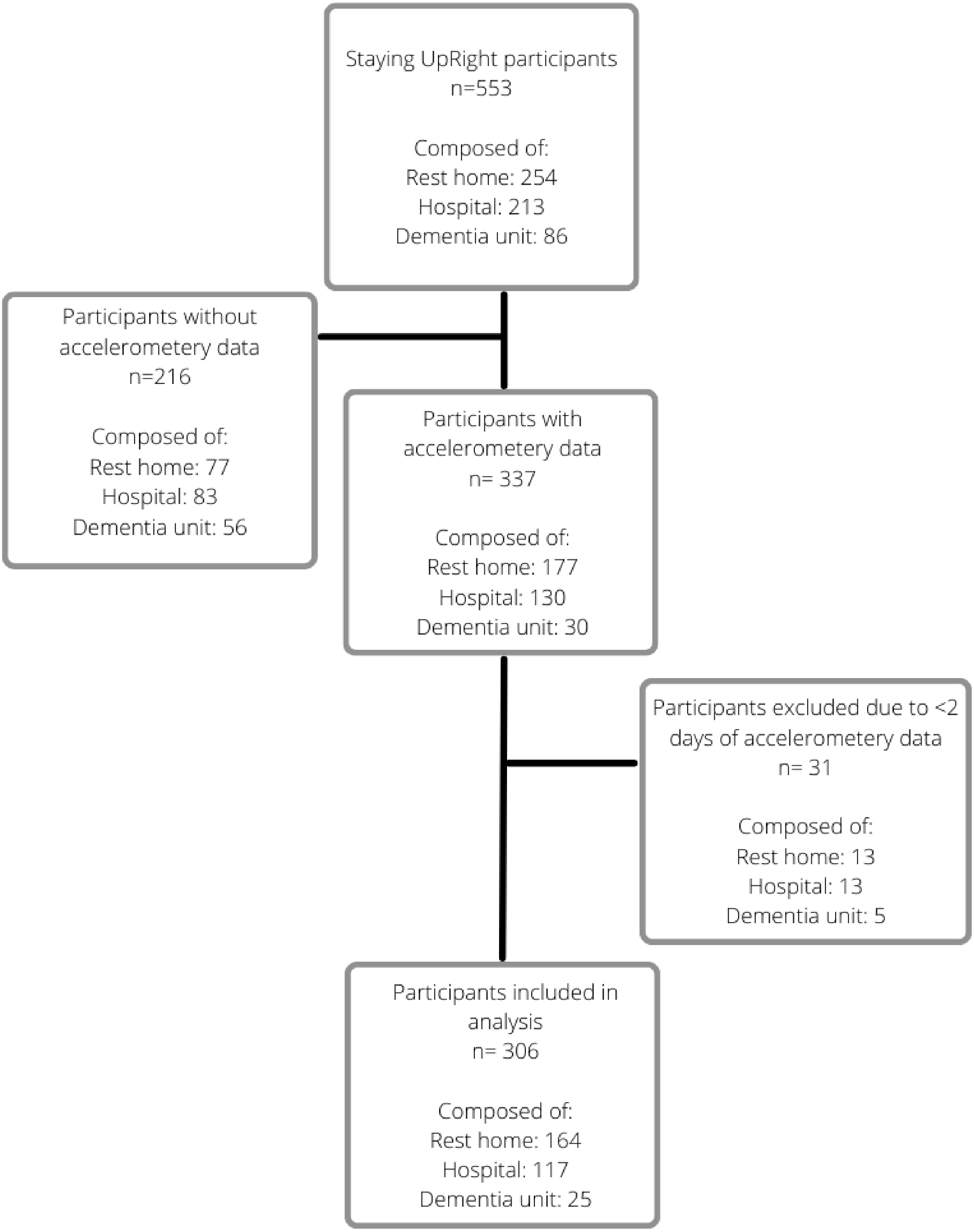
[i] Hospital vs dementia care.

[j] MoCA: Montreal Cognitive Assessment (9 participants in the "hospital" group, 5 participants in the "rest home" group, and 7 participants in the "dementia care" group were not tested).

[k] Rest home vs dementia care.

[l] Indicates the number of participants not tested in each group, so percentages are not applicable.

Figure 1. Flowchart for inclusion of participants in this analysis.



Walking Behaviors Across Care Levels

Dementia care residents demonstrated higher volumes of walking, with longer, more variable bout durations and lower alpha scores compared to residents in both rest homes and hospitals (moderate to large effect sizes). Residents in rest homes also showed higher volumes of walking compared to those in hospitals (small effect sizes). Table 2 provides further details; Multimedia Appendix 1 provides *P* values for post hoc tests and details regarding effect sizes. Notably, sensitivity analysis indicated that variability of walking bout length did not differ between groups following the removal of outliers (*P*=.16).

Table . Characterization of walking behaviors, categorized by level of care (N=306).

Characteristics		Hospital (n=117)	Rest home (n=164)	Dementia care (n=25)	Overall *P* value[a]
Walk time per day (min), mean (SD)		58 (37)[b,c]	74 (39)[b,d]	137 (59)[c,d]	<.001
Steps per day, mean (SD)		4138 (2766)[b,c]	5216 (2925)[b,d]	10,886 (5453)[c,d]	<.001
Bouts per day, mean (SD)		256 (165)[b,c]	321 (160)[b,d]	496 (238)[c,d]	<.001
Mean bout duration (s), mean (SD)		13.9 (3.6)[c]	14.1 (3.3)[d]	20.1 (20.4)[c,d]	<.001
Variability, mean (SD)		0.81 (0.11)[c]	0.80 (0.09)[d]	0.89 (0.18)[c,d]	.002
Alpha score, mean (SD)		1.68 (0.08)[c]	1.67 (0.07)[d]	1.61 (0.09)[c,d]	<.001
Distribution of walking bouts by discrete walking bout length (%), mean (SD)					
	<10-second bouts	65 (8)[c]	64 (8)[d]	56 (10)[c,d]	<.001
	10- to 30-second bouts	25.9 (5.5)[c]	27.6 (5.5)[d]	30.8 (5.8)[c,d]	<.001
	30- to 60-second bouts	5.81 (3.05)[c]	5.51 (2.42)[d]	8.64 (3.64)[c,d]	<.001
	>60-second bouts	3.20 (2.13)[c]	3.15 (2.06)[d]	4.82 (4.92)[c,d]	.01

[a] One-way ANOVA, controlling for age and sex.

[b] Hospital vs rest home.

[c] Hospital vs dementia care.

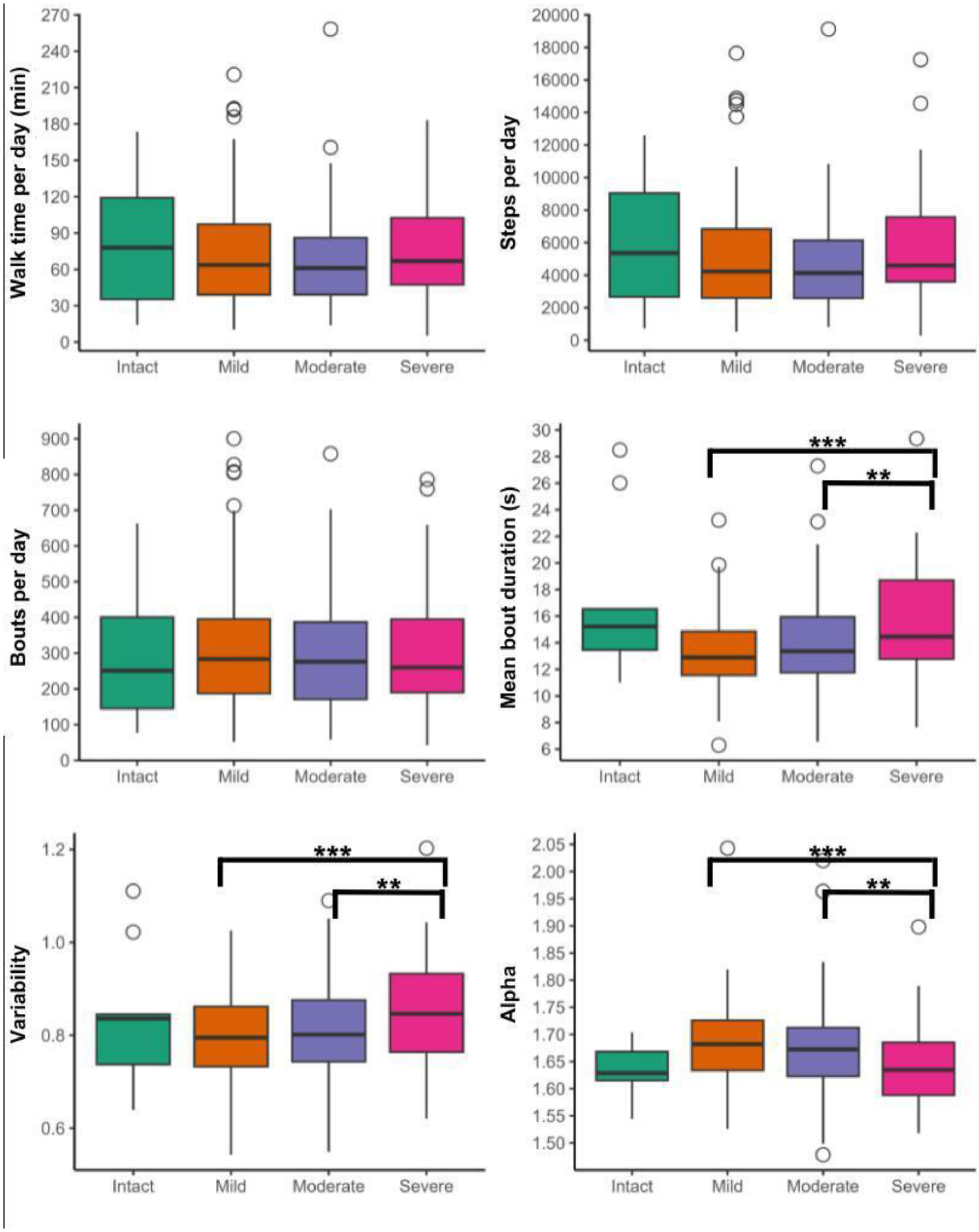
[d] Rest home vs dementia care.

Additionally, dementia care residents spent a significantly lower percentage of their walking bouts in very short bouts (eg, <10 s) and a greater percentage in short, medium, and prolonged walking bouts compared to residents in other care levels (moderate to large effect sizes; Table 2).

Walking Behaviors Across Cognitive Impairment Severities

There were no significant differences between cognitive groups for any volume characteristics (Figure 2 and Multimedia Appendix 2). People with severe cognitive impairment took longer, more variable walking bouts with a lower alpha score compared to those with mild (moderate to large effect sizes) and moderate cognitive impairment (small to moderate effect sizes). Figure 2 and Multimedia Appendix 2 provide further details.

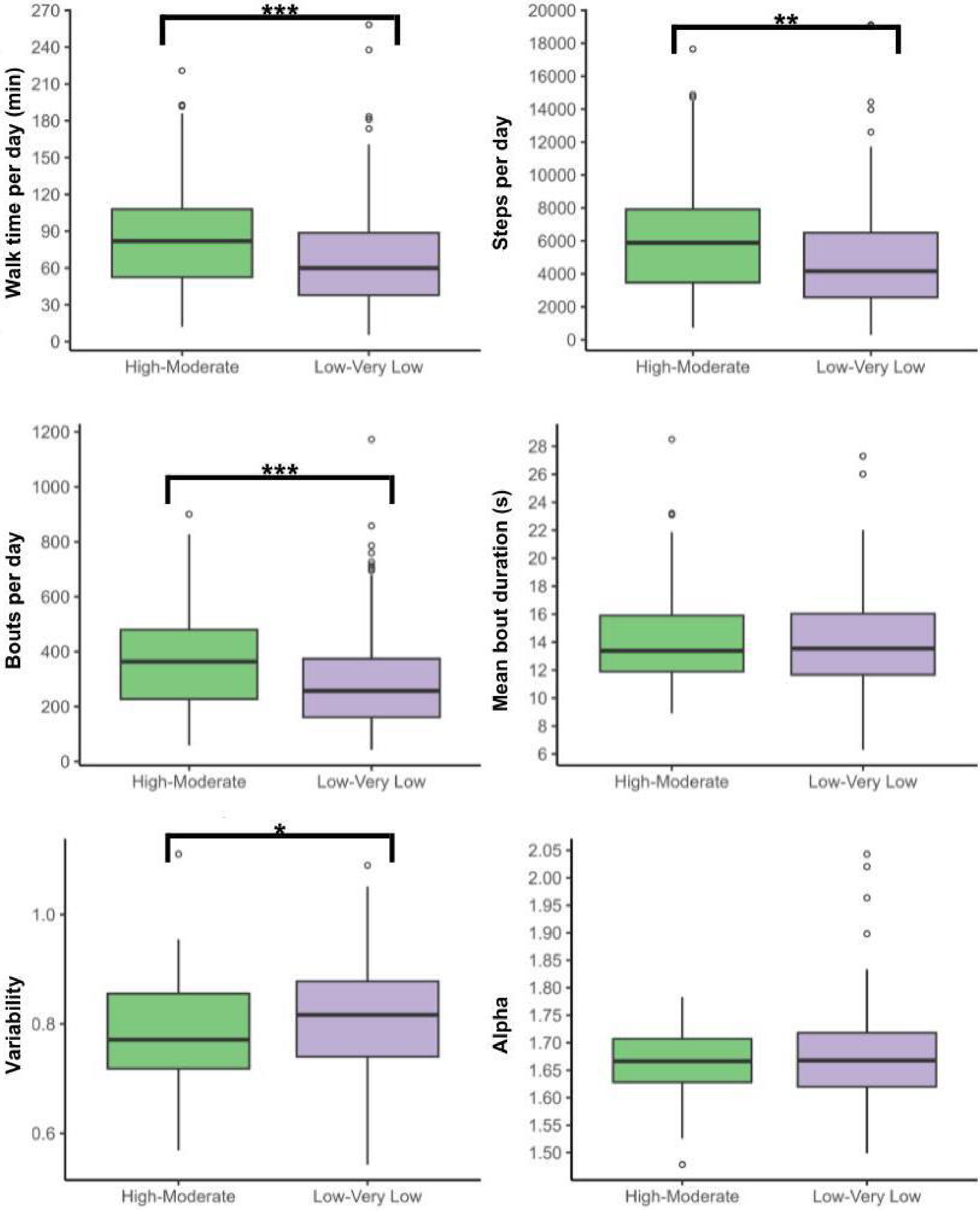
Figure 2. Volume, pattern, and variability of walking behaviors across cognitive groups. ***P≤.001; **P≤.01.



Walking Behaviors Across Physical Function Levels

ARC residents with high-moderate physical function spent more time walking and took more steps and bouts per day, with less variability for bout length, compared to those with low-very low physical function (Figure 3 and Multimedia Appendix 3 present further details).

Figure 3. Volume, pattern, and variability of walking behaviors across physical function groups. ***$P≤.001$; **$P≤.01$.



Discussion

Principal Findings

This is the first study to describe the volume, pattern, and variability of walking behaviors in ARC, captured by an accelerometer, with consideration of different care levels, cognitive abilities, and physical function, reflecting the typical population of residents. Key findings highlight that dementia care residents have significantly higher volumes of walking, take longer and more variable walking bouts on average, and spend proportionately more of their walking time in prolonged bouts of walking compared to rest home and hospital levels of care. Although the volume of walking is similar across different levels of cognitive impairment severity, people with more severe cognitive impairment show different patterns (eg, longer walking bouts) and greater variability compared to those who are less cognitively impaired. In contrast, people with lower physical function have significantly lower volumes of walking and higher variability of walking bout lengths but do not differ in terms of the pattern of this activity. ARC residents are a complex multimorbid population who often present with varying levels of both cognitive and physical abilities, and these nuances should be considered in further research aiming to improve mobility and reduce fall risk.

Walking Behaviors Across Different Care Environments

This is the first study to show that people living in a dementia unit participate in higher volumes of walking, with different patterns (ie, longer walking bouts) and greater variability compared to other ARC environments, with medium to large effect sizes. However, differences between groups for the variability of walking bout length disappeared following the removal of significant outliers, therefore, results should be interpreted with caution. As physical function scores are comparable between the dementia care and rest home residents (Table 1), the differences in walking behaviors may illustrate a behavioral component of dementia (eg, wandering—a dementia-related locomotor behavior involving frequent and repetitive movements, such as pacing). Objective remote monitoring of wandering behaviors using digital methods has previously been proposed to detect and monitor wandering behaviors [37,38]. We propose that variability of walking bout lengths should be considered in future research in this area, as it may reflect wandering behaviors[39]; clinical validation is required to investigate this hypothesis.

Contrary to our findings, baseline results from one previous RCT reported very low volumes of walking activity in dementia care units, showing <400 steps in one 24-hour period assessed via an activity armband [40]. However, these studies are difficult to compare due to differences in device location (ie, lower back compared to arm) and data collection periods. Moyle et al [40] noted that these activity armbands were unreliable and resulted in large amounts of missing data. Additionally, high volumes of walking activity reported here (eg, >4000 steps per day) are likely due to our low cutoff thresholds for defining walking activity, as most walking takes place in very short walking bouts in this population. The cutoff threshold applied to characterize walking behaviors can make significant differences in the volume of walking captured—with differences ranging from 2000 to 10,000 steps in previous literature [30]. This study has expanded beyond simple volume metrics and highlighted the importance of selecting validated and sensitive digital methods when assessing walking behaviors in this population [8].

Walking Behavior Across Cognitive Impairment Severity and Physical Capacities

This is the first study to demonstrate that people with severe cognitive impairment have similar volumes but significantly different patterns (ie, longer bouts) and greater variability of walking compared to less cognitively impaired groups, suggesting that although cognition does not influence the amount of activity, it may change the way this activity is carried out. This finding is supported by and extends our previous work, which excluded dementia care residents and highlighted that while worse physical function is associated with lower volumes of walking in ARC, cognitive impairment showed no effect on walking volume [10]. Perhaps this indicates that pattern and variability of walking behaviors are cognitively mediated outcomes and may be useful to monitor in ARC as a proxy for cognitive decline. For example, in line with our results from the dementia care unit, the literature indicates that people with severe dementia are more likely to wander [41] and we propose that this is reflected in the pattern and variability of walking. Longer walking bouts and higher variability of bout length are considered positive outcomes in cognitively healthy individuals, indicative of dynamic and varied routines [11], but perhaps higher variability in tandem with significant cognitive impairment is more reflective of repetitive lapping behaviors (ie, wandering). Clinical validation is required to address this speculation. Differences in pattern of walking behaviors have previously been reported between community-dwellers with mild cognitive impairment and normal aging [42], supporting the hypothesis that cognitive decline may influence these behaviors.

In contrast, people with worse physical function have significantly lower volumes of walking but show no differences in pattern or variability compared to those with better physical function. The association between higher walking volumes and better physical function confirms the findings of previous studies [43,44]. However, the cross-sectional design of this study precludes commentary on the direction of causality. Although from our results, we cannot determine if encouraging walking as part of a resident's daily activities can result in clinically meaningful improvements in function, previous research demonstrated that function-focused care (ie, increasing routine activities) leads to increased activity volumes and improved functional outcomes in ARC residents with moderate functional dependency [44] but not in dementia residents with severe functional dependency [45]. However, pattern and variability of walking are considered to reflect daily routines, and the effects of function-focused care may be more readily observed in these outcomes rather than in volume, especially in individuals with severe cognitive impairment. Additionally, marginal increases in the duration and variability of walking bouts may lead to significant improvements in function [28] and should be considered in very frail residents. These hypotheses could be considered in future intervention studies, with consideration for the multimorbid nature and varying levels of both cognitive and physical issues inherent in ARC residents.

Strengths and Limitations

Strengths of this study were the large sample, drawn from multiple facilities, distributed across 3 levels of care and encompassing a broad spectrum of cognitive and physical capacities. This is particularly notable, as there can be significant difficulties in collecting data using wearable technology from people with dementia in ARC facilities [29]. We used a technically appropriate digital method to collect low volumes of walking data¸ meeting the recommendations from Mc Ardle et al [8]. Additionally, we used a standardized framework to characterize walking behaviors, making our findings comparable to multiple other cohorts and enhancing our understanding of walking behaviors across the spectrum of care and cognition [11,12]. We addressed the reliability of our primary outcomes based on previous empirical evidence [27].

Our study has several limitations. Residents were only included if they could ambulate, and residents who could not complete the MoCA or SPPB were not included in our secondary analysis; therefore, we may have reduced representation of different levels of cognitive and physical capacities. Although this is only the second study to specifically characterize walking activity in a dementia care unit [8], it should be noted that our sample size for this group was low and likely to have limited statistical power; therefore, statistical analysis was exploratory and results should be considered with that in mind. This is a cross-sectional study; therefore, assessing changes in walking activity over time or establishing causality of influences on walking activity is not possible; in the future, a longitudinal study may offer valuable insights into predictors of walking behaviors in ARC. Although we adjusted for multiple corrections within statistical models (ie, Tukey HSD tests), we did not adjust for multiple comparisons for multiple outcomes, and there may be a risk of type I error. We also included participants with ≥2 days of walking activity data, as this is the number of days required to obtain reliable volume outcomes (ie, our primary outcome) in ARC [27]; however, our secondary outcomes of pattern and variability require 2-5 days of data to ensure reliability, pending on the discrete variable, and thus, results should be interpreted with caution. Although commonly assessed in ARC [8], we did not include outcomes relating to the intensity of walking activity, as this has been suggested to be inappropriate to characterize in this population, given that ARC residents primarily engage only in light-intensity activities [8]. Additionally, the ARC facilities included in this study reflect a New Zealand context, and findings may be different in other countries due to alternative organizational features and policies [46]. We recognize that apart from resident-related factors of physical function and cognition, walking activity may be influenced by the physical and organizational environment [46]—aspects that were not measured in our study. As previously noted, ARC residents may have varying levels of both cognitive and physical impairments, and the combined spectrum should be considered in future research. Finally, digital outcomes beyond those described in this analysis can provide important clinical information about ARC residents and should be considered in future research. For example, sleep disturbances can be measured using actigraphy. Sleep disturbances are common in people living in ARC and are associated with neuropsychiatric symptoms and prescription of psychotropic drugs, which can enhance fall risks and greater staff distress [47]. Although it is beyond the scope of this study, further research may consider using qualitative approaches to complement current findings and the wider literature [8], which would allow us to garner rich insights from ARC residents regarding which digital outcomes relate to their lived experiences and are meaningful to assess.

Conclusions

This is the first study to show the influence of care environment, cognitive status, and physical function on walking behaviors in ARC residents. Our results indicate that cognitive and physical abilities may discretely impact the volumes, pattern, and variability of walking. This work has addressed a significant gap in the literature and has generated new hypotheses regarding which digitally derived walking outcomes are meaningful to assess in ARC residents.

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All opinions are those of the authors and not the funders.

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Authors' Contributions

RMA, LT, LR, SDD, and NK contributed to the conceptualization and design of the study as well as data analysis and interpretation. RMA, LT, and SDD were in charge of data curation. RMA conducted data analysis and statistical work. AC provided support for statistical work. RMA and LT wrote the original draft. RMA, LT, LR, AC, SDD, and NK wrote the draft, reviewed, and edited it. All authors approved the final version of this manuscript. RMA and LT contributed equally to this manuscript; SDD and NK also contributed equally to this manuscript.

Conflicts of Interest

SDD reports consultancy activity with Hoffmann-La Roche Ltd. LR consults for MJ Fox Foundation for service on Endpoints Advisory Committee.

Multimedia Appendix 1
Detailed description of between-group analysis results for different care levels.
[DOCX File, 13 KB - aging_v7i1e53020_app1.docx]

Multimedia Appendix 2
Walking behaviors categorized by cognitive impairment severity.
[DOCX File, 19 KB - aging_v7i1e53020_app2.docx]

Multimedia Appendix 3
Walking behaviors categorized by physical function.
[DOCX File, 17 KB - aging_v7i1e53020_app3.docx]

References

1. Fritz S, Lusardi M. White paper: "walking speed: the sixth vital sign". J Geriatr Phys Ther 2009;32(2):46-49. [Medline: 20039582]
2. Polhemus A, Ortiz LD, Brittain G, et al. Walking on common ground: a cross-disciplinary scoping review on the clinical utility of digital mobility outcomes. NPJ Digit Med 2021 Oct 14;4(1):149. [doi: 10.1038/s41746-021-00513-5] [Medline: 34650191]
3. Delgado-Ortiz L, Polhemus A, Keogh A, et al. Listening to the patients' voice: a conceptual framework of the walking experience. Age Ageing 2023 Jan 8;52(1):afac233. [doi: 10.1093/ageing/afac233] [Medline: 36729471]
4. Sherrington C, Fairhall N, Kwok W, et al. Evidence on physical activity and falls prevention for people aged 65+ years: systematic review to inform the WHO guidelines on physical activity and sedentary behaviour. Int J Behav Nutr Phys Act 2020 Nov 26;17(1):144. [doi: 10.1186/s12966-020-01041-3] [Medline: 33239019]
5. Cunningham C, O'Sullivan R, Caserotti P, Tully MA. Consequences of physical inactivity in older adults: a systematic review of reviews and meta-analyses. Scand J Med Sci Sports 2020 May;30(5):816-827. [doi: 10.1111/sms.13616] [Medline: 32020713]
6. Baldelli G, De Santi M, De Felice F, Brandi G. Physical activity interventions to improve the quality of life of older adults living in residential care facilities: a systematic review. Geriatr Nurs 2021;42(4):806-815. [doi: 10.1016/j.gerinurse.2021.04.011] [Medline: 34090224]
7. de Souto Barreto P, Morley JE, Chodzko-Zajko W, et al. Recommendations on physical activity and exercise for older adults living in long-term care facilities: a taskforce report. J Am Med Dir Assoc 2016 May 1;17(5):381-392. [doi: 10.1016/j.jamda.2016.01.021] [Medline: 27012368]
8. Mc Ardle R, Sverdrup K, Del Din S, et al. Quantifying physical activity in aged residential care facilities: a structured review. Ageing Res Rev 2021 May;67:101298. [doi: 10.1016/j.arr.2021.101298] [Medline: 33592308]
9. Mc Ardle R, Jabbar KA, Del Din S, et al. Using digital technology to quantify habitual physical activity in community dwellers with cognitive impairment: systematic review. J Med Internet Res 2023 May 18;25:e44352. [doi: 10.2196/44352] [Medline: 37200065]
10. Taylor LM, Lord S, Parsons J, et al. Walking is associated with physical capacity and fatigue but not cognition in long-term care residents. J Am Med Dir Assoc 2022 Nov;23(11):e1-e2. [doi: 10.1016/j.jamda.2022.05.013] [Medline: 35714702]
11. Mc Ardle R, Del Din S, Donaghy P, Galna B, Thomas A, Rochester L. Factors that influence habitual activity in mild cognitive impairment and dementia. Gerontology 2020;66(2):197-208. [doi: 10.1159/000502288] [Medline: 31533101]
12. Mc Ardle R, Del Din S, Morris R, et al. Factors influencing habitual physical activity in Parkinson's disease: considering the psychosocial state and wellbeing of people with Parkinson's and their carers. Sensors (Basel) 2022 Jan 24;22(3):871. [doi: 10.3390/s22030871] [Medline: 35161617]
13. Del Din S, Godfrey A, Galna B, Lord S, Rochester L. Free-living gait characteristics in ageing and Parkinson's disease: impact of environment and ambulatory bout length. J Neuroeng Rehabil 2016 May 12;13(1):46. [doi: 10.1186/s12984-016-0154-5] [Medline: 27175731]
14. Mc Ardle R, Hamilton C, Del Din S, et al. Associations between local area deprivation and physical activity participation in people with cognitive impairment in the north east of England. J Alzheimers Dis 2023;95(1):265-273. [doi: 10.3233/JAD-230358] [Medline: 37483003]
15. Sverdrup K, Bergh S, Selbæk G, Røen I, Kirkevold Ø, Tangen GG. Mobility and cognition at admission to the nursing home - a cross-sectional study. BMC Geriatr 2018 Jan 30;18(1):30. [doi: 10.1186/s12877-018-0724-4] [Medline: 29378518]

16. Barker RO, Hanratty B, Kingston A, Ramsay SE, Matthews FE. Changes in health and functioning of care home residents over two decades: what can we learn from population-based studies? Age Ageing 2021 May 5;50(3):921-927. [doi: 10.1093/ageing/afaa227] [Medline: 33951152]
17. Zimmerman S, Sloane PD, Reed D. Dementia prevalence and care in assisted living. Health Aff (Millwood) 2014 Apr;33(4):658-666. [doi: 10.1377/hlthaff.2013.1255] [Medline: 24711328]
18. Kijowska V, Szczerbińska K. Prevalence of cognitive impairment among long-term care residents: a comparison between nursing homes and residential homes in Poland. Eur Geriatr Med 2018 Aug;9(4):467-476. [doi: 10.1007/s41999-018-0062-2] [Medline: 34674486]
19. Taylor L, Parsons J, Taylor D, et al. Evaluating the effects of an exercise program (Staying UpRight) for older adults in long-term care on rates of falls: study protocol for a randomised controlled trial. Trials 2020 Jan 8;21(1):46. [doi: 10.1186/s13063-019-3949-4] [Medline: 31915043]
20. Guralnik JM, Simonsick EM, Ferrucci L, et al. A short physical performance battery assessing lower extremity function: association with self-reported disability and prediction of mortality and nursing home admission. J Gerontol 1994 Mar;49(2):M85-M94. [doi: 10.1093/geronj/49.2.m85] [Medline: 8126356]
21. Podsiadlo D, Richardson S. The timed "Up & Go": a test of basic functional mobility for frail elderly persons. J Am Geriatr Soc 1991 Feb;39(2):142-148. [doi: 10.1111/j.1532-5415.1991.tb01616.x] [Medline: 1991946]
22. Nasreddine ZS, Phillips NA, Bédirian V, et al. The Montreal Cognitive Assessment, MoCa: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc 2005 Apr;53(4):695-699. [doi: 10.1111/j.1532-5415.2005.53221.x] [Medline: 15817019]
23. Mc Ardle R, Morris R, Hickey A, et al. Gait in mild Alzheimer's disease: feasibility of multi-center measurement in the clinic and home with body-worn sensors: a pilot study. J Alzheimers Dis 2018;63(1):331-341. [doi: 10.3233/JAD-171116] [Medline: 29614664]
24. Moore SA, Hickey A, Lord S, Del Din S, Godfrey A, Rochester L. Comprehensive measurement of stroke gait characteristics with a single accelerometer in the laboratory and community: a feasibility, validity and reliability study. J Neuroeng Rehabil 2017 Dec 29;14(1):130. [doi: 10.1186/s12984-017-0341-z] [Medline: 29284544]
25. MacLean MK, Rehman RZU, Kerse N, Taylor L, Rochester L, Del Din S. Walking bout detection for people living in long residential care: a computationally efficient algorithm for a 3-axis accelerometer on the lower back. Sensors (Basel) 2023 Nov 4;23(21):8973. [doi: 10.3390/s23218973] [Medline: 37960674]
26. Hickey A, Del Din S, Rochester L, Godfrey A. Detecting free-living steps and walking bouts: validating an algorithm for macro gait analysis. Physiol Meas 2017 Jan;38(1):N1-N15. [doi: 10.1088/1361-6579/38/1/N1] [Medline: 27941238]
27. Buckley C, Cavadino A, Del Din S, et al. Quantifying reliable walking activity with a wearable device in aged residential care: how many days are enough. Sensors (Basel) 2020 Nov 5;20(21):6314. [doi: 10.3390/s20216314] [Medline: 33167527]
28. Rochester L, Chastin SFM, Lord S, Baker K, Burn DJ. Understanding the impact of deep brain stimulation on ambulatory activity in advanced Parkinson's disease. J Neurol 2012 Jun;259(6):1081-1086. [doi: 10.1007/s00415-011-6301-9] [Medline: 22086738]
29. Teipel S, Heine C, Hein A, et al. Multidimensional assessment of challenging behaviors in advanced stages of dementia in nursing homes-the insideDEM framework. Alzheimers Dement (Amst) 2017;8:36-44. [doi: 10.1016/j.dadm.2017.03.006] [Medline: 28462388]
30. Del Din S, Godfrey A, Mazzà C, Lord S, Rochester L. Free-living monitoring of Parkinson's disease: lessons from the field. Mov Disord 2016 Sep;31(9):1293-1313. [doi: 10.1002/mds.26718] [Medline: 27452964]
31. Mc Ardle R, Del Din S, Donaghy P, Galna B, Thomas AJ, Rochester L. The impact of environment on gait assessment: considerations from real-world gait analysis in dementia subtypes. Sensors (Basel) 2021 Jan 26;21(3):813. [doi: 10.3390/s21030813] [Medline: 33530508]
32. Del Din S, Galna B, Godfrey A, et al. Analysis of free-living gait in older adults with and without Parkinson's disease and with and without a history of falls: identifying generic and disease-specific characteristics. J Gerontol A Biol Sci Med Sci 2019 Mar 14;74(4):500-506. [doi: 10.1093/gerona/glx254] [Medline: 29300849]
33. Orendurff MS, Schoen JA, Bernatz GC, Segal AD, Klute GK. How humans walk: bout duration, steps per bout, and rest duration. J Rehabil Res Dev 2008;45(7):1077-1089. [doi: 10.1682/jrrd.2007.11.0197] [Medline: 19165696]
34. Brydges CR. Effect size guidelines, sample size calculations, and statistical power in gerontology. Innov Aging 2019 Aug;3(4):igz036. [doi: 10.1093/geroni/igz036] [Medline: 31528719]
35. Canadian Task Force on Preventive Health Care, Pottie K, Rahal R, et al. Recommendations on screening for cognitive impairment in older adults. CMAJ 2016 Jan 5;188(1):37-46. [doi: 10.1503/cmaj.141165] [Medline: 26622001]
36. Guralnik JM, Ferrucci L, Pieper CF, et al. Lower extremity function and subsequent disability: consistency across studies, predictive models, and value of gait speed alone compared with the short physical performance battery. J Gerontol A Biol Sci Med Sci 2000 Apr;55(4):M221-M231. [doi: 10.1093/gerona/55.4.m221] [Medline: 10811152]
37. Lin Q, Zhang D, Chen L, Ni H, Zhou X. Managing elders' wandering behavior using sensors-based solutions: a survey. Int J Gerontol 2014 Jun;8(2):49-55. [doi: 10.1016/j.ijge.2013.08.007]

38. Kamil RJ, Bakar D, Ehrenburg M, et al. Detection of wandering behaviors using a body-worn inertial sensor in patients with cognitive impairment: a feasibility study. Front Neurol 2021 Mar 11;12:529661. [doi: 10.3389/fneur.2021.529661] [Medline: 33776875]
39. Agrawal AK, Gowda M, Achary U, Gowda GS, Harbishettar V. Approach to management of wandering in dementia: ethical and legal issue. Indian J Psychol Med 2021 Sep;43(5 Suppl):S53-S59. [doi: 10.1177/02537176211030979] [Medline: 34732955]
40. Moyle W, Jones C, Murfield J, et al. Effect of a robotic seal on the motor activity and sleep patterns of older people with dementia, as measured by wearable technology: a cluster-randomised controlled trial. Maturitas 2018 Apr;110:10-17. [doi: 10.1016/j.maturitas.2018.01.007] [Medline: 29563027]
41. Murata S, Takegami M, Ogata S, et al. Joint effect of cognitive decline and walking ability on incidence of wandering behavior in older adults with dementia: a cohort study. Int J Geriatr Psychiatry 2022 May;37(5). [doi: 10.1002/gps.5714] [Medline: 35451122]
42. Mc Ardle R, Jabbar KA, Del Din S, et al. Using digital technology to quantify habitual physical activity in community-dwellers with cognitive impairment: a systematic review. J Med Internet Res 2023 May 18;25:e44352. [doi: 10.2196/44352] [Medline: 37200065]
43. Corcoran MP, Chui KKH, White DK, et al. Accelerometer assessment of physical activity and its association with physical function in older adults residing at assisted care facilities. J Nutr Health Aging 2016;20(7):752-758. [doi: 10.1007/s12603-015-0640-7] [Medline: 27499309]
44. Buckinx F, Mouton A, Reginster JY, et al. Relationship between ambulatory physical activity assessed by activity trackers and physical frailty among nursing home residents. Gait Posture 2017 May;54:56-61. [doi: 10.1016/j.gaitpost.2017.02.010] [Medline: 28259040]
45. Galik EM, Resnick B, Holmes SD, et al. A cluster randomized controlled trial testing the impact of function and behavior focused care for nursing home residents with dementia. J Am Med Dir Assoc 2021 Jul;22(7):1421-1428. [doi: 10.1016/j.jamda.2020.12.020] [Medline: 33454311]
46. Benjamin K, Edwards N, Ploeg J, Legault F. Barriers to physical activity and restorative care for residents in long-term care: a review of the literature. J Aging Phys Act 2014 Jan;22(1):154-165. [doi: 10.1123/japa.2012-0139] [Medline: 23434919]
47. Webster L, Costafreda Gonzalez S, Stringer A, et al. Measuring the prevalence of sleep disturbances in people with dementia living in care homes: a systematic review and meta-analysis. Sleep 2020 Apr 15;43(4):zsz251. [doi: 10.1093/sleep/zsz251] [Medline: 31633188]

Abbreviations

ARC: aged residential care
HSD: honest significant difference
MoCA: Montreal Cognitive Assessment
RCT: randomized controlled trial
SPPB: Short Physical Performance Battery

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Original Paper

Digital Peer-Supported App Intervention to Promote Physical Activity Among Community-Dwelling Older Adults: Nonrandomized Controlled Trial

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Abstract

Background: The use of mobile apps has promoted physical activity levels. Recently, with an increasing number of older adults accessing the internet, app-based interventions may be feasible in older populations. Peer support–based interventions have become a common method for promoting health-related behavior change. To our knowledge, the feasibility of using digital peer support apps (DPSAs) to increase physical activity among older adults and its impact on physical activity and physical function have not been investigated.

Objective: This study aims to assess the feasibility of using DPSAs in older adults and to assess changes in physical activity and physical function in DPSA users.

Methods: We conducted a nonrandomized controlled trial of older adults aged ≥65 years. We recruited participants for 2 distinct 12-week programs designed to increase physical activity. Participants could choose between an intervention group (app program and exercise instruction) or a control group (exercise instruction only). DPSA creates a group chat for up to 5 people with a common goal, and participants anonymously post to each other in the group. Once a day, participants posted a set of their step counts, photos, and comments on a group chat box. The intervention group used the DPSA after receiving 2 face-to-face lectures on its use. The participants were characterized using questionnaires, accelerometers, and physical function assessments. The feasibility of the DPSA was assessed using retention and adherence rates. Physical activity was assessed using accelerometers to measure the daily step count, light intensity physical activity, moderate to vigorous intensity physical activity (MVPA), and sedentary behavior. Physical function was assessed using grip strength and the 30-second chair-stand test.

Results: The participants in the intervention group were more frequent users of apps, were more familiar with information and communication technology, and had a higher baseline physical activity level. The retention and adherence rates for the DPSA intervention were 88% (36/41) and 87.7%, respectively, indicating good feasibility. Participants in the intervention group increased their step count by at least 1000 steps and their MVPA by at least 10 minutes using the DPSA. There was a significant difference in the interaction between groups and intervention time points in the daily step count and MVPA (step count, *P*=.04; duration of MVPA, *P*=.02). The DPSA increased physical activity, especially in older adults with low baseline physical activity levels.

Conclusions: The feasibility of DPSA was found to be good, with the intervention group showing increases in daily steps and MVPA. The effects of DPSA on step count, physical activity, and physical function in older adults with low baseline physical activity should be investigated using randomized controlled trials.

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KEYWORDS

physical activity; physical function; gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; aged; digital peer support app; mHealth; mobile health; app; apps; application; applications; eHealth; peer support; exercise; mobile phone

Introduction

Background

The health benefits of regular physical activity are familiar [1]. Physical activity reduces the risk of chronic diseases such as type 2 diabetes, cardiovascular disease, and hypertension [2-4]. In addition, physical activity improves the overall physical and mental functioning and controls morbidity and mortality rates [5,6]. However, globally, the level of physical activity has remained stable or declined, despite several efforts to promote physical activity [7,8]. In addition, social distancing during the COVID-19 pandemic has caused changes in lifestyle and social behavior [9]. The level of physical activity among older adults in Japan is reported to have declined due to the COVID-19 pandemic [10,11] and needs to be increased.

Recently, mobile apps have been used successfully to increase physical activity levels [12,13]. eHealth encompasses health care services and information delivered with the aid of information and communication technology (ICT), including computers, mobile phones, and satellite communications. Mobile health (mHealth) refers to the use of smart or portable devices for providing health services and information [14]. With an increase in the population of older adults using the internet, mHealth and eHealth approaches may be feasible [15,16]. A total of 3 out of 4 reviews concluded that mHealth or eHealth interventions are effective in the short term in promoting physical activity in adults aged ≥50 years [17]. Furthermore, eHealth interventions targeting physical activity have revealed that theory-based interventions are more effective than interventions that are not grounded in theory [18]. However, there has been limited focus on social cognitive theory–based interventions aimed at promoting physical activity among older adults through peer support.

Peer support–based interventions have become a common method for promoting health-related behavior change [19]. Webel et al [20] defined peer support as “a method of teaching or facilitating health promotion that makes use of people sharing specific health messages with members of their own community.” The effectiveness of peer support–based interventions for physical activity has a theoretical basis, often explained by social cognitive theory [21]. The social cognitive theory proposed by Bandura [22] stipulates that behavior is learned by observing and imitating others. This process is called observational learning or modeling and has been extensively studied in the context of motor skill development and education. Peer-mediated delivery of information regarding physical activity through apps could facilitate attention, retention, and motivation to work on that information, as per social cognitive theory. Liu and Lachman [23] conducted a 4-week randomized controlled trial based on social cognitive theory in which older adults aged ≥60 years used the WeChat and WeRun apps to increase their step counts by recording and exchanging them through SMS text messages. This social engagement through SMS text messages increased the step count. However, the step count was the only physical activity outcome measure, and the effect of the intervention on physical activity intensity, sedentary behavior (SB), and physical function was not assessed. Therefore, using an app based on social cognitive theory, we examined the effects of a digital peer-supported intervention on step counts, physical activity intensity, SB, and physical function among older adults aged ≥65 years.

Objective

This study used a digital peer-supported app (DPSA) to conduct a 12-week intervention study on older adults aged ≥65 years. The objectives of this study were threefold: (1) to understand the characteristics of older adults who choose to use the DPSA to increase their physical activity; (2) to evaluate the feasibility of using the DPSA to promote physical activity in older adults; and (3) to measure the effect of using the DPSA on users’ level of physical activity, SB, physical function, and self-efficacy for exercise.

Methods

Study Design

This nonrandomized pretest-posttest comparison trial of 2 groups was conducted in Fujisawa City, Kanagawa Prefecture, Japan. In April 2022, the city had an area of 69.57 km^2 and a population of 442,892, of whom 108,472 (24.49%) were aged ≥65 years. The study was conducted as an industry-government-academia collaboration between the local government, an app-making company, and a university.

Ethical Considerations

The study was approved by the Research Ethics Committee of Sports Medicine Research Center at Keio University (approval number 2022-07). Informed consent was obtained from all participants. The study protocol was registered with the University Hospital Medical Information Network (UMIN000050618).

Participants

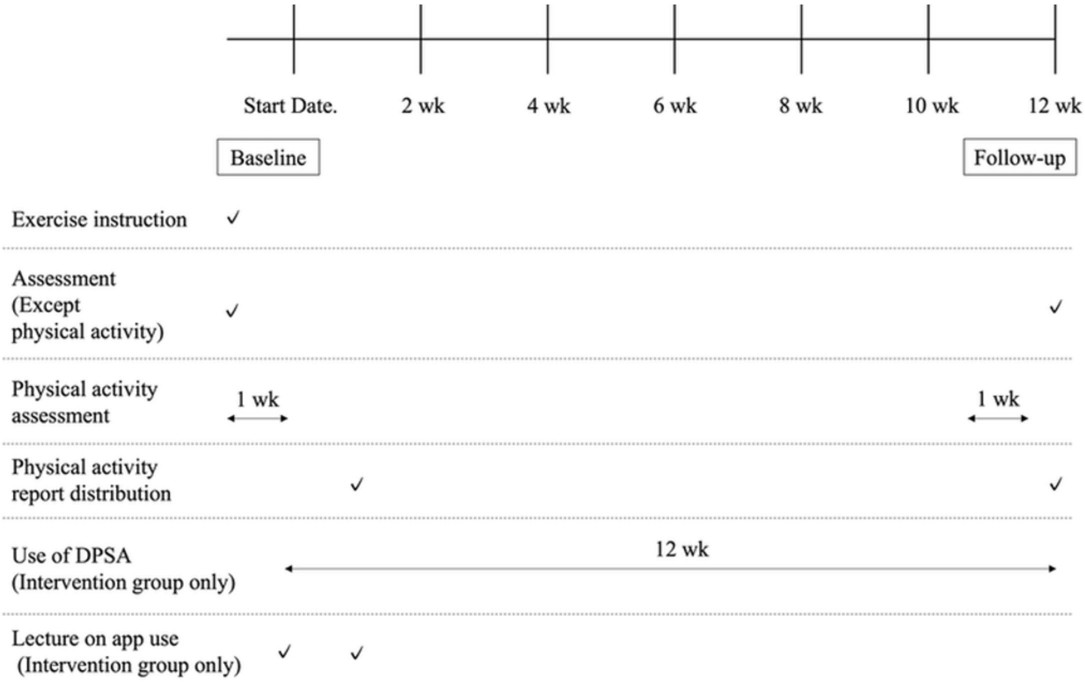
The study was conducted on Fujisawa City older adults aged ≥65 years. We recruited participants for 2 distinct 12-week programs designed to increase physical activity. Participants could choose between an intervention group (app program and exercise instruction) and a control group (exercise instruction only). Participants from different areas within the municipality were recruited through flyers, publicity, and calls to related organizations. The intervention was implemented in two phases: (1) from October 2022 to January 2023 and (2) from December 2022 to March 2023. Participants selected programs according to their preferences (the app program was for smartphone owners only). The eligibility criteria were older adults aged ≥65 years, who were able to walk independently and perform other activities of daily living and had not been advised to refrain from physical activity by a physician. Before participation, prospective participants were screened using a personal health status questionnaire based on the Physical Activity Readiness Questionnaire [24-26] to ascertain whether there were any potential problems with participation in the study. Because older adults are generally assumed to be less familiar with smartphones and apps than younger adults [27] and may not be able to completely use the DPSA, we provided 2 lectures about using the app; 1 lecture was conducted at the start of the DPSA use, and another was conducted 1 week later. Participants were instructed to download the app, and its use was explained during the first lecture. Each lecture lasted for 1 to 1.5 hours, and the participants were able to receive instructions directly from the instructor and ask questions.

Intervention

Program

The timeline of the study procedure is presented in Figure 1. Regardless of program selection, all participants participated in face-to-face exercise instruction, program introduction, and baseline assessment conducted by a physical therapist or a health fitness instructor. Exercise instructions focused on aerobic, stretching, muscle strengthening, and balance exercises based on the original “Fujisawa +10 exercise” program [28,29]. Exercise instruction was provided for 15 minutes for the intervention group and 30 minutes for the control group. Both intervention and control groups were instructed to increase their daily physical activity. Participants completed questionnaires and underwent physical activity and physical function assessments using a triaxial accelerometer at baseline (start date) and during follow-up (weeks 10-12). Individual physical activity reports were generated from the data obtained and fed back to the participants. The intervention group began using the app 1 week after the baseline outcome assessment was conducted. The timing of the evaluation of each measurement item is described in Multimedia Appendix 1.

Figure 1. Timeline of study procedures. DSPA: digital peer support app; wk: weeks.



DPSA Intervention

The study was conducted using Minchalle (A10 Lab Inc), a commercially available DPSA [30]. This app was developed in June 2015 and launched in November 2015. Figure 2 shows example screens from the app. The DPSA creates a group chat for up to 5 people with a common goal, and participants anonymously post messages to each other in the group. The common goal of the intervention group was to increase physical activity through walking and exercise. Once a day, participants posted a set of their step counts, photos, and comments on a group chat box. The main functions of the DPSA used in this study were to enable the participants to (1) post step counts, photos, and comments about the day; (2) post approvals from group members to each other’s postings; (3) set step count goals on a group basis; and (4) get feedback on the team’s total daily step count. Step counts were measured using a smartphone, with the DPSA reporting the number of steps taken on the day at the time of posting. Participants had the option to post comments or photos multiple times a day and engage with other members, although this was not mandatory. The app was available for participants to use free of charge.

Figure 2. Examples of app screens. (A) Select a group. (B) Post photos, step count, and comments on the group. Post a photo taken that day and comment on the day's events. (C) The contents of the posts are displayed in the group. The total number of steps for the group is displayed. (D) Response to posts by group members.

みんチャレ内で使うニックネームを教えてください

グリーン:「みんなで歩こう」チー...

ブルー:画像を送信しました

今日からがんばります！

[3,200歩]
今日からがんばります！

たんぽぽさんの初めてのチャレンジだよ～みんなお祝いしよ～🎉

初チャレンジだ～みんなでお祝いしよ～🎉

[4,000歩]
一緒に頑張りましょう♪

わ～い～いとうさんの初チャレンジ嬉しいな～みんなで祝お～🎉

(A) (B) (C) (D)

Measurements

Demographic Characteristics of Participants

In addition to general characteristics such as age and sex, the survey asked about smartphone ownership, the frequency of app use, exercise habits, the frequency of neighborhood interaction, participation in group exercise, history of falls in the past year, the effect of the COVID-19 pandemic on their level of physical activity, self-reported decrease in walking speed, the use of ICT, and self-efficacy for exercise.

Participant's body weight (kg) was measured using a digital scale, and height (m) was measured on a stadiometer after participants removed their shoes. BMI was then calculated as body weight divided by the square of height.

Exercise habits were defined as "those who exercise at least twice a week, for at least 30 minutes each time, for at least one year" [31].

The frequency of neighborhood interaction was assessed by asking how many times one interacts with people in the neighborhood within 1 week.

Group exercise participation was defined as those who participate in a group of three or more people who meet voluntarily to exercise.

Information about the use of ICT was collected using questions about "Gathering information and shopping on the internet," "Using social networking services (Facebook, LINE, Instagram, etc)," and "Do not use any information devices." The percentages for the intervention and control groups were compared with representative values from the Annual Report on the Ageing Society, published by the Japanese Cabinet Office, to determine the extent to which participants are using ICT compared with other older adults [32].

Outcome Measures of Participants

To assess physical activity, participants were asked to wear a triaxial accelerometer [33] (Active Style Pro HJA-750C Activity Meter, Omron Health Care) at waist level for 7 consecutive days before the intervention and 10 to 11 weeks after the intervention commenced. The accelerometer display was configured to prevent users from viewing the amount of physical activity for the day. Participants were instructed not to remove the device unless required for certain tasks, such as changing their clothes and bathing. At the end of the measurement, all the data collected were transferred from the accelerometer to a PC. Following the method suggested by Jefferis et al [34] for estimating physical activity, an individual needed to record at least 10 hours of activity per day for 3 days to be included in the subsequent analyses. The data were collected in 60-second epochs for data analysis and used to estimate the intensity of activity in metabolic equivalents (METs). The mean daily step count and time spent in SB (≤1.5 METs), light intensity physical activity (LPA; 1.6-2.9 METs), and moderate to vigorous intensity physical activity (MVPA: ≥3 METs) per day were used for outcome measurements of physical activity.

Physical function was assessed using grip strength and the 30-second chair-stand test (CS-30). Grip strength was measured using a digital dynamometer (Grip D, TKK 5401, Takei Scientific Instruments). Measurements were taken in the standing position, with the elbow joint in extension and the wrist joint in midextension. Both the left and right hands were measured once each, and the maximum value was used. For the CS-30 test [35], seated participants were instructed to stand up from the chair with their arms crossed at chest level as many times as possible in 30 seconds.

Self-efficacy for exercise was assessed using 4 questions pertaining to participants' self-confidence in exercising under each of the following conditions [36]: "Do you have the confidence to exercise regularly under the following conditions? physical fatigue, mental stress, lack of time, and bad weather."

In response to the question, participants were asked to select 1 of the 5 answers ranging from "No, I don't have any confidence at all (1 point)" to "Yes, I am quite confident (5 points)." The total score ranged from 4 to 20. Textbox 1 summarizes the measures related to the characteristics of the participants.

Textbox 1. Measurements related to participant characteristics.

Measurement methods and items

- Questionnaire
  - Age, sex, living alone, self-rated health, perceived household economic status, life satisfaction, employment status, smartphone ownership, frequency of app use, exercise habits, frequency of neighborhood interaction, participation in group exercise, history of falls in the past year, effect of the COVID-19 pandemic on decreased physical activity, self-reported decrease in walking speed, and self-efficacy for exercise
- Triaxial accelerometer
  - Steps, light intensity physical activity, moderate to vigorous intensity physical activity, and sedentary behavior
- Physical function assessment
  - BMI, grip strength, and 30-second chair-stand test

Feasibility of DPSA Intervention

The feasibility of DPSA intervention was assessed by retention and adherence rates during the 12-week program implementation. The DPSA could exclude a person from a group if they have not posted a set of their step counts, photos, and comments for 15 consecutive days. Dropouts were defined as those who were excluded from the group during the 12 weeks of DPSA intervention. The retention rate was calculated using a denominator of 41 participants including those who withdrew consent. The adherence rate of DPSA intervention was calculated by dividing the number of sets of their step counts, photos, and comments posted during the intervention period by the duration of the intervention. DPSA adherence rates were also calculated by group (9 groups: A-I). The number of all chat posts per person by group was calculated to assess group use. Negative physical effects that occurred during the intervention were ascertained by interviewing the participants during follow-up. We report on privacy breaches and technical problems with the app. Privacy breaches were identified by the municipality, and technical problems were identified by the app company. Continuity was evaluated using a questionnaire on factors that contributed to exercise continuation by the DPSA and the intention to continue using the DPSA after 12 weeks.

Changes in Physical Activity, SB, Physical Function, and Self-Efficacy for Exercise

Physical activity (step count, LPA, MVPA, and SB); physical function (grip strength and CS-30); and self-efficacy for exercise were assessed at 2 time points: baseline and follow-up. The follow-up data were measured in the same way as at baseline. For follow-up data, physical activity was measured between weeks 10 and 11 of the intervention. Physical function and self-efficacy for exercise were measured after 12 weeks of the intervention.

Statistical Analysis

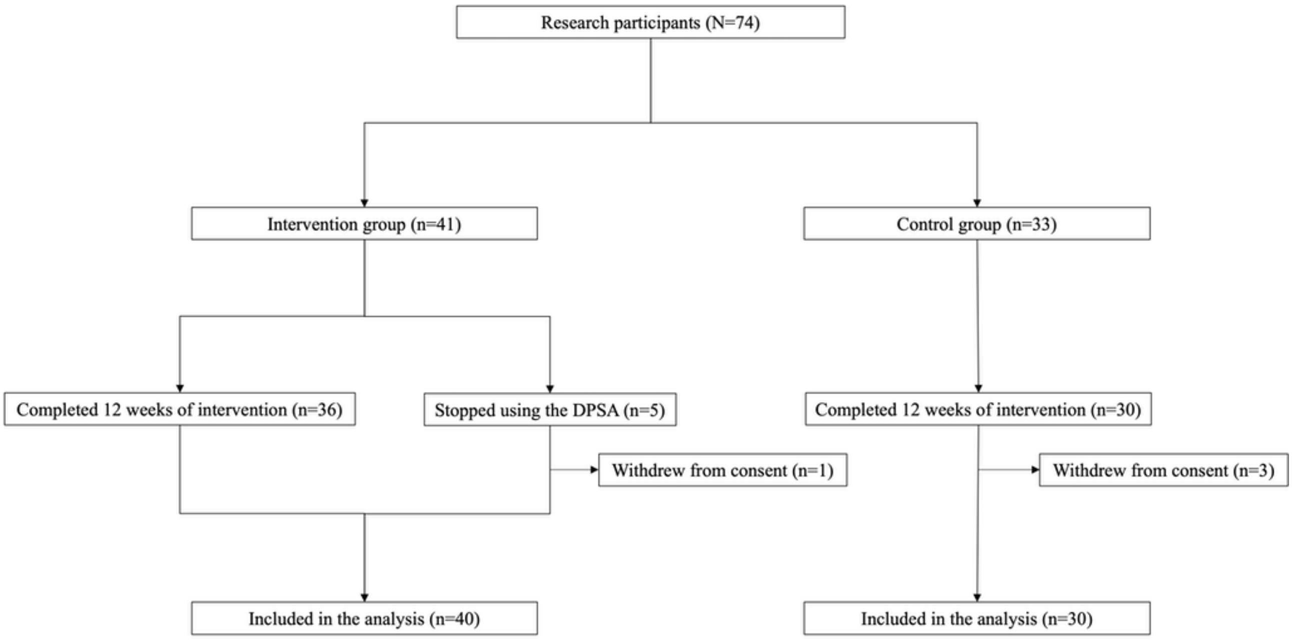
Comparisons of participant characteristics in each group were analyzed using the independent samples *t* test (2-tailed), chi-square test, and Mann-Whitney *U* test. The interaction between the group and time of intervention was analyzed using a linear mixed model with baseline and follow-up group differences adjusted for baseline age, sex, and frequency of app use (at baseline). Consent withdrawers were excluded, and older adults who dropped out of the intervention were included in the analysis in a modified intention-to-treat analysis. The daily step count, SB, LPA, MVPA, grip strength, CS-30, and self-efficacy for exercise were analyzed as dependent variables in separate models. The daily step counts were positively skewed; therefore, square root transformations were applied to improve normality. To increase the comprehensibility of the tables, raw descriptive data were reported, although analyses were conducted using the square root–transformed values. We defined high and low levels of physical activity based on step counts, using 7000 steps per day as the cutoff, as the recommended step goal for older adults is typically 7000 to 10,000 steps [37]. To examine the impact of physical activity at baseline on the intervention effect, a post hoc subgroup analysis was conducted on participants in the intervention group who had different levels of physical activity at baseline (≥7000 steps per day vs <7000 steps/day). The interaction between the physical activity level and intervention time point was analyzed in a linear mixed model adjusted for baseline age, sex, and frequency of app use. The data were analyzed using SPSS (version 29.0; IBM Corp). The statistical significance level was set at 5%.

Results

Participants

A total of 74 participants were initially enrolled in the study. However, 4 (5%) withdrew consent during the 12-week intervention period, with 1 (25%) withdrawal in the intervention group and 3 (75%) in the control group. The final analysis included 70 participants, 40 (57%) in the intervention group and 30 (43%) in the control group, in a modified intention-to-treat analysis, excluding those who withdrew consent (Figure 3). The intervention group comprised 9 groups of 4 to 5 participants each. A total of 5 (12%) out of 41 participants in the intervention group dropped out, including the 1 who withdrew consent.

Figure 3. Flow diagram of participants. DPSA: digital peer support app.



Participant Characteristics

The baseline participant characteristics are shown in Tables 1 and 2. The mean age of the participants (n=70) was 77.3 (SD 6.1) years, with 26 (37%) male participants included in the study. There were no differences in baseline demographic characteristics between the intervention and control groups. However, participants in the intervention group were more likely to use apps and exercise more frequently. “Gather information and shop on the internet” for the intervention group, the control group and representative percentage were 78%, 57%, and 23.7%, respectively. “Use social networking services” for the intervention group, the control group and representative percentage were 60%, 37%, and 13.1%, respectively. “Do not use any information devices” for the intervention group, the control group and representative percentage were 0%, 3%, and 17%, respectively. Compared to the representative percentage of Japanese older adults based on the Annual Report on the Ageing Society published by the Japan Cabinet Office [32], both groups used ICT, with the intervention group exhibiting greater ICT use compared to the control group.

Although the difference in the baseline daily step count between groups was not statistically significant, the step count was higher in the intervention group than in the control group, with a median difference of >1000 steps. There was a statistically significant difference in baseline LPA and MVPA between the 2 groups; the intervention group exhibited significantly higher MVPA levels, while the control group showed significantly higher LPA levels. Furthermore, grip strength was higher in the intervention group, likely owing to the greater proportion of male participants; however, the difference was not statistically significant.

Table 1. Demographic characteristics of the participants (n=70).

Characteristics	Total sample	Intervention group (n=40)	Control group (n=30)	*P* value
Age (years), mean (SD)	77.3 (6.1)	76.9 (6.1)	77.9 (6.1)	.49[a]
Sex, n (%)				.12[b]
Male	26 (37)	18 (45)	8 (27)	
Female	44 (63)	22 (55)	22 (73)	
BMI (kg/m^2), mean (SD)	22.8 (2.9)	23.0 (2.9)	22.4 (2.9)	.43[a]
Living alone, n (%)	19 (27)	13 (32)	6 (20)	.22[b]
Self-rated health, n (%)				.13[b]
Excellent, good, or normal	63 (90)	38 (95)	25 (83)	
Fair or poor	7 (10)	2 (5)	5 (17)	
Perceived household economic status, n (%)				.57[b]
Excellent, good, or normal	67 (96)	39 (98)	28 (93)	
Fair or poor	3 (4)	1 (2)	2 (7)	
Life satisfaction, n (%)				.53[b]
Excellent, good or normal	62 (89)	35 (88)	27 (90)	
Fair or poor	8 (11)	5 (12)	3 (10)	
Working, n (%)	18 (26)	9 (22)	9 (30)	.48[b]
Smartphone ownership, n (%)	67 (96)	40 (100)	27 (90)	.07[b]
Frequency of app use, n (%)				.07[b]
Usually or sometimes	54 (77)	34 (85)	20 (67)	
Rarely or never	16 (23)	6 (15)	10 (33)	
Exercise habits, n (%)	37 (53)	24 (60)	13 (43)	.17[b]
Frequency of neighborhood interaction, n (%)				.53[b]
≥3 times/week	31 (44)	19 (48)	12 (40)	
≤2 times/week	39 (56)	21 (52)	18 (60)	
Participation in group exercise, n (%)	34 (49)	18 (45)	16 (53)	.49[b]
History falls in the past year, n (%)	9 (13)	5 (12)	4 (13)	.60[b]
Effect of the COVID-19 pandemic on decreased physical activity, n (%)				.64[b]
Great or slight	51 (73)	30 (75)	21 (70)	
Not much or unchanged	19 (27)	10 (25)	9 (30)	
Self-reported decrease in walking speed, n (%)	49 (70)	28 (70)	21 (70)	>.99[b]

[a] Analysis was conducted using the independent samples *t* test (2-tailed).

[b] Analysis was conducted using the chi-square test.

Table 2. Baseline measures of the triaxial accelerometer, physical function assessment, and self-efficacy for exercise (n=70).

Outcome measures	Total sample	Intervention group (n=40)	Control group (n=30)	*P* value
Triaxial accelerometer[a]				
Steps/day, median (IQR)	5511 (3783-7852)	6310 (3936-8132)	5276 (3522-6275)	.08[b]
LPA[c] (minutes/day), mean (SD)	329.9 (91.0)	306.6 (79.7)	360.3 (97.0)	.01[d]
MVPA[e] (minutes/day), mean (SD)	45.5 (26.5)	51.0 (24.1)	38.4 (28.1)	.049[d]
SB[f] (minutes/day), mean (SD)	538.2 (110.3)	530.1 (86.0)	522.3 (116.8)	.54[d]
Triaxial accelerometer wearing time (minutes/day), mean (SD)	913.6 (121.8)	888.4 (80.0)	946.4 (159.6)	.07[d]
Physical function				
Grip strength (kg), mean (SD)	25.6 (8.1)	26.9 (8.7)	23.8 (7.0)	.12[d]
CS-30[g], mean (SD)	20.7 (6.4)	20.7 (7.2)	20.8 (5.2)	.92[d]
Self-efficacy for exercise, mean (SD)	13.6 (3.6)	13.9 (3.6)	13.3 (3.6)	.54[d]

[a] Participants with valid accelerometer data; total sample, n=69; intervention, n=39; and control, n=30.

[b] Analysis was conducted using the Mann-Whitney *U* test.

[c] LPA: light intensity physical activity.

[d] Analysis was conducted using the independent samples *t* test (2-tailed).

[e] MVPA: moderate to vigorous intensity physical activity.

[f] SB: sedentary behavior.

[g] CS-30: 30-second chair-stand test.

Feasibility: Retention Rate, Number of Posts, Negative Impact, Continuation Factors, and Willingness to Continue

A total of 5 (12%) out of the 41 participants in the intervention group dropped out, resulting in a DPSA continuation rate of 88% (36/41). Reasons for dropping out included “withdrew research consent,” “not a good fit for me,” and “unknown cause” (n=1, 20% each), as well as “poor health” (n=2, 40%). The average number of total posts per person was 2.76 (SD 1.99) per day. After excluding participants who dropped out, the adherence rate was 96%, and the average number of total posts per person was 3.02 (SD 1.93) per day (Table 3).

Table 3. Digital peer support app adherence rate and average number of total posts per day among participants in the intervention group.

Group	All participants (n=40)		Excluding participants who drop out (n=36)	
	n (adherence rate, %)	Total posts/person/day, mean (SD)	n (adherence rate, %)	Total posts/person/day, mean (SD)
All	40 (87.7)	2.76 (1.99)	36 (95.9)	3.02 (1.93)
A	4 (95.8)	1.55 (0.32)	4 (95.8)	1.55 (0.32)
B	5 (88.3)	1.83 (0.88)	5 (88.3)	1.83 (0.88)
C	5 (80.4)	2.62 (1.72)	4 (98.6)	3.24 (1.15)
D	5 (79.8)	1.12 (0.59)	4 (99.2)	1.38 (0.15)
E	5 (77.1)	1.19 (1.72)	4 (91.6)	1.22 (0.32)
F	4 (99.7)	6.25 (1.46)	4 (99.7)	6.25 (1.46)
G	4 (98.6)	3.36 (1.16)	4 (98.6)	3.36 (1.16)
H	4 (95.5)	4.20 (1.07)	4 (95.5)	4.20 (1.07)
I	4 (74.1)	3.83 (2.88)	3 (96.2)	4.88 (2.40)

A total of 3 minor negative physical effects were reported; 2 participants reported knee pain and 1 reported plantar pain. There were no breaches of privacy associated with the use of the app. A total of 14 inquiries were received about how to use the app. The average response took approximately 15.4 (10.7) minutes per case. The reported reasons for continuing to use the app were continuing fellowship (28/36, 78%), having a common goal (24/36, 67%), having fun (20/36, 56%), tracking their step counts (20/36, 56%), maintaining motivation (18/36, 50%), sense of improved mental health (17/36, 47%), sense of improved physical health (14/36, 39%), being on the internet (14/36, 39%) and Emotional painless (11/36, 31%). Figure 4 presents the intention to continue using the DPSA after the 12-week intervention. The responses were strongly agree (11/36, 31%), somewhat agree (12/36, 33%), undecided (11/36, 31%), somewhat disagree (1/36, 3%), and strongly disagree (1/36, 3%). More than half of the participants (23/36, 64%) indicated an intention to continue.

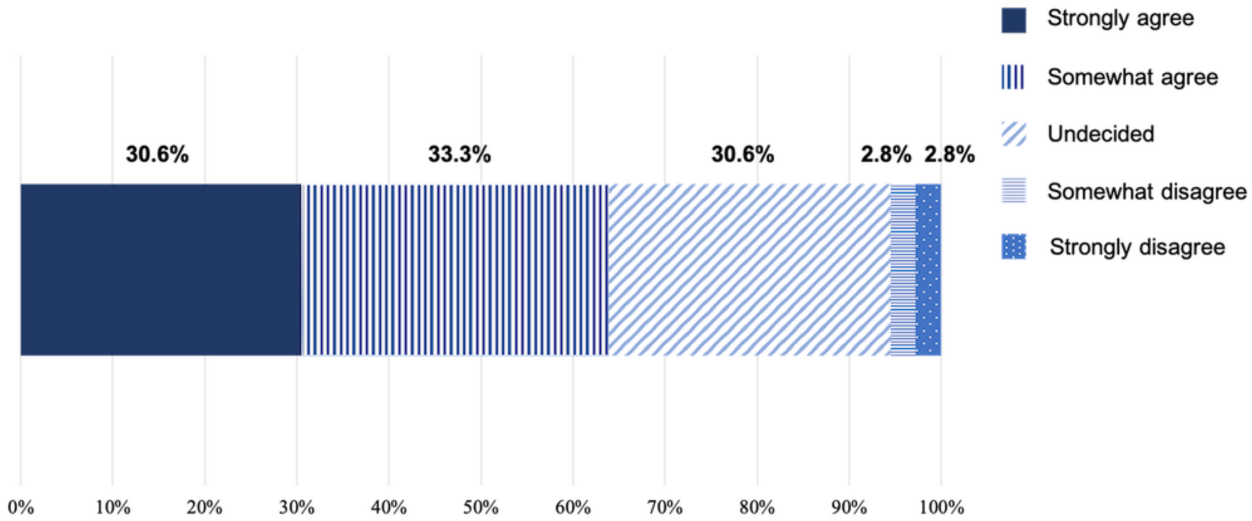


Figure 4. Intention to continue using the digital peer support app after the end of the study among participants in the intervention group.

Changes in Physical Activity, Physical Function, and Self-Efficacy for Exercise

The results of the linear mixed model analysis of physical activity, physical function, and self-efficacy for exercise are listed in Table 4. There was a significant difference in the interaction between groups and intervention time points in the daily step count and MVPA (daily step count: *P*=.04 and MVPA: *P*=.03) but not in LPA, SB, grip strength, CS-30, and self-efficacy for exercise.

A post hoc subgroup analysis was conducted by dividing the intervention group into high-level physical activity and low-level physical activity subgroups [37] based on their level of physical activity at baseline. The step count, LPA, MVPA, and SB were compared (Table 5). The analysis showed a significant difference in the interaction between the groups and the daily step count at baseline (*P*=.04).

Table 4. Intervention effects on physical activity, physical function, and self-efficacy for exercise before and after the intervention.

Outcome measures[a]	Intervention group		Control group		Group×time (adjusted) *P* value
	Baseline	Follow-up	Baseline	Follow-up	
Accelerometer data[b]					
Steps/day, median (IQR)	6310 (3936-8132)	8368 (5331-10,235)	5276 (3522-6275)	5143 (2715-6648)	.04
LPA[c] (minutes/day), mean (SD)	306.6 (79.7)	303.6 (91.0)	360.3 (97.0)	332.2 (81.7)	.06
MVPA[d] (minutes/day), mean (SD)	51.0 (24.1)	65.7 (32.0)	38.4 (28.1)	38.4 (28.1)	.02
SB[e] (minutes/day), mean (SD)	530.1 (86.0)	522.3 (116.8)	522.3 (116.8)	549.4 (113.7)	.55
Grip strength[f] (kg), mean (SD)	26.9 (8.7)	26.0 (9.3)	23.8 (7.0)	24.6 (7.4)	.09
CS-30[g], mean (SD)	20.7 (7.2)	22.2 (7.3)	20.8 (5.3)	20.4 (6.3)	.50
Self-efficacy for exercise[h], mean (SD)	13.9 (3.6)	14.8 (3.1)	13.3 (3.7)	14.0 (3.6)	.70

[a] Analyses were adjusted for age, sex, and frequency of app use (at baseline).

[b] Participants with valid accelerometer data; intervention group: baseline, n=39, and follow-up, n=35; control group: baseline, n=30, and follow-up, n=30.

[c] LPA: light intensity physical activity.

[d] MVPA: moderate to vigorous intensity physical activity.

[e] SB: sedentary behavior.

[f] Participants with valid grip strength data; intervention group: baseline, n=40, and follow-up, n=34; control group: baseline, n=30, and follow-up, n=23.

[g] CS-30; 30-second chair-stand test; participants with valid data; intervention group: baseline, n=40, and follow-up, n=32; control group: baseline, n=30, and follow-up, n=22.

[h] Participants with valid self-efficacy for exercise data; intervention group: baseline, n=40, and follow-up, n=36; control group: baseline, n=30, and follow-up, n=28.

Table 5. Comparison of intervention effects on accelerometer data between low-level and high-level physical activity subgroups at baseline and follow-up in the intervention group.

Outcome measures[a] (accelerometer data)[b]	<7000 steps/day (n=22)		≥7000 steps/day (n=18)		Group×time (adjusted) *P* value
	Baseline	Follow-up	Baseline	Follow-up	
Steps/day, median (IQR)	4338 (3207-5495)	5761 (4649-8680)	8581 (7571-10,117)	9277 (8133-10,980)	.007
LPA[c] (minutes/day), mean (SD)	296.7 (78.1)	301.1 (94.8)	318.0 (82.3)	306.2 (89.5)	.25
MVPA[d] (minutes/day), mean (SD)	33.1 (12.7)	52.0 (31.0)	71.9 (15.7)	80.2 (26.7)	.18
SB[e] (minutes/day), mean (SD)	538.2 (92.1)	513.3 (126.1)	522.4 (80.0)	531.7 (109.1)	.15

[a] Analyses were adjusted for age, sex, and frequency of app use (at baseline).

[b] Participants with valid accelerometer data; low-level physical activity (<7000 steps/day) group: baseline, n=21, and follow-up, n=18; high-level physical activity (≥7000 steps/day) group: baseline, n=18, and follow-up (n=18).

[c] LPA: light intensity physical activity.

[d] MVPA: moderate to vigorous intensity physical activity.

[e] SB: sedentary behavior.

Discussion

Principal Findings

The study aimed to determine the characteristics of older adults who wanted to use the DPSA, which aimed to increase physical activity among older adults, and to confirm the feasibility of the DPSA and its impact on physical activity. Older adults who wanted to use the DPSA were more likely to be frequent users of the app and were more familiar with the use of ICT. Participants who reported an exercise habit tended to be more physically active at baseline. The retention rate was 88% (36/41) and the adherence rate was 87.7%, demonstrating the feasibility of older adults using the DPSA. The step count and MVPA increased significantly in the intervention group compared with those in the control group, demonstrating that the DPSA effectively increased physical activity. In DPSA users, participants with lower levels of baseline physical activity showed a more significant increase in their daily step count compared with those with higher levels of physical activity.

Comparison With Previous Studies

In this study, the retention and adherence rates were 88% (36/41) and 87.7%, respectively. These values are favorable compared to those reported in previous studies that have used digital technology to increase physical activity among older adults [38-42]. The findings from this study show that it is feasible for older adults to use DPSA to increase their level of physical activity. While differences were observed in adherence rates and the average number of total posts per day between groups, it is unclear what factors contribute to these differences. Only 3 negative physical effects were reported, but they were all minor and did not cause privacy breach issues. In contrast to our findings, Kullgren et al [43] showed that peer support using a 4-person web-based SMS text message board did not lead to an increase in physical activity among older adults. The authors attributed this lack of effectiveness to the failure to facilitate communication. In this study, the average number of comments per day in the intervention group was 2.76 overall and 3.01 excluding dropouts, indicating that many participants were actively using the DPSA. In addition, the fellowship was the factor with the highest percentage of intention to continue using DPSA. These may indicate that peer support based on social cognitive theory increased physical activity, as hypothesized. Self-efficacy is a key aspect of social cognitive theory [21]. However, in this study, although there was an increase in self-efficacy for exercise scores, the change was not significant. Possible reasons for the lack of a significant increase in self-efficacy for exercise in this study include the high baseline self-efficacy for exercise of the study population, the ceiling effect, and the short intervention period. In addition, the questionnaire used in this study may not reflect the impact of DPSA on self-efficacy. In this study, DPSA users showed a significant increase in their daily step count and MVPA duration despite the winter season. Participants with lower baseline physical activity levels showed a greater increase than those with higher levels of physical activity, suggesting that older adults with lower levels of physical activity may benefit more from using the DPSA than those with higher levels of physical activity. In the intervention group, the daily step count increased by >1000 steps on average. A systematic review of 17 prospective studies by Hall et al [44] has shown that each 1000-step increase in the daily step count decreases the risk of death and heart disease, with a 6% to 36% decrease in all-cause mortality risk and a 5% to 21% decrease in heart disease risk. Furthermore, it has been shown that an increase of 1000 steps per day decreases a woman's risk of diabetes by 6% and an increase of 2000 steps per day decreases the risk of diabetes by 12% [45]. In this study, the duration of MVPA increased by >10 minutes. Previous studies conducted in the United States [46] have shown that adding 10 minutes per day of MVPA could prevent 6.9% of deaths per year in the US adult population aged between 45 and 85 years. A greater increase in physical activity is predicted to have a greater protective effect. In Japan, the Ministry of Health, Labour and Welfare published the ActiveGuide, the Japanese official physical activity guidelines for health promotion, in March 2013 [47]. The key message of this guideline is "+10," indicating "add 10 minutes of MVPA per day." We increased physical activity in older adults through a 5-year community-wide intervention that incorporated this guideline [48]. According to a meta-analysis of 26 cohort studies by Miyachi et al [49], an increase of 10 minutes of MVPA per day can cause a 3.2% reduction of the average relative risk of noncommunicable diseases, dementia, joint-musculoskeletal impairment, and mortality. The 2010 National Health and Nutrition Survey [50] found that 60.8% of the respondents are willing to take part in an additional 10 minutes of physical activity per day. Therefore, the "+10" recommendation could be feasible and efficient for the Japanese population [49]. On the basis of previous findings and the results of this study, DPSA is a viable and effective tool for increasing physical activity.

Limitations

This study has a few limitations. First, sampling problems such as small sample size and low statistical power, as well as the influence of confounding factors such as academic background, digital literacy, and motivation, cannot be ruled out. Indeed, there was a difference between the 2 groups regarding the percentage of information about the use of ICT. The enrolment to the intervention and control groups was nonrandomized, and participation was voluntary. A previous study by Tudor-Locke et al [37] has shown that healthy older adults tend to walk between 2000 and 9000 steps per day, with a median of 5500 steps. The control group had about the same number of steps as the average older adult in Japan, whereas the intervention group took approximately 1000 more steps per day than the average older adult in Japan. Both groups were highly interested in exercise, which might have influenced the effectiveness of the DPSA intervention. Second, this study used a short-term intervention period of 12 weeks. Previous studies have found that mHealth physical activity interventions are more effective over short periods of time (<16 and <12 weeks) than over longer periods of time and that the effects may not be maintained for longer periods of time [51,52]. Furthermore, other reviews have shown that mHealth interventions may promote small to moderate increases in physical activity and that the effects are maintained over time but that the effect size decreases over time [53]. In this study, 6% (2/36) of the participants stated that they did not have intention to continue the intervention after 12 weeks and 31% (11/36) answered undecided, indicating that high retention and adherence rates can be achieved for short-term use of 12 weeks but that the long-term retention rate is unknown. Third, the generalizability is limited, as participation in the intervention group was limited to those who owned a smartphone. In addition, they were already familiar with the use of ICT. In this study, training sessions were provided on the use of the app, so that even those who were less familiar with the use of the app could participate, but participation was low.

Conclusions

In this study, a 12-week intervention was conducted with older adults aged ≥65 years, using DPSA to increase physical activity. Older adults who used DPSA to increase physical activity tended to be more familiar with ICT and more physically active at baseline compared to the general older adult population. The feasibility of DPSA was good, with increases in daily steps and MVPA in the intervention group. Peer support–based interventions using digital apps may be effective in promoting physical activity among older adults. Notably, participants with lower levels of baseline physical activity showed a more significant increase in their daily step count compared with those with higher levels of physical activity. To confirm the effect of DPSA on physical activity and physical function in older adults, a randomized controlled trial should be conducted.

Acknowledgments

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Authors' Contributions

KT, YO, SY, and MS were responsible for designing this study. All authors were responsible for data collection. KT and YO were responsible for analyzing and interpreting the data. All authors edited, reviewed, and approved the final manuscript.

Conflicts of Interest

SY and MS were employees of A10 Lab Inc at the time of research.

Multimedia Appendix 1
The timing of the evaluation of each measurement item.
[DOCX File , 18 KB - aging_v7i1e56184_app1.docx]

References

1. Piercy KL, Troiano RP, Ballard RM, Carlson SA, Fulton JE, Galuska DA, et al. The physical activity guidelines for Americans. JAMA 2018 Nov 20;320(19):2020-2028. [doi: 10.1001/jama.2018.14854] [Medline: 30418471]
2. Schutzer KA, Graves BS. Barriers and motivations to exercise in older adults. Prev Med 2004 Nov;39(5):1056-1061. [doi: 10.1016/j.ypmed.2004.04.003] [Medline: 15475041]
3. Bean JF, Vora A, Frontera WR. Benefits of exercise for community-dwelling older adults. Arch Phys Med Rehabil 2004 Jul;85(7 Suppl 3):S31-42; quiz S43-4. [doi: 10.1016/j.apmr.2004.03.010] [Medline: 15221722]
4. Musich S, Wang SS, Hawkins K, Greame C. The frequency and health benefits of physical activity for older adults. Popul Health Manag 2017 Jun;20(3):199-207 [FREE Full text] [doi: 10.1089/pop.2016.0071] [Medline: 27623484]
5. Katzmarzyk PT, Lee IM, Martin CK, Blair SN. Epidemiology of physical activity and exercise training in the United States. Prog Cardiovasc Dis 2017;60(1):3-10. [doi: 10.1016/j.pcad.2017.01.004] [Medline: 28089610]
6. McPhee JS, French DP, Jackson D, Nazroo J, Pendleton N, Degens H. Physical activity in older age: perspectives for healthy ageing and frailty. Biogerontology 2016 Jun;17(3):567-580 [FREE Full text] [doi: 10.1007/s10522-016-9641-0] [Medline: 26936444]
7. Guthold R, Stevens GA, Riley LM, Bull FC. Worldwide trends in insufficient physical activity from 2001 to 2016: a pooled analysis of 358 population-based surveys with 1·9 million participants. Lancet Glob Health 2018 Oct;6(10):e1077-e1086 [FREE Full text] [doi: 10.1016/S2214-109X(18)30357-7] [Medline: 30193830]
8. Lee IM, Shiroma EJ, Lobelo F, Puska P, Blair SN, Katzmarzyk PT. Effect of physical inactivity on major non-communicable diseases worldwide: an analysis of burden of disease and life expectancy. Lancet 2012 Jul 21;380(9838):219-229 [FREE Full text] [doi: 10.1016/S0140-6736(12)61031-9] [Medline: 22818936]
9. Hall G, Laddu DR, Phillips SA, Lavie CJ, Arena R. A tale of two pandemics: how will COVID-19 and global trends in physical inactivity and sedentary behavior affect one another? Prog Cardiovasc Dis 2021;64:108-110 [FREE Full text] [doi: 10.1016/j.pcad.2020.04.005] [Medline: 32277997]
10. Yamada M, Kimura Y, Ishiyama D, Otobe Y, Suzuki M, Koyama S, et al. Effect of the COVID-19 epidemic on physical activity in community-dwelling older adults in Japan: a cross-sectional online survey. J Nutr Health Aging 2020 Sep;24(9):948-950. [doi: 10.1007/s12603-020-1501-6]
11. Yamada M, Kimura Y, Ishiyama D, Otobe Y, Suzuki M, Koyama S, et al. The influence of the COVID-19 pandemic on physical activity and new incidence of frailty among initially non-frail older adults in Japan: a follow-up online survey. J Nutr Health Aging 2021;25(6):751-756 [FREE Full text] [doi: 10.1007/s12603-021-1634-2] [Medline: 34179929]
12. Fukuoka Y, Haskell W, Lin F, Vittinghoff E. Short- and long-term effects of a mobile phone app in conjunction with brief in-person counseling on physical activity among physically inactive women: the mPED randomized clinical trial. JAMA Netw Open 2019 May 03;2(5):e194281 [FREE Full text] [doi: 10.1001/jamanetworkopen.2019.4281] [Medline: 31125101]

13. Laranjo L, Ding D, Heleno B, Kocaballi B, Quiroz JC, Tong HL, et al. Do smartphone applications and activity trackers increase physical activity in adults? Systematic review, meta-analysis and metaregression. Br J Sports Med 2021 Apr;55(8):422-432. [doi: 10.1136/bjsports-2020-102892] [Medline: 33355160]
14. Moss RJ, Süle A, Kohl S. eHealth and mHealth. Eur J Hosp Pharm 2019 Jan;26(1):57-58 [FREE Full text] [doi: 10.1136/ejhpharm-2018-001819] [Medline: 31157099]
15. Lyons EJ, Swartz MC, Lewis ZH, Martinez E, Jennings K. Feasibility and acceptability of a wearable technology physical activity intervention with telephone counseling for mid-aged and older adults: a randomized controlled pilot trial. JMIR Mhealth Uhealth 2017 Mar 06;5(3):e28 [FREE Full text] [doi: 10.2196/mhealth.6967] [Medline: 28264796]
16. Gell NM, Rosenberg DE, Demiris G, LaCroix AZ, Patel KV. Patterns of technology use among older adults with and without disabilities. Gerontologist 2015 Jun;55(3):412-421 [FREE Full text] [doi: 10.1093/geront/gnt166] [Medline: 24379019]
17. McGarrigle L, Todd C. Promotion of physical activity in older people using mHealth and ehealth technologies: rapid review of reviews. J Med Internet Res 2020 Dec 29;22(12):e22201 [FREE Full text] [doi: 10.2196/22201] [Medline: 33372894]
18. Duan Y, Shang B, Liang W, Du G, Yang M, Rhodes RE. Effects of eHealth-based multiple health behavior change interventions on physical activity, healthy diet, and weight in people with noncommunicable diseases: systematic review and meta-analysis. J Med Internet Res 2021 Feb 22;23(2):e23786 [FREE Full text] [doi: 10.2196/23786] [Medline: 33616534]
19. Posavac EJ, Kattapong KR, Dew DEJ. Peer-based interventions to influence health-related behaviors and attitudes: a meta-analysis. Psychol Rep 1999 Dec;85(3 Pt 2):1179-1194. [doi: 10.2466/pr0.1999.85.3f.1179] [Medline: 10710973]
20. Webel AR, Okonsky J, Trompeta J, Holzemer WL. A systematic review of the effectiveness of peer-based interventions on health-related behaviors in adults. Am J Public Health 2010 Feb;100(2):247-253 [FREE Full text] [doi: 10.2105/AJPH.2008.149419] [Medline: 20019321]
21. Ginis KA, Nigg CR, Smith AL. Peer-delivered physical activity interventions: an overlooked opportunity for physical activity promotion. Transl Behav Med 2013 Dec;3(4):434-443 [FREE Full text] [doi: 10.1007/s13142-013-0215-2] [Medline: 24294332]
22. Bandura A. Social Foundations of Thought and Action: A Social Cognitive Theory. Upper Saddle River, NJ: Prentice-Hall; 1986.
23. Liu Y, Lachman ME. A group-based walking study to enhance physical activity among older adults: the role of social engagement. Res Aging 2021;43(9-10):368-377 [FREE Full text] [doi: 10.1177/0164027520963613] [Medline: 33021146]
24. Bredin SS, Gledhill N, Jamnik VK, Warburton DE. PAR-Q+ and ePARmed-X+: new risk stratification and physical activity clearance strategy for physicians and patients alike. Can Fam Physician 2013 Mar;59(3):273-277 [FREE Full text] [Medline: 23486800]
25. Promotion of physical activity and exercise. Ministry of Health, Labor and Welfare, Japan. URL: http://www.mhlw.go.jp/seisakunitsuite/bunya/kenkou_iryou/kenkou/undou/index.html [accessed 2023-11-22]
26. Thomas S, Reading J, Shephard RJ. Revision of the physical activity readiness questionnaire (PAR-Q). Can J Sport Sci 1992 Dec;17(4):338-345. [Medline: 1330274]
27. Mubarak F, Suomi R. Elderly forgotten? Digital exclusion in the information age and the rising grey digital divide. Inquiry 2022;59:469580221096272 [FREE Full text] [doi: 10.1177/00469580221096272] [Medline: 35471138]
28. Health promotion. Fujisawa City Health and Medical Foundation Public Interest Incorporated Foundation Fujisawa City Health and Medical Center. URL: http://iryo.city.fujisawa.kanagawa.jp/health/health18_01.htm [accessed 2023-11-22]
29. Osawa Y, Saito Y, Tsunekawa N, Manabe T, Oguma Y. Exercise workload of the "Fujisawa +10 exercise" program in older women. J Exerc Physiol Online 2015;18(5):79-85.
30. Minchalle homepage. Minchale. URL: https://minchalle.com/ [accessed 2023-11-22]
31. 平成 29 年 国民健康 栄養調査結果の概要. Ministry of Health, Labour and Welfare, Japan. URL: https://www.mhlw.go.jp/content/10904750/000351576.pdf [accessed 2023-11-22]
32. Annual report on the ageing society. Cabinet Office Japan. 2022 Jun. URL: https://www8.cao.go.jp/kourei/english/annualreport/2022/pdf/2022.pdf [accessed 2023-11-22]
33. Ohkawara K, Oshima Y, Hikihara Y, Ishikawa-Takata K, Tabata I, Tanaka S. Real-time estimation of daily physical activity intensity by a triaxial accelerometer and a gravity-removal classification algorithm. Br J Nutr 2011 Jun;105(11):1681-1691. [doi: 10.1017/S0007114510005441] [Medline: 21262061]
34. Jefferis BJ, Sartini C, Ash S, Lennon LT, Wannamethee SG, Lee IM, et al. Trajectories of objectively measured physical activity in free-living older men. Med Sci Sports Exerc 2015 Feb;47(2):343-349 [FREE Full text] [doi: 10.1249/MSS.0000000000000410] [Medline: 24988411]
35. Jones CJ, Rikli RE, Beam WC. A 30-s chair-stand test as a measure of lower body strength in community-residing older adults. Res Q Exerc Sport 1999 Jun;70(2):113-119. [doi: 10.1080/02701367.1999.10608028] [Medline: 10380242]
36. Oka K. [Stages of change for exercise behavior and self-efficacy for exercise among middle-aged adults]. Nihon Koshu Eisei Zasshi 2003 Mar;50(3):208-215. [Medline: 12704833]
37. Tudor-Locke C, Craig CL, Aoyagi Y, Bell RC, Croteau KA, De Bourdeaudhuij I, et al. How many steps/day are enough? For older adults and special populations. Int J Behav Nutr Phys Act 2011 Jul 28;8:80 [FREE Full text] [doi: 10.1186/1479-5868-8-80] [Medline: 21798044]

38. Blair CK, Harding E, Wiggins C, Kang H, Schwartz M, Tarnower A, et al. A home-based mobile health intervention to replace sedentary time with light physical activity in older cancer survivors: randomized controlled pilot trial. JMIR Cancer 2021 Apr 13;7(2):e18819 [FREE Full text] [doi: 10.2196/18819] [Medline: 33847588]
39. Hosteng KR, Simmering JE, Polgreen LA, Cremer JF, Segre AM, Francis SL, et al. Multilevel mHealth intervention increases physical activity of older adults living in retirement community. J Phys Act Health 2021 May 26;18(7):851-857 [FREE Full text] [doi: 10.1123/jpah.2020-0592] [Medline: 34039774]
40. Mansson L, Lundin-Olsson L, Skelton DA, Janols R, Lindgren H, Rosendahl E, et al. Older adults' preferences for, adherence to and experiences of two self-management falls prevention home exercise programmes: a comparison between a digital programme and a paper booklet. BMC Geriatr 2020 Jun 15;20(1):209 [FREE Full text] [doi: 10.1186/s12877-020-01592-x] [Medline: 32539711]
41. Tam E, Boas PK, Ruaro F, Flesch J, Wu J, Thomas A, et al. Feasibility and adoption of a focused digital wellness program in older adults. Geriatrics (Basel) 2021 May 19;6(2):54 [FREE Full text] [doi: 10.3390/geriatrics6020054] [Medline: 34069637]
42. Van Dyck D, Herman K, Poppe L, Crombez G, De Bourdeaudhuij I, Gheysen F. Results of MyPlan 2.0 on physical activity in older Belgian adults: randomized controlled trial. J Med Internet Res 2019 Oct 07;21(10):e13219 [FREE Full text] [doi: 10.2196/13219] [Medline: 31593541]
43. Kullgren JT, Harkins KA, Bellamy SL, Gonzales A, Tao Y, Zhu J, et al. A mixed-methods randomized controlled trial of financial incentives and peer networks to promote walking among older adults. Health Educ Behav 2014 Oct;41(1 Suppl):43S-50S [FREE Full text] [doi: 10.1177/1090198114540464] [Medline: 25274710]
44. Hall KS, Hyde ET, Bassett DR, Carlson SA, Carnethon MR, Ekelund U, et al. Systematic review of the prospective association of daily step counts with risk of mortality, cardiovascular disease, and dysglycemia. Int J Behav Nutr Phys Act 2020 Jun 20;17(1):78 [FREE Full text] [doi: 10.1186/s12966-020-00978-9] [Medline: 32563261]
45. Garduno AC, LaCroix AZ, LaMonte MJ, Dunstan DW, Evenson KR, Wang G, et al. Associations of daily steps and step intensity with incident diabetes in a prospective cohort study of older women: the OPACH study. Diabetes Care 2022 Feb 01;45(2):339-347 [FREE Full text] [doi: 10.2337/dc21-1202] [Medline: 35050362]
46. Saint-Maurice PF, Graubard BI, Troiano RP, Berrigan D, Galuska DA, Fulton JE, et al. Estimated number of deaths prevented through increased physical activity among US adults. JAMA Intern Med 2022 Mar 01;182(3):349-352 [FREE Full text] [doi: 10.1001/jamainternmed.2021.7755] [Medline: 35072698]
47. ActiveGuide: Japanese official physical activity guidelines for health promotion. Ministry of Health, Labour and Welfare, Japan. 2013. URL: https://www.nibiohn.go.jp/eiken/info/pdf/active2013-e.pdf [accessed 2023-11-22]
48. Saito Y, Tanaka A, Tajima T, Ito T, Aihara Y, Nakano K, et al. A community-wide intervention to promote physical activity: a five-year quasi-experimental study. Prev Med 2021 Sep;150:106708 [FREE Full text] [doi: 10.1016/j.ypmed.2021.106708] [Medline: 34197869]
49. Miyachi M, Tripette J, Kawakami R, Murakami H. "+10 min of physical activity per day": Japan is looking for efficient but feasible recommendations for its population. J Nutr Sci Vitaminol (Tokyo) 2015;61 Suppl:S7-S9 [FREE Full text] [doi: 10.3177/jnsv.61.S7] [Medline: 26598893]
50. 平成22年国民健康 栄養調査報告. Ministry of Health, Labour and Welfare, Japan. URL: https://www.mhlw.go.jp/bunya/kenkou/eiyou/dl/h22-houkoku-01.pdf [accessed 2023-11-22]
51. Kirk MA, Amiri M, Pirbaglou M, Ritvo P. Wearable technology and physical activity behavior change in adults with chronic cardiometabolic disease: a systematic review and meta-analysis. Am J Health Promot 2019 Jun;33(5):778-791. [doi: 10.1177/0890117118816278] [Medline: 30586996]
52. Romeo A, Edney S, Plotnikoff R, Curtis R, Ryan J, Sanders I, et al. Can smartphone apps increase physical activity? Systematic review and meta-analysis. J Med Internet Res 2019 Mar 19;21(3):e12053 [FREE Full text] [doi: 10.2196/12053] [Medline: 30888321]
53. Mönninghoff A, Kramer JN, Hess AJ, Ismailova K, Teepe GW, Tudor Car L, et al. Long-term effectiveness of mHealth physical activity interventions: systematic review and meta-analysis of randomized controlled trials. J Med Internet Res 2021 Apr 30;23(4):e26699 [FREE Full text] [doi: 10.2196/26699] [Medline: 33811021]

Abbreviations

CS-30: 30-second chair-stand test
DPSA: digital peer support app
ICT: information and communication technology
LPA: light intensity physical activity
MET: metabolic equivalent
mHealth: mobile health
MVPA: moderate to vigorous intensity physical activity
SB: sedentary behavior

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Original Paper

Exploring the Feasibility of Digital Voice Assistants for Delivery of a Home-Based Exercise Intervention in Older Adults With Obesity and Type 2 Diabetes Mellitus: Randomized Controlled Trial

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Abstract

Background: Current clinical guidelines for the management of type 2 diabetes mellitus (T2DM) in older adults recommend the use of antihyperglycemic medications, monitoring of blood glucose levels, regular exercise, and a healthy diet to improve glycemic control and reduce associated comorbidities. However, adherence to traditional exercise programs is poor (<35%). Common barriers to adherence include fear of hypoglycemia and the need for blood glucose level monitoring before exercise. Digital health strategies offer great promise for managing T2DM as they facilitate patient-practitioner communication, support self-management, and improve access to health care services for underserved populations. We have developed a novel web-based software program allowing practitioners to create tailored interventions and deliver them to patients via digital voice assistants (DVAs) in their own homes.

Objective: We aim to evaluate the feasibility of a 12-week, home-based, personalized lifestyle intervention delivered and monitored by DVAs for older adults with obesity and T2DM.

Methods: In total, 50 older adults with obesity aged 50-75 years with oral hypoglycemic agent–treated T2DM were randomized to the intervention (DVA, n=25) or a control group (n=25). Participants allocated to the DVA group were prescribed a home-based muscle strengthening exercise program (~20- to 30-min sessions) and healthy eating intervention, delivered via DVAs (Alexa Echo Show 8; Amazon) using newly developed software ("Buddy Link"; Great Australian Pty Ltd). Control group participants received generalized physical activity information via email. Outcomes were feasibility, DVA usability (System Usability Scale), and objectively assessed physical activity and sedentary time (wrist-worn accelerometers).

Results: In total, 45 (90%) out of 50 participants completed this study. Mean adherence to prescribed exercise was 85% (SD 43%) with no intervention-related adverse events. System usability was rated above average (70.4, SD 16.9 out of 100). Compared with controls, the DVA group significantly decreased sedentary time (mean difference –67, SD 23; 95% CI –113 to –21 min/d), which was represented by a medium to large effect size (*d*=–0.6).

Conclusions: A home-based lifestyle intervention delivered and monitored by health professionals using DVAs was feasible for reducing sedentary behavior and increasing moderate-intensity activity in older adults with obesity and T2DM.

Trial Registration: Australian New Zealand Clinical Trials Registry (ANZCTR) ACTRN12621000307808; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=381364&isReview=true

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KEYWORDS

older adults; type 2 diabetes mellitus; voice activation; digital health; exercise

Introduction

Background

Current clinical guidelines for type 2 diabetes mellitus (T2DM) recommend the use of antihyperglycemic medications, self-monitoring of blood glucose levels (BGLs), regular exercise, and a healthy diet to improve glycemic control and reduce vascular complications associated with this disease [1]. However, a recent meta-analysis of older adults with chronic conditions including T2DM reported that 12-month adherence to exercise programs supervised by health professionals was poor (<35%) [2]. Furthermore, a 12-week feasibility trial investigating adherence to home-based exercise in 76 adults with T2DM (mean age 56.6, SD 9.6 years) reported that only 38% of participants in the exercise group adhered to approximately 80% of their prescribed exercises [3].

Common barriers to adhering to clinical exercise guidelines for the management of T2DM include fear of hypoglycemia, demands of day-to-day management, and the need for monitoring of BGLs before exercise [4]. Monitoring of BGLs before exercise is recommended in clinical guidelines [4], but health care professionals (HCPs) have limited capacity to monitor patients when delivering group-based exercise programs [5]. Furthermore, most exercise programs are center-based, and lack of time, transportation, and cost requirements are additional barriers to participation in such programs for older adults with T2DM [6].

Emerging evidence suggests that the implementation of digital health strategies offers great promise for managing T2DM as they allow for improvements to patient-practitioner communication, support patient self-management, improve clinical decision-making, and increase health care services for underserved populations [7]. Various studies support the role of digital health technologies as safe, effective, and even cost-effective models for the management of T2DM in older adults [8-17], but the prescription and monitoring of individually tailored exercise programs remains an ongoing challenge for HCPs [18-22]. Currently, HCPs using traditional methods of communication such as telephone and videoconferencing have a limited capacity to monitor patient progress throughout home-based exercise programs, and this limitation is magnified the more participants they have [18]. Self-administered programs which may be delivered via web-based or mobile technologies may reduce the burden on HCPs through the automation of exercise monitoring, but many older patients have difficulty using these technologies [23-25].

The introduction of digital voice assistants (DVAs), which include embedded home speakers and display units capable of interpreting human speech and providing automated, personalized responses, allows older adults to communicate with these devices via natural conversation. This may overcome barriers related to technological accessibility thereby allowing for an engaging and effective self-management experience.

We have developed a novel web-based software program ("Buddy Link") that allows HCPs to create individually tailored exercise programs and deliver these to patients via DVAs in their own homes. In a recent feasibility trial including 15 older adults living alone, we observed 100% participant retention and 115% (SD 57%) mean adherence (participants completed 15% more than their prescribed exercise sessions) to a 12-week exercise program with no adverse events and above-average system usability (score of 75 out of 100) [26]. A novel feature of this system is the capacity for DVAs to obtain self-reported health information (eg, BGL values) via patient voice responses, interpret these responses using artificial intelligence, and then direct patients to exercise or take action as appropriate using predefined algorithms consistent with clinical guidelines. As such, the use of DVAs may offer an effective approach to delivering personalized and safe remote exercise prescriptions for older adults with T2DM.

Aims and Hypotheses

The primary aim of this 12-week feasibility randomized controlled trial (RCT) of a DVA-delivered exercise program for older adults with obesity and T2DM was to assess retention rate, adherence, incidence of (and types) of adverse events, and perceived system usability to the DVA intervention. The secondary aims were to compare between-group changes in health-related quality of life using the EQ-5D-5L, diabetes self-care management using the Diabetes Self-Management Questionnaire (DSMQ), physical activity, and sedentary behavior.

Methods

Study Design

This was a 12-week feasibility RCT in which adults with obesity aged 50-75 years treated with oral hypoglycemic agent–controlled T2DM were randomized (1:1), stratified by gender, to an individually prescribed, DVA-delivered, home-based exercise and healthy eating nutrition program developed by an accredited exercise physiologist (AEP) and Accredited Practicing Dietician, or general physical activity and healthy eating information delivered via email (control group). Group randomization was computer generated (using Microsoft Excel) by an independent person not directly involved in this study. All assessments were conducted via web-based questionnaires at baseline and 12 weeks.

Participants and Recruitment

In total, 50 older men and women with obesity and T2DM were recruited via email invitation from a database of previous research participants who provided consent to be recontacted for future trials. We recruited 50 participants (25 per arm) in this trial as this is consistent with current sample size guidelines for feasibility studies [27]. Sample sizes of 25 participants per arm are also recommended for pilot studies as they are capable of detecting small effect sizes (0.2) with 90% power and 2-sided significance at 5% [28].

Interested participants were initially directed to complete a web-based form to register their interest. To be eligible, participants were required to be aged 50-75 years, treated with oral hypoglycemic agent for T2DM, have a self-reported BMI>30, English-speaking, residing anywhere in Australia, sedentary (≥9 h/d self-reported sitting), able to walk across a room unaided, and have access to a smart mobile phone capable of making and receiving phone calls on an Australian network and home Wi-Fi network. Participants were deemed ineligible if they had difficulty communicating with study personnel or a DVA device due to speech or hearing problems, were unwilling to be randomized, planned to be away from the DVA device for ≥4 weeks during the 12-week intervention period, had severe knee or hip osteoarthritis (awaiting a joint replacement) that would interfere with the ability to complete the exercises, had a recent fracture (past 3 months) limiting exercise, had renal disease requiring dialysis, had any disorder of such severity that life expectancy was less than 12 months, or any cognitive or physical impairment or disability that in the opinion of this study's investigators would result in the participant having difficulty interacting with DVAs or performing unsupervised exercise safely. Participants were also required to answer "no" to all 6 questions on the Exercise & Sports Science Australia pre-exercise screening tool to ensure safety for exercising unsupervised at home.

Intervention

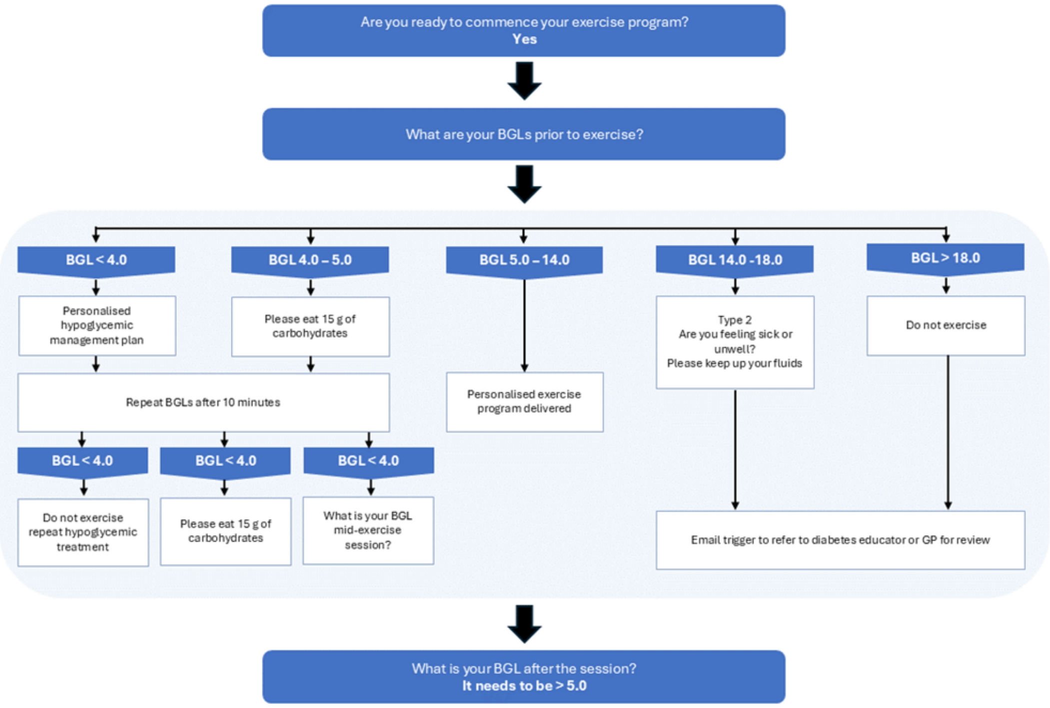
The DVA content was prepared and uploaded using the "Buddy Link" portal software (Great Australian Pty Ltd) [29]. Buddy Link allows HCPs to select existing, or create new, instructions and schedule these instructions to be broadcast (using both video and audio) to participants at specified times via the DVA device in their home. HCPs can also schedule questions to be broadcasted and review participant's responses which are recorded by the DVA. We have developed automated algorithms embedded within the Buddy Link software to allow the reporting of health outcomes such as BGLs and modify presented instructions automatically based on the reported data.

Each participant was provided with an Amazon Alexa Echo Show 8 ("Alexa") device delivered to their home via courier. The package included instructions on how to connect the Alexa device to a Wi-Fi network and how to initiate the preinstalled Alexa skill app ("TeleTrainer") to access the personalized content uploaded to Buddy Link. Both Buddy Link and TeleTrainer were developed and supported by Great Australian Pty Ltd.

The AEP prescribed a personalized, weekly exercise program for participants allocated to the intervention. Exercises were selected by the AEP using the health professional interface in Buddy Link and individually broadcast to participants via Alexa at specified times throughout the day, using video demonstrations and audio and written instructions based on Exercise & Sport Science Australia guidelines [30]. The exercise program used body weight or additional resistance such as weight plates, dumbbells, TheraBand, and weighted vests, if the participants had access to them (unless contraindicated). Participants performed up to 3 sets of 5 repetitions of 5 upper limb and lower limb exercises at a moderate intensity of approximately 4-6 on the 10-point modified Rating of Perceived Exertion scale [31]. Some examples of the exercises prescribed include chair squats, calf raises, and wall push-ups. Each participant was encouraged to increase the load of prescribed exercises each session while maintaining the desired intensity. Each exercise session was 20-30 minutes in duration. The protocol initially delivered 2 exercise sessions per week for the first 4 weeks of the intervention, 3 exercise sessions per week for the second 4 weeks, and 4 exercise sessions per week for the final 4 weeks. Following each exercise, Alexa broadcasted questions to determine whether participants completed their exercise, their self-perceived exertion, and if they had any other concerns (eg, pain or dizziness). Participants' responses to these questions were recorded and saved to the Buddy Link database, enabling the AEP to review weekly and modify or progress exercise prescriptions as required.

The DVA used a novel automated "decision to exercise tree" based on the current recommendations of the American Diabetes Association, as shown in Figure 1 [4]. Alexa provided BGL monitoring reminders using video, audio, and written instructions before and after each exercise session for the first 3 sessions (minimum) to establish BGL responses to each session, each week of the program. Participants were asked to report their BGLs to Alexa and the automated decision-to-exercise tree–adapted program content based on these responses. For example, the decision tree did not deliver exercise if participants had signs or symptoms of hypoglycemia, had self-reported BGLs less than 5 mmol/L, or were not feeling well enough to exercise. Instead, the decision tree would deliver audio and video instructions on how to self-administer a personalized hypoglycemia action plan. If self-reported BGLs less than 5 mmol/L, or greater than 14 mmol/L, were reported 3 sessions in a row, then the decision tree would recommend a referral to the participant's general practitioner or endocrinologist for completion of a Diabetes Management Plan.

Figure 1. Clinical decision-tree algorithm delivered by DVA. BGL: blood glucose level; DVA: digital voice assistant; GP: general practitioner.



An Accredited Practicing Dietician prescribed a healthy eating program delivered by the DVA to the intervention group for 12 weeks to increase whole grains, vegetable, and fruit daily intake in line with the Australian Dietary Guidelines [32]. In addition, generalized dietary educational videos tailored for T2DM management were displayed by the DVA. Examples include "meal planning," "making shopping lists using DVA," and "healthy snacking." The Buddy Link software was also accessed by study investigators to quantify the adherence of participant engagement with the educational videos.

The control group received a usual standard of care [33] and generic information on improving physical activity and nutrition sourced from Diabetes Australia [34] via weekly emails.

Outcome Measures

The primary outcomes related to feasibility with previously defined targets of ≥70% retention and completion of ≥66% (n=594) of prescribed exercise and dietary advice were determined based on the number of recorded voice responses from the DVA group. Adverse events were defined as health events that were considered possibly or probably related to the 12-week intervention and were measured using fortnightly phone calls by study investigators.

Secondary Measures

Accelerometer-Determined Physical Activity

Participants were provided with a wrist-worn ActiGraph GT9XLink accelerometer that was worn 24 hours per day, except while swimming or bathing, for 7 days at both baseline and post–12-week follow-up. Participants were also required to keep a diary to record wear times and reasons for not wearing their devices. These devices estimated average sedentary time (min/d), average light activity (min/d), average moderate activity (min/d), average vigorous activity (min/d), average very vigorous activity (min/d), average total moderate to vigorous activity per day (MVPA; min/d), and average number of steps per day.

Validated Questionnaires

Health-related quality of life was assessed at baseline and follow-up using the EQ-5D-5L [35,36]. This instrument contains 5 multiple-choice questions and a 100-point overall health state visual analog scale [35,36]. Self-care activities related to diabetes management were assessed using the DSMQ [37]. This instrument contains 16 questions, 6 relate to glucose management, 4 relate to dietary control, 3 relate to physical activity, and 3 relate to health care use [37]. Each subset is scored 0-3 with 0 not applying to participants and 3 being the most applicable [37]. All web-based questionnaires were administered by Qualtrics.

DVA System Usability

After the first week of use and again after follow-up, DVA participants were asked to complete a web-based System Usability Scale (SUS) [38] administered by Qualtrics. The SUS is a Likert scale of 10 items which projects a globalized subjective assessment of usability. SUS was administered to allow for a subjective evaluation of Alexa's usability by participants. Throughout the trial participants also received fortnightly emails inviting them to report any technical errors they may be experiencing with Alexa via a web-based form.

Data Analysis

Descriptive data were reported for feasibility outcomes. Each of the secondary outcomes was compared between groups using analysis of covariance adjusted for baseline values. Standardized effect sizes (Cohen *d*) were calculated for each secondary outcome. Alpha criterion level was set at P=.05. As this study was only a feasibility trial it may be underpowered to detect any significant changes, as such multiple hypothesis testing (Bonferroni correction) was taken into account [39]. All analyses were conducted using Stata (version 16.0; StataCorp).

Ethical Considerations

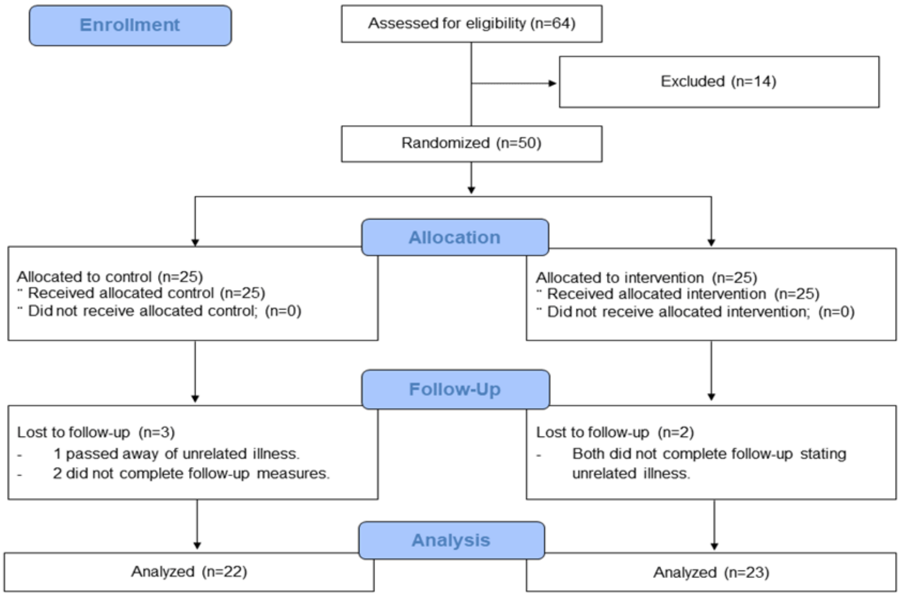
This study was approved by the Deakin University Human Research Ethics Committee (HREC 2021-009) and registered with the ANZCTR (Australian New Zealand Clinical Trials Registry; 12621000307808). Written informed consent was obtained from all participants. All the data has been anonymized and no compensation was provided to participants.

Results

Overview

A total of 64 potential participants were initially screened to recruit 50 eligible (self-reported BMI>30) men and women with obesity treated with oral hypoglycemic agents for T2DM, with equal numbers (n=25 each) randomly allocated to the DVA or control group (Figure 2).

Figure 2. CONSORT (Consolidated Standards of Reporting Trials) flowchart of participation throughout this study.



Participant Demographics

Table 1 summarizes baseline demographic characteristics. The mean age of the 50 participants was 66 (SD 5; range 50-75) years and included 29 men and 21 women. Over half (n=30, 60%) of the participants in both groups were educated at a university level or higher, and around half (n=33, 46%) were currently retired. All participants in both groups were obese (self-reported BMI>30) and reported at least 1 chronic disease in addition to T2DM.

Table 1. Baseline demographics of the digital voice-activated intervention and control groups.

Baseline demographics	DVA[a] group (n=25)	Control group (n=25)
Age (years), mean (SD)	65 (4.9)	67.3 (6)
Gender (female), n (%)	9 (36)	12 (48)
Parent's country of birth, n (%)		
Australia	0 (0)	4 (16)
Other	12 (48)	8 (32)
Not answered	13 (52)	13 (52)
Highest level of education, n (%)		
Secondary or high school	4 (16)	3 (12)
Technical or further educational institution	7 (28)	6 (24)
University or other higher educational institution	14 (56)	16 (64)
Current employment status, n (%)		
Employed or self-employed full-time	9 (36)	7 (28)
Employed or self-employed part-time	3 (12)	6 (24)
Unemployed	0 (0)	0 (0)
Retired	11 (44)	12 (48)
Home duties	0 (0)	0 (0)
Pension (including disability or sole pension)	2 (8)	0 (0)
Medical conditions, n (%)		
Coronary heart disease[b]	4 (16)	3 (14)
Hypertension (high blood pressure)	15 (60)	19 (76)
Hypercholesterolemia (high cholesterol)	12 (48)	10 (40)
Thrombosis (clot)	1 (4)	3 (12)
Asthma	6 (24)	2 (8)
Chronic bronchitis or emphysema	1 (4)	1 (4)
Any form of cancer	1 (4)	6 (24)
Osteoarthritis	3 (12)	4 (16)
Rheumatoid arthritis	0 (0)	3 (12)
Depression	0 (0)	0 (0)
Anxiety	0 (0)	0 (0)
Other major illness[c]	6 (24)	0 (0)
Reported at least one chronic health condition	25 (100)	25 (100)

[a] DVA: digital voice assistant.

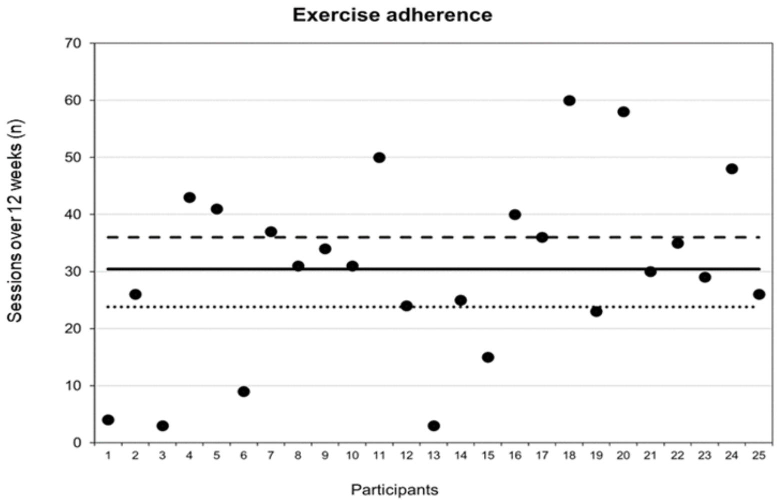
[b] Coronary heart disease included angina, stroke, peripheral vascular disease, and heart attack.

[c] Migraine, reflux, diverticulitis, hyperthyroidism, adenomyosis, polymyalgia rheumatica, epilepsy, sleep apnea, and peripheral neuropathy.

Primary Outcomes at 12-weeks—Adherence and Retention

Study retention was 90% (45/50), with 5 participants lost to follow-up (controls: n=3; DVA: n=2); 1 participant passed away due to unrelated causes, 2 participants withdrew (at weeks 5 and 9) due to unrelated illnesses, and 2 participants were lost to follow-up. The mean adherence of the DVA group to the prescribed exercise sessions was 85% (SD 43%; range 8%-167%). Overall, the 25 participants completed a total of 761 (84.5%) of the 900 total prescribed exercise sessions over 12 weeks (Figure 3). In total, 19 (76%) out of the 25 DVA group participants met the a priori exercise adherence target of 66%, inclusive of 9 (36%) participants who achieved ≥100% (n=900) exercise adherence (ie, initiated more exercise sessions than prescribed). Throughout the 12-week intervention, 24 (96%) out of 25 participants watched a total of 420 nutrition education videos. The mean adherence to the prescribed number of nutrition videos was 73% (SD 46%; 95% CI 61%-85%) over 12 weeks.

Figure 3. Individual participant adherence (●) to prescribed exercises over 12 weeks with the mean prescribed sessions highlighted by the dashed (--) line, mean observed adherence by the solid (—) line, and the target adherence by the dotted (. . .) line.



At 12 weeks, there was a total of 448 (49.7%) BGLs recorded out of the minimum prescribed 900 recordings. The mean BGLs self-reported by participants was 7.40 (SD 1.09) mmol/L, the normal preprandial blood glucose range was 4-7 mmol/L, and normal postprandial blood glucose range was 5-10 mmol/L [34]. Given there were no instances of BGLs lower than 5 mmol/L or higher than 14 mmol/L, the clinical decision-tree algorithm referred participants to their assigned exercise program on each occasion. Furthermore, no participants reported any other study-related adverse events across the 12-week intervention in both groups.

Secondary Outcomes

Accelerometer-Determined Physical Activity

Table 2 summarizes changes in secondary outcome measures for both groups. Regression coefficients represent the differences in change for these outcomes between groups over 12 weeks. After 12 weeks and accounting for multiple hypothesis testing, there was a significant decrease in average sedentary time (min/d) in the DVA group with a mean difference of –67 (SD 23; 95% CI –113 to –21) minutes per day when compared to controls (Table 2). This represented a medium to large effect size (*d*=–0.6). Furthermore, the DVA group's average moderate activity (min/d) and average MVPA (min/d) had medium to large effect sizes (*d*=0.6 and *d*=0.7 respectively) when compared to controls (Table 2).

Table 2. Baseline and 12-week values for secondary outcomes with adjusted regression coefficients (95% CI); *P* values for the mean differences in change between the groups and standardized effect sizes.

	DVA[a] group, mean (SD)		Control[b] group, mean (SD)		Estimated difference in groups after intervention (95% CI)[c]	*P* value	Standardized effect size
	Baseline (n=25)	12-weeks (n=23)	Baseline (n=25)	12-weeks (n=22)			
EQ-5D-5L							
VAS[d] (0 to 100)	79.2 (19.1)	79.6 (21.7[e])	70.6 (15.6)	72.9 (18.2[f])	1.6 (–9.1 to 12.3)	.76	0.1
Utility (0 to 1.0)	0.8 (0.2)	0.9 (0.2[e])	0.8 (0.2)	0.8 (0.2[f])	0.03 (–0.3 to 0.1)	.28	0.2
DSMQ[g]							
Glucose management (0 to 15)	4.8 (1.2)	4.9 (1.9)	4.8 (1.1)	4.2 (1.9)	0.7 (–0.3 to 1.7)	.17	0.6
Dietary control (0 to 12)	4.6 (1.5)	4.2 (2.0)	4.5 (1.3)	3.9 (1.8)	0.5 (–0.8 to 1.3)	.60	0.4
Physical activity (0 to 10)	3.2 (1.2)	2.8 (1.3)	3.5 (1.0)	3.2 (1.7)	–0.3 (–1.2 to 0.5)	.43	–0.3
Health care use (0 to 10)	3.8 (1.2)	3.4 (1.3)	3.6 (1.3)	3.1 (1.6)	0.3 (–0.6 to 1.1)	.56	0.2
Sum scale (0 to 10)	4.2 (0.7)	3.8 (1.4)	4.2 (0.8)	3.6 (1.6)	0.2 (–0.6 to 0.9)	.69	0.2
Accelerometer data							
Average sedentary time (min/d)	996 (80)	969 (83[h])	1013 (131[i])	1044 (94[h])	–67 (–113 to –21)	.006	–0.6
Average light activity (min/d)	263 (61)	268 (37[h])	237 (55[i])	236 (67[e])	15.5 (–10.4 to 41.2)	.23	0.3
Average moderate activity (min/d)	151 (37)	164 (48[h])	136 (39[i])	124 (39[e])	24.7 (1.2 to 48.2)	.04	0.6
Average vigorous activity (min/d)	1.0 (5.0)	3.3 (9.0[h])	3.3 (11.2[i])	0 (0[e])	3.2 (–0.9 to 7.3)	.12	0.4
Average very vigorous activity (min/d)	0.2 (0.9)	0.3 (0.8[h])	0.6 (2.3[i])	0 (0[e])	0.3 (–0.1 to 0.7)	.11	0.2
Average number of steps/days	10,943 (2842)	11,330 (2542[h])	9244 (2573[i])	8664 (3003[e])	1098 (–192 to 2388)	.09	0.4
Average total MVPA[j] (min/d)	149 (37)	169 (54[h]	139 (48[i])	132 (49[e])	30.9 (0.6 to 61.1)	.046[k]	0.7

[a] DVA=Alexa+home exercise+healthy eating.

[b] Control=standard of care+weekly emails on health.

[c] Adjusted for baseline value.

[d] VAS: visual analog scale.

[e] n=23.

[f] n=22.

[g] DSMQ: Diabetes Self-Management Questionnaire.

[h] n=20.

[i] n=24.

[j] MVPA: moderate to vigorous activity per day.

[k] Indicates significant difference in change between groups (*P*<.05).

DVA System Usability

At 12 weeks, the mean SUS score reported by the DVA group was 70.4 (SD 16.9; Table S1 in Multimedia Appendix 1). This exceeds the value consistent with “average” usability (n=68) for this instrument. Mean scores from the specific SUS components indicated that participants generally disagreed that they would need the assistance of technical support to use the system and that it was complex or difficult to use. Furthermore, participants generally agreed that they were confident in using the system and that most people would be able to learn the system quickly.

Validated Questionnaires

There were no significant differences between groups at 12 weeks for measures of health-related quality of life (EQ-5D-5L and visual analog scale) and diabetes self-care management (DSMQ) (Table 2).

Discussion

Principal Findings

This pilot feasibility RCT demonstrated that a 12-week home-based exercise intervention delivered and monitored by DVAs was feasible and safe for older adults with obesity and T2DM. This was demonstrated by the high adherence and study retention with no intervention-related adverse events and an above-average SUS score. Secondary analyses demonstrated that the DVA intervention reduced sedentary time and increased MVPA relative to participants receiving generic advice (control).

Few studies have previously assessed remotely delivered, home-based lifestyle interventions for older adults with chronic conditions including T2DM [26,40,41]. Our recent pilot study [26] used an Alexa device to deliver a 12-week home-based exercise program to 15 older adults living alone. We found an overall adherence to the prescribed exercise of 115% as participants completed more than their prescribed exercise sessions, and no participant reported any adverse event related to intervention [26]. Our study also observed excellent adherence to prescribed exercise (mean 85%, SD 43%) and no adverse events related to the intervention. It is possible that the decision to exercise tree provided confidence for participants to exercise and contributed to the lack of adverse events in terms of hypo- and hyperglycemic occurrences. This novel exercise delivery approach was well adhered to indicating that it is feasible for home-based exercise programs for the management of T2DM in older adults. A study reported on the design and application of an intelligent digital assistant to remotely support 20 older adults (aged ≥65 years) with T2DM in making lifestyle changes and improving medication adherence [42]. This digital assistant differed from Alexa as it was an app powered by a Unity (Unity Technologies) software engine allowing for the construction of a female 3D model, capable of speech articulation and emotional expression through animation [42]. Furthermore, lifestyle changes were based on a rule-based component behavioral model where the digital assistant worked to modify the behavior of participants by providing counseling and education on aspects of physical activity and then assigning tasks for participants to complete to reinforce the desired behavior [42]. This differs from our approach where an AEP prescribed a personalized exercise program to support self-management in older adults with T2DM. The previous study reported a mean system usability (SUS) of 73.8 (SD 13.3) out of 100, suggesting good to excellent usability of the software [42]. The improved system usability may indicate that the integration of automation into a digitally delivered, lifestyle intervention may reduce burdens on HCPs and be acceptable to patients.

While limited studies have examined outcomes related to the feasibility of using DVA devices to deliver lifestyle interventions while monitoring BGLs in older adults with T2DM, other trials have investigated similar feasibility outcomes to our study using other asynchronous digital devices [43,44]. Koot et al [43] examined the feasibility of a mobile lifestyle management program (GlycoLeap; Holmusk, Inc) to improve blood glucose monitoring, dietary advice, physical activity, and diabetes self-management in 100 older adults (mean age 54 years) with T2DM for over 6 months. The mean adherence to completing at least 1 web-based health lesson was 33% [43]. This differs from our own study as we observed high adherence throughout the intervention. Older adults with T2DM may find a DVA-delivered program more engaging than a mobile-based lifestyle program, however future, long-term studies are required to further understand patterns of participant adherence over longer periods of time.

Following the 12-week intervention, we reported a decrease in the average sedentary time (min/d) and an increase in average moderate physical activity time (min/d) and total MVPA (min/d) in the DVA compared to the control group. A study investigated the use of a mobile and web-based tool to deliver a lifestyle intervention to 199 older adults (mean age 58 years) with T2DM in primary care for over 9 months [44] and reported significant improvements in MVPA/day (mean difference 10.6 min, 95% CI 4.9 to 16.3) compared to control participants who received only standard T2DM care [44].

Our study observed an increase in MVPA of around 30 minutes over a much shorter period; some possible explanations for this may be that the participants in this study were healthier than participants in the previous study or that DVA delivery may have been more engaging. Analogous future studies are required to better understand the use of DVAs in this population. Another study explored the effects of web-based home exercise on physical activity levels in 65 older adults (mean age 53 years) with T2DM for over 8 weeks [45]. Similarly to our study, participants were required to self-monitor and report their BGLs before and after exercise sessions [45]. After 8 weeks, the web-based group was found to have significantly improved their average number of steps (30.5, SD 34.9; *P*=.01) compared to the control group [45]. However, we observed a net difference of >1000 steps per day, indicating DVAs may be more acceptable and effective in improving physical activity levels in older adults with obesity and T2DM.

We found no significant changes between groups in the DSMQ. A study [46] examined the use of digital modalities for improving the self-management of T2DM in 115 older adults, in which they investigated the first 3 months of a 12-month digitally delivered intervention consisting of telemonitoring and telephone-based coaching to improve diet, physical activity, and self-diabetes management [46]. The main findings from this study were that participants in the intervention group had improved glycemic control as evidenced by significantly decreased hemoglobin A_{1c} (mean difference=–0.36, SE 0.17; *P*=.04 between groups) and improved DSMQ scores (mean difference=1.13, SE 0.23; *P*<.001 between groups) [46]. This study demonstrates that DSMQ scores can be improved through digital modalities in older adults with T2DM, and the lack of differences in our study may be explained by the smaller cohort, or perhaps the use of standardized rather than personalized coaching.

To date, no previous studies have used DVAs to self-monitor BGLs in older adults with T2DM. A review of 58 papers investigated the use of digital technology in supporting the self-management of T2DM and found that it is effective, scalable, and also acceptable to both patients and HCPs [47]. Furthermore, a qualitative systematic review of 13 papers found similar evidence but suggested that both patients and HCPs were more inclined to use digital technology if it was easily accessible and had a relatively simple learning curve [48]. Our study implemented a simplistic modality for participants to self-report BGLs to Alexa and the DVA group participant's self-reported BGLs were consistently within a "fit to exercise" range (mean of 7.40, SD 1.09 mmol/L). This demonstrates that automated assessment of the appropriateness of exercise based on self-reported BGLs is feasible, but further studies are needed in less healthy older adult T2DM populations to fully explore the effectiveness of this model.

Remote diabetes support allows patients to better manage their T2DM and related chronic conditions and has been associated with a reduction in diabetes-related medical costs [49].

Strengths and Limitations

The strengths of this study were the high level of adherence to exercise, the novel implementation of a clinical decision-to-exercise tree considering BGLs before exercise, and the above-average system usability of the DVAs. The limitations of our study must be acknowledged when interpreting the findings. The population appeared to be well educated and with well-controlled BGLs; thus, the results may not be generalized to all older adult populations with T2DM. Another limitation was that adherence to the lifestyle program, including the BGL monitoring, was self-reported by participants via Alexa, which may be susceptible to both overestimation and underestimation biases. Therefore, we suggest that this should be interpreted with caution and that future studies should include objective measures, including real-time BGL monitoring via continuous measuring.

Conclusions

In conclusion, this feasibility study indicates that it is safe and feasible for older adults with obesity and T2DM to participate in a home-based exercise program delivered and monitored remotely by HCPs using DVAs. Future large-scale, longer-term studies are warranted to explore the clinical- and cost-effectiveness of this digital health approach to support self-management of T2DM in older adults.

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Authors' Contributions

Study design by CG, DS, SS, ESG, RMD, EG, BdC, and PJ. CG drafted this paper and conducted the statistical analysis. DS, SS, ESG, RMD, EG, BdC, and PJ were responsible for this paper's revision and preparation of this review. All authors have read and approved this paper.

Conflicts of Interest

EG is a director (unpaid position) of Great Australian Pty Ltd. Great Australian Pty Ltd provided in-kind technical support for software and had a nonfinancial interest in the development of a voice-based digital assistant software for telehealth. Great Australian had no input into this study's design, analysis, or interpretation of the results, or the decision to publish. Deakin University provided competitive funding to support this study.

Multimedia Appendix 1
Mean (SD) scores for the System Usability Scale in the digital voice assistant group at 12 weeks.
[DOCX File , 14 KB - aging_v7i1e53064_app1.docx]

Multimedia Appendix 2
CONSORT checklist.
[PDF File (Adobe PDF File), 1931 KB - aging_v7i1e53064_app2.pdf]

References

1. Moore G, Durstine JL, Painter P. ACSM's Exercise Management for Persons with Chronic Diseases and Disabilities. Champaign, IL: Human Kinetics; 2016.

2. Jansons PS, Haines TP, O'Brien L. Interventions to achieve ongoing exercise adherence for adults with chronic health conditions who have completed a supervised exercise program: systematic review and meta-analysis. Clin Rehabil 2017;31(4):465-477. [doi: 10.1177/0269215516653995] [Medline: 27301799]
3. Krousel-Wood M, Berger L, Jiang X, Blonde L, Myers L, Webber L. Does home-based exercise improve body mass index in patients with type 2 diabetes? Results of a feasibility trial. Diabetes Res Clin Pract 2008;79(2):230-236. [doi: 10.1016/j.diabres.2007.08.028] [Medline: 17942181]
4. Colberg SR, Sigal RJ, Yardley JE, Riddell MC, Dunstan DW, Dempsey PC, et al. Physical activity/exercise and diabetes: a position statement of the American diabetes association. Diabetes Care 2016;39(11):2065-2079 [FREE Full text] [doi: 10.2337/dc16-1728] [Medline: 27926890]
5. Molsted S, Kusk L, Esbensen SM, Mohr TM, Vind MB, Hess C, et al. Motives and barriers to exercise training during hospitalization in patients with type 2 diabetes: a cross-sectional study. Int J Environ Res Public Health 2022;19(3):1035 [FREE Full text] [doi: 10.3390/ijerph19031035] [Medline: 35162066]
6. Moorman D, Suri R, Hiremath S, Jegatheswaran J, Kumar T, Bugeja A, et al. Benefits and barriers to and desired outcomes with exercise in patients with ESKD. Clin J Am Soc Nephrol 2019;14(2):268-276 [FREE Full text] [doi: 10.2215/CJN.09700818] [Medline: 30696660]
7. Flodgren G, Rachas A, Farmer AJ, Inzitari M, Shepperd S. Interactive telemedicine: effects on professional practice and health care outcomes. Cochrane Database Syst Rev 2015;2015(9):CD002098 [FREE Full text] [doi: 10.1002/14651858.CD002098.pub2] [Medline: 26343551]
8. Bretschneider MP, Klásek J, Karbanová M, Timpel P, Herrmann S, Schwarz PEH. Impact of a digital lifestyle intervention on diabetes self-management: a pilot study. Nutrients 2022;14(9):1810 [FREE Full text] [doi: 10.3390/nu14091810] [Medline: 35565782]
9. Kirley K, Sachdev N. Digital health-supported lifestyle change programs to prevent type 2 diabetes. Diabetes Spectr 2018;31(4):303-309 [FREE Full text] [doi: 10.2337/ds18-0019] [Medline: 30510384]
10. Kooiman TJ, de Groot M, Hoogenberg K, Krijnen W, van der Schans CP, Kooy A. Self-tracking of physical activity in people with type 2 diabetes: a randomized controlled trial. Comput Inform Nurs 2018;36(7):340-349. [doi: 10.1097/CIN.0000000000000443] [Medline: 29742550]
11. Muller I, Rowsell A, Stuart B, Hayter V, Little P, Ganahl K, et al. Effects on engagement and health literacy outcomes of web-based materials promoting physical activity in people with diabetes: an international randomized trial. J Med Internet Res 2017;19(1):e21 [FREE Full text] [doi: 10.2196/jmir.6601] [Medline: 28115299]
12. Poppe L, de Bourdeaudhuij I, Verloigne M, Shadid S, van Cauwenberg J, Compernolle S, et al. Efficacy of a self-regulation-based electronic and mobile health intervention targeting an active lifestyle in adults having type 2 diabetes and in adults aged 50 years or older: two randomized controlled trials. J Med Internet Res 2019;21(8):e13363 [FREE Full text] [doi: 10.2196/13363] [Medline: 31376274]
13. Yom-Tov E, Feraru G, Kozdoba M, Mannor S, Tennenholtz M, Hochberg I. Encouraging physical activity in patients with diabetes: intervention using a reinforcement learning system. J Med Internet Res 2017;19(10):e338 [FREE Full text] [doi: 10.2196/jmir.7994] [Medline: 29017988]
14. Pal K, Dack C, Ross J, Michie S, May C, Stevenson F, et al. Digital health interventions for adults with type 2 diabetes: qualitative study of patient perspectives on diabetes self-management education and support. J Med Internet Res 2018;20(2):e40 [FREE Full text] [doi: 10.2196/jmir.8439] [Medline: 29463488]
15. Zangger G, Bricca A, Liaghat B, Juhl CB, Mortensen SR, Andersen RM, et al. Benefits and harms of digital health interventions promoting physical activity in people with chronic conditions: systematic review and meta-analysis. J Med Internet Res 2023;25:e46439 [FREE Full text] [doi: 10.2196/46439] [Medline: 37410534]
16. Bazzano AN, Patel T, Nauman E, Cernigliaro D, Shi L. Optimizing telehealth for diabetes management in the deep south of the United States: qualitative study of barriers and facilitators on the patient and clinician journey. J Med Internet Res 2024;26:e43583 [FREE Full text] [doi: 10.2196/43583] [Medline: 37976468]
17. Du Y, Dennis B, Rhodes SL, Sia M, Ko J, Jiwani R, et al. Technology-assisted self-monitoring of lifestyle behaviors and health indicators in diabetes: qualitative study. JMIR Diabetes 2020;5(3):e21183 [FREE Full text] [doi: 10.2196/21183] [Medline: 32857056]
18. Daly RM, Dunstan DW, Owen N, Jolley D, Shaw JE, Zimmet PZ. Does high-intensity resistance training maintain bone mass during moderate weight loss in older overweight adults with type 2 diabetes? Osteoporos Int 2005;16(12):1703-1712. [doi: 10.1007/s00198-005-1906-4] [Medline: 15937634]
19. Gajarawala SN, Pelkowski JN. Telehealth benefits and barriers. J Nurse Pract 2021;17(2):218-221 [FREE Full text] [doi: 10.1016/j.nurpra.2020.09.013] [Medline: 33106751]
20. Jansons PS, Robins L, Haines TP, O'Brien L. Barriers and enablers to ongoing exercise for people with chronic health conditions: participants' perspectives following a randomized controlled trial of two interventions. Arch Gerontol Geriatr 2018;76:92-99. [doi: 10.1016/j.archger.2018.02.010] [Medline: 29477950]
21. L'Esperance S, Perry DJ. Assessing advantages and barriers to telemedicine adoption in the practice setting: a MyCareTeam(TM) exemplar. J Am Assoc Nurse Pract 2016;28(6):311-319. [doi: 10.1002/2327-6924.12280] [Medline: 26178417]

22. Almathami HKY, Win KT, Vlahu-Gjorgievska E. Barriers and facilitators that influence telemedicine-based, real-time, online consultation at patients' homes: systematic literature review. J Med Internet Res 2020;22(2):e16407 [FREE Full text] [doi: 10.2196/16407] [Medline: 32130131]
23. Rush KL, Howlett L, Munro A, Burton L. Videoconference compared to telephone in healthcare delivery: a systematic review. Int J Med Inform 2018;118:44-53. [doi: 10.1016/j.ijmedinf.2018.07.007] [Medline: 30153920]
24. Gitlow L. Technology use by older adults and barriers to using technology. Phys Occup Ther Geriatr 2014;32(3):271-280. [doi: 10.3109/02703181.2014.946640]
25. Airola E. Learning and use of eHealth among older adults living at home in rural and nonrural settings: systematic review. J Med Internet Res 2021;23(12):e23804 [FREE Full text] [doi: 10.2196/23804] [Medline: 34860664]
26. Jansons P, Dalla Via J, Daly R, Fyfe J, Gvozdenko E, Scott D. Delivery of home-based exercise interventions in older adults facilitated by Amazon Alexa: a 12-week feasibility trial. J Nutr Health Aging 2022;26(1):96-102 [FREE Full text] [doi: 10.1007/s12603-021-1717-0] [Medline: 35067710]
27. Hooper R. Justifying sample size for a feasibility study. National Institute for Health Research. 2017. URL: https://www.rds-london.nihr.ac.uk/resources/justify-sample-size-for-a-feasibility-study/ [accessed 2024-08-16]
28. Whitehead AL, Julious SA, Cooper CL, Campbell MJ. Estimating the sample size for a pilot randomised trial to minimise the overall trial sample size for the external pilot and main trial for a continuous outcome variable. Stat Methods Med Res 2016;25(3):1057-1073 [FREE Full text] [doi: 10.1177/0962280215588241] [Medline: 26092476]
29. BuddyLink VIPA therapeutic program. BuddyLink. 2023. URL: https://www.buddylink.au [accessed 2024-08-16]
30. Hordern MD, Dunstan DW, Prins JB, Baker MK, Singh MAF, Coombes JS. Exercise prescription for patients with type 2 diabetes and pre-diabetes: a position statement from exercise and sport science Australia. J Sci Med Sport 2012;15(1):25-31. [doi: 10.1016/j.jsams.2011.04.005] [Medline: 21621458]
31. Williams N. The Borg Rating of Perceived Exertion (RPE) scale. Occup Med 2017;67(5):404-405. [doi: 10.1093/occmed/kqx063]
32. Colagiuri S, Dickinson S, Girgis S, Colagiuri R. National evidence based guideline for blood glucose control in type 2 diabetes. Diabetes Australia and the NHMRC: Canberra. 2009. URL: https://www.diabetesaustralia.com.au/wp-content/uploads/National-Evidence-Based-Guideline-for-Blood-Glucose-Control-in-Type-2-Diabetes.pdf [accessed 2024-08-16]
33. Ford I, Norrie J. Pragmatic Trials. N Engl J Med 2016;375(5):454-463 [FREE Full text] [doi: 10.1056/NEJMra1510059] [Medline: 27518663]
34. Blood glucose level range. Diabetes Australia. 2022. URL: https://www.diabetesaustralia.com.au/managing-diabetes/blood-glucose-range/ [accessed 2024-08-16]
35. EQ-5D-5L user guides. EuroQol Group. 2019. URL: https://euroqol.org/publications/user-guides [accessed 2022-08-09]
36. Stolk E, Ludwig K, Rand K, van Hout B, Ramos-Goñi JM. Overview, update, and lessons learned from the international EQ-5D-5L valuation work: version 2 of the EQ-5D-5L valuation protocol. Value Health 2019;22(1):23-30 [FREE Full text] [doi: 10.1016/j.jval.2018.05.010] [Medline: 30661630]
37. Schmitt A, Gahr A, Hermanns N, Kulzer B, Huber J, Haak T. The Diabetes Self-Management Questionnaire (DSMQ): development and evaluation of an instrument to assess diabetes self-care activities associated with glycaemic control. Health Qual Life Outcomes 2013;11:138 [FREE Full text] [doi: 10.1186/1477-7525-11-138] [Medline: 23937988]
38. Brooke J. SUS-a quick and dirty usability scale. Usability Evaluation in Industry 1996;189(194):4-7. [doi: 10.1201/9781498710411-35]
39. Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, et al. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ 2016;355:i5239 [FREE Full text] [doi: 10.1136/bmj.i5239] [Medline: 27777223]
40. Chambers R, Beaney P. The potential of placing a digital assistant in patients' homes. Br J Gen Pract 2020;70(690):8-9 [FREE Full text] [doi: 10.3399/bjgp20X707273] [Medline: 31879289]
41. O'Brien K, Liggett A, Ramirez-Zohfeld V, Sunkara P, Lindquist LA. Voice-controlled intelligent personal assistants to support aging in place. J Am Geriatr Soc 2020;68(1):176-179. [doi: 10.1111/jgs.16217] [Medline: 31617581]
42. Balsa J, Félix I, Cláudio AP, Carmo MB, Silva ICE, Guerreiro A, et al. Usability of an intelligent virtual assistant for promoting behavior change and self-care in older people with type 2 diabetes. J Med Syst 2020;44(7):130. [doi: 10.1007/s10916-020-01583-w] [Medline: 32533367]
43. Koot D, Goh PSC, Lim RSM, Tian Y, Yau TY, Tan NC, et al. A mobile lifestyle management program (GlycoLeap) for people with type 2 diabetes: single-arm feasibility study. JMIR mHealth uHealth 2019;7(5):e12965 [FREE Full text] [doi: 10.2196/12965] [Medline: 31127720]
44. van der Weegen S, Verwey R, Spreeuwenberg M, Tange H, van der Weijden T, de Witte L. It's LiFe! Mobile and web-based monitoring and feedback tool embedded in primary care increases physical activity: a cluster randomized controlled trial. J Med Internet Res 2015;17(7):e184 [FREE Full text] [doi: 10.2196/jmir.4579] [Medline: 26209025]
45. Akinci B, Yeldan I, Satman I, Dirican A, Ozdincler AR. The effects of Internet-based exercise compared with supervised group exercise in people with type 2 diabetes: a randomized controlled study. Clin Rehabil 2018;32(6):799-810. [doi: 10.1177/0269215518757052] [Medline: 29417832]
46. von Storch K, Graaf E, Wunderlich M, Rietz C, Polidori MC, Woopen C. Telemedicine-assisted self-management program for type 2 diabetes patients. Diabetes Technol Ther 2019;21(9):514-521. [doi: 10.1089/dia.2019.0056] [Medline: 31287736]

47. Fitzner K, Moss G. Telehealth—an effective delivery method for diabetes self-management education? Popul Health Manag 2013;16(3):169-177. [doi: 10.1089/pop.2012.0054] [Medline: 23216062]
48. Jain SR, Sui Y, Ng CH, Chen ZX, Goh LH, Shorey S. Patients' and healthcare professionals' perspectives towards technology-assisted diabetes self-management education. A qualitative systematic review. PLoS One 2020;15(8):e0237647 [FREE Full text] [doi: 10.1371/journal.pone.0237647] [Medline: 32804989]
49. Whaley CM, Bollyky JB, Lu W, Painter S, Schneider J, Zhao Z, et al. Reduced medical spending associated with increased use of a remote diabetes management program and lower mean blood glucose values. J Med Econ 2019;22(9):869-877 [FREE Full text] [doi: 10.1080/13696998.2019.1609483] [Medline: 31012392]

Abbreviations

AEP: accredited exercise physiologist
ANZCTR: Australian New Zealand Clinical Trials Registry
BGL: blood glucose level
DSMQ: Diabetes Self-Management Questionnaire
DVA: digital voice assistant
HCP: health care professional
MVPA: moderate to vigorous physical activity
RCT: randomized controlled trial
SUS: System Usability Scale
T2DM: type 2 diabetes mellitus

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Original Paper

Development of a 12-Week Unsupervised Online Tai Chi Program for People With Hip and Knee Osteoarthritis: Mixed Methods Study

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Abstract

Background: Osteoarthritis is a leading contributor to global disability. While evidence supports the effectiveness of Tai Chi in improving symptoms for people with hip/knee osteoarthritis, access to in-person Tai Chi classes may be difficult for many people. An unsupervised online Tai Chi intervention for people with osteoarthritis can help overcome accessibility barriers. The Approach to Human-Centered, Evidence-Driven Adaptive Design (AHEAD) framework provides a practical guide for co-designing such an intervention.

Objective: This study aims to develop an unsupervised online Tai Chi program for people with hip/knee osteoarthritis.

Methods: An iterative process was conducted using the AHEAD framework. Initially, a panel of Tai Chi instructors and people with osteoarthritis was assembled. A literature review was conducted to inform the content of a survey (survey 1), which was completed by the panel and additional Australian Tai Chi instructors to identify Tai Chi movements for potential inclusion. Selection of Tai Chi movements was based on 3 criteria: those that were appropriate (for people with hip/knee osteoarthritis aged 45+ years), safe (to be performed at home unsupervised), and practical (to be delivered online using prerecorded videos). Movements that met these criteria were then ranked in a second survey (survey 2; using conjoint analysis methodology). Survey findings were discussed in a focus group, and the Tai Chi movements for program use were identified. A draft of the online Tai Chi program was developed, and a final survey (survey 3) was conducted with the panel to rate the appropriateness and safety of the proposed program. The final program was developed, and usability testing (think-aloud protocol) was conducted with people with knee osteoarthritis.

Results: The panel consisted of 10 Tai Chi instructors and 3 people with osteoarthritis. The literature review identified Yang Style 24 as a common and effective Tai Chi style used in hip/knee osteoarthritis studies. Surveys 1 (n=35) and 2 (n=27) produced a ranked list of 24 Tai Chi movements for potential inclusion. This list was refined and informed by a focus group, with 10 Tai Chi movements being selected for inclusion (known as the Yang Style 10 form). Survey 3 (n=13) found that 92% (n=12) of the panel members believed that the proposed draft Tai Chi program was appropriate and safe, resulting in its adoption. The final program was produced and hosted on a customized website, “My Joint Tai Chi,” which was further refined based on user feedback (n=5). “My Joint Tai Chi” is currently being evaluated in a randomized controlled trial.

Conclusions: This study demonstrates the use of the AHEAD framework to develop an unsupervised online Tai Chi intervention (“My Joint Tai Chi”) for people with hip/knee osteoarthritis. This intervention is now being tested for effectiveness and safety in a randomized controlled trial.

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KEYWORDS

intervention development; osteoarthritis; Tai Chi; web-based intervention; online; telehealth; unsupervised exercise; exercise; physical activity; arthritis; development; web based; hip; knee; gerontology; geriatric; older adult; aging; bone; workout; digital health; eHealth; literature review; telemedicine

Introduction

Osteoarthritis is a leading contributor to disability and chronic pain, with a global prevalence of 365 million in 2019 [1]. The knee is the most common lower limb site for osteoarthritis, followed by the hip [2]. Globally, it is estimated that cases of osteoarthritis will increase by 75% for the knee and nearly 80% for the hip by 2050 compared with 2020 [2]. People with hip and knee osteoarthritis often experience pain and impaired function, as well as comorbidities such as depression and anxiety [3,4].

All clinical guidelines for osteoarthritis recommend education and physical activity, including structured exercise, as the fundamental approach to treatment [5-7]. Tai Chi is specifically recommended as an exercise option for people with hip and knee osteoarthritis [5,7]. Tai Chi is a traditional Chinese, mind-body, land-based exercise that combines meditation with slow, gentle movements; deep diaphragmatic breathing; and relaxation [8]. Clinical trials indicate that Tai Chi is effective in improving pain, function, and quality of life for people with osteoarthritis [5,9-13]. With its meditative and mindfulness component, Tai Chi has also been shown to have broader benefits, such as improved psychological health, cognitive function, and sleep quality [14,15]. Tai Chi is generally performed in person in a group setting with demonstration and supervision from an instructor. However, this format can be difficult or inconvenient for many people to access, especially in regional or rural areas where there is a higher prevalence of people with osteoarthritis but Tai Chi classes may not be readily available [16].

An unsupervised online Tai Chi program may be a scalable way to help patients participate in Tai Chi in their own homes. Online exercise interventions have the potential to reach a wide audience regardless of location and at less cost to users and the health care system [17]. Since the COVID-19 pandemic, a number of Tai Chi schools and organizations now offer Tai Chi classes online [18-22]. These classes are generally conducted in a “synchronous” videoconferencing format with an instructor and require payment [23-26]. However, most Tai Chi programs are not specifically designed for people with osteoarthritis, which can make them challenging to perform correctly and safely [27]. Currently, there is no Tai Chi exercise program that is online, unsupervised, free, and tailored for people with lower limb osteoarthritis.

When designing interventions, the use of a theoretical framework is recommended to provide researchers with systematic and clear guidance [28,29]. The Approach to Human-Centered, Evidence-Driven Adaptive Design (AHEAD) is a 7-step framework that provides a practical guide for co-designing pragmatic and impactful health care interventions [30]. Using the AHEAD framework, this study aimed to develop an online, unsupervised Tai Chi program for people with hip and knee osteoarthritis.

Methods

Development of the online Tai Chi program followed the 7 steps of the AHEAD framework, which are (1) define the problem and assemble a team, (2) review evidence, (3) seek inspiration, (4) synthesize, (5) develop guiding principles, (6) ideate, and (7) evaluate [30].

Step A: Define the Problem and Assemble the Team

We defined the problem as the poor accessibility of evidence-based Tai Chi classes for people with osteoarthritis. To address this issue, we first assembled an advisory panel that included Tai Chi instructors and people with osteoarthritis. Tai Chi instructors were eligible to be part of the panel if they (1) were a member of a Tai Chi association in Australia and (2) had at least 5 years of experience teaching Tai Chi for adults (aged 45+ years) with musculoskeletal conditions. Potentially eligible instructors were identified by searching websites of Tai Chi associations. People with osteoarthritis were eligible if they had (1) self-reported symptomatic knee and/or hip osteoarthritis and (2) had participated in supervised Tai Chi exercise in the past year in Australia. It is suggested that around 10 people is an ideal size for a panel group discussion [31]. Therefore, we planned to recruit around 10 panel participants. Recruitment was conducted through email invitations to the Tai Chi instructors and email advertisements to our center’s consumer network. Interested instructors and people with osteoarthritis were asked to email the researchers and were followed up by phone to assess eligibility. A Plain Language Statement was provided to eligible panelists, and consent was obtained digitally through REDCap (Research Electronic Data Capture; Vanderbilt University). Gift vouchers of Aus $350 (US $235) were provided as an honorarium. To gain broader insights from the Tai Chi community, additional Tai Chi instructors were recruited Australia-wide to participate as nonpanel participants. Recruitment was done through the dissemination of study information by Presidents of Australian Tai Chi organizations, Facebook advertisements, and snowball sampling. Eligibility and consent procedures were consistent with panelist recruitment but with no remuneration provided.

Step B: Gather Information—Review Evidence

There are many different styles of Tai Chi, each with different forms (a series of connected movements executed in a certain order) [32]. To identify the style and movements of Tai Chi to be considered for the online program, 1 researcher (SZ) first conducted a literature search (by Ovid, PubMed, and Google) to identify systematic reviews and randomized controlled trials (RCTs) evaluating the effects of Tai Chi in people with osteoarthritis and of online Tai Chi programs in any condition. The research team (RKN, KLB, RSH, and JH) discussed the findings from the literature search through meetings, phone calls, and emails and proposed a draft list of Tai Chi movements for potential inclusion in the unsupervised online Tai Chi program.

Step C: Gather Information—Seek Inspiration

It was proposed by the Tai Chi instructor in the research team (JH) that the ideal number of Tai Chi movements to be included in an online program should be between 8 and 12, as it was thought more than 12 movements would be challenging to effectively learn and practice independently. To select the specific movements from those identified in Step B, 2 online surveys were conducted, involving both panel and nonpanel participants.

Survey 1

The purpose of this survey (conducted using REDCap software) was to identify which Tai Chi movements would be appropriate, safe, and practical for inclusion in the program. The survey asked participants to rate each identified Tai Chi movement (from Step B) against two criteria, which are (1) appropriateness of the movement for people with knee and/or hip osteoarthritis who are 45 years old and older when performed correctly, and (2) safety of the movement if performed at home unsupervised. Each movement was scored using separate 11-point numerical rating scales from 0 (not appropriate or safe at all) to 10 (completely appropriate or safe). Participants were also asked whether each Tai Chi movement would be practical to be delivered online using prerecorded videos that someone would watch at home (response options yes or no). Participants also provided feedback regarding Tai Chi exercise prescription, including the recommended length of each Tai Chi video session (response options 20, 30, 40, 50, and 60 minutes), weekly practice frequency (d/wk, range 1-7), and total weekly practice time (min/wk). Open-ended questions gathered additional suggestions for developing the program. The research team determined a priori that a Tai Chi movement would be retained for potential inclusion in the program if at least 70% of participants scored it at least 5 out of 10 for both appropriateness and safety, and it was deemed practical.

Survey 2

The purpose of this survey was to rank the Tai Chi movements retained from survey 1 so that 12 movements could be selected. Using a pairwise ranking technique (1000Minds) [33], participants were shown pairs of Tai Chi movements (selected based on those considered appropriate, safe, and practical from survey 1) and asked to identify which of the pair should take priority for inclusion in the program. The number of pairwise rankings required from each participant varied depending on their responses to the presented alternatives. The pairwise ranking process continued until the background mathematics established a ranked list of all Tai Chi movements for each participant and averaged over the sample.

Step D: Synthesize

To synthesize information gathered from the first 2 surveys, an online focus group was conducted with panel participants, facilitated by the researchers (KLB, SZ, RKN, and JH). Discussion topics included results of the first 2 surveys, practicalities of recording the online Tai Chi program, Tai Chi exercise prescription, and Tai Chi education content that would supplement the Tai Chi exercise program. The focus group discussion was recorded (both audio and visual) and transcribed verbatim. Notes and recordings were reviewed, replayed, and analyzed qualitatively to gather the panelist's perspectives and to identify areas of consensus for the design of the Tai Chi program.

Step E: Intervention Design—Develop and Apply Guiding Principles

The criteria of appropriateness, safety, and practicality were deemed as the guiding principles for this 12-week, online, unsupervised Tai Chi program. Based on the results from the first 2 surveys and focus group, a proposed 12-week Tai Chi program was filmed by the research team Tai Chi instructor (JH). Panelists were then sent the prototype video, through a final REDCap survey (survey 3). In this survey, they were asked to rate their level of agreement that the proposed program as a whole was (1) appropriate (for people aged 45+ years old with knee and/or hip osteoarthritis) and (2) safe (to be performed at home unsupervised). Each criterion was scored using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). For the proposed program to be approved, 70% or more of participants were required to "strongly agree" or "agree" that the program was "appropriate" and "safe." Since all movements included in the program had already been judged to be practical, it was unnecessary to vote on this.

Step F: Intervention Design—Ideate (Brainstorm–Prototype–Test)

Finally, the 12-week, unsupervised, online Tai Chi program was filmed in a studio at the University of Melbourne. The produced videos were incorporated into a website prototype, "My Joint Tai Chi," which was constructed by the research team and 2 research assistants. The website was based on our other evidence-based unsupervised exercise programs for knee and/or hip osteoarthritis "My Knee Exercise" [34] and "My Hip Exercise" [35] and developed in accordance with recommendations outlined by the Health on the Net Foundation's Code of Conduct [36].

The website prototype underwent extensive usability testing with people with osteoarthritis, following a think-aloud protocol [37]. Volunteers from our previous osteoarthritis studies in Australia, who agreed to be contacted again, were invited through email to participate (by researcher SZ). Participants were eligible if they (1) had symptomatic knee osteoarthritis and (2) had no previous experience with Tai Chi exercise (in person or online) in the past 2 years. Purposive sampling was used to ensure diversity in age, sex, and symptom duration. A Plain Language Statement was provided, and consent was obtained digitally through REDCap. Participants received Aus $50 (US $35) gift vouchers as an honorarium.

Participants were scheduled for a 60-minute, one-on-one, online usability test with a researcher (SZ) through Zoom (Zoom Video Communications). During the usability test, participants were asked to share their screen and navigate the "My Joint Tai Chi" website prototype, as if they were commencing the Tai Chi program, while the researcher observed. Participants were encouraged to vocalize their thoughts on the website's design, content, and functionality, with the researcher asking open-ended questions for further feedback. Notes on usability were taken and sessions were audio and video recorded. Field notes and recordings were qualitatively analyzed to identify usability issues, which were addressed before the next participant. This iterative process continued until no further issues were identified.

Step G: Evaluate

The research team has designed and is currently conducting a 2-arm, parallel-design, superiority pragmatic RCT to assess the effectiveness of this unsupervised online Tai Chi intervention, ("My Joint Tai Chi"), compared with online osteoarthritis education control. Primary outcomes of self-reported pain during walking [38] and physical function [39] will be evaluated. A nested qualitative study has also been designed to explore the experience of people with osteoarthritis who use the "My Joint Tai Chi" intervention during the RCT. The RCT protocol and the results of the RCT will be published in separate subsequent papers.

Ethical Considerations

The Human Research Ethics Committee at the University of Melbourne approved this study (2023-25788-36959-4). All data collected in this study was de-identified and stored on secure university servers, accessible only to the researchers using a password.

Results

Overview

A summary of the development of the "My Joint Tai Chi" intervention using the AHEAD Framework is provided in Table 1 [30].

Table 1. Summary of the design of the "My Joint Tai Chi" intervention using the AHEAD[a] framework.

AHEAD framework domains	Intervention design stages
Define the problem and assemble the team (A)	• Problem: Poor accessibility of evidence-based Tai Chi classes for people with osteoarthritis • Team (n=17): Advisory panel including Tai Chi instructors (n=10) and people with osteoarthritis (n=3), and a research team including osteoarthritis researchers and/or physiotherapists (n=4; SZ, KLB, RKN, and RSH) and a Tai Chi instructor recruited from the panel.
Review evidence (B)	• Literature review identified Yang Style 24 form as a common and effective form of Tai Chi for osteoarthritis. Twelve weeks was the most common length.
Seek inspiration (C)	• Two surveys were completed by panel participants (Tai Chi instructors and people with osteoarthritis) and additional nonpanel Tai Chi instructors. • Survey 1 (n=35) rated Yang Style 24 form and modifications (total 33 Tai Chi movements) based on appropriateness, safety, and practicality. A total of 24 movements identified as appropriate, safe, and practical. • Survey 2 (n=27) produced a ranked list of the 24 movements retained from survey 1 (ranked based on most appropriate or safe to least appropriate or safe).
Synthesize (D)	• Met with the panel (n=12) to discuss results from surveys and additional Tai Chi program design considerations. This resulted in the adoption of the Yang Style 10 form.
Develop and apply guiding principles (E)	• Final survey with panel participants (n=13) rated a draft of the proposed program against the guiding principles of appropriateness (for people aged 45+ years with osteoarthritis) and safety (to be performed at home unsupervised). 92% (12/13) rated the program as both appropriate and safe.
Ideate (F)	• A 12-week Tai Chi exercise program was developed, produced, and housed within a website prototype called "My Joint Tai Chi". Usability testing was conducted with people with osteoarthritis (n=5) using a think-aloud protocol. Usability problems were identified, and the prototype was refined.
Evaluate (G)	• The final "My Joint Tai Chi" intervention is currently being evaluated in a 2-arm, parallel-design, superiority pragmatic RCT[b] (ACTRN12623000780651) and nested qualitative study. The methods and results of this RCT will be reported subsequently in separate papers.

[a] AHEAD: Approach to Human-Centered, Evidence-Driven Adaptive Design.

[b] RCT: randomized controlled trial.

Step A: Define the Problem and Assemble the Team

We recruited 10 Tai Chi instructors and 3 people with osteoarthritis (1 with hip and knee osteoarthritis and 2 with knee osteoarthritis only) as advisory panel participants and another 22 Tai Chi instructors as nonpanel participants. One Tai Chi instructor (JH) was recruited to join the research team (that comprised osteoarthritis researchers and physiotherapists) to provide professional opinions about Tai Chi during the development process. Participant demographic information is provided in Table 2.

Table 2. Demographic characteristics of participants in Step A.

Participant characteristics	Survey 1 participants (n=35)	
	Panel (n=13)	Nonpanel (n=22)
Tai Chi instructors, n	10	22
Sex, female, n (%)	6 (60)	11 (50)
Predominant style of Tai Chi taught, n (%)[a]		
Yang	9 (90)	19 (86)
Sun	5 (50)	5 (23)
Chen	2 (20)	1 (5)
Wu	1 (10)	1 (5)
Hao	2 (20)	0 (0)
Years of experience teaching Tai Chi, mean (SD)	24 (11)	16 (10)
Number of Tai Chi classes taught per week, mean (SD)	8 (6)	3 (2)
People with osteoarthritis, n	3	—[b]
Sex, female, n (%)	2 (67)	—
Age (years), mean (SD)	73 (2)	—
Years of symptom duration, mean (SD)	7 (3)	—
Years of Tai Chi practice, mean (SD)	7 (2)	—

[a] Some Tai Chi instructors taught more than 1 style of Tai Chi.

[b] Not applicable.

Step B: Gather Information—Review Evidence

Six systematic reviews and 14 RCTs were identified evaluating Tai Chi programs in people with osteoarthritis. Programs varied in length from 8 to 20 weeks, with 12 weeks being the most common [40-51]. The average Tai Chi exercise prescription was 3 Tai Chi sessions per week, each lasting 60 minutes [40-51]. Yang Style 24 form was the most commonly practiced [52]. This style was created in China in the 20th century and is known for its slow and graceful movements, with an emphasis on weight shifting in a wide stance [53]. It has been found to be effective in improving pain and physical function in people with osteoarthritis [54]. Hence, Yang Style was chosen as the foundational basis for the online Tai Chi program. There are 24 Tai Chi movements in the Yang Style 24 form. However, the Tai Chi instructor in the research team (JH) perceived some movements to be unsuitable for people with osteoarthritis and challenging to learn through online delivery, for example, movements that involve single-leg stance, maintained end-of-range hip and knee flexion, and multiple 180-degree turns. Therefore, the research team introduced 7 modifications and broke down certain movements, resulting in a total of 33 movements (Multimedia Appendix 1) for possible inclusion in the online program.

Four studies (2 feasibility trials, 1 longitudinal pilot study, and 1 RCT protocol) used telehealth-delivered Tai Chi for other chronic conditions such as long-term mobility disability, Parkinson disease, mild cognitive impairment, and cancer therapy–induced joint pain [23-25]. Programs were most commonly delivered synchronously using videoconferencing software Zoom (n=3). One study integrated Tai Chi training videos into a mobile phone app for people with Parkinson disease, which was connected to a clinician app for monitoring adherence [55]. Professional oversight through phone calls was also provided [55]. The Tai Chi for Arthritis program, endorsed by the US Centers for Disease Control and Prevention, does offer an online asynchronous course [56], but this has not been formally evaluated.

The research team determined that prerecorded videos of Tai Chi exercises would be the most convenient approach, allowing broader access without class scheduling or professional oversight. Moreover, it was decided to deliver the prerecorded Tai Chi videos by a dedicated website that also included osteoarthritis and Tai Chi education and exercise adherence support resources to allow for a potentially more effective multicomponent, osteoarthritis, digital, self-management intervention [57].

Step C: Gather Information—Seek Inspiration

Survey 1

All 35 participants (13 panel and 22 nonpanel) completed survey 1 (Multimedia Appendix 1). Out of the 33 movements, 24 (73%) achieved consensus (defined as at least 70% of participants rating it at least 5 out of 10 for appropriateness, safety, and considering it to be practical). For the 9 excluded movements, refer to Multimedia Appendix 2. Additional Tai Chi exercise prescription suggestions are summarized in Table 3.

Table 3. Tai Chi exercise prescription suggestions from survey 1 (N=35).

Tai Chi exercise prescription suggestions	Value
Length of each prerecorded video (min), n (%)	
30	17 (55)
20	9 (29)
40	2 (6)
50	2 (6)
60	1 (3)
Frequency of Tai Chi practice (d/wk), n (%)	
3	12 (40)
5	6 (20)
4	4 (13)
7	4 (13)
2	3 (10)
1	1 (3)
6	0 (0)
Weekly dosage of Tai Chi practice (total min/wk), mean (SD)	114 (60)

Survey 2

As 24 movements met the criteria in survey 1 (exceeding the 12 required), a 1000Minds survey was conducted for further prioritization. A total of 27 participants (13 panel and 14 nonpanel) completed survey 2, which produced a ranked list of movements (Multimedia Appendix 3) for potential inclusion. Kendall W was 0.124, indicating high variance and low agreement among participants [58]. Thus, this ranked list was used only as a guide to inform further discussions with the panel participants by a focus group.

Step D: Synthesize

Panel participants (12/13) were then involved in a 2-hour online focus group via Zoom. Suggestions provided during the focus group are listed in Multimedia Appendix 4. In summary, Tai Chi instructors advocated for the use of a recognized Tai Chi sequence, as opposed to solely relying on the ranked list of movements from the second survey (1000Minds). This is because the transition, stance, and flow between movements are vital in Tai Chi, rather than just presenting isolated "movements." It was decided to use the modified Yang Style 10 form (Textbox 1) for the program because 7 out of the 10 movements aligned with the top 10 ranked movements in survey 2 and it is a recognized Tai Chi sequence [54]. The other 3 moves were ranked 13th, 16th, and 20th out of the 24 moves in the results of survey 2 (Multimedia Appendix 3). Modifications were also discussed for certain Tai Chi movements to ensure suitability for people with osteoarthritis and little previous Tai Chi experience. It was also decided that each 12-week video should include 5-10 minutes of Qigong exercise for warm-up and cooldown (an ancient wellness practice that is performed with minimal footwork [59]). All panelists agreed on the program duration (12 weeks), and it was decided that the program should start with 30- to 40-minute sessions and progress to 40- to 45-minute sessions to build endurance. Incorporating explanations of the martial applications of each selected Tai Chi movement and the practicalities of recording the program were discussed. Finally, resources for those wanting to continue Tai Chi practice after completing the online program were also suggested.

Textbox 1. The Yang Style 10 form Tai Chi movements.

Movement name

- Commencement
- Repulse monkey
- Brush knee
- Part the wild horse's mane
- Cloud hands
- Golden rooster stands on one leg
- Cross hands and kick
- Stroke peacock's tail
- Embrace the tiger
- Closing

Step E: Intervention Design—Develop and Apply Guiding Principles

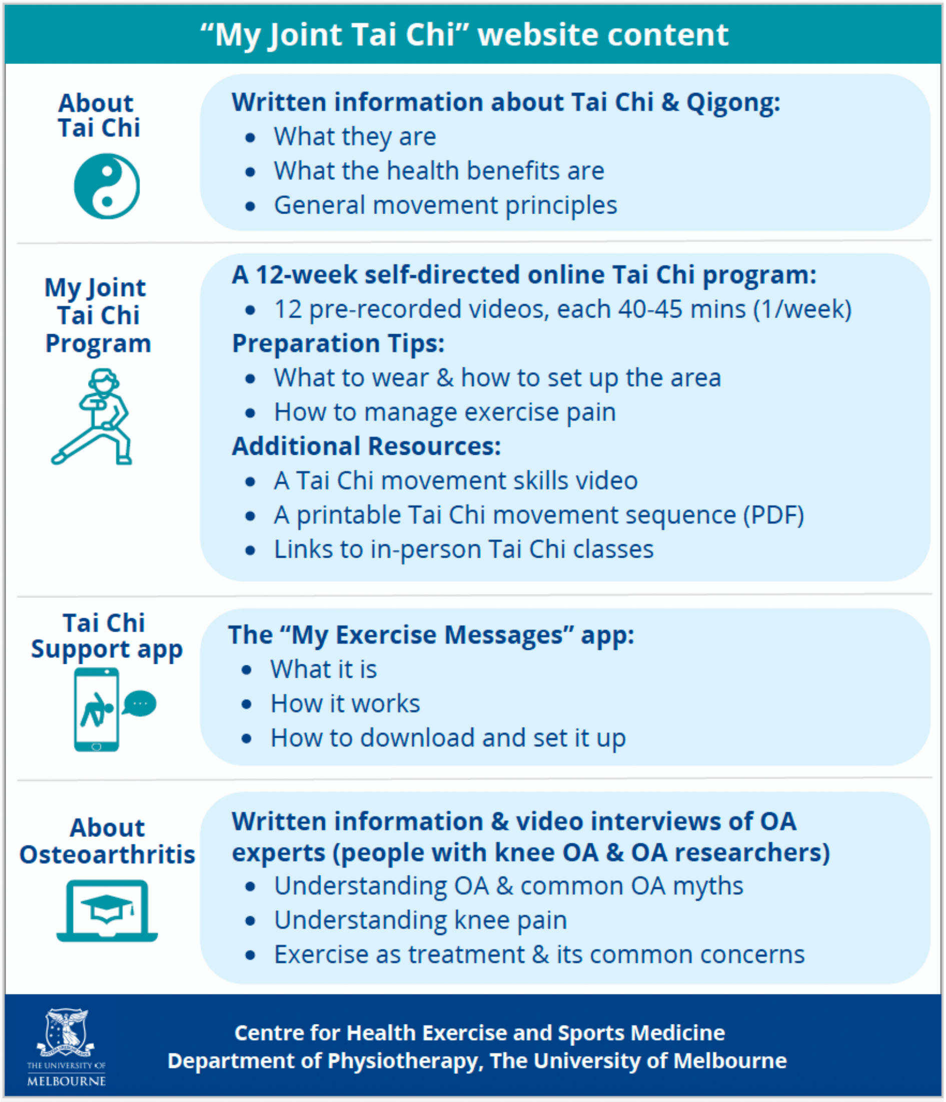
All panel participants (n=13) took part in the final survey that involved voting on the draft program's alignment with the guiding principles. A total of 92% (12/13) of participants rated "strongly agree" or "agree" to the draft 12-week Tai Chi program being (1) appropriate for people with knee and/or hip osteoarthritis and (2) safe to be performed at home unsupervised. The agreement reached the predetermined threshold (70%), and therefore, the draft online Tai Chi program was adopted as the final version.

Step F: Intervention Design—Ideate (Brainstorm–Prototype–Test)

"My Joint Tai Chi" Website

The 12 professionally filmed videos showing a Tai Chi instructor (JH) demonstrating the Tai Chi movements were housed on a website called "My Joint Tai Chi" (the website was built specifically for research purposes and was not yet widely publicly available). "My Joint Tai Chi" contains a home page with a video tutorial explaining how to use the website and four sections including (1) the Tai Chi program, (2) information about Tai Chi, (3) information about osteoarthritis, and (4) instructions on how to access an exercise adherence app to support engagement with the Tai Chi program. Figure 1 outlines the contents of the website, and further detail is provided in Multimedia Appendix 5. Still images of modified Yang Style 10 form in the "My Joint Tai Chi" program are provided in Multimedia Appendix 6.

Figure 1. Description of the content in the 4 discrete sections of the "My Joint Tai Chi" website. OA: osteoarthritis.



"My Joint Tai Chi" website content

About Tai Chi

Written information about Tai Chi & Qigong:

- What they are
- What the health benefits are
- General movement principles

My Joint Tai Chi Program

A 12-week self-directed online Tai Chi program:

- 12 pre-recorded videos, each 40-45 mins (1/week)

Preparation Tips:

- What to wear & how to set up the area
- How to manage exercise pain

Additional Resources:

- A Tai Chi movement skills video
- A printable Tai Chi movement sequence (PDF)
- Links to in-person Tai Chi classes

Tai Chi Support app

The "My Exercise Messages" app:

- What it is
- How it works
- How to download and set it up

About Osteoarthritis

Written information & video interviews of OA experts (people with knee OA & OA researchers)

- Understanding OA & common OA myths
- Understanding knee pain
- Exercise as treatment & its common concerns

THE UNIVERSITY OF MELBOURNE

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Usability Test

Five participants with osteoarthritis conducted website prototype usability testing. On average, they were 60 (SD 10) years old and had experienced knee pain for 2 (SD 1) years. Identified issues and implemented solutions are outlined in Multimedia Appendix 7. In summary, usability testing resulted in the redesign of the user interface and several pages for easier navigation. Page instructions were reworded for clearer and more explicit guidance.

Step G: Evaluate

The RCT evaluating the "My Joint Tai Chi" intervention is currently recruiting and expected to complete data collection in February 2025. The RCT has been prospectively registered (ACTRN12623000780651). The nested qualitative study is anticipated to commence data collection in July 2024. The RCT protocol will be published separately.

Discussion

Principal Findings

This study reports the systematic codevelopment of an unsupervised online Tai Chi intervention for people with osteoarthritis using the AHEAD framework. The intervention is a 12-week, web-based Tai Chi program that is complemented with educational information about osteoarthritis and Tai Chi and supported by an app to facilitate Tai Chi exercise adherence. Once the RCT evaluation is complete (and subsequently any required modifications are made), the finalized program will be released online for public access at no cost to the user. The program has the potential to boost participation in physical activity among people with osteoarthritis.

This study has several strengths. First, the use of the AHEAD framework provided a structured foundation for the transparent and thorough reporting of intervention design and intervention components. This approach addresses the previous lack of clarity in intervention development, with evidence showing that most Tai Chi studies do not meet the expected intervention reporting standards [60-62]. Second, by using an evidence-based, iterative, and robust process, we were able to incorporate opinions from a broad panel of Tai Chi experts and people with osteoarthritis (n=35 in total), along with physiotherapists and osteoarthritis researchers. To the best of our knowledge, only one other study has incorporated end-user feedback (n=14) into the design of an online, seated Tai Chi program for people with mobility disabilities [25]. However, that program was designed to include remote supervision, and its effectiveness has not been tested in an RCT [25]. Hence, no previous unsupervised online Tai Chi program has been codeveloped by such a large sample group nor subjected to rigorous evaluation. Third, since this Tai Chi exercise program was designed for people with knee and/or hip osteoarthritis, the panel also deemed it appropriate for people 45 years of age and older who do not have osteoarthritis. Hence, the Tai Chi exercise program videos developed could potentially be used as a strategy to increase access to Tai Chi exercise for a broader audience.

One limitation is that there were only 3 people with osteoarthritis out of a total of 35 participants involved in Step C (Seek Inspiration), indicating a potential underrepresentation of people with osteoarthritis. However, these 3 people provided constructive feedback in Step D (Synthesize), and an additional 5 people with osteoarthritis were involved in the final website usability testing in Step F. Another potential limitation is that we have developed an intervention that requires access to digital technologies and technological literacy. To fully gain the benefit from the "My Joint Tai Chi" program, the user is required to have a computer with internet access and preferably to have a mobile phone (to use the exercise support app). However, given that 94% of Australian households have a computer with 86% of them having internet access [63], and that 78% of Australian adults 65 years of age and older use a mobile phone [64], this suggests that the use of "My Joint Tai Chi" website is broadly accessible by most Australians.

Conclusions

A systematic design approach using the AHEAD framework was successful in developing this user-centered intervention and may serve as a guide for others developing unsupervised digital interventions. To our knowledge, "My Joint Tai Chi" is the first unsupervised online Tai Chi intervention designed for people with osteoarthritis. The program is now being evaluated in an RCT that will provide insights into the effectiveness and safety of the program compared with online osteoarthritis education control. The prerecorded Tai Chi exercise videos in the program can also be used to increase physical activity for people without osteoarthritis in the community at large.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey 1, including the 33 Tai Chi movements for potential inclusion in the Tai Chi program.
[PDF File (Adobe PDF File), 30979 KB - aging_v7i1e55322_app1.pdf]

Multimedia Appendix 2
The 9 movements excluded from survey 1.
[DOCX File , 14 KB - aging_v7i1e55322_app2.docx]

Multimedia Appendix 3
The ranked list of Tai Chi movements based on survey 2.
[DOCX File , 15 KB - aging_v7i1e55322_app3.docx]

Multimedia Appendix 4
Suggestions and recommendation from focus group discussion (n=12).
[DOCX File , 16 KB - aging_v7i1e55322_app4.docx]

Multimedia Appendix 5
"My Joint Tai Chi" website section description.

[DOCX File , 16 KB - aging_v7i1e55322_app5.docx]

Multimedia Appendix 6
Still images of modified Yang Style 10 form in the final "My Joint Tai Chi" program.
[PDF File (Adobe PDF File), 9198 KB - aging_v7i1e55322_app6.pdf]

Multimedia Appendix 7
Usability issues identified and corresponding implemented solutions.
[DOCX File , 15 KB - aging_v7i1e55322_app7.docx]

References

1. Yang G, Wang J, Liu Y, Lu H, He L, Ma C, et al. Burden of knee osteoarthritis in 204 countries and territories, 1990-2019: results from the Global Burden of Disease study 2019. Arthritis Care Res (Hoboken) 2023;75(12):2489-2500. [doi: 10.1002/acr.25158] [Medline: 37221154]
2. GBD 2021 Osteoarthritis Collaborators. Global, regional, and national burden of osteoarthritis, 1990-2020 and projections to 2050: a systematic analysis for the Global Burden of Disease study 2021. Lancet Rheumatol 2023;5(9):e508-e522 [FREE Full text] [doi: 10.1016/S2665-9913(23)00163-7] [Medline: 37675071]
3. Murphy LB, Sacks JJ, Brady TJ, Hootman JM, Chapman DP. Anxiety and depression among US adults with arthritis: prevalence and correlates. Arthritis Care Res (Hoboken) 2012;64(7):968-976 [FREE Full text] [doi: 10.1002/acr.21685] [Medline: 22550055]
4. Johnson VL, Hunter DJ. The epidemiology of osteoarthritis. Best Pract Res Clin Rheumatol 2014;28(1):5-15. [doi: 10.1016/j.berh.2014.01.004] [Medline: 24792942]
5. Kolasinski SL, Neogi T, Hochberg MC, Oatis C, Guyatt G, Block J, et al. 2019 American College of Rheumatology/Arthritis Foundation guideline for the management of osteoarthritis of the hand, hip, and knee. Arthritis Rheumatol 2020;72(2):220-233 [FREE Full text] [doi: 10.1002/art.41142] [Medline: 31908163]
6. Osteoarthritis in over 16s: diagnosis and management. National Institute for Health and Care Excellence. 2022. URL: https://www.nice.org.uk/guidance/ng226 [accessed 2024-07-12]
7. Bannuru RR, Osani MC, Vaysbrot EE, Arden NK, Bennell K, Bierma-Zeinstra SMA, et al. OARSI guidelines for the non-surgical management of knee, hip, and polyarticular osteoarthritis. Osteoarthritis Cartilage 2019;27(11):1578-1589 [FREE Full text] [doi: 10.1016/j.joca.2019.06.011] [Medline: 31278997]
8. Cui L, Tao S, Yin H, Shen Q, Wang Y, Zhu L, et al. Tai Chi chuan alters brain functional network plasticity and promotes cognitive flexibility. Front Psychol 2021;12:665419 [FREE Full text] [doi: 10.3389/fpsyg.2021.665419] [Medline: 34267705]
9. Hu L, Wang Y, Liu X, Ji X, Ma Y, Man S, et al. Tai Chi exercise can ameliorate physical and mental health of patients with knee osteoarthritis: systematic review and meta-analysis. Clin Rehabil 2021;35(1):64-79. [doi: 10.1177/0269215520954343] [Medline: 32954819]
10. Yan JH, Gu WJ, Sun J, Zhang WX, Li BW, Pan L. Efficacy of Tai Chi on pain, stiffness and function in patients with osteoarthritis: a meta-analysis. PLoS One 2013;8(4):e61672 [FREE Full text] [doi: 10.1371/journal.pone.0061672] [Medline: 23620778]
11. Li R, Chen H, Feng J, Xiao Y, Zhang H, Lam CWK, et al. Effectiveness of traditional Chinese exercise for symptoms of knee osteoarthritis: a systematic review and meta-analysis of randomized controlled trials. Int J Environ Res Public Health 2020;17(21):7873 [FREE Full text] [doi: 10.3390/ijerph17217873] [Medline: 33121082]
12. Chang W, Chen S, Lee C, Lin H, Lai P. The effects of Tai Chi chuan on improving mind-body health for knee osteoarthritis patients: a systematic review and meta-analysis. Evid Based Complement Alternat Med 2016;2016:1813979 [FREE Full text] [doi: 10.1155/2016/1813979] [Medline: 27635148]
13. Lauche R, Langhorst J, Dobos G, Cramer H. A systematic review and meta-analysis of Tai Chi for osteoarthritis of the knee. Complement Ther Med 2013;21(4):396-406. [doi: 10.1016/j.ctim.2013.06.001] [Medline: 23876571]
14. Leung LYL, Tam HL, Ho JKM. Effectiveness of Tai Chi on older adults: a systematic review of systematic reviews with re-meta-analysis. Arch Gerontol Geriatr 2022;103:104796. [doi: 10.1016/j.archger.2022.104796] [Medline: 36058045]
15. Yang GY, Hunter J, Bu FL, Hao WL, Zhang H, Wayne PM, et al. Determining the safety and effectiveness of Tai Chi: a critical overview of 210 systematic reviews of controlled clinical trials. Syst Rev 2022;11(1):260 [FREE Full text] [doi: 10.1186/s13643-022-02100-5] [Medline: 36463306]
16. Chronic musculoskeletal conditions. Australian Institute of Health and Welfare. 2023. URL: https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/musculoskeletal-conditions/contents/summary [accessed 2023-03-07]
17. Ekman B, Nero H, Lohmander LS, Dahlberg LE. Costing analysis of a digital first-line treatment platform for patients with knee and hip osteoarthritis in Sweden. PLoS One 2020;15(8):e0236342 [FREE Full text] [doi: 10.1371/journal.pone.0236342] [Medline: 32785226]
18. Rising Moon Tai Chi School. 2023. URL: https://www.risingmoontaichi.net/# [accessed 2023-11-29]

19. School: supreme ultimate Tai Chi. Wushu Tai Chi and Qigong Australia Inc. 2023. URL: https://www.wtqa.org.au/supreme-ultimate-tai-chi [accessed 2024-08-28]
20. Tai Chi Australia. 2021. URL: https://www.taichiaustralia.com.au/ [accessed 2023-11-29]
21. Jade Lady Tai Chi & Qigong. 2023. URL: https://www.jadeladytaichi.com.au/ [accessed 2023-11-29]
22. JinLi Wushu-Tai Chi. 2023. URL: https://www.jinli.com.au/ [accessed 2023-11-05]
23. Gomaa S, West C, Lopez AM, Zhan T, Schnoll M, Abu-Khalaf M, et al. A telehealth-delivered Tai Chi intervention (TaiChi4Joint) for managing aromatase inhibitor-induced arthralgia in patients with breast cancer during COVID-19: longitudinal pilot study. JMIR Form Res 2022;6(6):e34995 [FREE Full text] [doi: 10.2196/34995] [Medline: 35727609]
24. Li F, Harmer P, Fitzgerald K, Winters-Stone K. A cognitively enhanced online tai ji quan training intervention for community-dwelling older adults with mild cognitive impairment: a feasibility trial. BMC Geriatr 2022;22(1):76 [FREE Full text] [doi: 10.1186/s12877-021-02747-0] [Medline: 35078407]
25. Mitzner TL, Remillard ET, Mumma KT. Research-driven guidelines for delivering group exercise programs via videoconferencing to older adults. Int J Environ Res Public Health 2022;19(13):7562 [FREE Full text] [doi: 10.3390/ijerph19137562] [Medline: 35805221]
26. Tai Chi for Health Institute. 2018. URL: https://taichiforhealthinstitute.org/programs/tai-chi-for-arthritis/ [accessed 2023-11-12]
27. Wayne PM, Berkowitz DL, Litrownik DE, Buring JE, Yeh GY. What do we really know about the safety of Tai Chi?: A systematic review of adverse event reports in randomized trials. Arch Phys Med Rehabil 2014;95(12):2470-2483 [FREE Full text] [doi: 10.1016/j.apmr.2014.05.005] [Medline: 24878398]
28. Kowatsch T, Otto L, Harperink S, Cotti A, Schlieter H. A design and evaluation framework for digital health interventions. it - Information Technology 2019;61(5-6):253-263. [doi: 10.1515/itit-2019-0019]
29. Soobiah C, Cooper M, Kishimoto V, Bhatia RS, Scott T, Maloney S, et al. Identifying optimal frameworks to implement or evaluate digital health interventions: a scoping review protocol. BMJ Open 2020;10(8):e037643. [doi: 10.1136/bmjopen-2020-037643]
30. Fischer M, Safaeinili N, Haverfield MC, Brown-Johnson CG, Zionts D, Zulman DM. Approach to human-centered, evidence-driven adaptive design (AHEAD) for health care interventions: a proposed framework. J Gen Intern Med 2021;36(4):1041-1048 [FREE Full text] [doi: 10.1007/s11606-020-06451-4] [Medline: 33537952]
31. McQuarrie EF, Krueger RA. Focus Groups: A Practical Guide for Applied Research. US: SAGE Publications; 1989.
32. Tai Chi forms. Ji Hong Tai Chi & Qi Gong. 2023. URL: https://www.taichi.ca/programs/tai-chi-forms/ [accessed 2023-11-12]
33. 1000minds. 2023. URL: https://www.1000minds.com/ [accessed 2023-11-12]
34. Nelligan RK, Hinman RS, Kasza J, Crofts SJC, Bennell KL. Effects of a self-directed web-based strengthening exercise and physical activity program supported by automated text messages for people with knee osteoarthritis: a randomized clinical trial. JAMA Intern Med 2021;181(6):776-785 [FREE Full text] [doi: 10.1001/jamainternmed.2021.0991] [Medline: 33843948]
35. Bennell KL, Nelligan RK, Hall M, Stratulate S, McManus F, Lamb K, et al. A self-directed digital exercise program for hip osteoarthritis ("My Hip Exercise"): protocol for a randomised controlled trial. BMC Musculoskelet Disord 2023;24(1):906 [FREE Full text] [doi: 10.1186/s12891-023-07009-1] [Medline: 37990187]
36. Health On the Net Foundation. Health On the Net Foundation Code of Conduct for medical and health web sites. Dziedniecība Ltd. 1997. URL: https://www.mfd.lv/HONcode_en.htm [accessed 2023-11-18]
37. Charters E. The use of think-aloud methods in qualitative research an introduction to think-aloud methods. Brock Education Journal 2003;12(2):1-15. [doi: 10.26522/brocked.v12i2.38]
38. Bellamy N. Osteoarthritis clinical trials: candidate variables and clinimetric properties. J Rheumatol 1997;24(4):768-778. [Medline: 9101516]
39. Bellamy N, Buchanan WW, Goldsmith CH, Campbell J, Stitt LW. Validation study of WOMAC: a health status instrument for measuring clinically important patient relevant outcomes to antirheumatic drug therapy in patients with osteoarthritis of the hip or knee. J Rheumatol 1988;15(12):1833-1840. [Medline: 3068365]
40. Zhu Q, Huang L, Wu X, Wang L, Zhang Y, Fang M, et al. Effects of Tai ji quan training on gait kinematics in older Chinese women with knee osteoarthritis: a randomized controlled trial. J Sport Health Sci 2016;5(3):297-303 [FREE Full text] [doi: 10.1016/j.jshs.2016.02.003] [Medline: 30356529]
41. Wang C, Schmid CH, Iversen MD, Harvey WF, Fielding RA, Driban JB, et al. Comparative effectiveness of Tai Chi versus physical therapy for knee osteoarthritis: a randomized trial. Ann Intern Med 2016;165(2):77-86 [FREE Full text] [doi: 10.7326/M15-2143] [Medline: 27183035]
42. Wang C, Schmid CH, Hibberd PL, Kalish R, Roubenoff R, Rones R, et al. Tai Chi is effective in treating knee osteoarthritis: a randomized controlled trial. Arthritis Rheum 2009;61(11):1545-1553 [FREE Full text] [doi: 10.1002/art.24832] [Medline: 19877092]
43. Tsai P, Chang JY, Beck C, Kuo Y, Keefe FJ. A pilot cluster-randomized trial of a 20-week Tai Chi program in elders with cognitive impairment and osteoarthritic knee: effects on pain and other health outcomes. J Pain Symptom Manage 2013;45(4):660-669 [FREE Full text] [doi: 10.1016/j.jpainsymman.2012.04.009] [Medline: 23017610]

44. Lee HJ, Park HJ, Chae Y, Kim SY, Kim SN, Kim ST, et al. Tai Chi qigong for the quality of life of patients with knee osteoarthritis: a pilot, randomized, waiting list controlled trial. Clin Rehabil 2009;23(6):504-511. [doi: 10.1177/0269215508101746] [Medline: 19389743]
45. Fransen M, Nairn L, Winstanley J, Lam P, Edmonds J. Physical activity for osteoarthritis management: a randomized controlled clinical trial evaluating hydrotherapy or Tai Chi classes. Arthritis Rheum 2007;57(3):407-414 [FREE Full text] [doi: 10.1002/art.22621] [Medline: 17443749]
46. Song R, Lee E, Lam P, Bae S. Effects of Tai Chi exercise on pain, balance, muscle strength, and perceived difficulties in physical functioning in older women with osteoarthritis: a randomized clinical trial. J Rheumatol 2003;30(9):2039-2044. [Medline: 12966613]
47. Wortley M, Zhang S, Paquette M, Byrd E, Baumgartner L, Klipple G, et al. Effects of resistance and Tai ji training on mobility and symptoms in knee osteoarthritis patients. Journal of Sport and Health Science 2013;2(4):209-214. [doi: 10.1016/j.jshs.2013.01.001]
48. Ni G, Song L, Yu B, Huang CH, Lin JH. Tai Chi improves physical function in older Chinese women with knee osteoarthritis. J Clin Rheumatol 2010;16(2):64-67. [doi: 10.1097/RHU.0b013e3181cf344f] [Medline: 20130482]
49. Song R, Roberts BL, Lee E, Lam P, Bae S. A randomized study of the effects of t'ai Chi on muscle strength, bone mineral density, and fear of falling in women with osteoarthritis. J Altern Complement Med 2010;16(3):227-233 [FREE Full text] [doi: 10.1089/acm.2009.0165] [Medline: 20192907]
50. Brismée JM, Paige RL, Chyu MC, Boatright JD, Hagar JM, McCaleb JA, et al. Group and home-based Tai Chi in elderly subjects with knee osteoarthritis: a randomized controlled trial. Clin Rehabil 2007;21(2):99-111. [doi: 10.1177/0269215506070505] [Medline: 17264104]
51. Chen CH, Yen M, Fetzer S, Lo LH, Lam P. The effects of Tai Chi exercise on elders with osteoarthritis: a longitudinal study. Asian Nurs Res (Korean Soc Nurs Sci) 2008;2(4):235-241 [FREE Full text] [doi: 10.1016/S1976-1317(09)60005-0] [Medline: 25029961]
52. Liang S, Wu WC. Simplified Tai Chi Chuan: 24 Postures with Applications and Standard 48 Postures. US: YMAA Publication Center; 2014.
53. Everyday TaiChi. URL: http://www.everydaytaichi.org/yang-style-24-movements-short-form1.html [accessed 2024-09-15]
54. Huang J, Wang D, Wang J. Clinical evidence of Tai Chi exercise prescriptions: a systematic review. Evid Based Complement Alternat Med 2021;2021:5558805 [FREE Full text] [doi: 10.1155/2021/5558805] [Medline: 33777155]
55. Gao S, Kaudimba KK, Cai J, Tong Y, Tian Q, Liu P, et al. A mobile phone app-based Tai Chi training in Parkinson's disease: protocol for a randomized controlled study. Front Neurol 2020;11:615861 [FREE Full text] [doi: 10.3389/fneur.2020.615861] [Medline: 33519695]
56. Tai Chi for arthritis. Tai Chi for Health Institute. 2018. URL: https://taichiforhealthinstitute.org/programs/tai-chi-for-arthritis/ [accessed 2024-07-12]
57. Patten RK, Tacey A, Pile R, Parker A, de Gori M, Tran P, et al. Digital self-management interventions for osteoarthritis: a systematic scoping review of intervention characteristics, adherence and attrition. Arch Public Health 2022;80(1):103 [FREE Full text] [doi: 10.1186/s13690-022-00854-x] [Medline: 35361270]
58. Kendall’s coefficient of concordance (W). Real Statistics Using Excel. 2023. URL: https://real-statistics.com/reliability/interrater-reliability/kendalls-w/ [accessed 2024-07-12]
59. Jahnke R, Larkey L, Rogers C, Etnier J, Lin F. A comprehensive review of health benefits of qigong and Tai Chi. Am J Health Promot 2010;24(6):e1-e25 [FREE Full text] [doi: 10.4278/ajhp.081013-LIT-248] [Medline: 20594090]
60. Li JY, Zhang YF, Smith GS, Xue CJ, Luo YN, Chen WH, et al. Quality of reporting of randomized clinical trials in Tai Chi interventions-a systematic review. Evid Based Complement Alternat Med 2011;2011:383245 [FREE Full text] [doi: 10.1093/ecam/nep022] [Medline: 19351709]
61. Wu Y, MacDonald HV, Pescatello LS. Evaluating exercise prescription and instructional methods used in Tai Chi studies aimed at improving balance in older adults: a systematic review. J Am Geriatr Soc 2016;64(10):2074-2080. [doi: 10.1111/jgs.14242] [Medline: 27550094]
62. Yang G, Sabag A, Hao W, Zhang L, Jia M, Dai N, et al. Tai Chi for health and well-being: a bibliometric analysis of published clinical studies between 2010 and 2020. Complement Ther Med 2021;60:102748 [FREE Full text] [doi: 10.1016/j.ctim.2021.102748] [Medline: 34118389]
63. Household use of information technology. Australian Bureau of Statistics. Canberra, Australia; 2018. URL: https://www.abs.gov.au/statistics/industry/technology-and-innovation/household-use-information-technology/2016-17#key-findings [accessed 2023-11-28]
64. Digital lives of younger and older Australians revealed in ACMA report. Australian Communications and Media Authority. 2021. URL: https://www.acma.gov.au/publications/2021-05/report/digital-lives-younger-and-older-australians [accessed 2023-11-28]

Abbreviations

AHEAD: Approach to Human-Centered, Evidence-Driven Adaptive Design

RCT: randomized controlled trial
REDCap: Research Electronic Data Capture

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Original Paper

Designing Telemedicine for Older Adults With Multimorbidity: Content Analysis Study

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Abstract

Background: Telemedicine is a potential option for caring for older adults with multimorbidity. There is a need to explore the perceptions about telemedicine among older adults with multimorbidity to tailor it to the needs of older adults with multiple chronic conditions.

Objective: This study aims to explore the perceptions about telemedicine among older patients with multimorbidity.

Methods: A qualitative study was conducted using semistructured interviews. The interview questions examined older adults' perspectives about telemedicine, including their expectations regarding telemedicine services and the factors that affect its use. Thematic analysis was performed using NVivo (version 12; Lumivero). The study was reported using the Standards for Reporting Qualitative Research guidelines.

Results: In total, 29 patients with multimorbidity—21 (72%) female patients and 8 (28%) male patients with a mean age of 69 (SD 10.39) years—were included. Overall, 4 themes and 7 subthemes emerged: theme 1—perceived benefit of telemedicine among older adults with multimorbidities, theme 2—appropriate use of telemedicine for multimorbid care, theme 3—telemedicine system catering to the needs of older patients, and theme 4—respect patients' decision to decline to use telemedicine.

Conclusions: Telemedicine for older adults with multimorbidity should focus on those with stable conditions. This can help increase access to care for those requiring continuous condition monitoring. A structured telemedicine program and patient-centered services can help increase patient acceptance of telemedicine. However, health care providers must accept the limitations of older patients that may prevent them from receiving telemedicine services.

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KEYWORDS

telemedicine; telehealth; chronic disease; multimorbidity; older adults; mobile phone

Introduction

Background

The COVID-19 pandemic has led to the emergence of telemedicine as a viable alternative to traditional, in-person care. Telemedicine has the potential to provide convenient medical care for patients with disabilities, transportation limitations, or busy schedules, enabling them to receive care from home [1-3]. It has become an increasingly valuable tool for delivering care to patients with multimorbidity, who require regular monitoring or adjustments to their treatment plans [4,5]. An emerging care model illustrates the integration of a patient-centered approach for individuals and chronic care model with multimorbidity. The model offers comprehensive care across various patient aspects and uses a multidisciplinary approach to address the complexity of managing multimorbidity [6]. Telemedicine can provide remote consultations and monitoring, provide patient education, and facilitate continuity of care [7,8].

In many countries, telemedicine has been promoted in the post–COVID-19 era owing to comparable health outcomes and favorable cost-effectiveness compared with in-person visits [9]. In Thailand, telehealth projects have been launched by the National Broadcasting and Telecommunication Commission of Thailand and the Thai Ministry of Public Health to improve health care services' accessibility and quality [10]. As Thailand has become an aged society, with approximately 12 million people aged ≥60 years [11], telemedicine can help improve the quality of life of older adults by promoting healthy behavior, enhancing social functioning, and reducing depressive symptoms [12,13]. Telemedicine can also improve health for older patients, who often have multimorbidity, by helping to provide continuous medical care [14].

However, the lessons learned from using telemedicine during the COVID-19 pandemic have documented challenges for both older patients and health care providers (HCPs), as it was an unfamiliar mode of treatment compared with in-person service [15]. In addition, the literature suggests that older patients may prefer in-person visits owing to the frustration caused by technological challenges when using telemedicine [16]. However, their perceptions and preferences regarding telemedicine remain poorly understood. Therefore, the needs of older patients for telemedicine should be explored [17].

Moreover, there are gaps in understanding telemedicine for those with multimorbidity [6,18]. Many studies showed the effectiveness of telemedicine, but most focused on the use of telemedicine for a single disease [19-21]. Managing patients with multimorbidity is an increasing challenge in primary care practice [22]. In multimorbidity, there are many interactions such as disease-disease, treatment-treatment, and disease-treatment, which increase the complexity of management [23,24]. The rising question is what is the appropriate use of telemedicine in caring for older patients with multimorbidity [25].

Objective

Our study aimed to explore the perceptions about telemedicine among older patients with multimorbidity. By understanding the perceptions about expectations, preferences, and barriers regarding telemedicine, the results can be used to develop telemedicine strategies to support the management of multimorbidity in the older population.

Methods

Study Design

A qualitative study of older adults with multimorbidity attending a primary care outpatient clinic at a university hospital in Thailand was conducted in 2021. The study used the Standards for Reporting Qualitative Research guidelines, which is a list of 21 items considered essential for complete, transparent reporting of qualitative research [26].

Setting and Participants

The Family Medicine Clinic at the Faculty of Medicine, Chiang Mai University, is a primary care clinic that provides general medical care for chronic diseases. Approximately 80% of all patients are older adults (aged ≥60 y) with multimorbidity. Multimorbidity was defined as the patient's illness that includes the presence of multiple diseases or conditions, often with a cutoff of ≥2 conditions [27]. The most common conditions are hypertension, type 2 diabetes mellitus, and dyslipidemia. Approximately 90% of the patients had multimorbidity. Among those attending the clinic, the rate of controlled hypertension, type 2 diabetes mellitus, and dyslipidemia between August and October 2021 were 93.7%, 70.3%, and 79.8%, respectively.

Convenience sampling was used. Patients aged ≥60 years and diagnosed with at least 2 chronic conditions who were accessible and available were invited to participate in the study. The patients needed to have stable conditions, defined as being asymptomatic and not having any urgency or emergency conditions, according to the national clinical guidelines for managing hypertension [28], type 2 diabetes mellitus [29], and dyslipidemia [30].

Telemedicine Service

Telemedicine is the use of electronic information and communication technologies to provide and support health care when distance separates the participants [31]. In 2020, the Family Medicine Clinic in Thailand started a telemedicine service in response to the COVID-19 pandemic. After the COVID-19 pandemic, our facility continues to use telemedicine for delivering care to patients with chronic conditions. By considering patient safety, patients with moderate to well-controlled chronic conditions were approached to participate in the telemedicine service for continuous care [32]. In addition, it is essential to discuss with the patients the purpose of telemedicine and to address any limitations associated with its use [33]. In addition, the objective of telemedicine as ongoing care and limitations of telemedicine need to be discussed with the patients.

The clinic had adopted a published multimorbidity assessment checklist developed to help care for patients with multimorbidity

[6]. The 20-item assessment checklist (Simple Multimorbidity Assessment Checklist for Primary Care) incorporates patient-centered concepts into managing multimorbidity in primary care settings, including assessment of the patient, review of all diseases and conditions, review of all treatments, review of clinical practice guidelines, assessment of interactions, understanding patient context and concerns, finding common ground, setting individual care plan, and continuity of care and follow-up visits. The checklist was also extended for use in the telemedicine service for assessing patients who were suitable for telemedicine and health caregiving.

The telemedicine service was provided via video or audio call, depending on the patients' available devices and abilities. Physicians could collect patients' medical histories and evaluate emergency or urgent conditions during the consultation. If any patient had conditions that required further evaluation, they were advised to come to the hospital. If patients did not require any further in-person assessment, medications were prescribed and delivered to the patient's home via post.

Ethical Considerations

This study was reviewed and approved by the institutional ethics committee of the Faculty of Medicine, Chiang Mai University, Chiang Mai, Thailand (approval number 227/2021). All participants were informed about the research study and provided consent.

Data Collection and Analysis

Semistructured interviews were conducted between September and November 2021. The interview questions (Multimedia Appendix 1) focused on older patients' perceptions about telemedicine, including their preferences regarding expectations from telemedicine services, and factors that affect its use, using the Unified Theory of Acceptance and Use of Technology framework [34]. This framework illustrates a comprehensive understanding of all the factors that affect people's intentions to use the new technology. A research assistant, not involved in providing medical care, was trained in the interview method and interview questions by WJ and NB. Each interview lasted approximately 20 minutes and was conducted on-site. Interviewed information included baseline characteristics (age, sex, educational level, employment status, and their decision regarding telemedicine services) with permission for audio recording. Then, the interviews were transcribed verbatim. Data collection and analysis were performed iteratively by researchers. Recruitment ended when data saturation of the core analytic content had been achieved. Previous literature suggested that the sample size of 9 to 17 interviewees could help to reach saturation [35]. We further determined the sample size based on a previous study investigating the crucial factors for outpatient service selection among older adults. At least 16 patients were required to achieve data saturation [36]. Therefore, we considered collecting data from at least 16 patients until we achieved data saturation in the results [37].

Each transcript was evaluated multiple times to aid familiarization and understanding of the data. Descriptive analysis was used to describe the patient's characteristics. For qualitative analysis, 2 independent researchers (NB and WJ) conducted inductive thematic analysis [38]. The preliminary results were then interpreted and discussed with KP, SP, NN, and CA. Codes were then developed based on patterns in the data. The identified codes were compared and discussed for similarities and differences until consensus was reached regarding the emergent themes and subthemes. Data analysis was performed using NVivo (version 12; Lumivero).

Results

Overview

In total, 29 older patients with multimorbidity participated. Of the 29 participants, 21 (72%) were women and 8 (28%) were men. The mean age was 71 (SD 7.17) years. The 2 most prevalent underlying diseases were dyslipidemia (27/29, 93%) and hypertension (25/29, 86%). Most patients had completed primary school (11/29, 38%) or had a bachelor's degree (10/29, 35%). Of the 29 patients, 23 (79%) were retired and 6 (21%) were self-employed. Of the 29 patients, 18 (62%) patients were interested in using telemedicine, whereas 11 (38%) patients were not interested in telemedicine and rejected telemedicine when they were offered. Patients' characteristics are summarized in Table 1.

From the semistructured interviews, 4 themes and 7 subthemes emerged. The themes and subthemes are summarized in Textbox 1.

Table 1. Patients' characteristics (N=29).

Characteristics	Values
Age (y), mean (SD)	71 (7.17)
Sex, n (%)	
Female	21 (72)
Male	8 (28)
Chronic conditions, n (%)	
Dyslipidemia	27 (93)
Hypertension	25 (86)
Type 2 diabetes mellitus	9 (31)
Others	6 (21)
Number of chronic conditions, n (%)	
2	19 (66)
3	7 (24)
4	1 (3)
5	2 (7)
Educational level, n (%)	
No education	1 (3)
Primary school	11 (38)
Secondary school	5 (17)
Vocational certificate	1 (3)
Bachelor's degree	10 (34)
Master's degree	1 (3)
Working status, n (%)	
Retired	23 (79)
Self-employed	6 (21)
Decision regarding telemedicine, n (%)	
Accept	18 (62)
Decline	11 (38)

Textbox 1. Summary of themes and subthemes.

Theme 1: perceived benefit of telemedicine among older adults with multimorbidities

- Convenient to access without the need for travel
- Minimize the risk of COVID-19 transmission

Theme 2: appropriate use of telemedicine for multimorbidity

- Telemedicine for monitoring stable conditions
- Enhancing the self-management of chronic conditions

Theme 3: telemedicine system catering to the needs of older patients

- Telemedicine services should be as similar as possible to in-person care
- Telemedicine services should adopt a clear protocol that includes in-person visits
- Supporting the development of technological skills and providing resources

Theme 4: respecting patients' decision to decline to use telemedicine for various reasons

Theme 1: Perceived Benefit of Telemedicine Among Older Patients With Multimorbidity

Overview

The benefits of telemedicine were collected from older patients. They reported the reasons why telemedicine should be used and its benefits. These include eliminating the requirement for travel and reducing the risk of contracting COVID-19.

Subtheme 1: Convenient to Access Without the Need for Travel

The most mentioned benefit of telemedicine was eliminating the need for travel. Participants mentioned that telemedicine is convenient for accessing and receiving continuity of care. It can also save time and money, such as time spent in driving and finding parking. A patient mentioned that telemedicine reduces stress from long wait times at hospitals. It also eliminates the risk of driving accidents, especially in older patients with sensory problems owing to physiologic changes. In addition, there is no burden on family members or caregivers to come and drop them at the hospital:

> *...If we compare the advantages and disadvantages, there are more advantages, as it saves both time and cost. We don't have to drive, look for parking spots, or wait in line [to meet the doctor and receive medication]. The advantages are greater.* [Participant 13; female; aged 64 years; teacher; uncontrolled hypertension and obesity]
>
> *I like it because I don't have to go to the hospital. It's convenient. If I had to give [telemedicine] a score, it would be a ten because it's convenient for me. I don't have to drive there because I'm not good at driving right now. I have to ask my husband to take me there.* [Participant 5; female; aged 72 years; housemate; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]
>
> *Because we don't have to go to the hospital anymore. They send the medication to our house. It's difficult to go to the hospital now. We have to ask our children to take us, but everyone is working. I want to receive the medication at home because I take this medication regularly.* [Participant 26; female; aged 72 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]
>
> *Sometimes, if I go to the hospital to see a doctor, I have to wait a long time, and it can be stressful. With video calls, I can talk for a long time.* [Participant 23; male; aged 76 years; retired; uncontrolled type 2 diabetes mellitus, well-controlled hypertension, and dyslipidemia]

Subtheme 2: Minimize the Risk of COVID-19 Transmission

Patients perceive telemedicine as a helpful way to reduce the risk of SARS-CoV-2 infection by avoiding contact with individuals with infection at the hospital. By not having to physically go to the hospital, there is no need to wait in crowded areas for a physician or medication after treatment, resulting in decreased rate of contact:

> *I don't have to go to places with many COVID-19 cases. My daughter also likes it because I don't have to take risks. Using telemedicine is very good for me.* [Participant 2; female; aged 72 years; self-employed; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Theme 2: Appropriate Use of Telemedicine for Multimorbidity

The participants felt that telemedicine should be used to care for patients with stable conditions in evaluating, monitoring, and providing health promotion. Participants also acknowledged the limitations of telemedicine in providing medical care, such as the inability to perform a complete physical examination or blood tests.

Subtheme 1: Telemedicine for Monitoring Stable Conditions

Patients feel confident in receiving telemedicine services when they have stable conditions because they have no abnormal symptoms, and the on-site care provided is only in the form of conversation to monitor their condition. Telemedicine services for those with stable conditions can resemble on-site care. Telemedicine services should include monitoring of clinical symptoms, vital signs, body weight, and behavioral factors. Consultation time is also required, so that patients can consult with their physician and inquire about their condition and receive follow-up care:

> *It's just like when we see a doctor at the hospital. If we meet the doctor, we ask questions like this. We can also ask online like this and see each other's faces; finding a doctor this way is good and convenient. The doctor called, and we talked. If we have any questions, we ask, and the doctor answers. It's just like going to see a doctor.* [Participant 18; female; aged 69 years; retired; well-controlled type 2 diabetes mellitus and osteoporosis]

However, some patients still believe that if they experience new or more severe symptoms, they prefer to receive treatment in an in-person setting for more detailed examinations or blood tests:

> *It's [telemedicine] comprehensive, but only if I do not have severe symptoms...However, if the patient has more severe symptoms..., it's uncertain how effective the treatment [received through telemedicine] will be.* [Participant 19; female; aged 66 years; retired; well-controlled hypertension and type 2 diabetes mellitus]
>
> *It's [telemedicine] good. Luckily, there have been no issues during this period. But if any problems arise, I still have to go see a doctor.* [Participant 15; female; aged 73 years; retired; uncontrolled type 2 diabetes mellitus and well-controlled hypertension]

Subtheme 2: Enhancing the Self-Management of Chronic Conditions

The patients perceive that they can take better care of themselves when telemedicine provides health care information specific to their health problems. Some patients suggested incorporating self-monitoring and health promotion features into the telemedicine platform. They believe in sharing self-management information with physicians to improve disease management, such as home monitoring of blood pressure and blood sugar levels. The platform could also provide specific knowledge for lifestyle modification, such as exercise videos or electronic brochures about food exchange lists. This enhances the potential for self-management:

> *I normally check and record my blood sugar and blood pressure at home. Sometimes, I forget to bring the records to the hospital. However, in telemedicine, when the doctor calls, I can inform them of my records.* [Participant 2; female; aged 72 years; self-employed; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

> *I want to know more about blood pressure. We may think it's not a big deal, but actually, it's a silent danger. The doctor said it's a scary disease, and I want information on how to take care of this disease. It would be great if there were some tips on this matter.* [Participant 14; female; aged 66 years; government employee; uncontrolled hypertension and well-controlled type 2 diabetes mellitus]

> *If there is a LINE group [chat group], I would like to receive informative messages about health. Even seniors need to read news and information related to health, such as knowledge about [COVID] vaccines.* [Participant 21; female; aged 75 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

Theme 3: Telemedicine Services Catering to the Needs of Older Patients

For an effective telemedicine service for older patients, it is crucial to address patient concerns and establish a clear management protocol based on their health status. Providing supporting resources, having good communication skills, and being aware of potential barriers arising from unfamiliarity with technology are also essential in meeting their needs.

Subtheme 1: Telemedicine Services Should Be as Similar as Possible to In-Person Care

When using telemedicine, patient concerns must still be evaluated, similar to in-person service. Some concerns may persist even after receiving telemedicine services. Presenting conditions can influence their physical or mental well-being, making it crucial for HCPs to thoroughly understand patients' illnesses to ensure appropriate management. Some patients feel that video call feels more similar to an actual on-site visit than audio calls because they can see the facial expressions and gestures of the HCPs:

> *Video calls would be better because the doctor can see the patient's face and how they feel at that moment, whether they are feeling stressed or not. With video calls, I feel closer [to the doctor] and more comfortable.... I usually don't share things within my family unless it's with the doctor. But with video calls, I feel more comfortable because I can see the doctor's face, knowing that they care about me. I just want the doctor to call me and ask what I want to share or talk about.* [Participant 1; female; aged 62 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

> *With video calls, we feel close to each other. It feels like we're still talking to each other. It's good because we can talk to the doctor about anything comfortably. I think it's a good thing because patients can express themselves fully to the doctor.* [Participant 17; male; aged 76 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

Subtheme 2: Telemedicine Services Should Adopt a Clear Protocol That Includes In-Person Visits

Patients express concerns that telemedicine might replace traditional, in-person care, leading to a lack of access to physical examinations, blood tests, and additional symptom management. They desire telemedicine to complement a comprehensive multimorbidity management program while still having the option to see physicians in person at the hospital:

> *Sometimes I want to meet with the doctor in-person to talk directly or ask questions. The doctor can know my symptoms if I communicate directly. If I say that it hurts here or it is swollen here, the doctor can touch it and examine it for evaluation. This is the basic step of diagnosing symptoms. I mean, I want to meet the doctor sometimes, but not frequently. It's not like I don't see the doctor for a year. I just want to see the doctor once or twice to feel reassured.* [Participant 16; female; aged 74 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

The support system of telemedicine services was crucial for patients' decision-making regarding whether to accept or decline the service. Most patients are willing to accept telemedicine owing to clear operational systems, including appointment scheduling, notifications, web-based payment, and medication delivery. However, some patients still have doubts about payment systems and medication delivery. In addition, patients receiving telephone-based care may have uncertainties about the authenticity of the HCP:

> *After a case manager added me on LINE [application], they gave me an appointment for a video call. A day before the appointment, a nurse called me and said the doctor would have a video call tomorrow. When the appointment arrived, they would call me and ask if it was convenient for the doctor to have a video call now. I answered that it was. Then, the doctor called me. It was a very good process.* [Participant 15; female; aged 73 years; retired;

> uncontrolled type 2 diabetes mellitus and well-controlled hypertension]

> *It's possible to send the appointment time through LINE in advance; for example, if the doctor would come in the afternoon, someone would call in the morning to inform. The doctor could then ask about the symptoms very well. It was done quickly, in just a moment.* [Participant 21; female; aged 75 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

> *I asked about the cost of the medicine that sent text information by phone because I couldn't contact the finance department. It's very difficult.* [Participant 18; female; aged 69 years; retired; well-controlled type 2 diabetes mellitus and osteoporosis]

> *I don't know if they are doctors or not. To be honest, I don't know who is calling me. But if it's a video call, I can be more confident.* [Participant 13; female; aged 64 years; teacher; uncontrolled hypertension and obesity]

Subtheme 3: Supporting the Development of Technological Skills and Providing Resources

Most participants had limited technological skills and relied on their children to assist in using electronic telemedicine devices. Only a small minority were proficient in using such devices, with some preferring mobile phone calls over video calls owing to incompatible smartphones or unfamiliarity with more complex devices such as tablets or PCs. However, some older individuals expressed willingness to learn with proper support:

> *If necessary, I need to adapt. I have to learn to use additional equipment because I don't usually have a smartphone, so it might be difficult to learn. I can't even turn it on.* [Participant 9; female; aged 78 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

> *If it's time for telemedicine, I have to try to adapt and learn gradually.* [Participant 10; female; aged 71 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Theme 4: Respecting Patients' Decision to Decline to Use Telemedicine for Various Reasons

Older patients often reject telemedicine owing to various obstacles. They face challenges related to age-related physiological changes, including forgetfulness and cognitive difficulties such as finding phones or using video calls despite instructions. In addition, some patients do not regularly use electronic devices, whereas others feel burdensome relying on their children for telemedicine assistance. A few patients are unable to receive telemedicine service owing to their routine work commitments. Therefore, HCPs need to understand these obstacles and respect their decisions for declining telemedicine:

> *I don't want to use telemedicine. It's not difficult for me to see a doctor in person. If you teach me something, I will forget in three months. For example, when I wanted to take a video, my grandchild had to teach me ten times, but when I got home, I couldn't remember. My memory has not been good for a few years.* [Participant 12; male; aged 68 years; self-employed; well-controlled hypertension and type 2 diabetes mellitus]

> *Sometimes I am not with my phone. Like when I went to a restaurant, I forgot my phone there and didn't realize it for three days. I think it's a problem related to age, but if I were newly retired at 60-65 years old, I would be fine. But now that I'm nearly 80, I have problems, especially with memory and internet use.* [Participant 23; male; aged 76 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

> *If my child can help, that would be great. I need my child to be here because I don't know much. I'm forgetful, but I don't know if my child is available to help or not. I can't do it if I'm alone because I have to care for two other older people who are 90 years old. It's not easy for me because I have to take care of others as well.* [Participant 4; female; aged 63 years; retired; uncontrolled type 2 diabetes mellitus, well-controlled hypertension, and dyslipidemia]

> *I can participate, but I'm not familiar with it. I'm old and have never used LINE [chat application] before. Trying to learn it now may be difficult because my memory is not very good, and I tend to forget things easily. Although my grandchildren have computers and mobile phones, I don't want to bother them because they have to work all the time. If the doctor needs to call me, I have to ask my children. I don't know if they're available to answer or not.* [Participant 8; female; aged 71 years; retired; uncontrolled type 2 diabetes mellitus and well-controlled dyslipidemia]

Discussion

Principal Findings

Summary

In this qualitative study, participants perceived telemedicine as beneficial because it eliminates the need for travel and minimizes the risk of COVID-19 transmission. Older adults view telemedicine as a safe and effective way to manage stable chronic conditions. It is recommended to include health promotion in telemedicine services to enhance self-management. Regarding catering to older patients' needs, patients expressed that telemedicine should be presented as part of a continuous care program for multimorbidity, incorporating web-based monitoring with periodic in-person visits for physical examinations and laboratory screenings. Clear instructions, technological skills training, and access to resources such as equipment and caregivers are essential to make the program user-friendly for older patients. However, HCP should respect patients' decision to decline telemedicine owing to various obstacles that older patients may face when using it.

Patients accepted telemedicine as an effective method to improve access to health care for older patients. Some older patients face difficulties when coming to hospitals, such as finding transportation and parking space, long waits for the physician, and long queues for receiving medication [16,36]. This is in accordance with the literature that positive perceptions about telemedicine include cost savings [39]. During the COVID-19 pandemic, receiving treatment through telemedicine services also helped to reduce the risk of infection transmission by reducing the risk of overcrowding of patients and the risk of exposure for those who may not need to come to the hospital [40]. Telemedicine would be a necessary solution for addressing problems regarding access to care in the event of new pandemics.

Several studies have shown that telemedicine can effectively improve the health care outcomes of older patients, particularly those with chronic conditions such as diabetes [19], heart disease [20], and asthma [21]. A study found that telemedicine consultations reduced hospitalization rates among older patients with chronic heart failure compared with standard care [41]. Another study found that telemedicine consultations for older patients with chronic obstructive pulmonary disease improved symptom control and quality of life and reduced hospitalization rates [42]. There is evidence supporting that telemedicine services have the potential to enhance self-management among patients and their families, including improving medication adherence among older patients with chronic conditions and improving disease control and patient satisfaction [43,44].

Older patients, who often have >1 chronic condition, constitute a key group who use the health systems [45]. Owing to the situation in Thailand, it will be a superaged society in the next few decades [46]. The older adults would be the main target for health care delivery. There are potential opportunities in digital health such as telemedicine, emphasizing the management of chronic diseases in Thailand [47]. Cost-effectiveness was also another reason in the long run for telemedicine compared with an in-person visit [4,48]. On the basis of patients' perceptions obtained from our study and previous evidence supporting the health outcomes of telemedicine, we have the following 4 suggestions for enhancing telemedicine services tailored to the needs of older patients with multimorbidity.

Identify the Target Population as Individuals With Stable Chronic Conditions

Our study found that telemedicine is an accepted model for promoting continuous care for older patients with multimorbidity. In cases where patients have well-controlled chronic conditions and no abnormal symptoms, they can receive symptom monitoring and treatment through telemedicine [49]. Health care services for older patients with stable chronic diseases may not need to differ between telemedicine and in-person visits. The services should aim to monitor patients with stable conditions by regularly inquiring about their symptoms; offering self-care instructions at home (such as measuring blood pressure and blood sugar levels); and encouraging healthy behaviors such as medication adherence, maintaining a proper diet, and engaging in regular exercise. Telemedicine has the potential to replace nonurgent in-person medical visits for stable chronic diseases, as it can be used for symptom monitoring, detecting complications or disease progression, and prescribing medication delivery for stable chronic conditions [7,50].

Telemedicine Services Should Be Designed to Closely Resemble In-Person Visits With Scheduled Periodic In-Person Visits

Patients expressed concerns regarding the quality of care and maintaining the physician-patient relationship received through telemedicine. A previous study revealed that older patients perceived in-person visits as fostering a strong physician-patient relationship compared with telemedicine [16]. To address these concerns, telemedicine services should strive to deliver care that closely resembles an in-person visit in terms of the process and pattern of care. Telemedicine using video calls closely simulates an in-person visit over phone calls. It helps reduce medication errors, enhances diagnostic accuracy, and improves decision-making accuracy [51]. Telemedicine holds the potential to facilitate shared decision-making between patients and HCPs, thus promoting a patient-centered approach to care [52]. HCPs can also leverage telemedicine to provide education, promote behavior change, empower patients to take control of their health, boost their confidence, and ensure continuity of care [53].

Nevertheless, it is important to acknowledge the limitations of telemedicine. It is unable to perform comprehensive physical examinations and detailed laboratory tests, which means that it cannot fully replace in-person visits. Hence, it is crucial to integrate regular in-person visits with a physician at a hospital to adhere to standard medical practices. These in-person visits can be scheduled periodically on an annual basis, which can help instill confidence and satisfaction with the telemedicine services [54].

Integrated Support Systems for Telemedicine, Including Clear Protocols, Caregiver Assistance, and Electronic Health Literacy Training

When caring for older patients with multimorbidity through telemedicine, it is essential to establish a program that adheres to standard practices, incorporates clear protocols, and provides the necessary technical skills and resources. This will help ensure that telemedicine remains as a viable option beyond the COVID-19 pandemic, emphasizing ease of use and demonstrating its benefits. A well-defined service program enables patients to understand the process of care they will receive and empowers them to communicate their specific health needs [55]. In addition, telemedicine services for older adults may require assistance at various stages, including guidance for using tools such as smartphones, instruction for use, and involving caregivers in the process [56]. These supports could contribute to a smooth and more effective telemedicine experience for older patients and their caregivers.

Develop Alternative Services for Older Adults Who Cannot Use Telemedicine

Despite the potential benefits of telemedicine for the care of older adults, its use has some challenges and limitations. Some older patients may face various obstacles in using telemedicine, such as declining vision, hearing, and memory owing to aging; difficulty in learning new skills; unfamiliarity with technology; and feeling burdened to ask for support, which can lead to rejecting telemedicine services [56]. In addition, telemedicine is unsuitable for unstable patients requiring emergent management and detailed physical examinations that cannot be conducted remotely [57]. Some specific clinical contexts or onset of new symptom in multimorbidity, such as hemiparesis, require a comprehensive examination for critical diagnostic accuracy and severity evaluation. If possible, an in-person visit would be more appropriate [58]. Thus, in-person visits or other alternatives should be available [7].

Strengths and Limitations

The study has several strengths and limitations. The strength of this study lies in its structured approach to gathering insights about various aspects of telemedicine service tailored to the need of older adults with multiple chronic conditions. The study results can provide valuable guidance about preparing and delivering telemedicine services for this population. However, there are still some limitations to be considered. First, participants were recruited from a single health care facility. The results may be affected by the nature of the health care system and the educational level and digital literacy level of the population. Further studies from different settings and regions are needed to tailor telemedicine services to the needs of older adults with multimorbidity. In addition, future studies could explore more experiences of HCPs providing telemedicine services to this population and identify strategies to address their challenges and concerns. Next, we did not include uncontrolled conditions in this study, and we did not include health care professionals. Further studies may include other telemedicine users. Another consideration point that could influence the results of this study is gender. Gender is associated with differences in digital health care behavior and plays a role in the adoption of health technologies. For example, women exhibit high tendency to access health care services, book physician’s appointments, and search for nutrition-related information. In contrast, men are more likely to explore options related to smoking cessation and use health apps for monitoring sleep patterns and blood pressure than women [59].

As there are various guidelines for telemedicine management, the platform used depends on the facility in each hospital setting. Having many telemedicine providers may disrupt the continuity of care owing to regulation and personal data protection [60]. Furthermore, there remains an inequity in access to care in telemedicine for vulnerable population, such as older people. A strategy to promote electronic health education and provide the necessary equipment to ensure telemedicine equity is needed [61]. Therefore, the use of telemedicine should be tailored depending on the setting and needs of the population and health system.

To ensure the sustainability of telemedicine for older patients with multimorbidity, HCPs should consider patients’ needs, expectations, and abilities when designing telemedicine systems. Importantly, the findings also suggest that HCPs should respect the decision of older patients who decline to use telemedicine owing to multiple obstacles and find alternative ways.

Conclusions

The study highlights the importance of personalized and patient-centered care [62], where providers should understand older adults’ needs, preferences, and limitations to tailor telemedicine services for the population. The use of telemedicine for older patients with multimorbidity should focus on those with stable conditions. For this population, telemedicine can help increase access to medical services for patients who require continuous monitoring and care. A structured program incorporating periodic in-hospital visits can help increase patient acceptance of telemedicine. However, HCPs must also understand the limitations of older patients owing to various factors that may prevent them from receiving telemedicine services.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview questions.
[DOCX File , 13 KB - aging_v7i1e52031_app1.docx]

References

1. Nelson R. Telemedicine and telehealth: the potential to improve rural access to care. Am J Nurs 2017;117(6). [doi: 10.1097/01.naj.0000520244.60138.1c]

2. Angelopoulou E, Papachristou N, Bougea A, Stanitsa E, Kontaxopoulou D, Fragkiadaki S, et al. How telemedicine can improve the quality of care for patients with Alzheimer's disease and related dementias? A narrative review. Medicina (Kaunas) 2022 Nov 22;58(12):1705 [FREE Full text] [doi: 10.3390/medicina58121705] [Medline: 36556907]
3. Batsis JA, DiMilia PR, Seo LM, Fortuna KL, Kennedy MA, Blunt HB, et al. Effectiveness of ambulatory telemedicine care in older adults: a systematic review. J Am Geriatr Soc 2019 Aug;67(8):1737-1749 [FREE Full text] [doi: 10.1111/jgs.15959] [Medline: 31066916]
4. Haleem A, Javaid M, Singh RP, Suman R. Telemedicine for healthcare: capabilities, features, barriers, and applications. Sens Int 2021;2:100117 [FREE Full text] [doi: 10.1016/j.sintl.2021.100117] [Medline: 34806053]
5. Smith SM, Wallace E, O'Dowd T, Fortin M. Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. Cochrane Database Syst Rev 2016 Mar 14;3(3):CD006560 [FREE Full text] [doi: 10.1002/14651858.CD006560.pub3] [Medline: 26976529]
6. Aramrat C, Choksomngam Y, Jiraporncharoen W, Wiwatkunupakarn N, Pinyopornpanish K, Mallinson PA, et al. Advancing multimorbidity management in primary care: a narrative review. Prim Health Care Res Dev 2022 Jul 01;23:e36 [FREE Full text] [doi: 10.1017/S1463423622000238] [Medline: 35775363]
7. Monaco A, Palmer K, Holm Ravn Faber N, Kohler I, Silva M, Vatland A, et al. Digital health tools for managing noncommunicable diseases during and after the COVID-19 pandemic: perspectives of patients and caregivers. J Med Internet Res 2021 Jan 29;23(1):e25652 [FREE Full text] [doi: 10.2196/25652] [Medline: 33464206]
8. Monaco A, Maggi S, De Cola P, Hassan TA, Palmer K, Donde S. Information and communication technology for increasing healthy ageing in people with non-communicable diseases: identifying challenges and further areas for development. Aging Clin Exp Res 2019 Nov;31(11):1689-1693 [FREE Full text] [doi: 10.1007/s40520-019-01258-8] [Medline: 31317518]
9. Shaver J. The state of telehealth before and after the COVID-19 pandemic. Prim Care 2022 Dec;49(4):517-530 [FREE Full text] [doi: 10.1016/j.pop.2022.04.002] [Medline: 36357058]
10. Thanakijsombat T, Bhatiasevi V, Suwanposri C. Public adoption of telehealth technology in Thailand. J Glob Bus Rev 2022 Jan;24(1):24-33 [FREE Full text]
11. Statistics of the elderly population in 77 provinces of Thailand as of December 31, 2022. Department, of, Older, Persons. 2022. URL: https://www.dop.go.th/th/know/side/1/1/1766 [accessed 2023-12-11]
12. Maresca G, De Cola MC, Caliri S, De Luca R, Manuli A, Scarcella I, Sicilian Teleneurology Group. Moving towards novel multidisciplinary approaches for improving elderly quality of life: the emerging role of telemedicine in Sicily. J Telemed Telecare 2019 Jun;25(5):318-324. [doi: 10.1177/1357633X17753057] [Medline: 29409381]
13. Bakas T, Sampsel D, Israel J, Chamnikar A, Bodnarik B, Clark JG, et al. Using telehealth to optimize healthy independent living for older adults: a feasibility study. Geriatr Nurs 2018;39(5):566-573 [FREE Full text] [doi: 10.1016/j.gerinurse.2018.04.002] [Medline: 29804689]
14. Lee ES, Lee PS, Chew EA, Muthulingam G, Koh HL, Tan SY, et al. Video consultations for older adults with multimorbidity during the COVID-19 pandemic: protocol for an exploratory qualitative study. JMIR Res Protoc 2020 Oct 26;9(10):e22679 [FREE Full text] [doi: 10.2196/22679] [Medline: 33027034]
15. Ftouni R, AlJardali B, Hamdanieh M, Ftouni L, Salem N. Challenges of telemedicine during the COVID-19 pandemic: a systematic review. BMC Med Inform Decis Mak 2022 Aug 03;22(1):207 [FREE Full text] [doi: 10.1186/s12911-022-01952-0] [Medline: 35922817]
16. Bhatia R, Gilliam E, Aliberti G, Pinheiro A, Karamourtopoulos M, Davis RB, et al. Older adults' perspectives on primary care telemedicine during the COVID-19 pandemic. J Am Geriatr Soc 2022 Dec;70(12):3480-3492 [FREE Full text] [doi: 10.1111/jgs.18035] [Medline: 36169152]
17. van den Berg N, Schumann M, Kraft K, Hoffmann W. Telemedicine and telecare for older patients--a systematic review. Maturitas 2012 Oct;73(2):94-114. [doi: 10.1016/j.maturitas.2012.06.010] [Medline: 22809497]
18. Wiwatkunupakarn N, Aramrat C, Pliannuom S, Buawangpong N, Pinyopornpanish K, Nantsupawat N, et al. The integration of clinical decision support systems into telemedicine for patients with multimorbidity in primary care settings: scoping review. J Med Internet Res 2023 Jun 28;25:e45944 [FREE Full text] [doi: 10.2196/45944] [Medline: 37379066]
19. von Storch K, Graaf E, Wunderlich M, Rietz C, Polidori MC, Woopen C. Telemedicine-assisted self-management program for type 2 diabetes patients. Diabetes Technol Ther 2019 Sep;21(9):514-521. [doi: 10.1089/dia.2019.0056] [Medline: 31287736]
20. Alvarez P, Sianis A, Brown J, Ali A, Briasoulis A. Chronic disease management in heart failure: focus on telemedicine and remote monitoring. Rev Cardiovasc Med 2021 Jun 30;22(2):403-413 [FREE Full text] [doi: 10.31083/j.rcm2202046] [Medline: 34258907]
21. Persaud YK. Using telemedicine to care for the asthma patient. Curr Allergy Asthma Rep 2022 Apr;22(4):43-52 [FREE Full text] [doi: 10.1007/s11882-022-01030-5] [Medline: 35107807]
22. Liddy C, Blazkho V, Mill K. Challenges of self-management when living with multiple chronic conditions: systematic review of the qualitative literature. Can Fam Physician 2014 Dec;60(12):1123-1133 [FREE Full text] [Medline: 25642490]
23. Prados-Torres A, Poblador-Plou B, Calderón-Larrañaga A, Gimeno-Feliu LA, González-Rubio F, Poncel-Falcó A, et al. Multimorbidity patterns in primary care: interactions among chronic diseases using factor analysis. PLoS One 2012;7(2):e32190 [FREE Full text] [doi: 10.1371/journal.pone.0032190] [Medline: 22393389]

24. Marengoni A, Onder G. Guidelines, polypharmacy, and drug-drug interactions in patients with multimorbidity. BMJ 2015 Mar 11;350:h1059. [doi: 10.1136/bmj.h1059] [Medline: 25761379]
25. Kraef C, van der Meirschen M, Free C. Digital telemedicine interventions for patients with multimorbidity: a systematic review and meta-analysis. BMJ Open 2020 Oct 13;10(10):e036904 [FREE Full text] [doi: 10.1136/bmjopen-2020-036904] [Medline: 33051232]
26. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014 Sep;89(9):1245-1251 [FREE Full text] [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
27. Johnston MC, Crilly M, Black C, Prescott GJ, Mercer SW. Defining and measuring multimorbidity: a systematic review of systematic reviews. Eur J Public Health 2019 Feb 01;29(1):182-189. [doi: 10.1093/eurpub/cky098] [Medline: 29878097]
28. Thai guidelines on the treatment of hypertension. Thai Hypertension Society. 2019. URL: http://www.thaiheart.org/images/column_1563846428/Thai%20HT%20Guideline%202019.pdf [accessed 2023-12-11]
29. Diabetes Association of Thailand. Clinical Practice Guidelines for Diabetes 2017. HuayKwang, Thailand: Diabetes Association of Thailand; 2017.
30. Thai Atherosclerosis Society. Clinical Practice Guideline on Pharmacologic Therapy of Dyslipidemia for Atherosclerotic Cardiovascular Disease Prevention. Bangkok, Thailand: The Royal College of Physicians of Thailand (RCPT); 2016.
31. Institute, of, Medicine, (US), Committee, on. Telemedicine: A Guide to Assessing Telecommunications in Health Care. Washington, DC: National Academies Press (US); 1996:A.
32. Wakimizu R, Kuroki H, Ohbayashi K, Ohashi H, Yamaoka K, Sonoda A, et al. Perceptions and attitudes toward telemedicine by clinicians and patients in Japan during the COVID-19 pandemic. Telemed Rep 2021 Jul 01;2(1):197-204 [FREE Full text] [doi: 10.1089/tmr.2021.0012] [Medline: 35720764]
33. Galpin K, Sikka N, King SL, Horvath KA, Shipman SA, AAMC Telehealth Advisory Committee. Expert consensus: telehealth skills for health care professionals. Telemed J E Health 2021 Jul;27(7):820-824. [doi: 10.1089/tmj.2020.0420] [Medline: 33236964]
34. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Q 2003 Sep;27(3):425-478 [FREE Full text] [doi: 10.2307/30036540]
35. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. Soc Sci Med 2022 Jan;292:114523 [FREE Full text] [doi: 10.1016/j.socscimed.2021.114523] [Medline: 34785096]
36. Shih CI, Weng CC, Chen W, Yang HF, Fan SY. Consideration factors of older adults seeking medical treatment at outpatient services in Taiwan. BMC Health Serv Res 2021 Nov 09;21(1):1216 [FREE Full text] [doi: 10.1186/s12913-021-07251-0] [Medline: 34753473]
37. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 2018;52(4):1893-1907 [FREE Full text] [doi: 10.1007/s11135-017-0574-8] [Medline: 29937585]
38. Bernard HR. Research Methods in Anthropology: Qualitative and Quantitative Approaches. Lanham, MD: Rowman & Littlefield Publishers; 2011.
39. Alanazi AT, Al Hader B. Telemedicine patient satisfaction and cost: a comparative study in the COVID-19 era. Cureus 2022 Oct;14(10):e30671 [FREE Full text] [doi: 10.7759/cureus.30671] [Medline: 36426312]
40. Monaghesh E, Hajizadeh A. The role of telehealth during COVID-19 outbreak: a systematic review based on current evidence. BMC Public Health 2020 Aug 01;20(1):1193 [FREE Full text] [doi: 10.1186/s12889-020-09301-4] [Medline: 32738884]
41. Anker SD, Koehler F, Abraham WT. Telemedicine and remote management of patients with heart failure. Lancet 2011 Aug 20;378(9792):731-739. [doi: 10.1016/S0140-6736(11)61229-4] [Medline: 21856487]
42. Tupper OD, Gregersen TL, Ringbaek T, Brøndum E, Frausing E, Green A, et al. Effect of tele-health care on quality of life in patients with severe COPD: a randomized clinical trial. Int J Chron Obstruct Pulmon Dis 2018 Aug 29;13:2657-2662 [FREE Full text] [doi: 10.2147/COPD.S164121] [Medline: 30214183]
43. Hanlon P, Daines L, Campbell C, McKinstry B, Weller D, Pinnock H. Telehealth interventions to support self-management of long-term conditions: a systematic metareview of diabetes, heart failure, asthma, chronic obstructive pulmonary disease, and cancer. J Med Internet Res 2017 May 17;19(5):e172 [FREE Full text] [doi: 10.2196/jmir.6688] [Medline: 28526671]
44. Ma Y, Zhao C, Zhao Y, Lu J, Jiang H, Cao Y, et al. Telemedicine application in patients with chronic disease: a systematic review and meta-analysis. BMC Med Inform Decis Mak 2022 Apr 19;22(1):105 [FREE Full text] [doi: 10.1186/s12911-022-01845-2] [Medline: 35440082]
45. Lan YL, Chen HC. Telehealth care system for chronic disease management of middle-aged and older adults in remote areas. Health Informatics J 2022 Nov 29;28(4):14604582221141835 [FREE Full text] [doi: 10.1177/14604582221141835] [Medline: 36447304]
46. Thailand’s leadership and innovations towards healthy ageing. World Health Organization. 2023 Feb 09. URL: https://www.who.int/southeastasia/news/feature-stories/detail/thailands-leadership-and-innovation-towards-healthy-ageing [accessed 2023-12-11]

47. Rojanasumapong A, Jiraporncharoen W, Nantsupawat N, Gilder ME, Angkurawaranon C, Pinyopornpanish K. Internet use, electronic health literacy, and hypertension control among the elderly at an urban primary care center in Thailand: a cross-sectional study. Int J Environ Res Public Health 2021 Sep 11;18(18):9574 [FREE Full text] [doi: 10.3390/ijerph18189574] [Medline: 34574499]
48. Salsabilla A, Azzahra AB, Syafitri RI, Supadmi W, Suwantika AA. Cost-effectiveness of telemedicine in Asia: a scoping review. J Multidiscip Healthc 2021 Dec 29;14:3587-3596 [FREE Full text] [doi: 10.2147/JMDH.S332579] [Medline: 35002248]
49. Corbett JA, Opladen JM, Bisognano JD. Telemedicine can revolutionize the treatment of chronic disease. Int J Cardiol Hypertens 2020 Dec;7:100051 [FREE Full text] [doi: 10.1016/j.ijchy.2020.100051] [Medline: 33330846]
50. Omboni S, McManus RJ, Bosworth HB, Chappell LC, Green BB, Kario K, et al. Evidence and recommendations on the use of telemedicine for the management of arterial hypertension: an international expert position paper. Hypertension 2020 Nov;76(5):1368-1383. [doi: 10.1161/HYPERTENSIONAHA.120.15873] [Medline: 32921195]
51. Rush KL, Howlett L, Munro A, Burton L. Videoconference compared to telephone in healthcare delivery: a systematic review. Int J Med Inform 2018 Oct;118:44-53. [doi: 10.1016/j.ijmedinf.2018.07.007] [Medline: 30153920]
52. Hartasanchez SA, Heen AF, Kunneman M, García-Bautista A, Hargraves IG, Prokop LJ, et al. Remote shared decision making through telemedicine: a systematic review of the literature. Patient Educ Couns 2022 Feb;105(2):356-365. [doi: 10.1016/j.pec.2021.06.012] [Medline: 34147314]
53. Po YM. Telemedicine to improve patients' self-efficacy in managing diabetes. J Telemed Telecare 2000;6(5):263-267. [doi: 10.1258/1357633001935888] [Medline: 11070586]
54. Altinisik Ergur G, Nuhoglu S, Cobanoglu C, Sengul M, Eryildiz N, Ergur A. The patient perspective of telemedicine in the context of COVID-19 pandemic. Bull Sci Technol Soc 2022 Apr 12;42(1-2):39-53 [FREE Full text] [doi: 10.1177/02704676221094735]
55. Asbach P, Nerlich M. A telemedicine guideline for the practice of teleconsultation. Stud Health Technol Inform 2003;97:1-14. [Medline: 15537225]
56. Elbeddini A, Prabaharan T, Almasalkhi S, Tran C, Zhou Y. Barriers to conducting deprescribing in the elderly population amid the COVID-19 pandemic. Res Social Adm Pharm 2021 Jan;17(1):1942-1945 [FREE Full text] [doi: 10.1016/j.sapharm.2020.05.025] [Medline: 32499161]
57. Lin Z, Sim TB, Ong VY, Bin Ab Hamid Z, Ho WH. Telemedicine in the acute care setting during the COVID-19 pandemic. Intern Emerg Med 2020 Nov;15(8):1591-1593 [FREE Full text] [doi: 10.1007/s11739-020-02456-3] [Medline: 32748127]
58. Willis JS, Tyler Jr C, Schiff GD, Schreiner K. Ensuring primary care diagnostic quality in the era of telemedicine. Am J Med 2021 Sep;134(9):1101-1103 [FREE Full text] [doi: 10.1016/j.amjmed.2021.04.027] [Medline: 34051151]
59. Haluza D, Wernhart A. Does gender matter? Exploring perceptions regarding health technologies among employees and students at a medical university. Int J Med Inform 2019 Oct;130:103948. [doi: 10.1016/j.ijmedinf.2019.08.008] [Medline: 31442846]
60. Gajarawala SN, Pelkowski JN. Telehealth benefits and barriers. J Nurse Pract 2021 Feb;17(2):218-221 [FREE Full text] [doi: 10.1016/j.nurpra.2020.09.013] [Medline: 33106751]
61. Williams C, Shang D. Telehealth for chronic disease management among vulnerable populations. J Racial Ethn Health Disparities (Forthcoming) 2023 Apr 13:1-8 [FREE Full text] [doi: 10.1007/s40615-023-01588-4] [Medline: 37052797]
62. Record JD, Ziegelstein RC, Christmas C, Rand CS, Hanyok LA. Delivering personalized care at a distance: how telemedicine can foster getting to know the patient as a person. J Pers Med 2021 Feb 17;11(2) [FREE Full text] [doi: 10.3390/jpm11020137] [Medline: 33671324]

Abbreviations

HCP: health care provider

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Internet-Based Social Activities and Cognitive Functioning 2 Years Later Among Middle-Aged and Older Adults: Prospective Cohort Study

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Abstract

Background: A number of studies document the benefits of face-to-face social interactions for cognitive functioning among middle-aged and older adults. Social activities in virtual worlds may confer similar if not enhanced cognitive benefits as face-to-face social activities, given that virtual interactions require the additional cognitive tasks of learning and navigating communicative tools and technology platforms. Yet, few studies have examined whether social activities in internet-based settings may have synergistic effects on cognitive functioning beyond those of face-to-face interactions.

Objective: This study examined whether internet-based social activity participation is associated with concurrent and later cognitive functioning, after adjusting for face-to-face social activity participation and sociodemographic covariates.

Methods: For cross-sectional analyses, we included 3650 adults aged 50 years and older who completed questions in the 2020 Health and Retirement Study about social activity participation, including specific internet-based social activities such as emailing or accessing social networks. Cognitive functioning was measured using the standardized cognitive tasks assessing working memory, episodic memory, and attention and processing speed. The longitudinal analyses included the 2034 participants who also completed follow-up cognitive assessments in 2022.

Results: Our results revealed that those with higher levels of internet-based social activity participation had higher levels of concurrent cognitive functioning than those with low levels of internet-based social activity participation, after adjusting for demographic and health-related factors and face-to-face social activity participation (b=0.44, SE 0.07; P<.001). More internet-based social activity participation also predicted better cognitive functioning 2 years later, even when adjusting for baseline cognitive functioning and other covariates (b=0.35, SE 0.09; P<.001).

Conclusions: Our findings suggest that greater engagement in internet-based social activities is associated with higher levels of concurrent cognitive functioning and slower cognitive decline in middle-aged and older adults.

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KEYWORDS

online social interaction; cognitive health; age differences; Health and Retirement Study; social activity; internet use; isolation

Introduction

Social activity participation is strongly tied to multiple aspects of health and well-being in later life, including psychological well-being, depressive symptoms, physical health and functional limitations, and cognitive health [1-5]. Emerging research focusing on the cognitive benefits of social activity participation documents different aspects of social activity participation that are related to cognitive functioning, such as frequency (how often an individual engages in social activities) and variety (how many different types of activities an individual engages in social activities) [6]. For example, those who participate in social activities more frequently are likely to have enhanced concurrent cognitive functioning, slower age-related cognitive decline, and reduced dementia risk [7,8]. In addition to frequency of engagement, those who engage in a greater number of social activities show better later cognitive functioning than their socially inactive peers [6]. These social activities increasingly involve virtual interactions such as texting, video chats, or the use of other social media to stay connected [9]. Nevertheless, most research has focused predominantly on the benefits of face-to-face social activity participation on cognitive functioning [8]. This study investigated how engagement in a variety of internet-based social activities relates to cognitive functioning, especially for adults aged 50 years and above.

Communicating with others in virtual worlds can offer similar cognitive health benefits as face-to-face social activities [10]. For example, internet-based social activities such as posting status updates or liking others’ updates on Facebook are associated with high levels of cognitive functioning in adults aged over 55 years [11]. Emailing and texting, also forms of internet-based social connection, are related to a lower likelihood of cognitive impairment over 5 years in adults aged over 65 years [12]. Beyond engaging in any internet-based social activities, engagement in different types of internet-based social activities may also have cognitive benefits.

A variety of internet-based social activities may provide greater opportunities to learn novel information than engaging in fewer activities; moreover, it is related to greater hippocampal volume [13]. Novel information is also related to hippocampal neurogenesis and reduced age-related neural apoptosis, which are associated with cognitive functioning that relies on more than a single source of communication [14,15]. In addition, individuals can also share thoughts or feelings in a variety of virtual communities [16], which engage cognitive processes such as problem-solving and perspective-taking [17].

Unique aspects of internet-based social activities may boost the cognitive benefits of engaging in a variety of such activities. First, different types of internet-based social activities may require the use of various interactive tools such as internet searching or instant messaging. These different techniques and activities may be cognitively stimulating because they involve learning and memory [18]. Even simple internet searches are a neural exercise for middle-aged and older adults, activating multiple brain regions related to decision-making and complex reasoning [19]. Furthermore, content acquired through internet-based social activities is delivered in multiple formats such as sound, pictures, or videos [20]. Studies have demonstrated that the simultaneous presentation of information in visual and auditory modalities is associated with enhanced learning performance [21]. Moreover, each internet-based social activity may have its own function, offering an array of uses. For example, blogs or Facebook are used for information sharing, while Snapchat or Instagram is used for self-expression and self-documentation [22-24]. These findings about the use of different modalities and functions across various platforms suggest that internet-based social activity participation may be associated with better cognitive functioning.

Internet-based social activities may also benefit specific cognitive domains. Although research on the association between internet-based social activity participation and subdomains of cognitive functioning is still emerging, some studies provide initial evidence that benefits may particularly be related to memory. For example, internet use is linked to improved episodic memory, potentially through increased social contact [25]. Concurrent engagement in offline and internet-based social activities is also related to high levels of episodic memory [26]. This may be explained by people recalling previous social interactions and past experiences as well as by the processing and storing of new information, all of which are linked to episodic memory [27,28]. On the other hand, the relationship between internet-based social activity participation and executive functioning is more complex, as executive functioning encompasses a broad range of cognitive control processes such as reasoning, problem-solving, and attentional control [29]. Some studies suggest that learning to engage in internet-based social activities on laptop applications can enhance inhibition, but its relationship with working memory and attention and processing speed is less consistent [30]. Facebook users also exhibit higher scores in attention or inhibition, but not in working memory, than nonusers [11].

Studying technology use in the social domain for older adults may be particularly relevant because people are increasingly motivated to use technology for social motives as they age. According to socioemotional selectivity theory [31], people increasingly prioritize socioemotional goals with age. As a result, people are even more motivated to connect with others such as friends or grandchildren as they grow older, and thus, they are more likely to engage in internet-based platforms for socioemotional goals as opposed to nonsocial goals. While young adults may engage in internet-based social activities for various purposes such as self-representation or entertainment, older adults may be more motivated to engage in the virtual world for social reasons, such as maintaining interactions with their family, friends, or their community and receiving social support [32,33], which can be related to cognitive functioning [34].

For the aforementioned reasons, this study examined whether engagement in diverse internet-based social activities is positively related to concurrent and later cognitive functioning in middle-aged and older US adults beyond face-to-face social activities and whether this relationship varies by age. We hypothesized that internet-based social activity participation would be associated with high levels of concurrent cognitive functioning and slow cognitive decline across time, particularly in episodic memory. We also hypothesized that the relationship between internet-based social activity participation and cognitive functioning would be more pronounced in older adults. Data are from the Health and Retirement Study (HRS), a large national survey of adults aged 50 years and older. Information about technology use was first collected during the COVID-19 pandemic, a period when face-to-face interactions were limited and technology use among older adults increased [35].

Methods

Participants

The HRS is an ongoing project since 1992 that examines sociodemographic and psychological factors as well as health status to assess the well-being of US adults aged 50 years and older. The sample was recruited at the household financial unit level through a multistage area probability sampling method and required participants to complete an in-person interview and a telephone-administered short cognitive battery every 2 years [36]. From 2006 onward, a random 50% of participants were invited to complete a psychosocial survey returned to the researchers by mail. For the cross-sectional analysis, we used data from 2020 (n=3650), when survey questions about activity engagement in both internet-based and offline (face-to-face) settings in the self-administered psychosocial survey were first included. Data were collected from March 2020 through May 2021, amid the COVID-19 pandemic. For the longitudinal analysis, we included 2034 participants who completed cognitive assessments both in 2020 (wave 1) and 2022 (wave 2; collected from March 2022 through September 2023).

Measures

Cognitive Functioning

Cognitive functioning was assessed using the modified Telephone Interview for Cognitive Status [37,38]. The Telephone Interview for Cognitive Status measures episodic memory, working memory, and attention and processing speed with the following tasks: the immediate and delayed recall of a set of 10 words (episodic memory; range of 0 - 20), serial 7 subtraction (working memory; range of 0 - 5), and backward counting (attention and processing speed; range of 0 - 2). The scores for these 3 domains were summed together, with potential total scores ranging from 0 to 27, a method consistent with previous studies assessing overall cognitive functioningusing data from the HRS [39,40]. To address potential bias from missing cognitive data, the HRS imputed missing values in the 2020 dataset used in this study, using demographic factors (eg, birth year, years of education), wave-specific demographics (eg, age), economic status (eg, income), health factors (eg, chronic conditions, visual impairment), physical functioning (eg, instrumental activities of daily living [IADLs]), and prior cognitive functioning [41].

Internet-Based Social Activity

Internet-based social activity included the following 7 items: taking or sharing photos and videos; sending or receiving instant messages, text messages, or emails; writing or reading blogs, reviews, ratings, or comments on the internet; accessing a social network site like Facebook, Twitter, or Instagram; using other social media such as Linkedin to network with people; using WhatsApp, Snapchat, or similar apps to network with people; or connecting face-to-face with family and friends using an app (such as FaceTime or Skype). To calculate internet-based social activity scores, we first created binary variables indicating whether the participants reported having participated in such activity at least once a month or more (1=engaged at least once a month or more, 0=engaged less than once a month) and then summed these 7 binary composite variables, using a method consistent with the previous studies examining social activity variety [6,42]. Higher scores indicate more diverse internet-based social activities, with a possible range of 0 to 7.

Face-to-Face Social Activity

Face-to-face social activity included 11 items. Five items, indicative of socially oriented activities from prior research [43], included doing volunteer work with children or young people; doing any other volunteer or charity work; taking an educational or training course; going to a sporting, social, or other club event; and attending meetings of nonreligious organizations. The other 6 items, representing social activities in the previous literature [44], included caring for a sick or disabled adult; attending a religious service; doing activities with grandchildren, nieces, nephews, or neighborhood children; meeting up with children not living with the respondent; doing activities with other family members not living with the respondent; or meeting friends. We calculated the face-to-face social activity scores using the same method for internet-based social activity, with a possible range of 0 to 11. Higher scores indicate more diverse face-to-face social activities, following the existing studies on social activity variety [6,42].

Demographic and Health-Related Variables

We included the following demographic covariates in the model based on the previous studies on activity engagement [6,45]: age, sex (0=female, 1=male), race (0=racial and ethnic minority groups, 1=White), years of education (possible range: 0 - 17), working status (0=not working, 1=working), marital status (0=not married or partnered, 1=married). To capture subjective economic status, we included a question about participants' satisfaction with their financial situation (1=not at all satisfied, 5=completely satisfied). Two physical health-related factors were also included, one of which was IADLs (eg, difficulty with making phone calls, managing money, taking medications, shopping for groceries, preparing a hot meal), along with the number of chronic conditions (eg, hypertension, diabetes, cancer, lung disease, heart disease, stroke, arthritis). We also included an 8-item short form adapted from the 20-item Center for Epidemiologic Studies-Depression scale to measure depressive symptoms [46]. Participants indicated whether they had experienced any of the following during the past week with a yes (1) or no (0): felt depressed, felt that everything they did was an effort, slept restlessly, were happy (reverse coded), felt lonely, enjoyed life (reverse coded), felt sad, and could not get going.

Data Analysis

Using SAS 9.4, we conducted 2 separate linear regression models for overall cognitive functioning. Model 1 included only internet-based social activity and covariates as predictors. Model 2 incorporated face-to-face social activity in Model 1 to determine whether the effects were held after a measure of social activity without technology was included. Then, we ran a regression to examine whether internet-based social activity was related to a change in cognitive functioning, after adjusting for baseline cognitive functioning and face-to-face social activity and covariates, using cognitive functioning in 2022 as the outcome and including cognitive functioning in 2020 along with the covariates and social activity.

We also ran regression models to examine the relationship between internet-based social activity and each subdomain of cognitive functioning to determine whether effects varied across these domains. In addition, we explored whether age interacted with internet-based social activity in its association with cognitive functioning, reasoning that a 2-year change in cognitive functioning may be more likely to occur in older individuals. We also explored whether age was perhaps more sensitive to influences on cognitive functioning.

Ethical Considerations

This study used publicly available, deidentified secondary data from the HRS, which was approved by the University of Michigan Institutional Review Board and sponsored by the National Institute on Aging (NIA-U01AG009740). Therefore, institutional review board approval was not required.

Results

Characteristics of the Participants and Their Internet-Based Social Activity Participation

Participants in the cross-sectional sample (N=3650) were aged between 50 and 99 years (mean 67.68, SD 9.77) and most were female (2174/3650, 59.6%), White (2679/3650, 73.4%), not working (2579/3650, 70.7%), and married or partnered (2100/3650, 57.5%). Most participants were high school graduates with an average of 13.50 years of education and were, on average, satisfied with their current financial situation. Most reported good health, with a low average IADL score and few chronic conditions (3132/3650, 85.8%, had an IADL score of 0). On average, they engaged in 3.35 different types of face-to-face social activities and 3.50 types of internet-based social activities. Cognitive functioning ranged from 0 to 27 with an average score of 16.24 and an SD of 4.35. Table 1 presents additional demographic and health-related characteristics, along with details on social activities and cognitive functioning for the longitudinal sample and dropouts.

Table . Descriptive statistics in demographic factors, internet-based and offline social activity, and cognitive functioning.

	Cross-sectional sample (N=3650)	Longitudinal sample (n=2034)	Dropouts (n=1616)	Attrition analysis	
				t test or χ^2 (*df*)	*P* value
Age at wave 1 (years), mean (SD)	68.68 (9.77)	67.85 (9.63)	69.71 (9.86)	−5.71 (3426.4)[a]	<.001
Sex (female), n (%)	2174 (59.6)	1220 (60)	954 (59)	0.33 (1)[b]	.56
Race (White), n (%)	2679 (73.4)	1382 (67.9)	1297 (80.3)	69.95 (1)[b]	<.001
Marital status (married), n (%)	2100 (57.5)	1147 (56.4)	953 (59)	2.46 (1)[b]	.12
Working status (currently working), n (%)	1071 (29.3)	623 (30.6)	448 (27.7)	3.67 (1)[b]	.06
Years of education, mean (SD)	13.50 (2.79)	13.23 (2.82)	13.85 (2.72)	−6.68 (3513.7)[a]	<.001
Satisfaction with financial situation, mean (SD)	3.54 (1.09)	3.48 (1.10)	3.60 (1.07)	−3.34 (3500.7)[a]	<.001
Number of chronic conditions, mean (SD)	2.09 (1.36)	2.07 (1.31)	2.12 (1.41)	−1.11 (3648)[a]	.27
Instrumental activities of daily living, mean (SD)	0.23 (0.65)	0.22 (0.62)	0.24 (0.69)	−0.92 (3648)[a]	.36
Depressive symptoms, mean (SD)	1.31 (1.92)	1.35 (1.93)	1.28 (1.90)	1.10 (3485.3)[a]	.27
Face-to-face social activity, mean (SD)	3.35 (2.05)	3.36 (2.04)	3.33 (2.05)	0.40 (3452.7)[a]	.69
Internet-based social activity, mean (SD)	3.50 (2.00)	3.38 (2.09)	3.64 (1.88)	3.81 (3648)[a]	<.001
Cognitive functioning, mean (SD)	16.24 (4.35)	16.18 (4.31)	16.32 (4.40)	−0.99 (3430.3)[a]	.32

[a] *t* test.

[b] Chi-square test.

The 7 types of internet-based social activities varied in their frequency, with the most frequent being sending or receiving instant messages, text messages, or emails (3049/3650, 83.5%) and the least being using social media platforms such as LinkedIn (611/3650, 16.7%) (Table 2).

Table . Number of participants engaging in various internet-based social activities.

Internet-based social activity	Participants (N=3650), n (%)
Sending or receiving instant messages, text messages, or emails	3049 (83.5)
Taking or sharing photos and videos	2360 (64.7)
Accessing a social network site like Facebook, Twitter, or Instagram	2323 (63.6)
Writing or reading blogs, reviews, ratings, or comments on the internet	2011 (55.1)
Connecting face-to-face with family and friends using an app such as FaceTime or Skype	1695 (46.4)
Using WhatsApp, Snapchat, or similar apps to network with people	713 (19.5)
Using other social media such as LinkedIn to network with people	611 (16.7)

Internet-Based Social Activity Participation and Concurrent Cognitive Functioning

Table 3 presents the results from our regression models testing our hypothesis that a greater variety of internet-based social activity use would be related to higher concurrent cognitive functioning. As indicated in Model 1, those who engaged in more diverse internet-based social activities had better overall cognitive functioning after adjusting for demographic and health-related factors (*b*=0.46, SE 0.07, *P*<.001). Results remained significant when we added face-to-face social activity participation (*b*=0.44, SE 0.07, *P*<.001; Model 2).

Table . Cross-sectional associations of internet-based social activity at W1[a] with cognitive functioning at W1 (n=3650). Age, internet-based social activity participation, and face-to-face social activity participation were standardized.

Parameter	Model 1		Model 2	
	b (SE)	*P* value	*b* (SE)	*P* value
Intercept	11.09 (0.45)	<.001	11.13 (0.45)	<.001
Age	−0.75 (0.08)	<.001	−0.75 (0.08)	<.001
Men (vs women)	0.71 (0.13)	<.001	0.70 (0.13)	<.001
White (vs racial and ethnic minority groups)	−1.20 (0.15)	<.001	−1.21 (0.15)	<.001
Married (vs not married or partnered)	0.23 (0.14)	.09	0.22 (0.14)	.10
Currently working (vs not working)	0.29 (0.16)	.06	0.28 (0.16)	.08
Education	0.36 (0.02)	<.001	0.36 (0.02)	<.001
Satisfaction with financial situation	0.17 (0.06)	.008	0.16 (0.06)	.01
Instrumental activities of daily living	−1.05 (0.10)	<.001	−1.04 (0.10)	<.001
Number of chronic conditions	−0.06 (0.05)	.27	−0.06 (0.05)	.27
Depressive symptoms	−0.20 (0.04)	<.001	−0.20 (0.04)	<.001
Internet-based social activity at W1[b]	0.46 (0.07)	<.001	0.44 (0.07)	<.001
Face-to-face social activity at W1[c]	—[d]	—	0.11 (0.07)	.09
Adjusted R^2	0.24	—	0.24	—
F statistic	106.59	<.001	98.00	<.001

[a] W1: wave 1.

[b] Online social activity participation at W1 remained significant when we excluded the item “taking or sharing photos and videos” (*b*=0.39, SE 0.07; *P*<.001).

[c] When examining the relationship between face-to-face social activity participation and cognitive functioning, excluding internet-based participation, face-to-face social activity participation was related to high levels of cognitive functioning (*b*=0.18, SE 0.06; *P*<.001).

[d] Not applicable.

Internet-Based Social Activity Participation and Later Cognitive Functioning

We then examined our prediction that greater variety in internet-based social activity participation in 2020 would be related to a slower decline in cognitive functioning over 2 years. Results from our longitudinal regression analysis revealed that those who engaged in more diverse internet-based social activities had higher cognitive functioning 2 years later, after adjusting for demographic and health-related factors as well as for cognitive functioning at baseline (*b*=0.36, SE 0.09, *P*<.001; Model 1 in Table 4). Results remained significant when we added face-to-face social activity participation (*b*=0.35, SE 0.09, *P*<.001; Model 2 in Table 4).

Table . Longitudinal associations of internet-based social activity at W1[a] with cognitive functioning at W2[b] (n=2034). Age, internet-based social participation, and face-to-face social activity participation were standardized.

Parameter	Model 1		Model 2	
	b (SE)	*P* value	*b* (SE)	*P* value
Intercept	5.67 (0.56)	<.001	5.68 (0.56)	<.001
Age	−0.72 (0.09)	<.001	−0.72 (0.09)	<.001
Men (vs women)	−0.06 (0.16)	.70	−0.06 (0.16)	.69
White (vs racial and ethnic minority groups)	−0.54 (0.16)	.001	−0.54 (0.16)	.001
Married (vs not married or partnered)	0.11 (0.16)	.48	0.11 (0.16)	.49
Currently working (vs not working)	0.34 (0.18)	.06	0.34 (0.18)	.06
Education	0.19 (0.03)	<.001	0.19 (0.03)	<.001
Satisfaction with financial situation	0.03 (0.07)	.69	0.03 (0.07)	.71
Instrumental activities of daily living	−0.18 (0.13)	.16	−0.18 (0.13)	.17
Number of chronic conditions	−0.09 (0.06)	.13	−0.09 (0.06)	.13
Depressive symptoms	−0.08 (0.04)	.06	−0.08 (0.04)	.06
Cognitive functioning at W1	0.49 (0.02)	<.001	0.49 (0.02)	<.001
Internet-based social activity at W1	0.36 (0.09)	<.001	0.35 (0.09)	<.001
Face-to-face social activity at W1[c]	—[d]	—	0.03 (0.08)	.71
Adjusted R^2	0.44	—	0.44	—
F statistic	136.65	<.001	126.10	<.001

[a] W1: wave 1.

[b] W2: wave 2.

[c] When examining the relationship between face-to-face social activity participation and cognitive functioning, excluding internet-based participation, face-to-face social activity participation was not associated with change in cognitive functioning across time (*b*=0.08, SE 0.07; *P*=.27).

[d] Not applicable.

Additional Exploratory Analyses

When we examined the longitudinal association of internet-based social activity participation with changes in subdomains of cognitive functioning, those who participated in more diverse internet-based social activities had better later episodic memory (*b*=0.35, SE 0.08; *P*<.001), but not working memory or attention and processing speed, after adjusting for the baseline cognitive functioning (Table 5). In addition, we explored possible age differences in the association of social activity participation with later cognitive functioning, but the interaction effect of age and internet-based social activity participation was not significant for overall concurrent cognitive functioning (Table 6).

Table . Longitudinal associations of internet-based social activity at W1[a] with subdomains of cognitive functioning at W2[b] (n=2034). Age, internet-based social participation, and face-to-face social activity participation were standardized.

Parameter	Episodic memory		Working memory		Attention and processing speed	
	b (SE)	*P* value	*b* (SE)	P value	*b* (SE)	*P* value
Intercept	4.11 (0.47)	<.001	1.15 (0.20)	<.001	1.39 (0.08)	<.001
Age	−0.64 (0.08)	<.001	−0.10 (0.03)	.003	−0.03 (0.01)	.03
Men (vs women)	0.22 (0.14)	.11	−0.22 (0.06)	<.001	0.00 (0.02)	.90
White (vs racial and ethnic minority groups)	−0.31 (0.14)	.03	−0.24 (0.06)	<.001	−0.03 (0.02)	.16
Married (vs not married or partnered)	0.06 (0.14)	.67	0.06 (0.06)	.34	0.00 (0.02)	.96
Currently working (vs not working)	0.33 (0.16)	.03	0.02 (0.07)	.77	−0.01 (0.03)	.75
Education	0.13 (0.02)	<.001	0.06 (0.01)	<.001	0.02 (0.00)	<.001
Satisfaction with financial situation	0.01 (0.06)	.87	0.03 (0.03)	.25	0.00 (0.01)	.78
Instrumental activities of daily living	−0.15 (0.11)	.18	−0.05 (0.05)	.28	−0.01 (0.02)	.45
Number of chronic conditions	−0.08 (0.05)	.15	−0.03 (0.02)	.23	0.01 (0.01)	.29
Depressive symptoms	−0.07 (0.04)	.07	−0.01 (0.02)	.44	−0.01 (0.01)	.08
Episodic memory, working memory, or attention and processing speed	0.42 (0.02)	<.001	0.52 (0.02)	<.001	0.16 (0.02)	<.001
Face-to-face social activity at W1	0.05 (0.07)	.42	−0.01 (0.03)	.66	−0.01 (0.01)	.18
Internet-based social activity at W1	0.35 (0.08)	<.001	0.03 (0.03)	.30	−0.00 (0.01)	.70
Adjusted R^2	0.38	—[c]	0.37	—	0.04	—
F statistic	96.49	<.001	93.15	<.001	7.09	<.001

[a] W1: wave 1.

[b] W2: wave 2.

[c] Not applicable.

Table . Interaction effect of age and internet-based social activity participation with cognitive functioning at wave 2 (n=2034). Age, internet-based social participation, and face-to-face social activity participation were standardized.

Parameter	Model 1		Model 2	
	b (SE)	*P* value	*b* (SE)	*P* value
Intercept	5.65 (0.56)	<.001	5.65 (0.56)	<.001
Age	−0.74 (0.10)	<.001	−0.74 (0.10)	<.001
Men (vs women)	−0.07 (0.16)	.67	−0.07 (0.16)	.67
White (vs racial and ethnic minority groups)	−0.53 (0.16)	.001	−0.53 (0.16)	.001
Married (vs not married or partnered)	0.11 (0.16)	.48	0.11 (0.16)	.49
Currently working (vs not working)	0.32 (0.18)	.07	0.34 (0.18)	.07
Education	0.19 (0.03)	<.001	0.19 (0.03)	<.001
Satisfaction with financial situation	0.03 (0.07)	.72	0.02 (0.07)	.74
Instrumental activities of daily living	−0.18 (0.13)	.16	−0.18 (0.13)	.17
Number of chronic conditions	−0.09 (0.06)	.13	−0.09 (0.06)	.13
Depressive symptoms	−0.08 (0.04)	.06	−0.08 (0.04)	.06
Cognitive functioning at W1[a]	0.50 (0.02)	<.001	0.49 (0.02)	<.001
Internet-based social activity at W1	0.35 (0.09)	<.001	0.35 (0.09)	<.001
Face-to-face social activity at W1	—[b]	—	0.03 (0.08)	.71
Age × internet-based social activity participation	−0.06 (0.07)	.41	−0.06 (0.07)	.41
Adjusted R^2	0.44	—	0.44	—
F statistic	126.17	<.001	117.12	<.001

[a] W1: wave 1.

[b] Not applicable.

Discussion

Building on the importance of social activity in the real world, we examined the impact of a variety of social activities in virtual worlds on cognitive health. We found that greater engagement in internet-based social activities was associated with high levels of concurrent and later cognitive functioning, particularly in episodic memory, even after adjusting for face-to-face social activity, a relationship that did not vary by age.

Internet-Based Social Activity Participation With Cognitive Functioning

People have raised concerns that virtual social activities may not provide the same mental stimulation as face-to-face interactions, due to factors such as reduced social cues from the absence of facial expressions or voice tones [46]. The implication of these concerns is that less social stimuli would provide less cognitive stimulation. Yet, research finds that virtual communication offers a variety of different types of cues and multiple sensory stimulation [20]. For example, video-based communications involve similar verbal and nonverbal cues to face-to-face social activities [47]. Dynamic animations or videos also provide visual and auditory cues [48,49], which may enhance one's engagement with the environment. In addition to potential cognitive stimulation from communicating with others in these virtual worlds, internet-based social activity includes other tasks involving cognitive processing, such as recollecting, retrieving, and reminding functions [30]. Moreover, internet-based social activity participation may be a channel to exchange social support, which further relates to cognitive functioning [7]. Platforms like Snapchat or Instagram enable sharing moments across generations, while blogging fosters a sense of belonging and social support by connecting individuals with shared interests [50,51], all of which can be potential psychological mechanisms for cognitive benefits and may be reasons why engaging in virtual social activities was associated with high levels of both concurrent and later cognitive functioning in this study.

When examining the subdomains of cognitive functioning, engagement in diverse internet-based social activities was only related to episodic memory. Engagement in social activities in virtual worlds may facilitate learning and remembering new information, which has been related to better episodic memory in another study [52] and is consistent with our findings. On the other hand, activities included in this study, such as posting, messaging, and sharing photos, have not been associated with executive functioning in previous studies [30], similar to our null effects within this subdomain. A recent study, however, suggests an indirect relationship between internet-based social activity participation and executive functioning, as seen in individuals who receive social support through sustained use of internet-based social media [34]. We do not have the data to examine this indirect relationship, but future studies should examine the possibility of indirect effects of virtual social activity participation on executive functioning.

The relationship between internet-based social activity participation and cognitive functioning did not vary by age. Previous research raised concerns that older adults may derive fewer benefits from internet-based social activities because they are likely to have potential physical limitations restricting engagement in technology use in social interactions [53]. Yet, our results indicate that the cognitive benefits of internet-based social activity participation were consistent across age even without adjusting for health-related factors. In addition, the potential mechanisms that may link participation in internet-based social activities and cognitive functioning may be comparable across ages, as internet users of all ages tend to participate in various social networks [54].

Associations of Face-to-Face Social Activity Participation With Cognitive Functioning

Face-to-face social activity participation was also related to concurrent cognitive functioning, but not to later cognitive functioning, when internet-based participation was excluded from the model. Our results contrast previous findings indicating cognitive benefits of face-to-face social activities [8]. One potential reason why we failed to find a difference is that the effect size of the relationship between face-to-face social activity participation and cognitive functioning may be very small. Another reason may be that people who may experience cognitive decline or other cognitive issues may receive more social support from others and thus obscure the association. Finally, these data were collected during a time when face-to-face interactions were more limited than usual. Social activities outside the home, such as clubs, educational courses, or volunteer work, were strictly restricted during the COVID-19 pandemic. This may have led to a limited engagement in face-to-face social activities regardless of individuals' interests or motivations for engaging in them and may have contributed to the weaker association observed with cognitive functioning.

Another consideration is that cognitive health benefits of face-to-face social activity may be especially notable when individuals are involved in these activities consistently over an extended period of time [6]. Studies have supported the importance of sustained social activity participation by demonstrating that the relationship between face-to-face social activity and cognitive functioning was stronger when examining the participation across time rather than participation at the baseline [55]. We did not measure how long participants had been engaging in each of these activities.

Importantly, this study focused on cognitive functioning, one aspect of health, among older adults. Our findings suggest that virtual social activities, as opposed to face-to-face activities, were related to a slower decline in cognitive functioning over 2 years; however, other aspects of health may have a different pattern of results. For example, several studies on the health benefits of internet-based and face-to-face social activity participation have found that only face-to-face interactions are related to better emotional well-being [56]. In addition, several studies find that social interactions via technology such as emailing or texting cannot replace face-to-face interactions in combating loneliness [57], emphasizing the significance of face-to-face social interactions for other health outcomes, such as emotional health.

Limitations and Future Directions

This study has limitations that can be addressed in future studies. Internet-based social activities used in this study may not encompass all social activities in the virtual world. Further studies could examine a broader range of such activities, such as playing interactive computer games. Moreover, the item "taking or sharing photos and videos" may capture 2 distinct activities: taking photos or videos and sharing them. Since sharing involves social interaction, those who only took photos may not be engaging socially. We examined whether excluding this item from internet-based social activity impacts its relationship with cognitive functioning, and the results remained consistent. Although we used items with social components, future studies could explore which internet-based activities necessarily involve social interaction and how they relate to cognitive functioning. In addition, we used data that were collected during the COVID-19 pandemic, and as we mentioned, engagement in various internet-based social activities may have health benefits when in-person interactions are limited—benefits that may not appear when people are less socially restricted. Future studies could examine the relationship between internet-based social activity participation and cognitive functioning under other circumstances. Lastly, other psychological or sociodemographic factors, such as motivations for learning, could yield different patterns of the relationship between engagement in a variety of internet-based social activities and cognitive functioning. Further studies could explore this relationship across different backgrounds, such as in individuals with different levels of motivations or self-control.

Conclusion

Social activities through internet-based platforms, such as sharing moments or communicating with others, were related to higher levels of concurrent and future cognitive functioning in late adulthood when examined during the COVID-19 pandemic. This study contributes to the existing findings on the importance of social activity participation by promoting the role of engagement in diverse social activities in internet-based settings. Given that middle-aged and older adults are highly motivated to interact with their friends and family members, they may be more likely to use and benefit from technology that provides them with a way to maintain social connections.

Conflicts of Interest

None declared.

References

1. Bennett KM. Social engagement as a longitudinal predictor of objective and subjective health. Eur J Ageing 2005 Mar;2(1):48-55. [doi: 10.1007/s10433-005-0501-z] [Medline: 28794716]
2. Steptoe A, Fancourt D. Leading a meaningful life at older ages and its relationship with social engagement, prosperity, health, biology, and time use. Proc Natl Acad Sci U S A 2019 Jan 22;116(4):1207-1212. [doi: 10.1073/pnas.1814723116] [Medline: 30617082]
3. Glass TA, De Leon CFM, Bassuk SS, Berkman LF. Social engagement and depressive symptoms in late life: longitudinal findings. J Aging Health 2006 Aug;18(4):604-628. [doi: 10.1177/0898264306291017] [Medline: 16835392]
4. Luo M, Ding D, Bauman A, Negin J, Phongsavan P. Social engagement pattern, health behaviors and subjective well-being of older adults: an international perspective using WHO-SAGE survey data. BMC Public Health 2020 Jan 23;20(1):99. [doi: 10.1186/s12889-019-7841-7] [Medline: 31973695]
5. Tomioka K, Kurumatani N, Hosoi H. Association between social participation and 3-year change in instrumental activities of daily living in community-dwelling elderly adults. J Am Geriatr Soc 2017 Jan;65(1):107-113. [doi: 10.1111/jgs.14447] [Medline: 27673582]
6. Jeon S, Lee S, Charles ST. Not just how much, but how many: overall and domain-specific activity variety and cognitive functioning in adulthood. J Gerontol B Psychol Sci Soc Sci 2022 Jul 5;77(7):1229-1239. [doi: 10.1093/geronb/gbac053] [Medline: 35291012]
7. Kelly ME, Duff H, Kelly S, et al. The impact of social activities, social networks, social support and social relationships on the cognitive functioning of healthy older adults: a systematic review. Syst Rev 2017 Dec 19;6(1):259. [doi: 10.1186/s13643-017-0632-2] [Medline: 29258596]
8. Penninkilampi R, Casey AN, Singh MF, Brodaty H. The association between social engagement, loneliness, and risk of dementia: a systematic review and meta-analysis. J Alzheimers Dis 2018;66(4):1619-1633. [doi: 10.3233/JAD-180439] [Medline: 30452410]
9. Kakulla B. Personal tech and the pandemic: older adults are upgrading for a better online experience: 2021 tech trends and the 50+: top 10 biggest trends. AARP. 2021. URL: https://www.aarp.org/pri/topics/technology/internet-media-devices/2021-technology-trends-older-americans/ [accessed 2024-11-29]
10. Cheung CMK, Chiu PY, Lee MKO. Online social networks: why do students use Facebook? Comput Hum Behav 2011 Jul;27(4):1337-1343. [doi: 10.1016/j.chb.2010.07.028]
11. Yildirim E, Ogel-Balaban H. Cognitive functions among healthy older adults using online social networking. Appl Neuropsychol Adult 2023;30(4):401-408. [doi: 10.1080/23279095.2021.1951269] [Medline: 34310244]
12. Amini R, Chee KH, Mendieta M, Parker S. Online engagement and cognitive function among older adults. Geriatr Gerontol Int 2019 Sep;19(9):918-923. [doi: 10.1111/ggi.13749] [Medline: 31368165]
13. Urban-Wojcik EJ, Lee S, Grupe DW, et al. Diversity of daily activities is associated with greater hippocampal volume. Cogn Affect Behav Neurosci 2022 Feb;22(1):75-87. [doi: 10.3758/s13415-021-00942-5] [Medline: 34599488]
14. Birch AM, Kelly Á. Lifelong environmental enrichment in the absence of exercise protects the brain from age-related cognitive decline. Neuropharmacology 2019 Feb;145:59-74. [doi: 10.1016/j.neuropharm.2018.03.042] [Medline: 29630903]
15. Kempermann G. The neurogenic reserve hypothesis: what is adult hippocampal neurogenesis good for? Trends Neurosci 2008 Apr;31(4):163-169. [doi: 10.1016/j.tins.2008.01.002] [Medline: 18329110]
16. Ridings CM, Gefen D. Virtual community attraction: why people hang out online. J Comput Mediat Commun 2006;10(1). [doi: 10.1111/j.1083-6101.2004.tb00229.x]
17. Perry A, Shamay‐Tsoory S. Understanding emotional and cognitive empathy: a neuropsychological perspective. In: Understanding Other Minds: Perspectives From Developmental Social Neuroscience, 3rd edition: Oxford University Press; 2013:178-194. [doi: 10.1093/acprof:oso/9780199692972.003.0011]
18. Lindenberger U, Lövdén M, Schellenbach M, Li SC, Krüger A. Psychological principles of successful aging technologies: a mini-review. Gerontology 2008;54(1):59-68. [doi: 10.1159/000116114] [Medline: 18259095]
19. Small GW, Moody TD, Siddarth P, Bookheimer SY. Your brain on Google: patterns of cerebral activation during internet searching. Am J Geriatr Psychiatry 2009 Feb;17(2):116-126. [doi: 10.1097/JGP.0b013e3181953a02] [Medline: 19155745]
20. Shaw RS, Chen CC, Harris AL, Huang HJ. The impact of information richness on information security awareness training effectiveness. Computers & Education 2009 Jan;52(1):92-100. [doi: 10.1016/j.compedu.2008.06.011]
21. Mayer RE. Multimedia Learning, 2nd edition: Cambridge University Press; 2009. [doi: 10.1017/CBO9780511811678]

22. Celdrán M, Serrat R, Villar F, Montserrat R. Exploring the benefits of proactive participation among adults and older people by writing blogs. J Gerontol Soc Work 2022 Apr;65(3):320-336. [doi: 10.1080/01634372.2021.1965688] [Medline: 34379566]
23. Yau JC, Reich SM. “It’s just a lot of work”: adolescents’ self-presentation norms and practices on Facebook and instagram. J Res Adolesc 2019 Mar;29(1):196-209. [doi: 10.1111/jora.12376] [Medline: 29430759]
24. Alhabash S, Ma M. A tale of four platforms: motivations and uses of Facebook, Twitter, Instagram, and Snapchat among college students? Soc Media Soc 2017 Feb;3(1). [doi: 10.1177/2056305117691544]
25. Zhao X, Jin L, Sun SB. Bidirectional association between internet use and episodic memory among older adults: a longitudinal mediation study. J Appl Gerontol 2024 Jul;43(7):829-840. [doi: 10.1177/07334648231214944] [Medline: 38016114]
26. Rafnsson SB, Maharani A, Tampubolon G. Social contact mode and 15-year episodic memory trajectories in older adults with and without hearing loss: findings from the english longitudinal study of ageing. J Gerontol B Psychol Sci Soc Sci 2022 Jan 12;77(1):10-17. [doi: 10.1093/geronb/gbab029] [Medline: 33606882]
27. Mousavi-Nasab SMH, Kormi-Nouri R, Nilsson LG. Examination of the bidirectional influences of leisure activity and memory in old people: a dissociative effect on episodic memory. Br J Psychol 2014 Aug;105(3):382-398. [doi: 10.1111/bjop.12044] [Medline: 25040007]
28. Tulving E. What is episodic memory? Curr Directions Psychol Sci 1993 Jun;2(3):67-70. [doi: 10.1111/1467-8721.ep10770899]
29. Miyake A, Friedman NP, Emerson MJ, Witzki AH, Howerter A, Wager TD. The unity and diversity of executive functions and their contributions to complex “Frontal Lobe” tasks: a latent variable analysis. Cogn Psychol 2000 Aug;41(1):49-100. [doi: 10.1006/cogp.1999.0734] [Medline: 10945922]
30. Quinn K. Cognitive effects of social media use: a case of older adults. Soc Media Soc 2018;4(3). [doi: 10.1177/2056305118787203] [Medline: 37041879]
31. Carstensen LL, Isaacowitz DM, Charles ST. Taking time seriously. A theory of socioemotional selectivity. Am Psychol 1999 Mar;54(3):165-181. [doi: 10.1037/0003-066x.54.3.165] [Medline: 10199217]
32. Jung EH, Walden J, Johnson AC, Sundar SS. Social networking in the aging context: why older adults use or avoid Facebook. Telematics Informatics 2017 Nov;34(7):1071-1080. [doi: 10.1016/j.tele.2017.04.015]
33. Wu HY, Chiou AF. Social media usage, social support, intergenerational relationships, and depressive symptoms among older adults. Geriatr Nurs 2020;41(5):615-621. [doi: 10.1016/j.gerinurse.2020.03.016] [Medline: 32268948]
34. Khoo SS, Yang H. Social media use improves executive functions in middle-aged and older adults: a structural equation modeling analysis. Comput Hum Behav 2020 Oct;111:106388. [doi: 10.1016/j.chb.2020.106388]
35. Sixsmith A, Horst BR, Simeonov D, Mihailidis A. Older people’s use of digital technology during the COVID-19 pandemic. Bull Sci Technol Soc 2022 Jun;42:19-24. [doi: 10.1177/02704676221094731] [Medline: 38603230]
36. Fisher GG, Ryan LH. Overview of the Health and Retirement Study and introduction to the Special Issue. Work Aging Retire 2018 Jan;4(1):1-9. [doi: 10.1093/workar/wax032] [Medline: 29423243]
37. Brandt J, Spencer M, Folstein M. The Telephone Interview for Cognitive Status. Neuropsychiatry Neuropsychol Behav Neurol 1988;1(2):111-117.
38. Crimmins EM, Kim JK, Langa KM, Weir DR. Assessment of cognition using surveys and neuropsychological assessment: the Health and Retirement Study and the Aging, Demographics, and Memory Study. J Gerontol B Psychol Sci Soc Sci 2011 Jul;66:i162-i171. [doi: 10.1093/geronb/gbr048] [Medline: 21743047]
39. Lee YJ, Gonzales E, Andel R. Multifaceted demands of work and cognitive functioning: findings from the Health and Retirement Study. J Gerontol B Psychol Sci Soc Sci 2022 Feb 3;77(2):351-361. [doi: 10.1093/geronb/gbab087] [Medline: 33979436]
40. Lu W, Pai M, Scholes S, Xue B. Do depressive symptoms link chronic diseases to cognition among older adults? Evidence from the Health and Retirement Study in the United States. J Affect Disord 2021 Nov 1;294:357-365. [doi: 10.1016/j.jad.2021.07.012] [Medline: 34315097]
41. McCammon RJ, Fisher GG, Hassan H, Faul JD, Rodgers W, Weir DR. Health and Retirement Study Imputation of Cognitive Functioning Measures: 1992-2016: Survey Research Center, University of Michigan; 2019.
42. Jeon S, Turiano NA, Charles ST. A greater variety of social activities is associated with lower mortality risk. J Gerontology Series B 2024 May;79(5):gbae021. [doi: 10.1093/geronb/gbae021]
43. Howrey BT, Hand CL. Measuring social participation in the Health and Retirement Study. Gerontologist 2019 Sep 17;59(5):e415-e423. [doi: 10.1093/geront/gny094] [Medline: 30169644]
44. Karp A, Paillard-Borg S, Wang HX, Silverstein M, Winblad B, Fratiglioni L. Mental, physical and social components in leisure activities equally contribute to decrease dementia risk. Dement Geriatr Cogn Disord 2006;21(2):65-73. [doi: 10.1159/000089919] [Medline: 16319455]
45. Brown CJ, Jeon S, Ng YT, Lee S, Fingerman KL, Charles ST. Switching it up: activity diversity and cognitive functioning in later life. Psychol Aging 2023 Sep;38(6):483-493. [doi: 10.1037/pag0000770] [Medline: 37535516]
46. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. Applied Psychological Measurement 1977;1(3):385-401. [doi: 10.1177/014662167700100306]

47. Neureiter K, Murer M, Fuchsberger V, Tscheligi M. Hand and eyes: how eye contact is linked to gestures in video conferencing. Presented at: CHI'13 Extended Abstracts on Human Factors in Computing Systems; Apr 27 to May 2, 2013; New York, NY p. 127-132. [doi: 10.1145/2468356.2468380]
48. de Vries L, Gensler S, Leeflang PSH. Popularity of brand posts on brand fan pages: an investigation of the effects of social media marketing. J Interactive Marketing 2012 May;26(2):83-91. [doi: 10.1016/j.intmar.2012.01.003]
49. Steuer J. Defining virtual reality: dimensions determining telepresence. J Communication 1992;42(4):72-93. [doi: 10.1111/j.1460-2466.1992.tb00812.x]
50. Shang SSC, Wu YL, Li EY. Field effects of social media platforms on information-sharing continuance: do reach and richness matter? Inf Manage 2017 Mar;54(2):241-255. [doi: 10.1016/j.im.2016.06.008]
51. Tsai S, Crawford E, Strong J. Seeking virtual social support through blogging: a content analysis of published blog posts written by people with chronic pain. Digit Health 2018;4:2055207618772669. [doi: 10.1177/2055207618772669] [Medline: 29942635]
52. Myhre JW, Mehl MR, Glisky EL. Cognitive benefits of online social networking for healthy older adults. J Gerontol B Psychol Sci Soc Sci 2017 Sep 1;72(5):752-760. [doi: 10.1093/geronb/gbw025] [Medline: 26984523]
53. Zaphiris P, Kurniawan S, Ghiawadwala M. A systematic approach to the development of research-based web design guidelines for older people. Univ Access Inf Soc 2006 Nov 16;6:59-75. [doi: 10.1007/s10209-006-0054-8]
54. Hogeboom DL, McDermott RJ, Perrin KM, Osman H, Bell-Ellison BA. Internet use and social networking among middle aged and older adults. Educational Gerontology 2010 Jan 12;36(2):93-111. [doi: 10.1080/03601270903058507]
55. Shiba K, Torres JM, Daoud A, et al. Estimating the impact of sustained social participation on depressive symptoms in older adults. Epidemiology 2021 Nov 1;32(6):886-895. [doi: 10.1097/EDE.0000000000001395] [Medline: 34172690]
56. Fingerman KL, Ng YT, Zhang S, et al. Living alone during COVID-19: social contact and emotional well-being among older adults. J Gerontol B Psychol Sci Soc Sci 2021 Feb 17;76(3):e116-e121. [doi: 10.1093/geronb/gbaa200] [Medline: 33196815]
57. Macdonald B, Luo M, Hülür G. Daily social interactions and well-being in older adults: the role of interaction modality. J Soc Pers Relationships 2021 Nov;38(12):3566-3589. [doi: 10.1177/02654075211052536]

Abbreviations

HRS: Health and Retirement Study
IADL: instrumental activity of daily living

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Original Paper

Examining the Effect of Contactless Intergenerational Befriending Intervention on Social Isolation Among Older Adults and Students' Attitude Toward Companionship: Content Analysis

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Abstract

Background: Intergenerational friendship, a mechanism of social support, is an effective intervention to reduce the increasing risk of social isolation (SI) and develop companionship in the older adult population. The COVID-19 pandemic provided a unique opportunity to examine the psychosocial intervention of befriending via technology use as a primary form of contactless socialization.

Objective: The study aims to explore the effectiveness of the befriending intervention through a contactless, intergenerational service-learning project on older adult emotions, especially boredom and loneliness as the key attributes of SI, and on students' attitude toward companionship.

Methods: During the months of January to April 2022 , undergraduate students enrolled in a health administration course with a special focus on culture were asked to be involved in a contactless, intergenerational service-learning project (n=46). In this study, contactless intervention meant communication using the telephone and apps such as FaceTime and Zoom. Students were paired with older adults to have at least a 30-minute weekly conversation, for 8 weeks, via telephone or an internet-based app such as FaceTime. Students were asked to write a half-page diary after each interaction and a 1-page reflection at the end of the fourth week and at the end of the service-learning project. At the completion of the project, the researchers also surveyed the older adults to assess the impact of the project using a 5-item open-ended questionnaire. Following a heuristic approach and content analysis, student artifacts (110,970 words; 118-page, single-spaced Microsoft Word document) and the older adult surveys were analyzed using MAXQDA, (VERBI GmbH). Qualitative data were extracted to assess the impact of service learning on SI by measuring the attributes of boredom and loneliness among 46 older adults. Students' attitudes toward companionship were also assessed using data from their diaries and reflections.

Results: Overall, three major constructs were identified: (1) meaningful engagement, defined as feeling safe, having increased confidence, and having reduced boredom; (2) internal motivation to participate in the weekly interaction, defined as discussion about daily life experience, level of happiness, and ability to exert personal control over the situation; and (3) intergenerational befriending, defined as perceived benefits from the friendly nature of the interaction, ability to comfortably connect with students, and positive feeling and attitude toward the student.

Conclusions: The contactless, intergenerational befriending intervention reduced boredom and loneliness among older adults and enhanced positive attitude and confidence among university students. Students helped older adults to develop digital skills for the use of apps and social media. Older adults showed interest in the intervention and shared their daily life experiences with the students, which helped to reduce the gap between generations. Findings indicate the effectiveness of an intergenerational service-learning intervention on SI reduction and increased positive attitude among college students.

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KEYWORDS

intergenerational befriending; social isolation; boredom; contactless socialization; service learning; internal motivation; mobile phone

Introduction

Background

The growing surge of the aging population has shone a spotlight on social isolation (SI). With increasing age, an increasing proportion of older adults experience chronic boredom and feelings of loneliness [1]. In addition, COVID-19 confinement and quarantine disturbed their lifestyle behaviors, making the aging population susceptible to high levels of stress and depression. SI is exacerbated when people are living alone, especially vulnerable older adults, experiencing the loss of family or friends, having comorbid or chronic illnesses, and facing sensory impairments. Even in residential settings and older adults' living facilities, many older adults struggle to maintain their autonomy, self-determination needs [2], and competence as they are often disconnected from the broad community or dependent on unskilled nursing staff who lack social competence and training [2,3]. An intergenerational service-learning approach to befriending these individuals is an effective intervention to enhance their psychosocial well-being [4]. This approach demonstrates the importance of using reflective writing assignments to help university students deconstruct and reconstruct images, beliefs, and paradigms about older adults [5]. In addition, it is where the young individuals relate to older adults to discuss or share their life stories or day-to-day experiences to alleviate boredom, an attribute of SI [6].

Although SI is a global epidemic implying the absence of meaningful human relations and social connectedness, befriending is a psychosocial tonic to building social relationships and intergenerational friendships [7] that might reduce boredom and depression and significantly enhance the quality of life among older adults [8] and youth. The feeling of companionship is augmented when an intergenerational conversation is conducted purposefully, thereby negating the exacerbating consequences of SI such as boredom or even the feeling of loneliness. These negative subjective experiences result from discrepancies between an individual's desires and perceptions about the quality of social relationships [9].

Intergenerational conversations are a gateway to enduring socialization for older adults and students [9]. The quality of life is enhanced as both generations engage in purposeful activities in a safe and friendly environment [8] to the satisfaction of each other's psychosocial needs and well-being. Long-lasting intergenerational conversations can create a bonding between the older adult and the student, and it enhances the level of patience and builds social competence in youth, which are essential attributes to become skilled health care professionals in long-term care [10]. The social support provided by students can foster emotional health for the isolated, frail, older adult who is no longer at the center of a network of friends and acquaintances. Older adults with social connections have a high quality of life under social support [11], are motivated to work and engage in social activities, and have an inclusive attitude that promotes a healthy lifestyle [12]. Hence, they have low risk of conditions such as depression, additive behaviors, or dementia [13]. With social connectedness, even in living alone situations, these individuals have life satisfaction, with high cognitive stability [10,14].

Facets of SI

SI is one of the most disruptive transformations that exacerbate the quality of life, affecting human behavior, perceptions, and experiences [10,15]. It is a condition that leaves one with feelings of boredom and loneliness that are detrimental to physical and mental health [7]. Loneliness among older adults is the subjective, distressed feeling of being alone or separated, whereas SI is the objective physical separation from the community [14,16]. In addition, boredom is an emotion that often triggers negative thoughts such as self-harm and anxiety, and it is profound when the surrounding environment is mostly empty [17]. Hence, boredom, compounded by the feeling of loneliness over a prolonged period, may result in depression [18], which is a mental disorder that can be controlled in a timely way by identification of the needs of individuals and restoration of successful attention in meaningful activities such as intergenerational conversations. More than 56 million adults aged ≥65 years live in the United States, accounting for approximately 16.9% of the nation's population [19]. In this population, >7 million (13%) are socially isolated. Of those 7 million individuals, 1.3 million are severely socially isolated [5,7]. The crucial drivers of boredom [18,20], namely, lack of recreational opportunities; limited personal contacts; immobility; prescribed home office; and, especially, COVID-19 quarantine and isolation have dissuaded the everyday lives of older adults, triggering anxiety and monotony [4,16,21].

Boredom across the population increased significantly owing to the COVID-19 pandemic containment measures [22], and so did the behavioral intention to find information, access services, and connect socially [23]. For older adults, there is evidential increase of the benefits of technology interventions for social connectedness [10,24]. This may have helped the contactless, intergenerational, service-learning intervention to become especially effective, facilitating the feeling of companionship and social support that is felt bilaterally and actively by both parties [25].

Intergenerational Service Learning

Intergenerational service learning is an experiential learning, which is a course-based, credit-bearing, educational experience in which students participate in an organized, service-learning activity that meets identified community needs. Students reflect about the service activity to gain further understanding of a course content [26]. With an intent to develop a sense of companionship or friendship between both parties, the intergenerational service-learning intervention brings the socially isolated older adults back on the periphery of social activities as they engage in conversations with college students [27]. Recurrent interactive sessions are useful to enhance the level of subjective well-being among older adults and connect them to the social network [28].

Alternatively, the service-learning sessions provide a broad appreciation of discipline and an enhanced sense of civic responsibility to the students while connecting them in purposeful activity with community members [29]. Requesting students to write diaries and reflections regarding their interactions with older adult adults is a key component of service learning [25,29]. Although it is less likely to see older individuals readily embracing service-learning sessions involving students or even social media sites when compared with young adults, adoption rates for contactless interactions with students among individuals aged ≥65 years have approximately doubled in the United States in the past 4 years [14,30].

Intergenerational Befriending Approach

This study used an approach that aims to bolster a long-lasting, genuine connection or relation between generations, especially college students engaged in service learning and older adults who are socially isolated [31]. This connection is based on shared experiences of daily living, which is reflected in the recurrent interaction based on the multicultural project. Although the intergenerational connection may develop over a contactless platform, it fosters a sentiment of compassion and empathy through focused interactions that add purpose and engagement for participants. The befriending idea is based on reciprocity and what benefits the older adult in a relationship [32]. The interactions are mostly based around topics that are meaningful to the older adult [10,33] and benefit the student to understand the biases of ageism. The idea is to make the older adult feel valued and cared for in a relation that is free from any kind of service delivery, obligation, or family ties [26,34].

Contactless Socialization

The quality of life comprises components such as health; well-being; peaceful existence; living in harmony; social engagement; life satisfaction; and keeping oneself busy with hobbies, volunteer service, or work [8,35,36]. The older adults were subjected to a harsher reality during the pandemic than younger adults as old age was affirmed as a risk for COVID-19 complications [37]. This contention promoted contactless socialization through contactless service-learning sessions via SMS text message, FaceTime, and emails that connected the older adults to wide social networks [38]. Although user confidence remained as a dominant issue when using technology such as a smartphone or tablet for interaction needs [39], the willingness and interest of older adults let students train them on the use of technology. The training also facilitated the use of mobile health and telemedicine among older adults, which greatly enhanced their health-related quality of life [40]. Hence, technology-based, contactless, service-learning sessions provided safe interaction for both parties, fostering social support and technology skill augmentation for the older adults [41]. Simple telephonic calls were used to build intergenerational friendships [13,38] connecting student helpers with their clients through personal life experience, interpersonal interaction, collaboration, and understanding [42].

Study Purpose

The study aimed to explore the effectiveness of the befriending intervention through a contactless, intergenerational, service-learning project on older adult emotions, especially boredom and loneliness as the key attributes of SI, and on students’ attitude toward companionship.

Our approach was to forge an alliance and create an affective bond between the young student and the older adult to facilitate the possibility of friendship as they shared their life experiences and students engaged in technology training activities for the older adults regarding the use of apps and social media sites. The relationship that develops through befriending is seen as central to the experience while hypothesizing the facts that befriending would foster psychosocial well-being among older adults and that students’ attitudes toward older adults would become more positive throughout the service-learning course.

Methods

Study Setting and Recruitment

The research design was based on qualitative data analysis [43]. Data were collected through the survey of older adults and dialogues included in journal entries submitted by 46 undergraduate students enrolled in a Health Administration course. This core or required course had a special emphasis on cultural competency and diversity. The study followed 46 older adults, aged between 64 and 82 years, via intergenerational service-learning sessions during the months of January to April 2022. The older adults were recruited from residential facilities in Good Samaritan Society, Denton, Texas; Schertz Senior Living, Texas; Knowles Home, Nashville, Tennessee; Aguadilla Seniors, Puerto Rico; and Guadalajara Senior Center, Mexico. We selected these locations because these are the largest centers for older adults known to the researchers, and we asked the older adults in these centers to invite other participants known to them to participate in the study, to expand the sample size.

The inclusion criteria for older adult participants consisted of the following: those who (1) were interested in socialization activities, (2) were aged >65 years, (3) could read English, and (4) were willing to participate in the study. The exclusion criteria were the following: older adults who (1) were aged <65 years, (2) were already engaged in >1 socialization activity, and (3) did not pass the “attention check” in a meeting with the researcher conducted before the intervention to assess their interests and identify careless respondents, thereby improving the data quality. The inclusion criteria of student participants were the following: all students enrolled in the health administration course irrespective of age or involvement in socialization activity. No exclusion criteria for students were determined.

Data Collection Procedures

The service-learning sessions are an essential component of the undergraduate Health Administration course that has culture as a major topic. The course introduces undergraduate students to the historical and cultural development of health care in contemporary American society. During the months of January to April 2022 a total of 46 students were paired with 46 older adults from the abovementioned communities. Once a week, the students communicated with their assigned older adult partners and engaged in an unscripted conversation for at least half an hour, for a total of 8 weeks. Of the 46 pairs, 29 (63%) pairs engaged in telephonic conversations and 17 (37%) pairs engaged in internet-based conversations via casual calling app, such as FaceTime or Zoom. The risk of COVID-19 contamination restricted all possibilities of in-person meetings.

As part of service learning, students were required to create an artifact diary to document each conversation. Students were also asked to write a 1-page diary after each interaction with their older adult partners and 2 reflections. On the basis of the duration of the project, students were expected to write 8 diaries and 2 reflections, once at the end of their fourth interaction and then again at the end of their eighth interaction. The conversations were recorded by the students with their smartphones or technology used for internet-based interaction such as Zoom and then transcribed by the students.

As part of the study, older adults were surveyed (paper-based, 5-item open-ended questionnaire) by the researchers to determine their interest in conversation to reduce SI and evaluate the effectiveness of the project. This 1-time survey was mailed with return envelopes to the older adults at the end of the eighth interaction with students. Survey questions were open ended, so that older adults could write their answers. The students' transcribed conversations, diaries, and reflections and the older adults' answers to the open-ended questions in the survey were all used in the qualitative data analysis.

The open-ended survey questions for the older adults included the following: (1) Did you find the conversation interesting? If your answer is yes, please write a few lines what was interesting in the conversation. (2) Would you like to participate in our project again next semester?

The whole idea of the project was to provide a useful framework for befriending that may facilitate and create a meaningful bond between the young student and the older adult [44,45]. All questions were composed from previously validated survey instruments and contextualized for use in this study (refer to sources in Table 1). To assess older adult emotions, especially boredom and loneliness as the key attributes of SI, students focused on conversations (refer to definition in Table 1) based on life satisfaction and digital skill training in the context of meaningful engagement [46,47], internal motivation to participate in the intervention for both older adults and students [47-49], and human feelings in the context of intergenerational befriending or companionship [46,49,50]. Thus, in Table 1, we have presented 3 major constructs: meaningful engagement, internal motivation to participate, and intergenerational befriending.

Table 1. Study constructs, definitions, and sources.

Construct	Definition	Sources
Meaningful engagement	• Frequency of socially interactive activities • Feeling of reduced boredom • Cohesive interaction (confidence and safety)	Questions about satisfaction with life, contextualized from the studies by Diener et al [46] and Gierveld and Tilburg [47]
Internal motivation to participate	• Discussion about daily life experience • Level of happiness • Ability to exert personal control over the situation	Questions about social isolation and motivation, contextualized from the studies by Kozma and Stones [48], Gierveld and Tilburg [47], and Russell [49]
Intergenerational befriending	• Perceived benefits from the friendly nature of interaction that develops mutual trust • Ability of the older adults to comfortably connect with students • Positive feeling and attitude of the students	Questions about human feelings, contextualized from the studies by Diener et al [46], Russell [49], and Golden et al [50]

Ethical Considerations

This contactless, intergenerational, befriending interventional study was approved by the institutional review board (protocol number 2022-7046) of the Texas State University. Written informed consent was obtained from all participants (students and older adults) before the intervention. Participants had the option to exit the intervention after reading the informed consent information or to provide consent to participate in the study. The confidentiality of the participants was properly protected during the intervention and data analysis. The study data were fully deidentified. All records pertaining to the intervention were securely protected in the university database with protected passwords, which were only accessible by the researchers. As this study was not grant funded, participants (undergraduate students and older adults) were not compensated for participating in this study.

Data Analysis

The older adults' survey was mailed to the 46 older adult participants, and 21 (46%) returned the completed survey. Students' diaries and reflections were collected at the end of the intervention (46/46, 100%), and all the files were used for data analysis. The qualitative data used in the study to extract the constructs and subconstructs were obtained from the 21 older adults' surveys and 46 students' diaries and reflections. Our analytic data included all the 110,970 words in a 118-page, single-spaced Microsoft Word document.

Following a heuristic approach [51] and content analysis, the data were coded using the qualitative text analysis software, MAXQDA by numbering each line of the dialogue [52]. The "Advanced Coding Method" in MAXQDA Standard was used for content analysis with major keywords that were allocated to data segments. The "Lexical Search" function located the keywords in all the text that define the 3 major constructs as identified in Table 1. Once the keywords of befriending, SI, boredom, socialization, engagement, and motivation were identified, the thematic coding of the relevant texts was performed using MAXQDA's visual tool, "One Code Model." We explored the frequency of words and terms used in the sources and analyzed their semantic contexts in a quantitative way. A differentiated word frequency analysis was performed using the "MAXDictio Module" [52]. The data were then classified into several groups to reveal trends and patterns of response to each question in the survey and in each topic of conversation between the older adults and students from the student dairies and reflections. Topically similar codes were grouped together and then narrowed by code segments using the option "Subcode Statistics" in the context menu of the "Code System" of MAXQDA. For example, the code "intergenerational befriending" was further subcoded as "comfortability," "positive emotions," and "perceived benefits." Finally, using the MAXQDA function "Analysis Summary Grid," thematic compilations were presented in "Participant Comment Tables."

The use of heuristic inquiry [51,52] helped us to discover the nature of social phenomena, especially the intergenerational bonding that developed between participants, as we systematically coded the data. Owing to the complex nature of the emerging themes related to befriending and self-expression, heuristic inquiry appeared to be the most convenient method of sense making for this study. The heuristic depictions of the artifacts involved a synthesis of intuition and tacit understanding of researchers [53]. This understanding characterized the idea of befriending experience. The concepts that emerged from the study included relationship building, empathy, social interactions, and capacity for additional relational networks outside the family.

Results

In the older population of 46 adults, of which 19 (41%) were men and 27 (59%) were women, 3 main constructs were identified: intergenerational befriending, meaningful engagement, and internal motivation to participate in the program. According to the older adult participants, the perceived benefits of the friendly nature of intergenerational interaction were mainly the heightened feelings of comfort and reduced boredom. For both the student and older adult participants, trust in the interactions bolstered the positive emotions, enhancing the feeling of safety and social affinity. Table 2 displays the number of times the older adults' and student participants' specifics about the scope of befriending and engagement to reduce boredom. Meaningful engagement was described as "reduced boredom," "feeling safe," and "increased confidence." For a total of 253 times, the older adult participants mentioned that they were purposefully engaged, 96 times they reiterated their feeling of happiness, 58 times about feeling safe, and 98 times that there was an impressive increase in their level of confidence. Similarly, students mentioned 201 times that they were meaningfully engaged in the project, 91 times they felt happy, 55 times that they did not feel bored in the conversations with older adults, and 97 times about the increased level of confidence.

Intergenerational befriending was summarized as "comfortability" and "positive emotions." The older adult participants specified 97 times that they benefited from the program and that they made new friends. For many older people, "engagement to reduce boredom" specified 97 times, was the main reason for participating in these conversations. Intergenerational sessions enhanced the motivation level of the older adults 277 times, with improvement in emotional health or positive emotions (specified 80 times). Having company was more of an antidote to reduce boredom (specified 90 times). The discussions about daily life experience led to emotive bonding and friendship. For the students, the befriending experience (specified 201 times) enhanced the feeling of comfort (specified 70 times) and positive emotions (59 times). Both the students and older adult participants looked forward to the sessions and considered it as a reason to get up in the morning.

The intergenerational service-learning intervention mainly covered two activities: (1) discussions about daily life experience to reduce the gap between generations and (2) digital training to help older adults to use social media sites and apps such as Facebook or Uber. The main attributes of SI targeted in this study, namely, boredom and loneliness, were minimized to some extent with the befriending approach as people felt safe and happy as they interacted with the students. Importantly, older adults were extremely interested in the technology training from students regarding how to use social media sites and apps such as Facebook and Uber. Tables 3 and 4 reflect the confirmatory statements of the older adults and students toward the valuable "befriending" component that engaged older adult participants substantially with the undergraduate college students in digital training and motivated them to share their life experiences safely. The attributes of hesitation and fear, which were noticed in the initial stages, turned to compassion, trust, respect, empathy, honesty, and warmth in the later stages, which are the most essential attributes of friendship.

The positive attitude and the dedication of the students toward the project helped the older adults to find social support and feel safe. On most occasions, activities were based upon the interest of the older adults. The opportunities for social interaction were possible as students were proactive and flexible with time and the needs of their older adult partners. The results revealed the importance of students' positivity to support the older adults and the increased level of motivation for spontaneous interactions. The students created a friendly environment, or that of companionship, where the older adults had confidence that the discussions were appropriate based on their choices and preferences.

Another key finding was that older people define boredom and comfort differently and that there is a difference between the students' perceptions and older adults' perceptions related to interactions to alleviate boredom. Although befriending through these sessions cannot compensate for the loss of an attachment figure, such as a close friend, spouse, or a significant other, which is common in old age, people with poor social skills are likely to have trouble in developing and maintaining relationships. Negative perceptions about age and aging, at societal and individual levels, have adverse effects on older adults' health and well-being. Ageism, which means negative attitudes toward older adults, or unrealistic expectations about the intergenerational sessions can leave both the older adults and the young individuals with unmet social needs, resulting in increased boredom. Hence, the befriending approach must be understood from the individual's subjective point of view.

Table 2. Constructs and subconstructs identified from the intergenerational service-learning intervention.

Name of the constructs and subconstructs	Number of times specified by older adults (n=786), n (%)	Number of times specified by students (n=557), n (%)
Intergenerational befriending	256 (32.6)	179 (32.1)
Comfortability	79 (10.1)	70 (12.6)
Positive emotions	80 (10.2)	59 (10.6)
Perceived benefits	97 (12.3)	50 (8.9)
Internal motivation	277 (35.2)	177 (31.8)
Feeling of happiness	96 (12.2)	91 (16.3)
Discussion about daily life experiences	181 (23)	86 (15.4)
Meaningful engagement	253 (32.2)	201 (36.1)
Feeling safe	58 (7.4)	49 (8.8)
Increased confidence	98 (12.5)	97 (17.4)
Reduced boredom	97 (12.3)	55 (9.9)

Table 3. Comments of older adults about the key constructs.

Key construct	Comments
Meaningful engagement	• "Like to talk about you and the multicultural sensitivity project in the Zumba classes three times a week, and ballet classes twice a week." [Participant 2] • "Feel glad, I seem to have more control on anger unlike before, we have opportunities for social interaction and there is less counterproductive behavior." [Participant 45] • "She plays for the university's basketball team. Since the university is so close to where I live, I get to attend all her games and is eternally grateful for this." [Participant 5] • "The student group hosts a couple of social events every day, so there is always an event to attend and enjoy. Some of these events include- bingo, bible studies, stretching class, and physical fitness classes as well." [Participant 42] • "She is physically very active, I enjoyed our zoom discussion last week, me and my husband, engaging in either yoga, meditation, or going on 30-minute walks." [Participant 16]
Internal motivation to participate	• "Family reunion was over; it was a good day of our weekly conversation and i-phone training." [Participant 39] • "Grateful to be able to wake up each morning and do the things that I enjoy, like art and seeing family and talking to my student friend over the phone." [Participant 3] • "Like to talk to you about school, do you enjoy the simple pleasures in life like cooking?" [Participant 28]
Intergenerational approach to befriending	• "Now look forward to our weekly conversations and app training sessions." [Participant 40] • "I don't get to see my grandchildren as often as I would like, so having a person of the younger generation to talk to weekly reminds me a lot of them." [Participant 25]

Table 4. Comments of students about the key constructs.

Key construct	Comments
Meaningful engagement	• "At first the project was challenging, towards the end I felt relaxed, as I came to know the older adult partner more closely." [Participant 9] • "She explained it so well, I never thought before that smoothie making could be so simple." [Participant 11]
Internal motivation to participate	• "She loves everything about her life. Our hobbies are the same. She is blessed to be healthy at her age, and she wouldn't change a thing." [Participant 12] • "My grandmother used to tell me similar things, to be able to wake up each morning and enjoy breakfast with family." [Participant 1]
Intergenerational approach to befriending	• "Feels nice to be in an interesting conversation and write diaries." [Participant 46] • "So happy to help someone who sees her grandchild in me." [Participant 45]

Discussion

Summary

The befriending intervention delivered through the service-learning sessions promoted reciprocity and social support that enhanced the quality of life by fostering positive emotions and reduced boredom and loneliness. The intergenerational service-learning program fostered discussions about daily life experience that reduced the gap between generations and promoted companionship [54]. The proactiveness and dedication of the students for their project helped the older adults to find social support and feel safe and created a bonding between the generations with long-lasting friendships.

Meaningful Engagement

Through this specific intergenerational service-learning experiment, we found that most older adults try to keep themselves occupied through personal hobbies; talking to family over the phone; and occasionally, even work. Meaningful engagement was depicted well through the comments of older adult participant 42 who was happy and well engaged in programs and activities administered by the university such as telephone-based befriending and contactless luncheons with students. For these participants, social interaction through the service-learning program enhanced connectivity and reduced the risk of losing the motivation to maintain an active and healthy lifestyle. The conversations reduced the feelings of boredom and isolation that adversely affected their emotional health. These sessions helped the older adult to reengage in community networks and participate freely in cohesive neighborhood environments with other members of the older adult living facility. Older adult participant 2 found these sessions to be meaningful and interesting, explained the importance of these sessions to friends and community, and constantly spoke about the interactions in the Zumba and ballet classes 2 to 3 times a week. The intergenerational service-learning conversations toward the end of the project showed a heightened level of comfort for both the older adults and the youths and made the older adults feel that they are cared for while in conversation. Hence, they were not bored in their conversation with the students.

Internal Motivation to Participate

For the older adults, there is the need of a companion to share life experiences [55], which is profound when separated from the family owing to relocation, death of family members, or retirement [56]. The befriending activity reduced the boundaries between the 2 people involved, and the student befriender was asked to undertake tasks that the older adult wanted to do, such as using technology or having contactless visits during family reunion. This created a sense of internal motivation for older adult 40 to participate in the interactions. As students helped the older adults to interact with their family and share life stories, these interactive sessions fostered companionship that was of interest to the older adult and a reason for the student to find meaning and value in the conversations. Following the comments of older adult participant 25 and student participant 45, we found discussions about spouses to children and grandchildren and, for some, even to great grandchildren. All familial connections showed the importance of social support and motivated both parties in conversation on a day-to-day basis. Student participant 12 prayed for the well-being of his older adult partner and felt happy as he discovered a common hobby to talk about. Older adult participant 39 described her spouse returning from rehabilitation and mentioned that a welcome home party with her spouse's family resulted in her having a good day. Older adult participant 5 revealed that she is eternally grateful to be able to attend her befriender's basketball games; the joy and motivation to be able to socially connect seemed to have a positive effect on her well-being.

Intergenerational Approach to Befriending

Although several of the older adults in this study had various outlets to socialize such as hobbies, calling a friend, and family visits outside the intergenerational service-learning sessions, they still expressed appreciation toward the students for their time and companionship, which fulfilled the idea of befriending that we aimed for in this study. Student 45 noted that the older adult was nervous at the beginning but eventually looked forward to their weekly conversations, further mentioning that having someone from the young generation to talk to reminded her about her grandchildren whom she does not get to see often. In another instance, student participant 46 would write down events worth mentioning every week to discuss during the call. The overall evaluation of the intergenerational conversation was positive; older adult 40 wrote in the survey that she valued the ability to talk, listen, and share information with another human being whom she could trust and rely on. The befriending approach within these sessions appeared to expose the similarities between 2 different generations as the weeks passed. For example, student 28 revealed that he felt lucky to share the same religious and spiritual beliefs as the older adult partner. Similarly, student 42 stated that she and her older adult partner shared the same type of church. Most of the student's reflections revealed the idea of reliability, compatibility, intimacy, and reciprocity in the conversations, which had a positive effect on promoting friendship and reducing boredom and loneliness for both parties. In addition, the program improved the youth's social skills and assumptions related to one's privacy and safety.

Limitations

This study has some limitations. Several students reported being unable to communicate with their partners at the beginning of the project owing to difficulty with older adults' digital literacy, inability to answer phone calls or read SMS text messages, or inability to use apps such as Zoom or FaceTime. This ruled out the possibility of Zoom focus groups. In-person focus groups were also not possible owing to COVID-19 socialization restrictions. In some cases, there was dropout of older adults from the project owing to sickness or other health conditions. Although the authors clearly explained to the older adults that the service-learning project was completely contactless, some of them still preferred face-to-face interaction, which was not possible because of COVID-19 restrictions. Furthermore, student notes may not be free from bias. The findings from this study have limited generalizability because we used a sample of students from 1 course, and the results may not be applicable in other study settings. Variables such as overall health, stress, stigma, comorbid conditions, socioeconomic status, and discrimination were not considered while assessing older adult surveys or student artifacts in the study.

Conclusions

The need to feel important and be included in a large social group is vital regardless of age. The need is perhaps more during the later stages of life when one has more physical and mental challenges and is confined in living situations with very limited social networks. The effects of service-learning sessions on boredom and loneliness among older adults promoted interest in intergenerational practice to reduce SI and improved the feelings of companionship among both students and older adults as a long-term outcome of the intervention. Students identified the intergenerational component as a highlight of the health administration course, which increased their awareness of gerontological issues and knowledge about working with aging populations. The intervention enhanced students' attitude toward companionship and gerontological practices via intergenerational befriending opportunities and digital training sessions. As students developed an interest in service-learning programs through frequent interactions with older adults, the social interaction component in the program amplified social connectivity via contactless interactions, phone conversations, and digital training sessions for older adults. Consequently, it reduced the risk of losing the motivation to maintain a self-image and an active and healthy lifestyle among older adults. This study was designed for periodic or postpandemic follow-up of the participants experiencing SI. Our results showed that older adults wished to maintain their social connectedness and access to technology and digital networks. Driven by a desire to communicate and access information that stemmed from the need to connect to friends, family, or other internet-based services such as mobile health or social media, older adults showed appreciation and gratitude toward the youth for taking an interest in their lives and, often, would look forward to their weekly conversations.

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Data Availability

The institutional review board of this study does not allow data sharing because the data protection statement is an integral part of our institutional review board approval. Therefore, our data will not be made available.

Authors' Contributions

KS was involved in conceptualization, methodology, validation, formal analysis, investigation, resources, data curation, writing, and original draft preparation. ZR and NL wrote and prepared the original draft. All other authors reviewed and edited the manuscript.

Conflicts of Interest

None declared.

References

1. Fakoya OA, McCorry NK, Donnelly M. Loneliness and social isolation interventions for older adults: a scoping review of reviews. BMC Public Health 2020 Feb 14;20(1):129 [FREE Full text] [doi: 10.1186/s12889-020-8251-6] [Medline: 32054474]

2. Boamah SA, Weldrick R, Lee TS, Taylor N. Social isolation among older adults in long-term care: a scoping review. J Aging Health 2021 Mar 27;33(7-8):618-632 [FREE Full text] [doi: 10.1177/08982643211004174] [Medline: 33779366]
3. Artale RB, Artale LM. Benefits of intergenerational service-learning to human services majors. Educ Gerontol 2001 Jan;27(1):71-87 [FREE Full text] [doi: 10.1080/036012701750069058]
4. Wang Y, Fu P, Li J, Gao T, Jing Z, Wang Q, et al. Community-level social support to mitigate the impact of combined frailty and multimorbidity on psychological distress among rural Chinese older adults during the COVID-19 pandemic: multilevel modeling study. JMIR Public Health Surveill 2023 Mar 09;9:e43762 [FREE Full text] [doi: 10.2196/43762] [Medline: 36811848]
5. Cudjoe TK, Roth DL, Szanton SL, Wolff JL, Boyd CM, Thorpe Jr RJ. The epidemiology of social isolation: national health and aging trends study. J Gerontol B Psychol Sci Soc Sci 2020 Jan 01;75(1):107-113 [FREE Full text] [doi: 10.1093/geronb/gby037] [Medline: 29590462]
6. Yang X, Yip BH, Mak AD, Zhang D, Lee EK, Wong SY. The differential effects of social media on depressive symptoms and suicidal ideation among the younger and older adult population in Hong Kong during the COVID-19 pandemic: population-based cross-sectional survey study. JMIR Public Health Surveill 2021 May 25;7(5):e24623 [FREE Full text] [doi: 10.2196/24623] [Medline: 33835937]
7. Phang JK, Kwan YH, Yoon S, Goh H, Yee WQ, Tan CS, et al. Digital intergenerational program to reduce loneliness and social isolation among older adults: realist review. JMIR Aging 2023 Jan 04;6:e39848 [FREE Full text] [doi: 10.2196/39848] [Medline: 36598801]
8. Plummer J, Nguyen K, Everly J, Kiesow A, Leith K, Neils-Strunjas J. How an intergenerational book club can prevent cognitive decline in older adults: a pilot study. Gerontol Geriatr Med 2023 Jan 20;9:23337214221150061 [FREE Full text] [doi: 10.1177/23337214221150061] [Medline: 36698383]
9. Fakoya OA, McCorry NK, Donnelly M. How do befriending interventions alleviate loneliness and social isolation among older people? A realist evaluation study. PLoS One 2021 Sep 9;16(9):e0256900 [FREE Full text] [doi: 10.1371/journal.pone.0256900] [Medline: 34499682]
10. Neils-Strunjas J, Crandall KJ, Shackelford J, Dispennette K, Stevens LR, Glascock A. Students report more positive attitudes toward older adults following an interprofessional service-learning course. Gerontol Geriatr Educ 2020 Jul 12;41(2):175-185. [doi: 10.1080/02701960.2018.1479262] [Medline: 30001187]
11. Sen K, Prybutok V, Prybutok G, Senn W. Mechanisms of social interaction and virtual connections as strong predictors of wellbeing of older adults. Healthcare (Basel) 2022 Mar 16;10(3):553 [FREE Full text] [doi: 10.3390/healthcare10030553] [Medline: 35327031]
12. Zaine I, Frohlich DM, Rodrigues KR, Cunha BC, Orlando AF, Scalco LF, et al. Promoting social connection and deepening relations among older adults: design and qualitative evaluation of media parcels. J Med Internet Res 2019 Oct 03;21(10):e14112 [FREE Full text] [doi: 10.2196/14112] [Medline: 31584001]
13. Cohen HL, Hatchett B, Eastridge D. Intergenerational service-learning: an innovative teaching strategy to infuse gerontology content into foundation courses. J Gerontol Soc Work 2006;48(1-2):161-178. [doi: 10.1300/J083v48n01_11] [Medline: 17200077]
14. Sen K, Prybutok G, Prybutok V. The use of digital technology for social wellbeing reduces social isolation in older adults: a systematic review. SSM Popul Health 2022 Mar;17:101020 [FREE Full text] [doi: 10.1016/j.ssmph.2021.101020] [Medline: 35024424]
15. Tough H, Siegrist J, Fekete C. Social relationships, mental health and wellbeing in physical disability: a systematic review. BMC Public Health 2017 May 08;17(1):414 [FREE Full text] [doi: 10.1186/s12889-017-4308-6] [Medline: 28482878]
16. Morrow-Howell N, Galucia N, Swinford E. Recovering from the COVID-19 pandemic: a focus on older adults. J Aging Soc Policy 2020 Apr 26;32(4-5):526-535. [doi: 10.1080/08959420.2020.1759758] [Medline: 32336225]
17. LaMonica HM, Davenport TA, Roberts AE, Hickie IB. Understanding technology preferences and requirements for health information technologies designed to improve and maintain the mental health and well-being of older adults: participatory design study. JMIR Aging 2021 Jan 06;4(1):e21461 [FREE Full text] [doi: 10.2196/21461] [Medline: 33404509]
18. Greenfield EA, Russell D. Identifying living arrangements that heighten risk for loneliness in later life: evidence from the U.S. national social life, health, and aging project. J Appl Gerontol 2010 Apr 13;30(4):524-534. [doi: 10.1177/0733464810364985]
19. Prabhu D, Kholghi M, Sandhu M, Lu W, Packer K, Higgins L, et al. Sensor-based assessment of social isolation and loneliness in older adults: a survey. Sensors (Basel) 2022 Dec 16;22(24):9944 [FREE Full text] [doi: 10.3390/s22249944] [Medline: 36560312]
20. Bar-Tur L, Inbal-Jacobson M, Brik-Deshen S, Zilbershlag Y, Pearl Naim S, Brick Y. Telephone-based emotional support for older adults during the COVID-19 pandemic. J Aging Soc Policy 2021 Jul;33(4-5):522-538. [doi: 10.1080/08959420.2021.1924414] [Medline: 33957857]
21. Sepúlveda-Loyola W, Rodríguez-Sánchez I, Pérez-Rodríguez P, Ganz F, Torralba R, Oliveira DV, et al. Impact of social isolation due to COVID-19 on health in older people: mental and physical effects and recommendations. J Nutr Health Aging 2020 Sep 25;24(9):938-947 [FREE Full text] [doi: 10.1007/s12603-020-1500-7]

22. Loades ME, Chatburn E, Higson-Sweeney N, Reynolds S, Shafran R, Brigden A, et al. Rapid systematic review: the impact of social isolation and loneliness on the mental health of children and adolescents in the context of COVID-19. J Am Acad Child Adolesc Psychiatry 2020 Nov;59(11):1218-39.e3 [FREE Full text] [doi: 10.1016/j.jaac.2020.05.009] [Medline: 32504808]
23. Alwin DF, Felmlee DH, Kreager DA. Social Networks and the Life Course: Integrating the Development of Human Lives and Social Relational Networks. Cham, Switzerland: Springer; 2018.
24. Andreoletti C, Howard JL. Bridging the generation gap: intergenerational service-learning benefits young and old. Gerontol Geriatr Educ 2018 Sep 10;39(1):46-60. [doi: 10.1080/02701960.2016.1152266] [Medline: 26905456]
25. Ramamonjiarivelo Z, Osborne R, Renick O, Sen K. Assessing the effectiveness of intergenerational virtual service-learning intervention on loneliness and ageism: a pre-post study. Healthcare (Basel) 2022 May 12;10(5):893 [FREE Full text] [doi: 10.3390/healthcare10050893] [Medline: 35628031]
26. Johnson AM, Notah DJ. Service learning: history, literature review, and a pilot study of eighth graders. Elem Sch J 1999 May;99(5):453-467 [FREE Full text] [doi: 10.1086/461935]
27. Stewart T, Wubbena ZC. A systematic review of service-learning in medical education: 1998-2012. Teach Learn Med 2015 Apr 20;27(2):115-122. [doi: 10.1080/10401334.2015.1011647] [Medline: 25893932]
28. Liu RL, Lin PY. Changes in multicultural experience: action research on a service learning curriculum. Syst Pract Action Res 2016 Jul 6;30(3):239-256 [FREE Full text] [doi: 10.1007/s11213-016-9395-2]
29. Levy BR, Leifheit-Limson E. The stereotype-matching effect: greater influence on functioning when age stereotypes correspond to outcomes. Psychol Aging 2009 Mar;24(1):230-233 [FREE Full text] [doi: 10.1037/a0014563] [Medline: 19290757]
30. Angelou K, McDonnell C, Low LF, du Toit SH. Promoting meaningful engagement for residents living with dementia through intergenerational programs: a pilot study. Aging Ment Health 2023 May 13;27(5):938-947. [doi: 10.1080/13607863.2022.2098910] [Medline: 35822455]
31. Fearn M, Harper R, Major G, Bhar S, Bryant C, Dow B, et al. Befriending older adults in nursing homes: volunteer perceptions of switching to remote befriending in the COVID-19 era. Clin Gerontol 2021 Jul;44(4):430-438. [doi: 10.1080/07317115.2020.1868646] [Medline: 33403935]
32. Greenblatt-Kimron L, Shinan-Altman S, Alperin M, Levkovich I. Depression and medicine use among older adults during the COVID-19 pandemic: the role of psychosocial resources and COVID-19 perceived susceptibility. Int J Environ Res Public Health 2023 Feb 15;20(4):3398 [FREE Full text] [doi: 10.3390/ijerph20043398] [Medline: 36834090]
33. Lytle A, Macdonald J, Levy SR. An experimental investigation of a simulated online intergenerational friendship. Gerontol Geriatr Educ 2023 Jan 19;44(2):286-297. [doi: 10.1080/02701960.2021.2023810] [Medline: 35043755]
34. Bringle RG, Hatcher JA. Implementing service learning in higher education. J Higher Educ 2016 Nov;67(2):221-239 [FREE Full text] [doi: 10.1080/00221546.1996.11780257]
35. van Leeuwen KM, van Loon MS, van Nes FA, Bosmans JE, de Vet HC, Ket JC, et al. What does quality of life mean to older adults? A thematic synthesis. PLoS One 2019 Mar 8;14(3):e0213263 [FREE Full text] [doi: 10.1371/journal.pone.0213263] [Medline: 30849098]
36. Park LG, Meyer OL, Dougan MM, Golden B, Ta K, Nam B, et al. Social support and technology use and their association with mental and physical health during the COVID-19 pandemic among Asian Americans: the COMPASS cross-sectional study. JMIR Public Health Surveill 2023 Jan 23;9:e35748 [FREE Full text] [doi: 10.2196/35748] [Medline: 36395324]
37. Yeung P, Severinsen C, Good G, O'Donoghue K. Social environment and quality of life among older people with diabetes and multiple chronic illnesses in New Zealand: intermediary effects of psychosocial support and constraints. Disabil Rehabil 2022 Mar 06;44(5):768-780. [doi: 10.1080/09638288.2020.1783375] [Medline: 32623910]
38. Chopik WJ. The benefits of social technology use among older adults are mediated by reduced loneliness. Cyberpsychol Behav Soc Netw 2016 Sep;19(9):551-556 [FREE Full text] [doi: 10.1089/cyber.2016.0151] [Medline: 27541746]
39. Hwang J, Toma CL, Chen J, Shah DV, Gustafson D, Mares ML. Effects of web-based social connectedness on older adults' depressive symptoms: a two-wave cross-lagged panel study. J Med Internet Res 2021 Jan 13;23(1):e21275 [FREE Full text] [doi: 10.2196/21275] [Medline: 33439143]
40. Kruse CS, Sen K, Armenta V, Hubbard N, Brooks R. Leveraging mHealth and virtual reality to improve cognition for Alzheimer's patients: a systematic review. Healthcare (Basel) 2022 Sep 23;10(10):1845 [FREE Full text] [doi: 10.3390/healthcare10101845] [Medline: 36292292]
41. Meinert E, Milne-Ives M, Surodina S, Lam C. Agile requirements engineering and software planning for a digital health platform to engage the effects of isolation caused by social distancing: case study. JMIR Public Health Surveill 2020 May 06;6(2):e19297 [FREE Full text] [doi: 10.2196/19297] [Medline: 32348293]
42. Li C, Jiang S, Zhang X. Intergenerational relationship, family social support, and depression among Chinese elderly: a structural equation modeling analysis. J Affect Disord 2019 Apr 01;248:73-80. [doi: 10.1016/j.jad.2019.01.032] [Medline: 30716614]
43. Byrd R. Qualitative research methods. The University of Memphis. 2022. URL: https://www.memphis.edu/jrsm/syllabi/syllabi_pages/syllabi_pdfs/fall_2022/jrsm7085.s01.001.byrd.fall2022.pdf [accessed 2024-01-09]

44. Ohlmeier S, Klingler C, Schellartz I, Pfaff H. Having a break or being imprisoned: influence of subjective interpretations of quarantine and isolation on boredom. Int J Environ Res Public Health 2022 Feb 15;19(4):2207 [FREE Full text] [doi: 10.3390/ijerph19042207] [Medline: 35206395]
45. Schwartz-Mette RA, Shankman J, Dueweke AR, Borowski S, Rose AJ. Relations of friendship experiences with depressive symptoms and loneliness in childhood and adolescence: a meta-analytic review. Psychol Bull 2020 Aug;146(8):664-700. [doi: 10.1037/bul0000239] [Medline: 32406698]
46. Diener E, Emmons RA, Larsen RJ, Griffin S. The satisfaction with life scale. J Pers Assess 1985 Feb 10;49(1):71-75. [doi: 10.1207/s15327752jpa4901_13] [Medline: 16367493]
47. Gierveld JD, Tilburg TV. A 6-item scale for overall, emotional, and social loneliness: confirmatory tests on survey data. Res Aging 2016 Aug 18;28(5):582-598 [FREE Full text] [doi: 10.1177/0164027506289723]
48. Kozma A, Stones MJ. The measurement of happiness: development of the Memorial University of Newfoundland Scale of Happiness (MUNSH). J Gerontol 1980 Nov 01;35(6):906-912. [doi: 10.1093/geronj/35.6.906] [Medline: 7440930]
49. Russell DW. UCLA loneliness scale (Version 3): reliability, validity, and factor structure. J Pers Assess 1996 Feb;66(1):20-40. [doi: 10.1207/s15327752jpa6601_2] [Medline: 8576833]
50. Golden J, Conroy RM, Bruce I, Denihan A, Greene E, Kirby M, et al. Loneliness, social support networks, mood and wellbeing in community-dwelling elderly. Int J Geriatr Psychiatry 2009 Jul 09;24(7):694-700. [doi: 10.1002/gps.2181] [Medline: 19274642]
51. Douglass BG, Moustakas C. Heuristic inquiry: the internal search to know. J Humanist Psychol 1985;25(3):39-55 [FREE Full text] [doi: 10.1177/0022167885253004]
52. Kuckartz U, Rädiker S. Analyzing Qualitative Data with MAXQDA: Text, Audio, and Video. Cham, Switzerland: Springer; 2019.
53. Saillard EK. Systematic versus interpretive analysis with two CAQDAS packages: NVivo and MAXQDA. Forum Qual Sozialforschung 2011;12(1):34 [FREE Full text]
54. Krivanek TJ, Gale SA, McFeeley BM, Nicastri CM, Daffner KR. Promoting successful cognitive aging: a ten-year update. J Alzheimers Dis 2021;81(3):871-920 [FREE Full text] [doi: 10.3233/JAD-201462] [Medline: 33935078]
55. de Jong Gierveld J, van Tilburg T, Dykstra PA. Loneliness and social isolation. In: Vangelisti AL, Perlman D, editors. The Cambridge Handbook of Personal Relationships. Cambridge, MA: Cambridge University Press; 2006:485-500.
56. Dykstra PA, van Tilburg TG, Gierveld JD. Changes in older adult loneliness: results from a seven-year longitudinal study. Res Aging 2005;27(6):725-747 [FREE Full text] [doi: 10.1177/0164027505279712]

Abbreviations

SI: social isolation

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Determinants of Implementing an Information and Communication Technology Tool for Social Interaction Among Older People: Qualitative Content Analysis of Social Services Personnel Perspectives

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Abstract

Background: Older people are particularly vulnerable to social isolation and loneliness, which can lead to ill-health, both mentally and physically. Information and communication technology (ICT) can supplement health and social care and improve health among the vulnerable, older adult population. When ICT is used specifically for communication with others, it is associated with reduced loneliness in older populations. Research is sparse on how the implementation of ICT, used specifically for communication among older people in social services, can be performed. It is recommended to consider the determinants of implementation, that is, barriers to and facilitators of implementation. Determinants related to older people using ICT tools are reported in several studies. To the best of our knowledge, studies investigating the determinants related to the social services perspective are lacking.

Objective: This study aims to explore the determinants of implementing the Fik@ room, a new, co-designed, and research-based ICT tool for social interaction among older people, from a social services personnel perspective.

Methods: This study used an exploratory, qualitative design. An ICT tool called the Fik@ room was tested in an intervention study conducted in 2021 in 2 medium-sized municipalities in Sweden. Informants in this study were municipal social services personnel with experience of implementing this specific ICT tool in social services. We conducted a participatory workshop consisting of 2 parts, with 9 informants divided into 2 groups. We analyzed the data using qualitative content analysis with an inductive approach.

Results: The results included 7 categories of determinants for implementing the ICT tool. *Being able to introduce the ICT tool in an appropriate manner* concerns the personnel's options for introducing and supporting the ICT tool, including their competencies in using digital equipment. *Organizational structure* concerns a structure for communication within the organization. *Leadership* concerns engagement and enthusiasm as driving forces for implementation. *The digital maturity of the social services personnel* concerns the personnel's skills and attitudes toward using digital equipment. *Resources* concern time and money. *IT support* concerns accessibility, and *legal liability* concerns possibilities to fulfill legal responsibilities.

Conclusions: The results show that implementation involves an entire organization at varying degrees. Regardless of how much each level within the organization comes into direct contact with the ICT tool, all levels need to be involved to create the necessary conditions for successful implementation. The prerequisites for the implementation of an ICT tool will probably change depending on the digital maturity of future generations. As this study only included 9 informants, the results should be handled with care. The study was performed during the COVID-19 pandemic, which has probably affected the results.

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KEYWORDS

information and communication technology; implementation; determinants; social isolation; loneliness; organization; digitalization; facilitators; barriers; older people

Introduction

Older people are especially vulnerable to social isolation and loneliness, particularly because they are exposed to risk factors such as living alone and experiencing chronic illness [1]. There is robust evidence linking loneliness and isolation with physical decline; morbidity; increased mortality; and cognitive and mental health problems, such as depression and dementia; and increased risk of suicide [2-7]. Several studies point toward an increase in loneliness during the COVID-19 pandemic with *stay-at-home* orders and recommendations for social distancing [8-11], and the impact is particularly severe among people aged ≥80 years [12]. Information and communication technology (ICT) can supplement health and social care and improve health in the vulnerable, older population [4,13]. ICT is a part of welfare technology, which in one way or another, improves the lives of those who need it. When technology is used specifically for communication with others, it is associated with reduced loneliness [4,13-16] and increased well-being and life satisfaction [4] in older populations. Technology can improve social connectedness among older adults. The specific effectiveness rates favor ICT and videoconferencing [13]. Chen and Schultz [15] identified 4 important mechanisms for reducing social isolation using ICT: staying connected to other people, such as family and friends; gaining social support; participating in interesting activities; and boosting self-confidence. Studies show that ICT can support and maintain the social relationships and healthy and independent lives of older people at the individual level and should be prioritized as an early and preventive intervention in social services [17]. However, the use of ICT has been shown to decrease after 6 months of use [15,16]. Only few studies have investigated how the implementation of web-based social activities in social services can be performed. Thus, there is a need for sustainable, structured, and well-planned solutions for the implementation of ICT in social services.

To make ICT useful for older people, social services must consider the determinants for its implementation, that is, barriers to and facilitators of implementation. Determinants related to older people are reported in several studies. A literature review including 59 papers identified determinants related to this specific population's adoption of technology, such as perceived usefulness, potential benefits, user friendliness, ease of learning, perceived costs and savings, knowledge about existence, availability in the market, technical support, social support, perceived emotional and psychological benefits, and relevance with their previous experiences [18]. Other identified determinants related to older people are gaps in ICT literacy, fear of making mistakes when learning the ICT tool [19], privacy concerns, technical difficulties, lack of user-friendly options designed specifically for an older population, and lack of experience in using technology [20,21]. However, implementation of ICT does not depend on the older people alone. Social services personnel have an important role in introducing ICT to older people and to support its use [22]. Thus, ways of working to introduce and support the use of ICT among older people need to be implemented in the social services and other services they offer. To the best of our knowledge, determinants of implementing an ICT tool for social interaction among older people related to the social services personnel perspective are lacking.

The readiness and maturity to adopt digitalization and new ways of working vary among the social services provided by Swedish municipalities, for example, in residential care services and home care services. Few older people receive access to welfare technology services despite the benefits [23]. It is a large step for an organization to move from a limited project to implementation in their organization. Konttila et al [24] identified determinants of importance for digitalization in health care but not specifically for the care of older people, related to professionals' knowledge, skills, attitudes, and experiences and organizational and collegial support. One of the proposals from the Swedish Ministry of Health and Social Affairs [23] is that studies are needed to implement models for welfare technology in social services. A systematic review focused on facilitators and barriers that influence the implementation of welfare technology for older people, from the perspectives of older individuals, people with disabilities, informal caregivers, health and care personnel, organizations, infrastructure, and technology [25]. Overall, 6 themes of determinants were identified: capacity, attitudes and values, health, expectations of effects, shared decision-making, and identity and lifestyle. These determinants are within different levels in an organization and are consistent with other determinant frameworks for implementation [26,27]. However, most of the included papers in the systematic reviews of determinants for digitalization and implementation of welfare technology for older people [24,25] involved various types of technology, such as technology for smart homes, mobile devices in medicine and public health, self-care, medication, and surveillance systems, whereas ICT used specifically for communication among older people was not included. This study aimed to explore the determinants of implementing the Fik@ room, a new, co-designed, and research-based ICT tool for social interaction among older people, from a social services personnel perspective.

Methods

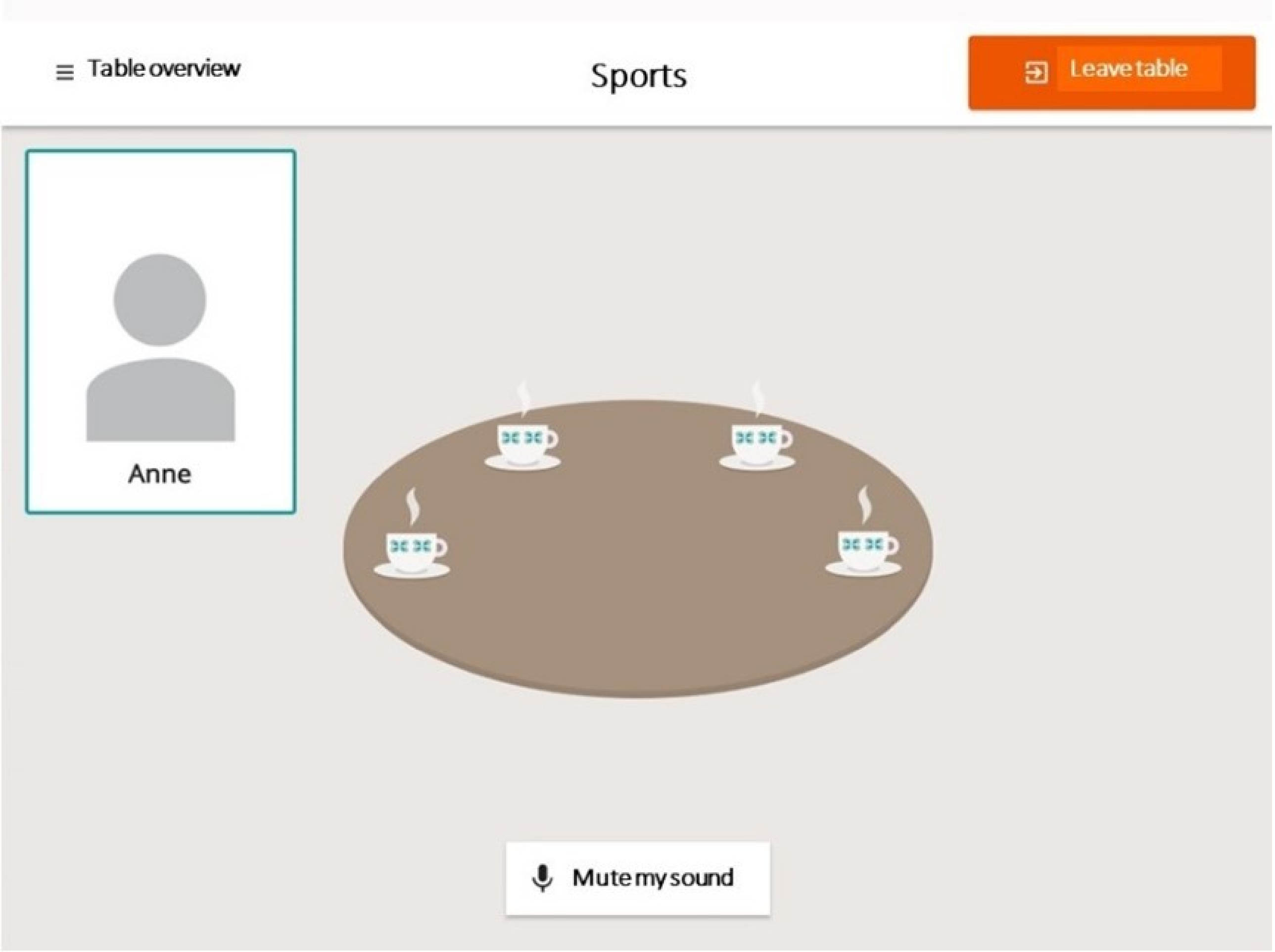
Design

This study used an exploratory, qualitative design [28,29]. An exploratory design is appropriate for conducting studies in a field that is relatively underexplored and hence, an inductive approach was adopted [30].

The Fik@ room: An ICT Tool for Social Interaction Among Older People

The Fik@ room is a research-based ICT tool, in the form of a web platform for safe web-based social interaction, created and developed by researchers in coproduction with older people aged ≥60 years, municipal health and social care personnel, and an IT company, based on focus group interviews and workshops. The content and design of the Fik@ room was based on the needs and wishes expressed by older people [31]. The older people who participated in the development process in 2019 and 2020 expressed the importance of knowing that others visiting the Fik@ room were equal, that is, experiencing loneliness, and access to the Fik@ room was protected by an individual password. This log-in procedure contributes to increase the safety and the feeling thereof for the older people. All older people with access to the Fik@ room have received personal log-ins from a contact person from the municipality. People who received log-ins were older people who had experienced loneliness or social isolation [31]. The Fik@ room consists of digital coffee tables with seating for up to 4 people at each table (Figure 1). The older people can start conversations regarding topics of their own choice using video, voice, or chat. They can also post messages to each other on a bulletin board. In the Fik@ room, older people can meet new friends and socialize as a way of forming routines in their everyday lives. The Fik@ room focuses on meeting peers (people in the same situation) and offers the opportunity to meet and discuss subjects related to users' interests. This foundation improves the quality of conversations in the Fik@ room and increases independence, participation, accessibility, and options for users to form their own social interactions as part of their everyday lives, which is associated with better quality of life for older people [17]. The Fik@ room is available on Google Play Store and Apple App Store (for iPad devices) but will not be available for logging in without permission from an authorized gatekeeper such as personnel in the municipality.

Figure 1. Illustration of a digital coffee table within the Fik@ room. The conversation theme of this table is sports, and in this example, only 1 person is attending.



Informants and Settings

The ICT tool was tested in an intervention study performed in May and June 2021 in 2 medium-sized municipalities in the middle of Sweden. The 2 municipalities were chosen because they are coproduction partners of the University and were both involved in the development of the Fik@ room. Informants in this study were social services personnel, with experiences of the intervention study and thus the implementation of this specific ICT tool in social services: municipal social services managers and social services personnel who recommended the ICT tool to older people in the intervention study (Table 1). The informants were chosen using a purposive sampling technique to capture different perspectives and experiences from the stakeholders in the implementation process, which provided the process with experience-related information and theory-based knowledge. In total, 9 informants from the 2 municipalities agreed to participate, who were basically all the people involved in the implementation process. Municipality 1 had an ongoing digitalization project running in parallel with the intervention study. This means that the municipality was appointed by The Swedish Association of Local Authorities and Regions as 1 of 10 model municipalities, which would function as a model for the digitalization of care for older people. These 10 municipalities received extra financial support to enable time for knowledge dissemination. Together with The Swedish Association of Local Authorities and Regions, they support other municipalities with knowledge about digital services and welfare technology. Municipality 2 was not involved in the parallel, ongoing digitalization project.

Table 1. Characteristics of the informants and settings.

Characteristics	Municipality 1 (n=6)	Municipality 2 (n=3)
Sex of the informants, n (%)		
Male	2 (33)	0 (0)
Female	4 (67)	3 (100)
Profession of the informants, n (%)		
Manager	2 (33)	1 (33)
Developer	1 (17)	0 (0)
Occupational therapist	0 (0)	1 (33)
Technology supporter[a]	2 (33)	0 (0)
Guide for older people[b]	1 (17)	1 (33)
Ongoing digitalization project	Yes	No

[a] Technology supporters were IT experts, employed in the municipality, who prepared the iPad devices for the older people in the intervention study by installing SIM cards and connecting them to the network and installing the Fik@ room app.

[b] Guides for older people were social services personnel with experience in IT, employed in the municipality, who worked at the meeting places for older people and supported the older individuals regarding the use of the iPad and the Fik@ room app.

Data Collection

Participatory workshops with 2 researchers acting as workshop leaders provided a valuable opportunity to learn together and discuss several perspectives. The informants both generated and analyzed data through a structured process for data collection and analysis that includes a combination of individual and group activities, inspired by the effect modifier assessment (EMA) method [32]. The EMA method consists of workshops and subsequent analyses. The workshop leaders facilitate the collection of information on past significant events; in this study, the event in focus was the introduction of the Fik@ room to older people. The method facilitates a combination of individual and group activities, which implies that all experiences from each informant is used and then developed in a group discussion. In this study, semiquantitative estimations were not used because all the determinants (barriers and facilitators) were considered important regardless of how many people had experienced them. The workshop guide (Multimedia Appendix 1) could be considered as a semistructured interview guide, but the workshop informants interactively influenced the interview guide by deciding what events and in what way the events are discussed. Each informant participated in 1 or 2 participatory workshops in August and September 2021, in groups of 3 to 6 participants. Each workshop began with casual conversation to help the informants feel at ease and more comfortable in the setting. The researchers served as workshop leaders to encourage a flow of discussion. To create a comfortable environment for the informants, the workshops were conducted separately for each municipality, ensuring that all the informants within a workshop were familiar with one another. The participatory workshop consisted of 2 parts. The first part focused on the determinants for implementing the ICT tool, and the workshop activities involved the identification of possibilities, obstacles, and challenges that were experienced during the intervention study. The first workshop leader (JF) asked the informants to individually note the possibilities, obstacles, and challenges on a paper in front of them and, thereafter, facilitated a group discussion regarding the same questions. The second workshop leader (CE) asked clarifying questions during the workshop and summarized the discussion at the end of the workshop. The second part started with a review of the first part, followed by the same individual and group processes as the first part, focusing on scenarios for the development of methods to support the implementation of the ICT tool. The workshop activities were regarding how to overcome the obstacles and reinforce the possibilities identified in the first part of the participatory workshop.

The workshops were performed using a web-based video communication tool, Microsoft Teams (Microsoft Corp). Municipality 1 performed the 2 parts of the workshop in separate sessions (2 hours each), and municipality 2 performed both the parts in the same session (2 hours). The informants' professions were requested at the beginning of the first workshop. The workshops were video recorded using the Microsoft Teams video platform.

Data Analysis

The data were analyzed using qualitative content analysis with an inductive approach [33]. The recordings were transcribed verbatim. The text was read several times for familiarization. Meaning units related to the determinants for implementing the ICT tool for social interaction among older people from the perspectives of the social services personnel were identified, coded, and grouped into subcategories and categories according to similarities. Examples of the abstraction of categories from meaning units are shown in Table 2. The identification of meaning units and categorization were performed by the first author. To validate the analysis, part of the categorization was also performed by 2 other authors (CE and PvHW) separately. In addition, the analysis was regularly discussed and validated among all the authors during the process to achieve consensus.

Table 2. Examples of the abstraction process: meaning units, codes, subcategories, and categories.

Meaning unit	Code	Subcategory	Category
...That they [the personnel] have a login so when they are there, they [personnel and older person] can talk to each other at a table [within the ICT[a] tool] just like we did.	Be able to log in to the ICT tool	Be able to show the tool	Be able to introduce the ICT tool in an appropriate manner
If it had been as usual [before the pandemic] then we would have done the same at home visits, and it would have been much easier because then you can show this leaflet, talk about it, and sell it in a better way, so it would have been much better.	Easy to show in person	Be able to show the tool	Be able to introduce the ICT tool in an appropriate manner
The pandemic, of course, because it has not been possible to visit people. They have not wanted to let us in, and not even homecare staff have been able to visit some people. They have declined home care and arranged help in another way because they do not want to expose themselves to the coronavirus.	The pandemic hindered in-person visits	Be able to show the tool	Be able to introduce the ICT tool in an appropriate manner

[a] ICT: information and communication technology.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki [34] and Swedish Ethical Review Act [35]. However, according to the act, ethics approval by the Swedish Ethical Review Authority is not needed when, for example, sensitive personal data are not collected (ie, when interviewing staff to determine how they perform their work), as in this study. However, the intervention study (in which older people were study participants) has obtained ethics approval by the Swedish Ethical Review Authority (Dno 2020-06640). Participation was voluntary, and all informants provided their verbal consent after receiving verbal and written information. Furthermore, they were allowed to withdraw at any time without consequences.

Results

Overview

The results included 7 categories of determinants for implementing the ICT tool: be able to introduce the ICT tool in an appropriate manner, organizational structure, leadership, digital maturity of the social services personnel, resources, IT support, and legal liability (Textbox 1). The results are presented using the categories as headings, and the subcategories are italicized in the text.

Textbox 1. Categories and subcategories of determinants for implementing the information and communication technology (ICT) tool for social interaction among older people.

Be able to introduce the ICT tool in an appropriate manner

- To tailor the information
- Be able to show the ICT tool
- To let the user practice
- The personnel need to have knowledge about the ICT tool

Organizational structure

- A system for effective communication
- Clear roles

Leadership

- The manager’s engagement
- Enthusiasts

The digital maturity of the social services personnel

- The personnel’s digital skills
- The attitudes among the personnel varied

Resources

- Costs
- Time
- Access to transport

IT support

- Accessibility
- Follow-up system

Legal liability (no subcategories)

Be Able to Introduce the ICT Tool in an Appropriate Manner

Older people need to be informed about the existence of the ICT tool. Reaching all potential users with information about the tool was a challenge that the informants did not know how to address. They found that written information sent via mail reached many potential users and was easy to distribute. However, when introducing the ICT tool to an older person, the informants found it important *to tailor the information*, for example, the amount of information that the older person was able to receive, according to their knowledge and attitude toward ICT. Knowing the person and meeting in person facilitated tailoring compared with written information and web-based meetings:

> *I have to know how to structure the conversation with the person I am calling, and I also have to do that when I call the person because I have to hear what status the person has, how should I handle the person, i.e., how should I structure my conversation so that I establish good communication with the person. I must choose my conversational tone mode, how I present it, and how I tell it, a lot is about structuring the conversation and I have to do that immediately when I get in touch with the person.* [Informant 4]

When introducing the ICT tool, the informants found it important to *be able to show the tool*. To enable this, the personnel also needed to have the prerequisites to log in to the ICT tool, which was not always a matter of course. The personnel also needed to have access to their own account, and the program needed to be installed in their digital equipment. To reduce older people’s fear of digital tools, the informants found it important *to let the users practice* using digital tools in a playful manner. Getting acquainted with digital equipment, such as tablets or computers, through playing games, watching movies, or reading newspapers can improve the ease of use of other digital tools such as the ICT tool. Some meeting places for older people offered these practices and integrated digital tools into their daily services. During the COVID-19 pandemic, in-person visits were not always possible but were considered a prerequisite for showing and practicing the ICT tool:

> *To dare to use the tablet...to use it for something they are familiar with, read the newspaper or whatever it may be, as a first step. It may not be the ICT tool that is the first step, but it may be the next step when they have learned to use the tablet. A game can be a little*

> *easier or reading the newspaper can be an easier way to start using it and then you take the next step.* [Informant 7]

To be able to provide information regarding the ICT tool, *personnel need to have knowledge about it*. The informants perceived the written information regarding the ICT tool as useful for understanding the purpose of the tool. However, it was difficult to inform older people about a tool without knowing how it looked or how it worked. Having both seen and tried the tool made the personnel more confident when informing older people about it:

> *It was great that we got to try the ICT tool first, because it also makes it easier when you are out with the user to show them how it works because you actually know what the picture looks like, how the sound sounds, what happens with the sound if we sit too close to each other. So, I thought it was great, you need to try it first.* [Informant 6]

Organizational Structure

When implementing the ICT tool, the informants perceived it as important to have *a system for effective communication* within the organization. A secure electronic communication system regarding personal data worked appropriately for communication among different parts of the organization regarding lists of potential users, who to call, who would visit whom, information needed for home visits, and so on. After the personnel had visited an older person, they used the same system for feedback about the visit and to document whether further support was needed. The informants also highlighted the importance of feedback among different levels within the organization, such as to the management team by whom new decisions could be made:

> *Lists were created so that we had a structure on which we had called, who would go to whom, all the information needed to make a home visit and even be able to write when you had been there, and it was a completed project...So, it was a very good structure in the lists.* [Informant 3]

> *Spontaneously, I would say that some structure will be required for the recruitment of these [older] people.* [Informant 2]

The informants expressed that *clear roles* facilitated the implementation of the ICT tool. Clarity about whom to ask regarding a special issue, whom to ask for support, and so on makes the work more efficient. Similarly, the person who holds the role knows what duties come with the role. They experienced that the implementation was facilitated if the selected personnel performed the introduction, skills training, and support of the ICT tool:

> *I thought a bit about this regarding whom to contact and so on. It should be incredibly clear, both for our users but for the employees as well. They should not have to think "who are we to contact to get support for this?" but there must be somewhere very, very clear so it can be done quickly, so that you do not have to run around and look and waste time looking for who to contact.* [Informant 7]

Leadership

The informants expressed that *the manager's engagement* was important to the implementation, and it became obvious when engagement was lacking. A manager who was open to the ICT tool and interested in its implementation spread their engagement to the rest of the working group. According to the participants, another success factor was having *enthusiasts* or champions as leaders. These were selected personnel with a clear mandate within the organization who had extra knowledge about ICT, who worked actively regarding its implementation, and who regulated the entire process:

> *That it is someone who owns the question, who has the question on their table, who is the one who then ensures that it is followed up, and the continuity of the whole thing I think is very important.* [Informant 6]

The Digital Maturity of the Social Services Personnel

The implementation of the ICT tool was affected by *the social services personnel's digital skills*. According to the informants, some of the personnel did not know how digital equipment worked, such as a tablet, which hindered them from informing others about and supporting the use of the ICT tool:

> *The personnel couldn't use a tablet either, you had to give them basic instructions on how to press the button to start it up. Of course, there were also those who were very talented. But you might think that it is only the older people that don't have the skills, but it is actually the personnel too.* [Informant 3]

The informants expressed that *the attitudes among the social services personnel varied*. Some were very interested, and the implementation was conducted smoothly. In other parts of the organization, the personnel did not even talk about the ICT tool. The informants thought that an ICT tool that can be used by both older people and personnel would create great interest among the personnel compared with a tool that can be used only by older people. For example, the personnel could conduct lectures or discussions about health-related subjects, such as diet and exercise, within the ICT tool. The informants thought that this digitalization investment had a positive impact on personnel's attitudes toward digital tools, which provided synergies and paved the way for the implementation of this specific ICT tool:

> *Yes, but what if we can have a table where we can talk about health and diet, and those who want to can come in and hear, listen, or participate in discussions.* [Informant 2]

Resources

Implementation requires resources of various types. In this case, the informants highlighted resources regarding *costs*, *time*, and *access to transportation*. They expressed concern about the *costs* that would be required to gain access to the tool and support. The implementation of the ICT tool would be at the expense of something else. According to the informants, a payment model based on different fees, depending on what is included, may facilitate implementation:

> *If you start from the scenario that it is the municipalities that in some way buy a license or something similar for the ICT tool, then the payment model itself could be for a lower amount if the municipality itself, so to speak, moderates what is said and not, and perhaps a higher amount then if it is a company who would be responsible for it.* [Informant 5]

Implementation takes *time*, and some of the most time-consuming parts, as mentioned by the informants, were sending and following up on information letters, delivering tablets, creating log-ins, and showing users what to do. The informants felt that time had been allocated at different levels (eg, to key individuals within the digitalization investment area of the model municipality):

> *It does not matter what we are going to do, time is required. And if you have decided to make a change like this, you should be aware that time is needed. So, it is obvious that it is something that really needs to be considered if it would be implemented somewhere else as well. That you actually make sure you have that time and resources, it costs to implement something, but in the end, it can generate so much more.* [Informant 7]

Access to transportation is a prerequisite for home visits. The informants experienced that there are always cars available as a means of transportation for home visits.

IT Support

The *accessibility* of the support, both for the users and personnel, was perceived as important for implementing the ICT tool. Contact information needed to be available, and it was preferable if all support could be reached using the same contact method (eg, the same phone number or email address). In addition, time needs to be allocated for support. According to the informants, support not only involved direct contact with the user but also involved communication with and recurring feedback between the supporters and the personnel. Support could be provided through various forums to increase accessibility, such as during home visits, at meeting places for older people, or at the public library. Support could also be provided via other digital media, which hindered accessibility, as the requested support was sometimes related to the difficulties in handling the digital equipment itself and, thus, also the digital support. During the COVID-19 pandemic, the accessibility of support was particularly limited, as digital support could not be received owing to some users' lack of skills, and the older people did not accept home visits owing to the risk of spreading the infection:

> *What needs to be strengthened is time, it is the key that we have talked about. It was also what was difficult, but we also saw that what still worked well was when there was allocated time for various steps: time to be at home with the user to practice and provide support and follow-ups, but also time for communication with personnel and recurring feedback: to ask how it works out. So, I think that resources and time really need to be strengthened, then you have all the prerequisites to succeed.* [Informant 6]

The personnel lacked a *follow-up system* for support. They expressed a need to be able to follow up regarding whether the user had used the ICT tool to facilitate implementation. It was not possible to assess whether the older person understood how to use the ICT tool after a short introduction. The informants suggested that it should be possible to obtain information about the number of log-ins on the ICT tool to be able to follow up with users who have few log-ins:

> *It would be interesting to get feedback on if these users have not been in at all. Then you could have maybe called them and asked: How are you? Do you want more help?* [Informant 9]

Legal Liability

The informants expressed doubts about whether the municipalities complied with the legislation if the ICT tool was offered by the municipality and used inappropriately, such as the use of racist statements. There was a concern that the municipality cannot guarantee that nothing inappropriate is said within the ICT tool without some form of supervisory function. Therefore, it was proposed that a moderator of the ICT tool could perform that function:

> *If the municipality buys it, we stand as some form of guarantor, we also have a responsibility not to release that freely, but to have some form of moderating function that can support what is said. Because racist statements may be used, for example, and then we also have a responsibility to take care of it.* [Informant 5]

Discussion

Principal Findings

The results included 7 categories of determinants for implementing the ICT tool. *Being able to introduce the* ICT *tool in an appropriate manner* concerns the personnel's options for introducing and supporting the ICT tool, including their competencies in using digital equipment. *Organizational structure* concerns a structure for communication within the organization. *Leadership* concerns engagement and enthusiasm as driving forces for implementation. *The digital maturity of thesocial services personnel* concerns the personnel's skills and attitudes toward using digital equipment. *Resources* concern time and money. *IT support* concerns accessibility, and *legal liability* concerns possibilities to fulfill legal responsibilities.

Comparison With Previous Studies

Determinants of implementing ICT tools related to older people have been reported in several studies and systematic reviews [18-21]. The novelty of our study lies in its knowledge about the determinants of implementing a new, co-designed, and research-based web platform, customized specifically for older adults, from a social services personnel perspective. The determinants identified in this study are concretized to increase the understanding of specific factors that influence the implementation of an ICT tool for social interaction among older people. Damschroder et al [27] and Flottorp et al [26] highlighted several domains of determinants, including factors related to the implemented intervention itself (in this case, the ICT tool) and patient factors. These 2 domains are not presented in our results but are reported in a related article [22]. The social services personnel's view about the determinants identified in this study were mainly related to the interaction between the personnel and older individual, and organizational factors. Our findings differ from those of other studies describing older people's views about determinants, which were mainly related to their own capacity, attitudes, and health-related benefits and the usefulness and ease of learning the technical tool [18-22]. However, the interaction between the professional and the older individual relates to strategies for supporting older people to overcome barriers mentioned as determinants by the older people themselves. Thus, although the determinants mentioned by social services personnel and older people differ, they are logically interconnected. The 7 categories of determinants reported in this study correspond to the following domains reported in the paper by Flottorp et al [26]: individual health professional factors; professional interactions; incentives and resources; capacity for organizational change; and social, political, and legal factors. Some of the factors within these domains were not mentioned as determinants by the informants in our study, such as the continuing education system, assistance (external) for organizational change, contracts, and political stability. As they were not mentioned by the informants, we interpreted them to be of less importance in this specific case.

Most of the identified determinants in our study were related to contextual factors at different levels, which confirms that contextual determinants play an important role in implementation [36]. Nilsen and Bernhardsson [36] highlighted contextual factors as determinants at the micro (interaction between the professional and patient), meso (the organization), and macro (influences from the wide environment) levels. The micro-meso-macro framework for analysis is a useful way of understanding the determinants of implementation, as implementation is a multilevel phenomenon [37]. In this study, the contextual determinants mostly involved the micro (*be able to introduce the ICT tool in an appropriate manner*) and meso levels (*organizational structure*, *leadership*, *resources*, and *IT support*). Only 1 category was identified at the macro level (*legal liability*). The Lancet and Financial Times Commission on Governing Health Futures 2030 [38] recommends interventions at the macro level to facilitate the digitalization of health and social care to achieve future health and well-being. From the perspective of the personnel, the impact of the identified determinants likely differs. As macrolevel determinants were not mentioned by the informants to the same extent as microlevel and mesolevel determinants, it could be assumed that macrolevel determinants were not perceived to have as great an impact as micro- and mesolevel determinants on the implementation of the ICT tool.

A category of determinants that we identified, *the digital maturity of the social services personnel*, was related to individual health professional factors according to the checklist by Flottorp et al [26] and, in particular, knowledge, skills, and cognition. A lack of digital competence has been identified across all professions within social services in Sweden, and the development of the personnel's competence is stated to be a success factor when implementing welfare technology in social services [23]. Konttila et al [24] recommend that learning how to use technical devices should be integrated into the personnel's daily work by providing education and sufficient time for learning. In previous studies, knowledge and skills primarily focused on digital and technical aspects. However, our results in the category, *be able to introduce the ICT tool in an appropriate manner*, also emphasize the importance of the personnel's pedagogical knowledge and skills in teaching older people how to use an ICT tool. This introduces additional demands on the personnel that must be considered when implementing an ICT tool in social services.

Our results are consistent with the barriers to and facilitators of the implementation of welfare technology identified by Zander et al [25]. All our identified determinants correspond to the themes reported by Zander et al [25] regarding capacity, attitudes, and values. In addition, we identified enthusiasts, as part of the *leadership* category, as an important driving force for implementation, which was not explicitly mentioned by Zander et al [25]. However, similarity can be seen with the theme of participation, as Zander et al [25] discussed the importance of involvement in the development, decision-making, and implementation processes as a facilitator of implementation. A theme of determinants that Zander et al [25] identified but were not identified in our results was expectations. Expectations were seen as a barrier to the implementation of welfare technology and were related to fear that the technology would affect the quality of care, threats to professional identity, and fear of losing jobs. It is possible that the ICT tool in our study was not perceived as a threat against the personnel's professional role, as it did not directly affect the quality of care or replace the care provider. It is also important to remember that the technology used in the literature review by Zander et al [25] did not include ICT used specifically for communication among older people, which can explain the differences in the results.

According to our results, enthusiasts seemed to be an important facilitating determinant for implementation. Enthusiasts can also be described as champions or local opinion leaders, depending on whether they are appointed by the management or considered informal, educationally influential leaders appointed by peers [39]. In our results, we interpret enthusiasts more consistently with the definition of champions. However, it remains unclear whether the enthusiasts only function through managerial status and process or also function through social influence, such as an opinion leader. To support implementation, the evidence for the role of local opinion leaders is more robust than that for champions, and it seems that involvement of local opinion leaders is an effective implementation strategy [39,40]. To understand the impact mechanisms of enthusiasts, the role and significance of enthusiasts need further clarification.

One of the 2 municipalities included was a model municipality for the digitalization of care for older people, which contributed to an important difference between these municipalities. The informants from the model municipality expressed the determinants by describing their own experiences as facilitators (eg, their experiences regarding how a system for effective communication among personnel facilitated the implementation of the ICT tool). The other municipality talked about the same determinant as a barrier, that is, the lack of a system for effective communication. It was obvious that the digitalization project positively influenced the implementation of the ICT tool, which also confirms the importance of determinants related to the organization. Although the ICT tool was supposed to be easy to use for older people [31], it is still important to have an organizational structure to support the older people in using the ICT tool. Previous studies highlight the importance of a shared vision within the organization for the implementation and involvement of leadership [25]. These determinants were perceived by the informants in the model municipality. They also experienced other facilitators identified in previous studies, such as a system for communication, clearly defined roles, enthusiasts, access to IT support, and resources that facilitated the implementation [24,25]. Digital maturity appears to be great in the model municipality, which also affected the implementation of the ICT tool.

Implementation is more likely to be successful if implementation strategies are chosen based on an assessment of determinants (facilitators and barriers) of implementation [40]. However, when selecting the implementation strategies, consideration must also be given to the effectiveness of different strategies based on well-designed studies and systematic reviews, the phases—implementation or maintenance—of the actual implementation process [41], and the theoretical underpinnings of the implementation [42,43]. Our findings can contribute to increasing the understanding of the complexity of implementing an ICT tool for social interaction among older people in municipal settings and guide the choice of implementation strategies.

Several studies have explored the determinants of using ICT tools, often in relation to older people. ICT tools can mean different types of technology that are used in health and social care and used by older people outside health and social care. Most ICT tools studied are not designed specifically for older people [18-21,23-25]. In this study, determinants are explored in relation to the Fik@ room, a specific ICT tool for social interaction among older people, developed for and in coproduction with older people. As ICT tools involve large variety, it can hinder the transferability of our results. Therefore, it is important that the readers themselves are aware of the type of ICT tools that are studied.

Strengths and Limitations

As determinants for improving professional practice have been identified at different levels [26,41], we wanted to include the informants involved in the implementation of the ICT tool in different ways. The combination of informants working with leadership and informants working directly with the older people in different ways enabled a comprehensive understanding of the determinants of the implementation of an ICT tool for social interaction among older people in municipal settings. It would have been desirable to have more informants from municipality 2. Although the study only included 9 informants, these informants had specific experiences pertinent to the study’s aim by being involved in the intervention study that introduced the Fik@ room to older people. Taken together with the specific phenomenon in question and a narrowly defined objective, the data were considered to have sufficient information power [44].

The use of participatory workshops inspired by the EMA method [32] contributed to a systematic approach to data collection and opportunities to learn from each other. The combination of individual and group activities meant that all experiences from each informant were used and developed in group discussions, which contributed to multifaceted and rich data. By including a second part of the workshop, focusing on how to overcome obstacles and reinforce the possibilities identified in the first part of the workshop, we were able to further use the informants’ thoughts and experiences.

Owing to the COVID-19 pandemic, the workshops were performed using the web-based video communication tool, Microsoft Teams. Although conducting qualitative studies over the internet facilitated the informants’ participation, it also involved some challenges [45]. A challenge was the informants’ familiarity with technological hardware and software. In this case, the informants had access to a reliable internet connection and a computer with a microphone and camera. The video communication tool, Microsoft Teams, was chosen because the informants were already familiar with this program because it was used in their organizations. All the informants (9/9, 100%) used digital communication tools in their daily work and were familiar with how to communicate using them. Another challenge is that web-based interviews seem to generate short responses and less contextual information [45], which could also apply to web-based workshops. Compared with in-person workshops, web-based groups need to be small, and 4 to 6 participants are recommended [45]. Therefore, we included a maximum of 6 informants in each workshop group. It might be a limitation that the informants in the workshops knew each other. A power imbalance might have occurred between managers and employees, which might have limited the issues that were raised for discussion during the workshops. However, the opinion of the 2 researchers participating in the workshops was that the informants spoke freely regarding the barriers to and facilitators of implementing the ICT tool. The fact that the implementation of the ICT tool was a project might have stimulated the informants to speak more freely than they might have done if the ICT tool was implemented as compulsory working task.

An exploratory design was considered appropriate for conducting research in this relatively underexplored field and thus, we adopted an inductive approach [30]. The choice of design was made to stimulate an open and creative discussion to enable the identification of new areas of determinants. In hindsight, a deductive approach would also have been possible to use because our results proved to be consistent with the checklist by Flottorp et al [26]. However, the use of the inductive approach contributed to a deep understanding of the determinants of implementing an ICT tool for social interaction among older people.

The findings present the determinants for the implementation of an ICT tool for social interaction among older people in municipal settings, but the determinants related to the ICT tool itself and older people are presented in a related article [22]. This division may complicate the possibility of obtaining an overall picture of the current determinants of importance for the implementation of the ICT tool. To make this easy for the reader, we refer to the related article by Gusdal et al [22] in the text.

The careful description of the data collection process and illustration of the findings with quotations increased the confirmability of the findings. Trustworthiness was strengthened through regular discussions among the authors during the analyses. The agreement between our findings and those of previous studies regarding the determinants of implementation in general [26] and implementation of welfare technology for older people in particular [25] increases the credibility of our findings, which is an important strength of our study and indicates wide transferability of the findings to the implementation of other ICT tools for older people in other contexts. However, the trustworthiness and transferability of the study results should be considered with caution because there were only 9 informants from 2 municipalities involved. Despite the small sample size, the study revealed important aspects to be considered when implementing ICT tools in municipality social services.

This study was conducted during the COVID-19 pandemic. The purpose was not to relate the results to the situation of older people specifically during the pandemic. However, the pandemic has probably affected the results in different ways. The problem of loneliness among older people increased during the COVID-19 pandemic [9-12], which increased the need for new solutions for communication among older people. This may have affected the attitude of both the older people and the personnel participating in this study toward ICT tools. The difficulties with meeting older people in person are also strongly associated with the restrictions during the pandemic and might have affected the results as the personnel did not have the prerequisites to meet older people and introduce the ICT tool (and the hardware) in the same way as without the pandemic and physical restrictions. Therefore, determinants with a direct connection to the pandemic are not as relevant during periods without a pandemic.

Conclusions

The ICT tool discussed in this study will be used by older people in their homes for the purpose of social interaction. Although the ICT tool is for use by older people in their homes, with limited involvement of others, the results show that the implementation involves an entire organization at different levels. Specifically, the following may be required: ability of the personnel to introduce and support the ICT tool, including their competencies in using digital equipment; structure for communication within an organization; leadership as a driving force; sufficient resources; and possibilities to fulfill legal responsibilities. Regardless of how much each level within the organization comes into direct contact with the ICT tool, all levels need to be involved to create the necessary conditions for successful implementation. The prerequisites for the implementation of an ICT tool will probably change depending on the digital maturity of future generations. As this study only included 9 informants, the results should be considered with caution. The study was performed during the COVID-19 pandemic, which has probably affected the results.

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

JF, CE, AKG, RMJP, and PvHW were involved in the methodology of the study. JF and CE conducted the workshops. JF conducted the content analysis and wrote the original draft. CE, AKG, RMJP, and PvHW supported the analysis and contributed to reviewing and editing the paper.

Conflicts of Interest

Coauthors CE, AKG, RMJP and PvHW own equity in the Fik@ room, a company that might benefit from this study’s findings. The company was founded after the data collection of this study and aims to make the Fik@ room available for its target audience. The first author (JF) led data analysis and manuscript preparation to ensure objectivity in the research.

Multimedia Appendix 1
Workshop guide.
[PDF File (Adobe PDF File), 110 KB - aging_v7i1e43999_app1.pdf]

References

1. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci 2015 Mar;10(2):227-237. [doi: 10.1177/1745691614568352] [Medline: 25910392]
2. Alpert PT. Self-perception of social isolation and loneliness in older adults. Home Health Care Manag Pract 2017 Sep 01;29(4):249-252. [doi: 10.1177/1084822317728265]
3. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 2020 Mar 14;395(10227):912-920 [FREE Full text] [doi: 10.1016/S0140-6736(20)30460-8] [Medline: 32112714]
4. Chen E, Wood D, Ysseldyk R. Online social networking and mental health among older adults: a scoping review. Can J Aging 2021 Mar 19;41(1):26-39. [doi: 10.1017/s0714980821000040]
5. Leigh-Hunt N, Bagguley D, Bash K, Turner V, Turnbull S, Valtorta N, et al. An overview of systematic reviews on the public health consequences of social isolation and loneliness. Public Health 2017 Nov;152:157-171. [doi: 10.1016/j.puhe.2017.07.035] [Medline: 28915435]
6. Neves BB, Franz RL, Munteanu C, Baecker R. Adoption and feasibility of a communication app to enhance social connectedness amongst frail institutionalized oldest old: an embedded case study. Inf Commun Soc 2017 Jul 13;21(11):1681-1699. [doi: 10.1080/1369118x.2017.1348534]
7. Valtorta NK, Kanaan M, Gilbody S, Ronzi S, Hanratty B. Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies. Heart 2016 Jul 01;102(13):1009-1016 [FREE Full text] [doi: 10.1136/heartjnl-2015-308790] [Medline: 27091846]
8. Dahlberg L. Loneliness during the COVID-19 pandemic. Aging Ment Health 2021 Jul;25(7):1161-1164. [doi: 10.1080/13607863.2021.1875195] [Medline: 33491474]
9. Elran-Barak R, Mozeikov M. One month into the reinforcement of social distancing due to the COVID-19 outbreak: subjective health, health behaviors, and loneliness among people with chronic medical conditions. Int J Environ Res Public Health 2020 Jul 27;17(15):5403 [FREE Full text] [doi: 10.3390/ijerph17155403] [Medline: 32727103]
10. Ernst M, Niederer D, Werner AM, Czaja SJ, Mikton C, Ong AD, et al. Loneliness before and during the COVID-19 pandemic: a systematic review with meta-analysis. Am Psychol 2022;77(5):660-677 [FREE Full text] [doi: 10.1037/amp0001005] [Medline: 35533109]
11. Johansson-Pajala RM, Alam M, Gusdal A, Heideken Wågert PV, Löwenmark A, Boström AM, et al. Anxiety and loneliness among older people living in residential care facilities or receiving home care services in Sweden during the COVID-19 pandemic: a national cross-sectional study. BMC Geriatr 2022 Dec 01;22(1):927 [FREE Full text] [doi: 10.1186/s12877-022-03544-z] [Medline: 36456904]
12. Dubois H, Nivakoski S, Fóti K, Patrini V, Mascherini M. COVID-19 and older people: impact on their lives, support and care. Publications Office of the European Union. 2022. URL: https://www.eurofound.europa.eu/en/publications/2022/covid-19-and-older-people-impact-their-lives-support-and-care [accessed 2024-01-29]
13. Balki E, Hayes N, Holland C. Effectiveness of technology interventions in addressing social isolation, connectedness, and loneliness in older adults: systematic umbrella review. JMIR Aging 2022 Oct 24;5(4):e40125 [FREE Full text] [doi: 10.2196/40125] [Medline: 36279155]
14. Casanova G, Zaccaria D, Rolandi E, Guaita A. The effect of information and communication technology and social networking site use on older people's well-being in relation to loneliness: review of experimental studies. J Med Internet Res 2021 Mar 01;23(3):e23588 [FREE Full text] [doi: 10.2196/23588] [Medline: 33439127]
15. Chen YR, Schulz PJ. The effect of information communication technology interventions on reducing social isolation in the elderly: a systematic review. J Med Internet Res 2016 Jan 28;18(1):e18 [FREE Full text] [doi: 10.2196/jmir.4596] [Medline: 26822073]
16. Czaja SJ, Boot WR, Charness N, Rogers WA, Sharit J. Improving social support for older adults through technology: findings from the PRISM randomized controlled trial. Gerontologist 2018 May 08;58(3):467-477 [FREE Full text] [doi: 10.1093/geront/gnw249] [Medline: 28201730]
17. SBU. Välfärdsteknik – digitala verktyg som social stimulans för äldre personer med eller vid risk för psykisk ohälsa. Statens beredning för medicinsk och social utvärdering. URL: https://www.sbu.se/268 [accessed 2024-01-29]
18. Lee C, Coughlin JF. PERSPECTIVE: older adults' adoption of technology: an integrated approach to identifying determinants and barriers. J Prod Innov Manage 2014 Jun 03;32(5):747-759. [doi: 10.1111/jpim.12176]
19. Castro Rojas MD. Barriers and supportive factors for older adults learning about and using information and communication technologies for healthy aging in Costa Rica. Educ Gerontol 2021 Oct 26;47(10):433-446. [doi: 10.1080/03601277.2021.1989228]
20. Nef T, Ganea RL, Müri RM, Mosimann UP. Social networking sites and older users - a systematic review. Int Psychogeriatr 2013 Jul;25(7):1041-1053 [FREE Full text] [doi: 10.1017/S1041610213000355] [Medline: 23552297]
21. Jiménez FN, Brazier JF, Davoodi NM, Florence LC, Thomas KS, Gadbois EA. A technology training program to alleviate social isolation and loneliness among homebound older adults: a community case study. Front Public Health 2021 Nov 18;9:750609 [FREE Full text] [doi: 10.3389/fpubh.2021.750609] [Medline: 34869167]

22. Gusdal AK, Florin U, Johansson-Pajala RM, Eklund C, Fritz J, von Heideken Wågert P. Older adults' use of a research-based web platform for social interaction. Healthcare (Basel) 2023 Jan 31;11(3):408 [FREE Full text] [doi: 10.3390/healthcare11030408] [Medline: 36766983]
23. Framtidens teknik i omsorgens tjänst. Regeringskansliet. 2020. URL: https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2020/03/sou-202014/ [accessed 2024-01-29]
24. Konttila J, Siira H, Kyngäs H, Lahtinen M, Elo S, Kääriäinen M, et al. Healthcare professionals' competence in digitalisation: a systematic review. J Clin Nurs 2019 Mar;28(5-6):745-761. [doi: 10.1111/jocn.14710] [Medline: 30376199]
25. Zander V, Gustafsson C, Landerdahl Stridsberg S, Borg J. Implementation of welfare technology: a systematic review of barriers and facilitators. Disabil Rehabil Assist Technol 2021 Jun 15:1-16. [doi: 10.1080/17483107.2021.1938707] [Medline: 34129802]
26. Flottorp SA, Oxman AD, Krause J, Musila NR, Wensing M, Godycki-Cwirko M, et al. A checklist for identifying determinants of practice: a systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice. Implement Sci 2013 Mar 23;8(1):35 [FREE Full text] [doi: 10.1186/1748-5908-8-35] [Medline: 23522377]
27. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009 Aug 07;4:50 [FREE Full text] [doi: 10.1186/1748-5908-4-50] [Medline: 19664226]
28. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health 2000 Aug;23(4):334-340. [doi: 10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g] [Medline: 10940958]
29. Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health 2010 Feb;33(1):77-84. [doi: 10.1002/nur.20362] [Medline: 20014004]
30. Stebbins RA. Exploratory Research in the Social Sciences. Thousand Oaks, CA: Sage Publications; 2001.
31. Johansson-Pajala RM, Gusdal A, Eklund C, Florin U, Wågert PH. A codesigned web platform for reducing social isolation and loneliness in older people: a feasibility study. Inform Health Soc Care 2023 Apr 03;48(2):109-124. [doi: 10.1080/17538157.2022.2070068] [Medline: 35579407]
32. Edwards K, Winkel J. A method for effect modifier assessment (EMA) in ergonomic intervention research. Appl Ergon 2018 Oct;72:113-120. [doi: 10.1016/j.apergo.2018.05.007] [Medline: 29885722]
33. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115. [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]
34. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA 2013 Nov 27;310(20):2191-2194. [doi: 10.1001/jama.2013.281053] [Medline: 24141714]
35. Swedish ethical review act. Ministry of Education. 2003. URL: https://rkrattsbaser.gov.se/sfst?bet=2003:460 [accessed 2024-01-29]
36. Nilsen P, Bernhardsson S. Context matters in implementation science: a scoping review of determinant frameworks that describe contextual determinants for implementation outcomes. BMC Health Serv Res 2019 Mar 25;19(1):189 [FREE Full text] [doi: 10.1186/s12913-019-4015-3] [Medline: 30909897]
37. Pope C, Robert G, Bate P, Le May A, Gabbay J. Lost in translation: a multi‐level case study of the metamorphosis of meanings and action in public sector organizational innovation. Public Adm 2006 Feb 10;84(1):59-79. [doi: 10.1111/j.0033-3298.2006.00493.x]
38. Kickbusch I, Piselli D, Agrawal A, Balicer R, Banner O, Adelhardt M, Secretariat of the Lancet and Financial Times Commission. The Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world. Lancet 2021 Nov 06;398(10312):1727-1776. [doi: 10.1016/S0140-6736(21)01824-9] [Medline: 34706260]
39. Flodgren G, O'Brien MA, Parmelli E, Grimshaw JM. Local opinion leaders: effects on professional practice and healthcare outcomes. Cochrane Database Syst Rev 2019 Jun 24;6(6):CD000125 [FREE Full text] [doi: 10.1002/14651858.CD000125.pub5] [Medline: 31232458]
40. Grimshaw JM, Eccles MP, Lavis JN, Hill SJ, Squires JE. Knowledge translation of research findings. Implement Sci 2012 May 31;7:50 [FREE Full text] [doi: 10.1186/1748-5908-7-50] [Medline: 22651257]
41. Grol R, Wensing M, Eccles M, Davis D. Improving Patient Care: The Implementation of Change in Health Care. 2nd edition. Hoboken, NJ: John Wiley & Sons; 2013.
42. Nilsen P. Making sense of implementation theories, models and frameworks. Implement Sci 2015 Apr 21;10:53 [FREE Full text] [doi: 10.1186/s13012-015-0242-0] [Medline: 25895742]
43. Eccles M, Grimshaw J, Walker A, Johnston M, Pitts N. Changing the behavior of healthcare professionals: the use of theory in promoting the uptake of research findings. J Clin Epidemiol 2005 Feb 21;58(2):107-112 [FREE Full text] [doi: 10.1016/j.jclinepi.2004.09.002] [Medline: 15680740]
44. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2016 Nov;26(13):1753-1760. [doi: 10.1177/1049732315617444] [Medline: 26613970]
45. Carter SM, Shih P, Williams J, Degeling C, Mooney-Somers J. Conducting Qualitative Research Online: Challenges and Solutions. Patient 2021 Nov;14(6):711-718 [FREE Full text] [doi: 10.1007/s40271-021-00528-w] [Medline: 34114170]

Abbreviations

EMA: effect modifier assessment
ICT: information and communication technology

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Perceptions Toward Telemedicine of Health Care Staff in Nursing Homes in Northern Germany: Cross-Sectional Study

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Abstract

Background: Digitalization in the German health care system is progressing slowly, even though it offers opportunities for improvement of care. In nursing homes, most of the staff's work is paper based. Following the pandemic, there has been a decrease in the use of telemedicine applications. To ensure long-term implementation, the views of users, in this case nurses, are of interest.

Objective: This cross-sectional study was conducted to describe which digital applications are already being used at inpatient care facilities, the attitude of nurses toward telemedicine, and for which areas the use of telemedicine in the facilities is considered appropriate by the participants.

Methods: All inpatient care facility staff in Schleswig-Holstein were invited to participate in the survey from August 1 to October 31, 2022. The questionnaire consists of 17 determinants that ask about the attitude, use, and possible applications of telemedicine. In addition to a descriptive analysis, the influence of the general attitude toward telemedicine on various determinants was examined using the Fisher exact test for nominal variables and Spearman correlation coefficient for metric variables.

Results: A total of 425 caregivers participated in the survey. Of these respondents, 10.7% (n=41) currently used video consultations, and 76.1% (n=321) of the respondents were in favor of video consultations being practiced in training. Furthermore, 74.8% (n=312) of the respondents would attend a training on telephone medical consultation. Respondents indicated that video consultations have a small added value compared to asynchronous telemedicine (eg, sending photos). However, video consultations were perceived as somewhat less time-consuming than other communication channels. Video consultations are perceived as most useful for clarifying urgent problems. The respondents estimated that one in five paramedic calls at their facilities could be reduced through telemedicine approaches. It was important to the participants that telemedicine is as simple as possible and that there is a high level of data security.

Conclusions: Although many caregivers have a positive attitude toward telemedicine and perceive its advantages, communication channels such as video consultation are still used infrequently in care facilities. To promote the use of telemedicine applications, it is important to emphasize their benefits. The presumed saving of paramedic calls thus represents a benefit, and it is crucial to train caregivers in the use of telemedicine to avoid uncertainties in dealing with the newer technologies. It is important to give them enough time and repetitions of the training.

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KEYWORDS

eHealth; telemedicine; nursing home; pandemic; Germany

Introduction

The digitalization of the German health care system offers opportunities for the improvement of care. For instance, established communication channels in paper-based form can be eliminated and faster communication between different providers can be strengthened [1,2]. Areas with less access to care can be supported by digital applications [2-4]. The benefits of telemedicine recognized by health care stakeholders include providing better access to care and further communication options [1,5,6]. Telemedicine applications may also help to reduce avoidable ambulance callouts and hospitalizations [7,8].

The term telemedicine is, based on the definition of the German National Association of Statutory Health Insurance Physicians, defined as follows: telemedicine includes applications that can be used for consultation, diagnostics, or therapy over a geographical or temporal distance. This can be done through a wide variety of applications such as video consultation, email, or an app [9].

Nevertheless, digitalization in the German health care system is progressing slowly. Approximately 70% of nursing staff still used paper-based methods. This causes incomplete documentation and is time-consuming [10]. A study from Germany shows that telemedicine applications, such as video consultations, simplify communication between doctors and nurses. Due to flexibilities in time and location, video consultations enable a faster exchange between the doctor and the nursing home [5,11]. Since there is a shortage of nursing staff and a chronic lack of time, the question arises as to why digitalization is not promoted more in this area of care.

In the first year of the COVID-19 pandemic, rapid implementation of telemedicine, and video consultations in particular, was predicted [12]. Nursing homes struggled with isolation rules (eg, shortage of protective clothing). To maintain continuity of care, telemedicine applications were often used during this time [1]. However, it is also apparent that telemedicine applications are being used less after the pandemic, including in nursing homes [13-16].

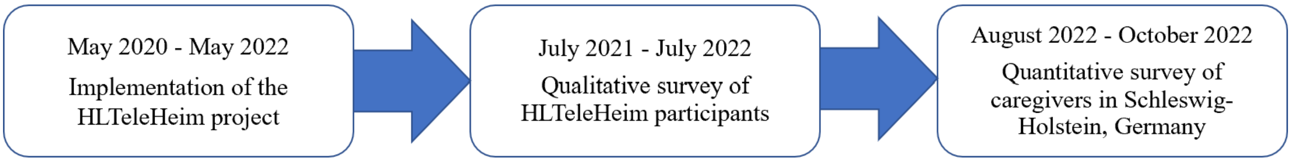
To successfully implement a telemedicine application in the long-term, it is necessary to explore the attitude of the nursing staff toward telemedicine. In this way, these expectations and perceptions toward telemedicine can be used to tailor the implementation process [13]. Therefore, this cross-sectional study aimed to explore the attitude of caregivers working at inpatient care facilities toward telemedicine, which applications are already used, and what is considered useful.

Methods

Study Design and Population

In the federal state of Schleswig-Holstein, Germany, the project (HLTeleHeim) was influenced by observations of the challenges in primary care during the COVID-19 pandemic when nursing homes and palliative care providers were performing video consultation with general practitioners, specialists, pastors, or family members. The aim was to support the care of residents during access restrictions in care facilities in the early phase of the SARS-CoV-2 pandemic. The equipment and the training on how to use it was free for the participants [9,13]. Figure 1 provides a better overview of the project's timeline.

Figure 1. Timeline of the study and evaluation.



For this cross-sectional study, all 567 inpatient care facilities in Schleswig-Holstein were contacted by mail. The letters contained information about the survey as well as 10 questionnaires and return envelopes. People 18 years or older who were active in providing care could participate in the inquiry. The questionnaires were mailed on August 1, 2022, and could be returned until October 31, 2022. On September 1 and October 1, 2022, reminders were sent to the nursing homes. From September 1, 2022, a web-based version was created on SurveyMonkey as an alternative to the paper-based questionnaire, which should have enabled as many nurses as possible to participate in the survey. Access via a QR code and link to the web-based survey was sent with the first and second reminders. The survey was carried out anonymously; it was not possible to conclude which person or care facility the completed questionnaire originated from.

Ethical Considerations

The study is a low-risk study since it is not an experimental study. The data were treated in accordance with the General Data Protection Regulation (European Union) 2016/679. Only employees of the study have access to the data contained in the questionnaires, and the data is protected from unauthorized access. Third parties do not have access to the original documents.

The participants were provided with written information before completing the questionnaire and informed that by submitting the questionnaire they were agreeing to participate in the study. They were also notified that it is not possible to subsequently delete the data received, as it is collected anonymously. The participants did not receive any compensation for participating.

The survey of nurses received a positive ethics vote by the ethics committee of the University of Lübeck (22 - 095).

Questionnaire

The questionnaire was developed based on interviews with nurses, physicians, and app developers from a preliminary project and the existing literature [13,17]. It consisted of 17 determinants; the whole questionnaire can be viewed in Multimedia Appendix 1. Those questions aimed to find out which telemedicine devices are used, whether the respondents had received training on the subject during their education, what the general attitude toward telemedicine is, and for which areas telemedicine devices would be suitable to use. It was also intended to find out which factors (eg, data protection aspects or costs) are particularly relevant in relation to telemedicine. Respondents were also allowed to write their comments on the topic in a free-text section. The questionnaire was pilot-tested for comprehensibility. Therefore, carers from the researchers' private circle of acquaintances were asked to complete the questionnaire and explain in a discussion round how the questions were perceived and what changes they would suggest. The paper-based questionnaire contains the same questions as the web-based questionnaire, so all responses were analyzed together.

Analyses

Data analysis was conducted using the IBM SPSS Statistics 28 program. A descriptive analysis of the data was performed. In addition, the influence of the general attitude toward telemedicine on various determinants was examined. For this purpose, the variable attitude toward telemedicine was summarized as a dichotomous variable. Values 1 - 3 (mostly positive to very positive) were defined as a positive attitude and values 4 - 6 (mostly negative to very negative) as a negative attitude. The prerequisites for a chi-square test were not fulfilled; therefore, the Fisher exact test was used for nominal variables. For metric variables, Spearman correlation coefficient was calculated. The original variable of the attitude toward telemedicine with 6 expressions was used for this purpose; furthermore, the age variable was created based on the year of birth variable. The significance level was set at .05.

Results

A total of 425 caregivers participated in the survey—22 of them completed the web-based survey. Table 1 shows the sociodemographic data of the sample.

In the open question for which scenarios the use of video consultation would also be useful, the following points were indicated: ordering medications and bandages, electrocardiograms, specialist consultations, discussions between physicians and residents, communication with guardians, new admissions, avoidance of hospitalizations, contact with training institutes, and clarification of queries. Three participants responded that video consultations would not be useful in general.

Table 2 shows the current use of telemedicine in nursing homes and for which areas the use of video consultation would be useful.

Table 3 illustrates the general attitude toward telemedicine, how the participants deal with the video consultation, and which aspects are particularly relevant to them.

Table . Sociodemographic data of the participating nursing staff from Schleswig-Holstein (N=425).

Variable		Participants
Age (years), mean (SD)		43.7 (12.2)
Sex, n (%)		
	Female	309 (72.8)
	Male	105 (24.6)
	Missing	11 (2.6)
Active in care, n (%)		
	Yes	330 (77.6)
	No	84 (19.8)
	Missing	11 (2.6)
Certified nurse (n=322), n (%)		
	Yes	268 (63.1)
	No	54 (12.6)
	Not active in care	90 (21.2)
	Missing	13 (3.1)
Work experience (years), mean (SD)		16.1 (10.6)
Location of the nursing facility, n (%)		
	Rural	226 (53.2)
	Urban	186 (43.7)
	Missing	13 (3.1)

Table . Current use and benefits of telemedicine of the participating nursing staff from Schleswig-Holstein (N=425).

Question		Yes, n (%)	No, n (%)	Missing, n (%)
During the last 12 months, the possibilities for using telemedicine have been...				
	...addressed within the team?	112 (26.4)	309 (72.7)	4 (0.9)
	...addressed by the residents?	36 (8.5)	383 (90.1)	6 (1.4)
	...addressed by external contacts?	162 (38.1)	257 (60.5)	6 (1.4)
Have you been trained in videoconferencing during vocational training?		76 (17.9)	349 (82.1)	0 (0.0)
Do you think that videoconferencing should be practiced during vocational training?		321 (75.5)	101 (23.8)	3 (0.7)
Would you attend an advanced training course on medical telephone consultation?		312 (73.4)	105 (24.7)	8 (1.9)
Do you document vital signs in a computer system at your facility?		329 (77.4)	93 (21.9)	3 (0.7)
Use in work				
	Fax	392 (92.2)	22 (5.2)	11 (2.6)
	Telephone	406 (95.5)	13 (3.1)	6 (1.4)
	Messaging app	57 (13.4)	310 (72.9)	58 (13.7)
	Emails	300 (70.6)	104 (24.5)	21 (4.9)
	Video consultation	41 (9.6)	341 (80.2)	43 (10.2)
Do you find the use of video consultations useful to/for...				
	...clarify in urgent issues?	300 (70.6)	117 (27.5)	8 (1.9)
	...discuss new findings that have arisen?	244 (57.4)	173 (40.7)	8 (1.9)
	...progress checks?	238 (56.0)	179 (42.1)	8 (1.9)
	...discuss lab results?	219 (51.5)	198 (46.6)	8 (1.9)
	...conversations between residents and family members?	190 (44.7)	226 (53.2)	9 (2.1)
	...routine house calls?	158 (37.2)	259 (60.9)	8 (1.9)

Table . Attitude and relevant aspects of telemedicine of the participating nursing staff from Schleswig-Holstein (N=425).

Question		Score[a]		Missing, n (%)
		Median	IQR	
How is your general attitude toward telemedicine?		2	2-3	11 (2.6)
If you use video consultations				
	How confident do you feel in using them?	2	2-3	8 (1.8)
	In your experience, how big is the additional benefit a video consultation offers compared to sending an image for health issues relating to a resident? (*n*=37)	3	2-4	6 (1.4)
	How would you rate the time aspect of video consultations compared to previous forms of communication? (*n*=37)	3	1-3.5	6 (1.4)
How relevant is/are...				
	...personal contact with doctors to clarify a question for your work?	1	1-2	2 (0.5)
	...personal contact with doctors for the residents?	1	1-2	2 (0.5)
	...digital communication for your work?	2	1-3	4 (0.9)
	...the cost-to-revenue aspect for you?	3	2-4	20 (4.7)
	...easy usability of a telemedicine workstation for you?	2	1-3	7 (1.6)
	...low costs for hardware and software for you?	3	1-4	20 (4.7)
	...clearly structured organizational processes for you?	2	1-2	9 (2.1)
	...data security aspects for you?	1	1-2	7 (1.6)
	...software compatibility with the information system for you?	2	1-3	16 (3.8)
	...it for you to have a contact person for IT issues?	1	1-2	10 (2.4)
How big was the influence of the COVID-19 pandemic on your day-to-day work in terms of the use of digital media?		2	1-4	8 (1.9)
How big is the influence of the staffing ratio for you when using videoconferencing systems?		3	2-5	21 (4.9)

[a] 1=very high/positive/relevant; 6=very low/negative/irrelevant.

When asked how much time the participants could spend per shift familiarizing themselves with topics such as telemedicine, an average of 28 (SD 26, median 30, min-max 0-180) minutes was determined. When estimating how long it would take to familiarize themselves with a telemedicine workplace, an average of 47 (SD 76, median 30, min-max 0-1000) minutes was reported.

On average, the emergency service was alerted 5 (SD 9, median 3, min-max 0-135) times per month per area of operation in the nursing homes. Among these, the nurses estimate that on average 1 (SD 2, median 0, min-max 0-15) of these emergency operations could be spared by telemedicine.

Looking at the Fisher exact test, there are differences ($P<.001$) between the positive and negative responses to the questions

"Do you think video consultation should be practiced in training?" and "Would you attend training on medical telephone consultation?" There were differences in the questions about whether video consultation is considered useful for conversations between residents and relatives (*P*=.002) and routine examinations (*P*=.03). Those with a negative attitude were more likely to answer "no" to these questions. There were no differences between the groups in the questions about whether video consultation is considered useful for discussing laboratory results and for new findings. There was a difference (*P*<.001) in the question about whether video consultation is considered useful for follow-up checks. Those with a positive attitude were more likely to answer "yes" to these questions, while those with a negative attitude were more likely to answer "no." Furthermore, there was a difference (*P*=.003) in the question about whether video consultation would be useful to clarify urgent questions. Those with a positive attitude were more likely to answer "yes" to this question. There were no differences in attitudes toward telemedicine based on the location of the nursing facility. In both rural and urban facilities, about 80% had a positive attitude toward telemedicine.

The calculation with Spearman ρ showed no correlation (0.079) between age and attitude toward telemedicine (*P*=.11). There was a significant (*P*<.001) negative correlation (−0.274) between attitude toward telemedicine and opinion of how many emergency service calls can be reduced per month.

Discussion

Principal Findings

This cross-sectional study aimed to describe which telemedicine devices are already being used at inpatient care facilities and to determine the attitude of nurses toward telemedicine and for which areas the use of telemedicine in the facilities is considered sensible by the nurses.

The survey shows that the telephone and the fax machine are the most frequently used digital tools among nurses in Schleswig-Holstein. Video consultations and messaging apps, on the other hand, are currently used less. According to the PraxisBarometer 2021, video consultations are used by 20% of contract physicians (in Germany there is no obligation to use telemedicine [18]). This may influence the use of video consultations in care facilities [19]. The higher use of the telephone in contrast to video consultation could be explained by the fact that telephone calls are currently faster to execute and that many questions can be answered through a telephone call [20]. This was not asked in the study and could be the subject of further research.

Few participants were educated in using video consultation in their training, but many consider training to be useful. This indicates that training should focus more on digital topics, such as how to conduct video consultations. This is in line with observations from other countries. In the United Kingdom, there is also a need for more training in online communication skills [21]. Further work is needed to determine whether training should and can be adapted in Germany. The large variance in the responses as to how much time is presumably required for familiarization indicates that the training and familiarization times must be individually adapted to the needs of the nurses.

Notably, video consultations are considered more useful for urgent cases and questions than for regular visits. Participants also noted that telemedicine applications could save around 1 emergency ambulance call per month. This is also consistent with observations from other studies [7,8]. In past research, video consultations were considered useful, especially for frequently needed follow-up appointments [5], for instance in the treatment of depression. However, this study was conducted with doctors and not with nurses. There seem to be different views on the appropriateness of video consultations [6,22]. Furthermore, it is noticeable in the survey that for the use of video consultations, more organizational/administrative topics are considered useful, such as ordering medication or communication with training facilities, than direct patient care. It was not possible to determine why nurses prefer video consultation for administrative activities, which could be further researched.

The general attitude of the participants was positive toward telemedicine. Nevertheless, personal contact with physicians was relevant for the respondents. Particular care should always be taken to ensure that video consultations are only used where they really can support care and not completely replace personal contact [11]. The age of the respondents and the location of the care facilities did not influence their attitude toward telemedicine. Therefore, younger people are not the only age group interested in using telemedicine [19,23].

According to the respondents, the COVID-19 pandemic had a strong influence on their use of digital media. This is consistent with other literature. The increased use may be attributed to the fact that in some cases digital solutions were better than no contact at all [24-28]. Whether this influence was perceived positively or negatively cannot be determined. A decrease in video consultations after the relaxation of restrictions during the pandemic has already been seen in physicians' practices [15,19]. Additionally, whether the influence will be long-lasting could not be determined.

Data protection and a contact person in case of technical problems are very important for the respondents. The compatibility of the systems is also a relevant point for the caregivers. Furthermore, a telemedicine workstation should be as easy to use as possible. The cost aspect is somewhat less relevant for the caregivers themselves. This would presumably be an aspect that is more relevant at the institution level, but this was not addressed in this study. In a possible implementation of telemedicine applications in full inpatient care facilities, these points should be taken into consideration to achieve more success [7,11]. Likewise, efforts should be made to ensure that nurses have enough time to familiarize themselves with telemedicine workstations [8,16]. The respondents in this study suspected that familiarization would take more time than they had available. General attitudes toward telemedicine should also be considered, as the study showed that respondents who were positive about telemedicine were more likely to consider attending further training on the subject, among other things. It is important to keep demonstrating the benefits of telemedicine applications to maximize the motivation to use them [27,29]. Uncertainties about new technologies should be addressed so that people feel comfortable and confident using them [30]. Additionally, the implementations should be designed for the relevant facilities so that they can be used as easily as possible, and familiarization provides more benefits [31]. New applications cannot be implemented if there is no acceptance from the nursing staff [29,32,33].

Strength and Limitations

A strength of this study is that all 567 full inpatient care facilities in Schleswig-Holstein were contacted. It is not possible to conclude how many institutions participated, as the questionnaires were sent anonymously, and the response rate could not be determined. Since significantly more paper-based questionnaires were completed than web-based questionnaires, it is possible that more people could have been reached if more questionnaires had been sent out per facility. Despite the anonymity of the questionnaires, it is possible that the participants were biased toward answers they perceived to be desirable. In addition, recall bias, especially for the question about emergency services, was possible and must be considered in the interpretation of our data. It is also important to consider that people who are interested in the topic of telemedicine were more inclined to participate in the survey [34,35].

Conclusion

Attitudes toward telemedicine among nurses in full inpatient care facilities were generally positive. However, newer telemedicine applications, such as video consultation or messaging apps, are infrequently used. The need for telemedicine is seen mainly for acute issues. For the future practice of telemedicine, related content and training should be included in the education of future caregivers. When implementing telemedicine, the specific needs of the users must be considered to be successful. For example, regular customized staff training could be helpful in this regard. Furthermore, caregivers need to be given time for this training. Finally, caregivers need to be involved in the training content.

Acknowledgments

We gratefully acknowledge the voluntary participation of all nurses in the study.

Data Availability

The data sets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Questionnaire.
[DOCX File, 49 KB - aging_v7i1e47072_app1.docx]

References

1. Tan AJ, Rusli KD, McKenna L, Tan LL, Liaw SY. Telemedicine experiences and perspectives of healthcare providers in long-term care: a scoping review. J Telemed Telecare 2024 Feb;30(2):230-249. [doi: 10.1177/1357633X211049206] [Medline: 34666535]
2. Digitalisierung im gesundheitswesen [Article in German]. Bundesministerium für Gesundheit. 2022. URL: https://www.bundesgesundheitsministerium.de/themen/digitalisierung/digitalisierung-im-gesundheitswesen.html [accessed 2022-11-28]
3. Beckers R, Strotbaum V. Telepflege – telemedizin in der pflege. In: Marx G, Rossaint R, Marx N, editors. Telemedizin [Book in German]: Springer; 2021. [doi: 10.1007/978-3-662-60611-7_23]
4. Dorsey ER, Topol EJ. State of telehealth. N Engl J Med 2016 Jul 14;375(2):154-161. [doi: 10.1056/NEJMra1601705] [Medline: 27410924]
5. May S, Jonas K, Fehler GV, Zahn T, Heinze M, Muehlensiepen F. Challenges in current nursing home care in rural Germany and how they can be reduced by telehealth - an exploratory qualitative pre-post study. BMC Health Serv Res 2021 Sep 6;21(1):925. [doi: 10.1186/s12913-021-06950-y] [Medline: 34488746]
6. May S, Fehler G, Jonas K, Zahn T, Heinze M, Muehlensiepen F. Potentiale und herausforderungen von ärztlichen videosprechstunden in der pflegeeinrichtung AUS der sicht der versorgenden - eine qualitative prä-post-studie [Article in German]. Z Evid Fortbild Qual Gesundhwes 2022 Apr;169:48-58. [doi: 10.1016/j.zefq.2021.11.007] [Medline: 35165047]
7. Gillespie SM, Moser AL, Gokula M, et al. Standards for the use of telemedicine for evaluation and management of resident change of condition in the nursing home. J Am Med Dir Assoc 2019 Feb;20(2):115-122. [doi: 10.1016/j.jamda.2018.11.022] [Medline: 30691620]
8. Valk-Draad MP, Bohnet-Joschko S. Nursing home-sensitive hospitalizations and the relevance of telemedicine: a scoping review. Int J Environ Res Public Health 2022 Oct 10;19(19):12944. [doi: 10.3390/ijerph191912944] [Medline: 36232255]

9. Telemedizin [Article in German]. Kassenärztliche Vereinigung. 2022. URL: https://www.kbv.de/html/telemedizin.php [accessed 2023-02-15]
10. Mania H. Die digitalisierung verändert (auch) die pflege: robotik, sensorik und KI im berufsalltag [Article in German]. Pflegemanagement 2022 Jan 3;3:40-42. [doi: 10.1007/s00735-022-1537-4]
11. Dai Z. Telehealth in long-term care facilities during the COVID-19 pandemic - lessons learned from patients, physicians, nurses and healthcare workers. BMC Digit Health 2023;1(1):2. [doi: 10.1186/s44247-022-00003-y] [Medline: 38014371]
12. Videosprechstunden nehmen in coronakrise stark zu [Article in German]. Ärzteblatt. 2021 Oct 27. URL: https://www.aerzteblatt.de/treffer?mode=s&wo=1041&typ=1&nid=128511&s=2020&s=Pandemie&s=Videosprechstunde [accessed 2023-02-14]
13. von Rekowski E. Telemedizin für pflegeheime und hospize [Article in German]. Mednic. 2020 Oct 23. URL: https://mednic.de/telemedizin-fuer-pflegeheime-und-hospize/15147 [accessed 2023-02-15]
14. Jäger C, Szecsenyi J, Freund T, et al. Entwicklung einer maßgeschneiderten intervention (tailoring) am beispiel der implementierung von empfehlungen zur polypharmakotherapie bei multimorbiden patienten (PomP) [Article in German]. Z Evid Fortbild Qual Gesundhwes 2014;108(5-6):270-277. [doi: 10.1016/j.zefq.2013.08.014] [Medline: 25066345]
15. Assing Hvidt E, Atherton H, Keuper J, et al. Low adoption of video consultations in post-COVID-19 general practice in northern Europe: barriers to use and potential action points. J Med Internet Res 2023 May 22;25:e47173. [doi: 10.2196/47173] [Medline: 37213196]
16. Ford JH, Jolles SA, Heller D, Langenstroer M, Crnich C. There and back again: the shape of telemedicine in U.S. nursing homes following COVID-19. BMC Geriatr 2022 Apr 19;22(1):337. [doi: 10.1186/s12877-022-03046-y] [Medline: 35436869]
17. Steinhäuser J. Pflegeeinrichtungen und hospize werden digital [Article in German]. Universität zu Lübeck. 2020 Oct 27. URL: https://www.uni-luebeck.de/forschung/aktuelles-zur-forschung/aktuelles-zur-forschung/artikel/pflegeeinrichtungen-und-hospize-werden-digital.html [accessed 2023-02-15]
18. Online in die praxis mit der videosprechstunde [Article in German]. Kassenärztliche Bundesvereinigung. 2023 May. URL: https://www.kbv.de/media/sp/Praxisinformation_Videosprechstunde.pdf [accessed 2023-02-27]
19. Schlussfolgerung: praxisbarometer digitalisierung 2021 [Article in German]. Kassenärztliche Bundesvereinigung. 2021. URL: https://www.kbv.de/media/sp/Schlussfolgerungen_Praxisbarometer_2021.pdf [accessed 2022-02-15]
20. Greenhalgh T, Ladds E, Hughes G, et al. Why do GPs rarely do video consultations? Qualitative study in UK general practice. Br J Gen Pract 2022 Apr 28;72(718):e351-e360. [doi: 10.3399/BJGP.2021.0658] [Medline: 35256385]
21. Mold F, Cooke D, Ip A, Roy P, Denton S, Armes J. COVID-19 and beyond: virtual consultations in primary care-reflecting on the evidence base for implementation and ensuring reach: commentary article. BMJ Health Care Inform 2021 Jan;28(1):e100256. [doi: 10.1136/bmjhci-2020-100256] [Medline: 33436372]
22. Johnsen TM, Norberg BL, Kristiansen E, et al. Suitability of video consultations during the COVID-19 pandemic lockdown: cross-sectional survey among Norwegian general practitioners. J Med Internet Res 2021 Feb 8;23(2):e26433. [doi: 10.2196/26433] [Medline: 33465037]
23. Viele senioren wollen telemedizin nutzen [Article in German]. Ärzteblatt. 2020 Aug 18. URL: https://www.aerzteblatt.de/nachrichten/115706/Viele-Senioren-wollen-Telemedizin-nutzen [accessed 2023-02-15]
24. Plunger P, Eitenberger M, Kletecka-Pulker M, et al. Using telemedicine in nursing homes during the COVID-19 pandemic: a multi-perspective view on the implementation process. Nurs Open 2022 Mar;9(2):1155-1163. [doi: 10.1002/nop2.1155] [Medline: 34918492]
25. Assing Hvidt E, Christensen NP, Grønning A, Jepsen C, Lüchau EC. What are patients' first-time experiences with video consulting? A qualitative interview study in Danish general practice in times of COVID-19. BMJ Open 2022 Apr 15;12(4):e054415. [doi: 10.1136/bmjopen-2021-054415] [Medline: 35428624]
26. Murphy M, Scott LJ, Salisbury C, et al. Implementation of remote consulting in UK primary care following the COVID-19 pandemic: a mixed-methods longitudinal study. Br J Gen Pract 2021 Feb 25;71(704):e166-e177. [doi: 10.3399/BJGP.2020.0948] [Medline: 33558332]
27. Meurs M, Keuper J, Sankatsing V, Batenburg R, van Tuyl L. "Get Used to the Fact that Some of the Care Is Really Going to Take Place in a Different Way": general practitioners' experiences with e-health during the COVID-19 pandemic. Int J Environ Res Public Health 2022 Apr 22;19(9):5120. [doi: 10.3390/ijerph19095120] [Medline: 35564519]
28. Waschkau A, Steinhaeuser J. Wandel des bedarfs an videosprechstunden in zeiten einer pandemie: eine qualitative betrachtung [Article in German]. Zeitschrift Allgemeinmedizin 2020 Jul 1;96(7):317-324. [doi: 10.3238/zfa.2020.0317-0324]
29. Harst L, Lantzsch H, Scheibe M. Theories predicting end-user acceptance of telemedicine use: systematic review. J Med Internet Res 2019 May 21;21(5):e13117. [doi: 10.2196/13117] [Medline: 31115340]
30. Nordtug M, Assing Hvidt E, Lüchau EC, Grønning A. General practitioners' experiences of professional uncertainties emerging from the introduction of video consultations in general practice: qualitative study. JMIR Form Res 2022 Jun 14;6(6):e36289. [doi: 10.2196/36289] [Medline: 35653607]
31. Warmoth K, Lynch J, Darlington N, Bunn F, Goodman C. Using video consultation technology between care homes and health and social care professionals: a scoping review and interview study during COVID-19 pandemic. Age Ageing 2022 Feb 2;51(2):afab279. [doi: 10.1093/ageing/afab279]

32. Hahnel E, Braeseke G, Rieckhoff S, et al. Studie zu den potenzialen der telepflege in der pflegerischen versorgung [Article in German]. Bundesministerium für Gesundheit. 2020 Nov 13. URL: https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/Endbericht_Potenziale_Telepflege.pdf [accessed 2023-02-15]
33. Studie und expertengespräch zu umsetzungshemmnissen telemedizinischer anwendungen: abschlussbericht [Article in German]. Serviceagentur Demografischer Wandel. 2018. URL: https://www.serviceagentur-demografie.de/media/seiten/themenjahr/mobilitaet_und_digitalisierung/studien/2019/BMBF-2018-Umsetzungshemmnisse-telemedizinischer-Anwendungen.pdf [accessed 2023-02-15]
34. Bosnjak M, Batinic B. Understanding the willingness to participate in online-surveys – the case of e-mail questionnaires. In: Batinic B, Reips UD, Bosnjak M, Werne A, editors. Online Social Science: Hogrefe Publishing; 2002.
35. Meterko M, Restuccia JD, Stolzmann K, et al. Response rates, nonresponse bias, and data quality: results from a national survey of senior healthcare leaders. Public Opinion Q 2015;79(1):130-144. [doi: 10.1093/poq/nfu052]

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Original Paper

Factors That Influence Successful Adoption of Real-Time Location Systems for Use in a Dementia Care Setting: Mixed Methods Study

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Abstract

Background: Technology has been identified as a potential solution to alleviate resource gaps and augment care delivery in dementia care settings such as hospitals, long-term care, and retirement homes. There has been an increasing interest in using real-time location systems (RTLS) across health care settings for older adults with dementia, specifically related to the ability to track a person's movement and location.

Objective: In this study, we aimed to explore the factors that influence the adoption or nonadoption of an RTLS during its implementation in a specialized inpatient dementia unit in a tertiary care rehabilitation hospital.

Methods: The study included data from a brief quantitative survey and interviews from a convenience sample of frontline participants. Our deductive analysis of the interview used the 3 categories of the Fit Between Individuals, Task, and Technology framework as follows: individual and task, individual and technology, and task and technology. The purpose of using this framework was to assess the quality of the fit between technology attributes and an individual's self-reported intentions to adopt RTLS technology.

Results: A total of 20 health care providers (HCPs) completed the survey, of which 16 (80%) participated in interviews. Coding and subsequent analysis identified 2 conceptual subthemes in the individual-task fit category, including the identification of the task and the perception that participants were missing *at-risk* patient events. The task-technology fit category consisted of 3 subthemes, including reorganization of the task, personal control in relation to the task, and efficiency or resource allocation. A total of 4 subthemes were identified in the individual-technology fit category, including privacy and personal agency, trust in the technology, user interfaces, and perceptions of increased safety.

Conclusions: By the end of the study, most of the unit's HCPs were using the tablet app based on their perception of its usefulness, its alignment with their comfort level with technology, and its ability to help them perform job responsibilities. HCPs perceived that they were able to reduce patient search time dramatically, yet any improvements in care were noted to be implied, as this was not measured. There was limited anecdotal evidence of reduced patient risk or adverse events, but greater reported peace of mind for HCPs overseeing patients' activity levels.

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KEYWORDS

remote sensing technologies; dementia; real-time location systems; Fit between Individuals, Tasks, and Technology framework; FITT framework; technology implementation

Introduction

Background

The increasing demands for efficiency and improvements in the delivery of care have prompted interest in the use of tracking technologies as a solution to monitor the movements of patients, providers, and equipment across health care settings, including hospitals and long-term care homes. As an example of this type of technology, real-time location systems (RTLSs) can be used to identify the physical location of people or assets across time and space [1,2]. RTLS technologies are local positioning systems that typically consists of a wireless device attached to objects or worn by people, with environmentally embedded reference points that receive wireless signals from these wireless devices. Software connected to this wireless network can provide continuous real-time visualizations of the location data on a facility map. RTLS installations have been studied in a wide variety of health care settings to monitor individuals' movements (eg, residents or patients and health care providers [HCPs]) [3-5] and assets (eg, surgical equipment) [6] and, more recently, to collect health data [3,7-9]. These systems are particularly well suited for monitoring movement and reducing the risk of unaccompanied exit (eg, elopement); however, RTLS data have also been used to inform clinical decision-making processes and to monitor health status or the effects of an intervention [10]. Similar systems using wireless geolocation have already been successfully implemented in other sectors, such as insurance [11] and telecommunications [12], but present novel challenges when deployed in health care settings, particularly when they are used to generate personal and life-space data from vulnerable populations [13,14].

In the context of dementia care, interest in RTLS has been driven by the desire to evaluate cognition and health status more objectively and to enable the prediction of patient decline from changes in patterns of movement [7]. Other potential benefits of RTLS may include allowing greater freedom of movement within secure units and reducing the risk of unaccompanied exits (eg, elopement). A recent review by Grigorovich et al [2] identified barriers and enablers to implementing RTLS in people with dementia. Barriers to implementation included the following: a lack of motivation for providers to engage due to issues, such as perceptions of low value in use; technology infrastructure and maintenance challenges, such as a lack of on-site technical support and maintenance; and myths and stories about the technology and its purpose that are shared informally due to a lack of understanding about the systems and poor communication about how they work. In contrast, enablers of implementation included the following: being sensitive and adapting to local workflows, policies, and technologies; usability and user-centered design of the RTLS system; frequent communication with care providers; and establishing policies, frameworks, governance, and evaluations to assess the utility and improve the quality of the installation. The review found a striking lack of evidence to support the use of RTLS technologies to improve the quality of residents' lives or the workflow of HCPs. RTLS adoption in acute care settings has been slow, with concerns regarding provider privacy pitted against the goal of patient safety and efficiency [3].

Objectives

While many technology adoption models are in use [4] and have provided considerable insight into the adoption of digital technologies in the health care domain [5,6], to date, no study has specifically examined the implementation of an RTLS in a tertiary dementia care setting. To better demonstrate the potential barriers and enablers of RTLS adoption in a clinical setting, we used the Fit Between Individuals, Tasks, and Technology (FITT) framework developed by Ammenwerth et al [8]. The FITT framework suggests that the adoption of new technology in a clinical environment will depend on the *fit* between the attributes of the users (eg, computer literacy and education), the attributes of the technology (eg, user interface and functionality), and the attributes of the clinical task (eg, degree of complexity and workflows) [8]. The framework can be used predictively [9] or retrospectively to identify "deltas" between the expectations of a technology's implementation in a clinical setting and its actual relevance in the workflows and to its users [15]. The FITT framework's strength is its emphasis on the interaction between the individual and the task, with the understanding that harmonization will positively impact the implementation and adoption of novel technologies. In this study, we aimed to identify the factors that influence the adoption or nonadoption of an RTLS during its implementation in a secure inpatient unit for persons living with dementia in a rehabilitation hospital.

Methods

Study Design

This partially mixed methods concurrent study [16] included a brief preinterview survey followed by an in-depth semistructured interview. We chose this study design due to the exploratory nature of the research and the combination of quantitative and qualitative data that provides a deeper and more comprehensive understanding of the topic [17,18].

Study Setting

This study was conducted in a 20-bed secure inpatient dementia care unit of a large urban rehabilitation hospital in Ontario, Canada. Patients were admitted primarily from long-term care homes to receive specialized assessment and a personalized care plan to manage agitation, aggression, and other behaviors that interfere with the quality of life and safety of individuals living with dementia and their caregivers (eg, formal and informal). The unit comprised a team of interprofessional care providers (eg, nurses, physiotherapists, occupational therapists, recreation therapists, and geriatric psychiatrists) with expertise in addressing the range of physical, mental, and emotional challenges often associated with dementia. As the unit was a secure unit, the team was familiar with using technology to help monitor patients' health status and movements. For instance, the unit used the WanderGuard elopement prevention system (Securitas Healthcare), which alerted providers if patients attempted to leave the unit unaccompanied.

Participants

Participants in this study were HCPs who regularly worked on the unit where the technology was implemented (eg, nursing aides, nurses, allied health professionals, and unit leadership). There were approximately 40 frontline staff members who interacted with patients, in addition to an advanced practice nurse and a unit manager. HCPs working on the unit were exposed to the RTLS and were individually able to decide to engage with the technology. The participants were recruited via an email distributed by the unit manager to all HCPs and by word of mouth during training sessions, team meetings, and daily report huddles.

RTLS Intervention

The implemented RTLS was a commercially packaged ultrawideband live monitoring system installed to locate and track patients on the unit. The hardware consisted of wall-mounted beacons that created a local Wi-Fi mesh and wearable tags that provided location data within the networked area. The wearable tags were fitted to patients on the unit as nonremovable bracelets. All participants' substitute decision makers were provided with an opportunity to consent (or refuse) to have the patient wear the bracelet and to separately consent (or refuse) to have the location data collected and stored for research purposes (eg, development of clinical algorithms).

In the nursing station, a tablet app provided a view-only dashboard of the unit map and a live feed of patient locations. The tablet was locked to "kiosk mode" after log-in, thus preventing the app display from timing out. We held in-service training sessions to familiarize HCPs with the app's layout and functions, including how to read the map and search for patients. Although the RTLS can be used in various ways (eg, nursing call bell), no other features were enabled in this study; the system was exclusively used to locate patients. The RTLS location data were stored on a secured and sectioned client cloud server approved by the Health Insurance Portability and Accountability Act.

Ethical Considerations

This study was approved by the University Health Network (UHN) Research Ethics Board (#20-6277) and the Wilfrid Laurier University Research Ethics Board (ID# 6767) and was conducted in accordance with the principles of the Declaration of Helsinki. The survey participants reviewed a web-based consent form, had an opportunity to contact the study team with any questions, and indicated their informed consent to participate through the UHN REDCap (Research Electronic Data Capture; Vanderbilt University) e-consenting process. Then, a personalized link was sent from the REDCap system via email for participants to complete the preinterview survey. Upon completion of the interview, HCPs received a gift card valued at CAD $20 (US $14.8).

Data Collection

Following installation, a research study team member (LS) held training sessions for HCPs to explain how the bracelets worked to track patient location and how to use the nursing station tablet and app. During the training sessions, HCPs were verbally informed that they would receive an email inviting them to participate in the study. Approximately 6 weeks after installation, HCPs were invited via email to participate in the study, which included a short survey followed by a more in-depth, semistructured interview. The survey (facilitated via the UHN-managed REDCap servers) took approximately 5 minutes to complete and included questions regarding their sociodemographic characteristics and attitudes toward the use of technology when caring for patients with dementia. These attitudinal questions asked HCPs regarding their perceptions of the following: (1) their comfort with technology generally and location-tracking technology in particular, (2) the appropriateness of using location-tracking technology on patients with dementia, (3) whether they planned to use the location-tracking system installed in their unit, and (4) the appropriateness of technology to monitor HCPs. Furthermore, staff were invited to provide free-text comments regarding why they planned to use or not use the technology. After completing the survey, the participants were contacted to participate in the semistructured phone interview. The interview comprised 12 primary questions (Multimedia Appendix 1), asking about their past experience (if any) using RTLS, expectations and goals of the system, user experiences with the system, and how they perceived the system to impact their care of patients. The interviews lasted approximately 1 hour and were audio recorded. The interviews continued until saturation was achieved.

Data Analysis

Qualitative analysis was conducted using NVivo (version 12; Lumivero). Anonymized interviews were transcribed verbatim. Transcripts were read by all the research team members (LHL, AG, JM, KN, and AB) to gain a comprehensive understanding of the content. Several team meetings were held to review the transcripts and develop a coding strategy. We used inductive and deductive analytic techniques, such as systematic coding and constant comparison to fit data with existing literature and to identify conceptual categories and insights [19]. After the first round of independent coding, the team met to ensure the optimal categorization of utterances within themes and subthemes. Each interview was coded by at least 2 team members. Group discussions and consensus were used to resolve any disagreements in coding.

Our deductive analysis of the interview data was informed by the FITT framework developed by Ammenwerth et al [8] and included the following categories: (1) individual and task, (2) individual and technology, and (3) task and technology. The FITT framework suggests that the adoption of new technology in a clinical environment will depend on the "fit" between the attributes of the individuals (eg, computer literacy), the attributes of the technology (eg, user interface and functionality), and clinical task attributes (eg, degree of complexity) [8]. The individual category represents not only the individuals using the technology but also groups of users (eg, HCPs) and considers constructs such as the physical settings in which they operate, thus representing any nontask phenomenon that may influence uptake and use of the technology. The technology category includes components of a digital application, such as hardware, software, and network infrastructure, or analog tools, such as paper-based care plans or manuals, used to complement a particular technology. The task category represents the clinical work and work-related processes that occur within a particular care setting.

Results

Participant Demographics

A total of 20 HCPs completed the preinterview survey. The survey's primary purpose was to characterize the participant sample and allow the study team to determine whether the diverse range of HCPs on the unit was represented in the interview process. Of the 20 HCPs who completed the survey, 16 (80%) completed interviews, a sample size deemed sufficient given the exploratory nature of the single-site study and relative professional homogeneity of the sample population that allowed us to achieve saturation (Table 1) [20]. The participants who completed the survey and interview were predominantly female individuals (16/20, 80%), aged <50 years (16/20, 80%), and provided direct patient care (eg, nursing and support staff and allied health staff; 14/20, 70%).

Table 1. Participant demographics (n=20).

Measure and item	Surveys (n=20), n (%)	Interviews (n=16), n (%)
Sex		
Female	16 (80)	14 (88)
Male	4 (20)	2 (12)
Age group (y)		
≥25 to <35	6 (30)	5 (31)
≥35 to <50	10 (50)	8 (50)
≥50	2 (10)	2 (12)
Did not answer	2 (10)	1 (6)
Education		
College, other nonuniversity certificate, or diploma	7 (35)	5 (31)
Bachelor's degree	10 (50)	8 (50)
Master's degree	3 (15)	3 (19)
Occupation		
Providing direct patient care (nursing and support staff)	14 (70)	10 (62)
Allied health (eg, OT[a] or PTA[b] and recreation therapy)	4 (20)	4 (25)
Leadership or administration	2 (10)	2 (12)
Work experience (y)		
≤1	3 (15)	3 (19)
2 to 5	1 (5)	0 (0)
6 to 10	3 (15)	2 (12)
>10	11 (55)	10 (62)
Did not answer	2 (10)	1 (6)
Current position (y)		
≤1	7 (35)	7 (44)
2 to 5	4 (20)	3 (19)
6 to 10	3 (15)	1 (6)
>10	4 (20)	4 (25)
Did not answer	2 (10)	1 (6)

[a] OT: occupational therapist.

[b] PTA: physiotherapy assistant.

All the participants who completed the survey agreed or somewhat agreed with the statements that they were "satisfied with their job," were "confident in their ability to learn a new technology," and were "familiar with location-tracking technology and how it works" and "agreed" or "somewhat agreed" that location-tracking technology was "acceptable when tracking the movements of persons living with dementia" (Table 2). There was less concordance of opinion regarding the use of location-tracking technology to monitor the movement of providers; 12 (60%) of the 20 respondents reported that its use would be "somewhat or completely unacceptable," and 4 (20%) reported its use as "somewhat or completely acceptable" (Tables 3 and 4).

Table 2. Survey question responses (N=20).

Questions	Agree, n (%)	Somewhat agree, n (%)	Neither disagree nor agree, n (%)	Somewhat disagree, n (%)	Disagree, n (%)
"I am satisfied with my job."	15 (75)	5 (25)	0 (0)	0 (0)	0 (0)
"Overall, I find technology is useful in my job."[a]	15 (79)	1 (5)	3 (16)	0 (0)	0 (0)
"I feel confident in my ability to learn how to use new technology."	17 (85)	3 (15)	0 (0)	0 (0)	0 (0)
"I am familiar with location-monitoring technology and how it works."	14 (70)	6 (30)	0 (0)	0 (0)	0 (0)

[a] n=19.

Table 3. Survey question responses (N=20).

Questions	Completely acceptable, n (%)	Somewhat acceptable, n (%)	Neither acceptable nor unacceptable, n (%)	Somewhat unacceptable, n (%)	Completely unacceptable, n (%)
"In general, I believe that using location-monitoring technology to track the movements of persons with dementia is"	16 (80)	4 (20)	0 (0)	0 (0)	0 (0)
"In general, I believe that using location-monitoring technology to track the movements of health care provider is"	1 (5)	3 (15)	4 (20)	7 (35)	5 (25)

Table 4. Survey question responses (N=20) to "I plan to use the location-monitoring technology (referred to as "RTLS[a]") during the pilot study at the SDU[b]."

Responses	Value, n (%)
Always	10 (50)
Often	5 (25)
Sometimes	4 (20)
Rarely	1 (5)
Never	0 (0)

[a] RTLS: real-time location system.

[b] SDU: special dementia unit.

Interview Results

Interview data were analyzed and reported in 3 categories that correspond to the FITT framework [8]. The quality of the fit between these constructs depends on each of their characteristics and their alignment and the ability of management or the technology adoption team to influence the adaptation of the task, the technology, or the individual to improve the quality and success of the implementation.

Individual-Task Fit

Overview

This category represents individual attributes, including individual users, user groups, the organization, and the working processes involved in completing the task, which in this case was using the RTLS to locate a patient in the unit. The ostensibly simple task of locating patients within a locked unit is complicated, given that many are mobile and some exhibit motor agitation, where restlessness keeps them in constant motion [21]. Using coding and subsequent analysis, we identified 2 conceptual subthemes: (1) characterization of the task and (2) the association between locating and monitoring patients for HCPs.

Characterization of the Task

In the first subtheme, participants identified the characteristics of the task, particularly the time-sensitive nature of some activities; for example, medication administration, which benefits from real-time monitoring, or conversely, the inability to locate a patient promptly when needed. One provider noted that the task of locating patients was more complicated with this specialized population as follows:

> *Because our patients are confused, and they have no concept of their own place or their own room, majority of them, they wander around the unit.* [P5]

Legacy closed-circuit television cameras that streamed video in real time to monitors located at the nursing desk only allowed the visualization of public spaces (eg, hallways). A provider articulated the difficulty with locating a patient using this existing system, as follows:

> *[T]here's no cameras in the patient rooms. Only in the hallway. Like [in] the public spaces...but not in the patient room. So, if you can't see them in like the more public spaces, then you would actually have to get up and search every single room because the patients might not be in their room...They could be in someone else's room, they could have fallen asleep on someone else's bed, maybe they're in someone else's bathroom.* [P21]

Furthermore, many HCPs shared that the task of locating patients manually made other tasks, such as medication administration, more complex:

> *Like if you wanted to give medication, [if] we couldn't find, um, patients, we have to go and look for them in room by room.* [P6]

Moreover, we conducted this study during the COVID-19 pandemic, during which patients who tested positive or were symptomatic of infection had to be isolated on the unit. While external doors were locked, most internal doors were not, particularly in patient rooms. The task of maintaining isolation for new patients, those who were exposed, or those who tested positive for COVID-19 in this unit was challenging, as they had difficulty remembering and understanding the need for isolation and physical distancing. HCPs had to monitor patients every 15 minutes to ensure that they stayed isolated and had to use a variety of strategies to encourage patients to remain in their rooms (eg, placing stop-strip door banners across the unit and stop signs on closed doors and sitting outside their rooms). Hallway cameras were perceived as inadequate for the task of supporting isolation, and providers felt that they did not allow for an anticipatory response when a patient was either moving from their bed or toward a restricted hallway or room.

In addition, this theme included the individuals' need to track items other than human or physical assets in a dynamic space. One HCP stated that putting tags on nurses could help them locate each other when one of their patients required assistance. Another suggested that they would be useful for quantifying direct care hours provided by different providers.

Similarly, some participants suggested that the RTLS may be helpful for monitoring assets such as patient's phones and walkers that are often misplaced. This is particularly important for assistive technologies, such as walkers, that support mobility and activities of daily living. One HCP noted as follows:

> *Someone who always uses their walker or, you know, always misplaces it...especially a lot of our patients now have, you know, like, personal items such as cell phones...and they've been misplaced and we're always looking for it.* [P8]
>
> *Especially with our...patient...group right now, a lot of them have their own cell phones. A lot of them, they put it in their pockets and a lot of the provider don't really track where they are. So, when the patients are looking for it, we're the ones who have to go around and look, you know, in the bag, in the laundry, in their closet.* [P8]

Association Between Locating and Monitoring Patients for HCPs

The second individual-task subtheme accounted for an HCP's perception that the act of locating or knowing the location of a patient on the unit was strongly associated with a better standard of care by helping to mitigate potentially "risky" events. One HCP noted as follows:

> *It gives me more stress if every time I keep on looking for my patient, I couldn't get my things done right away, 'cause I have to find them and always making sure that they're safe.* [P12]

Being unable to identify when one patient entered another patient's room was a common concern noted by HCPs:

> *So once in a while, we do our rounds, but if a patient sneaked into somebody's room, how would I know, until I really look at who is in bed?* [P5]
>
> *We cannot find them because they wander around, you know, they...pace and...they are so intrusive, they go to other, uh, patients' rooms.* [P6]

A number of HCPs noted that "distractions" would often interrupt the process of physically locating a patient on the floor, for example:

> *Another patient come(s) up to you and need(s) something, then you have to find someone else to help you.* [P21]
>
> *I would be finding one patient and then I would be distracted and go to another nurse who needed me.* [P14]

The same HCP mentioned that the task is never just a "straight search" and that their presence on the floor would be noted by other patients and staff, and they would be drawn into monitoring or supporting interactions in support of patients or their colleagues.

Task-Technology Fit

Overview

This category of the FITT framework represents the working processes involved in completing the task (locating a patient) and how they interact with the RTLS (consisting of the bracelet, the wall-mounted beacons receiving the ultrawideband signal, the app on the tablet at the nursing desk, and the software application). The task-technology fit category consisted of three subthemes: (1) reorganization of the task, (2) personal control in relation to the task, and (3) efficiency and resource allocation.

Reorganization of the Task

Reorganization of the task was expressed by HCPs as the ability to locate and monitor patients in real time without having to go into each patient room. HCPs using the technology started their search at the nursing station, where they interacted with the tablet to identify the location of the patient and then proceeded directly to the patient, rather than conducting a random search. Providers found this beneficial for several reasons, including using the tablet to “spot-check” to see where a patient was or being able to directly find a patient when they wanted to:

> *The purpose as I see it, is to be able to locate the patient when you need to locate a patient, whether it’s because of double checking that they haven’t eloped or you’re trying to locate them for a therapeutic reason or for you know, I think this is the big one was like family members coming to visit and they wanted, you know, to find their loved one.* [P4]

Furthermore, we found evidence of evolving work routines or stable actions that achieved work across time and space through adaptive routinization that supported HCPs use and adoption of the technology. However, adjustment of the technology (eg, tablet number and location) or routine (eg, shift change and anticipating interpatient altercations) to achieve a successful implementation was still clearly a work in progress at the time the interviews were conducted:

> *It’s been so new, it’s hard for us to remember that we have this...the more people are talking about it, the more that we’re remembering, “Oh we could use this instead of you know, running about the unit searching for patients.”* [P3]

> *Habitually, I would start the lap- and then realize that I’m wasting time, cut through the care station, find them on the monitor and then, yeah. So, it-it-it did change the fact that I-I wouldn’t do more than one lap before realizing that I could go use it.* [P8]

> *Right at shift change, I’m not gonna go in there and push through the nurses, trying to do their shift change to look at the monitor. I’ll just do a couple extra laps until I find them because it’s a reasonably small unit.* [P8]

Personal Control in Relation to the Task

The second subtheme in the task-technology fit category was the recognition of personal control in relation to the task of locating patients. The HCPs perceived that they had more control by being able to decide how and when to find patients using the app. For example, if they were in the nursing station performing another task, they were also able to see or locate a patient at a glance on the tablet. Examples of this narrative are as follows:

> *Instead of walking around three times around the entire unit, I know exactly where my patient is. I also can monitor them, uh, remotely.* [P5]

> *Especially, uh, at night-time it’s a lot better because, uh, we know that, uh, which patient is, uh, in the room and which one is out. When we are sitting in the nursing station, we can say like this...patient has come out of the room and is in a hallway or he has woken up.* [P6]

> *At night, like I wanna see which patients are asleep, or awaken, are awake, like, if the bed alarms don’t work.* [P13]

Efficiency and Resource Allocation

Efficiency and resource allocation were identified as a subtheme in the task-technology fit category. The HCPs stated that they were saving time and resources through their ability to find a patient directly using the app. They shared that a room-by-room search of the unit could potentially take up to 15 minutes each time as their patients were very mobile, which was challenging as they were also likely to be distracted by another patient during their search:

> *It saves me time from going from room to room because these patients, normally they walk around and go to other people’s rooms so where you least expect them to be that’s where they sometimes are. And, um, if you think they’re gonna be in their room, most times you’re wrong. They’re in somebody else’s room away from-- Maybe the other corner, you know, so it saves your time when you use this device. You located them faster.* [P11]

HCPs further reflected that the time they saved using the app to locate patients could potentially be used for accomplishing other tasks. For example, 2 providers stated as follows:

> *When time is saved, then I can invest that time more on patient care, and all the things that I can do with extra time.* [P13]

> *You still have to physically go look for the patient, but at least it does narrow it down for you.* [P4]

However, the location of a singular tablet installed at the nursing station may pinpoint a patient in 1 location only to find that they had moved by the time the HCPs reached there. Finally, the technology was considered helpful in locating multiple patients when the providers needed to run a group activity:

> *If I run groups, and I want to get, you know, specific patients of a certain group—um, then I would, you know, go to iPad and see where they are.* [P8]

Individual-Technology Fit

Overview

Individual-technology fit represents the relationship between the attributes of the individuals and the attributes of the technology and, in this study, comprised the most populous coding category for the interview data. The "individual" construct in the FITT model represents the HCP, who uses the technology to locate a patient; the patient, who wears the bracelet; the users as a group; and the organization, in which the technology is installed and the "tasks" and work processes are occurring. A total of four subthemes were identified in the individual-technology fit category: (1) privacy and personal agency, (2) trust in the technology, (3) user interfaces, and (4) perceptions of increased safety.

Privacy and Personal Agency

The subtheme of privacy and agency has multiple perspectives, given that while HCPs were the "users" of the technology, patients were the ones wearing the bracelet and being tracked. In alignment with the survey data, HCPs felt that patients on the unit had a limited right to privacy due to their perspective that these patients required close supervision to reduce their risk of harm (eg, preventing them from a fall or an altercation with another resident). This perception was expressed in narratives that suggested that patients with dementia lose their right to privacy (and conversely, their right to refuse to be monitored using the bracelet) as their cognitive impairment and behavior presents a risk to themselves, their family, and the organization:

> *There is no privacy for patients with dementia, with behaviors...privacy means that you are putting them in, uh, at risk.* [P6]

However, HCPs recognized that other patients (eg, those without dementia) had a right to privacy and may thus find the use of RTLS to monitor them unacceptable:

> *I don't know about the patients on other floors if...it's monitoring every move...they don't wanna be like, to know that they've gone to the washroom, you know? These just—these are- these are things they might not like.* [P6]

Despite HCPs belief that patients in the unit waived their right to privacy in return for what they believed to be better care and safety, in general, providers believed they were "entitled to their own privacy" (P16) and did not agree with the concept of using location tracking for HCPs. In particular, HCPs were worried that if the ability to track staff was initiated by management, it could be used to sanction them:

> *So, tracking staff, they would be depending on the culture, and I think just general trust of senior leadership. Like, are you tracking if I'm taking too many breaks, if I'm doing my job correctly?* [P21]

Those who personally felt that there may be value in tracking the movements of staff acknowledged that other HCPs might not agree but variously supported the tracking of providers to help locate each other, gather supporting data as it relates to workload monitoring, and build more efficient units. For example, they suggested that tracking providers' movements may be useful for showing how much they move in a day, how often they are in patient rooms, how many staff members are required to assist a patient, and for how long:

> *Cause I think we don't estimate that correctly.* [P22]

The potential risks associated with the collection and storage of patients' data were not a focus of concern; providers did not reflect on data use and storage until prompted during the interviews. Furthermore, providers made assumptions that the location data were kept on internal hospital servers; while for this study all data were stored on hospital secure servers, this is unusual and had to be negotiated with the equipment vendor who retained data on proprietary servers. One HCP stated as follows:

> *I would hope the security, or the data is secure and, um, only, you know, used for the study purposes.* [P3]

Another wondered if the data could be used for alternative purposes that they were not aware of:

> *I don't know that information is being used for some other sinister reason I don't know. Like whether they trust us with that information.* [P4]

Trust in the Technology

The subtheme of an individual's trust in the technology relates to the reliability of the system—that the technology was working when required—and how it was used or adopted as a result. However, HCPs displayed a tolerance for unreliability in this product, likely because there were workarounds; that is, the providers could revert to walking the unit to find a patient, which made the consequences of unreliability minor:

> *Okay. So, you have a little bit of a clue that there's something wrong with the bracelet if it's not moving then?* [Interviewer]
>
> *Yeah. Especially when the bracelet, uh, is on the screen in one location and patient is physically on a, in a completely different location.* [P5]
>
> *Okay. Do you think that it not working, um, will influence how you trust the system or how you use it?* [Interviewer]
>
> *Uh, no, because it doesn't happen often, it's just once in a while malfunction.* [P5]

User Interfaces

The individual-technology fit category includes a subtheme of how patients and HCPs interfaced with the technology. Many HCPs shared that some patients "fidgeted" with or attempted to remove the bracelets. When asked to expand on this, HCPs explained that "some patients do remove, like they have catheter or other bracelets, they remove it. It's just, uh, one of their behaviors" (P13). In response to a patient removing their RTLS bracelet or trying to remove it, providers reported that they would attempt to redirect the patient or move the bracelet to another location on their body (eg, an ankle) despite acknowledging that such attempts to remove the bracelet might be an expression of their desire to not wear the bracelet at all:

> *Sometimes we don't understand, but of course they're showing that they don't like it.* [P15]

Despite acknowledging this, HCPs did not explore the reasons why patients attempted to remove their bracelet. However, one provider did report that they would remove the bracelet if "the patient states exactly that he knows what the bracelet is and he states like, 'I don't want to be monitored'" (P13).

Furthermore, providers mentioned that the patient-technology interface was a tool for maintaining patients' dignity while wearing the bracelet, considering their lack of agency over whether they wore the tracking device. The bracelet esthetic mimicked something other than a surveillance device. For example, one provider reported that a patient "referred to the bracelet...as their Apple watch and it was kind of cool that they had a nice new watch, which was beautiful" (P07). She suggested that this was beneficial and stated as follows:

> *In the future, if it could even mimic a watch or have a watch face on it, that it, you know, when it goes into screensaver or whatever becomes a watch face, then it would be even more patient-friendly, user-friendly, right?"* [P7]

Similarly, another HCP stated as follows:

> *Even people with dementia want to feel ready for the day and wear important pieces like a watch, carry a wallet. Wearing such pieces give dignity and acknowledges that people still have purpose.* [P14]

Perceptions of Increased Safety

Another subtheme related to how providers supported and justified the use of the system by discussing potential (but not yet implemented) enhancements to the safety of patients. Specifically, providers felt that the technology might allow them to intervene or react more efficiently to a presumptive risk with the potential to avoid injury. One person in the study expressed an interest in using the RTLS to reduce the use of restraints, while others mentioned their desire for proximity alarms that would alert providers when patients who are "having an altercation" are in close proximity to each other and allow them to intervene. The narratives of this theme include the following:

> *In terms of safety, like interactions with other...other patients...like you could, you know, set up some kind of parameters that alert the staff when my patient X gets within vicinity of patient Y.* [P20]
>
> *I think maybe even physically if you see that a patient has entered the washroom, an alert could go off into the care station. Um, there's often times where I'll find someone in there and they're either beginning the process on their own and need help, or they are finishing the process and it's become messy and there's no way for us to know...But if an alert goes off in the care station, so and so has entered the bathroom, then whoever's in the care station can respond to that before it gets messy.* [P07]

Discussion

Principal Findings

In this study, the introduction of an RTLS with restricted functionality of tracking the location of people and assets within a secure inpatient unit for persons living with dementia represents one of the most elementary implementations of a single technology to achieve a single task. The successful adoption of the technology was uncomplicated, and its uptake by HCPs was thus predictably swift. We aimed to investigate the factors influencing the adoption or nonadoption of the RTLS technology. We found that the successful adoption of the RTLS was due to the strong fit between the technology and the task, which was locating the patients more efficiently, and the strong individual and task relationship on the unit.

First, we summarize the results of the interactions between the 3 pillars of the FITT framework to explain the success of the implementation and identify the factors that influenced the adoption of the technology. Second, we address related issues that warrant consideration for similar and more complex implementation.

Evaluating the FITT of the RTLS Implementation

The strong individual and task relationship on the unit was supported by an organization whose labor force was stressed due to the global pandemic and shortages and allied health and nursing HCPs who were aware of the challenges of ensuring that mobile individuals living with dementia were safe without constant one-to-one supervision. Individual providers who were responsible for locating patients in real time for events such as medication rounds, check-ins, patient visitors, and meals relied on installed closed-circuit television camera feeds. These cameras streamed to monitors mounted above the nursing station desk, providing real time but restricted line-of-sight hallway identification of patients and providers. However, the patient had to be in a hallway and remain in the same place long enough to be visualized. Depending on the patient, a care provider may need to search >1 bedroom to find a patient [22]. Providers' anticipation of negative outcomes, both personally and to the patient from less than round-the-clock monitoring or to respond to risky behaviors such as interpersonal altercations or elopement, was a strong motivator not only to continue with what was described as an inefficient and time-consuming process but also to find and adopt a more efficient solution. As demonstrated in the narratives, the strong fit between the RTLS technology and the task was perceived as a clear benefit to staff and, as such, an influencing factor of technology uptake. When staff perceive that using the technology is the best fit for the completion of their tasks, they are more likely to adopt its use [23]. With this type of technology, Doshi-Velez et al [22] identified that being able to find patients more efficiently provides nursing staff with a strong motivation to use RTLS technology. Our HCPs provided examples of the perceived limitations of the current method of completing the patient locating. The time and energy required to find patients by "roaming" the halls were not generally perceived as a valuable use of time. Similar to research by Griffin et al [3], the HCPs appreciated the efficiencies that the technology afforded them (eg, the ability to "multitask" by reviewing the tablet app at the nursing station while completing another task, such as charting). HCPs mentioned that this was especially helpful during night shifts when HCP-to-patient ratios were lower (eg, fewer HCPs were responsible for more patients). Although HCPs were universally appreciative of reducing patient search time, they mentioned the indirect value of HCP "walkarounds" in the facility during patient searches. This informal "rounding" on the unit and attending to "distractions" over time and space was suggested by one participant as an opportunity for HCPs to intervene early or to prevent risky events or behaviors.

As the RTLS technology in this study passively *surveils*, it is neither predictive nor prescriptive; therefore, while it may help identify potential issues (eg, a patient alone in a bathroom or exiting the facility), with the functionality activated for this pilot, the system still required a provider to identify an issue (by visualizing patient location on the tablet), judge the potential risk, and determine if they needed to respond in person. The transactional (locating task) and anticipatory (monitoring task) use of the technology were both highly suited to the task of reducing risk for the individual, the institution, and the patient and provided peace of mind to visiting care partners who may perceive that the providers were more aware of the presence of their family or loved one.

Another influencing factor for adoption was the fit between the individual and the technology, partly due to the intrinsic capacity of the HCPs. We conducted foundational preinstallation training on the operation and use of the RTLS, and the HCPs were comfortable with workflow changes as a result of being a research-intensive facility (eg, by way of social influence and facilitating conditions), which has been found to be beneficial for the adoption of technology [24,25]. In addition, as found in the preinterview survey, the HCPs self-reported a positive attitude toward technology in general and the RTLS in particular. However, the fact that the technology was introduced to the staff as a pilot research project may have impacted its adoption. One HCP noted that if it had been presented as the de facto and permanent new method of locating patients, they would have been more invested in it.

Similar to Griffin et al [3], the HCP's confidence in the RTLS system was based on trust. This included trust that the organization would not implement a system that did not secure patient location data, that the RTLS was reliable and presented accurate information, and that the organization's trust in them as professionals should preclude the expansion of RTLS technology to monitoring staff for any reason. Similarly, the trust extended to the reliability that the system would be functional when needed. While the implementation of the RTLS presented few technological issues, beyond unplugged beacons, frozen screens, and drained bracelet batteries, that were unable to be managed by the on-site research coordinator (in addition to its fit with the unit workflow and operations), other issues emerged that are noteworthy.

Perceptions of Safety

The decision to pilot or implement RTLS is frequently promoted as it has the potential to enhance unsupervised freedom of movement and improve the physical safety of persons living with dementia. Similar to the findings reported by Hall et al [26], the HCPs in our study identified that the primary rationale for using RTLS in this population was enhanced physical safety rather than freedom of movement. Providers alluded to technology-enhanced patient safety, yet it was difficult for them to articulate measurable outputs of related safety improvements compared to current interventions. It is important to distinguish between the "potential" of the technology's capabilities and the actual functionality that helps realize improved safety. In reality, the functionality of the installed technology for our study was not "smart" nor was it predictive or responsive; unless a human was monitoring the app the moment a patient was at risk, there was no intervention or lessening of risk. The installed off-the-shelf technology in this study had both geofencing alerts and call button features but required human monitoring and sufficient staffing to respond and therefore were not enabled. Installations that enable these types of alerts (related to being outside a restricted area, experiencing a fall, or being in a location that suggests more risky behaviors) must be monitored to allow for a response in real time. This has resource implications related to technology (eg, mobile phone apps or tablets that allow remote monitoring rather than using a fixed desktop application) and human resources (eg, alerts must be responded to); thus, additional staff must be recruited to monitor, investigate, and respond to alerts anywhere on the floor at any time. Infrastructure and funding challenges and labor force shortages must be addressed to encourage more widespread exploration of the value and use of technologies such as RTLS in long-term care.

Training and Adoption

HCPs in the study were oriented to the tablet app through training sessions, which focused on the features of the technology and its basic use, whether they voluntarily chose to use the location map app or not. The tablet was located beside the legacy surveillance camera feed, serving as a reminder of its availability. During the training sessions, those who were using the technology shared use cases and examples of when and how they found the system useful. At the start of the project, HCPs explained that their confidence in the system would be heightened if they could trust that it reliably showed the real location of patients and that the patients were unable to interfere with its operation. By the end of the study, most HCPs were using the tablet app based on their perception of its usefulness, its alignment with their comfort level with technology, and its ability to help them perform job responsibilities. As the pilot implementation progressed, "superusers" emerged [27,28], who were early adopters and who strongly advocated for its usefulness and value in the unit. Superusers often spontaneously helped others troubleshoot or navigate the RTLS and quickly identified alternative uses for the technology (eg, as asset tags). In one case, we downloaded a patient's activity reports (a management feature of this particular RTLS), which helped to identify that they walked an extraordinary distance daily, allowing providers to integrate changes into the care plan (eg, encouraging rest times and increased caloric intake). Furthermore, some HCP users identified that the technology would be potentially more helpful if it were available on their phones or if there were more tablets accessible throughout the unit at different locations.

The setting for this study was a locked inpatient unit that already used sensors fitted to each patient to prevent their unaccompanied exit from the unit. Within the unit, the patients were free to move as they wished or were able to. As a short-stay unit, its focus was on stabilizing or addressing behaviors and facilitating patients' return to the community. Unlike a long-term care home where residents' mobility is often compromised, many of the patients in this unit were ambulatory; the organization's interest in preserving patients' dignity and aligning their values with those of patients by allowing their free movement in the unit had operational implications, such as unsupervised interactions between patients and increased provider time in seeking out patients for treatment and well-being checks. It is unsurprising that organizations are moving to replace what they believe to be non–value-added tasks performed by providers with technology-enhanced solutions such as RTLS [29]. Patients' resistance to wearing the bracelet was reduced for some patients perceived the technology similar to an Apple Watch, which they described as "cool." Providers suggested that to avoid dissent, further disguising the transponder, what Sannon and Forte [30] describe as "dignity in design" where aesthetics are considered along with utility, would provide more dignity to their patients when the organization and substitute decision makers' values (to create a safe and risk-free environment) supersede patients' right to privacy.

During the training of HCPs on the RTLS and in our research interviews, we noted a lack of in-depth discussion regarding the complexities and potential challenges associated with implementing monitoring technologies in a health care setting [26]. This approach, while simplifying the training and implementation process, may have allowed staff to focus on its potential to enhance patient safety but failed to engage the HCPs, care partners, and, where feasible, patients in a dialogue about the implications and challenges associated with its deployment, such as its impact on privacy. Hall et al [26] suggested that for technology implementations to be successful, they must involve substantive discussions to anticipate and address these challenges. Such inclusive conversations involving all stakeholders in the decision-making process are crucial for a more effective implementation of novel technological systems.

In the survey, all participants identified that using this technology to track persons with dementia was either somewhat (16/20, 80%) or completely (4/20, 20%) acceptable. During the interviews, the staff did not initiate any ethical concerns. Prompted questions related to the ethical use of ubiquitous monitoring technologies that collect sensitive biometric data, the creation of a surveillance culture, and the responsibility of organizations to respect the rights and dignity of susceptible individuals when using these technologies were not identified as a care priority by staff in the interviews. This finding has considerable risks and implications that have been explored in more detail elsewhere [2].

In the survey, the HCPs demonstrated a mixed level of acceptance of the RTLS being used to monitor HCP movement. This finding was echoed in the interviews, where HCPs expressed a hesitancy to use the technologies on themselves despite overall satisfaction with their work; this is consistent with previous studies [3,31], where workforce monitoring was viewed as a lack of management-worker trust, a manifestation of the blame culture, and a foot in the door where monitoring for quality of care (eg, time spent with patients or handwashing) would be the first step to its use for individual performance tracking (eg, length of breaks and productivity). The shift of health care administration, toward the adoption of more scientific management where standardization, removal of inefficiencies, and process improvement, supports the notion that RTLS might be used in this fashion [32]. Overt messaging from the management that the monitoring in this study was limited to patients supported its successful adoption and implementation.

HCP Workload and Technology Support

Technology has increased the amount and complexity of information that employees are expected to process and has enabled HCPs to access unlimited amounts of information to do their jobs [33]. In the health care environment in which provider resources are scarce, workloads are high. Some HCPs on the floor did not use the RTLS (and did not volunteer to participate in our study); those who participated cited its simplicity, reliability, and ability to reduce their perceived workload as the reason for their continued use of the technology, rather than the rationale of safety as the rationale for adoption. Workload presented a challenge in relation to troubleshooting technological issues with the RTLS. Although providers were comfortable with the RTLS, none moved into a role where they were able to troubleshoot simple technological issues. Most cited the lack of time, the availability of a low-cost alternative (walking around), and the presence of a research team for technological support; however, this support was not available 24/7.

Limitations

The generalization of findings from data collected at a single location during one technology implementation has limitations. However, our focus on exploring the perspectives of HCPs working in an environment that provides specialized dementia care was both a strength and a limitation. The perspectives of the organizational decision makers on the rationale for adopting and implementing the RTLS technology in the unit were outside the scope of the study. These findings will be important to explore in future research on the adoption of RTLS in dementia care settings.

Providers' self-reported comfort with the installed RTLS was evident in the preinterview questionnaire responses and after providers were trained and had used the technology. Furthermore, the unit under study is a teaching and research-intensive hospital that frequently involves providers in technology-enabled research studies. The uniqueness of the unit may have impacted the self-reported providers' job satisfaction where, particularly during the pandemic, restricted access to the unit and the limited number of patients and providers offered some immunity from the ongoing pandemic pressures related to staffing shortages, frequent outbreaks, and increased workloads, which were experienced in other congregate settings for people living with dementia [34].

The staff members on the unit were acquainted with the principal investigator and the research coordinator of this study, who conveyed the study's purpose to the participants, responded to staff inquiries, and obtained participant consent. To ensure impartiality, the study team used deductive analysis of the data and applied the FITT framework as a standardized approach to analyze the data. This framework is a well-established and widely used approach in the literature, which helped to reduce the potential for researcher bias in data interpretation. Furthermore, the fact that the unit uses other technology, such as the elopement prevention system, suggests that staff members are accustomed to using technology in their daily work routine. This familiarity with technology may have helped to reduce any bias toward or against the RTLS technology used in this study.

Another limitation relates to the small scale of this study. Although the number of participants was sufficient to reach saturation with respect to our research questions, it is insufficient to generalize beyond the specific context of the featured location-tracking technology, its functionality, and the hospital-based dementia care setting in which it was implemented.

Conclusions

Similar to many novel technologies in the nascent stages of their adoption, evidence to support the utility and effectiveness of RTLS in improving the safety and quality of care in health care organizations and patients' experience is limited. While HCPs were able to reduce their self-reported patient search time dramatically, sometimes by half, any improvements in care were implied or perceived. While no participants self-reported evidence of reduced patient risk, reduced adverse events, or improved outcomes, they described greater perceived peace of mind for the staff responsible for oversight. As stewards of resource-constrained pragmatic organizations, decision makers in the health care sector will weigh the risks of RTLS adoption related to personal privacy, overreliance on untested technology, and cost against the benefits of ubiquitous monitoring of human and equipment assets, performance management, and automation of location tasks to improve staff efficiency. The decision to adopt novel technologies necessitates examination policies, workflows, and resource commitments beyond the initial purchase costs of the hardware, software, and training to identify technologies and adoption processes that best fit the organizational context and the tasks it must perform.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[DOCX File , 38 KB - aging_v7i1e45978_app1.docx]

References

1. Kamel Boulos MN, Berry G. Real-time locating systems (RTLS) in healthcare: a condensed primer. Int J Health Geogr 2012 Jun 28;11:25 [FREE Full text] [doi: 10.1186/1476-072X-11-25] [Medline: 22741760]
2. Grigorovich A, Kulandaivelu Y, Newman K, Bianchi A, Khan SS, Iaboni A, et al. Factors affecting the implementation, use, and adoption of real-time location system technology for persons living with cognitive disabilities in long-term care homes: systematic review. J Med Internet Res 2021 Jan 20;23(1):e22831 [FREE Full text] [doi: 10.2196/22831] [Medline: 33470949]
3. Griffin JM, Hellmich TR, Pasupathy KS, Funni SA, Pagel SM, Srinivasan SS, et al. Attitudes and behavior of health care workers before, during, and after implementation of real-time location system technology. Mayo Clin Proc Innov Qual Outcomes 2020 Feb;4(1):90-98 [FREE Full text] [doi: 10.1016/j.mayocpiqo.2019.10.007] [Medline: 32055774]
4. Yadegari M, Mohammadi S, Masoumi AH. Technology adoption: an analysis of the major models and theories. Technol Analysis Strat Manag 2022 May 04:1-15. [doi: 10.1080/09537325.2022.2071255]
5. Duarte P, Pinho JC. A mixed methods UTAUT2-based approach to assess mobile health adoption. J Bus Res 2019 Sep;102:140-150. [doi: 10.1016/j.jbusres.2019.05.022]
6. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Analysing the role of complexity in explaining the fortunes of technology programmes: empirical application of the NASSS framework. BMC Med 2018 May 14;16(1):66 [FREE Full text] [doi: 10.1186/s12916-018-1050-6] [Medline: 29754584]
7. Bowen ME, Cacchione P. Changes in motor behavior predict falls and identify acute events. West J Nurs Res 2022 Dec 20;44(12):1100-1107. [doi: 10.1177/01939459211031981] [Medline: 34282682]
8. Ammenwerth E, Iller C, Mahler C. IT-adoption and the interaction of task, technology and individuals: a fit framework and a case study. BMC Med Inform Decis Mak 2006 Jan 09;6:3 [FREE Full text] [doi: 10.1186/1472-6947-6-3] [Medline: 16401336]
9. Ostermann H, Honekamp W. Application of the FITT framework to evaluate a prototype health information system. Qucosa. URL: https://slub.qucosa.de/api/qucosa%3A1176/attachment/ATT-0/?L=1 [accessed 2024-03-08]

10. Haslam-Larmer L, Shum L, Chu CH, McGilton K, McArthur C, Flint AJ, et al. Real-time location systems technology in the care of older adults with cognitive impairment living in residential care: a scoping review. Front Psychiatry 2022 Nov 10;13:1038008 [FREE Full text] [doi: 10.3389/fpsyt.2022.1038008] [Medline: 36440422]
11. Niddam M, Barsley N, Gard JC, Cotroneo U. Evolution and revolution: how insurers stay relevant in a digital future. Boston Consulting Group. 2014 Sep 11. URL: https://www.bcg.com/publications/2014/insurance-technology-strategy-evolution-revolution-how-insurers-stay-relevant-digital-world#:~:text=Evolution%20and%20Revolution%3A%20How%20Insurers%20Stay%20Relevant%20in%20a%20Digital%20Future,-September%2011%2C%202014&text=The%20insurance%20industry%20is%20on,Group%20and%20Morgan%20Stanley%20Research [accessed 2024-03-08]
12. Rost M, Cramer H, Belloni N, Holmquist LE. Geolocation in the mobile web browser. In: Proceedings of the 12th ACM international conference adjunct papers on Ubiquitous computing - Adjunct. 2010 Presented at: UbiComp '10 Adjunct; September 26-29, 2010; Copenhagen, Denmark. [doi: 10.1145/1864431.1864468]
13. Wood WA, Bennett AV, Basch E. Emerging uses of patient generated health data in clinical research. Mol Oncol 2015 May 27;9(5):1018-1024 [FREE Full text] [doi: 10.1016/j.molonc.2014.08.006] [Medline: 25248998]
14. Jansen CP, Diegelmann M, Schnabel EL, Wahl HW, Hauer K. Life-space and movement behavior in nursing home residents: results of a new sensor-based assessment and associated factors. BMC Geriatr 2017 Jan 28;17(1):36 [FREE Full text] [doi: 10.1186/s12877-017-0430-7] [Medline: 28129741]
15. Honekamp W, Ostermann H. Evaluation of a prototype health information system using the FITT framework. Inform Prim Care 2011;19(1):47-49 [FREE Full text] [doi: 10.14236/jhi.v19i1.793] [Medline: 22118336]
16. Leech NL, Onwuegbuzie AJ. A typology of mixed methods research designs. Qual Quant 2007 Mar 27;43(2):265-275. [doi: 10.1007/s11135-007-9105-3]
17. Curry L, Nunez-Smith M. Mixed Methods in Health Sciences Research: A Practical Primer. Thousand Oaks, CA: SAGE Publications; 2014.
18. Creswell JW, Creswell · JD. Research Design: Qualitative, Quantitative, and Mixed Methods Approaches · Volume 14. Thousand Oaks, CA: SAGE Publications; 2017.
19. Wiesche M, Jurisch MC, Yetton PW, Krcmar H. Grounded theory methodology in information systems research. MIS Q 2017 Mar 3;41(3):685-701. [doi: 10.25300/misq/2017/41.3.02]
20. Saunders MN, Townsend K. Reporting and justifying the number of interview participants in organization and workplace research. Brit J Manag 2016 Aug;27(4):836-852 [FREE Full text] [doi: 10.1111/1467-8551.12182]
21. Choi SS, Cajita MI, Gitlin LN. A review of measures of three common dementia-related behaviors: rejection of care, aggression, and agitation. Geriatr Nurs 2020;41(6):692-708. [doi: 10.1016/j.gerinurse.2020.04.003] [Medline: 32402574]
22. Doshi-Velez F, Li W, Battat Y, Charrow B, Curtis D, Park JG, et al. Improving safety and operational efficiency in residential care settings with WiFi-based localization. J Am Med Dir Assoc 2012 Jul;13(6):558-563. [doi: 10.1016/j.jamda.2012.04.010] [Medline: 22748720]
23. Prgomet M, Georgiou A, Callen A, Westbrook J. Fit between individuals, tasks, technology, and environment (FITTE) framework: a proposed extension of FITT to evaluate and optimise health information technology use. Stud Health Technol Inform 2019 Aug 21;264:744-748. [doi: 10.3233/SHTI190322] [Medline: 31438023]
24. Barchielli C, Marullo C, Bonciani M, Vainieri M. Nurses and the acceptance of innovations in technology-intensive contexts: the need for tailored management strategies. BMC Health Serv Res 2021 Jul 03;21(1):639 [FREE Full text] [doi: 10.1186/s12913-021-06628-5] [Medline: 34215228]
25. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q 2004;82(4):581-629 [FREE Full text] [doi: 10.1111/j.0887-378X.2004.00325.x] [Medline: 15595944]
26. Hall A, Wilson CB, Stanmore E, Todd C. Implementing monitoring technologies in care homes for people with dementia: a qualitative exploration using Normalization Process Theory. Int J Nurs Stud 2017 Jul;72:60-70 [FREE Full text] [doi: 10.1016/j.ijnurstu.2017.04.008] [Medline: 28494333]
27. Yuan CT, Bradley EH, Nembhard IM. A mixed methods study of how clinician 'super users' influence others during the implementation of electronic health records. BMC Med Inform Decis Mak 2015 Apr 10;15:26 [FREE Full text] [doi: 10.1186/s12911-015-0154-6] [Medline: 25889076]
28. Thielst CB. Effective management of technology implementation. J Healthc Manag 2007;52(4):216-219. [doi: 10.1097/00115514-200707000-00003]
29. Gholamhosseini L, Sadoughi F, Safaei A. Hospital real-time location system (a practical approach in healthcare): a narrative review article. Iran J Public Health 2019 Apr;48(4):593-602 [FREE Full text] [Medline: 31110969]
30. Sannon S, Forte A. Privacy research with marginalized groups: what we know, what's needed, and what's next. Proc ACM Hum Comput Interact 2022 Nov 11;6(CSCW2):1-33. [doi: 10.1145/3555556]
31. Hall A, Brown Wilson C, Stanmore E, Todd C. Moving beyond 'safety' versus 'autonomy': a qualitative exploration of the ethics of using monitoring technologies in long-term dementia care. BMC Geriatr 2019 May 24;19(1):145 [FREE Full text] [doi: 10.1186/s12877-019-1155-6] [Medline: 31126240]

32. Overmann KM, Wu DT, Xu CT, Bindhu SS, Barrick L. Real-time locating systems to improve healthcare delivery: a systematic review. J Am Med Inform Assoc 2021 Jun 12;28(6):1308-1317 [FREE Full text] [doi: 10.1093/jamia/ocab026] [Medline: 33682009]
33. Bowen ME, Wingrave CA, Klanchar A, Craighead J. Tracking technology: lessons learned in two health care sites. Technol Health Care 2013 Jun 01;21(3):191-197. [doi: 10.3233/thc-130738]
34. McGilton KS, Escrig-Pinol A, Gordon A, Chu CH, Zúñiga F, Sanchez MG, et al. Uncovering the devaluation of nursing home staff during COVID-19: are we fuelling the next health care crisis? J Am Med Dir Assoc 2020 Jul;21(7):962-965 [FREE Full text] [doi: 10.1016/j.jamda.2020.06.010] [Medline: 32674829]

Abbreviations

FITT: Fit Between Individuals, Tasks, and Technology
HCP: health care provider
REDCap: Research Electronic Data Capture
RTLS: real-time location system
UHN: University Health Network

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Original Paper

Using the TrueLoo Smart Device to Record Toileting Sessions in Older Adults: Retrospective Validation and Acceptance Study

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Abstract

Background: Because of the relationship between independent living and activities of daily living, care teams spend significant time managing assisted living residents' toileting problems. Recently, the TrueLoo was developed as a connected toilet seat to automatically log and monitor toileting sessions.

Objective: This study aimed to demonstrate the validity of the TrueLoo to (1) record and identify toileting sessions with regard to stool and urine events; (2) compare the results with the person-reported, standard-of-care methods; and (3) establish metrics of user acceptability and ease of use in a assisted living facility population.

Methods: We used two phases: (1) initial development of the TrueLoo algorithms to accurately identify urine and stool events and (2) evaluation of the algorithms against person-reported, standard-of-care methods commonly used in assisted living facilities. Phase 2 analyzed data over a 3-day period from 52 devices. Participants' age ranged from 63 to 101 (mean 84, SD 9.35) years. Acceptability and ease-of-use data were also collected.

Results: Regarding the development of the TrueLoo algorithm for urine assessment, sensitivity and specificity of 96% and 85% were observed when evaluating a gold-standard labeled data set, respectively (F_1-score=0.95). For stool, sensitivity and specificity of 90% and 79% were observed, respectively (F_1-score=0.85). Regarding the TrueLoo algorithm in assisted living settings, classification performance statistics for urine assessment revealed sensitivity and specificity of 84% and 94%, respectively (F_1-score=0.90), and for stool, 92% and 98%, respectively (F_1-score=0.91). Throughout the study, 46 person-reported instances of urine were documented, compared with 630 recorded by the TrueLoo. For stool events, 116 person-reported events were reported, compared with 153 by the TrueLoo. This indicates that person-reported events were captured 7% (46/630) of the time for urine and 76% (116/153) of the time for stool. Overall, 45% (32/71) of participants said that the new toilet seat was better than their previous one, 84% (60/71) reported that using the TrueLoo was easy, and 99% (69/71) said that they believed the system could help aging adults. Over 98% (69/71) of participants reported that they would find alerts related to their health valuable and would be willing to share this information with their doctor. When asked about sharing information with caregivers, 66% (46/71) reported that they would prefer the TrueLoo to send information and alerts to their caregiver, as opposed to the participant having to personally communicate those details.

Conclusions: The TrueLoo accurately recorded toileting sessions compared with standard-of-care methods, successfully establishing metrics of user acceptability and ease of use in assisted living populations. While additional validation studies are warranted, data presented in this paper support the use of the TrueLoo in assisted living settings as a model of event monitoring during toileting.

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KEYWORDS

activities of daily living; toileting habits; bowel movements; elder care; smart toileting; monitoring technology

Introduction

The global population is aging rapidly, and by the year 2050, the number of people aged 60 years and older will drastically increase to over 2 billion [1]. Concurrent with this increase in the number of older individuals, life expectancy is projected to increase in the coming decades [2]. However, as is often the case with advanced aging, this increased life expectancy will almost certainly be associated with accompanying morbidities and their associated costs to individuals and health systems [3,4].

These aging demographics will increase the burden of care in assisted living facilities. As part of their regular responsibilities, care staff in these facilities spend significant time and effort documenting and managing their residents' toileting habits and events [5,6]. This also means they play a key role in the assessment and prevention of toileting-related issues.

While toileting measurement and assistance is an important part of management in assisted living facilities, there is little evidence on how these individuals actually manage bowel problems and the quality of the interventions performed [7]. Furthermore, to track these events and monitor for issues, staff often rely on human reporting. This can come in the form of second-hand information from the resident or the staff member's own memory when recording multiple residents' toileting habits at once near the end of a shift; as a result, these methods are incomplete and prone to error.

Because of the relationship between independent living and activities of daily living [8], care teams spend a significant amount of time managing residents' bowel and bladder problems. Besides common bladder issues such as urinary tract infections [9], bowel problems such as constipation [10], diarrhea [11], and fecal incontinence [12] are highly prevalent among assisted living residents and present several challenges for care staff with regard to monitoring and reporting. Furthermore, these types of events cannot be identified without proper monitoring and recording of toileting events. Recently, the TrueLoo (TL; Toi Labs) was developed as a connected toilet seat to automatically log and monitor toileting sessions, removing the burden from the patient or facility staff. Reporting and monitoring stool and urine characteristics is shown to notably improve the quality of care that residents in assisted living facilities receive, especially those living with multiple comorbidities [13]. The TrueLooprovides concurrent monitoring of toileting sessions, providing caregivers with data to improve their clinical decision-making through evidence-based technology.

Previous investigations and review papers have evaluated the efficacy, practicality, and use of smart toilet seats as a model to longitudinally monitor individual toileting habits. Initial work provided evidence of usability and proof of concept for such a design through the use of a colorimetric assay tracing red-green-blue values from images of urinalysis strips [14]. They also included cameras to collect "analprints" used as unique identifiers. However, there were limitations related to device scalability as well as privacy from upward facing cameras; nevertheless, this was important work to demonstrate functionality of the process [14]. Further work demonstrated the ability to use an image-based data set to classify stool according to the well-established Bristol Stool Form Scale [15], demonstrating the feasibility of using such a technique to automatically evaluate samples [16]. However, while the groundwork for using smart toileting technology has been demonstrated, no data currently exist demonstrating the efficacy and applicability of accurately capturing and evaluating toileting events in a real-world setting.

Therefore, the purpose of this retrospective study was to demonstrate the validity of the TrueLooto (1) record and identify toileting sessions with regard to stool and urine events; (2) compare the results with the person-reported, standard-of-care methods; and (3) establish metrics of user acceptability and ease of use in a assisted living facility population. We hypothesized that the TrueLoowould demonstrate significant improvements in the event capture of toileting sessions compared with the current reporting systems, while being well accepted in the target population.

Methods

Ethical Considerations

This was a retrospective analysis, and all procedures were approved by the Western Institutional Review Board (TLSD-001); the study was conducted in accordance with the Declaration of Helsinki.

Subject Demographics and Recruitment

The participants in the study were aged between 63 and 101 (mean 84, SD 9.35) years. All study participants were from a skilled nursing facility located in Dallas, Texas. Of the 52 participants, 27 (52%) were female. The eligible participants were contacted by community staff, and all individuals who agreed to participate in this investigation were provided with an extensive overview of the product and its capabilities; there were no residents who declined participation. The use of the technology was noted in each resident's care plan, and community staff were extensively trained by Toi Labs on the capabilities of the product. Finally, Toi Labs provided additional materials to the community to distribute to residents and their families to address concerns about privacy protocols, product overview questions, or other questions regarding the reporting system.

Inclusion and Exclusion Criteria

This study was conducted as a retrospective analysis, and, as such, there was no participant consent required. However, to participate in the original commercial program, each participant was required to meet all of the following inclusion criteria: (1) willing to participate and provide consent for the program, (2) aged 55 years or older, (3) a resident of the assisted living facility where the data were collected, and (4) had regular access to a TrueLoo.

Additionally, participants satisfying any of the following exclusion criteria were precluded from participation in the study: (1) unwilling or unable to accept the requirements associated with installing the TrueLooin their residence, including power and Wi-Fi connectivity, and (2) used certain types of toileting assistance devices that, at this time, are not compatible with the TrueLoo(eg, padded toilet seat risers).

Study Design

This study was conducted in two phases:

1. Development of the TrueLoo algorithms to accurately identify urine and stool events
2. Evaluation of the algorithms against the real-world person-reported, standard-of-care methods commonly used in assisted living facilities

It is suggested that traditional methods for developing robust evidence are incongruent with the agile approach commonly used in software development, as there is often an incongruence between the length of traditional registered controlled trials and the development and update cycle for software [17]. Given the agreement that more traditional approaches present fundamental limitations for proper evidence generation for digital health solutions, this 2-phase approach allowed for the controlled development of the algorithms from real-world data collected as part of a commercial program and then analyzed and evaluated retrospectively for efficacy.

For phase 1, details surrounding the development of the initial algorithm for identifying stool and urine events are described below. For phase 2 (real-world data collection), participants were enrolled independent of symptoms, disease diagnosis, or state. Furthermore, in an effort to attain real-world applicability, there was no stratification of the population by sex, age, race, or disease severity. Each participant was monitored in their residences within their respective community. For each resident, a TrueLootoilet seat was installed in their private bathroom along with an initial health assessment to collect demographic information and any preexisting conditions. During this phase, 52 devices were deployed and reviewed for a 3-day period. Data were collected on each of the 52 participants using the TrueLoo.

Measures

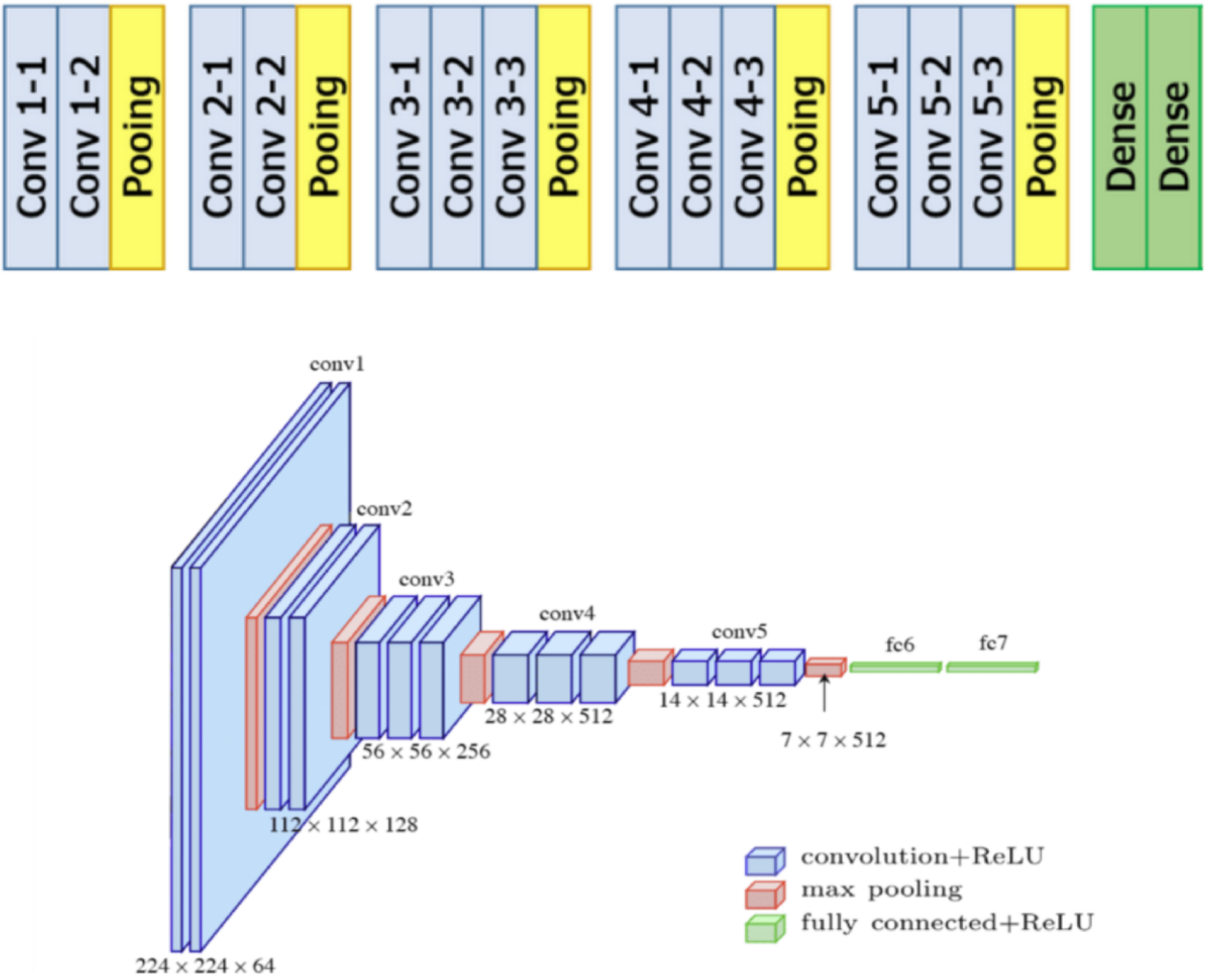
Development of the TrueLooAlgorithm for Identifying Urine and Stool Events

To verify urine and stool events that were accurately captured in the development of the algorithm, a panel of board-certified, gastroenterologist, subject-matter experts were first enlisted to create a “gold-standard” database. The subject-matter experts created a rule set for image annotators, who were trained to accurately identify image content. These image annotators provided our ground truth and produced a labeled data set that was then used to train the machine learning algorithms before being run on the full data set. The applied labels were used to create digital biomarkers for toileting event imagery. As of this investigation, more than 10,000 sessions (times people have used the toilet) were labeled, with more than 40,000 images. A session was activated when a user is in proximity to or sitting on the toilet seat. Each session comprises multiple images that depict the physical characteristics of urine and stool seen throughout the session in a time series.

The TrueLoo algorithms were developed using an existing large image model that is pretrained to extract fundamental image features such as shapes, colors, and textures. This model is then trained on proprietary image data collected by the TrueLoo that have been human annotated with label taxonomy of over 20 contextual labels that include relevant health metrics such as the Bristol Stool Scale and nonhealth metric such as toilet cleaning. The labeled data set is used to refine the large image model to create the proprietary TrueLoo algorithms.

A classic deep learning network structure was used for the neural network architecture, as illustrated in Figure 1. The network consists of 5 convolutional blocks with max pooling for feature learning and extraction, followed by 2 dense layers. A sigmoid activation function on the final layer is used for the final multilabel classification task and a binary cross-entropy loss function. This architecture has been very successful in traditional image classification tasks, and pretrained weight configurations based on classic benchmarks are readily available, making it an ideal candidate for fine-tuning and transfer learning.

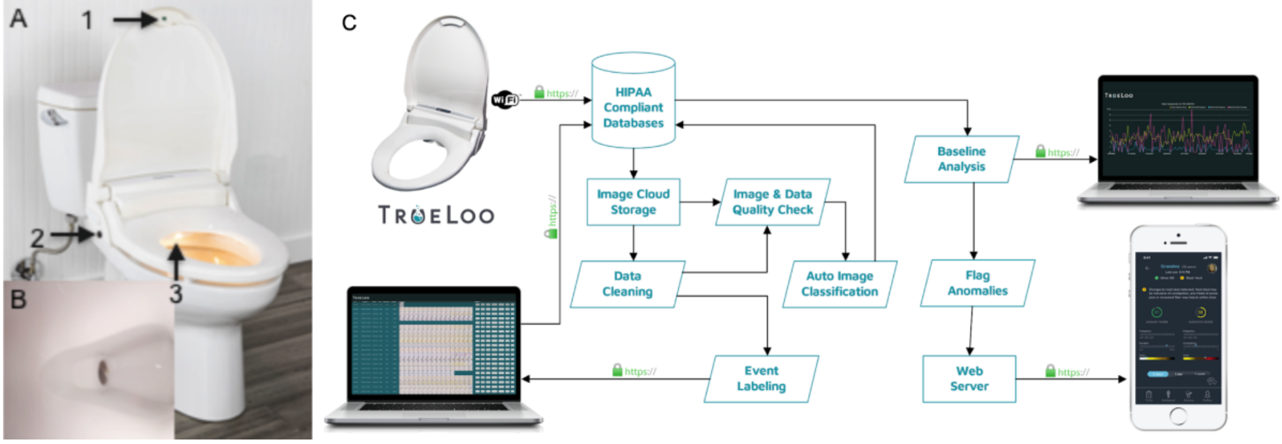
Figure 1. Convolutional neural network architecture. Conv: convolutional block; ReLu: rectified linear unit.



Detailed Working Description of the TrueLoo Technology

The TrueLoo consists of 2 parts: a hardware component that is delivered as a replacement toilet seat and a software system for analysis and reporting. Figure 2A shows a photograph of the TrueLoo seat with features called out and an image (example in Figure 2B) captured from the optical system. The TrueLoo seat has 2 user presence sensors: a contact sensor bound to the seat with no visible sign to the user and a noncontact time-of-flight distance sensor (Figure 2A.1) that activates when the user does not sit on the seat (ie, standing while urinating). By using the 2 sensors, the system distinguishes between standing and seated events as well as nonevent classification. The rear housing is used to mount the optical system and support electronics. The bowl is illuminated (Figure 2A.3) uniformly by red-green-blue-white LEDs to control color balance and some narrow band imaging illuminating with only 1 color. This allows for consistent imaging conditions for all currently encountered toilet geometries. Not shown in the image is the red-green-blue 8-megapixel manual focused camera and needed control and communication electronics. The system is powered by a single-board computer with integrated Wi-Fi communications for transmitting the images. The TrueLoo seat has a guest button (Figure 2A.2) to disable the system if a guest needs to use the toilet. The guest button automatically resets after each use. No images are recorded from guest events; however, they are registered in the database as an activation of the TrueLoo. Not shown in the figure is the cable routing using a conduit to fix the cable to the wall and connect the unit to power using a wall mount type AC-DC transformer at the outlet allowing for a long cable run with a low-voltage thin wire; this setup does not require a new outlet or the replacement or recharging of batteries. The seat is fixed to the toilet using a standard commercial mounting system for replacement toilet seats. After the TrueLoo seat is installed, it requires minimal to no ongoing maintenance, other than ensuring that the optics stay clean.

Figure 2. The TrueLoo platform and associated dataflow. (A) Image of TrueLoo installed on a toilet: (1) user presence sensor for risers and male standing urinating; (2) multifunction guest button: excludes guests who may use the toilet; (3) bowl illumination, optical system that scans the contents of the toilet bowl. (B) Example frame captured by TrueLoo. (C) TrueLoo software block diagram; data captured by TrueLoo is uploaded to HIPAA-compliant databases and data flow begins. HIPAA: Health Insurance Portability and Accountability Act.



When a user activates the TrueLoo by sitting on the seat or standing in front of the toilet, the system activates an event and immediately starts imaging at 1.2 frames per second. The TrueLoo continuously captures images of the bowl for the duration of time the user is seated or standing in front of the device. Immediately after the event is finished the images are transferred via Wi-Fi to Health Insurance Portability and Accountability Act (HIPAA)–compliant servers for storage and analysis (Figure 2C). Duplicate images are not uploaded but are registered to ensure correct time sequencing and more.

Because of the non–battery power and Wi-Fi connectivity configuration, data could be logged and monitored to ensure that the device was connected and working properly. The device can save approximately 1 week of data locally and resume uploading data if and when a Wi-Fi connection is compromised. This capability provides added capture and integrity in the event of a prolonged Wi-Fi outage.

Tracking of Toileting Events in Assisted Living Facilities

As previously mentioned, person-reported methods of bowel movement and urinary event tracking are considered the standard of care in assisted living settings. For phase 2 of this study, the same annotators retrospectively labeled toileting images captured through a commercial engagement, creating a real-world ground truth data set. We then analyzed recorded TL-captured events through the algorithm developed in phase 1, comparing them with the person-reported events captured by facility staff, broken down into urinations and bowel movements.

The current practice for reporting toileting events among facility staff involves documentation at the end of a shift, sometimes manually (pen to paper in a chart), or other times in the electronic medical record. The analysis done was for a community that reports this information in the electronic medical record. The data recorded in bowel and bladder logs are often inadequate, with limited description. For example, the logging for urination only allows facility staff to notate “Void? Yes or No.” Many of the entries are listed as “Not Applicable.”

Bowel elimination questions include (1) the size of bowel movement (small, medium, large, resident not available, resident refused, and not applicable), (2) consistency of bowel movement (formed or normal, loose or diarrhea, constipation or hard, putty like, resident not available, resident refused, and not applicable), and (3) bowel continence (continent, incontinent, no bowel movement, continence not rated due to ostomy, resident not available, resident refused, and not applicable).

The TrueLoo system automatically classifies on an established scale based on the Bristol Stool Scale [15]. The following classifications were used to inform the TrueLoo algorithms: separate, hard lump nut-like stool; soft blobs with distinct edges; sausage-like stool with surface cracks; lumpy, sausage-like stool; smooth, sausage-snake stool; fluffy, mushy stool with ragged edges; and watery liquid, no solid stool.

Most of the data captured by the TrueLoo are supplemental when benchmarked against the information recorded by facility staff through the logs. As seen in our analysis, although the elimination questions in the electronic records have the potential to capture the characteristics of stool and urine, they are not accurately completed by care staff, if at all.

Data Safety and Integrity

Protocols are included as a part of the TrueLoo implementation’s standard process to ensure that privacy is maintained at all times through the data collection process.

1. The TrueLoo imaging system faces down into the toilet bowl and is designed specifically to scan stool and urine; it does not capture any body parts.
2. User information is completely deidentified, from data capture to analysis.
3. The seat itself does not carry the name or location of the user.
4. All deidentified data are stored internally—none of the data that are viewed or used are associated with any sort of identifier—and are completely anonymized.

Secure servers and connections allow reports to only be shared with onsite care teams tasked with caring for the user. The reports can be shared with outside care partners (such as physicians) or families. Toi Labs’ team members review and validate reports to ensure compliance of privacy protocols and offer the best service and care to users.

Information is not identifiable on capture. Multiple protocols are in place throughout data capture to ensure that the data remain completely deidentified. No TrueLoo seat or its data are directly linked to a resident's name or room number. This information is secured internally and is only used when providing reports to care teams. Otherwise, all data that are captured and uploaded are deidentified and anonymized. Secure servers and connections allow reports to only be shared with onsite care teams tasked with caring for the user. Upon the authorization of the user or their responsible party, the reports can be shared with outside care partners or families as they see fit. The reports are not distributed to anyone outside of the circle of care of the user.

Participant Satisfaction and Acceptability

At the end of the study, a survey about user satisfaction was provided to all participants to evaluate acceptability and comfort with the use of the TrueLoo. This survey can be found in Multimedia Appendix 1.

Data Analyses

Python version 3.9 (Python Software Foundation) and R version 4.1.3 (R Foundation) were used to conduct all analyses. Descriptive statistics were calculated for age and sex. For the development of the initial algorithms, sensitivity, specificity, precision, recall, F_1-scores, and receiver operating characteristic (ROC) area-under-the-curve (AUC) were calculated to evaluate the classification performance of stool and urine events. Bootstrapping was used to calculate 95% confidence intervals for AUC.

For evaluation of the algorithm in real-world evidence (RWE) settings, sensitivity, specificity, precision, recall, F_1-scores, and ROC analyses were performed. Overall results were compared with the person-reported events as a percent to determine effectiveness to the standard of care.

Results

Data Characteristics

Throughout the period involved in the study's retrospective analysis, a total of 645 toileting sessions were recorded by the TrueLoo. Of the 645 total recorded events, 630 included urine and 153 included stool. There was overlap between the number of sessions containing both urine and stool. In this investigation, the average age of the participants was 84 (SD 9) years, with 52% (27/52) of the participants identifying as female. All of the individuals in the setting in question used the TrueLoo for the 3 days as planned. No participants declined the use of the TrueLoo.

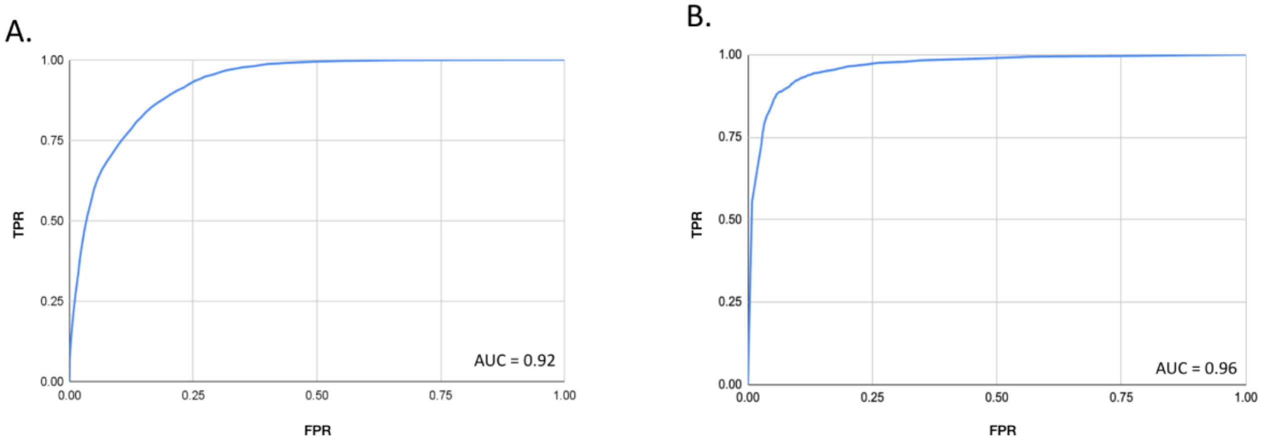
Development of the TrueLoo Algorithm for Identifying Urine and Stool Events

With regard to the development of the TrueLoo algorithm, classification performance statistics for all urine and stool events can be found in Table 1, and ROC curves can be found in Figure 3. For urine assessment, AUC was 0.92, with sensitivity and specificity of 96% and 85% observed, respectively. For stool, AUC was 0.96, with sensitivity and specificity of 90% and 79% observed, respectively.

Table 1. Classification performance of the TrueLoo algorithm for detecting urine and stool events.

Event	Precision	Recall	Sensitivity	Specificity	F_1-score
Urine	0.94	0.96	0.96	0.85	0.95
Stool	0.80	0.90	0.90	0.79	0.85

Figure 3. Receiver operating characteristic area-under-the-curve (AUC) analysis for the TrueLoo algorithm to identify (A) urine and (B) stool events. fpr: false positive rate; tpr: true positive rate.



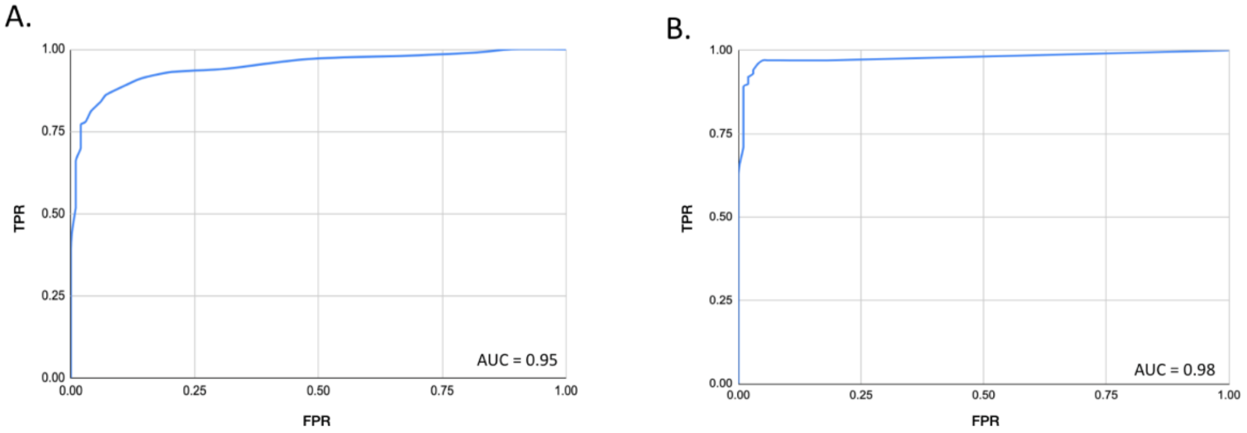
Toileting Sessions Compared With Standard of Care

With regard to the evaluation of the TrueLoo algorithm in RWE settings, classification performance statistics for all events can be found in Table 2, while ROC curves can be found in Figure 4. For urine assessment, AUC was 0.95, with sensitivity and specificity of 84% and 94% observed, respectively. For stool, AUC was 0.98, with sensitivity and specificity of 92% and 98% observed, respectively.

Table 2. Classification performance of TrueLoo for detecting urine and stool events in assisted living settings (real-world evidence analysis).

Event	Precision	Recall	Sensitivity	Specificity	F_1-score
Urine	0.97	0.84	0.84	0.94	0.90
Stool	0.91	0.92	0.92	0.98	0.91

Figure 4. Receiver operating characteristic area-under-the-curve (AUC) analysis for the TrueLoo algorithm in real-world evidence settings (ie, standard of care) to identify (A) urine and (B) stool events. fpr: false positive rate; tpr: true positive rate.



To compare the TrueLoo with the person-reported standard of care, we compared the number of reported instances in the skilled nursing facility with the number of events recorded by the TrueLoo. Over the course of the study, there were 46 person-reported instances of urine documented, compared with 630 by the TrueLoo. For stool events, there were 116 person-reported events compared with 153 events reported by the TrueLoo. This indicates that, when compared with the TL, person-reported events were captured 7% (46/630) of the time for urine and 76% (116/153) of the time for stool.

Survey Feedback on Acceptability and Ease of Use

A high degree of user satisfaction was found in the exit survey. Overall, 45% (32/71) of participants said the new toilet seat was better than their previous seat, while 46% (33/71) said it was the same. Importantly, 84% (60/71) of participants reported that using the TrueLoo was easy and required no effort; 99% (69/71) said they believed that the monitoring system had the potential to help aging adults.

With regard to the transmitting and interpretation of data, 99% (69/71) of participants reported that they would find alerts related to their health valuable and would also be willing to share this information with their doctor. When asked about sharing information with caregivers, 66% (46/71) reported that they would prefer the TrueLoo to send information and alerts to their caregiver, as opposed to the participant having to personally communicate those details.

Discussion

Principal Findings

The purpose of this retrospective study was to demonstrate the validity of the TrueLoo to (1) record and identify toileting sessions with regard to stool and urine events; (2) compare the results with the person-reported, standard-of-care methods; and (3) establish metrics of user acceptability and ease of use in a assisted living facility population. Our hypothesis that the TrueLoo would accurately identify urine and stool events, as well as capture more toileting sessions than were captured via the standard of care, was confirmed. We also confirmed our hypothesis that this method would be well accepted by residents.

Ability to Record and Identify Toileting Sessions

In this investigation, the TrueLoo algorithm demonstrated high sensitivity, specificity, and accuracy for detecting urine and stool events in real-world settings. Toileting issues such as urinary tract infections [9], constipation [10], diarrhea [11], and fecal incontinence [12] are highly prevalent among assisted living residents; however, if regular monitoring of toileting events are not accurate, it becomes difficult to identify and manage these conditions. Being able to manage these clinical events begins with the identification and monitoring of toileting; if it cannot be tracked, it cannot be measured and therefore cannot be improved.

Previous research investigating the use of smart toileting technology provides an initial look into the feasibility and proof of concept related to successfully executing this type of monitoring model [14-16]. However, these designs and models were limited as it pertains to real-world applicability. Early work used a colorimetric assay tracing red-green-blue values from images of urinalysis strips as well as upward facing cameras to collect “analprints” used as unique identifiers [14]. Based on the recommendation by Ge et al [18], “To enhance data quality, devices should be designed in ways that are physically or psychologically unobtrusive so as not to influence normal toileting behavior,” this initial model becomes problematic as the process can be intrusive and pose risks to data privacy.

Comparison of TrueLoo With Traditional Standard of Care

The standard of care (facility staff manual reporting) requires an individual to remember each event, manually track the event, and recall specific details about the event that would be relevant to a clinical issue. While this is theoretically feasible, it is unrealistic to expect these individuals to remember specific details and document each event without error throughout the course of a shift. Furthermore, expecting patients to remember and accurately report their own events is difficult due to recall bias and the natural discomfort of discussing one’s own toileting habits [19], especially if the events are different or unusual. This can be combined with the fact that, perhaps unsurprisingly, residents in seniors living facilities report that noninvasive methods of care are preferable to more invasive methods when it comes to the development of toileting programs [19,20]. This concept that there is a reluctance to openly discuss excreta [21,22] has hampered the development and acceptance of smart toilets; however, the use of smart toileting technology, such as the TL, creates a way to seamlessly integrate toileting analyses as part of routine monitoring, serving as a gateway to the digitalization of health care in the home [18].

Through this investigation, we found that facility staff underreport toileting events when compared with the TrueLoo. Given the active versus passive nature of the 2 methods, this is unremarkable, provided the limitations naturally inherent on the time and resources of human monitoring. Not only are facility staff dependent on their own timing for successfully monitoring a resident’s toileting habits, but they are also highly reliant on residents being honest about their own habits in the instances when they cannot be monitored or observed directly [13]. Furthermore, it appears that staff tend to log these data points in batches, often from memory. For example, most sites use a shift system where their staff are working from 6:00 to 14:00 hours, from 14:00 to 23:00 hours, and from 23:00 to 6:00 hours. Based on a single day of data provided by the site from their self-reporting logs (Multimedia Appendix 2), the majority of toileting events are reported toward the end of their respective shift. This is especially evident in the later evening shifts where the majority of reports from the 14:00-23:00 shift were reported from memory within a 2-hour time span. The level of cognitive load required with this method, in addition to their other responsibilities [7], is highly prone to error.

Many assisted living residents require more complex and advanced care compared with the general population, and evidence supports the fact that nursing home clinical outcomes are heavily reliant on geriatric approaches and care leadership. Proper care of these residents requires a multidimensional and specialized approach from facility staff [23,24]; however, recognition for this type of skill and the effort involved is frequently undervalued, thus leading to staff turnover and vacancies [25]. Furthermore, the high prevalence of toileting issues among nursing home residents indicates that there is demonstrable potential for improvement within this population. Such issues among residents are largely related to remediable factors, which can potentially be prevented or improved [7], and current nursing home practices do not adequately address these challenges. Providing a passive monitoring toileting solution that captures these types of data automatically, analyzes them, and transmits them back to the facility can reduce time and discomfort required for staff. This would allow an already underappreciated group [25] to focus on alternative needs in their respective facilities, removing burden and potentially increasing staff morale and attitude. The latter is, perhaps, most important because previous research from assisted living settings has shown that attitudes of care staff toward their organization, residents, and families have a significant effect on the quality of care provided to the residents [26].

Clinical Relevance in Real-World Settings

As discussed above, current standard-of-care methods are error prone and inconsistent. This inconsistency of monitoring potentially creates a larger issue for identifying critical conditions associated with greater costs and health care needs. Residents in assisted living facilities are at significant risk of developing issues such as urinary tract infections [9] and bowel problems such as constipation [10], diarrhea [11], and fecal incontinence [12], to name a few. These issues cannot be consistently identified without proper monitoring of toileting events. For example, when evaluating the prevalence of inpatient falls in a Michigan community hospital, 45.2% were related to toileting-based issues [27]. Importantly, 82.3% of patients who fell had completed a fall risk assessment before the incidents, indicating minimal relationship between fall assessment and actual falls. These results were further confirmed in a secondary data analysis conducted on 281,865 high-risk falls assessments collected in a multisite study where toileting issues were the third most powerful predictor of falls after “falls in the last 6 months” and “confusion” [28]. Furthermore, a retrospective analysis of falls related to nighttime toileting over a 1-year period found that 34% of falls were related to toileting-related issues [29]. Finally, a cross-sectional report evaluating the association between toileting and falls in older adults admitted to an emergency department discovered that the rate of recurrent falls was significantly higher in a toileting-related falls group than a non–toileting-related falls group [30]. As such, it is critical that toileting issues be addressed upstream to prevent larger, related issues from occurring. The use of the TrueLoo to accurately, consistently, and passively track toileting habits and related issues may provide the necessary feedback to ensure that residents receive the care and attention required to prevent falls from occurring, instead of requiring active response after the fall occurs.

Acceptability and Ease of Use

There are an ever-growing number of technological solutions offering potential benefits for older adults. However, despite the potential benefits, older adults regularly demonstrate lower adoption rates compared with their younger peers [31-33]. In the older adult population, perceived value, confidence in the ability to learn the technology, and the perceived impact on quality of life are reported to be some of the most robust predictors of willingness to adopt technology [34]. In this investigation, 84% (60/71) participants reported that using the TrueLoo was easy and required no effort (ability to learn) and 99% (69/71) said they believed that the monitoring system had the potential to help aging adults (perceived impact). Additionally, 99% (69/71) of participants reported that they would find alerts related to their health valuable and would also be willing to share this information with their doctor, and 66% (46/71) reported that they would prefer the TrueLoo to send information and alerts to their caregiver, as opposed to the participant having to personally communicate those details (quality-of-life improvements). These data points triangulate to the TrueLoo being not only efficacious but also successfully adopted as a passive monitoring intervention in this age group.

Strengths and Limitations

The strengths of this study include the process of initially developing the algorithm for identifying stool and urine events against a gold-standard labeled data set and then retrospectively analyzing it in an RWE setting. This methodology allowed for the ability to generate real-world insights into how the TrueLoo could most effectively be used in assisted living facilities. Additionally, the ability to get direct feedback from the end users provides subjective validation, in addition to the efficacy of the TrueLoo to evaluate sessions. There is often a disconnect between clinical efficacy and practical use, which prevents new technology from being properly implemented. While RWE designs are powerful for real-world practicality, there are associated limitations. In this study, there was a lack of ability to control certain parameters (monitoring and reporting habits of facility staff) and collect certain data points (detailed health reports) on the participants. Ameliorating these limitations would change facility workflows, therefore affecting the validity of real-world efficacy. As such, we accept these limitations but recommend that this study be followed up with additional controlled investigations into the clinical efficacy of the TrueLoo. Such controlled investigations would also allow for the evaluation of other indications such as loose or bloody stool or cloudy urine. Given the clinical applicability of these indications, they are a recommended next step for future research.

Conclusions

In this retrospective validation and acceptance study, we demonstrated the validity of the TrueLoo to record toileting sessions compared with the standard-of-care methods, while categorizing them into clinically relevant events. Additionally, the TrueLoo successfully established metrics of user acceptability and ease of use in assisted living populations. While additional validation studies are warranted, the data presented in this paper support the use of the TrueLoo in assisted living settings as a model of session monitoring during toileting.

Acknowledgments

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Conflicts of Interest

At the time of the publication, VK, PS, THL, and GK were employees at Toi Labs, receiving salary, stock options, and benefits. PC worked in a consultancy role and received stock options. JG has no conflicts of interest to report at the time of this publication.

Multimedia Appendix 1

Exit survey on user acceptance and satisfaction.

[DOCX File , 15 KB - aging_v7i1e50856_app1.docx]

Multimedia Appendix 2

Example chart of a facility's toileting logging timing throughout a single day.

[DOCX File , 72 KB - aging_v7i1e50856_app2.docx]

References

1. World Population Prospects 2022. United Nations. URL: https://population.un.org/wpp/ [accessed 2023-02-07]
2. Fried LP, Wong JEL, Dzau V. A global roadmap to seize the opportunities of healthy longevity. Nat Aging 2022;2(12):1080-1083 [FREE Full text] [doi: 10.1038/s43587-022-00332-7] [Medline: 37118540]
3. Rowe JW, Berkman L. Decompression of morbidity and the workforce. Nat Aging 2022;2(1):3-4 [FREE Full text] [doi: 10.1038/s43587-021-00163-y] [Medline: 37118358]
4. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: a systematic review of the literature. Ageing Res Rev 2011;10(4):430-439. [doi: 10.1016/j.arr.2011.03.003] [Medline: 21402176]

5. Sandberg L, Nilsson I, Rosenberg L, Borell L, Boström AM. Home care services for older clients with and without cognitive impairment in Sweden. Health Soc Care Community 2019;27(1):139-150 [FREE Full text] [doi: 10.1111/hsc.12631] [Medline: 30062814]
6. Haley WE, Allen JY, Grant JS, Clay OJ, Perkins M, Roth DL. Problems and benefits reported by stroke family caregivers: results from a prospective epidemiological study. Stroke 2009;40(6):2129-2133 [FREE Full text] [doi: 10.1161/STROKEAHA.108.545269] [Medline: 19407230]
7. Saga S, Seim A, Mørkved S, Norton C, Vinsnes AG. Bowel problem management among nursing home residents: a mixed methods study. BMC Nurs 2014;13(1):35 [FREE Full text] [doi: 10.1186/s12912-014-0035-9] [Medline: 25469107]
8. Edemekong PF, Bomgaars DL, Sukumaran S, Schoo C. Activities of Daily Living. Treasure Island, FL: StatPearls Publishing; 2022.
9. Rodriguez-Mañas L. Urinary tract infections in the elderly: a review of disease characteristics and current treatment options. Drugs Context 2020;9:2020-4-13 [FREE Full text] [doi: 10.7573/dic.2020-4-13] [Medline: 32699546]
10. Nazarko L. Understanding and managing constipation in older adults. Pract Nurs 2017;28(12):517-526 [FREE Full text] [doi: 10.12968/pnur.2017.28.12.517]
11. Holt PR. Diarrhea and malabsorption in the elderly. Gastroenterol Clin North Am 2001;30(2):427-444. [doi: 10.1016/s0889-8553(05)70189-8] [Medline: 11432299]
12. Frank C, Molnar F, Spencer M. Fecal incontinence in older adults. Can Fam Physician 2020;66(4):264 [FREE Full text] [Medline: 32273412]
13. Maung TZ, Singh K. Regular monitoring with stool chart prevents constipation, urinary retention and delirium in elderly patients: an audit leading to clinical effectiveness, efficiency and patient centredness. Future Healthc J 2019;6(Suppl 2):3 [FREE Full text] [doi: 10.7861/futurehosp.6-2s-s3] [Medline: 31572904]
14. Park SM, Won DD, Lee BJ, Escobedo D, Esteva A, Aalipour A, et al. A mountable toilet system for personalized health monitoring via the analysis of excreta. Nat Biomed Eng 2020;4(6):624-635 [FREE Full text] [doi: 10.1038/s41551-020-0534-9] [Medline: 32251391]
15. Blake MR, Raker JM, Whelan K. Validity and reliability of the bristol stool form scale in healthy adults and patients with diarrhoea-predominant irritable bowel syndrome. Aliment Pharmacol Ther 2016;44(7):693-703 [FREE Full text] [doi: 10.1111/apt.13746] [Medline: 27492648]
16. Zhou J, McNabb J, DeCapite N, Ruiz JR, Fisher DA, Grego S, et al. Stool image analysis for digital health monitoring by smart toilets. IEEE Internet Things J 2023;10(5):3720-3734 [FREE Full text] [doi: 10.1109/jiot.2022.3158886]
17. Guo C, Ashrafian H, Ghafur S, Fontana G, Gardner C, Prime M. Challenges for the evaluation of digital health solutions—a call for innovative evidence generation approaches. NPJ Digit Med 2020;3:110 [FREE Full text] [doi: 10.1038/s41746-020-00314-2] [Medline: 32904379]
18. Ge TJ, Rahimzadeh VN, Mintz K, Park WG, Martinez-Martin N, Liao JC, et al. Passive monitoring by smart toilets for precision health. Sci Transl Med 2023;15(681):eabk3489 [FREE Full text] [doi: 10.1126/scitranslmed.abk3489] [Medline: 36724240]
19. MacDonald CD, Butler L. Silent no more: elderly women's stories of living with urinary incontinence in long-term care. J Gerontol Nurs 2007;33(1):14-20 [FREE Full text] [doi: 10.3928/00989134-20070101-05] [Medline: 17305265]
20. Roe B, Flanagan L, Jack B, Shaw C, Williams K, Chung A, et al. Systematic review of descriptive studies that investigated associated factors with the management of incontinence in older people in care homes. Int J Older People Nurs 2013;8(1):29-49 [FREE Full text] [doi: 10.1111/j.1748-3743.2011.00300.x] [Medline: 22182302]
21. Editorial. Break the taboo with poo. Nat Rev Gastroenterol Hepatol 2021;18(11):743 [FREE Full text] [doi: 10.1038/s41575-021-00528-z]
22. Editorial. We need to talk about crapping. Nat Microbiol 2018;3(11):1189 [FREE Full text] [doi: 10.1038/s41564-018-0287-3] [Medline: 30356153]
23. Rowland FN, Cowles M, Dickstein C, Katz PR. Impact of medical director certification on nursing home quality of care. J Am Med Dir Assoc 2009;10(6):431-435. [doi: 10.1016/j.jamda.2009.05.012] [Medline: 19560722]
24. Morley JE. Clinical practice in nursing homes as a key for progress. J Nutr Health Aging 2010;14(7):586-593 [FREE Full text] [doi: 10.1007/s12603-010-0039-4] [Medline: 20818475]
25. Rolland Y, Aquino JP, Andrieu S, Beard J, Benetos A, Berrut G, et al. Identification of the main domains for quality of care and clinical research in nursing homes. J Nutr Health Aging 2011;15(5):410-424 [FREE Full text] [doi: 10.1007/s12603-011-0091-8] [Medline: 21528170]
26. Beeber AS, Cohen LW, Zimmerman S, Gwyther LP, Washington T, Cagle JG, et al. Differences in assisted living staff perceptions, experiences, and attitudes. J Gerontol Nurs 2014;40(1):41-49 [FREE Full text] [doi: 10.3928/00989134-20130731-03] [Medline: 23937102]
27. Tzeng HM. Understanding the prevalence of inpatient falls associated with toileting in adult acute care settings. J Nurs Care Qual 2010;25(1):22-30 [FREE Full text] [doi: 10.1097/NCQ.0b013e3181afa321] [Medline: 19553863]
28. Moe K, Brockopp D, McCowan D, Merritt S, Hall B. Major predictors of inpatient falls: a multisite study. J Nurs Adm 2015;45(10):498-502 [FREE Full text] [doi: 10.1097/NNA.0000000000000241] [Medline: 26425974]

29. Rose G, Decalf V, Everaert K, Bower WF. Toileting-related falls at night in hospitalised patients: the role of nocturia. Australas J Ageing 2020;39(1):e70-e76 [FREE Full text] [doi: 10.1111/ajag.12696] [Medline: 31321899]
30. Zou M, Lu R, Jiang Y, Liu P, Tian B, Liang Y, et al. Association between toileting and falls in older adults admitted to the emergency department and hospitalised: a cross-sectional study. BMJ Open 2023;13(6):e065544 [FREE Full text] [doi: 10.1136/bmjopen-2022-065544] [Medline: 37263694]
31. Anderson M, Perrin A. Tech adoption climbs among older adults. Pew Research Center: Internet, Science & Tech Internet. 2017. URL: http://www.pewresearch.org/internet/2017/05/17/tech-adoption-climbs-among-older-adults/ [accessed 2023-02-27]
32. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: internet use patterns, eHealth literacy, and attitudes toward computer/internet use. J Med Internet Res 2013;15(5):e93 [FREE Full text] [doi: 10.2196/jmir.2645] [Medline: 23639979]
33. Friemel TN. The digital divide has grown old: determinants of a digital divide among seniors. New Media Soc 2014;18(2):313-331. [doi: 10.1177/1461444814538648]
34. Berkowsky RW, Sharit J, Czaja SJ. Factors predicting decisions about technology adoption among older adults. Innov Aging 2018;2(1):igy002 [FREE Full text] [doi: 10.1093/geroni/igy002] [Medline: 30480129]

Abbreviations

AUC: area under the curve
HIPAA: Health Insurance Portability and Accountability Act
ROC: receiver operating characteristic
RWE: real-world evidence
TL: TrueLoo

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Original Paper

Efficacy of COMPAs, an App Designed to Support Communication Between Persons Living With Dementia in Long-Term Care Settings and Their Caregivers: Mixed Methods Implementation Study

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Abstract

Background: Persons living with dementia experience autonomy loss and require caregiver support on a daily basis. Dementia involves a gradual decline in communication skills, leading to fewer interactions and isolation for both people living with dementia and their caregivers, negatively impacting the quality of life for both members of the dyad. The resulting stress and burden on caregivers make them particularly susceptible to burnout.

Objective: This study aims to examine the efficacy of Communication Proches Aidants (COMPAs), an app designed following the principles of person-centered and emotional communication, which is intended to improve well-being in persons living with dementia and caregivers and reduce caregiver burden.

Methods: In this implementation study, volunteer caregivers in 2 long-term care facilities (n=17) were trained in using COMPAs and strategies to improve communication with persons living with dementia. Qualitative and quantitative analyses, semistructured interviews, and questionnaires were completed before and after 8 weeks of intervention with COMPAs.

Results: Semistructured interviews revealed that all caregivers perceived a positive impact following COMPAs interventions, namely, improved quality of communication and quality of life among persons living with dementia and caregivers. Improved quality of life was also supported by a statistically significant reduction in the General Health Questionnaire-12 scores (caregivers who improved: 9/17, 53%; z=2.537; P=.01). COMPAs interventions were also associated with a statistically significant increased feeling of personal accomplishment (caregivers improved: 11/17, 65%; t_{15}=2.430; P=.03; d=0.61 [medium effect size]).

Conclusions: COMPAs intervention improved well-being in persons living with dementia and their caregivers by developing person-centered communication within the dyad, increasing empathy, and reducing burden in caregivers although most caregivers were unfamiliar with technology. The results hold promise for COMPAs interventions in long-term care settings. Larger group-controlled studies with different populations, in different contexts, and at different stages of dementia will provide a clearer picture of the benefits of COMPAs interventions.

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KEYWORDS

dementia; communication; caregivers; technology; burden; mixed methods design; quality of life; mobile phone; tablet

Introduction

Background

Dementia is a progressive or chronic syndrome, affecting memory, reasoning, orientation, understanding, calculation, learning ability, language, and judgment; it represents a greater impairment of cognitive function than might be expected, while being the main cause of disability and dependence among older people [1]. Dementia is the consequence of diverse diseases, the most common being Alzheimer disease [1].

According to the World Health Organization, 55 million individuals worldwide live with dementia, making it one of the main causes of disability and social deprivation among older adults [2]. These figures are set to rise over the next few years, with an estimated 78 million people expected to be living with dementia by 2030. The report states that support for the care of people living with dementia and help for caregivers need to be stepped up urgently. As dementia progresses, it has an impact on the autonomy of the person affected. At the advanced stage, persons living with dementia can no longer live at home because they are no longer able to carry out everyday tasks (eg, dressing, eating, and washing), and this is often difficult to manage for those around them.

Person-Centered Communication and Dementia

Dementia is characterized by a progressive deterioration of cognitive functions and particularly affects language [3]. As the disease progresses, persons living with dementia will experience increasing communication deficits that impact all aspects of life. Frequent communication breakdowns lead to feelings of frustration that can trigger reactive behaviors known as behavioral and psychological symptoms of dementia (BPSD) [4]. Communication breakdowns complexify care, increase caregiver burden, and decrease the quality of life (QoL) for persons living with dementia and caregivers [5,6]. In the later stages of dementia, sustaining a simple communicative exchange (eg, greetings or short conversation between the caregiver and the person living with dementia) is practically impossible. Because they are unable to express their needs or understand others, persons living with dementia often express frustration [7] and generally require more attention than other older adults, which also contributes to increasing the burden on caregivers and decreasing QoL [8,9].

The literature shows that communication is a key component of quality care [10-13] and a core component of person-centered care, promoting positive social interactions around topics of the life story of persons living with dementia [5]. Person-centered care, considered state of the art in dementia care [14], recognizes the individual as a person and aims to respond to the individual’s feelings, preferences, and needs [15,16]. Furthermore, person-centered care precludes perceiving the person living with dementia exclusively as a person with illness, and such perception contributes to cognitive decline, adds to communication difficulties, and contributes to depersonalization [13]. A person-centered nondirective approach considers the person’s lifestyle, culture, and history, including their likes and dislikes, preferences, and interests, while always considering the person’s point of view [5].

In sum, communication breakdowns contribute to depersonalization and weakening of person-centered care [17], requiring continuous adaptation from the caregiver. In contrast, person-centered care develops leadership in caregivers, prompting management changes toward a more personalized philosophy of care.

Impact of Communication on Care

Communication deficits in the context of dementia have negative impacts on several aspects of the caregiver and resident relation within a long-term care (LTC) setting. More specifically, the progressive nature of the illness entails frequent communication breakdowns, which generate frustration in both the caregiver and the person living with dementia (referred to as the dyad) [5,6]. Indeed, most persons living with dementia show signs of frustration when they cannot understand a conversation or make themselves understood [7,18]. Frustration increases emotional tension, which in turn contributes to the caregiver’s burden [9]. Poor-quality interactions also increase the risk of agitation and apathy in persons living with dementia [8]. While the quality of communication within the dyad is known to modulate caregiver burden [9], it also affects person-centered care, both of which are essential to QoL [19,20]. Greater burden and a higher prevalence of anxiety disorders are observed in caregivers working with persons living with dementia [21,22]. Burden is described along 2 dimensions: objective burden, which refers to the degree of dependence of the person living with dementia and the presence of BPSD, and subjective burden, which is associated with the physical, social, and emotional dimensions of caring, as well as the resources available to the caregiver [23]. A systematic review by Queluz et al [24] grouped professional caregiver needs into 3 main themes: emotional health, formal or informal help received from third parties, and need for information about dementia and associated care.

Several variables related to the physical and social environment in which communication occurs can create living conditions that promote or hamper QoL in caregivers and persons living with dementia [20]. These include the quality of caregivers’ engagement in care (ie, a positive attitude), enjoyable communication as reflected by personalized exchanges [25], and social activities [26]. In addition, the progression in communication deficits often results in avoidance of communication within the dyad, a factor that contributes to accelerating cognitive decline and triggering BPSD, which are particularly disruptive in LTC settings [27]; it also impacts caregivers’ QoL [28]. A review by Scott-Cawiezell et al [29] on 995 staff members has shown that improvements are required to achieve open, accurate, and timely communication in nursing homes. More specifically, according to McCormack et al [30], while some staff members know of residents’ preferences, this information is not routinely communicated to all staff members in a facility. By sharing information about communication topics and strategies facilitating person-centered communication with each resident, caregivers may become more efficient in providing care and less exposed to communication breakdowns and the resulting increase in their burden. Moreover, according to Kolanowski et al [31], available communication systems do not consider the time and resource constraints of nursing homes.

There is a strong consensus on the need to empower caregivers and give them strategies so that they can optimize communication with persons living with dementia [28]. Particularly in the context of LTC residences, the evidence shows that adopting a person-centered care approach significantly influences quality of care and the QoL of both caregivers and persons living with dementia, by improving care compliance and reducing caregivers' burden [26,28]. Moreover, the literature shows that personalized, emotionally relevant contents facilitate person-centered care, preserve personhood, and prevent dehumanization and isolation of persons living with dementia [5]. Sharing complete information with the persons living with dementia and their families, ensuring participation of persons living with dementia and their families in decision-making, and securing the collaboration of persons living with dementia in policy and program development are among the key elements of person-centered care [32]. Thus, while communicating with persons living with dementia in the provision of care, it is important to consider the unique life history, feelings, cultural background, values, and preferences of each person. This consideration is a challenge for a caregiver in an LTC setting who meets a person living with dementia in the advanced stages when they are unable to tell their life story. Communication tools that consider this important aspect of person-centered care while fitting into the reality of LTC settings (including tight schedules, resources, and constraints, together with administrative investment in nursing leadership) are therefore required to achieve beneficial changes.

Sustaining person-centered care and communication between persons living with dementia and their caregivers, especially in LTC settings, requires adapted communication tools. It was with this purpose that our team designed Communication Proches Aidants (COMPAs; it also refers to the compass, the instrument that orients sailors in troubled seas).

COMPAs was designed to support person-centered communication between persons with severe communication impairments and their caregivers, professional or informal. It is based on the concept of person-centered communication, as reflected by its personalized audiovisual content in line with the life trajectory, preferences, interests, and culture of the persons living with dementia. Through coviewing, it engages the person living with dementia and the caregiver in a form of dialogue beyond words as they share verbal and nonverbal expressions of joy and well-being. Unlike the purely transactional communication that is characteristic of basic care [17], COMPAs puts the person living with dementia at the center of communication, thereby providing a unique framework for person-centered care in the context of dementia.

In sum, the person-centered care approach acknowledges the person living with dementia as their own person. Communication is an essential tool in the implementation of this approach and the maintenance of personhood [33]. Persons living with dementia have trouble expressing their needs, which often leads to the perception that they have no awareness, and their interactions lack mutuality [33]. However, persons living with dementia need meaningful interactions [34], and caregivers need adequate communication tools to meet the care and social needs of persons living with dementia. Unfortunately, caregivers lack sufficient communication training and adapted tools to support social communication in order to overcome the communication deficits of persons living with dementia. Furthermore, LTC settings are environments where there are multiple, often changing, caregivers who revolve around the persons living with dementia. Technology could play a crucial role in care for persons living with dementia. According to Koo and Vizer [35], technology facilitates daily activities, maintains social interactions, supports autobiographical memory, and promotes leisure activities, all while allowing storing and monitoring the clinical status of individuals. Overall, technology could improve the QoL of persons living with dementia, reducing the BPSD and burden on caregivers [35].

Technology and Communication

Overview

Although the evidence shows that technology is relevant for promoting social interactions [35-37], there is a need for rigorous studies on the use of digital tablets in the context of persons living with dementia and their caregivers. Specifically, a scoping review on this topic points to the benefits of technology for intergenerational communication [38], in particular, by means of suggested conversation topics related to the life trajectory of the person living with dementia, which generate positive emotions; however, the review acknowledged that little attention is paid to higher-level needs, such as self-esteem and preserving personhood [35]. Regarding the use of tablets, evidence shows that persons living with dementia may enjoy using tablets at all stages of dementia [38,39]. Hung et al [40] has pointed out the utility of tablets in the context of one-on-one, small-group, and large-group activities, thereby facilitating relationship building and resident engagement and helping caregivers gain better knowledge of the interests and abilities of the persons living with dementia. Furthermore, a recent review [37] has identified a series of apps that could potentially prevent and overcome communication barriers. However, none of these apps were designed to promote person-centered communication or were tested in an LTC setting. Finally, a recent scoping review [35] on the use of technology in LTC has shown some positive impacts on behavior engagement and mood in LTC residents. Importantly, the authors highlight that this finding is not specific to persons living with dementia, who are generally excluded from such studies, while pointing out the importance of examining the impact of technology use specifically in this population [35].

In sum, technology offers some promise for supporting communication in persons with dementia. However, there is limited empirical research on the use of technology to support communication between caregivers and residents in LTC residences [35,41], and only 1 study examined the caregivers' perspectives on the ability of mobile apps to support caregiver-resident communication [36]. The consensus in the literature is that more research on the use of communication apps involving persons living with dementia in LTC settings is imperative [35]. Moreover, there is a need for evidence-based apps specifically designed to promote person-centered communication in cases of advanced dementia when the possibilities of verbal communication are very limited.

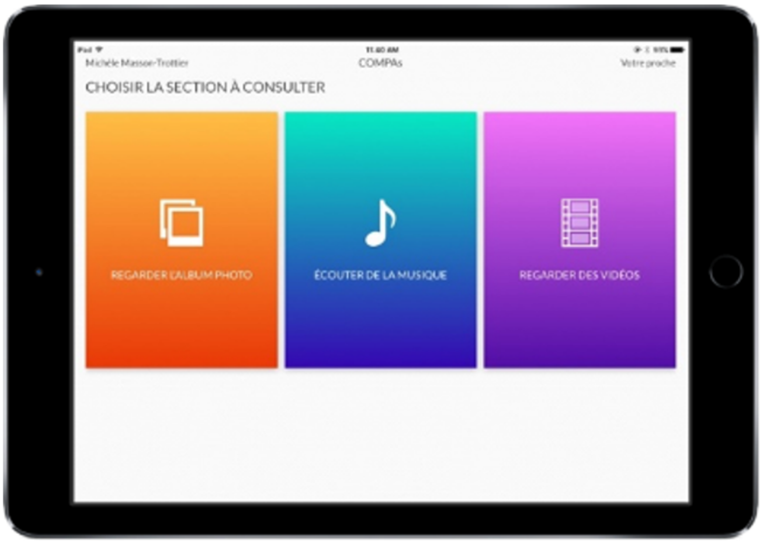
COMPAs App

COMPAs is an evidence-based app available on digital tablets to facilitate portability and participation of persons living with dementia. It is designed to support person-centered care between persons living with dementia and their caregivers. This app integrates knowledge from proven therapies [6,15,42-46] and has the advantage of combining these concepts in a single medium [47]. COMPAs is a secure platform that collects photos, music, and videos that have marked the life of the persons living with dementia. It was designed by speech language pathologists (SLPs) and media experts and offers an intuitive environment to promote positive communicative moments; its content is fully customizable to reflect the relevant life events of each person living with dementia and is constantly adaptable as the person's dementia evolves.

With COMPAs, caregivers gain secure access to personalized libraries of audiovisual materials that are selected according to residents' personal preferences, cultural background, and life history. Specifically, photographs, music, and videos can be uploaded to a secure space through the tablet or the COMPAs website, allowing families to remotely add content to enrich their loved one's COMPAs space. Apart from the content provided by the family, the COMPAs artificial intelligence module provides access to personalized internet content related to the person's life history (eg, places where the person lived, favorite sports, animals, and hobbies). Caregivers can also add music pieces (from music libraries available on the tablet or through a Spotify account) as well as excerpts from movies or shows available on YouTube, while family caregivers can safely add personal videos. A "like" allows users to highlight particularly meaningful content. Before closing COMPAs each time, the caregiver is given a short multiple-choice questionnaire, which gathers a more personal perspective on the COMPAs session, while providing a means to follow up its effects and share relevant information on session outcomes with the members of the team. Coviewing sessions with COMPAs have been shown to facilitate person-centered care, the gold standard in dementia care. Studies conducted during the COVID-19 pandemic showed that COMPAs sessions triggered emotional communication, characterized by shared verbal and nonverbal exchanges related to positive emotions, while increasing social engagement between persons living with dementia and caregivers [47]. Finally, by adding likes to specific music, videos, or photographs in the residents' personalized space and writing comments, caregivers can share information with the team about the best communication strategies and topics to sustain person-centered communication.

The application was initially developed in French; however, because it uses little written language and is very intuitive, neither language impairments nor language barriers prevent its use by speakers of other languages (see Figure 1 showing the app's interface).

Figure 1. Communication Proches Aidants (COMPAs) interface.



The rationale behind COMPAs lies in the person-centered care approach and emotional communication. Its personalized, meaningful content reduces the impact of communication deficits by encouraging nonverbal and emotional communication. Regulation of positive emotions has been shown to optimize care in the context of dementia, while favoring trust and promoting well-being for the person living with dementia [48] and the caregiver [49].

Pilot work by our team has shown that COMPAs allows caregivers and LTC residents to enjoy moments of person-centered interaction, breaking the vicious circle of noncommunication, thereby reducing both residents' isolation and caregivers' burden. COMPAs's theoretical background and our pilot findings offer some promise regarding the app's potential to support person-centered communication between persons living in LTC residences and their caregivers.

Purpose of the Study

In light of these pilot findings and considering the need for evidence-based technology tools to support person-centered communication between persons living with dementia and their caregivers in LTC settings [35,41], the purpose of this study was to test the use of COMPAs in LTC settings. Specifically, we implemented COMPAs in the context of LTC daily routines and measured its effects on the communication between residents and caregivers, caregivers' burden, and the QoL of persons living with dementia and caregivers.

In line with the literature, and considering the rationale underlying COMPAs, it was expected that interventions with COMPAs would achieve the following:

1. Improve the quality of communication between the person living with dementia and the caregiver, as measured through improvements in questionnaire scores and semistructured interviews.
2. Enhance the QoL of the persons living with dementia, as measured through improvements in questionnaire scores and semistructured interviews.
3. Reduce the burden on caregivers, as measured through improvements in questionnaire scores and semistructured interviews.

In addition, we anticipated that COMPAs would be adapted to the LTC environment. This had been assessed through participant adherence and satisfaction with the use of COMPAs in this study.

Methods

Study Design

This study used a pretest-posttest experimental design, with a COMPAs intervention administered over 8 weeks. The total duration of the study, including recruitment and assessments, was 14 weeks. The timeline depicted in Figure 2 shows the various stages of the COMPAs study.

Figure 2. Study timeline.

Participant Selection Process, Inclusion, and Exclusion Criteria

Caregivers

In total, 17 caregivers were recruited. The inclusion criteria were being a caregiver at the Paul-Bruchési LTC Center in Montreal, Québec, Canada, or Saint-Victor LTC center in Amiens, France, and caring for a person living with dementia who presented communication impairments as described in their chart or perceived by the caregiver. There were no exclusion criteria for caregivers. However, 1 participant from the Saint-Victor center was subsequently excluded from the study analyses, as only quantitative data were available for this participant; consequently, 16 caregivers completed the study. Most of the caregivers included in this study were women (14/17, 82%). Caregivers were between the ages of 24 and 57 years and had between 1 and 29 years of work experience in the health sector. Before this study, none of the caregivers had used a digital tablet, and only some used a smartphone (4/17, 22%) at work, although they were all familiar with these technologies since more than half of them used a digital tablet (10/17, 59%) or a smartphone (15/17, 88%) at home. Of the 22 caregivers who attended the information session and were not included in the study, 3 (14%) were not able to participate because they were transferred to another workplace, 1 (4%) refused to participate for personal reasons, and 1 (4%) left on parental leave.

Residents

The inclusion criteria were having an assigned caregiver enrolled in the project and experiencing communication difficulties, as identified by a caregiver, in the context of a diagnosis of major neurocognitive impairment, whether isolated or in combination with hearing and visual loss, or other conditions that can challenge communication, including a linguistic barrier. To make the samples as representative of the LTC population as possible, there were no exclusion criteria for persons living with dementia. A total of 17 residents participated in the study; they were aged between 61 and 96 years. Most of the residents (11/17, 65%) had a diagnosis of dementia (mixed dementia: n=6, 35%; Alzheimer disease: n=3, 18%; vascular dementia: n=1, 6%; severe dementia: n=1, 6%; and Lewy body disease: n=1, 6%). Other diagnoses were hippocampal atrophy (n=1, 6%), generalized anxiety (n=1, 6%), and cancer (n=1, 6%). Most of the residents (n=12, 71%) included in this study were women and still had some ability to express themselves verbally in isolated words or short utterances, with fluctuating comprehension of short sentences (n=15, 88%), including due to hearing limitations (n=6, 36%).

Recruitment Process

The recruitment process for caregivers was on a voluntary basis. Specifically, the project was presented by the research assistant (RA) and the laboratory director (Ana Inés Ansaldo) during a staff meeting. The purpose of the presentation was to stimulate interest in the study and to introduce COMPAs to the staff members. Staff members were asked to contact the head of the LTC unit to express their interest in participating in the study. Each caregiver identified a resident with whom they wanted to improve communication. The research team then asked the residents if they were interested in participating.

Ethical Considerations

Ethics approval was obtained from the Centre de recherche de l'Institut universitaire de gériatrie de Montréal (CRIUGM) Ethics

Committee (approval number CER-18-19-14), and informed written consent was obtained from the residents or their representatives in cases of incapacity. Caregivers were invited to sign consent forms with the RA after they had expressed interest to participate in the study.

Pre-Experimental Phase

Information Session

The first week of the study was dedicated to describing the project's purpose, the procedures, the measurement tools, and COMPAs's characteristics and use.

Training Sessions on COMPAs Use

Caregivers received two 30-minute training sessions on COMPAs during the daily planned team meetings. Facilitated by an SLP or a trained RA, the training session focused on COMPAs's rationale and principles and a demonstration of its use by the trainer. There was a hands-on practice session at the end of the training.

Pre-Experimental Measures

The measures administered to caregivers included questionnaires investigating QoL (General Health Questionnaire-12 [GHQ-12] items) [50] and the burden at work (Maslach Burnout Inventory [MBI]) [51]. The RA also administered measures related to residents, including an overview of residents' communication deficits (*Grille d'évaluation des difficultés de communication dans la démence* [GCOM]) [52] and a QoL questionnaire (*Qualité de vie dans la démence de type Alzheimer* [QDV-DTA]) [53]. Information on the residents' and caregivers' age, sex, and other sociodemographic data was also collected, as was information on residents' neurocognitive disorders from their medical charts.

The GHQ-12 was used to acquire data on the caregivers' general QoL. It includes 12 questions, scored on a 4-point Likert scale where 1=not at all, 2=not more than usual, 3=a little less than usual, and 4=a lot more than usual. In the standard scoring system, scores of 1 or 2 are given 0 point, and scores of 3 or 4 are given 1 point. The overall score is the sum of 0 and 1 points. If the sum is higher than 2, it is considered problematic.

The MBI measures caregiver burden at work. It comprises (1) an emotional exhaustion score (9 questions; scores of <17, 18-29, and >30 denote low, moderate, and high emotional exhaustion levels, respectively); (2) a depersonalization score (5 questions; scores of <5, 6-11, and >12 denote low, moderate, and high empathy loss, respectively); and (3) a personal achievement score (8 questions; scores >40, 34-39, and <33 denote low, moderate, and high achievement levels, respectively). Caregivers were asked to rate their own scores on this test.

The GCOM measures the severity of communication difficulties. The caregiver is asked to score communication behaviors for each resident (eg, "The person has word-finding difficulties") on a Likert scale ranging from 1 (always) to 4 (never); it is also possible to select "does not speak enough for me to judge." All scores are added up to give a final communication score. The QDV-DTA measures residents' QoL. It consists of 13 questions, with higher scores indicating better QoL.

Setting Up Personalized COMPAs Libraries

Before the intervention, the RA completed a personal history with the residents' representatives. The caregivers, along with an SLP or a trained RA, created a personalized communication space for each resident by adding significant personal content such as personal photos, images, videos, and music selected based on their life history questionnaire and the information provided by the residents' representatives.

Experimental Phase

Caregivers used COMPAs for 8 weeks in the context of their daily LTC routine (eg, family visits; recreation time; birthday celebrations; and situations triggering reactive behaviors, such as personal care or specific interventions). COMPAs sessions could be very short (2-5 minutes) or longer (up to 20 minutes). They consisted of coviewing sessions (ie, resident and caregiver) during which personalized material in the resident's library was presented by the caregiver, with the purpose of eliciting positive emotions and triggering verbal and nonverbal exchanges within the dyad, according to the principles learned during the training sessions.

Caregivers were instructed to ensure that residents always used their hearing and visual aids during COMPAs sessions. Furthermore, following caregivers' comments, we made adaptations such as using personal hearing amplifiers or Bluetooth speakers to improve listening to the music. In addition, since COMPAs is a person-centered approach, we encouraged caregivers to focus on the person's strengths and therefore used more photos and videos with people with hearing loss and more music and audio clips with those with visual loss.

Caregivers could modify the number and duration of COMPAs sessions according to what was possible for them (eg, workload and residents' status), as long as they respected a minimum of 15 minutes a day, at a time they considered appropriate. During the first 2 weeks of the intervention, with the purpose of facilitating COMPAs use, the SLP and the trained RA provided direct support to the caregivers on the telephone, by email, or during visits to the LTC facility. All caregiver shifts were covered so that everyone had the chance to ask questions. Indirect support (by telephone and email) was available throughout the 8-week duration of the intervention.

Postexperimental Phase and Measures

Following the 8 weeks of COMPAs intervention, the same measures administered before the experiment were administered by the RA to the caregivers and residents. Semistructured interviews with the participating caregivers were also completed: individual, semistructured 20- to 40-minute interviews were conducted with the caregivers in person, and on the Zoom (Zoom Video Communications Inc) platform. Only the interviewer and the caregiver were present at the meeting. The questions came from an interview guide developed by the last author (CD), based on interview guides from previous studies [54,55]. The interview consisted of open-ended questions and began with a very general question ("Could you please talk about your experience with COMPAs in the last few weeks?"). Uncertainties arising from participants' answers were elucidated with follow-up questions. At the end, the interviewer also asked the caregiver if they wished to provide any additional information. Overall, 17 interviews were conducted with the 17 participants.

Data Analysis Plan

Quantitative Analyses

Data analyses include quantitative and qualitative approaches. Primary outcome measures are scores on the GHQ-12 [50] and the BMI [51] with caregivers and scores on the GCOM [52] and QDV-DTA [53] with persons living with dementia. The 4 outcome measures were used as dependent variables, and the 2 measurement points before and after the COMPAs intervention were considered as independent variables. The results were entered in paired sample 2-tailed *t* tests with an α of .05 to define significance. The paired-sample *t* test allows to control for individual variables that potentially affect outcome measures. Furthermore, paired-sample *t* tests are suitable to analyze data from small samples, as in this study. When the assumptions of the paired-sample *t* test were not fulfilled (ie, difference scores were not normally distributed and within-participant variability was not consistent), a nonparametric alternative, the Wilcoxon signed-rank test, was used. For all measures, outliers were detected by inspection; criteria to exclude data from analyses were set at values >1.5 box lengths from the edge of the box plot.

Qualitative Analyses

The qualitative measures involved a qualitative content analysis approach [56], as described by Intissar and Rabeb [57] and Vallée et al [58]. To analyze data from semistructured interviews with caregivers, MAXQDA software (VERBI GmbH), a qualitative analysis program for discourse content analyses was used [59]. The interviews were audio recorded and manually transcribed verbatim by BD and JD, and the interjudge validity was assessed, followed by thematic coding. The corpus of the interviews was read multiple times separately by 2 authors to achieve a full understanding of the data. Transcripts were coded individually by 2 authors (CD and JD), and multiple meetings took place to reach intercoder reliability. Each author separately generated codes, following which they met to discuss them and reached consensus on the coding tree, which was further discussed with the last author (CD) of this manuscript. Quotations presented in this paper were translated from French into English. Caregivers were assigned numbers from P1 to P17.

Results

Quantitative Findings

Caregivers

Outlier values were detected in the difference scores for the GHQ-12, the MBI-depersonalization score and the MBI-personal achievement score. All data points >1.5 box lengths, each associated with a different participant, were removed from this specific analysis. The differences between the MBI-emotional exhaustion score, MBI-depersonalization score, and MBI-personal achievement score scores were normally distributed (*P*=.39, *P*=.29, and *P*=.74, respectively). Thus, paired-sample *t* tests were used to analyze these differences. The results are presented in Table 1. In contrast, the GHQ-12 scores were not normally distributed (*P*=.02), and therefore, a Wilcoxon signed-rank test was used to analyze these differences. The results are presented in Table 2. Data are presented as mean (SD), unless otherwise stated.

Table 1. Individual scores and mean (SD) values on subsections of the Maslach Burnout Inventory.

	Emotional exhaustion			Depersonalization			Personal achievement		
	Pretest	Postest	Difference	Pretest	Posttest	Difference	Pretest	Posttest	Difference
ID (scores)									
CA[a]3	43	33	–10	18	11	–6	38	36	–2
CA4	18	21	3	9	6	–3	43	45	2
CA6	16	19	3	6	6	0	45	46	1
CA7	20	4	–16	0	0	0	45	48	3
CA10	9	28	19	13	17	–2	31	33	2
CA11	17	15	–2	7	4	–4	43	39	–4
CA15	10	7	–3	11	6	–5	41	47	6
CA16	14	6	–8	4	1	–1	44	44	0
FR[b]1	14	14	0	6	14	8	37	27	–10
FR2	11	1	–10	11	5	–7	43	42	–1
FR4	20	22	2	15	6	–9	42	44	2
FR5	11	12	1	1	2	2	35	39	4
FR6	20	9	–11	5	5	0	32	33	1
FR7	54	51	–3	6	5	–1	45	44	–1
FR8	13	16	3	6	2	1	39	44	5
FR9	36	33	–3	6	14	8	26	36	10
FR10	2	15	13	4	13	12	4	11	7
Values									
Group, mean (SD)	19.29 (13.2)	18.00 (12.67)	–1.29 (8.68)	7.53 (4.77)	6.88 (5.06)	–0.41 (5.57)	37.24 (10.21)	38.71 (9.20)	1.47 (4.57)
Outlier, mean (SD)	—[c]	—	—	7.75 (4.83)	6.5 (4.96)	1.18 (4.70)	37.25 (10.54)	39.43 (8.98)	2.18 (3.60)

[a] CA: caregivers from the Canadian site.

[b] FR: caregivers from the French site.

[c] Not applicable.

Table 2. Individual scores for caregivers on the General Health Questionnaire-12 (GHQ-12) and pre- and postintervention mean scores with all participants.

	GHQ-12		
	Pretest	Posttest	Difference
ID			
CA[a]3	4	3	–1
CA4	0	1	1
CA6	3	3	0
CA7	0	0	0
CA10	3	0	–3
CA11	0	0	0
CA15	1	0	–1
CA16	0	0	0
FR[b]1	0	0	0
FR2	0	0	0
FR4	2	0	–2
FR5	1	0	–1
FR6	5	2	–3
FR7	8	3	–5
FR8	0	0	0
FR9	2	1	–1
FR10	3	0	–3
Values			
Group, mean (SD)	1.88 (2.26)	0.76 (1.20)	–1.11 (1.57)
Mean without outliers (SD)	1.5 (1.67)	0.62 (1.08)	–0.87 (1.25)

[a] CA: caregivers from the Canadian site.

[b] FR: caregivers from the French site.

To determine whether the use of COMPAs by caregivers in LTC settings influenced their scores on the GHQ-12 questionnaire, the Wilcoxon signed-rank test was used to measure QoL scores. The difference scores were approximately symmetrically distributed, as assessed by a histogram with a superimposed normal curve. Of the 17 caregivers who participated in this study, 9 (53%) showed a decrease in score difference, 7 (41%) showed a tied score, and 1 (6%) showed an increase in score difference. There was a statistically significant change (mean –0.88, SD 1.26; median –0.5, IQR 2.50) between GHQ-12 scores at T3 (mean 1.50, SD 1.67; median 1, IQR 3.0) and at T14 (mean 0.63, SD 1.09; median 0, IQR 1.5; $z=2.54$; $P=.01$). At T14, 1 (6%) caregiver's score had worsened, 9 (53%) had improved, and 7 (41%) remained the same.

A 2-tailed paired-sample *t* test was used to determine whether COMPAs influenced caregivers' scores on the MBI-emotional exhaustion scale, MBI-depersonalization scale, and MBI-personal achievement scale. No significant change from T3 (mean 19.29, SD 13.20) to T14 (mean 18.00, SD 12.67; $t_{16}=–0.62$; $P=.55$) was found on the MBI-emotional exhaustion scale. Specifically, at T3, 10 (59%) caregivers scored a low level of emotional exhaustion, 4 (24%) scored a moderate level, and 3 (18%) scored an elevated level. At T14, 10 (59%) caregivers were at a low level, 4 (24%) at a moderate level, and 3 (18%) at an elevated level; scores had worsened for 7 (41%) caregivers, improved for 9 (53%), and remained the same for 1 (6%).

There was also no significant change on the MBI-depersonalization scale (T3: mean 7.75, SD 4.84; T14: mean 6.88, SD 5.06; $t_{15}=–1.01$; $P=.33$). At T3, 5 (29%) caregivers had a low level of empathy loss, 9 (53%) had a moderate level, and 3 (18%) had a high level. At T14, 8 (47%) caregivers scored a low level of empathy loss, 5 (29%) scored a moderate level, and 4 (24%) scored a high level; 9 (53%) caregivers had improved, 5 (29%) had worsened, and 3 (18%) remained at the same level.

Regarding personal achievement, according to the MBI-personal achievement scale, there was a significant change following COMPAs use (T3: mean 37.24, SD 10.21; T14: mean 38.71, SD 9.2; $t_{15}=2.43$; $P=.03$; $d=0.61$ for a medium effect size). Specifically, at T3, a total of 9 (53%) caregivers scored a high level of personal achievement, 4 (24%) scored a moderate level, and 4 (24%) scored a low level. At T14, 9 (53%) caregivers scored a high level of personal achievement, 4 (24%) scored a moderate level, and 4 (24%) scored a low level; 5 (29%) caregivers had worsened, 11 (65%) had improved, and 1 (6%) remained the same.

Residents

A paired-sample *t* test was used to determine whether there was a statistically significant mean difference between residents' overall scores on the QDV-DTA and the GCOM before and after the use of COMPAs by caregivers in the LTC setting. There were no outliers in the data or in the QDV-DTA differences or in the GCOM differences, as assessed by the inspection of a box plot for values >1.5 box lengths from the edge of the box.

The assumption of normality was not violated, as assessed by the Shapiro-Wilk test for the QDV-DTA or the GCOM (*P*=.78 and *P*=.78, respectively). The results did not reveal any significant change in the overall score on the QDV-DTA (QDV-DTA: preintervention mean 33.42, SD 3.92; postintervention mean 34.58, SD 5.42; t_{11}=0.84; *P*=.42) or the GCOM (GCOM: preintervention mean 16.42, SD 10.08; postintervention mean 20.67, SD 12.92; t_{11}=1.89; *P*=.09). However, 2-tailed *t* tests revealed a significant worsening for the following questions in the GCOM: "They tend to repeat something that someone just said" (*P*=.03); "They use filler words ('thing,' 'whatchamacallit') instead of precise words ('pencil,' 'balloon')" (*P*=.04).

Although the QoL questionnaire and the GCOM did not show a significant change, the semistructured interviews with all caregivers (n=17) revealed that they felt COMPAs had a positive impact on the lives of persons living with dementia (please refer to the *Qualitative Findings* section). Some caregivers described these positive impacts as positive emotions during nonverbal communication revealed by a positive facial expression in the person living with dementia or the simple fact that the person living with dementia started dancing while using COMPAs.

Qualitative Findings

The qualitative analyses of semistructured interviews with the caregivers regarding the effects of COMPAs use with persons living with dementia in the LTC setting highlighted 3 main themes: capacity of COMPAs to elicit positive emotions, decrease in caregiver burden, and versatility of COMPAs.

Eliciting Positive Emotions

The interviews highlighted COMPAs's capacity to elicit positive emotions in persons living with dementia and caregivers. This increase in positive emotions led to an increase in feelings of joy, pleasure, and happiness.

Persons With Dementia

Caregivers (16/16, 100%) reported on COMPAs's capacity to elicit positive emotions in persons living with dementia, who had expressed well-being and the pleasure they got from their COMPAs session both verbally and nonverbally via changes in their facial expression (eg, smiles and eye contact):

> *This nonverbal person's face would light up.* [P6]

Almost all caregivers discussed the positive effects of personalized content on persons living with dementia: how pictures or music from their past can evoke positive memories (15/17, 88%) and positive emotions (16/17, 94%). Persons living with dementia enjoyed reminiscing and sharing former moments of their life with their caregivers:

> *COMPAs calms them, and does them good too, because it reminds them of memories, good memories, there are pictures of their kids, their pet, their house.* [P14]
>
> *I would say cheerfulness. They were happy to see the pictures, listen to their favorite music.* [P17]

Caregivers

Caregivers (14/17, 82%) reported that using COMPAs gave them joy, pleasure, and overall positive effects on their daily lives. They said that they looked forward to using COMPAs with their patients and appreciated these moments in their week:

> *To me, it is my moment of pleasure, when I am working.* [P5]
>
> *It was good for them but for me too because I felt their well-being.* [P17]

Some of the caregivers (14/17, 82%) said that simply seeing the enjoyment of the persons living with dementia gave them pleasure too:

> *Yes, I would see that it brought them joy, so it brought me pleasure too.* [P14]

Caregivers also reported on how they appreciated the effects of the app on the persons living with dementia. They valued COMPAs's capacity to contribute to the well-being of persons living with dementia:

> *It's great, because we give the resident the chance not to feel lost, and without this tool, you can't really do it.* [P10]

Decrease in Caregiver Burden

The analysis highlighted how COMPAs gave caregivers a solution to deal with their everyday struggles, helped them feel empowered, and resulted in better bonds with the residents.

COMPAs was used as a tool and, in some cases, as an excellent way out of difficult situations involving persons with dementia, such as opposition, disorientation, and apathy. Caregivers (12/17, 71%) saw COMPAs as a solution that worked with residents who had required more attention. They were grateful to have an effective solution in these types of cases:

> *Interviewer: Did you have the impression of having a solution?*
>
> *P13: Yes, exactly, now I have a solution.*

P2:But, with some residents, the device also helps us to do the tasks.There are some cases that are more difficult, but with the device, it improves our interaction with certain residents a bit.

The implementation of COMPAs also contributed to caregivers' feelings of personal achievement in the workplace. Caregivers (15/17, 88%) felt more useful and believed that they made a real difference in the lives of the persons living with dementia, as they could go beyond providing primary care. Caregivers enjoyed learning about the residents, their lives, and their personal tastes, and they felt empowered by having an additional clinical role:

> *It lifts you up, in your work...you are not only there to help them with comfort care or to feed them.* [P10]
>
> *I can say it adds something good to the atmosphere, it adds more...How can I say this...I could say particularly with PWDs, it makes us want...with people who communicate less. It is like us; it makes us want to reach out to those people.* [P6]

Caregivers (11/17, 65%) discussed how COMPAs enabled the development of more personalized relationships with persons living with dementia. They felt closer to the residents and more interested in them. Spending more time with persons living with dementia helped caregivers to create a bond and spend quality time with them despite the communication difficulties:

> *P9: ...just spending fifteen minutes with them, it was a moment of joy and relaxation. Because I was also learning plenty of things.*
>
> *Interviewer: Do you mean that it provided you with joy to spending time with them?*
>
> *P9: Yes, exactly. We never take enough time; we do not take the time to talk to them.*

Caregivers (11/17, 65%) also said that COMPAs allowed them to have better interactions with the residents. They talked about better-quality exchanges, and generally enhanced communication, including communication by the persons living with dementia themselves:

> *We can communicate with the device.* [P14]
>
> *Even their speech is more fluent.* [P10]

Versatility of COMPAs

Caregivers highlighted the flexibility of COMPAs, as it could be used for different reasons, in different settings, and for different durations.

COMPAs was implemented in different ways by different caregivers. They could adapt it to their working conditions, and over time, they incorporated the tool into their daily routine. Some caregivers used it while providing grooming care:

> *And there are moments, like grooming care, that are a bit stressful, I would put his music on, and we sang, we danced in front of the mirror, and we giggled.* [P13]

Some used it in a group setting, while others used it individually. Some caregivers had a fixed time in their day dedicated to COMPAs, while others used it at different times depending on the situation:

> *A big asset of COMPAs, is that in fact, we can use it at any time of day.* [P11]

The duration of a COMPAs session also varied between caregivers, ranging from 5 minutes to around 20 minutes:

> *When I have five minutes, ten minutes, I would take the iPad, go to the room, and we listened together. Sometimes when I have more time, l stay longer.* [P4]

Challenges for Caregivers

Caregivers reported some issues during the implementation of COMPAs. Lack of time, technological issues, and the responsibility for or availability of the device were mentioned as challenges.

Lack of Time

Close to half of the caregivers (8/17, 47%) stated that they lacked the time to use COMPAs. They commented that it was not always easy to take the time to conduct a COMPAs session because of workload or when time permitted, the resident might be unavailable:

> *The evening shift, it is hard to find the time to enjoy it.* [P3]
>
> *It was hard in the mornings with grooming care: there is too much work to do it properly. However, we would do, I would do one in the morning from time to time.* [P15]

Technological Issues

The participants encountered some technological issues during the implementation. Caregivers (3/17, 18%) discussed how the bugs could disrupt their sessions, making the residents lose interest in the content presented:

> *The videos did not work. I would have liked to do it with Mrs. B, watch videos, but it was not working.* [P17]

Responsibility for and Availability of the Device

Caregivers (6/17, 35%) raised the issue of being responsible for an iPad. Being responsible for a valuable object was a concern for them. In other cases, the iPad was locked, and a nurse had to make it available to the caregiver (5/17, 29%). Their busy schedules made it difficult for them to access the device when they needed it.

Challenges for Residents

A few residents (6/17, 35%) faced some problems while using COMPAs. Confusion, negative emotions, and disinterest were mentioned as challenges for residents.

Caregivers reported that some of their residents considered the app to be an intrusion; they did not understand how their personal information came to be in the attendant's hand:

> *P10: People like Mrs. G, this dementia, well, for her, it's not positive, because it's difficult, she starts questioning. She wonders what is going on.*
>
> *Interviewer: You think Mrs. G., it makes her wary?*
>
> *P10: Mrs. G., she did it once and it was very hard to do it again, because she takes it as an intrusion.*

Others were troubled by not being able to recognize the pictures shown to them. Negative emotions could also be elicited by the content:

> *A little bit of melancholy at times.* [P12]

Caregivers (4/17, 24%) reported that some residents were disengaged from COMPAs. This disinterest was related to the device, the redundancy of the content, or the resident's attitude:

> *Well, there were some residents who weren't even slightly interested.* [P13]
>
> *Some residents weren't interested in watching the screen or were troubled by the screen.* [P13]

Discussion

Principal Findings

The purpose of this study was to implement and validate the effect of COMPAs, an app designed to elicit positive emotions triggering communication between persons living with dementia and their caregivers in an LTC setting.

Using a combination of quantitative and qualitative methods, the main results of the study validate our hypotheses. Specifically, the qualitative results from the semistructured interviews show that COMPAs improved person-centered communication between caregivers and persons living with dementia; its use resulted in more verbal and nonverbal exchanges in different contexts (eg, personal care and dedicated time). In particular, caregivers reported an improvement in the quality of exchanges and a more personal care relationship. Moreover, the use of COMPAs was associated with an improvement in QoL for both persons living with dementia and caregivers. The caregivers reported that COMPAs elicited positive emotions in persons living with dementia, contributing to emotional communication and helping the caregivers see the person living with dementia beyond the illness. In so doing, COMPAs supported person-centered care and communication between persons living with dementia and their caregivers. In addition, statistically significant results were observed in the form of increased caregiver empowerment, as reflected by the accomplishment score in the MBI. Caregivers also described COMPAs as a solution that helped them create opportunities to develop meaningful bonds with persons living with dementia, easing the caregiver communication burden. Finally, COMPAs was deemed well suited to the LTC context, particularly due to its versatility. These results were observed although 40% (7/17) of the caregivers were not accustomed to using an iPad, which provides evidence for the versatility of COMPAs in empowering even caregivers with limited technological literacy.

Quality of Communication Between Persons Living With Dementia and Caregivers

The GCOM showed some deterioration in specific oral expression components for persons living with dementia, which is expected in the context of progressive conditions. Interestingly, the COMPAs intervention was associated with stable general communication skills in residents. This may be a result of the GCOM's poor sensitivity to the communication patterns characterizing advanced neurocognitive disease, or it might reflect the benefits of daily stimulation with COMPAs in reducing morbidity, despite the progressive nature of neurocognitive disease [7]. The results on the GCOM also highlighted the positive nonverbal communication markers of well-being and positive emotions that COMPAs induced in residents, including smiling; raising eyebrows; touching the caregiver's hand while coviewing; smiling, dancing, or singing to personalized music; and laughing with the caregiver. These findings highlight the app's efficacy in promoting person-centered communication between LTC residents with dementia and their caregivers. They also attest to the benefits of COMPAs training, which increases caregivers' awareness of nonverbal and emotional aspects of communication. These findings are in line with those of previous work showing that integrating communication strategies into care and using elements of a patient's life story in informal discussions enhance meaningful communication between caregivers and LTC residents [6]. Moreover, the results of the semistructured interviews showed that following the COMPAs trial, caregivers focused more on nonverbal and emotional person-centered communication and less on verbal and transactional communication. These results reveal the importance of combining a good tool with suitable training in order to promote awareness of all dimensions of communication and the potential facilitators and barriers [31].

Studies conducted during the COVID-19 pandemic also found that COMPAs had positive effects on communication between caregivers and persons living with dementia in an LTC setting, even during periods of extreme isolation [47]. Specifically, caregivers reported that residents showed increased engagement, as opposed to apathy, together with verbal and nonverbal expressions of joy, well-being, and calmness while using COMPAs, despite major public health restrictions and the use of personal protective equipment [47].

Residents' and Caregivers' QoL

Caregivers' QoL

The results on the GHQ-12 showed that caregivers' QoL increased following COMPAs use, and so did their sense of personal accomplishment (measured by the MBI-personal achievement scale). More specifically, an improvement in the feeling of personal accomplishment was observed in the level of energy that the caregiver felt when working closely with the resident. This is in line with the findings of previous studies showing that significant communication between persons living with dementia and caregivers is associated with a better QoL [60,61].

The analyses of semistructured interviews show that caregivers described COMPAs-supported interactions with residents as pleasant times, moments of relaxation, and even as therapeutic for them. Thus, caregivers saw COMPAs as a solution to their struggles with persons living with dementia: a quick and effective way out of the challenges they faced in managing difficult behaviors (eg, apathy and agitation) and engage in more natural communication. It was probably this factor that led to the association between reduced caregiver burden and COMPAs use. Similar findings were reported in previous work showing the relationship between caregiver burden and the quality of communication [9,62]. Furthermore, there was a decrease in the score of the MBI-depersonalization scale for over half of the participating caregivers (9/17, 53%). This may have been related to the personalized COMPAs content, which helps caregivers appreciate the person beyond the disease and become aware of the individual traits of the persons living with dementia including their history, culture, tastes, and preferences, that is, the opposite of depersonalization.

The caregivers expressed their satisfaction with knowing more about the person they were caring for, spending more time with them, getting to know their life story better, and seeing the residents happier in this context. Indeed, personalized content is shown to be relevant in facilitating communication among persons living with dementia [63]. Thus, improving the quality of communication had positive effects on the dyad and helped to establish an empathic relationship. As a result, caregivers felt valued and satisfied with their work:

> *It lifts you up in your job: you're not there just to help them with their comfort care or feed them.*

Using COMPAs empowered the caregivers, and this is probably a key reason for reduced caregivers' burden.

Residents' QoL

The QDV-DTA scores did not show any significant changes in the residents' QoL. However, caregivers reported that COMPAs triggered positive expressions in the residents, demonstrated by their nonverbal communication. They viewed COMPAs as a tool helping residents change their routine, remember positive times, break out of their isolation, and feel well. They considered COMPAs to be a valuable tool to support meaningful communication, thus supporting social engagement in persons with dementia. During the semistructured interviews, caregivers mentioned COMPAs's ability to support a meaningful activity, which meant persons living with dementia were involved in stimulating activities. In light of the literature, residents' QoL is promoted by social contacts, a good relationship with the caregiver, and the caregiver's involvement in providing care [26,28]. These factors are also associated with better self-esteem in persons living with dementia, an essential component of their well-being [5] and dignity [17]. Furthermore, it is essential to address the socialization needs of persons living with dementia and provide person-centered care [64]. In line with this literature and considering the verbal and nonverbal manifestations of well-being in residents documented by caregivers in the semistructured interviews, the results of this study prove the relevance of COMPAs for communication and QoL. They illustrate the value of orienting communication around emotional content linked to the residents' own life trajectory, which improves interactions in the dyad, and in turn promotes positive relationships [16,33].

Burden on Caregivers

QoL at work refers to various factors such as satisfaction, mental health, and stress level [65]; these 3 factors contribute to caregiver burden. More specifically, stress arises when caregivers fear not having the necessary resources to face the physical and psychological challenges that they may encounter in geriatric care. The reduction in caregiver burden and increased personal achievement found in this study may be related to several factors. One is the fact that caregivers received a training session on communication strategies and barriers in LTC. Thus, the literature shows that training on strategies for communicating with persons living with dementia improves caregivers' communication skills and is associated with a decrease in their burden [61].

Another factor that may have contributed to reducing caregiver burden is reflected by the results on the MBI and by the thematic analyses concerning the stress and frustration associated with communication barriers [9], all of which were reduced in this project. Specifically, the quantitative results on the MBI following 8 weeks of COMPAs use showed a significant reduction in the burden score, concurrently with a significant improvement in the personal achievement score and a reduction in feelings of tiredness. Hence, COMPAs was a resource for caregivers, allowing them to feel more accomplished and less exhausted at work. These effects are also illustrated by the semistructured interviews; caregivers reported that adding COMPAs to their daily routine did not result in work overload.

In fact, caregivers noticed the positive effect of COMPAs on the residents and wanted to continue using the app, although they occasionally mentioned not having time to use COMPAs to their satisfaction or to add material to the libraries. The key will be to find more time in everyday life situations for caregivers to use COMPAs and to simplify the addition of personalized material. We are currently working on these 2 elements to meet these needs.

In sum, the results on the MBI and semistructured interviews show that COMPAs reduced caregiver burden, a factor that is associated with more relaxed care, which in turn further reduces their burden [66,67]. Furthermore, the emotional component of COMPAs interventions contributed to the expression of empathy, which is also known to reduce caregivers' burden.

Strengths and Limitations of the Study

To our knowledge, this is the first study to explore the implementation of a communication-based app in the context of LTC settings. The qualitative results of this study demonstrate COMPAs's effectiveness in positively influencing the lives of persons living with dementia and caregivers in an efficient and timely manner. It should be noted that COMPAs's positive effects on caregivers might perhaps be influenced by a selection bias; they volunteered for the study, and therefore, they might have a positive bias toward the method and would not necessarily be representative of the target population. However, according to the LTC administrators, the caregivers' demographic profile in the sample was representative of the vast majority of caregivers in Québec and Canada, mostly immigrant women aged between 20 and 60 years. Following the launch of the project, more caregivers saw the benefits and told the research team that they wish they had enrolled. Future studies could explore COMPAs's effects and adherence in a larger community of caregivers as a function of cultural background, age, gender, and technological literacy, among other things.

Finally, we acknowledge that the statistical significance of the quantitative results is limited. This may be a consequence of the small sample size and the diversity of residents' clinical profiles. Hence, although we find medium effect sizes, these results should be considered as only a tendency. Future studies with larger samples of participants are required to confirm these results and test the generalizability of these findings in broader populations, including family caregivers of persons living with dementia in LTC residences or other LTC populations without dementia but with severe communication impairments following stroke, or severe sensory impairments in the context of behavioral disturbances, or major psychiatric disorders.

COMPAs interventions proved to be suitable for implementation in LTC residences, as caregivers could choose the duration, time, and modality of their sessions with persons living with dementia. Caregivers could adapt the app to their working conditions, making COMPAs a versatile tool that can be modulated to the users' needs.

The literature shows that technology is underused to support the communication between caregivers and persons living with dementia in LTC settings [37], and no available evidence was found to support the use of apps for such communication. This study provides evidence that COMPAs is suitable to support person-centered care in the caregiver-LTC resident dyad. To our knowledge, this is the first app that supports communication through a person-centered care approach and that is fully customizable to the person living with dementia.

Although the information gathered from caregivers in the questionnaires and the semistructured interviews is an effective way to understand COMPAs's effects on persons living with dementia, we acknowledge that the perspectives of persons living with dementia were not included. Including them in the research team entails ethical and logistical challenges [68,69]. To be in line with the person-centered care approach, future studies should include their point of view [32]. The research team created the personalized libraries, which saved time for the caregivers, who were overloaded with everyday work, but persons with dementia could be more involved in choosing the material. This will be done in future studies.

In a context where human resources and time are limited, it will be important to develop efficient ways to create user-friendly personalized libraries. Future work will focus on improving the COMPAs interface by adding artificial intelligence modules that will assist in more efficiently creating sophisticated personalized libraries.

Conclusions

COMPAs proved to be effective in improving communication between caregivers and residents while reducing the burden on caregivers and improving both groups' QoL.

The evidence shows that COMPAs facilitates person-centered communication. Positive emotions generated in residents resonate in caregivers, stimulating empathy and well-being in the dyad. This state of shared well-being promotes social engagement, defocuses attention from impairments and disabilities, and fosters exchanges between the dyad and what they share. The impressive gains in relevant outcome measures obtained with residents and caregivers underscore the relevance of COMPAs in LTC settings. Large-scale studies are necessary to validate the observed tendencies and optimize COMPAs's potential benefits in persons with living dementia in LTC settings and their caregivers, while examining its use with other susceptible populations presenting communication deficits. Studies could also explore the barriers to technology use in caregivers and persons living with dementia and ways to overcome them; they must also consider the ethical issues related to technology use with susceptible populations, including privacy and security, to identify best practices for safe implementation of technology in dementia care.

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Conflicts of Interest

None declared.

References

1. Global status report on the public health response to dementia. World Health Organization. URL: https://www.who.int/publications/i/item/9789240033245 [accessed 2024-04-29]
2. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 08;396(10248):413-446 [FREE Full text] [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
3. Bayles KA, Kim ES, Azuma T, Chapman SB, Cleary S, Hopper T, et al. Developing evidence-based practice guidelines for speech-language pathologists serving individuals with Alzheimer's dementia. J Med Speech Lang Pathol 2005 Dec;13(4):000234694500003.
4. Potkins D, Myint P, Bannister C, Tadros G, Chithramohan R, Swann A, et al. Language impairment in dementia: impact on symptoms and care needs in residential homes. Int J Geriatr Psychiatry 2003 Nov;18(11):1002-1006. [doi: 10.1002/gps.1002] [Medline: 14618551]

5. Kitwood T, Bredin K. Towards a theory of dementia care: personhood and well-being. Ageing Soc 1992;12:269-287. [doi: 10.1017/s0144686x0000502x] [Medline: 11654434]
6. Vasse E, Vernooij-Dassen M, Spijker A, Rikkert MO, Koopmans R. A systematic review of communication strategies for people with dementia in residential and nursing homes. Int Psychogeriatr 2010 Mar;22(2):189-200. [doi: 10.1017/S1041610209990615] [Medline: 19638257]
7. Lubinski R. Dementia and Communication. San Diego, CA: Singular Pub Group; Jan 01, 1995.
8. Bourgeois MS. “Where is my wife and when am i going home?” The challenge of communicating with persons with dementia. Alzheimers Care Today 2002;3(2):132-144 [FREE Full text]
9. Savundranayagam MY, Hummert ML, Montgomery RJV. Investigating the effects of communication problems on caregiver burden. J Gerontol B Psychol Sci Soc Sci 2005 Jan;60(1):S48-S55. [doi: 10.1093/geronb/60.1.s48] [Medline: 15643047]
10. McGilton KS, Rochon E, Sidani S, Shaw A, Ben-David BM, Saragosa M, et al. Can we help care providers communicate more effectively with persons having dementia living in long-term care homes? Am J Alzheimers Dis Other Demen 2017 Feb 30;32(1):41-50 [FREE Full text] [doi: 10.1177/1533317516680899] [Medline: 27899433]
11. Stein-Parbury J, Chenoweth L, Jeon YH, Brodaty H, Haas M, Norman R. Implementing person-centered care in residential dementia care. Clin Gerontol 2012 Oct;35(5):404-424. [doi: 10.1080/07317115.2012.702654]
12. Nguyen H, Terry D, Phan H, Vickers J, McInerney F. Communication training and its effects on carer and care-receiver outcomes in dementia settings: a systematic review. J Clin Nurs 2019 Apr;28(7-8):1050-1069. [doi: 10.1111/jocn.14697] [Medline: 30357952]
13. Savundranayagam MY, Sibalija J, Scotchmer E. Resident reactions to person-centered communication by long-term care staff. Am J Alzheimers Dis Other Demen 2016 Sep;31(6):530-537 [FREE Full text] [doi: 10.1177/1533317515622291] [Medline: 26744507]
14. Fazio S, Pace D, Flinner J, Kallmyer B. The fundamentals of person-centered care for individuals with dementia. Gerontologist 2018 Jan 18;58(suppl_1):S10-S19. [doi: 10.1093/geront/gnx122] [Medline: 29361064]
15. Clerc L. La relation avec une personne sévèrement atteinte de démence de type Alzheimer et l'impact des symptômes comportementaux et psychologiques sur les soignants dans un contexte d'EMS : une revue de littérature étoffée. The Swiss Open Access Repository. 2011. URL: https://sonar.ch/hesso/documents/313688 [accessed 2024-04-29]
16. Edvardsson D, Winblad B, Sandman PO. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. Lancet Neurol 2008 Apr;7(4):362-367. [doi: 10.1016/s1474-4422(08)70063-2]
17. Torossian MR. The dignity of older individuals with Alzheimer's disease and related dementias: a scoping review. Dementia (London) 2021 Nov;20(8):2891-2915. [doi: 10.1177/14713012211021722] [Medline: 34039079]
18. Yorkston KM, Bourgeois MS, Baylor CR. Communication and aging. Phys Med Rehabil Clin N Am 2010 May;21(2):309-319 [FREE Full text] [doi: 10.1016/j.pmr.2009.12.011] [Medline: 20494279]
19. Ansaldo AI. Préserver la communication en situation d’isolement extrême dans le contexte de pandémie COVID-19 : l’importance de la composante émotionnelle. Rev Neuropsychol 2020;12(2):158-160 [FREE Full text]
20. Missotten P, Ylieff M, Di Notte D, Paquay L, De Lepeleire J, Buntinx F, et al. Quality of life in dementia: a 2-year follow-up study. Int J Geriatr Psychiatry 2007 Dec 15;22(12):1201-1207. [doi: 10.1002/gps.1814] [Medline: 17503544]
21. Cooper C, Balamurali TB, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. Int Psychogeriatr 2007 Apr;19(2):175-195. [doi: 10.1017/S1041610206004297] [Medline: 17005068]
22. Alzheimer's Association. 2012 Alzheimer's disease facts and figures. Alzheimers Dement 2012 Mar;8(2):131-168. [doi: 10.1016/j.jalz.2012.02.001] [Medline: 22404854]
23. Seidel D, Thyrian JR. Burden of caring for people with dementia - comparing family caregivers and professional caregivers. A descriptive study. J Multidiscip Healthc 2019;12:655-663 [FREE Full text] [doi: 10.2147/JMDH.S209106] [Medline: 31616154]
24. Queluz FN, Kervin E, Wozney L, Fancey P, McGrath PJ, Keefe J. Understanding the needs of caregivers of persons with dementia: a scoping review. Int Psychogeriatr 2020 Jan;32(1):35-52. [doi: 10.1017/S1041610219000243] [Medline: 30967164]
25. Smebye KL, Kirkevold M. The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study. BMC Nurs 2013 Dec 20;12(1):29 [FREE Full text] [doi: 10.1186/1472-6955-12-29] [Medline: 24359589]
26. Downs M, Collins L. Person-centred communication in dementia care. Nurs Stand 2015 Nov 11;30(11):37-41. [doi: 10.7748/ns.30.11.37.s45] [Medline: 26554996]
27. Stanyon MR, Griffiths A, Thomas SA, Gordon AL. The facilitators of communication with people with dementia in a care setting: an interview study with healthcare workers. Age Ageing 2016 Jan 13;45(1):164-170 [FREE Full text] [doi: 10.1093/ageing/afv161] [Medline: 26764403]
28. Watson BJ. Communication and burden in dementia care. Int J Healthc 2017 Dec 12;4(1):5-15. [doi: 10.5430/ijh.v4n1p5]
29. Scott-Cawiezell J, Schenkman M, Moore L, Vojir C, Connoly RP, Pratt M, et al. Exploring nursing home staff's perceptions of communication and leadership to facilitate quality improvement. J Nurs Care Qual 2004;19(3):242-252. [doi: 10.1097/00001786-200407000-00011] [Medline: 15326994]
30. McCormack B, Karlsson B, Dewing J, Lerdal A. Exploring person-centredness: a qualitative meta-synthesis of four studies. Scand J Caring Sci 2010 Sep;24(3):620-634. [doi: 10.1111/j.1471-6712.2010.00814.x] [Medline: 21050249]

31. Kolanowski A, Van Haitsma K, Penrod J, Hill N, Yevchak A. "Wish we would have known that!" communication breakdown impedes person-centered care. Gerontologist 2015 Jun;55 Suppl 1:S50-S60. [doi: 10.1093/geront/gnv014] [Medline: 26055781]
32. Guidelines for care: person-centred care of people with dementia living in care homes. Alzheimer Society of Canada. URL: https://alzheimer.ca/en/help-support/im-healthcare-provider/person-centred-care-people-dementia-living-care-homes [accessed 2024-04-29]
33. Savundranayagam MY, Orange JB. Matched and mismatched appraisals of the effectiveness of communication strategies by family caregivers of persons with Alzheimer's disease. Int J Lang Commun Disord 2014 Oct 24;49(1):49-59. [doi: 10.1111/1460-6984.12043] [Medline: 24372885]
34. Williams K, Kemper S, Hummert ML. Improving nursing home communication: an intervention to reduce elderspeak. Gerontologist 2003 Apr 01;43(2):242-247. [doi: 10.1093/geront/43.2.242] [Medline: 12677081]
35. Koo BM, Vizer LM. Examining mobile technologies to support older adults with dementia through the lens of personhood and human needs: scoping review. JMIR Mhealth Uhealth 2019 Nov 11;7(11):e15122 [FREE Full text] [doi: 10.2196/15122] [Medline: 31710305]
36. Wilson R, Small J. Care staff perspectives on using mobile technology to support communication in long-term care: mixed methods study. JMIR Nurs 2020 Sep 29;3(1):e21881 [FREE Full text] [doi: 10.2196/21881] [Medline: 34406973]
37. Wilson R, Cochrane D, Mihailidis A, Small J. Mobile apps to support caregiver-resident communication in long-term care: systematic search and content analysis. JMIR Aging 2020 Apr 08;3(1):e17136 [FREE Full text] [doi: 10.2196/17136] [Medline: 32267236]
38. Lim FS, Wallace T, Luszcz MA, Reynolds KJ. Usability of tablet computers by people with early-stage dementia. Gerontology 2013;59(2):174-182. [doi: 10.1159/000343986] [Medline: 23257664]
39. Alm N, Dye R, Gowans G, Campbell J, Astell A, Ellis M. A communication support system for older people with dementia. Computer 2007;40(5):35-41. [doi: 10.1056/NEJM196803212781204] [Medline: 5637250]
40. Hung L, Chow B, Shadarevian J, O'Neill R, Berndt A, Wallsworth C, et al. Using touchscreen tablets to support social connections and reduce responsive behaviours among people with dementia in care settings: a scoping review. Dementia (London) 2021 Apr;20(3):1124-1143 [FREE Full text] [doi: 10.1177/1471301220922745] [Medline: 32380856]
41. Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M, Damant J. Technology-based tools and services for people with dementia and carers: mapping technology onto the dementia care pathway. Dementia (London) 2019 Feb;18(2):725-741. [doi: 10.1177/1471301217691617] [Medline: 28178858]
42. Burns I, Cox H, Plant H. Leisure or therapeutics? Snoezelen and the care of older persons with dementia. Int J Nurs Pract 2000 Jun;6(3):118-126. [doi: 10.1046/j.1440-172x.2000.00196.x] [Medline: 11249409]
43. Cocchio C. Les capacités musicales dans la maladie d'Alzheimer. Médecine humaine et pathologie. 2012. URL: https://dumas.ccsd.cnrs.fr/dumas-01511499v1/file/ORTH_2012_COCCHIO_CHRISTELLE.pdf [accessed 2024-04-29]
44. Cohen-Mansfield J, Libin A, Marx MS. Nonpharmacological treatment of agitation: a controlled trial of systematic individualized intervention. J Gerontol A Biol Sci Med Sci 2007 Aug 01;62(8):908-916. [doi: 10.1093/gerona/62.8.908] [Medline: 17702884]
45. Cohen-Mansfield J, Marx MS, Dakheel-Ali M, Regier NG, Thein K, Freedman L. Can agitated behavior of nursing home residents with dementia be prevented with the use of standardized stimuli? J Am Geriatr Soc 2010 Aug 03;58(8):1459-1464 [FREE Full text] [doi: 10.1111/j.1532-5415.2010.02951.x] [Medline: 20579167]
46. Fisher JE, Buchanan JA. Presentation of preferred stimuli as an intervention for aggression in a person with dementia. Behav Anal Res Pract 2018 Feb;18(1):33-40. [doi: 10.1037/bar0000086]
47. Ansaldo AI, Delacourt B, Dubé C, García EL, Durand E. L'approche COMPAs et la communication émotionnelle dans un contexte d'isolement extrême et de démence. Revue Neurologique 2021 Apr;13(2):139-143. [doi: 10.1016/j.neurol.2021.02.083]
48. O'Rourke N, Cappeliez P, Claxton A. Functions of reminiscence and the psychological well-being of young-old and older adults over time. Aging Ment Health 2011 Mar;15(2):272-281. [doi: 10.1080/13607861003713281] [Medline: 21140308]
49. Moskowitz JT, Cheung EO, Snowberg KE, Verstaen A, Merrilees J, Salsman JM, et al. Randomized controlled trial of a facilitated online positive emotion regulation intervention for dementia caregivers. Health Psychol 2019 May;38(5):391-402 [FREE Full text] [doi: 10.1037/hea0000680] [Medline: 31045422]
50. Goldberg DP, Gater R, Sartorius N, Ustun TB, Piccinelli M, Gureje O, et al. The validity of two versions of the GHQ in the WHO study of mental illness in general health care. Psychol Med 1997 Jan;27(1):191-197. [doi: 10.1017/s0033291796004242] [Medline: 9122299]
51. Maslach C, Knapp T. Burnout. In: Galam É, editor. L'erreur Médicale, le burn-out et le Soignant. Paris, France: Springer; 2006.
52. Murphy J, Gray CM, Cox S. Communication and dementia: how talking mats can help people with dementia to express themselves. University of Glasgow. 2007. URL: http://eprints.gla.ac.uk/61498/ [accessed 2024-04-29]
53. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of life in Alzheimer's disease: patient and caregiver reports. J Ment Health Aging 1999;5(1):21-32 [FREE Full text]

54. Ready RE, Ott BR. Quality of life measures for dementia. Health Qual Life Outcomes 2003 Apr 23;1:11 [FREE Full text] [doi: 10.1186/1477-7525-1-11] [Medline: 12740036]
55. Kehyayan V, Hirdes JP, Tyas SL, Stolee P. Residents' self-reported quality of life in long-term care facilities in Canada. Can J Aging 2015 Jun;34(2):149-164. [doi: 10.1017/S0714980814000579] [Medline: 25752798]
56. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004 Feb;24(2):105-112. [doi: 10.1016/j.nedt.2003.10.001] [Medline: 14769454]
57. Intissar S, Rabeb C. Étapes à suivre dans une analyse qualitative de données selon trois méthodes d'analyse : la théorisation ancrée de Strauss et Corbin, la méthode d'analyse qualitative de Miles et Huberman et l'analyse thématique de Paillé et Mucchielli, une revue de la littérature. Rev Francoph Int Rech Infirm 2015 Sep;1(3):161-168. [doi: 10.1016/j.refiri.2015.07.002]
58. Vallée A, Verdier-Parent A, Vallée JN, Hervé C. Évaluation du ressenti des aidants, filles et fils de personnes âgées dépendantes atteintes de démence. Ethique Sante 2016 Jun;13(2):83-90. [doi: 10.1016/j.etiqe.2016.02.001]
59. MAXQDA. VERBI Software. URL: https://www.maxqda.com/about [accessed 2024-04-29]
60. Mortazavizadeh Z, Maercker A, Roth T, Savaskan E, Forstmeier S. Quality of the caregiving relationship and quality of life in mild Alzheimer's dementia. Psychogeriatrics 2020 Sep 26;20(5):568-577 [FREE Full text] [doi: 10.1111/psyg.12546] [Medline: 32219988]
61. Sprangers S, Dijkstra K, Romijn-Luijten A. Communication skills training in a nursing home: effects of a brief intervention on residents and nursing aides. Clin Interv Aging 2015;10:311-319 [FREE Full text] [doi: 10.2147/CIA.S73053] [Medline: 25653513]
62. Zimmerman S, Sloane PD, Williams CS, Reed PS, Preisser JS, Eckert JK, et al. Dementia care and quality of life in assisted living and nursing homes. Gerontologist 2005 Oct;45 Spec No 1(1):133-146. [doi: 10.1093/geront/45.suppl_1.133] [Medline: 16230760]
63. Hird N, Osaki T, Ghosh S, Palaniappan SK, Maeda K. Enabling personalization for digital cognitive stimulation to support communication with people with dementia: pilot intervention study as a prelude to AI development. JMIR Form Res 2024 Jan 16;8:e51732 [FREE Full text] [doi: 10.2196/51732] [Medline: 38227357]
64. Cohen-Mansfield J. The rights of persons with dementia and their meanings. J Am Med Dir Assoc 2021 Jul;22(7):1381-1385 [FREE Full text] [doi: 10.1016/j.jamda.2021.03.007] [Medline: 33844989]
65. Easton S, Van Laar D. QoWL (quality of working life)—what, how, and why? Psychol Res 2013 Oct 28;3(10):596-605. [doi: 10.17265/2159-5542/2013.10.006]
66. Neumann M, Edelhäuser F, Tauschel D, Fischer MR, Wirtz M, Woopen C, et al. Empathy decline and its reasons: a systematic review of studies with medical students and residents. Acad Med 2011 Aug;86(8):996-1009. [doi: 10.1097/ACM.0b013e318221e615] [Medline: 21670661]
67. Dyrbye LN, Massie Jr FS, Eacker A, Harper W, Power D, Durning SJ, et al. Relationship between burnout and professional conduct and attitudes among US medical students. JAMA 2010 Sep 15;304(11):1173-1180. [doi: 10.1001/jama.2010.1318] [Medline: 20841530]
68. Hellström I, Nolan M, Nordenfelt L, Lundh U. Ethical and methodological issues in interviewing persons with dementia. Nurs Ethics 2007 Sep;14(5):608-619. [doi: 10.1177/0969733007080206] [Medline: 17901172]
69. Kirby P, Lai H, Horrocks S, Harrison M, Wilson D, Daniels S, et al. Patient and public involvement in technology-related dementia research: scoping review. JMIR Aging 2024 Mar 04;7:e48292 [FREE Full text] [doi: 10.2196/48292] [Medline: 38437014]

Abbreviations

BPSD: behavioral and psychological symptoms of dementia
COMPAs: Communication Proches Aidants
GCOM: grille d'évaluation des difficultés de communication dans la démence
GHQ-12: General Health Questionnaire-12
LTC: long-term care
MBI: Maslach Burnout Inventory
QDV-DTA: qualité de vie dans la démence de type Alzheimer
QoL: quality of life
RA: research assistant
SLP: speech language pathologist

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The Frailty Trajectory's Additional Edge Over the Frailty Index: Retrospective Cohort Study of Veterans With Heart Failure

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KEYWORDS

gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; frailty; frailty index; frailty trajectory; frail; weak; weakness; heart failure; HF; cardiovascular disease; CVD; congestive heart failure; CHF; myocardial infarction; MI; unstable angina; angina; cardiac arrest; atherosclerosis; cardiology; cardiac; cardiologist; cardiologists

Introduction

Individuals with heart failure (HF) have a high burden of health care utilization, costs, and morbidity in the year following hospitalization for an acute HF exacerbation. Frailty, which has been described as increased vulnerability to adverse events, is common among those with HF and increases with age [1]. Health systems worldwide are integrating automated tools within electronic health records to measure frailty. However, using longitudinal data to measure frailty and better predict outcomes among those with HF has rarely been considered [2-5]. We sought to evaluate the predictive value of adding longitudinal data to a standard frailty index (FI) and evaluate predictions of 1-year outcomes in patients with HF.

Methods

Study Design

This was a retrospective cohort study that used national Veterans Health Administration (VA) data. Veterans aged ≥50 years with an index hospital admission for HF from 2016 to 2019 were included. We excluded veterans with <2 primary care visits in the 3 years before their date of admission to indicate regular use of VA care. We included those with documentation of ejection fraction. We used the validated VA FI, which captures 31 deficits in health based on *International Classification of Diseases, Tenth Revision*, and Current Procedural Terminology codes [6]. We estimated the FI for each preceding year, without overlap. We fit a linear line to 3 calculated FIs for each year prior to the index date of admission and reported the slope and intercept individually. This method provided a 3-year longitudinal estimate of frailty at admission. We used 1-year all-cause mortality following the index date of admission as the primary outcome. We reported the area under the curve (AUC) for predicting outcomes, using logistic regression. We estimated two AUCs: (1) FI at the time of admission (AUC_{FI}) and (2) FI at time of admission plus slope and intercept ($AUC_{\text{frailty trajectory (FT)+FI}}$). Changes in the AUCs were reported as the percentage of improvement ($\Delta_{AUC} = 100\% \times [AUC_{FT+FI} - AUC_{FI}]/AUC_{FI}$). We recursively calculated the AUCs and Δ_{AUC} by including patients whose FIs at admission were <0.1 and, at each step, increased the FI level by 0.01 to 0.4.

Ethical Considerations

The study protocol was approved by the Research & Development Committee of the Michael E. DeBakey VA Medical Center and Baylor College of Medicine Institutional Review Board (institutional review board number: H-464220).

Results

In total, 54,774 veterans were included (age: mean 73.3, SD 10.1 y; BMI: mean 30.1, SD 7.5 kg/m^2; male: n=53,899, 98.4%; White: n=30,406, 55.5%; Table 1). Figure 1 shows the AUC_{FI} and AUC_{FT+FI} across the distribution of frailty ranges, from prefrail (FI: 0.1-0.2) to frail; an FI of 0.2 is equivalent to an accumulation of 7 deficits among 31 variables, and the Δ_{AUC} is also displayed. For all veterans across all FI thresholds, the AUC improved by at least 4.1% when adding the FT to the FI. The highest Δ_{AUC} (24%) was observed for FIs of 0.13 to 0.16, and it decreased to ≤10% for FIs of ≥0.2.

Table . Characteristics of patients (N=54,774) with an index admission to the Veterans Health Administration for heart failure from January 1, 2016, to January 1, 2020.

Characteristics		Patients
Admit year 2016, n (%)		12,875 (23.5)
Admit year 2017, n (%)		13,585 (24.8)
Admit year 2018, n (%)		14,082 (25.7)
Admit year 2019, n (%)		14,232 (26)
Age (y), mean (SD)		73.3 (10.1)
	<65, n (%)	9776 (17.8)
	65 - 75, n (%)	22,772 (41.6)
	≥85, n (%)	22,226 (40.6)
Sex, n (%)		
	Male	53,899 (98.4)
	Female	875 (1.6)
Race, n (%)		
	White	30,406 (55.5)
	Black	9340 (17.1)
	Other[a]	15,028 (27.4)
Hispanic ethnicity, n (%)		2093 (3.8)
BMI (kg/m^2), mean (SD)		30.1 (7.5)
	≥30, n (%)	24,352 (44.5)
Frailty status (frailty index), mean (SD)		0.35 (0.11)
	Robust (<0.1), n (%)[b]	297 (0.5)
	Prefrail (0.1 - 0.2), n (%)[b]	5715 (10.5)
	Frail (>0.2), n (%)[b]	48,762 (89)
All-cause mortality, n (%)		
	30-day mortality	2848 (5.2)
	1-year mortality	14,460 (26.4)
	All-time mortality	37,027 (67.6)
Time to death (mo), median (IQR)		18.2 (5.6-36.4)
HFrEF[c], n (%)		27,223 (49.7)
HFmEF[d], n (%)		4546 (8.3)
HFpEF[e], n (%)		23,005 (42.0)
Living in a CLC[f], n (%)		1808 (3.3)

[a] “Other” includes Asian, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, and unknown.

[b] Standardized frailty status cut points drawn from validated studies [6].

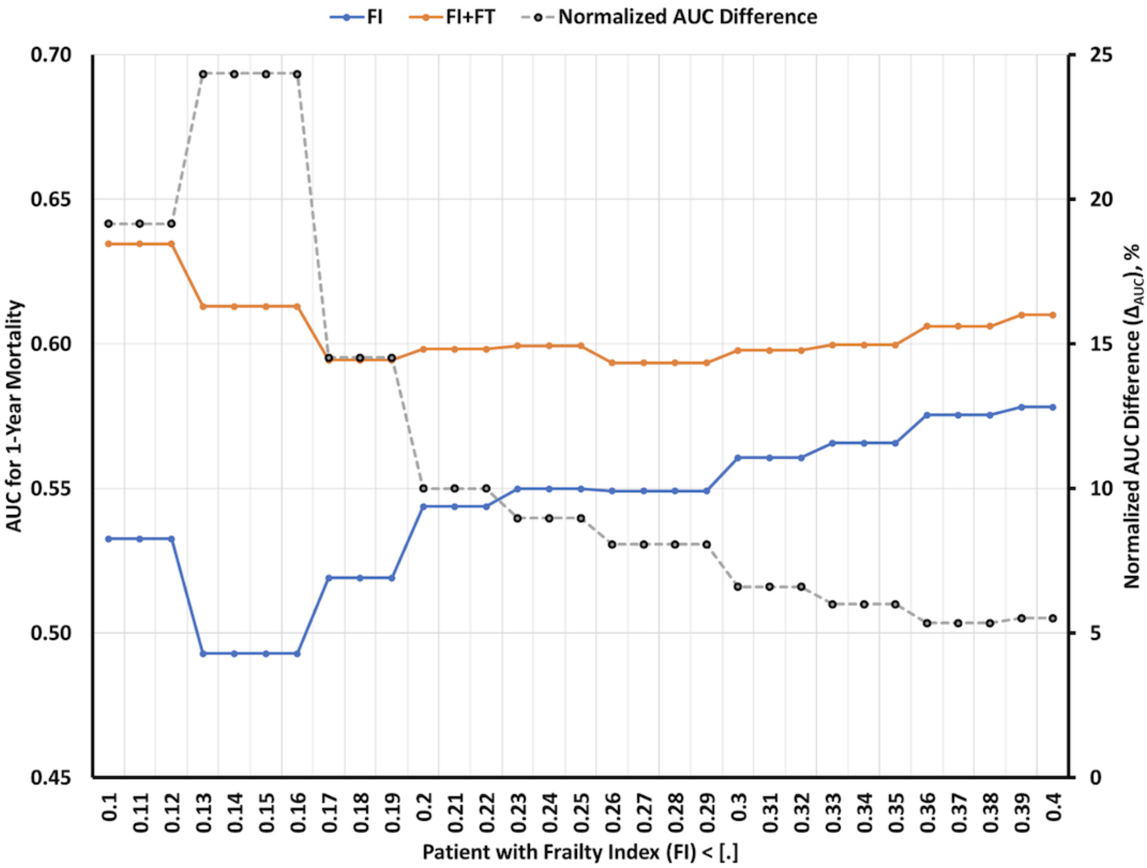
[c] HFrEF: heart failure with reduced ejection fraction of <40%.

[d] HFmEF: heart failure with modified reduced ejection fraction of 40%-50%.

[e] HFpEF: heart failure with preserved ejection fraction of >50%.

[f] CLC: community living center.

Figure 1. AUCs for patients who were admitted, for the first time, to the Veterans Health Administration for heart failure from January 1, 2016, to January 1, 2020, and had an FI of 0.1-0.4 (as shown on the x-axis in increments of 0.01). We compared the AUCs of FIs (in blue; AUC_{FI}) versus the AUCs of FIs and FTs combined (in orange; AUC_{FI+FT}). The percentage of improvement in AUCs resulting from the addition of the FT to the FI was reported in black (Δ_{AUC}) and calculated by using the following formula: ΔAUC= (AUCFI+FT−AUCFI)AUCFI ×100. AUC: area under the curve; FI: frailty index; FT: frailty trajectory.



Discussion

In a national cohort of veterans who were admitted to the VA for HF, the addition of longitudinal FT data resulted in a clinically significant (up to 24%) improvement in 1-year mortality prediction when compared to a standard FI alone among patients in the prefrail range. In contrast, we observed a modest (at least 4.1%) improvement in 1-year mortality prediction in the overall population. Enhancing AUC prediction for patients in the prefrail range is clinically important, as interventions that mitigate frailty may be most impactful in this population [7]. Patients with prefrailty may benefit from interventions (eg, cardiac rehabilitation) that improve frailty status and cardiovascular outcomes [1]. These findings enrich our understanding of the importance of FT in patients at lower FI levels, and a previous study compared the importance of FIs to that of FTs alone [5]. These results may not generalize to nonveteran populations. The sample was predominately male but did include a diverse population in terms of race, ethnicity, and geographic distribution. In summary, methods for calculating frailty provide useful predictions of adverse outcomes among adults with HF. The addition of longitudinal frailty data improves predictions for patients with HF and prefrailty. These findings aid clinician and health system decision-making, as this population benefits most from interventions that slow or prevent frailty progression, and suggest that longitudinal data for modeling FT provide additional evidence for tailoring interventions to patients with HF who may benefit most from tailored interventions.

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Conflicts of Interest

None declared.

References

1. Ijaz N, Buta B, Xue QL, et al. Interventions for frailty among older adults with cardiovascular disease: JACC state-of-the-art review. J Am Coll Cardiol 2022 Feb 8;79(5):482-503. [doi: 10.1016/j.jacc.2021.11.029] [Medline: 35115105]
2. Verghese J, Ayers E, Sathyan S, et al. Trajectories of frailty in aging: prospective cohort study. PLoS One 2021 Jul 12;16(7):e0253976. [doi: 10.1371/journal.pone.0253976] [Medline: 34252094]
3. Stolz E, Mayerl H, Hoogendijk EO, Armstrong JJ, Roller-Wirnsberger R, Freidl W. Acceleration of health deficit accumulation in late-life: evidence of terminal decline in frailty index three years before death in the US Health and Retirement Study. Ann Epidemiol 2021 Jun;58:156-161. [doi: 10.1016/j.annepidem.2021.03.008] [Medline: 33812966]
4. Stolz E, Hoogendijk EO, Mayerl H, Freidl W. Frailty changes predict mortality in 4 longitudinal studies of aging. J Gerontol A Biol Sci Med Sci 2021 Aug 13;76(9):1619-1626. [doi: 10.1093/gerona/glaa266] [Medline: 33103718]
5. Bai G, Szwajda A, Wang Y, et al. Frailty trajectories in three longitudinal studies of aging: is the level or the rate of change more predictive of mortality? Age Ageing 2021 Nov 10;50(6):2174-2182. [doi: 10.1093/ageing/afab106] [Medline: 34120182]
6. Orkaby AR, Nussbaum L, Ho YL, et al. The burden of frailty among US veterans and its association with mortality, 2002–2012. J Gerontol A Biol Sci Med Sci 2019 Jul 12;74(8):1257-1264. [doi: 10.1093/gerona/gly232] [Medline: 30307533]
7. Ushijima A, Morita N, Hama T, et al. Effects of cardiac rehabilitation on physical function and exercise capacity in elderly cardiovascular patients with frailty. J Cardiol 2021 Apr;77(4):424-431. [doi: 10.1016/j.jjcc.2020.11.012] [Medline: 33288376]

Abbreviations

AUC: area under the curve
FI: frailty index
FT: frailty trajectory
HF: heart failure
VA: Veterans Health Administration

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Original Paper

Factors Influencing Drug Prescribing for Patients With Hospitalization History in Circulatory Disease–Patient Severity, Composite Adherence, and Physician-Patient Relationship: Retrospective Cohort Study

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Abstract

Background: With countries promoting generic drug prescribing, their growth may plateau, warranting further investigation into the factors influencing this trend, including physician and patient perspectives. Additional strategies may be needed to maximize the switch to generic drugs while ensuring health care system sustainability, focusing on factors beyond mere low cost. Emphasizing affordability and clarifying other prescription considerations are essential.

Objective: This study aimed to provide initial insights into how patient severity, composite adherence, and physician-patient relationships impact generic switching.

Methods: This study used a long-term retrospective cohort design by analyzing data from a national health care database. The population included patients of all ages, primarily older adults, who required primary-to-tertiary preventive actions with a history of hospitalization for cardiovascular diseases (*ICD-10* [*International Statistical Classification of Diseases, Tenth Revision*]) from April 2014 to March 2018 (4 years). We focused on switching to generic drugs, with temporal variations in clinical parameters as independent variables. Lifestyle factors (smoking and drinking) were also considered. Adherence was measured as a composite score comprising 11 elements. The physician-patient relationship was established based on the interval between physician change and prescription. Logistic regression analysis and propensity score matching were used, along with complementary analysis of physician-patient relationships, proportion of days covered, and adherence for a subset of the population.

Results: The study included 48,456 patients with an average follow-up of 36.1 (SD 8.8) months. The mean age was 68.3 (SD 9.9) years; BMI, 23.4 (SD 3.4) kg/m^2; systolic blood pressure, 131.2 (SD 15) mm Hg; low-density lipoprotein cholesterol level, 116.6 (SD 29.3) mg/dL; hemoglobin A_{1c} (HbA_{1c}), 5.9% (SD 0.8%); and serum creatinine level, 0.9 (SD 0.8) mg/dL. Logistic regression analysis revealed significant associations between generic switching and systolic blood pressure (odds ratio [OR] 0.996, 95% CI 0.993-0.999), serum creatinine levels (OR 0.837, 95% CI 0.729-0.962), glutamic oxaloacetic transaminase levels (OR 0.994, 95% CI 0.990-0.997), proportion of days covered score (OR 0.959, 95% CI 0.948-0.97), and adherence score (OR 0.910, 95% CI 0.875-0.947). In addition, generic drug rates increased with improvements in the HbA_{1c} level band and smoking level ($P<.01$ and $P<.001$). The group with a superior physician-patient relationship after propensity score matching had a significantly higher rate of generic drug prescribing (51.6%, SD 15.2%) than the inferior relationship group (47.7%, SD17.7%; $P<.001$).

Conclusions: Although physicians' understanding influences the choice of generic drugs, patient condition (severity) and adherence also impact this decision. For example, improved creatinine levels are associated with generic drug choice, while stronger physician-patient relationships correlate with higher rates of generic drug use. These findings may contribute to the appropriate prescription of pharmaceuticals if the policy diffusion of generic drugs begins to slow down. Thus, preventing serious illness while building trust may result in clinical benefits and positive socioeconomic outcomes.

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KEYWORDS

medication adherence; drug prescription switch; generic drug; logistic model; long-term longitudinal study; patient severity; systolic blood pressure; serum creatinine; aging; big data

Introduction

Background

Many high-income countries with mature health care systems are actively expanding the use of generic drugs [1,2]. However, as generic drug use reaches a certain level, growth may slow (eg, Japan: 71.2% in 2018, annual rate of 5.45%; 77.8% in 2020, annual rate of 1.15%) [3,4]. Therefore, additional strategies may be required to maximize the switch to generic drugs with the sustainability of the health care system in mind, focusing on factors other than the conventional low cost. Specifically, it is important not only to emphasize the affordability of generic drugs but also to clarify other prescription considerations. For further promotion, the biological quality of generic drugs must be ensured, and their long-term health economics must be evaluated. Furthermore, both medical practitioners and patients must have a good understanding of the clinical characteristics and health care economics of generic drugs. Addressing the concerns of all stakeholders is crucial for optimizing prescriptions. This discussion should particularly focus on patient factors, including intrinsic adherence and physician-patient relationships.

The factors influencing the prescription of generic drugs can be classified into 3 major categories: patients, physicians, and regulations. While many studies have focused on physicians and regulatory factors, majority of the research on physicians is based on questionnaire surveys assessing their trust and knowledge of generic drugs, particularly among doctors and pharmacists [5-13]. Regarding regulatory factors, numerous studies have discussed the socioeconomic significance of the low prices of generic drugs against the backdrop of the medical insurance system [7,10,11,14,15]. However, patient characteristics have received less attention; although some reports have analyzed these factors as part of treatment outcome evaluations, few studies have specifically focused on how patient characteristics influence the selection of generic drugs [16].

Another theme related to the study of the factors influencing the prescription of generic drugs is the scattered outcome evaluation. Regarding this topic, relatively more study designs tend to compare clinical outcomes and patient compliance (eg, the proportion of days covered [PDC]) between brand names and generic drugs [17-30]. In addition, the analysis may address therapeutic inertia, which is characteristic of this theme. Studies tend to target diseases, such as cardiovascular diseases (CVDs) [17-22] and pain syndromes, for which generic drugs have been introduced as an alternative for expensive brand-name drugs. In this light, research on the factors influencing generic drug prescriptions is closely related to medical innovation (drug discovery) and the sustainability of the health care system (health insurance).

Aim of This Study

Many studies have investigated the biological quality and economic use of generic drugs. However, as mentioned earlier, research on patient characteristics as limiting factors in generic drug prescriptions is lacking. For instance, few studies have explored the impact of complex diseases (severity) and inherent adherence on the switch to generic drugs. Most existing research has used the PDC as a surrogate for adherence, and no studies have analyzed widespread adherence (overall health-related behaviors), including disease prevention. In addition, while the impact of physician attitudes on PDC has been reported [13], no reports related to the patient-physician relationship for PDC or generic drug rates have been found.

In this context, we previously published a study suggesting that the selection of generic drugs could improve long-term life prognosis and reduce medical costs, influenced by composite adherence using drug dispensing data based on doctors' prescriptions [26]. In the previous study, multivariate analyses were conducted to identify factors affecting long-term changes in the prognosis and clinical indicators from both public benefit and economic efficiency perspectives. The findings indicated that patient severity plays a significant role in the decision to switch to generic drugs. In addition, it was hypothesized that the patient-physician relationship, grounded in adherence, also plays a role in generic drug switching. Therefore, this study aimed to verify these hypotheses.

Thus, we conducted a study focusing on patient characteristics, primarily older adults, as a factor influencing generic prescribing. The study aimed to provide preliminary insights into how patient severity, composite adherence, and the patient-physician relationship impact the switch to generic drugs.

Methods

Application of Findings From Data Science

This study is a continuation of our previous study [26] on the development of a validation and prediction model for the long-term prognostic impact of adherence on health care costs and clinical outcomes in circulatory diseases. This was a long-term longitudinal multicenter retrospective cohort study.

In a previous study, we developed a predictive model of integrated health care resource consumption (Adherence Score for Healthcare Resource Outcome [ASHRO]) that incorporated patient health behaviors and examined their association with clinical outcomes. Predictive models, including neural networks and random forest learning (artificial intelligence), were used in that study. Adherence, measured by the ASHRO score, was considered a broad concept encompassing moral and public interest perspectives [26]. This adherence score was also selected as a key factor in this study owing to the socioeconomic implications of drug prescriptions, which form the context of this research.

In the previous study, the examination of the basic model by machine learning was summarized as follows: Traditional empirical statistical methods, which involve obtaining a dataset with results, predictors, and fit coefficients, were not optimal for this exploratory study's multivariate analysis on large samples. Consequently, we used machine learning techniques, specifically random forests, and K-fold cross-validation, to select and integrate explanatory variables and establish weights from the previous study.

Random forests are machine learning techniques used for classification and regression that can help minimize overfitting [27,28]. The advantage of medical big data is their ability to efficiently handle large samples with thousands of input variables. In addition, random forests can accommodate various data scales (eg, blood pressure and glomerular filtration rates have different normal ranges) and remain robust even when unrelated variables are included [29,30].

The study developed a basic prediction model for medical and long-term care costs using random forests. We included over 100 variables related to medical practices, clinical tests, and preventive activities as explanatory factors. Machine learning was used to evaluate parameter integration and feature importance by randomly selecting multiple sample sets and feature variables using the bootstrap method (sampling with replacement).

Data Sources and Populations

Data Sources

A previous study that developed a composite adherence score used a national health care database (Kokuho Database) that individually links health checkups, health insurance claims, and long-term care insurance data. This study used the same data source, and extracted a cohort from it.

The Kokuho Database is a large-scale repository that includes self-employed and retired individuals covered by National Health Insurance. It provides long-term medical and care insurance data, with a personal collusion rate between medical and long-term care information exceeding 99%. The regions included in the database accounted for 6.1% of Japan's total population. In addition to the demographic trends and social structures, the main conditions of medical and long-term care generally reflect the average level in Japan. The data were managed and analyzed as part of the Health Economics Big Data of the University of Tokyo.

Data from each patient, anonymized under a unified identification, included basic characteristics, medical expenses related to hospitalization, outpatient care, dispensing, and dentistry; diagnostic information; breakdown of medical treatments; frequency of medical examinations; hospitalization duration; nursing care costs and required care level; usage frequency and duration; health checkup guidance content; laboratory and biological test results; and the number of unhealthy behaviors. We excluded samples with missing data to address potential bias in the large dataset.

Although the long-term care insurance system operated by the Japanese government focuses primarily on long-term care, it also covers chronic care. Nursing care is a key indicator of "functional impairment" and is a crucial metric, particularly in geriatric research. The system classifies daily living abilities using the nursing care level, which measures the degree of care required [31]. This classification includes 7 categories: "two stages of support required" and "five stages of nursing required"; higher numbers indicate greater severity. These care categories were scored and analyzed in this study.

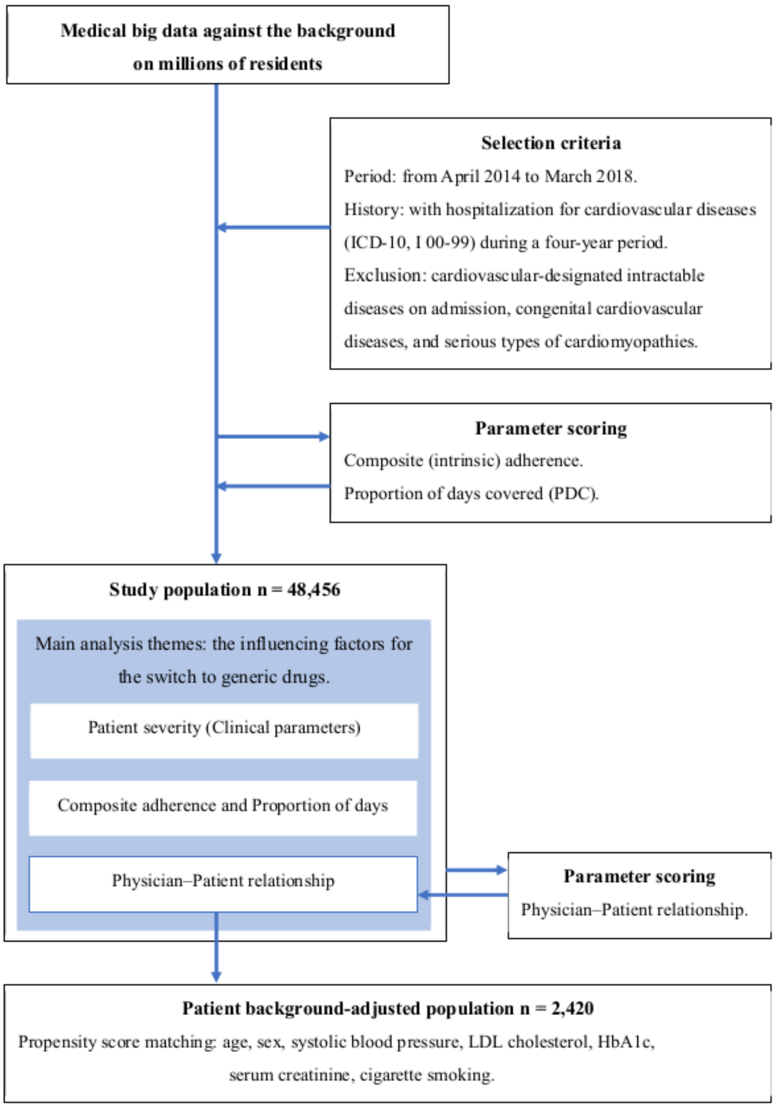
Data Populations

The study cohort comprised patients of all ages requiring preventive actions from first-to-tertiary levels, with a history of hospitalization for CVDs (*ICD-10* [*International Statistical Classification of Diseases, Tenth Revision*] codes I00-I99) from April 2014 to March 2018 (Figure 1) [32]. The cohort predominantly included older adults. This single-gate, multicenter retrospective observational study used real-world population data from an area with over 3 million residents. Exclusion criteria included cardiovascular intractable diseases upon admission, congenital CVDs, and serious types of cardiomyopathies [26,33].

As this was a longitudinal study, missing data at follow-up due to participants' death or relocation were censored. Furthermore, we adjusted for patient background using the basic characteristics of sex and age, clinical indices of cardiac function, renal function, endocrine metabolism, and lifestyle habits, such as smoking, to reduce bias in the analysis of physician-patient relationships.

Sex differences in CVD are well-documented, with female generally having a lower incidence of ischemic heart disease than men [34]. In addition, coronary artery disease in female often develops later in life, with many cases involving cumulative risks, such as hypertension and dyslipidemia [35]. The population composition in this study reflected these trends.

Figure 1. Flow chart of the study cohort setting. The propensity score method was used to compare the level of generic rates according to patient-physician relationship. LDL: low-density lipoprotein; HbA_{1c}: hemoglobin A_{1c}; ICD: International Classification of Diseases.



Definition of Key Indicators

Concept of Adherence Indicators

In our previous study, adherence was developed as a broad concept to discuss the behavioral changes in social groups and factors intrinsic to individual patients. Against this background, adherence is considered a composite measure. The 11 components comprising the final composite adherence (ASHRO) included indicators related to health promotion, prevention of disease severity, rational resource consumption behavior (moral hazard), medical attitude behavior, and public behavior (Multimedia Appendix 1) [26].

The following 11 indicators were calculated as the ratio of the difference between the mean value of the population and the mean value of each individual during the 1-year follow-up period after enrolment: number of health check-ups, units of rehabilitation intensity, number of guidance sessions, number of overlapping outpatient visits, clinical laboratory and physiological tests, inpatient days, number of outpatient visits, dispensing, PDC, and generic drug rate. This study used drug dispensing data based on doctors' prescriptions.

Composite adherence (ASHRO) was scored while ensuring a significant correlation with risk factors, such as systolic blood pressure, serum creatinine, low-density lipoprotein cholesterol (LDL-C), and hemoglobin A_{1c} (HbA_{1c}) levels, and the estimated glomerular filtration rate.

Overlapping outpatient services for the same diseases during the same period were similar. The generic drug rate is calculated as the proportion of prescriptions for generic drugs listed by the government, with the number of generic prescriptions as the numerator. The PDC was calculated based on the duration and continuity of prescriptions rather than individual medication adherence data. It is important to note that the PDC rate data reflect actual results, and the PDC score was incorporated into the ASHRO score. Each score serves a distinct purpose with different scales and interpretations.

Indicator of the Physician-Patient Relationship

In this study, we examined the relationship between physicians and patients. Although a questionnaire survey could be used to explain the relationship quantitatively, it was deemed unrealistic due to concerns about reliability from subjective judgments and the technical challenges or burden of integrating it with big data. Therefore, we extracted surrogate indices related to the relationship between doctors and patients from big data to prepare quantitative data matching actual clinical practice. Furthermore, we constructed a proxy index for trustworthy relationships using two elements: (1) change in the doctors or facilities for the same patient and (2) continuation of prescriptions at the same institution.

To examine this surrogate index, we proposed the following conditions hypotheses. First, a strong physician-patient relationship would be associated with fewer changes in physicians (eg, doctor shopping) [36]. Second, due to the characteristics of the cohort in this study, it was assumed that continuous (regular) medical care would be provided if the relationship was appropriate. Based on these hypotheses, we assessed the physician-patient relationship by evaluating the presence or absence of facility changes during the observation period and interval between consultations and classified the samples accordingly.

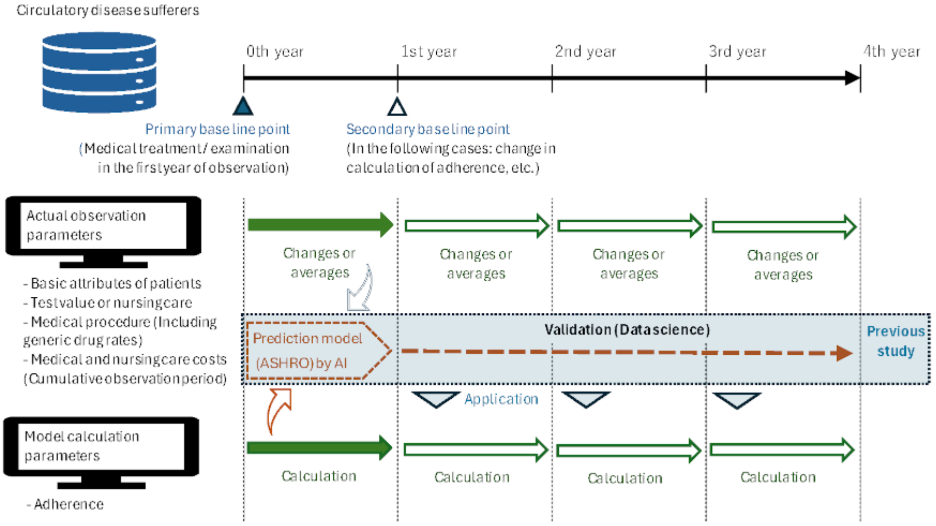
We categorized patients into 2 groups: those who experienced a change in facilities and those who did not, based on their visits for the same disease during the observation period. In addition, we considered information on the changes in the address. We labeled conditions with no change in the facility and a practice interval of 365 days or less as a superior relationship group (coded as 0) to indicate a strong physician-patient relationship. The other groups were considered as inferior relationship groups (coded as 1). The interval between treatments was set using a cutoff value derived from the receiver operating characteristic curve for a conservative assessment.

Statistical Analysis

Logistic regression analysis was performed to examine the influence of the clinical indicators on the choice of generic drug prescriptions. We also performed a logistic regression analysis to examine the complementary factors in the physician-patient relationship. Mann-Whitney *U* test was used to compare the percentage of generic drug prescription choices by high and low physician-patient relationships, and multiple regression analysis was performed to determine the relationship between PDC rate and other factors.

The influence of the clinical indicators on the choice of generic drug prescriptions was organized based on the relationship between the displacement (annual mean value) of each indicator and the generic drug rate. Change was calculated as the change from the previous year's value, either increasing or decreasing. The annual mean serum creatinine level was used as a surrogate because the progression mechanism was irreversible in the medium-term. The PDC and adherence indices were calculated based on 4 years of data; therefore, data on change were not used (Figure 2).

Figure 2. Timeline of this study and measurement methods for each parameter. This study was not an interventional study, so no fixed index time point was set. AI: Artificial intelligence; ASHRO: Adherence Score for Healthcare Resource Outcome.



A comparison of the levels of generic rates by patient-physician relationship was performed for the generic switch factor, adjusted for patient background using propensity score matching (PSM). Propensity scores for each case were calculated, and a 1:1 matching method was applied to align the sample numbers and ensure the data distribution and balance between both groups. It is important to note that because this study aimed to assess the influence of actual measured severity (laboratory values) on prescription choice, we did not perform background adjustment using PSM was not performed in the overall basic analysis. Categorical variables are expressed as numeric values (%), and continuous variables are expressed as mean (SD). The statistical significance level was set at 5%. The probability of an outcome occurring was organized in terms of odds ratios (ORs). The software used was SPSS Statistics for Windows (version 27; IBM Corp).

In Japan, medical policy has encouraged the prescription of generic drugs, resulting in a steady annual growth (average annual rate: 4.27%) [4]. We also performed an analysis that considered this growth trend, adjusting for the displacement of generic drug use rate over time.

Ethical Considerations

This study was approved by the Research Ethics Committee (2018167 N1: The Health Economics Big Data) of The

University of Tokyo Hospital and involved strict data confidentiality in accordance with the Helsinki Declaration and Japanese Government's Guidelines for Clinical Research Ethics and Reporting of Studies Conducted using the Observational Routinely Collected Data Statement.

Results

The findings of this study are as follows. For reference, we compiled a summary (list) of all results in an additional file (Multimedia Appendix 2).

Cohort Characteristics

A total of 48,456 patients were enrolled, with an average follow-up period of 36.1 (SD 8.8) months. The mean age was 68.3 (SD 9.9) years, and most patients were males (61.9%). At the baseline major health check-up, the BMI was 23.4 (SD 3.4) kg/m^2, systolic blood pressure was 131.2 (SD 15) mm Hg, triglyceride level was 120.8 (SD 5.2) mg/dL, LDL-C was 116.6 (SD 29.3) mg/dL, HbA$_{1c}$ was 5.9% (SD 0.8%), and serum creatinine was 0.9 (SD 0.8) mg/dL (Table 1).

Table 1. Cohort characteristics.

Parameter	Mean (SD)	Median (IQR)
Sample		
Patients, n	48,456	—[a]
Health check-up examination		
Age, years	68.3 (9.9)	69 (65-73)
Male sex, n (%)	29,994 (61.9)	—[a]
Physical examination		
Height, cm	160 (8.8)	160.3 (153.4-166.6)
Weight, kg	60.0 (11.3)	59.5 (52.1-67.1)
BMI, kg/m^2	23.4 (3.4)	23.2 (21.1-25.3)
Waist, cm	84.4 (9.3)	84.2 (78.5-90)
Systolic blood pressure, mm Hg	131.2 (15)	130.5 (121.8-140)
Diastolic blood pressure, mm Hg	75.7 (10.3)	75.3 (69.3-81.8)
Lipid profile		
Triglycerides, mg/dL	120.8 (75.2)	103.3 (76-143.5)
HDL[b] cholesterol, mg/dL	59.4 (15.9)	57.5 (48-68.8)
LDL[c] cholesterol, mg/dL	116.6 (29.3)	116 (97-134.5)
Kidney function		
Serum creatinine, mg/dL	0.9 (0.8)	0.8 (0.6-0.9)
Serum uric acid, mg/dL	5.4 (1.4)	5.4 (4.5-6.3)
eGFR[d], mL/min/1.73 m^2	69.2 (17.1)	69.6 (60.2-79.1)
Blood sugar		
HbA$_{1c}$[e] (%)	5.9 (0.8)	5.7 (5.5-6.1)
Follow-up period, months	36.1 (8.8)	44 (25-48)

[a] —: not applicable.

[b] HDL: high-density lipoprotein.

[c] LDL: low-density lipoprotein.

[d] GFR: glomerular filtration rate.

[e] HbA$_{1c}$: hemoglobin A$_{1c}$.

The superior physician-patient relationship group comprised 10,332 patients. The mean age was 70.03 (SD 10.10) years for this group and 66.26 (SD 8.47) years for the inferior relationship group. The proportion of males was 67.15% in the superior relationship group and 60.44% in the inferior relationship group.

After PSM, no statistically significant differences were observed between the 2 patient-physician relationship groups (inferior and superior groups): mean change in the systolic blood pressure was 8.9 (SD 5.6) mm Hg in the inferior group and 8.5 (SD 5.5) mm Hg in the superior group (*P*=.14), and the mean serum creatinine levels were 0.6 (SD 0.8) mg/dL and 0.7 (SD 1.1) mg/dL in the inferior and superior groups, respectively (P=.13) during the observation period (Table 2). The sample size was 1210 in each group.

Table 2. Adjusted backgrounds of physician-patient relationship groups using propensity score matching.

Parameter	Inferior group	Superior group	P value
Sample, n	1210	1210	—[a]
Age (year), mean (SD)	70.2 (6.6)	70.2 (6.8)	.44
Sex[b], male, n (%)	816 (67.4)	836 (69.1)	.41
Systolic blood pressure, mm Hg, mean (SD) change per observation period	8.9 (5.6)	8.5 (5.5)	.14
LDL[c] cholesterol, mg/dL, mean (SD) change per observation period	7.8 (5.3)	7.4 (5.1)	.09
HbA_{1c}[d], % mean (SD) change per observation period	0.3 (0.2)	0.3 (0.2)	.28
Serum creatinine, mg/dL, mean (SD) per observation period	0.6 (0.8)	0.7 (1.1)	.13
Cigarette smoking[e], binary, mean (SD) per observation period	0.2 (0.3)	0.2 (0.3)	.73

[a] —: not applicable.

[b] Sex: binary (male; 1, female; 2).

[c] LDL: low-density lipoprotein.

[d] HbA_{1c}: hemoglobin A_{1c}.

[e] Cigarette smoking: binary (presence; 0, existence; 1).

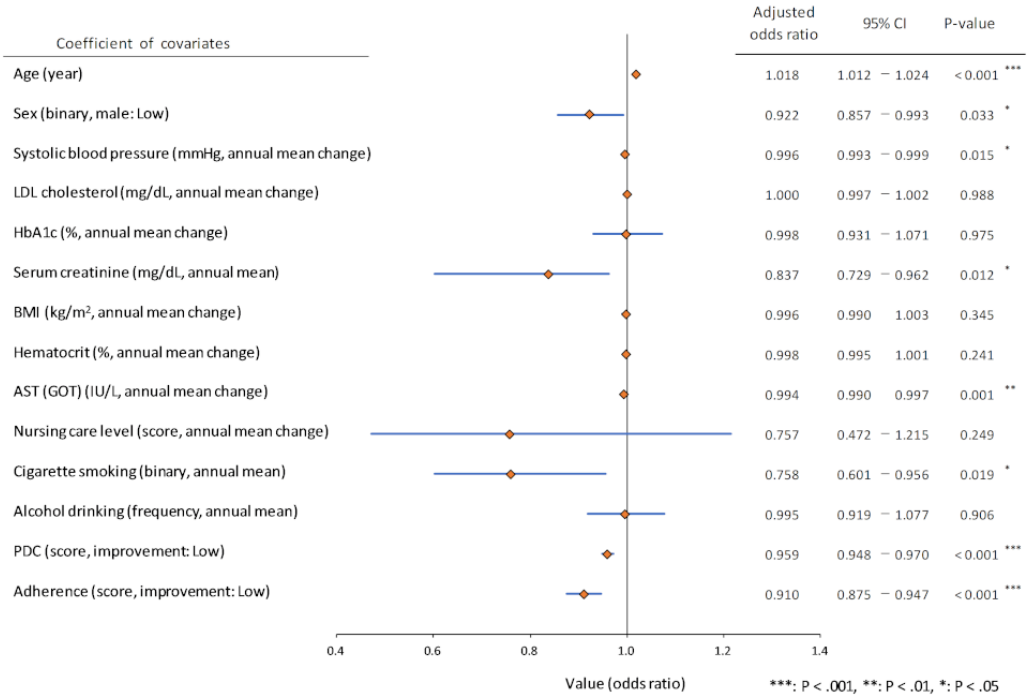
Clinical Factors Influencing the Switch to Generic Drugs

Logistic regression analysis was performed by switching to a generic drug as the variable and various clinical parameters related to CVD as independent variables. Significant predictors included systolic blood pressure (OR 0.996, 95% CI 0.993-0.999; P<.05), serum creatinine (OR 0.837, 95% CI 0.729-0.962; P<.05), aspartate aminotransferase (OR 0.994, 95% CI 0.990-0.997; P<.01), PDC score (OR 0.959, 95% CI 0.948-0.970; P<.001), and adherence (OR 0.910; 95% CI 0.875-0.947; P<.001), all of which demonstrated significant associations with generic drug switching (Figure 3). Smoking also significantly influenced generic drug switching (OR 0.758; 95% CI 0.601-0.956; P<.05). No significant differences were observed in the LDL-C and HbA_{1c} levels between the groups.

The analysis corrected the rising trend in the generic drug use rate in Japan; thus, the impact of each parameter did not change compared with the previously mentioned OR results (systolic blood pressure, 0.997 and serum creatinine level, 0.878).

We organized the relationship between the amount of displacement and cost of dispensing (a surrogate for generic drug rates: integral of the unit price and quantity of the prescription drug) to complement the results for the OR of systolic blood pressure. The results showed a statistically significant reduction in dispensing costs with a decrease in blood pressure (population mean difference between all pressure displacement ranges: P<.001; Figure 4). For reference, we analyzed the generic drug rate according to LDL-C level bands. No significant differences were observed between the normal LDL-C level band and the other bands (Figure 5). In addition, we analyzed the generic drug rates using the HbA_{1c} level band. A significant decrease was observed between the normal LDL-C level band and other bands (HbA_{1c}: 5%-5.6% vs 6%-6.4%, generic drug rate: 48.5% vs 47.4%; P<.01; Figure 6).

Figure 3. Clinical factors that influence the switch to generic drugs: logistic regression analysis. Nursing care is an indicator (degree of care) of the nursing care insurance system operated by the Japanese government. The level of nursing care is an index of the degree to which the older adults require nursing care. Depending on the physical and mental condition of the person being cared for, the condition will be classified into one of seven categories: “two stages of Support Required” or “five stages of Nursing Required”; the higher the number, the more severe the condition. Sex: binary (male: 1, female: 2), nursing care level: score (3 levels), cigarette smoking: binary (presence; 0, existence; 1), alcohol drinking: frequency (3 levels). LDL: low-density lipoprotein; HbA_{1c}: hemoglobin A_{1c}; BMI: body mass index; AST (GOT): aspartate aminotransferase (glutamic oxaloacetic transaminase); PDC: proportion of days covered.



Coefficient of covariates	Adjusted odds ratio	95% CI	P-value
Age (year)	1.018	1.012 − 1.024	< 0.001 ***
Sex (binary, male: Low)	0.922	0.857 − 0.993	0.033 *
Systolic blood pressure (mmHg, annual mean change)	0.996	0.993 − 0.999	0.015 *
LDL cholesterol (mg/dL, annual mean change)	1.000	0.997 − 1.002	0.988
HbA1c (%, annual mean change)	0.998	0.931 − 1.071	0.975
Serum creatinine (mg/dL, annual mean)	0.837	0.729 − 0.962	0.012 *
BMI (kg/m^2, annual mean change)	0.996	0.990 1.003	0.345
Hematocrit (%, annual mean change)	0.998	0.995 1.001	0.241
AST (GOT) (IU/L, annual mean change)	0.994	0.990 0.997	0.001 **
Nursing care level (score, annual mean change)	0.757	0.472 − 1.215	0.249
Cigarette smoking (binary, annual mean)	0.758	0.601 − 0.956	0.019 *
Alcohol drinking (frequency, annual mean)	0.995	0.919 − 1.077	0.906
PDC (score, improvement: Low)	0.959	0.948 − 0.970	< 0.001 ***
Adherence (score, improvement: Low)	0.910	0.875 − 0.947	< 0.001 ***

Figure 4. Relationship between systolic blood pressure variation and dispensing cost (percentage to mean value) SBP: systolic blood pressure.

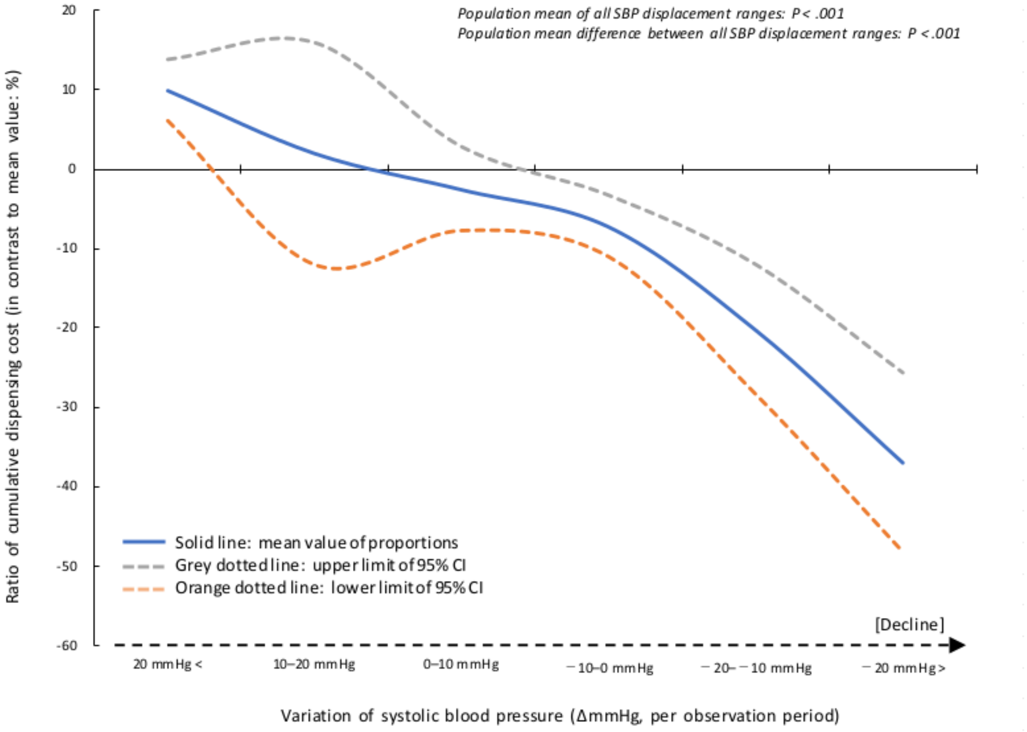


Figure 5. Generic drug rates at different mean low-density lipoprotein levels. Groups were compared using the Mann–Whitney U test, and no significant differences were detected. LDL-C: low-density lipoprotein cholesterol; NS: not significant.

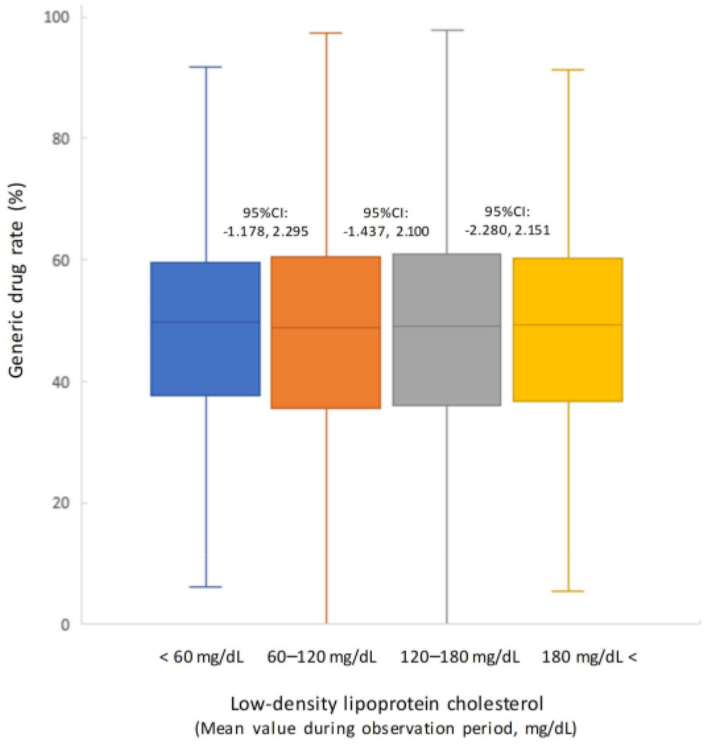
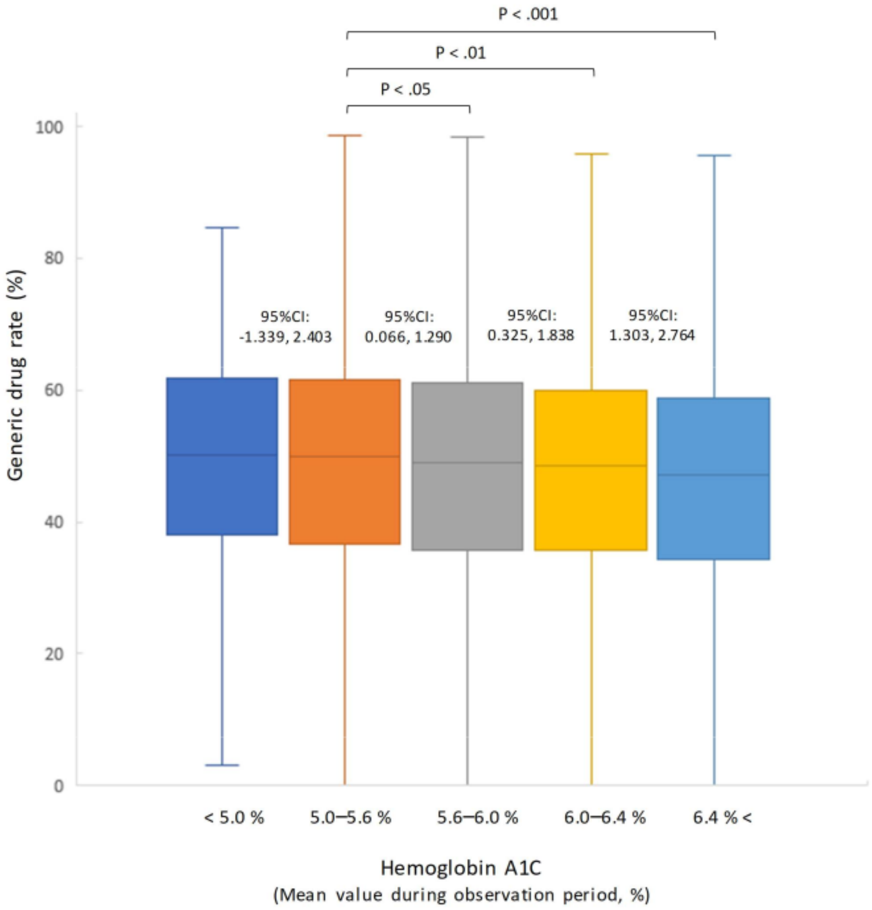


Figure 6. Generic drug rates at different mean hemoglobin A_{1c} levels. Groups were compared using the Mann–Whitney U test.



Physician-Patient Relationship and PDC as Adherence Indicators

When generic drug rates were sorted by physician-patient relationship after PSM, the superior relationship group had a significantly higher generic drug rate than the inferior relationship group (51.6%, SD 15.2% vs 47.7%, SD 17.7%; *P*<.001; Figure 7). The treatment interval cutoff value applied to the physician-patient relationship grouping (365 days) was a conservative estimate, as confirmed by the cutoff value derived from the receiver operating characteristic curve (494 days; area under the curve, 0.848; 95% CI 0.840-0.856; *P*<.001).

Multiple regression analysis with the PDC rate as the dependent variable revealed that an increase in the physician-patient relationship (standard partial regression coefficient:–0.254, *P*<.001) was a statistically significant factor for improving PDC (Table 3). The regression model (multiple regression equation, dependent variable: PDC rate) was statistically significant (*P*<.001, *df*: 10531).

Figure 7. Generic drug rate according to the physician–patient relationship after adjustment for patient background. Groups were compared using the Mann–Whitney U test. PSM: propensity score matching.

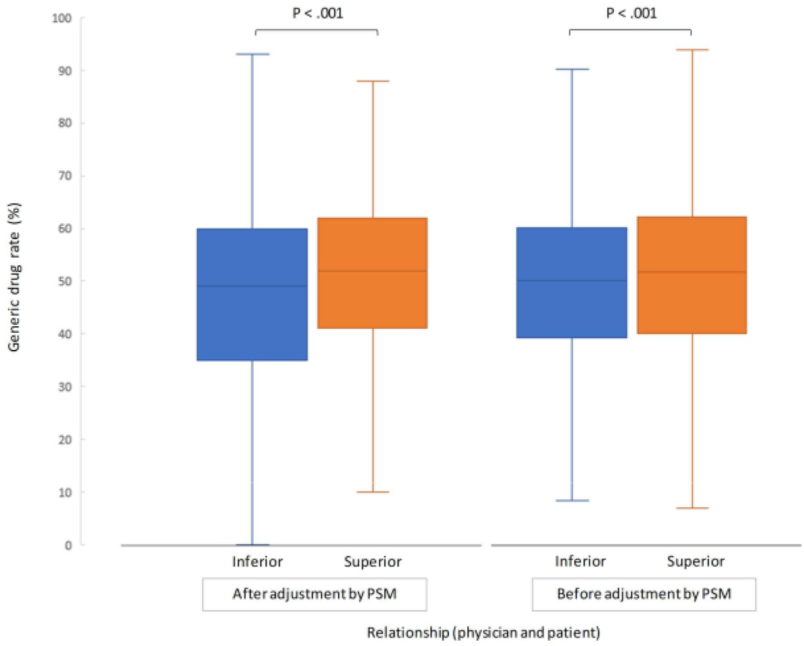


Table 3. Analysis of factors affecting the proportion of days covered rate: multiple regression analysis.

Parameter	Standard partial regression coefficient	*F* test value (*df*=10531)	VIF[a]	95% CI (partial regression coefficient)	*P* value
Relationship (binarization)[b]	–0.254	733.169	1.04	–0.018 to –0.016	<.001
Age (year)	0.136	214.004	1.03	0.000-0.001	<.001
Sex (binarization)[c]	–0.020	4.787	1.00	–0.050 to 0.003	.029
Constant term	—[d]	19.152	—[d]	0.006-0.016	<.001

[a] VIF: variance inflation factor.

[b] Relationship: binary (superior: 0, inferior: 1).

[c] Sex: binary (male: 1, female: 2).

[d] —: not applicable.

Logistic regression analysis with the physician-patient relationship as the dependent variable suggested that adherence (ASHRO: OR 1.025; 95% CI 1.021-1.029; *P*<.001) was a statistically significant factor in improving the relationship (Table 4). Age tended to improve the PDC rate (standard partial regression coefficient: 0.136, *P*<.001, Table 3) and physician-patient relationship (OR 0.982; 95% CI 0.977-0.986; *P*<.001; Table 4). The regression model (logistic regression, dependent variable: relationship) was statistically significant (*P*<.001).

Table 4. Analysis of the effect of attribute factors on physician-patient relationships logistic regression analysis.

Parameter	Standard partial regression coefficient	Standard error	Odds ratio (95% CI; partial regression coefficient)	*P* value
Age (years)	–0.064	0.002	0.982 (0.977-0.986)	<.001
Sex (binarization)[a]	0.024	0.044	1.145 (1.050-1.249)	.002
Adherence (score, improvement: low)	0.104	0.002	1.025 (1.021-1.029)	<.001

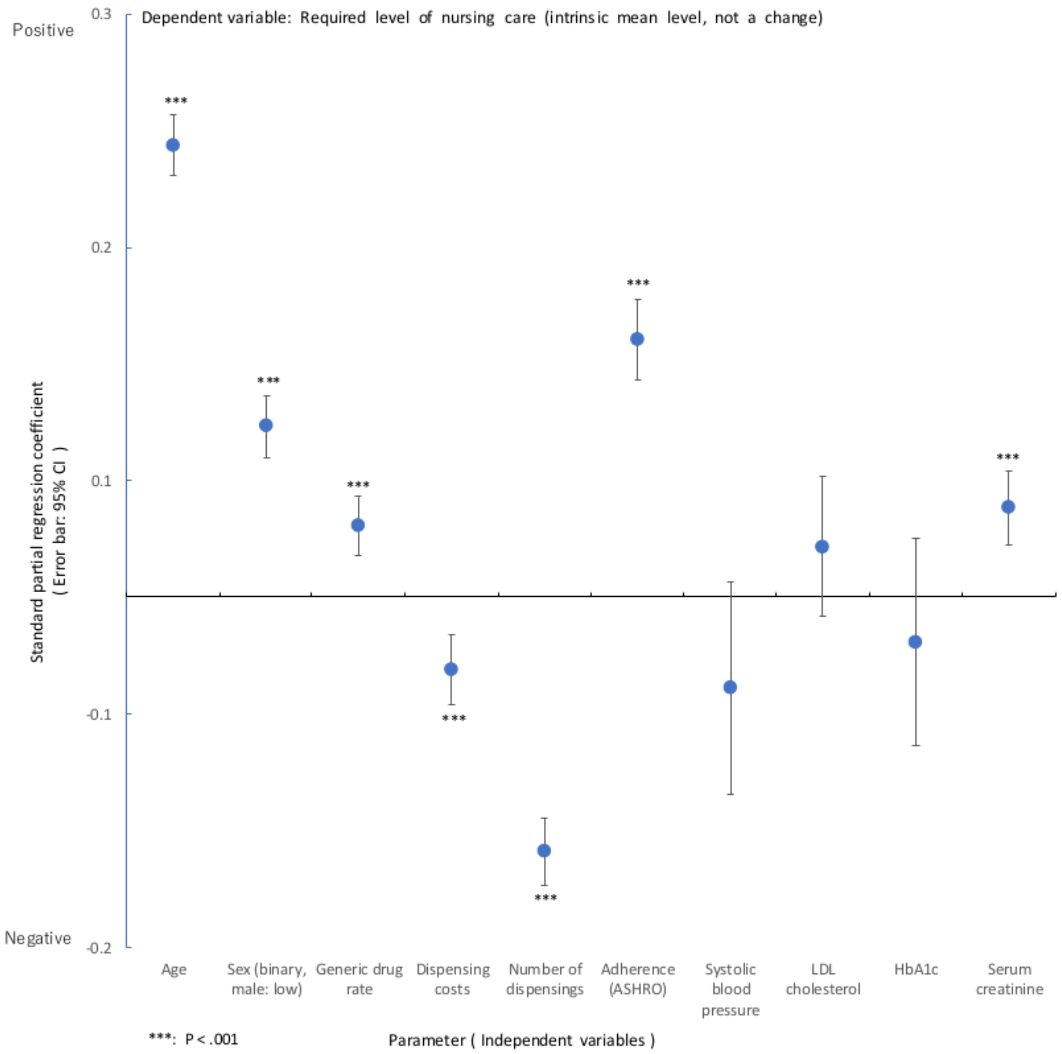
[a] Sex: binary (male: 1, female: 2).

Supplementary Analysis: Analysis Focusing on the Nursing Care Level Required, Which is a Phenomenon of Aging

In the logistic regression analysis mentioned above, no statistically significant relationship was found between the displacement in the required nursing care level and switch to generic drugs for the study population, the majority of which were older adults. This finding is noteworthy as the level of nursing care is often associated with aging, thus indicating the need to explore whether declining daily functioning owing to aging influences pharmacotherapy choices and their socioeconomic implications.

In a multiple regression analysis using the intrinsic level of nursing care (as an aging phenomenon) as the dependent variable, the rate of generic drug use among older adults requiring nursing care was found to increase (standard partial regression coefficient, 0.051, 95% CI 0.043-0.059; Figure 8). While nursing care assessments focus on daily living functions and generally show little correlation with medical severity, cognitive function was included but did not reveal significant risk factors (eg, systolic blood pressure, –0.039, *P*=.09).

Figure 8. Analysis using the required level of nursing care (intrinsic mean level, not a change), which is a phenomenon of aging, as the dependent variable: multiple regression analysis. LDL: low-density lipoprotein; HbA$_{1c}$, hemoglobin A$_{1c}$.



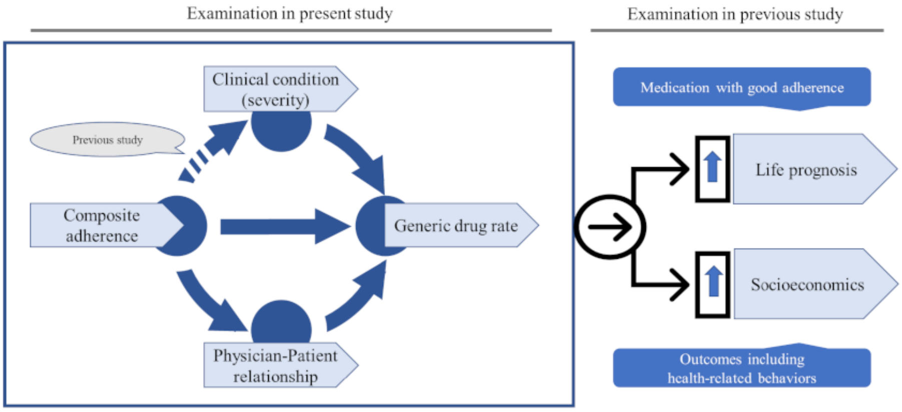
Furthermore, exploring the clinical and economic relationship between drug therapy and nursing care level, we observed that average nursing care levels tended to increase with a decrease in the dispensing frequency (standard partial regression coefficient, –0.109, 95% CI –0.123 to –0.094) and drug costs (standard partial regression coefficient, –0.031, 95% CI –0.045 to –0.016; Figure 8). Conversely, poor adherence (ASHRO) was associated with an increased nursing care level (standard partial regression coefficient, 0.110, 95% CI 0.093-0.127).

Discussion

Principal Findings

The results of this study demonstrated that improvements in the patient condition (severity) and intrinsic composite adherence were generally associated with increased generic drug switching. Furthermore, the rate of generic drug use tended to increase with improvement in the physician-patient relationship. The results also suggest that a better physician-patient relationship positively affects the PDC rate. Thus, enhancing comprehensive medical management and improving the medical environment is essential for further promotion of the appropriate selection of generic drugs. This includes fostering better relationships among stakeholders and increasing awareness among health care providers. Based on the above results and considerations, we organized the following mechanisms regarding the significance and social background of promoting generic drugs. Improvements in composite adherence improved the severity of patient illness and physician-patient relationships. Consequently, the number of prescriptions for generic drugs increased. Our previous study indicated that enhanced adherence positively impacts clinical outcomes and economic factors, such as life prognosis and medical costs [26]. Based on these conditions, it was speculated that generic drug selection would contribute to long-term clinical benefits and good socioeconomic impact (Figure 9). In addition, we speculate that the findings obtained in this study will contribute to the discussion on the prescription of brand-name drugs. However, future large-scale prospective studies are warranted to test this hypothesis.

Figure 9. Summary of the findings and interrelationships of this study.



As this study included patients with CVD who were hospitalized at least once, the cohort had a wide range of patient backgrounds. Therefore, the compositions of the prescribed medications were also widely distributed, not only for heart failure (CVD) but also for renal failure (chronic kidney disease [CKD]), endocrinology, and metabolism. For disease characteristics that repeat between the acute and chronic phases, we hypothesized that the sensitivity of health care providers to the severity (or complexity) of a patient's condition would be high. The results of this study support this hypothesis. The presence of physician distrust and patient anxiety about generics was also considered terms of the diversity of diseases and drugs addressed in the study. In previous studies, there have been many reports investigating the confidence in or validation of clinical outcomes for generic drugs [16-25]. Scattered reports involving statins and warfarin showed no difference in the clinical outcomes and PDC between brand-name and generic drugs [18-21]. On the contrary, although only as a reference, the validation of generic drugs against pregabalin and gabapentin in the pain management of neuropathic pain showed that brand-name drugs were superior in improving PDC and reducing pain [23-25]. As described above, the evaluation of generic drugs varies according to the disease mechanism and drug class. This study did not delve deeply into individual drug characteristics, as it focused on organizing the overall trends from a long-term longitudinal analysis of a large real-world sample. This is one of the limitations of this study. Future studies elaborating on the patient characteristics and drug effect categories are warranted.

Many studies on the risk factors for CVDs (angina pectoris and myocardial infarction) have been conducted in Japan. Epidemiological studies in Japan and overseas have reported that hypertension is an independent risk factor not only for stroke but also for CVDs. For example, a 10-mm Hg increase in systolic blood pressure was associated with a 1.16- to 1.40-fold increase in the risk of developing or dying from ischemic heart disease [37,38]. In this study, the switch to generic drugs tended to increase considerably with an improvement in the systolic blood pressure, despite the OR to be small. Numerous epidemiological studies have shown that hypercholesterolemia is a risk factor for CVD [39]. Hyperlipidemia is the most important risk factor for CVDs. Japanese medical insurance targets the use of relatively new PCSK9 inhibitors in patients with statin intolerance. According to the analysis in this study, the OR of the LDL-C level for switching to a generic drug was neutral. Recent reports indicate that elevated LDL-C levels do not significantly affect the risk of death or vascular events [40,41]. A similar trend was observed in this study (Multimedia Appendix 3). Given the limited information available for deeper interpretation, future studies should extensively examine marker characteristics (such as diurnal variation), pharmacotherapy control status, and the evolution of target values in clinical guidelines. In addition, diabetes mellitus, a significant risk factor for CVD, should be considered in this context [42]. In contrast, the OR of the period change of HbA_{1c} levels for switching to a generic drug was neutral in this study. However, when the generic drug rate was analyzed according to HbA_{1c} level bands, a significant decrease was observed in the abnormal values than in the normal values. The estimated glomerular filtration rate and albumin-creatinine ratio were reported to be independent predictors of future acute kidney injury, CVD, CKD, nonfatal cardiovascular accidents, and death [43,44]. In this study, an improvement in the serum creatinine levels was associated with a marked trend toward switching to generic drugs. Aspartate aminotransferase displacement was also associated with the generic drug rate. Considering these findings comprehensively, improvements in the clinical indicators may influence the decision to switch to generic drugs.

Although the OR results showed statistical significance, there were also some indicators with extremely small numerical values. Caution should be exercised when interpreting these indicators clinically. The OR represents the degree of change (risk) of the target variable relative to the change of one unit of the independent variable. Considering the blood pressure index as an example, a change of 1 mm Hg in clinical practice is considered to have minimal clinical significance for a single patient because it may be affected by measurement errors and diurnal fluctuations. Typically, a change of 10 mm Hg is considered the standard for clinical discussion. Previous research has shown that an increase of 10 mm Hg increases the risk by 1.16 to 1.40 times [37,38]. In this analysis, we did not adjust the levels of the independent variables (eg, by a factor of 10), which may explain why some indicators showed smaller results. Therefore, when interpreted in terms of actual clinical practice, results with small ORs (indicating statistical significance) can be inferred to be significant in clinical practice. Particularly when discussing the representativeness of long-term fluctuations in large groups, even small ORs can be considered meaningful in the real world. Further examination of the data processing method for each analysis and the clinical usefulness of the results is desired through the development of new research.

In this study, it was inferred that many drugs had a high percentage of effects on the treatment outcomes due to medication compliance among the drugs studied. Therefore, patient adherence is an important factor in defining treatment outcomes. Given the characteristics of the study cohort, it was desirable to consider PDC as well as other health-related behavioral factors with regard to adherence. Particularly, the contribution of disease prevention interventions to improving long-term outcomes tended to be higher in populations with CVD and CKD associated with lifestyle-related diseases. Considering these factors, this study used the composite (intrinsic) adherence (ASHRO score). The results showed that improvements in the adherence scores, along with improvements in the levels of key clinical indicators, had a remarkable effect on the rate of generic drug use. Previous reports have suggested that improved PDC contributes to improved clinical outcomes [45-47]. The results of the analysis in this study suggest that composite adherence contributes to clinical outcomes since improved adherence scores improve PDC rates. In a previous study, the group with better ASHRO scores had better long-term life expectancy [26]. Incidentally, as adherence is an integrated index that also includes a PDC component, caution should be exercised when interpreting multivariate analyses involving PDC due to multicollinearity. Considering these points, this study has certain limitations in discussing causal inferences. Therefore, further verification of the representativeness of the data sources and the accuracy of the study design is desired.

A trial analysis of the relationship between physicians and patients was conducted to consider factors other than clinical indicators and adherence when examining factors leading to generic drug switching. Due to the difficulty in developing quantitative indicators of relationships, no previous studies have been conducted. A few studies have examined the effects of the level of information provision and medical personnel’s attitudes on PDC, and no clear effects have been found [11,13,46]. According to the results of this study, improving physician-patient relationships promoted generic drug rates. Composite adherence is positively related to this relationship. Therefore, promoting a good physician-patient relationship is expected to have a clinical effect. The PDC and this relationship tended to increase as patients’ age increased, which may be due to an increase in morbidities and a learning effect on patients [10]. Because this study was a long-term longitudinal observation, the physician-patient relationship indicator, which consisted of the visit interval component, included a time effect. Therefore, we cannot rule out the possibility that this effect may have influenced the aging trends described above. In this study, the physician-patient relationship was derived vicariously from the prescription entity, with medical ethics (including medical treatment institutional contracts) as a background. Therefore, this proxy indicator has limitations in discussing the psychological “relationship of trust” as a human relationship. In addition, the influence of confounding factors on analysis is also expected. Therefore, we believe that these findings should be interpreted with caution, and further studies are warranted to verify these mechanisms.

This study also considered the influence of government health care policies that promote the use of generic drugs. However, even after adjusting for current policies, the effect of clinical parameters on the rate of generic drug use remained largely unchanged. These findings may further encourage appropriate pharmaceutical prescribing, especially if the policy diffusion of generic drugs starts to slow. Prescribing generic drugs when appropriate could yield significant long-term socioeconomic benefits in clinical settings. For example, the argument above not only highlights clinical and economic benefits but also expands health policy options, potentially reducing social risks [48]. The findings of this study are particularly relevant for older adults requiring nursing care or end-of-life care, where multifaceted decision-making (shared decision-making) by various medical professionals is essential. The results of this study provide valuable insights into the realization of this objective.

The analysis revealed that patients requiring higher levels of nursing care tended to have higher prescription rates of generic drugs. This trend may seem contradictory to the earlier discussion on the relationship between medical severity and generic drug rates. However, examining the issue from different perspectives provides clarity. Two primary hypotheses could explain this phenomenon. First, long-term care insurance often involves higher out-of-pocket costs and services not covered by insurance. This may financially constrain individuals, especially after retirement, leading them to prefer lower-cost generic drugs [49]. Second, in nursing care facilities, which typically lack pharmacists, the preference for generic drugs may be driven by their lower prices and easier handling, reflecting the practical and financial constraints of managing long-term care services.

The interpretation that higher levels of nursing care are associated with increased generic drug prescriptions was supported by the general lack of a relationship between the unchanging average nursing care level and clinical indicators. This suggests that the level of nursing care and its degree of displacement do not necessarily align. One hypothesis is that the transition from medical institutions, where new drug prescriptions are more common, to nursing care facilities, where generic drugs are preferred owing to lower costs and ease of handling, could explain this discrepancy. The finding that drug costs decrease as the required care level increases and that adherence (measured by ASHRO) is related to the nursing care level supports this hypothesis. Specifically, drugs like donepezil hydrochloride, which is used to manage cognitive function, show a relationship between adherence and the nursing care level [50]. Despite this, the population with worsening nursing care had poorer adherence, highlighting that the dimensions of care level and medical severity may differ. Adherence appears to be more sensitive to medical severity, reflecting the complex interplay between care needs and medical management.

To our knowledge, this study is the first to focus on the patient-side factors involved in switching to generic drugs, using a long-term longitudinal cohort study design. This approach offers a novel perspective on how patient characteristics, adherence, and physician-patient relationships impact generic drug use over time. However, as shown in this study, the causal relationships related to the theme were complex. In particular, there was significant variability in changes in physical function and facility type among older adults. Therefore, we believe that leveraging data science is crucial for developing research strategies tailored to drug therapy for populations with such pathological characteristics. Moving forward, it would be beneficial to expand the application of reinforcement learning, particularly using prioritized experience replay. It is known for its effectiveness in addressing diverse problems, such as game theory and resource optimization, which holds promise for advancements in preventive medicine and social medicine.

This study has the following limitations. First, it did not delve deeply into the characteristics of individual drugs and the specific backgrounds of patients. Second, careful adjustment was not made for bias among the independent variables. Third, the physician-patient relationship was analyzed using proxy indicators. Consequently, the study's design has limitations in terms of making causal inferences about this relationship.

Conclusions

The patient condition (severity) and composite adherence (intrinsic) influenced the choice of generic drugs. Adherence tended to improve, and generic rates increased as physician-patient relationships improved. To further promote the appropriate selection of generic drugs, relationships with stakeholders must be improved, and patient awareness must be raised. Further development of methods to accurately evaluate adherence and relationships would be beneficial. The findings of this study suggest a novel approach for effectively promoting the use of both generic and brand-name drugs. However, the study possesses limitations affecting its ability to draw causal inferences.

Acknowledgments

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Conflicts of Interest

TT reports grants from the Nihon Medi-Physics Co Ltd, Terumo Corporation, and Fujifilm Toyama Chemical Co, Ltd, outside the submitted work. The other authors have no conflicts of interest to declare.

Multimedia Appendix 1
Predictors of integrated medical and long-term care resource consumption.
[PDF File (Adobe PDF File), 282 KB - aging_v7i1e59234_app1.pdf]

Multimedia Appendix 2
List of the results of each analysis.
[PDF File (Adobe PDF File), 155 KB - aging_v7i1e59234_app2.pdf]

Multimedia Appendix 3
Relationship between 4-year average LDL level and 4-year cumulative all-cause mortality rate. Abbreviations: LDL, Low-density Lipoprotein Cholesterol Test: Spearman’s rank correlation coefficient.
[PDF File (Adobe PDF File), 54 KB - aging_v7i1e59234_app3.pdf]

References

1. Mishuk AU, Fasina I, Qian J. Impact of U.S. federal and state generic drug policies on drug use, spending, and patient outcomes: a systematic review. Res Social Adm Pharm 2020;16(6):736-745. [doi: 10.1016/j.sapharm.2019.08.031] [Medline: 31445986]
2. Kasuga M, Kuribayashi R, Ogawa T, Ugi A, Yamaguchi T, Takagi K, et al. Generic drug product development in Japan: regulatory updates during 2014-2019 and the future. Eur J Drug Metab Pharmacokinet 2021;46(6):711-719. [doi: 10.1007/s13318-021-00720-1] [Medline: 34586614]
3. Mazmudar RS, Tripathi R, Bordeaux JS, Scott JF. Trends in brand and generic drug utilization for dermatology providers from 2013-2019. Arch Dermatol Res 2023;315(4):1041-1044. [doi: 10.1007/s00403-022-02431-2] [Medline: 36309878]
4. Visualization of medical cost data.: Ministry of Health, Labor and Welfare of Japan URL: https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/0000190726.html [accessed 2024-10-27]
5. Al Zoubi S, Gharaibeh L, Al-Masri B, Alsahele AB, Al-Masaeid B. Generic switching: Do future physicians in Jordan have enough knowledge and a positive attitude? Front Pharmacol 2022;13:1037112 [FREE Full text] [doi: 10.3389/fphar.2022.1037112] [Medline: 36561340]
6. Toverud E, Hartmann K, Håkonsen H. A systematic review of physicians' and pharmacists' perspectives on generic drug use: what are the global challenges? Appl Health Econ Health Policy 2015;13 Suppl 1(Suppl 1):S35-S45 [FREE Full text] [doi: 10.1007/s40258-014-0145-2] [Medline: 25963230]
7. Kwon HY, Godman B. Do newly marketed generic medicines expand markets using descriptive time series analysis and mixed logit models? Korea as an exemplar and its implications. BMC Health Serv Res 2016;16:130 [FREE Full text] [doi: 10.1186/s12913-016-1356-z] [Medline: 27080530]
8. Mohammed AS, Woldekidan NA, Mohammed FA. Knowledge, attitude, and practice of pharmacy professionals on generic medicines in Eastern Ethiopia: a cross-sectional study. PLoS One 2020;15(7):e0235205 [FREE Full text] [doi: 10.1371/journal.pone.0235205] [Medline: 32658918]
9. Drozdowska A, Hermanowski T. Exploring factors underlying the attitude of community pharmacists to generic substitution: a nationwide study from Poland. Int J Clin Pharm 2016;38(1):162-170 [FREE Full text] [doi: 10.1007/s11096-015-0227-8] [Medline: 26620450]
10. Saposnik G, Mamdani M, Terzaghi M, Saladino ML, Silva B, Tobler PN, et al. The role of prescribing generic (non-proprietary) drugs in the prevalence of therapeutic inertia in multiple sclerosis care. Front Neurol 2018;9:835 [FREE Full text] [doi: 10.3389/fneur.2018.00835] [Medline: 30369904]
11. Almusalam N, Oh J, Terzaghi M, Maurino J, Bakdache F, Montoya A, et al. Comparison of physician therapeutic inertia for management of patients with multiple sclerosis in Canada, Argentina, Chile, and Spain. JAMA Netw Open 2019;2(7):e197093 [FREE Full text] [doi: 10.1001/jamanetworkopen.2019.7093] [Medline: 31314113]
12. Carrera M, Skipper N. Physicians are more likely than non-physicians to use brand-name drugs to treat their chronic conditions. J Epidemiol Community Health 2017;71(9):874-881. [doi: 10.1136/jech-2016-208837] [Medline: 28674077]
13. Barfoed BL, Paulsen MS, Christensen PM, Halvorsen PA, Jarbøl DE, Larsen ML, et al. Associations between patients' adherence and GPs' attitudes towards risk, statin therapy and management of non-adherence--a survey and register-based study. Fam Pract 2016;33(2):140-147. [doi: 10.1093/fampra/cmw005] [Medline: 26936208]
14. Kim DS, Shin J, Chung J. Analysis of the Korean generic medicine market: factors affecting the market share of generic medicines. Clin Transl Sci 2022;15(2):433-441 [FREE Full text] [doi: 10.1111/cts.13161] [Medline: 34585837]
15. Tachi T, Saito K, Esaki H, Kanematsu Y, Yoshida A, Sugita I, et al. Medical and economic factors influencing generic drug use in the Japanese public health system: influencing factors in different populations. Int J Health Plann Manage 2018;33(2):489-501. [doi: 10.1002/hpm.2489] [Medline: 29315859]
16. Kim S, Shin DW, Yun JM, Hwang Y, Park SK, Ko Y, et al. Medication adherence and the risk of cardiovascular mortality and hospitalization among patients with newly prescribed antihypertensive medications. Hypertension 2016;67(3):506-512. [doi: 10.1161/HYPERTENSIONAHA.115.06731] [Medline: 26865198]
17. Sicras-Mainar A, Sánchez-Álvarez L, Navarro-Artieda R, Darbà J. Treatment persistence and adherence and their consequences on patient outcomes of generic versus brand-name statins routinely used to treat high cholesterol levels in Spain: a retrospective cost-consequences analysis. Lipids Health Dis 2018;17(1):277 [FREE Full text] [doi: 10.1186/s12944-018-0918-y] [Medline: 30522491]

18. Dentali F, Donadini MP, Clark N, Crowther MA, Garcia D, Hylek E, Warfarin Associated Research ProjectsOther Endeavors (WARPED) Consortium. Brand name versus generic warfarin: a systematic review of the literature. Pharmacotherapy 2011;31(4):386-393. [doi: 10.1592/phco.31.4.386] [Medline: 21449627]
19. Swenson C, Fundak G. Observational cohort study of switching warfarin sodium products in a managed care organization. Am J Health Syst Pharm 2000;57(5):452-455. [doi: 10.1093/ajhp/57.5.452] [Medline: 10711525]
20. Manzoli L, Flacco ME, Boccia S, D'Andrea E, Panic N, Marzuillo C, et al. Generic versus brand-name drugs used in cardiovascular diseases. Eur J Epidemiol 2016;31(4):351-368 [FREE Full text] [doi: 10.1007/s10654-015-0104-8] [Medline: 26620809]
21. Gao J, Seki T, Kawakami K. Comparison of adherence, persistence, and clinical outcome of generic and brand-name statin users: a retrospective cohort study using the Japanese claims database. J Cardiol 2021;77(5):545-551 [FREE Full text] [doi: 10.1016/j.jjcc.2020.12.003] [Medline: 33371973]
22. Mano Y, Fukushima S, Kuroda H, Ohshima H, Kato Y, Ohuchi K, et al. Adherence to changing from brand-name to generic atorvastatin in newly treated patients: a retrospective cohort study using health insurance claims. J Pharm Health Care Sci 2015;1:12 [FREE Full text] [doi: 10.1186/s40780-015-0013-8] [Medline: 26819723]
23. Sicras-Mainar A, Rejas-Gutiérrez J, Pérez-Paramo M, Sánchez-Alvarez L, Navarro-Artieda R, Darbà J. Consequences on economic outcomes of generic versus brand-name drugs used in routine clinical practice: the case of treating peripheral neuropathic pain or generalized anxiety disorder with pregabalin. Expert Rev Pharmacoecon Outcomes Res 2019;19(1):45-57. [doi: 10.1080/14737167.2019.1519399] [Medline: 30182806]
24. Navarro-Artieda R, Rejas-Gutiérrez J, Pérez-Paramo M, Sicras-Mainar A. Clinical and economic consequences of treating patients with peripheral neuropathic pain with brand name or generic drugs in routine clinical practice: the effects of age and sex. Neurologia (Engl Ed) 2018;33(3):141-153 [FREE Full text] [doi: 10.1016/j.nrl.2016.03.012] [Medline: 27321171]
25. Sicras-Mainar A, Rejas-Gutiérrez J, Navarro-Artieda R. Comparative effectiveness and costs of generic and brand-name gabapentin and venlafaxine in patients with neuropathic pain or generalized anxiety disorder in Spain. Clinicoecon Outcomes Res 2015;7:299-312 [FREE Full text] [doi: 10.2147/CEOR.S85756] [Medline: 26082655]
26. Takura T, Hirano Goto K, Honda A. Development of a predictive model for integrated medical and long-term care resource consumption based on health behaviour: application of healthcare big data of patients with circulatory diseases. BMC Med 2021;19(1):15 [FREE Full text] [doi: 10.1186/s12916-020-01874-6] [Medline: 33413377]
27. Taylor RA, Pare JR, Venkatesh AK, Mowafi H, Melnick ER, Fleischman W, et al. Prediction of in-hospital mortality in emergency department patients with sepsis: a local big data-driven, machine learning approach. Acad Emerg Med 2016;23(3):269-278 [FREE Full text] [doi: 10.1111/acem.12876] [Medline: 26679719]
28. Hsu PL, Robbins H. Complete convergence and the law of large numbers. Proc Natl Acad Sci U S A 1947;33(2):25-31 [FREE Full text] [doi: 10.1073/pnas.33.2.25] [Medline: 16578237]
29. Kaukonen K, Bailey M, Pilcher D, Cooper DJ, Bellomo R. Systemic inflammatory response syndrome criteria in defining severe sepsis. N Engl J Med 2015;372(17):1629-1638. [doi: 10.1056/NEJMoa1415236] [Medline: 25776936]
30. Liaw A, Wiener M. Classification and regression by randomForest. Radiology News 2002;2/3:18-22.
31. How nursing care certification works under the long-term care insurance system.: Ministry of Health, Labor and Welfare URL: https://www.mhlw.go.jp/topics/kaigo/kentou/15kourei/sankou3.html [accessed 2024-10-26]
32. Hariri EH, Al Hammoud MM, Nissen SE, Hammer DF. Primary and secondary prevention of atherosclerotic cardiovascular disease: a case-based approach. Cleve Clin J Med 2022;89(9):513-522 [FREE Full text] [doi: 10.3949/ccjm.89a.21103] [Medline: 37907442]
33. Outline of designated intractable diseases, diagnostic criteria, etc., individual clinical survey form.: Ministry of Health, Labor and Welfare URL: https://www.mhlw.go.jp/stf/newpage_36011.html [accessed 2024-10-26]
34. Ueshima H, Sekikawa A, Miura K, Turin TC, Takashima N, Kita Y, et al. Cardiovascular disease and risk factors in Asia: a selected review. Circulation 2008;118(25):2702-2709 [FREE Full text] [doi: 10.1161/CIRCULATIONAHA.108.790048] [Medline: 19106393]
35. Shaw LJ, Bairey Merz CN, Pepine CJ, Reis SE, Bittner V, Kelsey SF, WISE Investigators. Insights from the NHLBI-sponsored women's ischemia syndrome evaluation (WISE) study: part I: gender differences in traditional and novel risk factors, symptom evaluation, and gender-optimized diagnostic strategies. J Am Coll Cardiol 2006;47(3 Suppl):S4-S20 [FREE Full text] [doi: 10.1016/j.jacc.2005.01.072] [Medline: 16458170]
36. Delcher C, Bae J, Wang Y, Doung M, Fink D, Young H. Defining "Doctor Shopping" with dispensing data: a scoping review. Pain Med 2022;23(7):1323-1332. [doi: 10.1093/pm/pnab344] [Medline: 34931686]
37. Nishimura K, Okamura T, Watanabe M, Nakai M, Takegami M, Higashiyama A, et al. Predicting coronary heart disease using risk factor categories for a Japanese urban population, and comparison with the framingham risk score: the suita study. J Atheroscler Thromb 2014;21(8):784-798 [FREE Full text] [doi: 10.5551/jat.19356] [Medline: 24671110]
38. Tanabe N, Iso H, Okada K, Nakamura Y, Harada A, Ohashi Y, Japan Arteriosclerosis Longitudinal Study Group. Serum total and non-high-density lipoprotein cholesterol and the risk prediction of cardiovascular events - the JALS-ECC -. Circ J 2010;74(7):1346-1356 [FREE Full text] [doi: 10.1253/circj.cj-09-0861] [Medline: 20526038]

39. Okamura T, Tanaka H, Miyamatsu N, Hayakawa T, Kadowaki T, Kita Y, NIPPON DATA80 Research Group. The relationship between serum total cholesterol and all-cause or cause-specific mortality in a 17.3-year study of a Japanese cohort. Atherosclerosis 2007;190(1):216-223. [doi: 10.1016/j.atherosclerosis.2006.01.024] [Medline: 16529754]
40. Johannesen CDL, Langsted A, Mortensen MB, Nordestgaard BG. Association between low density lipoprotein and all cause and cause specific mortality in Denmark: prospective cohort study. BMJ 2020;371:m4266 [FREE Full text] [doi: 10.1136/bmj.m4266] [Medline: 33293274]
41. Schubert J, Lindahl B, Melhus H, Renlund H, Leosdottir M, Yari A, et al. Elevated low-density lipoprotein cholesterol: an inverse marker of morbidity and mortality in patients with myocardial infarction. J Intern Med 2023;294(5):616-627. [doi: 10.1111/joim.13656] [Medline: 37254886]
42. Fujishima M, Kiyohara Y, Kato I, Ohmura T, Iwamoto H, Nakayama K, et al. Diabetes and cardiovascular disease in a prospective population survey in Japan: the hisayama study. Diabetes 1996;45 Suppl 3:S14-S16. [doi: 10.2337/diab.45.3.s14] [Medline: 8674881]
43. Nagata M, Ninomiya T, Kiyohara Y, Murakami Y, Irie F, Sairenchi T, EPOCH-JAPAN Research Group. Prediction of cardiovascular disease mortality by proteinuria and reduced kidney function: pooled analysis of 39,000 individuals from 7 cohort studies in Japan. Am J Epidemiol 2013;178(1):1-11. [doi: 10.1093/aje/kws447] [Medline: 23752917]
44. Wannamethee SG, Shaper AG, Perry IJ. Serum creatinine concentration and risk of cardiovascular disease: a possible marker for increased risk of stroke. Stroke 1997;28(3):557-563. [doi: 10.1161/01.str.28.3.557] [Medline: 9056611]
45. Jožef M, Locatelli I, Brecl Jakob G, Rot U, Kos M. Medication adherence and health outcomes in persons with multiple sclerosis treated with dimethyl fumarate. Mult Scler Relat Disord 2023;72:104615. [doi: 10.1016/j.msard.2023.104615] [Medline: 36933300]
46. Patsiou V, Samaras A, Kartas A, Moysidis DV, Papazoglou AS, Bekiaridou A, et al. Prognostic implications of adherence to oral anticoagulants among patients with atrial fibrillation: insights from MISOAC-AF trial. J Cardiol 2023;81(4):390-396 [FREE Full text] [doi: 10.1016/j.jjcc.2022.09.009] [Medline: 36179772]
47. Akao M, Tsuji H, Kusano K, Matsui K, Hiramitsu S, Hatori Y, et al. Clinical characteristics and outcomes of Japanese atrial fibrillation patients with poor medication adherence: a sub-analysis of the GENERAL study. J Cardiol 2023;81(2):209-214 [FREE Full text] [doi: 10.1016/j.jjcc.2022.07.022] [Medline: 35985869]
48. Rogosnitzky M, Berkowitz E, Jadad AR. Delivering benefits at speed through real-world repurposing of off-patent drugs: the COVID-19 pandemic as a case in point. JMIR Public Health Surveill 2020;6(2):e19199 [FREE Full text] [doi: 10.2196/19199] [Medline: 32374264]
49. Qin X, Huckfeldt P, Abraham J, Yee D, Virnig B. Hormonal therapy drug switching, out-of-pocket costs, and adherence among older women with breast cancer. J Natl Cancer Inst 2022;114(7):1029-1035 [FREE Full text] [doi: 10.1093/jnci/djac062] [Medline: 35333338]
50. Blier P, Margolese HC, Wilson EA, Boucher M. Switching medication products during the treatment of psychiatric illness. Int J Psychiatry Clin Pract 2019;23(1):2-13. [doi: 10.1080/13651501.2018.1508724] [Medline: 30732488]

Abbreviations

ASHRO: Adherence Score for Healthcare Resource Outcome
CKD: chronic kidney disease
CVD: cardiovascular disease
HbA_{1c}: hemoglobin A_{1c}
ICD-10: International Statistical Classification of Diseases, Tenth Revision
LDL-C: low-density lipoprotein cholesterol
OR: odds ratio
PDC: proportion of days covered
PSM: propensity score matching

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Medication Self-Management for Home Care Users Receiving Multidose Drug Dispensing: Qualitative Interview Study

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Abstract

Background: Multidose drug dispensing (MDD) is an adherence aid where medicines are machine-dispensed in disposable unit bags, usually for a 14-day period. MDD replaces manually filled dosettes in many home care services in Norway. While evidence suggests that MDD can improve medication adherence and reduce errors, there are few studies on how patients manage MDD at home and how this affects their daily routines.

Objective: The aim of the study is to identify factors influencing medication self-management behavior among MDD users living at home and explore how MDD affects medication self-management.

Methods: We conducted semistructured interviews with 19 MDD users in Oslo between August 2019 and February 2020. The interviews were held at the participants' homes, and the interview transcripts were analyzed thematically.

Results: All participants in the study received some form of assistance with medication management from home care services. This assistance ranged from MDD delivery every other week to actual assistance with medication administration multiple times daily. However, regardless of the level of assistance received, participants primarily managed their MDD medications themselves. Daily medication routines and knowledge about medicines varied among the participants, with some taking an active role in their medication management, while others relied on others to take responsibility. The degree of involvement seemed determined by motivation rather than capability.

Conclusions: MDD can support medication self-management, but its effectiveness varies among patients. The level of medication management by MDD users is not solely determined by their actual capabilities. Factors such as interest in self-care and independence, available support, information, and cognitive capacity all play a role in determining the degree of autonomy.

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KEYWORDS

home care; medication management; adherence; self-management; multidose drug dispensing; Norway; primary care; older adults

Introduction

Medications play a crucial role in modern medicine. However, various studies have indicated that patients encounter drug-related problems and struggle with medication management [1-5]. Medication nonadherence, when medications are not taken as prescribed, has significant consequences, leading to poorer health outcomes and increased costs for society [5].

To adhere to a medication regimen, patients must undertake a series of actions that demand specific knowledge, skills, and behavior. According to the model developed by Bailey et al [6], medication self-management can be categorized into 6 phases: filling the prescription, understanding how to take the medications correctly, organizing the medication use, taking the medication, monitoring effects and side effects, and sustaining use. These phases necessitate various skills, and numerous factors can contribute to patients being unable to manage their medications correctly. For instance, the complexity of the medication regimen, impaired vision and manual dexterity, polypharmacy, medication knowledge, perceptions about the severity of one's illness, and experiences of side effects are among the contributing factors [7]. Additionally, there are medication-related risk factors, such as confusion between generic and brand names, lack of medication administration routines, hoarding, retaining discontinued medication, and involvement of multiple prescribers [8].

In Norway, as in several other countries, there is now a trend toward shorter hospital stays due to an increased focus on providing health and care services in patients' homes [9,10]. Consequently, more individuals with medication management problems are living at home with help from home care services. One of the main goals of the service is to enable individuals to live in their homes for as long as possible, both to improve the quality of life and to contain costs for the health system. One area of support often provided by home care nurses is to help with medication dispensing and administration. In Norway, about one-third of home care users get help administering their medications through multidose drug dispensing (MDD) [11].

MDD is a dispensing system where solid medications are machine-dispensed in unit-of-use disposable bags, 1 bag for each dose occasion [12]. The bags are labeled with patient information, name and strength of the medications, and date and time of day the medications should be taken. Only solid medications such as tablets and capsules can be dispensed as MDD. Although MDD systems are common in many hospitals across the world where the system has shown to reduce certain types of medication errors, only some countries use it in primary care [13]. The MDD system has the potential to reduce medication costs, improve medication adherence, and reduce medication errors also in a primary care setting [12,14]; however, like with other adherence aids, the scientific evidence to support these claims is limited [12,15-18]. In general, there are few studies on how patients manage MDD at home and how this affects their daily routines [12,17-19].

In this study, we aim to explore how MDD is used by patients living at home and how the service affects medication self-management and to identify factors influencing medication self-management behavior.

Methods

Study Design

A qualitative approach with face-to-face, semistructured, in-depth interviews was used. We used the 32-item checklist of COREQ (Consolidated Criteria for Reporting Qualitative Research) for the reporting of this study [20].

Setting

All residents in Norway have a legal right to home care services provided by municipalities [9]. In 2022, approximately 172,000 citizens in Norway received home nursing services, with about one-third receiving help with administering medications through MDD services [11].

Municipalities purchase the MDD service from 2 main suppliers in Norway. The packaging fee varies between municipalities due to tender prices, but each municipality can be reimbursed 500 NOK (US $47) per MDD user per year [21]. Home care services are responsible for selecting patients for the MDD service, although it is recommended that both the patient and their general practitioner (GP) are involved in the decision [22]. Once a patient starts MDD, the pharmacist creates an MDD “prescription card” that includes a complete list of prescribed medications, regular medications (both dispensed as MDD and in their original packaging), as-needed medications, medical devices, and dietary supplements. MDD bags are usually dispensed every 2 weeks, while other medications are dispensed in their original packaging from a local pharmacy.

MDD bags do not include package inserts, but the MDD supplier provides a copy of the prescription card, which includes dosing schedules and short descriptions of each medication’s indication for use. They also provide pictures and descriptions of the dispensed medications, including instructions on whether tablets should be swallowed whole, split, or crushed. Some MDD users have automated dispensers for their MDD bags, which can remind them when to take medications and notify home care services if medications are not taken. However, most users manage their medications directly from the MDD bags without dispensers.

Recruitment

Due to privacy reasons, recruitment had to be done via the home care service. The study recruited MDD users from 4 different home care districts in Oslo, targeting both high and low socioeconomic areas. A nurse from each district contacted users and asked if they could give their phone numbers to the first author (AVJ) for participation in this study. The nurses were asked to recruit users with varying levels of independence. The inclusion criteria were MDD use, being 18 years or older, and able to consent. Of 25 - 40 users per district, a total of 21 agreed to be contacted by the researcher (AVJ), 19 ultimately participated in the interview study. The researchers did not know the nurses or informants prior to the study.

Data Collection

An interview guide (Multimedia Appendix 1) was developed by both authors, guided by findings from previous research [23,24]. The 2 main topics of the interview guides were the use of medications and information about medications. Before the interview started, the users were also asked to put their medications in clear view, where appropriate. The interview guide was pilot-tested on 2 MDD users in November 2018, which led to minor changes in the guide. These pilot interviews were not included in the results of this study.

All interviews were completed by the first author (AVJ) in the user’s home. Two interviews had 2 participants (spouses, where both used MDD), the remaining were individual interviews. The interviews lasted from 26 to 86 minutes. Fifteen were recorded on tape and transcribed verbatim by one of the researchers (AVJ). In the remaining 2 interviews, the participants did not want to be audiotaped, and AVJ wrote down the dialogue by shorthand. Immediately after these interviews, AVJ repeated the interviews for herself based on the notes and memory. After completing approximately 15 interviews, no new data emerged; however, 2 additional interviews were made to ensure data saturation [25]. The study was conducted from October 2019 to February 2020.

Authors’ Preunderstanding

The 2 researchers (AVJ and TSB) had different backgrounds providing different perspectives. AVJ is a pharmacist, and at the time of the study, a PhD student in social pharmacy. She has worked at a community pharmacy, providing MDD to nursing home patients, and at an MDD manufacturer for many years prior to this study. TSB is a senior researcher in health service research, with previous 7 years of clinical experience as a registered nurse. Both authors have some experience (3 - 4 studies) with qualitative research.

Data Analyses

The transcripts were coded manually in Microsoft Word (Microsoft Corp). Both authors read, discussed, and structured the transcribed material and participated in the analysis of the data. To identify factors influencing medication self-management, we followed the 6 steps of thematic analysis as described by Braun and Clarke [26]. This resulted in the themes and subthemes shown in the Results section.

Ethical Considerations

This study was approved by the data protection officer at the University Hospital of North Norway (project 02003). Participants were recruited by a home care nurse due to privacy reasons. The participants received both written and oral information, including information about the length of the interviews, anonymity of responses, and data management, before signing an informed consent form. The interviews were labeled with a study identification number and not the informant’s name. During the transcribing, names of persons or places were deleted, and the recordings were deleted after all interviews were transcribed.

Results

Overview

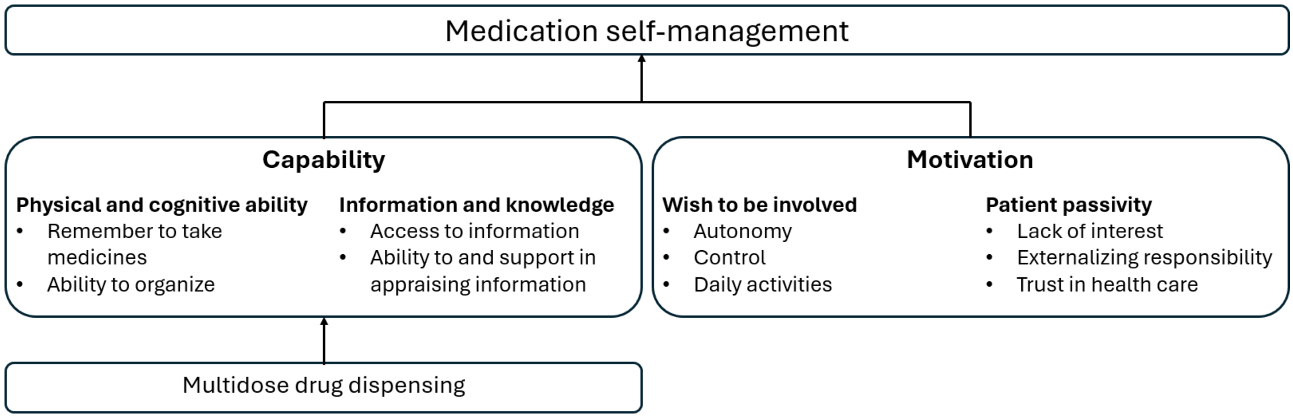
In total, 19 informants were interviewed. The majority (n=14) were female, the age range was from 59 to 92 years (Table 1). All the participants in this study had assistance with medication management from home care. For some, this only included getting the MDD delivered every other week and no other assistance, while for others this included help with both administering medications and other daily living activities several times a day. Two of the users got MDD dispensers.

Table . Characteristics of respondents.

ID	Age (years)	Sex	Home care visits
#1	76	Female	3 per day
#2	62	Female	1 per day
#3	88	Female	2 per month
#4	82	Female	3 per day
#5	71	Male	1 per week
#6	59	Female	2 per day
#7a	88	Male	1 per day
#7b	89	Female	1 per day
#8	87	Female	3 per day
#9	87	Female	1 per day
#10	92	Female	1 per day
#11	82	Male	2 per week
#12	66	Male	2 per month
#13	91	Female	1 per day
#14	72	Female	1 per day
#15	83	Female	2 per day
#16	62	Female	2 per day
#17a	82	Male	3 per day
#17b	82	Female	3 per day

There was a high degree of variation in the informants’ daily medication-taking routines as well as interest and knowledge about medications. We identified four main themes that influence the MDD user’s medication self-management at home: (1) physical and cognitive ability, (2) information and knowledge, (3) wish to be involved, and (4) patient passivity (Figure 1).

Figure 1. Main themes and subcategories of factors influencing medication self-management.



Physical and Cognitive Ability

Participants in the study highlighted the convenience of having MDDs delivered to their homes, eliminating the need to keep track of prescriptions. One participant cited this as the reason for starting MDD, as she was no longer able to walk to the pharmacy to collect her medications and had no other issues with managing them. While some participants faced challenges with opening the bags and experienced tablets falling out; overall, they expressed satisfaction with the MDD system, finding it easier to take medication correctly and appreciating the clear instructions provided.

> *Many old people have declining vision, and it's very easy to make mistakes, but when you have one of these [MDD bags] you cannot make mistakes. Everything is written here, the time to take them and everything [you need]. So, this is one of the best things they [home care] have ever started.* [Participant #15]

Mental capabilities were also discussed as a crucial factor in medication management. Organizing medication use was often cited as a challenge, leading participants or their families to request MDD services when they felt they could no longer safely keep track of their medications. Participants expressed relief in having one less thing to worry about in their daily lives when their medications were organized in the MDD bags.

> *I'm very happy with the MDD (...). Here it says the time and date and everything. Every day, so I don't have to think about it. And the dosing is correct too I assume because it's pharmacists who've done it.* [Participant #5]

While the MDD system did not provide reminders for medication intake, most participants had established routines that helped them remember to take their medications. They linked medication intake to daily activities, such as eating breakfast. Despite the assistance provided by the MDD system in organizing medication use, participants emphasized the importance of personal capacity and the potential for mistakes even with the use of adherence aids like MDD.

> *You know, when you read about things that has happened with medications. Maybe someone has got something they're not supposed to. Imagine that you've started forgetting, that can easily happen. If they have dosette boxes, that doesn't help. You can make mistakes with dosettes.* [Participant #13]

Information and Knowledge

The level of information and knowledge about medication use varied among the study participants. Some had a comprehensive understanding of their prescribed medications, including the reasons for taking them and the correct dosage. However, others had limited knowledge and were unsure why they were taking certain medications. The desire for more information did not necessarily correlate with the participant's level of knowledge. Even those with minimal knowledge expressed satisfaction with the information they received and did not express a desire to learn more.

> *I do get it [information] sometimes. A printed thing. But like I said, I'm not interested in it. I do have it around here somewhere, but I don't really know what's going on (...) I at least hope they [the medicines] don't harm me.* [Participant #4]

While most participants were aware of the prescription card that accompanied their MDD bags, many did not actively use it to keep track of their medications. Some participants found the MDD system helpful because it provided them with information about the names of their medications, which they struggled to remember before. However, there were also participants who felt that the MDD system made it harder for them to maintain an overview of their medications. One participant mentioned that they used to fill their own dosette boxes, which gave them a better understanding of their medications, but after transitioning to the MDD system, they felt they had lost control and struggled to keep track of what they were taking.

Participants expressed difficulties in obtaining the information they desired about their medications. Only a few participants actively used computers or the internet to access information. Some participants missed the information leaflets that were included with medications dispensed in their original packaging, while others desired more information on the prescription card provided with the MDD bags. Some participants felt that it was not just the lack of information itself that was challenging but also the lack of time to discuss their medications with their health care providers and receive help in understanding the information they had received.

> *I have asked [the home workers] many times. You can just read this, but that doesn't help me, I need help to understand it.* [Participant #16]

Wish to Be Involved

The patients who actively participated in the medication management process often expressed a wish or felt the need to be involved in the process. Organizing medication use and taking medications were the 2 steps they were mostly engaged in, but also to some extent seeking information about their medications. One informant phrased this as an active decision that one had to make:

> *You have to want to (...) people can't stand outside of your door telling you they will help you, you have to do something yourself as well. (...) Things don't come by itself. That's how it is with people, we tend to take the easiest way out.* [Participant #15]

Despite receiving medications in the form of MDD, participants still had to establish routines to integrate medication intake into their daily schedules. Many viewed this as the primary reason to engage in medication self-management. Several participants described how they adjusted their medication schedules based on their daily plans and activities, either by bringing the MDD bags with them or modifying the timing of medication intake. Some mentioned receiving assistance with afternoon medications only, as home care services were not available early enough for morning medication help.

Additionally, participants made adjustments to their medication routines based on their health-related needs. For instance, one participant described how she every evening opened the MDD bag for the next morning and took out the painkillers from the bag. She placed these on the nightstand so she could take them as she woke up, while the rest of the medications in the bag she left by the breakfast table to be taken a few hours later.

The desire to maintain independence and a sense of control over their situation motivated some participants to engage in self-management. For them, being able to perform tasks they were capable of themselves, rather than relying entirely on home care workers, was important for their independence and self-esteem.

> *They [home care workers] would prefer to apply the plaster (...) but I do not like being dependent on them doing it. I tell them that I manage it myself, and they have accepted that.* [Participant #10]

For users who had problems with organizing medications, the need to be involved manifested as routines to double-check the home care workers' work or the content of the MDD bags. This included actions such as sorting the tablets into egg glasses or visually inspecting and counting tablets before taking them.

Patient Passivity

All participants stated that they were capable of managing their MDD medications on their own, even those who required assistance with non-MDD medications such as inhalers, creams, or eye drops. However, not all participants took on this responsibility. One participant explained that while she was capable of taking her medications, she believed it was the home care worker's responsibility to provide them, and she only took the MDD bags herself if the home care workers had forgotten to give them to her during their visit. Another participant expressed a lack of interest in learning more about her medications, as she did not see medication management as her responsibility.

> *I take the medicines I am given. If anything goes wrong it is not my fault.* [Participant #4]

In many instances, the lack of engagement in medication self-management seemed to be related to a high level of trust in the GP or the MDD system. Participants expressed a significant amount of trust in their GPs, relying on their decisions and not questioning their prescribing practices. Most participants had been seeing the same GP for a long time and found it easy to contact them if they needed a new prescription or had questions. Given this trust in the GP and the MDD system, participants did not perceive a need to be actively involved in the medication management process.

> *No, I don't know. I take [the medicines] they tell me to take. As long as they're in the multidose bags I don't think more about it. And as you see here, there are pictures of all the tablets.* [Participant #2]

How the MDD System Affects Medication Self-Management

Many of the informants described how the MDD system helped them manage their medications, particularly with removing the need to keep track of prescriptions and help in organizing use. Based on the model of medication self-management by Bailey et al [6], the MDD system, however, affected all 5 initial phases of medication self-management:

- The first step in medication self-management—filling prescriptions and keeping track of prescriptions—was eliminated by the MDD system.
- In terms of understanding how to take medications, the MDD system appeared to reduce patients' ability to keep track of their medications, especially for those who desired and were capable of actively participating in their medication management. On the other hand, for patients who were less interested in self-care, the MDD system had either no impact or a positive one, as it reduced the amount of information they had to process.
- In terms of organizing medication use, the MDD system generally facilitated the organization of medication intake. However, participants still needed to adjust their timings and routines to accommodate their daily schedules.
- When it came to taking medications, the participants reported good overall adherence. However, there were instances of both intentional and unintentional medication nonadherence. The MDD bags provided clear instructions for the safe administration of medications, but they did not inherently help patients remember to take their medications.
- Finally, in terms of monitoring, the absence of information leaflets accompanying the MDD bags seemed to reduce users' knowledge and, consequently, their ability to monitor the effects of their medications. This lack of information

posed a potential drawback to the monitoring phase of medication self-management.

Discussion

Principal Findings

This study explored how MDD users living at home self-manage their medications. All the participants received assistance with medication management from home care. Some participants only got their MDD delivered every other week, while others received help multiple times a day. The level of engagement in medication management varied greatly among patients, primarily dependent on their motivation rather than their actual capabilities. The MDD service showed a positive impact on patient's ability to keep track of and filling prescriptions and on medication organization. However, the service could also adversely affect patient's ability to monitor their medications and decrease their knowledge about them.

Motivation to Participate

Perhaps one of the most obvious factors we found influencing medication self-management was the informants' preferences and motivation for involvement in the process. This came across as a choice informants made, which was not necessarily related to their capabilities of self-management. The reason for wanting to be involved could differ, and the users were thus not necessarily motivated and interested in being involved in all the steps. For instance, individuals who wanted to be involved for the purpose of fitting medication management into their daily schedules were not necessarily motivated to learn more about their medications or how to use them correctly.

In contrast, other participants clearly stated that they were not interested in participating and were happy with simply "following the doctor's orders." This type of "passive" medication user, who trusts their GP and with little interest of more information about their treatment, has also been described in previous studies [27-31]. There seems to be a correlation between increasing age and lower desire for participation [20,31], and in our study, most participants were older patients. The high degree of trust in the doctor's medical expertise is a predictor of medication adherence [21]. However, to accept information without question can also be a sign of inadequate health literacy, which again is associated with poorer medication adherence [22,32].

Patient preferences, while important, may not necessarily indicate how safely patients are managing their medications. Patients relying on their doctor's decisions can still make informed health choices, while those solely relying on their own judgment may make risky decisions [33]. The key lies in recognizing when to act autonomously and when to seek guidance from a physician [21].

Physical and Mental Capabilities

Poor cognition is associated with poor adherence and medication management capacity [7,34]. Informants in our study also stressed the importance of cognitive abilities in relation to medication self-management. Some had started the MDD service because of a decline in cognitive abilities and not being able to dose their medications safely anymore. However, even with adherence aids, such as MDD, informants described that cognitive abilities were still important to be able to manage these safely. This illustrates that even though MDD can support users in parts of medication management, it does not support all the phases of the process [6,35].

It is important to note that patients' capabilities and motivations to manage their medications are not always directly connected. Some capable patients choose not to manage their medications, while others who struggle still want to be involved and develop routines to maintain control, for example, sorting medications into other containers, inspecting or counting tablets, or intentionally adjusting their medication intake to fit their daily schedules. Although such alterations have previously been described as potentially reducing the safety of the MDD system and increasing the risk of medication errors [12,23,28], our participants described them as a way to regain control after transitioning to the MDD system, and in such a way, have a positive effect on their autonomy.

For some patients, MDD solved physical problems, such as difficulty walking to the pharmacy, but questions remain about whether MDD is the right tool for patients with such issues. A previous study from the Netherlands has shown that about 30% of patients with MDD, despite having some challenges, might not have lost their capacity to manage medications [36]. This raises concerns about the appropriateness of the MDD system, especially considering potential negative impacts on other phases of medication self-management.

Knowledge of Medications

Knowledge about medications is crucial for patients' ability to manage them [6,21,33]. However, studies have shown that MDD users often have less knowledge about their medications compared to those with regular prescriptions [37,38]. Many of our informants also described limited knowledge about their own medications, and more worrying some reported that the MDD service made it harder to track medications and reduced their sense of control. This is worrying, as initiation of the MDD service for patients who do not have problems with this part of medication management may lead to patients becoming more passive and less involved in their treatment, ultimately reducing their ability to self-manage medications [28,35,37,38].

However, not all users felt that MDD reduced their knowledge. One informant actually felt that their knowledge improved because the names of the medications were written on the MDD bags. This user was primarily interested in the names, and the MDD service made this information more accessible, empowering them to evaluate it. Our findings suggest that the lack of medication knowledge found in previous studies may be due to a decline in medication management capacity prior to MDD initiation. For patients with low interest or ability to evaluate information, MDD can provide much-needed support and relief, allowing them to feel more confident about correct dosing [28]. This can have a positive effect on autonomy and involvement. Therefore, a user's initial interest and capacity to evaluate medication information are crucial factors in determining whether the MDD service empowers or enables self-management.

Impact on the MDD Service and Policy

When MDD has been implemented in home care, it has been mostly seen as an aid to relieve the burden of dispensing and reduce medication errors [12]; however, this study shows that the service can affect all steps in medication management. It is thus important to consider the user's individual preferences and routines to ensure safe medication use:

- There should be a standardized assessment of the patient's medication management capabilities and motivation before starting MDD to help decide if MDD is the best solution for the patient or whether there are other forms of assistance that would be more beneficial. This assessment should identify which steps of medication management the patients have challenges with as well as to what degree they want to engage in the various steps.
- If MDD is deemed appropriate for the patient, the daily schedule of the patient should be noted so that the MDD bags can be adjusted accordingly (eg, making sure the time printed on the bags corresponds with the time the user gets up in the morning and have meals). This can help users making routines to remember to take medications.
- To ensure that patients have essential information about how to take their medications, the MDD service should make simplified medication information leaflets available to the patients. Patients should also be instructed to report to health care personnel if they experience side effects or other problems with their medication. In addition, home care workers should also have sufficient training to be able to educate and assist patients in understanding their medications better.
- For patients who have a low capacity to self-manage but still want to take an active part, the patients should be encouraged to make routines that provide a sense of control and flexibility (eg, routines for checking the contents of the MDD bags and allow for alterations of the bags under supervision).

Strength and Limitations

This study is one of the few to examine how patients use adherence aids at home [12,17-19]. We included users from diverse socioeconomic backgrounds and with varying levels of home care assistance. However, it is important to note that the participants were all from one municipality, so the findings may not be easily applicable to other municipalities with different organization of home care services. It is also important to consider that patients who were very unhappy with the MDD service may have stopped using it, and their perspectives are not included in this study. Additionally, the voluntary nature of participation and recruitment by home care nurses may introduce a bias toward more empowered patients. Although the researchers have different educational background and age, both are female and Norwegian, and we discussed our sociocultural positions and value systems during the research process to try to limit the effect of preunderstanding bias.

Conclusions

This study gives valuable insight into how the MDD service is used by home care users to support medication self-management. This study indicates that MDD can support users in their medication self-management and increase patient's autonomy. However, the service does not support all phases of the medication process or support self-management for all patients. The degree to which MDD users manage their medications is not necessarily related to their actual capabilities for medication self-management. The patients' own motivation for participating seems to be the most important factor affecting participation.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[PDF File, 222 KB - aging_v7i1e57651_app1.pdf]

References

1. Devik SA, Olsen RM, Fiskvik IL, et al. Variations in drug-related problems detected by multidisciplinary teams in Norwegian nursing homes and home nursing care. Scand J Prim Health Care 2018 Sep;36(3):291-299. [doi: 10.1080/02813432.2018.1499581] [Medline: 30139278]
2. Sorensen L, Stokes JA, Purdie DM, Woodward M, Roberts MS. Medication management at home: medication risk factor prevalence and inter-relationships. J Clin Pharm Ther 2006 Oct;31(5):485-491. [doi: 10.1111/j.1365-2710.2006.00768.x] [Medline: 16958827]
3. Kwint HF, Faber A, Gussekloo J, Bouvy ML. The contribution of patient interviews to the identification of drug-related problems in home medication review. J Clin Pharm Ther 2012 Dec;37(6):674-680. [doi: 10.1111/j.1365-2710.2012.01370.x] [Medline: 22861493]

4. Lenander C, Elfsson B, Danielsson B, Midlöv P, Hasselström J. Effects of a pharmacist-led structured medication review in primary care on drug-related problems and hospital admission rates: a randomized controlled trial. Scand J Prim Health Care 2014 Dec;32(4):180-186. [doi: 10.3109/02813432.2014.972062] [Medline: 25347723]
5. Brown MT, Bussell JK. Medication adherence: WHO cares? Mayo Clin Proc 2011 Apr;86(4):304-314. [doi: 10.4065/mcp.2010.0575] [Medline: 21389250]
6. Bailey SC, Oramasionwu CU, Wolf MS. Rethinking adherence: a health literacy-informed model of medication self-management. J Health Commun 2013;18(Suppl 1):20-30. [doi: 10.1080/10810730.2013.825672] [Medline: 24093342]
7. Marek KD, Antle L. Medication management of the community-dwelling older adult. In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses: Agency for Healthcare Research and Quality; 2008.
8. Sorensen L, Stokes JA, Purdie DM, Woodward M, Roberts MS. Medication management at home: medication-related risk factors associated with poor health outcomes. Age Ageing 2005 Nov;34(6):626-632. [doi: 10.1093/ageing/afi202] [Medline: 16267190]
9. Holm SG, Mathisen TA, Sæterstrand TM, Brinchmann BS. Allocation of home care services by municipalities in Norway: a document analysis. BMC Health Serv Res 2017 Sep 22;17(1):673. [doi: 10.1186/s12913-017-2623-3] [Medline: 28938892]
10. Health at a glance 2019: OECD indicators. OECD Publishing. 2019. [doi: 10.1787/4dd50c09-en]
11. Pharmacy statistics (in Norwegian). Norwegian Pharmacy Association. 2022. URL: http://www.apotek.no/statistikk/apotekstatistikk/kunden [accessed 2024-09-13]
12. Jøsendal AV, Bergmo TS, Granås AG. Multidose drug dispensing in primary care: a review of the literature. In: Olsen RM, Sletvold H, editors. Medication Safety in Municipal Health and Care Services: Cappelen Damm Akademisk; 2022. [doi: 10.23865/noasp.172.ch15]
13. Rechel B. Hub-and-spoke dispensing models for community pharmacies in Europe. Eurohealth (Lond) 2018;24(4):3-6. [doi: 10.23865/noasp.172.ch15]
14. Sæther EM, Aandstad M, Hesthamar B. Multidose drug dispensing: an economic assessment of measures. : Social-og Helsedirektoratet; 2007 PWC-rapport nr 1/2007.
15. Sinnemäki J, Sihvo S, Isojärvi J, Blom M, Airaksinen M, Mäntylä A. Automated dose dispensing service for primary healthcare patients: a systematic review. Syst Rev 2013 Jan 8;2:1. [doi: 10.1186/2046-4053-2-1] [Medline: 23295105]
16. Halvorsen KH, Granas AG. Multi-dose dispensed drugs in Scandinavia—a systematic review of possibilities and limitations [in Norwegian]. Nor Farm Tidsskr 2012;4:22-28.
17. Boeni F, Spinatsch E, Suter K, Hersberger KE, Arnet I. Effect of drug reminder packaging on medication adherence: a systematic review revealing research gaps. Syst Rev 2014 Mar 24;3:29. [doi: 10.1186/2046-4053-3-29] [Medline: 24661495]
18. Mahtani KR, Heneghan CJ, Glasziou PP, Perera R. Reminder packaging for improving adherence to self-administered long-term medications. Cochrane Database Syst Rev 2011 Sep 7(9):CD005025. [doi: 10.1002/14651858.CD005025.pub3] [Medline: 21901694]
19. Mertz L, Tornbjerg K, Nøhr C. User perception of automated dose dispensed medicine in home care: a scoping review. Healthcare (Basel) 2021;9(10):1381. [doi: 10.3390/healthcare9101381]
20. Schneider A, Körner T, Mehring M, Wensing M, Elwyn G, Szecsenyi J. Impact of age, health locus of control and psychological co-morbidity on patients' preferences for shared decision making in general practice. Patient Educ Couns 2006 May;61(2):292-298. [doi: 10.1016/j.pec.2005.04.008] [Medline: 15896943]
21. Náfrádi L, Nakamoto K, Schulz PJ. Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. PLoS One 2017;12(10):e0186458. [doi: 10.1371/journal.pone.0186458] [Medline: 29040335]
22. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health 2013 Jul 16;13:658. [doi: 10.1186/1471-2458-13-658] [Medline: 23855504]
23. Holbø K, Das A, Bøthun S, Formanek MN, Halvorsen T. Multidose service for home dwellers—the users' experiences and a need for new solutions [in Norwegian]. Nord Welfare Res 2019;4(1):20-31. [doi: 10.18261/issn.2464-4161-2019-01-03]
24. Larsen AB, Haugbølle LS. The impact of an automated dose-dispensing scheme on user compliance, medication understanding, and medication stockpiles. Res Social Adm Pharm 2007 Sep;3(3):265-284. [doi: 10.1016/j.sapharm.2006.10.002] [Medline: 17945158]
25. Robson C. Real World Research: Blackwell; 2002.
26. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
27. Dowell J, Hudson H. A qualitative study of medication-taking behaviour in primary care. Fam Pract 1997 Oct;14(5):369-375. [doi: 10.1093/fampra/14.5.369] [Medline: 9472370]
28. Nunney J, Raynor DK, Knapp P, Closs SJ. How do the attitudes and beliefs of older people and healthcare professionals impact on the use of multi-compartment compliance aids? Drugs Aging 2011 May;28(5):403-414. [doi: 10.2165/11587180-000000000-00000]

29. Bell HT, Steinsbekk A, Granas AG. Elderly users of fall-risk-increasing drug perceptions of fall risk and the relation to their drug use—a qualitative study. Scand J Prim Health Care 2017 Sep;35(3):247-255. [doi: 10.1080/02813432.2017.1358438] [Medline: 28793815]
30. Ekdahl AW, Andersson L, Friedrichsen M. “They do what they think is the best for me.” Frail elderly patients’ preferences for participation in their care during hospitalization. Patient Educ Couns 2010 Aug;80(2):233-240. [doi: 10.1016/j.pec.2009.10.026] [Medline: 19945814]
31. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. J Gen Intern Med 2005 Jun;20(6):531-535. [doi: 10.1111/j.1525-1497.2005.04101.x]
32. Miller TA. Health literacy and adherence to medical treatment in chronic and acute illness: a meta-analysis. Patient Educ Couns 2016 Jul;99(7):1079-1086. [doi: 10.1016/j.pec.2016.01.020] [Medline: 26899632]
33. Schulz PJ, Nakamoto K. Health literacy and patient empowerment in health communication: the importance of separating conjoined twins. Patient Educ Couns 2013 Jan;90(1):4-11. [doi: 10.1016/j.pec.2012.09.006] [Medline: 23063359]
34. Hayes TL, Larimer N, Adami A, Kaye JA. Medication adherence in healthy elders: small cognitive changes make a big difference. J Aging Health 2009 Jun;21(4):567-580. [doi: 10.1177/0898264309332836] [Medline: 19339680]
35. Elliott RA. Appropriate use of dose administration aids. Aust Prescr 2014 Apr 1;37(2):46-50. [doi: 10.18773/austprescr.2014.020]
36. Mertens BJ, Kwint HF, van Marum RJ, Bouvy ML. Are multidose drug dispensing systems initiated for the appropriate patients? Eur J Clin Pharmacol 2018 Sep;74(9):1159-1164. [doi: 10.1007/s00228-018-2478-5] [Medline: 29770839]
37. Kwint HF, Stolk G, Faber A, Gussekloo J, Bouvy ML. Medication adherence and knowledge of older patients with and without multidose drug dispensing. Age Ageing 2013 Sep;42(5):620-626. [doi: 10.1093/ageing/aft083] [Medline: 23832265]
38. Modig S, Kristensson J, Ekwall AK, Hallberg IR, Midlöv P. Frail elderly patients in primary care—their medication knowledge and beliefs about prescribed medicines. Eur J Clin Pharmacol 2009 Feb;65(2):151-155. [doi: 10.1007/s00228-008-0581-8] [Medline: 18958457]

Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
GP: general practitioner
MDD: multidose drug dispensing

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Original Paper

Functional Monitoring of Patients With Knee Osteoarthritis Based on Multidimensional Wearable Plantar Pressure Features: Cross-Sectional Study

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Abstract

Background: Patients with knee osteoarthritis (KOA) often present lower extremity motor dysfunction. However, traditional radiography is a static assessment and cannot achieve long-term dynamic functional monitoring. Plantar pressure signals have demonstrated potential applications in the diagnosis and rehabilitation monitoring of KOA.

Objective: Through wearable gait analysis technology, we aim to obtain abundant gait information based on machine learning techniques to develop a simple, rapid, effective, and patient-friendly functional assessment model for the KOA rehabilitation process to provide long-term remote monitoring, which is conducive to reducing the burden of social health care system.

Methods: This cross-sectional study enrolled patients diagnosed with KOA who were able to walk independently for 2 minutes. Participants were given clinically recommended functional tests, including the 40-m fast-paced walk test (40mFPWT) and timed up-and-go test (TUGT). We used a smart shoe system to gather gait pressure data from patients with KOA. The multidimensional gait features extracted from the data and physical characteristics were used to establish the KOA functional feature database for the plantar pressure measurement system. 40mFPWT and TUGT regression prediction models were trained using a series of mature machine learning algorithms. Furthermore, model stacking and average ensemble learning methods were adopted to further improve the generalization performance of the model. Mean absolute error (MAE), mean absolute percentage error (MAPE), and root mean squared error (RMSE) were used as regression performance metrics to evaluate the results of different models.

Results: A total of 92 patients with KOA were included, exhibiting varying degrees of severity as evaluated by the Kellgren and Lawrence classification. A total of 380 gait features and 4 physical characteristics were extracted to form the feature database. Effective stepwise feature selection determined optimal feature subsets of 11 variables for the 40mFPWT and 10 variables for the TUGT. Among all models, the weighted average ensemble model using 4 tree-based models had the best generalization performance in the test set, with an MAE of 2.686 seconds, MAPE of 9.602%, and RMSE of 3.316 seconds for the prediction of the 40mFPWT and an MAE of 1.280 seconds, MAPE of 12.389%, and RMSE of 1.905 seconds for the prediction of the TUGT.

Conclusions: This wearable plantar pressure feature technique can objectively quantify indicators that reflect functional status and is promising as a new tool for long-term remote functional monitoring of patients with KOA. Future work is needed to further explore and investigate the relationship between gait characteristics and functional status with more functional tests and in larger sample cohorts.

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KEYWORDS

knee osteoarthritis; KOA; 40-m fast-paced walk test; 40mFPWT; timed up-and-go test; TUGT; timed up and go; TUG; functional assessment; monitoring; wearable; gait; walk test; plantar; knee; joint; arthritis; gait analysis; regression model; machine learning

Introduction

Knee osteoarthritis (KOA) is a degenerative and irreversible joint disease with typical symptoms including pain, stiffness, decreased joint mobility, and gait disturbance [1,2]. These symptoms worsen with the progression of the disease and may lead to serious treatment consequences, such as total knee replacement and the need for corresponding gait correction rehabilitation training. In recent years, the number of individuals diagnosed with KOA has rapidly increased owing to the aging of the global population and the rising prevalence of obesity. KOA is the primary cause of dysfunction among older adults, placing an extensive burden on both socioeconomic and medical systems [3]. Assessment of physical function in KOA is a crucial component of documenting and evaluating rehabilitation progress [4,5], which will accelerate the establishment of new diagnostic criteria and effective rehabilitation methods [6-8]. Traditional radiography presents limitations as a static assessment tool and cannot achieve long-term dynamic functional monitoring [9]. Both patient-reported outcomes (PROs) and performance-based measures (PBMs) have been used to assess physical function in KOA, but there is no universally recognized gold standard for evaluation [10]. Although PROs are convenient and cost-effective, their high subjectivity and susceptibility to patient's pain and emotions can lead to biased results. Moreover, they are not suitable for individuals with depression or cognitive impairment [5,11]. PBMs are objective and effective evaluation methods, considering factors such as time, cost, equipment, space, and management burden comprehensively. The OARSI (Osteoarthritis Research Society International) recommended a set of performance-based physical function tests, such as the 40-m fast-paced walk test (40mFPWT) and timed up-and-go test (TUGT) [12], whose validity and reliability have been validated by many research reports [13]. However, PBMs still need to be conducted in specific locations, such as hospitals or rehabilitation clinics, and under the supervision of well-trained medical practitioners. Therefore, developing a simple, fast, effective, and user-friendly method for functional assessment is beneficial to relieve the burden on the health care system in society.

Researchers are now able to easily acquire vast amounts of biomedical data through wearable sensors, including pressure sensors [14], inertial measurement units [15,16], and electromyography sensors [17]. The application of machine learning technology for the analyzing and processing of this data facilitates the identification and prediction of human physiological conditions and disease risks [18], thereby offering new opportunities for attaining personalized health care and health management [19]. Plantar pressure signal has shown potential applications in the diagnosis and rehabilitation evaluation of KOA. Studies [20-24] have shown that patients with KOA are prone to abnormal gait or gait dysfunction due to pain, stiffness, limited joint range of motion, and other symptoms, and their gait patterns are specifically characterized by unstable gait and high variability. Naili et al [1] found gait deviations between patients with KOA and healthy population through 3D gait analysis and suggested that PBMs may be more closely associated with overall gait pattern deviations in patients with KOA than PROs or perceived pain. In addition, statistical analysis of foot pressure parameters measured by the F-Scan (Tekscan, Inc) system showed that the pressure in the thumb and heel area of patients with KOA as a percentage of weight was significantly lower than that in healthy people, but the central region was higher [25,26]. Moreover, the center of pressure (COP) path range was smaller in the KOA group than in the healthy group, which may be due to incomplete gait in patients with KOA [27].

Unlike inertial measurement units, plantar pressure sensors provide stable and accurate plantar pressure distribution data, which is essential for accurate gait analysis, without being affected by changes in the wearing position or method. In contrast to force platforms, instrumented treadmills, and 3D gait analysis technologies [28], footwear systems with embedded foot pressure sensors can overcome the limitations of laboratory settings and enable long-term remote monitoring by inconspicuously integrating them into everyday footwear. Previous work on the functional evaluation of KOA using wearable pressure sensors has focused on PROs such as the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) [19,29] and Knee Osteoarthritis Outcome Score [8]. However, the connection between KOA gait characteristics and more objective PBMs has rarely been explored. Table 1 summarizes the differences between important relevant studies and ours per methods, gait features, and objectives.

Therefore, in this study, a wireless in-shoe system integrating a low-cost, high-durability foot pressure sensor was used to collect plantar pressure data during walking for patients with KOA. The performance of the shoe system used has been validated in previous research, demonstrating its ability to effectively monitor human gait dynamics information in real time for daily use, and has been applied to the detection of diabetic feet [30] and fall risk assessment studies in older adults [31,32]. We suggest that there is a mapping correlation between functional performance and gait features in patients with KOA. From the raw plantar pressure data, spatiotemporal parameters were extracted to construct a KOA gait feature database customized for wearable plantar pressure sensors. This construction involved expanding the dimensionality of gait features through mathematical methodologies. Effective feature selection and analysis were performed for the 40mFPWT and TUGT tasks, respectively. The objective of this study is to develop a functional evaluation model using multidimensional plantar pressure features to monitor and assess the functional performance of patients with KOA, potentially serving as a self-managed rehabilitation tool to provide long-term remote dynamic functional monitoring and progress recording for patients with KOA [33].

Table 1. Review of related works.

References	Methods	Gait features	Objectives
Kwon et al [19]	3D gait analysis and machine learning	Kinetic, kinematic, and spatial-temporal data	Develop estimation models for WOMAC[a] scores of patients with KOA[b]
Ofran et al [28]	3D gait analysis and multiple regression analysis	Spatiotemporal gait parameters	Predict common functional tests by spatiotemporal gait parameters in patients post stroke
Wada et al [24]	IMUs[c] and statistical analysis	Scalar product and time features	Clarify the gait characteristics of patients with KOA
Saito et al [25]	Pressure sensors (F-Scan) and statistical analysis	Walking speed, COP[d], %PFP[e], %Long[f], %Trans[g], navicular height ratio, etc.	Clarified foot pressure patterns and hindfoot deformities in KOA and analyzed their associations with foot pain
Ours	Pressure sensors and machine learning	Multidimensional wearable plantar pressure features	Develop a functional assessment model for PBMs[h] scores of patients with KOA

[a] WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index.

[b] KOA: knee osteoarthritis.

[c] IMU: inertial measurement units.

[d] COP: center of pressure.

[e] %PFP: partial foot pressure as the percentage of body weight.

[f] %Long: anteroposterior length of the center of pressure path as a percentage of foot length.

[g] %Trans: transverse width of the center of pressure path as the percentage of foot width.

[h] PBM: performance-based measure.

Methods

Recruitment and Data Collection

The research enlisted 92 adults diagnosed clinically as patients with KOA, exhibiting varying degrees of severity as evaluated by the Kellgren and Lawrence classification. These participants demonstrated independent walking capability for a duration of 2 minutes. All participants were sourced from Zhujiang Hospital of Southern Medical University, and the tests were administered under the guidance of proficiently trained medical personnel.

Participants were thoroughly briefed on the procedures and paradigm of the functional tests before they underwent the assessments. Adequate intervals were implemented between each test session to avoid the impact of fatigue. Successively, the participants underwent the TUGT and 40mFPWT to respectively evaluate the patients' overall functional mobility, balance capacity, short-distance walking performance, and gait speed. The TUGT and 40mFPWT scores indicate the time taken to complete the test, with higher scores representing worse patient function. Table 2 summarizes the participants' demographic characteristics and physical function tests. The results of the Mann-Whitney *U* tests revealed no statistical difference between male and female groups in the 40mFPWT and TUGT outcomes (*P*=.48 and *P*=.50, respectively).

The footwear system used for the collection of plantar pressure data has been detailed in prior studies [30]. Each shoe is equipped with eight integrated pressure sensors capable of detecting vertical ground reaction forces during walking. The sensor position distributions and corresponding pressure-sensing regions are illustrated in Figure 1A. Before formal data collection, participants were required to wear suitable socks and shoes. Ample time was provided for participants to adjust and ensure proper fitting of the shoes before engaging in natural walking. The participants were then asked to walk independently back and forth in a 20 m corridor at a freely walking speed for 2 minutes to simulate everyday locomotor activities. The shoe system collected plantar pressure signal data during walking at a frequency of 20 Hz and transmitted it to a mobile phone in real time via Bluetooth (Bluetooth Special Interest Group; Figure 1B).

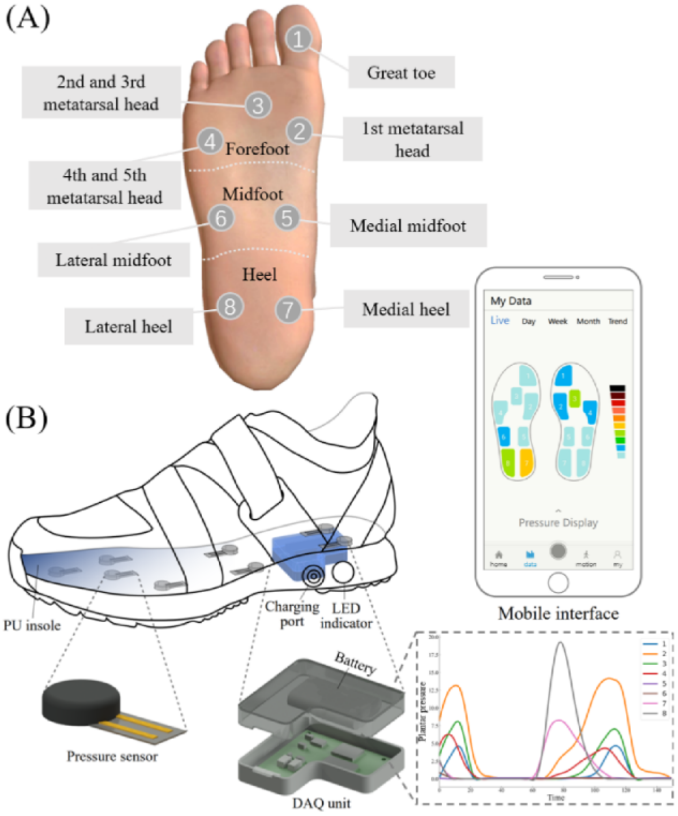
Table 2. Participants' characteristics.

Variable	Values
Age (years), mean (SD)	62.95 (8.4)
Gender, n	
Male	17
Female	75
Height (cm), mean (SD)	158.08 (7.85)
Weight (kg), mean (SD)	61.33 (10.47)
BMI (kg/m²), mean (SD)	24.51 (3.43)
TUGT[a](s), mean (SD)	11.39 (2.99)
40mFPWT[b] (s), mean (SD)	28.61 (6.19)

[a] TUGT: timed up-and-go test.

[b] 40mFPWT: 40-m fast-paced walk test.

Figure 1. (A) Location of sensor deployment. (B) The composition of plantar pressure shoe measurement system. DAQ: data acquisition; PU: polyurethane.



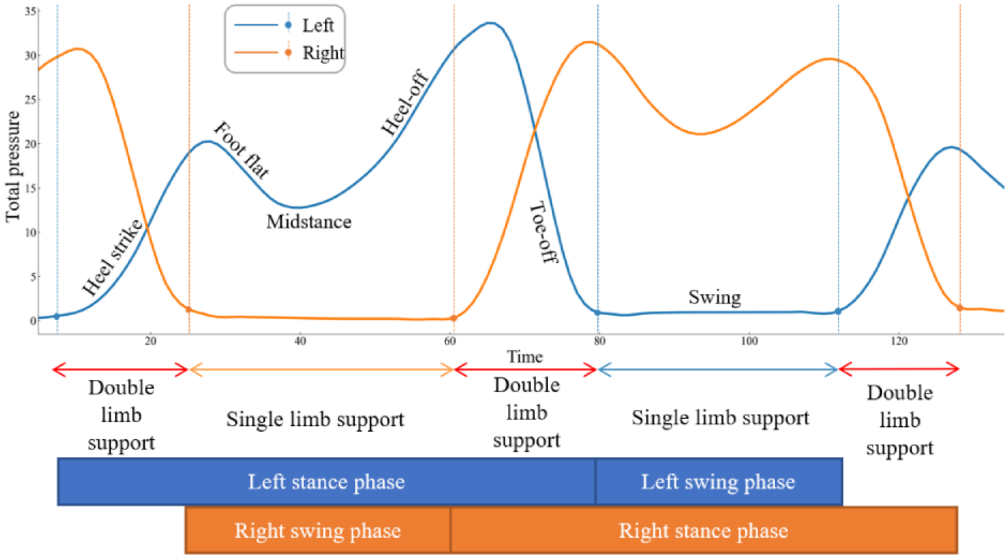
Feature Extraction

Overview

Feature extraction is a crucial step in gait data analysis and should adhere to the following principles. First, the features should have clear biomechanical meaning and be objectively observable. This ensures the physiological relevance of the extracted variables. Second, these features should exhibit generality across all participant types. The second principle is particularly pivotal because generalization directly affects the robustness of machine learning techniques [34]. Human gait is a periodic activity composed of the stance phase and the swing phase. In the stance phase, the pressure sensors in the corresponding regions of the heel, middle foot, and forefoot are activated successively as the gait advances. Before feature extraction, gait cycle segmentation is performed on the acquired temporal signal data of plantar pressure. A single gait cycle is divided by identifying the rise point of the total pressure curve from the 8 sensors when the heel strikes the ground, representing a gait cycle from heel strike to the end of the swing phase. When the toe is off the ground, the total pressure curve drops to its minimum value as the dividing point of the terminal stance and preswing phases, as shown in Figure 2. Excluding the starting step of the first 2 steps, the next 50 gait cycles with the left and right feet adjacent were selected as a sample for feature extraction and analysis.

Multidimensional features would be extracted based on the weight-normalized plantar pressure data obtained by the shoe system. The basic features include the single-foot feature extracted for each foot and the bipedal feature. Then the symmetry coefficient feature, SD feature, and the weak foot feature were calculated based on the single foot feature, which greatly enrich the plantar pressure feature database. We refer to some common plantar pressure feature extraction methods reported in previous studies [25,30,31] and perform corresponding feature extraction according to the sensor deployment position of our plantar pressure shoe measurement system. In addition, we not only focus on the extreme value features of a single sensing unit but also analyze the plantar pressure features corresponding to the transition of different stages in the gait cycle. The relevant features of the single sensing region and the combined sensing region corresponding to the subphases of the stance phase were extracted.

Figure 2. The total VGRF of the left and right feet in a gait cycle and the segmentation points of gait stages are shown. VGRF: vertical ground reaction forces.



Peak Plantar Pressure

Peak plantar pressure (PPP) represents the maximum load on the underfoot area during one step. Taking the left foot as an example, the calculation formula for each sensor's PPP is expressed as equation 1. The maximum pressure values for the eight regions of both the left and right feet are extracted respectively within one step. Here, s ∊ (1,8) denotes the sensor number, $P_s(n)$ represents the pressure data sequence of the corresponding sensor s, and n indicates the time sampling points. $L_{1\text{-}4}$PPP, $L_{5\text{-}6}$PPP, and $L_{7\text{-}8}$PPP represent the peak pressure combination of the sensors corresponding to the left forefoot, middle foot, and heel in one gait cycle, respectively. The total vertical ground reaction forces in a gait cycle exhibit a bimodal pattern, where the first vertical force peak (L_peak1) is caused by a heel strike, and the second peak (L_peak2) is attributed to the forward movement of the center of gravity during walking. The $L_{4/2}$PPP and $L_{8/7}$PPP represents the ratio of peak pressure in the lateral and medial regions of the left forefoot and heel, respectively. In this part, a total of 30 left and right foot features were extracted.

Pressure Gradient

Pressure gradient (PG) quantifies the rate of change of pressure over time, reflecting the rapidity of pressure curve fluctuations beneath the foot during locomotion. Positive PG indicates rapid pressure rises during foot-floor contact phases, while negative PG corresponds to swift pressure declines. The maximum and minimum PG of each sensing curve of both feet can be calculated by equations 2 and 3, where Δt is the sampling time interval. Partial region combination sensing can be used to describe the characteristics of state transition between substages of the gait cycle. For instance, $L_{1\text{-}4}$MaxPG represents the maximum gradient change upward when the center of gravity shifts to the forefoot of the left foot. On the other hand, $L_{1\text{-}4}$MinPG signifies the maximum negative gradient change when the toes lift off the ground, corresponding to the downward pressure curve. The $L_{5\text{-}6}$MaxPG and $L_{5\text{-}6}$MinPG in the midfoot region reflect the pressure change during the foot flat and heel-off phases, respectively. Similarly, $L_{7\text{-}8}$MaxPG and $L_{7\text{-}8}$MinPG in the heel region denote the changes during the heel strike and foot flat phases, respectively. The loading rate (L_loadr) is PG calculated by the first peak pressure and the initial contact pressure of the stance phase. The off-loading rate (L_unloadr) is PG calculated by the second peak pressure and the end pressure of the stance phase. The L_valleyPG represents the sum of the absolute values of the gradient at each sampling point between the 2 peaks for the total pressure curve, describing the degree of pressure variation of the 2 peaks. This section extracts a total of 50 features from both feet.

Temporal Features

As depicted in Figure 2, the gait cycle can be divided into the stance and swing phases. Taking the left foot as an example, the single-foot temporal features include the ratio of time between the stance and swing phases (L_tst/sw), the gait cycle time (L_tT), the ratio of stance phase to gait cycle time (L_tst/T), and the proportion of the time to reach the first ($L_t t_1$/T) and second peaks ($L_t t_2$/T) in the total gait cycle time. Bipedal temporal features include single-limb support time and double-limb support time [35]. This section extracts a total of 12 temporal features.

Pressure Time Integral

By quantifying the accumulated pressure over the duration of the stance phase beneath discrete foot regions, the pressure time integral (PTI) depicts the total mechanical dose imparted to soft tissues during one step. However, PTI shows a high concordance with PPP [36]. To avoid redundancy, only the PTI of the global region is extracted here. PTI from heel strike to the first peak pressure (LPTI_1) and PTI of the stance phase (LPTI_st) were extracted from equation 4. In this part, a total of 4 left and right foot features were extracted.

COP Features

COP is a commonly used dynamic parameter to track weight transfer. During the gait cycle from heel strike to toe-off, a series of coordinates for the COP trajectory can be obtained by calculating the weighted average of all pressure inputs acting on the foot, as defined by equation 5. Here x_s and y_s represent the sensor coordinates, which are converted into a unified coordinate system before computation, considering different shoe sizes [31]. Take the left foot during one step, for example, the mean and SD of COP trajectory in the medial-lateral direction (L_{xcop}mean, L_{xcop}std) and for anterior-posterior direction (L_{ycop}mean, L_{ycop}std) were calculated. Length of the COP trajectory (L_{cop}len) can be calculated by equation 6. The resultant distance (RD) is the Euclidean distance between 2 points in COP coordinates. The mean (L_{cop}MRD) and SD of RD (L_{cop}SRD) can be calculated by equations 7 and 8, respectively [31]. In this part, 14 features of the left and right feet were extracted.

So far, a total of 54 single-foot features and 2 bipedal temporal features during one step have been extracted, and these will be averaged over 50 gait cycles. The following feature construction is to further expand the dimension of gait features through mathematical methods.

Symmetry Index

Asymmetrical gait patterns may be present in patients with KOA with functional impairment [37]. The symmetry index (SI) for the mentioned 54 single-foot features can be calculated by equation 9, where L_f and R_f represent the corresponding left and right foot features, respectively. In this part, 54 corresponding SI features are extracted and named with SI prefixes.

SD Feature

Patients with KOA often exhibit an unstable and highly variable gait pattern. Therefore, it is essential to extract the variability of relevant features across consecutive gait cycles. In this session, the SDs of 108 single foot features on both sides during 50 gait cycles were calculated and named with the suffix STD.

Weak Foot Feature

In previous studies [38], values reflecting lower performance were chosen from the features calculated separately for each leg. To further enhance the value of the extracted data variables and reduce the dependence of predictive models on extraction sides, this study refers to previous research on fall risk prediction in older adults [31] and extracts the weak foot features, that is, the features of the foot with weaker functional performance between the 2 feet. Features derived from the weaker side are posited to perhaps carry more predictive value for functional estimations. Weak foot features can be identified by anterior-posterior direction variability:

In this part, 108 weak-foot features named with the W prefix are extracted from the mean and SD of both foot single-foot features.

Physical Characteristics

Physical characteristics correlate with functional performance, so age, height, weight, and BMI are also included in the feature database.

All extracted features contained in the feature database are listed in Table 3. The related features of the left foot are named with the prefix L and the right foot with the prefix R.

Table 3. List of features.

Kinds of features	Features	Number
Single foot features		
PPP[a]	L_sPPP[b,c], s ∈ (1,8)[d]; L_{1-4}PPP[e]; L_{5-6}PPP[f]; L_{7-8}PPP[g]; L_peak1[h]; L_peak2[i]; $L_{4/2}$PPP[j]; $L_{8/7}$PPP[k]; R_sPPP[l], s ∈ (1,8); R_{1-4}PPP; R_{5-6}PPP; R_{7-8}PPP; R_peak1; R_peak2; $R_{4/2}$PPP; $R_{8/7}$PPP	15×2
PG[m]	L_sMaxPG[m], L_sMinPG[o], s ∈ (1,8); L_{1-4}MaxPG[p]; L_{1-4}MinPG[q]; L_{5-6}MaxPG[r]; L_{5-6}MinPG[s]; L_{7-8}MaxPG[t]; L_{7-8}MinPG[u]; L_loadr[v]; L_unloadr[w]; L_valleyPG[x]; R_sMaxPG, R_sMinPG, s ∈ (1,8); R_{1-4}MaxPG; R_{1-4}MinPG; R_{5-6}MaxPG; R_{5-6}MinPG; R_{7-8}MaxPG; R_{7-8}MinPG; R_loadr; R_unloadr; R_valleyPG	25×2
Temporal	L_tst/sw[y-aa]; L_tT[ab]; L_tst/T; $L_t t_1$/T[ac]; $L_t t_2$/T[ad]; R_tst/sw; R_tT; R_tst/T; $R_t t_1$/T; $R_t t_2$/T	5×2
PTI[ae]	LPTI_1; LPTI_st; RPTI_1; RPTI_st	2×2
COP[af]	L_{xcop}mean[ag]; L_{xcop}std[ah]; L_{ycop}mean[ai]; L_{ycop}std; L_{cop}len[aj]; L_{cop}MRD[ak]; L_{cop}SRD[al]; R_{xcop}mean; R_{xcop}std; R_{ycop}mean; R_{ycop}std; R_{cop}len; R_{cop}MRD; R_{cop}SRD	7×2
Bipedal features	Single limb support time; double limb support time	2
Symmetry index features	SI_f[am]	54
SD features	L_f_STD; R_f_STD	108
Weak foot features	W_f[an]; W_f_STD[ao]	108
Physical characteristics	Age; height; weight; BMI	4

[a] PPP: peak plantar pressure.

[b] L: left foot.

[c] $_s$: sensor.

[d] s: sensor.

[e] $_{1-4}$: forefoot.

[f] $_{5-6}$: middle foot.

[g] $_{7-8}$: heel.

[h] peak1: first vertical force peak.

[i] peak2: second vertical force peak.

[j] $_{4/2}$PPP represents the ratio of peak pressure in the lateral and medial regions of the forefoot.

[k] $_{8/7}$PPP represents the ratio of peak pressure in the lateral and medial regions of the heel.

[l] R: right foot.

[m] PG: pressure gradient.

[n] Min: minimum.

[o] Max: maximum.

[p] $_{1-4}$MaxPG represents the maximum gradient change upward when the center of gravity shifts to the forefoot.

[q] $_{1-4}$MinPG signifies the maximum negative gradient change when the toes lift off the ground, corresponding to the downward pressure curve.

[r] $_{5-6}$MaxPG in the midfoot region reflect the pressure change during the foot flat phase.

[s] $_{5-6}$MinPG in the midfoot region reflect the pressure change during the heel-off phase.

[t] $_{7-8}$MaxPG in the heel region denote the changes during the heel strike phase.

[u] $_{7-8}$MinPG: in the heel region denote the changes during the foot flat phase.

[v] loadr: loading rate.

[w] unloadr: off-loading rate.

[x] valleyPG: the sum of the absolute values of the gradient at each sampling point between the 2 peaks for the total pressure curve, describing the degree of pressure variation of the 2 peaks.

[y] $_t$: time.

[z] st: stance phase.

[aa] sw: swing phase.

[ab] T: gait cycle time.

[ac] t_1: first peak.

[ad] t_1: second peak.

[ae] PTI: pressure time integral.

[af] COP: center of pressure.

[ag] $_x$: medial-lateral direction.

[ah] std: SD.

[ai] $_y$: anterior-posterior direction.

[aj] len: length of the center of pressure trajectory.

[ak] MRD: mean of resultant distance.

[al] SRD: SD of resultant distance.

[am] SI_f: The corresponding symmetry index features of both feet.

[an] W_f: mean value of weak foot features.

[ao] W_f_STD: SD of weak foot features.

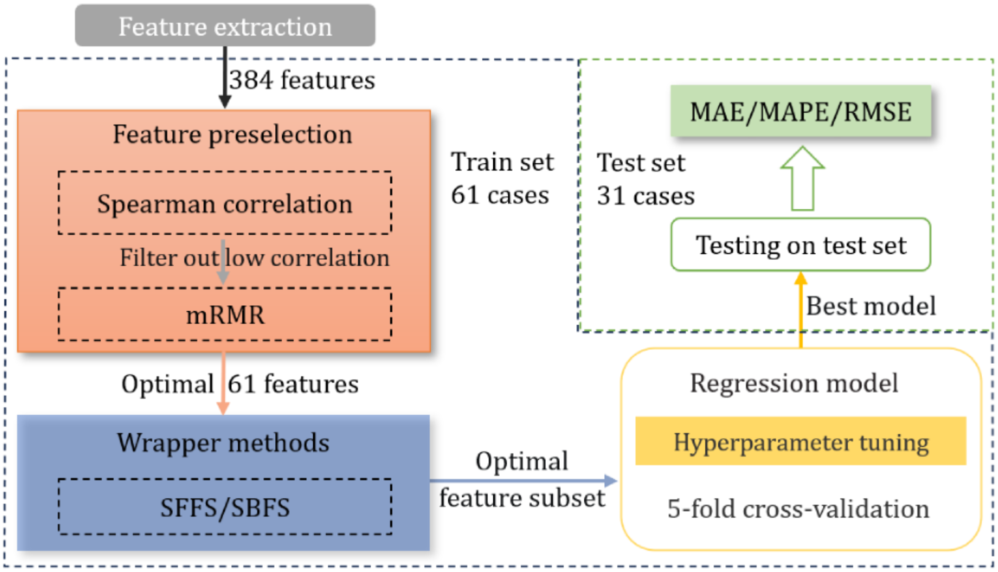
Feature Selection

Overview

In the feature extraction process, a total of 380 gait features and 4 physical characteristics were extracted to form the feature database. For machine learning model training, high-dimensional data not only increases computational workload but also results in severe overfitting, leading to poor generalization performance of the model. Therefore, before developing regression prediction models, it is necessary to undertake feature selection from the extensive feature database to alleviate the curse of dimensionality [39]. If the data of all participants is used during the feature selection process, it may lead to premature use of the testing set in feature selection, causing information leakage and inflating the model's performance. Therefore, before feature selection, we used a holdout method by randomly partitioning 33% (31 cases) of the data as an external testing set, while the remaining 67% (61 cases) of the data is designated as the training set for feature selection, model development, and performance comparison. The testing set is strictly excluded from both the feature selection and model development processes, ensuring that the model exhibits objective and genuine generalization performance when confronted with new participants. Figure 3 illustrates the pipeline of feature selection and model development.

There are various methods for feature selection, mainly categorized into filter, embedded, and wrapper methods. This study used correlation analysis and the filter method, specifically the Minimum Redundancy and Maximum Relevance (mRMR) [40], as a preliminary feature selection. Subsequently, the wrapper methods were used to further determine the optimal feature subset. The stepwise reduction of the feature space through the combination of multiple methods proved effective in identifying valuable features. Meanwhile, principal component analysis [41], a popular feature dimensionality reduction method, was used as a benchmark for comparison to evaluate the effectiveness of the stepwise feature selection approach. The same machine learning model was trained on the reduced datasets and cross-validation was used to evaluate the performance of different methods.

Figure 3. Pipeline of feature selection and model development. MAE: mean absolute error; MAPE: mean absolute percentage error; mRMR: Minimum Redundancy and Maximum Relevance; RMSE: root mean squared error; SBFS: Sequential Backward Floating Selection; SFFS: Sequential Forward Floating Selection.



Spearman Correlation Coefficient

Conducting Spearman correlation analysis between each feature and the corresponding task labels on the training set, features with low correlation ($|r|<0.2$) are eliminated to enhance computational efficiency.

About mRMR

Owing to the possible information redundancy between single-foot features and weak-foot features, it is not conducive to the speed, accuracy, and interpretability of the training results. The mRMR is a minimal-optimal feature selection algorithm that can find a subset of features in a machine learning task that has the greatest correlation with the target variables and the least redundancy between them [40]. Choose the optimal feature for the next feature selection, ensuring that its number does not exceed the number of samples in the training set.

Wrapper Methods

After feature preselection using statistical analysis methods, the wrapper methods based on the machine learning model are used for a more comprehensive feature selection. The wrapper methods determine the optimal feature subset through the average performance of cross-validation. This paper uses Sequential Feature Selection algorithms, including Sequential Forward Floating Selection and Sequential Backward Floating Selection, to automatically determine the optimal feature subset based on their impact on the performance of a user-defined model [42]. These 2 algorithms are implemented using *mlxtend* (version 0.20.0 for Python 3.7; Python Software Foundation) [43].

Regression Model Development and Evaluation

After stepwise feature selection, a subset of features most relevant to the current problem is identified for developing machine learning models. The models considered include linear regression (LR), support vector machine (SVM), random forest (RF), Adaptive Boosting (AdaBoost), Extreme Gradient Boosting (XGBoost), and Light Gradient Boosting Machine (LGBM). Hyperparametric tuning of each model was performed using Optuna (Preferred Networks, Inc) [44] and 5-fold cross-validation was used to evaluate the results.

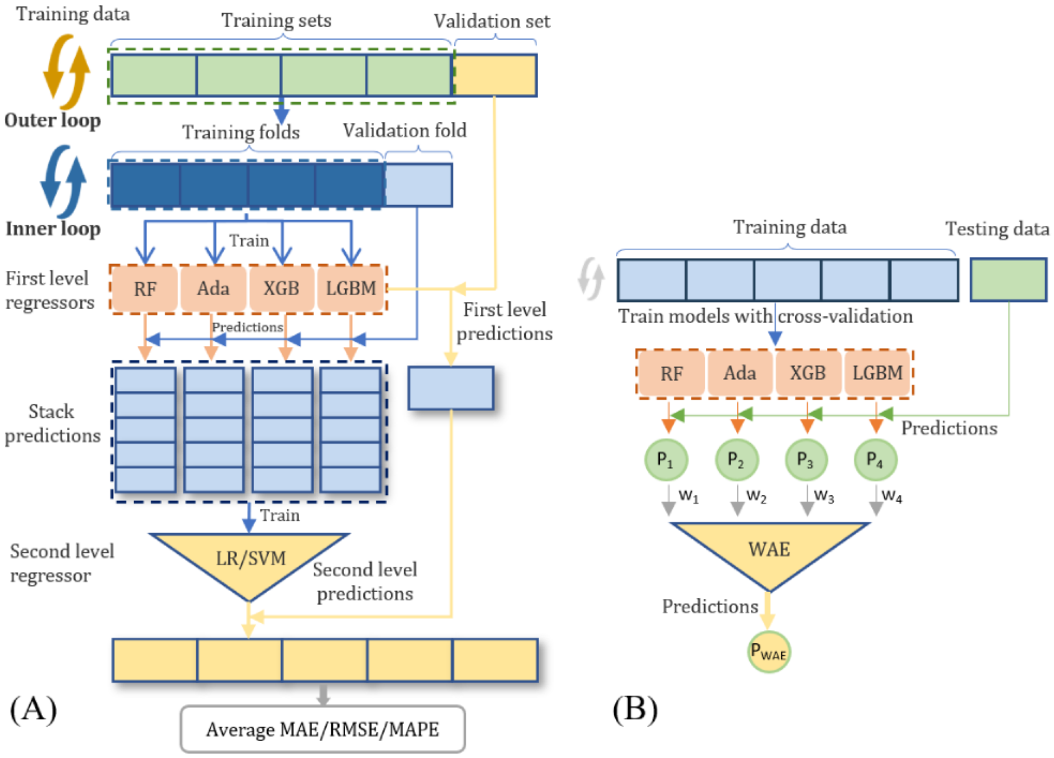
Based on the training results of each model and referring to previous studies [45], the 2-level ensemble learning model was constructed using the stacking regression method [46], as shown in Figure 4A. The training data were randomly partitioned into 5 mutually exclusive subsets, 4 of which were used as 5-fold cross-validation of the inner loop to train the models. At the first level, 4 decision-tree-based regressors including RF, AdaBoost, XGBoost, and LGBM were used to fit the training folds, respectively, and then predict the validation fold. The predictions from these 5 rounds were stacked to form the input features for the second-level regressor, which uses a simple model such as LR or SVM. The validation set of the external loop is used to evaluate the performance of the stacking model and hyperparameter tuning. Additionally, for comparison purposes, simple average ensemble (SAE) and weighted average ensemble (WAE) were also adopted to construct 2-level models for these 4 tree-based models. The final prediction of the SAE model is obtained by taking the average of the predictions from all individual models, while WAE assigns different weights to the predictions of each model according to their performance, allowing models with better performance to have a greater influence on the final prediction, as shown in Figure 4B. The ensemble model can reduce variance, enhance robustness, and improve generalizability by combining the prediction results from multiple models.

Mean absolute error (MAE), mean absolute percentage error (MAPE), and root mean squared error (RMSE) were used as regression performance metrics to evaluate the results of different models [47,48]. To avoid deceiving performance caused by data bias, the average of the known training set labels is used as the prediction of the unknown test set to calculate these metrics as the performance of the baseline model. The improvement of each metric for each model relative to the baseline model is calculated and normalized into a regress relative index (RI) to comprehensively evaluate the model performance [49,50], as shown in equation 11.

Where $model_i$ and $baseline_i$ represent the performance metrics corresponding to each model and the baseline model, respectively.

Models with high RI values will be considered as candidate regressors for 2-level ensemble learning models. The contribution of each model in WAE prediction was weighted according to the proportion of their RI value. The final predicted value $\hat{y}_{WAE}$ of the WAE model can be calculated by equation 12.

Figure 4. (A) Flowchart of stacking regressors with nested 5-fold cross-validation. (B) The prediction process of the WAE model. Ada: Adaptive Boosting; LGBM: Light Gradient Boosting Machine; LR: linear regression; MAE: mean absolute error; P: prediction; RF: random forest; RMSE: root mean squared error; MAPE: mean absolute percentage error; SVM: support vector machine; W: weight; WAE: weighted average ensemble; XGB: Extreme Gradient Boosting.



Ethical Considerations

All experimental procedures were approved by the institutional review board of Zhujiang Hospital of Southern Medical University (IRB 2019-KY-016-02). This study ensures informed consent with the right to withdraw. Participants' privacy is safeguarded through data anonymization. Compensation for human subjects involved a payment of CN ¥200 (CN ¥1=US $0.14) per individual.

Results

Feature Selection Results

Table 4 shows the benchmark experimental results of feature selection, comparing the performance of various algorithms using the RF regressor as the base model, and it can be seen that the method using stepwise feature selection performs better than the principal component analysis algorithm in both tasks.

After applying the Spearman correlation coefficient to filter out low-correlation noise features, the 40mFPWT task retained 161 features and the TUGT task retained 131 features. Then select an optimal subset of 61 features with mRMR, which was set to not exceed the number of training samples. For 40mFPWT, the subset of 11 features identified by the Sequential Backward Floating Selection method yields the best performance. For TUGT, the optimal feature subset determined by the Sequential Forward Floating Selection method consists of 10 features. The optimized feature subsets and Spearman correlation coefficients for both tasks are depicted in Figure 5.

Table 4. Results of benchmark experiment on the feature selection algorithm.

Tasks and methods	MAE[a] (s)	MAPE[b] (%)	RMSE[c] (s)
40 mFPWT[d]			
PCA[e]	4.638	15.223	6.023
SFFS[f]	2.813	9.167	3.791
SBFS[g]	2.698	8.854	3.66
TUGT[h]			
PCA	2.063	17.121	2.771
SFFS	1.589	12.801	2.285
SBFS	1.643	13.38	2.236

[a] MAE: mean absolute error.

[b] MAPE: mean absolute percentage error.

[c] RMSE: root mean squared error.

[d] 40mFPWT: 40-m fast-paced walk test.

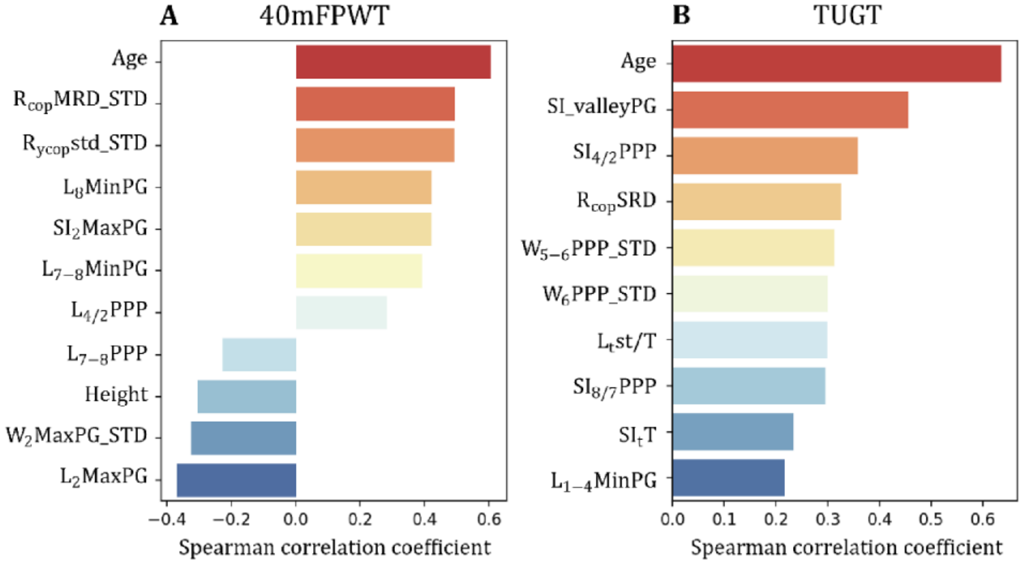
[e] PCA: principal component analysis.

[f] SFFS: Sequential Forward Floating Selection.

[g] SBFS: Sequential Backward Floating Selection.

[h] TUGT: timed up-and-go test.

Figure 5. The optimized feature subsets and Spearman correlation coefficients for (A) the 40mFPWT task and (B) the TUGT task. $_{1\text{-}4}$MinPG: the maximum negative gradient change when the toes lift off the ground, corresponding to the downward pressure curve; $_2$: medial region of the forefoot; $_{4/2}$PPP: ratio of peak pressure in the lateral and medial regions of the forefoot; 40mFPWT: 40-m fast-paced walk test; $_{5\text{-}6}$: middle foot; $_{7\text{-}8}$: heel; $_{7\text{-}8}$MinPG: changes during the foot flat phase in the heel region; $_8$: lateral region of the heel; $_{8/7}$PPP: ratio of peak pressure in the lateral and medial regions of the heel; COP: center of pressure; L: left foot; Max: maximum; Min: minimum; MRD: mean of resultant distance; PG: pressure gradient; PPP: peak plantar pressure; R: right foot; SI: symmetry index; SRD: SD of resultant distance; st: stance phase; std: SD; STD: SD; $_t$: time; T: gait cycle time; TUGT: timed up-and-go test; valley: the sum of the absolute values of the gradient at each sampling point between the 2 peaks for the total pressure curve, describing the degree of pressure variation of the 2 peaks; W: weight; $_y$: anterior-posterior direction.



Evaluation of Machine Learning Regression Model

After feature selection, six regression models were trained and their hyperparameters were tuned using Optuna with 5-fold cross-validation for both the 40mFPWT and TUGT tasks, respectively. RF, AdaBoost, XGBoost, and LGBM were used as first-level regressors for the stacked model, and the performance of LR and SVM as second-level regressors were compared, respectively. SAE combines the predictions from 4 trained tree-based models equally, while WAE weighs the contribution of each ensemble member proportionally based on RI value. The performance of each model compared with the baseline model is shown in Table 5 for 40mFPWT and Table 6 for TUGT. Among individual models, the LGBM model achieved the best predictive performance in the 40mFPWT task, while the XGBoost model performed best in the TUGT task.

The performance of the stacking model using SVM as the second-level regressor is better than that using LR in both tasks. The average integration model using the WAE strategy has better performance than that using SAE in both tasks.

Table 5. Results of cross-validation of regression models in the 40mFPWT[a] training set.

Model	MAE[b] (s)	MAPE[c] (%)	RMSE[d] (s)	RI[e]
Baseline	4.925	16.461	6.219	0
Individual models				
LR[f]	3.793	12.426	4.966	0.676
SVM[g]	3.318	10.653	4.526	0.951
RF[h]	2.59	8.407	3.546	1.393
AdaBoost[i]	2.541	8.137	3.546	1.42
XGBoost[j]	2.495	7.758	3.527	1.455
LGBM[k,l]	2.373[l]	7.473[l]	3.381[l]	1.521[l]
Stacked model				
Stack (linear)	2.518	7.921	3.432	1.456
Stack (SVM)[l]	2.223[l]	6.929[l]	3.152[l]	1.621[l]
Average ensemble				
SAE[m]	2.345	7.42	3.334	1.537
WAE[n,l]	2.34[l]	7.399[l]	3.329[l]	1.54[l]

[a] 40mFPWT: 40-m fast-paced walk test.

[b] MAE: mean absolute error.

[c] MAPE: mean absolute percentage error.

[d] RMSE: root mean squared error.

[e] RI: relative index.

[f] LR: linear regression.

[g] SVM: support vector machine.

[h] RF: random forest.

[i] AdaBoost: Adaptive Boosting.

[j] XGBoost: Extreme Gradient Boosting.

[k] LGBM: Light Gradient Boosting Machine.

[l] the optimal result in the various model methods.

[m] SAE: simple average ensemble.

[n] WAE: weighted average ensemble.

Table 6. Results of cross-validation of regression models in the TUGT[a] training set.

Model	MAE[b] (s)	MAPE[c] (%)	RMSE[d] (s)	RI[e]
Baseline	2.475	20.969	3.267	0
Individual model				
LR[f]	1.739	14.174	2.285	0.922
SVM[g]	1.717	13.859	2.318	0.936
RF[h]	1.538	12.396	2.16	1.126
AdaBoost[i]	1.399	11.218	2.043	1.274
XGBoost[j,k]	1.306[k]	10.365[k]	1.891[k]	1.399[k]
LGBM[l]	1.397	11.012	1.944	1.315
Stacked model				
Stack (linear)	1.473	11.775	2.033	1.221
Stack (SVM)[k]	1.3[k]	10.2[k]	1.873[k]	1.415[k]
Average ensemble				
SAE[m]	1.347	10.701	1.945	1.35
WAE[n,k]	1.339[k]	10.633[k]	1.936[k]	1.359[k]

[a] TUGT: timed up-and-go test.

[b] MAE: mean absolute error.

[c] MAPE: mean absolute percentage error.

[d] RMSE: root mean squared error.

[e] RI: relative index.

[f] LR: linear regression.

[g] SVM: support vector machine.

[h] RF: random forest.

[i] AdaBoost: Adaptive Boosting.

[j] XGBoost: Extreme Gradient Boosting.

[k] the optimal result in the various model methods.

[l] LGBM: Light Gradient Boosting Machine.

[m] SAE: simple average ensemble.

[n] WAE: weighted average ensemble.

Prediction Outcomes for Functional Tests

The best-performing trained models obtained from optimizing hyperparameters on the training set were used to generate predictions for the holdout test set, including the individual model, stacked model, and average ensemble model. The results in the holdout test set for the 40mFPWT are shown in Table 7 and for the TUGT are shown in Table 8. Among all models, the WAE model using 4 tree-based models has the best generalization performance in the test set, with MAE of 2.686 seconds, MAPE of 9.602%, and RMSE of 3.316 seconds for the prediction of 40mFPWT, and for TUGT with MAE of 1.280 seconds, MAPE of 12.389%, and RMSE of 1.905 seconds.

Table 7. Results of the models in the 40mFPWT[a] testing set.

Model	MAE[b] (s)	MAPE[c] (%)	RMSE[d] (s)
Baseline	3.9	14.664	4.515
LGBM[e]	2.918	10.404	3.578
Stack (SVM[f])	2.787	9.77	3.514
WAE[g]	2.686	9.602	3.316

[a] 40mFPWT: 40-m fast-paced walk test.

[b] MAE: mean absolute error.

[c] MAPE: mean absolute percentage error.

[d] RMSE: root mean squared error.

[e] LGBM: Light Gradient Boosting Machine.

[f] SVM: support vector machine.

[g] WAE: weighted average ensemble.

Table 8. Results of the models in the TUGT[a] testing set.

Model	MAE[b] (s)	MAPE[c] (%)	RMSE[d] (s)
Baseline	1.608	15.637	1.999
XGBoost[e]	1.437	13.714	2.128
Stack (SVM[f])	1.465	13.91	2.1
WAE[g]	1.280	12.389	1.905

[a] TUGT: timed up-and-go test.

[b] MAE: mean absolute error.

[c] MAPE: mean absolute percentage error.

[d] RMSE: root mean squared error.

[e] XGBoost: Extreme Gradient Boosting.

[f] SVM: support vector machine.

[g] WAE: weighted average ensemble.

Discussion

Principal Findings

This study developed a functional evaluation model using multidimensional plantar pressure features to predict the functional performance of patients with KOA. The plantar pressure data collected by the shoe system were preprocessed through feature engineering. These features were then input into the trained model to enable prediction and thereby realize functional assessment and monitoring of patients with KOA.

The results of feature selection indicated that age was the most relevant predictor of functional performance on the 2 tasks. It is reasonable that higher age correlated with a longer duration to finish the function tests, and therefore poorer function (Figure 5). Notably, 4 features showed negative correlations with 40mFPWT outcomes (Figure 5A). Specifically, higher values of the $L_{7\text{-}8}$PPP feature were associated with better functionality, aligned with previous findings that individuals with KOA tend to exhibit diminished plantar pressure in the heel region [25,26]. Four SI features were selected for the TUGT task. This is likely because diseases or impairments that impact proprioception or postural stability could thereby influence balance performance on the TUGT by altering one's symmetry [51]. The results showed that plantar pressure–derived features in the forefoot and rearfoot regions, specifically PG and PPP values, exhibited relatively strong correlations with functional test outcomes. In addition, COP-derived features, SI features, and weak foot features were selected and exhibited relatively strong correlations with functional test outcomes. These observed relationships are biologically plausible and concordant with existing understandings of pathological gait patterns in populations with KOA.

The performance of the baseline model, which uses the mean of known labels in the training set as predictions for the test set, provides an unbiased evaluation metric without issues of overfitting or overoptimism. The model-free nature of this design ensures a fair assessment of predictive gains attributable to model architecture rather than data traits. The RI value of each model was obtained by calculating the sum of the improvement of each performance metric relative to the baseline. A higher RI value represents better overall model performance. The results demonstrate that tree-based models outperform LR and SVM models significantly (Tables 3 and 4). Using SVM as the second-level regressor in the stacked model yields better results than LR, primarily attributable to SVM's ability to handle nonlinear relationships and demonstrate robustness against outliers in the data. Within the averaged ensemble framework, the WAE model outperformed the SAE model, possibly due to its weighted aggregation mechanism. The WAE model produced superior outcomes by assigning higher weights to individual models with higher predictive power, thereby generating more refined ensemble predictions.

Due to feature selection being performed on the training set, the models may still overfit the training set even with the use of cross-validation techniques, resulting in overly optimistic performance estimates. Therefore, in general, the model performs better on a training set than on a holdout test set containing unknown samples. The performance on the test set provides a more robust evaluation of the models' generalization capability when encountering new data. The results indicate that the WAE model demonstrated the best generalization performance in both tasks, rather than the stacked model that used SVM as the second-level regressor (Tables 5 and 6). This aligns with the principle of Occam razor in model selection which is to prefer the more parsimonious model when performance is otherwise comparable [52].

Based on the prediction results from the 2 functional tests, the features we extracted appear to have a reasonably close correlation with functional performance. The models demonstrated good generalization for predicting traditional clinical function tests. In the future, the model could be integrated into a terminal application to longitudinally monitor patients' functional status. The identified plantar pressure features could serve as an evaluation tool to guide the rehabilitation and assessment of progress for patients with KOA, offering clear advantages per time efficiency, longitudinal documentation, and accuracy compared to conventional functional tests.

The findings of this study have significant clinical implications for the management and rehabilitation of patients with KOA. The proposed techniques enable continuous, real-time monitoring of patients' functional status beyond clinical settings. This capability facilitates more personalized and timely interventions. By accurately assessing functional performance, patients gain greater insight into their condition thereby improving overall management. Additionally, the system's ability to decrease the frequency of hospital visits and extensive clinical assessments contributes to cost-effectiveness, alleviating the burden on health care systems.

Limitations and Strengths

Several limitations of this study should be noted. First, this study's cohort consisted exclusively of patients diagnosed with KOA without the inclusion of data from healthy control participants for comparative analysis. The validity of the model prediction is limited to the patients' population with KOA. The participant data of this study are mostly female, and the validity of the model may be biased toward female patients. Second, this was a cross-sectional study without long-term longitudinal monitoring of patients in their daily living environments. Third, it only conducted a feasibility study on functional estimation based on wearable plantar pressure features for 2 clinical functional tests recommended by OARSI for KOA. Hence, the proposed techniques require further validation in larger prospective cohorts and preferably multicenter trials to corroborate generalizability.

Despite its limitations, we believe that this wearable plantar pressure technique captures objective quantitative indicators of functional status and has great application value. The preliminary findings indicate this methodology holds promise for enabling remote, quantitative monitoring of rehabilitation progress over time. Further work will refine the system for broader clinical application and validation.

Conclusions

This study aims to develop a lower extremity motor function evaluation model for patients with KOA based on multidimensional gait features, which was suitable for a wearable plantar pressure measurement system. The average performance and variability of left and right foot features were extracted from the raw plantar pressure data. An extensive feature database including 380 gait features and 4 physical characteristics was established by mathematical methodologies. Optimal feature subsets for both tasks are selected after stepwise feature selection including Spearman correlation coefficient, mRMR, and wrapper methods. Individual regression models and a 2-level ensemble learning model were trained for the 40mFPWT and TUGT tasks, respectively. The WAE model that weighs the contribution of each ensemble member proportionally based on RI value has the best performance in the testing set, with an MAE of 2.686 seconds, MAPE of 9.602%, and RMSE of 3.316 seconds for the 40mFPWT and an MAE of 1.280 seconds, MAPE of 12.389%, and RMSE of 1.905 seconds for the TUGT. The proposed technique has the potential to be a novel approach for objectively quantifying the functionally dependent gait features, which could be developed as a tool for the rehabilitation evaluation of motor function in individuals with KOA. This study fills the vacancy in dynamic functional assessment for patients with KOA based on wearable devices. In future work, a variety of sensing technologies will be integrated to evaluate and predict more functional tests, providing more accurate and scientific support in fields such as sports medicine and rehabilitation therapy.

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Conflicts of Interest

None declared.

References

1. Naili JE, Esbjörnsson AC, Iversen MD, Schwartz MH, Hedström M, Häger CK, et al. The impact of symptomatic knee osteoarthritis on overall gait pattern deviations and its association with performance-based measures and patient-reported outcomes. Knee 2017;24(3):536-546. [doi: 10.1016/j.knee.2017.02.006] [Medline: 28279568]
2. Mills K, Hunt MA, Ferber R. Biomechanical deviations during level walking associated with knee osteoarthritis: a systematic review and meta-analysis. Arthritis Care Res (Hoboken) 2013;65(10):1643-1665 [FREE Full text] [doi: 10.1002/acr.22015] [Medline: 23554153]
3. Stetter BJ, Krafft FC, Ringhof S, Stein T, Sell S. A machine learning and wearable sensor based approach to estimate external knee flexion and adduction moments during various locomotion tasks. Front Bioeng Biotechnol 2020;8:9 [FREE Full text] [doi: 10.3389/fbioe.2020.00009] [Medline: 32039192]
4. Mizner RL, Petterson SC, Clements KE, Zeni JA, Irrgang JJ, Snyder-Mackler L. Measuring functional improvement after total knee arthroplasty requires both performance-based and patient-report assessments: a longitudinal analysis of outcomes. J Arthroplasty 2011;26(5):728-737. [doi: 10.1016/j.arth.2010.06.004] [Medline: 20851566]
5. Wright AA, Hegedus EJ, Baxter G, Abbott JH. Measurement of function in hip osteoarthritis: developing a standardized approach for physical performance measures. Physiother Theory Pract 2011;27(4):253-262. [doi: 10.3109/09593985.2010.491150] [Medline: 20649479]
6. Shimoura K, Shimizu H, Iijima H, Suzuki Y, Aoyama T. Functional manifestation in patients with early knee osteoarthritis toward the preservation of joint health -a systematic review and meta-analysis. Osteoarthritis Cartilage 2021;29:S395-S396. [doi: 10.1016/j.joca.2021.02.512]
7. Gandhi R, Tsvetkov D, Davey JR, Syed KA, Mahomed NN. Relationship between self-reported and performance-based tests in a hip and knee joint replacement population. Clin Rheumatol 2009;28(3):253-257. [doi: 10.1007/s10067-008-1021-y] [Medline: 18853222]
8. Nüesch C, Ismailidis P, Koch D, Pagenstert G, Ilchmann T, Eckardt A, et al. Assessing site specificity of osteoarthritic gait kinematics with wearable sensors and their association with patient reported outcome measures (PROMs): knee versus hip osteoarthritis. Sensors (Basel) 2021;21(16):5363. [doi: 10.3390/s21165363] [Medline: 34450828]
9. Laslett LL, Pelletier JP, Cicuttini FM, Jones G, Martel-Pelletier J. Measuring disease progression in osteoarthritis. Curr Treat Options in Rheum 2016;2(2):97-110. [doi: 10.1007/s40674-016-0041-z]
10. Davis AM, King LK, Stanaitis I, Hawker GA. Fundamentals of osteoarthritis: outcome evaluation with patient-reported measures and functional tests. Osteoarthritis Cartilage 2022;30(6):775-785 [FREE Full text] [doi: 10.1016/j.joca.2021.07.016] [Medline: 34534660]
11. Kwon SB, Ro DH, Song MK, Han H, Lee MC, Kim HC. Identifying key gait features associated with the radiological grade of knee osteoarthritis. Osteoarthritis Cartilage 2019;27(12):1755-1760 [FREE Full text] [doi: 10.1016/j.joca.2019.07.014] [Medline: 31400498]
12. Dobson F, Hinman RS, Roos EM, Abbott JH, Stratford P, Davis AM, et al. OARSI recommended performance-based tests to assess physical function in people diagnosed with hip or knee osteoarthritis. Osteoarthritis Cartilage 2013;21(8):1042-1052 [FREE Full text] [doi: 10.1016/j.joca.2013.05.002] [Medline: 23680877]
13. Lee SH, Kao CC, Liang HW, Wu HT. Validity of the Osteoarthritis Research Society International (OARSI) recommended performance-based tests of physical function in individuals with symptomatic Kellgren and Lawrence grade 0-2 knee osteoarthritis. BMC Musculoskelet Disord 2022;23(1):1040 [FREE Full text] [doi: 10.1186/s12891-022-06012-2] [Medline: 36451167]
14. Chen JL, Dai YN, Grimaldi NS, Lin JJ, Hu BY, Wu YF, et al. Plantar pressure ‐ based insole gait monitoring techniques for diseases monitoring and analysis: a review. Adv Mater Technol 2022;7(1):2100566 [FREE Full text] [doi: 10.1002/admt.202100566]
15. Semwal VB, Gaud N, Lalwani P, Bijalwan V, Alok AK. Pattern identification of different human joints for different human walking styles using inertial measurement unit (IMU) sensor. Artif Intell Rev 2021;55(2):1149-1169. [doi: 10.1007/s10462-021-09979-x]
16. Bo F, Yerebakan M, Dai Y, Wang W, Li J, Hu B, et al. IMU-based monitoring for assistive diagnosis and management of IoHT: a review. Healthcare (Basel) 2022;10(7):1210 [FREE Full text] [doi: 10.3390/healthcare10071210] [Medline: 35885736]

17. Tokas P, Semwal VB, Jain S. Deep ensemble learning approach for lower limb movement recognition from multichannel sEMG signals. Neural Comput Appl 2024;36(13):7373-7388. [doi: 10.1007/s00521-024-09465-9]
18. Beam AL, Kohane IS. Big data and machine learning in health care. JAMA 2018;319(13):1317-1318. [doi: 10.1001/jama.2017.18391] [Medline: 29532063]
19. Kwon SB, Ku Y, Han HS, Lee MC, Kim HC, Ro DH. A machine learning-based diagnostic model associated with knee osteoarthritis severity. Sci Rep 2020;10(1):15743 [FREE Full text] [doi: 10.1038/s41598-020-72941-4] [Medline: 32978506]
20. Kour N, Gupta S, Arora S. A survey of knee osteoarthritis assessment based on gait. Arch Computat Methods Eng 2020;28(2):345-385. [doi: 10.1007/s11831-019-09379-z]
21. Lidtke RH, Muehleman C, Kwasny M, Block JA. Foot center of pressure and medial knee osteoarthritis. J Am Podiatr Med Assoc 2010 May;100(3):178-184. [doi: 10.7547/1000178] [Medline: 20479447]
22. Kato N, Fukusaki C, Leetawesup K, Kadokura Y, Ishii N. Improvement in gait asymmetry during nordic walking in patients with lower extremity osteoarthritis. JPFSM 2020;9(2):65-73. [doi: 10.7600/jpfsm.9.65]
23. Chen Z, Shen Z, Ye X, Wu J, Wu H, Xu X. Association between foot posture asymmetry and static stability in patients with knee osteoarthritis: a case-control study. Biomed Res Int 2020;2020:1890917. [doi: 10.1155/2020/1890917] [Medline: 32596282]
24. Wada S, Murakami H, Tajima G, Maruyama M, Sugawara A, Oikawa S, et al. Analysis of characteristics required for gait evaluation of patients with knee osteoarthritis using a wireless accelerometer. Knee 2021;32:37-45. [doi: 10.1016/j.knee.2021.07.002] [Medline: 34375906]
25. Saito I, Okada K, Wakasa M, Abe H, Saito A. Foot pressure pattern, hindfoot deformities, and their associations with foot pain in individuals with advanced medial knee osteoarthritis. Gait Posture 2018;59:83-88. [doi: 10.1016/j.gaitpost.2017.09.041] [Medline: 29028624]
26. Saito I, Okada K, Nishi T, Wakasa M, Saito A, Sugawara K, et al. Foot pressure pattern and its correlation with knee range of motion limitations for individuals with medial knee osteoarthritis. Arch Phys Med Rehabil 2013;94(12):2502-2508. [doi: 10.1016/j.apmr.2013.07.017] [Medline: 23916619]
27. Panyarachun P, Angthong C, Jindasakchai P, Rajbhandari P, Rungrattanawilai N. Abnormal foot pressure in older adults with knee osteoarthritis: a systematic review. Eur Rev Med Pharmacol Sci 2022;26(17):6236-6241 [FREE Full text] [doi: 10.26355/eurrev_202209_29646] [Medline: 36111924]
28. Ofran Y, Karniel N, Tsenter J, Schwartz I, Portnoy S. Functional gait measures prediction by spatiotemporal and gait symmetry in individuals post stroke. J Dev Phys Disabil 2019;31(5):611-622. [doi: 10.1007/s10882-019-09664-6]
29. Ornetti P, Maillefert JF, Laroche D, Morisset C, Dougados M, Gossec L. Gait analysis as a quantifiable outcome measure in hip or knee osteoarthritis: a systematic review. Joint Bone Spine 2010;77(5):421-425. [doi: 10.1016/j.jbspin.2009.12.009] [Medline: 20471899]
30. Wang D, Ouyang J, Zhou P, Yan J, Shu L, Xu X. A novel low-cost wireless footwear system for monitoring diabetic foot patients. IEEE Trans Biomed Circuits Syst 2021;15(1):43-54. [doi: 10.1109/TBCAS.2020.3043538] [Medline: 33296308]
31. Song Z, Ou J, Shu L, Hu G, Wu S, Xu X, et al. Fall risk assessment for the elderly based on weak foot features of wearable plantar pressure. IEEE Trans Neural Syst Rehabil Eng 2022;30:1060-1070. [doi: 10.1109/TNSRE.2022.3167473] [Medline: 35420987]
32. Wu S, Ou J, Shu L, Hu G, Song Z, Xu X, et al. MhNet: multi-scale spatio-temporal hierarchical network for real-time wearable fall risk assessment of the elderly. Comput Biol Med 2022;144:105355. [doi: 10.1016/j.compbiomed.2022.105355] [Medline: 35286891]
33. Feng Y, Liu Y, Fang Y, Chang J, Deng F, Liu J, et al. Advances in the application of wearable sensors for gait analysis after total knee arthroplasty: a systematic review. Arthroplasty 2023;5(1):49 [FREE Full text] [doi: 10.1186/s42836-023-00204-4] [Medline: 37779198]
34. Best R, Begg R. Overview of movement analysis and gait features. In: Computational Intelligence for Movement Sciences. Hershey, PA: IGI Global; 2006:1-69.
35. Elbaz A, Mor A, Segal O, Agar G, Halperin N, Haim A, et al. Can single limb support objectively assess the functional severity of knee osteoarthritis? Knee 2012;19(1):32-35. [doi: 10.1016/j.knee.2010.12.004] [Medline: 21269835]
36. Melai T, IJzerman TH, Schaper NC, de Lange TLH, Willems PJB, Meijer K, et al. Calculation of plantar pressure time integral, an alternative approach. Gait Posture 2011;34(3):379-383 [FREE Full text] [doi: 10.1016/j.gaitpost.2011.06.005] [Medline: 21737281]
37. Wu J, Wu B. The novel quantitative technique for assessment of gait symmetry using advanced statistical learning algorithm. Biomed Res Int 2015:528971 [FREE Full text] [doi: 10.1155/2015/528971] [Medline: 25705672]
38. Elbaz A, Mor A, Segal G, Debi R, Shazar N, Herman A. Novel classification of knee osteoarthritis severity based on spatiotemporal gait analysis. Osteoarthritis Cartilage 2014;22(3):457-463 [FREE Full text] [doi: 10.1016/j.joca.2013.12.015] [Medline: 24418677]
39. Lever J, Krzywinski M, Altman N. Model selection and overfitting. Nat Methods 2016;13(9):703-704. [doi: 10.1038/nmeth.3968]

40. Zhao Z, Anand R, Wang M. Relevance and minimum redundancy feature selection methods for a marketing machine learning platform. 2019 Presented at: IEEE International Conference on Data Science and Advanced Analytics; Oct 3, 2019; Washington, DC p. 5-8. [doi: 10.1109/dsaa.2019.00059]
41. Abdi H, Williams LJ. Principal component analysis. WIREs Computational Stats 2010;2(4):433-459 [FREE Full text] [doi: 10.1002/wics.101]
42. Nakariyakul S, Casasent DP. An improvement on floating search algorithms for feature subset selection. Pattern Recognition 2009;42(9):1932-1940. [doi: 10.1016/j.patcog.2008.11.018]
43. Raschka S. MLxtend: Providing machine learning and data science utilities and extensions to Python’s scientific computing stack. JOSS 2018;3(24):638.
44. Akiba T, Sano S, Yanase T, Ohta T, Koyama M. Optuna: a next-generation hyperparameter optimization framework. 2019 Presented at: The 25th ACM SIGKDD Conference on Knowledge Discovery and Data Mining; Aug 8, 2019; Anchorage, AK. [doi: 10.1145/3292500.3330701]
45. Zhang Y, Zhang L, Hua H, Jin J, Zhu L, Shu L, et al. Relaxation degree analysis using frontal electroencephalogram under virtual reality relaxation scenes. Front Neurosci 2021;15:719869 [FREE Full text] [doi: 10.3389/fnins.2021.719869] [Medline: 34630012]
46. Breiman L. Stacked regressions. Mach Learn 1996;24(1):49-64. [doi: 10.1007/bf00117832]
47. Shcherbakov M, Brebels A, Shcherbakova NL, Tyukov A, Janovsky TA, Kamaev VA. A survey of forecast error measures. World Applied Sciences Journal 2013;24(24):171-176. [doi: 10.5829/idosi.wasj.2013.24.itmies.80032]
48. Botchkarev A. A new typology design of performance metrics to measure errors in machine learning regression algorithms. IJIKM 2019;14:045-076. [doi: 10.28945/4184]
49. Chou JS, Chiu CK, Farfoura M, Al-Taharwa I. Optimizing the prediction accuracy of concrete compressive strength based on a comparison of data-mining techniques. J Comput Civ Eng 2011;25(3):242-253. [doi: 10.1061/(asce)cp.1943-5487.0000088]
50. Cheng MY, Firdausi PM, Prayogo D. High-performance concrete compressive strength prediction using Genetic Weighted Pyramid Operation Tree (GWPOT). Eng Appl Artif Intell 2014;29:104-113. [doi: 10.1016/j.engappai.2013.11.014]
51. Lawson T, Morrison A, Blaxland S, Wenman M, Schmidt CG, Hunt MA. Laboratory-based measurement of standing balance in individuals with knee osteoarthritis: a systematic review. Clin Biomech (Bristol, Avon) 2015;30(4):330-342. [doi: 10.1016/j.clinbiomech.2015.02.011] [Medline: 25735929]
52. Piasini E, Liu S, Chaudhari P, Balasubramanian V, Gold JI. How Occam's razor guides human decision-making. bioRxiv Preprint posted online on February 8, 2023 [FREE Full text] [doi: 10.1101/2023.01.10.523479] [Medline: 36712067]

Abbreviations

40mFPWT: 40-m fast-paced walk test
AdaBoost: Adaptive Boosting
COP: center of pressure
KOA: knee osteoarthritis
LGBM: Light Gradient Boosting Machine
LR: linear regression
MAE: mean absolute error
MAPE: mean absolute percentage error
mRMR: Minimum Redundancy and Maximum Relevance
OARSI: Osteoarthritis Research Society International
PBM: performance-based measure
PG: pressure gradient
PPP: peak plantar pressure
PRO: patient-reported outcome
PTI: pressure time integral
RD: resultant distance
RF: random forest
RI: relative index
RMSE: root mean squared error
SAE: simple average ensemble
SI: symmetry index
SVM: support vector machine
TUGT: timed up-and-go test
WAE: weighted average ensemble
WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index
XGBoost: Extreme Gradient Boosting

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Development and Usability of an Advance Care Planning Website (My Voice) to Empower Patients With Heart Failure and Their Caregivers: Mixed Methods Study

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Abstract

Background: Web-based advance care planning (ACP) interventions offer a promising solution to improve ACP engagement, but none are specifically designed to meet the needs of patients with heart failure and their caregivers.

Objective: We aimed to develop and assess the usability and acceptability of a web-based ACP decision aid called “My Voice,” which is tailored for patients with heart failure and their caregivers.

Methods: This study’s team and advisory board codeveloped the content for both patient and caregiver modules in “My Voice.” Using a mixed methods approach, we iteratively tested usability and acceptability, incorporating feedback from patients, caregivers, and health care professionals (HCPs).

Results: We interviewed 30 participants (11 patients, 9 caregivers, and 10 HCPs). Participants found the website easy to navigate, with simple and clear content facilitating communication of patients’ values and goals. They also appreciated that it allowed them to revisit their care goals periodically. The average System Usability Scale score was 74 (SD 14.8; range: 42.5-95), indicating good usability. Over 80% (8/11) of patients and 87% (7/8) of caregivers rated the website’s acceptability as good or excellent. Additionally, 70% (7/10) of HCPs strongly agreed or agreed with 11 of the 15 items testing the website’s acceptability.

Conclusions: “My Voice” shows promise as a tool for patients with heart failure to initiate and revisit ACP conversations with HCPs and caregivers. We will evaluate its efficacy in improving patient and caregiver outcomes in a randomized controlled trial.

Trial Registration: ClinicalTrials.gov NCT06090734; https://clinicaltrials.gov/study/NCT06090734

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KEYWORDS

advance care planning; decision aid; heart; website; heart failure; care plan; caregiver; usability; acceptability

Introduction

Advance care planning (ACP) is a process to support individuals in understanding and sharing their values, goals, and preferences regarding medical care [1]. Systematic reviews by our team reveal that while ACP may not consistently result in goal-concordant care for patients [2], improve their quality of life, or reduce health care expenditures, it can enhance communication of patient values and goals with health care professionals (HCPs) and caregivers or surrogate decision makers [3,4]. This, in turn, equips patients, caregivers, and HCPs to be better prepared for making in-the-moment health care decisions, emphasizing “preparation” rather than “planning” as an objective for ACP [5]. This emphasis on preparation is crucial, considering that most patients and caregivers are often unprepared for making these decisions [6]. Effective preparation involves educating patients about their illness and enabling them to share their values and goals with their doctors and surrogate decision makers.

Despite these clear benefits, ACP completion rates remain low worldwide [7-12]. This is particularly concerning for patients with conditions such as heart failure, which have an unpredictable clinical trajectory that makes prognostication difficult. This uncertainty in prognosis often leads to delays or avoidance of ACP conversations [13,14]. Furthermore, ACP conversations and documentation require substantial time and effort, often dissuading clinicians from initiating them [15-17]. Patients themselves may lack the readiness, initiative, and knowledge to initiate these conversations [18-21]. Most notably, even when ACP conversations happen, they are conducted as a one-time occurrence rather than as part of an ongoing process [2]. Our previous research has revealed that patients’ care goals change over time, thus limiting the value of one-time ACP conversations, and requiring that ACP conversations be revisited periodically [22-25].

To enhance ACP completion rates among patients with heart failure and foster a truly patient-centered approach, it is crucial to empower patients to initiate ACP conversations with their caregivers and HCPs. ACP web-based decision aids offer a promising solution, preparing patients for these conversations while alleviating the time burden for clinicians. Yet, a scoping review of 11 web-based ACP decision aids for patients identified only two applicable for patients with heart failure, with only one specifically tailored for this group [26,27]. Furthermore, while these decision aids also hold promise for enabling periodic patient-driven revisions and providing access to the latest updates on patients’ evolving care goals, none of the existing decision aids incorporated mechanisms to promote a systematic reconsideration of patients’ care goals. With the exception of few web-based decision aids, most existing ACP decision aids also do not encourage the active involvement of caregivers in the ACP process, and simply coach patients to engage with them [28-33]. The latter is particularly pertinent given the crucial role caregivers play in the decision-making process in many settings including Singapore, where this study is based [34].

To address these gaps, we developed “My Voice,” a web-based ACP decision aid tailored for patients with heart failure and their caregivers. It educates users about their illness, enables sharing and systematic reconsideration of patients’ values and goals, and actively involves caregivers. This paper aims to present the development process, and usability and acceptability of “My Voice” among patients, caregivers, and HCPs. Given the extensive engagement with patient representatives and HCPs during its development, we hypothesize that “My Voice” will meet the standardized System Usability Scale (SUS) score cutoff of 68, as proposed by Lewis and Sauro [35].

Methods

Development of ”My Voice”

Between April 2022 and May 2023, we engaged in an extensive process involving literature reviews, examining existing ACP decision aids, and consultations with a study team comprising diverse experts including health services researchers, cardiologists, palliative care physicians, social workers, communication coaches, and information technology professionals. We also established a study advisory board consisting of patient representatives and HCPs trained to conduct ACP conversations and gathered their inputs regarding content and structure for the interactive web-based application “My Voice.” Guided by the COM-B model that focuses on capability (C), opportunity (O), motivation (M) to enhance behaviors (B) [36], “My Voice” aimed to improve patients’ capability for engaging in ACP conversations, creating opportunities for them to have these conversations and revisit them periodically, and motivating them to do so.

A professional production house produced narration-style videos featuring HCPs from this study’s team. The website content and videos were initially developed in English and subsequently professionally translated into two local languages (Mandarin and Malay) to ensure inclusivity and accessibility. Upon completion of the content development phase, we developed the initial prototype of “My Voice.” To ensure the security of participants’ identifiable information, we incorporated password protection and a two-factor authorization process. The research team obtained relevant institutional approvals at all stages of web application development.

Description of “My Voice”

“My Voice” includes patient and caregiver modules. The patient module consists of a series of educational videos lasting 1-2 minutes each, organized into five steps: (1) learn about heart failure, (2) think about what is important to you, (3) why and how to choose a spokesperson, (4) speak to your doctor about what is important to you, and (5) revisit “My Voice.”

In addition to the videos, step 1 includes a knowledge quiz. Step 2 incorporates questions to elicit patient values and goals (referred to as value clarification questions), which were based on the Serious Illness Conversation Guide [37]. Step 3 provides fields for nominating up to two surrogate decision makers, known locally as the nominated health care spokespersons. Upon completion of step 5, the patients’ responses to the value clarification questions and the details of their spokespersons are automatically populated into a summary document called the “My Voice” document. Patients can view and edit the document before it is saved on the website. The website then triggers automated emails and phone text messages containing the document to both patients and their designated surrogate decision makers. Patients and their designated surrogate decision makers can also view and print the document anytime through the website. The website also sends phone reminders to patients to revisit “My Voice.” Multimedia Appendix 1 highlights select pages from the “My Voice” website.

The caregiver module includes educational videos lasting 1-2 minutes structured into three steps: (1) learn about heart failure, (2) talk to your loved one, and (3) support your loved one. As with the patient module, step 1 incorporates a knowledge quiz. At the end of the module, caregivers have the option to view the patient's "My Voice" document.

Between May and August 2023, we recruited a convenience sample of patients with heart failure, their caregivers, and HCPs, from four public hospitals in Singapore. These groups of participants are the key stakeholders in ACP conversations, and hence best positioned to provide feedback on the website. We recruited patients from outpatient clinics and wards, based on the following inclusion criteria: (1) adults aged 21 years or older; (2) diagnosed with heart failure; (3) Singaporean or permanent resident; (4) able to understand either English, Mandarin, or Malay; and (5) willing to use a web-based intervention. Caregivers of the above eligible patients were approached independently and included if they consented. Caregivers were: (1) adults aged 21 years or older; (2) providing informal care or ensuring the provision of care, or serving as the main decision maker for the patients with heart failure with no expectation of financial compensation; (3) able to understand either English, Mandarin or Malay; and (4) willing to engage with a web-based intervention. HCPs from department of cardiology namely cardiologists, cardiology nurses, and medical social workers trained in having ACP conversations were included.

Testing Procedure

We used a mixed methods design incorporating both qualitative interviews that provided feedback to iteratively revise the website's content and design to improve the overall user experience, and quantitative surveys to estimate the website functionalities including its usability and acceptability. The results from qualitative and quantitative sections were integrated during interpretation as a narrative discussion.

Trained research staff (IC and SNK) conducted usability testing on a tablet device provided by the research team. Patients and caregivers viewed their respective modules while HCPs viewed both modules. On viewing the relevant modules, participants responded to open-ended questions during a qualitative interview and answered a brief questionnaire. Research staff facilitated navigation and ensured participants viewed all steps. All study procedures were completed in one sitting.

Qualitative Feedback

A topic guide developed by the research team based on concepts from the user-experience model [38]. The guide comprised of open-ended questions eliciting participants' perceptions and satisfaction with the design and content of the website, and feedback for enhancement. Questions were tailored for each participant group (Multimedia Appendix 2). Participants were given time to explore and navigate each page of the website. Subsequently, they were prompted to provide feedback on the website's navigational ease, and clarity of on-page explanations for each step. Research staff facilitated website navigation and ensured the participants completed all steps. Specifically, patients and HCPs were probed on the comprehensibility of the value-clarification questions and whether they could easily select their preferred answers from a potential list of response options. Their suggestions for refining the questions and the response options were elicited. Lastly, participants were asked about their overall impressions of the website, its perceived usefulness, aspects they liked most or least, and recommendations for improvement. Participant responses were audio-recorded and transcribed (to English if conducted in Mandarin or Malay) for analysis. The interviews were conducted in a private room within the health care facility and lasted between 30 - 80 minutes. We analyzed qualitative data concurrently with data collection. Data saturation was achieved by the 27th interview, when no new feedback about the website emerged.

Survey

After viewing the respective modules, participants answered a survey in the language participants viewed the website (English, Mandarin, or Malay). The survey collected demographic information, and questions assessing usability and acceptability. Usability was evaluated by the 10-item SUS; each item was rated on a 5-point Likert scale (strongly disagree to strongly agree) [39,40]. We assessed acceptability using the acceptability rating scale developed by the Ottawa Hospital Research Institute adapting it to specific decision-making aspects of our study [41]. Patients and caregivers, rated items on a 4-point Likert scale ranging from poor to excellent (score: 1 - 4), and for HCPs used a 5-point Likert scale ranging from strongly disagree to strongly agree (score: 1 - 5). Example items included, "it will be easy for me to use 'My Voice' for introducing ACP to my patients" and "this 'My Voice' website is better than how I usually go about conducting ACP" [41]. Lastly, patients and caregivers rated the length (too long, too short, or just right) and amount of information (too much, too little, or just right) for "My Voice."

The surveys were first developed in English and then translated by native speakers into Mandarin and Malay and verified by a second team member fluent in the language. Before fielding, the surveys were tested with volunteers from a nonclinical setting.

Sample Size

Previous literature suggests that a sample of 20 participants can identify 95% of usability problems [42]. Thus, a sample size of 30 was deemed to be sufficient for usability testing. Previous studies assessing usability of digital interventions also had similar sample sizes [43].

Data Analysis

Two authors CR and IC analyzed the open-ended interview transcripts using qualitative description methodology [44]. We categorized the interview feedback from participants into broad concepts (eg, language or layout) paying close attention to positive and negative views toward the website to derive themes and subthemes inductively. The two authors verified each other's coding carried out in Excel (Microsoft Corp), discussed and agreed upon the final themes derived. From the survey data we described participants' demographic and health status characteristics. We also calculated the total SUS score as a sum of each item score and rescaled it within the range of 0 to 100. A higher score signified greater usability, and a score greater than 68 indicated good usability [39,40]. We then present the total scores for each participant group and overall sample. For each item on the acceptability scale, we calculated the proportion of patients and caregivers responding as good or excellent and HCPs rating as agree or strongly agree.

Ethical Considerations

This study was approved by the SingHealth Centralized Institutional Review Board in Singapore (2022/2482) and was conducted in compliance to the institutional guidelines. Participants were briefed on this study's purpose and had the option to withdraw at any time. We obtained written informed consent and provided US $20 cash as compensation upon completion of usability testing procedures. All data was deidentified to protect participants' privacy and confidentiality.

Results

Participant Characteristics

A total of 30 participants out of 44 (response rate 68%) consented including 11 patients, 9 caregivers, and 10 HCPs. Among them 21 (10 HCPs, 6 patients, and 5 caregivers) reviewed the English version, 7 (4 patients and 3 carergivers) reviewed the Mandarin version, and 2 (1 patient and 1 caregvier) reviewed the Malay version of the website, respectively, and completed the surveys in the respective languages. Participants' mean age was 49 (SD 14.9) years and 60% (18/30) were females. Participant characteristics are described in Table 1.

Table . Participant characteristics (N=30).

Item	Patients (n=11)	Caregivers (n=9)	Health care professionals (n=10)
Age (years), mean (SD)	60.7 (13)	44.9 (15.4)	39.8 (6.1)
Gender, n (%)			
Male	7 (64)	2 (22)	3 (30)
Female	4 (36)	7 (78)	7 (70)
Ethnicity, n (%)			
Chinese	8 (73)	7 (78)	—[a]
Malay	2 (18)	1 (11)	—
Indian	1 (9)	0 (0)	—
Other	0 (0)	1 (11)	—
Marital status, n (%)			
Married	8 (73)	6 (67)	—
Widowed	1 (9)	0 (0)	—
Never married	2 (18)	3 (33)	—
Education, n (%)			
Secondary school	5 (46)	4 (44)	—
Junior college, polytechnic, diploma, or vocational	2 (18)	2 (22)	—
University and above	4 (36)	3 (34)	—
Duration of heart failure, n (%)			
<5 years	5 (45.5)	—	—
5 to <10 years	5 (45.5)	—	—
10 years and above	1 (9)	—	—
Relationship with patient, n (%)			
Spouse	—	1 (11)	—
Child (son or daughter)	—	7 (78)	—
Others (relative)	—	1 (11)	—
Profession, n (%)			
Cardiologist	—	—	4 (40)
Nurse	—	—	3 (30)
Medical social workers trained in advance care planning	—	—	3 (30)
Experience with treating patients with heart failure, n (%)			
Less than 5 years	—	—	1 (10)
5 to <10 years	—	—	5 (50)
10 years and above	—	—	4 (40)
Advance care planning training, n (%)			
Yes	—	—	6 (60)
No	—	—	4 (40)

[a] Not applicable.

Qualitative Feedback and Iterative Redesign

Overview

The following three themes describe participants' feedback and suggestions, and highlight the revisions made by the research team.

Theme 1: User Experience of Navigating the Website

Many participants provided positive feedback about the ease of navigation and layout of the website. Patients, caregivers, and HCPs described the interactive features as easy to use and appreciated the simple layout of the website. However, two HCPs anticipated that older patients may have difficulty reading extensive text due to poor eyesight, scrolling down the web page, and navigating the site.

To address these concerns and enhance user experience and accessibility for older patients, we added a note on the expected time to complete the website and a progress bar to allow users to track their progress. We also increased the frequency of navigational buttons such as the "submit My Voice document," increased the font size and changed the font color to improve readability. Lastly, within the help section, in addition to allowing the participants to type their queries, we incorporated a drop-down list for them to select from. This enhanced the ease of reaching out to the research team in case of difficulties.

Theme 2: Acceptability of Website Content and Duration

Patients, caregivers, and HCPs found the language clear and straightforward with "no jargon." However, two HCPs suggested reducing the wordiness of the web page. Most participants also found the duration of the website to be suitable although one HCP recommended adding a pause button for patients who may need breaks or prefer to complete the website in smaller segments.

Some patients expressed that the quiz explanations were overly direct and demoralizing. Given the discomfort surrounding the topic of death and dying, they suggested incorporating elements of hope to make the website more comforting.

We received extensive feedback about the value-clarification questions and their response options. One HCP recommended adding details about caregiving arrangements and clarifying terms such as "physically comfortable" or "at peace." Another HCP highlighted that being dependent on others did not equate to being a burden on the family. Participants also had challenges understanding and responding to a question asking patients' willingness to trade-off between quality and length of life, despite multiple iterations and revisions. These revisions aimed to clarify the question, prompting patients to imagine a situation where such a trade-off would occur. We also changed the initial 3-point response to a 2-point response option, excluding the choice to prioritize both aspects simultaneously. Participants described this question as vague and difficult to relate to.

In response to these concerns, we shortened the introduction section of the website and reduced the wordiness of each web page. To enable participants to complete the website in multiple sessions, we implemented a feature that displays their previous responses if they have not submitted their "My Voice" document. We also simplified the phrasing of key terms and modified the explanations for the quiz responses to be more emphathic, acknowledging patients' desire for a cure and emphasizing that symptoms can be managed even though heart failure is incurable. We clarified the response options for the value-clarification questions by making them more specific and split up the initial option of "being dependent on others for their daily activities and being a burden on their family" into two separate response options. We removed the question assessing the trade-off on quality and length of life.

Theme 3: Usefulness in Understanding Patient's Values and Goals

Many HCPs noted that the website could complement and enhance existing ACP processes by helping patients reflect on their values and care goals, thereby preparing them for the challenging in-person ACP conversations ahead of time. This preparation could potentially save time during dedicated clinic appointments for ACP conversations. Patients and caregivers also found the website useful as it encouraged them to communicate with each other. Caregivers particularly appreciated that patients' "My Voice" document could be updated periodically to reflect their changing care goals.

Table 2 presents example quotes illustrating feedback obtained, and Table 3 outlines participants' suggestions for improvement alongside the corresponding revisions made.

Table . Participant feedback on “My Voice” website.

Subtheme		Patients	Caregivers	HCPs[a]	Selective positive quotes
Theme 1: user experience of navigating the website					
	Ease of navigation	✓✓×[b]	✓✓✓	✓✓×	• “Easy and straightforward. Quite nice to use” [UAT25, patient] • “Like most interfaces used in Singapore, it’s not particularly difficult…overall quite easy to use…I am quite sure that they (elderly) will need somebody to go through with them, for the elderly patients” [UAT05, cardiologist]
	Simple layout	✓✓✓	✓✓✓	✓✓✓	• “My favourite part is the document that is generated with the spokesperson. It’s written very clearly” [UAT24, caregiver] • “Not too cluttered, quite clearly delineated” [UAT05, cardiologist]
Theme 2: acceptability of website duration and content					
	Ease of understanding	✓✓✓	✓✓✓	✓✓✓	• “Very easy, very simple to understand” [UAT29, patient] • “I think the options listed inside are easy to understand…Questions quite straightforward” [UAT01, ACP[c] facilitator] • “Videos did not contain any jargon, so it’s quite clear” [UAT05, cardiologist]

Subtheme		Patients	Caregivers	HCPs[a]	Selective positive quotes
	Informative	✓✓	✓✓✓	✓✓✓	• "Very succinct, it tells me exactly what I need to do" [UAT25, patient] • "I think it's good that we have all this background learning, at least we know and can be more educated...it is important that we get the information directly from them (patient) [rather than making assumptions]" [UAT20, caregiver] • "They are very concise, not too long, not too short, but every point that is important I guess it's all mentioned" [UAT03, medical social worker]
	Suitable duration	✓✓✓	✓✓✓	✓✓	• "The length of My Voice is just right" [UAT13, patient]
Theme 3: usefulness in understanding the patient's values and goals					

Subtheme		Patients	Caregivers	HCPs[a]	Selective positive quotes
	Complementary to ACP	—[d]	—	✓✓	• "I think this website is in a way like helping the patient to do the first part [of ACP] to get them to think about it before they come and really start to think in detail what are the treatments they want" [UAT01, ACP facilitator] • "It's more effective to reach the mass rather than in every admission or outpatient when we refer to ACP coordinator" [UAT03, medical social worker]
	Understanding values and goals	✓✓✓	✓✓✓	✓	• "It addresses the issue (by allowing the patient to let their preferences be known) especially when my husband does not want to listen … if there is an additional step that can tell me what to do when my husband doesn't want to listen to me that will be great" [UAT25, patient] • "It is really true that based on their condition, they might change. It's not always that – and then human heart or mind may be a bit fickle, or they might change based on their condition. So, this (frequent updates) is quite a good way" [UAT20, caregiver]
	Saves time	—	—	✓	• "This will cut down a lot of professional's time and caregiver's time [during the ACP process]" [UAT03, medical social worker]

[a] HCP: health care professional.

[b] ✓ indicates a positive response and x indicates a negative response. Number of ✓ indicates strength of the responses (✓✓✓ strong, ✓✓ moderate, and ✓ mild), and likewise for x.

[c] ACP: advance care planning.

[d] Not applicable.

Table . Participant suggestions for improving "My Voice" website.

Suggestion		Changes made to "My Voice"
User experience of navigating the website		
	"I think the layout for most pages it's fine, except for those on the boxes right, with a solid background of blue or dark blue, the white fonts could be bolder, I think that would be more clear to the respondents" [UAT03, medical social worker]	• Replaced red text on blue background with yellow text on blue background for better readability.
	"A little bit lengthy, especially for the elderly patients whose eyesight is not so good … The shorter the better. Otherwise, they have a lot to scroll, and read, and their attention span is already so short" [UAT10, nurse]	• Added expected time to completion of the website - "This program will take approximately 30 min to complete." • Reduced the length of on-page explanation before the value-clarification questions. • Added a color coded progress bar on the pages to track completion.
Acceptability of website content and duration		
	"The options in the respective pages… can streamline them… can further divide them like personal, family, work, or finances" [UAT03, medical social worker]	• Merged similar terms to shorten the text in responses options for the value-clarification questions (eg including "pain" under "symptoms" instead of 2 separate fields). • Added explanations in brackets for terms that are not immediately understandable such as: "Make a legacy (something that is passed on, monetary or non-monetary)" and "Being cared for at home, rather than in an institution (eg, hospital)."
	"Don't just give the bitter truth, add some element of sweetness. Give some hope" [UAT26, patient]	• Rephrased explanations for answers to the knowledge quiz to be more empathetic (eg, "Heart failure is a serious condition that can shorten life. For some patients, heart failure is stable for a long time then gets worse. Others have a gradual decline over time." → "We wish heart failure got better over time. Unfortunately, heart failure is a serious condition. For some patients, heart failure is stable for a long time then gets worse. Others have a gradual decline over time."
	"Some thoughts about the Step 4 when it mentions about the medical records, patients may not know how to go about. They may have queries about this part, like how do I document, who do I approach" [UAT01, advance care planning facilitator]	• In the patient module, integrated the step for documenting patient preferences in medical records with the step to speak to your doctor (step 4).
	"You will need to use simple words because sometimes when they age, complicated words they won't understand" [UAT29, patient]	• Replaced wordy introduction with simple bullet points for describing the steps involved. • Used simpler terms (eg, "spokesperson 1" and "spokesperson 2" instead of "primary spokesperson" and "secondary spokesperson").

Survey Results

The overall mean SUS score of 74 (SD 14.8; range: 42.5 to 95), with mean scores in each of the three groups of participants exceeding the minimum cutoff score of 68, indicated good usability. Specifically, 70% of participants had scores above 68, which included 64% (7/11) of patients, 78% (7/9) of caregivers, and 70% (7/10) of HCPs (Table 4).

Table . System Usability Scale (SUS) scores by participant group.

	Patients (n=11)	Caregivers (n=9)	Health care professionals (n=10)	Overall (N=30)
SUS score				
Range (0 - 100)	47.5 - 92.5	50 - 95	42.5 - 95	42.5 - 95
Mean (SD)	72.3 (15.2)	76.4 (15.3)	73.8 (15.2)	74 (14.8)
SUS score category, n (%)				
>87	2 (18)	2 (22)	3 (30)	7 (23)
69 - 87	5 (46)	5 (56)	4 (40)	14 (47)
50 - 68	3 (27)	2 (22)	2 (20)	7 (23)
<50	1 (9)	0 (0)	1 (10)	2 (7)

Patients highly rated the way information was presented in the 5 steps, with over 80% of patients rating each of the 12 items on acceptability as good or excellent. Likewise, over 88% of caregivers rated each of the 3 items about acceptability as good or excellent (Table 5). Except for one patient who found the length of the website to be “too long,” 19 of 20 patients and caregivers (95%) rated the website length to be “just right,” and 18 of 20 patients and caregivers (90%) rated the amount of information presented to be “just right.” Seven of 10 HCPs (70%) rated 11 of the 15 items as strongly agree or agree. Items that received lowest levels of agreement (agree or strongly agree) included—“My Voice website is better than how I usually go about conducting ACP” (30%), “using My Voice website does not involve making major changes to the way I usually do things” (50%), “My Voice website is compatible with the way I think things should be done” (60%), and “the use of My Voice website is more cost-effective than my usual approach to conducting ACP” (60%; Table 5)

Table . Acceptability ratings by patients (n=11), caregivers (n=9), and health care professionals (n=10).

Item	Value, n (%)
Patients: good or excellent rating	
About heart failure (step 1)	10 (91)
Thinking about goals for end-of-life care (step 2)	10 (91)
Understanding what is important to you when it comes to your health	11 (100)
Questions on what makes life meaningful to you	11 (100)
Questions on when it gets to my health getting worse, what worries me most	9 (82)
Questions on choosing a preferred treatment	10 (91)
Questions on what matters most to you and choosing top 3 goals	9 (82)
Ranking the order of the top 3 goals	9 (82)
Choosing a healthcare spokesperson (step 3)	9 (82)
Document what is important to you in medical record	10 (91)
Discussing with the doctor about “My Voice” document (step 4)	9 (82)
Revisiting “My Voice” document periodically (step 5)	9 (82)
Caregivers: good or excellent rating	
About heart failure (step 1)	8 (89)
Talking to your loved ones about goals for end-of-life care (step 2)	9 (100)
Supporting your loved ones (step 3)	8 (89)
Healthcare professionals: agree or strongly agree	
It will be easy for me to use “My Voice” for introducing advance care planning (ACP[a]) to my patients.	8 (80)
It is easy for me to understand “My Voice.”	9 (90)
It will be easy for me to use “My Voice” website for advocating advance care planning.	8 (80)
The results of using “My Voice” website will be easy to see (increase in self-administered ACP-My Voice document)	8 (80)
This “My Voice” website is better than how I usually go about conducting ACP	3 (30)
This “My Voice” website is compatible with the way I think things should be done.	6 (60)
The use of “My Voice” website is more cost-effective than my usual approach to conducting ACP	6 (60)
Compared with my usual approach, “My Voice” website will result in my patients making more informed decisions.	8 (80)
Using “My Voice” website will save me time.	10 (100)
This “My Voice” website is a reliable method of helping patients do an ACP.	7 (70)
Pieces or components of the “My Voice” website can be used by themselves.	7 (70)
This type of “My Voice” website is suitable for helping patients make value laden choices.	9 (90)
This “My Voice” website complements my usual approach to conducting ACP.	8 (80)
Using this “My Voice” website does not involve making major changes to the way I usually do things.	5 (50)
There is a high probability that using this “My Voice” website may cause / result in more benefit than harm.	7 (70)

[a]ACP: advance care planning.

Discussion

Principal Findings

Study results show that “My Voice” ACP website was well received by patients with heart failure, their caregivers, and HCPs. Most participants provided positive feedback regarding their experience using “My Voice.” They found the website easy to navigate, its duration and content acceptable, and valuable in conveying and comprehending patient values and goals. The mean usability score of 74 (SD 14.8) exceeded the a priori threshold (68 and above) for both overall and within each participant group. Additionally, patients and caregivers’ acceptability ratings were high for all items, and 80% (8/11) of patients and 78% (7/9) of caregivers rated the website as good or excellent, while 70% (7/10) of HCPs rated 11 of the 15 items as strongly agree or agree. Most patients and caregivers (19/20, 95%) and 90% (18/20) of patients and caregivers found the length and amount of information in “My Voice” just right. These findings confirm the usability and acceptability of “My Voice.”

The findings on usability and acceptability are consistent with those of other web-based ACP decision aids [45-47]. Our findings regarding HCPs’ views of the decision aid as a tool for initiating ACP discussions also align with previous research [48]. However, in contrast to our findings, one study reported that participants had difficulty understanding and engaging with some website content [49].

Given that a significant proportion of patients with heart failure are older with lower literacy levels [50], feedback primarily focused on enhancing the website accessibility for this demographic. Suggestions included simplifying the login process, improving the layout, reducing wordiness, increasing font size, and simplifying terminology. Moreover, some patients expressed surprise upon learning about the incurable nature of their illness, indicating that they had not engaged in serious illness conversations with their HCPs. Our previous studies have also shown similar findings [51,52].

Patients and caregivers rated “My Voice” to be both acceptable and usable. However, while, HCPs rated its usability highly, they provided lower ratings to certain aspects of acceptability. These included suggestions that “My Voice” could potentially be more effective and replace the current ACP facilitation method. It is important to note that “My Voice” is primarily a patient preparation tool intended to complement, rather than replace, the patient-HCP conversations. Therefore, the concerns raised are not unexpected given its supplementary role in the process.

While web-based ACP interventions are increasingly prevalent in the literature, our intervention is innovative in several respects. First, it incorporates structured mechanisms to encourage frequent revisits to “My Voice,” through educating patients and caregivers about its importance and sending reminders to them via phone. Our previous research revealed that ACP conversations typically occur as one-time events despite evolving patient preferences [22-25]. “My Voice” thus addresses this current gap in ACP implementation by facilitating ongoing reflection on values and goals and fostering periodic ACP conversations with HCPs. Second, it is tailored specifically to patients with heart failure, featuring educational videos and a quiz regarding their illness. This targeted education not only imparts urgency but also provides the context for patients to reflect on their values and goals. Third, “My Voice” seamlessly integrates active caregiver involvement into the ACP process. Not only do we coach patients to choose a surrogate decision maker and engage with them, but our dedicated caregiver module educates the chosen surrogate about the patient’s illness and guides them on how to communicate with the patient and the HCPs. This caregiver module also facilitates the sharing of the patient’s “My Voice document” with the surrogate. This approach enhances the caregiver’s understanding of patient values and goals, preparing them to make end-of-life decisions for their loved ones. Importantly, caregivers in our usability study appreciated the “My Voice” website’s unique features, particularly its capability for patients to periodically update their goals and share them with their surrogates. Lastly, the inclusion of content in three different languages enhances the accessibility of “My Voice” to a broader range of ethnic and language groups, promoting inclusivity and ensuring that individuals from diverse backgrounds can effectively engage in the ACP process.

“My Voice” is one of the first web-based ACP interventions for patients with heart failure in the Asian context. This study’s strength lies in its use of a mixed methods design to gather participant feedback, agile methodology implementation to enhance user satisfaction, and inclusion of different ethnic and language groups across multiple sites. However, there are some limitations. The response rate from patients was low (46%), partly attributed to the older age of many participants approached and their reluctance to engage in web-interventions. Future studies could improve response rates by involving health and social care providers, community organizations, or adult children to facilitate initial contact with older individuals. Additionally, although the sample size was adequate to achieve thematic saturation, it was too small to discern variations across age, gender, and other sociodemographics.

Practice Implications

“My Voice” is a usable and acceptable tool for empowering patients to engage in ACP conversations with their caregivers and HCPs. The efficacy of the “My Voice” website in improving patient and caregiver outcomes is being assessed through a randomized controlled trial.

Conclusion

The findings support the usability and acceptability of the web-based ACP intervention, “My Voice,” among patients with heart failure and their caregivers. Participants largely endorsed the interactive website as a valuable tool for communication and understanding patients’ values and goals, offering constructive feedback to enhance its user-friendliness for older patients.

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Data Availability

The data used during this study are available from the corresponding author on reasonable request.

Authors' Contributions

CM did the conceptualization, methodology, funding acquisition, supervision, and writing of the original draft. AY handled the conceptualization, validation, and review and editing of the writing. CR worked on the data curation, formal analysis, validation, writing of the original draft, validation, and visualization. SNK carried out the project administration, investigation, and formal analysis. IC performed on the investigation and formal analysis. JRL conducted the review and editing of the writing. DS, IB, VGJL, HW, and LFL aided in project administration, resources, and review and editing of the writing. KIP assisted with supervision and review and editing of the writing. All authors read and approved the final paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Select pages from "My Voice" website.
[PDF File, 331 KB - aging_v7i1e60117_app1.pdf]

Multimedia Appendix 2
Qualitative interview guide.
[PDF File, 139 KB - aging_v7i1e60117_app2.pdf]

References

1. Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary delphi panel. J Pain Symptom Manage 2017 May;53(5):821-832. [doi: 10.1016/j.jpainsymman.2016.12.331] [Medline: 28062339]
2. Malhotra C, Sim D, Jaufeerally FR, et al. Impact of a formal advance care planning program on end-of-life care for patients with heart failure: results from a randomized controlled trial. J Card Fail 2020 Jul;26(7):594-598. [doi: 10.1016/j.cardfail.2020.01.015] [Medline: 31991216]
3. Malhotra C, Huynh VA, Shafiq M, Batcagan-Abueg APM. Advance care planning and caregiver outcomes: intervention efficacy – systematic review. BMJ Support Palliat Care 2023 Dec;13(e3):e537-e546. [doi: 10.1136/spcare-2021-003488]
4. Malhotra C, Shafiq M, Batcagan-Abueg APM. What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomised controlled trials. BMJ Open 2022 Jul;12(7):e060201. [doi: 10.1136/bmjopen-2021-060201]
5. Malhotra C. Advance care planning: It is time to rethink our goals. J Am Geriatr Soc 2023 Dec;71(12):3963-3966. [doi: 10.1111/jgs.18511] [Medline: 37522615]
6. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. Ann Intern Med 2010 Aug 17;153(4):256-261. [doi: 10.7326/0003-4819-153-4-201008170-00008] [Medline: 20713793]
7. Konda M, Ananthula A, Baltz A, et al. Low advance directive completion rates in hospitalized oncology patients: room for improvement. J C O 2019 Nov 1;37(31_suppl):1-1. [doi: 10.1200/JCO.2019.37.31_suppl.1]
8. Block BL, Jeon SY, Sudore RL, Matthay MA, Boscardin WJ, Smith AK. Patterns and trends in advance care planning among older adults who received intensive care at the end of life. JAMA Intern Med 2020 May 1;180(5):786-789. [doi: 10.1001/jamainternmed.2019.7535] [Medline: 32119031]
9. Panozzo L, Harvey P, Adams MJ, O’Connor D, Ward B. Communication of advance care planning decisions: a retrospective cohort study of documents in general practice. BMC Palliat Care 2020 Jul 14;19(1):108. [doi: 10.1186/s12904-020-00613-1] [Medline: 32664925]
10. Heyland DK, Barwich D, Pichora D, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. JAMA Intern Med 2013 May 13;173(9):778-787. [doi: 10.1001/jamainternmed.2013.180] [Medline: 23545563]
11. Tay M, Chia SE, Sng J. Knowledge, attitudes and practices of the Advance Medical Directive in a residential estate in Singapore. Ann Acad Med Singap 2010 Jun;39(6):424-428. [Medline: 20625616]

12. Ng R, Chan S, Ng TW, Chiam AL, Lim S. An exploratory study of the knowledge, attitudes and perceptions of advance care planning in family caregivers of patients with advanced illness in Singapore. BMJ Support Palliat Care 2013 Sep;3(3):343-348. [doi: 10.1136/bmjspcare-2012-000243]
13. Rogers AE, Addington-Hall JM, Abery AJ, et al. Knowledge and communication difficulties for patients with chronic heart failure: qualitative study. BMJ 2000 Sep 9;321(7261):605-607. [doi: 10.1136/bmj.321.7261.605] [Medline: 10977838]
14. Garland EL, Bruce A, Stajduhar K. Exposing barriers to end-of-life communication in heart failure: an integrative review. Can J Cardiovasc Nurs 2013;23(1):12-18. [Medline: 23461239]
15. Malhotra C, Ramakrishnan C. Complexity of implementing a nationwide advance care planning program: results from a qualitative evaluation. Age Ageing 2022 Oct 6;51(10):10. [doi: 10.1093/ageing/afac224] [Medline: 36273345]
16. Malhotra C, Chaudhry I. Barriers to advance care planning among patients with advanced serious illnesses: a national survey of health-care professionals in Singapore. Palliat Support Care 2023 Apr 3:1-8. [doi: 10.1017/S1478951523000214] [Medline: 37005352]
17. Malhotra C, Ramakrishnan C, Yue SMG. Challenges in providing end-of-life care consistent with documented patient preferences. Ann Palliat Med 2022 Dec;11(12):3610-3619. [doi: 10.21037/apm-22-790] [Medline: 36510456]
18. Shin DW, Cho J, Kim SY, et al. Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. Psychooncology 2015 Feb;24(2):212-219. [doi: 10.1002/pon.3631] [Medline: 25099223]
19. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. J Clin Oncol 2010 Mar 1;28(7):1203-1208. [doi: 10.1200/JCO.2009.25.4672] [Medline: 20124172]
20. Modes ME, Engelberg RA, Downey L, et al. Toward understanding the relationship between prioritized values and preferences for cardiopulmonary resuscitation among seriously ill adults. J Pain Symptom Manage 2019 Oct;58(4):567-577. [doi: 10.1016/j.jpainsymman.2019.06.011] [Medline: 31228534]
21. Cohen SM, Volandes AE, Shaffer ML, Hanson LC, Habtemariam D, Mitchell SL. Concordance between proxy level of care preference and advance directives among nursing home residents with advanced dementia: a cluster randomized clinical trial. J Pain Symptom Manage 2019 Jan;57(1):37-46. [doi: 10.1016/j.jpainsymman.2018.09.018] [Medline: 30273717]
22. Malhotra C, Hu M, Malhotra R, et al. Instability in end-of-life care preference among heart failure patients: secondary analysis of a randomized controlled trial in singapore. J Gen Intern Med 2020 Jul;35(7):2010-2016. [doi: 10.1007/s11606-020-05740-2] [Medline: 32103441]
23. Malhotra C, Bundoc FG, Sim D, Jaufeerally FR, Finkelstein EA. Instability in preference for place of death among patients with symptoms of advanced heart failure. J Am Med Dir Assoc 2021 Feb;22(2):349. [doi: 10.1016/j.jamda.2020.05.030] [Medline: 32693993]
24. Malhotra C, Koh LE, Teo I, Ozdemir S, Chaudhry I, Finkelstein E. A prospective cohort study of stability in preferred place of death among patients with stage IV cancer in Singapore. J Natl Compr Canc Netw 2022;20(1):20-28. [doi: 10.6004/jnccn.2020.7795]
25. Malhotra C, Balasubramanian I, PISCES study group. Caregivers' end-of-life care goals for persons with severe dementia change over time. J Alzheimers Dis 2023;93(3):967-975. [doi: 10.3233/JAD-221161] [Medline: 37125548]
26. El-Jawahri A, Paasche-Orlow MK, Matlock D, et al. Randomized, controlled trial of an advance care planning video decision support tool for patients with advanced heart failure. Circulation 2016 Jul 5;134(1):52-60. [doi: 10.1161/CIRCULATIONAHA.116.021937] [Medline: 27358437]
27. Van Scoy LJ, Green MJ, Dimmock AE, et al. High satisfaction and low decisional conflict with advance care planning among chronically ill patients with advanced chronic obstructive pulmonary disease or heart failure using an online decision aid: a pilot study. Chron Illn 2016 Sep;12(3):227-235. [doi: 10.1177/1742395316633511] [Medline: 27055468]
28. Volandes AE, Levin TT, Slovin S, et al. Augmenting advance care planning in poor prognosis cancer with a video decision aid: a preintervention-postintervention study. Cancer 2012 Sep 1;118(17):4331-4338. [doi: 10.1002/cncr.27423] [Medline: 22252775]
29. Epstein AS, Volandes AE, Chen LY, et al. A randomized controlled trial of a cardiopulmonary resuscitation video in advance care planning for progressive pancreas and hepatobiliary cancer patients. J Palliat Med 2013 Jun;16(6):623-631. [doi: 10.1089/jpm.2012.0524] [Medline: 23725233]
30. Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE. Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: a randomized clinical trial. JAMA Intern Med 2017 Aug 1;177(8):1102-1109. [doi: 10.1001/jamainternmed.2017.1607] [Medline: 28520838]
31. Lindquist LA, Ramirez-Zohfeld V, Sunkara PD, et al. PlanYourLifeSpan.org - an intervention to help seniors make choices for their fourth quarter of life: results from the randomized clinical trial. Pat Educ Couns 2017 Nov;100(11):1996-2004. [doi: 10.1016/j.pec.2017.06.028] [Medline: 28689855]
32. Green MJ, Levi BH. Development of an interactive computer program for advance care planning. Health Expect 2009 Mar;12(1):60-69. [doi: 10.1111/j.1369-7625.2008.00517.x] [Medline: 18823445]

33. Green MJ, Van Scoy LJ, Foy AJ, et al. A randomized controlled trial of strategies to improve family members' preparedness for surrogate decision-making. Am J Hosp Palliat Care 2018 Jun;35(6):866-874. [doi: 10.1177/1049909117744554] [Medline: 29186982]
34. Martina D, Lin CP, Kristanti MS, et al. Advance care planning in Asia: a systematic narrative review of healthcare professionals' knowledge, attitude, and experience. J Am Med Dir Assoc 2021 Feb;22(2):349. [doi: 10.1016/j.jamda.2020.12.018] [Medline: 33421371]
35. Lewis JR, Sauro J. The Factor Structure of the System Usability Scale: Springer; 2009.
36. Menon S, Kars MC, Malhotra C, Campbell AV, van Delden JJM. Advance care planning in a multicultural family centric community: a qualitative study of health care professionals', patients', and caregivers' perspectives. J Pain Symptom Manage 2018 Aug;56(2):213-221. [doi: 10.1016/j.jpainsymman.2018.05.007] [Medline: 29775694]
37. Bernacki RE, Block SD, American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med 2014 Dec;174(12):1994-2003. [doi: 10.1001/jamainternmed.2014.5271] [Medline: 25330167]
38. Lewis JR, Sauro J. Usability and user experience: design and evaluation. In: Salvendy G, Karwowski W, editors. Handbook of Human Factors and Ergonomics: Wiley; 2021:972-1015. [doi: 10.1002/9781119636113]
39. Brooke J. SUS -- a quick and dirty usability scale. In: Usability Evaluation in Industry: CRC Press; 1995:189.
40. Bangor A, Kortum P, Miller J. Determining what individual SUS scores mean: adding an adjective rating scale. J Usability Stud 2009;4(3):114-123 [FREE Full text]
41. O'Connor AM, Cranney A. User manual-acceptability. The Ottawa Hospital. 1996. URL: https://decisionaid.ohri.ca/docs/develop/user_manuals/um_acceptability.pdf [accessed 2024-12-04]
42. Faulkner L. Beyond the five-user assumption: benefits of increased sample sizes in usability testing. Behav Res Methods Instrum Comput 2003 Aug;35(3):379-383. [doi: 10.3758/bf03195514] [Medline: 14587545]
43. Hong Y, Goldberg D, Dahlke DV, et al. Testing usability and acceptability of a web application to promote physical activity (iCanFit) among older adults. JMIR Hum Factors 2014 Oct 13;1(1):e2. [doi: 10.2196/humanfactors.3787] [Medline: 27025254]
44. Bradshaw C, Atkinson S, Doody O. Employing a qualitative description approach in health care research. Glob Qual Nurs Res 2017;4:2333393617742282. [doi: 10.1177/2333393617742282] [Medline: 29204457]
45. Uhler LM, Pérez Figueroa RE, Dickson M, et al. InformedTogether: usability evaluation of a web-based decision aid to facilitate shared advance care planning for severe chronic obstructive pulmonary disease. JMIR Hum Factors 2015 Feb 25;2(1):e2. [doi: 10.2196/humanfactors.3842] [Medline: 27025896]
46. Walsh CA, Miller SJ, Smith CB, et al. Acceptability and usability of the Planning Advance Care Together (PACT) website for improving patients' engagement in advance care planning. PEC Innov 2024 Dec;4:100245. [doi: 10.1016/j.pecinn.2023.100245] [Medline: 38145252]
47. Benton E, Metzger M, Hollen P, Allen L, McIlvennan C. Enhancing shared decision making in a chronic population. use of an advance directive decision aid for patients with heart failure and their caregivers. J Card Fail 2020 Oct;26(10):S5. [doi: 10.1016/j.cardfail.2020.09.022]
48. Behrens LL, Morgan B, Summerhayes E, et al. Feasibility and acceptability of a web-based advance care plan for dementia. Geriatr Nurs (Lond) 2022 Mar;44:251-258. [doi: 10.1016/j.gerinurse.2022.02.022]
49. van der Smissen D, Overbeek A, van Dulmen S, et al. The feasibility and effectiveness of web-based advance care planning programs: scoping review. J Med Internet Res 2020 Mar 17;22(3):e15578. [doi: 10.2196/15578] [Medline: 32181750]
50. Zeng W, Chia SY, Chan YH, Tan SC, Low EJH, Fong MK. Factors impacting heart failure patients' knowledge of heart disease and self-care management. Proc Singap Healthc 2017 Mar;26(1):26-34. [doi: 10.1177/2010105816664537]
51. Malhotra C, Sim D, Jaufeerally F, Finkelstein EA. Associations between understanding of current treatment intent, communication with healthcare providers, preferences for invasive life-sustaining interventions and decisional conflict: results from a survey of patients with advanced heart failure in Singapore. BMJ Open 2018 Sep 19;8(9):e021688. [doi: 10.1136/bmjopen-2018-021688] [Medline: 30232107]
52. Ozdemir S, Lee JJ, Malhotra C, et al. Associations between prognostic awareness, acceptance of illness, and psychological and spiritual well-being among patients with heart failure. J Card Fail 2022 May;28(5):736-743. [doi: 10.1016/j.cardfail.2021.08.026] [Medline: 34655774]

Abbreviation

ACP: advance care planning
COM-B: capability, opportunity, motivation to enhance behaviors
HCP: health care professional
SUS: System Usability Scale

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Determinants of Successful Implementation of Assistive Technologies for Dementia: Exploratory Survey

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Abstract

Background: Despite positive results for the use of assistive technologies (ATs) in dementia, the uptake of ATs lags behind. It is considered important to assess determinants of successful or unsuccessful implementation of ATs.

Objective: We explored factors that influence the implementation of ATs for community-dwelling people with dementia, with the aim to better understand potentially effective implementation strategies.

Methods: A cross-sectional survey for researchers was developed and disseminated, exploring factors that influence either successful or unsuccessful implementation of ATs for dementia. The survey consisted of closed and open questions.

Results: The response rate was 10% (21/206); the 21 respondents who completed the survey were from 8 countries. Determinants of implementation were described for 21 ATs, of which 12 were successfully and 9 were unsuccessfully implemented. Various types of ATs were included, such as online platforms, sensors, or physical aids. The main determinants of implementation success were related to the AT itself, contextual factors, research activities, and implementation strategies. There was a lack of research data on some ethical issues and cost-effectiveness.

Conclusions: This study provided insight into some main barriers to and facilitators of implementation of ATs in dementia related to the AT itself, context, research-related activities, and applied implementation strategies. Lessons were formulated for various stakeholders to improve the implementation effectiveness of ATs in dementia.

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KEYWORDS

assistive technology; dementia; implementation; caregiving; psychosocial research

Introduction

The importance of assistive technology (AT) in the delivery of health care and support is increasingly being recognized [1,2]. AT in dementia care has been defined as “any item, piece of equipment, product or system driven by electronics, whether acquired commercially, off-the-shelf, modified or customized, that is used to help persons with dementia in dealing with the consequences of dementia” [3,4]. A perceived advantage of AT is improved access to care, even for people in remote areas. AT can make it easier to provide customized care, can be more entertaining, and can save time and costs [5-10]. Specifically for people with dementia and their carers, positive effects have been reported from the use of AT. For people with dementia, AT has been found to positively affect, for example, cognition, task performance, participation in enjoyable and meaningful activities, social contacts, self-esteem and well-being, behavioral and psychological symptoms, and safety [4,11-13]. For family carers, the following benefits have been reported: feelings of reassurance, lessened burden, improved self-efficacy, more caregiving knowledge, and improved mental health [11,14,15]. Furthermore, systematic literature reviews on technology-based dementia education for professional carers showed positive effects on dementia knowledge, readiness to change, receptiveness to training, communication skills, and self-efficacy [13,16]. Finally, the potential of AT to improve access to dementia care is even more crucial given the context of the COVID-19 pandemic. During this period, AT provided an alternative means of support for closed day programs and services, as well as an alternative to the downscaled professional and social support for people with dementia and their caregivers. Recent articles have advised care professionals to use technology to organize support remotely [13,17].

Despite these positive results, the uptake of AT in dementia care has been disappointing. Various issues may account for this, such as relevant stakeholders and potential users not being included early on in the development of ATs, lack of high-quality effectiveness and cost-effectiveness studies, lack of easily accessible information about existing ATs, and negative attitudes toward technology among family and professional caregivers [4,18-20]. Numerous implementation models and theories have been developed to help identify and map factors that influence implementation, such as the nonadoption, abandonment, scale-up, spread, sustainability framework [21] and the Consolidated Framework for Implementation Research [22]. These factors include the characteristics of the innovation (eg, added value as compared to regular support, the development process, and reliability and ease of use), characteristics of the adopters (professionals) and the end users (people with dementia and family carers), characteristics of the context (organization, social setting, community, laws, and regulations), characteristics of the implementation process (implementation strategies used), and implementation outcomes. In a market study in the European Union, it was concluded that there are 7 potential categories of barriers to the uptake of AT: cultural, regulatory and policy, social security, industrial and technical, knowledge, financial, and market related. These types of barriers exist in all European countries but differ across countries in the extent to which they affect uptake [2]. This underscores the need to tailor AT implementation to specific contexts.

In this paper, we report on a study in which we explored factors that influence the implementation of AT for community-dwelling people with dementia, with the aim to better understand potentially effective implementation strategies. Implementation was defined as "the process of putting to use or integrating evidence-based interventions within a setting" [23]. We targeted community-based dementia care settings and focused on ATs that aim to promote social health in people with dementia, that is, technologies that intend to (1) help people living with dementia manage their everyday lives across the disease journey, such as electronic calendars and reminders for activities, medication reminders, aids to perform activities of daily life, robots, and navigation systems; (2) help people to engage in meaningful and pleasurable activities, such as cognitive stimulation and physical activities; and (3) improve participation in social and meaningful activities [24].

The objective of this exploratory study was to describe factors that determine (1) successful implementation of evidence-based ATs and (2) unsuccessful implementation of ATs. Based on understanding the determinants of successful or unsuccessful implementation, we made a set of recommendations for the benefit of various stakeholders, including researchers who wish to bring their ATs into practice, clinicians who wish to be informed about, and implement, best practices in AT, and policy makers who need to make decisions about effective ways to fund development, research, and implementation of ATs.

Methods

Design

A cross-sectional design was used in which data were collected digitally through a web-based survey accessible from October until December 2019. On the survey platform, all participants received an information letter explaining the aims of the study and guaranteeing the pseudonymous processing of their data and responses, as well as the option to discontinue participation in the study at any time. To ensure the anonymity of the participants, the studied interventions are not reported by name; only their characteristics are described.

The survey was sent out in October 2019 via email, and subsequently 2 reminders were sent after 2 and 4 weeks. Participants could decide for themselves whether they completed the survey on successful implementation of AT, unsuccessful implementation of AT, or both surveys.

Participants and Setting

Participants were recruited via the European Interdem network, which consists of psychosocial researchers from 19 countries in Europe and beyond, working together in the field of early, timely, and quality psychosocial interventions in dementia [25], as the objective of the survey was to map the determinants of the implementation of AT interventions for people with dementia that were developed in a research context. As such, researchers from this network are best placed to provide an overview of such interventions. The survey was sent out to all Interdem members (n=206). Those who were or have been working on projects on AT aiming to support people with dementia in the community were invited to participate. Members were also invited to forward the survey to colleagues known to work in this area (snowball sampling).

The Survey

The survey was developed based on the literature on implementation and on expert opinions. From the literature, we proposed 5 categories of influencing factors: characteristics of the innovation, the adopters and end users, contextual factors, implementation strategies, and outcomes of the implementation [26-28]. In addition, expert opinions about the content of the survey were collected during a symposium organized by the Interdem Taskforce Assistive Technologies at the Alzheimer Europe conference in 2018. The team of authors further finalized the survey with this input. Also, background characteristics of respondents were included, such as country of residence, type of work organization and area of work, job description, gender, and age. As this was a new survey designed for the purposes of this study, it has not been psychometrically validated as of yet.

The surveys for both successfully and unsuccessfully implemented ATs contained 67 identical structured and open-ended items regarding factors that potentially influence the implementation of ATs as described by respondents (Table 1).

Both surveys were programmed in dedicated survey software (QDNA version 1.1.4; ZorgDNA BV).

Table . Survey themes and subthemes.

Themes	Subthemes
Characteristics of the AT[a]	• The aim of the AT with respect to the 3 areas of promoting social health • Type of device • Dementia-specific development • Pricing • Training requirements • User-friendliness (personalization options, required support)
Characteristics of adopters and end users	• End user of the AT • Ownership of the AT • Main beneficiary • Required training or user criteria
Contextual factors	• Care setting • Policies and legislation • Ethical issues
Implementation strategies	• Stakeholder involvement • Conducted studies on usefulness, effectiveness, cost-effectiveness, and implementation • Presence of business plan; financing
Outcomes of the implementation	• Scale of uptake of the AT; facilitators and barriers for implementation

[a] AT: assistive technology.

Analyses

Descriptive statistics were used to describe the results of the survey and to explore differences between successful and unsuccessful implementations. Due to the small sample size and relatively large number of parameters, statistical tests could not be executed. The qualitative responses to the survey's open-ended items provided only additional information to the quantitative data, such as to clarify a type of device used in the AT, and these responses were not analyzed separately.

Ethical Considerations

This study did not fall under the scope of the Medical Research Involving Human Subjects Act. Therefore, ethical approval by an institutional review board was not obtained. The respondents were informed of the purpose of the study before the survey and gave their consent to the survey data being collected and analyzed pseudonymously (it was not possible to guarantee full anonymity during analyses because the AT was discussed by name by study participants—for many ATs, it is possible to ascertain which researchers or technological developers were behind their development). All AT names were removed from the final data, allowing for pseudonymous reporting of the results. The respondents did not receive any compensation.

Results

Respondents

Thirty-two of the 206 invitees declined to participate as they were not active in the field of AT; the survey was forwarded to at least 13 other researchers. The response rate was 10%; 21 of 206 respondents completed the web-based survey. The participants were employed in a variety of settings: 17 respondents indicated that they were employed in a university setting, 4 in a hospital setting, 4 in care organizations, and 1 in a research organization (nonacademic). Fifteen of the respondents described their main area of work as research, 5 as clinical (1 with inpatients and 4 with outpatients), and 1 as policy. The mean age of the respondents was 49 (SD 12) years, and 71% (15/21) were female. Respondents were from the Netherlands (n=9), the United Kingdom (n=4), Germany (n=2), the Czech Republic (n=1), Denmark (n=1), France (n=1), Hong Kong (n=1), and Italy (n=1). One response was missing.

Included ATs

All 21 respondents filled in the survey for a single AT. However, 2 respondents independently filled in the survey for the same AT, so the total of number of ATs included in this study was 20. Table 2 is an overview of the types of ATs included.

The respondents described the implementation of 12 of these ATs as successful, while 9 were described as unsuccessful. Successfully implemented ATs were associated with national uptake (7/12, 58%), as opposed to international (1/12, 8%) or regional (3/12, 25%) uptake. Only 2 of the 9 unsuccessfully implemented ATs were deployed on a national level (22%).

Table . Types of assistive technology (AT) included.

Type of AT	Responses (n=21), n	
	Successful (n=12)	Unsuccessful (n=9)
Online platform	6	4
Robot	0	1
Monitoring, sensors, or GPS	3	1
Physical aids	2	2
Virtual reality	1	1

Characteristics of the ATs

The survey responses showed that the majority of ATs were aimed at the management of everyday life (15/21, 71%). ATs that were available through multiple devices were more often implemented successfully. The devices most often used in successfully implemented ATs were personal computers (9/12, 75%), smartphones (7/12, 58%), and tablets (5/12, 42%). The range of devices used in unsuccessfully implemented ATs was less diverse, with tablets being reported most frequently (5/9, 56%). Moreover, mobile devices were more often implemented unsuccessfully, while apps were more often implemented successfully. The AT was not specifically developed for people with dementia in all cases; one-third to a quarter were described as “mainstream technology.”

Successfully implemented ATs tended to be more often developed specifically for people with dementia. An association between implementation success and personalization options of the AT was not clear. The design of almost all successfully implemented ATs was considered good or very good; the design of unsuccessfully implemented ATs was considered good by 56% (5/9) of the respondents and bad or very bad by 33% (3/9; the remainder were missing).

Successfully implemented ATs were more often freely available or considered as value for money and deemed affordable for everybody, while unsuccessfully implemented ATs were considered expensive or very expensive by one-third of the respondents. In contrast to the majority of the successfully implemented ATs, none of the unsuccessfully implemented ATs were described as functioning stably. Table 3 provides an overview of how the various device characteristics related to AT implementation success.

Table . Characteristics of the assistive technologies (ATs) and their contributions to implementation success. Note: missing answers are not reported but are taken into account in the calculation of the overall percentages per category (successful ATs and unsuccessful ATs).

AT characteristics		Successfully implemented ATs (n=12), n (%)	Unsuccessfully implemented ATs (n=9), n (%)
Aim [a]			
	Fulfillment of one’s potential	3 (25)	1 (11)
	Management of everyday life	9 (75)	6 (67)
	Participation in social activities	1 (8)	2 (22)
Supporting device			
	Multiple devices	10 (83)	5 (56)
	PC	9 (75)	3 (33)
	Television	2 (17)	0 (0)
	Tablet	5 (42)	5 (56)
	Smartphone	7 (58)	2 (22)
	Smartwatch	1 (8)	0 (0)
	Actuator	1 (8)	0 (0)
	Sensors	3 (25)	2 (22)
	Camera	2 (17)	0 (0)
	Other	3 (25)	3 (33)
Type of AT [a]			
	Mobile	1 (8)	4 (44)
	Stand-alone	2 (17)	2 (22)
	Integrated	2 (17)	3 (33)
	Software/app	6 (50)	3 (33)
Specificity of the AT			
	Specifically for people with dementia	9 (75)	5 (56)
	Mainstream	3 (25)	3 (33)
Personalization options			
	Yes, to a large extent	5 (42)	2 (22)
	Yes, to some extent	3 (25)	3 (33)
	No	4 (33)	3 (33)
Design			
	Very good	3 (25)	0 (0)
	Good	8 (67)	5 (56)
	Bad or very bad	1 (8)	3 (33)
Pricing			
	Freely available	6 (50)	3 (33)
	Value for money	4 (33)	0 (0)
	Expensive or very expensive	0 (0)	3 (33)
Affordability			
	For everybody	8 (67)	2 (22)
Stability			
	No problems	9 (75)	0 (0)

[a]Multiple answers could be provided.

Characteristics of the Adopters and End Users

Approximately half of all ATs were owned by the person with dementia or informal caregiver. This was not clearly associated with implementation success. However, successfully implemented ATs were slightly more often owned by a care organization. Successfully implemented ATs were more often deemed affordable to everybody than unsuccessfully implemented ATs. ATs mainly benefiting the person with dementia were more often successfully implemented. If criteria were defined for users, this was associated with successful implementation of ATs. Relatively more unsuccessfully implemented ATs required a preassessment to advise on or tailor the AT to the user. Most of the ATs required training to be used well. Unsuccessfully implemented ATs slightly more often required training of informal and professional carers. Few ATs could be managed independently by the person with dementia, and support by an informal carer was more often associated with successfully implemented ATs (Table 4).

Table . Characteristics of adopters and end users. Note: missing answers are not reported but are taken into account in the calculation of the overall percentages per category (successful assistive technologies [ATs] and unsuccessful ATs).

Characteristics of adopters and end users		Successfully implemented ATs (n=12), n (%)	Unsuccessfully implemented ATs (n=9), n (%)
Ownership [a]			
	Person with dementia	6 (50)	5 (56)
	Informal carer	6 (50)	3 (33)
	Care organization	4 (33)	1 (11)
	Hospital	1 (8)	0 (0)
Main beneficiary			
	Person with dementia	7 (58)	4 (44)
User criteria			
	Defined	10 (83)	6 (67)
Preassessment			
	Needed	3 (25)	4 (44)
Required training [a]			
	None	3 (25)	3 (33)
	Person with dementia	6 (50)	3 (33)
	Informal carer	6 (50)	5 (56)
	Professional carer	5 (42)	5 (56)
Required support for person with dementia [a]			
	None	2 (17)	3 (33)
	From informal carer	9 (75)	4 (44)
	From professional carer	4 (33)	2 (22)

[a]Multiple answers could be provided.

Contextual Factors

Most of the ATs were used in the home environment, without clear differences between successfully and unsuccessfully implemented ATs. Furthermore, interventions that were described as nonintrusive home ATs were more often seen as successfully implemented. Stable, continuous Wi-Fi was associated with successful implementation. Finally, while the majority of ATs were used within the home context, this was not associated with successful implementation. In contrast, ATs used outdoors were more often associated with successful implementation. When alternative products were available that addressed similar needs as the new AT, the AT was slightly more associated with successful implementation. Successfully implemented ATs were more often reimbursed by insurance or benefits or were paid by a care organization (Table 5).

Table . Contextual factors. Note: missing answers are not reported but are taken into account in the calculation of the overall percentages per category (successful assistive technologies [ATs] and unsuccessful ATs).

Contextual factors		Successfully implemented ATs (n=12), n (%)	Unsuccessfully implemented ATs (n=9), n (%)
User setting [a]			
	Home	9 (75)	8 (89)
	Outside	4 (33)	1 (11)
	Day center	1 (8)	0 (0)
Intrusiveness			
	Nonintrusive	11 (92)	6 (75)
Connection			
	Continuous internet/Wi-Fi needed	8 (67)	3 (33)
Alternative AT			
	Available	7 (64)	4 (44)
Means of financing [a]			
	Out of pocket	2 (17)	3 (33)
	Public health care insurance	4 (33)	1 (11)
	Social welfare benefits	1 (8)	1 (11)
	Care organization	3 (25)	0 (0)
	For rent	1 (8)	1 (11)
	For free	3 (25)	2 (22)

[a] Multiple answers could be provided.

Implementation Strategies

Stakeholder Involvement

The findings on the ATs' stakeholder involvement indicate that, in general, the involvement of people with dementia, informal caregivers, commercial parties, researchers, and care organizations was associated with successful implementation. Only the involvement of governments did not seem to affect implementation success (Table 6).

Table . Stakeholder involvement and assistive technology (AT) implementation success.

Stakeholder group involvement	Successfully implemented ATs (n=12), n (%)	Unsuccessfully implemented ATs (n=9), n (%)
Person with dementia	6 (50)	2 (22)
Informal caregiver	7 (58)	2 (22)
Commercial party	7 (58)	4 (44)
Government	3 (25)	2 (22)
Research	9 (75)	5 (55)
Care organization	7 (58)	2 (22)

Research Activities

It appears that ATs whose user friendliness has been studied are more often successfully implemented (10/12, 83% vs 4/9, 44%), independent of the outcome of the study. Also, effectiveness studies were more often part of the development process in successfully implemented ATs (7/12, 58%) than in unsuccessful trajectories (2/9, 22%). Few cost-effectiveness studies were performed—for just 4 ATs in total—and this was not associated with implementation success. Ethical issues were considered for 57% (12/21) of all included ATs. This happened equally often for successfully and unsuccessfully implemented ATs. Most respondents referred to the obtainment of medical ethical approval; for one study, AT ethical issues were registered, while another study addressed potential ethical issues in an intervention protocol. Ethics were considered most often in the development phase of ATs and least often during the implementation phase, in 25% (3/12) and 11% (1/9), respectively, of successfully and unsuccessfully implemented ATs. Regarding privacy and data security, these were taken into account for most ATs (16/21, 76% in total) and were not associated with implementation success. However, studies on barriers to and facilitators of implementation and the presence of a business plan were associated with successfully implemented ATs (6/12, 50% and 5/12, 42% for successfully implemented ATs, respectively, vs 2/9, 22% and 1/9, 11% for unsuccessfully implemented ATs).

Main Facilitators and Barriers

The respondents were also asked to select a maximum of 5 facilitators considered as most important and a maximum of 5 most relevant barriers out of 30 factors that applied to the implementation of their ATs.

Facilitators that were most often mentioned were associated with the AT itself, including user-friendliness, the type of device (ie, personal computers, smartphones, and tablets were more often successfully implemented), and the availability of the AT on multiple devices. For successfully implemented ATs, personalization options were also considered to facilitate implementation. Contextual factors were only considered relevant for successful implementation; availability of a continuous internet or Wi-Fi connection in particular appeared to be the major facilitator.

In general, barriers were mentioned more often in unsuccessfully implemented ATs. The main barriers were, foremost, the opposite of the facilitators: a lack of user-friendliness and the unavailability of the AT on multiple devices. Next, contextual factors, such as an internet connection, available alternatives, ethics, privacy and data security, intrusiveness of the AT, and policy and laws, were mentioned as factors impeding the implementation. No main barrier could be identified.

Also, for successfully implemented ATs, respondents reported that the lack of financing and business plans for the AT was a major barrier that needed to be addressed in the implementation strategy. On the other hand, barriers for unsuccessfully implemented ATs were related to not being effective or cost-effective and lacking a marketing strategy and business plan (Table 7).

Table . Frequency of mentioned main facilitators of and barriers to implementation of assistive technologies (ATs) per category.

	Facilitators		Barriers	
	Successfully implemented ATs (n=12), n (%)	Unsuccessfully implemented ATs (n=9), n (%)	Successfully implemented ATs (n=12), n (%)	Unsuccessfully implemented ATs (n=9), n (%)
Adopters	3 (25)	2 (22)	1 (8)	3 (33)
Technology	7 (58)	5 (56)	3 (25)	7 (78)
Contextual	4 (33)	0 (0)	3 (25)	5 (56)
End user	2 (17)	2 (22)	1 (8)	4 (44)
Implementation strategy	2 (17)	2 (22)	3 (25)	3 (33)

Discussion

Main Findings

This study used a cross-sectional design to survey Interdem researchers with experience in AT projects for people with dementia on factors that influence the implementation of AT. This resulted in 21 survey responses, describing 12 successfully and 9 unsuccessfully implemented ATs. The main finding was that certain characteristics of the AT itself, such as the type of device used and the user-friendliness of the AT, seemed to be the most important for implementation success. Usability is one of the most relevant issues for successful implementation of technology [29]. The results also showed that contextual factors, although they can contribute to an AT's successful implementation, were mostly considered as barriers. Furthermore, research activities carried out during the development process of an AT, such as studies on the user-friendliness and effectiveness of the AT, were more often related to successful implementation. The findings add value to the existing literature by helping fill the identified gap in knowledge [29,30] on implementation determinants in AT for dementia. This study on AT implementation has resulted in several important lessons for researchers, clinicians, and policy makers that can be considered as guidelines for successful implementation of AT in dementia.

Lesson 1: Enhancing Value

The first lesson concerns how specific characteristics of the AT device are associated with implementation success. First, the ability to use the AT on multiple devices proved to be an important facilitator. This enables users to select a device matching their preferences and their capability to operate it. The possibility of multiple devices could also be related to another finding, namely the benefit of the availability of multiple delivery options for implementation success, such as the possibility of using a device not only indoors but also outdoors. The finding that an AT's flexible delivery on multiple devices was an implementation determinant is consistent with previous research that identified a lack of interoperability as the biggest barrier to innovation, as it is often very hard to integrate new ATs into existing systems and devices [31]. Second, the finding that an AT's user-friendliness played a considerable role in implementation success is in line with the outcomes of a previous systematic review on the implementation determinants of ATs for dementia [29]. However, as previously advocated by Bennett et al [32], it is important to find a balance between ease of use (for example, few or only simple actions required by the user) and proper diligence in terms of privacy and data security. This involves a thorough analysis of the implications of an AT for human rights laws, such as impacts on freedom of movement or privacy. Services such as surveillance technology should be refined to find the best balance between privacy and usefulness [33]. In sum, it is recommended to enhance an AT's value through specific device characteristics, such as interoperability, user-friendliness, and an ethical approach to data security.

Lesson 2: Optimizing Fit

The survey showed the importance of involving different stakeholders to facilitate implementation success. Previous research has emphasized the need to involve people with dementia throughout the development, evaluation, and implementation of ATs for dementia [34]. However, this study also makes clear that successful implementation depends on a wide involvement of actors in the dementia care network. Rigorously mapping stakeholder needs for a particular AT not only contributes to a more appropriate business model and sustainability, it also facilitates person-centered care [35] by taking into account the needs of all persons involved in the dementia care network. Potential barriers and facilitators such as workload and lack of resources in formal care, as well as easy access to and affordability of the AT for informal carers can be considered timely [36]. Moreover, the study findings indicate that the same feature can both hinder or facilitate implementation, depending on the context. This implies that there is no universal rule for implementing ATs successfully, and it remains necessary to adapt each AT to its implementation context, resulting in a better fit [36,37]. The findings of this study thus suggest that people with dementia as well as other stakeholders should be engaged in the cocreation of new technologies for dementia and that new ways and methodologies should be developed to promote this cooperation [38]. In sum, it is recommended to optimize the fit to the target group or groups by involving a wide range of stakeholders, in addition to people with dementia, at every stage of AT development and evaluation.

Lesson 3: Ensuring Equity and Sustainability

A third lesson is that the affordability of ATs in dementia care is important for equal access to care and, in turn, for sustainable implementation. This has also been stressed by Moyle [39], who pointed out that ATs can be quite expensive, as personalized solutions are preferred. A recurring criticism of ATs such as eHealth has been that they can foster exclusion, as users must have a high level of digital and mental health skills to engage with some ATs, as well as sufficient resources to purchase the required devices [40]. Moreover, the COVID-19 pandemic has exacerbated health inequalities around the world [41]. Not only did the disease itself lead to worse health outcomes in vulnerable populations, the limitations on human contact disproportionately affected older people, accelerated cognitive decline in people with dementia, and increased social isolation of informal carers [42,43]. ATs could prevent understimulation and support social contact at a distance. Thus, successful implementation of ATs is important.

A first way AT developers can mitigate these inequities in AT implementation for dementia is by ensuring affordability through business modeling [44]. Previous research has emphasized the benefits of preliminary business models for new ATs. A study of AT applications in dementia not only helped to determine (affordable) costs and revenues, but also showed that establishing a business model facilitates decision-making by potential implementers, as there is an indication that the AT will be available beyond the study period and that efforts to apply the AT will not be wasted [45]. A second way is for AT developers to emphasize the importance of rigorous research regarding evaluation and implementation that takes the diverse characteristics of potential target users into account. This study confirmed that the execution of certain research activities, such as research into user-friendliness and effectiveness, was in itself a success factor in AT implementation. An intersectional research approach would strongly contribute to better implementation of ATs in dementia. Intersectionality is centered around "a variety of multi-level interacting social locations, forces, factors and power structures that shape and influence human life," which goes beyond gender-specific and social-determinant frameworks [46]. An intersectional approach can help broaden the impact of ATs intended for dementia care to a more diverse group by taking a wider range of needs into account and not reducing individuals to one defining characteristic, such as age, gender, migration status, education, sexuality, or ethnicity. It can also reduce implementation barriers by avoiding an unpersonalized, one-size-fits-all approach [47]. In sum, it is recommended to ensure equity and sustainability in AT implementation through an intersectional approach and business modeling.

General Recommendations

The findings from this study have produced a number of useful lessons for a variety of stakeholders, including researchers who wish to bring their ATs into practice, clinicians who want to provide the most suitable AT to their clients, and policy makers who wish to know the most effective ways to fund AT development, research, and implementation. In general, based on these findings, we recommend considering alternative study designs that are flexible and suit the fast-paced, changing, and innovative nature of technology, as well as the progressive disease trajectory of dementia, to complement more rigid and resource-intensive designs, such as randomized controlled trials. These alternative study designs can iteratively and responsively examine the user-friendliness, effectiveness, cost-effectiveness, and sustainability of the implementation of ATs, with varying relevant outcome measures depending on the studied stakeholder group.

These recommendations for improving successful implementation of ATs in dementia care are in line with previous implementation research findings [48-50]. For example, Ienca et al [51] proposed a proactive approach, taking into account four normative principles that may help successful implementation: (1) minimization of power imbalances in decision-making, which could be achieved through cooperation among different stakeholders, including end users; (2) compliance with biomedical ethics, such as beneficence, nonmaleficence, autonomy, and justice; (3) translation of research into practice; and (4) raising social awareness and sharing knowledge across society. They additionally complement the recent recommendations made in the *INDUCT/DISTINCT Best Practice Guidance on Human Interaction with Technology in Dementia*, including its recommendations around business modeling and optimizing AT fit to the implementation context [30].

Strengths and Limitations

A first major strength of this study is the multidisciplinary range of respondents' professional backgrounds. Although it is not clear how representative the Interdem Network is of researchers in the field of psychosocial dementia care in Europe, the multidisciplinarity of the network, ranging from physicians (psychiatrists, geriatric care physicians, and neurologists); clinical, social, and neuropsychologists; social scientists; paramedics; palliative care specialists; and movement scientists, allowed us to potentially involve a broad group of participants from diverse backgrounds in this survey. A second major strength of this study is the combined use of qualitative and quantitative research methods to paint a rich and detailed picture of the current field of implementation of ATs for dementia. This richness of data also sheds light on what happens after the end of the research phase, during which the interventions are well controlled and care professionals are motivated to participate. Hence, the added value of this research to the existing literature is its assessment of implementation results in real environments, in addition to quantitative data.

This study also had some important limitations, which need to be mentioned. First, the study had a cross-sectional design, which does not allow for any causal interpretations of the associations found between the studied implementation determinants. Furthermore, the survey questionnaire is in its first iteration and not psychometrically tested. Nonetheless, this study constitutes a first, important step toward identifying relevant determinants of successful implementation of ATs in dementia care for future study. Second, this study had a rather limited sample size and large variety of ATs and surveyed countries, making it difficult to generalize the findings. Also, we do not know the exact response rate as we do not know how many Interdem members had done research with AT at the time the survey was conducted. Also, the small sample size may have resulted in a biased sample. As a result, the analysis of this exploratory study was limited to a descriptive approach. Altogether, 20 different ATs were considered by the respondents, with specific issues addressed. Given the involvement of the respondents in the different ATs, despite the small sample size, valuable information has been obtained in this study. Third, the terminology used in the survey in this study regarding "free-to-use" interventions may have led to different interpretations, making it hard to draw definitive conclusions on this. It is possible that this was interpreted as "without costs for the end user," even though there are still costs for other parties, such as the implementing organizations or health insurers. Finally, this study focused only on a limited number of high-income implementation contexts. Therefore, the study's insights may not all apply to a wider variety of contexts, such as low- and middle-income countries.

Directions for Future Research

This study highlights several important areas for future research. First, while a number of implementation determinants were associated with successful implementation, future research could attempt to infer which strategies are the most effective in facilitating AT implementation by differentially evaluating these strategies in experimental designs tailored to specific types of AT and implementation contexts. Second, it would be useful to explore AT implementation in different contexts, including low- and middle-income countries. Finally, this study should be followed up, and participants should be asked to provide more qualitative first-hand data on their implementation experiences. In doing so, it will be important to ask people with dementia, informal carers, and care professionals about why they want or do not want to use these interventions.

Conclusions

This study provides insight into some main facilitators of and barriers to successful implementation of ATs in dementia care, such as factors related to the AT itself, contextual factors, if accompanying research activities were done into the AT, and applied implementation strategies. Based on this, lessons and recommendations were formulated to improve the implementation of AT in dementia care.

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Data Availability

The pseudonymized data that support the findings of this study are available from the corresponding author upon request.

Conflicts of Interest

All authors are members of Interdem or the Interdem Academy.

References

1. eHealth action plan 2012-2020. European Commission. 2012. URL: https://health.ec.europa.eu/publications/ehealth-action-plan-2012-2020_en [accessed 2024-08-22]
2. European Commission. Market Study on Telemedicine: Publications Office of the European Union; 2018. URL: https://ec.europa.eu/health/sites/default/files/ehealth/docs/2018_provision_marketstudy_telemedicine_en.pdf [accessed 2024-08-15]
3. Marshall M. State of the Art in Dementia Care: Centre for Policy on Ageing; 1997.

4. Meiland F, Innes A, Mountain G, et al. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR Rehabil Assist Technol 2017 Jan 16;4(1):e1. [doi: 10.2196/rehab.6376] [Medline: 28582262]
5. Kaplan RM, Stone AA. Bringing the laboratory and clinic to the community: mobile technologies for health promotion and disease prevention. Annu Rev Psychol 2013;64:471-498. [doi: 10.1146/annurev-psych-113011-143736] [Medline: 22994919]
6. Janssen R, Hettinga M, Visser S, et al. Innovation routes and evidence guidelines for eHealth small and medium-sized enterprises. Int J Adv Life Sc 2013 Dec;5(3&4):188-203 [FREE Full text]
7. Lau HM, Smit JH, Fleming TM, Riper H. Serious games for mental health: are they accessible, feasible, and effective? A systematic review and meta-analysis. Front Psychiatry 2016;7:209. [doi: 10.3389/fpsyt.2016.00209] [Medline: 28149281]
8. van Santen J, Dröes RM, Holstege M, et al. Effects of exergaming in people with dementia: results of a systematic literature review. J Alzheimers Dis 2018;63(2):741-760. [doi: 10.3233/JAD-170667] [Medline: 29689716]
9. Egan KJ, Pinto-Bruno Á, Bighelli I, et al. Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. J Am Med Dir Assoc 2018 Mar;19(3):200-206. [doi: 10.1016/j.jamda.2017.10.023] [Medline: 29306605]
10. Best practice guidance: human interaction with technology in dementia. INDUCT. 2023. URL: https://www.dementiainduct.eu/wp-content/uploads/2023/06/D6.2-D6.5-BPG-website-format-update-15-6-2023-v6.2-FINAL.pdf [accessed 2024-08-22]
11. Dequanter S, Gagnon MP, Ndiaye MA, et al. The effectiveness of e-health solutions for ageing with cognitive impairment: a systematic review. Gerontol 2021 Sep 13;61(7):e373-e394. [doi: 10.1093/geront/gnaa065] [Medline: 32525977]
12. García-Casal JA, Loizeau A, Csipke E, Franco-Martín M, Perea-Bartolomé MV, Orrell M. Computer-based cognitive interventions for people living with dementia: a systematic literature review and meta-analysis. Aging Ment Health 2017 May;21(5):454-467. [doi: 10.1080/13607863.2015.1132677] [Medline: 26806365]
13. Pappadà A, Chattat R, Chirico I, Valente M, Ottoboni G. Assistive technologies in dementia care: an updated analysis of the literature. Front Psychol 2021;12:644587. [doi: 10.3389/fpsyg.2021.644587] [Medline: 33841281]
14. Boots LMM, de Vugt ME, van Knippenberg RJM, Kempen G, Verhey FRJ. A systematic review of internet-based supportive interventions for caregivers of patients with dementia. Int J Geriatr Psychiatry 2014 Apr;29(4):331-344. [doi: 10.1002/gps.4016] [Medline: 23963684]
15. Teahan Á, Lafferty A, McAuliffe E, et al. Psychosocial interventions for family carers of people with dementia: a systematic review and meta-analysis. J Aging Health 2020 Oct;32(9):1198-1213. [doi: 10.1177/0898264319899793] [Medline: 31957536]
16. Scerbe A, O'Connell ME, Astell A, Morgan D, Kosteniuk J, DesRoches A. Digital tools for delivery of dementia education for health-care providers: a systematic review. Educ Gerontol 2019 Nov 2;45(11):681-699. [doi: 10.1080/03601277.2019.1687149] [Medline: 37196022]
17. Wang H, Li T, Barbarino P, et al. Dementia care during COVID-19. Lancet 2020 Apr 11;395(10231):1190-1191. [doi: 10.1016/S0140-6736(20)30755-8] [Medline: 32240625]
18. Christie HL, Martin JL, Connor J, et al. eHealth interventions to support caregivers of people with dementia may be proven effective, but are they implementation-ready? Internet Interv 2019 Dec;18:100260. [doi: 10.1016/j.invent.2019.100260] [Medline: 31890613]
19. Ienca M, Fabrice J, Elger B, et al. Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. J Alzheimers Dis 2017;56(4):1301-1340. [doi: 10.3233/JAD-161037] [Medline: 28222516]
20. Irazoki E, Contreras-Somoza LM, Toribio-Guzmán JM, Jenaro-Río C, van der Roest H, Franco-Martín MA. Technologies for cognitive training and cognitive rehabilitation for people with mild cognitive impairment and dementia. A systematic review. Front Psychol 2020;11:648. [doi: 10.3389/fpsyg.2020.00648] [Medline: 32373018]
21. Greenhalgh T, Abimbola S. The NASSS framework - a synthesis of multiple theories of technology implementation. Stud Health Technol Inform 2019 Jul 30;263:193-204. [doi: 10.3233/SHTI190123] [Medline: 31411163]
22. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Impl Sci 2009 Dec;4(1):1-15. [doi: 10.1186/1748-5908-4-50] [Medline: 19664226]
23. Rabin BA, Brownson RC, Haire-Joshu D, Kreuter MW, Weaver NL. A glossary for dissemination and implementation research in health. J Public Health Manag Pract 2008;14(2):117-123. [doi: 10.1097/01.PHH.0000311888.06252.bb] [Medline: 18287916]
24. Dröes RM, Chattat R, Diaz A, et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. Aging Ment Health 2017 Jan;21(1):4-17. [doi: 10.1080/13607863.2016.1254596] [Medline: 27869503]
25. Interdem. URL: https://interdem.org/ [accessed 2024-08-14]
26. Nilsen P. Making sense of implementation theories, models, and frameworks. Impl Sci 2020;30:53-79. [doi: 10.1007/978-3-030-03874-8_3] [Medline: 25895742]

27. Peek STM, Luijkx KG, Rijnaard MD, et al. Older adults' reasons for using technology while aging in place. Gerontology 2016;62(2):226-237. [doi: 10.1159/000430949] [Medline: 26044243]
28. Peek STM, Wouters EJM, Luijkx KG, Vrijhoef HJM. What it takes to successfully implement technology for aging in place: focus groups with stakeholders. J Med Internet Res 2016 May 3;18(5):e98. [doi: 10.2196/jmir.5253] [Medline: 27143097]
29. Christie HL, Bartels SL, Boots LMM, Tange HJ, Verhey FJJ, de Vugt ME. A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. Internet Interv 2018 Sep;13:51-59. [doi: 10.1016/j.invent.2018.07.002] [Medline: 30206519]
30. Dröes RM, Vermeer Y, Libert S, et al. Best practice guidance on human interaction with technology in dementia–recommendations from the INDUCT network. Int Psychogeriatr 2020 Oct;32(S1):103-103. [doi: 10.1017/S1041610220002434]
31. Haritou M, Glickman Y, Androulidakis A, et al. A technology platform for a novel home care delivery service to patients with dementia. J Med Imaging Hlth Inform 2012 Mar 1;2(1):49-55. [doi: 10.1166/jmihi.2012.1060]
32. Bennett B, McDonald F, Beattie E, et al. Assistive technologies for people with dementia: ethical considerations. Bull World Health Organ 2017 Nov 1;95(11):749-755. [doi: 10.2471/BLT.16.187484] [Medline: 29147055]
33. Mulvenna M, Hutton A, Coates V, et al. Views of caregivers on the ethics of assistive technology used for home surveillance of people living with dementia. Neuroethics 2017;10(2):255-266. [doi: 10.1007/s12152-017-9305-z] [Medline: 28725288]
34. Rai HK, Cavalcanti Barroso A, Yates L, Schneider J, Orrell M. Involvement of people with dementia in the development of technology-based interventions: narrative synthesis review and best practice guidelines. J Med Internet Res 2020 Dec 3;22(12):e17531. [doi: 10.2196/17531] [Medline: 33270034]
35. Coulter A, Oldham J. Person-centred care: what is it and how do we get there? Fut Hosp J 2016 Jun;3(2):114-116. [doi: 10.7861/futurehosp.3-2-114] [Medline: 31098200]
36. Christie HL, Boots LMM, Hermans I, et al. Business models of eHealth interventions to support informal caregivers of people with dementia in the Netherlands: analysis of case studies. J Aging 2021 Jun 3;4(2):e24724. [doi: 10.2196/24724] [Medline: 34081009]
37. Hingle M, Patrick H, Sacher PM, Sweet CC. The intersection of behavioral science and digital health: the case for academic–industry partnerships. Health Educ Behav 2019 Feb;46(1):5-9. [doi: 10.1177/1090198118788600] [Medline: 30041556]
38. Molinari-Ulate M, Woodcock R, Smith I, van der Roest HG, Franco-Martín MA, Craven MP. Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: supporting the development of an "E-nabling digital co-production" framework. Res Involv Engagem 2022 Jul 26;8(1):33. [doi: 10.1186/s40900-022-00371-9] [Medline: 35883132]
39. Moyle W. The promise of technology in the future of dementia care. Nat Rev Neurol 2019 Jun;15(6):353-359. [doi: 10.1038/s41582-019-0188-y] [Medline: 31073242]
40. George C, Whitehouse D, Duquenoy P. eHealth: Legal, Ethical and Governance Challenges: Springer Science & Business Media; 2012. [doi: 10.1007/978-3-642-22474-4]
41. Abedi V, Olulana O, Avula V, et al. Racial, economic, and health inequality and COVID-19 infection in the United States. J Racial Ethn Health Disparities 2021 Jun;8(3):732-742. [doi: 10.1007/s40615-020-00833-4] [Medline: 32875535]
42. Resultaten corona peiling onder mantelzorgers van mensen met dementie. Alzheimer Netherlands. 2020. URL: https://media.alzheimer-nederland.nl/s3fs-public/media/2023-01/documents/AN_resultaten-coronapeiling_04-2020.pdf [accessed 2024-08-22]
43. Gerritsen D, van der Roest H, Evans S, et al. The impact of the COVID-19 pandemic on the well-being of people living with dementia. In: Dementia and Society: Cambridge University Press; 2022. [doi: 10.1017/9781108918954.011]
44. Christie HL, Boots LMM, Peetoom K, Tange HJ, Verhey FRJ, de Vugt ME. Developing a plan for the sustainable implementation of an electronic health intervention (Partner in Balance) to support caregivers of people with dementia: case study. JMIR Aging 2020 Jun 25;3(1):e18624. [doi: 10.2196/18624] [Medline: 32584261]
45. Christie HL, Schichel MCP, Tange HJ, Veenstra MY, Verhey FRJ, de Vugt ME. Perspectives from municipality officials on the adoption, dissemination, and implementation of electronic health interventions to support caregivers of people with dementia: inductive thematic analysis. JMIR Aging 2020 May 13;3(1):e17255. [doi: 10.2196/17255] [Medline: 32401217]
46. Hankivsky O, Grace D, Hunting G, Ferlatte O. Introduction: why intersectionality matters for health equity and policy analysis. In: An Intersectionality-Based Policy Analysis Framework: Institute for Intersectionality Research and Policy, Simon Fraser University; 2012:7-30.
47. Dilworth-Anderson P, Moon H, Aranda MP. Dementia caregiving research: expanding and reframing the lens of diversity, inclusivity, and intersectionality. Gerontol 2020 Jul 15;60(5):797-805. [doi: 10.1093/geront/gnaa050] [Medline: 32667672]
48. Schulz R, Wahl HW, Matthews JT, De Vito Dabbs A, Beach SR, Czaja SJ. Advancing the aging and technology agenda in gerontology. Gerontol 2015 Oct;55(5):724-734. [doi: 10.1093/geront/gnu071] [Medline: 25165042]
49. Tannou T, Lihoreau T, Couture M, et al. Is research on 'smart living environments' based on unobtrusive technologies for older adults going in circles? Evidence from an umbrella review. Ageing Res Rev 2023 Feb;84:101830. [doi: 10.1016/j.arr.2022.101830] [Medline: 36565962]

50. Wang RH, Kenyon LK, McGilton KS, et al. The time is now: a FASTER approach to generate research evidence for technology-based interventions in the field of disability and rehabilitation. Arch Phys Med Rehabil 2021 Sep;102(9):1848-1859. [doi: 10.1016/j.apmr.2021.04.009] [Medline: 33992634]
51. Ienca M, Kressig RW, Jotterand F, Elger B. Proactive ethical design for neuroengineering, assistive and rehabilitation technologies: the cybathlon lesson. J Neuroeng Rehabil 2017 Nov 14;14(1):115. [doi: 10.1186/s12984-017-0325-z] [Medline: 29137639]

Abbreviations

AT: assistive technology

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How Time, Living Situation, and Stress Related to Technology Influence User Acceptance and Usability of a Socialization Service for Older Adults and Their Formal and Informal Caregivers: Six-Month Pilot Study

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Abstract

Background: Considering the growing population of older adults, addressing the influence of loneliness among this demographic group has become imperative, especially due to the link between social isolation and deterioration of mental and physical well-being. Technology has the potential to be used to create innovative solutions to increase socialization and potentially promote healthy aging.

Objective: This 6-month study examined the usability and acceptability of a technology-based socialization service and explored how stress and living situation affect older adults' and their ecosystem's perceptions of technology, investigating cross-sectional and longitudinal differences among and across user groups.

Methods: Participants were recruited in Tuscany and Apulia (Italy) through a network of social cooperatives and a research hospital, respectively. A total of 20 older adults were provided with the same technology installed on a tablet and on a smart television. The technology has three functionalities: video calling, playing games, and sharing news. Additionally, 20 informal caregivers (IC) and 13 formal caregivers (FC) connected to the older adults were included in the study. After both initial training in the use of the system (T0) and 6 months of using the system (T6), questionnaires on usability, acceptability, and technostress were filled in by older adults, IC, and FC. Nonparametric or parametric tests were conducted to investigate group differences at both time points and changes over time. Additional analyses on older adults were done to assess whether differences in usability and acceptability were related to living situation (ie, alone or with someone). Furthermore, correlation analyses were performed between usability, acceptability, and stress toward technology at T0 and T6.

Results: At both T0 and T6, older adults had lower usability scores than IC and FC and higher anxiety than IC. Over time, there was a significant decrease in older adults' attitudes toward technology score, depicting a negative attitude over time (T0 median 4.2, IQR 0.5; T6 median 3.7, IQR 0.8; Cohen *d*=0.7), while there was no change for IC and FC. At T0, those living alone had lower acceptability than those living with someone but this difference disappeared at T6. People or participants living with someone had a decline in anxiety, attitudes toward technology, enjoyment, and perceived usefulness. Stress toward technology affected usability and acceptability in the older adult group entering the study ($\rho=-.85$) but this was not observed after 6 months. In the IC group, stress affected trust at T0 ($\rho=-.23$) but not at T6.

Conclusions: At the start of the study, older adults judged the system to be less usable and more stressful than did the caregivers. Indeed, at first, technostress was correlated with usability and acceptability; however, with repeated use, technostress did not influence the perception of technology. Overall, getting accustomed to technology decreased anxiety and stress toward technology.

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KEYWORDS

active aging; longitudinal study; technostress; technology usability and acceptance; scaling up

Introduction

Technological advances in health care research have extended the longevity of the population. However, solely increasing lifespan does not assure healthy aging or prevent age-related diseases. Older adults commonly report feeling lonely and socially isolated, feelings which are linked to decreased mental and physical health [1,2]. In Italy, 31.5% of people aged 65 years and older have limited autonomy due to health problems [3]. In 2019, it was estimated that 11.3% of older adults had depression, with the presence of comorbidity (ie, of other chronic conditions). Currently, about 65% of older adults with limited autonomy are helped by relatives, paid services, or others [3].

In this context, technological devices may play a pivotal role in supporting activities of daily living and promoting independent living. Technological devices are products that can be used to assist by increasing, maintaining, or improving functional capabilities of people with disabilities or difficulties [4]. These can range from communication devices to wheelchairs to visual or hearing aids. In recent years, there have been several research projects that have tried to develop technological devices to promote independent living and active aging [5,6]. Additionally, older adults are more likely to be experiencing or using new internet-driven personal devices such as smartphones and computers in their daily lives than before, boosted by the effects of the COVID-19 pandemic [7]. In that regard, formal caregivers (FC) and informal caregivers (IC) can play a crucial role in fostering the adoption of these technologies by older adults [8].

Contrary to stereotypes, many older adults show positive attitudes and expectations toward technological devices [9,10]. For instance, several studies have highlighted an association between social interaction through internet use and the quality of life of older adults [11]. Internet communication provides an inexpensive tool to stay connected with friends, family, and society. However, currently, the older population for the most part is not digitally experienced and decreased cognitive and physical abilities could be barriers to learning how to use technology [12,13]. Furthermore, personal susceptibility to stress could influence performance by increasing cognitive load [14].

The settings and environments in which technological devices, products, and services may be used are numerous and extend from older adults' homes to nursing homes and hospitals. In an independent living situation, technology can be used to monitor older adults by constantly monitoring their living environment, physical activity/exercise, medicine uptake, blood pressure, and heart rate, and it can also support caregivers in their daily tasks [15-17]. In a survey conducted during the COVID-19 pandemic, more than half of older adults reported that they used technology to connect with others and that they adopted new technologies since the start of the pandemic. The study also indicated that one of the main factors that supported older adults' willingness to learn was keeping in touch with family members, especially grandchildren [18]. The same study also highlighted that older adults living in rural areas experienced greater technological barriers to technology use. Moreover, since social isolation and loneliness are associated with higher mortality risk [19], it is important to investigate ways to increase socialization and promote social connectedness; technology could help in this matter. Indeed, although living alone has been suggested to be a risk factor for poor health, studies showed that it was a lack of social connectedness (measured by social network size), rather than the condition of living alone, that was associated with adverse health outcomes [20-22]. Furthermore, results from a systematic review and meta-analysis showed that technological interventions to support older adults in long-term care have one of the largest effect sizes in reducing social isolation and loneliness [23]. Regarding technology-supported interventions to improve well-being and socialization, from a recent systematic review [24], it was evident that the available studies had a short time span and less than half employed tailored solutions. The short time span between baseline and follow-up found in previous studies does not allow for an in-depth investigation of the effects of the use of different technological devices among older adults. Furthermore, as noted by an embedded case study [25] and reviews [26,27], adoption and acceptance are influenced by social influence from family, friends, and caregivers. It is therefore important to explore the whole ecosystem that revolves around older adults to understand the reasons behind low usage of a device or user acceptance. Additionally, soliciting a multistakeholder perspective by engaging both older adults and their caregivers in a study would be advantageous and provide further support for research outcomes.

In this context, this paper presents a service designed to increase socialization in older adults through a technological device. The study is part of the Pharaon project [28], which is a large-scale pilot under the "Digitising European Industry" strategy. The project aims to promote active aging using already available and mature platforms and technologies. The Pharaon project uses the action research method, which entails 4 cyclical actions: reflect, plan, act, observe, and then reflect again to continue through the cycle. Specifically, after deployment and data collection, reflection meetings were organized to assess how the deployment was proceeding and to better plan next actions.

For this particular socialization service, the same technology was installed on two different user interfaces (UIs): a smart television or a tablet. This technology allowed video calling between older adults (n=20) and their IC (n=20) and FC (n=13), and it offered the ability to share news/pictures and play games. The service was implemented for 6 months in the home of the older adult. The 3 cohorts were compared with each other and over time in terms of usability and acceptability in a cross-sectional and longitudinal design. Furthermore, we explored whether stress or living alone/with someone affected user perception of the older adult. Specifically, we aimed to answer the following research questions (RQ):

- RQ1: Are there any differences in acceptability and usability intergroup and between cohorts (ie, older adults, IC, FC) over time? For the older adults, are differences related to different devices?
- RQ2: Can living situation represent a discriminant factor for acceptance and usability of technology by older adults?
- RQ3: Will stress related to technology usage affect usability and acceptability as reported by older adults?

Methods

System Service Description

The types of technologies were selected based on feedback received from older adults and their caregivers during the needs analysis phase of the project. In the Italian pilot, the needs analysis led to the identification and deployment of two services: monitoring and socialization [29]. In this paper, we focus only on the socialization service.

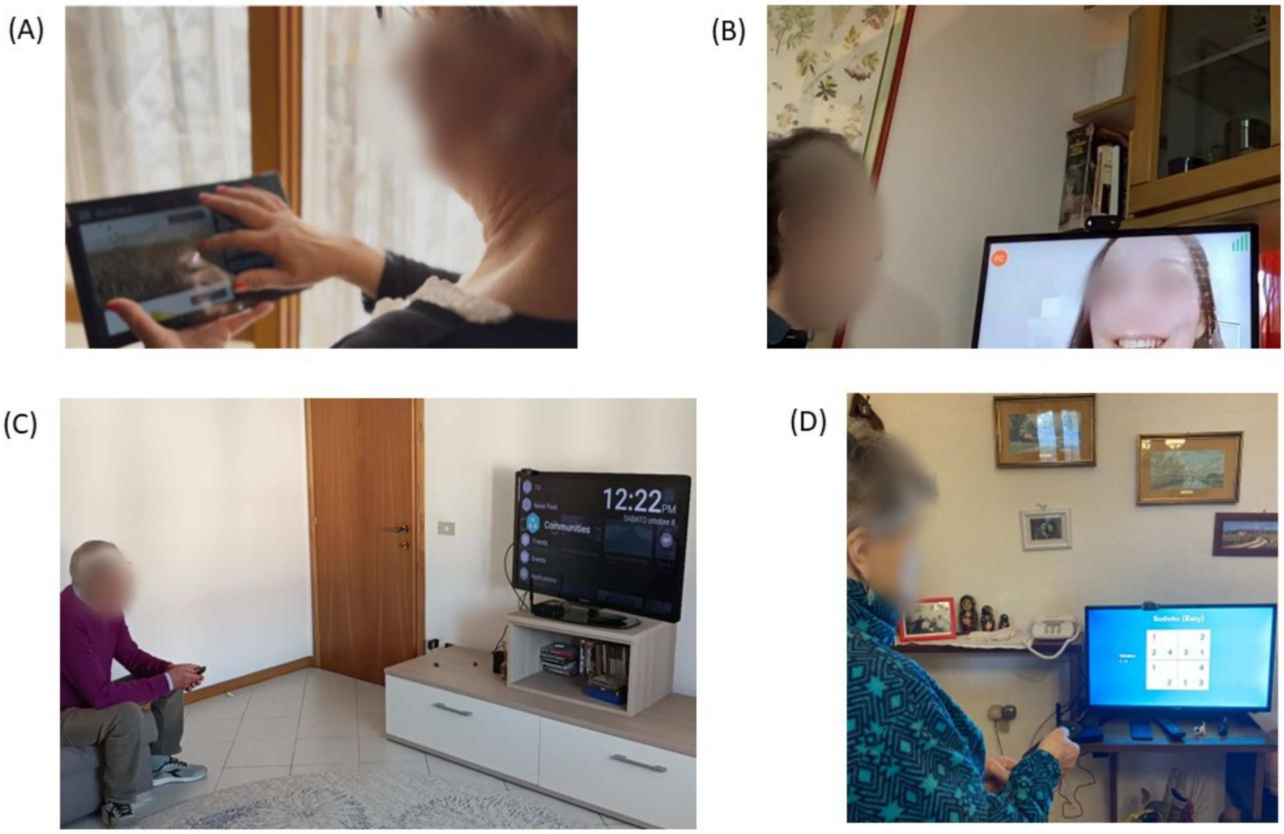
The socialization service is based on Sentab technology (Sentab Estonia OÜ). The system was developed around a UI working on the web, Android, iOS, and Android TV. From a technical perspective, the Sentab backend solution was based on Enterprise Java on Jetty, open source RabbitMQ, and Redis dockers. Information was stored in a MySQL database on Ubuntu servers. The content delivery network was built on Amazon CloudFront and S3.

In the project, two UIs were used: an Android application installed on tablets (Apulia) and televisions (Tuscany) and an Android app for caregivers installed on their mobile phone. This final choice was made based on the feedback received from pilot managers as an outcome of the needs assessment. It is worth underscoring that the service was the same for both technologies—only the devices changed.

The older adults could interact with the tablet using the touch screen, whereas for the television, a separate remote control was provided and Sentab was accessed using the arrows and an “OK” button (Figure 1). For both technologies (ie, tablet and television), the Sentab technology has the following functionalities: (1) a video calling function, where older adults and their caregivers could video call through the UIs; (2) a stimulating game function, where older adults can access some cognitive games (eg, sudoku, picture memory) and monitor their improvement by checking the cognitive index calculated by Sentab; and (3) a stay-informed function, where older adults and IC can access news and information shared by hospital clinicians regarding best practices for maintaining a healthy and active lifestyle.

An overview of the socialization service can be found online [30]. By connecting to their UIs, caregivers could communicate with their relative (or “assigned” older adult) and share photos or news.

Figure 1. Photographs illustrating participants enrolled in the study. All participants agreed and consented to have their picture taken and used in publications. (A) Older adult checking the “stay informed” function on the tablet. (B) Older adult video calling their formal caregiver on a smart television. (C) Older adult using the smart television. (D) Older adult participant using the television game app.



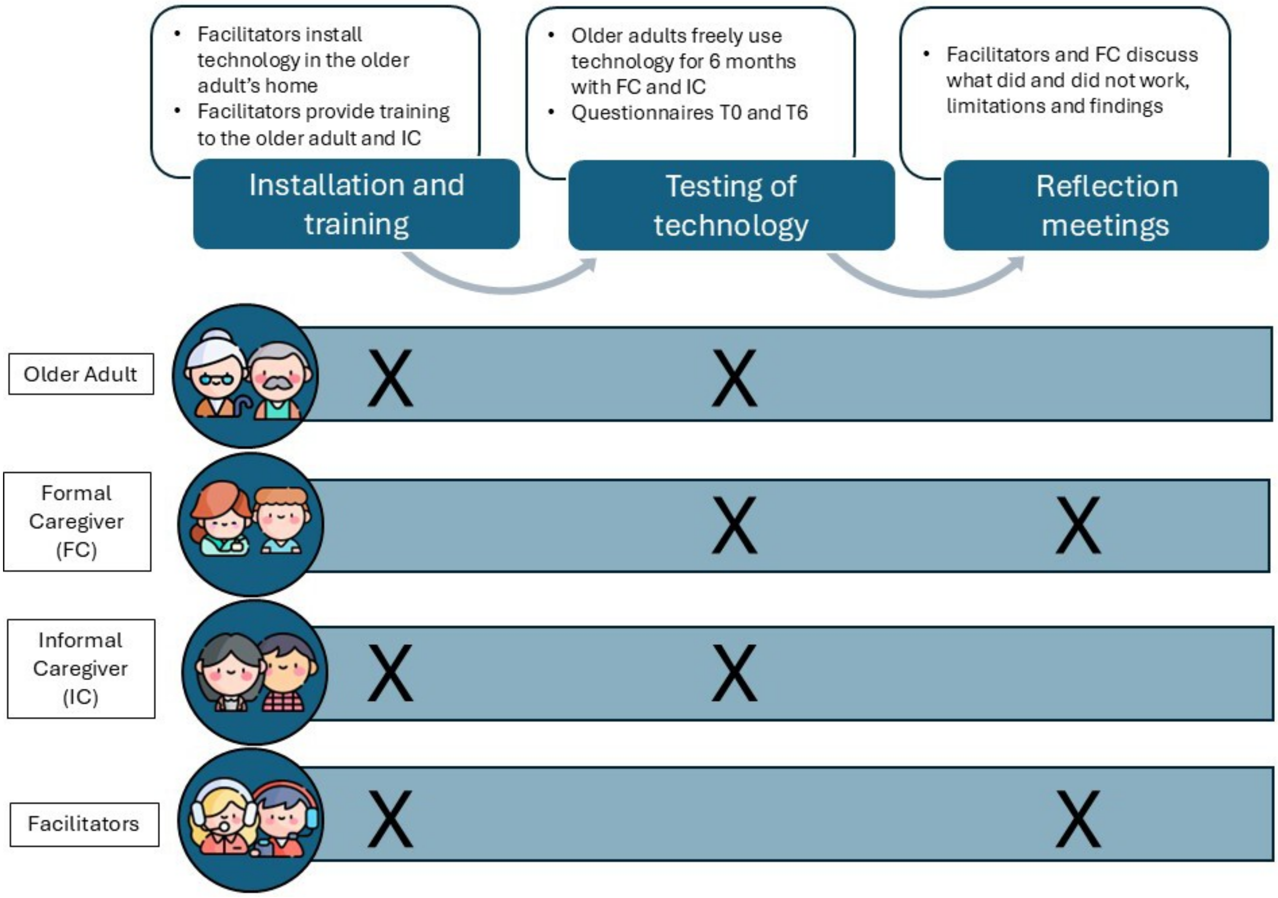
Experimental Protocol

The experimental protocol was composed of the following phases: installation and training, testing of technology, and a reflection meeting. An overview of these phases is presented in Figure 2.

As mentioned in the System Service Description section, Tuscany and Apulia tested different devices. In Tuscany, the smart television was installed in the older adult’s home and then facilitators trained them in the use of the technology. On the other hand, in the Apulian pilot, facilitators trained the IC together with the older adult and the tablet was subsequently given to the older adult to take home and use freely. The participants could ask questions for clarification. At the end of the training, facilitators gave the participants the user manual along with their contact details.

As soon as the participants felt confident with the technology, the facilitators administered the questionnaires, providing baseline data (T0). Participants were then requested to freely use the technology and the service functionalities in their daily life. After 6 months of use (T6), they were requested to fill in the same questionnaire that was administered at T0. A description of the questionnaires is provided in the Questionnaires section.

Figure 2. Graphical description of the experimental protocol of the 3 consecutive phases. The “X” represents when a certain cohort participated in a specific phase. Icons were downloaded from Flaticon [31]. FC: formal caregiver; IC: informal caregiver; T0: start of study; T6: end of study (after 6 months of technology use).



To better understand the end users, we used an action research approach that suggests organizing reflection meetings to critically reflect on the “results of action” [32] and to underscore the lessons learned in terms of aspects that did or did not work well in the pilot. The reflection meeting was scheduled after the first 6 months of use to collect feedback and it involved meeting facilitators, facilitators, and FCs. The meeting facilitators were in charge of presenting the results, fostering discussion, and taking notes during the meeting.

The meeting was divided in three parts: presentation of the results following the first 6 months of use, discussion with the facilitators and FCs, and an online survey. After the initial presentation, the quantitative results were discussed to understand whether the facilitators and FCs expected or were surprised by these results and whether they could explain the results in a qualitative way. The discussion touched on the following: (1) the things that did and did not work properly; (2) the limitations of the technology; and (3) the findings of the study, including acceptance of the technology. After the plenary discussion, before closing the meeting, participants were asked to complete an online survey to give feedback on the main factors related to technology readiness and its acceptability; additionally, participants were asked to report what they considered to be a significant outcome from the perspective of the older adult, IC, and FC. The results of this meeting and survey were then aggregated to critically discuss the results of the questionnaires and to plan and suggest corrective actions for future tests.

Participants

In order to answer this study’s RQs, three cohorts of participants were recruited: older adults, IC, and FC (professionals in charge of their monitoring). A total of 105 people were recruited to be part of the study: 40 older adults, 40 IC, and 25 FC. The older adults were recruited and were randomized 1:1 into either the control or intervention group. The IC and FC were divided into control and intervention groups according to their older adult’s randomization.

The inclusion criteria for the older adults were aged ≥60 years, intact cognitive status (Mini-Mental State Examination score >24), and a frailty score from well to moderately frail; exclusion criteria were presence of severe cognitive impairment and other conditions that cause memory impairment or engagement difficulties. Participants in the control group were recruited with the same inclusion and exclusion criteria; this group did not interact with the technology and was only required to fill in the sociodemographic questionnaire. In this study, we will focus on the user experience of technology use, and thus only focus on the intervention group (older adults: n=20; IC: n=20; FC: n=13).

Participants were enrolled in two Italian regions (Apulia and Tuscany) that composed the Pharaon Italian Pilot. The recruitment strategies were different across the two pilots; in Apulia, the IC was recruited first, whereas in Tuscany, the older adult was recruited first. In Apulia, the participants were recruited at the Casa Sollievo della Sofferenza research hospital (San Giovanni Rotondo, Foggia, Italy) in different clinical units and at the University of the Third Age, and no participants were cognitively or medically compromised. In Tuscany, the participants were recruited among people that were already accessing home services provided by the Umana Persone S.r.l. (Grosseto, Italy) network of social cooperatives. The research was approved by the Comitato Etico Clinico, Azienda USL Toscana Sud Est on July 22, 2021 (Prot. 2021/000227), and by the Azienda USL Toscana Centro on October 18, 2022 (Prot. 2022/22131_spe). Furthermore, the two pilot sites used the technology either on a tablet or a smart television according to guidelines and feedback acquired in the needs analysis [29].

Ethical Considerations

The ethical committee of the Casa Sollievo della Sofferenza research hospital approved the research on June 14th, 2021, with protocol number 89/CE. All participants read and signed the informed consent form before entering the study. The collected data were anonymized and no compensation was provided to participants.

Facilitators

Following the action research framework and to better discuss and reflect on the RQs, we also involved the facilitators, who have different professional backgrounds ranging from engineers to cooperative managers to health professionals, and whose main task was to ease the use of technology in all 3 cohorts and solve any problems that arose during the experimentation. Additionally, facilitators installed the technology and delivered the training to the intervention group and administered the questionnaires.

A total of 20 participants joined the reflection meeting: 5 participants from the University of Florence, who acted as meeting facilitators; 3 participants from the Apulian pilot site (Casa Sollievo della Sofferenza Research Hospital); and the remaining 12 participants were from the Tuscan pilot site (Umana Persone network of social cooperatives). Only 8 facilitators (3 from the Apulian pilot and 5 from the Tuscan pilot) agreed to fill out the final survey.

Questionnaires

To gather information about the participants' characteristics, sex, age, education, and living situation/environment, a semistructured interview was conducted at the beginning of the study. The Mini-Mental State Examination [33] was administered to assess the older adults' cognitive status.

Usability was measured with the system usability scale (SUS) [34] (Italian version [35]), which is composed of 10 items on a 5-point Likert scale where 1 stands for "strongly disagree" and 5 stands for "strongly agree." Items 2, 4, 6, 8, and 10 need to be reversed. The total SUS score is obtained by adding all the score contributions and multiplying the sum by 2.5. The SUS ranges from 0 to 100; scores lower than 68 are considered below average.

Acceptance was evaluated through the Almere model questionnaire (AMQ) [36], which is composed of 41 items on a 5-point agreement Likert scale. The AMQ is composed of 12 constructs created by combining specific items: anxiety (ANX), attitude toward technology (ATT), facilitating conditions, intention to use (ITU), perceived adaptiveness, perceived enjoyment (ENJ), perceived ease of use, perceived sociability, perceived usefulness (PU), social influence, social presence, and trust (TRUST). We investigated 6 of these 12 constructs: ANX, ATT, ITU, ENJ, PU, and TRUST. Note that ANX is reversed, therefore a higher ANX score translates to lower levels of anxiety.

To measure the quantity of perceived stress related to technology use (technostress), the Perceived Stress Scale [37] (Italian version [38] adapted as in [39]) was administered. The test comprises 10 items with a 0 - 4 Likert scale with 0 meaning "never" and 4 being "very often." Items 4, 5, 7, and 8 have reverse scoring. The total score is calculated as the sum of the single item contributions. A total score from 0-13 is considered low stress, 14-26 is moderate stress, and ≥27 is high stress.

At T6, participants were also asked to estimate how frequently they used technology by asking how many times they used it per day and per month.

A schematic overview of when and to whom the questionnaires were administered is presented in Table 1.

Table . Overview of the interview topics and questionnaires including when they were conducted and with whom.

	T0[a]	T6[b]
Semistructured interview		
Age, sex, education, digital skills	OA[c], IC[d]	—[e]
Living situation (alone/not alone) and living environment (urban/rural)	OA	—
Technology usage question	—	OA
Questionnaires		
Mini-Mental State Examination [33]	OA	—
System usability scale [34], Almere model questionnaire [36], and technostress [39]	OA, IC, FC[f]	OA, IC, FC

[a] T0: start of the study.

[b] T6: following 6 months of technology use.

[c] OA: older adult.

[d] IC: informal caregiver.

[e] Not applicable.

[f] FC: formal caregiver.

Statistical Analysis

Overview

We performed statistical analyses to evaluate longitudinal intragroup and cohort differences in usability and acceptability among the older adults, IC, and FC. Moreover, we investigated the effect of the older adults' living situation (ie, living alone or with someone) and stress related to technology on usability and acceptability. Each analysis is described in detail in the following subparagraphs. For each questionnaire, we calculated reliability with Cronbach α. Given the low sample size, a value of ≥.6 was deemed acceptable [40,41]. Effect sizes of significant results were calculated with Cohen *d*. In the statistical tests performed, a *P* value <.05 was considered statistically significant. Statistical analyses and graphical illustrations were performed using RStudio [42] (version 4.2.3; Posit team).

Differences in Usability and Acceptability

Data for SUS and AMQ were checked for normality using the Shapiro test. For changes over time in each cohort (intragroup), we checked for normality the distribution of the differences between T0 and T6. If the data were normally distributed, we performed a two-tailed paired *t* test to examine differences over time, otherwise a paired Wilcoxon signed-rank test was preferred. For older adults, additional analyses were performed to investigate differences between pilot sites.

A two-way mixed ANOVA was used to compare the scores for older adults, IC, and FC at T0 and T6, as well as changes over time (cohort differences). For older adults and IC, the models were also repeated including age and sex in the model to account for demographic differences in the two cohorts. If there was a statistically significant effect, post hoc two-tailed pair-wise *t* tests were Bonferroni corrected.

Effects of Living Situation on Usability and Acceptability in Older Adults

For older adults, a two-tailed *t* test was performed to investigate the effects of living situation (ie, alone or with someone) at T0 and T6, and a two-tailed paired *t* test was used to assess change over time between T0 and T6.

Effects of Technostress on Usability and Acceptability

For the older adult, IC, and FC groups, correlations were performed between technostress, SUS, and AMQ results. Data for technostress, SUS, and AMQ were checked for normality using the Shapiro test. If data were normally distributed, the correlation was Pearson, otherwise it was Kendall.

Results

Participant Characteristics

The demographic and cognitive characteristics as well as technostress at T0 and T6 for older adults and IC are presented in Table 2.

Participants on average used the technology 4 times per week. Overall, 85% (17/20) of the older adults lived in an urban area, and 60% (12/20) of the older adults lived with someone, of which 42% (5/12) lived with their IC. The older adults' associated FC were predominantly women (69%, 9/13). The FC were of various professional backgrounds including psychologists, nurses, and care workers. No other demographic information was collected for FC.

Table . Demographic and cognitive characteristics and technostress in the older adult and informal caregiver groups.

Characteristics		Older adults (n=20)	Informal caregivers (n=20)
Age (years), mean (SD)		77.15 (7.07)	47.85 (13.10)
Sex (women), n (%)		14 (70)	9 (45)
Education, n (%)			
	Primary education	13 (65)	0 (0)
	Secondary education	5 (25)	10 (50)
	Tertiary education	2 (10)	10 (50)
Mini-Mental State Examination score, median (IQR)[a]		26.45 (6.55)	—[b]
Technostress, median (IQR)[a]			
	T0[c]	13 (11.50)	7.00 (9.25)
	T6[d]	10.50 (3.50)	5.50 (5.50)

[a] Median values and IQR are presented when the variables were not normally distributed.

[b] Not applicable.

[c] T0: start of the study.

[d] T6: following 6 months of technology use.

Differences in Usability

Intragroup and Pilot Site Differences in Usability

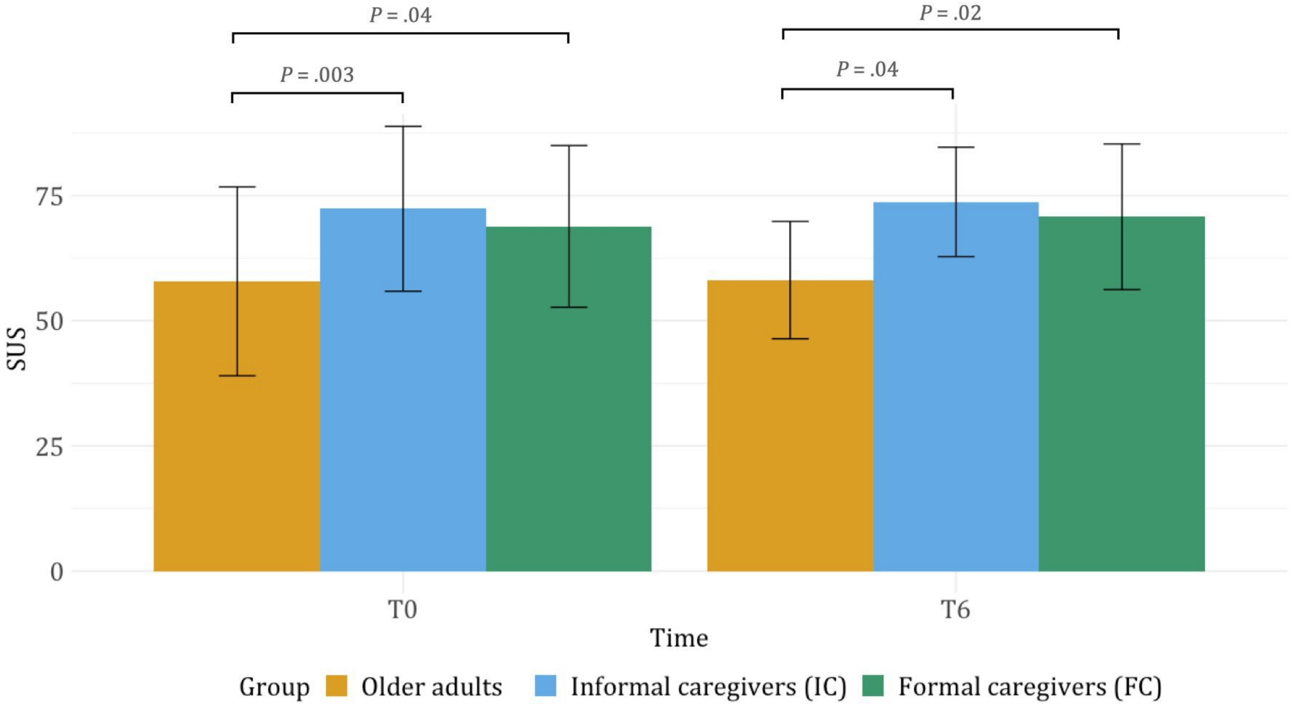
The Cronbach α for the SUS in all groups was higher than .6 at both T0 and T6.

In the older adults group, the distribution of the difference over time in the whole sample was not significantly different from a normal distribution, and normality was assumed. The mean SUS score increased slightly over time; however, this increase was not significant (Figure 3).

Both the Apulian and Tuscan pilot differences over time were distributed normally; still, there was no significant change over time. The mean of the Tuscan pilot increased and the standard deviation decreased, whereas in the Apulian pilot, mean SUS score decreased from T0 to T6 (Apulia T0: 70.8, SD 12.2 vs T6: 66.5, SD 4.7; Tuscany T0: 45.0, SD 15.3 vs T6: 49.8, SD 10.6).

In the IC group, the distribution of the differences over time in the whole sample was not significantly different from a normal distribution, whereas it was normally distributed for the FC group. The SUS score did not change over time in both groups (Figure 3).

Figure 3. SUS score in older adults, informal caregivers, and formal caregivers at T0 and T6. The error bars represent the standard deviation for each group. The brackets highlight statistical differences between groups. Note that the difference between older adults and FC at T0 and T6 was not significant after post hoc Bonferroni correction. SUS: system usability scale.



Cohort Differences in Usability

A 2-way mixed ANOVA with group (older adult, IC, and FC), time, and group × time interaction showed an effect of group on SUS score, but not of time or group × time interaction. Post hoc pair-wise *t* test showed a significant difference between older adults and IC at T0 (older adults: mean 57.9, SD 18.9; IC: mean 72.4, SD 16.5; *P*=.003; Cohen *d*=0.8) and T6 (older adults: mean 58.2, SD 11.7; IC: mean 73.8, SD 10.9; *P*=.001; Cohen *d*=1.4), and between older adults and FC both at T0 (FC: mean 68.8, SD 16.2; *P*=.04; Cohen *d*=0.6) and T6 (FC: mean 70.8, SD 14.6; *P*=.02; Cohen *d*=0.9) (Figure 3). At both time points, the older adults had significantly lower SUS scores than the IC and FC. The difference between older adults and IC was not statistically significant when considering age and sex in the model (group × time interaction *P*=.86). The difference between older adults and FC was not statistically significant after post hoc Bonferroni correction (T0: *P*=.13; T6: *P*=.06).

Differences in Acceptability

Intragroup and Pilot Site Differences in Acceptability

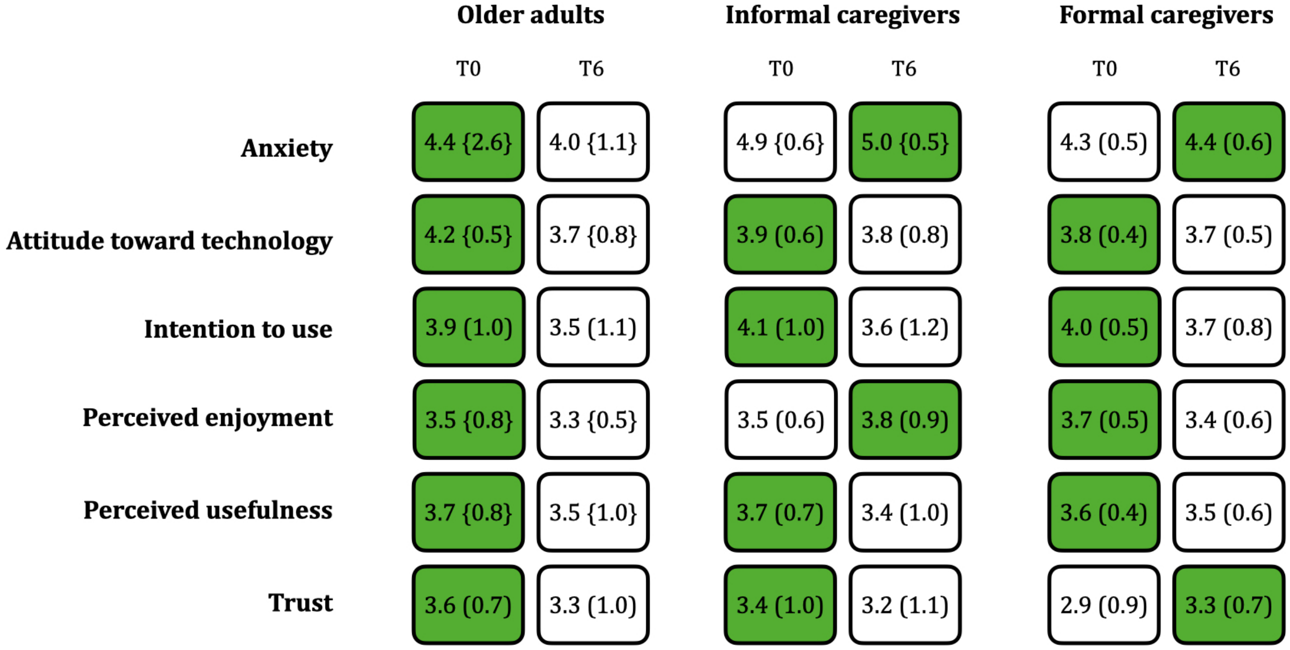
For the older adults and IC groups, Cronbach α for each construct of the AMQ was ≥.7 at T0 and T6. In the FC group, at T0, Cronbach α was greater than .6 for all constructs except PU, for which it was .2. At T6, reliability was greater than .7 for all AMQ constructs.

In the older adults group, for ITU and TRUST, the distribution of the difference over time was not different from a normal distribution. The distributions of the difference over time in the other constructs (ie, ANX, ATT, ENJ, TRUST) were not normal.

ATT significantly decreased (*P*=.01; Cohen *d*=0.7), whereas the other constructs did not significantly increase or decrease over time (Figure 4). In the Apulian pilot, there was a significant decrease in ANX over time (T0: 4.9 and T6: 4.3; *P*=.03; Cohen *d*=1.0) but no other significant changes in constructs were found. No changes in AMQ constructs over time were found in the Tuscan pilot (see Table S1 in Multimedia Appendix 1 for mean and median values).

In the IC group, the distribution of the differences was different from a normal distribution for ANX, but the distribution of the differences for other constructs could be assumed to be normal. In the FC group, the distribution of the differences in all constructs was not different from a normal distribution. There was no significant change over time in any construct in either the IC or FC group (Figure 4).

Figure 4. Mean values and standard deviations in parentheses for all acceptability constructs for older adults, informal caregivers, and formal caregivers at T0 (start of the study) and T6 (after 6 months of technology use). The green background highlights the higher value for each row, either at T0 or T6. Note that values are mean (SD) or median {IQR} according to the normality of the differences over time.



	Older adults		Informal caregivers		Formal caregivers	
	T0	T6	T0	T6	T0	T6
Anxiety	4.4 {2.6}	4.0 {1.1}	4.9 {0.6}	5.0 {0.5}	4.3 (0.5)	4.4 (0.6)
Attitude toward technology	4.2 {0.5}	3.7 {0.8}	3.9 (0.6)	3.8 (0.8)	3.8 (0.4)	3.7 (0.5)
Intention to use	3.9 (1.0)	3.5 (1.1)	4.1 (1.0)	3.6 (1.2)	4.0 (0.5)	3.7 (0.8)
Perceived enjoyment	3.5 {0.8}	3.3 {0.5}	3.5 (0.6)	3.8 (0.9)	3.7 (0.5)	3.4 (0.6)
Perceived usefulness	3.7 {0.8}	3.5 {1.0}	3.7 (0.7)	3.4 (1.0)	3.6 (0.4)	3.5 (0.6)
Trust	3.6 (0.7)	3.3 (1.0)	3.4 (1.0)	3.2 (1.1)	2.9 (0.9)	3.3 (0.7)

Cohort Differences in Acceptability

A 2-way mixed ANOVA with group (older adult, IC, and FC), time, and group × time interaction showed an effect of group on ANX, and time for ATT and ITU. No other group, time, or group × time interactions were found.

For ANX, post hoc pair-wise *t* test showed a significant difference between older adults and IC at T0 (*P*=.005; Cohen *d*=0.7) and T6 (*P*=.002; Cohen *d*=1.2), with older adults having higher anxiety than IC. The significant difference in ANX between older adults and IC remained after post hoc Bonferroni correction but disappeared when accounting for age and sex in the model (T0: *P*=.20; T6 *P*=.68). For ATT, there was a significant effect of time for only the older adults, as discussed in the Differences in Acceptability section (Figure 4). There was no effect of time on ITU for any group.

Effects of Living Situation on Usability and Acceptability in Older Adults

For usability, at T0 and T6, there was no difference between those living alone and those living with someone. There was no significant change over time in SUS score in either living situation.

For acceptability, at T0, those living alone had significantly lower AMQ constructs than those living with someone (ANX *P*=.02, Cohen *d*=1.1; ATT *P*=.04, Cohen *d*=0.9; ITU *P*=.01, Cohen *d*=1.3; ENJ *P*=.03, Cohen *d*=1.0; PU *P*=.01, Cohen *d*=1.4; TRUST *P*=.01, Cohen *d*=1.3). After 6 months, the difference disappeared (see Table S2 in Multimedia Appendix 1 for mean and median values).

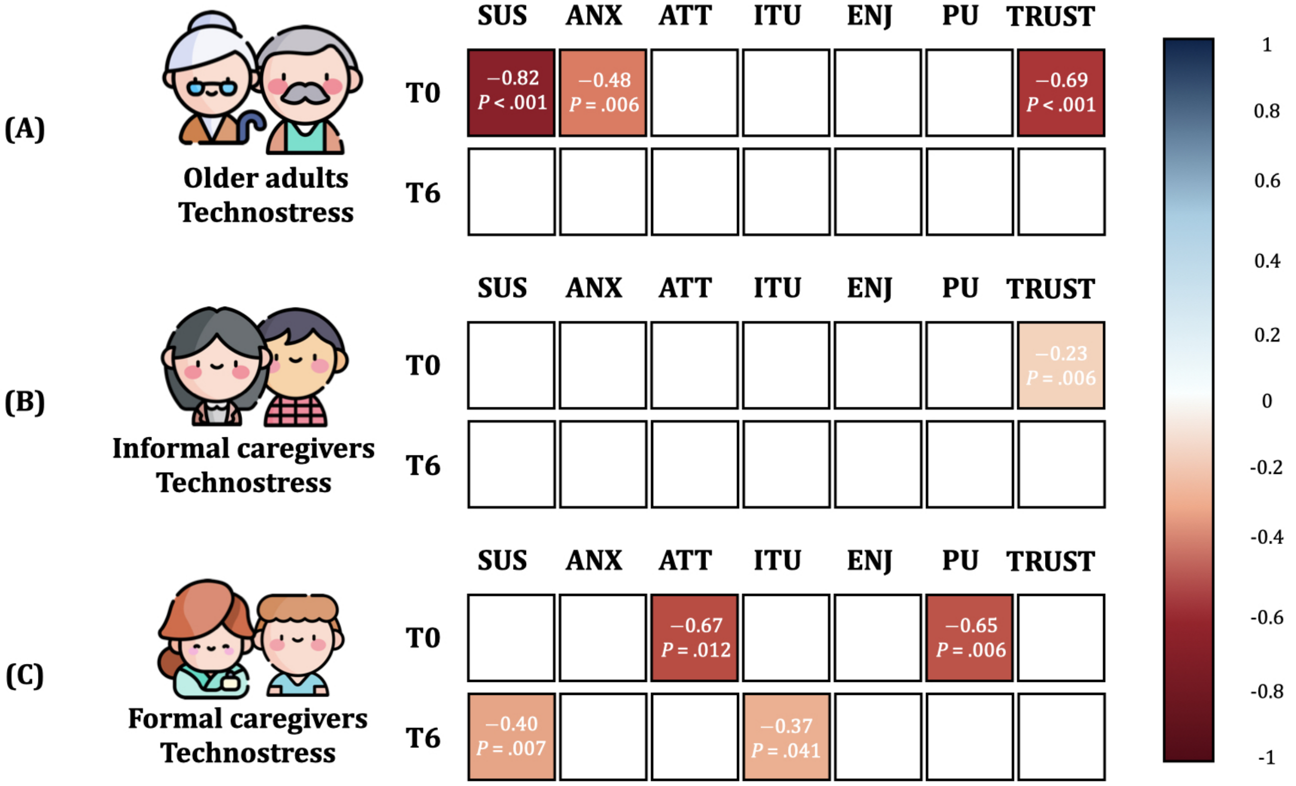
In older adults living alone, there was no change in AMQ constructs over time, whereas in those living with someone, ANX, ATT, ENJ, and PU declined over time (ANX *P*=.03, Cohen *d*=0.7; ATT *P*=.02, Cohen *d*=0.8; ENJ *P*=.03, Cohen *d*=0.7; PU *P*=.04, Cohen *d*=0.6; see Table S2 in Multimedia Appendix 1 for mean and median values).

Effects of Technostress on Usability and Acceptability

Older Adults

At T0, the ANX and ITU constructs of AMQ were not normally distributed, thus Kendall correlation was used; the same applied to technostress, ITU, and PU at T6. We found that technostress was highly negatively correlated with SUS score and TRUST and moderately negatively correlated with ANX (Figure 5A). After 6 months, technostress was not associated with SUS score or AMQ (Figure 5A).

Figure 5. Correlations between stress toward technology (technostress) and user experience (SUS and AMQ constructs) in (A) older adults, (B) informal caregivers, and (C) formal caregivers at T0 (start of study) and at T6 (following 6 months of technology use). Only statistically significant results are presented. AMQ: Almere model questionnaire; ANX: anxiety; ATT: attitude toward technology; ENJ: enjoyment; ITU: intention to use; PU: perceived usefulness; SUS: system usability scale; TRUST; trust.



Informal Caregivers

In the IC group, at T0, technostress, ANX, ITU, PU, and TRUST were not normally distributed; at T6, ANX, ITU, and PU were not normally distributed. At T0, technostress was significantly negatively correlated with TRUST, yet technostress was not associated with SUS score or other acceptability constructs (Figure 5B). After 6 months, the significant correlation between technostress and TRUST was no longer present (Figure 5B).

Formal Caregivers

ENJ and PU at T0 and technostress, SUS, ANX, and TRUST at T6 were not normally distributed. At T0, there was a significant moderate negative correlation between technostress and ATT and between technostress and PU (Figure 5C). At T6, technostress was moderately negatively correlated with SUS score and with ITU; there were no other significant correlations between technostress and AMQ constructs (Figure 5C).

Results of the Reflection Meeting With Facilitators

Overview

The reflection meeting lasted 2 hours and began with the presentation of the results, followed by a discussion. The discussion focused on the personal experiences and perceptions that facilitators and FC had, then touched upon aspects that did and did not work, technical limitations, and findings. The collected feedback was transcribed and combined with the responses collected by means of a questionnaire that dealt with similar topics. These arguments were aggregated and then summarized into concepts that could limit the use of technology. The identified barriers are summarized in the following sections and were used to discuss the quantitative results.

Digital Skills

All facilitators highlighted that in Italy, the educational level and digital skills of older adults are low, a finding confirmed by other studies [43]. These contextual factors could represent a barrier at the start of the study. Particularly, facilitators noticed differences in the ATT between older adults aged 65-70 years old and those aged ≥70 years. They also stated that the younger cohort of older adults was more skilled and "ready" to accept the technology compared to the older group. Indeed, the younger cohort was more likely to have a smartphone and use apps for SMS text messaging (eg, WhatsApp).

Recruitment

During the meeting, the facilitator highlighted some difficulties they had in recruiting the older adults and IC. As mentioned in the Methods section, the two pilots used two different strategies for recruiting participants. In Apulia, facilitators first recruited the IC by asking if they would like to participate in the study with her/his older relatives. Conversely, in Tuscany, the older adults were the first to be recruited. Facilitators also noticed that older adults were more likely to agree to be part of the study when they were part of domiciliary services (Tuscany pilot) or if they already had a relationship of trust with them. During the meeting, the facilitator exchanged ideas and strategies to optimize recruitment in the pilots.

Technology Reliability and Ease of Use

Technology reliability affects the user experience; indeed, facilitators indicated that when there were issues with the technology, such as "internet connection issues" or "other bugs," this had a negative influence on the experience, whereas ease of use was one of the key factors that positively influenced the overall user experience. During the meeting, the Tuscan facilitators reported some difficulties for older adults in accessing the service because the user must switch the "input" source on the television before using the Sentab technology, and the remote needed to be pointed directly at the Sentab box instead of the television. This procedure was considered confusing and complex. It was also noticed that after training, although the older adults were able to make the input switch and were able to use the technology, they tended not to use it independently. This feedback reflects the usability data; indeed, the older adults' usability was lower in the Tuscan pilot than in the Apulian one. However, older adults who were more motivated in using the technology used it without problem; this was the case for a 90 year old enrolled in Tuscany that loved the sudoku game. On the contrary, the Apulian facilitators did not experience any barriers related to technology use (ie, tablets). Indeed, they confirmed that it was the right technology for the older adult population enrolled in the study. Specifically, older adults in Apulia appreciated the size of the digital keyboard letters they were using.

Training

Facilitators observed and reported that older adults had some prejudice and mistrust of new technologies; therefore, we believe that the initial contact and explanation of the project must be effective. Facilitators noticed that older adults often forgot the instructions for the technology, therefore a more effective training process should be composed of multiple training sessions. Indeed, facilitators decided to call back the older adults after the initial training to refresh the instructions during the first weeks of testing.

Cognitive and Living Situation Profile

Facilitators highlighted that the older adults' cognitive profile may impact technology acceptance. Additionally, the older adults' cognitive profile may also impact their understanding of the questionnaire; indeed, the facilitators noticed that sometimes the older adults did not fully understand the questions. Facilitators also noticed some differences in technology perceptions linked to their living situation; namely, that the older adults living alone were overall more enthusiastic and perceived the technology as more useful than those living with someone, qualitatively confirming the research hypothesis.

Engagement

Facilitators highlighted that engagement and use of the technology were related to finding intrinsic motivation and perceiving the added value the technology may have on the older adult's life. Additionally, another suggestion from the facilitator was to foster interaction with other people using the same technology. As a matter of fact, older adults appreciated the presence of the operator and if and when they were unable to play a game, they called the facilitators. In Apulia, the facilitators re-explained the game to one older adult, and she really enjoyed the technology. Therefore, if the older adults are appropriately stimulated, they consequently use the technology. For instance, in the case of the "stay informed" function, the periodical publication of news acted as a "stimulus," so the older adults were more likely to read it. Additionally, facilitators were concerned that the technology could be used by the older adults not solely for the socialization service, but more as a means to foster the relationship with the caregiver. Indeed, in projects such as Pharaon, when the participant is recruited, he/she experiences more physical presence and connection with the operator compared to the usual home assistance service. Therefore, conceivably, the older adults tend to use the technology only with the operator and not independently because they do not know how to use it without assistance or do not have a real reason to use it.

Discussion

This paper aims to investigate the role of time spent using technologies, living situation, and technostress in older adults and their caregivers that were using a technological device aimed at increasing older adults' socialization.

Principal Results and Comparison With the Literature

The first research question aimed to investigate the role of time in technology perception intragroup and between cohorts of participants (RQ1). As for the acceptance evaluated intragroup, except for ATT, the differences reported in Figure 4 are just trends, as they are not statistically significant. It is worth mentioning that the older adult values for ITU (T0=3.88; T6=3.53) and ATT (T0=4.20; T6=3.65) were comparable to the intention to use and attitude measured in a related work (ITU=3.34; ATT=3.73) [44]. Moreover, values for ENJ, TRUST, and PU were similar to those of an older Chinese sample, demonstrating that the values we reported are aligned with the literature [45] even though the populations are geographically different. Note that we evaluated ITU and ATT with different models, but these constructs had comparable items. Additionally, in this study we observed a decrease of ATT for all 3 cohorts of participants over time. This result is aligned with the feedback collected during the reflection meeting; indeed, the facilitators emphasized how engagement is strongly interconnected with the personal intrinsic motivation that leads to long-term use of the technology. It was also noted that the FC or IC contacting the older adults through the technology (whether video calling or news sharing) helped in keeping the participant engaged. The higher value of ATT at T0 may be due to the older adults' initial high expectations. Nevertheless, despite the decrease in ATT, the participants stated they used the system on average 4 times per week.

It is also worth noting that we observed a higher TRUST value for the FC after use compared to the other two cohorts. Higher trust is important because trust is strictly linked with the use of technology. These results are aligned with the feedback collected during the reflection session that highlighted some participants' mistrust in technology use at the beginning of the study, during the training session.

Usability was rated differently between older adults and their caregivers, who on average rated the system higher through SUS. These results are aligned with a recent survey [10] that highlighted a different attitude and expectation toward technology according to age group. Indeed, the statistical difference between the older adults and IC group disappeared when including age and sex as controlling variables. Other than age and sex, there could be other factors that contributed to this result, such as the older adults' digital competence. Furthermore, as described in the Technology Reliability and Ease of Use section, it emerged that in Tuscany, the system was perceived as more difficult to use by older adults, and they needed the caregivers' support to use it. Nevertheless, despite the lower values, the usability for older adults increased over time, though not significantly. This suggests that older adults overcame their initial technical barrier and learned how to use the system, and this was independent of their living situation. Facilitators also noted that technical problems that occurred during the trial or problems surrounding the older adults' experience of using the technology negatively impacted technology acceptance, as also observed by Peek et al [27].

In the Apulian pilot, there was a decrease in ANX, which translated into an unexpectedly higher anxiety perception (see Table S1 in Multimedia Appendix 1 for mean and median values). On the other hand, in the Tuscan pilot, there was no significant decrease or increase in acceptability. However, it is also worth noting that the recruitment of the older adults in the Tuscan cohort was performed among those using domiciliary care services and thus included older adults with higher frailty and lower Mini-Mental State Examination score compared to the older adults in the Apulian pilot site, which might influence perception of the technology. This was also brought up in the reflection meeting. The difference in user experience between the 2 pilots could be related to the different types of technology (television and tablet) selected at the beginning of the study or to the slightly different profile of the 2 cohorts of older adults.

RQ2 aimed to investigate the role of living situation on acceptance; we found that those living alone had significantly lower AMQ constructs compared to those living with someone. However, this difference disappeared at T6. It should also be pointed out that those living with someone had decreased ANX, ATT, and PU over time, indicating that the anxiety toward the system increased, and the usefulness and attitude toward technology lowered, suggesting that having someone helping them use the system may remove the perceived usefulness of the technology. This finding could suggest that living situation may be a barrier at the beginning of the study: people that are living alone may be more skeptical at the beginning, whereas people who are living with someone may have had higher expectations, yet the reality after 6 months of use was disappointing, which lowered the acceptability of the system.

Finally, this paper aimed to investigate how stress related to technology may affect the acceptance and usability of a certain technology (RQ3). The results highlighted a strong correlation between technostress and usability, anxiety, and trust in the older adults at T0 (Figure 5A) but all the correlations disappeared at T6. The results obtained at T0 are aligned with our previous findings [39], where we highlighted a link between perceived stress and related acceptance. However, these results may suggest that technostress could be a barrier only at the beginning of the study; as soon as the older adult becomes familiar with the technology, the link between perceived stress and related acceptance disappears. To mitigate the effects of stress at the beginning of the study, proper training sessions should be organized. These sessions ought to be devoted to successfully teaching participants how to use the technology and recall the functionality of the system after the training session, adapting the training to the participant's cognitive and educational level. As remarked by facilitators, oftentimes older adults forgot how to use the devices and tended not to use them unless facilitators retaught them how to use the technologies. Indeed, well-conceived training is a key feature of success and critical for technology acceptance.

At T0, for the IC group, higher perceived stress was a barrier to trusting technology, and in the FC group, stress affected attitude and usefulness of technology, possibly because of fear of substitution or the worry that the technology may involve extra work for them [46-48]. Nevertheless, the correlations were not significant at T6 (Figure 5B,C). This highlights how technology-related stress for the proposed socialization service can be a barrier to technology acceptance; as caregivers can influence older adults' perception of technology, it is crucial to include them in the study to get a multistakeholder perspective to support and reassure their older adults and promote a positive attitude toward technology.

Limitations

The main limitations of this work are the sample sizes and the duration of the test phase (6 months), as well as the different recruitment strategies carried out at the 2 different sites. As for the sample size, we aim to increase the number of participants in the 2 pilots while tracking their cognitive abilities, thus evaluating the effect of this variable on the use of technology. Further studies should also be planned to extend the duration of the testing phase, given that our preliminary results at 6 months seemed to indicate that it was not long enough to get information regarding the impact of this service in real life. This is also of interest to policy makers who are coping with staff shortages and increasing health care expenses. Another encountered limitation was the different recruitment process between pilot sites and the lack of randomization for the technologies. These factors can all contribute to different results between samples; researchers should aim to standardize procedures as much as possible to obtain generalizable results. Future studies should also investigate the factors that may influence the low use of the technology and come up with countermeasures to encourage the use of technology, which can also have an impact on acceptability [27].

Conclusions

This paper investigates the role of time, living situation, and stress related to technology use on the usability and the acceptance of a socialization service. This paper presents the results collected after 6 months of use considering a multistakeholder perspective. In this study, we found that the older adults had higher stress and anxiety toward technology than the caregivers. Nevertheless, getting accustomed to technology over 6 months of use removed this initial barrier. It is also important to consider the living situation of the older adults as those living alone had lower acceptability than those living with someone, which could suggest an increased resistance to change. However, counterintuitively, the older adults living with someone had a decrease in enjoyment, usefulness, and attitudes toward technology, possibly because living with someone limits the need of the older adults to socialize with others. The reflection meeting with the facilitators qualitatively highlighted demographic barriers in the use of technology that should be further evaluated quantitatively.

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Authors' Contributions

JP and LF wrote the original draft. JP performed all formal analyses and graphical visualization. Investigation, resources, and data collection were conducted by LL, F Ciccone, LT, SR, FG, and GV. LL and NC oversaw data curation and LL, DS, GD, F Ciccone, and NC oversaw data collection. TP was responsible for the software. ER and LF provided supervision. ER and F Cavallo were project administrators. LF and F Cavallo conceptualized the work and F Cavallo managed funding acquisition. All authors provided input to the draft, discussed the results, and reviewed the final manuscript.

Conflicts of Interest

None declared

Multimedia Appendix 1
Supplementary materials.
[PDF File, 58 KB - aging_v7i1e54736_app1.pdf]

References

1. Cornwell EY, Waite LJ. Social disconnectedness, perceived isolation, and health among older adults. J Health Soc Behav 2009 Mar;50(1):31-48. [doi: 10.1177/002214650905000103] [Medline: 19413133]
2. Golden J, Conroy RM, Lawlor BA. Social support network structure in older people: underlying dimensions and association with psychological and physical health. Psychol Health Med 2009 May;14(3):280-290. [doi: 10.1080/13548500902730135] [Medline: 19444706]
3. ISTAT. Le condizioni di salute della popolazione anziana in Italia [Report in Italian]. 2019 URL: https://www.istat.it/comunicato-stampa/le-condizioni-di-salute-della-popolazione-anziana-in-italia-anno-2019/ [accessed 2024-09-30]
4. Zallio M, Ohashi T. The evolution of assistive technology: a literature review of technology developments and applications. Presented at: 13th International Conference on Applied Human Factors and Ergonomics (AHFE 2022); Jul 24-28, 2022; New York, USA. [doi: 10.54941/ahfe1001646]
5. Calvaresi D, Cesarini D, Sernani P, Marinoni M, Dragoni AF, Sturm A. Exploring the ambient assisted living domain: a systematic review. J Ambient Intell Human Comput 2017 Apr;8(2):239-257. [doi: 10.1007/s12652-016-0374-3]
6. Ganesan B, Gowda T, Al-Jumaily A, Fong KNK, Meena SK, Tong RKY. Ambient assisted living technologies for older adults with cognitive and physical impairments: a review. Eur Rev Med Pharmacol Sci 2019 Dec;23(23):10470-10481. [doi: 10.26355/eurrev_201912_19686] [Medline: 31841201]
7. Smith EM, Toro Hernandez ML, Ebuenyi ID, et al. Assistive technology use and provision during COVID-19: results from a rapid global survey. Int J Health Policy Manag 2022 Jun 1;11(6):747-756. [doi: 10.34172/ijhpm.2020.210] [Medline: 33201656]
8. Øksnebjerg L, Woods B, Ruth K, et al. A tablet app supporting self-management for people with dementia: explorative study of adoption and use patterns. JMIR mHealth uHealth 2020 Jan 17;8(1):e14694. [doi: 10.2196/14694] [Medline: 31951217]
9. Mitzner TL, Boron JB, Fausset CB, et al. Older adults talk technology: technology usage and attitudes. Comput Hum Behav 2010 Nov 1;26(6):1710-1721. [doi: 10.1016/j.chb.2010.06.020] [Medline: 20967133]
10. Offerman J, Fristedt S, Schmidt SM, Lofqvist C, Iwarsson S. Attitudes related to technology for active and healthy aging in a national multigenerational survey. Nat Aging 2023 May;3(5):617-625. [doi: 10.1038/s43587-023-00392-3] [Medline: 37118552]
11. Aggarwal B, Xiong Q, Schroeder-Butterfill E. Impact of the use of the internet on quality of life in older adults: review of literature. Prim Health Care Res Dev 2020 Dec 2;21:e55. [doi: 10.1017/S1463423620000584] [Medline: 33263273]

12. Yazdani-Darki M, Rahemi Z, Adib-Hajbaghery M, Izadi F. Older adults' barriers to use technology in daily life: a qualitative study. Nurs Midwif Stud 2020;9(4):229-236. [doi: 10.4103/nms.nms_91_19]
13. Wildenbos GA, Peute L, Jaspers M. Aging barriers influencing mobile health usability for older adults: a literature based framework (MOLD-US). Int J Med Inform 2018 Jun;114:66-75. [doi: 10.1016/j.ijmedinf.2018.03.012] [Medline: 29673606]
14. Kim SY, Park H, Kim H, Kim J, Seo K. Technostress causes cognitive overload in high-stress people: eye tracking analysis in a virtual kiosk test. Inf Process Manag 2022 Nov;59(6):103093. [doi: 10.1016/j.ipm.2022.103093] [Medline: 36119755]
15. Al-Shaqi R, Mourshed M, Rezgui Y. Progress in ambient assisted systems for independent living by the elderly. Springerplus 2016;5:624. [doi: 10.1186/s40064-016-2272-8] [Medline: 27330890]
16. Cavallo F, Aquilano M, Bonaccorsi M, et al. Improving domiciliary robotic services by integrating the ASTRO robot in an AmI infrastructure. In: Springer Tracts in Advanced Robotics 2014 2014. [doi: 10.1007/978-3-319-02934-4_13]
17. Fiorini L, Rovini E, Russo S, et al. On the use of assistive technology during the COVID-19 outbreak: results and lessons learned from pilot studies. Sensors (Basel) 2022 Sep 2;22(17):6631. [doi: 10.3390/s22176631] [Medline: 36081090]
18. Haase KR, Cosco T, Kervin L, Riadi I, O'Connell ME. Older adults' experiences with using technology for socialization during the COVID-19 pandemic: cross-sectional survey study. JMIR Aging 2021 Apr 23;4(2):e28010. [doi: 10.2196/28010] [Medline: 33739929]
19. Freedman A, Nicolle J. Social isolation and loneliness: the new geriatric giants: approach for primary care. Can Fam Physician 2020 Mar;66(3):176-182. [Medline: 32165464]
20. Tang D, Lin Z, Chen F. Moving beyond living arrangements: the role of family and friendship ties in promoting mental health for urban and rural older adults in China. Aging Ment Health 2020 Sep;24(9):1523-1532. [doi: 10.1080/13607863.2019.1602589] [Medline: 30977378]
21. Hamid TA, Din HM, Bagat MF, Ibrahim R. Do living arrangements and social network influence the mental health status of older adults in Malaysia? Front Public Health 2021;9:624394. [doi: 10.3389/fpubh.2021.624394] [Medline: 34026706]
22. Sakurai R, Kawai H, Suzuki H, et al. Poor social network, not living alone, is associated with incidence of adverse health outcomes in older adults. J Am Med Dir Assoc 2019 Nov;20(11):1438-1443. [doi: 10.1016/j.jamda.2019.02.021] [Medline: 31000349]
23. Hoang P, King JA, Moore S, et al. Interventions associated with reduced loneliness and social isolation in older adults: a systematic review and meta-analysis. JAMA Netw Open 2022 Oct 3;5(10):e2236676. [doi: 10.1001/jamanetworkopen.2022.36676] [Medline: 36251294]
24. Ibarra F, Baez M, Cernuzzi L, Casati F. A systematic review on technology-supported interventions to improve old-age social wellbeing: loneliness, social isolation, and connectedness. J Healthc Eng 2020;2020:2036842. [doi: 10.1155/2020/2036842] [Medline: 32765823]
25. Neves BB, Franz RL, Munteanu C, Baecker R. Adoption and feasibility of a communication app to enhance social connectedness amongst frail institutionalized oldest old: an embedded case study. Inf Comm Soc 2018 Nov 2;21(11):1681-1699. [doi: 10.1080/1369118X.2017.1348534]
26. Tsertsidis A, Kolkowska E, Hedström K. Factors influencing seniors' acceptance of technology for ageing in place in the post-implementation stage: a literature review. Int J Med Inform 2019 Sep;129:324-333. [doi: 10.1016/j.ijmedinf.2019.06.027] [Medline: 31445274]
27. Peek STM, Wouters EJM, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJM. Factors influencing acceptance of technology for aging in place: a systematic review. Int J Med Inform 2014 Apr;83(4):235-248. [doi: 10.1016/j.ijmedinf.2014.01.004] [Medline: 24529817]
28. The Pharaon Project. URL: www.pharaon.eu [accessed 2024-09-24]
29. D'Onofrio G, Fiorini L, Toccafondi L, et al. Pilots for Healthy and Active Ageing (PHArA-ON) project: definition of new technological solutions for older people in Italian pilot sites based on elicited user needs. Sensors (Basel) 2021 Dec 27;22(1):163. [doi: 10.3390/s22010163] [Medline: 35009706]
30. YouTube. Pharaon Italian pilot demonstrator - Socialization & Stimulation. URL: https://www.youtube.com/watch?feature=shared&v=5-u5YHvVbT8 [accessed 2024-09-30]
31. Flaticon. URL: flaticon.com [accessed 2024-09-30]
32. Reason P, Brandbury H. The SAGE Handbook of Action Research Participative Inquiry and Practice, 2nd edition: Sage Publications; 2008.
33. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975 Nov;12(3):189-198. [doi: 10.1016/0022-3956(75)90026-6] [Medline: 1202204]
34. Brooke J. SUS: A "quick and dirty" usability scale. In: Usability Evaluation in Industry 1996:189-194. [doi: 10.1201/9781498710411]
35. Borsci S, Federici S, Lauriola M. On the dimensionality of the System Usability Scale: a test of alternative measurement models. Cogn Process 2009 Aug;10(3):193-197. [doi: 10.1007/s10339-009-0268-9] [Medline: 19565283]
36. Heerink M, Kröse B, Evers V, Wielinga B. Assessing acceptance of assistive social agent technology by older adults: the Almere model. Int J Soc Robotics 2010 Dec;2(4):361-375. [doi: 10.1007/s12369-010-0068-5]
37. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav 1983 Dec;24(4):385-396. [doi: 10.2307/2136404] [Medline: 6668417]

38. Mondo M, Sechi C, Cabras C. Psychometric evaluation of three versions of the Italian Perceived Stress Scale. Curr Psychol 2021 Apr;40(4):1884-1892. [doi: 10.1007/s12144-019-0132-8]
39. Lorusso L, Mosmondor M, Grguric A, et al. Design and evaluation of personalized services to foster active aging: the experience of technology pre-validation in Italian pilots. Sensors (Basel) 2023 Jan 10;23(2):797. [doi: 10.3390/s23020797] [Medline: 36679590]
40. Taber KS. The use of Cronbach's alpha when developing and reporting research instruments in science education. Res Sci Educ 2018 Dec;48(6):1273-1296. [doi: 10.1007/s11165-016-9602-2]
41. Schrepp M. On the usage of Cronbach's alpha to measure reliability of UX scales. J User Exp 2020;15(4):247-258 [FREE Full text]
42. Posit team. RStudio: integrated development environment for R. 2024. URL: https://posit.co/ [accessed 2024-09-23]
43. Di Giacomo D, Ranieri J, D'Amico M, Guerra F, Passafiume D. Psychological barriers to digital living in older adults: computer anxiety as predictive mechanism for technophobia. Behav Sci (Basel) 2019 Sep 11;9(9):96. [doi: 10.3390/bs9090096] [Medline: 31514364]
44. Jaschinski C, Ben Allouch S, Peters O, Cachucho R, van Dijk J. Acceptance of technologies for aging in place: a conceptual model. J Med Internet Res 2021 Mar 31;23(3):e22613. [doi: 10.2196/22613] [Medline: 33787505]
45. He Q, He Y, Liu Q, Ma C. Acceptance of social assistant robots for the older adults living in the community in China. Geriatr Nurs (Lond) 2023 Jul;52:191-198. [doi: 10.1016/j.gerinurse.2023.06.006]
46. Sriram V, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. BMC Geriatr 2019 Jun 14;19(1):160. [doi: 10.1186/s12877-019-1169-0] [Medline: 31196003]
47. Aaen J. Organizing for emerging welfare technology: launching a drug-dispensing robot for independent living. Presented at: Selected Papers of the IRIS; Aug 11-14, 2019; Nokia, Finland.
48. Boyle LD, Husebo BS, Vislapuu M. Promotors and barriers to the implementation and adoption of assistive technology and telecare for people with dementia and their caregivers: a systematic review of the literature. BMC Health Serv Res 2022 Dec 23;22(1):1573. [doi: 10.1186/s12913-022-08968-2] [Medline: 36550456]

Abbreviations

AMQ: Almere model questionnaire
ANX: anxiety
ATT: attitude toward technology
ENJ: enjoyment
FC: formal caregiver
IC: informal caregiver
ITU: intention to use
PU: perceived usefulness
RQ: research question
SUS: system usability scale
T0: time point 0 (beginning of the study)
T6: time point 6 (6 months from baseline)
UI: user interface

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Hospital Staff Perspectives on the Drivers and Challenges in Implementing a Virtual Rehabilitation Ward: Qualitative Study

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Abstract

Background: Over the past decade, the adoption of virtual wards has surged. Virtual wards aim to prevent unnecessary hospital admissions, expedite home discharge, and enhance patient satisfaction, which are particularly beneficial for the older adult population who faces risks associated with hospitalization. Consequently, substantial investments are being made in virtual rehabilitation wards (VRWs), despite evidence of varying levels of success in their implementation. However, the facilitators and barriers experienced by virtual ward staff for the rapid implementation of these innovative care models remain poorly understood.

Objective: This paper presents insights from hospital staff working on an Australian VRW in response to the growing demand for programs aimed at preventing hospital admissions. We explore staff's perspectives on the facilitators and barriers of the VRW, shedding light on service setup and delivery.

Methods: Qualitative interviews were conducted with 21 VRW staff using the Nonadoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework. The analysis of data was performed using framework analysis and the 7 domains of the NASSS framework.

Results: The results were mapped onto the 7 domains of the NASSS framework. (1) Condition: Managing certain conditions, especially those involving comorbidities and sociocultural factors, can be challenging. (2) Technology: The VRW demonstrated suitability for technologically engaged patients without cognitive impairment, offering advantages in clinical decision-making through remote monitoring and video calls. However, interoperability issues and equipment malfunctions caused staff frustration, highlighting the importance of promptly addressing technical challenges. (3) Value proposition: The VRW empowered patients to choose their care location, extending access to care for rural communities and enabling home-based treatment for older adults. (4) Adopters and (5) organizations: Despite these benefits, the cultural shift from in-person to remote treatment introduced uncertainties in workflows, professional responsibilities, resource allocation, and intake processes. (6) Wider system and (7) embedding: As the service continues to develop to address gaps in hospital capacity, it is imperative to prioritize ongoing adaptation. This includes refining the process of smoothly transferring patients back to the hospital, addressing technical aspects, ensuring seamless continuity of care, and thoughtfully considering how the burden of care may shift to patients and their families.

Conclusions: In this qualitative study exploring health care staff's experience of an innovative VRW, we identified several drivers and challenges to implementation and acceptability. The findings have implications for future services considering implementing VRWs for older adults in terms of service setup and delivery. Future work will focus on assessing patient and carer experiences of the VRW.

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KEYWORDS

gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; aged; telerehabilitation; rehabilitation; rehab; workflow; hospitalization; health services accessibility; accessibility; clinical decision-making; equipment failure; telemedicine; telehealth; tele-medicine; tele-health; virtual care; virtual health; virtual medicine; remote consultation; telephone consultation; video consultation; remote consultations; telephone consultations; video consultations; personnel; hospital

Introduction

Implementation rates of virtual wards have increased over the last decade, mainly driven by technological advancements and the COVID-19 pandemic [1-5]. The UK National Health Service (NHS) report that virtual wards, including hospital-at-home services, are a safe and efficient substitute for inpatient care that is facilitated by technology [2,6,7]. Virtual wards offer at-home acute care in the form of monitoring and treatment to individuals who would otherwise require a hospital bed, using a flexible combination of remote and in-person services [2,6]. As virtual models of care are relatively novel, there can be ambiguity around terminology [2,8]. In the NHS model, virtual wards for older individuals function akin to hospital-at-home services, primarily delivering care through face-to-face interactions [8].

Virtual wards aim to prevent avoidable hospital admissions, facilitate early discharge home, and increase patient satisfaction [3,6,9]. For the older adult population, hospital admissions carry potential risks, including deconditioning, delirium, and hospital-acquired infections [10], so opting for home-based treatments may be beneficial [11]. Consequently, significant investments are being directed toward the expansion of virtual care models in health care systems, such as the UK NHS, encompassing patients with frailty [12,13]. However, economic assessments of virtual models often fail to meet quality criteria, leading to varying estimated cost savings [2].

The implementation of virtual care models has been hindered by issues such as nonadoption, abandonment, and difficulties with scaling up, particularly if the model requires significant changes to the broader care system [14-16]. There is a paucity of research investigating the sustainability of virtual models [15], particularly virtual wards [2]. Despite substantial policy-level discussions and modest proof-of-concept studies, virtual health care models are seldom mainstreamed [17-19]. The success or failure of implementing innovative virtual health care models is often attributed to a complex combination of facilitators and barriers, rather than individual factors alone, such as time pressures, infrastructure, unreliable equipment, and staff and service user preferences [20]. Understanding these issues is important as virtual care marks a monumental change in the delivery of health care for older individuals [2].

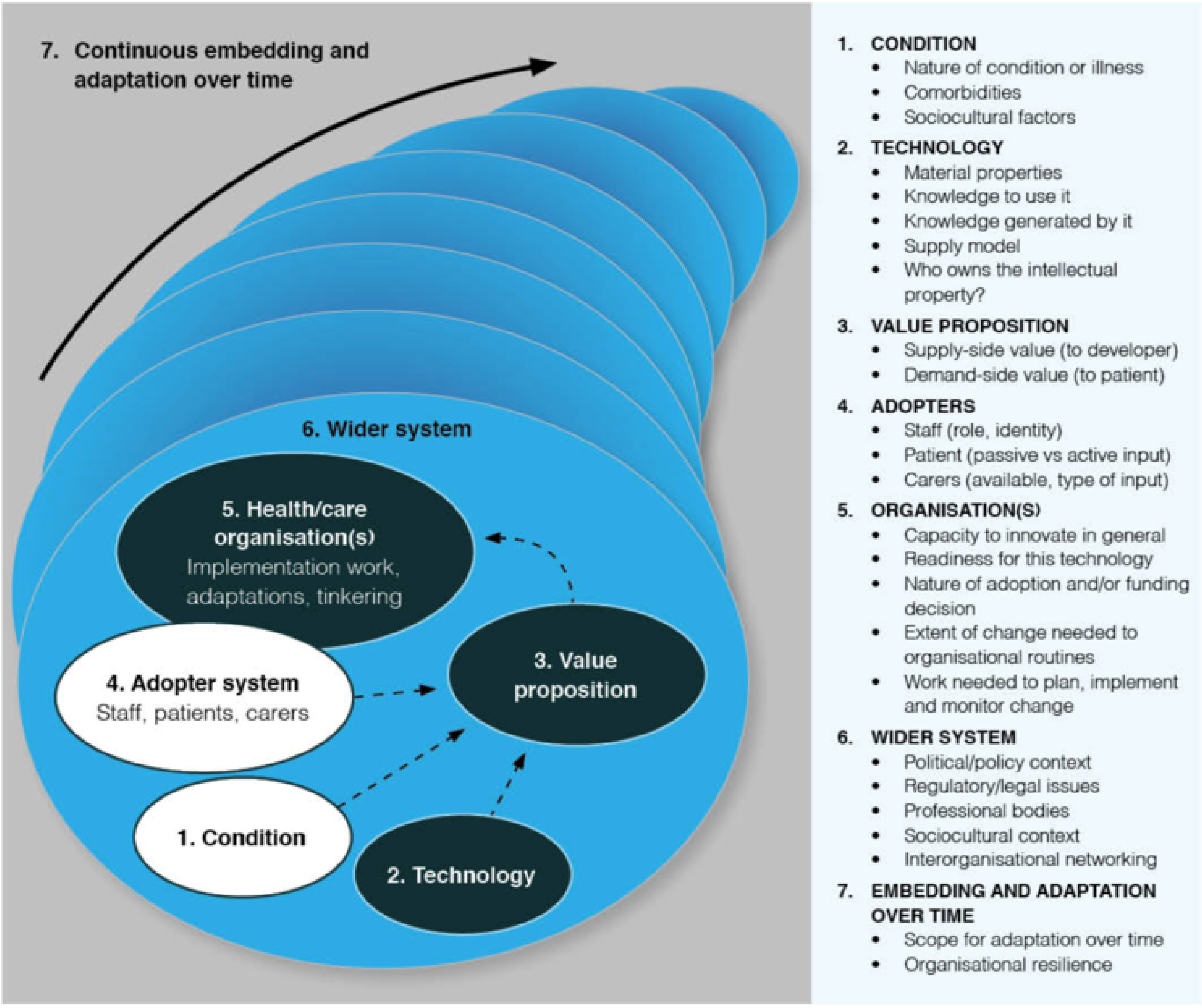
In practice, virtual wards are often added to existing hospital services as a solution to a bed capacity problem rather than being designed from the ground up as new freestanding services [21-23]. When hospital-based staff are asked to establish a virtual ward and commence providing services through videoconferencing and monitoring, significant shifts in practice are required. The facilitators and barriers experienced by hospital staff for the rapid implementation of these novel care models are not well understood, as evidenced by the paucity of literature in the area. There is also a lack of guidance for the provision of virtual wards, with calls for information on how these new models of care are being implemented [8]. This paper addresses a gap in the existing literature by offering insights into the experiences, perceptions, and attitudes of hospital staff working within a newly established Australian virtual rehabilitation ward (VRW). To our knowledge, no previous studies have delved into this specific research area. The implementation of the VRW was undertaken by the Flinders Medical Centre, part of the Southern Adelaide Local Health Network (SALHN) in South Australia, in response to the increasing demand for programs aimed at preventing hospital admissions. We explored the facilitators and barriers of the VRW from the view of staffs and present reflections for service setup and delivery.

Methods

Design

A multidisciplinary research team (clinicians and academic researchers) conducted this study under a constructivist paradigm [24]. Data were integrated and analyzed using the Nonadoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework [15] to understand staff experiences (Figure 1). Interview questions focused on the 7 domains of the NASSS framework including condition, technology, value proposition, adopters, organizations, wider system, and embedding and adaptation over time. These domains provided an analytical framework for organizing, classifying, and contrasting staff experiences into a rich narrative. The NASSS framework was chosen as it was designed to evaluate technology-supported change projects in health or social care [15] and, therefore, fitted with the aim of our research. Moreover, it has been previously used to evaluate technology-supported health care programs [25-27]. Other frameworks such as the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework [28]; Precede-Proceed model; Dynamic Sustainability framework; or the Practical, Robust Implementation and Sustainability Model (PRISM) [29] were not chosen as they lacked the technology focus of the NASSS framework. We also report our study according to the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines [30] to improve the quality and transparency of our work.

Figure 1. The Nonadoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework, first published in 2017, provides a structured approach to examine the factors that impact the adoption, nonadoption, abandonment, spread, scale-up, and sustainability of health care technology (reproduced from Abimbola et al [27], which is published under Creative Commons Attribution 4.0 International License [31]).



Ethical Considerations

Ethics approval was received from the SALHN (Southern Adelaide Clinical Human Research Ethics Committee; 2022/HRE00107). Written informed consent was obtained from all participants, who were informed of their right to withdraw from the study at any time. The data presented in this article have been deidentified. Participants did not receive any compensation.

Setting

South Australia spans a geographical area of 983,482 km^2 with a population of 1.8 million [32]. SALHN services a community of approximately 400,000 people in the southern metropolitan area of Adelaide. The population in Southern Adelaide skews toward older age groups compared to other areas of Adelaide and the broader Australian population, with a projected accelerated aging rate [33]. The prevalence of lone-person households, concentrated among older age groups, is rising, and these demographic shifts will likely amplify the demand for health care services [33]. The Flinders Medical Centre is the second-largest tertiary hospital in Adelaide with nearly 600 beds, offering a wide range of medical, surgical, obstetric, and pediatric services.

Virtual Rehabilitation Service

The virtual rehabilitation ward (VRW) provides acute clinical care through rapid assessment and rehabilitation to patients with a range of diagnoses in their own homes. The service provides an alternative to hospital-based rehabilitation and allows patients to be discharged earlier from inpatient wards. A team of multidisciplinary staff (see Table 1), including doctors, nurses, and allied health professionals, work with the individual to achieve rehabilitation goals via a mix of tailored video calls and home visits over a 2-week period with daily clinical reviews. The patient’s medical status is also monitored remotely, for instance, blood pressure, oxygen saturation, temperature, and weight. All equipment is loaned to the patient (eg, iPad with cellular connection via SIM card and monitoring equipment), and training on how to use the equipment is provided by care staff. Home visits can occur as required, and an initial visit is made to set up equipment and provide training.

Table . Virtual rehabilitation ward workforce structure.

Profession	Full-time equivalent (hours)
Medical consultant, registrar, and resident medical officer	2.8
Nursing (clinical and enrolled)	10.5
Allied health professionals (physiotherapist, occupational therapist, pharmacy, psychology, exercise physiologist, social worker, speech pathologist, dietetics, and allied health assistants)	16

The service is available to individuals over the age of 18 years, but most patients are older adults. Between the commencement of the service in January 2022 and August 2022, a total of 181 (79%) out of 229 patients were aged 65 years or older, with an average age of 73.9 years and a median age of 75.0 years. Local hospital ward staff refer patients to the VRW, and a VRW coordinator assesses the individual's suitability for the program, usually in person while they are still an inpatient. The VRW accepts a wide range of patients with complex care needs, including individuals recovering from trauma, patients undergoing cancer rehabilitation, or those who require postsurgery care. The service delivers time-limited interventions and monitoring (usually 2 weeks) based on clinical needs. The service runs 7 days a week 24 hours a day, with full staffing between 8 AM and 8 PM and access to an on-call doctor available outside these hours. Patients are provided with a telephone number to contact if their symptoms worsen. The VRW is supported by a contracted external telecommunication provider, which supplements internal SALHN digital health support.

Participant Recruitment

Between July and September 2023, staff previously (ie, rotational junior doctors) or presently employed by the VRW were invited to participate in a semistructured interview exploring the implementation of the VRW. In phenomenological studies, a purposive sampling strategy—in this research, maximum variation sampling—is supported to recruit participants who have experienced the phenomenon under study. We aimed to recruit a diverse range of health care staff (ie, clinical, administration, and information technology) to capture various perspectives on the topic of interest, thereby illuminating diversity and revealing patterns or commonalities in traits across the spectrum [34-38]. Recruitment occurred through the ward managers circulating research information via email and word of mouth. Overall, 21 interviews were conducted, and participant characteristics are presented in Table 2. Data collection was ceased when all the staff who wanted to take part in the study had been interviewed. The number of VRW staff was smaller compared to conventional inpatient rehabilitation wards (Table 1). A total of 9 staff members declined because they were not interested in taking part in research or because they did not have the time to take part in an interview. No participants withdrew from the research after consenting. Each participant was interviewed only once, and no relationship was established prior to study commencement.

Table . Participant demographics (N=21).

Demographics		Value
Occupation, n (%)		
	Doctor	6 (29)
	Nurse	3 (14)
	Physiotherapist	3 (14)
	Exercise physiologist	1 (5)
	Occupational therapist	1 (5)
	Information technology officer	2 (10)
	Administrative assistant	1 (5)
	Manager	2 (10)
	Social worker	1 (5)
	Pharmacist	1 (5)
Age (years), mean (range)		39.1 (25-62)
Sex, n (%)		
	Female	15 (71)
	Male	6 (29)

Qualitative Data Collection and Analysis

We used phenomenology to understand the meaning of the perspectives of staff who worked on the VRW [37]. A researcher independent of the health service conducted the semistructured, audio-recorded interviews (LG). Field notes were made during the interviews to aid reflexivity [39]. A total of 20 interviews were in person and 1 was conducted virtually via Microsoft Teams. To ensure convenience for the staff, in-person interviews were held in a meeting room on the same floor of the hospital as the VRW offices. For the virtual interview, both the researcher and the participant were in their respective homes. Interviews lasted between 45 - 60 minutes and no one else was present besides the participants and researcher. Interview questions and descriptions of the 7 NASSS domains are provided in Multimedia Appendix 1. Questions were tailored for each staff discipline, for example, doctors were asked about remote prescribing while allied health professionals were asked about remote therapy. We did not conduct a pilot test for this piece of research.

Deidentified, audio-recorded interviews were transcribed verbatim by a professional transcription service. One participant requested for their transcript to be returned to them for comment, but no amendments were made. The data were analyzed by 2 coders (LG and MR) using framework analysis [40] to identify the key themes and meanings that emerged from the participants' descriptions. This method was chosen as it provides a rigorous and transparent approach for researchers to analyze multidisciplinary health research [41]. Moreover, as framework analysis is not aligned with a specific epistemological, philosophical, or theoretical perspective, it adapted well to the use of a preexisting theoretical framework (deductive analysis) while allowing room for revisions with inductive aspects of analysis [40]. In brief, the process of framework analysis involves organizing significant themes and issues into 5 distinct stages: becoming familiar with the data; identifying a thematic framework; indexing; charting; and finally, mapping and interpretation. Multimedia Appendix 2 [15,41-46] provides a detailed description of the methodology. NVivo 12 (QSR International) was used for coding and indexing the data into the 7 NASSS domains. The information was subsequently condensed and organized into a matrix. Multimedia Appendix 3 provides a description of our coding tree.

Results

Overview

Due to the small size of the VRW staff, where sometimes only 1 member represented each discipline, to ensure anonymity within quoted content, we have grouped them. Physiotherapists, exercise physiologists, occupational therapists, and social workers are grouped under the collective name "Allied Health Professional" and managers and administrative staff are grouped under "Leadership/Admin Team." Two participants provided feedback on the findings via email and during an informal face-to-face meeting.

In summary, the VRW sought to serve patients with varied health conditions. Challenges arose in managing complex cases such as heart failure and cognitive impairments, impacting staff confidence in virtual care delivery. Despite technological benefits such as remote monitoring, interoperability issues persisted, hindering adoption. The service's value lay in offering choice and access to care, particularly benefiting rural communities. However, risks included communication challenges with community care teams and less intensive therapy compared to inpatient settings. The transition to virtual care posed workflow and responsibility challenges, highlighting the need for staff training and support. Ambiguity surrounding the service's identity and referral processes impacted resource allocation and patient expectations. Challenges in patient transfer and continuity of care were observed, along with resistance to hospital readmission and overcrowded emergency departments. Staff recognized the service's potential but emphasized the need for specialized planning and ongoing adaptation. Adaptive actions included refining technology and identifying areas for improvement in patient care and service delivery.

Domain 1: The Condition

The VRW services patients with several health conditions, including ones that require high-level care (Multimedia Appendix 4). Participants commented on how certain conditions, such as heart failure, fluid retention, and complex wounds, were more challenging to manage using a virtual ward approach in comparison to a traditional inpatient setting.

> *We'd have fluid overloaded patients, and you just don't know how much they're drinking, or you can't do the same monitoring as you can in hospital.* [Doctor]

Comorbidities (including cognitive impairments, polypharmacy, frailty, disability [eg, limb impairments and tremors], and sensory impairments) were also discussed by all participants as factors impacting how confident the staff felt in engaging patients in the virtual ward service. There was a sense that the service might be better suited for patients with minimal cognitive impairment who are willing to engage with technology.

> *In the right population, yes. I think again, if they're cognitively not good, or they're really not wanting to engage through technology, then it's very difficult. But yeah, I think if they're willing to engage in that, I think it's no different to being in the room with them.* [Allied Health Professional]

The service's suitability was also influenced by sociocultural factors such as living arrangements. For example, the staff reported relying on carers to assist with virtual sessions or remote monitoring. Therefore, living alone or residing in a care home could potentially pose challenges.

> *I think it depends on what support the person has…So if they've got someone else there with them who can use the technology that works really well, and there's definitely no issues there.* [Allied Health Professional]

Domain 2: The Technology

A lack of interoperability between hardware and software systems was discussed by all 21 participants. There was agreement that the integration between different health care systems, service providers, technology, and security was poor and impeded adoption (Multimedia Appendix 4). This complexity appeared to make it difficult to pinpoint the exact sources of problems when difficulties occurred. Additional challenges came from unforeseen software updates, with the equipment dispersed across patients' homes (Multimedia Appendix 4).

> *It's like, "Don't really care whose fault it is, can someone just fix it?"* [Allied Health Professional]

The remote monitoring equipment and the capability to make video calls was perceived as advantageous, since it has assisted staff in monitoring patient conditions and facilitating the escalation of care or transferring to another health care service when necessary. This was particularly commented on by doctors, although other staff also made reference to the equipment's benefits in escalation. Despite staff's efforts to streamline the process for simplicity, there were reliability and usability concerns, occasionally affecting rapport (Multimedia Appendix 4).

> *...it's not 100% reliable for us, and for us to escalate care of patients based on an unreliable system is difficult to do…We need to have technology that we can rely on, that is safe.* [Leadership/Admin Team]

There was, however, recognition that some of these technology failures could stem from a lack of knowledge and education among both staff and patients (Multimedia Appendix 4).

> *...maybe we don't facilitate the education as good as we should. We are out there for what, maybe half an hour. And then, "Here's your kit, off you go."* [Leadership/Admin Team]

Medtasker, a mobile communication and task management platform, was widely used and commended for its ability to minimize work duplication and reduce the need for excessive phone calls and emails.

> *Because the virtual team is sort of here mornings, evenings, there might be people that might have seen the patient a few days and then they're not the next and so forth. We're trying to work out the best ways of managing communication. And I think a program like Medtasker helps.* [Doctor]

Domain 3: Value Proposition

The value of the service was the choice it provided patients on where they received their care (Multimedia Appendix 4). The staff felt that home-based treatment, especially for older individuals, would be a preferred and more comfortable option than staying in hospital. The service was considered empowering and enabled access to care for rural communities who might not be able to access rehabilitation services otherwise (Multimedia Appendix 4).

> *I think the gaps that it bridges is amazing and huge, because our country patients, who aren't able to travel…I see cancer patients who are palliative who really benefit from that ability to be able to connect via video link.* [Doctor]

The value of the VRW for patients was also discussed by identifying risks. The opinions about this varied, but in general, there was a sense that the VRW did not pose more risks, just different risks. One concern, particularly with doctors, was that patients often resumed contact with their community care teams (general practitioners [GPs] and community-based medical specialists).

> *…managing patients who are still attending their GPs, their specialists in other hospitals in the background, and if you do not have an understanding of what there is happening there and you are involved, I think that is somewhere where some confusion can happen.* [Doctor]

Additionally, there were fewer opportunities for physical evaluation, monitoring, and therapy, leading to concerns that clinicians might miss early signs of deterioration. This concern was elaborated upon by 4 of the interviewed doctors, while nurses and allied health professionals also indicated unease about not being able to examine severely ill patients as thoroughly as they typically would on a ward. Allied health professionals discussed patients having less-intense therapy compared to inpatient wards (Multimedia Appendix 4).

> *...a lot of clinical signs we aren't able to pick up by a video link, so we'll assess them a particular way, but then when the registrar's gone and done a home visit just because we were worried for whatever reason, we've actually found other signs which have triggered escalation of care later, which we weren't able to identify through video links.* [Doctor]

Domain 4: The Adopters

The commencement of the VRW has imposed many changes to staff practices. The interviews delved into the need for a cultural shift and how some participants (and their colleagues) were resistant to adopting the virtual approach. Face-to-face patient interactions were preferred by many, either because they were accustomed to it or because they perceived clinical advantages in such treatments. There was a tendency for conducting initial meetings in person, followed by remote reviews, whenever feasible.

> *That's just the way that I've nursed for 30 years…I'm not used to trying to do that over a screen.* [Nurse]

There appeared to be some uncertainty surrounding workflows and professional responsibilities, leading to concerns that clinical staff might be required to assume technology or administrative duties (Multimedia Appendix 4).

> *We're clinical, we're not IT.* [Leadership/Admin Team]

As the service developed, the participants described how they have acquired valuable knowledge about the essential support, training, and resources needed. For instance, the team has recently gained a pharmacist, and this addition has helped alleviate previous prescription medication challenges. Furthermore, due to the unanticipated complex care needs of the referred patients, it has been crucial to have experienced staff to handle the workload effectively. As such, the clinical team has made staffing adjustments to accommodate for the large number of junior staff working within the service

(Multimedia Appendix 4). It was highlighted that for a virtual ward service to succeed, the staff should possess strong clinical skills to ensure adaptability and flexibility in care delivery (Multimedia Appendix 4).

> *…just the more experience and the more training and the more feeding off each other and learning of each other, the more we're adapting the telehealth. There is a huge education component that's needed for junior staff and a lot of support for people that aren't experienced.* [Allied Health Professional]

A shift in the burden of care to the patient and their family was also discussed. Staff particularly recognized the essential role that carers play in the patients' journey during virtual care.

> *...we heavily use carers and family in this model because not only can they help a lot of the time with setting up the technology and working it out and things like that, they're quite often present during the reviews and we quite often use them to just be our hands.* [Allied Health Professional]

Domain 5: The Organization

There was a sense of ambiguity surrounding the identity of the service both for the staff and patients. The service was set up to provide rehabilitation with a primary focus on functional recovery, but hospital pressures resulted in large numbers of referrals from acute wards, leading to more medically complex referrals than the team had anticipated. This presented a particular challenge for allied health professionals who felt that their roles became almost redundant for certain patients, such as those from oncology wards with newly diagnosed conditions that they were struggling to come to terms with.

> *We have a lot of pal[liative] care patients coming through lately. And just the questions that they ask, and the difficult conversations, and where to go with rehab. Because it's not really restorative, it's more maintenance and optimizing.* [Allied Health Professional]

Participants expressed frustration with the intake process, as they believed that referrals should involve patients who are willing and able to use technology as part of their rehabilitation journey.

> *There needs to be more done in the triage of people's capacity to use technology…we've been getting people who've just said to us, "I'm not using the iPad."* [Allied Health Professional]

There was a perception that patients were not accurately informed about the service or that some patients did not fully understand the implications of the term "Virtual Rehabilitation Ward." Patients often had unrealistic expectations, assuming that rehabilitation at home would be less intensive than in a traditional ward setting (Multimedia Appendix 4).

> *...they would think that it's a ward, but then the virtual part of it, sometimes, well some people don't know what that means. Some people think it's purely virtual so that there's no home visiting service.* [Leadership/Admin Team]

The importance of resource allocation and the environmental setup was also discussed. Given the rise in the complex patient population requiring more in-person care, vehicle access was often an issue, particularly for nursing and allied health care staff (Multimedia Appendix 4). Open-plan offices and a lack of private spaces for confidential calls were among the challenges discussed (Multimedia Appendix 4). Staff emphasized that the organization and setup of the service were crucial factors in its successful adoption, stressing the need for a balanced approach that offers a supportive office environment and has enough room and resources to deliver care flexibly.

> *Because you want to have the team together and interacting like they would on ward in a way because they have that, there's then that team camaraderie but also that informal sharing of knowledge and teaching each other…but you also need space to be able to operate and talk to patients and hear them.* [Doctor]

Domain 6: The Wider Context

Staff felt that the new service aimed to fill gaps in the existing health care system, but it lacked a clear pathway structure and well-defined boundaries.

> *...a lot of people are starting to get frustrated because there's just no clear pathway structure, anything of what we are and what we're meant to be doing and where we can set those boundaries of that's not our role. It just seems to be like take everything, deal with it when it's there.*
>
> *[Allied Health Professional]*

All staff members were mindful that patients are eager to leave the hospital and might be willing to accept any form of home service. They were also aware of the hospital's pressure to discharge patients promptly due to the scarcity of available beds.

> *I think so many of them are just so desperate to get out of hospital they'll agree to anything. And I think that the hospital is so desperate to get them out of hospital as well that they will sign them up to whatever program will take them.* [Leadership/Admin Team]

The wider context, especially in terms of the continuity of care, was discussed from service and interorganizational perspectives. Staff emphasized the importance of connecting with GPs before a patient's discharge to ensure the continuity of care; however, this was rarely done in practice.

> *Especially with our frailty pathway, we're meant to call the GP and talk about our frailty management plan once they're discharged from our service, but that's just been really difficult. Haven't been able to get through to the GP.* [Allied Health Professional]

Support and knowing how to connect patients with services following discharge were also discussed as a matter of importance.

> *…discharging patients from inpatient rehab, there's only a couple of go-to places, but then it's very different if patients are already out in the community.*

> *Because there's a lot of options for further support that you can link them with.* [Doctor]

Transferring patients back to the hospital when their health deteriorated presented challenges. Staff encountered resistance from patients who were reluctant to return to the hospital setting. Moreover, escalation pathways were impeded by overcrowded emergency departments and a shortage of available beds in the hospital. These issues were encountered by all clinical staff.

> *The difficulty has been once we identify they need to come in, what pathway they go towards. ED'S ramping, there's no beds in [local hospital], and then you've got to take those measured risks.* [Doctor]

Domain 7: Embedding and Adaptation Over Time

In general, all of the staff recognized the advantages that the service could provide to clinicians, patients, and the broader health care system (Multimedia Appendix 4). Nevertheless, they emphasized the need for planning that considered the distinctive and specialized requirements of virtual wards.

> *We try and introduce new models like technology and you're trying to just do it on the edge of everything else that is happening but really it needs its own setup…that's one of the challenges really, is trying to introduce a new model of care into an old system.* [Leadership/Admin Team]

Staff were engaged with adapting and embedding the technology within the service in response to their patient's needs. There was recognition that the service is in its early stages of development (Multimedia Appendix 4), and as a result, certain aspects are not yet finely tuned. While some staff regarded glitches as failures, many understood that creating a new service is a gradual process that demands refinement over time.

> *It's changing that mindset, not seeing it as a failure. It's just seeing it as a sidestep again for now…They see that as a failure, which it isn't. Sometimes we've just got to fine tune things a little bit to be able to safely manage you at home.* [Nurse]

Sensemaking and collective reflection were evident throughout the interviews, with strengths of the service being the implementation of Medtasker as a platform for team communication and accountability, and remote health monitoring to help clinicians escalate care. Adaptive action is ongoing to ensure that the technology is more dependable and the service is reaching its target patient cohort. The team is continually learning and identifying areas for adaption: for example, having a stock of common medications to trial patients on them, and having more technology applicable to an older cohort with frailty such as fall devices, echocardiograms, and telemetry.

Discussion

This paper addresses the knowledge gap related to the facilitators and barriers experienced by hospital staff during the implementation of a new VRW [2]. The service aimed to provide early discharge with a functional and medical care program for adults who are able to rehabilitate at home. The perspectives of staff are pivotal as previous research has suggested that clinician endorsement can account for a significant portion of the variability in the adoption, growth, and continuity of telehealth services [47-49].

The VRW team successfully managed complex patients in the community but highlighted how some conditions were more challenging than others, such as individuals with fluid retention or severe wounds. This was particularly pertinent for older individuals, especially those with comorbidities and those who reside alone or in care homes, where they might lack the capacity to manage monitoring and communication equipment. Older people who were not proficient with digital technology were not disadvantaged in terms of quality of care or through digital exclusion [2], as the team was flexible in providing tailored care and would provide in-person services. Yet, it appears that for a virtual ward to achieve success, the service must possess a clear identity that is supported by its triage and intake process. A mismatch was described between staff expectations of medically stable patients focused on rehabilitation and the actual referrals of frail patients of varied case mix who were discharged early in response to hospital pressures. These findings underscore the importance of the consideration of patient characteristics prior to enrollment and the necessity of tailored care.

Regarding technology, interoperability was poor, a common issue in virtual care [50,51], and there were delays in pinpointing problems that impeded adoption. Nevertheless, some of these challenges appeared to be rooted in a lack of staff and patient training on correct technology use, an issue that appears common in new technology-supported health care models [15,16]. The brevity of the VRW program (typically 2 weeks) posed challenges, as there is limited time available for staff to adequately train patients, particularly older individuals who may need more support [52]. The substantial effort required may also seem disproportionate to the program's short duration. The attitudes around technology were multifaceted. While there was a consensus that the technology was useful, particularly in the escalation of care, promotion of self-management, and team communication and task management, there was recognition that it sometimes created burden for the patient and carers and that it was not always accurate in detecting health decline [53-55]. In line with recent reports, simplifying hardware and software use were deemed crucial for success [2].

The primary value proposition encompassed offering patients the option to select their care location and increasing access to rehabilitation without waiting in hospital for a bed. This was particularly pertinent for older individuals, considering the potential risks associated with hospital admissions [10], as well as for patients residing far from rehabilitation hospitals. Opinions on risk were varied; yet, overall, there was agreement that the VRW did not entail greater risks but rather presented different risks compared to inpatient rehabilitation. A notable concern was that patients reestablished contact with their community care teams, including GPs, a factor that could make cohesive care challenging. Additionally, fewer chances for in-person physical assessment, monitoring, and therapy raised concerns about clinicians possibly missing early signs of decline or patients receiving less intensive treatment compared to inpatient wards.

In terms of adopters, changing staff culture toward virtual care was recognized as an area for improvement. Many staff still preferred face-to-face visits due to familiarity or ease compared to dealing with technology. Uncertainty surrounding workflows and professional roles raised concerns that clinical staff were being asked to take on technology or administrative tasks. Furthermore, there were changes in staffing to align with the complexity of the patient cohort including the employment of a pharmacist and more experienced nurses. There was also a recognition of a shift in care responsibility to the patient and their family. Staff particularly acknowledged the crucial role that caregivers play in the patients' journey during virtual care. Little is known about carers roles in virtual models [2], and our ongoing work is exploring the experiences of patients and their family members who were referred to the VRW.

Clear pathways for early recognition of patient deterioration and appropriate escalation procedures were in place to ensure patient safety (eg, patients having a single phone number to call and the availability of remote monitoring equipment). However, challenges arose from wider pressures on public Australian hospitals, including overcrowded emergency departments and insufficient ward beds, which hindered patient transfers. Patients were reluctant to return to the hospital for these reasons. This holds significance because prior research has indicated that a major concern among staff regarding virtual care is the ability to swiftly admit patients to the hospital if their condition deteriorates [56]. Interorganizational collaboration, particularly handovers with GPs, occurred infrequently, leading to difficulties in seamless patient care transitions.

To our knowledge, this study addresses a significant gap in understanding by delving into the perspectives of hospital staff regarding the facilitators and obstacles in implementing a VRW. A key strength of this research lies in its qualitative methodology, allowing for a deep exploration of the topic within its natural context and enabling a nuanced examination of the multifaceted social, cultural, and environmental factors at play. Moreover, by centering the voices and experiences of hospital staff, an often-marginalized group in research as evidenced by the paucity of published literature, we aim to provide a platform for their narratives to be heard and valued.

Virtual wards represent a relatively novel concept, and there exists some ambiguity regarding their terminology [2]. Subsequent studies might prioritize the global standardization of the model, recognizing the importance of precise terminology in ensuring the generalizability of insights within the literature. Despite these variations, our research findings retain applicability to services that use monitoring and virtual technologies for postdischarge patient care.

To summarize, most staff acknowledged the benefits of the VRW service but emphasized the need for sufficient resource allocation and additional time to plan and implement the service and address early hurdles. In terms of health care access and equity, it appears that in a rehabilitation setting with a primarily older cohort, technology complements physical consultations but does not replace them and this must be factored into service design and delivery. We underscore that new health care models cannot exist on the fringes of traditional frameworks, as they require their own well-defined structure and setup with clear workflow and professional responsibilities.

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Conflicts of Interest

MC has a dual role with Flinders University and the South Adelaide Local Health Network.

Multimedia Appendix 1
Interview questions.
[DOCX File, 28 KB - aging_v7i1e54774_app1.docx]

Multimedia Appendix 2
Additional analysis information and researcher credentials.
[DOCX File, 20 KB - aging_v7i1e54774_app2.docx]

Multimedia Appendix 3
Coding tree.
[DOCX File, 16 KB - aging_v7i1e54774_app3.docx]

Multimedia Appendix 4
Additional quotes from hospital staff interviews.
[DOCX File, 30 KB - aging_v7i1e54774_app4.docx]

References

1. Tech-enabled virtual wards: relieving pressure on the NHS while caring for patients at home. NHS England. 2022. URL: https://transform.england.nhs.uk/key-tools-and-info/data-saves-lives/improving-individual-care-and-patient-safety/virtual-wards-relieving-pressure-on-the-nhs-while-caring-for-patients-at-home/ [accessed 2024-06-19]
2. Norman G, Bennett P, Vardy ERLC. Virtual wards: a rapid evidence synthesis and implications for the care of older people. Age Ageing 2023 Jan 8;52(1):afac319. [doi: 10.1093/ageing/afac319] [Medline: 36633298]
3. Best J. The virtual wards aiming to ease hospital pressures. BMJ 2022 Jul 6;378:1603. [doi: 10.1136/bmj.o1603]
4. Lewis G, Vaithianathan R, Wright L, et al. Integrating care for high-risk patients in England using the virtual ward model: lessons in the process of care integration from three case sites. Int J Integr Care 2013 Nov 3;13:e046. [doi: 10.5334/ijic.1150] [Medline: 24250284]
5. Toal D, Ryan A, Ryan K. The response of hospital at home services during the COVID-19 pandemic: a scoping review. Home Health Care Management & Practice 2024 May;36(2):120-133. [doi: 10.1177/10848223231188714]
6. Supporting information for ICS leads: enablers for success: virtual wards including hospital at home. NHS England. 2022 Apr 25. URL: https://www.england.nhs.uk/publication/enablers-for-success-virtual-wards/ [accessed 2024-06-19]
7. Virtual wards. NHS England. 2024. URL: https://www.england.nhs.uk/virtual-wards/#:~:text=Virtual%20wards%20(also%20known%20as,rather%20than%20being%20in%20hospital [accessed 2024-06-19]
8. Bringing hospital care home: virtual wards and hospital at home for older people. British Geriatrics Society. 2022 Aug 17. URL: https://www.bgs.org.uk/virtualwards [accessed 2024-06-19]
9. Chua CMS, Ko SQ, Lai YF, Lim YW, Shorey S. Perceptions of hospital-at-home among stakeholders: a meta-synthesis. J Gen Intern Med 2022 Feb;37(3):637-650. [doi: 10.1007/s11606-021-07065-0] [Medline: 34363185]
10. Chen Y, Almirall-Sánchez A, Mockler D, Adrion E, Domínguez-Vivero C, Romero-Ortuño R. Hospital-associated deconditioning: not only physical, but also cognitive. Int J Geriatr Psychiatry 2022 Feb 2;37(3):10.1002/gps.5687. [doi: 10.1002/gps.5687] [Medline: 35142397]
11. Shepperd S, Butler C, Cradduck-Bamford A, et al. Is comprehensive geriatric assessment admission avoidance hospital at home an alternative to hospital admission for older persons?: a randomized trial. Ann Intern Med 2021 Jul;174(7):889-898. [doi: 10.7326/M20-5688] [Medline: 33872045]
12. Guidance note: frailty virtual ward (hospital at home for those living with frailty). NHS England. 2021 Dec 22. URL: https://www.england.nhs.uk/publication/guidance-note-frailty-virtual-ward-hospital-at-home-for-those-living-with-frailty/ [accessed 2024-06-19]
13. Hakim R. Realising the potential of virtual wards. NHS Confederation. 2023 May 23. URL: https://www.nhsconfed.org/publications/realising-potential-virtual-wards [accessed 2024-06-19]
14. van Limburg M, van Gemert-Pijnen JEWC, Nijland N, Ossebaard HC, Hendrix RMG, Seydel ER. Why business modeling is crucial in the development of eHealth technologies. J Med Internet Res 2011 Dec 28;13(4):e124. [doi: 10.2196/jmir.1674] [Medline: 22204896]
15. Greenhalgh T, Wherton J, Papoutsi C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. J Med Internet Res 2017 Nov 1;19(11):e367. [doi: 10.2196/jmir.8775] [Medline: 29092808]
16. Vindrola-Padros C, Singh KE, Sidhu MS, et al. Remote home monitoring (virtual wards) for confirmed or suspected COVID-19 patients: a rapid systematic review. EClinicalMedicine 2021 Jul;37:100965. [doi: 10.1016/j.eclinm.2021.100965] [Medline: 34179736]
17. James HM, Papoutsi C, Wherton J, Greenhalgh T, Shaw SE. Spread, scale-up, and sustainability of video consulting in health care: systematic review and synthesis guided by the NASSS framework. J Med Internet Res 2021 Jan 26;23(1):e23775. [doi: 10.2196/23775] [Medline: 33434141]
18. Sligo J, Gauld R, Roberts V, Villa L. A literature review for large-scale health information system project planning, implementation and evaluation. Int J Med Inform 2017 Jan;97:86-97. [doi: 10.1016/j.ijmedinf.2016.09.007] [Medline: 27919399]
19. Greenhalgh T, Stramer K, Bratan T, Byrne E, Russell J, Potts HWW. Adoption and non-adoption of a shared electronic summary record in England: a mixed-method case study. BMJ 2010 Jun 16;340:c3111. [doi: 10.1136/bmj.c3111] [Medline: 20554687]
20. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q 2004 Dec 9;82(4):581-629. [doi: 10.1111/j.0887-378X.2004.00325.x] [Medline: 15595944]
21. Hunter W. Virtual wards: a bridge between hospitals and the community? Nursing in Practice. 2022 Dec 19. URL: https://www.nursinginpractice.com/analysis/virtual-wards-a-bridge-between-hospitals-and-the-community/ [accessed 2024-06-19]
22. Sheasby L. Virtual ward challenges and how to overcome them. The Access Group. URL: https://www.theaccessgroup.com/en-gb/health-social-care/healthcare-software/virtual-wards/virtual-ward-challenges/ [accessed 2024-06-19]
23. Hutchings R, Edwards E. Virtual wards: the lessons so far and future priorities. Nuffield Trust. 2023 Mar 22. URL: https://www.nuffieldtrust.org.uk/news-item/virtual-wards-the-lessons-so-far-and-future-priorities [accessed 2024-06-19]
24. Guba EG, Lincoln YS. Fourth Generation Evaluation: Sage Publications; 1989.

25. Dyb K, Berntsen GR, Kvam L. Adopt, adapt, or abandon technology-supported person-centred care initiatives: healthcare providers' beliefs matter. BMC Health Serv Res 2021 Mar 17;21(1):240. [doi: 10.1186/s12913-021-06262-1] [Medline: 33731078]
26. Thomas EE, Taylor ML, Ward EC, et al. Beyond forced telehealth adoption: a framework to sustain telehealth among allied health services. J Telemed Telecare 2024 Apr;30(3):559-569. [doi: 10.1177/1357633X221074499] [Medline: 35130099]
27. Abimbola S, Patel B, Peiris D, et al. The NASSS framework for ex post theorisation of technology-supported change in healthcare: worked example of the TORPEDO programme. BMC Med 2019 Dec 30;17(1):233. [doi: 10.1186/s12916-019-1463-x] [Medline: 31888718]
28. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health 1999 Sep;89(9):1322-1327. [doi: 10.2105/ajph.89.9.1322] [Medline: 10474547]
29. Feldstein AC, Glasgow RE. A practical, robust implementation and sustainability model (PRISM) for integrating research findings into practice. Jt Comm J Qual Patient Saf 2008 Apr;34(4):228-243. [doi: 10.1016/s1553-7250(08)34030-6] [Medline: 18468362]
30. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357. [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
31. CC BY 4.0 deed. Creative Commons. URL: https://creativecommons.org/licenses/by/4.0/ [accessed 2024-06-19]
32. Snapshot of South Australia - high level summary data for South Australia in 2021. Australian Bureau of Statistics. 2022 Jun 28. URL: https://www.abs.gov.au/articles/snapshot-sa-2021#:~:text=Housing-,Population,Census%20counted%201.1%20million%20people [accessed 2024-06-19]
33. Flavel J, Baum F, Musolino C, Freeman T, van Eyk H, Southgate Institute for Health, Society and Equity. Healthy south: population health and social determinants in Southern Adelaide. Flinders University. 2020. URL: https://www.flinders.edu.au/content/dam/documents/research/southgate-institute/Population-Health-and-Social-Determinants-in-Southern-Adelaide-report.pdf [accessed 2024-06-19]
34. Luciani M, Campbell K, Tschirhart H, Ausili D, Jack SM. How to design a qualitative health research study. part 1: design and purposeful sampling considerations. Prof Inferm 2019;72(2):152-161. [Medline: 31550432]
35. Creswell JW, Poth CN. Qualitative Inquiry and Research Design: Choosing Among Five Approaches: Sage Publications; 2016.
36. Patton MQ. Qualitative Research & Evaluation Methods: Integrating Theory and Practice: Sage Publications; 2014.
37. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. Qual Health Res 2007 Dec;17(10):1372-1380. [doi: 10.1177/1049732307307031] [Medline: 18000076]
38. Hamm LM, Boluk KA, Black JM, Dai S, Thompson B. Phenomenological approach to childhood cataract treatment in New Zealand using semi-structured interviews: how might we improve provision of care. BMJ Open 2019 Jan 28;9(1):e024869. [doi: 10.1136/bmjopen-2018-024869] [Medline: 30782745]
39. Buys T, Casteleijn D, Heyns T, Untiedt H. A reflexive lens on preparing and conducting semi-structured interviews with academic colleagues. Qual Health Res 2022 Nov;32(13):2030-2039. [doi: 10.1177/10497323221130832] [Medline: 36194785]
40. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess B, editors. Analyzing Qualitative Data: Routledge; 1994:187-208. [doi: 10.4324/9780203413081-10]
41. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013 Sep 18;13:117. [doi: 10.1186/1471-2288-13-117] [Medline: 24047204]
42. Iliffe S, Wilcock J, Drennan V, et al. Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM). Programme Grants Appl Res 2015;3(3). [doi: 10.3310/pgfar03030]
43. Olmos-Vega FM, Stalmeijer RE, Varpio L, Kahlke R. A practical guide to Reflexivity in qualitative research: AMEE guide no. 149. Med Teach 2022 Apr 7:1-11. [doi: 10.1080/0142159X.2022.2057287] [Medline: 35389310]
44. Walsh R. The methods of reflexivity. The Humanistic Psychologist 2003;31(4):51-66. [doi: 10.1080/08873267.2003.9986934]
45. Parkinson S, Eatough V, Holmes J, Stapley E, Midgley N. Framework analysis: a worked example of a study exploring young people’s experiences of depression. Qualitative Research in Psychology 2016 Apr 2;13(2):109-129. [doi: 10.1080/14780887.2015.1119228]
46. Pope C, Ziebland S, Mays N. Qualitative research in health care. analysing qualitative data. BMJ 2000 Jan 8;320(7227):114-116. [doi: 10.1136/bmj.320.7227.114] [Medline: 10625273]
47. Collins B. Staff engagement: six building blocks for harnessing the creativity and enthusiasm of NHS staff. The King’s Fund. 2015 Feb 19. URL: https://www.kingsfund.org.uk/insight-and-analysis/reports/staff-engagement-creativity-enthusiasm [accessed 2024-06-19]
48. Sharma U, Clarke M. Nurses' and community support workers' experience of telehealth: a longitudinal case study. BMC Health Serv Res 2014 Apr 10;14:164. [doi: 10.1186/1472-6963-14-164] [Medline: 24721599]

49. Wade VA, Eliott JA, Hiller JE. Clinician acceptance is the key factor for sustainable telehealth services. Qual Health Res 2014 May;24(5):682-694. [doi: 10.1177/1049732314528809] [Medline: 24685708]
50. Mohammed HT, Hyseni L, Bui V, et al. Exploring the use and challenges of implementing virtual visits during COVID-19 in primary care and lessons for sustained use. PLoS One 2021 Jun 24;16(6):e0253665. [doi: 10.1371/journal.pone.0253665] [Medline: 34166441]
51. Zhang X, Saltman R. Impact of electronic health record interoperability on telehealth service outcomes. JMIR Med Inform 2022 Jan 11;10(1):e31837. [doi: 10.2196/31837] [Medline: 34890347]
52. Callisaya ML, Lee AHC, Khushu A. Rapid implementation of telehealth in geriatric outpatient clinics due to COVID-19. Intern Med J 2021 Jul;51(7):1151-1155. [doi: 10.1111/imj.15306] [Medline: 34143563]
53. Talbot B, Farnbach S, Tong A, et al. Patient and clinician perspectives on the use of remote patient monitoring in peritoneal dialysis. Can J Kidney Health Dis 2022 Mar;9:20543581221084499. [doi: 10.1177/20543581221084499] [Medline: 35340772]
54. Thomas EE, Taylor ML, Banbury A, et al. Factors influencing the effectiveness of remote patient monitoring interventions: a realist review. BMJ Open 2021 Aug 25;11(8):e051844. [doi: 10.1136/bmjopen-2021-051844] [Medline: 34433611]
55. Primholdt Christensen N, Skou KE, Boe Danbjørg D. Health care professionals' experiences with the use of video consultation: qualitative study. JMIR Form Res 2021 Jul 21;5(7):e27094. [doi: 10.2196/27094] [Medline: 34287207]
56. Thornton N, Horton T, Hardie T. How do the public and NHS staff feel about virtual wards? The Health Foundation. 2023 Jul 29. URL: https://www.health.org.uk/news-and-comment/charts-and-infographics/how-do-the-public-and-nhs-staff-feel-about-virtual-wards [accessed 2024-06-19]

Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
GP: general practitioner
NASSS: Nonadoption, Abandonment, Scale-up, Spread, and Sustainability
NHS: National Health Service
PRISM: Practical, Robust Implementation and Sustainability Model
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance
SALHN: Southern Adelaide Local Health Network
VRW: virtual rehabilitation ward

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Phase Angle and Impedance Ratio as Indicators of Physical Function and Fear of Falling in Older Adult Women: Cross-Sectional Analysis

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Abstract

Background: Older adults experience a significant decline in muscle integrity and function with aging. Early detection of decreased muscle quality can pave the way for interventions to mitigate the progression of age-related physical declines. Phase angle (PhA) and impedance ratio (IR) are measures of muscle integrity, which can be assessed quickly via bioelectrical impedance analysis (BIA) and may be indicative of physical function.

Objective: This study aimed to characterize the relationships among handgrip strength (HGS), sit-to-stand (STS), BTrackS balance scores, fear of falling (evaluated using the Short Falls Efficacy Scale–International [Short FES-I]), and IR among community-dwelling older adult women classified as having a low or high PhA.

Methods: A cross-sectional analysis was conducted with 85 older women (mean age 75.0, SD 7.2 years; mean weight 71.0, SD 15.0 kg; mean height 162.6, SD 6.1 cm). To examine the influence of PhA on performance measures, participants were divided into 2 PhA groups: high (>4.1°; n=56) and low (≤4.1°; n=29). Data were nonnormative; hence, the Mann-Whitney *U* test was used to evaluate between-group differences, and Kendall τ coefficients were used to determine the partial correlations.

Results: The low PhA group had a significantly higher IR (mean 0.85, SD 0.03) than the high PhA group (mean 0.81, SD 0.03; *r*=.92; *P*<.001). The high PhA group had superior HGS (mean 21.4, SD 6.2 kg; *P*=.007; *r*=0.36), BTrackS balance scores (mean 26.6, SD 9.5 cm; *P*=.03; *r*=0.30), and STS scores (mean 16.0, SD 5.5; *P*<.001; *r*=0.49) than the low PhA group (mean HGS 17.6, SD 4.7 kg; mean BTrackS balance score 37.1, SD 21.1 cm; mean STS score 10.7, SD 6.2). Both PhA and IR were significantly correlated with HGS and BTrackS balance, STS, and Short FES-I scores (*P*<.05). However, on adjusting for the whole sample's age, only PhA was strongly correlated with HGS (τb=0.75; *P*=.003) and STS scores (τb=0.76; *P*=.002). Short FES-I scores were moderately correlated with IR (τb=0.46; *P*=.07) after controlling for age. No significant between-group differences were observed for height, weight, or BMI.

Conclusions: PhA and IR are associated with physical function and the fear of falling in older women. However, only PhA was significantly associated with physical function (HGS and STS) independent of age. Conversely, only IR was significantly associated with the fear of falling. Diminished physical function and increased IR appear to be characteristics of older women with a PhA of ≤4.1°. These findings suggest that PhA and IR measured through BIA together may serve as a valuable tool for early identification of older women at the risk of functional decline and a heightened fear of falling.

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KEYWORDS

handgrip; sit-to-stand; fitness; assessment; functionality; body composition; balance; fall; impedance; bioelectrical

Introduction

By 2060, the population of American adults older than 65 years is projected to surge, doubling from 52 million in 2018 to 95 million [1]. Muscle weakness and functional loss contribute to falls; in 2020, approximately 3 million adults older than 65 years were treated in emergency rooms as a result of falling, with 800,000 of them having been hospitalized [2]. The annual cost of falls has exceeded US $50 billion, with Medicare and Medicaid covering 75% of these costs [2]. These older adults often experience a significant decline in muscle quality, quantity, and function [3]. Such age-related functional limitations can make everyday tasks, such as cooking, cleaning, and interacting with grandchildren, increasingly challenging [3]. The natural aging process brings about changes in body composition, often directly affecting physical function, as seen in sarcopenia [4]. Sarcopenia is characterized by a rapid loss of muscle strength with aging and is significantly associated with physical disability, decreased quality of life, and increased mortality [5,6]. Moreover, aging exacerbates traits of frailty, a syndrome characterized by a decrease in reserve capacity across various physiological systems, reducing their ability to withstand minor stressors [7,8]. This can result in an increased risk of falls, fractures, and disabilities [9,10], as well as higher mortality rates [7,8].

Aging also affects the musculoskeletal system, causing a decrease in skeletal muscle integrity, mass, strength, and function, along with an increase in the accumulation of noncontractile and adipose tissue [11,12]. Decreases in skeletal muscle integrity can result from a diminished cross-sectional area of muscle fibers, a transition from type II to type I fibers, and a loss of innervation [13]. A loss of skeletal muscle integrity can manifest through impaired balance and subsequently decreased physical function [13]. While not a physical characteristic, a fear of falling can also impose a restriction on physical activity and exacerbate functional loss [14]. Brouwer et al [15] assessed the fear of falling in healthy older adults and concluded that fear of falling was associated with poorer physical function characterized by a lower walking speed and lower limb weakness. Commonly assessed through questionnaires, early detection of the fear of falling can lead to interventions designed to increase physical activity in older adults and mitigate functional loss [16]. Likewise, early detection of decreased muscle quality can pave the way for interventions that may mitigate the clinical progression of sarcopenia and frailty [17].

Bioelectrical impedance analysis (BIA) is a quick, noninvasive, cost-effective method for assessing body composition within the Two-Compartment Model. It has also gained popularity, especially among older populations, as an assessment for skeletal muscle integrity and cellular health [10]. The BIA involves directing a constant low-level electrical current through the body [18]. This system has 3 main components: reactance (X_c), which measures the ability of cell membranes to store electrical charge (capacitance); resistance (R), which represents the resistive properties of cells due to intracellular water (ICW) and extracellular water (ECW) [19]; and impedance (Z), which represents the overall opposition to the electrical current [20]. Impedance provides another opportunity to examine cellular integrity with body cell mass [21]. Impedance ratio (IR) measures Z at high and low frequencies (in kHz) and can be indicative of possible cell membrane dysfunction based on body cell mass [22]. The IR for the whole body, upper limbs, and lower limbs is commonly calculated at 250 kHz or 5 kHz [21,23]. At higher frequencies, Z can penetrate cell membranes, therefore allowing for total body water (ECW + ICW) to be measured; however, at lower frequencies, Z can only measure ECW [24]. An IR ratio closer to 1 is indicative of cell membrane disruption, allowing more fluids, proteins, and electrolytes to shift into the extracellular space [22]. A strong inverse correlation has been reported between the phase angle (PhA) and IR in different clinical populations [22]. PhA is defined as the delay in current flow caused by a reduction in cell membrane capacitance [25].

PhA is calculated as the ratio of R to X_c at a frequency of 50 kHz, as measured through BIA [26]. Furthermore, PhA is influenced by hydration status and lean body mass [27]. Therefore, it directly relates to the electrical functioning of cell membranes, skeletal muscle integrity, and PhA itself [12,27]. Higher PhA values are indicative of superior cell membrane integrity and cellular health [10]. Disease, dehydration, inflammation, malnutrition, and functional disabilities can cause disturbances in electrical tissue properties, reflected by a lower PhA [28-30]. A low PhA increases the risks for disability, falls, sarcopenia, frailty, and mortality among older populations [29]. PhA can be used as a proactive measure against physical weakening by identifying older individuals at the risk of muscle loss and mortality [10,17,19].

Previous research has established relationships between PhA and handgrip strength (HGS) [31], balance [13], gait speed [32], age [10], sex [30], sarcopenia [33], and BMI [34]. However, previously reported regression models have only been able to account for approximately ≤30% of the variance in PhA [31,35] and have largely left the fear of falling unaccounted for. Therefore, the primary objective of this study was to compare HGS, sit-to-stand (STS) scores, BTrackS balance scores, and fear of falling between groups of older women categorized as having high or low PhA. Additionally, we aimed to assess the relationships among PhA, IR, and physical function metrics while controlling for age, and determine which variables are most strongly associated with PhA and IR in this population. We hypothesized that those with a high PhA would perform better on functional assessments and have a lower fear of falling, and that HGS would have the strongest association with PhA and IR when controlling for age.

Methods

Ethical Considerations

All study procedures were conducted in accordance with the tenets of the Declaration of Helsinki, approved by the University of Central Florida’s institutional review board (ID: STUDY00002473), and preregistered on ClinicalTrials.gov (NCT06063187).

Recruitment

The 85 female participants (n=64, 75% White; n=15, 17% Hispanic; n=4, 5% African American; n=2, 2% Asian) included in this analysis were part of a larger study funded by the National Institutes on Aging (R03AG069799) [36]. This analysis used data from female participants only to specifically characterize the relationships between bioelectrical impedance parameters and physical function metrics in older women. This study used a cross-sectional design to determine whether there were differences in HGS, STS, BTrackS balance scores, fear of falling, and IR based on a low or high PhA among older adult women. The sample of 85 older adult women had a mean age of 75.0 (SD 7.2) years, mean weight of 71.0 (SD 15.0) kg, and mean height of 162.6 (SD 6.1) cm. The study was conducted in low-income communities around central Florida, United States. Recruitment was achieved through flyer distribution, face-to-face engagement, local newsletters, and word of mouth. Community partners and clinical sites facilitated our introduction to potential participants for informed consent, initial screening, and eligibility verification using a checklist. Upon completion of the study, the participants received a US $30 gift card.

Eligible participants met all of the following inclusion criteria: (1) being aged ≥60 years; (2) being of low income status, based on 2019 poverty thresholds relative to family size and the number of children aged ≤18 years [18]; (3) absence of marked cognitive impairment, defined by a memory impairment screen score of ≥5 [37]; and (4) living independently in their own homes or apartments. Exclusion criteria were (1) medical conditions that inhibit balance testing or physical activity, such as the inability to stand on the balance plate or experiencing shortness of breath during physical activity; (2) active treatment from a rehabilitation facility; or (3) the presence of medical implants, such as pacemakers.

Measurements

Grouping of Participants: Low and High PhA

To verify the influence of PhA on performance measures, participants were divided into 2 groups: low PhA (≤4.1°; n=56) and high PhA (>4.1°; n=29). This cutoff was based on previous research that observed a higher prevalence of physical dysfunction and sarcopenia among community-dwelling women aged ≥65 years with a PhA less than 4.1° [34,38].

BIA

Body composition was assessed using the InBody s10, a direct segmental multifrequency BIA device from InBody Co, located in Seoul, South Korea. This device is designed to measure Z at 6 different frequencies—1, 5, 50, 250, 500, and 1000 kHz—for both the entire body and individual body segments. All BIA assessments were conducted before performing all other assessments, and all assessments were completed between 9 AM and 12 PM. To ensure accuracy, participants were instructed to fast for a duration of 3-4 hours, abstain from caffeine or alcohol for 24 hours, and avoid exercising for a period of 6-12 hours before testing. Participants were asked to maintain their normal dietary habits and arrive for testing adequately hydrated. On the day of assessment, participants were asked to remove their shoes, socks, and any metallic items. Height and weight were assessed using a digital physician scale and stadiometer (Health-O-Meter, Model 402 KL). Participants were then seated as their skin was prepared with an InBody wipe (InBody Co), and touch-type electrodes were then positioned on their left and right ankles, middle fingers, and thumbs. Participants were required to remain still for 1 minute before the electrodes were removed. PhA was derived by calculating the ratio of R to X_c at 50 kHz using the following formula: arc tangent $(X_c/R) \times (180/\pi)$ [26]. Moreover, IR was determined by dividing Z at 250 kHz by Z at 5 kHz [22,23]. The InBody s10 has good test-retest reliability among adults aged 65 years and older, with an intraclass correlation coefficient (ICC) of 0.82 [39].

HGS

Following BIA assessments, HGS was measured using a JAMAR Plus digital handgrip dynamometer (JLW Instruments) to ascertain maximal isometric force in kilograms. Participants, seated with feet flat on the floor and elbow bent at 90°, held the dynamometer in their hand, which was adjusted to allow for a flat second metacarpal and 90° bend at the knuckles. Participants then squeezed the dynamometer as hard as possible for 3-5 seconds across 3 trials, with 30-second rest intervals between each trial. All 3 trials were completed for 1 hand before performing 3 trials with the opposite hand. The maximum value for each hand was recorded, averaged, and used for analysis. The JAMAR handgrip dynamometer is a sound method to test HGS in the clinical setting with good intra- and intertester reliability [36,40].

BTrackS Balance Scores

BTrackS balance scores were gauged using the BTrackS balance system (Balance Tracking Systems) following HGS assessments. The BTrackS balance plate and BTrackS Assess Balance software (version 5.5.9) were used to measure center-of-pressure sway during a static stance. The scores and percentile rankings (0-100) were determined in accordance with age group and sex. A score of ≤30 signifies normal balance, while a score of ≥31 indicates poor balance and a moderate to high fall risk [41]. For each trial, participants were instructed to place their hands on their hips, close their eyes, and maintain a static position on the BTrackS Balance Plate for 20 seconds. Participants first underwent a familiarization trial that did not count toward their average score, followed by 3 trials that were averaged into their final score. To mitigate the risk of falls, a piece of sturdy furniture or a walker was placed within the participants’ reach during the test. The BTrackS balance system has been validated and has excellent reliability, with a Pearson correlation coefficient (r) of >0.90 and high test-retest reliability with an ICC of 0.83 [41].

STS

After BTrackS balance assessments, participants completed the 30-second STS test. STS scores were evaluated by instructing participants to stand up from a chair as many times as possible within 30 seconds. During the test, participants sat in the middle of the chair with their wrists crossed and hands resting on opposite shoulders. The 30-second STS test is a well-validated functional function measure in clinical research and practice, with good test-retest and interrater reliability [42].

Short Falls Efficacy Scale–International

Participants were asked to fill out the Short Falls Efficacy Scale–International (Short FES-I) questionnaire, which includes answering 7 questions on a scale of 1-4 that indicates if the participant would be concerned about falling during different activities. In the Short FES-I, a 1 indicates no concern at all and a 4 indicates being very concerned. The Short FES-I has been validated as a predictor of future falls and declines in functional capacity with balance and gait, and it has excellent test-retest ability [16].

Statistical Analysis

All statistical analyses were conducted using SPSS (version 28; IBM Corp). Descriptive data are presented as mean (SD) values along with ranges where appropriate. The Mann-Whitney *U* test was used to evaluate between-group differences for all variables. A Kolmogorov-Smirnov test determined that the data were nonnormal, so Kendall τ coefficients were used to determine the partial correlations between variables controlled for age. The α value was set considering a *P* value of <.05.

Results

A total of 88 older women were screened for eligibility and 85 were included in the analysis, with 34% (29/85) of them in the low PhA group and 66% (56/85) of them in the high PhA group. As shown in Table 1, women in the low PhA group were significantly older than those in the high PhA group (*P*=.001). As anticipated, the group with a low PhA had a lower PhA (*P*<.001) and a higher IR (*P*<.001) than those in the high PhA group. In the high PhA group, PhA ranged from 4.2° to 7.0°, and IR ranged from 0.69 to 0.84. In the low PhA group, PhA ranged from 2.5° to 4.1°, and IR ranged from 0.83 to 0.89. No significant between-group differences in height, weight, or BMI were observed. Approximately 52% (44/85) of participants were considered overweight or obese with a BMI of ≥25.9 kg/m^2.

Table . Participants' characteristics and bioelectric impedance analysis (n=85).

Characteristics	Total (n=85), mean (SD)	Low phase angle (n=29), mean (SD)	High phase angle (n=56), mean (SD)	*P* value[a]	Effect size[b]
Age (years)	75.0 (7.2)	79.6 (8.2)	71.0 (5.6)	.001	0.43
Height (cm)	162.6 (6.1)	162.0 (6.0)	163.0 (6.2)	.52	0.09
Weight (kg)	71.0 (15.0)	71.9 (15.7)	71.8 (14.8)	.81	0.03
BMI (kg/m^2)	26.8 (5.0)	27.3 (5.2)	26.9 (4.9)	.48	0.09
Body fat (%)	33 (10)	38 (9)	31 (10)	.003	0.40
Phase angle (°)	4.4 (0.8)	3.6 (0.4)	4.8 (0.6)	<.001	1.00
Impedance ratio	0.82 (0.03)	0.85 (0.01)	0.81 (0.03)	<.001	0.92

[a] *P* values refer to the difference between the groups (Mann-Whitney *U* test).

[b] Effect sizes are provided as rank biserial correlation, whereby 0.10, 0.30, and 0.50 represent small, medium, or large effects, respectively.

Table 2 shows that women in the low PhA group demonstrated poorer physical function than those in the high PhA group. Specifically, the low PhA group had significantly lower average HGS (*P*=.007) and STS scores (*P*<.001). The low PhA group also showed significantly higher balance scores (*P*=.03) and Short FES-I scores (*P*=.001) than the high PhA group.

Table . Physical function parameters (n=85).

Variable	Low phase angle (n=29), mean (SD)	High phase angle (n=56), mean (SD)	*P* value[a]	Effect size[b]
Average handgrip strength (kg)	17.6 (4.7)	21.4 (6.2)	.007	0.36
Sit-to-stand score	10.7 (6.2)	16.0 (5.5)	<.001	0.49
BTrackS balance score	37.1 (21.1)	26.6 (9.5)	.03	0.30
Short FES-I[c] score	11.6 (4.2)	9.3 (3.3)	.001	0.42

[a] *P* values refer to the difference between the groups (Mann-Whitney *U* test).

[b] Effect sizes are provided as rank biserial correlation, whereby 0.10, 0.30, and 0.50 represent small, medium, or large effects, respectively.

[c] Short FES-I: Short Falls Efficacy Scale–International.

Kendall rank correlation analysis (Table 3) revealed significant inverse correlations between PhA and age (τb=–0.37; *P*<.001) and between PhA and IR (τb=−0.79; *P*<.001). Significant moderate direct correlations were observed between PhA and STS scores (τb=0.34; *P*<.001) and between PhA and average HGS (τb=0.22; *P*=.002). Small but significant correlations were found between PhA and balance scores (τb=−0.19; *P*=.01) and between PhA and Short FES-I scores (τb=−0.25; *P*=.001). IR had a significant and direct relationship with age (τb=0.37; *P*<.001) and Short FES-I scores (τb=0.26; *P*<.001). IR had a significant and inverse relationship with average HGS (τb=−0.21; *P*=.004) and STS scores (τb=−0.33; *P*<.001).

Table . Relationships of phase angle and impedance ratio with participant characteristics (n=85).

Variable	Phase angle		Impedance ratio	
	τb[a]	*P* value[b]	τb	*P* value
Age	−0.37	<.001	0.37	<.001
Height	0.09	.25	0.02	.81
Weight	0.06	.39	−0.03	.70
BMI	0.03	.64	−0.04	.60
Impedence ratio	−0.79	<.001	—[c]	—
Average handgrip strength	0.22	.002	−0.21	.004
Sit-to-stand score	0.34	<.001	−0.33	<.001
BTrackS balance score	−0.19	.01	0.18	.02
Short FES-I[d] score	−0.25	.001	0.26	<.001

[a] τb=Kendall τ b correlation coefficient.

[b] *P* values refer to the correlation between variables.

[c] Not available.

[d] Short FES-I: Short Falls Efficacy Scale–International.

After controlling for age (Table 4), strong direct correlations were observed between PhA and average HGS (τb=0.75; *P*=.003) and between PhA and STS scores (τb=0.76; *P*=.002). A large direct correlation was observed between IR and Short FES-I scores (τb=0.46; *P*=.07). A moderate inverse correlation was found between IR and STS scores (τb=−0.32; *P*=.20).

Table . Partial correlations between phase angle and impedance ratio (n=85).

Variable	Phase angle		Impedance ratio	
	τb[a]	*P* value[b]	τb	*P* value
Height	0.50	.04	−0.06	.81
Weight	0.21	.41	0.25	.31
BMI	0.10	.68	0.26	.29
Average handgrip strength	0.75	.003	−0.003	.99
Sit-to-stand score	0.76	.002	−0.32	.20
BTrackS balance score	−0.04	.87	0.11	.66
Short FES-I[c] score	−0.24	.33	0.46	.07

[a] τb=Kendall’s τ b partial correlation coefficient.

[b] *P* values refer to the correlation between variables, controlling for age.

[c] Short FES-I: Short Falls Efficacy Scale–International.

Discussion

Principal Results

The purpose of this study was to examine the relationships among HGS, STS score, balance, fear of falling, PhA, and IR in older adult women classified as having low or high PhA. When comparing physical function between high and low PhA groups, our results demonstrate significant differences in physical function between the high and low PhA groups. We observed a significantly lower IR within the high PhA group (*P*<.001; r_{rb}=0.92) and a strong negative correlation between PhA and IR (τb=−0.79; *P*<.001). The low PhA group had a significantly higher IR (*P*<.001; r_{rb}=0.92) and lower PhA (*P*<.001; r_{rb}=1.0).

When comparing physical function between the high and low PhA groups, our results demonstrate significant differences in physical function between groups. The low PhA group showed significantly lower HGS (*P*=.007; r_{rb}=0.36), STS scores (*P*<.001; r_{rb}=0.49), and higher balance scores (*P*=.03; r_{rb}=0.30) than the high PhA group. Additionally, when examining relationships among PhA, IR, and physical function on controlling for age, moderate correlations were observed between PhA and HGS (τb=0.75; *P*=.003) and STS scores (τb=0.76; *P*=.002). However, balance scores (τb=−0.04; *P*=.87) and fear of falling (τb=−0.24; *P*=.33) showed only weak correlations with PhA when controlling for age. The low PhA group demonstrated a significantly higher Short FES-I score than the high PhA group (*P*=.001; r_{rb}=0.42).

Comparison With Previous Literature

Previous literature has demonstrated an increased prevalence of physical dysfunction corresponding with a PhA less than 4.1° in older community-dwelling women, which informed our cutoff value of 4.1° to classify participants as having a low or high PhA [34,38]. Beyond a difference in PhA, the low PhA group also had a significantly lower IR of 0.85 (SD 0.01). This supports previous literature indicating that an IR closer to 1 is indicative of poor cellular health [22]. We observed a significantly lower IR in the high PhA group (Table 1) and a strong negative correlation between PhA and IR (Table 3). This aligns with previous evidence associating both a higher PhA and a lower IR with improved cellular integrity and health [22].

Reduced muscular strength and physical function in older adults has been associated with a lower PhA and higher IR [12,30]. In our study, we did not observe a strong correlation between HGS and PhA (Table 3). This is contrary to previous research, where IR and HGS were significantly correlated (r=0.46; P<.001) when controlling for age [24]. This discrepancy may be due to differences in methodology; Ballarin et al [24] assessed IR among 19-35–year-olds using a 300 kHz/5 kHz frequency ratio, while our study used a 250 kHz/5 kHz frequency ratio and included participants no younger than 60 years. IR is understood to be lower in younger populations [27], and younger populations still experience increases in HGS. This is contrasted by the higher IR and declining HGS experienced by older individuals.

Few studies have examined the relationship between STS score and PhA. Previous studies have instead used the gait speed test to assess physical function [43]. While STS and gait speed tests are not synonymous, both are dynamic multijoint movements that require both muscular strength and balance. This may explain why STS and gait speed performance are consistently observed as strong predictors of PhA in healthy individuals. This aligns with previous studies showing associations between lower limb strength and PhA [44]. Retaining muscle mass and physical function in the lower legs would have a direct impact on the R, X_c, and Z measured by BIA via an increase in muscular tissue and intracellular hydration [45]. A recent systematic review and meta-analysis of randomized controlled trials supports this theory, reporting that resistance training of at least 8 weeks increases PhA in older adults [45]. Furthermore, 6 out of the 7 studies included only involved female participants, which aligns with our sample [45]. Within clinical settings where the risks of conducting an STS test or other physical assessments may outweigh the benefits, BIA may serve as a proxy for skeletal muscle quality and physical functioning. PhA has been shown to change with physical functioning longitudinally, as numerous studies have focused on sarcopenia and frailty regarding PhA [29].

The poorer physical function seen in the low PhA group suggests that a lower PhA reflects diminished skeletal muscle integrity and functionality in older adult women. Balance scores were significantly higher in the low PhA group, which are representative of poor balance and moderate to high fall risk (Table 1). A longitudinal study conducted by Asano et al [13] concluded that lower body strength diminishes with aging, and the observed poor balance score was associated with low PhA. We observed a greater fear of falling in the low PhA group (Table 2), and a moderate correlation between IR and fear of falling (Table 4). One study concluded that in women with osteoporosis, slower walking speed, decreased muscular strength, and greater postural sway were correlated with an increased fear of falling [46]. An increase in the fear of falling is associated with decreased muscular strength, which aligns with our findings [15].

Strengths and Limitations

One of the strengths of this study was the diverse population, including low-income female participants from 4 different racial and ethnic backgrounds. This study also intentionally used portable, accessible, and valid instruments to increase the applicability of the results to clinical practice. However, there are limitations to the study that should be considered. The main findings were raw BIA variables that are directly influenced by fluid distribution throughout the body, as the different frequencies used in calculated IR allow for the assessment of ECW and ICW. Hydration status may thus be a confounding variable as it was not assessed or controlled, although all testing occurred in the late morning for all participants after they were encouraged to void their bladders. In addition, the nonnormal data distribution was accounted for by using robust nonparametric tests during statistical analysis.

Implications and Future Directions

BIA is a brisk assessment that can be used in older adults to evaluate body composition and cellular health. This study concluded that PhA and IR are both linked to physical function and fear of falling in older women but associate differently when controlling for age. Although they are both measures of cellular health, our study demonstrates how PhA and IR differ in their relationship with physical function and fear of falling. As BIA continues to grow as a clinical assessment, there is a need to better understand how its measures relate to other assessments. A higher IR closer to 1 is indicative of poorer cellular health, which was observed in our low PhA group [22], and is also associated with diminished physical function and a heightened fear of falling in this study. Our study aligns with previous research reporting a strong inverse correlation between PhA and IR [21]; yet, there has been a lack of research investigating IR and its relationship with physical function. IR is a direct reflection of hydration status; therefore, we believe that IR is a helpful passive assessment to use, given the noninvasive and simple nature of the tool. More research on IR in older adults is needed to further examine its relationships with functional assessments.

Aging is associated with a change in body composition and decline in physical function. Therefore, PhA may reflect skeletal muscle health and can be assessed along with physical function. Based on this study, a PhA of ≤4.1° would be indicative of decreased physical function in older women, and an intervention can be implemented to help improve PhA. Additionally, in instances where physical function assessments cannot take place, measuring PhA and IR may be valuable as indicators of physical function for that period. Our results suggest that muscular strength assessments such as HGS and STS may be more closely related to PhA than balance in older adult women. STS scores are indicative of lower body strength, suggesting that lower body strength may be an important factor in PhA and IR. Balance scores can be indicative of muscle integrity, which is associated with frailty, sarcopenia, and malnutrition [29]. It is plausible that lower body strength may be particularly important when evaluating cellular health and physical function via bioimpedance parameters in older women, but more research is needed.

While physical function assessments are commonplace among older adults, psychological and physiological assessments should also be considered. Our results show that the fear of falling has an inverse relationship with physical function and PhA and a direct relationship with IR. Future research should further examine the relationships among fear of falling, physical function, PhA, and IR as they change over time. Understanding how these variables influence each other may aid in designing interventions to improve the health and quality of life of older adults.

Conclusions

Our results indicate that low PhA (≤4.1°) and high IR are linked with poorer physical function in older women, particularly for HGS and STS ability. PhA and IR are variables that can be assessed regularly during routine checkups and provide an indication of physical function and cellular health. Despite being indicative of cellular integrity and health, IR has not been widely studied in older adults. Assessing hydration status along with BIA measurements may help strengthen the design of future studies. Future research should also compare IR and physical function to our results and assess changes in IR longitudinally within older adults.

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Data Availability

The data that support the results of this study are available from the corresponding author upon reasonable request.

Authors' Contributions

DAS, JRS, JP, and LT contributed to conceptualization. JRS, JP, and LT contributed to the methodology. DAS, JRS, JP, DHF, and LT contributed to the investigation. DAS, KL, DHF, and LT contributed to data curation. DAS, JRS, and KL contributed to formal analysis. DAS and KL contributed to writing (original draft preparation). DAS, JRS, KL, JP, DHF, and LT contributed to writing (review and editing). JRS, JP, DHF, and LT contributed to supervision. LT contributed to project administration and funding acquisition. All authors read and agreed to the version of the manuscript intended for publication.

Conflicts of Interest

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References

1. Fact sheet: aging in the United States. Population Reference Bureau. 2024 Jan 9. URL: https://www.prb.org/resources/fact-sheet-aging-in-the-united-states/ [accessed 2024-02-14]
2. Older adult fall prevention. Centers for Disease Control and Prevention. 2023. URL: https://www.cdc.gov/falls/facts.html [accessed 2024-02-14]
3. Mayhew AJ, Amog K, Phillips S, et al. The prevalence of sarcopenia in community-dwelling older adults, an exploration of differences between studies and within definitions: a systematic review and meta-analyses. Age Ageing 2019 Jan 1;48(1):48-56. [doi: 10.1093/ageing/afy106] [Medline: 30052707]
4. Rosenberg IH. Sarcopenia: origins and clinical relevance. J Nutr 1997 May;127(5 Suppl):990S-991S. [doi: 10.1093/jn/127.5.990S] [Medline: 9164280]
5. Dugan SA, Gabriel KP, Lange-Maia BS, Karvonen-Gutierrez C. Physical activity and physical function: moving and aging. Obstet Gynecol Clin North Am 2018 Dec;45(4):723-736. [doi: 10.1016/j.ogc.2018.07.009] [Medline: 30401553]

6. Murdock DJ, Wu N, Grimsby JS, et al. The prevalence of low muscle mass associated with obesity in the USA. Skelet Muscle 2022 Dec 21;12(1):26. [doi: 10.1186/s13395-022-00309-5] [Medline: 36539856]
7. Cadore EL, Pinto RS, Bottaro M, Izquierdo M. Strength and endurance training prescription in healthy and frail elderly. Aging Dis 2014 Jun;5(3):183-195. [doi: 10.14336/AD.2014.0500183] [Medline: 24900941]
8. Campbell AJ, Buchner DM. Unstable disability and the fluctuations of frailty. Age Ageing 1997 Jul;26(4):315-318. [doi: 10.1093/ageing/26.4.315] [Medline: 9271296]
9. Cawthon PM, Blackwell TL, Cauley J, et al. Evaluation of the usefulness of consensus definitions of sarcopenia in older men: results from the observational Osteoporotic Fractures in Men cohort study. J Am Geriatr Soc 2015 Nov;63(11):2247-2259. [doi: 10.1111/jgs.13788] [Medline: 26502831]
10. Uemura K, Doi T, Tsutsumimoto K, et al. Predictivity of bioimpedance phase angle for incident disability in older adults. J Cachexia Sarcopenia Muscle 2020 Feb;11(1):46-54. [doi: 10.1002/jcsm.12492] [Medline: 31436391]
11. Iwasaka C, Yamada Y, Nishida Y, et al. Association of appendicular extracellular-to-intracellular water ratio with age, muscle strength, and physical activity in 8,018 community-dwelling middle-aged and older adults. Arch Gerontol Geriatr 2023 May;108:104931. [doi: 10.1016/j.archger.2023.104931] [Medline: 36701946]
12. Unterberger S, Aschauer R, Zöhrer PA, et al. Association of bioelectrical impedance phase angle with physical performance and nutrient intake of older adults. Nutrients 2023 Mar 17;15(6):1458. [doi: 10.3390/nu15061458] [Medline: 36986185]
13. Asano Y, Tsuji T, Kim M, et al. Cross-sectional and longitudinal study of the relationship between phase angle and physical function in older adults. Geriatr Gerontol Int 2023 Feb;23(2):141-147. [doi: 10.1111/ggi.14532] [Medline: 36655478]
14. Howland J, Lachman ME, Peterson EW, Cote J, Kasten L, Jette A. Covariates of fear of falling and associated activity curtailment. Gerontologist 1998 Oct;38(5):549-555. [doi: 10.1093/geront/38.5.549] [Medline: 9803643]
15. Brouwer B, Musselman K, Culham E. Physical function and health status among seniors with and without a fear of falling. Gerontology 2004;50(3):135-141. [doi: 10.1159/000076771] [Medline: 15114034]
16. Kempen G, Yardley L, van Haastregt JCM, et al. The Short FES-I: a shortened version of the falls efficacy scale-International to assess fear of falling. Age Ageing 2008 Jan;37(1):45-50. [doi: 10.1093/ageing/afm157] [Medline: 18032400]
17. Bittencourt DCD, Schieferdecker MEM, Macedo DS, Biesek S, Gomes ARS, Rabito EI. Phase angle reflects loss of functionality in older women. J Nutr Health Aging 2020;24(3):251-254. [doi: 10.1007/s12603-020-1324-5] [Medline: 32115604]
18. Poverty thresholds. United States Census Bureau. 2020. URL: https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html [accessed 2024-02-14]
19. Genton L, Norman K, Spoerri A, et al. Bioimpedance-derived phase angle and mortality among older people. Rejuvenation Res 2017 Apr;20(2):118-124. [doi: 10.1089/rej.2016.1879] [Medline: 27796163]
20. Sardinha LB. Physiology of exercise and phase angle: another look at BIA. Eur J Clin Nutr 2018 Sep;72(9):1323-1327. [doi: 10.1038/s41430-018-0215-x] [Medline: 30185857]
21. Ballarin G, Scalfi L, Monfrecola F, et al. Body composition and bioelectrical-impedance-analysis-derived raw variables in pole dancers. Int J Environ Res Public Health 2021 Nov 30;18(23):12638. [doi: 10.3390/ijerph182312638] [Medline: 34886363]
22. Rinninella E, Cintoni M, Addolorato G, et al. Phase angle and impedance ratio: two specular ways to analyze body composition. Ann Clin Nutr 2018;1(1). [doi: 10.33582/2638-1370/1003]
23. Alicante P, Di Gregorio A, Sacco A, Monfrecola F, Scalfi L, Valerio G. Association between handgrip strength and raw BIA variables in adolescents aged 14-17 years. In: Proceedings of the 8th International Conference on Sport Sciences Research and Technology Support (icSPORTS2020): SCITEPRESS; 2020. [doi: 10.5220/0010066501390143]
24. Ballarin G, Monfrecola F, Alicante P, et al. Raw bioelectrical impedance analysis variables (impedance ratio and phase angle) and physical fitness in cross-fit® athletes. In: Proceedings of the 8th International Conference on Sport Sciences Research and Technology Support (icSPORTS2020): SCITEPRESS; 2020. [doi: 10.5220/0010066001030108]
25. Ward LC, Brantlov S. Bioimpedance basics and phase angle fundamentals. Rev Endocr Metab Disord 2023 Jun;24(3):381-391. [doi: 10.1007/s11154-022-09780-3] [Medline: 36749540]
26. Martins PC, de Lima TR, Silva AM, Silva DAS. Association of phase angle with muscle strength and aerobic fitness in different populations: a systematic review. Nutrition 2022 Jan;93:111489. [doi: 10.1016/j.nut.2021.111489] [Medline: 34688022]
27. Di Vincenzo O, Marra M, Di Gregorio A, Pasanisi F, Scalfi L. Bioelectrical impedance analysis (BIA)-derived phase angle in sarcopenia: a systematic review. Clin Nutr 2021 May;40(5):3052-3061. [doi: 10.1016/j.clnu.2020.10.048] [Medline: 33183880]
28. Garlini LM, Alves FD, Ceretta LB, Perry IS, Souza GC, Clausell NO. Phase angle and mortality: a systematic review. Eur J Clin Nutr 2019 Apr;73(4):495-508. [doi: 10.1038/s41430-018-0159-1] [Medline: 29695763]
29. Norman K, Herpich C, Müller-Werdan U. Role of phase angle in older adults with focus on the geriatric syndromes sarcopenia and frailty. Rev Endocr Metab Disord 2023 Jun;24(3):429-437. [doi: 10.1007/s11154-022-09772-3] [Medline: 36456777]

30. Norman K, Wirth R, Neubauer M, Eckardt R, Stobäus N. The bioimpedance phase angle predicts low muscle strength, impaired quality of life, and increased mortality in old patients with cancer. J Am Med Dir Assoc 2015 Feb;16(2):173. [doi: 10.1016/j.jamda.2014.10.024] [Medline: 25499428]
31. Kawakami W, Umehara T, Iwamoto Y, Takahashi M, Katayama N. Phase angle is associated with handgrip strength in older patients with heart failure. Ann Rehabil Med 2023 Apr;47(2):129-137. [doi: 10.5535/arm.22138] [Medline: 36944350]
32. Bellido D, García-García C, Talluri A, Lukaski HC, García-Almeida JM. Future lines of research on phase angle: strengths and limitations. Rev Endocr Metab Disord 2023 Jun;24(3):563-583. [doi: 10.1007/s11154-023-09803-7] [Medline: 37043140]
33. Ding Y, Chang L, Zhang H, Wang S. Predictive value of phase angle in sarcopenia in patients on maintenance hemodialysis. Nutrition 2022 Feb;94:111527. [doi: 10.1016/j.nut.2021.111527] [Medline: 34896667]
34. Rosas-Carrasco O, Ruiz-Valenzuela RE, López-Teros MT. Phase angle cut-off points and their association with sarcopenia and frailty in adults of 50-64 years old and older adults in Mexico City. Front Med (Lausanne) 2021 Mar 15;8:617126. [doi: 10.3389/fmed.2021.617126] [Medline: 33791322]
35. Germano ML, Dos Santos Gomes C, Azevedo IG, Fernandes J, de Medeiros Freitas RV, Guerra RO. Relationship between phase angle and physical performance measures in community-dwelling older adults. Exp Gerontol 2021 Sep;152:111466. [doi: 10.1016/j.exger.2021.111466] [Medline: 34242686]
36. Thiamwong L, Stout JR, Park JH, Yan X. Technology-based fall risk assessments for older adults in low-income settings: protocol for a cross-sectional study. JMIR Res Protoc 2021 Apr 7;10(4):e27381. [doi: 10.2196/27381] [Medline: 33825688]
37. Böhm P, Peña-Casanova J, Gramunt N, Manero RM, Terrón C, Quiñones-Ubeda S. Spanish version of the Memory Impairment Screen (MIS): normative data and discriminant validity. Neurologia 2005 Oct;20(8):402-411. [Medline: 16217689]
38. Wu H, Ding P, Wu J, Yang P, Tian Y, Zhao Q. Phase angle derived from bioelectrical impedance analysis as a marker for predicting sarcopenia. Front Nutr 2022;9:1060224. [doi: 10.3389/fnut.2022.1060224] [Medline: 36590205]
39. Buckinx F, Reginster JY, Dardenne N, et al. Concordance between muscle mass assessed by bioelectrical impedance analysis and by dual energy x-ray absorptiometry: a cross-sectional study. BMC Musculoskelet Disord 2015 Mar 18;16:60. [doi: 10.1186/s12891-015-0510-9] [Medline: 25887598]
40. Peolsson A, Hedlund R, Oberg B. Intra- and inter-tester reliability and reference values for hand strength. J Rehabil Med 2001 Jan;33(1):36-41. [doi: 10.1080/165019701300006524] [Medline: 11480468]
41. Goble DJ, Baweja HS. Postural sway normative data across the adult lifespan: results from 6280 individuals on the balance tracking system balance test. Geriatr Gerontol Int 2018 Aug;18(8):1225-1229. [doi: 10.1111/ggi.13452] [Medline: 29897159]
42. Yee XS, Ng YS, Allen JC, et al. Performance on sit-to-stand tests in relation to measures of functional fitness and sarcopenia diagnosis in community-dwelling older adults. Eur Rev Aging Phys Act 2021 Jan 8;18(1):1. [doi: 10.1186/s11556-020-00255-5] [Medline: 33419399]
43. Hirano Y, Yamada Y, Matsui Y, Ota S, Arai H. Lower limb muscle quality and phase angle contribute to the reduced walking speed among older adults. Geriatr Gerontol Int 2022 Aug;22(8):603-609. [doi: 10.1111/ggi.14423] [Medline: 35781752]
44. Oliveira R, Leão C, Silva AF, et al. Comparisons between bioelectrical impedance variables, functional tests and blood markers based on BMI in older women and their association with phase angle. Int J Environ Res Public Health 2022 Jun 3;19(11):6851. [doi: 10.3390/ijerph19116851] [Medline: 35682434]
45. Campa F, Colognesi LA, Moro T, et al. Effect of resistance training on bioelectrical phase angle in older adults: a systematic review with meta-analysis of randomized controlled trials. Rev Endocr Metab Disord 2023 Jun;24(3):439-449. [doi: 10.1007/s11154-022-09747-4] [Medline: 35918569]
46. Hübscher M, Vogt L, Schmidt K, Fink M, Banzer W. Perceived pain, fear of falling and physical function in women with osteoporosis. Gait Posture 2010 Jul;32(3):383-385. [doi: 10.1016/j.gaitpost.2010.06.018] [Medline: 20663672]

Abbreviations

BIA: bioelectrical impedance analysis
ECW: extracellular water
HGS: handgrip strength
ICC: intraclass correlation coefficient
ICW: intracellular water
IR: impedance ratio
PhA: phase angle
R: resistance
Short FES-I: Short Falls Efficacy Scale–International
STS: sit-to-stand
X_c: reactance
Z: impedance

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Development and Usability Testing of a Mobile App–Based Clinical Decision Support System for Delirium: Randomized Crossover Trial

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Abstract

Background: The 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium (3D-CAM) is an instrument specially developed for the assessment of delirium in general wards, with high reported sensitivity and specificity. However, the use of the 3D-CAM by bedside nurses in routine practice showed relatively poor usability, with multiple human errors during assessment.

Objective: This study aimed to develop a mobile app–based delirium assessment tool based on the 3D-CAM and evaluate its usability among older patients by bedside nurses.

Methods: The Delirium Assessment Tool With Decision Support Based on the 3D-CAM (3D-DST) was developed to address existing issues of the 3D-CAM and optimize the assessment process. Following a randomized crossover design, questionnaires were used to evaluate the usability of the 3D-DST among older adults by bedside nurses. Meanwhile, the performances of both the 3D-DST and the 3D-CAM paper version, including the assessment completion rate, time required for completing the assessment, and the number of human errors made by nurses during assessment, were recorded, and their differences were compared.

Results: The 3D-DST included 3 assessment modules, 9 evaluation interfaces, and 16 results interfaces, with built-in reminders to guide nurses in completing the delirium assessment. In the usability testing, a total of 432 delirium assessments (216 pairs) on 148 older adults were performed by 72 bedside nurses with the 3D-CAM paper version and the 3D-DST. Compared to the 3D-CAM paper version, the mean usability score was significantly higher when using the 3D-DST (4.35 vs 3.40; *P*<.001). The median scores of the 6 domains of the satisfactory evaluation questionnaire for nurses using the 3D-CAM paper version and the 3D-DST were above 2.83 and 4.33 points, respectively (*P*<.001). The average time for completing the assessment reduced by 2.1 minutes (4.4 vs 2.3 min; *P*<.001) when the 3D-DST was used.

Conclusions: This study demonstrated that the 3D-DST significantly improved the efficiency of delirium assessment and was considered highly acceptable by bedside nurses.

Trial Registration: Chinese Clinical Trial Registry, ChiCTR-IOR-17010368; https://www.chictr.org.cn/showproj.html?proj=17671

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KEYWORDS

delirium; 3D-CAM; older adults; clinical decision support system; nurse; 3-Minute Diagnostic Interview for Confusion Assessment Method-Defined Delirium

Introduction

Delirium is a common complication that is highly prevalent among hospitalized older adults; it can affect up to 40% of hospitalized older patients [1,2]. Delirium is associated with many adverse outcomes, including cognitive and functional impairment, increased hospital stay, care burden, and mortality, and therefore leads to increased care needs and poor prognosis [3,4]. The severity of the adverse consequences of delirium are positively correlated with the severity and duration of delirium [5]. Therefore, early recognition of delirium is essential for timely management of delirium to improve the patient's prognosis [6].

Although many clinical guidelines and representative societies have recommended the use of standardized assessment tools for daily delirium screening in clinical practice, delirium is still poorly recognized among hospitalized older adults [6,7]. A previous study has shown that up to 66% of older adults with delirium went unrecognized in routine practice [8]. The possible reasons for underdiagnoses of delirium include communication barrier, inadequate use of the screening tools, and a lack of education on and conceptual understanding of delirium [9].

The Confusion Assessment Method (CAM) has been used as the reference standard for delirium screening [10]. However, the use of the CAM to assess delirium requires a combination of cognitive testing and subjective judgment based on clinical experience. Lemiengre et al [11] found that the sensitivity on the daily use of the CAM by bedside nurses was only 30%. Therefore, to overcome the feasibility issues associated with the use of the CAM, Marcantonio et al [12] developed the 3-Minute Diagnostic Interview for CAM-Defined Delirium (3D-CAM) based on the key features of the CAM and simplified the evaluation process. The 3D-CAM was perceived as easy to use, and it had a sensitivity of 92% to 100% and a specificity of 88% to 94% among studies that were tested in different ethnic groups [12-15]. Kuczmarska et al [15] has identified that the 3D-CAM is appropriate for delirium assessment in general wards.

However, a previous study has shown that the use of the 3D-CAM by bedside nurses in routine practice demonstrated relatively poor usability, with multiple errors (such as human error, misunderstanding of item content, and incomplete or missing nursing records) during assessment [16]. The assessment of alteration on attention and thinking must be combined with cognitive assessment. During the process, nurses need to memorize, calculate, and make a judgment according to the patient’s response, which is prone to human errors. Meanwhile, the patient’s consciousness status needs to be compared with the assessment results at admission by reviewing the patient’s medical records. With these identified challenges, nurses often fail to complete the assessment successfully due to communication problems and difficulties in finding or loss of related materials. Moreover, due to the limited knowledge level on delirium among clinical nurses, adding prompts or cues to the items can effectively improve nurses’ identification of delirium, in addition to providing training on basic delirium knowledge before the use of the 3D-CAM [16]. Therefore, there is an urgent need to develop and adopt innovative ways to promote prompt delirium assessment in routine practice both effectively and accurately.

Several studies have reported that a clinical decision support system (CDSS) with some degree of autonomy may help solve this issue and improve the accuracy and adequacy of delirium assessment among bedside nurses [17,18]. Marcantonio et al [19] developed a brief app-based delirium identification tool, and it has shown good performance. Based on the Confusion Assessment Method for Intensive Care Unit (CAM-ICU), mobile apps have also been developed for delirium screening of patients in intensive care units (ICUs), and they showed acceptable usability and accuracy when used by bedside nurses [20-22]. Therefore, in this study, we aimed to develop the Delirium Assessment Tool With Decision Support Function Based on the 3D-CAM (3D-DST) and to evaluate its usability among older patients by bedside nurses.

Methods

Ethical Considerations

The research protocol and secondary data analysis were approved by the institutional review committee of Capital Medical University (2015SY49). This was a substudy under a clinical trial, which was registered at the Chinese Clinical Registry (ChiCTR-IOR-17,010,368). Verbal informed consent was obtained from each participant before the start of the program, and participants had the right to withdraw during the study. The data were anonymized. The study protocol was safe and reliable and did not provide any compensation to the participants.

Design and Development of the 3D-DST

Previous Work

The 3D-CAM was translated into Chinese in a previous study and validated by nurse researchers; it showed acceptable sensitivity and specificity among hospitalized Chinese older patients [23].

Phase 1: Analysis of Problems in the Use of the 3D-CAM Paper Version

The task walkthrough method was used to fully address the end users’ needs and achieve the overall goal of automatic delirium evaluation [16].

Phase 2: Design of the 3D-DST

In this phase, we first formed a multidisciplinary team that included experts with rich experience in delirium assessment. Bedside nurses, nursing researchers, software engineers, and user interface designers who were specialized in developing nursing information systems (NISs) were involved in the designing phase. The 3D-DST was designed and developed following the American Medical Informatics Association usability design principle [24]. Details of the design principle are shown in Multimedia Appendix 1.

Evaluation Process Analysis and Optimization of the 3D-DST

Based on the evaluation content and rules of the original 3D-CAM, this study scrutinized and analyzed the 3D-CAM evaluation process, identified the best path, and reoptimized and standardized the 3D-CAM evaluation process. By optimizing the 3D-CAM evaluation process, only the necessary paths to support the delirium evaluation were reserved, unnecessary links were eliminated, and the assessment was standardized to reduce intermediate errors; , thus, a clinical decision-making system for delirium screening was established. Automatic evaluation logic jumps were incorporated into the system design according to the evaluation rules. Based on the problems identified by bedside nurses and the overall goals of the system, the key functional modules of the 3D-DST were initially drafted in mind-mapping software (Xmind software, version: 3.7.4.0; XMIND LTD).

User Interface Design of the 3D-DST

Overview

The interface design was completed in several steps. First, we used AxureRP (Axure Rapid Prototyping) to draft the logical diagrams, workflow, functional components, and user interfaces of the 3D-DST. Second, we made a web page to facilitate communication with engineers and team members. This was achieved via WuliHub (a domestic data hosting and sharing platform), and the interface prototype diagram and interaction components drawn by AxureRP were uploaded into this web browser–based demonstration scheme. Via WuliHub, a set of HTML files were generated based on the interface prototypes and interaction schemes drawn by AxureRP; they were compressed and uploaded to the platform for easy sharing. Third, following the American Medical Informatics Association interface design principle, the order of the evaluation content of each interface was determined based on the evaluation content and the optimal evaluation process of the 3D-DST. Finally, the prototype design of the evaluation interface of the 3D-DST was completed with the identified functions, including evaluator registration, log-in authentication, and user log out. Corresponding functional assessment modules were also developed, along with the result-reporting interface. The 3D-DST was designed by following the existing delirium assessment system [23], with easy access and a friendly display; for example, the patient's identification was obtained by scanning their wristband, and different color selection, buttons, and information composition were used to increase its feasibility and usability.

Phase 3: Architecture and Development of the 3D-DST

In this phase, the system architecture, databases related to personal information and assessment data, and the user interfaces were identified. The 3D-DST was developed to fit on Android-compatible devices (Huawei nova 3), as the personal digital assistant used in clinical practice was largely based on the Android system rather than the iOS system in China.

We used Java, Spring Boot, and RouYi-Vue to program the backend framework and Vue for the front-end framework. Mysql was used to formulate the databases. GitLab and Docker were used to release the 3D-DST. To make the 3D-DST system more stable, the model-view-viewmodel (MVVM) was used as the architecture scheme. The synchronization between view and model was completely automatic without human interference, the data maintenance was completely managed by the MVVM, and the operating environments were Linux and Windows [25,26]. To maintain information security, the 3D-DST set a cookie scheme with a time limit. The users needed to log in and verify their identity again when the cookie expired.

Usability Evaluation of the 3D-DST

Overview

The usability of the 3D-DST was evaluated using the acceptance questionnaire, and the results were compared to the 3D-CAM paper version when it was used by bedside nurses. The questionnaire included 6 domains regarding usability: perceived usefulness, ease of use, ease of learning, trustworthiness, intention to use, and satisfaction. The performance of the app was evaluated on 4 domains and compared to that of the 3D-CAM paper version, which included the successful completion rate of delirium assessment (proportion of nurses who completed the assessment correctly when they used the 3D-CAM paper version and the 3D-DST), evaluation completion time (time used to complete the assessment), the number of mistakes made during assessment against the results from a researcher, and satisfactory evaluation using an acceptance questionnaire.

Design, Setting, and Participants

This study was conducted among 72 bedside nurses from 3 tertiary hospitals in Beijing, China. Eligible patients from 3 internal medical wards (neurology, respiratory, and cardiology) and 1 surgical ward (orthopedic) of the study hospitals were assessed by participating bedside nurses using both the 3D-DST and the original 3D-CAM paper version. All participating patients and bedside nurses provided informed consent before study initiation.

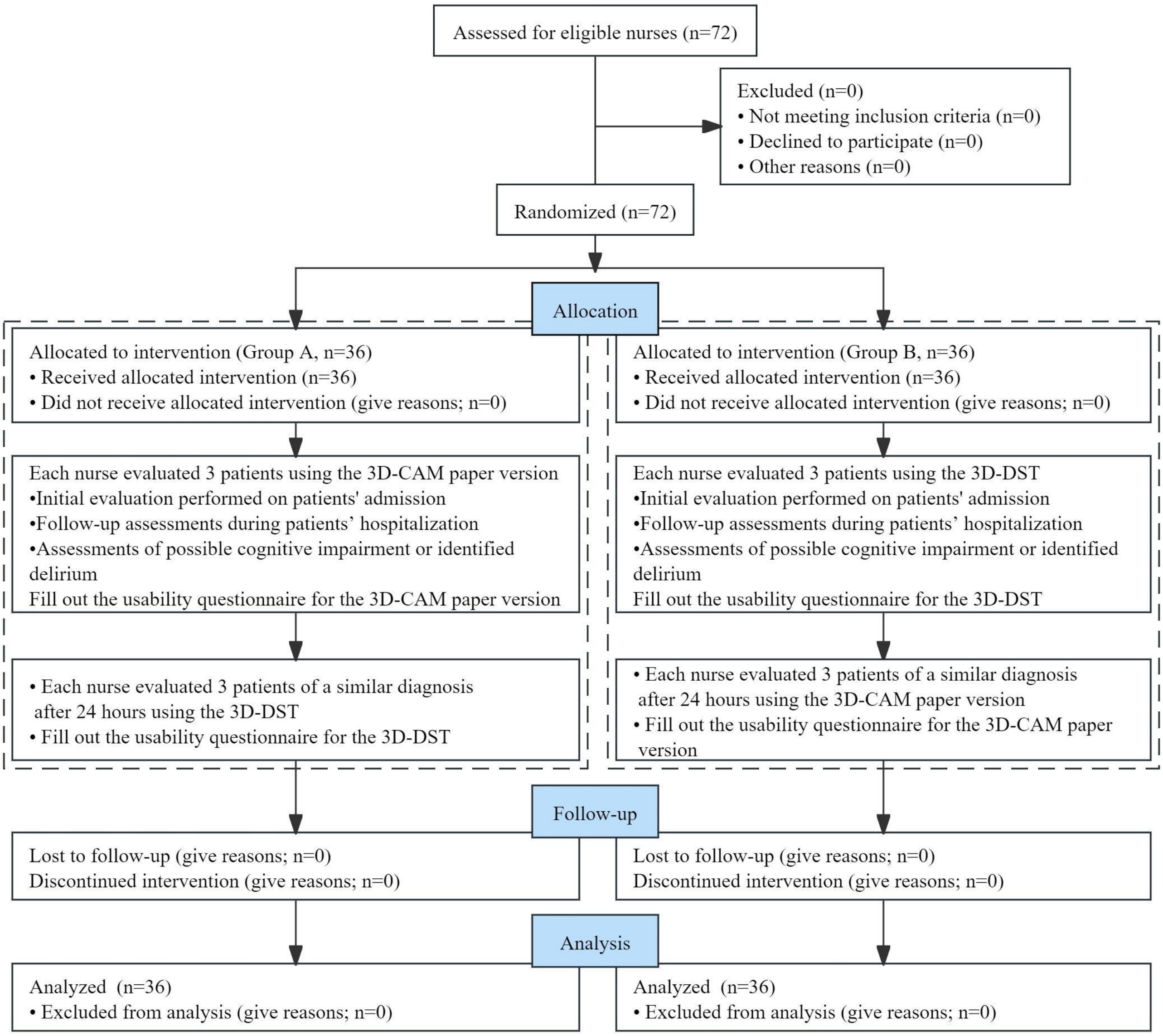
Following convenient sampling, bedside nurses who met the following criteria were included in the usability testing phase: (1) registered nurse with a valid license; (2) had more than 1 year of working experience and had been working continuously in their department for more than 3 months; and (3) willing to participate in this research. Hospitalized older adults who were aged 65 years or older and could communicate effectively in Mandarin were included in the study, and those with identified severe visual or hearing impairment were excluded from delirium assessment. Nurses who declined to participate during the study period were also excluded from the final analysis.

Usability Evaluation

The usability evaluation of both the 3D-CAM paper version and the 3D-DST was conducted using the usability testing questionnaire designed by Feng et al [27]. The content validity index scores for the 3 areas in the questionnaire (topic suitability, topic importance, and content clarity) were 1.00, 1.00 and 0.96, respectively. Since the dimensions for evaluating the usability of the CAM-ICU and 3D-CAM are similar, the questionnaire can also be used to evaluate the usability of the 3D-CAM. In this study, we revised several items of the questionnaire to make it suitable for the 3D-CAM paper version or the 3D-DST. For example, we changed the item "I think this tool meets the requirements of ICU nurses for a delirium assessment tool" to "I think this tool meets the requirements of nurses for a delirium assessment tool in general wards." In addition, the term "CAM-ICU" in the items evaluating the ease of use was replaced with "3D-CAM." The reliability of the revised questionnaire was tested for overall internal consistency, and the Cronbach α coefficient was 0.907. The questionnaire was rated on a 5-point Likert scale ranging from "1=strongly disagree" to "5=strongly agree." A higher score indicated better user acceptance. The usability evaluation was evaluated on 6 domains: perceived usefulness, ease of use, ease of learning, trustworthiness, intention to use, and user satisfaction. To evaluate the acceptability of the 3D-DST, items to evaluate the interfaces of the app were added to the questionnaire, so the usability questionnaire contained 26 and 43 items for the 3D-CAM paper version and the 3D-DST, respectively.

Before study initiation, researchers used a computer program to generate random numbers and made an assignment sequential table. Eligible bedside nurses were numbered according to the order they participated in. One group of nurses (Group A) used the 3D-CAM paper version first to evaluate 3 patients (initial evaluation at admission and follow-up assessments during the patients' hospitalization, including assessments of possible cognitive impairment or identified delirium). Subsequently, the same group of bedside nurses used the 3D-DST to evaluate patients with a similar admission diagnosis after 24 hours to avoid the impact of short-term memorization on the evaluation process. Conversely, nurses from the other group (Group B) used the 3D-DST first and then the 3D-CAM paper version second to evaluate 2 different sets of patients (3 patients per nurse). Nurses who participated in the study only assessed patients admitted in the wards where they worked. A nurse researcher conducted training sessions for all bedside nurses on the use of the 3D-CAM and the 3D-DST before their assessments; the nurse researcher also selected the eligible patients based on their admission diagnosis prior to being approached. Usability testing of both the 3D-CAM paper version and the 3D-DST was carried out when each set of assessment was completed (Figure 1).

Figure 1. Flowchart of participant recruitment and participation. 3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium; 3D-DST: Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.



Performance of the 3D-DST

During each assessment, 1 experienced nurse researcher observed the performance of bedside nurses and completed the patients' delirium screening using the 3D-CAM paper version at the same time. The successful completion rate of delirium assessments in terms of the proportion of correctly identified delirium, whether using the 3D-CAM paper version or the 3D-DST by bedside nurses, was recorded. In addition, the number of mistakes made during the assessments (compared to the researcher's assessment results) and the evaluation completion time were also recorded for each nurse. Nurses were blinded to the researcher's assessment results.

Sample Size

The highest score for each item of the usability questionnaire was 5 points (the higher the score, the better the usability). We expected that an average score of 4 or more would be achieved when the 3D-DST was used by bedside nurses, which is 1 point higher than the average score of the 3D-CAM paper version. With the SD being 1.0 and α=.05, at least 54 bedside nurses were needed to achieve 90% power. Considering that a quarter of bedside nurses might not be able to complete the study, a final sample of 72 nurses was required for this study.

Data Analysis

SPSS software (version 21.0; IBM Corp) was used to perform the data analysis. Normally distributed variables were presented using the mean and SD, whereas nonnormally distributed variables were presented using the median and range. Categorical variables were presented with frequencies and proportions as appropriate. The χ^2 test or Fisher exact test was used to compare the differences between nurses' baseline data (different age groups, sex, etc) and the evaluation success rate. The comparison of evaluation completion time, the total usability score, and the impact of the sequential use of the 3D-CAM paper version and the 3D-DST between 2 groups were achieved using ANOVA. A nonparametric test was used to test the differences between the scores of each domain of the usability questionnaire and the order of using the 2 types of assessments. *P*<.05 was considered statistically significant.

Results

Design and Development of the 3D-DST

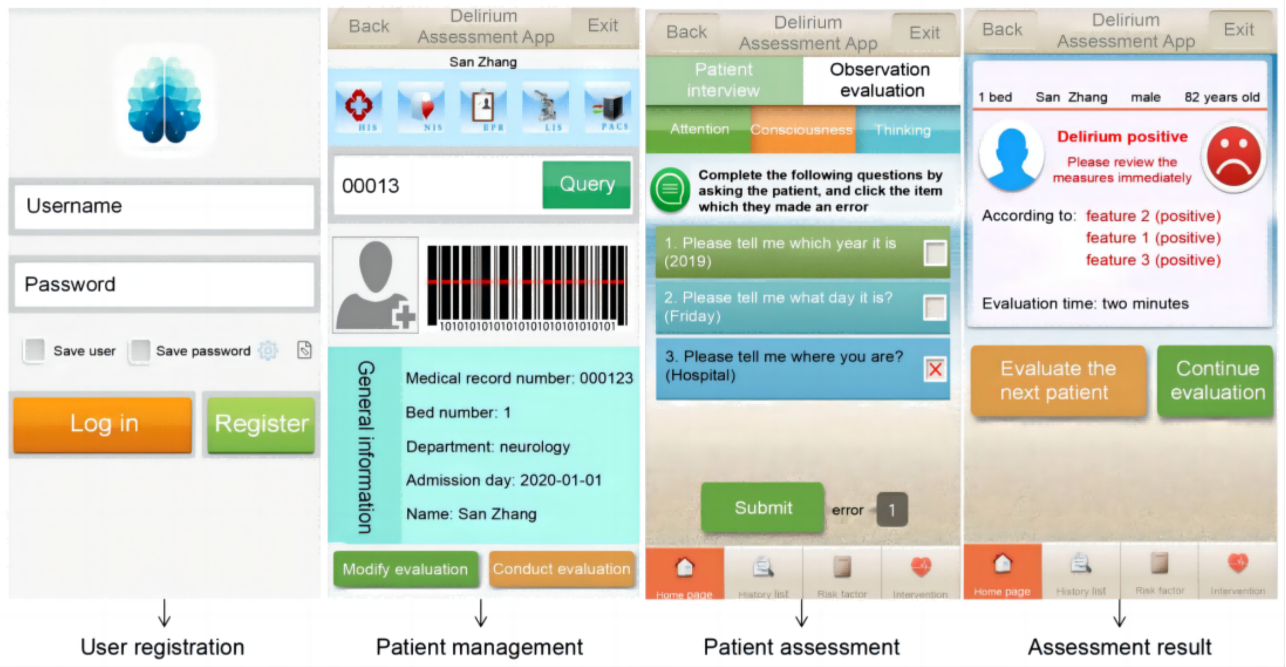
Phase 1: Analysis of Problems in the Use of the 3D-CAM Paper Version

Several problems were identified with the use of the 3D-CAM paper version by bedside nurses, including human errors, insufficient or incorrect understanding of the assessment contents, and incomplete or failed retrieval of the relevant information from the nursing record [16]. In developing the 3D-DST, the delirium evaluation process was simplified as unnecessary steps were automatically omitted after sorting out the procedural results related to specific features of the 3D-CAM. The evaluation processes of the 3D-CAM paper version and the 3D-DST are shown in Multimedia Appendices 2 and 3.

Phase 2: Design of the 3D-DST

The 3D-DST was installed on mobile phones with an Android (8.1.0) system, 128 GB, 8-core processor, and 1.8 GHz. Three evaluation modules were incorporated into the 3D-DST, reflecting the inquiry, observation, and selective evaluations. The evaluation interfaces (Figure 2) of the 3D-DST included 8 evaluation pages and 16 different evaluation result interfaces (3 delirium-positive interfaces and 13 delirium-negative interfaces).

Figure 2. Interfaces of the Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium (3D-DST).



Medical record number: 000123
Bed number: 1
Department: neurology
Admission day: 2020-01-01
Name: San Zhang

Complete the following questions by asking the patient, and click the item which they made an error

1. Please tell me which year it is (2019) ☐
2. Please tell me what day it is? (Friday) ☐
3. Please tell me where you are? (Hospital) ☒

1 bed San Zhang male 82 years old

Delirium positive

Please review the measures immediately

According to: feature 2 (positive)
feature 1 (positive)
feature 3 (positive)

Evaluation time: two minutes

Auxiliary reminders based on the common mistakes reported by nurses in phase 1 were added to the system. In overcoming these burdens, the 3D-DST was developed to include reminders on the correct answers regarding items 1, 2, and 5. Nurses only needed to check whether the patient's response was consistent with the reminder or not. As the 3D-DST can automatically record and retrieve previous evaluation results, item 22 was not displayed in the 3D-DST but was incorporated into the algorithm of the 3D-DST, and the result was generated automatically. To address issues associated with "incorrect understanding of item content," cues were incorporated into the 3D-DST to facilitate better understanding of the contents of related items (11 through 20) during assessment.

In the development of the 3D-DST, we also included functions to automatically retrieve necessary information from the record for comparison, which was incorporated to the 3D-DST. Nurses using the 3D-DST do not need to manually search and compare the previous evaluation results, which could increase the successful completion rate of the assessment.

Usability Evaluation of the 3D-DST

A total of 72 bedside nurses completed the usability testing of the 3D-DST. The demographic characteristics of participating bedside nurses are shown in Table 1. They were mainly female (n=67, 93%), with 44 (61%) nurses holding a bachelor's degree. A total of 148 patients were evaluated by nurses in this study, with 98 (66%) being female and a mean age of 76 (SD 7.18) years.

Table . Demographic characteristics of the participating bedside nurses.

Characteristics		Group A (n=36), n (%)	Group B (n=36), n (%)	*P* value
Age group (years)				.93
	20-30	20 (56)	20 (56)	
	31-47	16 (44)	16 (44)	
Sex				>.99
	Female	33 (92)	34 (9)	
	Male	3 (8)	2 (56)	
Education level				>.99
	Junior college	12 (33)	13 (36)	
	College and above	24 (67)	23 (64)	
Work experience (years)				.71
	<5	15 (42)	16 (44)	
	5-10	11 (31)	9 (25)	
	≥11	10 (28)	11 (31)	

A total of 432 delirium assessments (216 pairs) were performed by the bedside nurses on 148 older adults with the 3D-CAM paper version and the 3D-DST, of which 38 (26%) older adults were confirmed as delirium positive by a nurse researcher using the 3D-CAM paper version.

The mean usability scores of bedside nurses using the 3D-CAM paper version and the 3D-DST were 3.40 (SD 0.43) and 4.35 (SD 0.31), respectively, with the score of the 3D-DST being 0.95 points higher than that of the 3D-CAM paper version (*P*<.001). The median scores of the 6 domains of the satisfactory evaluation questionnaire for nurses using the 3D-CAM paper version and the 3D-DST were above 2.83 points and 4.33 point, respectively. As shown in Table 2, the median scores on the ease of use, ease of learning, and trustworthiness were 1 point higher than the other 3 domains (*P*<.001). The total satisfactory score of the 3D-DST was higher than that of the 3D-CAM paper version (*P*<.001), whereas the order of assessments, whether using the 3D-CAM paper version first or the 3D-DST first, had no effect on the results.

Table . Comparison of the effectiveness and efficiency of the 3D-CAM[a] paper version and the 3D-DST[b].

Domain		Score, median (range)	*Z* value	*P* value
Perceived usefulness			–6.903	<.001
	3D-DST	4.57 (3.29-5.00)		
	3D-CAM paper version	3.86 (2.71-4.86)		
Perceived ease of use			–6.973	<.001
	3D-DST	4.33 (3.00-5.00)		
	3D-CAM paper version	2.83 (1.83-4.33)		
Learnability			–7.014	<.001
	3D-DST	4.33 (3.00-5.00)		
	3D-CAM paper version	3.33 (2.33-4.67)		
Trustworthiness			–6.697	<.001
	3D-DST	4.33 (3.00-5.00)		
	3D-CAM paper version	3.33 (2.00-5.00)		
Intention to use			–6.446	<.001
	3D-DST	4.40 (3.20-5.00)		
	3D-CAM paper version	3.67 (1.33-5.00)		
Satisfaction			–6.985	<.001
	3D-DST	4.33 (3.33-5.00)		
	3D-CAM paper version	3.60 (1.60-4.20)		

[a] 3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.

[b] 3D-DST: Delirium Assessment Tool With Decision Support Function based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.

The assessment success rate of the 3D-CAM paper version was a little lower compared to that of the 3D-DST (203/216, 94% vs 212/216, 98.1%; *P*=.045). The median time of assessment using the 3D-CAM paper version was 2.1 minutes longer than that of the 3D-DST (4.4 vs 2.3 min; *P*<.001). The overall performances of the 3D-DST and the 3D-CAM paper version are displayed in Table 3.

Table . Comparison of the performances between the 3D-CAM[a] paper version and the 3D-DST[b] by bedside nurses.

Performance		Nurses, n	Assessments, n	Group A	Group B	*P* value
Successful completion rate, n/N (%)						.045
	3D-CAM paper version	72	216	103/108 (95.4)	100/108 (92.6)	
	3D-DST	72	216	107/108 (99.1)	105/108 (97.2)	
Human errors, n						.62
	3D-CAM paper version	72	N/A[c]	6	9	
	3D-DST	72	N/A	2	3	
Evaluation completion time (min), median (IQR)						<.001
	3D-CAM paper version	72	203	4.45 (2.5-5.4)	4.35 (2.4-5.3)	
	3D-DST	72	212	2.25 (1.25-3.55)	2.35 (1.4-3.6)	

[a] 3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.

[b] 3D-DST: Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.

[c] N/A: not applicable.

Discussion

Principal Findings

This study described the development process of a CDSS based on the 3D-CAM and evaluated its usability in delirium screening among older patients. Our results demonstrated that the 3D-DST was perceived as highly satisfactory with acceptable usability when used by bedside nurses, and it improved the completion rate and reduced the evaluation completion time when bedside nurses used the app among older patients.

CDSSs are tools incorporated with a significant clinical knowledge base and are designed to provide users (health care professionals, patients, and caregivers) with an intelligent way to assist in clinical decision-making [28]. Previous studies have found that well-designed CDSSs are effective and can improve clinical outcomes and health processes [29]. Therefore, it is very important to ensure the quality of CDSSs and avoid unpleasant situations when deploying unreliable systems.

Functional suitability is a very important feature when developing CDSSs; it refers to the extent to which a system meets the stated and implied requirements through its functional components under certain conditions [30-32]. In our study, the 3D-DST is aimed to connect with the hospital information system or NIS, so that it can automatically retrieve the patients' information via the hospital information system. The 3D-DST can obtain information by scanning the QR code on the patient's wristband, which allows the 3D-DST to be easily integrated into the portable NIS and facilitates efficient delirium assessment by bedside nurses.

As indicated by the study results, the median scores on the ease of use, ease of learning, and trustworthiness of the 3D-DST were over 1 point higher than those of the 3D-CAM paper version. It was demonstrated that the development of the 3D-DST met the requirements of bedside nurses, improving the acceptability and usefulness of the screening tool. There were several possible reasons. First, the 3D-DST was designed through process optimization, which incorporated strategies such as automatic evaluation logic jumps, embedded prompts, automatic comparison function, etc. The design process made full use of information technologies, such as automatic recording, calculation, and other intelligent functions, that could effectively solve the problems identified by nurses when they used the 3D-CAM paper version. The 3D-DST was well accepted by bedside nurses, the burden on the memorization of information was reduced, and the ease of use of the 3D-CAM was improved. Second, nurses only needed to complete the evaluation process by following the interfaces and the embedded prompts. Nurses did not need to learn the specific instructions, and the system could automatically record, calculate, and output the results, therefore improving this tool's learnability and scalability. Third, since the content of the 3D-CAM is mostly a routine assessment, nurses needed less training time to use the tool. Moreover, with reduced time to complete the delirium assessment, nurses perceived the 3D-DST as highly acceptable, which generated trustworthiness and solved the existing problems associated with the use of the 3D-CAM paper version.

The improvement of the perceived usefulness, intention to use, and satisfaction scores was less than 1 point when comparing the 3D-DST with the 3D-CAM paper version. This could be attributed to the following reasons. The scores on these 3 domains of the 3D-CAM paper version were considerably high. Perceived usefulness was mainly evaluated based on nurses' knowledge of delirium assessment, whereas intention to use mainly referred to whether nurses were willing to use the tool and whether the nurses could accept the method of using the tool or not, notwithstanding the evaluation completion time. Since this study was only conducted in a short period of time, nurses may not fully understand and appreciate that the 3D-DST can standardize the assessment process and improve the recognition rate and accuracy of the delirium assessment. In the future, the duration that the nurses use the 3D-DST should be extended before the acceptance evaluation. Furthermore, the intention to use the 3D-DST and satisfaction perceived by nurses may be affected by organizational factors.

Our study found that the 3D-DST had a slightly higher successful completion rate than the 3D-CAM paper version in assessing delirium among bedside nurses (212/216, 98.1% vs 203/216, 94%; P=.045). In the 3D-DST, reminders of the correct responses for items 1, 2 and 5 (objectively testing patients' cognition) were incorporated into the app, which can increase the accuracy of the delirium assessment, reduce the information processing time, and improve nurses' work efficiency. When nurses evaluate delirium using the 3D-DST, the system will automatically record and generate the evaluation results without manual input; this prevented possible human errors that are introduced by the nurses. The 3D-DST also added prompts that aimed to reduce the assessment failure rate caused by incorrect or inadequate understanding of the content of the items. By integrating prompts into the 3D-DST, it may have contributed to the reduced failure rate among bedside nurses by guiding and standardizing the assessment process; thus, insufficient knowledge and possible human errors are fully addressed during the assessment. Therefore, the 3D-DST improved the success rate of the delirium assessment. With assistance of CDSSs, decision-making can be incorporated into the routine assessment to guide nurses to complete the assessment successfully with standardized procedures [33-35].

The advantages of the study are multifactorial. The 3D-DST was developed to solve the problems associated with the use of 3D-CAM paper version in routine practice by nurses. The research team included multidisciplinary members such as delirium assessment experts and software development engineers, and we used a combination of multiple architectures to ensure the stability of the system during the development process. In addition, in evaluating the usability and performance (completion rate, time required for completing the assessment, and the number of human errors made by nurses during the assessment) of the 3D-DST, both subjective and objective approaches were used by comparing the 3D-CAM paper version with the 3D-DST among bedside nurses, which showed the promising results of the 3D-DST.

This study also has several limitations. First, each bedside nurse only used the 3D-CAM to evaluate 6 patients, which may have limited the nurses' possibility to evaluate all types of patients with different admission diagnoses in general wards. Therefore, our result may not be generalizable to other clinical settings. Second, this study only applied a quantitative approach to evaluate the usability of the 3D-DST; interviews can be added to explore the usability of the 3D-DST among bedside nurses in the future. Third, during the usability testing phase, some usability issues in our system may not be adequately reflected due to limitations in the patients' admission types and the limited number of assessments. Fourth, bedside nurses were not physically involved in the interface design process, which may have affected the usability of the interface. However, we have examined the problems and issues associated with the use of the 3D-CAM paper version among bedside nurses, and the 3D-DST was developed to address these problems by including experienced nursing researchers during the development process, so the results should not be affected. Finally, this study did not analyze the accuracy of the 3D-DST in assessing delirium, as this was not required for the study objectives at this stage, and it was completed as a separate study.

Conclusion

This study demonstrated that the 3D-DST was perceived as highly acceptable and useful in assisting bedside nurses to identify delirium among older adults in routine practice. The integration of this app with existing health systems could enhance its positive impact on the efficiency and accuracy of delirium screening in the future.

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Authors' Contributions

JW contributed to conceptualization, methodology, software, and writing—original draft. MJ contributed to writing—review and editing. YH contributed to conceptualization, methodology, software, validation, formal analysis, and investigation. YW contributed to conceptualization, methodology, software, validation, resources, writing—review and editing, supervision, project administration, and funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Details of the design principle.
[DOCX File, 13 KB - aging_v7i1e51264_app1.docx]

Multimedia Appendix 2
Evaluation process of the original 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium (3D-CAM) paper version.
[PNG File, 162 KB - aging_v7i1e51264_app2.png]

Multimedia Appendix 3
Evaluation process of the Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium (3D-DST).
[PNG File, 330 KB - aging_v7i1e51264_app3.png]

Checklist 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File, 1742 KB - aging_v7i1e51264_app4.pdf]

References

1. Kim CM, van der Heide EM, van Rompay TJL, Verkerke GJ, Ludden GDS. Overview and strategy analysis of technology-based nonpharmacological interventions for in-hospital delirium prevention and reduction: systematic scoping review. J Med Internet Res 2021 Aug 26;23(8):e26079. [doi: 10.2196/26079] [Medline: 34435955]
2. Ahmed S, Leurent B, Sampson EL. Risk factors for incident delirium among older people in acute hospital medical units: a systematic review and meta-analysis. Age Ageing 2014 May;43(3):326-333. [doi: 10.1093/ageing/afu022] [Medline: 24610863]
3. Solberg LM, Duckworth LJ, Dunn EM, et al. Use of a data repository to identify delirium as a presenting symptom of COVID-19 infection in hospitalized adults: cross-sectional cohort pilot study. JMIR Aging 2023 Nov 30;6:e43185. [doi: 10.2196/43185] [Medline: 37910448]

4. Hur S, Ko RE, Yoo J, Ha J, Cha WC, Chung CR. A machine learning-based algorithm for the Prediction of Intensive Care Unit Delirium (PRIDE): retrospective study. JMIR Med Inform 2021 Jul 26;9(7):e23401. [doi: 10.2196/23401] [Medline: 34309567]
5. Wilcox ME, Girard TD, Hough CL. Delirium and long term cognition in critically ill patients. BMJ 2021 Jun 8;373:n1007. [doi: 10.1136/bmj.n1007] [Medline: 34103334]
6. Hoch J, Bauer JM, Bizer M, Arnold C, Benzinger P. Nurses' competence in recognition and management of delirium in older patients: development and piloting of a self-assessment tool. BMC Geriatr 2022 Nov 19;22(1):879. [doi: 10.1186/s12877-022-03573-8] [Medline: 36402941]
7. Chen L, Li N, Zheng Y, et al. A novel semiautomatic Chinese keywords instrument screening delirium based on electronic medical records. BMC Geriatr 2022 Oct 4;22(1):779. [doi: 10.1186/s12877-022-03474-w] [Medline: 36192690]
8. Geriatric Medicine Research Collaborative. Delirium is prevalent in older hospital inpatients and associated with adverse outcomes: results of a prospective multi-centre study on World Delirium Awareness Day. BMC Med 2019 Dec 14;17(1):229. [doi: 10.1186/s12916-019-1458-7] [Medline: 31837711]
9. El Hussein M, Hirst S, Salyers V. Factors that contribute to underrecognition of delirium by registered nurses in acute care settings: a scoping review of the literature to explain this phenomenon. J Clin Nurs 2015 Apr;24(7-8):906-915. [doi: 10.1111/jocn.12693] [Medline: 25293502]
10. Brefka S, Eschweiler GW, Dallmeier D, Denkinger M, Leinert C. Comparison of delirium detection tools in acute care: a rapid review. Z Gerontol Geriatr 2022 Mar;55(2):105-115. [doi: 10.1007/s00391-021-02003-5] [Medline: 35029755]
11. Lemiengre J, Nelis T, Joosten E, et al. Detection of delirium by bedside nurses using the confusion assessment method. J Am Geriatr Soc 2006 Apr;54(4):685-689. [doi: 10.1111/j.1532-5415.2006.00667.x] [Medline: 16686883]
12. Marcantonio ER, Ngo LH, O’Connor M, et al. 3D-CAM: derivation and validation of a 3-Minute Diagnostic Interview for CAM-Defined Delirium: a cross-sectional diagnostic test study. Ann Intern Med 2014 Oct 21;161(8):554-561. [doi: 10.7326/M14-0865] [Medline: 25329203]
13. Wang J, Lu S, Huang Y, et al. A nurse-administered 3-Minute Diagnostic Interview for CAM-Defined Delirium (3D-CAM Chinese version) in hospitalized elderly patients: a validation study. Int J Nurs Stud 2020 Oct;110:103701. [doi: 10.1016/j.ijnurstu.2020.103701] [Medline: 32736252]
14. Olbert M, Eckert S, Mörgeli R, Kruppa J, Spies CD. Validation of 3-Minute Diagnostic Interview for CAM-Defined Delirium to detect postoperative delirium in the recovery room: a prospective diagnostic study. Eur J Anaesthesiol 2019 Sep;36(9):683-687. [doi: 10.1097/EJA.0000000000001048] [Medline: 31306183]
15. Kuczmarska A, Ngo LH, Guess J, et al. Detection of delirium in hospitalized older general medicine patients: a comparison of the 3D-CAM and CAM-ICU. J Gen Intern Med 2016 Mar;31(3):297-303. [doi: 10.1007/s11606-015-3514-0] [Medline: 26443577]
16. Han Y, Zhang S, Wu Y. Problem analysis in nurses’ daily use of 3-Minute Diagnostic Interview for CAM-Defined Delirium. Article in Chinese. Chinese Journal of Modern Nursing 2019 Jul 25;25(13):1619-1624. [doi: 10.3760/cma.j.issn.1674-2907.2019.13.008]
17. Damoiseaux-Volman BA, van der Velde N, Ruige SG, Romijn JA, Abu-Hanna A, Medlock S. Effect of interventions with a clinical decision support system for hospitalized older patients: systematic review mapping implementation and design factors. JMIR Med Inform 2021 Jul 16;9(7):e28023. [doi: 10.2196/28023] [Medline: 34269682]
18. Yoo J, Lee J, Min JY, et al. Development of an Interoperable and easily transferable clinical decision support system deployment platform: system design and development study. J Med Internet Res 2022 Jul 27;24(7):e37928. [doi: 10.2196/37928] [Medline: 35896020]
19. Marcantonio ER, Fick DM, Jung Y, et al. Comparative implementation of a brief app-directed protocol for delirium identification by hospitalists, nurses, and nursing assistants: a cohort study. Ann Intern Med 2022 Jan;175(1):65-73. [doi: 10.7326/M21-1687] [Medline: 34748377]
20. Yang F, Ji M, Wu Y, et al. Delirium screening for patients in the intensive care unit: a prospective validation study of the iCAM-ICU by nurse researchers and bedside nurses in routine practice. Int J Nurs Stud 2021 May;117:103886. [doi: 10.1016/j.ijnurstu.2021.103886] [Medline: 33631399]
21. Mohseni Moallem Kolaei N, Ayatollahi H, Elyasi F. Delirium in burn patients: developing a mobile application for assessment and diagnosis. J Burn Care Res 2021 Feb 3;42(1):87-92. [doi: 10.1093/jbcr/iraa122] [Medline: 32761052]
22. Ji M, Wu Y, Chang P, Yang X, Yang F, Xu S. Development and usability evaluation of the mobile delirium assessment app based on confusion assessment method for intensive care unit (CAM-ICU). Stud Health Technol Inform 2015 Aug;216:899. [doi: 10.3233/978-1-61499-564-7-899] [Medline: 26262201]
23. Yang X, Xiao Y, Huang Y, Wu Y. Chinese version of 3-Minute Diagnostic Interview for CAM-Defined Delirium and its reliability. Article in Chinese. Chinese Journal of Modern Nursing 2018 Jun 5;24(15):1774-1778. [doi: 10.3760/cma.j.issn.1674-2907.2018.15.009]
24. Middleton B, Bloomrosen M, Dente MA, et al. Enhancing patient safety and quality of care by improving the usability of electronic health record systems: recommendations from AMIA. J Am Med Inform Assoc 2013 Jun;20(e1):e2-e8. [doi: 10.1136/amiajnl-2012-001458] [Medline: 23355463]

25. Liu L. Analysis and application of MVVM pattern. Article in Chinese. Microcomputer Applications 2012 Dec:57-60 [FREE Full text]
26. Chen H, Wang T, He X, et al. BRAD V3.0: an upgraded Brassicaceae database. Nucleic Acids Res 2022 Jan 7;50(D1):D1432-D1441. [doi: 10.1093/nar/gkab1057] [Medline: 34755871]
27. Feng Y, Yang F, Li J. User acceptance evaluation of the mobile delirium assessment app based on CAM-ICU. Article in Chinese. Chinese Journal of Modern Nursing 2016 Nov 30;22(15):2073-2078 [FREE Full text]
28. Sutton RT, Pincock D, Baumgart DC, Sadowski DC, Fedorak RN, Kroeker KI. An overview of clinical decision support systems: benefits, risks, and strategies for success. NPJ Digit Med 2020 Feb 6;3:17. [doi: 10.1038/s41746-020-0221-y] [Medline: 32047862]
29. Calvo-Cidoncha E, Verdinelli J, González-Bueno J, et al. An ontology-based approach to improving medication appropriateness in older patients: algorithm development and validation study. JMIR Med Inform 2023 Jul 13;11:e45850. [doi: 10.2196/45850] [Medline: 37477131]
30. Solomon J, Dauber-Decker K, Richardson S, et al. Integrating clinical decision support into electronic health record systems using a novel platform (EvidencePoint): developmental study. JMIR Form Res 2023 Oct 19;7:e44065. [doi: 10.2196/44065] [Medline: 37856193]
31. Souza-Pereira L, Ouhbi S, Pombo N. Quality-in-use characteristics for clinical diagnostic support tool assessment. Comput Methods Programs Biomed 2021 Aug;207:106169. [doi: 10.1016/j.cmpb.2021.106169] [Medline: 34062492]
32. Marcolino MS, Oliveira JAQ, Cimini CCR, et al. Development and implementation of a decision support system to improve control of hypertension and diabetes in a resource-constrained area in Brazil: mixed methods study. J Med Internet Res 2021 Jan 11;23(1):e18872. [doi: 10.2196/18872] [Medline: 33427686]
33. Withall JB, Schwartz JM, Usseglio J, Cato KD. A scoping review of integrated medical devices and clinical decision support in the acute care setting. Appl Clin Inform 2022 Oct;13(5):1223-1236. [doi: 10.1055/s-0042-1759513] [Medline: 36577503]
34. Diogo RCDS, Gengo RDC, Butcher S, Peres HHC. Evaluation of the accuracy of nursing diagnoses determined by users of a clinical decision support system. J Nurs Scholarsh 2021 Jul;53(4):519-526. [doi: 10.1111/jnu.12659] [Medline: 33860621]
35. Jones EK, Banks A, Melton GB, Porta CM, Tignanelli CJ. Barriers to and facilitators for acceptance of comprehensive clinical decision support system-driven care maps for patients with thoracic trauma: interview study among health care providers and nurses. JMIR Hum Factors 2022 Mar 16;9(1):e29019. [doi: 10.2196/29019] [Medline: 35293873]

Abbreviations

3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium
3D-DST: Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium
CAM: Confusion Assessment Method
CAM-ICU: Confusion Assessment Method for Intensive Care Unit
CDSS: clinical decision support system
ICU: intensive care unit
MVVM: model-view-viewmodel
NIS: nursing information system

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Original Paper

Digital Storytelling Intervention for Enhancing the Social Participation of People With Mild Cognitive Impairment: Co-Design and Usability Study

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Abstract

Background: Community-based social participation has shown promise in delaying cognitive decline in older adults with mild cognitive impairment (MCI) who are at risk of developing dementia. Although group storytelling interventions have proven effective, the need for a skilled workforce to support people with MCI can limit broader community implementation. Technology-based interventions may offer a solution to this limitation by replicating the abilities of therapists.

Objective: This study aims to co-design a digital storytelling intervention and evaluate its usability.

Methods: This co-design process involved 3 stages, engaging people with MCI (n=12), their caregivers (n=4), and therapists (n=5) in Beijing, China. In the first stage, we used card sorting and voting methods to identify potential incentives for social participation and target the specific abilities that people with MCI wanted to enhance. In the second stage, we conducted brainstorming sessions with people with MCI and their caregivers to identify the potential features of a digital storytelling application named Huiyou (“meeting new friends” in Chinese). Finally, we assessed Huiyou’s usability with people with MCI and therapists, leading to iterative improvements based on the usability findings.

Results: We uncovered a crucial link between boosting the self-confidence of people with MCI and their ability to address social participation challenges. Notably, we identified memory improvement and enhanced language expression as key factors for effective communication with grandchildren. Subsequently, participants suggested features and interfaces to address these challenges, leading to the development of Huiyou, a group-based digital storytelling application featuring functions such as generating story materials, conducting memory retrieval activities, and sharing stories. It received an “excellent” rating in the User Experience Questionnaire benchmark, displaying high levels of attractiveness, dependability, stimulation, and novelty. People with MCI achieved an average task completion rate of 87% (n=19; SD 0.13) of the 22 tasks. However, feedback from people with MCI and therapists highlighted usability issues in navigation, activity management, user interface, and feature optimization, indicating a need for improved accessibility and efficiency.

Conclusions: The co-design approach contributed to developing the Huiyou prototype, supporting community-based social participation. User feedback highlighted the potential of Huiyou to enhance well-being and facilitate meaningful social interactions while maintaining crucial existing relationships.

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KEYWORDS

co-design; digital storytelling; people with mild cognitive impairment; MCI; technology-based intervention development; dementia; mobile phone

Introduction

Background

Social participation has proven efficacious in decelerating the progression of dementia from mild cognitive impairment (MCI) [1], particularly in low- and middle-income countries [2]. To enhance social participation among older adults with MCI, researchers are engaged in reducing the obstructions to social participation [3] and creating and customizing a variety of constructive social activities [4]. To expand social participation, researchers have explored an assortment of interventions aimed at improving memory, communication, and familial relationships among older adults with MCI [5]. Social participation is considered at different levels: societal, community, relationship, and individual levels [6]. Community involvement is defined by its significance and the sense of satisfaction it generates in people's lives as well as its potential for creating social support [7]. Older adults reported that technology could assist them in maintaining social connections [8]. For example, researchers used cameras, enabling people with MCI to memorialize their daily lives [9]. Most interventions concentrate on enhancing cognitive abilities [10] or facilitating recreational and sports activities [11]. The former relies upon participants' strong motivation to participate in interventions, whereas the latter has less impact on cognitive ability. Storytelling tools can simultaneously enhance cognitive abilities and create a novel form of social interaction. Incorporating storytelling as a therapeutic intervention possesses enormous potential for improving health care outcomes and promoting well-being among people with MCI [12]. Studies have demonstrated that socially isolated people with MCI may experience lower psychological well-being and exhibit more negative states of mind than older adults considered to have cognitive normality [13]. Owing to cognitive impairments, people with MCI may encounter the following issues: (1) reduced interest in and initiation of social interactions, suggesting a lack of proactive engagement [14]; (2) difficulties in establishing and maintaining interpersonal relationships, implying an impaired sense of social synchrony; and (3) challenges in recognizing and adhering to social boundaries and norms [15]. It is imperative to explore behavior change strategies aimed at fostering a positive social health lifestyle among people with MCI. Technology could be a beneficial tool to maintain social connection [8]. For example, ElderConnect is a web-based app designed to assist senior citizens in recognizing, preventing, and easing feelings of loneliness. It offers information and tactics to help them establish new social connections and sustain existing ones [16]. Notably, storytelling serves as an essential activity for promoting positive social health [17,18]. Harnessing the power of storytelling, people with MCI can be encouraged to participate more proactively in their health care by identifying their unique needs and knowledge gaps while fostering strong connections and support networks with peers with similar disease-related experiences [19].

However, these storytelling interventions often lack a focus on community-based social activities, primarily being individual interventions without emphasis on interpersonal interactions. Furthermore, community-based programs depend on skilled facilitators, such as therapists or social workers, to maintain quality. For instance, providing training for facilitators before they lead a group reminiscence program ensures expertise in techniques and effective program management [20]. In integrative group storytelling therapy, participants exhibited strong social integration, supported one another, displayed valuable life skills, and fostered positive self-worth and institutional loyalty during reminiscing and feedback sharing [21]. Consequently, participants felt supported and experienced a sense of belonging when performing digital group activities [22]. Community-based social participation relies on facilitators who organize activities and provide support in securing spaces and promoting events. Therefore, using a technology-based storytelling intervention to boost community-based social engagement can enhance community belonging.

The 3 main features of a digital storytelling application are multimedia material editing, memory recall, and story sharing. Some memory retrieval interventions may combine multiple functions of the interventions, such as people with MCI simultaneously reminiscing and sharing their recollections [23]. Challenges in using technology remain an unsolved issue; people with MCI typically exhibit lower digital literacy [24]. Most storytelling programs include training sessions before the intervention, such as storytelling classes [25], as mostly commercial, off-the-shelf technology is used to support digital storytelling [12], and these programs require digital literacy for multimedia editing and digital storytelling. Some studies required trained volunteers [26] or caregivers [23,27] to support people with dementia in developing stories. However, these settings are intended to enable people with MCI to adapt to existing environments and interactive tools rather than customizing the software to their specific needs (thus enhancing the usability of the storytelling application while simultaneously reducing learning costs). The applicability of these methods for memory retrieval among adults with MCI is currently not fully understood [28]. Therefore, our aim was to co-design a technology-based group memory retrieval intervention, which is a key form of digital storytelling intervention, to support social participation. We also investigated how to design user-friendly storytelling applications to manage digital resources and reduce learning costs for people with MCI.

Theoretical Framework

Co-design pertains to the collaborative involvement of people (users and stakeholders) in the design of a product or service [29]. Co-design workshops for interventions for people with MCI involve people with MCI, caregivers, and therapists in designing the intervention programs, providing unique perspectives. Involving users in design sessions helps engineers and researchers better understand requirements. A co-design approach would be helpful in identifying the requirements for designing technology-based group memory retrieval interventions for people with MCI. In our study, the development of the storytelling prototype was guided by 2 behavioral and theoretical frameworks to raise participants' awareness about their social health behaviors and tailor adequate actions for behavior change, namely the Behavior Change Wheel [30] and Theoretical Domains Framework (TDF). Beginning with the Behavior Change Wheel, a behavioral analysis enables intervention designers to select particular areas for exploration, thereby guiding the development of the digital storytelling approach. TDF deepens the understanding of psychological and behavioral factors influencing effective interventions. This integration aligned our application's features with identified behavior change strategies, fostering a comprehensive approach to promoting social health. In addition, a communication strategy called MESSAGE (an acronym representing 7 key communication strategies, each encapsulated by its initial letter; within each strategy, specific suggestions are aimed at enhancing effective communication: maximizing attention [M], focusing on expression and body language [E], keeping it simple [S], providing support for their conversation [S], assisting with aids [A], getting their message [G], and encouraging and engaging in conversation [E]) [31] was used to support digital storytelling communication. Considering the critical importance of providing caregivers with effective tools to bolster memory and communication abilities in individuals with dementia [32], the implementation of specific communication strategies between people with MCI and the Huiyou application is paramount.

Methods

Ethical Considerations

The Swinburne University of Technology's Human Research and Ethics Committee provided ethics approval for this research (20226525-11105) on September 26, 2022. All workshop participants provided written informed consent to participate and gave permission for their audio recordings and sketches to be used in publications. All methods were performed in accordance with relevant guidelines and regulations. We collected no identifying information from the research participants, such as their names or email addresses. Each participant was assigned a unique ID number to ensure their anonymity. In addition, we provided informed consent forms, including a project information sheet, to uphold their privacy rights.

Research Team

The research team is a collaborative ensemble of specialists in human-computer interaction, user experience, and design, each contributing their distinct expertise to the success of the project. AAM has an extensive background in design research and human-computer interaction, and WL has engaged in and performed research on user experience extensively. DZ is a doctor of philosophy student specializing in design.

Sample

A social work organization named Jingshilaonian, located in Beijing, China, expressed willingness to participate in this research. Situated within the Tiantongyuan community in Beijing, this institution specializes in providing psychosocial support, mental health services, and daily activity assistance to older adults, including those with MCI. Jingshilaonian played a vital role by assisting us with the recruitment and screening of people with MCI by administering the Montreal Cognitive Assessment, as developed by Nasreddine [33]. The inclusion criteria for people with MCI encompassed independent community dwelling, age >65 years, no visual or hearing impairments, and adequate reading ability. The exclusion criteria for people with MCI included significant neurological conditions, such as stroke or brain injury, because of potential confounding effects. Caregivers had no specific inclusion criteria. For therapists, the inclusion criteria were postgraduate qualifications and >3 years of experience in social interventions. To engage participants, we collaborated with the organization's manager to distribute information sheets to people with MCI and their caregivers, inviting them to participate in the study. We co-designed a storytelling intervention with people with MCI (n=12), their caregivers (n=4), and therapists (n=5) in Beijing, China. The brainstorming stage and rough prototyping stage for the intervention were attended by people with MCI and caregivers in a group setting, and the user testing stage was attended by people with MCI and therapists. People with MCI (n=12) were aged 65 to 77 (mean 69.91, SD 4.20) years, and their average Montreal Cognitive Assessment-Chinese version score was 23.58 (SD 1.38). A total of 4 caregivers participated in the workshops. Table 1 summarizes the demographics of people with MCI.

Table 1. Demographics of participants with mild cognitive impairment (n=12).

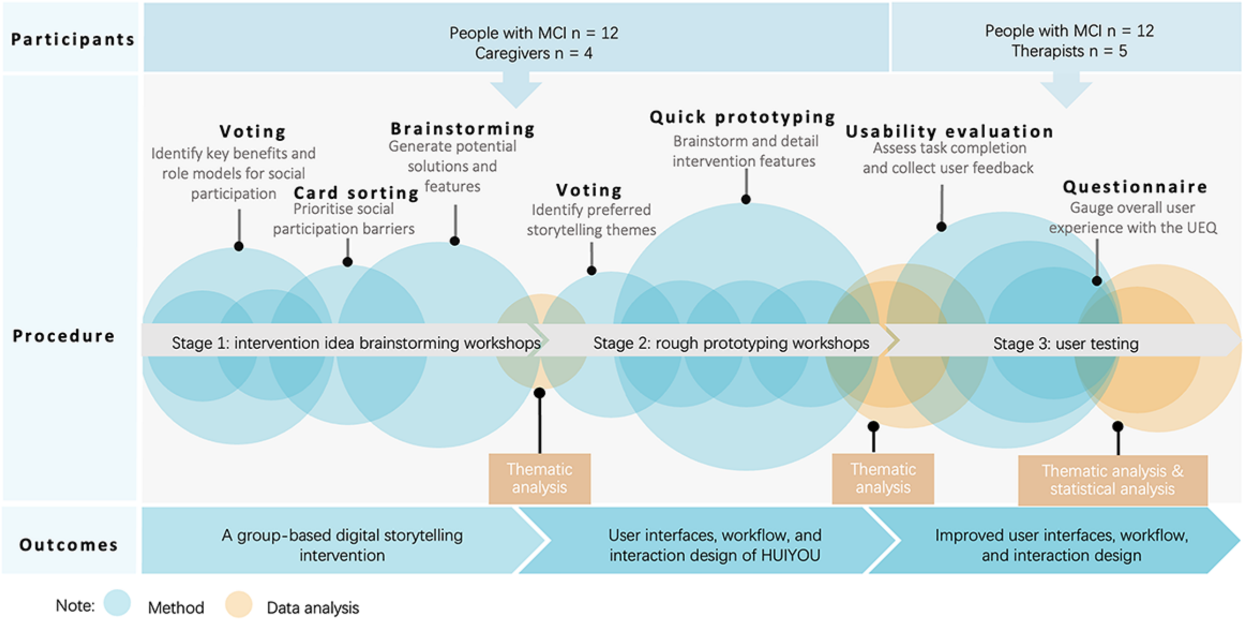
Characteristic	Values
Sex, n (%)	
Male	3 (25)
Female	9 (75)
Age (y), mean (SD)	69.92 (4.20)
Age (y), n (%)	
65-69	5 (42)
70-74	6 (50)
75-79	1 (8)
Educational background, n (%)	
Bachelor’s degree	2 (17)
High school	3 (25)
Junior high school	7 (58)

Procedure

Overview

We adopted the co-design stages proposed by Robinson et al [34], namely scoping (stage 1), participatory design workshops (stage 1), and prototype development (stage 2). After developing the prototype, we conducted a usability evaluation (stage 3; Figure 1). The specific tools and procedures used can be found in the protocol paper [14].

Figure 1. The process of data collection. MCI: mild cognitive impairment; UEQ: User Experience Questionnaire.



Stage 1: Intervention Idea Brainstorming Workshops

In this initial phase, it took 45 minutes to uncover the essential aspects of significant social participation for people with MCI and their caregivers. This stage involved a sequence of 4 workshops designed to identify the most compelling benefits, role models, and barriers related to social participation. By prioritizing these aspects, we sought to deepen our understanding of the significance of social participation for people with MCI and enhance the quality of data for the subsequent phase. During each workshop, people with MCI and caregivers voted on the most compelling benefits and role models, and people with MCI selected 2 abilities that they wished to improve. These insights were critical for informing the design of our digital storytelling intervention.

Stage 2: Prototyping Workshops

Building on the insights gained from stage 1, we focused on collaborative brainstorming sessions involving people with MCI and their caregivers in stage 2. The goal was to explore the design and interaction logic of the interface through 60-minute workshops. Digital storytelling interventions involve recalling past actions, events, and feelings using physical prompts. In addition to building on the insights gained from the literature review of digital storytelling interventions, we identified the main features of digital storytelling applications as story creation, memory retrieval, and story sharing [12]. Furthermore, we found that the themes of stories significantly impacted the storytelling experience [35]. Therefore, the research team proposed 4 primary properties for potential features of the digital storytelling intervention: identification of preferred storytelling themes, support for story material generation, memory retrieval, and story sharing. Participants were encouraged to describe, illustrate, or display sample interfaces on their mobile devices. Figures 2-6 were generated during the prototyping workshops by participants and facilitator DZ. The key objectives were to define the program's main goals; propose relevant features, interactions, workflow, and interface elements; and create rough prototypes to visualize the intervention's interfaces and interactions. The outcomes of this stage provided the foundation for designing the prototype of our digital storytelling application.

Figure 2. A sketch showing browsing and reminiscing topics and details.

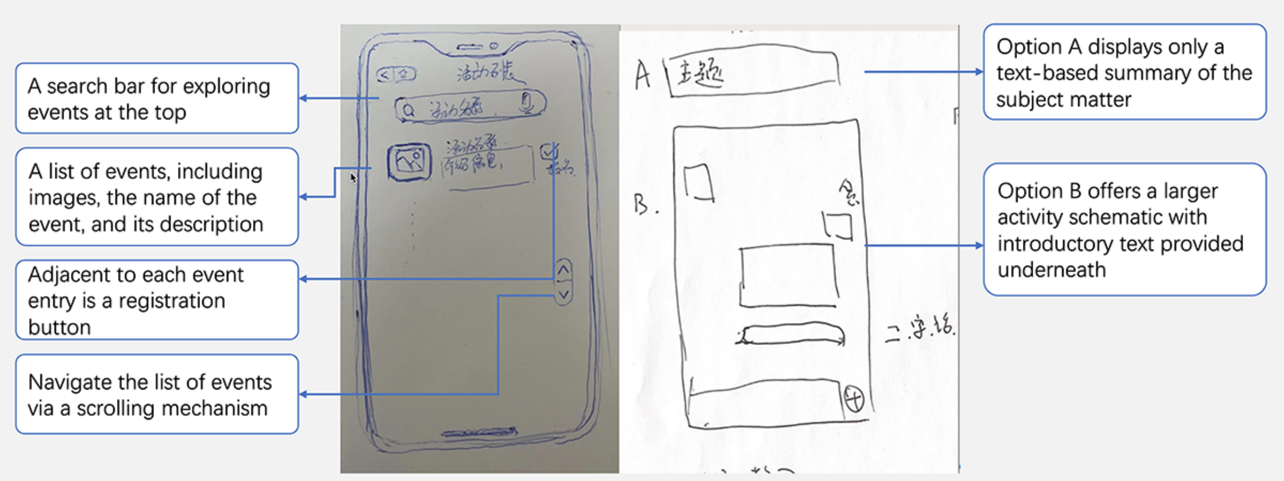


Figure 3. A sketch of (A) material addition entry point indicated by a "+" icon and (B) adding material description of story materials.

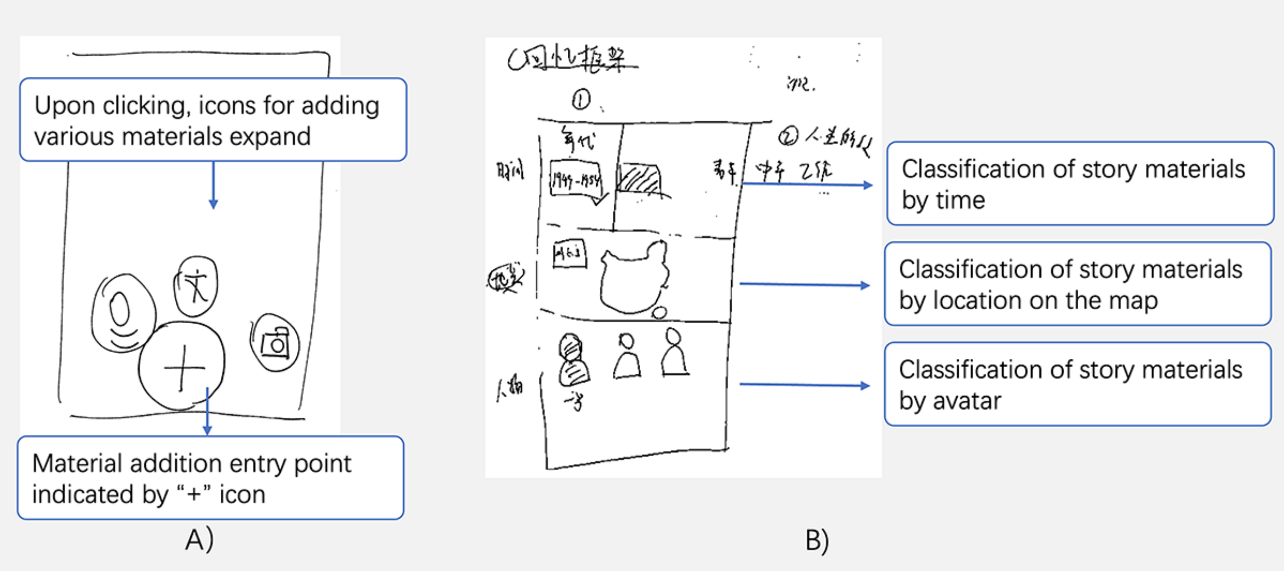


Figure 4. A sketch of changing the sequence of the content.

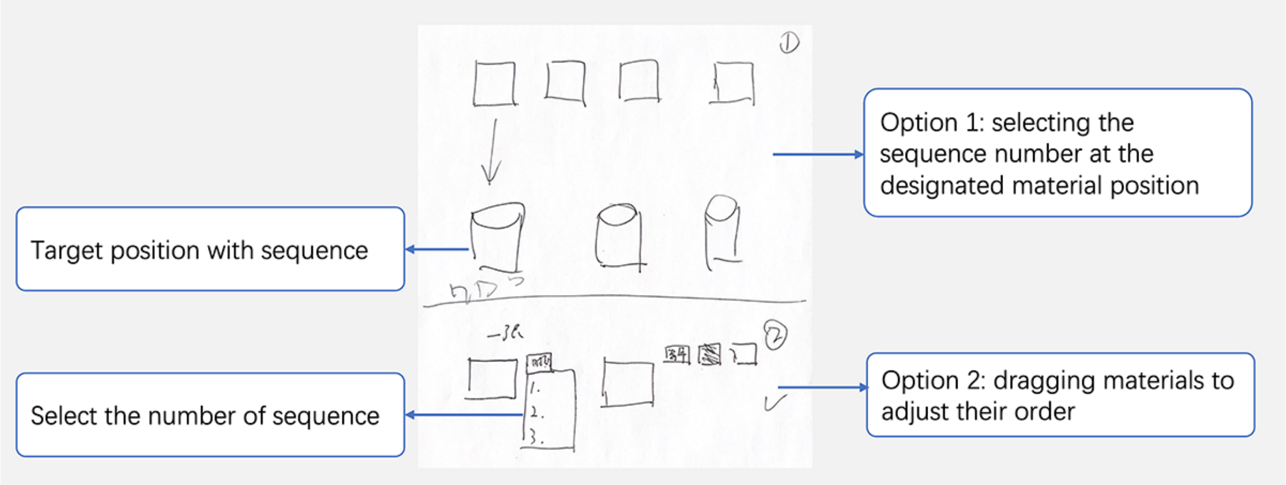


Figure 5. Cheat sheet example.

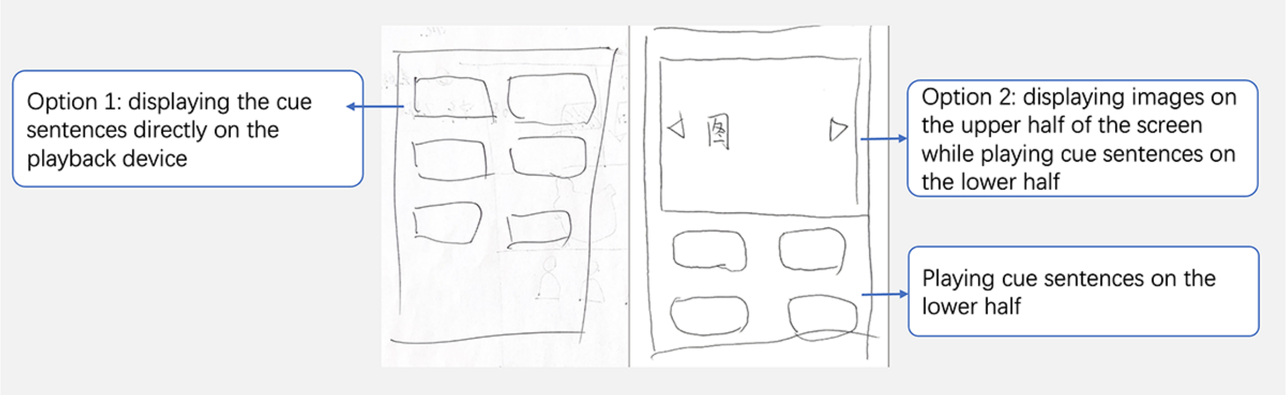
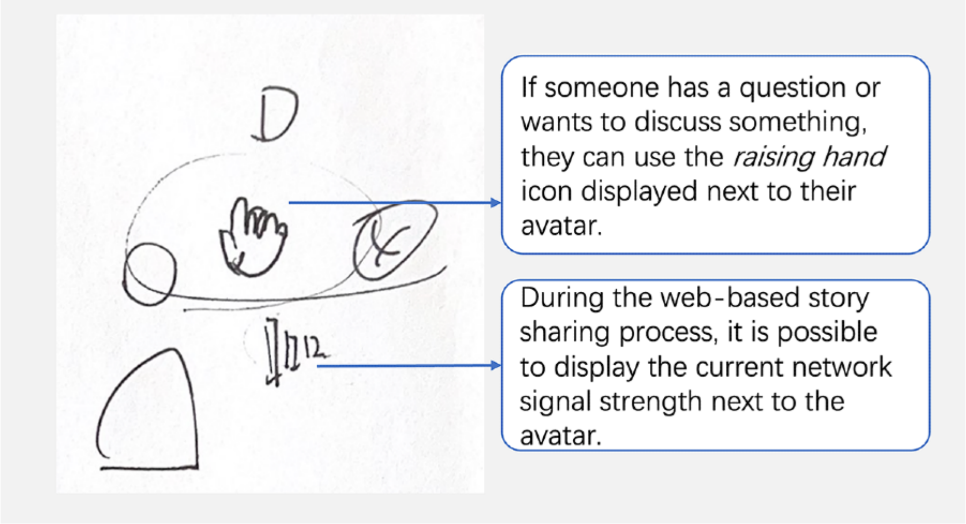


Figure 6. Participants can raise their hand with any question they wished to ask.



Stage 3: User Testing

We created the Huiyou prototype based on the insights and ideas gathered from stages 1 and 2. To evaluate the application's usability, we identified 22 specific tasks aligned with its features and interaction logic. These tasks were meticulously selected to ensure that the intervention's primary objectives, including enhancing social connection and community participation for people with MCI, could be effectively achieved. Participants, including people with MCI and therapists, engaged in usability testing sessions, where they completed these tasks and provided feedback on their experiences. The usability test session was 45 minutes long. Feedback gathered from these sessions included task success rates, concerns, and preferences. We also collected data on individual task completion rates and task completion with facilitator assistance. In our usability testing, we used a comprehensive approach to evaluate the features and subtasks of the Huiyou intervention. For instance, in testing the story sharing feature, participants were tasked with actions such as entering the speech mode, locating speech prompts, assessing speech length on the page, and identifying the screen projection button. If participants independently interacted with the interfaces successfully, the facilitator recorded it as task completion without assistance. However, if participants encountered difficulties in completing a task even after thoroughly examining the entire interface, the facilitator intervened by offering predefined tips, such as suggesting checking the bottom of the screen. In such cases where participants were able to successfully interact with the interfaces with the facilitator's assistance, the facilitator recorded it as completion with facilitator assistance. Following this, we initiated an iterative design process to refine and enhance the user interfaces (UIs) based on participant feedback, ensuring the application's usability and effectiveness.

Data Collection

Qualitative data were gathered through interviews, sketches, and focus group discussions at different stages of the research via audio recordings. In stage 1, focus group discussions were conducted to analyze the prioritized aspects of social participation. Stage 2 involved brainstorming activities during which participants generated sketches and discussed the potential features of Huiyou. In stage 3, participants' feedback was collected through self-reporting during usability testing and structured interviews. It is important to note that the Chinese version of the User Experience Questionnaire (UEQ) had previously undergone psychological validation [36]. A total of 22 usability tasks were used to evaluate task completion, providing a comprehensive approach to gaining valuable insights into the user experience of Huiyou and effectively assessing its usability.

Data Analysis

Qualitative data analysis followed a thematic analysis approach [37,38]. Two individual researchers reviewed and coded the interview transcripts and organized the codes into themes using NVivo (version 12.0; Lumivero) [39]. Labels, such as "Stage 1-group 2-people with MCI number 2," were used to distinguish different groups and participants.

In the design phase, the research team used the JiShiSheJi design to create the interface. After usability testing, a redesign phase was initiated, involving a detailed analysis of participant feedback and interview responses. These data were systematically summarized to identify improvement areas. An iterative design process was then used to enhance the UIs by incorporating participants' feedback. This approach ensured that the final version of Huiyou aligned better with the needs and preferences of people with MCI.

Quantitative data analysis involved calculating completion rates using Excel (Microsoft Corp) to determine the average completion rate and feature rankings. The UEQ results were assessed using the UEQ Handbook [40], whereas the UEQ Data Analysis Tool Version 12 was used to compute mean values, SD, and CI for various usability dimensions of attractiveness, ease of use, efficiency, dependability, stimulation, and novelty. We also used Excel to calculate the mean values of task completion rates with and without assistance.

Results

The key findings from each stage of this study are summarized as follows.

Stage 1 Findings: Intervention Idea Brainstorming Workshops

Overview

Our exploration unfolded into 3 distinctive themes, each shedding light on a crucial aspect of participants' experiences. We examined how social participation can be a powerful catalyst for enhancing physical health and fostering lifelong learning. Through the inspiring stories of confident older adults who wholeheartedly embraced challenges, our second theme showcased exemplars of unreserved social participation. Finally, we delved into the primary barriers people with MCI aimed to overcome, with a particular focus on memory, language expression, and the mastery of essential smartphone skills.

Enhancing Physical Health and Lifelong Learning Through Social Participation

Most participants with MCI (8/12, 67%) regarded social participation as an approach to maintaining physical health. They found that attending social activities can enhance their health status because they are less prone to catching colds when actively participating in social activities. People with MCI pay more attention to physical health; therefore, the benefits of physical health may attract people with MCI to participate in social activities.

Most participants with MCI (8/12, 67%) reported that engaging in activities with older adults positively impacted their physical well-being; these activities, such as exercise programs or outdoor group activities, helped improve their physical condition, increased their mobility, and supported their overall health. In addition, the social interaction involved in these activities afforded them a support system, along with accountability and the motivation to stay active and adopt a healthy lifestyle. In agreement with this, participants stated the following:

> *Engaging with others and staying socially active can help improve my physical health. It encourages me to stay active, spend time with people, and motivates me to maintain a healthy lifestyle.* [Stage 1, G2-P3]

Few participants with MCI (3/12, 25%) emphasized the value of lifelong learning and intellectual stimulation; participating in social activities provided these participants with a platform for communication, exploration, and the imparting of knowledge. By engaging in collaborative social activities and exchanging ideas with others, they were encouraged to continuously learn and discover new things. One of the participants commented the following:

> *Engaging in social activities can improve my mental health by allowing me to interact with others, receive emotional support, reduce feelings of loneliness, and*

> *enhance positive emotional experiences.* [Stage 1, G1-P2]

People With MCI Admire Peers Who Face Challenges Confidently

Most participants with MCI (9/12, 75%) admired older adults who displayed the confidence to attend various activities. Interacting with confident older adults allowed these participants to gain a new perspective on aging and life experiences; they were inspired to embrace challenges, overcome impediments, and approach life with a positive mindset:

> *They give me strength and inspiration, demonstrating passion and a positive attitude in caring for others, making me believe that I can still have a fulfilling and meaningful life even in challenging circumstances.* [Stage 1, G3-P3]

People With MCI Want to Improve Their Memory and Language Deficit and Smartphone Skills

Table 2 indicates that most people with MCI wish to improve their memory and expression of language, as participants mentioned that memory affects them frequently and that language expression can affect communication with their grandchildren. Of the 12 participants with MCI, 7 (58%) prioritized the improvement of memory, as this affected them the most:

> *I have poor memory; as I spoke, I forgot where I was talking. Therefore, I want to improve it first.* [Stage 1, G2-P2]

Table 2. The top 3 barriers identified (N=24).

Barriers to overcome	Votes[a], n (%)
Memory ability	7 (29)
Language expression	5 (21)
Smartphone use	4 (17)

[a] Each person with mild cognitive impairment had 2 votes; in total, there were 24 votes from the 12 participants.

Of the 12 participants with MCI, 5 (42%) mentioned that their storytelling ability also affected communication, mainly when talking with their grandchildren:

> *My education level is limited, and I hope I can improve my language skills so that I can tell my granddaughter vivid stories.* [Stage 1, G3-P1]

Among the 12 participants with MCI, 4 (33%) felt that using a smartphone was difficult, and some (3/12, 25%) people with MCI believed that the requirement for the ability to navigate a smartphone might prevent them from further social participation:

> *As I get older, I cannot use many functions of my phone. I always have to consult others, but it is more convenient to learn them myself.* [Stage 1, G2-P3]

All the participants with MCI (12/12, 100%) selected smartphones as the suitable device on which to install the application because they all had access to a smartphone, with only a few participants reporting that they owned an iPad (Apple Inc); smartphone was viewed as the more favorable option, being more portable than tablets or computers:

> *I have a smartphone; if the application could be installed on my phone, it would be more convenient since I carry the phone all the time.* [Stage 1, G2-P2]

In summary, the benefits of social participation for people with MCI included the improvement of physical health through engagement in activities, the fostering of a support network, and increased confidence among older adults. Memory and language expression were the primary barriers they wished to improve and were crucial for their communication with their grandchildren. Furthermore, their smartphone skills required enhancement to facilitate continued social participation.

Stage 2 Findings: Prototyping Workshops

Overview

Following the analysis of the findings from stage 1, the research team believed that the creation of a group-based digital storytelling intervention would be beneficial for improving memory, language expression, and smartphone use skills, and eventually, it could enhance social connection and participation. We have outlined the findings regarding the 4 primary features of the digital storytelling application as follows.

Preferred Storytelling Themes for Sharing With Others

All the participants with MCI (12/12, 100%) stated that they would like to share recent activities, including hobbies (as well as the changes they perceived around them), social activities, and current politics. Hobbies were most commonly cited because the participants were eager to share them with others and had invested much time and effort in them. The participants with MCI reported the following:

> *I enjoy content related to technology, as well as driving. I like observing different cars; whenever a related topic arises, I cannot stop talking about it.* [Stage 2, G2-P2]

Moreover, participants suggested receiving memory retrieval themes to ensure a well-defined topic to reminisce and allow them to gather relevant materials beforehand, expediting the process for smoother implementation.

Design of the Story Material Generation

After defining the storytelling themes, users could generate story materials by obtaining topics for memory retrieval, collecting materials, adding material descriptions, and integrating materials for further story sharing. The facilitator encouraged participants with MCI to create sketches; however, only 4 (33%) of the 12 participants with MCI were inclined to do so (Figures 5 and 6). Consequently, the facilitator assisted those who were unwilling to draw in visualizing their ideas.

Figure 2 presents a sketch for browsing a topic for memory retrieval; on the left side of the page, there are a search bar for exploring events at the top and a list of events, including images, the name of the event, and its description at the bottom. The user navigates the list of events via a scrolling mechanism. Adjacent to each event entry is a registration button. The page on the right offers 2 options for displaying the activity. Option A displays only a text-based summary of the subject matter. By contrast, option B displayed a more significant activity schematic with introductory text provided underneath:

> *For example, for my son's wedding, just get a few photos, just two or three.* [Stage 2, G2-P3]

The material collection feature enhances content by providing explanatory details and enriches the collection by sourcing pictures from various internet platforms. Recording snippets of information further aids by capturing valuable insights. In addition to collecting the target content, participants also suggested recording fragmented information informally. Figure 3 presents a sketch of an entry point for the supplementary material at the bottom of the page, indicated by a plus icon, which reveals 3 input methods when clicked. The input methods include voice input, text input, and video input:

> *The function of voice recognition is very convenient. With just a press of a button, recording starts, and in the end, it can be converted into text for preservation, making it easy to view later.* [Stage 2, G1-P2]

The adding material description feature aims to optimize the collection of data by associating individuals with each story (Figure 3); for instance, the developmental stages of the country, timeline, and the type of activities connecting people with MCI with the country's developmental stages and arranging them chronologically and by different activities for easy navigation. Participants recommended the provision of a framework of memories to aid them in refining the story; for example, participants could select the time stage, such as the founding of the People's Republic of China in 1949, and the stage of their life at the selected time, such as youth, middle-age, working, or retired. The choice of location is provided using a map. Finally, participants can apply labels for characters, including their avatars and names. One of the participants explained this as follows:

> *We can label the key characters that appear inside.* [Stage 2, G3-P2]
>
> *I like to categorize these [materials] by age and objectively exist since I am willing to use classification methods that are specific, not easily confused, preferably objectively present, and not prone to misunderstanding.* [Stage 2, G3-P3]

The integrating material feature aims to create a cohesive memory retrieval experience by uploading selected materials to the topic in question and adjusting sequences to promote a seamless and engaging narrative flow (Figure 4). The participants provided 2 options: option 1 displayed the candidate photos in the first row, and below, each theme was listed, with the corresponding material dragged and dropped into the theme; and option 2 allowed users to select the order of presentation after choosing the related theme. One of the participants with MCI commented the following:

> *After uploading these photos, we need to associate them with the story to be told based on different story themes. Before sharing, we could easily change the sequence of the materials.* [Stage 2, G2-P1]

Memory Retrieval Activity Design Through Facilitation Strategies

The digital storytelling application uses various strategies to enhance the experience in the memory retrieval function. It has 3 features: a story presentation, group discussion, and story summary.

During story presentation, the digital storytelling application has cheat sheets for recall, minimizing interruptions by using timers, promoting interactive discussions, and creating permanent records. Mobile technology facilitates the easy capture of memories, forming meaningful connections with cherished life events. Preparing a cheat sheet with helpful tips can provide valuable guidance to ensure a smooth and engaging memory retrieval experience (as shown in Figure 5). The cheat sheet might present either keyword prompts or corresponding content. A cue word switches to the content of the corresponding material, depending on the selected content format:

> *Sometimes [my] memory is poor, and this software can provide a cheat sheet to prevent me from forgetting what I need to share at the moment.* [Stage 2, G1-P2]

During the session, avoiding interruptions allowed participants to immerse themselves fully in their nostalgic journey, and a visual timer helped them manage their time effectively:

> *You can only limit the time. One is that most of the time, how many people cannot all stand on the same question, or you cannot all stand on your own time for a few minutes.* [Stage 2, G4-P2]

During a group discussion, the approach integrates memory retrieval with open discussion groups. Encouraging participants to pose questions by raising their hands fosters an interactive and dynamic environment (Figure 6). During the presentation, each participant has an avatar, and the Wi-Fi signal strength is displayed next to the avatar. If the participant has a question they wish to ask, they may raise their hand, and a small, raised hand icon is displayed next to their profile. These discussions can be informal, fostering a sense of engagement in shared experiences and collective memories:

> *Ask each other questions. This form is quite good. Ask each other because it is to discuss different opinions on a subject, and this is the best way. Yes, if there are no different opinions, this question may be a little biased.* [Stage 2, G3-P3]
>
> *I want to ask questions. If you want to ask questions that I am interested in, I can also raise my hand and answer them.* [Stage 2, G1-C1]

The story summary feature aims to make memory retrieval more tangible; facilitators can generate records or memories from the discussions, providing a lasting and meaningful resource for participants to cherish and revisit:

> *Currently, mobile phones are very convenient. When I take a group photo and see everyone's photos, I can recall what happened at that time. I also like to keep a diary and can simply remember one or two sentences.* [Stage 2, G4-C1]

Story Sharing to a Broader Audience

To share the records of their recollections with the desired person or group, participants suggested using WeChat (Tencent Holdings Limited), which allows for the convenient and efficient sharing of memories, ensuring that the memory retrieval experience can be cherished and enjoyed by those involved. Most participants with MCI (8/12, 67%) wished to share this experience with certain persons or groups, primarily through WeChat:

> *Based on different themes, [we can] send today's activities to corresponding people, such as those with common interests or children. Share with them through WeChat and let them know the latest situation as well.* [Stage 2, G2-P3]

However, one of the people with MCI showed no interest in sharing the content with others:

> *At this age, I'm not willing to share with more people; at least subjectively, I have no intention to please anyone.* [Stage 2, G1-P2]

In summary, Table 3 outlines the key functionalities and features of the memory log system, along with valuable suggestions for their implementation. To generate materials, the inclusion of memory topics aids in focused preparation. Collecting materials might include adding explanations to materials, collecting pictures from the internet, and the informal recording of fragments of discussions. While adding material description, users could add details such as time, location, and key characters to the material. Users could integrate materials into each presentation by changing the sequence of materials. During memory retrieval, facilitators can benefit from cheat sheets, minimize interruptions, and use visual timers in presentations. Open discussions, hand raising, and interactive dialogues further enrich the experience. Summarizing these records enhanced memory retention. Sharing options, such as WeChat, extend the impact beyond the scope of the audience.

Table 3. The main features of Huiyou identified from stage 2 (ie, prototyping workshops).

Functionalities and features	Suggestions to implement
Generating story materials	
Obtain a topic for memory retrieval	• Inform the topic and collect relevant materials in advance
Collect materials	• Add a description to each record • Collect pictures from others via the internet • Casually record fragmented information
Add material description	• Add essential character to each material • Link to the sequential steps of the country's development • Follow the timeline to show the content • Categorize by different activities
Integrate materials	• Upload selected materials to the target topic • Change the sequence of the materials
Memory retrieval activity	
Story presentation	• Prepare a cheat sheet to obtain tips • Avoid interruptions during the presentation • Set visual timer
Group discussion	• Combine memories and discuss • Raise hands to ask questions • Open discussion
Story summary	• Generate a record or memory
Sharing story	
Share storytelling records with certain a person or group	• Share the record via WeChat (Tencent Holdings Limited)

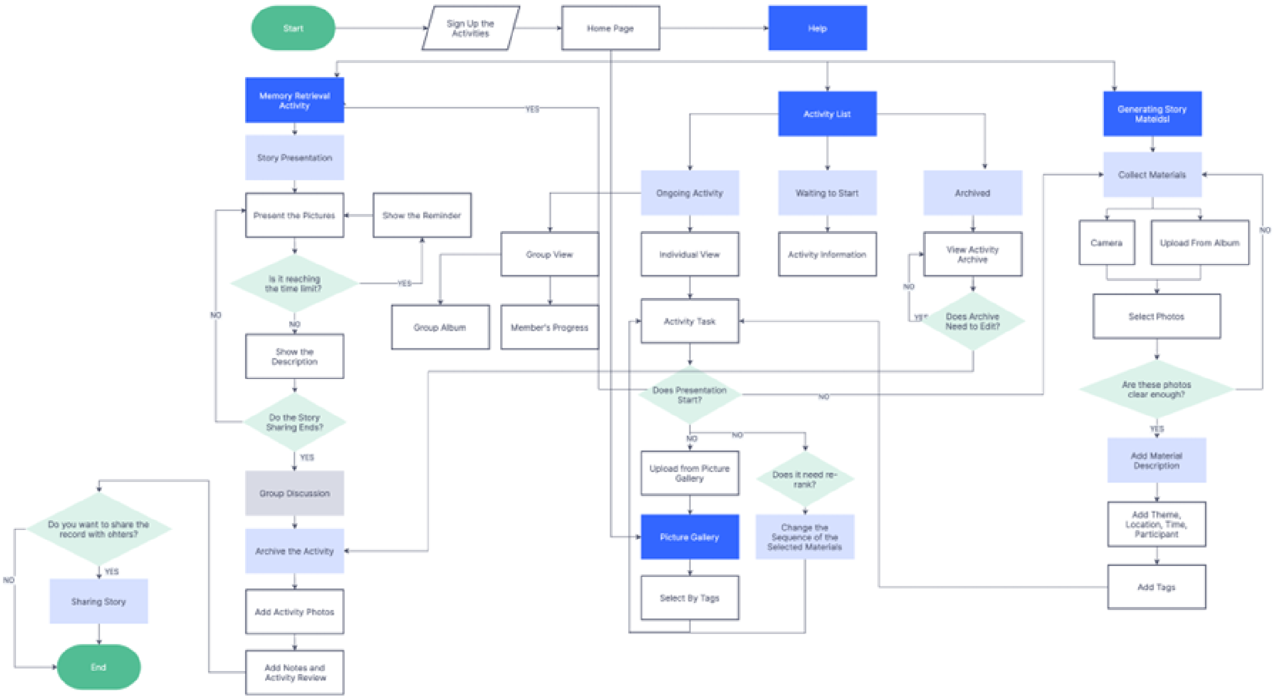
Developing the First Prototype of Huiyou

The first digital prototype of Huiyou (Figure 7) was produced in JiShiSheJi [41], a web-based free software prototype design and development tool, following an iterative process of co-design workshops and feedback collected from the meetings. The software name 会友, Huiyou, derived from the Pinyin pronunciation, means "meeting new friends" in Chinese. It is inspired by a classic quote from Confucius in the Analects: “A gentleman seeks friendship through literature and reinforces goodness through friendship.” This statement emphasizes the idea that individuals cultivate friendships through literary exchange and support virtue through companionship. The name reflects a positive vision of fostering social connections through literature, friendship, and benevolence. Users can leverage technological means through the software to expand their social circles, facilitating deeper communication and connections with others. The name embodies the social nature of the software and its goal of promoting friendship. Huiyou effectively stores memories from daily life and encourages people with MCI to reminisce and discuss favorable memories with new friends. Huiyou has 2 main features: supporting people with MCI to conduct self-reflection daily (preparing materials with cues) on certain topics and facilitating group memory retrieval (presenting a story and promoting a discussion with group members). Two innovative aspects of Huiyou are embedded memory retrieval for capturing daily life and its ability to collect recent, valuable memories. Another such feature is combined self-reflection and group reflection to enhance social interaction during the discussion, in addition to sharing and participating in social activities outside the home.

Figure 7. Huiyou prototype: home page.

As Figure 8 illustrates, the process of registering an activity on the Huiyou application begins with the user navigating from the home page to the activity page, where they can browse and select the activity they wish to register for; they then upload the material and edit it on the active page. When an event is about to commence, the user enters the event details page from the home screen. Next, they enter the activity and encounter a start screen for analyzing memories. The activity may be recorded and shared with others. If the user has any issues with the software, they can click the help button to discover operation guidelines.

Figure 8. Workflow of Huiyou. A higher resolution version of this figure can be found in Multimedia Appendix 1.



Stage 3 Findings: User Testing

Results From Task Analysis

Through this comprehensive usability testing stage, we identified minor areas of improvements in the interaction logic and interface layout to optimize user experience. In the 22 tasks, the participants scored an average success rate of 59% without assistance and 87% with assistance from the facilitator. Most challenges were identified to be associated with the direction of interaction; after knowing the direction, the success rate increased. Table 4 lists 5 tasks within the Huiyou digital storytelling application that demonstrated notably high usability, with completion rates exceeding 90% when performed individually. These tasks included “upload pictures” and “recording new materials,” both of which achieved perfect task completion rates of 100% with facilitator assistance. In addition, tasks such as “entering speech mode,” “find speech prompts,” and “insert a group photo after the event” also exhibited exceptional usability, with 92% individual task completion rates and 100% task completion rates with facilitator assistance.

This effectively communicates that within the Huiyou digital storytelling application, 5 tasks have a completion rate ≤75%, indicating the need for improvement. Tasks such as “add material description,” “browse registration activities,” and “switch the view of the activities” exhibited relatively lower individual task completion rates of 8%, whereas the presence of a facilitator notably enhanced completion rates to 58%. Similarly, the “judge whether the speech is too long on the page” and “enter the activity interface” tasks had initial completion rates of 25%, which significantly improved to 75% with facilitator assistance. These findings emphasize areas where the application’s UI and task guidance may benefit from refinement to ensure a more user-friendly and accessible experience, particularly for people with MCI.

Table 4. Task descriptions and completion rates of people with mild cognitive impairment (n=12).

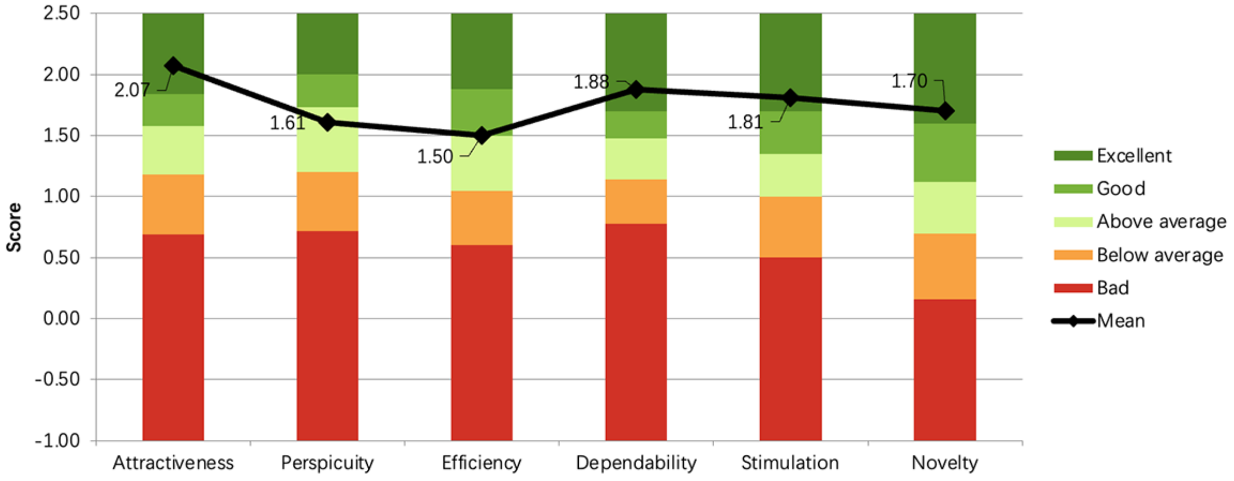
Features and task	Task completion without assistance, n (%)	Task completion with facilitator assistance, n (%)
Generating story materials		
Upload pictures	11 (92)	12 (100)
New materials for text input	6 (50)	10 (83)
New materials for voice input	7 (58)	10 (83)
Record new materials	12 (100)	12 (100)
Add material description	1 (8)	7 (58)
Add material tags	9 (75)	11 (92)
Edit material permissions	5 (42)	11 (92)
Enter my material	9 (75)	11 (92)
Change the sequence of materials	7 (58)	12 (100)
Browse registration activities	3 (25)	9 (75)
Enter the activity interface	6 (50)	9 (75)
Switch the view of the activities	1 (8)	7 (58)
Sign up for activities and add groups	5 (42)	9 (75)
View task progress	6 (50)	12 (100)
Enter task	10 (83)	11 (92)
Memory retrieval activity		
Enter speech mode	11 (92)	12 (100)
Find speech prompts	12 (100)	12 (100)
Judge whether the speech is too long on the page	3 (25)	9 (75)
Find the screen projection button	9 (75)	12 (100)
Sharing story		
Insert a group photo after the event	11 (92)	12 (100)
Use help features	4 (33)	10 (83)

Results From the UEQ

When comparing the ratings to the UEQ benchmark [36], it was noted that the application falls within the average and above range, suggesting that there is room for improvement. The combined ratings for all users, including both people with MCI and therapists organized by the value of each UEQ item can be seen in Figure 9, wherein the average score pertaining to attractiveness is 2.073 (SD 0.82), ease of use is 1.609 (SD 1.15), efficiency is 1.5 (SD 0.85), dependability is 1.875 (SD 0.76), stimulation is 1.813 (SD 0.96), and novelty is 1.703 (SD 1.33).

In the results obtained from the UEQ (7-point positive and negative scale; Figure 9), participants with MCI expressed favorable opinions about Huiyou, perceiving it as an enjoyable (mean 2.7, SD 0.6), supportive (mean 2.3, SD 0.7), clear (mean 2.5, SD 0.7), and friendly (mean 2.3, SD 0.8) application. However, they found learning challenging (mean 1.5, SD 1.9) and somewhat complex (mean 0.9, SD 2.1).

Figure 9. User Experience Questionnaire benchmark diagram for the Huiyou application.



Results From Usability Testing

On the basis of the interviews conducted and feedback collected during usability testing, we identified 15 usability issues to improve (Table 5). These issues were linked to the features of the application, including the home page and navigation, sign-up activities, adding material descriptions, changing the sequence of selected materials, sharing stories, uploading material, UI and design, and picture gallery. The main change was made to the home page (resolving the first usability issue in Table 5), addressing the user feedback that there was a lot of information on the home page and that the activity entrance was not clear, making it difficult to locate it quickly. One of the participants with MCI mentioned the following:

> *I'm not sure how to find the activities I want to participate in. The location of the activities should be more prominent. Those generated memories don't necessarily have to be on the first page.* [Stage 3, P3]

Therefore, notable enhancements included moving activity records to a separate tab, thereby streamlining the navigation and organization processes. In addition, more activity entries were added to the home page, providing users with a broader range of options. We followed all recommendations to redesign the Huiyou application.

Table 5. Usability issues and recommendations.

Features and issues	Recommendations
Home page and navigation	
There is a lot of information on the home page, and the activity entrance is not clear	• Show the activities list. Each activity may have a different status: ongoing activity (in a dark green rounded rectangle) and waiting to start (in a gray rounded rectangle) • Move the entrance of the "casually record fragmented information" feature from being suspended in the lower right corner to being fixed in the lower center
Category activity is hard to find	• Move activity records to a separate tab • Add more entries on the home page
Sign-up activities	
Activity registration setup issues	• Display activity registration first, followed by recent activities
Adding material description	
Unable to understand the edit permissions	• Change the heading to "invite others to edit"
Unable to find materials and view photos that have already been uploaded	• Integrate the image library and add tags • Allow easy switching and searching for images
Unable to understand content edit functions	• Change to content description, integrating the description on 1 page, including time, location, characters, events, and others • User should be able to add pictures' tags from material, including family, friend, sightseeing, group photo, and item
Changing the sequence of selected materials	
Unable to sort materials	• Provide operating instructions and make the font color of the instructions more eye-catching • Provide support for 2 sorting methods: drag and click
Sharing story	
The "share the screen" button is too small	• Make the screen projection button larger and highlight the color more prominently
Face-to-face discussions require no "raise hand" button	• Remove the "raise hand" button for inquiries in face-to-face discussions
Uploading material	
No need to find internet resources	• Delete the option of "upload material through internet"
User interface and design and picture gallery	
Need colorful and simple icons	• Update icons to be colorful, eye-catching, and more solid
The return icon is not prominent	• Increase the size of the return icon • Change the dark background of the "help" icon to a lighter background
Keyboard input and voice input	• Default voice input
The picture gallery contains too much information	• Reduce the number of images displayed in galleries and preset some images in advance

Discussion

Principal Findings

This study outlines the process and outcomes of co-designing and prototyping Huiyou, a digital storytelling application intended to facilitate social engagement and enhance the cognitive well-being of people with MCI in community-based settings. Insights collected from usability testing shed light on both strengths and areas for improvement in terms of user-friendliness and accessibility within the application's design and functionality. Furthermore, some functions have been simplified, including the path for uploading material without internet resources. People with MCI may take 15 minutes to collect the materials they want to present and 10 minutes to present their stories. Each story is original, proposed by people with MCI, and they may ask for the support of volunteers or caregivers. The storytelling process has 2 phases: preparation of materials and memory retrieval. Emphasizing the recollection of recent memories was found to encourage social engagement and foster a sense of belonging. Huiyou, the storytelling application used in this study, facilitated material generation by providing preset content prompts and allowing independent material collection, setting it apart from other interventions. During the memory retrieval activity, participants used personalized cues and multimedia elements, triggering meaningful conversations and connections. This study's findings suggested that storytelling themes for people with MCI should revolve around recent positive experiences and significant life periods. Notably, the application scored highly in attractiveness, dependability, stimulation, and novelty, although it required ease of use and efficiency enhancements. Recommendations for interface design included emphasizing crucial elements, minimizing cognitive complexity, and streamlining information presentation for improved user accessibility and experience.

Comparison With Prior Work

This research highlights the importance of selecting storytelling themes that evoke recent positive experiences for people with MCI in China. The emphasis on significant life stages and changes, excluding marital experiences, is supported by existing literature [37]. Surprisingly, the study observed a keen interest among older male adults in political subjects, deviating from expectations based on previous research on political engagement among older Chinese adults [42]. It is proposed that prioritizing recent positive memories through Huiyou can encourage social engagement, fostering a sense of belonging and participation among people with MCI. Huiyou facilitates the storytelling process for people with MCI through self-collected materials rather than preset content prompts [43,44], engaging them to share their stories. According to the Capability, Opportunity, and Motivation–Behavior (COM-B) system, Huiyou aims to enhance psychological capability, create social opportunities, organize social activities regularly, and reinforce reflective and automatic motivations. In addition, the following TDF components were embedded in the prototype: skills, social role and identity, beliefs about capabilities, goals, memory, attention and decision processes, and social influences. For example, Huiyou incorporates behavior change strategies in the TDF that involve social influence [45], such as group discussions that monitor group progress. As the therapists said, these design features can foster peer pressure, enhancing adherence to task completion and effectively facilitating the establishment of social connections. During group discussions, Huiyou implements the MESSAGE communication strategy to involve people with MCI actively. For instance, it allows users to add notes to materials, which are then displayed on the screen during memory retrieval. Unlike other interventions, Huiyou enables users to collect and arrange materials themselves, enhancing their sense of accomplishment and reducing the need for external support. The application's approach of facilitating material generation and arranging sequences aims to stimulate positive memories and encourage active engagement during the memory retrieval process. Therefore, Huiyou supports people with MCI in arranging the display sequences of materials, as OurStory does [23]. In memory retrieval activities, a substantial number of stimuli are prepared in advance and presented randomly to prompt older adults to narrate stories [46]. However, this approach relies on the divergent thinking abilities of older adults. Unfortunately, this method does not support the possibility of multiple stimuli coming together to form a more complete story. Unlike older adults with dementia, people with MCI possess the autonomy to select cues for their storytelling, fostering interpersonal connections and evoking positive emotions [47]. Personal topics serve as effective memory tests, enhancing storytelling and social memory [48]. Huiyou uses visual cues, music, and various technological platforms to stimulate memory retrieval and trigger discussions among older adults. By encouraging the recall of recent positive memories and promoting group discussions [49], Huiyou enhances the confidence of people with MCI, empowering them to actively participate in social interactions and community activities. Group discussions not only provide opportunities for self-expression but also foster reflection and inspiration from shared social experiences. Sharing recent memories via Huiyou fosters dialogue and active social engagement among individuals with MCI. They can either share their stories during group reminiscing sessions or record and distribute their memories to family and friends. Unlike some interventions that lack a structured approach to memory retrieval [50], Huiyou allows for the systematic recording and sharing of stories [51], primarily using WeChat as the chosen platform for its broad reach among friends and family.

Usability Issues of Huiyou

On the basis of the UEQ benchmark results diagram, Huiyou earned a place in the "excellent" category [36]. These insights serve as invaluable pointers for refining the user experience of the application. People with MCI typically adhere to a top-to-bottom, left-to-right reading pattern [52], emphasizing the importance of placing essential interactive elements at the center or the top of the screen. Furthermore, adopting a more noticeable design approach, such as incorporating colored buttons, may be beneficial. The cognitive complexity experienced by people is influenced by the quantity of content displayed on a single screen. Even subtle variations in interface design demand additional information processing time for people with MCI. To mitigate cognitive strain, it is advisable to minimize the amount of information displayed on each screen and segment tasks into more manageable steps.

Limitations

One limitation was the small number of participants with MCI throughout the study. To mitigate the impact of a small sample size, the research team invited the same participants to engage in multiple stages of the study, gathering diverse research data, including interview outcomes, hand-drawn interfaces, and usability task data, and introduced the perspective of caregivers of people with MCI. Reusing the participants was an efficient approach to prototype development and, to some extent, mitigated the impact on people with MCI as well as clinician time. Another limitation was that the Huiyou prototype was redesigned based on the participants' feedback; however, in this study, we did not evaluate the refined prototype. In the future, field testing with people with MCI will be used to measure the effectiveness of the tool in improving social participation.

Conclusions

We described the co-design processes of developing a digital storytelling intervention, Huiyou, in collaboration with people with MCI and caregivers. We then evaluated the user experience of the application based on the feedback of people with MCI, caregivers, and therapists. Huiyou incorporates story-sharing themes that align with the needs of people with MCI in China. These themes foster common topics and evoke positive emotions without delving into excessive privacy. Unlike traditional reminiscence therapy, it is confined to memory enhancement during intervention sessions, neglecting other potential intervention times. Huiyou transforms reminiscence into an everyday activity that individuals can engage in at their own convenience. This provides more opportunities to collect and cherish fond memories. Huiyou excelled in usability testing, earning an “excellent” rating in the UEQ benchmark for attractiveness, reliability, stimulation, and novelty. However, there is room for improvement in accessibility and efficiency. By combining social participation with the fostering of relationships and the stimulus to contact friends, the application not only promotes individual well-being but also meaningful social interactions and maintains vital relationships for people with MCI.

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Authors' Contributions

AAM and DZ conceptualized this study. DZ collected and analyzed the data. AAM directed several rounds of feedback and contributed significantly to the manuscript’s writing and revision. AAM and WL supervised the project. All the authors examined and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Higher resolution version of Figure 8.
[PNG File , 1075 KB - aging_v7i1e54138_app1.png]

References

1. Sommerlad A, Kivimäki M, Larson EB, Röhr S, Shirai K, Singh-Manoux A, et al. Social participation and risk of developing dementia. Nat Aging 2023 May 18;3(5):532-545. [doi: 10.1038/s43587-023-00387-0] [Medline: 37202513]
2. Smith L, Shin JI, López Sánchez GF, Oh H, Kostev K, Jacob L, et al. Social participation and mild cognitive impairment in low- and middle-income countries. Prev Med 2022 Nov;164:107230 [FREE Full text] [doi: 10.1016/j.ypmed.2022.107230] [Medline: 36057392]
3. Townsend BG, Chen JT, Wuthrich VM. Barriers and facilitators to social participation in older adults: a systematic literature review. Clin Gerontol 2021;44(4):359-380. [doi: 10.1080/07317115.2020.1863890] [Medline: 33393443]
4. Hughes TF, Flatt JD, Fu B, Chang CC, Ganguli M. Engagement in social activities and progression from mild to severe cognitive impairment: the MYHAT study. Int Psychogeriatr 2012 Dec 21;25(4):587-595. [doi: 10.1017/s1041610212002086]
5. Heins P, Boots LM, Koh WQ, Neven A, Verhey FR, de Vugt ME. The effects of technological interventions on social participation of community-dwelling older adults with and without dementia: a systematic review. J Clin Med 2021 May 25;10(11):2308 [FREE Full text] [doi: 10.3390/jcm10112308] [Medline: 34070660]
6. Cotterell N, Buffel T, Phillipson C. Preventing social isolation in older people. Maturitas 2018 Jul;113:80-84. [doi: 10.1016/j.maturitas.2018.04.014] [Medline: 29903652]
7. Levasseur M, St-Cyr Tribble D, Desrosiers J. Meaning of quality of life for older adults: importance of human functioning components. Arch Gerontol Geriatr 2009 Sep;49(2):e91-100. [doi: 10.1016/j.archger.2008.08.013] [Medline: 18977542]
8. Long KM, Casey K, Bhar S, Al Mahmud A, Curran S, Hunter K, et al. Understanding perspectives of older adults on the role of technology in the wider context of their social relationships. Ageing Soc 2022 Sep 19:1-24. [doi: 10.1017/s0144686x2200085x]
9. Li FM, Chen DL, Fan M, Truong KN. FMT: a wearable camera-based object tracking memory aid for older adults. Proc ACM Interact Mob Wearable Ubiquitous Technol 2019 Sep 09;3(3):1-25. [doi: 10.1145/3351253]
10. Greenaway MC, Duncan NL, Smith GE. The memory support system for mild cognitive impairment: randomized trial of a cognitive rehabilitation intervention. Int J Geriatr Psychiatry 2013 Apr;28(4):402-409 [FREE Full text] [doi: 10.1002/gps.3838] [Medline: 22678947]
11. Reel CD, Allen RS, Lanai B, Yuk MC, Potts DC. Bringing art to life: social and activity engagement through art in persons living with dementia. Clin Gerontol 2022 Jun 08;45(2):327-337. [doi: 10.1080/07317115.2021.1936737] [Medline: 34100338]

12. Rios Rincon AM, Miguel Cruz A, Daum C, Neubauer N, Comeau A, Liu L. Digital storytelling in older adults with typical aging, and with mild cognitive impairment or dementia: a systematic literature review. J Appl Gerontol 2022 Mar 19;41(3):867-880 [FREE Full text] [doi: 10.1177/07334648211015456] [Medline: 34009053]
13. Yu K, Wild K, Dowling NM, Kaye JA, Silbert LC, Dodge HH. Emotional characteristics of socially isolated older adults with MCI using tablet administered NIH toolbox: I-CONECT study. Alzheimers Dement (Amst) 2022 Nov 11;14(1):e12372 [FREE Full text] [doi: 10.1002/dad2.12372] [Medline: 36381558]
14. Zhu D, Al Mahmud A, Liu W. Social connections and participation among people with mild cognitive impairment: barriers and recommendations. Front Psychiatry 2023;14:1188887 [FREE Full text] [doi: 10.3389/fpsyt.2023.1188887] [Medline: 37476544]
15. Barsuglia JP, Nedjat-Haiem FR, Shapira JS, Velasco C, Jimenez EE, Mather MJ, et al. Observational themes of social behavioral disturbances in frontotemporal dementia. Int Psychogeriatr 2014 May 20;26(9):1475-1481. [doi: 10.1017/s104161021400091x]
16. Al Mahmud A, Long KM, Harrington KD, Casey K, Bhar S, Curran S, et al. Developing a digital psychoeducational tool to reduce loneliness in older adults: a design case study. Int J Hum Comput Interact 2021 Aug 04;38(6):499-528. [doi: 10.1080/10447318.2021.1949854]
17. Brushwood Rose C. The subjective spaces of social engagement: cultivating creative living through community-based digital storytelling. Psychoanal Cult Soc 2016 Dec 21;21(4):386-402. [doi: 10.1057/pcs.2015.56]
18. Stargatt J, Bhar S, Bhowmik J, Al Mahmud A. Digital storytelling for health-related outcomes in older adults: systematic review. J Med Internet Res 2022 Jan 12;24(1):e28113 [FREE Full text] [doi: 10.2196/28113] [Medline: 35019845]
19. Gucciardi E, Jean-Pierre N, Karam G, Sidani S. Designing and delivering facilitated storytelling interventions for chronic disease self-management: a scoping review. BMC Health Serv Res 2016 Jul 11;16:249 [FREE Full text] [doi: 10.1186/s12913-016-1474-7] [Medline: 27401836]
20. Wang JJ, Yen M, OuYang WC. Group reminiscence intervention in Taiwanese elders with dementia. Arch Gerontol Geriatr 2009 Sep;49(2):227-232. [doi: 10.1016/j.archger.2008.08.007] [Medline: 18930560]
21. Wu LF. Group integrative reminiscence therapy on self-esteem, life satisfaction and depressive symptoms in institutionalised older veterans. J Clin Nurs 2011 Aug;20(15-16):2195-2203. [doi: 10.1111/j.1365-2702.2011.03699.x] [Medline: 21631615]
22. Brandão L, Bauer MA, Haas AN, Silveira RD, Alves CP, Souza DN, et al. Playing remotely in times of crisis: a program to overcome social isolation. Int J Geriatr Psychiatry 2021 Oct 10;37(1):10.1002/gps.5638 [FREE Full text] [doi: 10.1002/gps.5638] [Medline: 34628669]
23. Critten V, Kucirkova N. 'It brings it all back, all those good times; it makes me go close to tears'. Creating digital personalised stories with people who have dementia. Dementia (London) 2019 Apr 05;18(3):864-881. [doi: 10.1177/1471301217691162] [Medline: 28161989]
24. Qi S, Sun Y, Yin P, Zhang H, Wang Z. Mobile phone use and cognitive impairment among elderly Chinese: a national cross-sectional survey study. Int J Environ Res Public Health 2021 May 26;18(11):5695 [FREE Full text] [doi: 10.3390/ijerph18115695] [Medline: 34073323]
25. Chonody J, Wang D. Connecting older adults to the community through multimedia: an intergenerational reminiscence program. Act Adapt Aging 2013 Jan;37(1):79-93. [doi: 10.1080/01924788.2012.760140]
26. Elfrink TR, Ullrich C, Kunz M, Zuidema SU, Westerhof GJ. The online life story book: a randomized controlled trial on the effects of a digital reminiscence intervention for people with (very) mild dementia and their informal caregivers. PLoS One 2021 Sep 15;16(9):e0256251 [FREE Full text] [doi: 10.1371/journal.pone.0256251] [Medline: 34525105]
27. Sarne-Fleischmann V, Tractinsky N, Dwolatzky T, Rief I. Personalized reminiscence therapy for patients with Alzheimer's disease using a computerized system. In: Proceedings of the 4th International Conference on PErvasive Technologies Related to Assistive Environments. 2011 Presented at: PETRA '11; May 25-27, 2011; Heraklion, Greece. [doi: 10.1145/2141622.2141679]
28. McCauley CO, Bond RB, Ryan A, Mulvenna MD, Laird L, Gibson A, et al. Evaluating user engagement with a reminiscence app using cross-comparative analysis of user event logs and qualitative data. Cyberpsychol Behav Soc Netw 2019 Aug;22(8):543-551. [doi: 10.1089/cyber.2019.0076] [Medline: 31403855]
29. Goh AM, Doyle C, Gaffy E, Batchelor F, Polacsek M, Savvas S, et al. Co-designing a dementia-specific education and training program for home care workers: the 'Promoting Independence Through Quality Dementia Care at Home' project. Dementia (London) 2022 Apr 09;21(3):899-917. [doi: 10.1177/14713012211065377] [Medline: 35135380]
30. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr 23;6:42 [FREE Full text] [doi: 10.1186/1748-5908-6-42] [Medline: 21513547]
31. Conway ER, Chenery HJ. Evaluating the MESSAGE communication strategies in dementia training for use with community-based aged care staff working with people with dementia: a controlled pretest-post-test study. J Clin Nurs 2016 Apr 29;25(7-8):1145-1155. [doi: 10.1111/jocn.13134] [Medline: 26821868]
32. Smith ER, Broughton M, Baker R, Pachana NA, Angwin AJ, Humphreys MS, et al. Memory and communication support in dementia: research-based strategies for caregivers. Int Psychogeriatr 2010 Sep 20;23(2):256-263. [doi: 10.1017/s1041610210001845]

33. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc 2005 Apr;53(4):695-699. [doi: 10.1111/j.1532-5415.2005.53221.x] [Medline: 15817019]
34. Robinson L, Brittain K, Lindsay S, Jackson D, Olivier P. Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. Int Psychogeriatr 2009 Feb 5;21(03):494. [doi: 10.1017/s1041610209008448]
35. Park E, Owens H, Kaufman D, Liu L. Digital storytelling and dementia. In: Proceedings of the Human Aspects of IT for the Aged Population. Applications, Services and Contexts. 2017 Presented at: ITAP 2017; July 9-14, 2017; Vancouver, BC. [doi: 10.1007/978-3-319-58536-9_35]
36. Schrepp M, Hinderks A, Thomaschewski J. Design and evaluation of a short version of the user experience questionnaire (UEQ-S). Int J Interact Multimed Artif Intell 2017;4(6):103-108. [doi: 10.9781/ijimai.2017.09.001]
37. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
38. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019 Jun 13;11(4):589-597. [doi: 10.1080/2159676x.2019.1628806]
39. NVivo 12. Lumivero. URL: https://lumivero.com/products/nvivo/ [accessed 2023-06-18]
40. Schrepp M. User experience questionnaire handbook. User Experience Questionnaire. URL: https://www.ueq-online.org/Material/Handbook.pdf [accessed 2023-12-17]
41. Home page. Gees AI. URL: http://gees.ai/ [accessed 2023-12-25]
42. Xie B, Jaeger PT. Older adults and political participation on the internet: a cross-cultural comparison of the USA and China. J Cross Cult Gerontol 2008 Mar 24;23(1):1-15. [doi: 10.1007/s10823-007-9050-6] [Medline: 17957462]
43. Zheng M, Zhang X, Xiao H. Effects of a WeChat-based life review program for patients with digestive system cancer: 3-arm parallel randomized controlled trial. J Med Internet Res 2022 Aug 25;24(8):e36000 [FREE Full text] [doi: 10.2196/36000] [Medline: 36006665]
44. Li C, Lin X, Kang K, Hu J, Hengeveld B, Hummels C, et al. Interactive gallery: enhance social interaction for elders by story sharing. In: Ioannides M, Martins J, Žarnić R, Lim V, editors. Advances in Digital Cultural Heritage. Cham, Switzerland: Springer; 2018.
45. Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. Implement Sci 2012 Apr 24;7:37 [FREE Full text] [doi: 10.1186/1748-5908-7-37] [Medline: 22530986]
46. Moon S, Park K. The effect of digital reminiscence therapy on people with dementia: a pilot randomized controlled trial. BMC Geriatr 2020 May 06;20(1):166 [FREE Full text] [doi: 10.1186/s12877-020-01563-2] [Medline: 32375661]
47. Niedderer K, Holthoff-Detto V, van Rompay TJ, Karahanoğlu A, Ludden GD, Almeida R, et al. This is me: evaluation of a boardgame to promote social engagement, wellbeing and agency in people with dementia through mindful life-storytelling. J Aging Stud 2022 Mar;60:100995 [FREE Full text] [doi: 10.1016/j.jaging.2021.100995] [Medline: 35248311]
48. Astell AJ, Ellis MP, Alm N, Dye R, Gowans G. Stimulating people with dementia to reminisce using personal and generic photographs. Int J Comput Healthc 2010;1(2):177. [doi: 10.1504/ijcih.2010.037461]
49. Kinsella GJ, Mullaly E, Rand E, Pike KE, Reilly A, Cavuoto MG. Bridging the gap between clinical trials and community care: translating a memory group for older people with mild cognitive impairment into a community-based organisation. Australas J Ageing 2020 Jun;39(2):e168-e177. [doi: 10.1111/ajag.12724] [Medline: 31532074]
50. Lancioni GE, Singh NN, O'Reilly MF, Sigafoos J, Ferlisi G, Zullo V, et al. A computer-aided program for helping patients with moderate Alzheimer's disease engage in verbal reminiscence. Res Dev Disabil 2014 Nov;35(11):3026-3033. [doi: 10.1016/j.ridd.2014.07.047] [Medline: 25124700]
51. Filoteo JV, Cox EM, Split M, Gross M, Culjat M, Keene D. Evaluation of ReminX as a behavioral intervention for mild to moderate dementia. In: Proceedings of the 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC). 2018 Presented at: 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC); July 18-21, 2018; Honolulu, HI. [doi: 10.1109/embc.2018.8513049]
52. Castilla D, Suso-Ribera C, Zaragoza I, Garcia-Palacios A, Botella C. Designing ICTs for users with mild cognitive impairment: a usability study. Int J Environ Res Public Health 2020 Jul 17;17(14):5153 [FREE Full text] [doi: 10.3390/ijerph17145153] [Medline: 32708861]

Abbreviations

COM-B: Capability, Opportunity, and Motivation–Behavior
MCI: mild cognitive impairment
MESSAGE: maximizing attention, focusing on expression and body language, keeping it simple, providing support for their conversation, assisting with aids, getting their message, and encouraging and engaging in conversation
TDF: Theoretical Domains Framework

UEQ: User Experience Questionnaire
UI: user interface

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Original Paper

Experiences of Older Adults, Physiotherapists, and Aged Care Staff in the TOP UP Telephysiotherapy Program: Interview Study of the TOP UP Interventions

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Abstract

Background: Telehealth provides opportunities for older adults to access health care. However, limited research exists on the use of telehealth within aged care services, particularly regarding physiotherapy-led fall prevention and mobility programs. Understanding the experiences and interactions of older adults, physiotherapists, and aged care service providers is crucial for the scale-up and sustainability of such essential programs. The TOP UP study, a hybrid type 1 effectiveness-implementation randomized controlled trial in aged care, used a supported multidisciplinary telephysiotherapy model to motivate older adults to engage in exercises to improve mobility and reduce falls.

Objective: This qualitative substudy aims to achieve 2 primary objectives: to describe the experiences and acceptability of the TOP UP intervention for older people, physiotherapists, and aged care support workers and managers and to gain an in-depth understanding of program implementation.

Methods: A purposive recruitment strategy was used to select 18 older adults who participated in the TOP UP intervention, ensuring variation in age, gender, residential status (home or residential aged care), geographic location, and cognitive levels. In addition, 7 physiotherapists, 8 aged care support workers, and 6 managers from 7 different aged care provider partners participated in this study. Semistructured interviews were conducted to explore stakeholders’ experiences with the TOP UP program, gather suggestions for improvement, and obtain insights for the future implementation of similar telephysiotherapy programs. The interview framework and coding processes were informed by behavior changes and implementation frameworks. Data were analyzed using an abductive approach, informed by 2 behavioral change theories (Capability, Opportunity, Motivation, and Behavior Model and Self-Determination Theory) and the Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies framework.

Results: All participants (n=39) reported high levels of acceptability for the TOP UP program and cited multiple perceived benefits. The thematic analysis generated 6 main themes: telephysiotherapy expands opportunity; tailored physiotherapy care with local support enhances motivation; engaging, older adult–friendly educational resources build capability; flexible reablement approach fosters autonomy; telephysiotherapy is safe, effective, and acceptable for many; and organizational commitment is required to embed telehealth. The motivation to exercise was enhanced by Zoom’s convenience, use of tailored web-based exercise resources, and companionable local support.

Conclusions: This study highlights the inherent value of telephysiotherapy in aged care, emphasizing the need for investment in staff training, local support, and older adult–friendly resources in future telephysiotherapy iterations. TOP UP represents a convenient and flexible web-based care model that empowers many older adults to receive sustainable, high-quality care precisely when and where they need it.

Trial Registration: Australian New Zealand Clinical Trials Registry (ANZCTR) ACTRN 1261000734864; https://anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12621000734864

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KEYWORDS

physiotherapy; telehealth; telephysiotherapy; exercise; aged care; qualitative methods; behavior change; technology; virtual care

Introduction

Background

The proportion of older people in the population is increasing worldwide. From 2020 to 2050, the number of older people aged ≥60 years will double to 2.1 billion, representing 22% of the world's population [1]. By 2050, the number of people aged ≥80 years is expected to triple to 426 million [1]. Older people experience poor mobility and higher rates of falls than younger people, leading to significant morbidity, mortality, and poor quality of life [2-4]. Poor mobility and falls are 2 of the biggest cost drivers in hospital and aged care services [2,5]. In 2021, a total of 10.7% of people aged ≥65 years living in the Organization for Economic Co-operation and Development countries received long-term care, either at home or in care facilities, costing these governments 1.5% of the gross domestic product [6,7]. Aged care spending has increased over the last 15 years in most Organization for Economic Co-operation and Development countries, and population aging will continue to increase the demand on stretched health care systems [7].

Strong evidence supports the effectiveness and cost-effectiveness of physiotherapy-led exercise programs for enhancing mobility and reducing falls in aged care settings [8]. However, the Australian Royal Commission into Aged Care highlighted significant barriers to accessing mobility-promoting and fall prevention interventions delivered by allied health professionals, such as physiotherapists [9]. Qualitative evidence suggests that (referred and defined in this manuscript as telephysiotherapy) could be a feasible, acceptable, and effective approach for delivering mobility and fall prevention programs to older adults living in the community [10]. Telephysiotherapy could be particularly advantageous in increasing access and convenience for people with travel constraints and mobility limitations or who live in regional and remote areas [11].

Telerehabilitation that has provided telephysiotherapy has been found to have similar effectiveness compared with in-person rehabilitation services for community-dwelling older people, and it shows no increased risk of adverse events [12]. However, there is no evidence supporting the effectiveness, cost-effectiveness, and implementation feasibility of telephysiotherapy for improving mobility, reducing falls, and enhancing the quality of life for older adults receiving aged care services in their homes or residential aged care.

Telehealth is currently being used in aged care, but there is limited guidance on how best to implement it [13]. Hybrid effectiveness and implementation research has been shown to accelerate research translation into clinical practice [14]. Implementation research explores the experience of a complex intervention such as telehealth and its relationship to other factors, such as intervention engagement and adherence, perceived effectiveness, acceptability, and self-efficacy, which can support implementation translation [15].

The TOP UP Trial

TOP UP is designed to provide a scalable solution for delivering physiotherapy exercise interventions via telehealth to improve mobility, reduce falls, and enhance the quality of life in aged care. The TOP UP program was developed in collaboration with our aged care partners, physiotherapists, and aged care service users and their caregivers. A series of workshops identified potential facilitators to improve older people's engagement with technology and motivation to exercise. The program's co-design was also influenced by behavior change models, such as Self-Determination Theory (SDT) [16] and the capability, opportunity, motivation, and behavior (COM-B) framework [17].

TOP UP is investigating synchronous and asynchronous care to optimize both personalized health care and self-directed exercise [18] in aged care settings. It involves the delivery of real-time physiotherapy assessments through videoconferencing (synchronous telehealth) using the Zoom app (Zoom Video Communications Inc) by older adults receiving aged care services at home or in residential care. These service users are given access to evidence-based exercise videos on the TOP UP website and the StandingTall app (asynchronous telehealth) to support their exercise program. Each participant has the weekly support of a trained aged care worker to help them access the Zoom app and follow the exercise program. The outcomes being measured include effectiveness (mobility, falls, and quality of life), cost-effectiveness, and implementation measures (acceptability, reach, fidelity, dose delivered, and adoption).

The program is being tested in a hybrid type 1 effectiveness-implementation randomized controlled trial. Older adults were screened by their aged care service providers. Eligibility criteria included the age of older people (≥65 years); possessing sufficient physical, sensory, cognitive, and English language skills to participate; and having individual consent or consent from the person responsible. Those with terminal or unstable illness, with severe dementia, having participated in a similar physiotherapy program in the previous year, or being unable to walk 10 m were excluded from the study. A total of 242 participants were recruited from a screening pool of 1348 aged care service users (older people).

A total of 242 participants (120 per group) will provide 80% power to detect a 0.9 point between-group difference in 12-point

Short Physical Performance Battery test scores at 6 months (assuming SD 2.8, *P*=.05, and 20% dropouts) [19]. A 0.5-point between-group difference in the Short Physical Performance Battery test was considered clinically significant. This sample size was expected to be sufficient to detect between-group differences of 10% to 15% for the secondary outcome measures. Quantitative data analysis is expected to be completed in 2024.

Participants randomized to the intervention group received 10 videoconference physiotherapy sessions over 6 months using the Zoom app and received an individualized balance and strength exercise program. These exercise programs are based on the World Health Organization 2020 guidelines on physical activity and sedentary behavior [20] and the Otago exercise programs [21]. Existing aged care support staff, called “coaches,” have been trained to supervise participants to access the technology and provide “hands-on” exercise support once per week with the assistance of exercise videos designed by the research team. The waitlist control group receives a 3-month version of the program once the intervention period at each site is completed.

To inform the successful development of programs such as TOP UP, it is essential to examine not just if but how and why TOP UP worked (or not) and what strategies could best improve it. The aim of this paper was to use interview data to provide detailed insights into the experiences of older people, physiotherapists, coaches, and aged care managers with the telephysiotherapy intervention. The objective was to understand how contextual factors mediate the delivery of the TOP UP program and to produce transferable lessons for the potential use of future telephysiotherapy in aged care [22].

Methods

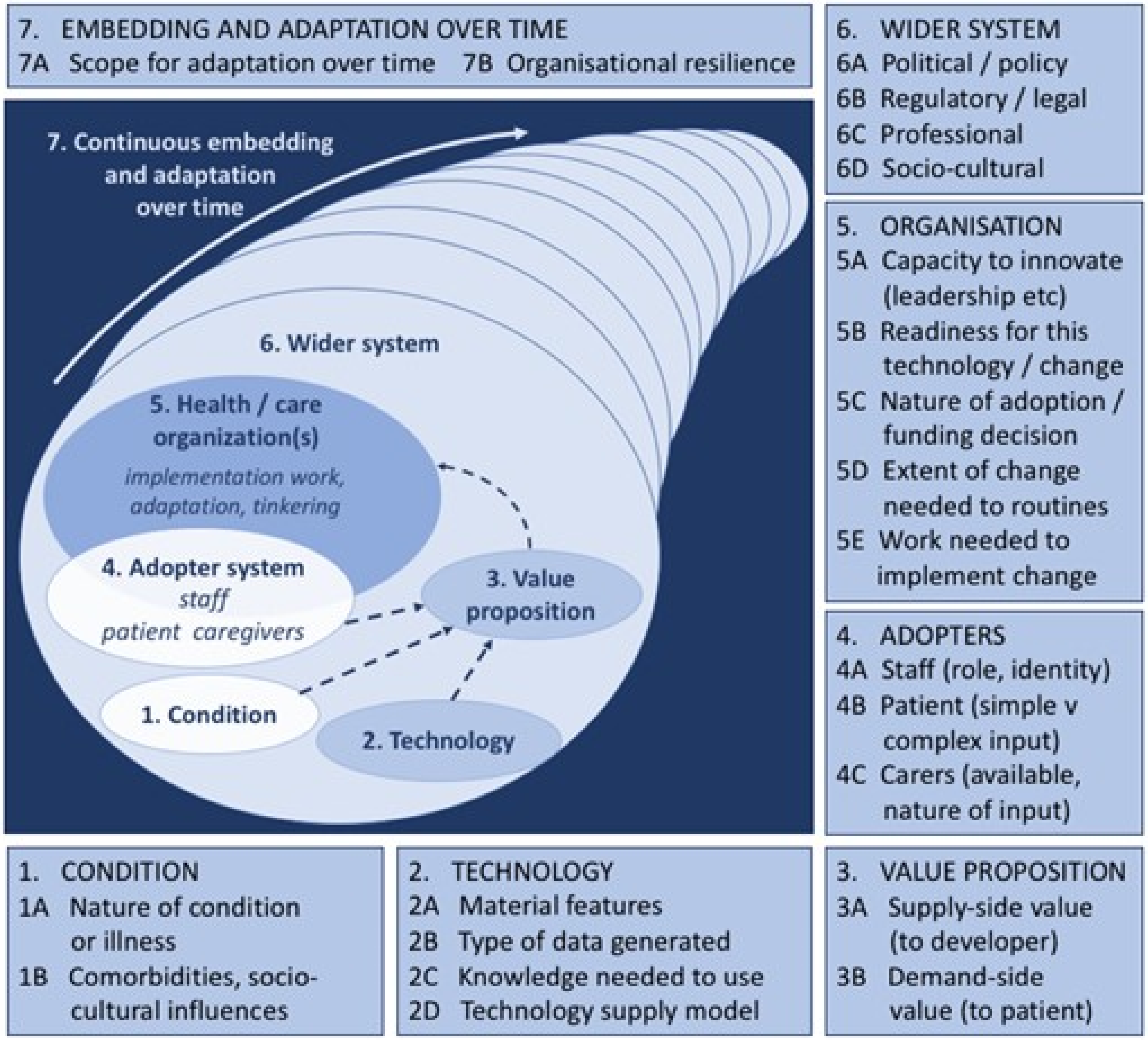
Study Design and Context

This study used a qualitative, descriptive approach through semistructured one-on-one interviews [23]. Qualitative description is increasingly used in conjunction with effectiveness and implementation trials and aims to present a straightforward description of participants’ experiences [24]. The analysis is grounded in the participants’ own words, making the results accessible to vulnerable groups, valid, highly translatable, and useful for refining interventions [25]. Qualitative description sits within a constructivist paradigm, considers multiple meanings, and recognizes that the research process is never neutral [26]. To strengthen the research rigor, we included triangulated data sources (by drawing on perspectives of different stakeholder groups) and a reflective discussion of emergent findings among the multidisciplinary research team [27].

Conceptual Framework

We used 2 behavior change theories, COM-B and SDT, and the Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies (NASSS) framework to provide a conceptual “lens” to inform data collection and analysis [28]. The COM-B model of behavior change proposes that to engage in a behavior such as exercise (B), a person must be physically and psychologically capable (C) and have the opportunity (O) to engage in the behavior, as well as the motivation to do so (M). COM-B simplifies complex factors and recognizes that to modify behavior, we need to address at least one of these components [17]. SDT focuses on the motivation underpinning behavior change, positing that effective programs must support autonomy, competency, and relatedness [16]. The NASSS framework is an evidence-based, theory-informed, and pragmatic framework that can help predict and evaluate the success of a technology-supported health program. It consolidates multiple implementation frameworks, targeting key issues relating to the implementation and uptake of telehealth at the microlevel of individual staff and consumers, the mesolevel challenges of organizational engagement and adoption, and macrolevel policy and regulatory factors (Figure 1) [28].

Figure 1. The Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies framework.



Recruitment and Data Collection

At the initial TOP UP recruitment, all aged care service users, coaches, physiotherapists, and aged care managers received an information sheet inviting them to participate in an interview for this qualitative study. After participants read the informational letter and confirmed their interest in participating in an interview, they received an informed consent letter to be signed by themselves or their person responsible before the interview appointment. A list of potential aged care service users and their coaches and physiotherapists was created in consultation with 3 of our aged care partners (Ashfield Baptist Homes, Whiddon, and Uniting AgeWell).

A purposive recruitment strategy was used to select 18 older adults who participated in the TOP UP intervention, ensuring variation in age, gender, residential status (home or residential aged care), geographic location, and cognitive levels. All 39 participants contacted agreed verbally and in writing before and on the day of the Zoom interview. None of the participants declined to participate in the interviews. The interviews were conducted 3 to 6 months after the interviewees commenced the program. Recruitment was stopped at the point when data adequacy had been reached, that is, when we judged that we had sufficient rich data across our purposive sample with which to answer our research questions [29].

The interview guide was created in consultation with the wider research team and representatives from our aged care partners (Multimedia Appendix 1). Interview questions targeted concepts from the COM-B model, SDT, and NASSS framework (described earlier). Specific questions explored the relative value of the different components of TOP UP (eg, Zoom, exercise videos, and the level of support provided). Questions regarding its implementation and effectiveness were also included. We also asked interviewees to identify local and potential system-wide barriers and facilitators to the successful adoption of telephysiotherapy, such as TOP UP and other programs aimed at delivering fall prevention and mobility programs in aged care. We used open-ended questions and active listening to confirm our understanding of the interviewees’ perspectives. RD and KN conducted the interviews individually on Zoom. They were involved in the delivery of the program, so to reduce sociability bias, interviewees were encouraged to critique the TOP UP program and its implementation to identify improvements [30].

Aged care participants had a family member or someone familiar to them from their aged care organization that was not their coach to assist them with connection to the Zoom app and to support them through the interview. The participants were reminded that they could stop the interview at any time. No repeat interviews were conducted. RD and KN completed memos after the interviews and met to discuss the data and the emerging thematic content. Interview audio recordings were automatically transcribed using Zoom's free transcription service, and transcripts were corrected by RD. Transcripts were not returned to the participants.

Data Analysis

The transcripts and interview field notes were uploaded to NVivo 12 (Lumivero) for data management and coding [31]. The transcripts were coded by one researcher (RD) using an abductive analytical approach. RD drafted an initial thematic framework drawing on emergent themes in the data and was informed by domains from the NASSS framework. In total, 2 researchers (RD and AH) tested and refined the coding framework on 2 manuscripts, adding codes and modifying existing codes from inductively identified concepts in the data. RD coded the remaining data. RD, CS, and AH met regularly to discuss emergent codes and themes.

Recurrent themes were generated from reading across the coded data and reviewed against concepts from SDT [16] and the COM-B framework [17,29] to understand how aspects of the TOP UP program influenced exercise engagement. An early overview of the findings was discussed with all coauthors and our consumer representative to explore a wider range of possible thematic interpretations and to help ensure that we had answered our research questions, including considering the implications of our findings. Disagreements were resolved through discussion. The criteria for reporting qualitative research was used as a reporting checklist (Multimedia Appendix 2) [32].

Ethical Considerations

Ethics approval for this qualitative substudy was included in the TOP UP study approval granted by the Ethics Review Committee at the Sydney Local Health District Research Ethics and Governance Office, Concord, Australia (approval number CH62/6/2021-009). The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN 1261000734864).

Results

Participants

In total, 39 people participated in semistructured interviews: 18 (46%) aged care service users who completed the TOP UP program, 7 (18%) aged care physiotherapists, 8 (21%) coaches, and 6 (15%) aged care managers. Interviews took an average of 19 (range 8-53) minutes. These service users were aged from 70 to 93 (median 87.5) years at the start of the intervention; 11 (61%) were female and 7 (39%) were male; 11 (61%) used a 4-wheeled walking frame to walk and 7 (39%) did not need a walking aid to walk; 7 (39%) lived in metropolitan cities in New South Wales and 11 (61%) lived in rural or remote areas in New South Wales and Victoria; 6 (33%) had mild to moderate cognitive impairment and 12 (77%) had no cognitive impairment; all had multiple comorbidities (median 7, range 2-11); and 10 (56%; median 1, range 1-7) had one or more falls in the last 12 months. The median Technology Readiness Index score was 2 out of 5 (range 1-3.9), which classified aged care users as technology *avoiders*, people who tend to have a high degree of resistance and a low degree of motivation to use technology [33]. A total of 4 (22%) aged care service users had used phone-based telehealth before with their general practitioner, but none had used a videoconferencing app such as Zoom before the study or used telehealth to receive physiotherapy.

Of the 7 physiotherapists interviewed, 4 were based in metropolitan areas and 3 were based in rural areas. A total of 4 coaches supported aged care service users from residential aged care, and 4 coaches supported aged care service users from home aged care. In addition, 1 aged care manager worked at a remote residential aged care site, 1 managed a rural residential aged care site, and 4 were home care managers from rural areas.

Main Findings

Overview

Our qualitative analysis revealed that all interviewees found the TOP UP program to be acceptable and would recommend similar telephysiotherapy programs to other older people receiving aged care services. Thematic analysis generated 6 key themes related to the experiences of TOP UP. We also compiled evidence of these experiences to identify and manage emergent possibilities, uncertainties, and interdependence that could guide the adoption of telephysiotherapy in aged care using the NASSS framework. Quotations were used to illustrate each theme. We annotated the quotes for anonymity with aged care service users referred to as P1, P2, and so on, and other stakeholders are descriptively described.

Theme 1: Telephysiotherapy Expands Opportunity

Theme 1 highlights the expanded opportunities for accessing the physiotherapy that TOP UP provided. TOP UP minimized barriers to physiotherapy access related to travel and associated costs:

> *Travel in country areas is just too hard and having telehealth in the home makes it so easy to do. I can't do a 70 km round trip – it is too expensive.* [P10]

This was also echoed by service users whose significant disabilities created access barriers:

> *Because of my health, there's no way I can go out to see a physio. One, I've got to get someone to take me, like a relation, or pay someone to take you, it's not practical. It's hard to park anywhere near the physio, you've got to walk, so by the time you get to the physio you're exhausted.* [P1]

All the physiotherapists and aged care service managers indicated that telehealth could deliver physiotherapy care efficiently, improving opportunities for older adults receiving aged care services to receive physiotherapy where and when they need it:

> *Some people need to be able to see a physio quickly, and we can provide telehealth services quickly, it is so efficient.* [Home care physiotherapist, metro]

TOP UP had the greatest impact on rural and remote services, especially in areas where telehealth has the potential to address chronic health inequity issues related to workforce shortages:

> *Our town has a physio that visits once a month. Recently, one of our residents had a fall so I called the clinic and found out that we can't get an appointment to take our resident to see a physio for 6 weeks, if someone has a fall like this, we just can't wait six weeks. Telehealth really helps us.* [Residential manager, remote]

Theme 2: Tailored Physiotherapy With Local Support Enhances Motivation

Regular local support was identified by all interviewees as important for enhancing older people's confidence to try the exercise program and to support their motivation to "stick with" the program, including coping with TOP UP's increasing challenge over time. Many interviewees across the 4 stakeholder groups explained that it was not just physical and technological support that the coaches offered (eg, providing stand-by assistance while performing balance exercises and managing the Zoom app) but also companionship and emotional support:

> *I can't get out much and I began to look forward to the weekly session with my care worker as I really appreciated the support, she gave me to do something positive for my health. My coach understood what was going on in my life and she gave me the confidence to keep doing the exercises.* [P12]

All the physiotherapists interviewed indicated that the coaches' "hands-on" support was vital to the success of the program, as it helped to build capability and confidence. Importantly, TOP UP was a tailored program in which physiotherapists were able to modify exercises according to the individual needs of each service user, mirroring the person-centered approach typical in-person physiotherapy sessions. This tailored approach was particularly important to aged care service users whose health changes required program adaption:

> *My physio understood that I needed a break when I had some surgery, but was ready for me when I got back home and quickly helped me regain the fitness that I had lost in the hospital.* [P18]

The TOP UP program used technology and behavior change techniques to maximize program adherence. Zoom provided physiotherapists with a platform to deliver individualized real-time health coaching and goal setting, which has been shown in the literature to increase participant adherence [34]. Interview data indicated that these techniques were being used across program implementation, consistent with the behavior change theory:

> *Physiotherapists start with building external motivation by setting goals, by encouraging them, and highlighting their progress we help them develop internal motivation to keep going. If we can motivate them internally, half the job is done, and exercise will become a routine and a lifestyle habit.* [Home care physiotherapist, metro]

Further evidence emerged that these techniques were having the desired effect:

> *Their motivation seemed to improve when they reached their goals, and they wanted to keep on trying. Their motivation is the most important thing.* [Residential coach, metro]

However, it was the combination of live tailored physiotherapy with enthusiastic and companionable local support that seemed to both develop confidence and underpin motivation:

> *The individual sessions on Zoom were important, so I could ask some questions about how I was doing, and having my physio give me some individual feedback was important for my confidence to keep exercising. My coach has made it possible, and her support has been great, she is so lively, and she exercises with me which makes it fun, we had such a laugh, she keeps me motivated, and she takes the monotony out of it. If you are not having fun, it is not worth it.* [P10]

The previous quote also highlights the vital role of enjoyment in exercise and how this can be enhanced with a trained support worker acting as a coach. This may be especially important for engagement in the TOP UP program, given that many of the physiotherapists interviewed suggested that telehealth requires more time to develop a therapeutic alliance. Therapeutic alliance refers to how people experience the empathy of clinicians, and research shows that a strong therapeutic alliance is connected to positive treatment adherence and results in physical therapy [35]:

> *It's not until you get to the fourth or fifth telehealth session that people start getting to really know you and feel like you can be an advocate for them. I think that telehealth does allow for a personal connection which adds to exercise adherence.* [Physiotherapist, home care, rural]

TOP UP physiotherapists and coaches' person-centered approach to goal setting, highlighting progress during the program and celebrating any achievements, seemed to enhance the aged care service user's motivation to exercise:

> *TOP UP helped me care about my future before I just didn't care. I loved the way the physio explained things to me carefully, so I understood. I really appreciate having the support worker exercise with me and reinforce what to do, and how to do the exercises. All of this made me feel like I mattered and now I can walk further, do my shopping, which is a big improvement.* [P12]

Theme 3: Engaging, Older Adult–Friendly Educational Resources Build Capability

Interviewees expressed enthusiasm for the instructional videos that were designed to support high-quality independent exercises throughout the program. The videos incorporated exercises modeled by an older person, slow-paced dialog in a warm conversational style, natural lighting to maximize visibility, minimal visual distractions, and gentle humor, all of which seemed to increase exercise engagement by older people. In the following quotes, 2 participants describe the importance of “seeing” another older person in web-based videos:

> *It was great to see an older person do the exercises, really motivating to see someone my age doing the program. The videos were at the right pace, and I like how they got harder over time. It was fun.* [P17]
>
> *The exercise videos are motivating because I feel like I am doing it with someone – it’s interactive and fun. Following a book can be boring.* [P5]

Many stakeholders commented positively on the video design that incorporated slow demonstration and simple dialog that aimed to teach aged care service users how to perform safe and effective home exercise:

> *The physiotherapist in the videos demonstrated the exercises slowly and explained things easily. I was really surprised how the residents were able to follow everything without any help.* [Residential coach, metro]
>
> *Having online exercise resources really helps because people aren’t familiar with exercise techniques, they can follow their prescribed video and it helps keep their exercise dose up.* [Home care physiotherapist, regional]

Many of the physiotherapists interviewed commented that the TOP UP program was complex and challenged participants to navigate different apps and printed resources such as exercise diaries while using Zoom. They suggested that simpler telephysiotherapy programs (or simpler mechanisms for accessing program components) could be developed to enhance the user experience and minimize program dropout. One physiotherapist commented:

> *I think having an easy to navigate, no fuss system where our clients can look up an exercise, record their exercise program and any problems they may have had, a fall, etc. I think an app where physiotherapists could get access to this information easily during a session and to help prepare for another session would be useful.* [Home care physiotherapist, rural]

Theme 4: A Flexible Reablement Approach Fosters Autonomy

TOP UP is designed to encourage older adults to take a lead in their program planning; flexibility is emphasized, including choices about what resources to use (printed and web-based) and what skills they wish to develop that would enable them to engage in activities they found most important:

> *I liked how it started easily, and I moved my way up the program. There is structure to the program, and you commit to it. I often plan to do a session but if something comes up, I make an appointment with myself to make sure I do it another time.* [P16]
>
> *I liked that I could stop and start the videos according to my own needs on the day.* [P1]

This can be described as a reablement approach, and the physiotherapist and coaches were encouraged to build the aged care service users’ physical capability and support them in transferring their new skills to access other activities in their community independently:

> *Residents lack enough physical activity here, sometimes we are short staffed, and sometimes the staff don’t have time to help. It was great to see our residents on the TOP UP program improve their mobility and begin to walk to different activities on their own.* [Residential manager, rural]

All stakeholders valued the reablement approach, and it was reported that TOP UP seemed to be a catalyst for reablement, as many of their clients began to engage in more socialization with friends and families and embrace other physical activities as they became stronger and more mobile:

> *Physios and coaches can work together to ensure that the participant becomes independent and autonomous in their use of telehealth and do more exercise as the program progresses. As they improved, we had discussions with them and their coach about how they could do more outdoor walking.* [Home care physiotherapist, rural]
>
> *I was surprised about the other quality of life benefits of telehealth, talking to their physio on zoom, seeing their support workers in this new way, learning how to get out and about in the community, all seemed to reduce social isolation, which is so important for our customers.* [Home care manager, rural]

Theme 5: Telephysiotherapy Can Be Safe, Effective, and Acceptable for Many

Most interviewees regarded TOP UP as a safe, effective, and acceptable program. Interviewees reported positive physical and quality of life improvements:

> *I think it’s fabulous. I wouldn’t have imagined that I would be given the opportunity to get physio. Physically, I can walk further. My breathing is better. I’m stronger, it gives you more independence.* [P1]
>
> *Telehealth has not only helped my customer’s strength, mobility and coordination, but it seemed to help their overall quality of life, they seemed happier and more confident to walk.* [Residential care manager, rural]

Many interviewees reported that the combination of physiotherapist-led instructional exercise videos and supervision by trained support workers increased the safety of the TOP UP:

> *I think having a physio run exercises in the videos gives the intervention more authority, frees up my*

> *time to motivate the residents and keep them safe.* [Residential coach, remote]
>
> *I think having the care worker there with the client to help set up Zoom, hold the iPad, and angling the video so I can see them clearly makes the program safer and more successful.* [Home care physiotherapist, rural]

However, TOP UP was not considered to be suitable for all aged care service users. All stakeholders agreed that telehealth presents challenges for frail clients in residential aged care, who often have higher levels of mobility and sensory and cognitive disability. A total of 2 cognitive and sensory impaired aged care service users found using Zoom to "see" their physiotherapist frustrating and as a result, pulled out of the program:

> *First of all, not all dementia residents get used to it, and second, people with hearing and vision problems struggle to follow.* [Residential aged care manager, rural]

Some physiotherapists would hesitate to use telehealth without local support for those aged care service users with high fall risks:

> *For people who are mostly independent I wasn't worried, but if I did have someone who was who was frailer and there was no one there with them I was worried they might fall.* [Home care physiotherapist, regional]

Some aged care service users and managers suggested that although telephysiotherapy is a good secondary option, they would still prefer in-person physiotherapy, especially for older adults with more complex needs:

> *I prefer a blend of face-to-face physio and telehealth. I need some hands-on physio from time to time to manage the arthritis in my back, but I liked the telehealth program because I could follow the physio exercise videos at home, it was so convenient.* [P18]

It appears that a hybrid model that incorporates a blend of face-to-face physiotherapy and web-based exercise resources, such as exercise videos, was viewed as particularly acceptable for those with significant health challenges:

> *I don't know if someone with severe dementia or disabilities would be able to access telehealth. I also think a lot of clients would like a hybrid telehealth model starting with a face-to-face assessment.* [Home care physiotherapist, rural]

Finally, our screening process uncovered many technological hesitations and potential telehealth data concerns that prevented the recruitment of many potential aged care service users into the TOP UP trial:

> *There is some hesitancy around technology use due to recent cybersecurity anxiety in the community- for example the Optus and Medibank breaches.* [Home care manager, rural]

Theme 6: Organizational Commitment Is Required to Embed Telephysiotherapy

Interviewees explained that considerable organizational commitment is required to embed telehealth programs such as TOP UP in aged care. Sufficient investment is required to train staff, conduct more meetings with their physiotherapy service providers to plan for the development of a new service, such as telephysiotherapy, prioritize TOP UP sessions within busy service schedules, and, where necessary, direct funds toward supportive technology. Some coaches and physiotherapists commented that the use of devices such as large iPads and smart televisions enhanced telehealth engagement by improving the visibility and hearing experience of service users:

> *Zoom worked well when we connected the iPad to the TV, we were able to turn the volume of the TV up so the resident could hear better. It also gives a bigger picture as well, so they can see the physio better.* [Residential care coach, rural]

However, such equipment can be costly, and telehealth-specific funding was raised by physiotherapy, aged care managers, and coaches as a key condition for ongoing sustainability of telephysiotherapy in aged care:

> *I think that maybe there needs to be funding support. Telehealth is an important and easy way to increase access and uptake. One physio could service several homes in a full-time caseload.* [Residential care physiotherapist, rural]

TOP UP required 3 people to be available for appointments (the older person, their coach, and the physiotherapist on Zoom); thus, scheduling was more challenging than 2-person face-to-face health care interactions:

> *There are always challenges whenever it comes to scheduling, especially during COVID when we were short of staff. But if you have a good relationship with your physiotherapy provider, who is responsive to time slot suggestions, then our scheduling team could work their magic and get it all booked.* [Home care manager, rural]

Training was provided to older adults to increase their confidence using an iPad, our website, and relevant apps (Zoom and StandingTall). Coaches were trained to increase their level of comfort by navigating the TOP UP website and Zoom. Physiotherapists were trained to deliver effective telephysiotherapy assessments using Zoom and provided strategies to enhance relationship development with older adults and their coaches. All interviewees highlighted this training as an important factor in overcoming "telehealth hesitancy" both for service users and program providers:

> *There was a lot of telehealth hesitancy at the beginning, but with education they slowly got quite comfortable in doing it.* [Home care physiotherapist, metro]
>
> *There is a need to have some general training so we [physiotherapists] know how to use it [telehealth technology] effectively: make sure your voice is coming through, how to pace instruction so our clients*

> *understand us. The coaches and customers need training to know how to set up a shot, to make sure that they are visible to ensure that the client becomes independent and autonomous in their use of telehealth.* [Home care physiotherapist, rural]

The aged care service managers also noted the challenge of training adequate numbers of care workers to facilitate TOP UP and ensure that the coaches are safe and competent:

> *There is a need to train a large proportion of our support workforce so that we have more trained staff who know how the program works, how to use technology and how to supervise our customers safely.* [Home care manager, rural]

Some aged care service managers and physiotherapists indicated that more frequent and more detailed web-based exercise training programs would be useful to improve the skill level of a wider group of support staff:

> *It is very important to have lots of staff trained. For example, if the regular coach is sick, another staff member could take over and keep the program going.* [Home care manager, rural]

All stakeholders indicated the need for specific investment into better internet connectivity to ensure the sustainability of future telephysiotherapy programs:

> *I've found is there are still a lot of places in rural Australia where older people don't have fast Internet, they don't have smart TVs, or they don't have the technology that metro places have. People are ready to engage with telehealth, but there's no infrastructure in rural areas.* [Residential physiotherapist, metro]

Implementation Guidance Through the Lens of the NASSS Framework

TOP UP appears to be well positioned for sustainable adoption, and learnings from this study have informed the translation of telephysiotherapy services by our aged care partners into practice. Table 1 uses the NASSS framework to help explain TOP UP's successes and failures and explore the facilitators required to embed similar telephysiotherapy programs in aged care.

Table 1. An overview of TOP UP implementation guidance in relation to the Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies framework domains.

Domain	Definition of domain	Implementation guidance derived from study findings	Illustrative quotes from interviewees
The condition	The suitability of the participant's attributes/needs and their interaction with the intervention.	TOP UP is suitable for aged care service users with mobility challenges who can walk short distances. It is not suitable for those with significant sensory and cognitive disability	"Someone with severe dementia or severe disabilities would not be able to have that skill to access telehealth." [Residential coach, rural]
The technology	Technical features related to the usability of telehealth and its support requirements.	TOP UP requires access to the internet via an iPad or similar device. Aged care service users do not need technological skills due to the weekly support they received from trained care workers to help them use the iPad, navigate Zoom, and access exercise videos on a website. However, basic technological skills were often developed, which increased autonomy.	"One of my clients is really good with technology but other clients need my help to turn on the iPad and follow the program." [Residential coach, metro]
The value proposition	The value proposition of telehealth for upstream end users (aged care service providers) and downstream users (physiotherapists and their clients).	All stakeholders saw telephysiotherapy as a valuable addition because of its convenience and perceived effectiveness, especially for those with poor mobility or who are living in rural or remote areas. The value proposition for telehealth to treat musculoskeletal pain is less as stakeholders prefer a more "hands-on" experience. A hybrid model would add value for some.	"Telehealth would save us time and travel and help us to see more people." [Home care physiotherapist, regional]
The adopter system	The ongoing investment required to support the telehealth intervention and the ongoing acceptability of stakeholders.	TOP UP requires consistent investment in training, human (physio, coaches), and physical infrastructure (devices, fast internet, senior-friendly exercise resources) to create sustainable success. However, high levels of system support are likely to be reinforced as positive returns on investment due to their perceived positive impacts on mobility and well-being.	"TOP UP is more than just a fall prevention program, it offers a truly reablement focus where our clients can build their strength and balance and get out into the community again. I think many of our clients could benefit from telehealth." [Home care manager, rural]
The organization	An organization's capacity to embrace the telehealth intervention and the supports required to establish and maintain it as a viable service offering.	Not all aged care services chose to participate in TOP UP because of the perceived burden of working with technology. Providers who joined TOP UP wanted to investigate telehealth's impact on access to fall prevention and mobility programs, in areas where there are physiotherapy shortages. Providers offered considerable support via technology provision, extra administration support for scheduling of telephysiotherapy sessions, and enough care workers to support the program.	"I was surprised at how easy telehealth was to get started. We gave the clients an iPad and the assistance the care workers gave them was important to help them engage with telehealth. Our scheduling team are fantastic, and they managed to solve the scheduling challenges really well." [Home care manager, rural]
The wider context	The wider organizational and policy impacts on telehealth uptake and sustainability.	Stakeholders agreed that funders need to provide telehealth-specific funding and education for interventions such as TOP UP to reduce technology hesitation and improve telehealth systems that enhance its adoption and sustainability.	"I feel that people would be greatly advantaged if there was a separate pocket of funding for allied health so that we could afford to deliver ongoing telehealth" [Home care manager, rural]

Discussion

Principal Findings

This study, which included participants such as older adults, physiotherapists, aged care support workers, and managers in the TOP UP trial, offers valuable insights. Our thematic analysis identified key factors for the telephysiotherapy program's acceptability, including advice from physiotherapists, consistent support from trained care workers, older adult–friendly web-based exercise resources, and a flexible reablement approach. The interview data supported multiple themes, suggesting that the synergistic integration of these ingredients within the TOP UP contributed to its high acceptability. The discussion explores the impact of single components and emphasizes their combined contribution to TOP UP's acceptability.

TOP UP Study Is Acceptable

Acceptability is an important consideration in the design and implementation of complex health care interventions, such as TOP UP [36]. Our findings align with the increasing body of literature indicating acceptance of telehealth among older adults in community settings despite high levels of technology hesitation [37,38]. A cohort study of a telehealth program incorporating physiotherapy for rural older adults found that telehealth was safe (no adverse events) and feasible (average telehealth attendance 85%) [38]. A 2021 cross-sectional survey of health care providers further affirmed increasing telehealth acceptability over time among homebound older adults [39].

Barriers and Facilitators Related to Telehealth Adoption

TOP UP identified several barriers and facilitators that enabled aged care service users to overcome high levels of technology hesitation and, if appropriately addressed, could improve the translation of telehealth programs into aged care [40]. TOP UP's qualitative findings are reflected in the literature, which demonstrate that barriers related to this population's innate technology hesitation and greater sensory, physical, and cognitive impairments could be addressed by the provision of local support, internet-connected devices, fast internet, and appropriate telehealth training can mitigate these barriers [39,41,42].

A recent US survey of physician providers of homebound older adults during the COVID-19 pandemic revealed that a significant proportion of their patients were technology avoidant [39] (only a third of their patients had used video-based telehealth before, 310/873, 35.5%). Among patients who had not used telehealth before, providers deemed that one in 4 (153/563, 27.5%) of their patients would not be able "interact over video" due to cognitive or sensory impairments. This survey found other barriers: providers lacked knowledge of their patients' internet connectivity, and participants faced financial constraints in obtaining internet plans and were unable to pay for internet plans or video-capable devices. Similar findings emerged in the TOP UP, where most trial participants had limited access (10/18, 56%) to video-capable devices, limited telehealth experience (4/18, 22%), and low telehealth readiness (Technology Readiness Index 2 out of 5). Addressing barriers related to the purchase of telehealth infrastructure and providing local support can facilitate wider acceptance within aged care settings.

A recent qualitative exploration of factors influencing acceptability in dementia management revealed that videoconferencing had potential benefits over in-person appointments by improving access to care for those with mobility limitations and reducing the stress associated with clinic appointments [43]. A crucial insight from this study emphasized the necessity of technical support and telehealth training involving information on how to access and use different telehealth apps and tips for setting up the video camera for maximum visibility. Similarly, another study examining telehealth's role in enhancing oncology care for older adults emphasized that appropriate technology training integrated into the screening process and program delivery could enhance telehealth adoption [44]. These studies align with TOP UP's findings that emphasized the delivery of appropriate education at screening and recruitment to reduce technology avoidant behaviors, preprogram technology training to support adoption, and training to troubleshoot any emerging technology issues to enhance sustainability.

TOP UP demonstrated that behavior change training for physiotherapists and coaches in health coaching techniques, motivational interviewing, and collaborative goal setting can facilitate telehealth adoption. Behavior change training has been shown to increase therapeutic alliance and enhance exercise program outcomes in other studies [45]. A strong therapeutic alliance has been identified as a crucial facilitator in previous telehealth interventions [46]. In our study, physiotherapists, coaches, and aged care service users found telehealth suitable for effective behavioral change coaching and suggested that specific training on skills to enhance therapeutic alliance is important to augment telehealth acceptability. Specific examples included targeted training on using Zoom emojis to acknowledge client achievements and building a personal connection through virtual tours of the older person's home and garden. However, they noted that establishing a successful therapeutic alliance through telehealth demands more time compared with in-person sessions, potentially increasing program costs.

Telehealth Can Provide Key Ingredients for Behavior Change

TOP UP was co-designed to incorporate the COM-B model to create positive behavior changes related to exercise adherence [17]. Recent data from the Australian Institute for Health and Welfare have shown the critical significance of addressing insufficient physical activity in older individuals, given their 50% contribution to 2.5% of the overall disease burden in Australia [47]. Consequently, increasing motivation and opportunities for exercise in this demographic is crucial in mitigating the adverse health consequences stemming from sedentary behavior [19] and in supporting the efficiency of the health care system [48]. TOP UP's tailored approach and use of older adult–friendly resources appeared to increase the capability (C) of older adults to exercise. The program provided increased opportunities (O) for exercise by facilitating increased access to physiotherapists. Furthermore, TOP UP heightened motivation (M) through its reablement approach, goal-setting mechanisms, and cultivation of enjoyment via companionable coaching [16].

The TOP UP program strategically incorporated the principles of SDT to promote increased exercise adherence. According to SDT, intrinsic motivation thrives when individuals perceive a sense of autonomy and control over their activities [49]. Our study findings suggest that the aged care service users valued the opportunity to regain independence through self-directed exercise. The TOP UP program effectively nurtured feelings of competence through its personalized and progressive exercise routines program, fostering a sense of relatedness through local support and the rapport established during the telephysiotherapy sessions that actively promoted enjoyment. This observation aligns with the systematic review by Teixeira et al [50] on SDT and exercise adherence, affirming the positive correlation between intrinsic motivation, enjoyment, personal achievement, and heightened program acceptability.

Our study has provided insights into the potential explanatory effects of the social learning theory by Bandura [51] and Motivational Theory of Role Modeling in supporting the high acceptability of TOP UP. The social learning theory by Bandura [51] underscores the significance of observation and imitation in driving behavior change. When individuals perceive the modeled behavior as valuable, and the model possesses an admired status while being relatable, the likelihood of behavioral change increases. In this context, physiotherapists, esteemed as exercise professionals in the community [52], played a crucial role in enhancing the perceived value of the TOP UP program. Furthermore, the Motivational Theory of Role Modeling highlights another critical aspect of TOP UP's acceptability [53]. Many interviewees emphasized the importance of including older adults as role models in exercise videos. Both theories suggest that the inclusion of older role models was a pivotal factor inspiring behavioral change, explaining the positive reception of TOP UP exercise videos.

Scale-Up and Sustainability of Telephysiotherapy in Aged Care

Telehealth has emerged as a prominent method for implementing scalable health care interventions, a trend that has intensified during the COVID-19 pandemic [54]. However, the challenge of sustaining these programs is pressing, as is evident from reports of high participant attrition rates in telehealth-led exercise programs [55]. Successfully delivering cost-effective exercise programs to frail older adults with multiple comorbidities in the aged care environment is challenging and complex, demanding significant resourcing [8]. Insights gained from the NASSS framework [28] underscore the need for careful screening of older adults for telephysiotherapy participation and the provision of targeted training to all stakeholders to enhance its feasibility. Our analysis indicates that while TOP UP was acceptable, a hybrid model of virtual care that combines in-person initial assessments, subsequent synchronous telephysiotherapy sessions for program progression, and the integration of local support and older adult–friendly web-based exercise resources may further increase telephysiotherapy uptake and sustainability in aged care.

Although the cost-effectiveness analysis of TOP UP is pending, our qualitative observations indicate that establishing telephysiotherapy programs requires substantial investment in both physical and human infrastructure. The telehealth literature discusses the critical role governments play in developing policies and guidelines to foster telehealth adoption [56]. Our interviews revealed a consensus on the need for dedicated funding for telehealth to enhance adoption and sustainability.

Strengths, Limitations, and Future Studies

This qualitative study had several strengths. It triangulates empirical data relating to the uptake and sustainability of telephysiotherapy in aged care from 4 perspectives: older adults receiving physiotherapy within aged care services, physiotherapists, trained support workers who deliver the intervention, and aged care managers who are charged with case management and overseeing aged care service resource allocation and delivery. Our partnerships with aged care providers and their ongoing input in the research have enabled us to develop a deep understanding of how the TOP UP program was delivered in aged care and, if proven effective, this will speed up its translation into wider practice [14].

Qualitative research serves as a valuable tool for refining program design, deepening insights into the outcomes of quantitative research, and offering valuable guidance for enhancing the implementation of complex interventions such as telephysiotherapy in aged care [26]. In this study, we adopted a broad sampling strategy aimed at delivering a rich description of diverse intervention experiences, enlisting the perspectives of 18 older adults encompassing a range of sociodemographic characteristics distributed across 10 distinct sites. Moreover, the inclusion of independent physiotherapists, separate from both the aged care service partners and the research team, in our study design may have reduced potential social desirability bias, enhancing the credibility of our findings [30].

Several limitations of this study necessitate careful consideration. TOP UP excluded participants from culturally and linguistically diverse backgrounds and thus presented a notable gap in our understanding of their experiences. To address this gap, future trials that prioritize the inclusion of culturally and linguistically diverse communities are required. In addition, although the interviewee cohort was purposefully selected to encompass maximum variation, it is essential to acknowledge that this pool primarily consisted of individuals who voluntarily participated in the trial, potentially predisposing them to higher levels of exercise engagement and receptiveness to telehealth. Consequently, this may limit the generalizability of our findings.

Several aged care service users and coaches were interviewed by either a physiotherapist or aged care service provider who delivered the program. This can lead to social desirability biases, which may undermine the credibility of the study results [57]. Given this context, aged care service users and staff might hesitate to openly share negative experiences with their interviewers despite the research team’s assurances that their feedback would have no bearing on their ongoing care or employment status. To mitigate this bias, interviewers made concerted efforts to positioning themselves as eager learners, actively encouraging interviewees to share their “insider” perspectives on quality improvement and expressing genuine appreciation for any criticism offered. Future larger-scale mixed methods studies should be designed to enhance research quality and further explore the impact of telephysiotherapy uptake and sustainability in aged care while carefully addressing social desirability bias.

This study suggests a need for the development of simplified telephysiotherapy exercise programs to facilitate greater adoption in aged care. A recent scoping review conducted in 2021, examining the barriers and facilitators to the use of telehealth by older adults, found several impediments associated with current technology, including challenges related to small screens, text size, small icons, insufficient color contrast between text and background, and complex functionality [58]. The review also identified ease of use as a key facilitator of telehealth adoption. Some TOP UP stakeholders interviewed indicated a preference for simplified functionality tailored to this demographic. Respondents expressed a desire for telehealth programs that incorporated TOP UP program features such as Zoom, exercise diaries, and videos, into one user-friendly application. These findings advocate for further research aimed at enhancing the user experience.

Conclusions

This interview study explored the program experiences of aged care service users, physiotherapists, and aged care staff involved in the TOP UP trial, a telehealth-led exercise program designed to improve mobility, reduce falls, and enhance quality of life. All stakeholders indicated high program acceptability, underscored by its safety, and perceived effectiveness. The thematic analysis uncovered key insights: TOP UP’s provision of convenient access to physiotherapy services for aged care recipients, the positive impact of tailored physiotherapy coupled with local support on exercise motivation, the effectiveness of engaging older adult–friendly resources in fostering program adherence, and the facilitation of greater independence through a flexible reablement approach. This study emphasizes the importance of sustained organizational commitment for the successful implementation of telephysiotherapy programs, such as TOP UP, highlighting the need for training and external funding to ensure telephysiotherapy's adoption and sustainability.

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Data Availability

The data sets generated during this study are not publicly available because of the confidentiality promised to the participants as part of the informed consent process. However, data sets are available from the corresponding author upon reasonable request.

Authors' Contributions

All authors reviewed the thematic analysis. RD, AH, and KN drafted the semistructured interview guide. RD drafted the manuscript as the lead author. All authors critically revised the manuscript for intellectual content.

Conflicts of Interest

RD receives scholarship funding, and JO receives salary support from the National Health and Medical Research Council–funded Centre for Research Excellence—Prevention of Fall-related Injuries. MP holds a National Health and Medical Research Council of Australia Early Career Fellowship. KN is employed by Whiddon, and NB is employed by Uniting AgeWell. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Semistructured interview guide.
[DOCX File , 17 KB - aging_v7i1e53010_app1.docx]

Multimedia Appendix 2
The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.
[DOCX File , 16 KB - aging_v7i1e53010_app2.docx]

References

1. Ageing and health. World Health Organization. 2022 Oct 1. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2023-03-16]
2. People using aged care. Australian Institute of Health and Welfare. 2023 Apr 26. URL: https://www.gen-agedcaredata.gov.au/Topics/People-using-aged-care [accessed 2023-03-16]
3. Vaishya R, Vaish A. Falls in older adults are serious. Indian J Orthop 2020 Feb 24;54(1):69-74 [FREE Full text] [doi: 10.1007/s43465-019-00037-x] [Medline: 32257019]
4. Davis JC, Bryan S, Best JR, Li LC, Hsu CL, Gomez C, et al. Mobility predicts change in older adults' health-related quality of life: evidence from a Vancouver falls prevention prospective cohort study. Health Qual Life Outcomes 2015 Jul 15;13(1):101 [FREE Full text] [doi: 10.1186/s12955-015-0299-0] [Medline: 26168922]
5. de Vries M, Seppala LJ, Daams JG, van de Glind EM, Masud T, van der Velde N. Fall-risk-increasing drugs: a systematic review and meta-analysis: I. Cardiovascular drugs. J Am Med Dir Assoc 2018 Apr;19(4):371.e1-371.e9 [FREE Full text] [doi: 10.1016/j.jamda.2017.12.013] [Medline: 29396189]
6. Health at a glance 2021: OECD indicators 2021. Organisation for Economic Cooperation and Devolpment. URL: https://www.oecd-ilibrary.org/sites/4c4694a2-en/index.html?itemId=/content/component/4c4694a2-en [accessed 2023-03-16]
7. Spending on long-term care. Organisation for Economic Cooperation and Devolpment. 2020 Nov. URL: https://www.oecd.org/health/health-systems/Spending-on-long-term-care-Brief-November-2020.pdf [accessed 2023-03-16]

8. Hewitt J, Saing S, Goodall S, Henwood T, Clemson L, Refshauge K. An economic evaluation of the SUNBEAM programme: a falls-prevention randomized controlled trial in residential aged care. Clin Rehabil 2019 Mar 30;33(3):524-534. [doi: 10.1177/0269215518808051] [Medline: 30375234]
9. Aged care quality and safety. Royal Commissions. URL: https://agedcare.royalcommission.gov.au/publications/final-report [accessed 2023-03-16]
10. Batsis JA, DiMilia PR, Seo LM, Fortuna KL, Kennedy MA, Blunt HB, et al. Effectiveness of ambulatory telemedicine care in older adults: a systematic review. J Am Geriatr Soc 2019 Aug;67(8):1737-1749 [FREE Full text] [doi: 10.1111/jgs.15959] [Medline: 31066916]
11. Kaambwa B, Ratcliffe J, Shulver W, Killington M, Taylor A, Crotty M, et al. Investigating the preferences of older people for telehealth as a new model of health care service delivery: a discrete choice experiment. J Telemed Telecare 2017 Feb;23(2):301-313. [doi: 10.1177/1357633X16637725] [Medline: 26985004]
12. Laver KE, Adey-Wakeling Z, Crotty M, Lannin NA, George S, Sherrington C. Telerehabilitation services for stroke. Cochrane Database Syst Rev 2020 Jan 31;1(1):CD010255 [FREE Full text] [doi: 10.1002/14651858.CD010255.pub3] [Medline: 32002991]
13. Shulver W, Killington M, Crotty M. 'Massive potential' or 'safety risk'? Health worker views on telehealth in the care of older people and implications for successful normalization. BMC Med Inform Decis Mak 2016 Oct 12;16(1):131 [FREE Full text] [doi: 10.1186/s12911-016-0373-5] [Medline: 27733195]
14. Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. Med Care 2012 Mar;50(3):217-226 [FREE Full text] [doi: 10.1097/MLR.0b013e3182408812] [Medline: 22310560]
15. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. BMC Health Serv Res 2017 Jan 26;17(1):88 [FREE Full text] [doi: 10.1186/s12913-017-2031-8] [Medline: 28126032]
16. Ryan RM, Deci EL. Self-Determination Theory: Basic Psychological Needs in Motivation, Development, and Wellness. New York, NY: Guilford Publications; 2017.
17. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr 23;6:42 [FREE Full text] [doi: 10.1186/1748-5908-6-42] [Medline: 21513547]
18. Wang RH, Barbieri JS, Kovarik CL, Lipoff JB. Synchronous and asynchronous teledermatology: a narrative review of strengths and limitations. J Telemed Telecare 2022 Feb 02;28(7):533-538. [doi: 10.1177/1357633x221074504]
19. Kwon S, Perera S, Pahor M, Katula JA, King AC, Groessl EJ, et al. What is a meaningful change in physical performance? Findings from a clinical trial in older adults (the LIFE-P study). J Nutr Health Aging 2009 Jun 4;13(6):538-544 [FREE Full text] [doi: 10.1007/s12603-009-0104-z] [Medline: 19536422]
20. Bull FC, Al-Ansari SS, Biddle S, Borodulin K, Buman MP, Cardon G, et al. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. Br J Sports Med 2020 Dec 25;54(24):1451-1462 [FREE Full text] [doi: 10.1136/bjsports-2020-102955] [Medline: 33239350]
21. Robertson MC, Gardner MM, Devlin N, McGee R, Campbell AJ. Effectiveness and economic evaluation of a nurse delivered home exercise programme to prevent falls. 2: controlled trial in multiple centres. BMJ 2001 Mar 24;322(7288):701-704 [FREE Full text] [doi: 10.1136/bmj.322.7288.701] [Medline: 11264207]
22. Broom A. Conceptualizing qualitative data. Qual Health Res 2021 Aug 24;31(10):1767-1770. [doi: 10.1177/10497323211024951] [Medline: 34166154]
23. Schoenfelder DP. A fall prevention program for elderly individuals. Exercise in long-term care settings. J Gerontol Nurs 2000 Mar;26(3):43-51. [doi: 10.3928/0098-9134-20000301-09] [Medline: 11111630]
24. Drabble SJ, O'Cathain A, Thomas KJ, Rudolph A, Hewison J. Describing qualitative research undertaken with randomised controlled trials in grant proposals: a documentary analysis. BMC Med Res Methodol 2014 Feb 18;14:24 [FREE Full text] [doi: 10.1186/1471-2288-14-24] [Medline: 24533771]
25. Sullivan-Bolyai S, Bova C, Harper D. Developing and refining interventions in persons with health disparities: the use of qualitative description. Nurs Outlook 2005 May;53(3):127-133. [doi: 10.1016/j.outlook.2005.03.005] [Medline: 15988449]
26. Chafe R. The value of qualitative description in health services and policy research. Healthc Policy 2017 Feb 06;12(3):12-18. [doi: 10.12927/hcpol.2017.25030]
27. Patton MQ. Enhancing the quality and credibility of qualitative analysis. Health Serv Res 1999 Dec;34(5 Pt 2):1189-1208 [FREE Full text] [Medline: 10591279]
28. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. J Med Internet Res 2017 Nov 01;19(11):e367 [FREE Full text] [doi: 10.2196/jmir.8775] [Medline: 29092808]
29. Varpio L, Ajjawi R, Monrouxe LV, O'Brien BC, Rees CE. Shedding the cobra effect: problematising thematic emergence, triangulation, saturation and member checking. Med Educ 2017 Jan 16;51(1):40-50. [doi: 10.1111/medu.13124] [Medline: 27981658]
30. Larson RB. Controlling social desirability bias. Int J Mark Res 2018 Oct 14;61(5):534-547. [doi: 10.1177/1470785318805305]
31. NVivo 14. Lumivero. URL: https://lumivero.com/product/nvivo-14/ [accessed 2023-12-28]

32. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357. [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
33. Parasuraman A, Colby CL. An updated and streamlined technology readiness index: TRI 2.0. J Serv Res 2014 Jun 22;18(1):59-74. [doi: 10.1177/1094670514539730]
34. Oliveira JS, Sherrington C, Amorim AB, Dario AB, Tiedemann A. What is the effect of health coaching on physical activity participation in people aged 60 years and over? A systematic review of randomised controlled trials. Br J Sports Med 2017 Oct 20;51(19):1425-1432. [doi: 10.1136/bjsports-2016-096943] [Medline: 28320732]
35. Fuentes J, Armijo-Olivo S, Funabashi M, Miciak M, Dick B, Warren S, et al. Enhanced therapeutic alliance modulates pain intensity and muscle pain sensitivity in patients with chronic low back pain: an experimental controlled study. Phys Ther 2014 Apr;94(4):477-489. [doi: 10.2522/ptj.20130118] [Medline: 24309616]
36. Craig P, Petticrew M. Developing and evaluating complex interventions: reflections on the 2008 MRC guidance. Int J Nurs Stud 2013 May;50(5):585-587. [doi: 10.1016/j.ijnurstu.2012.09.009] [Medline: 23159017]
37. Coley N, Andre L, Hoevenaar-Blom MP, Ngandu T, Beishuizen C, Barbera M, et al. Factors predicting engagement of older adults with a coach-supported eHealth intervention promoting lifestyle change and associations between engagement and changes in cardiovascular and dementia risk: secondary analysis of an 18-month multinational randomized controlled trial. J Med Internet Res 2022 May 09;24(5):e32006 [FREE Full text] [doi: 10.2196/32006] [Medline: 35385395]
38. Cooley Hidecker MJ, Landers MR, Piccorelli A, Bush E, Singh R. Coordinated speech therapy, physiotherapy, and pharmaceutical care telehealth for people with Parkinson disease in rural communities: an exploratory, 8-week cohort study for feasibility, safety, and signal of efficacy. Rural Remote Health 2022;22:6679. [doi: 10.22605/rrh6679]
39. Kalicki A, Moody K, Franzosa E, Gliatto P, Ornstein K. Barriers to telehealth access among homebound older adults. J Am Geriatr Soc 2021;69(9):2404-2411. [doi: 10.1111/jgs.17163]
40. Stellefson M, Chaney B, Barry AE, Chavarria E, Tennant B, Walsh-Childers K, et al. Web 2.0 chronic disease self-management for older adults: a systematic review. J Med Internet Res 2013 Feb 14;15(2):e35 [FREE Full text] [doi: 10.2196/jmir.2439] [Medline: 23410671]
41. Yi JS, Pittman CA, Price CL, Nieman CL, Oh ES. Telemedicine and dementia care: a systematic review of barriers and facilitators. J Am Med Dir Assoc 2021 Jul;22(7):1396-402.e18 [FREE Full text] [doi: 10.1016/j.jamda.2021.03.015] [Medline: 33887231]
42. Barton C, Morris R, Rothlind J, Yaffe K. Video-telemedicine in a memory disorders clinic: evaluation and management of rural elders with cognitive impairment. Telemed J E Health 2011 Dec;17(10):789-793. [doi: 10.1089/tmj.2011.0083] [Medline: 22023458]
43. Gately ME, Tickle-Degnen L, McLaren JE, Ward N, Ladin K, Moo LR. Factors influencing barriers and facilitators to in-home video telehealth for dementia management. Clin Gerontol 2022 Jun 06;45(4):1020-1033. [doi: 10.1080/07317115.2021.1930316] [Medline: 34096477]
44. Lopez AM, Lam K, Thota R. Barriers and facilitators to telemedicine: can you hear me now? Am Soc Clin Oncol Educ Book 2021 Jun;41:25-36. [doi: 10.1200/edbk_320827]
45. Pinto RZ, Ferreira ML, Oliveira VC, Franco MR, Adams R, Maher CG, et al. Patient-centred communication is associated with positive therapeutic alliance: a systematic review. J Physiother 2012 Jun;58(2):77-87. [doi: 10.1016/s1836-9553(12)70087-5]
46. Haynes A, Sherrington C, Ramsay E, Kirkham C, Manning S, Wallbank G, et al. "Sharing success with someone": building therapeutic alliance in physiotherapist-delivered physical activity coaching for healthy aging. Physiother Theory Pract 2022 Nov 29;38(13):2771-2787. [doi: 10.1080/09593985.2021.1946872] [Medline: 34324406]
47. Australian Burden of Disease Study 2018: interactive data on risk factor burden. Australian Institute for Health and Welfare. URL: https://www.aihw.gov.au/reports/burden-of-disease/abds-2018-interactive-data-risk-factors/contents/physical-inactivity [accessed 2023-03-03]
48. Gibson‐Moore H. UK Chief Medical Officers' physical activity guidelines 2019: what's new and how can we get people more active? Nutr Bull 2019 Nov 25;44(4):320-328. [doi: 10.1111/nbu.12409]
49. Ryan RM, Deci EL. Intrinsic and extrinsic motivation from a self-determination theory perspective: definitions, theory, practices, and future directions. Contemp Educ Psychol 2020 Apr;61:101860. [doi: 10.1016/j.cedpsych.2020.101860]
50. Teixeira PJ, Carraça EV, Markland D, Silva MN, Ryan RM. Exercise, physical activity, and self-determination theory: a systematic review. Int J Behav Nutr Phys Act 2012 Jun 22;9:78 [FREE Full text] [doi: 10.1186/1479-5868-9-78] [Medline: 22726453]
51. Bandura A. Health promotion from the perspective of social cognitive theory. Psychol Health 1998 Jul;13(4):623-649. [doi: 10.1080/08870449808407422]
52. Ellner AL, Phillips RS. The coming primary care revolution. J Gen Intern Med 2017 Apr 27;32(4):380-386 [FREE Full text] [doi: 10.1007/s11606-016-3944-3] [Medline: 28243869]
53. Morgenroth T, Ryan MK, Peters K. The motivational theory of role modeling: how role models influence role aspirants' goals. Rev Gen Psychol 2015 Dec 01;19(4):465-483. [doi: 10.1037/gpr0000059]

54. Dai Z, Sezgin G, Li J, Franco GS, McGuire P, Datta S, et al. Telehealth utilisation in residential aged care facilities during the COVID-19 pandemic: a retrospective cohort study in Australian general practice. J Telemed Telecare 2022 May 11. [doi: 10.1177/1357633x221094406]
55. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. J Med Internet Res 2012 Nov 14;14(6):e152 [FREE Full text] [doi: 10.2196/jmir.2104] [Medline: 23151820]
56. Wardlow L, Leff B, Biese K, Roberts C, Archbald-Pannone L, Ritchie C, et al. Development of telehealth principles and guidelines for older adults: a modified Delphi approach. J Am Geriatr Soc 2023 Feb 19;71(2):371-382. [doi: 10.1111/jgs.18123] [Medline: 36534900]
57. Bergen N, Labonté R. "Everything is perfect, and we have no problems": detecting and limiting social desirability bias in qualitative research. Qual Health Res 2020 Apr;30(5):783-792. [doi: 10.1177/1049732319889354] [Medline: 31830860]
58. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021 Aug 17;21(1):1556 [FREE Full text] [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]

Abbreviations

COM-B: capability, opportunity, motivation, and behavior
NASSS: Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies
SDT: Self-Determination Theory

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Original Paper

Acceptance of a Digital Assistant (Anne4Care) for Older Adult Immigrants Living With Dementia: Qualitative Descriptive Study

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Abstract

Background: There is a need to develop and coordinate dementia care plans that use assistive technology for vulnerable groups such as immigrant populations. However, immigrant populations are seldom included in various stages of the development and implementation of assistive technology, which does not optimize technology acceptance.

Objective: This study aims to gain an in-depth understanding of the acceptance of a digital personal assistant, called Anne4Care, by older adult immigrants living with dementia in their own homes.

Methods: This study used a qualitative descriptive research design with naturalistic inquiry. A total of 13 older adults participated in this study. The participants were invited for 2 interviews. After an introduction of Anne4Care, the first interview examined the lives and needs of participants, their expectations, and previous experiences with assistive technology in daily life. Four months later, the second interview sought to understand facilitators and barriers, suggestions for modifications, and the role of health care professionals. Three semistructured interviews were conducted with health care professionals to examine the roles and challenges they experienced in the use and implementation of Anne4Care. Content analysis, using NVivo11, was performed on all transcripts.

Results: All 13 participants had an immigration background. There were 10 male and 3 female participants, with ages ranging from 52 to 83 years. Participants were diagnosed with an early-stage form of dementia or acquired brain injury. None of the older adult participants knew or used digital assistive technology at the beginning. They obtained assistance from health care professionals and family caregivers who explained and set up the technology. Four themes were found to be critical aspects of the acceptance of the digital personal assistant Anne4Care: (1) use of Anne4Care, (2) positive aspects of Anne4Care, (3) challenges with Anne4Care, and (4) expectations. Assistance at first increased the burden on health care professionals and families. After the initial effort, most health care professionals and families experienced that Anne4Care reduced their tasks and stress. Contributions of Anne4Care included companionship, help with daily tasks, and opportunities to communicate in multiple languages. On the other hand, some participants expressed anxiety toward the use of Anne4Care. Furthermore, the platform required an internet connection at home and Anne4Care could not be used outside the home.

Conclusions: Although older adult immigrants living with dementia had no previous experience with digital assistive technology specifically, the acceptance of the digital personal assistant, called Anne4Care, by older adult immigrants living with dementia was rather high. The digital assistant can be further developed to allow for interactive conversations and for use outside of one's home. Participation of end users during various stages of the development, refinement, and implementation of health technology innovations is of utmost importance to maximize technology acceptance.

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KEYWORDS

assistive technology; technology acceptance; immigrant; dementia; marginalized older adults

Introduction

Background

Dementia is a global health problem associated with emotional and financial challenges for people living with dementia, their relatives, health care professionals, and health organizations [1,2]. Worldwide, approximately 47 million people are diagnosed with dementia [3]. Around 280,000 persons are presently living with dementia in the Netherlands among a population of nearly 19 million [4]. The number of people living with dementia is expected to increase in the coming years. People with an immigration background are at an increased risk of developing dementia and are more likely to experience barriers in accessing dementia services and care, which may lead to health inequities and a reduction of quality of life [5-7]. Hence, there is a need to develop and coordinate dementia care plans, including the use of technology, for marginalized older adults living with dementia, such as those with an immigration background and low literacy levels [8].

Health Literacy and Health Technology

Health literacy has been defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [9]. Adequate health literacy and access to services among immigrant populations are important to empower, support or facilitate these persons to become active participants in their health [10]. Persons with limited health literacy have difficulty finding, understanding, and applying information about health and health care. Health technology–based solutions that support health promotion, for example, mental and physical health, offer opportunities to increase health literacy in vulnerable populations [11,12].

The World Health Organization reports that innovative health technologies are promising tools to enhance knowledge, skills, and coping mechanisms to improve the daily lives of people with dementia and their caregivers [13]. In recent years, a variety of technologies to support self-management have been developed for people with dementia and their caregivers. Studies have focused on the effect of these technologies on the physical, mental, and social well-being of people with dementia and their relatives and families [14,15]. Technology seems to stimulate cognitive function and communication skills and reduce loneliness among people with dementia, but these results are personal and context-dependent [14,15]. Acceptance of technology is a major challenge and prerequisite for the implementation of technology in practice. For successful technology implementation in the daily lives of people, it is important to have insight into the acceptance of technology among end users. Although studies have examined the acceptance of technology among people living with dementia and their caregivers [16-18], the number of studies that focus specifically on older adult immigrants living with dementia is minimal.

Citizen Science

Co-design and the involvement of people with dementia and their professional and family caregivers are crucial elements for the acceptance of technology [17]. However, immigrant populations are seldom included in stages of development, refinement, and implementation of assistive technology innovations [19]. This can be associated with low levels of acceptance of health technology innovations, which can contribute to health inequities among populations. One opportunity to increase the involvement of end users is through citizen science, which is an approach that engages end users to be partners in research so that their experiences and needs are considered [20]. Citizen science is a powerful approach to include public participation in research as well as optimize acceptance of technologies [20,21]. In citizen science, scientific principles and methods are used by nonprofessional "scientists" in close collaboration with scientific researchers [22]. The involvement of older adults in the development, refinement, and implementation of technology, acknowledging their expertise and needs, and working together in short iterations to adapt the technology for their specific needs are reported to be valuable elements by scientific researchers, older adults, and health care professionals [23].

Aim

This qualitative descriptive study aimed to provide an in-depth understanding of the acceptance of a digital personal assistant, called Anne4Care, among older adult immigrants living with dementia by using a citizen science approach.

Methods

Research Design

This study used a qualitative descriptive research design with a naturalistic inquiry [24] and citizen science principles [20]. In this study, Anne4Care was extended with the development of a Turkish version. All the involved older adults had the task of testing the device as well as communicating with each other, their care professionals, and the Anne4Care help desk. For example, there were workshop-like meetings in which all shared experiences, assisted each other with difficulties, and expressed the need to further develop the Turkish version of Anne4Care. Furthermore, participants actively collaborated with scientific researchers, for example, in discussing the topics for the interview guide and analyzing the data from the interviews.

Aligning with citizen science principles there was a close collaboration between older adults participating as co-researchers, health care professionals, and scientific researchers. A detailed description of how older adults with an immigration background were engaged in this study is described in a separate paper [23]. The team of researchers closely collaborated with a group of citizens representing the target group and health care professionals in their role as co-researcher, during all phases of this study: recruitment, obtaining informed consent, data collection, and analysis.

Setting

This research was part of the TOPFIT Citizenlab program, a research and innovation program in which citizens, health care professionals, and companies join forces with scientific researchers to develop and implement technology for health.

The Technology

Anne4Care is a digital personal assistant that includes video-calling, a personal agenda, medication reminders, reading the news, and games that can be used in one’s home. Anne4Care is a technological platform created to help people with dementia to continue living independently in their own homes and supporting caregivers in their tasks [25]. Anne4Care included hardware as well as a software platform. Anne4Care is available in Dutch, German, Italian, and English. The company was developing a Turkish version of Anne4Care and saw the embedding of Anne4Care in homes of older adults with an immigration background as an opportunity to test, improve, and implement the latest version.

Recruitment Strategy

The recruitment of participants was performed by 3 health care professionals from 2 health care organizations. These organizations provide care for clients with an immigration background with cognitive impairments.

Inclusion criteria were as follows:

- Diagnosed with an early-stage form of dementia or acquired brain injury;
- Having an immigrant background;
- Visiting the activity program of 1 of the 2 participating health care organizations

Exclusion criteria were as follows:

- Diagnosed with a severe stage form of dementia limiting their ability to participate

All clients of the 2 health care organizations (IMEAN Consultancy & Care and Alifa Wellbeing Older Adults) were invited by their health care professionals to participate in this study. All older adult participants had an immigration background, that is, 1 came from Britain and the other 12 came from Turkey (Table 1). They visited the activity program of 1 of the 2 health care organizations, which are situated in the Twente region of the Netherlands. In addition to an immigration background, all 13 older adult participants, or co-researchers, had an early-stage form of dementia or acquired brain injury. The sample included 10 male and 3 female participants, and their ages ranged from 52 to 83 years. There were no exclusion criteria based on digital literacy, that is, participants did not need any experience with technology. Internet access was provided to participants who did not have an internet connection at home.

Table 1. Demographic characteristics of the participants (N=13).

Variables	Values
Age (years)	
Mean (SD)	71 (9.8)
Range	52-83
Age group (years), n (%)	
45-54	1 (7.7)
55-64	1 (7.7)
65-74	6 (46.2)
75-84	5 (38.5)
Sex at birth, n (%)	
Female	3 (23.1)
Male	10 (76.9)
Nationality, n (%)	
Turkish	12 (92.3)
British	1 (7.7)

All 3 health care professionals involved in this study were female. They introduced Anne4Care to the older adults, assisted them, and were in close contact with the participants during all phases of this study. The health care professionals took care of the clients and spoke their native language, which created a safe and trustful environment. The health care professionals also served as a voice for the participants who could not communicate in the Dutch language.

Data Collection

Anne4Care was introduced to allow health care professionals to communicate with and monitor older adults. Data were collected between September 2020 and November 2021. Semistructured in-depth interviews took place at the care organization or at the home of the older adult immigrants. The location was chosen based on a participant's preference. During the interviews, a care professional was present and served as an interpreter. Participants were invited for 2 interviews. The first interview was planned shortly after the introduction of Anne4Care in their home, and a second interview 4 months later. Participants had the opportunity to continue using Anne4Care after the data collection period, funded through a stimulation subsidy for eHealth at home during the COVID-19 pandemic. Five researchers with mixed credentials, training, occupation, location, and gender conducted the interviews (MB, CMvL, TJJO, ES, and ZM). To secure interrater reliability, the researchers had biweekly meetings to discuss the procedure and previous interviews. Two researchers were present during each interview; the teams of 2 were different for each interview. One was the main interviewer and the other took notes and asked additional questions. The follow-up interviews were conducted by the same researchers to ensure the established relationship between researchers and older adults.

The topic guide was developed in collaboration with 1 participant from the daycare facility and 3 health care professionals. Thirteen first interviews were conducted focusing on understanding the lives and care needs of the participants, learning about their expectations regarding Anne4Care, and sharing previous experiences with care and technologies, what facilitators and barriers they encountered while using technology (Multimedia Appendix 1). The first interviews lasted between 30 and 60 minutes. A total of 8-second interviews were conducted with the same participants who participated in the first interview (5 of the participants were not able to participate in the second interview due to COVID-19 illness). The second interview focused on the facilitators and barriers participants experienced when using Anne4Care, suggestions for modifications of Anne4Care, and the role of health care professionals in using technology (Multimedia Appendix 1). The second interview lasted between 20 and 45 minutes.

Three semistructured interviews were conducted with the 3 health care professionals. These interviews took place at the care organization and lasted for 60 minutes. The aim of these interviews was to talk about their role and the challenges they experienced as professionals in the use and implementation of Anne4Care (Multimedia Appendix 2). Furthermore, the findings of the interviews with the older adults were shared with the care professionals.

Data Analysis

All interviews were audio recorded and transcribed verbatim. The transcripts were made in English and Dutch. All Turkish spoken words were translated by an interpreter during the interviews. Only these translations were part of the transcripts. Content analysis of transcripts used an inductive approach [26,27]. We used the software package NVivo11 to support data coding. Open coding was used to identify relevant themes, there were no themes in advance of the data analysis. Several steps were taken to develop a code book. First, 3 researchers (MB, CMvL, and TJJO) performed the analysis of 2 transcripts and compared codes. A preliminary codebook was developed comprising these themes. Second, the coding of one transcript was discussed together with one older adult. This participant was motivated and had some previous experience with research and data analysis. Together with the co-researcher, additional themes were added to the code book. Last, the other transcripts were analyzed by 1 researcher (CMvL). The data analysis and application of codes were discussed during biweekly meetings with the research team. Data saturation was reached after analyzing the data obtained with all involved older adults and care professionals. During the data analysis, similar and confirmation of all findings appeared when analyzing and coding the transcripts. In preparation for the paper, the quotes in the raw data were translated into English.

Ethical Considerations

Ethics approval was obtained from the ethical advice committee of the University of Applied Sciences Saxion (reference number SEAC-2020-005). The participants were informed about the study before the start of the research period with Anne4Care. Thirteen participants gave written consent and were informed about their right to withdraw at any time. Data were anonymized, confidentiality was maintained, and the data will be retained for a period of 10 years after which they will be destroyed.

Results

Overview

The analysis of data revealed that the personal situation and perceptions of participants regarding access to dementia services and care (in short: care) were 2 underlying themes that described the adopter system from the older adult immigrants living with dementia. The code tree is presented in Multimedia Appendix 3.

Personal Situation

Personal situation considers the perceptions of older adult immigrants regarding their health status (physically and mentally), level of spirituality, quality of life, social and societal participation, and daily functioning. The personal lives of participants were diverse, with their immigration background as a main commonality. They were all born in another country and moved to the Netherlands for their work. Most of the participants worked in the textile or metal industry. The participants were all retired and visited the facility for daytime activities once or twice a week. On other days, their daily activities consisted of grocery shopping, housekeeping, or just doing nothing. Spirituality (eg, religion) was an important part of the lives of most participants. The physical and mental health of all participants is deteriorating, with illnesses that range in severity. In addition to dementia or acquired brain injury, some have health conditions such as diabetes, high blood pressure, and cataracts. These deteriorating health conditions had a major impact on their daily functioning as well as their quality of life. In the earlier years of their lives, some participants experienced challenges in participating in Dutch society, but this became even more difficult during the COVID-19 pandemic. Social relations were mainly with family members, and some had close contact with their neighbors.

> *Since I came here in the Netherlands, in the year 1977, I bought a house and since then until now I live in the same street, the same neighborhood with the same neighbors and this was always a very good network. It is a community with the Turkish and Dutch neighbors, in which I am a beloved man, I go to the mosque a lot and had several board positions for a while, such as a board member of the mosque.* [Participant H]

Care

Care refers to the perceptions of participants regarding access to dementia services and care in including all assistive and care needs of the participants. All participants acknowledged the fact that they became older and had increasing trouble taking care of themselves. Some participants had troublesome experiences with care in the past or could not find suitable and personalized care. In most cases, family members, partners, children, or neighbors assisted and provided support and care. However, most participants perceived this as a burden for their relatives and, therefore, was not a desirable situation.

> *Now there is someone who assists in housekeeping, and our children assist with the more administrative tasks. Next-door there are some younger neighbors who offered to help for example with the garden. I have a lot of help from all of them. However, in the past I had a lot of frustrations with health care professionals. When we arranged a time, they did not show up and none made any record of my needs. Then the agency went bankrupt and the clients were left in the dark.* [Participant G]

Acceptance of Anne4Care

In addition to the 2 underlying themes, the analysis of the acceptance of Anne4Care by older adult immigrants revealed four themes: (1) use of Anne4Care, (2) positive aspects of Anne4Care, (3) challenges with Anne4Care, and (4) expectations. In this section, results are presented for each theme. The code tree is presented in Multimedia Appendix 3. Multimedia Appendix 4 provides visual information about Anne4Care.

Use of Anne4Care

This theme refers to the acceptance and actual use of the digital personal assistant Anne4Care by older adult immigrants living with dementia in their own homes. The use of Anne4Care applies to how someone uses Anne4Care, what someone does with Anne4Care, and how health care professionals or families are involved. None of the participants knew or used an assistive technology similar to Anne4Care. All were unfamiliar with the existence of these types of digital assistive technologies. One participant acknowledged that technology like Anne4Care could assist health care professionals. In addition, the health care professionals underlined the potential of Anne4Care for supporting clients at a distance. Although the participants were unfamiliar with technologies like Anne4Care, they were familiar with technologies such as a doorbell with a flashlight or a talking clock, and 1 participant owned a robot vacuum cleaner.

> *I was so pleased when I saw the result, this robot really cleans everything. You can just leave your home and it will clean everywhere.* [Participant L]

Anne4Care was mainly used as a memory assistive tool, for appointments and medication.

> *It is very useful. Anne4Care tells me when I must take my medication. She helps me to remembers, she is tough and fun. I am very happy with it.* [Participant M]

In addition to the agenda function and medication reminders, the game, radio, and newspaper functions of Anne4Care were used or requested by some participants. A health care professional would need to be aware of participants’ requests in order to activate the radio or newspaper functions.

> *He would like to receive more radio channels. He has a Turkish music channel, but would like to receive Dutch channels as well. We can add these channels easily to the list, I will ask him at a later moment which he would prefer.* [Health care professional B]

Thus, the health care professionals and sometimes family were responsible for adding new functions as well as appointments in the agenda, and changes in the medication list. In the beginning, this costed time and was a source of burden. Some assistance to understand Anne4Care was needed at the start. However, after this initial adjustment, most health care professionals and families experienced the tablet as a task relieving as well as stress relieving. Anne4Care gave the reminders so that care partners did not have to keep track of everything during the day. Some participants admitted that continuous reminders from their partners made them angry, but reminders from Anne4Care were received more positively, causing fewer troubling situations at home. Furthermore, some participants preferred to update the agenda themselves if they could learn to work with Anne4Care. This feature is currently not possible with the platform.

> *I just need a keyboard to add appointments in my agenda. It is important for me to do this myself without any assistance, just some explanation and exercises in the beginning. It would be great if that would work!* [Participant E]

After a few months, 3 participants decided to stop using Anne4Care. Two participants did not see the additional value, Anne4Care did not give them any new tools, and 1 participant stopped using them due to illness.

Positive Aspects of Anne4Care

This theme refers to participant experiences regarding the advantages and benefits of Anne4Care. During the interviews, participants were asked to share the positive aspects of Anne4Care. The avatar of Anne4Care was received positively by the participants. Coincidentally, “Anne” is also the Turkish word for mother. Although Anne does not look like a Turkish mom, she gave a feeling that there was someone in their homes because she talks, makes movements, and looks like a nurturing health care professional. Another positive aspect was the choice of language. Most participants chose their native language because Dutch was progressively more difficult to use with age and since the onset of dementia. However, some participants chose the Dutch language intentionally in order to develop and maintain their Dutch language skills.

With regard to positive aspects, the participants commented on the functionalities of Anne4Care: video calling, agenda, medication reminders, games, radio, and newspaper. The most positive aspect of the video calling was the quality and the size of the screen (respectively 10-12.3 inch diagonal). They could see the other person more clearly on the tablet than, for example, on their smartphone. The most positive aspect about Anne4Care was the agenda function with the reminders of appointments and the medication reminder function. These reminders were very essential for the participants’ personal life and health. One health care professional explained that any event or task could be added.

> *Take for example the timing for their regular prayers. These are essential for someone’s life, and we can easily add these into the agenda.* [Health care professional]

Another participant talked about the assistance of Anne4Care in the daily cooking routine.

> *There are reminders when I need to start cooking, but also already before which groceries I have to purchase. After a while Anne4Care asks: ‘did you turn off the stove?’ That is very helpful and important for me.* [Participant K]

The game function was experienced as a fun activity to do during the day. Furthermore, the radio and newspapers provided by Anne4Care were perceived to be valuable. For example, some radio channels with music from their past gave the participants an opportunity to escape from their current time and place. The newspapers were seen as essential to keep up to date with current events; the read-aloud option was an asset.

> *It is wonderful that the radio and newspapers can provide the news into my home. The news keeps me up to date, and I also know what happens in Turkey where my family is.* [Participant H]

Challenges With Anne4Care

After using Anne4Care, the participants were asked about any challenges they experienced. As mentioned, the agenda and medication reminder functions were experienced as positive. However, the video calling option presented challenges. The main challenge was in making a connection with others. A video call required both the caller and receiver to activate Anne4Care. Therefore, all participants had to first send an SMS text message with their mobile phone to request the recipient to activate Anne4Care in order to receive a video call. With this extra step, most participants decided to simply use their mobile device instead of Anne4Care to make a video call. In addition, the newspaper and radio functions do not allow participants to search for radio stations, other than the ones preprogrammed.

> *I cannot find that newspaper, also the radio channel is absent. When I try to search, I get the massage ‘no stations available’, so there is nothing programmed I think.* [Participant B]

Another challenge was real interactions with Anne4Care. The participants expected the possibility to have a conversation, but that was not possible. Furthermore, part of this interaction was the commands to which Anne4Care often does not react. For example, when a participant asked Anne4Care for the time, or to call someone, Anne4Care may not respond. This could have been caused by the fact that Anne4Care did not recognize all the verbal commands in the Turkish language.

> *We cannot talk together, because she does not respond. Every morning I hear ‘good morning’, but that is it.* [Participant B]

The Anne4Care device itself presented some challenges. One challenge was the anxiety among participants for the devices to overheat, which caused the participants to turn off Anne4Care. Another challenge was the requirement for an internet connection at home. Some of the participants did not have internet at the start of the study. Internet access was provided to participants who did not have an internet connection at home during the study period. However, internet access is not free. Some of the participants are strapped for cash. This makes it difficult for them to pay for Anne4Care and an internet connection when the study ends. They have to make difficult trade-offs.

> *Now we are using Anne4Care for free, but in a couple of weeks there are probably some costs involved. We do not have Internet connection. I only have a mobile phone subscription with which I am happy. But I am also happy with Anne4Care, so the costs make it quite difficult to make a trade-off.* [Participant N]

Because Anne4Care is now only available with an internet connection at home, another challenge is to receive messages from Anne4Care when someone is outside. It would be great, for example, to transfer this with the Anne4Care message app on their mobile phone in case they are not at home. According to some participants, Anne4Care is currently a device only for people who are at home most of the day.

Expectations

This theme represents the ideas, wishes, and future plans of the participants for Anne4Care. In the beginning, some of the participants expressed anxiety toward Anne. They turned the tablet off at night because they thought someone could see or listen to them through the device. One of the new plans most of the participants came up with during the use of Anne4Care was the addition of an option to connect quickly to emergency care services. This connection could be activated by the user, but it should also be activated automatically when older adult immigrants living with dementia do not respond to a call within a period of time. Although all participants expected that Anne4Care would improve the health care of people with deteriorating health or dementia, their expectations were higher at the start.

> *Anne4Care needs to be improved. At the moment, it is too basic and does not meet the needs of some people. We can do more by ourselves, it is a bit of a disappointment.* [Participant D]

As mentioned, it is a challenge to use Anne4Care outside the home because the platform requires the internet. Outside the home, it would be helpful if people could receive medication reminders, therefore, this platform should also be compatible with their mobile devices.

> *It would be great if I could just take Anne4Care outside. Then I have my medication reminders when I am outside, she will tell me to take the medication and I could take them at the right moment.* [Participant M]

There were different ideas for new functions on the current Anne4Care tablet. For example, the addition of short movies or documentaries would allow it to be used for entertainment. Additions to the game function and more options, such as multiplayer games allow an older adult to play with a partner. A range of memory or language-related games, and more challenging puzzles would help meet user preferences. The memory and language games were specifically mentioned by several participants and health care professionals, because of the perceived benefits of cognitive engagement for older adult immigrants living with dementia.

Discussion

Summary of Findings

This study aimed to understand the acceptance of Anne4Care as perceived by older adult immigrants living with dementia using a citizen science approach. This study showed that although older adult immigrants living with dementia had no previous experiences with digital assistive technology specifically, the acceptance of the digital personal assistant, called Anne4Care, by these participants was rather high. Anne4Care was mainly used as a memory assistive tool, for appointments and medication. The use of Anne4Care at first increased the burden of health care professionals and families because health care professionals and sometimes families were responsible for adding new functions as well as appointments in the agenda and changes in the medication list. After the initial effort, most health care professionals and families experienced that Anne4Care reduced their tasks and stress. Contributions of Anne4Care included companionship, help with daily tasks, and opportunities to communicate in multiple languages. On the other hand, some participants expressed anxiety toward the use of Anne4Care and experienced challenges in the use of functionalities, for example, video calling and having real interaction with the avatar. Furthermore, the platform required an internet connection at home and Anne4Care could not be used outside the home.

Reflection on the Literature

The personal digital assistant, Anne4Care, offered companionship for older adult immigrants living with dementia and helped them perform daily activities. Participants mentioned that Anne4Care was very useful as a remember assistive tool, especially for appointments and medications. This finding is consistent with the results of previous studies about technology acceptance in rehabilitation and assistive technologies, and in health care technologies in general [28-30]. Technology acceptance models, for example, the Unified Theory of Acceptance and Use of Technology suggest that if performance expectancy is high, that is, people believe that technologies can help them to achieve their therapeutic goals or achieve their health expectations, this increases the acceptability and actual use of health technologies [31].

A key finding in this study was that participants believed that they did not have all the conditions to use and adopt Anne4Care for a longer period. These conditions are also known as facilitating conditions in technology acceptance theories, for example, the Unified Theory of Acceptance and Use of Technology [31]. Facilitating conditions include, for example, internet connection, technical infrastructure, as well as other internal support such as health care professional involvement and supporting staff (eg, availability of engineers to support the system) [32,33]. In our study, participants reported a lack of internet connection as a main limitation for the acceptance of Anne4Care. There is an extensive body of literature in the field of technology acceptance and use that points toward facilitating conditions as an important determinant factor in technology use [34]. Our result shows that to take full advantage of the potential of digital technologies like Anne4Care, these digital technologies should be accessible also to people of lower socioeconomic status which may have an influence on a person's autonomy and independence [35].

In our study, health care professionals were involved in using Anne4Care. These health care professionals had close contact and a trustful and respectful relationship with the participants. They played an important role in giving participants information and instruction regarding Anne4Care, in which they can be supportive of the acceptance of technology. Some participants were concerned about their privacy when using Anne4Care. They turned the tablet off at night because they thought someone could see or listen to them through the device. The important role of the health care professionals in this study warrants discussion. The health care professionals, all with a Turkish background, had the expertise to provide access and involve the participants. They were an important frame of reference and guided the participants whenever they received questions, or observed discomfort or doubts. Furthermore, they were key users of health care technology and had a positive attitude toward implementing the new technology. Research suggests that creating a positive, supportive atmosphere is instrumental to the sustainability of technology use [36]. Other studies describe that caregiver engagement is important for the everyday use of technology among people with dementia [33,37].

Although in recent years several technologies have been developed for people with dementia and their caregivers to support self-management, in our study none of the participants knew or used an assistive technology comparable to Anne4Care. All were unfamiliar with the existence of these types of technologies. Globally, there is an increasing aging population and more people staying longer in their own homes which has an impact on society and health care [38]. Although evidence shows that technology for people with dementia seems to stimulate cognitive function and communication skills and reduce loneliness [14,15,39], the implementation of technology can also contribute to the burden of health care professionals and informal caregivers. In our study, participants needed the assistance of health care professionals or families, which increased the demand for health care professionals and families. However, after this initial effort, most health care professionals and families experienced that the tablet facilitated their caregiving roles.

Immigrant populations typically have limited involvement in the development, refinement, and implementation of health care technology. This may be reflected in lower levels of adoption of health care technology. The citizens' science approach within this study was important for this specific target group. A citizen science approach calls for the optimal involvement of the target group as co-researchers. This extra time and dedication was positively experienced by the older adult immigrant group. It was mentioned that it felt like having a real purpose and gave a sense of fulfillment. This collaboration resulted in an alignment of the technology with the needs and practices of the participants. In future studies, the citizen science approach could also be applied in the development of new technologies as this study focused on the refinement of a technology for a specific target population. Citizen science for health and well-being could provide an effective way to involve vulnerable groups within society to participate in research.

Recommendations for Future Research

Future research could examine ways to increase the implementation of technology among older adult immigrants living with dementia and how to develop the technology competencies of clients, caregivers, and health care professionals. Furthermore, for future research conducting mixed method research using both qualitative and quantitative research methods is recommended to provide more insight into the added value of these kinds of assistive technologies for end users and professionals or family members.

Strengths and Limitations

Although we included only 13 older adults, they were involved in the entire process and collaborated with the researchers as well as with the other participants and their health care professionals. All older adults of the 2 organizations with whom the company Anne4Care started collaboration in the Twente region were invited for this study. The 13 participants who were interested in collaborating were all involved in this study. Another strength of our study was the quadruple collaboration. In our citizen science approach, there was active collaboration between the researchers, older adults, health care professionals, and the company that developed Anne4Care. However, we only involved older adults with an early-stage form of dementia, and 5 older adults were not able to join the second interview, due to COVID-19 illness. In addition, assessing exact levels of health literacy would have provided additional information about the influence of these kinds of assistive technologies on health literacy levels. Finally, a care professional was present and served as an interpreter. This may have impacted the quality of the data collected and nuances in the conversations may have been missed. On the other hand, the presence of the care professional ensured a safe and trustworthy environment.

In this study, a qualitative descriptive research design with a naturalistic inquiry has been used. Four themes were found to be related to acceptance of Anne4Care: (1) use of Anne4Care, (2) positive aspects of Anne4Care, (3) challenges with Anne4Care, and (4) expectations. Data saturation regarding the acceptance of Anne4Care was reached. During the data analysis, similar and confirmation of all findings appeared when analyzing and coding the transcripts. However, besides these 4 themes, there might be other factors relevant to the acceptance of digital personal assistant technology for older persons to stay safe in their homes and be able to age in place.

Conclusions

Although older adult immigrants living with dementia had no experience with digital assistive technology specifically, the acceptance of the digital personal assistant, called Anne4Care, by older adult immigrants living with dementia was rather high. In our study, older adult immigrants living with dementia learned and used Anne4Care with the help of family caregivers. Most older adults accepted Anne4Care into their lives in which Anne4Care offered companionship and helped them to perform daily activities. Older adults provided suggestions for the continued development of Anne4Care.

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Authors' Contributions

MB, CMvL, TJJO, ES, and ZM conducted the interviews. MB, CMvL, and TJJO performed the analysis of 2 transcripts and compared codes. Peer debriefing took place at weekly meetings with the project team when scientific and organizational aspects were discussed. All authors contributed to writing the paper and have approved the latest version of the paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide for first and second interviews with older adults with an immigration background.
[DOCX File , 17 KB - aging_v7i1e50219_app1.docx]

Multimedia Appendix 2
Interview guide for interviews with health care professionals.
[DOCX File , 17 KB - aging_v7i1e50219_app2.docx]

Multimedia Appendix 3
Coding tree.
[DOCX File , 134 KB - aging_v7i1e50219_app3.docx]

Multimedia Appendix 4
Visual information about Anne4Care.
[DOCX File , 727 KB - aging_v7i1e50219_app4.docx]

References

1. Patterson C. World Alzheimer report 2018. Alzheimer's Disease International. 2018. URL: https://www.alzint.org/resource/world-alzheimer-report-2018/ [accessed 2024-03-19]
2. Alzhheimer's disease and healthy aging. Centers of Disease Control and Prevention. URL: https://www.cdc.gov/aging/index.html [accessed 2023-04-18]
3. Dementia. World Health Organization. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2023-04-18]
4. National dementia strategy 2021-2023. Ministry of Health, Welfare and Sports. URL: https://www.government.nl/documents/publications/2020/11/30/national-dementia-strategy-2021-2030 [accessed 2024-03-19]
5. Selten JP, Termorshuizen F, van Sonsbeek M, Bogers J, Schmand B. Migration and dementia: a meta-analysis of epidemiological studies in Europe. Psychol Med 2021;51(11):1838-1845 [FREE Full text] [doi: 10.1017/S0033291720000586] [Medline: 32264980]
6. Parlevliet JL, Uysal-Bozkir Ö, Goudsmit M, van Campen JP, Kok RM, Riet GT, et al. Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. Int J Geriatr Psychiatry 2016;31(9):1040-1049. [doi: 10.1002/gps.4417] [Medline: 26799690]
7. Kenning C, Daker-White G, Blakemore A, Panagioti M, Waheed W. Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. BMC Psychiatry 2017;17(1):316 [FREE Full text] [doi: 10.1186/s12888-017-1474-0] [Medline: 28854922]
8. Chen Y, Caramelli P. Dementia among international migrants: an urgent call for better care. Eur J Neurol 2022;29(7):1865-1866 [FREE Full text] [doi: 10.1111/ene.15361] [Medline: 35434895]
9. Institute of Medicine (US) Committee on Health Literacy. In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. Health Literacy: A Prescription to End Confusion. Washington (DC): National Academies Press (US); 2004.
10. Duran-Kiraç G, Uysal-Bozkir Ö, Uittenbroek R, van Hout H, Broese van Groenou MI. Accessibility of health care experienced by persons with dementia from ethnic minority groups and formal and informal caregivers: a scoping review of European literature. Dementia (London) 2022 Feb;21(2):677-700 [FREE Full text] [doi: 10.1177/14713012211055307] [Medline: 34879748]
11. Riza E, Lazarou A, Karnaki P, Zota D, Nassi M, Kantzanou M, et al. Using an IT-based algorithm for health promotion in temporary settlements to improve migrant and refugee health. Healthcare (Basel) 2021 Sep 28;9(10):1284 [FREE Full text] [doi: 10.3390/healthcare9101284] [Medline: 34682964]
12. Fernández-Gutiérrez M, Bas-Sarmiento P, Poza-Méndez M. Effect of an mHealth intervention to improve health literacy in immigrant populations: a quasi-experimental study. Comput Inform Nurs 2019;37(3):142-150. [doi: 10.1097/CIN.0000000000000497] [Medline: 30531321]

13. Global action plan on the public health response to dementia 2017-2025. World Health Organization. URL: https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025 [accessed 2024-03-19]
14. Brown A, O'Connor S. Mobile health applications for people with dementia: a systematic review and synthesis of qualitative studies. Inform Health Soc Care 2020;45(4):343-359. [doi: 10.1080/17538157.2020.1728536] [Medline: 32237937]
15. Anderson M, Menon R, Oak K, Allan L. The use of technology for social interaction by people with dementia: a scoping review. PLOS Digit Health 2022;1(6):e0000053 [FREE Full text] [doi: 10.1371/journal.pdig.0000053] [Medline: 36812560]
16. Xu YA, Wang Y, Kim SSY, Kim DOD, Sun Y, McLaughlin ML. Safe at home: acceptance of surveillance technology among caregivers for persons with dementia. Health Informatics J 2023;29(1):14604582231152188 [FREE Full text] [doi: 10.1177/14604582231152188] [Medline: 36680337]
17. Boyle LD, Husebo BS, Vislapuu M. Promotors and barriers to the implementation and adoption of assistive technology and telecare for people with dementia and their caregivers: a systematic review of the literature. BMC Health Serv Res 2022;22(1):1573 [FREE Full text] [doi: 10.1186/s12913-022-08968-2] [Medline: 36550456]
18. Conway A, Ryan A, Harkin D, Mc Cauley C, Goode D. A review of the factors influencing adoption of digital health applications for people living with dementia. Digit Health 2023;9:20552076231162985 [FREE Full text] [doi: 10.1177/20552076231162985] [Medline: 36937696]
19. Suijkerbuijk S, Nap HH, Cornelisse L, IJsselsteijn WA, de Kort YAW, Minkman MMN. Active involvement of people with dementia: a systematic review of studies developing supportive technologies. J Alzheimers Dis 2019;69(4):1041-1065 [FREE Full text] [doi: 10.3233/JAD-190050] [Medline: 31156158]
20. Wiggins A, Wilbanks J. The rise of citizen science in health and biomedical research. Am J Bioeth 2019;19(8):3-14 [FREE Full text] [doi: 10.1080/15265161.2019.1619859] [Medline: 31339831]
21. Newman G, Wiggins A, Crall A, Graham E, Newman S, Crowston K. The future of citizen science: emerging technologies and shifting paradigms. Front Ecol Environ 2012;10(6):298-304 [FREE Full text] [doi: 10.1890/110294]
22. Robinson LD, Cawthray JL, West SE, Bonn A, Ansine J. Ten principles of citizen science. In: Hecker S, Haklay M, Bowser A, Makuch Z, Vogel J, Bonn A, editors. Citizen Science: Innovation in Open Science, Society and Policy. London: UCL Press; 2018:1-23.
23. van Leersum CM, Konrad KE, Siebrand E, Malik ZB, den Ouden MEM, Bults M. Engaging older adults with a migration background to explore the usage of digital technologies in coping with dementia. Front Public Health 2023;11:1125834 [FREE Full text] [doi: 10.3389/fpubh.2023.1125834] [Medline: 37124775]
24. Lincoln YS, Guba EG, Pilotta JJ. Naturalistic Inquiry. Thousand Oaks, CA: SAGE Publications; 1985.
25. Stara V, De Jong M, Felici E, Bolliger D, Birrer E, von Döllen V, et al. The design adaptation of the virtual assistant Anne for moderate dementia patients and their formal caregivers in protected environment tests. Adv Hum Fact Ergonomi Healthcare Med Dev 2020;957:270-279. [doi: 10.1007/978-3-030-20451-8_27]
26. Huber M, van Vliet M, Giezenberg M, Winkens B, Heerkens Y, Dagnelie PC, et al. Towards a 'patient-centred' operationalisation of the new dynamic concept of health: a mixed methods study. BMJ Open 2016;6(1):e010091 [FREE Full text] [doi: 10.1136/bmjopen-2015-010091] [Medline: 26758267]
27. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008;62(1):107-115. [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]
28. Neubauer N, Spenrath C, Philip S, Daum C, Liu L, Miguel-Cruz A. Identifying adoption and usability factors of locator devices for persons living with dementia. Dementia (London) 2022;21(3):862-881 [FREE Full text] [doi: 10.1177/14713012211065381] [Medline: 34964391]
29. Liu L, Cruz AM, Ruptash T, Barnard S, Juzwishin D. Acceptance of Global Positioning System (GPS) technology among dementia clients and family caregivers. J Technol Hum Serv 2017;35(2):99-119. [doi: 10.1080/15228835.2016.1266724]
30. Miguel Cruz A, Lopez Portillo HP, Daum C, Rutledge E, King S, Liu L. Technology acceptance and usability of a mobile app to support the workflow of health care aides who provide services to older adults: pilot mixed methods study. JMIR Aging 2022 May 18;5(2):e37521 [FREE Full text] [doi: 10.2196/37521] [Medline: 35583930]
31. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Q 2003;27(3):425-478. [doi: 10.2307/30036540]
32. Liu L, Cruz AM, Rincon AR, Buttar V, Ranson Q, Goertzen D. What factors determine therapists' acceptance of new technologies for rehabilitation—a study using the Unified Theory of Acceptance and Use of Technology (UTAUT). Disabil Rehabil 2015;37(5):447-455. [doi: 10.3109/09638288.2014.923529] [Medline: 24901351]
33. Øksnebjerg L, Woods B, Ruth K, Lauridsen A, Kristiansen S, Holst HD, et al. A tablet app supporting self-management for people with dementia: explorative study of adoption and use patterns. JMIR Mhealth Uhealth 2020 Jan 17;8(1):e14694 [FREE Full text] [doi: 10.2196/14694] [Medline: 31951217]
34. Perez H, Neubauer N, Marshall S, Philip S, Miguel-Cruz A, Liu L. Barriers and benefits of information communication technologies used by health care aides. Appl Clin Inform 2022 Jan;13(1):270-286 [FREE Full text] [doi: 10.1055/s-0042-1743238] [Medline: 35263800]
35. Liu L, Rios-Rincon AM, Miguel CA, Daum C, Neubauer N. Autonomy and Independence in An Era of Technology. Synthesis Lectures on Technology and Health. San Rafael, CA: Morgan & Claypool; 2022:i-237.

36. Huryk LA. Factors influencing nurses' attitudes towards healthcare information technology. J Nurs Manag 2010;18(5):606-612. [doi: 10.1111/j.1365-2834.2010.01084.x] [Medline: 20636510]
37. Gibson G, Dickinson C, Brittain K, Robinson L. Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. Ageing Soc 2018;39(11):2502-2519. [doi: 10.1017/s0144686x18000661]
38. Cristea M, Noja GG, Stefea P, Sala AL. The impact of population aging and public health support on EU labor markets. Int J Environ Res Public Health 2020 Feb 24;17(4):1439 [FREE Full text] [doi: 10.3390/ijerph17041439] [Medline: 32102277]
39. Kelleher J, Zola S, Cui X, Chen S, Gerber C, Parker MW, et al. Personalized visual mapping assistive technology to improve functional ability in persons with dementia: feasibility cohort study. JMIR Aging 2021 Oct 19;4(4):e28165 [FREE Full text] [doi: 10.2196/28165] [Medline: 34269690]

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Original Paper

Technology Usability for People Living With Dementia: Concept Analysis

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Abstract

Background: Usability is a key indicator of the quality of technology products. In tandem with technological advancements, potential use by individuals with dementia is increasing. However, defining the usability of technology for individuals with dementia remains an ongoing challenge. The diverse and progressive nature of dementia adds complexity to the creation of universal usability criteria, highlighting the need for focused deliberations. Technological interventions offer potential benefits for people living with dementia and caregivers. Amid COVID-19, technology's role in health care access is growing, especially among older adults. Enabling the diverse population of people living with dementia to enjoy the benefits of technologies requires particular attention to their needs, desires, capabilities, and vulnerabilities to potential harm from technologies. Successful technological interventions for dementia require meticulous consideration of technology usability.

Objective: This concept analysis aims to examine the usability of technology in the context of individuals living with dementia to establish a clear definition for usability within this specific demographic.

Methods: The framework by Walker and Avant was used to guide this concept analysis. We conducted a literature review spanning 1984 to 2024, exploring technology usability for people with dementia through the PubMed, Web of Science, and Google Scholar databases using the keywords "technology usability" and "dementia." We also incorporated clinical definitions and integrated interview data from 29 dyads comprising individuals with mild Alzheimer dementia and their respective care partners, resulting in a total of 58 older adults. This approach aimed to offer a more comprehensive portrayal of the usability needs of individuals living with dementia, emphasizing practical application.

Results: The evidence from the literature review unveiled that usability encompasses attributes such as acceptable learnability, efficiency, and satisfaction. The clinical perspective on dementia stages, subtypes, and symptoms underscores the importance of tailored technology usability assessment. Feedback from 29 dyads also emphasized the value of simplicity, clear navigation, age-sensitive design, personalized features, and audio support. Thus, design should prioritize personalized assistance for individuals living with dementia, moving away from standardized technological approaches. Synthesized from various sources, the defined usability attributes for individuals living with dementia not only encompass the general usability properties of effectiveness, efficiency, and satisfaction but also include other key factors: adaptability, personalization, intuitiveness, and simplicity, to ensure that technology is supportive and yields tangible benefits for this demographic.

Conclusions: Usability is crucial for people living with dementia when designing technological interventions. It necessitates an understanding of user characteristics, dementia stages, symptoms, needs, and tasks, as well as consideration of varied physical requirements, potential sensory loss, and age-related changes. Disease progression requires adapting to evolving symptoms. Recommendations include versatile, multifunctional technology designs; accommodating diverse needs; and adjusting software functionalities for personalization. Product feature classification can be flexible based on user conditions.

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KEYWORDS

usability; dementia; older adults; technology; concept analysis; mobile phone

Introduction

Improving Technology Usability for Dementia

Usability, a critical determinant of technology's quality, influences user acceptance and overall experience, with its importance magnified for individuals with mild cognitive impairment or dementia [1-3]. The intricate nature of modern technologies necessitates designs that accommodate cognitive limitations, ensuring accessibility and ease of use for this demographic. However, the specific usability needs of those with dementia are often not adequately defined given the condition's variability and progression [4]. This underdefinition underscores the necessity for technology products to be designed with a deep understanding of the cognitive, memory, and learning challenges faced by individuals with dementia. It is critical to ensure that technology is designed not only to be convenient but also to address specific needs and enhance usability across the spectrum of dementia types, thereby facilitating its adoption and effective use.

Worldwide, >50 million people are living with dementia, a number projected to triple by 2050 [5,6]. Every 3 seconds, someone is diagnosed with dementia, posing significant challenges to health care, care provision, and social services worldwide [7]. Technological interventions, including digital tools such as calendars and talking watches, assistive devices, and telecare, offer potential benefits by aiding daily function, improving safety, and enhancing social connectedness, thereby improving life quality and mood [8-11]. Moreover, these interventions can alleviate caregiver burden by providing monitoring and reminders, with a potential to supplement human care [8,12]. The COVID-19 pandemic has further highlighted the crucial role of technology in health care, emphasizing its importance in maintaining quality care [13]. In alignment with the World Health Organization's "Dementia: a public health priority" report, advancements in communication and assistive technologies have provided a variety of intervention methods to improve the lives and health of people living with dementia, including maintaining independent living and enhancing safety and autonomy [14].

However, technological solutions must be designed with the specific needs and abilities of people living with dementia in mind to avoid confusion, frustration, and potential rejection due to complexity or unintuitive interfaces [15,16]. The World Health Organization's 2022 policy brief on agism in artificial intelligence (AI) technologies underscores the importance of addressing stereotypes, biases, or discrimination in AI, ensuring quality care for older adults [17]. Tailoring AI technology to the diverse needs, desires, capabilities, and vulnerabilities of people with dementia is essential for harnessing AI benefits while mitigating risks [18]. Thus, considering the usability of technology for dementia care is paramount for successful implementation.

Challenges and Considerations in Technology Usability for Dementia Care

Addressing technology usability for individuals with dementia and their caregivers is recognized worldwide as a priority in national and international funding programs. Despite an increase in information and communications technologies (ICTs) for dementia care, standardized methods for evaluating ICT acceptance and usability for this demographic are lacking [19]. The technology acceptance model (TAM) and its subsequent evolutions, including the TAM 2 and the senior TAM (STAM), highlight perceived ease of use and usefulness as critical to technology adoption [20-23]. These models account for personal factors, such as cognitive abilities, and system features, such as product design and instructional support, emphasizing the adaptability of the latter to enhance usability [24,25]. Therefore, to reduce the digital divide, one of the current promising strategies is to start with product design, adopt user-centered design, and use machine learning techniques to provide timely prompts or suggestions to support and help users [24-26].

The limited adoption of digital technologies by individuals with dementia suggests that usability aspects related to product requirements and design have not been sufficiently addressed [27]. While technology usability research is advancing, there is a notable gap in literature specifically addressing the unique needs of individuals living with dementia [28,29]. This gap in clarity and consistency hampers the advancement of nursing and health science knowledge and the development of theoretical models in technology research [30]. To bridge this knowledge gap and enhance technology usability for dementia care, a concerted effort focusing on clear, tailored design principles and user-centered approaches is crucial.

Aims

This concept analysis sought to examine the usability of technology in the context of individuals living with dementia to establish a clear definition for usability within this specific demographic.

Methods

Overview

Multiple sources were used to delineate the definitions and key attributes of usability specific to people living with dementia. Using the method by Walker and Avant [31], this paper offers a detailed analysis of the essential attributes of usability in the context of dementia. Their methodology uses a 7-step process that facilitates a comprehensive understanding of a concept. The process is structured as follows: (1) select a concept; (2) determine the aim of the analysis; (3) identify all uses of the concept; (4) determine the defining attributes; (5) construct model, borderline, related, and contrary cases; (6) identify antecedents and consequences of the concept; and (7) define the concept's empirical referents.

For the literature review on technology usability for people living with dementia, works from 1984 to 2024 were searched in the electronic databases PubMed, Web of Science, and Google Scholar. The keywords applied were "technology usability" and "dementia."

To illustrate the usability considerations of technology for individuals with mild dementia, we drew the interview data from a pilot study conducted by the third author (CB). This study involved the design and evaluation of a web-based interface tailored specifically for this population [32]. This study initially enrolled 33 dyads consisting of individuals living with dementia and their care partners. A total of 4 dyads did not complete the study for various reasons, including health-related issues and the difficulty presented by the standardized survey scales for those with dementia. Consequently, the pilot of the web application was conducted with 29 mild Alzheimer disease dementia dyads, totaling 58 older adults (29 with mild dementia and their respective care partners, with all but 1 pair being spousal dyads). Following the pilot, each dyad was interviewed regarding their experience with the web application. The participant characteristics were as follows. The average age among those living with dementia (n=29) was 70 (SD 7.06) years, ranging from 59 to 82 years, with a male majority (18/29, 62% of individuals). Most were White (28/29, 97%), and 1 participant was African American (3%). The care partners (n=29) had an average age of 68 (SD 6.73) years, ranging from 55 to 83 years, with 38% (n=11) identifying as male. Most were White (27/29, 93%), with 2 (7%) Asian American participants.

Ethical Considerations

The interview data were drawn from a pilot study designed and evaluated by the third author (CB), focusing on a web-based interface specifically for people living with dementia [33]. The study was approved by the University of Washington Division of Human Subjects (STUDY00014226). Informed consent was obtained from all participants. The data are anonymous and have been deidentified. Each individual participant received a Visa gift card for US $150 for their time upon completion of the 3 study components.

Results

Concept Definition

As of now, there has been no comprehensive conceptual analysis concerning the usability of technology for individuals living with dementia. Consequently, to elucidate the use and implications of related concepts, an examination of various sources defining usability, encompassing dictionaries, organizations, and academic studies, is imperative.

Dictionary Definitions

Usability is an abstract and interdisciplinary concept. Merriam-Webster's Online Dictionary [34] defines usability as "the quality or state of being usable: ease of use." In the Cambridge Dictionary [35], usability is "the fact of something being easy to use, or the degree to which it is easy to use." The Oxford English Dictionary [36] offers the following definition: "the degree to which something is able or fit to be used." These descriptions collectively converge on a comprehensive understanding of usability as a measure of a product's accessibility and ease of operation. Specifically, when considering individuals living with dementia, the concept of usability is tailored to the degree to which a product is easy to use or suitable for use by people living with dementia.

Definition From the International Organization for Standardization

The introduction section of the guidance on usability by the International Organization for Standardization [27,37] presents one of the most universally acknowledged definitions of usability. According to the International Organization for Standardization standard 9241-11, usability is defined as "the extent to which a system, product, or service can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" (part 11, paragraph 2) [37]. This delineation emphasizes the importance of a user-centered approach in evaluating how well a product or service facilitates the attainment of goals by individuals. Therefore, in assessing usability for people with dementia, the focus is on determining the degree to which the product or service enables effective and efficient goal achievement for this specific user group, underlining the significance of tailoring technology to meet their unique needs and enhance their quality of life.

Literature Definitions

While the studies reviewed did not offer explicit definitions of "usability for individuals living with dementia," the prevailing focus within the literature revolves around the examination and assessment of technology interventions tailored for this demographic. These interventions encompass a spectrum of tools and methodologies designed to gauge acceptance, adoption, and usability among individuals living with dementia. Thus, by analyzing the content of these articles, we can derive insights into the underlying characteristics and properties associated with usability in this context. The concept of technology usability integrates essential characteristics, including ease of use, satisfaction, learnability, utility, effectiveness, efficiency, flexibility, familiarity, responsiveness, and the clarity and visibility of feedback mechanisms [38]. This comprehensive understanding of usability encompasses both objective and subjective elements, considering objective performance indicators such as actual use efficiency, effectiveness, and error rates alongside the subjective user experience and perceptions [4]. The seminal work by Meiland et al [39] classifies usability into dimensions of "user friendliness" (marked by gratification and manageability), "usefulness" (satisfying the requirements and aspirations of individuals living with dementia), and "effectiveness" (promoting independence, coping strategies, and overall well-being). These efforts to operationalize usability take into careful consideration the end users' goals, encountered obstacles during task execution, and the selection of assistive technologies [40].

Research indicates that 40% of individuals with dementia require additional assistance and time to understand and use technological tools, including navigation through certain icons and devices. This underscores the necessity for facilitators or supervisors to aid in explaining operational steps and the use of technological intervention tools [4]. The analysis by Shultz and Hand [30] enriches our understanding of usability as the degree to which technology is perceived by users as learnable, efficient, and satisfactory. In parallel, Gibson et al [41] defined usability as the degree to which the user perceives acceptable learnability, efficiency, and satisfaction when using the technology. Gibson et al [41] advocate for a design philosophy that emphasizes personalized and adaptable support for individuals living with dementia, advocating against the use of generic technological solutions.

Further elaborating on these insights, Asghar et al [42] articulate how assistive technologies enable social interaction, health monitoring, independent mobility, and punctual medication adherence, thereby supporting daily living activities and enhancing the quality of life of those living with dementia. This perspective reiterates usability's core definition as ease of use, efficiency, and the capacity to meet specific user needs.

The investigative effort by Miguel Cruz et al [19] into the assessment methods for the acceptance, adoption, and usability of ICTs by people living with dementia and their caregivers highlights the critical gap in standardized evaluation methodologies. This gap signals the need for further research and development to measure such technologies effectively. Hence, usability for people living with dementia hinges on the extent to which they can use specific technologies effectively, satisfactorily, and safely considering their unique requirements and cognitive limitations.

In the domain of mobile app development [43], the initiative to enhance the quality of life of those living with dementia and Alzheimer disease by creating older adult–friendly apps is paramount. This initiative directly addresses the cognitive and usability challenges faced by this demographic, aiming to make technology both accessible and beneficial.

The usability of mobile apps is fundamentally tied to 9 thematic areas: user interface design, physical considerations, screen size, interaction challenges, meeting user needs, addressing the lack of self-awareness regarding app necessities, mitigating the stigma associated with app use, overcoming technological inexperience, and emphasizing the importance of technical support [32]. These areas highlight the critical need for developing intuitive, user-friendly apps tailored to the unique challenges encountered by individuals with dementia, thereby significantly enhancing their autonomy and quality of life.

Considering the specific needs and limitations of individuals with dementia or mild cognitive impairments when designing and implementing technological interventions is critical. Through appropriate support and assistance, their user experience and the effectiveness of the intervention can be improved [4]. Usability is related to user friendliness and ease of use and learning, serving as a means for older adults and those with reduced capabilities to participate in activities and engage equally in society. Highlighting the value of involving users in technology development and clinical trials, the design of intervention studies should include people with dementia and their caregivers to understand the design features necessary to enhance usability and acceptance [9].

Kung and Chen [28] conducted a concept analysis on the usability of health promotion mobile apps, summarizing the characteristics of usability. The most common attributes of usability identified in their study included efficiency, user satisfaction, and learnability [28]. These attributes are crucial for health promotion apps, ensuring that user expectations are met, providing satisfaction, and facilitating ease of learning and use. Textbox 1 organizes the characteristics of usability for people living with dementia from the literature review. Notably, ease of use, effectiveness, efficiency, and satisfaction were frequently mentioned across various studies; these attributes are generally recognized as core characteristics of usability across various fields, not just in the context of designing for people living with dementia. Other significant attributes that repeatedly appear in the literature on usability for people living with dementia include adaptability, personalization, intuitiveness, and simplicity, suggesting a comprehensive approach to addressing the unique needs and challenges faced by people living with dementia.

Textbox 1. Summary of the characteristics of the definition of usability for people living with dementia.

Sources and attributes of usability for people living with dementia

- Boulay et al [44], 2011: effectiveness, efficiency, and satisfaction
- Lim et al [45], 2012: intuitive, engagement, and adaptability to users' needs
- Meiland et al [39], 2012: user friendliness, usefulness, and effectiveness
- González-Palau et al [46], 2013: effectiveness, efficiency, and satisfaction
- Yamagata et al [43], 2013: ease of use, personalization, accessibility, adaptability, and engagement
- Boger et al [47], 2015: intuitiveness, simplicity, customization, and adaptability
- Manera et al [48], 2015: effectiveness, efficiency, satisfaction, and engagement
- Martins et al [38], 2015: ease of use, satisfaction, learnability, efficacy, coherence, flexibility, and responsiveness
- Lindqvist et al [40], 2015: ease of use, effectiveness, and adaptability to users' needs
- Shultz and Hand [30], 2015: learnability, efficiency, and satisfaction
- Ben-Sadoun et al [49], 2016: effectiveness, efficiency, and satisfaction
- Garcia-Sanjuan et al [50], 2017: effectiveness, efficiency, satisfaction, and engagement
- Meiland et al [51], 2017: effectiveness, efficiency, simplicity, intuitiveness, personalization, and engagement
- Tziraki et al [52], 2017: engagement, acceptability, and accessibility
- Asghar et al [42], 2018: effectiveness, adaptability, and satisfaction
- Holthe et al [9], 2018: effectiveness, efficiency, and satisfaction
- Gibson et al [41], 2019: adaptability, accessibility, and effectiveness
- Tuena et al [53], 2020: ease of use, intuitiveness, effectiveness, engagement, personalization, and adaptability
- Contreras-Somoza et al [4], 2021: effectiveness, efficiency, and satisfaction
- Engelsma et al [54], 2021: personalization, simplicity, clarity, engagement, and adaptability
- Koh et al [55], 2022: ease of use and engagement, customizability, and adaptability
- Neubauer et al [56], 2022: effectiveness, efficiency, simplicity, and satisfaction
- Miguel Cruz et al [19], 2023: simplicity and adaptability
- Ye et al [32], 2023: ease of use, accessibility, personalization, and effectiveness
- Zheng et al [57], 2023: effectiveness, efficiency, satisfaction, simplicity and clarity, and engagement
- Zhu et al [58], 2024: ease of use, accessibility, personalization, and engagement

Potentially Related but Distinct Concept of Acceptability

Acceptability of technology is the extent of the primary users' predisposition to implement the technology in their daily activities as a result of their diverse perceptions of the product's characteristics [59]. The primary users of technologies for people living with dementia may include individuals living with dementia or their care partners. Some studies have reported the technology acceptability of people with mild to moderate dementia and their caregivers. For example, an inaesthetic device may be interpreted as unacceptable because of its unappealing appearance and, therefore, has lower acceptability.

Describing Usability for People Living With Dementia From the Clinical Standpoint

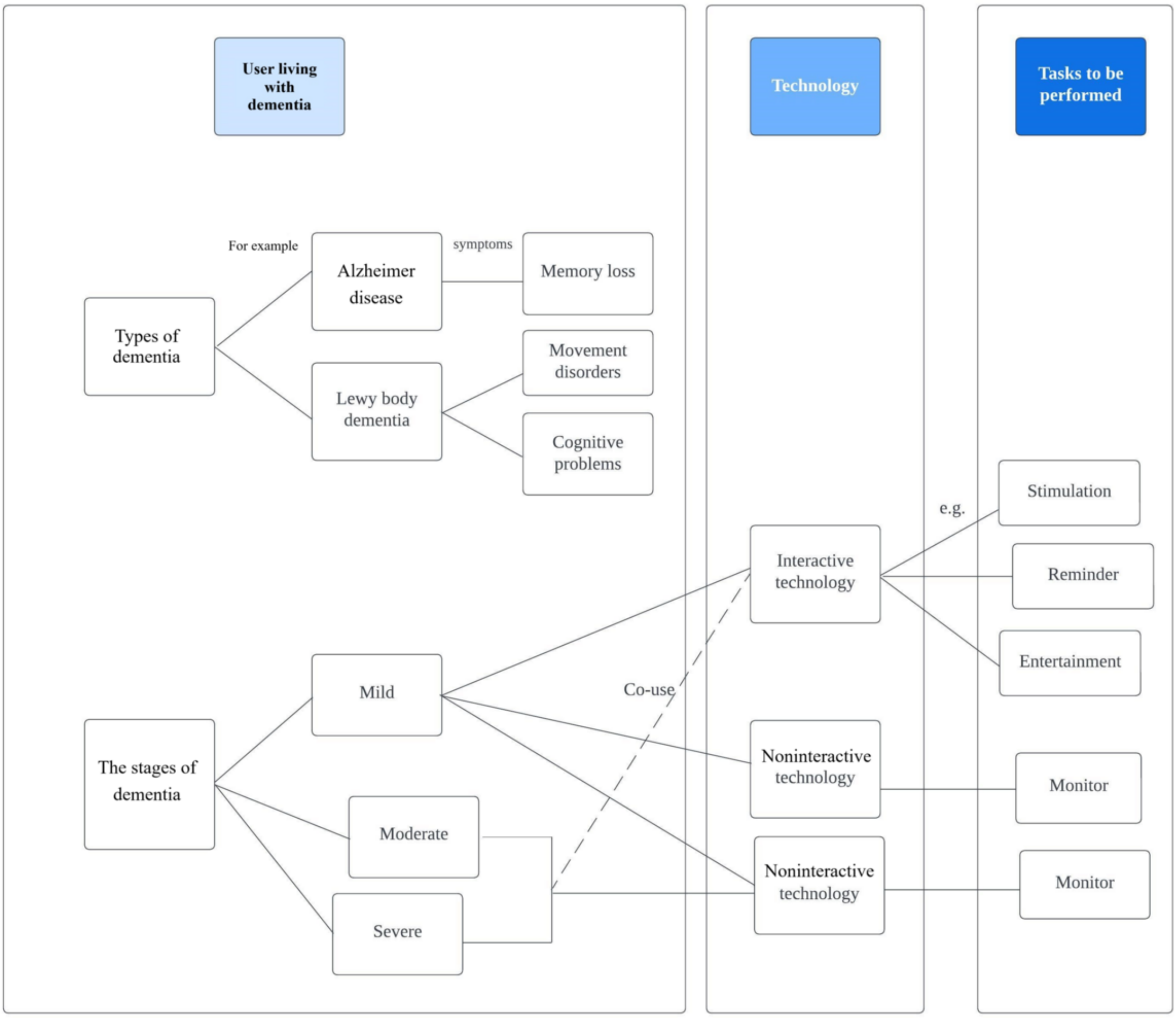
Dementia progresses slowly into 3 stages: mild, moderate, and severe, which can also be called early, middle, and late stages [60]. According to the Clinical Dementia Rating (CDR), there are different stages of dementia; based on an individual's cognitive functions, a 5-point system is used to describe each stage of dementia. A person in CDR-0 does not have dementia, and stage CDR-0.5 is considered very mild dementia or mild cognitive impairment, with slight but consistent memory problems. The expected duration of this stage is 3 to 7 years. Someone with CDR-1 has mild dementia. The average duration of this stage is 2 years, with memory loss, particularly recent events, and having trouble with the inability to perform daily tasks. In stage CDR-2, a person living with moderate dementia experiences more profound memory loss and is typically disoriented to time and place for the expected duration of 2 to 4 years. A person in stage CDR-3 is considered to have severe dementia. One might have multiple medical comorbidities, which often result in the end of functional independence. The average duration of stage CDR-3 is typically 1 to 2.5 years [60-63]. These stages help us understand how dementia may change over time and serve as a guide for the design of technology products at different stages, addressing different needs and usability.

Interactive technology refers to systems and devices that can respond to user inputs in real time, allowing for a dynamic exchange of information between the user and the technology. This domain of technology is characterized by the bidirectional provision and reception of information through actions such as language, text, movement, and touch. The key features of interactive technology include user input, real-time processing, and outputs that adjust based on user actions. Users communicate their requirements, and the technology delivers the results of their operations back to them through the interface [64,65]. Common forms of interactive technology, such as touch screens on smartphones, tablets, and information kiosks, as well as virtual reality, augmented reality, smart home devices, social media, and video games, enable users to directly interact with displayed content. Noninteractive technologies refer to products that do not require or allow for instant user input or feedback to operate. Unlike interactive technologies, which are designed to involve users in 2-way communication or interaction, noninteractive technologies, once activated or triggered, operate independently of user inputs. These technologies are often designed to perform specific tasks, display information, or execute commands without requiring ongoing user interaction. Television, smart speakers, sensors, static websites, and radio are typical examples of noninteractive technology. Operating interactive technology typically requires hand-eye coordination and precise control of the product, as well as reading or memorizing the steps or instructions on how to operate the technological product. It may even involve understanding complex user interfaces or executing multistep tasks to achieve the intended use of the product. Compared with the middle and late stages, people with mild dementia are still able to retain independence to complete many daily activities or do so with little assistance or guidance [60,66], and they are more likely to use interactive technology. For example, people living with mild dementia who attempt to have cognitive training using interactive tools to stimulate their cognitive functions might have one set of usability needs. The course of dementia is progressive, and when it enters the middle stage, people living with dementia have more profound memory loss. Their ability to cope with daily life becomes more complicated [60,66]. Due to the decline in memory functions and the ability to perform fine movements, the demand for technology products in the mid to late stages may be more often focused on noninteractive products due to usability issues.

In addition, different individuals may have different symptomology. There are different subtypes of dementia. Alzheimer disease and Lewy body dementia are the 2 most common progressive dementias. In addition to cognitive impairment, Lewy body dementia may be accompanied by muscle stiffness, hand tremors, and unsteady gait at an early stage [66]. A person with Lewy body dementia might have mobility issues that might imply the usability concern of motor activity, and someone with Alzheimer dementia might have issues with remembering instructions.

In short, from a clinical point of view, to look at the technology usability for people living with dementia, many factors require assessment, such as the stage, type, and symptoms of dementia. Furthermore, the categories of technology—interactive or noninteractive technology—should be considered based on the characteristics and needs of the disease, focusing precisely on the needs of tasks to be performed (Figure 1). In addition, people living with dementia retain certain relevant functions that are crucial for designers to consider. Despite the cognitive decline associated with dementia, individuals often maintain sensory and motor abilities provided they do not have other chronic conditions or age-related changes [67]. For designers, it is essential to recognize and leverage these retained functions when developing tools for this population. For instance, people living with dementia may be able to recall distant personal memories, which can be used in product design to evoke positive emotional and behavioral outcomes. By understanding and designing with knowledge of these maintained functions, digital tools can be better aligned with the abilities and needs of people living with dementia, thereby enhancing their engagement, enjoyment, and overall quality of life [67].

Figure 1. Factors affecting the use of technology for people living with dementia.



Definition From Interviews With People Living With Dementia

To illustrate technology usability considerations in people with mild dementia, we drew from a pilot study in which the third author designed and evaluated a web-based interface specifically for this population. In brief, the project aimed to investigate the experience of using a web application interface designed for people living with dementia and their care partners [33]. Its design complied with the criteria of the Web Content Accessibility Guidelines 2.1 at level AA, which is the standard for web accessibility developed by the World Wide Web Consortium. Components to enhance accessibility for people with sensory loss and with dementia included an audio option; screen reader compatibility; and clear, short sentences that avoided abstractions and multiple constructs. After conducting a pilot of the web application with 29 dyads of people with mild Alzheimer disease dementia and their care partners for a total of 58 older adults, each dyad was interviewed about their experience using it together. The interviewees indicated what they found positive about the web application that contributed to usability. They stated that they liked that the web application's interface was simple, clean, straightforward, and easy to use and that there were not too many options. The buttons were specific and clearly visible, and there were not too many distractions on the screen to create confusion. Participants appreciated how age-related vision changes were considered in the design. For example, the buttons on the web application were large enough, and the texts were of a size suitable for reading. Furthermore, because they could forget the operation steps or the functions of unmarked buttons, they found the clear and explicit wayfinding directions helpful and felt that they did not risk "getting lost" in the web application. Pilot participants further appreciated personalization options, such as open-text boxes to type in explanations so that the information could be entered in a familiar way. In addition, users said that they liked the app's summary feature, which reports the answers they chose for their future reference.

Many dyads of people with dementia and their care partners said that it was helpful to have an audio option, which read the text on the screen when selected while visually highlighting each sentence. It assisted people living with dementia in concentrating, and the care partners enjoyed not needing to read the text on the application aloud to their partners. Approximately

1 in 3 older adults experience age-related hearing loss, and their hearing sensitivity, especially high-frequency hearing, decreases gradually [68,69]. However, the ability to hear low-pitched sounds is often not affected [70]. Therefore, the web application used a male-sounding (lower) voice for reading, which can be heard more clearly by older adults. This and other age-related physiological changes are factors that must be taken into account as dementia is associated with older age [5].

Finally, in the usability-testing phase, the pilot found that it was sometimes challenging to obtain feedback from people living with dementia on the web application within a few days due to short-term memory difficulties. Some participants noted that they were unable to remember details of their experience or the web application well enough to report on it. Hence, to understand the user experience, it is necessary to find creative solutions such as soliciting real-time feedback during or immediately after using the application.

Defining Attributes

Overview

Following the approach by Walker and Avant [31], after the concept of usability is defined, its essential attributes must also be defined. Particular attributes are mentioned repeatedly in the literature and can be used to distinguish this concept from those that are similar or related. The current definition and characteristics of usability are not entirely applicable to individuals with dementia. Therefore, this study synthesized a definition of usability for patients with dementia based on multiple resources, including dictionaries, a literature review, and data from interviews with people living with dementia and their caregivers. In addition to ease of use, effectiveness, acceptable learnability, and satisfaction, special attention is required for dementia symptoms and aging. Personalization becomes a crucial attribute, with adaptations based on dementia stages, subtypes, and symptoms. It emphasizes the value of simplicity, clear navigation, age-sensitive design, and personalized features, making the design of the technology or interface more specific and intuitive.

Constructed Cases

The application of technology to people living with dementia can be divided into the following five categories: (1) cognitive training and daily living, (2) screening, (3) health and safety monitoring, (4) leisure and socialization, and (5) navigation [71]. Selected clinical cases are listed herein to clarify and illustrate the concept of usability for people living with dementia. The case scenarios presented in this study are a combination of adapted cases from the first author's previous clinical work and fictional scenarios, and all mentioned names are of a fictional nature. On the basis of the work by Walker and Avant [31], the exemplar case contains all the defining attributes of the concept. The borderline case possesses not all but most of the defining attributes of the concept, and the related case is related to the main defining attributes but does not contain all of them. In addition, a contrary case that has no defining attributes of this concept but is contrary to it is presented.

Exemplary Case

Mr Wang is a patient who was diagnosed with mild dementia 6 months ago. He experiences memory impairment, has difficulties in concentration, becomes lost easily, frequently forgets to lock the door and turn off the tap, is unable to plan trips or prepare meals as he once could, and often feels depressed. Nevertheless, he can maintain his daily life. To delay deterioration, stimulate the brain, and relieve emotional distress, his nurse provided him with a tablet computer. A total of 11 apps were preinstalled on the tablet computer based on 3 categories. The creative (art and music) app enables users to produce artwork on a blank canvas by accessing various brush types and a wide array of colors. Simple interactive games allow users to interact with virtual animals that respond to a user's touch and gestures. Relaxation apps allow users to play relaxing background music while the tablet screen displays nature pictures [45].

After 30 minutes of demonstration, guidance, and practical exercises by the nurse, Mr Wang learned how to operate the device, including turning it on and off, charging it, adjusting the volume, navigating the home screen, and starting and exiting apps. He also received a cell phone to contact someone in case of any operation problems. After completing the standard training checklist, Mr Wang returned home with the tablet and used it for 7 days to evaluate it and the apps' effectiveness.

The nurse invited Mr Wang's primary caregivers to observe the status of his use of the device. Mr Wang used the tablet computer for an average of 50 minutes per day, which exceeded the recommended 30 minutes. Mr Wang expressed satisfaction with using the tablet and the apps and was willing to continue using it. According to his caregivers' observations, Mr Wang spent more time on interactive gaming and listening to music. He spent an average of 15 minutes independently using the tablet, and he was able to independently store and charge it. Use of the tablet also enhanced his emotional stability.

Borderline Case

A person living with mild dementia tried to use a mobile app to buy train tickets, and their caregiver, also an older adult, assisted him in its operation (co-use). However, the app's user interface was complicated to operate. They were finally able to buy the ticket using the app, but the process was too time intensive. This scenario involves a user living with dementia, technology, tasks to be performed (buying train tickets), and the consequences of co-use with the patient's caregiver. The patient used the app several times afterward and became more proficient, indicating that the operation of the app is learnable for a person living with dementia. Moreover, compared with visiting the train station to purchase train tickets directly, using the app to buy tickets is more efficient. Although the purpose of using this tool was achieved, that is, it is applicable, the patient was dissatisfied with the complex and time-intensive user experience; therefore, the satisfaction attribute was not met.

Related Case

Mrs Smith has a diagnosis of mild dementia and lives with her family. Her daughter assisted her in downloading a diet and fitness app on her tablet computer to track nutrition, fitness, and health data. The app offered a menu and colorful photos of various diet types as well as daily exercise videos to follow. In addition, users could upload pictures and share their progress and weight control results in the app's discussion forum, where other users could "like" and comment on the posts.

Mrs Smith enjoyed using the app for its vivid food pictures, animated exercise videos, and users sharing positive posts related to fitness progress on the forum; she felt delighted and vibrant when "liking" forum posts. For Mrs Smith, this app was useful, engaging, and a source of pleasure in her life. Hence, usefulness was present as a defining attribute. However, she could not comprehend how to record diet and health information because the operation interface was too difficult to use; the app lacked the learnability attribute. In addition, the app did not achieve the expected outcomes of its design (healthy diet and fitness), although effectiveness was not included as a defining attribute in this case. Despite this, Mrs Smith was satisfied with using this app, fulfilling the satisfaction attribute.

Contrary Case

A patient with severe dementia lives in a long-term care facility and is cared for by nursing staff. Because of his age and symptoms, this patient has a high risk of falling. The staff assisted in outfitting the patient with a medical alert necklace that automatically sent messages to set recipients if the patient had an emergency, such as a fall. Because this product has an automatic detection system, the patient is not required to learn how to use it, and no learnability attribute is present. The patient himself was unable to understand the function and benefits of the product as a result of the deterioration of his cognitive function; he thought something uncomfortable was stuck on his neck and often removed the necklacelike detector. Despite staff perception that it was essential to his personal safety, he was dissatisfied with it. He often removed the detector and failed to carry it, reducing the usefulness and effectiveness of the product.

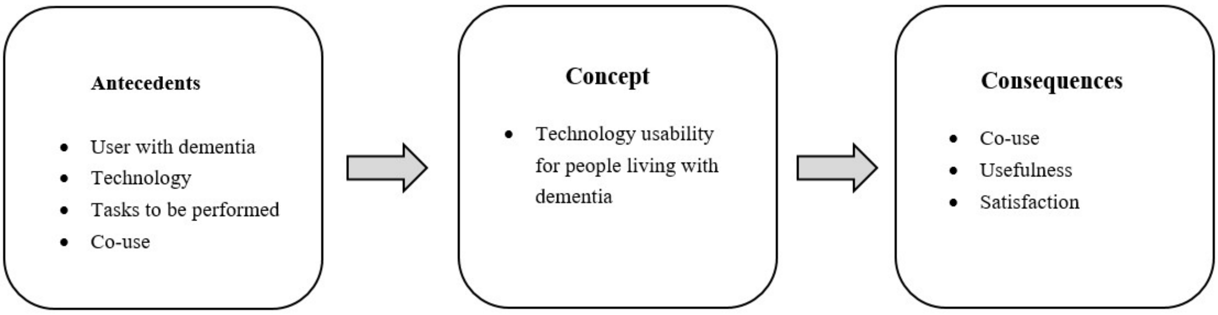
Antecedents

The antecedents of usability for people living with dementia encompass a complex interplay among the individual living with dementia, the technology in use, the tasks to be performed, and the concept of co-use. The usability concept for people living with dementia is profoundly influenced by a complex interplay of social, environmental, and personal factors. The unique needs and capabilities of people living with dementia present various variables that affect usability, making the user living with dementia the most relevant antecedent. However, beyond the individual user, it is essential to consider the broader context of technology use. This includes the availability of space, the skills and knowledge required to operate the technology, existing support systems (such as caregivers or health care professionals), and the financial resources needed to access the technology. Furthermore, depending on the severity of dementia, patients may face greater challenges in using technological tools independently, necessitating co-use or shared use with their caregivers [72]. The concept of "co-use" underscores the importance of social dynamics in usability.

Consequences

The consequences of people living with dementia using technology include co-use, usefulness, and satisfaction. As progressive and irreversible cognitive impairment can affect the capability of people living with dementia to operate technological products, being able to co-use the products is one of the criteria of the consequences of the concept of technology usability. On the basis of the varying degrees of dementia severity, patients who exhibit more pronounced symptoms often encounter greater challenges in independently using technological tools. This situation necessitates a collaborative approach where co-use or shared use with caregivers becomes essential. The need for such support intensifies as the severity of the dementia increases, highlighting the importance of adaptable technological solutions and the involvement of caregivers in the use process to ensure effective and safe interaction with these tools [72]. In addition, the research by Astell et al [73] on the use of interactive multimedia touch screen systems for people living with dementia found that interacting with caregivers through touch screen tablets was intriguing and engaging for people living with dementia. These consequences are similar to the attributes that define usability. Nevertheless, the consequence of usability is the result of the direct evaluation of specific technological applications by people living with dementia, including co-use, perceptions of usefulness, and satisfaction [30] (Figure 2).

Figure 2. Overview of antecedents, attributes, and consequences of technology usability for people living with dementia.



Empirical Referents

Overview

A deeper understanding of the concept of technology usability for people living with dementia can be used as a reference index for clinical practice in assisting those living with dementia in locating suitable technological interventions that promote a healthy and comfortable life. Although the exact definitions and testing of usability vary for different products, their effectiveness is reflected in the actual user operation, that is, whether the device achieves its main goal and is satisfactory for the users (people living with dementia). When testing usability, certain elements must be considered, such as the target users; their learning abilities, desires, and needs; the environment in which they operate; and what advantages the product offers [73]. Usability evaluation methods include quantitative methods such as questionnaires and task completion and qualitative methods such as the "think-aloud" protocol, focus groups, and interviews [74].

Think-Aloud Methods

Among the evaluation methods, the think-aloud (or thinking-aloud) protocol is the most commonly applied qualitative method used to collect data in usability testing. Users are required to speak their thoughts, actions, and perceptions aloud while operating a product, with observers objectively recording the user's speech verbatim without interpreting their behaviors or statements [75]. Customarily, the test is filmed for developer review; developers observe the user process of operating the product as well as users' response to ascertain their experience of the application [76].

System Usability Scale

This is the most widely used and validated questionnaire and comprises a 10-item Likert scale. This simple, standardized questionnaire is advantageous for its objectivity, generality, repeatability, and quantifiability. The questions focus on frequency of use, complexity of operation, consistency, degree of preference, and achievability of the product goal [77]. However, because the think-aloud protocol has higher demands of cognitive load for people living with dementia [76] and the System Usability Scale, a posttest tool, cannot reflect how people living with dementia interact with technology products timely, there is currently no clear, standardized method to assess usability for people living with dementia. Hence, there is still a higher need to design more consistent and reliable evaluation instruments for people living with dementia [19,76].

Observation and Logging

Other primary methods for evaluating usability for people living with dementia are observational methods and logging, which present more objective data, with observations enhanced by video recordings for more reliable results [32,76]. However, observer bias, the presence and perceptions of the observer, can influence both the observer's interpretations of what is seen and possibly the behavior of the participants being observed.

Therefore, it is advised to combine both objective and subjective measures for a comprehensive understanding of usability needs [78,79] and consider the aims of the research to select the proper measuring tool.

We suggest that, when considering usability for people living with dementia, it is necessary to understand the characteristics of users. First, the symptoms and needs of dementia at each stage, the designing purpose, and the tasks to be performed should be understood. Furthermore, dementia mostly affects older adults, so corresponding designs should take into account diverse physical needs, potential sensory loss, and other age-related changes. In addition, primary caregivers spend a lot of time and energy accompanying and caring for people living with dementia. Their firsthand observations, insights, and opinions can be informative when testing products, particularly for technology products designed for co-use. As the disease progresses, changes in condition and symptoms need to be considered. Another suggestion is to design diversified and multifunctional technological products to provide more inclusive and flexible choices and adjust software features to meet individual needs. Product function classification could be upgradable or downgradable as the condition of the user changes, and these functions could be selected by the user.

Furthermore, Sebastian et al [80] have raised a question about the potential of rhetoric in enhancing the adoption of AI; their study results suggest that the adoption of strategic communication techniques (ethos, pathos, and logos) can significantly impact people's willingness to accept AI technologies. Our conceptual analysis also acknowledges the importance of effective communication strategies in facilitating technology adoption. This insight is particularly significant in technology adoption among individuals living with dementia, where trust in and understanding of technology plays a crucial role. Therefore, future research could explore how customized communication strategies based on rhetorical principles can address the concerns and needs of people living with dementia and their caregivers.

Discussion

Clarifying and Validating the Concept of Usability for Individuals With Dementia

To our knowledge, this study represents the first concept analysis specifically focused on usability for individuals with dementia. This paper integrates existing literature and combines empirical data obtained from interviews to relate the concept to specific real-world situations. It offers insights into usability within the context of dementia, covering its practical significance and applications as well as directions for future research.

The concept of usability, particularly for individuals living with dementia, demands a nuanced understanding that accounts for the rapid advancements in technology and its increasing application in supporting these individuals and their caregivers. The specific needs of individuals with dementia, tailored to accommodate common symptoms and optimize their capabilities, underline the critical need for a precise and comprehensive definition of technology usability within this context.

Usability is acknowledged as a multidimensional construct that becomes tangible only when technology is actively used by individuals. The variability of the usability definition, contingent on the context and specific application field, presents a challenge in achieving a unified conceptualization [19,81]. This challenge is further compounded for individuals living with dementia due to the complex interplay between the severity and subtype of dementia and specific technological requirements, including the necessary level of interactivity, technical characteristics, and intended tasks.

Given the diverse severities and progression rates of dementia, individuals experience varying needs across different stages of the condition, necessitating distinct technological interventions and, consequently, different usability requirements at each phase. Therefore, as delineated in Textbox 1, beyond the standard usability attributes—ease of use, effectiveness, efficiency, and satisfaction—additional attributes pertinent to individuals living with dementia include intuitiveness, simplicity, personalization, and adaptability.

Intuitiveness refers to the ease with which users can understand and interact with technology or an interface without previous instruction. When technology is intuitive, individuals living with dementia are more likely to use it independently, fostering a sense of autonomy and confidence. Simplicity, on the other hand, emphasizes clean design and straightforward functionalities that avoid overwhelming the user. It ensures that the cognitive load is minimized, which is particularly important given the cognitive challenges associated with dementia. Together, these attributes create a user-friendly environment that supports the engagement and sustained use of technology by minimizing frustration and maximizing ease of use.

Personalization significantly enhances usability and the overall user experience. Although not a traditional usability attribute, it reflects an understanding of the variability in dementia symptoms and stages, requiring solutions tailored to the individual's changing needs. This approach specifically addresses the challenges associated with various stages and types of dementia. Adaptability complements this concept by ensuring that technology can adjust to the user's changing condition over time, particularly as dementia progresses.

Exploring the Integration With Existing Theoretical Frameworks

The TAM posits that perceived ease of use and perceived usefulness are the 2 main factors affecting one's beliefs, intentions, and attitudes toward using novel technology [20,21]. These factors become even more significant in the context of technology development for patients with dementia, where cognitive impairments necessitate a more detailed and specific consideration of usability. This underscores the need to optimize technology products based on the specific abilities of users. Venkatesh and Davis [22] developed the TAM 2, an expansion of the original TAM, which highlights the importance of social influence and cognitive instrumental processes in technology acceptance and use, including aspects such as subjective norms, voluntariness, and individual experiences. These factors may play a crucial role in determining whether patients with dementia are willing to adopt certain technologies. However, for individuals with dementia, the usability of technology products is particularly critical as they may encounter specific challenges in cognition and perception that are not as pronounced in the general user groups highlighted by the TAM and TAM 2. This means that, for this unique population, perceived ease of use and perceived usefulness remain critical factors but there is also a need to further consider how products can be designed and supported to meet their specific needs.

The STAM, built on the foundation of the TAM and specifically designed to address the needs of older adults, including those with dementia, focuses on technology adoption among older adults [23]. The STAM maintains that perceived usefulness and ease of use, key factors in technology adoption across different age groups, are especially critical for older adults. Moreover, it adds that gerontechnology self-efficacy, gerontechnology anxiety, and facilitating conditions, which are age-related health and ability characteristics more relevant to older adults, are vital in designing technology products for patients with dementia. These considerations emphasize the necessity of considering their cognitive limitations and technology use experience as well as how to minimize barriers to technology use through facilitating conditions.

Therefore, based on the usability for people living with dementia, it is suggested to develop or expand the existing TAMs and theories by (1) incorporating specific factors related to cognitive impairments, adding variables related to cognitive load, information processing speed, and memory retention capabilities; (2) considering contextual and environmental factors such as the home environment, support from care institutions, and the impact of social and cultural backgrounds on technology acceptance and use; (3) emphasizing the importance of user experience design, especially in terms of how design can reduce anxiety and boost confidence among users with dementia, thereby promoting technology acceptance [4]; and (4) focusing on personalized and adaptive design for patients with dementia, expanding the model to include principles of adaptability and personalization according to individual differences, considering the varying needs of people at different stages of dementia [32].

Recommendations for Standardized Usability Testing for People Living With Dementia

We recommend that, when developing a standardized usability test for people with dementia, it is essential to integrate several elements, particularly considering the progression and variability of symptoms. In addressing the usability attributes relevant to people living with dementia, the use of adaptive testing methods is advised. These methods involve designing usability tests that can be customized for different stages of dementia, adjusting protocols based on the cognitive, physical, and emotional states of participants. Due to the progressive nature of dementia, regular re-evaluation is necessary. Immediate feedback after testing is important due to short-term memory difficulties in people living with dementia. To prevent attention deficits or fatigue in people living with mild to moderate stages of dementia, testing durations should be limited as participants might become distracted and fatigued after 30 to 35 minutes of continuous dialogue [33]. Inclusive design principles must consider a broad range of abilities and limitations, ensuring test accessibility for various dementia stages. Finally, collaboration with experts such as health care professionals and dementia specialists is vital for deeper insights into the needs and challenges of people living with dementia.

Potential Frameworks for Usability Assessment for People Living With Dementia

Furthermore, given the unique needs and challenges faced by people living with dementia, addressing the need for a standardized usability assessment specifically tailored to them is important. Some potential frameworks or methods that could be considered or developed for this purpose include, first, human-centered design approach. In this approach, the focus is on involving people living with dementia and their caregivers in the design process by adopting a human-centered design for the intervention, involving an interactive development process that focuses on the users and their needs and requirements [82]. This could include interviews, focus groups, and usability testing sessions with prototypes [74]. Participants are the ones who understand their needs best; using this method, they will also be the designers, involved in the designing phase. It is crucial to incorporate their feedback into the development process to tailor the product to meet their specific capabilities, needs, and preferences. The second potential method is contextual design and observational studies. This method consists of observing people living with dementia interacting with technology in their usual environment. It helps understand how they use technology, what challenges they face, and what aspects of the technology are most beneficial or problematic for them [83]. The third method is heuristic evaluation, a method in which usability experts analyze a product using a set of 10 heuristics [84] and that can be adapted for people living with dementia by involving dementia specialists and usability professionals [85]. The fourth method is longitudinal studies. As dementia is a progressive condition, longitudinal studies can be valuable in assessing how usability needs change over time and how well technology adapts to these changing needs.

Limitations and Future Research Directions

Despite obtaining rich information through interview data, this research still has limitations. One of the limitations is the high homogeneity in terms of the participants’ race and ethnicity, which could potentially impact the generalizability of the research findings. In addition, it is suggested that future research collect data on participants’ educational background and socioeconomic status as these factors may be related to their willingness and ability to use technology products.

Conclusions

This study, through a concept analysis that included interviews with people living with dementia and their caregivers, clarified the definition and attributes of usability tailored for this population. A precise definition of usability in this context is crucial to guide future research and practical applications. This study stresses the importance of considering dementia-specific aspects such as the symptoms and aging process. Customization, guided by the disease’s stages, subtypes, and symptoms, is emphasized as critical. Therefore, the design of interventions for individuals with dementia should prioritize simplicity, clear navigation, age-appropriate esthetics, and personalization to enhance specificity and intuitiveness. Furthermore, it is necessary to consider the antecedents, attributes, and consequences of technology usability for this demographic. Adopting a comprehensive approach is pivotal for developing technology solutions that are finely attuned to the unique needs of people living with dementia, fostering a nuanced understanding of usability in this context.

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Data Availability

The data sets analyzed during this study are not publicly available due to the reuse restrictions outlined in the consent form.

Conflicts of Interest

None declared.

References

1. Alonso-Ríos D, Vázquez-García A, Mosqueira-Rey E, Moret-Bonillo V. Usability: a critical analysis and a taxonomy. Int J Hum Comput Interact 2010 Jan 06;26(1):53-74. [doi: 10.1080/10447310903025552]
2. Vlachogianni P, Tselios N. Perceived usability evaluation of educational technology using the System Usability Scale (SUS): a systematic review. J Res Technol Educ 2021 Feb 23;54(3):392-409. [doi: 10.1080/15391523.2020.1867938]

3. Hyzy M, Bond R, Mulvenna M, Bai L, Dix A, Leigh S, et al. System usability scale benchmarking for digital health apps: meta-analysis. JMIR Mhealth Uhealth 2022 Aug 18;10(8):e37290 [FREE Full text] [doi: 10.2196/37290] [Medline: 35980732]
4. Contreras-Somoza LM, Irazoki E, Toribio-Guzmán JM, de la Torre-Díez I, Diaz-Baquero AA, Parra-Vidales E, et al. Usability and user experience of cognitive intervention technologies for elderly people with MCI or dementia: a systematic review. Front Psychol 2021 Apr 22;12:636116 [FREE Full text] [doi: 10.3389/fpsyg.2021.636116] [Medline: 33967901]
5. About Dementia. Centers for Disease Control and Prevention. URL: https://www.cdc.gov/aging/dementia/index.html [accessed 2023-11-01]
6. Zeisel J, Bennett K, Fleming R. World Alzheimer Report 2020: design dignity dementia: dementia-related design and the built environment volume 1. Alzheimer’s Disease International. 2020. URL: https://www.alzint.org/u/WorldAlzheimerReport2020Vol1.pdf [accessed 2024-03-20]
7. Dementia statistics. Alzheimer's Disease International. URL: https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/ [accessed 2023-11-01]
8. Faucounau V, Wu YH, Boulay M, de Rotrou J, Rigaud AS. Cognitive intervention programmes on patients affected by Mild Cognitive Impairment: a promising intervention tool for MCI? J Nutr Health Aging 2010 Jan;14(1):31-35 [FREE Full text] [doi: 10.1007/s12603-010-0006-0] [Medline: 20082051]
9. Holthe T, Halvorsrud L, Karterud D, Hoel KA, Lund A. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. Clin Interv Aging 2018 May;Volume 13:863-886. [doi: 10.2147/cia.s154717]
10. Astell AJ, Smith SK, Potter S, Preston-Jones E. Computer interactive reminiscence and conversation aid groups-delivering cognitive stimulation with technology. Alzheimers Dement (N Y) 2018 Sep 05;4(1):481-487 [FREE Full text] [doi: 10.1016/j.trci.2018.08.003] [Medline: 30258977]
11. Gathercole RL, Howard RJ. P4-628: assistive technology and telecare to maintain independent living at home for people with dementia: the Attila RCT. Alzheimers Demen 2019 Jul;15(7S_Part_30):P1568. [doi: 10.1016/j.jalz.2019.08.177]
12. Godwin KM, Mills WL, Anderson JA, Kunik ME. Technology-driven interventions for caregivers of persons with dementia: a systematic review. Am J Alzheimers Dis Other Demen 2013 May;28(3):216-222 [FREE Full text] [doi: 10.1177/1533317513481091] [Medline: 23528881]
13. Thimbleby H. Technology and the future of healthcare. J Public Health Res 2013 Dec 01;2(3):e28 [FREE Full text] [doi: 10.4081/jphr.2013.e28] [Medline: 25170499]
14. Dementia: a public health priority. World Health Organization. 2012. URL: https://iris.who.int/bitstream/handle/10665/75263/9789241564458_eng.pdf?sequence=1 [accessed 2024-04-11]
15. Smeenk W, Sturm J, Eggen B. Empathic handover: how would you feel? handing over dementia experiences and feelings in empathic co-design. CoDesign 2017 Mar 22;14(4):259-274. [doi: 10.1080/15710882.2017.1301960]
16. Boot W, Charness N, Czaja SJ, Rogers WA. Designing for Older Adults: Case Studies, Methods, and Tools. Boca Raton, FL: CRC Press; 2020.
17. Ageism in artificial intelligence for health. World Health Organization. 2022 Feb 9. URL: https://www.who.int/publications/i/item/9789240040793 [accessed 2023-11-03]
18. Lazar A, Edasis C, Piper AM. A critical lens on dementia and design in HCI. In: Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. 2017 Presented at: CHI '17; May 6-11, 2017; Denver, CO.
19. Miguel Cruz A, Daum C, Comeau A, Salamanca JD, McLennan L, Neubauer N, et al. Acceptance, adoption, and usability of information and communication technologies for people living with dementia and their care partners: a systematic review. Disabil Rehabil Assist Technol 2023 May 30;18(4):443-457. [doi: 10.1080/17483107.2020.1864671] [Medline: 33378627]
20. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Manag Sci 1989 Aug;35(8):982-1003. [doi: 10.1287/mnsc.35.8.982]
21. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Q 1989 Sep;13(3):319-340. [doi: 10.2307/249008]
22. Venkatesh V, Davis FD. A theoretical extension of the Technology Acceptance Model: four longitudinal field studies. Manag Sci 2000 Feb;46(2):186-204. [doi: 10.1287/mnsc.46.2.186.11926]
23. Chen K, Chan AH. Gerontechnology acceptance by elderly Hong Kong Chinese: a senior technology acceptance model (STAM). Ergonomics 2014 Mar 24;57(5):635-652. [doi: 10.1080/00140139.2014.895855] [Medline: 24655221]
24. Charness N, Boot WR. A grand challenge for psychology: reducing the age-related digital divide. Curr Dir Psychol Sci 2022 Mar 16;31(2):187-193 [FREE Full text] [doi: 10.1177/09637214211068144] [Medline: 35754678]
25. Harris MT, Blocker KA, Rogers WA. Older adults and smart technology: facilitators and barriers to use. Front Comput Sci 2022 May 4;4:835927. [doi: 10.3389/fcomp.2022.835927]
26. Ollevier A, Aguiar G, Palomino M, Simpelaere IS. How can technology support ageing in place in healthy older adults? a systematic review. Public Health Rev 2020 Nov 23;41(1):26 [FREE Full text] [doi: 10.1186/s40985-020-00143-4] [Medline: 33292707]

27. Suijkerbuijk S, Nap HH, Cornelisse L, IJsselsteijn WA, de Kort YA, Minkman MM. Active involvement of people with dementia: a systematic review of studies developing supportive technologies. J Alzheimers Dis 2019 Jun 18;69(4):1041-1065. [doi: 10.3233/jad-190050]
28. Kung PJ, Chen CM. Usability of mobile applications: a concept analysis in health promotion. Taiwan J Public Health 2022;41(2):142-155. [doi: 10.6288/TJPH.202204_41(2).110113]
29. Brooke J. SUS: a retrospective. J Usability Stud 2013;8(2):29-40 [FREE Full text]
30. Shultz S, Hand MW. Usability: a concept analysis. J Theory Constr Test 2015;19(2):65-69.
31. Walker LO, Avant KC. Strategies for Theory Construction in Nursing. New York, NY: Pearson Education; 2019.
32. Ye B, Chu CH, Bayat S, Babineau J, How TV, Mihailidis A. Researched apps used in dementia care for people living with dementia and their informal caregivers: systematic review on app features, security, and usability. J Med Internet Res 2023 Oct 12;25:e46188 [FREE Full text] [doi: 10.2196/46188] [Medline: 37824187]
33. Berridge C, Turner NR, Liu L, Karras SW, Chen A, Fredriksen-Goldsen K, et al. Advance planning for technology use in dementia care: development, design, and feasibility of a novel self-administered decision-making tool. JMIR Aging 2022 Jul 27;5(3):e39335 [FREE Full text] [doi: 10.2196/39335] [Medline: 35896014]
34. Usability. Merriam-Webster. URL: https://www.merriam-webster.com/dictionary/usability [accessed 2023-11-15]
35. Usability. Cambridge Dictionary. URL: https://dictionary.cambridge.org/us/dictionary/english/usability [accessed 2023-11-15]
36. Usability. Oxford English Dictionary. URL: https://www.oed.com/search/dictionary/?scope=Entries&q=usability [accessed 2023-11-15]
37. ISO 9241-11:2018(en): ergonomics of human-system interaction — part 11: usability: definitions and concepts. International Organization for Standardization. 2018. URL: https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-2:v1:en [accessed 2023-11-15]
38. Martins AI, Rosa AF, Queirós A, Silva A, Rocha NP. Definition and validation of the ICF – Usability Scale. Procedia Comput Sci 2015;67:132-139. [doi: 10.1016/j.procs.2015.09.257]
39. Meiland FJ, Bouman AI, Sävenstedt S, Bentvelzen S, Davies RJ, Mulvenna MD, et al. Usability of a new electronic assistive device for community-dwelling persons with mild dementia. Aging Ment Health 2012;16(5):584-591. [doi: 10.1080/13607863.2011.651433] [Medline: 22360649]
40. Lindqvist E, Larsson TJ, Borell L. Experienced usability of assistive technology for cognitive support with respect to user goals. NeuroRehabilitation 2015 Feb 25;36(1):135-149. [doi: 10.3233/NRE-141201] [Medline: 25547777]
41. Gibson G, Dickinson C, Brittain K, Robinson L. Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. Ageing Soc 2018 Jun 27;39(11):2502-2519. [doi: 10.1017/s0144686x18000661]
42. Asghar I, Cang S, Yu H. Usability evaluation of assistive technologies through qualitative research focusing on people with mild dementia. Comput Hum Behav 2018 Feb;79:192-201. [doi: 10.1016/j.chb.2017.08.034]
43. Yamagata C, Coppola JF, Kowtko M, Joyce S. Mobile app development and usability research to help dementia and Alzheimer patients. In: Proceedings of the IEEE Long Island Systems, Applications and Technology Conference. 2013 Presented at: LISAT 2013; May 3, 2013; Farmingdale, NY. [doi: 10.1109/LISAT.2013.6578252]
44. Boulay M, Benveniste S, Boespflug S, Jouvelot P, Rigaud AS. A pilot usability study of MINWii, a music therapy game for demented patients. Technol Health Care 2011;19(4):233-246. [doi: 10.3233/THC-2011-0628] [Medline: 21849735]
45. Lim FS, Wallace T, Luszcz MA, Reynolds KJ. Usability of tablet computers by people with early-stage dementia. Gerontology 2013;59(2):174-182. [doi: 10.1159/000343986] [Medline: 23257664]
46. González-Palau F, Franco M, Toribio JM, Losada R, Parra E, Bamidis P. Designing a computer-based rehabilitation solution for older adults: the importance of testing usability. PsychNology J 2013;11(2):119-136.
47. Boger J, Taati B, Mihailidis A. Interdisciplinary development of manual and automated product usability assessments for older adults with dementia: lessons learned. Disabil Rehabil Assist Technol 2016 Oct 02;11(7):581-587. [doi: 10.3109/17483107.2015.1063714] [Medline: 26135222]
48. Manera V, Petit PD, Derreumaux A, Orvieto I, Romagnoli M, Lyttle G, et al. 'Kitchen and cooking,' a serious game for mild cognitive impairment and Alzheimer's disease: a pilot study. Front Aging Neurosci 2015;7:24 [FREE Full text] [doi: 10.3389/fnagi.2015.00024] [Medline: 25852542]
49. Ben-Sadoun G, Sacco G, Manera V, Bourgeois J, König A, Foulon P, et al. Physical and cognitive stimulation using an exergame in subjects with normal aging, mild and moderate cognitive impairment. J Alzheimers Dis 2016 Jun 30;53(4):1299-1314. [doi: 10.3233/JAD-160268] [Medline: 27372645]
50. Garcia-Sanjuan F, Jaen J, Nacher V. Tangibot: a tangible-mediated robot to support cognitive games for ageing people—A usability study. Pervasive Mob Comput 2017 Jan;34:91-105. [doi: 10.1016/j.pmcj.2016.08.007]
51. Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, et al. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR Rehabil Assist Technol 2017 Jan 16;4(1):e1 [FREE Full text] [doi: 10.2196/rehab.6376] [Medline: 28582262]

52. Tziraki C, Berenbaum R, Gross D, Abikhzer J, Ben-David BM. Designing serious computer games for people with moderate and advanced dementia: interdisciplinary theory-driven pilot study. JMIR Serious Games 2017 Jul 31;5(3):e16 [FREE Full text] [doi: 10.2196/games.6514] [Medline: 28760730]
53. Tuena C, Pedroli E, Trimarchi PD, Gallucci A, Chiappini M, Goulene K, et al. Usability issues of clinical and research applications of virtual reality in older people: a systematic review. Front Hum Neurosci 2020 Apr 8;14:93 [FREE Full text] [doi: 10.3389/fnhum.2020.00093] [Medline: 32322194]
54. Engelsma T, Jaspers MW, Peute LW. Considerate mHealth design for older adults with Alzheimer's disease and related dementias (ADRD): a scoping review on usability barriers and design suggestions. Int J Med Inform 2021 Aug;152:104494 [FREE Full text] [doi: 10.1016/j.ijmedinf.2021.104494] [Medline: 34015657]
55. Koh WQ, Whelan S, Heins P, Casey D, Toomey E, Dröes RM. The usability and impact of a low-cost pet robot for older adults and people with dementia: qualitative content analysis of user experiences and perceptions on consumer websites. JMIR Aging 2022 Feb 22;5(1):e29224 [FREE Full text] [doi: 10.2196/29224] [Medline: 35191844]
56. Neubauer N, Spenrath C, Philip S, Daum C, Liu L, Miguel-Cruz A. Identifying adoption and usability factors of locator devices for persons living with dementia. Dementia (London) 2022 Apr 29;21(3):862-881 [FREE Full text] [doi: 10.1177/14713012211065381] [Medline: 34964391]
57. Zheng J, Gresham M, Phillipson L, Hall D, Jeon YH, Brodaty H, et al. Exploring the usability, user experience and usefulness of a supportive website for people with dementia and carers. Disabil Rehabil Assist Technol 2024 May 22;19(4):1369-1381. [doi: 10.1080/17483107.2023.2180546] [Medline: 37086036]
58. Zhu D, Al Mahmud A, Liu W. Digital storytelling intervention for enhancing the social participation of people with mild cognitive impairment: co-design and usability study. JMIR Aging 2024 Jan 17;7:e54138 [FREE Full text] [doi: 10.2196/54138] [Medline: 38231541]
59. Cavallo F, Aquilano M, Arvati M. An ambient assisted living approach in designing domiciliary services combined with innovative technologies for patients with Alzheimer's disease: a case study. Am J Alzheimers Dis Other Demen 2015 Feb;30(1):69-77 [FREE Full text] [doi: 10.1177/1533317514539724] [Medline: 24951634]
60. Stages of Alzheimer's. Alzheimer's Association. URL: https://www.alz.org/alzheimers-dementia/stages [accessed 2023-11-23]
61. Morris JC. Clinical dementia rating: a reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. Int Psychogeriatr 1997 Jan 10;9 Suppl 1(S1):173-6; discussion 177. [doi: 10.1017/s1041610297004870] [Medline: 9447441]
62. Dementia Care Central. URL: https://www.dementiacarecentral.com/aboutdementia/facts/stages/ [accessed 2023-11-23]
63. Williams MM, Storandt M, Roe CM, Morris JC. Progression of Alzheimer's disease as measured by Clinical Dementia Rating Sum of Boxes scores. Alzheimers Dement 2013 Feb 03;9(1 Suppl):S39-S44 [FREE Full text] [doi: 10.1016/j.jalz.2012.01.005] [Medline: 22858530]
64. Khosrow-Pour M. Encyclopedia of Information Science and Technology, Fourth Edition. Hershey, PA: IGI Global; 2017.
65. National Library of Medicine programs and services, fiscal year 1990. U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health. 1990. URL: https://www.nlm.nih.gov/hmd/manuscripts/nlmarchives/annualreport/1990.pdf [accessed 2024-06-24]
66. Earlstein F. Dementia: Dementia Types, Diagnosis, Symptoms, Treatment, Causes, Neurocognitive Disorders, Prognosis, Research, History, Myths, and More! Facts & Information. Longview, TX: NRB Publishing; 2016.
67. Berridge C, Turner AM, Zaslavsky O, Parsey C. Design for dementia: a call from the health sciences. Interactions (N Y) 2022 Feb 25;29(2):46-49 [FREE Full text] [doi: 10.1145/3512346] [Medline: 35935455]
68. Wiley TL, Cruickshanks KJ, Nondahl DM, Tweed TS, Klein R, Klein R, et al. Aging and high-frequency hearing sensitivity. J Speech Lang Hear Res 1998 Oct;41(5):1061-1072. [doi: 10.1044/jslhr.4105.1061] [Medline: 9771629]
69. Walling AD, Dickson GM. Hearing loss in older adults. Am Fam Physician 2012 Jun 15;85(12):1150-1156 [FREE Full text] [Medline: 22962895]
70. Kurakata K, Mizunami T. Comparison of equal-loudness-level contours between otologically normal young and older adults. Acoust Sci Technol 2014 Sep;35(5):243-250. [doi: 10.1250/ast.35.243]
71. Yousaf K, Mehmood Z, Saba T, Rehman A, Munshi AM, Alharbey R, et al. Mobile-health applications for the efficient delivery of health care facility to people with dementia (PwD) and support to their carers: a survey. Biomed Res Int 2019;2019:7151475 [FREE Full text] [doi: 10.1155/2019/7151475] [Medline: 31032361]
72. Mikula CM, Perry C, Boone AE, Benge JF, Scullin MK, Kiselica AM. Dementia caregiver insights on use of assistive technologies. Work Aging Retire 2024 Jan;10(1):14-24. [doi: 10.1093/workar/waac027]
73. Astell AJ, Ellis MP, Bernardi L, Alm N, Dye R, Gowans G, et al. Using a touch screen computer to support relationships between people with dementia and caregivers. Interact Comput 2010 Jul;22(4):267-275. [doi: 10.1016/j.intcom.2010.03.003]
74. Harte R, Glynn L, Rodríguez-Molinero A, Baker PM, Scharf T, Quinlan LR, et al. A human-centered design methodology to enhance the usability, human factors, and user experience of connected health systems: a three-phase methodology. JMIR Hum Factors 2017 Mar 16;4(1):e8 [FREE Full text] [doi: 10.2196/humanfactors.5443] [Medline: 28302594]
75. Maramba I, Chatterjee A, Newman C. Methods of usability testing in the development of eHealth applications: a scoping review. Int J Med Inform 2019 Jun;126:95-104. [doi: 10.1016/j.ijmedinf.2019.03.018] [Medline: 31029270]

76. Nielsen J. Thinking aloud: the #1 usability tool. Nielsen Norman Group. 2012 Jan 15. URL: https://www.nngroup.com/articles/thinking-aloud-the-1-usability-tool/ [accessed 2023-11-30]
77. Gibson A, McCauley C, Mulvenna M, Ryan A, Laird L, Curran K, et al. Assessing usability testing for people living with dementia. In: Proceedings of the 4th Workshop on ICTs for Improving Patients Rehabilitation Research Techniques. 2016 Presented at: REHAB '16; October 13-14, 2016; Lisbon, Portugal. [doi: 10.1145/3051488.3051492]
78. Rai HK, Griffiths R, Yates L, Schneider J, Orrell M. Field-testing an iCST touch-screen application with people with dementia and carers: a mixed method study. Aging Ment Health 2021 Jun;25(6):1008-1018. [doi: 10.1080/13607863.2020.1783515] [Medline: 32578445]
79. Thorpe JR, Rønn-Andersen KV, Bień P, Özkil AG, Forchhammer BH, Maier AM. Pervasive assistive technology for people with dementia: a UCD case. Healthc Technol Lett 2016 Dec;3(4):297-302 [FREE Full text] [doi: 10.1049/htl.2016.0057] [Medline: 28008366]
80. Sebastian G, George A, Jackson GJ. Persuading patients using rhetoric to improve artificial intelligence adoption: experimental study. J Med Internet Res 2023 Mar 13;25:e41430 [FREE Full text] [doi: 10.2196/41430] [Medline: 36912869]
81. Liu L, Cruz AM, Rincon AM. Technology acceptance, adoption, and usability: arriving at consistent terminologies and measurement approaches. In: Hayre CM, Muller D, Scherer M, editors. Everyday Technologies in Healthcare. Boca Raton, FL: CRC Press; 2019.
82. Karaosmanoglu S, Rings S, Kruse L, Stein C, Steinicke F. Lessons learned from a human-centered design of an immersive exergame for people with dementia. Proc ACM Hum Comput Interact 2021 Oct 06;5(CHI PLAY):1-27. [doi: 10.1145/3474679]
83. Fleck MJ, Marsden N. Contextual design of an novel elderly-centered system for video-based communication. Mensch und Computer 2021 - Workshopband. 2021. URL: https://dl.gi.de/items/bb5177c1-a6f3-4093-ba6e-1e89394f9077 [accessed 2024-04-25]
84. Nielsen J. 10 Usability heuristics for user interface design. Nielsen Norman Group. 1994 Apr 24. URL: https://www.nngroup.com/articles/ten-usability-heuristics/ [accessed 2023-11-30]
85. Strohmaier R, Sprung G, Nischelwitzer A, Schadenbauer S. Usability testing of mixed reality scenarios: a hands-on report. In: Updates on Software Usability. London, UK: IntechOpen; 2022.

Abbreviations

AI: artificial intelligence
CDR: Clinical Dementia Rating
ICT: information and communications technology
STAM: senior technology acceptance model
TAM: technology acceptance model

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Original Paper

A Voice-Activated Device Exercise and Social Engagement Program for Older Adult–Care Partner Dyads: Pilot Clinical Trial and Focus Group Study Evaluating the Feasibility, Use, and Estimated Functional Impact of EngAGE

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Abstract

Background: Maintaining exercise is essential for healthy aging but difficult to sustain. EngAGE is a socially motivated exercise program delivered over a voice-activated device that targets older adult–care partner dyads.

Objective: This 10-week pilot study aimed to assess EngAGE feasibility and use, obtain user experience feedback, and estimate potential impact on function.

Methods: In total, 10 older adults aged ≥65 years were recruited from an independent living residence together with their self-identified care partners. EngAGE delivered National Institute on Aging Go4Life exercises to older adults daily, while care partners received progress reports and prompts to send encouraging messages that were read aloud by the device to the older adult. Older adults' use was tracked, and physical function was assessed at baseline and follow-up. Follow-up focus group data provided qualitative feedback.

Results: On average, participants completed 393.7 individual exercises over the 10-week intervention period or 39.4 exercises/wk (range 48-492, median 431, IQR 384-481, SD 112.4) without injury and used EngAGE on an average of 41 of 70 days or 4.1 d/wk (range 7-66, median 51, IQR 23-56, and SD 21.2 days). Mean grip strength increased nonsignificantly by 1.3 kg (preintervention mean 26.3 kg, SD 11.0; postintervention mean 27.6 kg, SD 11.6; P=.34), and 4 of 10 participants improved by a minimal clinically important difference (MCID) of 2.5 kg. Further, the time for 5-repeated chair stands significantly reduced by 2.3 seconds (preintervention mean 12, SD 3.6 s; postintervention mean 9.7, SD 2.7 s; P=.02), and 3 of 9 participants improved by an MCID of –2.3 seconds. Furthermore, 3-meter usual walk performance was brisk at baseline (mean 2.1, SD 0.4 s) and decreased by 0.1 seconds (postintervention 2, SD 0.4 s; P=.13), although 5 of 9 participants improved by a MCID of 0.05 m/s. Qualitative results showed perceived benefits, favored program features, and areas for improvement.

Conclusions: We present a pilot study of a new voice-activated device application customized to older adult users that may serve as a guide to other technology development for older adults. Our pilot study served to further refine the application and to inform a larger trial testing EngAGE's impact on functional outcomes, a necessary step for developing evidence-based technology tools.

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KEYWORDS

voice-activated device; voice-activated devices; frailty; frail; weak; weakness; technology; activity; physical activity; exercise; exercising; caregiver; caregivers; caregiving; caretaker; caretakers; caretaking; care-giver; care-givers; care-giving; care-taker; care-takers; care-taking; gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; voice activation; digital health; technology; exercises; online exercises; participatory design; new devices; health devices; technology development; mobile phone

Introduction

Voice-activated devices offer the possibility of assisting the rising number of older adults with maintaining physical and cognitive function, enhancing social connectivity, and accessing health and social resources from their homes [1,2]. Voice-activated devices reduce technology interface barriers by allowing users to simply talk to interact with a device [3,4]. They have shown promising early acceptability, use, and adoption among older adults, including low-income older adults [5-7]. Given the ease of use and early acceptability, commercial health care platforms incorporating a voice-activated element are on the rise [8,9]. However, the development of evidence-based health content tailored to older adults for use with voice-activated devices is in its infancy. As a result, no examples of developing voice-activated device programs for older adult users are in the literature to serve as a participatory design template.

EngAGE is a novel exercise program customized for older adults that is delivered over an Amazon Echo Show voice-activated device. The program has dual and interconnected aims to improve the physical functioning and social engagement of older adults. EngAGE supports physical functioning by delivering daily exercise routines from the National Institute on Aging (NIA) Go4Life program [10] to older adults in their home. EngAGE supports social engagement by leveraging meaningful social relationships to provide active social reinforcement that encourages behavior change [11], to provide occasions for additional social contact, and to provide passive safety oversight. EngAGE uniquely targets older adult–care partner dyads as paired users, providing a complementary resource that supports both roles. EngAGE was co-designed with older adults and their care partners through iterative, participatory design to ensure ease of adoption and meaningful content—a strategy recommended by experts in the field [12,13]. First, the concept was informally discussed with >40 stakeholders in the field through 1:1 conversations for feedback. Second, static wireframes representing possible program features were presented to predominantly minority older adults and care partners residing in the community around the University of Chicago for feedback in co-design focus groups or 1:1 interviews for homebound participants. Finally, a prototype was presented to predominantly minority older adults and care partners residing in the community around the University of Chicago for feedback in focus groups. At the final set of co-design focus groups, participants were asked to interact with the prototype as well as use a draft command tip sheet. At each stage, feedback was incorporated into the program.

As an extension of our participatory design process, we conducted a pilot study to (1) determine the feasibility of in-home administration of the EngAGE program to older adult–care partner dyads; (2) quantify the use of EngAGE during a 10-week intervention phase; (3) obtain qualitative feedback on the perceived program benefits, favored program features, and areas for improvement; and (4) estimate the potential impact of the EngAGE program on functional outcomes. These findings have relevance to clinicians and researchers exploring the utility of voice-activated devices to deliver health care resources to older adults, and to technology developers seeking to contribute useful and usable voice-activated device tools for the delivery of older adult health care resources. In an era of increasing reliance on telehealth and remote health care delivery and a shortage of geriatrics-trained health care workers [14], we anticipate a growing need for easy-to-use digital interventions for physical, social, and all other aspects of health for older adults and their care partners. Voice-activated devices are candidate technology vehicles for delivering health care programming that may be particularly suited for older adult users; however, deploying participatory design and collecting user input in feasibility studies such as this one help ensure that interventions align with older adults' own preferences, lifestyle, and priorities to support adoption.

Methods

EngAGE

EngAGE is a program that delivers socially motivated exercise routines tailored to older adults in their home on voice-activated devices. The corresponding application was optimized for an Amazon Echo Show or Amazon Fire tablet but can be used on any Amazon Alexa device. It is currently not adapted for use on any other platform (eg, Google Nest). We contracted Orbita, Inc, which is a preferred Amazon Alexa programmer company, to program our EngAGE application. EngAGE leverages a software platform created by our programming partner [15] that has three user portals: (1) a browser, (2) a mobile app, and (3) a voice-activated device. Older adult users primarily interface with the voice-activated device, while care partners interface entirely with the browser and mobile application.

Older adult users activate EngAGE using voice on their screened Alexa device (eg, "Alexa, start EngAGE"). Once started, EngAGE then reads aloud any new messages from their care partner (eg, "You have a new message from [NAME]. Great job doing your exercises! Can't wait to see you this weekend!"). Following this communication, EngAGE delivers exercise routines that alternate daily. The exercises were selected from the NIA Go4Life program [10] and were designed to be carried out with equipment found in the home (Table S1 in Multimedia

Appendix 1). The subset of exercises was selected in consultation with a physical therapist who specializes in aging; they target critical, major muscle groups needed for daily functioning. For each exercise, EngAGE provides audio and visual instructions (eg, “Let’s start arm curls. Find some hand weights, water bottles or soup cans. Stand up. Hold the weights straight down at your sides, palms facing forward. Slowly bend your elbows and lift the weights toward your chest. Keep your elbows at your sides. Hold this position for 1 second. Slowly lower your arms. Do ten arm curls.”) and displays an image of a person completing the exercise. Each exercise is then accompanied by rhythmic music allowing the older adult time to perform the exercise on their own. A total of 13 strength, flexibility, and balance exercises are divided into 2 routines of 6 and 7 exercises each. Each routine begins with a 3-minute warm-up of walking around one’s home or in place. Alternating routines target different muscles to avoid overuse if completed daily. All older adult users are started at a very low intensity with the lowest number of repetitions for each exercise. Users rate the exercise difficulty after completion of each unique exercise. EngAGE then auto-adjusts the number of repetitions for that exercise in subsequent sessions. For example, if an exercise was rated “too easy” 3 times in a row, the number of repetitions would subsequently increase. On the other hand, if an exercise was rated “too difficult” one time, the number of repetitions would subsequently decrease. This process both enables gentle increases in difficulty to promote muscle building and protects against injury that could come from too rapid of a progression.

Care partners interface with the website or mobile app to view their paired older adult’s daily recommended exercise routines and to monitor exercise completion. They also receive a daily email with a summary of exercises completed, whether any exercise was rated “too difficult” by the older adult (as a safety feature), and a prompt to send an encouraging message via the website or mobile application to be read by the older adult’s voice-activated device.

Study Design

We conducted a 12-week pilot study between May 13, 2019, and August 19, 2019, to test the feasibility and to estimate the use and potential functional impact of EngAGE among older adult–care partner dyads. The results from this pilot study were used to inform a randomized clinical controlled trial. Baseline survey and physical performance measures were assessed in person and in the homes of older adult participants. The 12-week pilot was divided into 2 phases: a 2-week run-in phase and a 10-week intervention phase. In-home setup of preprogrammed Echo Show devices and Alexa Fire tablets (eg, using anonymous, study email, Amazon accounts, and study phone numbers) was then conducted over 2 weeks. Research staff ensured connectivity, demonstrated how to use the program, and addressed privacy concerns, including demonstrating Alexa’s muting function, which is useful for protecting private conversations. During the 2-week run-in phase, participants reported any connectivity or program glitches encountered while familiarizing themselves with EngAGE. All problems were addressed and resolved before participants were asked to use the EngAGE program ad-lib over a 10-week intervention phase. Follow-up data collection, including physical performance measures and focus groups, occurred at the end of the intervention phase in the facility. Of note, 1 participant was wheelchair-bound with limited leg function, requiring lower extremity exercise adaptations that were provided in a paper supplement that was given to the participant during setup.

Study Sample

Recruitment and Eligibility

After obtaining institutional review board approval, older adults and care partners were recruited together.

Older Adult Participants

Older adult participant recruitment activities occurred between December 10, 2018, and May 7, 2019, at a single independent living facility in Chicago, IL: a facility already equipped with Alexa Dot devices in about 150 residential apartments. Alexa Dots are voice-activated devices without a screen. The residents who participated in this study were familiar with using the Alexa Dots. The EngAGE program was optimized for use on the Echo Show device, a screened voice-activated device. We selected this participant group because it helped us isolate this study of the EngAGE program experience from the more general experience using a voice-activated device. Adults 65 years and older with unlimited Wi-Fi and data plans were eligible to participate. Older adults were excluded only if they had known moderate to severe dementia or were unable to understand the consent form in a teach-back approach. Participants with early cognitive impairment who were still able to consent were allowed to participate. Functionally impaired adults were encouraged to apply, and the use of walking devices or wheelchairs did not preclude participation. Recruitment of participants took place via in-person presentations and fliers at the independent living facility. Study participants meeting eligibility criteria were consented in person.

Care Partner Participants

Older adults who consented to participate were asked to identify a trusted social contact to act as their care partner. Care partners were eligible if they were 18 years or older, had unlimited Wi-Fi and data plans, and reported being comfortable using web browser and mobile applications. If older adults did not have a care partner in mind (n=2), the team worked with them to identify a staff member they knew and were comfortable with.

Older Adult Measures

Demographics

Older adults self-reported their date of birth, race (Asian, Black or African-American, White, or other race), Hispanic ethnicity (yes or no), gender (female or male), education (≤high school or >high school), marital status (single, engaged or living with a partner, married or civil union, separated, divorced, widowed, or other), number of household members, and monthly household income (≤US $2000 or >US $2000 per month). They also separately reported their access to and use of the internet (yes or no) and any devices (check all that apply: computer, cell phone, smartphone, tablet, television, landline, or other).

Physical Function Measures

Physical Function

We administered 2 functional assessments at baseline and follow-up.

Adapted Physical Frailty Phenotype

The adapted frailty phenotype included 5 components: unintentional weight loss in the prior year (5% or 10 pounds), weakness (average of 3 dominant grip strength measures), exhaustion (2 self-reported questions from the Center for Epidemiologic Studies Depression Scale [16,17]), slowness (average of 3 15-foot usual walks), and low physical activity level (6-item version of the Minnesota Leisure Time Physical Activities Questionnaire [16,18]; Text S1 in Multimedia Appendix 2 [16-19]).

Short Physical Performance Battery

The SPPB consisted of three assessments: 3 static balance poses (side-by-side, semitandem, and tandem stance), a 3-meter usual walk, and 5-repeated chair stands [19] (Text S1 in Multimedia Appendix 2 [16-19]).

Program Use

The software platform [15] that hosts the EngAGE program recorded every exercise completed by the participant and the corresponding level of difficulty ratings throughout the intervention and stored use data on a Health Insurance Portability and Accountability Act–compliant server. Once the participant rated the level of difficulty following each exercise, the exercise was deemed “completed” regardless of the number of repetitions.

Care Partner Measure

Care partners were asked to report their relationship to the older adult participant (eg, friend, family, spouse, or staff).

Follow-Up Focus Groups

Three 1.5-hour focus groups of 2-4 older adult participants were held after the completion of the 10-week intervention phase. The small focus group size accommodated participant availability. This study team’s qualitative specialist (RFN) acted as the moderator for each focus group and guided the discussion using the same semistructured interview guide for each focus group to obtain feedback, with other research team members also contributing to focus group discussion. Prompts included the following topics: how EngAGE fit with pre-existing exercise habits; the role of EngAGE’s social component; participants’ current technology usage; perceptions of EngAGE’s benefits; user interface feedback; and user experience, including favored program features and areas for improvement, barriers to use, and feature evaluation. Care partners completed exploratory interviews or focus groups only, and the findings are not reported.

Analysis

Analytic Approach

Data collected from the mixed methods were analyzed using several steps.

Older Adult Sample Characteristics

Older adult and care partner demographic characteristics were summarized for each group using the number of participants and percent of the sample for demographic categories.

Implementation Experiences

The total number and type of technology glitches reported during the 2-week run-in period were reported.

Program Use

Program use was quantified by summing the number of exercises each older adult completed over the 10-week intervention phase, and then averaging across all participants.

Physical Function Performance

Older adults’ physical performance measures were summarized as means (continuous measures) or frequencies (categorical measures) plus SEs and SDs for each of the 5 physical frailty phenotypes and 3 SPPB components as well as the total scale scores at baseline and follow-up. Each continuous outcome variable was assessed for normality using the Shapiro-Wilk test. Normally distributed baseline and follow-up continuous measures (average 15-foot usual walk, self-reported physical activity energy expenditure, frailty phenotype score, the fastest of two 3-meter usual walks, 5-repeated chair stands, and total SBBP score) were compared using unadjusted, paired, 2-tailed *t* tests. Nonnormally distributed baseline and follow-up continuous measures (average dominant grip strength) were compared using an unadjusted Wilcoxon matched-pairs sign rank test. Categorical variables demonstrated no change; therefore, no statistical tests were conducted. Statistical significance was set at $P<.05$. We additionally calculated the effect size of the change between pre- and postmeasurements. For each measure, we also identified the minimal clinically important differences (MCIDs) based on the literature (as available) to assess the number of participants demonstrating clinical improvement. In many cases, the MCIDs reported in the literature were not well established; therefore, we chose informed but conservative cut points. We reported the number of participants meeting the following MCID criteria: 2.5-kg increase in grip strength [20], 1-point decrease in frailty [21], 0.05-mps increase in 15-foot or 3-meter usual walk [22], 2.3-second decrease in 5 repeated chair stands [23], and 0.5-point increase in SPPB score [24]. The MCID is not established for exhaustion; self-reported physical activity on the 6-item Minnesota Leisure Time Physical Activity Questionnaire; and side-by-side, semitandem, and tandem balance performances. For these measures, we chose to report the number of participants meeting the following: (1) no longer meeting physical frailty “low physical activity” criteria (physical activity), (2) no longer meeting physical frailty “exhaustion” criteria (exhaustion), (3) number able to hold for 10 seconds pre- and postintervention (side-by-side stance), (4) number able to hold for 10 seconds pre- and postintervention (semitandem stance), and (5) number able to hold for 10 seconds pre- and postintervention (tandem stance). We did not report a clinically meaningful change in weight.

Qualitative Results for Perceived Benefits, Favored Program Features, and Areas for Improvement

The qualitative data were analyzed to determine perceived benefits, favored program features, and areas for improvement. Audio recordings of the focus groups were transcribed and deidentified. They were analyzed using Dedoose software [25]. Further, 2 team members (RFN and CS) independently read the transcripts to identify preliminary codes and major theme categories for qualitative analysis. Deductive themes were related to a priori topics of interest that were integrated into the focus group prompts, and inductive themes were based on topics or insights drawn from transcripts themselves. Themes and codes were then organized and compiled into an initial codebook created by the team's qualitative specialist (RFN). The codebook was reviewed by the final coding team (RFN and MHS). Adjustments were made to the codes, themes, and definitions based on discussion options to calibrate the understanding of codes and ensure intercoder agreement of all code definitions. Then, 2 members of the team (RFN and MHS) independently reviewed the transcripts again, labeling appropriate excerpts with corresponding codes from the final codebook. Memos attached to ambiguous excerpts were discussed to reach a consensus, and where needed, adjustments to the codebook were made or recoding was accomplished. Upon completion of coding, any coding discrepancies between coders were discussed and resolved.

Ethical Considerations

This study was approved by the University of Chicago Institutional Review Board (IRB #19-0130).

Results

Older Adult Sample Characteristics

The older adults represented a broad range of ages (range 65-84 years) with 7 of the 10 being 75 years or older. A majority of the sample was female (7 of 10 participants), White (9 of 10 participants), college educated (10 of 10 participants), and lived alone (8 of 10 participants). Further, 9 of 10 participants reported having access to and using a computer and smartphone (Table S2 in Multimedia Appendix 3).

Care Partner Sample Characteristics

Each older adult identified an eligible care partner; of the 10 care partners invited to participate, all consented. Immediately after consenting, 1 discontinued due to schedule conflicts. Of the 9 remaining care partners, 3 identified themselves as a "friend," 3 as a "child," 2 as "staff," and 1 as a "spouse."

Implementation Experiences

Having the necessary Orbita, Inc, software preinstalled on the care partner tablets and in-home setup of the Alexa devices facilitated participation. The 2-week run-in phase with easy access to technology phone support enabled the identification of 32 technical issues, most identified during the first 2 weeks. The majority were for programming glitches (n=20). Other issues addressed included requests to correct spelling errors (n=1), resolve clock inconsistency (n=1), increase the font size (n=1), address poor wireless connectivity (n=1), correct errors in exercise text instructions (n=2), clarify web application capabilities (n=2), remove a floor exercise (n=1), resolve a log-in error (n=1), resolve an EngAGE program setup problem (n=1), and resend the EngAGE program invitation email (n=1).

Program Use

User-level analytic data indicated that the older adult participants cumulatively completed an average of completed 393.7 individual exercises over the 10-week intervention period or 39.4 exercises/wk (range 48-492, median 431, IQR 384-481, SD 112.4). Since each routine included 6-7 exercises, older adult participants completed approximately 6 exercise routines per week. Participants opened EngAGE an average of 41 of 70 days or 4.1 d/wk (range 7-66, median 51, IQR 23-56, SD 21.2 days). Further, 8 of the 10 older adult participants completed at least 2 full strength, balance, and flexibility exercise routines per week on average—the minimum recommended by the American College of Sports Medicine [26]—while 2 of the 10 participants did not meet this threshold (Table 1).

Table 1. Cumulative 10-week use of EngAGE by study participant.

Participant	Exercises completed, n	Days program used, n
1	140	13
2	431	59
3	449	56
4	384	50
5	398	52
6	481	66
7	48	7
8	170	23
9	492	56
10	196	28

Physical Performance

Table 2 and Table S3 in Multimedia Appendix 4 summarize changes in physical performance in specific domains and across the frailty phenotype and SPPB scales. Functional improvements were noted in hand grip strength (mean grip strength pre 26.3 and SD 11 kg, post 27.6 and SD 11.6 kg, *P*=.34, effect size=0.32, 7/10 participants improved, 4/10 participants met MCID criteria); 5-repeated chair stands performance time (excluded wheelchair-bound participant, mean 5-repeated chair stand time pre 12 and SD 3.6 s, post 9.7 and SD 2.7 s, *P*=.02, effect size=–0.93, 6/9 participants improved, 6/9 participants met MCID criteria); and in tandem balance (excludes wheelchair-bound participant, pre 5.9 s, post 6.5 s, *P*=.78, effect size=–0.10, 4 participants held stance for 10 seconds at baseline, 3 participants at follow-up), though only change in 5-repeated chair stands performance time was statistically significant in this small pilot sample. The group (excluding the wheelchair-bound participant) had an equally brisk 15-foot and 3-meter usual walk times at baseline (mean 2.1, SD 0.4 s) and follow-up (mean 2, SD 0.4 s; 15-foot walk *P*=.86, effect size=0.06; 3-meter walk *P*=.13, effect size=–0.57), but 5/9 participants had improved usual walk times in both tests, and 3 and 5 met MCID criteria in the 15-foot and 3-meter walks, respectively. Among those not wheelchair-bound (n=9), all were capable of holding the side-by-side and semitandem balance stances for the full 10 seconds at baseline and follow-up. The mean frailty score at baseline was 0.7 (SD 0.7) and 0.0 (SD 0) at follow-up (*P*=.01) with 6/10 participants showing improvement and meeting MCID criteria. The mean SPPB score at baseline was 10.2 (SD 1.6) and 10.9 (SD 0.6) at follow-up (*P*=.22) with 5/10 participants showing improvement and meeting MCID criteria.

Table 2. Physical function performance measures before and after 10 weeks of EngAGE use among older adults.

Functional measures	Participants, n	Before 10 weeks			After 10 weeks			*P* value[a]	Any improvement, n	Met MCID[b] criteria, n[c]
		Pre	SE	SD	Post	SE	SD			
Frailty phenotype										
Dominant handgrip strength (kg), mean	10	26.3	3.5	11	27.6	3.7	11.6	0.33	7	4
Average 15-foot usual pace walk (s), mean[d]	9	4.3	0.3	0.8	4.3	0.2	0.7	0.86	5	3
Self-reported physical activity energy expenditure (kcal/wk), mean	10	1304.3	407	1287	1687.7	615.9	1947.7	0.56	6	2
Exhaustion, n	10	0	0	0	0	0	0	0	0	0
Self-reported weight (lb), mean	10	168.4	14.3	45.1	172.5	16.4	52	0.4	NR[e]	NR
Frailty total score (range 0-5), mean	10	0.7	0.2	0.7	0	0	0	0.01[f]	6	6
SPPB[g]										
Usual pace 3-meter walk (s), mean[d]	9	2.1	0.1	0.4	2	0.1	0.4	0.13	5	5
5 repeated chair stands (s), mean[d]	9	12	1.2	3.6	9.7	0.9	2.7	0.02[f]	8	3
Side-by-side stance[d] (s), mean	9	10	0	0	10	0	0	N/A[h]	—[i]	—
Side-by-side stance held 10 seconds[d], n	9	9	N/A	N/A	9	N/A	N/A	N/A	N/A	N/A
Semitandem stance[d] (s), mean	9	10	0	0	10	0	0	N/A	—	—
Semitandem stance held 10 seconds[d], n	9	9	N/A	N/A	9	N/A	N/A	N/A	N/A	N/A
Tandem stance[d] (s), mean	9	5.9	1.5	4.4	6.5	1.2	3.6	0.78	5	—
Tandem stance held 10 seconds[d], n	9	4	N/A	N/A	3	N/A	N/A	N/A	N/A	N/A
SPPB total score (range 0-12), mean[d]	9	10.2	0.6	1.6	10.9	0.2	0.6	0.22	5	5

[a] Unadjusted, paired, 2-tailed *t* tests were used for normally distributed continuous variables, Wilcoxon matched-pairs sign rank test was used for nonnormally distributed continuous variables.

[b] MCID: minimal clinically important difference.

[c] Grip strength change: +2.5 kg; 15-foot usual walk: +0.05 m/s; physical activity: no longer meeting physical frailty “low physical activity” criteria; exhaustion: no longer meeting physical frailty “exhaustion” criteria; weight: not reported; frailty: –1 point; 3-meter usual walk: +0.05 mps; 5 repeated chair stands: –2.3 s; side-by-side stance: number able to hold for 10 seconds; semitandem stance: number able to hold for 10 seconds; tandem stance: number able to hold for 10 seconds; Short Physical Performance Battery score: +0.5 points.

[d] Excludes the wheelchair-bound participant.

[e] NR: Not reported.

[f] Statistically significant.

[g] SPPB: Short Physical Performance Battery.

[h] N/A: not applicable.

[i] Not available.

Qualitative Results for Perceived Benefits, Favored Program Features, and Areas for Improvement

Perceived Benefits and Favored Program Features

Focus group participants described several positive outcomes resulting from their use of EngAGE, including improvement in upper and lower physical strength, balance or flexibility, knowledge gained, and social benefits (including adherence, interactions with other participants, and relationships with care partners).

Many of these comments provided “real world” examples that suggested clinically relevant strength improvements. For example, a participant attributed the improvement in grip strength from EngAGE to their ability to open a pickle jar and bottle of wine that their companions were struggling with. Another participant described the benefits derived from sit-stand exercises when using low toilets without grab bars.

Overall, balance and flexibility were less frequently mentioned than strength gains in focus group discussions of program benefits. Both participants who described flexibility improvements had not been previously doing this type of exercise, with one noting that:

> *I am not sure I would have chosen [the hamstring stretch], if I had been asked to pick the exercises I wanted to do.*

That participant also reported balance improvements, and in both cases, these exercises were among the most difficult for her at the start of the program.

The most dramatic of the physical health benefits was described by a wheelchair-bound participant who was provided with adapted EngAGE exercises to accommodate his physical limitations. In focus groups, the participant reported:

> *...one of the benefits to this program is that it had side benefits to me, it helped me lose weight, helped me stop eating so much, and helped me psychologically.*

The participant also reported being able to sleep through the night, due in part to the elimination of nighttime muscle stiffness and spasms, which the participant attributed to the stretching exercises.

Another benefit participants noted was the knowledge gained through the program. Further, A user praised EngAGE for providing greater knowledge about how to perform certain exercises, noting that in their prior experiences with exercise class settings:

> *...by the time I figured how I am supposed to do it we would be moving onto the next thing sometimes. So I like that and I could, sometimes I would pause between the first rep and the second [and] think, ‘okay, now do I know what I am supposed to be doing?’ So I like being able to do that.*

Another participant whose prior exercise regime focused on recumbent biking and walking praised the program for emphasizing the need for a comprehensive range of exercise, stating:

> *It reminded me that I needed exercising for everything.*

This was echoed by another participant who praised the greater self-awareness of the need for comprehensive physical exercise that the program provided, saying:

> *I just realized I was getting lazy and at our age we can't afford to be lazy because I mean the muscles are going to go and they go quickly. So that's forced me to remember and to think about how I'm doing things, and I find myself taking the hard road sometimes simply because I know I can do it and I need to do it.*

Lastly, participants described positive outcomes related to the social component of EngAGE for motivating adherence, contributing to insight regarding the fitness benefits, and strengthening social relationships. Multiple participants reported that having a partner who could monitor their progress aided with their adherence to the program. Further, 1 participant also described the questions that she received from her care partner as “creating a dialogue, forcing you to think about it a little bit and that does help.” These interactions with care partners were occasions for reminding participants of the progress that they had made: “It was always something that would make you, really force you to think about, geez, yes, the sit-stand is really helping. I've really improved that.”

Participants also described benefits related to their relationships with their care partners and other participants. Some of this was related to the encouragement and social support that they received. Interestingly, 2 participants felt that this sort of “rah, rah, your chief cheerleader” support was better suited to the EngAGE messaging format, noting “it might seem a little bit corny if she said it to you in-person but in the email, in the message, it seems great.” Since all participants resided in the same building, participants also described their camaraderie with each other and reported interest in program features that would permit communication across exercisers, with 1 suggesting an interface “almost like a Facebook page.” Further, 1 participant also described the benefits of EngAGE for participants who prefer to exercise alone but still desire social reinforcement, noting:

> *That doesn't mean I don't like to talk about it. It doesn't mean I don't want to interact with somebody about it. I just don't want anybody there while I'm doing it.*

Finally, 1 participant whose care partner was an adult child described the messaging functionality as an opportunity for increased communication on topics unrelated to exercise. Another participant whose care partner was a friend noted that the program “certainly added to communication between us, although we still usually fairly often communicate.”

Areas for Improvement

The most common program criticism was the lack of exercise variety. Study participants wanted more than 2 alternating routines in a week and additional exercise types as skill levels increased. Multiple participants reported the 2 daily alternating routines became “boring” or “tedious.”

Additionally, some participants felt the length of exercise instructions was longer than required, especially once familiar with the exercise, with 1 older adult noting that “the full prompt every time, got to be a little bit much,” and others reporting they began the exercise while still listening to the instructions. In other cases, participants mentioned the length of the repeated exercise sets, with 1 noting:

> *...when I would hit the third one it was starting, I was starting to feel like, is this ever going to end?... And yeah, that was hard. And I'll be honest, I didn't always do the third set.*

Other feedback centered around the functionality of the EngAGE interface. Multiple participants, particularly the more experienced exercisers, requested more control over exercise difficulty rather than the automatic changes based on the exercise rating. Other sources of user frustration included difficulty pausing and returning to the same place when unexpectedly interrupted by a phone call or visitor, difficulty successfully skipping instructions, and exercises not registering as completed. Further, 1 participant found the audio instructions more useful than the written instructions or pictures on the screen:

> *...I basically ignored the screen and listened to the verbal.*

Another theme emerged about care partners not meeting expectations. For example, 1 participant emphasized that:

> *The quality of partner is an issue.*

Another mentioned that:

> *I was kind of hoping that she would get a little more into it, I guess, than she did.*

She further explained that:

> *I would have liked her to ask more questions about the exercises... I think you need more of a dialogue than just a pat on the back or their head.*

Discussion

Summary of Findings

This paper summarizes a participatory design approach for developing new voice-activated device programs with older adult users, and it reports results from the final stage of participatory design, a pilot study. In this pilot study, we found the voice-activated device and EngAGE were feasible to set up on-site. The program was moderately used on average by study participants but with a wide range. User feedback provided targeted opportunities to improve the user experience. We estimated the potential impact on physical function to inform the sample size needed for a subsequent efficacy trial. We found participants were the most likely to experience improvement in chair stand time performance of all outcomes assessed. The results from this pilot study offered feasibility considerations for future aging technology studies, provided a reference range for voice-activated device program use among older users for future studies, recommended sensitive objective and patient-reported outcome targets for older adult exercise trials, and introduced a shift in targeted technology users from the older adult to the older adult–care partner dyad.

This study provided several key feasibility implications for future voice-activated device intervention studies in older adults. First, the in-home device setup and data collection provided for older adults greatly streamlined onboarding and facilitated the completion of important objective functional measures but will be challenging for large-scale studies. Potential strategies to address home technology setup needs for larger scale studies include (1) leveraging the paired care partner to assist the older adult with device setup, (2) using setup instruction manuals that have undergone participatory design with older adults to ensure ease of use paired with telephone support, and (3) partnering with an organization that has existing on-the-ground technology support teams. Remote functional data collection may be carried out using videoconferencing [27] or by leveraging wearable sensors in the future [28-32]. Second, our 2-week run-in phase helped address many technical issues before the intervention phase that could have interfered with a successful intervention adoption. Larger technology intervention studies should consider budgeting for phone and on-the-ground technology support, particularly in the first few weeks of technology use. Third, privacy concerns were not the participation barrier we anticipated they could be. We heavily addressed privacy issues during consent and provided strategies for maintaining privacy during device setup, which may have alleviated concerns up front. Everyone in this group was an existing Alexa user, so future studies may encounter these concerns more frequently. Finally, we had to adapt the EngAGE exercises to accommodate a wheelchair-bound participant; future studies should anticipate functionally limited users and prepare alternative exercises in advance.

In this study, the older adults who were familiar with Alexa at baseline used this program on more than half of the days per week on average, but the wide range of EngAGE program use was an important finding for future tech researchers. Adherence will probably be lower among users with less familiarity with Alexa at baseline or those who are more functionally impaired; therefore, a longer intervention period may be necessary to see significant functional gains in a trial targeting these subgroups. Further, 1 option to boost voice-activated device program use among older adults would be to leverage regular visits from care partners such as a state-sponsored homemaker or paid care partners. The care partners could provide direct technology support and help the older adult use the EngAGE program or other healthy aging programs in the home at each visit.

In our pilot sample of mostly current exercisers, chair stand times improved significantly, and we observed a nonsignificant improvement in dominant grip strength over the 10-week intervention phase. These findings inform the sample size needed for a larger EngAGE efficacy trial in older adults and may serve to inform similar technology-based exercise trials in older adults. The fact that a relatively high-functioning group of older adults exhibited improvement in some aspects of physical performance suggests EngAGE or similar programs may have even greater potential to improve outcomes for less robust older adults.

In addition to informing adjustments needed to the EngAGE program, the results of our qualitative analyses provided insights regarding the potential subjective outcome targets for larger technology-based exercise trials. Several participants self-reported meaningful functional gains in activities requiring the hand (opening a jar) and proximal hip (improvement in standing up from a low seat), suggesting these are sensitive patient-reported outcomes for a larger trial. A small number of participants also noted subjective improvement in flexibility, weight loss, diet, mood, and sleep, which may be helpful outcomes to include in larger studies. Finally, while nearly all older participants in the pilot study were exercisers at baseline, participants described gaining knowledge from the comprehensiveness of the exercises—we did not measure knowledge gains directly but would be important for future studies.

Older adult dyadic relationships within their social network are important to healthy aging [33], but health care technology programs infrequently target both users as a unit. The EngAGE program uniquely leverages existing social relationships to motivate activity while allowing older users to exercise alone and at their own pace—both welcomed features in this pilot sample. This strategy aims to both improve older adult physical independence and simultaneously increase opportunities for social engagement. Most older adult exercisers reported that the care partners successfully provided accountability, promoted adherence, increased social communication, and even encouraged older adults to reflect on their progress. In technology interventions, this partnership could be leveraged even more to assist with things such as device setup, addressing technical issues, monitoring safety, or even participating in a program such as EngAGE with the older user. This pilot study also showed that not all social relationships are equally effective. The most positive responses came from those who had care partners who were thoughtful, creative, and engaging. Further, one strategy for increasing the odds of receiving meaningful exercise motivation might be to increase the number of care partners paired with each older adult or to allow the older adult users to be connected. For example, children, grandchildren, and friends could be paired with a single older adult—a feature that is available on the EngAGE platform. Another strategy might be to provide care partners with tips for motivating healthy behavior. A key message from this pilot is the critical nature of care partners in implementing and sustaining healthy aging behavior among older adults.

Study Limitations

By design, our pilot sample was small, the team and participants were unblinded and the participants' familiarity with Alexa devices enabled us to primarily test the EngAGE program including its use, experience, and potential impact. However, these restrictions limit the generalizability of our findings and could introduce bias. Many of those recruited were higher functioning and better resourced than frail older adults (our ultimate target users). Before this feasibility study, however, our participatory design process included less resourced, physically limited, less technology savvy, and predominantly minority older adults. This sample was selected because they were existing Alexa users and could provide feedback on the EngAGE program experience and not the Alexa experience, allowing us to identify areas we could improve before testing in a more vulnerable group. Future participatory design studies must include functionally impaired and less tech-savvy older adults during development so that their needs and concerns are addressed in the program design.

Conclusion

Voice-activated devices hold great promise for overcoming many technology use challenges for older adults, making them a potential vehicle for delivering healthy aging resources broadly to older adults [2,34]. EngAGE is unique in that it targets older adult–care partner dyads and underwent an iterative participatory design process throughout development with vulnerable users to improve the likelihood of perceived ease of use, perceived usefulness, and technology adoption among all older adults. Our pilot study demonstrated that screened voice-activated devices are well-suited to remote delivery of exercise routines that do not require specialized equipment. Using the NIA Go4Life content, EngAGE appears capable of producing statistically and clinically significant improvements in objective and subjective physical function measures. The social component of EngAGE was, overall, viewed positively as an exercise motivator and as a means of strengthening bonds and increasing communication between dyad members. This study also has important feasibility implications for larger technology program trials, including the need for 1:1 device setup infrastructure and technology support. These findings are relevant to all future aging technology studies but especially to voice-activated device studies.

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Data Availability

This study’s data are available from the corresponding author (MHS) upon reasonable request and after completion of a Data Use Agreement and Institutional Review Board assessment.

Conflicts of Interest

For MHS and LCH, the University of Chicago and National Opinion Research Center jointly own the intellectual property of the customized portions of the EngAGE Alexa skill. MHS and LCH have not received any funds related to this intellectual property through the time of submission. RFN, CS, SS, MD, LF, and YM declare no conflicts of interest.

Multimedia Appendix 1
Exercises from the National Institute on Aging's Go4Life Program included in the EngAGE Program.
[DOCX File , 16 KB - aging_v7i1e56502_app1.docx]

Multimedia Appendix 2
Detailed physical function measure descriptions.
[DOCX File , 20 KB - aging_v7i1e56502_app2.docx]

Multimedia Appendix 3
Older adult sample characteristics (N=10).
[DOCX File , 17 KB - aging_v7i1e56502_app3.docx]

Multimedia Appendix 4
Physical function performance measures before and after 10 weeks of EngAGE use among older adults including effect sizes.
[DOCX File , 20 KB - aging_v7i1e56502_app4.docx]

References

1. Rogers WA, Mitzner TL. Envisioning the future for older adults: autonomy, health, well-being, and social connectedness with technology support. Futures 2017;87:133-139 [FREE Full text] [doi: 10.1016/j.futures.2016.07.002] [Medline: 28458395]
2. Cotten SR. Examining the roles of technology in aging and quality of life. J Gerontol B Psychol Sci Soc Sci 2017;72(5):823-826. [doi: 10.1093/geronb/gbx109] [Medline: 28817928]
3. Hoy MB. Alexa, Siri, Cortana, and more: an introduction to voice assistants. Med Ref Serv Q 2018;37(1):81-88. [doi: 10.1080/02763869.2018.1404391] [Medline: 29327988]
4. Choi YK, Thompson HJ, Demiris G. Internet-of-Things smart home technology to support aging-in-place: older adults' perceptions and attitudes. J Gerontol Nurs 2021;47(4):15-21. [doi: 10.3928/00989134-20210310-03] [Medline: 34038251]
5. McCloud R, Perez C, Bekalu MA, Viswanath K. Using smart speaker technology for health and well-being in an older adult population: pre-post feasibility study. JMIR Aging 2022;5(2):e33498 [FREE Full text] [doi: 10.2196/33498] [Medline: 35532979]
6. Choi YK, Thompson HJ, Demiris G. Use of an internet-of-things smart home system for healthy aging in older adults in residential settings: pilot feasibility study. JMIR Aging 2020;3(2):e21964 [FREE Full text] [doi: 10.2196/21964] [Medline: 33170128]
7. O'Brien K, Liggett A, Ramirez-Zohfeld V, Sunkara P, Lindquist LA. Voice-controlled intelligent personal assistants to support aging in place. J Am Geriatr Soc 2020;68(1):176-179. [doi: 10.1111/jgs.16217] [Medline: 31617581]
8. Sezgin E, Huang Y, Ramtekkar U, Lin S. Readiness for voice assistants to support healthcare delivery during a health crisis and pandemic. NPJ Digit Med 2020;3(1):122 [FREE Full text] [doi: 10.1038/s41746-020-00332-0] [Medline: 33015374]
9. Etkin K. AgeTech Market Map 7th Edition. 2021. URL: https://www.thegerontechnologist.com/ [accessed 2021-05-06]
10. Exercise and physical activity. National Institute on Aging. URL: https://www.nia.nih.gov/health/exercise-and-physical-activity [accessed 2013-11-18]
11. Holt-Lunstad J. Why social relationships are important for physical health: a systems approach to understanding and modifying risk and protection. Annu Rev Psychol 2018;69:437-458. [doi: 10.1146/annurev-psych-122216-011902] [Medline: 29035688]
12. Rogers WA, Fisk AD. Toward a psychological science of advanced technology design for older adults. J Gerontol B Psychol Sci Soc Sci 2010;65(6):645-653 [FREE Full text] [doi: 10.1093/geronb/gbq065] [Medline: 20833690]
13. Tiersen F, Batey P, Harrison MJC, Naar LI, Serban AI, Daniels SJC, et al. Smart home sensing and monitoring in households with dementia: user-centered design approach. JMIR Aging 2021;4(3):e27047 [FREE Full text] [doi: 10.2196/27047] [Medline: 34383672]

14. Lee WC, Sumaya CV. Geriatric workforce capacity: a pending crisis for nursing home residents. Front Public Health 2013;1:24 [FREE Full text] [doi: 10.3389/fpubh.2013.00024] [Medline: 24350193]
15. OrbitaENGAGE. OrbitaInc. 2021. URL: https://orbita.atlassian.net/wiki/spaces/OCS/pages/1261633633/3.8.1+OrbitaENGAGE+-+Coming+Soon [accessed 2021-09-07]
16. Fried LP, Tangen CM, Walston J, Newman AB, Hirsch C, Gottdiener J, Cardiovascular Health Study Collaborative Research Group. Frailty in older adults: evidence for a phenotype. J Gerontol A Biol Sci Med Sci 2001;56(3):M146-M156. [doi: 10.1093/gerona/56.3.m146] [Medline: 11253156]
17. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. Appl Psychol Meas 1977;1(3):385-401. [doi: 10.1177/014662167700100306]
18. Eckel SP, Bandeen-Roche K, Chaves PHM, Fried LP, Louis TA. Surrogate screening models for the low physical activity criterion of frailty. Aging Clin Exp Res 2011;23(3):209-216 [FREE Full text] [doi: 10.1007/BF03324962] [Medline: 21993168]
19. Guralnik JM, Simonsick EM, Ferrucci L, Glynn RJ, Berkman LF, Blazer DG, et al. A short physical performance battery assessing lower extremity function: association with self-reported disability and prediction of mortality and nursing home admission. J Gerontol 1994;49(2):M85-M94. [doi: 10.1093/geronj/49.2.m85] [Medline: 8126356]
20. Villafañe JH, Valdes K, Bertozzi L, Negrini S. Minimal clinically important difference of grip and pinch strength in women with thumb carpometacarpal osteoarthritis when compared to healthy subjects. Rehabil Nurs 2017;42(3):139-145. [doi: 10.1002/rnj.196] [Medline: 25557054]
21. Jang IY, Jung HW, Lee HY, Park H, Lee E, Kim DH. Evaluation of clinically meaningful changes in measures of frailty. J Gerontol A Biol Sci Med Sci 2020;75(6):1143-1147 [FREE Full text] [doi: 10.1093/gerona/glaa003] [Medline: 32145016]
22. Kwon S, Perera S, Pahor M, Katula JA, King AC, Groessl EJ, et al. What is a meaningful change in physical performance? Findings from a clinical trial in older adults (the LIFE-P study). J Nutr Health Aging 2009;13(6):538-544 [FREE Full text] [doi: 10.1007/s12603-009-0104-z] [Medline: 19536422]
23. Meretta BM, Whitney SL, Marchetti GF, Sparto PJ, Muirhead RJ. The five times sit to stand test: responsiveness to change and concurrent validity in adults undergoing vestibular rehabilitation**. J Vestibular Res 2006;16(4-5):233-243. [doi: 10.3233/ves-2006-164-510]
24. Perera S, Mody SH, Woodman RC, Studenski SA. Meaningful change and responsiveness in common physical performance measures in older adults. J Am Geriatr Soc 2006;54(5):743-749. [doi: 10.1111/j.1532-5415.2006.00701.x] [Medline: 16696738]
25. Dedoose Version 8.3.45 wafm, analyzing and presenting qualitative and mixed method research data. Los Angeles, CA: SocioCultural Research Consultants, LLC; 2020.
26. Haskell WL, Lee IM, Pate RR, Powell KE, Blair SN, Franklin BA, et al. Physical activity and public health: updated recommendation for adults from the American college of sports medicine and the American heart association. Med Sci Sports Exerc 2007;39(8):1423-1434. [doi: 10.1249/mss.0b013e3180616b27] [Medline: 17762377]
27. Hwang R, Mandrusiak A, Morris NR, Peters R, Korczyk D, Russell T. Assessing functional exercise capacity using telehealth: is it valid and reliable in patients with chronic heart failure? J Telemed Telecare 2017;23(2):225-232. [doi: 10.1177/1357633X16634258] [Medline: 26915366]
28. Huisingh-Scheetz M, Wroblewski K, Waite L, Huang ES, Schumm LP, Hedeker D. Variability in hourly activity levels: statistical noise or insight into older adult frailty? J Gerontol A Biol Sci Med Sci 2021 Aug 13;76(9):1608-1618 [FREE Full text] [doi: 10.1093/gerona/glaa262] [Medline: 33049032]
29. Huisingh-Scheetz M, Wroblewski K, Kocherginsky M, Huang E, Dale W, Waite L, et al. The relationship between physical activity and frailty among U.S. older adults based on hourly accelerometry data. J Gerontol A Biol Sci Med Sci 2018;73(5):622-629 [FREE Full text] [doi: 10.1093/gerona/glx208] [Medline: 29106478]
30. Huisingh-Scheetz MJ, Kocherginsky M, Magett E, Rush P, Dale W, Waite L. Relating wrist accelerometry measures to disability in older adults. Arch Gerontol Geriatr 2016;62:68-74 [FREE Full text] [doi: 10.1016/j.archger.2015.09.004] [Medline: 26452423]
31. Huisingh-Scheetz M, Kocherginsky M, Dugas L, Payne C, Dale W, Conroy DE, et al. Wrist accelerometry in the health, functional, and social assessment of older adults. J Am Geriatr Soc 2016;64(4):889-891 [FREE Full text] [doi: 10.1111/jgs.14051] [Medline: 27100590]
32. Chan A, Cohen R, Robinson KM, Bhardwaj D, Gregson G, Jutai JW, et al. Evidence and user considerations of home health monitoring for older adults: scoping review. JMIR Aging 2022;5(4):e40079 [FREE Full text] [doi: 10.2196/40079] [Medline: 36441572]
33. Kotwal AA, Lauderdale DS, Waite LJ, Dale W. Differences between husbands and wives in colonoscopy use: results from a national sample of married couples. Prev Med 2016;88:46-52 [FREE Full text] [doi: 10.1016/j.ypmed.2016.03.011] [Medline: 27009632]
34. Anderson M, Perrin A. Tech adoption climbs among older adults. Pew Research Center. 2017 May 17. URL: https://www.pewresearch.org/internet/2017/05/17/tech-adoption-climbs-among-older-adults/ [accessed 2024-08-06]

Abbreviations

NIA: National Institute on Aging
SPPB: Short Physical Performance Battery

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Original Paper

Decoding the Influence of eHealth on Autonomy, Competence, and Relatedness in Older Adults: Qualitative Analysis of Self-Determination Through the Motivational Technology Model

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Abstract

Background: Older adults adopt and use eHealth systems to build autonomy, competence, and relatedness and engage in healthy behaviors. The motivational technology model posits that technology features, such as those on websites, smart displays, and mobile phones, must allow for navigability, interactivity, and customizability, which spur feelings of self-determination and intrinsic motivation. We studied ElderTree, an online system for older adults that provides on-demand videos of healthy living content, self-monitoring, and weekly researcher-hosted video meetings.

Objective: We aimed to understand the theoretical crossover between the motivational technology model and self-determination theory using features of ElderTree to understand the usability of the technology and how it may support older adults' autonomy, competence, and relatedness.

Methods: Drawing participants from a randomized controlled trial of a mobile health app for older adults with multiple chronic conditions, we conducted qualitative interviews with 22 older adults about their use of the app; the interviews were coded using qualitative thematic analysis.

Results: Older adults did find that features within ElderTree such as content available on demand, good navigation, and weekly researcher-led video calls supported feelings of autonomy, competence, and relatedness, respectively. Individual differences such as a background using computers also influenced participants' experiences with the smart displays.

Conclusions: Participants confirmed the features that increased internal motivation, such as interactivity correlating with feelings of relatedness, but they also found other ways to support autonomous health behavior change beyond narrow views of navigability, interactivity, and customization.

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KEYWORDS

self-determination theory; usability; mobile technology model; aging; eHealth; mobile health; mHealth; smart displays; video calls; older adult; chronic conditions; mobile phone

Introduction

Background

With the vast array of health resources available online, many systems to support individual-level health are available to the older adults who may need them. As older adults face a growing number of health concerns—chronic metabolic issues such as diabetes, hypertension, and obesity [1]; physical ailments such as pain or arthritis; and emotional concerns of loneliness and depression [2]—they increasingly seek such health information and services [3]. Web-based health technologies (eHealth) or mobile health (mHealth) technologies delivered through internet-connected devices focus on providing social support and increasing positive health behaviors [4]. One way to understand the adoption and continued use of eHealth technologies is using self-determination theory, which provides insights into the internal and external motivational factors that guide individuals' drive to engage in healthy behaviors.

Self-determination theory, developed by Deci and Ryan [5], identifies 3 needs that drive motivation, specifically, the need for competence, autonomy, and relatedness. Competence is the ability for individuals to feel mastery over their environment, that the behaviors they want to do are within reach [6]. Increasing people's perceived competence increases internalization of motivation to do a behavior and, thus, the likelihood of adopting it [7,8]. The need for autonomy describes the experience of volitional self-direction in thought and action. High levels of autonomy increase intrinsic motivation such that individuals feel more interest and enjoyment in the behaviors [7]. Autonomy is a key factor in many components of well-being as people with high levels of autonomy have lower rates of anxiety and depression and overall higher life satisfaction [9]. The relatedness factor is derived from the need to belong, highlighting how individual-level actions are significantly impacted by our need to be socially accepted and have regular contact with others and to have mutual care for another's well-being [10]. Relatedness includes feelings that people of authority (eg, parents, teachers, and health care providers) provide respect and finding a sense of belonging within one's peer community [6]. While all 3 components function independently, they also support each other in increasing intrinsic motivation [5,11].

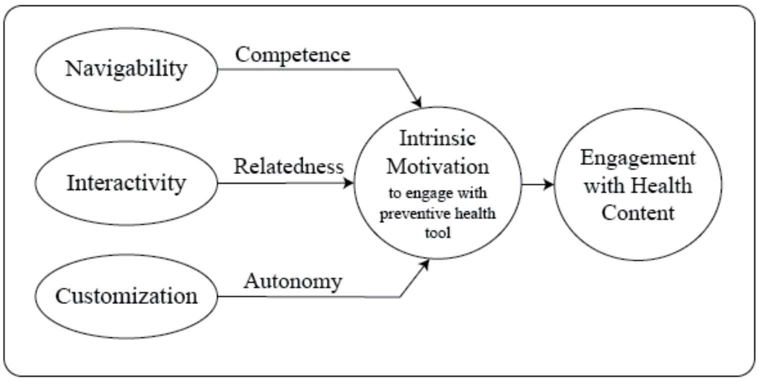
In the context of health technologies, enhancing self-determination can increase an individual's self-efficacy and commitment to healthy behaviors [4,12,13]. Broadly, the impact of self-determination theory on various measures of overall health has been well documented in several meta-analyses [9,14,15]. For example, self-determination factors increase positive health behaviors in the realms of exercise [16,17], mental health [18], and health communication [19]. However, understanding the specific components of eHealth and the way in which they influence autonomy, competence, and relatedness would greatly enhance practitioners' ability to target features that increase positive health behaviors. The goal of this study was to examine how older adults engage with an eHealth tool, describe specific features of the tool, and consider the technological affordances of those features that can support older adults' self-determination, as well as individual-level differences that may influence how the affordances impact the user experience.

Motivational Technology Model and eHealth Applications

The motivational technology model (MTM) is a framework for understanding how technological affordances or perceived and actual properties of the technology that shape and structure its possible uses [20] may impact self-determination. The MTM specifically supports ways in which technology features influence an individual's self-determination (Figure 1 [21]) within the broader framework of the theory of interactive media effects (TIME) [22]. Sundar et al [21] identified technological affordances of navigability, interactivity, and customization that can improve an individual's self-efficacy and intrinsic motivation to use the application for health improvement. Navigability describes how features allow users to easily search for and find the relevant content, which in turn can increase feelings of competence, decrease cognitive load, and improve user satisfaction [23,24]. Features such as menus, search functions, and breadcrumbs and being able to navigate to particular pieces of content all add to navigability [25]. Interactivity, in part, highlights the way in which technology connects people to increase their sense of relatedness. Such computer-mediated peer communication, both receiving messages from others and posting messages to others, shows promise in improving health and well-being [26-28]. Customization refers to how much an individual can make choices about the content or interface, allowing changes to what is available through user-driven tailoring, which increases a sense of autonomous motivation [21]. The MTM theorizes that eHealth tools support intrinsic motivation through the creation and use of technology that increases autonomy, competence, and relatedness, fulfilling needs that drive the motivation to pursue healthy behaviors.

Several studies in the literature specifically look at the overlap between the MTM and self-determination theory. These studies broadly support the links between technological affordances and self-determination [29], with evidence that interactivity increases feelings of relatedness but also competence and autonomy [25] and that customization could also increase all 3 components of self-determination [30]. For example, a cross-sectional study of smartwatches found that participants who rated the tools as interactive, navigable, and customizable also rated the tools as providing them with stronger feelings of relatedness, competence, and autonomy, respectively, and these increased engagement with the health apps [30]. A study of fitness apps using the MTM framework found that apps emphasizing interactivity increased feelings of relatedness, which ultimately increased motivation to engage in physical activity [25]. It also found that interactivity predicted all 3 components of self-determination and that relatedness mediated the relationship with health outcomes [25]. Another study found that the ability to customize physical health trackers increased all 3 components (competence, autonomy, and relatedness) in participants who used them, all of which increased engagement [30]. Finally, a qualitative exploration study using the MTM as a framework for designing a new mHealth app for managing rheumatoid arthritis found trade-offs between navigability and customization, observing that more choices made the interface more complicated [31].

Figure 1. Theoretical motivational technology model of affordances that increase self-determination and promote preventive health behaviors, a focused view based on the work (reproduced from Sundar et al [21], which is published under Creative Commons Attribution 4.0 International License [32]).



Customization as a Tool for Increasing Autonomy

Many more studies have looked at specific eHealth and mHealth features that influence self-determination. For example, customization, such as self-monitoring and providing individualized feedback, is most commonly used in eHealth systems to increase autonomy [33]. Additional research has identified several ways in which customization has influenced feelings of autonomy. An experimental study on mHealth apps found that users' subjective ratings of perceived interactivity, or the degree to which users could customize the content, were positively correlated with autonomous motivation [34]. User-personalized conversations can also increase user satisfaction and general engagement [35]. An mHealth app for increasing physical activity that manipulated customization of the interface was expected to change autonomous motivation. While using the app did not directly influence participants' feelings of autonomy, they did experience moderated mediation through the feeling of perceived control, moderated by a need for autonomy [36]. In mHealth gaming, user customization and content personalization can be persuasive for some types of people [33]. A review of mHealth studies found that participants often requested the ability to personalize their technology and that, if customization options were not available, they opted for other technologies that allowed for customization options [37]. Overall, customization appears to be tied to autonomy, defined by choices within and across apps.

Interactivity to Increase Feelings of Relatedness

Many mHealth apps use interactivity to motivate and support users, create a sense of relatedness and bonding, and encourage continued use. The need for relatedness in health and health care leads humans to find and connect with health care providers as well as other people with similar health conditions [38,39] and is a key component of many online health interventions. In mHealth games, for example, cooperation and competition increase relatedness, such as having collective goals, opportunities to cheer others on or share stories, leaderboards, and individual or group competition [40]. These social features are seen as highly persuasive at increasing positive health behaviors in mHealth [33]. While gamification features are sometimes used in certain types of mHealth apps, health care–focused mHealth apps typically refer to interactivity as one-on-one or one-to-many computer-mediated conversations with health care providers or other system participants, often those struggling with similar chronic illnesses [41]. In the peer-to-peer context, the expression and reception of messages, both via personal messaging and through public posting on social platforms, is related to increases in bonding, social connectedness, and feelings of well-being [26]. In contrast, conversations with providers are often centered on health concerns more than supportive, relationship-building exchanges [42]. The role of eHealth applications in connecting individuals with peers, support networks, and health care providers may support a sense of relatedness in different ways.

Navigability to Increase User Competence

Navigability can describe the ease with which users can move through an interface, and through the creation of a user-friendly site, users feel competent in accessing the content [22]. One measure of competence is the degree to which individuals can navigate and understand the app or web-based tool. The navigability of mHealth apps correlates with increased feelings of competence [25]. Applications with navigable user interfaces obtain more users who use the app for longer compared to apps with complex and cluttered interfaces [43,44]. Notably, navigable apps with better user experience have also been found to be more expensive to build. Overall, specific design features to increase navigability include a simple navigation scheme, clean esthetic style, personalized feedback and tailoring, and user customization [44]. These features can increase usability and enhance the user experience, which may bolster user competence within the mHealth app.

Another measure of competence is the degree to which technology provides users with educational content and increases their knowledge about health topics. mHealth apps can build user competence by providing access to helpful content, knowledgeable or experienced people, or a space to reflect on that content, allowing users to seek subjects and sources that build competence. Doing so has improved competence in a range of contexts: healthy eating [45,46], dementia care [47], and cancer care [45,48]. This same relationship was not observed for sexual health [49] or heart failure [50], suggesting limits to information subsidies.

Intrinsic Motivation and eHealth for Older Adults

From this evidence on the ways in which eHealth affordances of customization, interactivity, and navigability can influence participants' feelings of self-determination and their overall well-being, we expect that older adults, too, would experience increased self-determination when using eHealth tools; however, there are likely some differences from the general population. These differences might be due to age, engagement with eHealth broadly, and the ways in which self-determination is experienced differently by older adults.

Individual person-level characteristics may determine to what degree autonomy, competence, or relatedness create and sustain health behavior change. Advancing age is a significant predictor of reduced technology use [51], health behaviors, and overall health outcomes [52-54]. Older adults are much less likely to adopt eHealth and mHealth technologies [13] unless they have specific utility, such as offering needed social supports [55]. Generally, older adults are most likely to adopt mHealth when they perceive the technology as useful and feel confident in their ability to use it [37].

Higher perceived self-determination for engaging in health behaviors is correlated with improved health status among older adults [56] and linked to increased adoption of mHealth [57]. Age also has a significant impact on need for autonomy, with older people being more autonomy focused [58,59]. Finally, a study about Facebook use and older adults' perceived self-determination and well-being found that the affordance of customization correlated with autonomy; interactivity correlated with relatedness; and, broadly, both correlated with enjoyment of using Facebook [29]. In addition, only feelings of competence correlated with increased well-being; however, Facebook is not an eHealth platform, so these increases were not expected.

ElderTree: An eHealth Application

ElderTree, a website and eHealth application for older adults, provides on-demand videos of healthy living content, self-monitoring, and weekly researcher-hosted video meetings (ie, weekly meetups) [60,61]. The application effectively increases individual well-being and self-determination through encouraging social connections and providing health-focused content [62]. Users have a profile viewable to other study participants and can share content or chat with other users. ElderTree provides weekly updated health content, including blog posts (eg, about hearing aids, alcohol, and sleep); chair-based exercise videos for increased mobility, flexibility, and strength; guided meditation; and other content relevant to older adults, such as finance or just-for-fun videos [11,62]. A weekly health tracker helps users monitor their health in areas such as sleep, mood, medication adherence, and falls. Screenshots are available in Multimedia Appendix 1.

A key part of current ElderTree research is identifying how best to provide content to older adults, so participants are randomized to receive either a laptop or a Google Nest Hub Max smart screen. On the laptop, participants access ElderTree through a web browser. On the smart screen, they access an app triggered by the command "Hey Google, living well." Both systems are touch screen based. Although ElderTree has been designed and studied as a tool for increasing self-determination, the specific technical features that can increase autonomy, relatedness, and competence and their role in self-determination have not been examined. Thus, we pose the following research questions (RQs):

1. In what ways do participants report that ElderTree, including an eHealth tool and weekly video calls, supported their autonomy, competence, and relatedness? (RQ1)
2. In what ways did the constructs of self-determination theory—autonomy, relatedness, and competence—map to the affordances of customization, interactivity, and navigability within ElderTree? (RQ 2)

Methods

Study Design

This study drew participants from the ElderTree study, a randomized controlled trial of adults aged >60 years with multiple chronic health conditions (N=216). Participants were randomized to use the evidence-based intervention (ElderTree) either on a smart display or on a laptop. The full research protocol is available in the work by Gustafson et al [61]. While the original study intended to enroll participants for 12 months, a change in the Google Nest Hub Max interface made the system incompatible with the ElderTree eHealth tool. The study was subsequently ended early and considered a pilot test.

Recruitment

We conducted 22 interviews with participants from the original ElderTree sample pool. This number was selected to allow for enough variation and is generally considered an appropriate sample size for in-depth qualitative interviewing [63,64]. To select participants to interview, the research team first stratified all participants by research arm—laptop or smart display—and by weekly meetup attendance records—people who did not attend the weekly meetups, people who attended the weekly meetups but did not often speak, and people who attended the weekly meetups and most often spoke. In total, 4 to 5 participants from each group were contacted for interviews, capturing a wide variety of participant engagement and experience. Participants were contacted via email, SMS text message, and phone call. Interviews were conducted and recorded, with permission, by the lead author and held over Zoom (Zoom Video Communications) or phone call using a semistructured interview guide [64] after participants gave verbal consent to participate.

The interview guide was developed iteratively by all study authors to identify how participants experienced the affordances of navigability, customization, and interactivity. The interview guide first asked participants generally about their experience using ElderTree, motivations for joining the study and using the tool, how they felt about the navigational experiences, their experiences customizing the tool, and their use of the features that supported interactivity. Participants were also specifically asked about their experience with the weekly meetups. The complete interview guide with probes is available in Multimedia Appendix 2.

Ethical Considerations

To ensure participant privacy and data security, participant contact information remained separate from all other information and on a secure server. Interviews included only participant ID numbers, and all identifiable information was removed from transcripts and notes. Participants were compensated for study enrollment by receiving either a laptop or a smart display, 12 months of internet service, and US $10 for each of up to 4 surveys throughout the study period. The study protocol and interviews received ethics approval from the University of Wisconsin Health Sciences and Minimal Risk Research Institutional Review Board (reference 2020-0868). Survey data were collected in REDCap (Research Electronic Data Capture; Vanderbilt University) as part of the original grant [65].

Coding Process

To code the interviews, the authors used qualitative thematic analysis [66] through inductive and deductive coding to capture relevant themes [67]. The first author started the codebook with themes and codes from self-determination theory [6] and the MTM [21], adding more codes by reviewing the data and finding other salient themes. Coauthors then reviewed and modified the codes. To establish interrater agreement, 2 interviews were microcoded for specific features by 2 reviewers separately and then reviewed together to discuss and resolve disagreements [68]. A total of 2 authors then jointly reviewed 2 additional interviews and discussed the coding schemes identifying other potential new codes. When new codes were identified, all interviews were then recoded for those additional codes. Both reviewers coded all interviews and then combined and deduplicated their codes for final analysis. Data were analyzed using NVivo (version 1.7.1; Lumivero).

Results

Participants

The overall response rate was 88% (22/25) of the contacted participants. Interviews lasted an average of 33.1 (SD 10.4; range 10-50) minutes. Participants, who were aged between 61 and 92 years, were predominantly female (14/22, 64%) and White (17/22, 77%; Table 1).

Table 1. Sociodemographics and participant characteristics by device type (N=22).

	Laptop (n=13)	Smart display (n=9)	Overall
Age (y), mean (SD; range)	69.4 (7.3; 61-84)	70.1 (9.6; 62-92)	69.7 (8.1; 61-92)
Sex, n (%)			
Female	9 (69)	6 (67)	14 (64)
Male	4 (31)	3 (33)	7 (32)
Race, n (%)			
African American	3 (23)	0 (0)	3 (14)
Asian	0 (0)	1 (11)	1 (5)
White	10 (77)	8 (89)	17 (77)
Educational level, n (%)			
High school	2 (15)	1 (11)	3 (14)
Technical school	0 (0)	1 (11)	1 (5)
Some college	3 (23)	2 (22)	5 (23)
College graduate	5 (38)	4 (44)	8 (36)
Postgraduate or professional	3 (23)	1 (11)	4 (18)
Social ties, n (%)			
Do you have a significant other?	4 (31)	5 (56)	9 (41)
Does anyone else live with you?	7 (54)	5 (56)	11 (50)
Engagement with weekly meetups, n (%)			
No or limited attendance	4 (31)	4 (44)	8 (36)
High attendance, low participation	3 (23)	2 (22)	5 (23)
High attendance, high participation	6 (46)	3 (33)	9 (41)
Comfort with technology, n (%)			
Has a smartphone	11 (85)	7 (78)	18 (82)
Has ever used a smart display, n (%)			
Never or rarely	5 (38)	6 (67)	11 (50)
Sometimes, often, or very often	8 (62)	3 (33)	11 (50)

Linking Self-Determination Theory and the MTM

Customization and Autonomy

Overall, participants discussed several features that led to feelings of autonomy, including content availability and system customization (Table 2). Participants reported customizing when they wanted to exercise and watch curated health or exercise videos and how the content being available anytime supported their autonomous use of the system, particularly for the participants in the laptop condition:

> *Oh, two or three o'clock in the morning I'll be on, on the, you know, the computer, and it was just so good...It's just there and it's available. I love that.* [P06; laptop]

Participants also liked that they were able to access the content themselves without requiring talking to others, again supporting their autonomy:

> *I think it has [helped me] because...it's something to go to without bothering anybody or needing anybody's help.* [P25; laptop]

Participants also customized how they used the application and what they used it for. The ability to use it for many different purposes was present both in the laptop and the smart display group, with participants using it to generally browse the web—"The fact that it, you know, I was able to get to all websites and not just ElderTree, that's another bonus. I'm all over the Y[MCA] and everything" (P06; laptop)—or during the holidays to play Christmas music through the smart screen. The ability to select parts of the intervention that suited their needs was important, allowing them to set goals and engage in physical exercise either with or without the app:

> *Well, I watched them to get the general idea of how to do [the exercises] on my own, if I can do it on my own, and I wouldn't have to actually watch it...[I integrated] the exercises in my daily routine or whatever. Like cooking, or if I'm walking in the house, I'll be incorporating the instructions into what I'm doing, like balancing.* [P23; laptop]

Participants used ElderTree to relax and were happy to have a tool that could help them do so:

> *I would go back to ElderTree after gardening in the evening, to relax.* [P06; laptop]
>
> *It was nice to do the calming exercise. It just took ten minutes to settle my brain...When I wanted to relax, I would listen to the ones that had you close your eyes...the next thing I knew I was asleep!* [P15; laptop]

Participants were able to control their mood by customizing what type of content they accessed on the devices.

Table 2. Components of ElderTree that seemed to support user autonomy, competence, and relatedness and the number of participants reporting that experience by device type [69] (N=22).

Self Determination Theory construct and applicable device types[a]	Description	Participants, n (%)
Autonomy		
Use customization		
Laptop	Accessing content whenever (eg, in the middle of the night) and wherever (eg, bringing the laptop to another state to use it or moving from room to room)	13 (59)
Content customization		
Laptop and smart display	Using the system as desired, including outside ElderTree (eg, music, images, and searches)	2 (9)
Competence		
Content access and navigation		
Laptop and smart display	Being provided with quality content without searching	9 (41)
Content navigation		
Smart display	Figuring out the system and how to navigate	13 (59)
Health competence		
Laptop and smart display	Having access to regularly updated exercise, meditation, and entertainment content	9 (41)
Laptop and smart display	Using the system to learn about physical and mental health, aging well, and managing pain	3 (14)
Technology competence		
Laptop	Bringing previous experience with computers and technology to navigating and using the system	8 (36)
Smart display	Finding excitement and enjoyment in learning new technology	4 (18)
Relatedness		
Weekly meetups		
Laptop and smart display	Connecting with other participants	15 (68)
Laptop and smart display	Seeing other participants	4 (18)
Laptop and smart display	Chatting in small breakout groups	2 (9)
Weekly tracker		
Laptop and smart display	Talking to health care providers about ElderTree and the weekly self-report health status	6 (27)
Asking others for help		
Laptop and smart display	Connecting participants with others who could help them, including connecting with study staff	3 (14)
Discussion boards		
Laptop and smart display	Reading what others wrote and finding new information	3 (14)

[a] Device type has been italicized.

Features That Detracted From User Autonomy

Table 3 reports specific counts of features that participants reported as detracting from feelings of autonomy, competence, and relatedness. Participants described feeling less autonomous when they were unable to customize the tool to their liking. The specific customization feature of favoriting content for later was used by only 5% (1/22) of the participants. Many did not know about the "favoriting" feature when asked whether they used it, and the participants who did know about it found it frustrating:

> *Instead of having to do down the tree to go find it, you could add [a video to] favorites and you could have "favorite" ones that you do all the time...but that didn't work either.* [P09; smart display]

There were other customization options that participants might have liked. One participant, for example, discussed wanting more self-tracking options, such as for blood pressure.

Participants also wanted the smart display to be portable, saying that “It felt a bit outdated...[the smart display] had to be plugged in, and it was not mobile. We are so used to everything being mobile now” (P04; smart display). The difficulty in customizing the location felt constricting for participants.

Table 3. Components of ElderTree that seemed to detract from user autonomy, competence, and relatedness and the number of participants reporting that experience by device type (N=22).

Self-determination theory construct and applicable device types[a]	Description	Participants, n (%)
Autonomy		
Interest		
Laptop and smart display	Not being interested in using ElderTree	4 (18)
Content customization		
Laptop and smart display	Finding the tool and content not customizable to their needs or wanting more customization options, such as tracking blood pressure	4 (18)
Competence		
Technological issues		
Laptop and smart display	Experiencing technical issues using the system, accessing content, or joining the weekly meetups	14 (64)
Previous work experience with computers		
Laptop and smart display	Not having previous experience with computers or technology	7 (32)
Content newness		
Laptop and smart display	Finding the content stale or not growing with participants’ abilities	6 (27)
System navigation		
Smart display	Finding the tool difficult to navigate	3 (14)
Relatedness		
Weekly meetups		
Laptop and smart display	Feeling too old, too young, or too healthy for the group by comparison	3 (14)
Laptop and smart display	Feeling bored or otherwise just not interested in connecting with other participants	7 (32)
Laptop and smart display	Feeling like the meetings were too large	4 (18)
Weekly tracker		
Laptop and smart display	Being unable to connect with health care providers about their weekly tracker results (ie, finding that providers did not care)	7 (32)
Discussion boards		
Smart display	Not having knowledge about the feature	4 (18)

[a] Device type has been italicized.

Navigability and Competence

While there were a few examples of how application navigability was related to a participant’s feeling of competence using it, that was not the only way in which they talked about feeling competent with the technology. Participants generally did not discuss the navigability of the application much, but when prompted, many said that they had no problems finding what they needed:

> *Yeah, I did, the ElderTree site was pretty straightforward.* [P24; laptop]
>
> *...it took a little bit to figure it out but eventually I figured it out.* [P31; smart display]
>
> *...if [the technology] is complicated, I’m not prepared to learn.* [P04; smart display]

In this way, competence and navigability were connected. One participant described feeling competent because they did not have to search through a huge number of videos to find ones applicable to them, in contrast to a public website such as YouTube, where they felt less able to find the quality of videos that they were looking for:

> *I was interested in specific kinds of topics that I was able to find. I mean if you go to YouTube, you can find videos about how to maintain your balance, or work at your balance, but it’s so disorganized. Because that’s curated, and I guess that’s a real*

> *benefit of what something like ElderTree accomplished.* [P25; laptop]

Familiar user interfaces and navigation cues on the laptop created feelings of competence, such as using the touch screen:

> *I'm glad I was in the laptop group and was able to do more on a computer. I used the touch screen functionality, I preferred it, but I could use the mouse.* [P53; laptop]

Another participant reflected how it was easier to correct errors using the touch screen, which made the experience more enjoyable:

> *They gave me the mouse and the pad but it's all touch screen...I can just touch it and then like backspace or whatever I need to do and then fix it and go on...It's so awesome for me because that's what I was looking for and, I never, you know, knew that I would enjoy that as much as I do, it just makes it so easy for me.* [P25; laptop]

While some of the smart screen participants had initial trepidation, many had positive experiences after becoming familiar with it, such as one participant who stated the following:

> *It took a little bit to figure it all out but eventually, I got the swing of it. [The smart screen] was kind of fun, something new to figure out.* [P31; smart display]

Other participants described how fun it was to both figure out the new technology and find the content:

> *It was kind of a novelty to have this little piece of equipment that would have a little message every morning, or day depending on what time you listen to, looked at it...I liked going in there and...doing some of the exercises,also, um, asking it to play certain music.* [P12; smart display]

Participants sought new content along with new technologies, and it was the system navigability that supported their desire to try out all the existing content or a drive to look at the application regularly to see when new content was introduced:

> *Overall, I tried every single [exercise video], and some of them I did twice or three times...I tried out everything.* [P01; laptop]

This supported their competence with finding and using health information:

> *I wanted to see what everything was. Late nights, at night, I would do some of the meditations, and movement, too. I liked exploring and was glad to do that because I found things I otherwise wouldn't see.* [P53; laptop]

Several participants mentioned that regularly updated content was a motivator for checking and using the app, such as the inspirational quotes or new content:

> *You know, and I tried, whenever they said something new was on it, I tried to go to it sometime during the week.* [P29; laptop]

The new content motivated them to initially log on to the system and then often kept their attention.

Finally, the content on ElderTree supported users' competence and knowledge of specific health topics, particularly the modules on pain:

> *A lot of us deal with pain. They had good information about pain, and we would use that information.* [P01; laptop]

Another participant found that, again, the pain modules provided important information for how they could handle their pain:

> *There was some videos that went into a lot more detail about pain [on ElderTree] and...it was really interesting.* [P15; laptop]

Inherent in the ability to learn about how to manage pain was the ability to find and watch the video segments about pain or other topics of interest. Participants also learned how to do physical activity movements that could help manage and reduce their pain:

> *Every night, I'd sit there and do two or three of those [mindful movements videos on ElderTree]...to get that shoulder moving again.* [P09; smart display]

Features That Detracted From Competence

Within the system, there were components that the participants discussed negatively, particularly in the smart screen condition. The participants with a smart screen mentioned various issues, such as not being able to log in or their camera not functioning properly for the meetings, which hindered their interest in using the application by reducing their feelings of competence. They described how they wanted to be a part of the video calls or do the exercise videos but that they were challenged by the system and some technological issues:

> *To have to go through all the, all the hoops to get the ah, Google display thing to work...I do have computer skills. It's like, I actually used the original internet back in the seventies.* [P48; smart display]

Another participant found the content helpful but the system cumbersome, so they went outside of it:

> *A lot of the videos I found on YouTube...I wouldn't even try to mess with [ElderTree]. The only time I would use it with ElderTree was when we were online [for the weekly meetups].* [P48; smart display]

Technical troubles were likely to deter participants.

Stale content was also a deterrent for some participants. For one, because new content prompted participants to look at ElderTree and browse, participants mentioned forgetting to use the application when they did not expect anything new, with one participant saying the following:

> *I can't be bothered, because it's not new, it's not on your mind, you don't think about, don't bother going back and having a look at it.* [P04; smart display]

Other participants felt like the content needed to progress with them, to become more challenging as they became more able, such as the following participant, who used ElderTree a lot while they were healing but not as much after they recovered from their surgery:

> *After my shoulder got better, I needed more. I tried the balance ones, but the content got stale.* [P09; smart display]

New content engaged participants, but not having content that grew with them deterred participants from regular use.

Interactivity and Relatedness

To examine the role of ElderTree and the device regarding relatedness, the interviewer asked questions about the weekly meetups and the online discussion board. Table 2 reports resulting counts of specific features that participants reported as supporting autonomy, competence, and relatedness. The researchers found that technological features that increased the interactivity affordance, and participants' feelings of relatedness were closely linked concepts. In times when technology afforded interactivity through an interactive social experience, participants were able to connect with others, interested in doing so, and discussed the importance of that connection. While participants never met in person, nor were they required to attend the weekly meetings, they often found the meetings to be a very impactful part of the study. The meetings connected participants with each other and were discussed as an experience that supported their feelings of being closer to the people in the group. They discussed that being in the meetings gave them "the knowledge that you're not alone and that there are other people fighting through difficulties. It's a whole lot different knowing that than sitting at home by yourself thinking you're the only one going through it" (P29; laptop). Regardless of their similarities or differences, participants felt like they were a part of a group, saying that "Whatever condition you are in, it gives you a way to socialize" (P04; smart display). The participants identified that the group was diverse:

> *It was uplifting to talk to different people...I liked the conversations. Over the phone we got pretty close. We never met, but we had a good group, for such a large group.* [P40; laptop]

The weekly meetups provided opportunities for older adults to learn from others:

> *[The ElderTree Meetup] helps you mentally because just hearing about what other people are going through, and what things have helped them, what resources they used, was very helpful.* [P07; smart display]

Another participant commented that "ElderTree makes us thankful...it gives you another perspective on things" (P22; laptop). The interactivity experienced through the weekly video calls seemed to correspond with feelings of relatedness by providing users with a social network to corroborate the difficulties of growing older and resources for new and ongoing health and social issues.

There were certain technical features as well that increased relatedness by giving participants specific ways to interact with each other, such as the hand-raising function that created organization regarding who could speak:

> *I'm a little shy about speaking up and it can be hard for me but um, it was nice that they had the hand raising function [on Google Meet], because that helped a little bit to be called. So, sometimes, I would wait and then if it seemed like there weren't a lot of people talking, I would raise my hand.* [P15; laptop]

The chat feature within the breakout groups also garnered positive responses from participants, who said that "We had a good time with the chat feature" (P01; laptop) but that they wanted more—"It would be nice to have a chat option, a one-on-one chat within the meetings" (P15; laptop)—to support a smaller community. The breakout groups also created a closer sense of community by encouraging a smaller group to come together and chat:

> *I like the fact that we could all contribute first thing, you know, I mean when they get the breakout groups that was nice because I need a chance to offer what was good for the week and, you know, one good thing or one, you know, thing that wasn't so good.* [P5; smart display]

These structural components supporting interactivity seemed important to participants' feelings of relatedness to other participants and their general engagement with ElderTree.

A few unexpected features of the study design supported participants' feelings of relatedness. Participants reported that emailing or calling study staff when they had a question was particularly helpful, as one participant said:

> *[The ElderTree study staff] were really great. We'd go to them with any question...there was always somebody there that would help.* [P30; smart display]

In addition, participants talked about the importance of the racial and age diversity on the calls, as one participant reported:

> *I am a white person, and I have some interaction with people of other races and backgrounds but not necessarily that much. It was good for me to listen to the gentleman and the ladies that were of other races.* [P07; smart display]

Features That Decreased Relatedness

While many participants appreciated the diversity, some reported feeling like outsiders if they were not like other participants because they were older or healthier than most participants. Specific features of the system were also brought up when asked about whether they felt that they related to other participants. For example, participants reported being uncomfortable not being able to see the other participants when their videos were not on or when there were technical difficulties so they could not share their own video streams:

> *I could get in and my camera wasn't working, so, and I don't like, I like being able to see it if I'm going to be talking to people, I like to have them to be able to see me as well.* [P30; smart display]
>
> *There were people who didn't even have their cameras on. I could only see a handful with video on, many with videos off the whole time. I always had the video on.* [P24; laptop]

The anonymity affordance [20], in which participants could turn off their camera during the video calls, may have decreased a sense of relatedness for some participants who would engage only partially:

> *At the end of every meeting, you know, we did...an exercise dance or whatever, but you do it sitting down. I do not know if it's my own self-consciousness or whatever, but usually I would do it up to a point, but I would turn the video off.* [P24; laptop]

There were a variety of reasons why participants did not want to have their cameras on, such as technical difficulties or because they did not want to share information about themselves, such as them doing an exercise video or showing the inside of their house:

> *I didn't have my camera on because I was at my messy desk downstairs.* [P26; laptop]

One participant commented that it was difficult to truly connect with the other participants because they were only connecting online and not in person:

> *It's hard to look at a video, to be engaged that way, you know, at a deeper level. It's not as if we're in the same room at a party or a live event where you get to see [people] It's harder to replicate and it's harder for me to open up...Maybe it's just my generation, I don't know.* [P22; laptop]

Finally, the weekly health tracker prevented some feelings of relatedness for participants who wanted to discuss it with their physicians:

> *I usually did [the weekly survey]. But I thought they were kind of ridiculous. Because, they were nice for me, but the few times that I got them and took them to my doctors, they didn't give a ding-dang.* [P29; laptop]

Expecting their care team to want the data and finding out that they did not isolated the participants.

Personal Factors That Influenced Intrinsic Motivation to Use ElderTree

Individual participant characteristics influenced how they used the system, such as having work experience with computers or having a learning disposition. Some participants came to the study with an established sense of technological competence gained from years of working with computers. Although many participants were already retired, several talked about how their job required them to use computers and smartphones. Competence in using the ElderTree platform for these older adults was, for some participants, unrelated to how it was laid out and, instead, a function of a participant's lifetime of experiences, such as for one participant, who worked in technical services and would use video calls to troubleshoot issues. Other participants did not enter the study with a lifetime of work experience that involved interactive technology or digital media, and they lacked competence as they entered the study, such as one participant who stated the following:

> *My life was as a secretary, and I said no office machine was going to get the better of me, but the electronic age has.* [P10; smart display]

Other participants mentioned jobs as bus drivers and childcare providers or other jobs that were not completed on a computer, and for some of these participants, the system was not usable based on their past life experiences.

Another driver to use the system was participants' desire to learn technology and engage with something new. Some participants found that the novelty of the technology was what prompted them to use it even if they had no particular health goal, such as one participant who said that his motivation for enrolling in the study was the newness of the technology:

> *I've wanted to learn to do more typing, learn a new technology.* [P11; smart display]

Other participants also positively portrayed their interest in the novelty of a laptop or smart screen or just learning how to incorporate new technology into their lives, such as the following excited claim:

> *I love [technology]. I'm all in. I try to learn as I go, utilize it and that's where you keep your calendar and all appointments.* [P06; laptop]

Individual differences and preferences for exploring new technologies were often discussed by participants as reasons for engaging with or stopping use of ElderTree.

Discussion

Principal Findings

In attempting to understand the crossover between self-determination and the eHealth affordances of customization, interactivity, and navigability, we interviewed 22 participants who used either a smart screen or laptop for a 6- to 12-month period and asked them about their experience, things that motivated them to use the application, components that were useful, and whether and how they connected with other ElderTree participants. We used the frameworks provided by the MTM and self-determination theory to guide our collections and coding. Structuring our questions around core needs of autonomy, relatedness, and competence and tracing connections with customizability, interactivity, and navigability provided new insights into how these affordances shape how older adults use eHealth tools. The participants discussed how the ElderTree application specifically supported all 3 human needs that drive internal motivation. While having a platform that afforded interactivity through discussion boards and a hosted weekly meeting supported participants' feelings of relatedness and got them moving with an exercise video, they also talked about how on-demand, curated videos and hardware that could move around their house allowed them to customize their use of the platform and gave them more autonomy over when they wanted to exercise. Some specific content on ElderTree that participants particularly found beneficial were the pain modules and the calming movements that encouraged stretching and breathing. However, many of the experiences that users had could be benefits of any health application that connects older adults with content and other participants. These benefits need not be unique to the ElderTree platform, but they do require more than just access to content. Confirming previous findings, directly engaging with other study participants and study staff was critical to supporting participant relatedness and general interest in the application [37].

Individual characteristics, such as technological competence, differing interest in the ways in which they could track their own health, and preferences in meetup groups, seemed to reflect differences in how participants used ElderTree. Older adults are closing the digital divide [51], and many are willing to try new eHealth and mHealth options [70]. However, there are individual differences in interest in experimenting with technologies, so considering not only the technological affordances of eHealth platforms but also the personal characteristics, such as through a measure of technological innovativeness [71] or technology adoption [72], may capture individual differences in older adults' interest in the challenges of using eHealth [22] or interest in health-tracking applications [73]. Measures of technology self-competence [71,74,75] may also help describe some of the differences observed among older adults using eHealth to account for the technological comfort and competence that older adults bring to a study, such as being worried that they will break the device or make an irreversible change, and those fears have can have a significant impact on how they see the eHealth and potential outcomes regardless of how navigable it is. This means that some older adults will use the technology even if they do not feel comfortable with the navigation, whereas for others, that will be a barrier [37]. There are many ways in which technological features may impact older adults' experience of using an eHealth application.

Implications for eHealth Designers and Researchers

Future designers creating these technologies can consider that certain eHealth affordances support older adults' intrinsic motivation to engage with health content, such as exercise videos, meditations, and social interactions. Interactivity is a useful way to support relatedness, and ElderTree used scheduled socializing and exercise time through the weekly meetups. While these were generally liked, future implementations could better engage participants through smaller groups that are organized around common interests or health concerns, a finding shared with those of other eHealth studies [31]. Customization, too, supports participants, and in this study, participants asked for several additional customization options, such as including more exercise content of varied difficulty and tracking additional health elements in the weekly tracker, and users in the smart device group asked for the ability to customize where they used the devices, a commonly cited request for supporting autonomy [76]. While we only explored the affordances of interactivity, navigability, and customization based on the MTM, there were several other concepts that may be considered in future work exploring affordances of eHealth applications. ElderTree afforded participants access to newly updated content, which they found was a motivator for engaging in positive health activities, such as meditation and physical activity, and in general can support older adults' healthy aging [77]. Given the complicated nature of defining affordances [78], we defer the work of declaring the aforementioned features as such to future researchers.

The hardware also offered customization options, and future designers could consider technological affordances beyond just what is in the eHealth application itself. In this study, participants used the smart display to play music; read inspirational quotes; and view inspirational, beautiful pictures for enjoyment. People in the laptop group were able to use it for visiting other health- and non–health-related sites or to connect with their family and friends. These extracurricular uses should be considered for their potential to support participants' engagement with health technology and opportunity to engender further health activities.

The last design consideration is that technology use, particularly by older adults, is done in a complex environment in which the other users and available support staff play a critical role in maintaining an individual's interest in the eHealth application. In this way, designers may not be able to successfully deploy an eHealth application into an app store without staff and without synchronous ways for users to connect. ElderTree does this by providing users with unlimited support staff available via phone or email and through hosting weekly calls. Participants brought histories and experiences with technology and social connection and had different abilities and interests to learn and engage.

Limitations and Future Research

This study has several limitations. First, the qualitative research provided a richer understanding of how participants experienced the application, but there was a wide variety within the population. We captured some of that variety in this study, but older adults are incredibly diverse [79], and we likely were not able to fully elucidate all the experiences that the participants had with the affordances of ElderTree. Furthermore, while we attempted to increase the racial and ethnic diversity of the sample, we were not able to reach as many participants of racial or ethnic minority groups as we would have liked. These findings may not reflect the experiences of minority populations, who are often left out of research on eHealth [80], leading to worsening digital divides. Ongoing ElderTree research is prioritizing enrolling a diverse population, and future qualitative studies will be able to reflect that diversity. Additional research should also consider the degree to which participants desire a homogeneous or diverse group, and the potentially different social groups and functions that older adults desire.

Another limitation is that participants likely experienced recall bias in what they remembered about using the system and what modules they used. ElderTree and other eHealth tools often show significant participant attrition [81] such that people use the system more when they first receive it but then stop using it. Future studies should use system logs to quantitatively measure participant use and the relationship between system use and participant self-reported autonomy, competence, relatedness, and well-being to help support the results presented in this paper. Finally, while this study used a Google platform for ElderTree, that platform is no longer compatible with ElderTree, and future studies will be conducted on alternative smart display platforms.

Conclusions

The aging population continues to adopt new technologies, and we need insights to shape the design of eHealth applications to best support older adults. This study found that there was excitement among the participants to use new technologies such as smart screens, although some participants needed extra support to use them most effectively. Self-determination theory can help app designers build products that support older adults with both low and high digital literacy. For example, providing multipurpose technology, such as a laptop, can better support older adults who bring competence and autonomous interest in using it. The MTM and self-determination theory components overlap, but there are also personal differences that have strong influences on how older adults use technology. In this way, future research can include additional eHealth affordances and personal-level characteristics to support individuals' self-determination in engaging in healthy behaviors.

Authors' Contributions

LMC, DS, and MLM devised the study. LMC, DS, MLM, and DHG created the interview guide. LMC conducted the interviews, and GL, SS, and KT supported data collection. LMC and KB coded all responses and conducted data analysis. MLM, DS, AM, DHG, and DG edited the manuscript and provided critical input. DHG is the co–principal investigator of the study. GL is the project manager for the study. KP-R is the study implementation coordinator. AM developed the software for the study. All authors contributed to the design of the study and have approved the manuscript.

Conflicts of Interest

DHG has a small shareholder interest in Center for Health Enhancement System Studies Health, a corporation that develops health care technology for patients and family members struggling with addiction. The other authors have no disclosures to report.

Multimedia Appendix 1
Screenshots of the ElderTree system taken from the laptop condition.
[DOCX File , 2569 KB - aging_v7i1e56923_app1.docx]

Multimedia Appendix 2
Semistructured interview protocol used with ElderTree participants.
[DOCX File , 393 KB - aging_v7i1e56923_app2.docx]

References

1. FastStats: older person's health. Centers for Disease Control and Prevention. URL: https://www.cdc.gov/nchs/fastats/older-american-health.htm [accessed 2023-09-07]
2. Zenebe Y, Akele B, W/Selassie M, Necho M. Prevalence and determinants of depression among old age: a systematic review and meta-analysis. Ann Gen Psychiatry 2021 Dec 18;20(1):55 [FREE Full text] [doi: 10.1186/s12991-021-00375-x] [Medline: 34922595]
3. Zhao YC, Zhao M, Song S. Online health information seeking behaviors among older adults: systematic scoping review. J Med Internet Res 2022 Feb 16;24(2):e34790 [FREE Full text] [doi: 10.2196/34790] [Medline: 35171099]
4. Gosetto L, Ehrler F, Falquet G. Personalization dimensions for mHealth to improve behavior change: a scoping review. Stud Health Technol Inform 2020 Nov 23;275:77-81. [doi: 10.3233/SHTI200698] [Medline: 33227744]
5. Deci EL, Ryan RM. Self-determination theory. In: Van Lange PA, Kruglanski AW, Higgins ET, editors. Handbook of Theories of Social Psychology. Thousand Oaks, CA: SAGE Publications; 2012.
6. Niemiec CP, Ryan RM. Autonomy, competence, and relatedness in the classroom: applying self-determination theory to educational practice. Theory Res Educ 2009 Jun 25;7(2):133-144. [doi: 10.1177/1477878509104318]
7. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol 2000 Jan;55(1):68-78. [doi: 10.1037//0003-066x.55.1.68] [Medline: 11392867]
8. Sheeran P, Wright CE, Avishai A, Villegas ME, Rothman AJ, Klein WM. Does increasing autonomous motivation or perceived competence lead to health behavior change? A meta-analysis. Health Psychol 2021 Oct;40(10):706-716. [doi: 10.1037/hea0001111] [Medline: 34881939]
9. Tang M, Wang D, Guerrien A. A systematic review and meta-analysis on basic psychological need satisfaction, motivation, and well-being in later life: contributions of self-determination theory. Psych J 2020 Feb;9(1):5-33. [doi: 10.1002/pchj.293] [Medline: 31177644]
10. Baumeister RF, Leary MR. The need to belong: desire for interpersonal attachments as a fundamental human motivation. Psychol Bull 1995 May;117(3):497-529. [Medline: 7777651]
11. Hull SJ, Abril EP, Shah DV, Choi M, Chih M, Kim SC, et al. Self-determination theory and computer-mediated support: modeling effects on breast cancer patient's quality-of-life. Health Commun 2016 Oct;31(10):1205-1214. [doi: 10.1080/10410236.2015.1048422] [Medline: 26881789]

12. Chib A, Lin SH. Theoretical advancements in mHealth: a systematic review of mobile apps. J Health Commun 2018;23(10-11):909-955. [doi: 10.1080/10810730.2018.1544676] [Medline: 30449261]
13. Wang C, Qi H. Influencing factors of acceptance and use behavior of mobile health application users: systematic review. Healthcare (Basel) 2021 Mar 22;9(3):357 [FREE Full text] [doi: 10.3390/healthcare9030357] [Medline: 33809828]
14. Ng JY, Ntoumanis N, Thøgersen-Ntoumani C, Deci EL, Ryan RM, Duda JL, et al. Self-determination theory applied to health contexts: a meta-analysis. Perspect Psychol Sci 2012 Jul;7(4):325-340. [doi: 10.1177/1745691612447309] [Medline: 26168470]
15. Ntoumanis N, Ng JY, Prestwich A, Quested E, Hancox JE, Thøgersen-Ntoumani C, et al. A meta-analysis of self-determination theory-informed intervention studies in the health domain: effects on motivation, health behavior, physical, and psychological health. Health Psychol Rev 2021 Jun;15(2):214-244 [FREE Full text] [doi: 10.1080/17437199.2020.1718529] [Medline: 31983293]
16. Brooks JM, Huck G, Iwanaga K, Chan F, Wu JR, Finnicum CA, et al. Towards an integration of the health promotion models of self-determination theory and theory of planned behavior among people with chronic pain. Rehabil Psychol 2018 Nov;63(4):553-562. [doi: 10.1037/rep0000245] [Medline: 30211605]
17. Morgan K, Tan MP. Behaviour change theories and techniques for promoting physical activity among older people. In: Nyman S, editor. The Palgrave Handbook of Ageing and Physical Activity Promotion. Cham, Switzerland: Palgrave Macmillan; 2018.
18. Mackenzie CS, Karaoylas EC, Starzyk KB. Lifespan differences in a self determination theory model of eudaimonia: a cross-sectional survey of younger, middle-aged, and older adults. J Happiness Stud 2017 Nov 9;19:2465-2487. [doi: 10.1007/s10902-017-9932-4]
19. Martela F, Hankonen N, Ryan RM, Vansteenkiste M. Motivating voluntary compliance to behavioural restrictions: self-determination theory–based checklist of principles for COVID-19 and other emergency communications. Eur Rev Soc Psychol 2021 Jan 18;32(2):305-347. [doi: 10.1080/10463283.2020.1857082]
20. Conole G, Dyke M. What are the affordances of information and communication technologies? Res Learn Technol 2004 Jun 01;12(2):113-124. [doi: 10.3402/rlt.v12i2.11246]
21. Sundar SS, Bellur S, Jia H. Motivational technologies: a theoretical framework for designing preventive health applications. In: Proceedings of the 7th International Conference on Persuasive Technology: Design for Health and Safety. 2012 Presented at: PERSUASIVE 2012; June 6-8, 2012; Linköping, Sweden. [doi: 10.1007/978-3-642-31037-9_10]
22. Sundar SS, Jia H, Waddell TF, Huang Y. Toward a theory of interactive media effects (TIME): four models for explaining how interface features affect user psychology. In: The Handbook of the Psychology of Communication Technology. Hoboken, NJ: John Wiley & Sons; 2015.
23. Johansson T, Eklund A, Schmid A, Gudmundson K, Andersson L, Sörme M, et al. Navigability of a web application: how different factors alter the perceived navigability of a web application focused on letting users rent out private belongings. Linköping University. 2023. URL: https://liu.diva-portal.org/smash/record.jsf?pid=diva2%3A1771596&dswid=8824 [accessed 2024-09-19]
24. Hu PJ, Hu HF, Fang X. Examining the mediating roles of cognitive load and performance outcomes in user satisfaction with a website. MIS Q 2017 Sep;41(3):975-988.
25. Molina MD, Zhan ES, Agnihotri D, Abdullah S, Deka P. Motivation to use fitness application for improving physical activity among hispanic users: the pivotal role of interactivity and relatedness. In: Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems. 2023 Presented at: CHI '23; April 23-28, 2023; Hamburg, Germany. [doi: 10.1145/3544548.3581200]
26. Naslund JA, Bondre A, Torous J, Aschbrenner KA. Social media and mental health: benefits, risks, and opportunities for research and practice. J Technol Behav Sci 2020 Sep;5(3):245-257 [FREE Full text] [doi: 10.1007/s41347-020-00134-x] [Medline: 33415185]
27. Yoo W, Namkoong K, Choi M, Shah DV, Tsang S, Hong Y, et al. Giving and receiving emotional support online: communication competence as a moderator of psychosocial benefits for women with breast cancer. Comput Human Behav 2014 Jan;30:13-22 [FREE Full text] [doi: 10.1016/j.chb.2013.07.024] [Medline: 24058261]
28. Sen K, Prybutok G, Prybutok V. The use of digital technology for social wellbeing reduces social isolation in older adults: a systematic review. SSM Popul Health 2021 Dec 30;17:101020 [FREE Full text] [doi: 10.1016/j.ssmph.2021.101020] [Medline: 35024424]
29. Jung EH, Sundar SS. Older adults' activities on Facebook: can affordances predict intrinsic motivation and well-being? Health Commun 2022 May;37(5):597-607. [doi: 10.1080/10410236.2020.1859722] [Medline: 33393823]
30. Zhou X, Krishnan A, Dincelli E. Examining user engagement and use of fitness tracking technology through the lens of technology affordances. Behav Inform Technol 2021 Apr 17;41(9):2018-2033. [doi: 10.1080/0144929x.2021.1915383]
31. Movin A. Designing a preventive health application: how to motivate and empower users. KTH Royal Institute of Technology. 2015. URL: http://kth.diva-portal.org/smash/get/diva2:865114/FULLTEXT02.pdf [accessed 2024-09-18]
32. Attribution 4.0 International (CC BY 4.0). Creative Commons. URL: https://creativecommons.org/licenses/by/4.0/ [accessed 2024-09-26]

33. Orji R, Vassileva J, Mandryk RL. Modeling the efficacy of persuasive strategies for different gamer types in serious games for health. User Model User Adap Inter 2014 Jul 14;24:453-498. [doi: 10.1007/s11257-014-9149-8]
34. Bellur S, DeVoss C. Apps and autonomy: perceived interactivity and autonomous regulation in mHealth applications. Commun Res Rep 2018 Aug 20;35(4):314-324. [doi: 10.1080/08824096.2018.1501672]
35. Kocaballi AB, Berkovsky S, Quiroz JC, Laranjo L, Tong HL, Rezazadegan D, et al. The personalization of conversational agents in health care: systematic review. J Med Internet Res 2019 Nov 07;21(11):e15360 [FREE Full text] [doi: 10.2196/15360] [Medline: 31697237]
36. Bol N, Høie NM, Nguyen MH, Smit ES. Customization in mobile health apps: explaining effects on physical activity intentions by the need for autonomy. Digit Health 2019 Nov 10;5:2055207619888074 [FREE Full text] [doi: 10.1177/2055207619888074] [Medline: 31807312]
37. Spann A, Stewart EA. Barriers and facilitators of older people's mHealth usage: a qualitative review of older people's views. Hum Technol 2018 Nov;14(3):264-296. [doi: 10.17011/ht/urn.201811224834]
38. Fortuna KL, Brooks JM, Umucu E, Walker R, Chow PI. Peer support: a human factor to enhance engagement in digital health behavior change interventions. J Technol Behav Sci 2019 Jun 15;4(2):152-161 [FREE Full text] [doi: 10.1007/s41347-019-00105-x] [Medline: 34337145]
39. Moran GS, Russinova Z, Yim JY, Sprague C. Motivations of persons with psychiatric disabilities to work in mental health peer services: a qualitative study using self-determination theory. J Occup Rehabil 2014 Mar;24(1):32-41. [doi: 10.1007/s10926-013-9440-2] [Medline: 23576121]
40. Oinas-Kukkonen H, Harjumaa M. A systematic framework for designing and evaluating persuasive systems. In: Proceedings of the Third International Conference on Persuasive Technology. 2008 Presented at: PERSUASIVE 2008; June 4-6, 2008; Oulu, Finland. [doi: 10.1007/978-3-540-68504-3_15]
41. Cao W, Milks MW, Liu X, Gregory ME, Addison D, Zhang P, et al. mHealth interventions for self-management of hypertension: framework and systematic review on engagement, interactivity, and tailoring. JMIR Mhealth Uhealth 2022 Mar 02;10(3):e29415 [FREE Full text] [doi: 10.2196/29415] [Medline: 35234655]
42. Chandler J, Sox L, Kellam K, Feder L, Nemeth L, Treiber F. Impact of a culturally tailored mHealth medication regimen self-management program upon blood pressure among hypertensive Hispanic adults. Int J Environ Res Public Health 2019 Apr 06;16(7):1226 [FREE Full text] [doi: 10.3390/ijerph16071226] [Medline: 30959858]
43. Mustafa AS, Ali N, Dhillon JS, Alkawsi G, Baashar Y. User engagement and abandonment of mHealth: a cross-sectional survey. Healthcare (Basel) 2022 Jan 24;10(2):221 [FREE Full text] [doi: 10.3390/healthcare10020221] [Medline: 35206837]
44. Wei Y, Zheng P, Deng H, Wang X, Li X, Fu H. Design features for improving mobile health intervention user engagement: systematic review and thematic analysis. J Med Internet Res 2020 Dec 09;22(12):e21687 [FREE Full text] [doi: 10.2196/21687] [Medline: 33295292]
45. Kim H, Tietsort C, Posteher K, Michaelides A, Toro-Ramos T. Enabling self-management of a chronic condition through patient-centered coaching: a case of an mHealth diabetes prevention program for older adults. Health Commun 2020 Dec;35(14):1791-1799. [doi: 10.1080/10410236.2019.1663583] [Medline: 31514532]
46. Lu Y, Lu Y, Gupta S. Do mHealth apps influence consumers' safe food choice decisions? Role of technology affordances. J Electron Commer Res 2022;23(4):223-235.
47. Rathnayake S, Moyle W, Jones C, Calleja P. mHealth applications as an educational and supportive resource for family carers of people with dementia: an integrative review. Dementia (London) 2019;18(7-8):3091-3112. [doi: 10.1177/1471301218768903] [Medline: 29631492]
48. Bandani-Susan B, Montazeri A, Haghighizadeh MH, Araban M. The effect of mobile health educational intervention on body image and fatigue in breast cancer survivors: a randomized controlled trial. Ir J Med Sci 2022 Aug;191(4):1599-1605. [doi: 10.1007/s11845-021-02738-5] [Medline: 34370166]
49. Jamison JC, Karlan D, Raffler P. Mixed method evaluation of a passive mHealth sexual information texting service in Uganda. National Bureau of Economic Research. 2013 Jun. URL: https://www.nber.org/papers/w19107 [accessed 2024-09-18]
50. Allida S, Du H, Xu X, Prichard R, Chang S, Hickman LD, et al. mHealth education interventions in heart failure. Cochrane Database Syst Rev 2020 Jul 02;7(7):CD011845 [FREE Full text] [doi: 10.1002/14651858.CD011845.pub2] [Medline: 32613635]
51. Francis J, Ball C, Kadylak T, Cotten SR. Aging in the digital age: conceptualizing technology adoption and digital inequalities. In: Neves B, Vetere F, editors. Ageing and Digital Technology. Singapore, Singapore: Springer; Jan 09, 2019.
52. Conner M. Initiation and maintenance of health behaviors. Appl Psychol 2008 Jan 30;57(1):42-50. [doi: 10.1111/j.1464-0597.2007.00321.x]
53. Rakowski W, Julius M, Hickey T, Halter JB. Correlates of preventive health behavior in late life. Res Aging 1987 Sep;9(3):331-355 [FREE Full text] [doi: 10.1177/0164027587093001] [Medline: 3685621]
54. Yingwattanakul P, Moschis GP. A life course study of the effects of experienced life events on the onset and continuity of preventive healthcare behaviors. Health Mark Q 2019;36(1):71-91. [doi: 10.1080/07359683.2019.1567005] [Medline: 30776992]

55. Flickinger TE, Campbell BR, Timm A, Baee S, Datta D, Shenoi SV, et al. Use of a mobile health intervention by older versus younger people with HIV: analysis of usage, social support, and network interactions. Telemed Rep 2022 Dec 20;3(1):191-200 [FREE Full text] [doi: 10.1089/tmr.2022.0035] [Medline: 36636167]
56. Grembowski D, Patrick D, Diehr P, Durham M, Beresford S, Kay E, et al. Self-efficacy and health behavior among older adults. J Health Soc Behav 1993 Jun;34(2):89-104. [doi: 10.2307/2137237]
57. Kavandi H, Jaana M. Factors that affect health information technology adoption by seniors: a systematic review. Health Soc Care Community 2020 Nov;28(6):1827-1842. [doi: 10.1111/hsc.13011] [Medline: 32378769]
58. Jung EH, Kang H. Self-determination in wearable fitness technology: the moderating effect of age. Int J Hum Comput Interact 2021 Nov 29;38(15):1399-1409. [doi: 10.1080/10447318.2021.2002048]
59. Smit ES, Bol N. From self-reliers to expert-dependents: identifying classes based on health-related need for autonomy and need for external control among mobile users. Media Psychol 2019 Apr 30;23(3):391-414. [doi: 10.1080/15213269.2019.1604235]
60. Gustafson DHS, Mares ML, Johnston DC, Mahoney JE, Brown RT, Landucci G, et al. A web-based eHealth intervention to improve the quality of life of older adults with multiple chronic conditions: protocol for a randomized controlled trial. JMIR Res Protoc 2021 Feb 19;10(2):e25175 [FREE Full text] [doi: 10.2196/25175] [Medline: 33605887]
61. Gustafson DHS, Mares ML, Johnston DC, Landucci G, Pe-Romashko K, Vjorn OJ, et al. Using smart displays to implement an eHealth system for older adults with multiple chronic conditions: protocol for a randomized controlled trial. JMIR Res Protoc 2022 May 05;11(5):e37522 [FREE Full text] [doi: 10.2196/37522] [Medline: 35511229]
62. Gustafson DHS, Kornfield R, Mares ML, Johnston DC, Cody OJ, Yang EF, et al. Effect of an eHealth intervention on older adults' quality of life and health-related outcomes: a randomized clinical trial. J Gen Intern Med 2022 Feb;37(3):521-530 [FREE Full text] [doi: 10.1007/s11606-021-06888-1] [Medline: 34100234]
63. Ebrahimi Belil F, Alhani F, Ebadi A, Kazemnejad A. Self-efficacy of people with chronic conditions: a qualitative directed content analysis. J Clin Med 2018 Nov 03;7(11):411 [FREE Full text] [doi: 10.3390/jcm7110411] [Medline: 30400316]
64. Lazar J, Feng JH, Hochheiser H. Research Methods in Human-Computer Interaction. Hoboken, NJ: John Wiley & Sons; 2014.
65. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381 [FREE Full text] [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
66. Braun V, Clarke V. Thematic analysis. In: Cooper H, Camic PM, Long DL, Panter AT, Rindskopf D, Sher KJ, editors. APA Handbook of Research Methods in Psychology. Washington, DC: American Psychological Association; 2012.
67. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. Int J Qual Methods 2006;5(1):80-92. [doi: 10.1177/160940690600500107]
68. Raskind IG, Shelton RC, Comeau DL, Cooper HL, Griffith DM, Kegler MC. A review of qualitative data analysis practices in health education and health behavior research. Health Educ Behav 2019 Feb;46(1):32-39 [FREE Full text] [doi: 10.1177/1090198118795019] [Medline: 30227078]
69. Touch screen icons and symbols. Flaticon. URL: https://www.flaticon.com/free-icons/touch-screen [accessed 2024-06-28]
70. Aranha M, James K, Deasy C, Heavin C. "Exploring the barriers and facilitators which influence mHealth adoption among older adults: a literature review". Gerontechnology 2021;20(2):1-16. [doi: 10.4017/gt.2021.20.2.424.06]
71. Boyle RJ, Ruppel CP. The effects of personal innovativeness , perceived risk , and computer self-efficacy on online purchasing intent. J Int Technol Inf Manag 2006;15(2):61-74. [doi: 10.58729/1941-6679.1168]
72. Liao C, Palvia P, Chen JL. Information technology adoption behavior life cycle: toward a Technology Continuance Theory (TCT). Int J Inf Manage 2009 Aug;29(4):309-320. [doi: 10.1016/j.ijinfomgt.2009.03.004]
73. Cajamarca G, Herskovic V, Rossel PO. Enabling older adults' health self-management through self-report and visualization-a systematic literature review. Sensors (Basel) 2020 Aug 04;20(15):4348 [FREE Full text] [doi: 10.3390/s20154348] [Medline: 32759801]
74. Compeau DR, Higgins CA. Computer self-efficacy: development of a measure and initial test. MIS Q 1995 Jun;19(2):189-211 [FREE Full text] [doi: 10.2307/249688]
75. Meng F, Guo X, Peng Z, Lai KH, Zhao X. Investigating the adoption of mobile health services by elderly users: trust transfer model and survey study. JMIR Mhealth Uhealth 2019 Jan 08;7(1):e12269 [FREE Full text] [doi: 10.2196/12269] [Medline: 30622092]
76. Matthew-Maich N, Harris L, Ploeg J, Markle-Reid M, Valaitis R, Ibrahim S, et al. Designing, implementing, and evaluating mobile health technologies for managing chronic conditions in older adults: a scoping review. JMIR Mhealth Uhealth 2016 Jun 09;4(2):e29 [FREE Full text] [doi: 10.2196/mhealth.5127] [Medline: 27282195]
77. Cohen Elimelech O, Rosenblum S, Tsadok-Cohen M, Meyer S, Ferrante S, Demeter N. Three perspectives on older adults' daily performance, health, and technology use during COVID-19: focus group study. JMIR Aging 2024 May 30;7:e53141 [FREE Full text] [doi: 10.2196/53141] [Medline: 38825851]
78. Nagy P, Neff G. Imagined affordance: reconstructing a keyword for communication theory. Soc Media Society 2015 Sep 30;1(2). [doi: 10.1177/2056305115603385]

79. van Boekel LC, Peek ST, Luijkx KG. Diversity in older adults' use of the internet: identifying subgroups through latent class analysis. J Med Internet Res 2017 May 24;19(5):e180 [FREE Full text] [doi: 10.2196/jmir.6853] [Medline: 28539302]
80. Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. J Am Med Inform Assoc 2018 Aug 01;25(8):1080-1088 [FREE Full text] [doi: 10.1093/jamia/ocy052] [Medline: 29788380]
81. Meyerowitz-Katz G, Ravi S, Arnolda L, Feng X, Maberly G, Astell-Burt T. Rates of attrition and dropout in app-based interventions for chronic disease: systematic review and meta-analysis. J Med Internet Res 2020 Sep 29;22(9):e20283 [FREE Full text] [doi: 10.2196/20283] [Medline: 32990635]

Abbreviations

mHealth: mobile health
MTM: motivational technology model
REDCap: Research Electronic Data Capture
RQ: research question
TIME: theory of interactive media effects

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Original Paper

Exploring How Older Adults Experience semAPP, a 360° Media–Based Tool for Memory Assessment: Qualitative Study

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Abstract

Background: Technology is already a part of our daily lives, and its influence is growing rapidly. This evolution has not spared the health care field. Nowadays, a crucial challenge is considering aspects such as design, development, and implementation, highlighting their functionality, ease of use, compatibility, performance, and safety when a new technological tool is developed. As noted in many works, the abandonment rate is usually higher when a user has a terrible experience with these instruments. It would be appropriate to incorporate the final users—whether they are patients, health care professionals, or both—in the stages of instrument design to understand their needs and preferences. Since most apps that fail did not include end users and health care professionals in the development phase, their involvement at all stages of app development may increase their commitment and improve integration, self-management, and health outcomes.

Objective: This study aims (1) to develop semAPP (spatial and episodic memory assessment application), a 360° media–based tool, to assess memory in aging by simulating a real-life situation and (2) to test the usability of the app and the connected experience in an end-user population.

Methods: A total of 34 older adults participated in the study: 16 (47%) healthy individuals and 18 (53%) patients with mild cognitive impairment. They used semAPP and completed qualitative and quantitative measures. The app includes 2 parts: object recognition and spatial memory tasks. During the first task, users have to navigate in an apartment freely and visit rooms, and then they must recognize the right map of the house. In the second task, users are immersed in a living room, and they have to encode and then recall some target objects, simulating a relocation. We deployed this app on an 11.2-inch iPad, and we tested its usability and the experience of users interacting with the app. We conducted descriptive analyses for both the entire sample and each subgroup; we also conducted parametric and correlation analyses to compare groups and to examine the relationship between task execution and the virtual experience, as well as the acceptance of technology.

Results: Both groups judged the app as an easy-to-use tool, and they were willing to use it. Moreover, the results match the idea that usability might be influenced by different factors depending on instrument and personal features, such as presentation, functionality, system performance, interactive behavior, attitudes, skills, and personality.

Conclusions: The findings support the possibility of using semAPP in older patients, as well as the importance of designing and evaluating new technological tools, considering not only the general population but also the specific target ones.

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KEYWORDS

assessment; virtual reality; 360-degree videos; user experience; memory; aging; psycho gerontology

Introduction

Technology integration into our daily lives has become increasingly prevalent and shows no signs of abating. The use of mobile devices and videoconferencing for interpersonal communication among family and friends, as well as the prevalence of programmable household appliances such as the microwave, dishwasher, coffee maker, and oven, serve as illustrative instances of the pervasive presence of technology in our everyday existence. Modern entertainment technology encompasses a variety of sophisticated devices, such as smart televisions equipped with multiple functions, digital video recorders, digital music players, and cameras, among others. These examples illustrate the diverse range of options available in the realm of contemporary entertainment technology. Hence, people are compelled to cultivate additional skills to interact with these technological advancements. Moreover, older people must acclimate themselves to the modifications imposed by the ongoing expansion of technology. One of the key concerns pertains to the provision of training for older individuals to enable them to engage with new technologies securely and proficiently [1]. On one hand, the advancements in technology present significant opportunities for older individuals to derive advantages from these novel innovations. However, many older people hesitate to use technology due to several obstacles, including a lack of assistance, unclear instructions, or a lack of confidence [2]. Generally, age-related problems (eg, the impairment of cognitive abilities), personal perception (eg, computer self-efficacy and anxiety related to the use of technology), and technology-related barriers (eg, interface usability) may influence the experience with technology [3,4]. Even so, the computer tablet is a widely adopted and user-friendly technological solution. The interface exhibits an easy-to-use nature and comparatively lower complexity than alternative interfaces, while also obviating the need for wired infrastructure. Consequently, an increasing number of researchers are using this instrument to provide health care interventions in aging [5]. However, this solution is not exempt from criticism. Vaportzis et al [2] identified several obstacles associated with the use of tablets. The barriers to technology adoption among older individuals include insufficient or overly complex instructions and guidance, limited knowledge or confidence in using devices, concerns about the potential risks associated with technology, health-related obstacles, and the high costs of devices. Additionally, older individuals tend to be slower in adapting to new technologies compared to younger individuals, resulting in lower technology use and less enthusiasm toward its adoption. Notably, the integration of technology into geriatric care is becoming increasingly important, particularly considering the impending shift toward technologically driven cognitive assessment tools.

Technological advancements offer the potential for more precise, efficient, and accessible cognitive assessment tools that can provide real-time data, remote monitoring, and personalized interventions. Traditional assessments are provided through paper-and-pencil tests or computerized tools; however, an open-ended question in the neuropsychological field regards the ecological validity of the employed measures, that is, how to measure cognitive functions reliably and validly [6]. Research suggests that assessment tools do not accurately reflect the demands of the everyday world in predicting cognitive functioning [6,7]. Due to their ability to produce realistic surroundings in a controlled and safe manner, 360° media may be the greatest approach to address this issue and enhance the accuracy of the neuropsychological assessment process [8-11]. In the same way as computer-generated virtual reality games and other interactive experiences are designed to be viewed through headsets, 360° videos and images, sometimes referred to as immersive videos or spherical media, may also be viewed on flat-screen devices like a smartphone or computer by dragging the viewpoint with a mouse or a finger, as well as more immersive devices. Live action in the real world is recorded using special cameras that capture the entire environment. Media are recorded thanks to omnidirectional lenses with a circular fisheye view of the surrounding environment, allowing us to get files of the complete environment. Moreover, they provide the possibility to capture different points of view: by placing the camera on the recorder’s head while a video is being made, the user can obtain a first-person perspective of the action. If not, the user can position the camera anywhere in the scene to view it from the perspective of an outsider (third-person perspective). Because 360° media show the full globe instead of just a small section of it, they are different from 2D videos. Technology and software elements that trick the user into believing they are surrounded by an alternate dimension can also be used to establish a sensation of presence using 360° media [12]. This technology offers several additional advantages including cost-effectiveness, ease of use compared to computer environments, and a user-friendly design [13]. The ability to modify the participant’s position in space and place in a realistic virtual environment also increases the ecological validity of the tests and promotes an embodied experience significantly [14].

Characteristics of 360° media could be attractive for memory testing, boosting the procedure’s precision. Memory plays a central role in various aspects of daily life, such as recalling important information, managing medications, and navigating familiar environments. For older adults, maintaining optimal memory function is essential to ensure their independence, safety, and quality of life. The efficacy or efficiency of processing measures typically show a linear decline with age in the cognitive profile of aging [15], and memory performance, attention, and executive functions are some of the abilities that decline over time [16], risking cognitive impairment when problems are significant. In particular, memory problems may be crucial in predicting the chance of acquiring dementia, such as Alzheimer disease [17,18]. However, the early indications of cognitive impairment are typically ignored because they are confused about the consequences of physiological aging. Thus, a prompt evaluation is the most effective way to ascertain the extent of the problems that distinguish pathological from healthy aging. To stop the progression and avoid disability, it is therefore essential to identify issues swiftly and effectively. Implementing timely neuropsychological evaluations and cutting-edge techniques, such as virtual reality–based approaches that demonstrate enhanced sensitivity for the early detection of cognitive deficits, may represent a promising option [19].

The examination of the challenges that older adults encounter when using technology is crucial to identifying the most efficacious approaches for introducing technology within the clinical domain, given its significant benefits and necessity in this context [20]. The elements that affect older people's adoption and use of technology must be identified to better understand and anticipate their technology use behavior. One of the most significant indicators of the adoption and use of technology is technology acceptance, which is the attitudinal perception and behavioral desire to use technology [21]. Several models or theories have been proposed to explain technology acceptance behavior; among these, Chen and Chan [21] developed the first theoretical model to predict older people's acceptance of everyday technology (ie, the senior technology acceptance model), considering individual attributes, gerontechnology self-efficacy, anxiety, health, and ability characteristics. Moreover, a crucial feature to provide an instrument usable and accepted by users is to design the tool based on the target population, to make sure that the scenario will meet the needs, concerns, and expectations listed by individuals. Thus, understanding and addressing the health care needs of older adults have become increasingly crucial. Among these needs, the evaluation of cognitive functions stands out as a fundamental aspect of comprehensive geriatric care. It is well recognized that including clinicians, user experience (UX) experts, and end users allows for the consideration of useful information targeted at creating a suitable interaction between the patient, the technology, and health care organizations [22]. Since most apps that fail did not include end users and health care professionals in the development phase, their involvement could increase their commitment and improve integration, self-management, and health results. However, when a new app is developed, most tests are improperly provided to a general population engaged in evaluating critical aspects, judging their experience, and predicting the adoption of the presented product.

Based on these considerations, we developed a new app to evaluate memory in aging: semAPP (spatial and episodic memory assessment application), testing the connected experience in a population typically characterized by memory problems: mild cognitive impairment (MCI). We compared their experience with that of the healthy population to expand our knowledge of older people's experience with technology. This study aims to present the UX of a 360° tool designed to assess memory in aging.

Methods

Recruitment

A total of 34 older adults (mean age 74.65, SD 7.64 years) were recruited at the Medical Rehabilitation Department of IRCCS (Istituto di Ricovero e Cura a Carattere Scientifico) Istituto Auxologico Italiano in Milan. Patients and outpatients aged 60 years and older from the clinical institution were selected for this study. During their hospitalizations, comprehensive information regarding the research was provided, and participation was entirely voluntary. Similarly, outpatients received the same information during routine clinical visits, allowing them to make an informed decision to participate in the experiment. The entire sample consisted of 15 (44%) male participants and 19 (56%) female participants. All participants were native Italian speakers and took part voluntarily in the study after signing an informed consent form. Based on an initial neuropsychological assessment, participants were divided into 2 groups: healthy participants (n=16, 47%) and patients with MCI (n=18, 53%). The inclusion criteria were (1) aged 60 years and older (without maximum age limitation) and (2) normal or corrected-to-normal vision. Exclusion criteria were (1) invalidating internist, psychiatric, and neurological conditions that could affect the performances and (2) cognitive impairments certifiable by a score lower than 24 points on the Mini-Mental State Examination, Italian version [23,24]. On the other hand, patients with MCI were identified based on self-reported (or reported by a caregiver) cognitive decline, an objective impairment on the neuropsychological testing, preservation in functional abilities, and no evidence of significant impairment in social or occupational functioning (ie, not demented) [17].

Ethical Considerations

The data collection has been conducted anonymously, according to the Regulation (EU) 2016/679 of the European Parliament and of the Council (General Data Protection Regulation). The study received ethical approval from the Ethical Committee of the IRCCS Istituto Auxologico Italiano (2022_01_25_04) and complies with the ethical principles set out in the Helsinki Declaration. No financial compensation was provided to the participants. All patients provided informed consent for the study and no financial compensation was provided.

semAPP

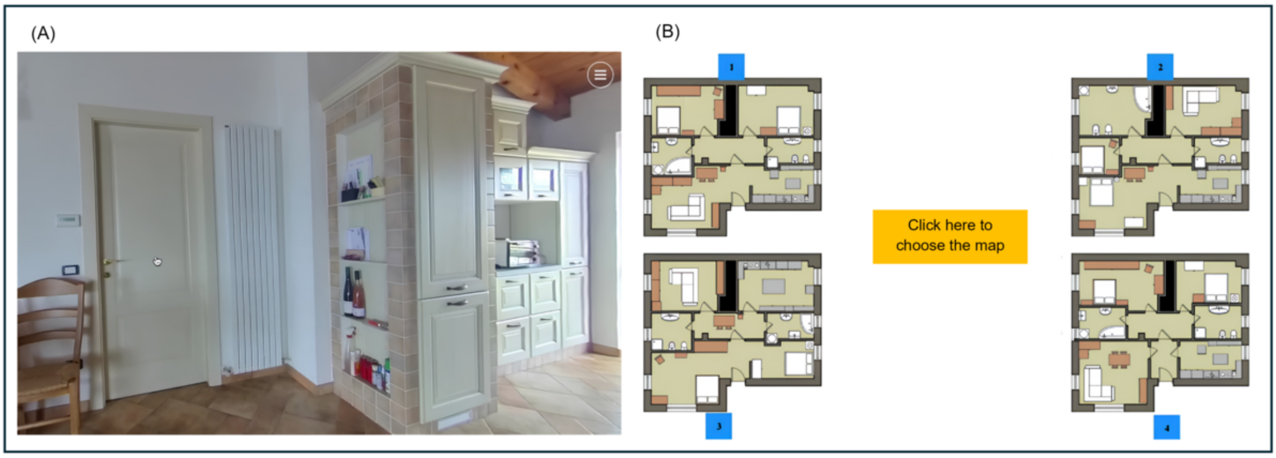
Overview

semAPP consists of 2 memory tasks created with 360° media aimed to assess memory by simulating a real-life situation. The 2 exercises are focused on episodic and spatial memory, respectively. Both are structured into 2 main phases: learning, in which the user has to memorize specific features, and recalling, in which what was learned in the first phase has to be used to answer new requests.

Spatial Memory Task

This task takes place in a virtual home, in which users have to freely explore the diverse rooms and then identify the right map of the apartment (in an allocentric way). The residence encompasses a kitchen area that incorporates a centrally positioned table, along with intricate elements such as appliances, shelves, and furnishings. The spatial configuration of the apartment encompasses the living room with a primary ingress and a portal that grants access to a passageway. The corridor is bordered by 6 doors, each leading to separate rooms, including the living room, 2 bedrooms, and 2 bathrooms. Participants were presented with the instructions to enter the apartment and examine the various rooms while considering their spatial arrangement within the dwelling. The task starts from the dining room and kitchen area. The participant is afforded the freedom to engage in interactions by clicking on the different doors to transition between rooms. Once the participants believe they have completed their exploration of all the rooms, the clinician instructs them to return to the main room to continue with the testing process. Upon activating the main entrance, a set of instructions appears, presenting 4 distinct maps depicting the layout of the previously explored domicile. The request is to look through the available options and identify the appropriate one throughout the maps displayed on the screen in an allocentric perspective (Figure 1). The score is defined by the correct or incorrect response of the participant.

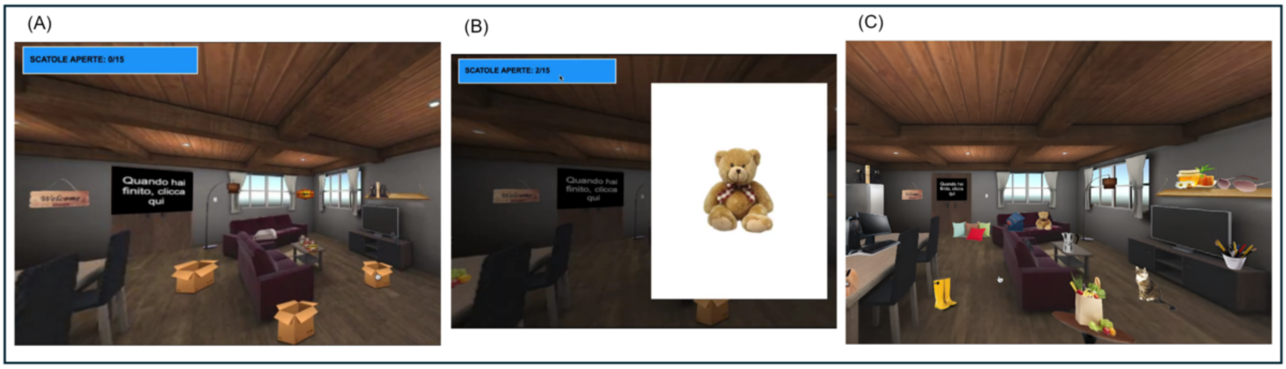
Figure 1. (A) The encoding phase: participants navigate in the 360° house by clicking on each door and (B) the retrieval phase: participants have to choose the right maps of the apartment.



Episodic Memory Tasks

This task is composed of a virtual house with several distinct areas. A total of 45 objects were generated to populate the virtual house and serve as either targets or distractors. Initially, 4 distinct semantic categories were identified: kitchen items, living room items, musical instruments, and home decor items. All the objects mentioned were tangible items that are typically encountered in residential dwellings. In the learning phase, the objective entailed the identification of 15 distinct entities enclosed within various boxes distributed in the house's environments, with each object being easily recognizable. To carry out the task, participants were provided with instructions to open each of the boxes and verbally identify the objects contained within. Specifically, they were instructed to imagine themselves entering Marco's new residence to aid him in relocating his stuff; this aspect was introduced to improve the ecological aspect. Among the 15 target objects, 15 distractors, which shared a semantic category with the target items, were strategically positioned in comparable locations. The task concluded upon the completion of opening all the boxes. At this point, it is advised that participants proceed to select the primary entrance of the house by clicking on the designated area, and a neutral gray environment is presented, accompanied by the following prompt: "Reflect upon the contents of the boxes that were previously opened and record any items that you remember." This phase is referred to as the free recall phase. Following a 10-minute interval, the recalling phase takes place and the user (revisiting Marco's residence) has to navigate the apartment and select objects that have been previously extracted from the boxes by tapping on them. Within the confines of the dwelling, one can observe the presence of various objects that are dispersed throughout the space. These objects are comprised of the contents of the boxes, as well as an additional set of 15 distractors that were initially introduced during the encoding phase and an additional set of new 15 objects, belonging to the same semantic categories as the distractors. Upon selecting an object, a luminous outline emerges, serving as a form of feedback for the user. Users can select and deselect objects. The task concludes when the participant indicates that they have chosen all the objects, selecting the primary entrance of the house by clicking on the designated area (Figure 2).

Figure 2. (A) The encoding phase: participants explore the 360° house and click on each box; (B) participants have to label the objects that appear; and (C) the retrieval phase: participants have to explore the previous environment and click only the objects they previously saw in the boxes.



The scoring considers the number of objects freely recalled and the number of objects recognized during the recall phase. These are divided into target objects, distractors that were displayed during the encoding phase, and the new set of distractors.

Before spatial and episodic tasks, participants underwent a familiarization phase in which they were introduced to the virtual devices within a simulated household setting. During this phase, participants were instructed to navigate through the virtual environment and adhere to the provided instructions. According to the instructions provided in the tablet version, users are instructed to swipe their fingers horizontally and vertically. This directive is used to establish the comprehensibility of the environment's navigability in a complete circle of 360°, as well as to indicate that the objects within said environment possess the capability of being interacted with through clicking. Moreover, participants are requested to select a door to move to a different room. This instruction serves to convey the concept of interactivity within the environment, emphasizing that the act of clicking on the doors enables the transition between rooms. This functionality is integral to the execution of the spatial memory task.

Each scene provided in the app allows users to look around while performing the tasks. At any time, the interaction is provided either through buttons superimposed on the video or through a specific user interface. Instructions are given to the user in the form of written text before the learning and recalling phases. In particular, the virtual environment refers to a tangible living space that has been captured through the use of the Insta360 One X 360° camera configuration.

SemAPP was developed thanks to a new ad hoc platform incorporating preexisting software capable of playing 360° media, in addition to JavaScript and HTML extensions. A group of clinicians and experts in UX participated in the development of the app. Tasks were chosen based on the most common issues in the literature regarding older people at risk of dementia [18,25]. Furthermore, we draw inspiration from numerous well-used tests to assess cognitive deficits in ecological settings [18] and adapt them to 360° technology.

UX Measures

Quantitative and qualitative measures were captured following and during the experience with the app. We use the System Usability Scale (SUS) [26,27], the Senior Technology Acceptance Model (STAM) [28], the Independent Television Commission Sense of Presence Inventory (ITC-SOPI) [29], and the Thinking Aloud Protocol (TAP) [30].

SUS is a self-report tool, introduced by Brooke [26], which provides a global measure of the usability of a system, based on the following criteria: effectiveness (the ability of users to complete tasks using the system, and the quality of the output of those tasks), efficiency (the level of resource consumed in performing tasks), and satisfaction (users' subjective reactions to using the system). The SUS is composed of 10 items, where the participants could indicate their degree of agreement through a 5-point Likert scale (from 1=strongly disagree to 5=strongly agree). SUS scores range from 0 to 100; the higher the score, the more the system reflects the criteria of effectiveness, efficiency, and satisfaction.

The STAM is a questionnaire that explores older people's acceptance of technology and age-related health characteristics. The questionnaire used in this study is a shorter 14-item version of the original one, which aimed to predict older people's multidimensional acceptance of everyday technology. In particular, the factors explored are attitude through technologies, perception of control, anxiety related to technologies, and general health status. For each area, participants must define their degree of agreement with some statements using a 10-point Likert scale ranging from 1=strongly disagree to 10=strongly agree. For each subscale the score ranges from 1 to 10; the higher the score more the results are satisfactory in terms of attitude, control, less anxiety, and health status.

The ITC-SOPI is a self-report scale that explores the individual's feelings during the experience. The questionnaire is structured in parts A and B, which respectively investigate the user's experience after and during the mediated environment. Participants must indicate their degree of agreement through a 5-point Likert scale (from 1=strongly disagree to 5=strongly agree). The specific factors explored through the 42 items of the questionnaire are the sense of physical space, engagement, ecological validity, and negative effects. Each subscale received a maximum score of 5; the higher the score, the better the result.

We use the TAP to investigate a wide range of mental processes and to analyze the cognitive problems people have with learning and using technology. The TAP is a qualitative instrument consisting of detailed observation and documentation of the users' interaction with the proposed system. During the interaction, participants were asked to comment out loud about their thoughts, doubts, and expectations related to the characteristics of the experience. The real-time evaluation is important because it avoids relevant information being lost if it is collected after the experiment [31,32].

Procedures

Participants took part in 2 different sessions, roughly 1.5 hours. The first one consists of a preliminary discussion with the user about the aim of the study, an informative consensus sign, gathering participant personal data (age, sex, and education) and their confidence with technology and electronic devices, and assessing their general cognitive state with a neuropsychological battery. Based on the results of the assessment phase, we assigned participants in one of the 2 experimental conditions: healthy individuals and patients with MCI. In the second phase, the UX measures were implemented. Participants were asked to accomplish the 2 tasks of semAPP in a randomized order. The only information given to participants was to read and follow the instructions on the screen. Experimenters provided more information when participants did not understand the instructions or if they had issues in using the device (according to the TAP). During the experiment, each issue related to the usability (observed by the experimenter or declared by the participant) of the app was reported on the protocol. After completing the tasks, the participants had to fill out questionnaires. We ran the app on an 11.2-inch iPad.

Statistical Analysis

The statistical analysis was conducted using jamovi (version 2.5; jamovi Project). A significance level of *P*<.05 was established for all tests. In the initial phase, we conducted descriptive analyses on demographic and usability data for both the entire sample and each subgroup, namely the healthy control (HC) and MCI groups. Subsequently, parametric analyses, specifically the independent 2-tailed *t* test (also known as the Student *t* test), were performed to compare groups. Subsequently, we performed correlation analyses using the parametric Pearson test to examine the relationship between the virtual task experience, as evaluated by the SUS, and the 4 scales of the ITC-SOPI questionnaire, as well as the measures of older individuals' acceptance of technology known as the STAM. We carefully considered the appropriateness of both parametric and nonparametric methods. To determine the most suitable approach, we initially conducted a graphical analysis of the data. Through this preliminary graphical examination, we observed that the data distribution closely approximates a normal distribution. Moreover, we performed the Shapiro-Wilk test to verify if our samples were from a normal distribution. This visual inspection and analysis suggested that the assumptions underlying parametric tests might be reasonable. Given these observations, we decided to proceed with parametric methods for comparing groups and correlation analyses. Parametric methods can be robust even with smaller samples if the data are approximately normally distributed. This allows us to take advantage of the greater statistical power offered by parametric tests.

Results

Starting with qualitative data, all participants had some difficulties in comprehending the instruction during the familiarization phase. Certain individuals encountered challenges when attempting to engage with the tablet, specifically regarding the execution of finger-dragging gestures on the screen. A substantial number of users encountered difficulties while attempting to execute the exercises due to the challenging nature of exploring the environment, necessitating the need for additional support. Tables 1 and 2 show detailed results of the TAP for the 2 groups.

Regarding the quantitative data, according to Bangor et al [27], the mean score of the SUS indicates that users perceived the app as having a good level of acceptability (mean 70.22, SD 16.46), as shown in Figure 3 [27]. There were no differences between groups.

The results of the STAM scale reveal that users have a positive attitudinal belief toward technology (mean 7.39, SD 2.16 out of 10), as well as a high level of control belief (mean 7.42, SD 2.06 out of 10). However, the MCI group presented a mean average score significantly higher than HC in both variables (*P*=.049 and *P*=.02, respectively). Users presented a medium level of anxiety related to technology (mean 5.81, SD 2.59 out of 10) and considered themselves in good health conditions (mean 7.78, SD 1.50 out of 10). As shown by the ITC-SOPI subscale investigating spatial presence, participants felt a generally low level of being there in the virtual environment (mean 2.82, SD 0.90 out of 5); they experienced a good level of engagement (mean 3.38, SD .64 out of 5) and naturalness of the environments (mean 3.58, SD 0.89 out of 5). Referring to the subscale of negative effects, all participants reported a low score of side effects (mean 1.57, SD 0.53 out of 5), indicating that the use of semAPP did not induce dizziness and cybersickness. Descriptive statistics for demographics and all UX questionnaires in the sample are shown in Table 3.

Moreover, we analyze the correlations between older adults' experience with the virtual assessment task, as measured by the SUS and the ITC-SOPI, and their attitudes and willingness to use the technology, as assessed by the STAM. The objective is to determine whether older adults who exhibit more favorable attitudes toward technology use also perceive the virtual assessment task as more usable and user-friendly (as indicated by SUS scores) and experience a greater sense of presence and immersion during the task (as indicated by ITC-SOPI scores). Considering the total sample, SUS positively correlated with the STAM perception of control (*r*=0.48; *P*=.004) and STAM health conditions (*r*=0.45; *P*=.008) scales: those who perceive the virtual assessment task to be more usable and user-friendly might also more likely to feel a sense of control over the technology they are utilizing and a more positive perception of their health. When we consider separately the 2 groups, the correlation between the SUS and STAM remains in the MCI group, but not in the HC group. Furthermore, there was a positive correlation observed between the ecological validity scale of the ITC-SOPI and the attitudinal beliefs (*r*=0.35; *P*=.04) and control beliefs (*r*=0.42; *P*=.02) subscales of the STAM . Additionally, a positive correlation was found between the STAM health conditions subscale and the engagement subscale of the ITC-SOPI (*r*=0.36; *P*=.04). The observed correlation suggests that individuals who obtained higher scores on the STAM health conditions subscale, which reflects their perception of their health and well-being, demonstrated a greater likelihood of experiencing heightened levels of engagement within the virtual environment. In other words, participants who possessed the belief that the utilization of technology had positive impacts on their well-being exhibited higher levels of immersion and engagement in the virtual experience. This is true when we consider the MCI group alone, not for the HC group. Correlations for the entire sample and each group are shown in Figures 4 and 5.

Table 1. Qualitative usability results of the Thinking Aloud Protocol in the HC[a] group (n=16).

Task	Problem	Solution	Participants, n (%)
Familiarization			
Reading the instructions	—[b]	—	—
Comprehension of the instructions	Difficulties in understanding the instructions concerning the direction of exploration	Clarify the instructions	15 (94)
Device interaction			
	Instructions do not appear in a functional position to read on the screen	Insert the instructions in the middle of the screen	2 (13)
	Difficulties with dragging the finger on the screen	Provide a previous tutorial on using the touchscreen	2 (13)
Execution	—	—	—
Task 1: figure recognition			
Reading the instructions	Unread instructions	Insert auditory instructions; provide a button to begin the exercise that appears after a few seconds	1 (6)
Comprehension of the instructions	Difficulties in understanding the instructions for selecting the items	Improve the quality of the instructions	1 (6)
Device interaction	—	—	—
Execution			
	Difficulties in exploring the environment	Insert a more functional hotspot; provide more precise instructions to complete the task	10 (63)
	Item selected after operator suggestion	Insert a more functional hotspot; provide more precise instructions to complete the task	2 (13)
	Difficulties in understanding how to finish the exercise during the Encoding phase	Insert a more functional hotspot; provide more precise instructions to complete the task	3 (19)
	Difficulties in selecting desired items during the Recognition phase	Improve the target's dimension; spacing the targets further apart; implement the quality of the video	1 (6)
Task 2: spatial memory task			
Reading the instructions	—	—	—
Comprehension of the instructions	Difficulties in understanding the instructions	Clarify the instructions	1 (6)
Device interaction	—	—	—
Execution			
	Difficulties in understanding how to finish the exercise	Insert more specific instructions; identify an ad hoc hotspot that indicates in a functional way how to exit	2 (13)
	Difficulties in selecting the hotspot to finish the exercise	Extend hotspots throughout the target	1 (6)
	Too many steps in the map selection process	Provide a lean selection process; delete unnecessary steps	5 (31)
	Difficulty in exploring the environment without operator support	Insert a more functional hotspot	2 (13)

[a] HC: healthy control.

[b] Not available.

Table 2. Qualitative usability results of the Thinking Aloud Protocol in the MCI[a] group (n=18).

Task	Problem	Solution	Participants, n (%)
Familiarization			
Reading the instructions	—[b]	—	—
Comprehension of the instructions	Difficulties in understanding the instruction concerning the direction of exploration	Clarify the instructions	12 (67)
Device interaction			
	Instructions do not appear in a functional position to read on the screen	Insert the instructions in the middle of the screen	1 (6)
	Difficulties with dragging the finger on the screen	Provide a previous tutorial on using the touchscreen	1 (6)
	Difficulties in clicking on the screen	Provide a previous tutorial on using the touchscreen	1 (6)
Execution			
	Difficulties in exploring the environment	Provide more specific or intuitive instructions to explore; provide a more functional hotspot	5 (28)
	Difficulties in finding the items	Provide more specific or intuitive instructions to explore; provide a more functional hotspot	2 (11)
	Difficulties in finding the hotspot to move forward to the next environment	Provide more specific or intuitive instructions to explore; provide a more functional hotspot	3 (17)
Task 1: figure recognition			
Reading the instructions	Unread instructions	Insert auditory instructions; provide a button to begin the exercise that appears after a few seconds	1 (6)
Comprehension of the instructions	Difficulties in understanding the instructions	Insert auditory instructions; provide a button to begin the exercise that appears after a few seconds	1 (6)
Device interaction	—	—	—
Execution			
	Difficulties in exploring the environment	Provide more specific or intuitive instructions to explore; provide a more functional hotspot	10 (56)
	Difficulties in selecting desired items during the recognition phase	Improve the target's dimension; spacing the targets further apart; implement the quality of the video	1 (6)
Task 2: spatial memory task			
Reading the instructions	—	—	—
Comprehension of the instructions	Difficulties in understanding the instructions	Insert auditory instructions; clarify the instructions	1 (6)
Device interaction	Difficulties in selecting the items to provide the answer	Insert a tutorial; improve the dimensions of the buttons	1 (6)
Execution			
	Difficulties to explore the environment without operator support	Implement the house exploration in a tutorial	6 (33)
	Too many steps in the map selection process	Provide a lean selection process; delete unnecessary steps	3 (17)

[a] MCI: mild cognitive impairment.

[b] Not available.

Figure 3. Graphical representation of the interpretation of SUS. The red vertical line indicates the mean score (70.22, SD 16.46), according to the rating comparison scale provided by Bangor et al. SUS: System Usability Scale.

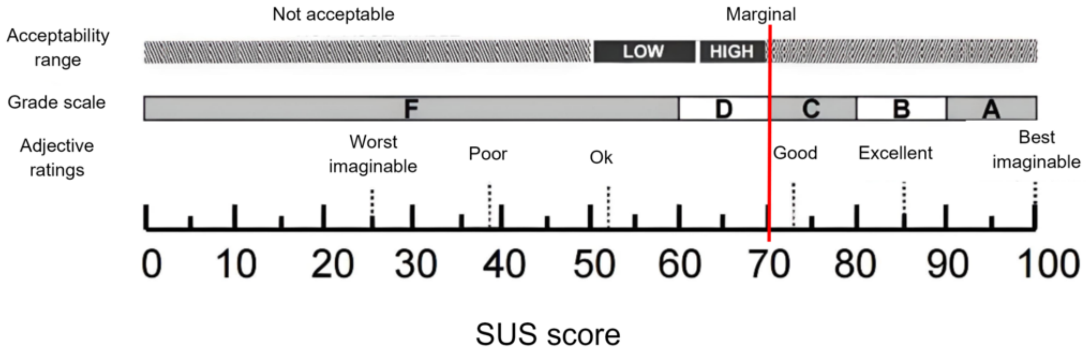


Table 3. Descriptive statistics for demographics and UX[a] questionnaires.

	Total sample (N=34), mean (SD)	MCI[b] (n=18), mean (SD)	HC[c] (n=16), mean (SD)	Student *t* test (*df*=32)	*P* value
Age (years)	74.65 (7.64)	73.44 (7.32)	76.00 (8.01)	0.972	.34
Education	13.62 (4.24)	13.33 (4.43)	13.94 (4.14)	0.409	.68
ADL[d]	5.82 (0.58)	5.94 (0.24)	5.69 (0.79)	–1.313	.20
MMSE[e]	27.07 (1.69)	27.31 (1.97)	26.80 (1.31)	–0.871	.39
SUS[f]	70.22 (16.46)	73.61 (16.32)	66.41 (16.29)	–1.286	.21
STAM-ab[g]	7.39 (2.16)	8.07 (1.36)	6.62 (2.65)	–2.051	.049[h]
STAM-cb[i]	7.42 (2.06)	8.18 (1.11)	6.57 (2.54)	–2.452	.02[h]
STAM-anx[j]	5.81 (2.59)	5.44 (2.58)	6.22 (2.61)	0.868	.39
STAM-h[k]	7.58 (1.50)	7.90 (0.99)	7.22 (1.88)	–1.328	.19
ITC-sp[l]	2.82 (0.90)	2.71 (0.86)	2.94 (0.96)	0.752	.46
ITC-e[m]	3.38 (0.64)	3.31 (0.58)	3.46 (0.71)	0.682	.50
ITC-ev[n]	3.58 (0.89)	3.61 (0.79)	3.54 (1.02)	–0.243	.81
ITC-ne[o]	1.57 (0.53)	1.46 (0.481)	1.69 (0.58)	1.268	.21

[a] UX: user experience.

[b] MCI: mild cognitive impairment.

[c] HC: healthy control.

[d] ADL: activity of daily life.

[e] MMSE: Mini-Mental State Examination.

[f] SUS: System Usability Scale.

[g] STAM-ab: Senior Technology Acceptance Model attitude through technologies subscale.

[h] Significant group difference between HC and MCI.

[i] STAM-cb: Senior Technology Acceptance Model perception of control subscale.

[j] STAM-anx: Senior Technology Acceptance Model anxiety related to technologies subscale.

[k] STAM-h: Senior Technology Acceptance Model health conditions subscale.

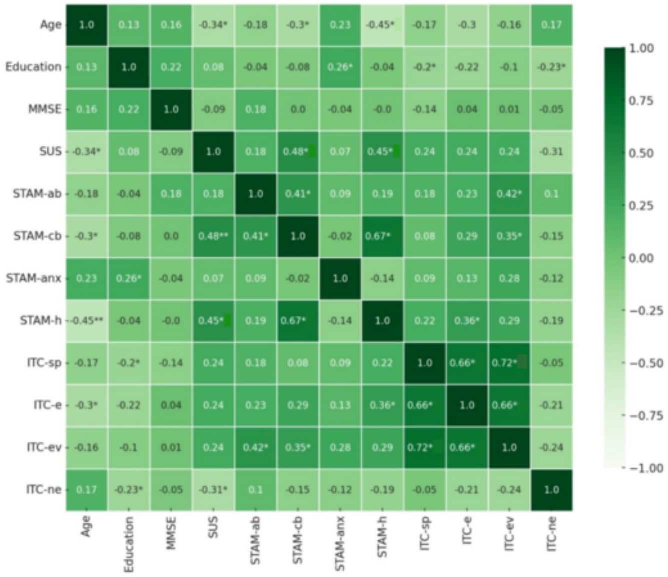
[l] ITC-sp: International Test Commission–Sense of Presence Inventory spatial presence subscale.

[m] ITC-e: International Test Commission–Sense of Presence Inventory engagement subscale.

[n] ITC-ev: International Test Commission–Sense of Presence Inventory ecological validity subscale.

[o] ITC-ne: International Test Commission–Sense of Presence Inventory negative effects subscale.

Figure 4. Graphical representation of the correlation matrix of the total sample. ITC-e: International Test Commission–Sense of Presence Inventory engagement subscale; ITC-ev: International Test Commission–Sense of Presence Inventory ecological validity subscale; ITC-ne: International Test Commission–Sense of Presence Inventory negative effects subscale; ITC-sp: International Test Commission–Sense of Presence Inventory spatial presence subscale; MMSE: Mini-Mental State Examination; STAM-ab: senior technology acceptance model attitude through technologies subscale; STAM-anx: senior technology acceptance model anxiety related to technologies subscale; STAM-cb: senior technology acceptance model perception of control subscale; STAM-h: senior technology acceptance model health conditions subscale; SUS: System Usability Scale.

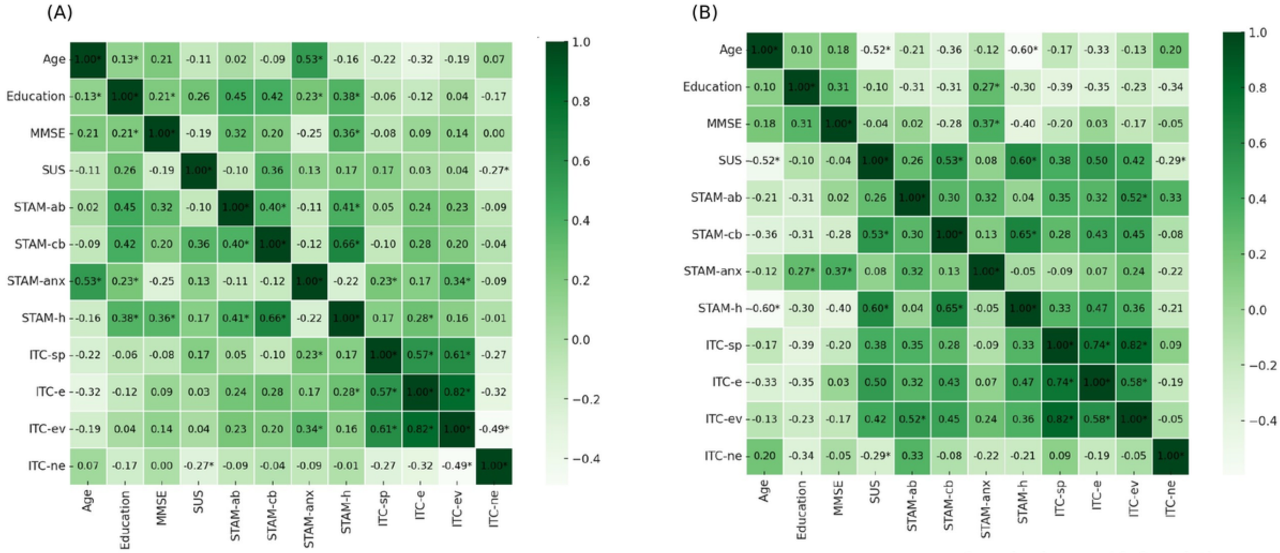


	Age	Education	MMSE	SUS	STAM-ab	STAM-cb	STAM-anx	STAM-h	ITC-sp	ITC-e	ITC-ev	ITC-ne
Age	1.0	0.13	0.16	-0.34*	-0.18	-0.3*	0.23	-0.45*	-0.17	-0.3	-0.16	0.17
Education	0.13	1.0	0.22	0.08	-0.04	-0.08	0.26*	-0.04	-0.2*	-0.22	-0.1	-0.23*
MMSE	0.16	0.22	1.0	-0.09	0.18	0.0	-0.04	-0.0	-0.14	0.04	0.01	-0.05
SUS	-0.34*	0.08	-0.09	1.0	0.18	0.48*	0.07	0.45*	0.24	0.24	0.24	-0.31
STAM-ab	-0.18	-0.04	0.18	0.18	1.0	0.41*	0.09	0.19	0.18	0.23	0.42*	0.1
STAM-cb	-0.3*	-0.08	0.0	0.48**	0.41*	1.0	-0.02	0.67*	0.08	0.29	0.35*	-0.15
STAM-anx	0.23	0.26*	-0.04	0.07	0.09	-0.02	1.0	-0.14	0.09	0.13	0.28	-0.12
STAM-h	-0.45**	-0.04	-0.0	0.45*	0.19	0.67*	-0.14	1.0	0.22	0.36*	0.29	-0.19
ITC-sp	-0.17	-0.2*	-0.14	0.24	0.18	0.08	0.09	0.22	1.0	0.66*	0.72*	-0.05
ITC-e	-0.3*	-0.22	0.04	0.24	0.23	0.29	0.13	0.36*	0.66*	1.0	0.66*	-0.21
ITC-ev	-0.16	-0.1	0.01	0.24	0.42*	0.35*	0.28	0.29	0.72*	0.66*	1.0	-0.24
ITC-ne	0.17	-0.23*	-0.05	-0.31*	0.1	-0.15	-0.12	-0.19	-0.05	-0.21	-0.24	1.0

Sample sizes: n=35. Correlation : Pearson

*=p<.05

Figure 5. (A) The graphical representation of the correlation matrix of the HC group and (B) the graphical representation of the correlation matrix of the patients with MCI. HC: healthy control; ITC-e: International Test Commission–Sense of Presence Inventory engagement subscale; ITC-ev: International Test Commission–Sense of Presence Inventory ecological validity subscale; ITC-ne: International Test Commission–Sense of Presence Inventory negative effects subscale; ITC-sp: International Test Commission–Sense of Presence Inventory spatial presence subscale; MCI: mild cognitive impairment; MMSE: Mini-Mental State Examination; STAM-ab: senior technology acceptance model attitude through technologies subscale; STAM-anx: senior technology acceptance model anxiety related to technologies subscale; STAM-cb: senior technology acceptance model perception of control subscale; STAM-h: senior technology acceptance model health conditions subscale; SUS: System Usability Scale.



(A)

	Age	Education	MMSE	SUS	STAM-ab	STAM-cb	STAM-anx	STAM-h	ITC-sp	ITC-e	ITC-ev	ITC-ne
Age	1.00*	0.13*	0.21	-0.11	0.02	-0.09	0.53*	-0.16	-0.22	-0.32	-0.19	0.07
Education	0.13*	1.00*	0.21*	0.26	0.45	0.42	0.23*	0.38*	-0.06	-0.12	0.04	-0.17
MMSE	0.21	0.21*	1.00*	-0.19	0.32	0.20	-0.25	0.36*	-0.08	0.09	0.14	0.00
SUS	-0.11	0.26	-0.19	1.00*	-0.10	0.36	0.13	0.17	0.17	0.03	0.04	-0.27*
STAM-ab	0.02	0.45	0.32	-0.10	1.00*	0.40*	-0.11	0.41*	0.05	0.24	0.23	-0.09
STAM-cb	-0.09	0.42	0.20	0.36	0.40*	1.00*	-0.12	0.66*	-0.10	0.28	0.20	-0.04
STAM-anx	0.53*	0.23*	-0.25	0.13	-0.11	-0.12	1.00*	-0.22	0.23*	0.17	0.34*	-0.09
STAM-h	-0.16	0.38*	0.36*	0.17	0.41*	0.66*	-0.22	1.00*	0.17	0.28*	0.16	-0.01
ITC-sp	-0.22	-0.06	-0.08	0.17	0.05	-0.10	0.23*	0.17	1.00*	0.57*	0.61*	-0.27
ITC-e	-0.32	-0.12	0.09	0.03	0.24	0.28	0.17	0.28*	0.57*	1.00*	0.82*	-0.32
ITC-ev	-0.19	0.04	0.14	0.04	0.23	0.20	0.34*	0.16	0.61*	0.82*	1.00*	-0.49*
ITC-ne	0.07	-0.17	0.00	-0.27*	-0.09	-0.04	-0.09	-0.01	-0.27	-0.32	-0.49*	1.00*

Sample sizes: n=18. **Correlation**: Pearson

*=p<.05

(B)

	Age	Education	MMSE	SUS	STAM-ab	STAM-cb	STAM-anx	STAM-h	ITC-sp	ITC-e	ITC-ev	ITC-ne
Age	1.00*	0.10	0.18	-0.52*	-0.21	-0.36	-0.12	-0.60*	-0.17	-0.33	-0.13	0.20
Education	0.10	1.00*	0.31	-0.10	-0.31	-0.31	0.27*	-0.30	-0.39	-0.35	-0.23	-0.34
MMSE	0.18	0.31	1.00*	-0.04	0.02	-0.28	0.37*	-0.40	-0.20	0.03	-0.17	-0.05
SUS	−0.52*	-0.10	-0.04	1.00*	0.26	0.53*	0.08	0.60*	0.38	0.50	0.42	-0.29*
STAM-ab	-0.21	-0.31	0.02	0.26	1.00*	0.30	0.32	0.04	0.35	0.32	0.52*	0.33
STAM-cb	-0.36	-0.31	-0.28	0.53*	0.30	1.00*	0.13	0.65*	0.28	0.43	0.45	-0.08
STAM-anx	-0.12	0.27*	0.37*	0.08	0.32	0.13	1.00*	-0.05	-0.09	0.07	0.24	-0.22
STAM-h	−0.60*	-0.30	-0.40	0.60*	0.04	0.65*	-0.05	1.00*	0.33	0.47	0.36	-0.21
ITC-sp	-0.17	-0.39	-0.20	0.38	0.35	0.28	-0.09	0.33	1.00*	0.74*	0.82*	0.09
ITC-e	-0.33	-0.35	0.03	0.50	0.32	0.43	0.07	0.47	0.74*	1.00*	0.58*	-0.19
ITC-ev	-0.13	-0.23	-0.17	0.42	0.52*	0.45	0.24	0.36	0.82*	0.58*	1.00*	-0.05
ITC-ne	0.20	-0.34	-0.05	-0.29*	0.33	-0.08	-0.22	-0.21	0.09	-0.19	-0.05	1.00*

Sample sizes: n=16. **Correlation**: Pearson

*=p<.05

Discussion

Principal Findings

It is necessary to measure cognitive processes in a way that is similar to what happens in real life to provide functional feedback that accurately reflects the patient’s capacity to respond to daily problems. In this study, a novel tablet-based app with 360° media has been developed to solve the issue of the ecological validity of the currently available test, which used abstract settings. With the increasing scientific discussions supporting the use of new technologies in neuropsychological assessment [33], semAPP was developed using 360° content to simulate real-world circumstances.

The idea behind this app was inspired by the evidence that virtual environments, recreating real situations, might enhance the engagement and pleasure of users, as well as measuring ability that reflects what happens in daily life. As cognitive evaluation increasingly relies on immersive technology, it is crucial to develop user-friendly programs that enable academics, physicians, and patients without engineering skills to access cognitive activities. Attention in their design and execution is a critical issue if one wishes to ensure task reliability and validity. Thus, the final users' experience is an essential element in designing instruments that reflect population needs and expectations. On these bases, a team of experts took part in the design of the app, and the prototype was tested on a group of final users. Our data promise to provide an app usable and accepted by users. SemAPP was judged as an easy-to-use tool for all participants who could interact with it independently under the supervision of clinicians; users evaluated semAPP to be usable and they were willing to use it. They were satisfied and expressed interest in using it. The users were fascinated by using the tablet to explore the virtual environment and enjoyed performing exercises in this innovative way. They were also able to accomplish all expected goals without learning a lot of processes or complex actions; they were at ease using the device because they were familiar with it, and many of them claimed to do so frequently. This is in line with the core features of satisfaction, effectiveness, and efficiency used to define usability [26]. Moreover, users who perceived the virtual assessment task to be more usable and user-friendly have also a positive perception of health and a sense of being able to use apps successfully and effortlessly. Our results are independent of groups; this is promising for the future use of semAPP, which is in line with the needs and expectations of a healthy and aging population with MCI. Thus, it could be used effectively and efficiently by different pools of people.

The results derived from the users' ideas about technology show that all users have a positive appraisal of using technology and they believe that using it would be beneficial for their quality of life. They also believe that using the proposed technology might be free of effort and feel a sense of being able to use it successfully. Contrary to our expectations, these features are significantly higher in the MCI group. The results could be explained by the clinical condition. Patients with MCI are conscious of their deficits, and they could be more engaged in having positive feelings with the app to improve their abilities [34]. All users experience a sense of apprehension when they are faced with the possibility of using technology, for example, due to the fear of making some mistake; this is common in aging [35]. Additionally, older people feel themselves in a good health condition related to biological, psychological, and social capabilities, which decrease with aging (ie, as age increases, there is a decrease in the perception of good health) [35].

Investigating the experience with the virtual scenes, participants reported that the app offered them a sense of engagement and the natural environment, as shown by the ITC-SOPI. However, they detected a generally low level of being in the virtual environment, which may be attributed to the low degree of immersion offered by the tablet. We chose the tablet because it can be used more quickly and easily than other tools for reproducing 360° media, even without the guidance of a therapist or caregiver. However, the media were deployed on a flat screen in a less ecological situation than a head-mounted display, for example. This feature may influence the feeling of immersion [14]. On the other hand, side effects and cybersickness were minimal.

Our findings also support literature that suggests that engagement and a sense of ecological validity improve when users have expectations of positive feelings in using technology, potentially beneficial effects for quality of life, no effortlessness, and a sense of being able to use technology successfully [36,37]. In other words, users' ideas are closely related to how they encounter and evaluate experiences, reflecting anticipated behavior, direct attention, and interpretation, influencing the perceptions of the product [38]. Likewise, older adults who believed that the use of technology had positive impacts on their well-being exhibited higher levels of immersion and engagement in the virtual experience. These results reinforce how a greater likelihood of experiencing heightened levels of engagement within the virtual environment is linked to personal expectations.

Some technical and interface problems were brought up by the TAP during the study, and it is possible that these issues could be resolved by making the instructions clearer and adding the possibility of hearing them. To solve the issues related to interacting with the tablet, we could add a specific training phase focused on the technical use of the device. Thanks to these upgrades, the app should be easier to use.

Nevertheless, while several virtual reality instruments exist to assess memory, only a limited number leverage the unique advantages of 360° media, using computer-generated scenarios [39]. Additionally, some of these tools are delivered using sophisticated solutions, such as head-mounted displays, which can present significant barriers to adoption among elderly individuals [11,40]. Older adults often hesitate to use such advanced technology due to various perceived obstacles [2]. In contrast, semAPP is a highly customizable app designed to be delivered through a range of devices, from smartphones to head-mounted displays. This flexibility offers a more accessible and user-friendly solution that accommodates the varying technological comfort levels of older adults, striking a balance between environmental control and realism.

Given the promising data and the potential of semAPP, further research is essential to fully integrate the app into existing health care frameworks. Integrating our app into these systems would streamline the collection and accessibility of data, enhancing the overall efficiency of cognitive assessments. Additionally, by facilitating remote evaluations through telemedicine, semAPP can become a usable and valuable tool for managing and monitoring cognitive health in aging populations.

Limitations

This work is not exempt from limitations. The market for 360° devices currently offers a few benefits that might give the measurements obtained a higher ecological worth. However, because of the lack of active navigation and the restricted opportunity for engagement within the surroundings, the low degree of immersion that 360° media distributed with tablet exhibits represents one of their most significant drawbacks. In the given context, this can be detrimental in terms of involvement and emotions of naturalness. However, for older people who lacked the necessary abilities to work with more sophisticated technologies, the absence of these characteristics might have been seen as a benefit rather than a limitation.

Despite the widespread adoption and user-friendly nature of tablets as a technological solution, potential biases and variances may arise due to differing levels of familiarity and comfort with technology among participants. While many participants reported frequent tablet use and demonstrated familiarity with the device, they might initially encounter challenges with the 360° media, which possesses distinct characteristics compared to traditional media. These challenges could indicate that differences in technological familiarity can introduce biases and variances in the data, potentially affecting the validity of the findings. Although the participants were able to accomplish all expected goals, we will incorporate a familiarization phase before the test to mitigate these limitations. This phase is designed to acclimate participants to the specific media, ensuring they have sufficient exposure and comfort with the new media format, thereby standardizing their level of comfort and familiarity.

Taking our sample size into account is essential. Based on prior research that used a small number of participants to measure usability [41], as also highlighted by Virzi [42], we chose to use a small number of users. Most usability issues, according to the researchers, are discovered in 4 to 5 individuals, who are progressively less likely to divulge fresh information. We chose 34 users to represent a range of demographics, technical proficiency, and technology knowledge; yet many of them noted the same usability issue at the TAP.

Finally, the heavy reliance on self-reported data may introduce subjective biases. Implementing additional objective measures, while beneficial, is challenging with an older adult population and limits capturing UX in a manner that is both simple and well-accepted. Nonetheless, future research should consider integrating objective measures to complement self-reported data providing a more comprehensive assessment.

Even with its limitations, these findings support the usability of 360° assessment, implementing the objective evaluation of ecological situations. However, additional work will be implemented to improve the problems revealed by the TAP and to explore the validity of the instrument.

Conclusions

We developed a new 360° tool to assess memory in aging, and we explored its usability and the correlated experience in using it. We focused on 2 different populations: healthy older adults and patients with MCI, to examine possible differences in terms of usability and, thus, to verify if our app was designed to be used by both target user groups excellently. Our results were satisfactory, showing the achievement of goals relating to the possibility of using the app by the target sample, with a positive experience.

Our research also supports the importance of a user-centered approach that adapts the app to the target population, analyzing the needs and clinical conditions of older people. To achieve this goal, we require a team of clinicians who have clinical competencies and UX experts. They designed an app focused on the clinical features of patients, in line with the major requirement to create the best possible experience in terms of usability and accessibility of the app. Our findings support the idea that users' thoughts about technology might influence how the product is seen, as well as the experience in the virtual environments (ie, the engagement and sense of being there). Given the complexity of human experiences, the usability and effective use of an instrument potentially depends on a great variety of parameters. The experience presupposes that all personal and technological factors are connected, interact, and change one another and the experience is what comes out of this process [36]. In this panorama, evaluating the product while considering end users could be crucial. Researchers must be aware that, depending on the personal experience and clinical condition at hand, users can have different experiences with the same product [43]. Indeed, if we do not consider the end user's experience, there may be a potential mismatch between the designers' intentions and users' actual anticipation.

Acknowledgments

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Authors' Contributions

FB conceived the study and discussed it with all the authors. FB and VM were involved in protocol development, gaining ethical approval, and data analysis. VM developed the used app. FB wrote the first draft of the manuscript. JP was involved in patient recruitment and contributed to writing the first version of the draft. MSB contributed to the reviewed version of the manuscript and the supervision of the data collection. PC and EP have supervised the study. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

Conflicts of Interest

None declared.

References

1. Hickman JM, Rogers WA, Fisk AD. Training older adults to use new technology. J Gerontol B Psychol Sci Soc Sci 2007;62(1):77-84 [FREE Full text] [doi: 10.1093/geronb/62.special_issue_1.77] [Medline: 17565168]
2. Vaportzis E, Clausen MG, Gow A. Older adults perceptions of technology and barriers to interacting with tablet computers: a focus group study. Front Psychol 2017;8:1687 [FREE Full text] [doi: 10.3389/fpsyg.2017.01687] [Medline: 29071004]
3. Alvseike H, Brønnick K. Feasibility of the iPad as a hub for smart house technology in the elderly; effects of cognition, self-efficacy, and technology experience. J Multidisciplinary Healthc 2012:299. [doi: 10.2147/jmdh.s35344] [Medline: 23226024]
4. Czaja SJ, Charness N, Fisk AD, Hertzog C, Nair SN, Rogers WA, et al. Factors predicting the use of technology: findings from the Center for Research and Education on Aging and Technology Enhancement (CREATE). Psychol Aging 2006;21(2):333-352 [FREE Full text] [doi: 10.1037/0882-7974.21.2.333] [Medline: 16768579]
5. Dasgupta D, Chaudhry B, Koh E, Chawla NV. A survey of tablet applications for promoting successful aging in older adults. IEEE Access 2016;4:9005-9017. [doi: 10.1109/ACCESS.2016.2632818]
6. Chaytor N, Schmitter-Edgecombe M. The ecological validity of neuropsychological tests: a review of the literature on everyday cognitive skills. Neuropsychol Rev 2003;13(4):181-197. [doi: 10.1023/b:nerv.0000009483.91468.fb] [Medline: 15000225]
7. Matheis RJ, Schultheis MT, Tiersky LA, DeLuca J, Millis SR, Rizzo A. Is learning and memory different in a virtual environment? Clin Neuropsychol 2007;21(1):146-161. [doi: 10.1080/13854040601100668] [Medline: 17366282]
8. Cavedoni S, Chirico A, Pedroli E, Cipresso P, Riva G. Digital biomarkers for the early detection of mild cognitive impairment: artificial intelligence meets virtual reality. Front Hum Neurosci 2020;14:245. [doi: 10.3389/fnhum.2020.00245] [Medline: 32848660]
9. Negu A, Matu S, Sava FA, David D. Virtual reality measures in neuropsychological assessment: a meta-analytic review. Clin Neuropsychol 2016;30(2):165-184. [doi: 10.1080/13854046.2016.1144793] [Medline: 26923937]
10. Realdon O, Serino S, Savazzi F, Rossetto F, Cipresso P, Parsons TD, et al. An ecological measure to screen executive functioning in MS: the picture interpretation test (PIT) 360°. Sci Rep 2019;9(1):5690 [FREE Full text] [doi: 10.1038/s41598-019-42201-1] [Medline: 30952936]
11. Bruni F, Mancuso V, Stramba-Badiale C, Greci L, Cavallo M, Borghesi F, et al. ObReco-2: two-step validation of a tool to assess memory deficits using 360° videos. Front Aging Neurosci 2022;14:875748 [FREE Full text] [doi: 10.3389/fnagi.2022.875748] [Medline: 35966782]
12. Borghesi F, Mancuso V, Pedroli ECP. From virtual reality to 360° videos: upgrade or downgrade? The multidimensional healthcare VR technology. In: Ugliotti FM, Osella A, editors. Handbook of Research on Implementing Digital Reality and Interactive Technologies to Achieve Society 5.0. Hershey, PA: IGI Global; 2022.
13. Bohil CJ, Alicea B, Biocca FA. Virtual reality in neuroscience research and therapy. Nat Rev Neurosci 2011;12(12):752-762. [doi: 10.1038/nrn3122] [Medline: 22048061]
14. Riva G, Wiederhold BK, Mantovani F. Neuroscience of virtual reality: from virtual exposure to embodied medicine. Cyberpsychol Behav Soc Netw 2019;22(1):82-96 [FREE Full text] [doi: 10.1089/cyber.2017.29099.gri] [Medline: 30183347]
15. Salthouse TA. Selective review of cognitive aging. J Int Neuropsychol Soc 2010;16(5):754-760. [doi: 10.1017/s1355617710000706] [Medline: 20673381]
16. Delrieu J, Andrieu S, Pahor M, Cantet C, Cesari M, Ousset P, et al. Neuropsychological profile of "cognitive frailty" subjects in MAPT study. J Prev Alzheimers Dis 2016;3(3):151-159 [FREE Full text] [doi: 10.14283/jpad.2016.94] [Medline: 27547746]
17. Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox NC, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 2011;7(3):270-290 [FREE Full text] [doi: 10.1016/j.jalz.2011.03.008] [Medline: 21514249]
18. Serino S, Cipresso P, Morganti F, Riva G. The role of egocentric and allocentric abilities in Alzheimer's disease: a systematic review. Ageing Res Rev 2014;16:32-44. [doi: 10.1016/j.arr.2014.04.004] [Medline: 24943907]
19. Cipresso P, Albani G, Serino S, Pedroli E, Pallavicini F, Mauro A, et al. Virtual multiple errands test (VMET): a virtual reality-based tool to detect early executive functions deficit in Parkinson's disease. Front Behav Neurosci 2014;8:405 [FREE Full text] [doi: 10.3389/fnbeh.2014.00405] [Medline: 25538578]
20. Chan MY, Haber S, Drew LM, Park DC. Training older adults to use tablet computers: Does it enhance cognitive function? Gerontologist 2016;56(3):475-484 [FREE Full text] [doi: 10.1093/geront/gnu057] [Medline: 24928557]
21. Chen K, Chan AHS. Gerontechnology acceptance by elderly Hong Kong Chinese: a senior technology acceptance model (STAM). Ergonomics 2014;57(5):635-652. [doi: 10.1080/00140139.2014.895855] [Medline: 24655221]
22. Molina-Recio G, Molina-Luque R, Jiménez-García AM, Ventura-Puertos PE, Hernández-Reyes A, Romero-Saldaña M. Proposal for the user-centered design approach for health apps based on successful experiences: integrative review. JMIR Mhealth Uhealth 2020;8(4):e14376 [FREE Full text] [doi: 10.2196/14376] [Medline: 32319965]
23. Measso G, Cavarzeran F, Zappalà G, Lebowitz BD, Crook TH, Pirozzolo FJ, et al. The Mini-Mental State Examination: normative study of an Italian random sample. Dev Neuropsychol 1993;9(2):77-85. [doi: 10.1080/87565649109540545]

24. Magni E, Binetti G, Bianchetti A, Rozzini R, Trabucchi M. Mini-Mental State Examination: a normative study in Italian elderly population. Eur J Neurol 1996;3(3):198-202. [doi: 10.1111/j.1468-1331.1996.tb00423.x] [Medline: 21284770]
25. Silverberg NB, Ryan LM, Carrillo MC, Sperling R, Petersen RC, Posner HB, et al. Assessment of cognition in early dementia. Alzheimers Dement 2011;7(3):e60-e76 [FREE Full text] [doi: 10.1016/j.jalz.2011.05.001] [Medline: 23559893]
26. Brooke J. SUS: a 'quick and dirty' usability scale. In: Jordan PW, Thomas B, McClelland IL, Weerdmeester B, editors. Usability Evaluation in Industry. London, United Kingdom: CRC Press; 1996.
27. Bangor A, Kortum P, Miller J. Determining what individual SUS scores mean: adding an adjective rating scale. J usability Stud 2009;4(3):114-123 [FREE Full text]
28. Chen K, Lou VWQ. Measuring senior technology acceptance: development of a brief, 14-item scale. Innov Aging 2020;4(3):igaa016 [FREE Full text] [doi: 10.1093/geroni/igaa016] [Medline: 32617418]
29. Lessiter J, Freeman J, Keogh E, Davidoff J. A cross-media presence questionnaire: the ITC-Sense of Presence Inventory. Presence Teleoperators Virtual Environ 2001;10(3):282-297. [doi: 10.1162/105474601300343612]
30. Lewis C. Using the "Thinking-Aloud" Method in Cognitive Interface Design. New York, NY: IBM T. J. Watson Research Center; 1982.
31. Kujala S, Vogel M, Pohlmeyer AE, Obrist M. Lost in time: the meaning of temporal aspects in user experience. 2013 Presented at: Conference on Human Factors in Computing Systems; April 27, 2013; New Orleans, LA p. 559-564.
32. Minge M. Dynamics of user experience. 2008 Presented at: NordiCHI08: 5th Nordic Conference on Human-Computer Interaction; October 20-22, 2008; Lund, Sweden p. 2-6 URL: https://www.researchgate.net/publication/228982807_Dynamics_of_User_Experience
33. Parsey CM, Schmitter-Edgecombe M. Applications of technology in neuropsychological assessment. Clin Neuropsychol 2013;27(8):1328-1361 [FREE Full text] [doi: 10.1080/13854046.2013.834971] [Medline: 24041037]
34. D'Cunha NM, Nguyen D, Naumovski N, McKune A, Kellett J, Georgousopoulou E, et al. A mini-review of virtual reality-based interventions to promote well-being for people living with dementia and mild cognitive impairment. Gerontology 2019;65(4):430-440 [FREE Full text] [doi: 10.1159/000500040] [Medline: 31108489]
35. Henchoz K, Cavalli S, Girardin M. Health perception and health status in advanced old age: a paradox of association. J Aging Stud 2008;22(3):282-290. [doi: 10.1016/j.jaging.2007.03.002]
36. Hassenzahl M, Tractinsky N. User experience—a research agenda. Behav Inf Technol 2006;25(2):91-97. [doi: 10.1080/01449290500330331]
37. Tuena C, Pedroli E, Trimarchi PD, Gallucci A, Chiappini M, Goulene K, et al. Usability issues of clinical and research applications of virtual reality in older people: a systematic review. Front Hum Neurosci 2020;14:93 [FREE Full text] [doi: 10.3389/fnhum.2020.00093] [Medline: 32322194]
38. Kaasinen E, Kymäläinen T, Niemelä M, Olsson T, Kanerva M, Ikonen V. A user-centric view of intelligent environments: user expectations, user experience and user role in building intelligent environments. Computers 2012;2(1):1-33. [doi: 10.3390/computers2010001]
39. Mancuso V, Sarcinella ED, Bruni F, Arlati S, Di Santo SG, Cavallo M, et al. Systematic review of memory assessment in virtual reality: evaluating convergent and divergent validity with traditional neuropsychological measures. Front Hum Neurosci 2024;18:1380575 [FREE Full text] [doi: 10.3389/fnhum.2024.1380575] [Medline: 38818031]
40. da Costa RQM, Pompeu JE, Moretto E, Silva JM, dos Santos MD, Nitrini R, et al. Two immersive virtual reality tasks for the assessment of spatial orientation in older adults with and without cognitive impairment: concurrent validity, group comparison, and accuracy results. J Int Neuropsychol Soc 2021;28(5):460-472. [doi: 10.1017/s1355617721000655]
41. Guillén-Climent S, Garzo A, Muñoz-Alcaraz MN, Casado-Adam P, Arcas-Ruiz-Ruano J, Mejías-Ruiz M, et al. A usability study in patients with stroke using MERLIN, a robotic system based on serious games for upper limb rehabilitation in the home setting. J Neuroeng Rehabil 2021;18(1):41 [FREE Full text] [doi: 10.1186/s12984-021-00837-z] [Medline: 33622344]
42. Virzi RA. Refining the test phase of usability evaluation: how many subjects Is enough? Hum Factors 1992;34(4):457-468 [FREE Full text] [doi: 10.1177/001872089203400407]
43. Rebelo F, Noriega P, Duarte E, Soares M. Using virtual reality to assess user experience. Hum Factors 2012;54(6):964-982 [FREE Full text] [doi: 10.1177/0018720812465006] [Medline: 23397807]

Abbreviations

HC: healthy control
IRCCS: Istituto di Ricovero e Cura a Carattere Scientifico
ITC-SOPI: Independent Television Commission Sense of Presence Inventory
MCI: mild cognitive impairment
semAPP: spatial and episodic memory assessment application
STAM: Senior Technology Acceptance Model
SUS: System Usability Scale
TAP: Thinking Aloud Protocol
UX: user experience

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Review

Characteristics and Range of Reviews About Technologies for Aging in Place: Scoping Review of Reviews

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Abstract

Background: It is a contemporary and global challenge that the increasing number of older people requiring care will surpass the available caregivers. Solutions are needed to help older people maintain their health, prevent disability, and delay or avoid dependency on others. Technology can enable older people to age in place while maintaining their dignity and quality of life. Literature reviews on this topic have become important tools for researchers, practitioners, policy makers, and decision makers who need to navigate and access the extensive available evidence. Due to the large number and diversity of existing reviews, there is a need for a review of reviews that provides an overview of the range and characteristics of the evidence on technology for aging in place.

Objective: This study aimed to explore the characteristics and the range of evidence on technologies for aging in place by conducting a scoping review of reviews and presenting an evidence map that researchers, policy makers, and practitioners may use to identify gaps and reviews of interest.

Methods: The review was conducted in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews). Literature searches were conducted in Web of Science, PubMed, and Scopus using a search string that consisted of the terms “older people” and “technology for ageing in place,” with alternate terms using Boolean operators and truncation, adapted to the rules for each database.

Results: A total of 5447 studies were screened, with 344 studies included after full-text screening. The number of reviews on this topic has increased dramatically over time, and the literature is scattered across a variety of journals. Vocabularies and approaches used to describe technology, populations, and problems are highly heterogeneous. We have identified 3 principal ways that reviews have dealt with populations, 5 strategies that the reviews draw on to conceptualize technology, and 4 principal types of problems that they have dealt with. These may be understood as methods that can inform future reviews on this topic. The relationships among populations, technologies, and problems studied in the reviews are presented in an evidence map that includes pertinent gaps.

Conclusions: Redundancies and unexploited synergies between bodies of evidence on technology for aging in place are highly likely. These results can be used to decrease this risk if they are used to inform the design of future reviews on this topic. There is a need for an examination of the current state of the art in knowledge on technology for aging in place in low- and middle-income countries, especially in Africa.

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KEYWORDS

aging in place; technology; gerontechnology; assistive technology; gerontology; geriatric; geriatrics; older adult; older adults; aging; aging; scoping; review methods; review methodology; older people; evidence map; evidence mapping

Introduction

Background

The World Health Organization (WHO) estimates that the global population aged 60 years and older will increase from 12% to 22% between 2015 and 2050, with the most dramatic increase in low- and middle-income countries (LMICs) [1]. This will change the age composition in populations globally. Demographic aging refers to shifts in the age composition of populations where the proportion of the population that consists of older people grows significantly. The fact that people are now living longer than ever and that they are expected to continue doing so is the result of positive developments in public health and survival [2]. Yet, demographic aging is also one of the key challenges of our time [3].

This concern is caused by how demographic aging will impact nation states. As people grow older, they tend to become increasingly reliant on both formal and informal care. For instance, older people are more likely to have functional limitations, need assistance with everyday tasks, and need medical care [4-6]. Moreover, older individuals have lower incomes, which compound the challenges of their increasing need for care [7]. As a result, nation states have a variety of systems in place to care for older people, including systems of shouldering the cost of that care.

In countries where welfare and care systems are heavily subsidized, demographic aging is predicted to lead to heavy financial strain and a decreased quality of life for older people, unless solutions that cater to the need to maintain good health and affordable health care into a longer set of retirement years are developed [8]. Still, the adverse consequences of demographic aging will be even greater in LMICs. In LMICs, welfare systems often function poorly or are nonexistent, meaning that the burden of caring for older people falls on families or on the older individuals to care for themselves. This has caused concerns that LMICs will “grow old before growing rich” [7].

To neutralize the overwhelming demand for health care, solutions are needed to enable older people maintain their health for longer and postpone or avoid disability and dependency [1,9,10]. Against this background, interest in technology that enables older people to age in place while maintaining their dignity and quality of life has grown rapidly over the past 2 decades [11].

Aging in place is a concept that refers to the shared responsibility of individuals and public authorities to enable older people to continue to live safely, relatively independently, and comfortably in the community either in their current home or in appropriate housing, regardless of age, income, or level of competence [1,12-14]. The idea is that policies and public services should address the challenges posed by demographic aging by finding alternatives to traditional forms of older adult care and creating solutions that are less resource-intensive. In welfare states where health and care services are heavily subsidized, this shift toward less resource-intensive solutions generally refers to options that maintain a high quality of life for older people while simultaneously preventing or delaying the need to relocate to a nursing home or becoming dependent on care [15], as well as to solutions that minimize the use of resources in nursing homes and other forms of formal care, without compromising their quality. Meanwhile, in LMICs, the main challenge is that welfare systems are weak and even nonexistent. Assistive technology and related services are marginal and not available for the majority, particularly for the poor rural populations. Ensuring assistive technology for all, including the growing number of older adults, requires resources and build-up of competence through a sustainable systems approach [16]. In this context, innovations are needed in service delivery, and community-based models as well as adaptation of existing assistive technology and development of new and contextually relevant assistive technology are needed to ensure that older people live well and as autonomously as possible [17].

Technologies that enable aging in place encompass a wide variety of technologies designed to monitor or support the health and activities of older people or strengthen their contact with others [11,15]. In some cases, older people are the intended users, but technology can also be used to establish links between older adults and their circles of care. Technologies for aging in place include both high- and low-tech solutions, including but not limited to mobility devices, information and communication technologies, assistive technologies, sensor technology, telemedicine, health monitoring, games, wearables and medication reminders, and the internet of things [15,18-27].

Rationale

Alongside the interest in technology that can enable older people to age in place, the number of publications on this topic has increased dramatically. In this context, literature reviews can be important tools for researchers as well as practitioners, policy makers, and decision makers who need to navigate current debates and access syntheses of the available evidence. Yet, to date, there is no review of the available published reviews that provide an overview of the range and characteristics of the evidence on technology for aging in place.

While reviews of reviews on technologies for aging in place do exist, they typically limit the scope to health conditions, diseases, technologies, or caring practices, for instance, by focusing on the self-efficacy of older people using technology to self-manage chronic obstructive pulmonary disease, hypertension, heart failure, or dementia at home [28]; on the effects of digital technologies on older people’s access to health and social care [29]; on the promotion of physical activity in older people using mobile health (mHealth) and eHealth technologies [30]; or on how mHealth technology may support aging in place [31] and procedures of user-centered usability assessment for digital solutions [32].

Objective

The objective of this review of reviews is to explore the characteristics and the range of evidence on technologies for aging in place by conducting a scoping review of reviews in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for

Scoping Reviews) [33]. The PRISMA-ScR checklist is available in Multimedia Appendix 1.

By exploring the included reviews, we are particularly interested in what year and in which journals they are published, which review methods that characterize reviews in this field, and whether there are any reviews that are explicitly concerned with LMICs. By LMICs, we mean the countries identified by the Organization for Economic Co-operation and Development as having low-income or middle income economies, which may be updated from time to time by the Organization for Economic Co-operation and Development [34]. In exploring the range of evidence presented in reviews on technologies for aging in place, we are particularly interested in which types of populations, technologies, and problems they have been concerned with.

Methods

Eligibility Criteria

We included literature reviews in English about technology for older people or older adult care, including informal care, that we were able to access. To ensure the quality of our sources, we limited our scope to peer-reviewed literature reviews that have been published in academic journals. For the same reason, we only included reviews where the methods were clearly described. We did not apply any limits to the year of publication.

Information Sources

Our method of selecting databases included making a list of the most relevant journals in the field that the authors were aware of (Multimedia Appendix 2). The complete list was sent to a panel of experts consisting of members from the WHO and the International Society of Gerontechnology, who were asked to add any potentially relevant journals missing from the list. After the list was considered complete, the authors identified the databases where these journals were indexed. The final selection of databases was Web of Science (Table 1), PubMed (Table 2), and Scopus (Table 3). The searches in Web of Science and Scopus were conducted on September 13, 2022, and the search in PubMed was conducted on September 14, 2022.

Table 1. Web of Science—core collection (n=1741).

	Search	Results
1	(((((((((((TS=("old* per*")) OR TS=("old* peo*") OR TS=("old* age*")) OR TS=("old* adu*") OR TS=("old* use*")) OR TS=(geriatric)) OR TS=("aged per*")) OR TS=("aged peo*") OR TS=("aged use*") OR TS=(ag$ing)) OR TS=(elder*)) OR TS=(senior)) OR TS=(retire*)) OR TS=(pension*)) OR TS=("later life"))	4,027,248
2	(TS=(ai) OR TS=("ag$ in place") OR TS=(gerontechnology) OR TS=("assisted living") OR TS=("assist* tech") OR TS=(assist* device*) OR TS=("tele*") OR TS=("welfare tech*") OR TS=("digital* health") OR TS=("digital* care") OR TS=("smart hom*") OR TS=("smart hea*") OR TS=("mobile health") OR TS=(mhealth) OR TS=(ehealth) OR TS=(robot*))	1,067,363
3	#6 AND #5 and Review Article (Document Types) and English (Languages)	1741

Table 2. PubMed (n=2402).

	Search	Results
1	("old per*"[Title/Abstract] OR "old peo*"[Title/Abstract] OR "old adu*"[Title/Abstract] OR "old use*"[Title/Abstract] OR "geriatric"[Title/Abstract] OR "aged pe*"[Title/Abstract] OR "aging"[Title/Abstract] OR "ageing"[Title/Abstract] OR "elder*"[Title/Abstract] OR "senior"[Title/Abstract] OR "retire*"[Title/Abstract] OR "pension*"[Title/Abstract] OR "later life"[Title/Abstract]) AND (english[Filter])	584,813
2	("ai"[Title/Abstract] OR "aging in place"[Title/Abstract] OR "ageing in place"[Title/Abstract] OR "gerontechnology"[Title/Abstract] OR "assisted living"[Title/Abstract] OR "assistive living"[Title/Abstract] OR "assist* tech*"[Title/Abstract] OR "assist* device*"[Title/Abstract] OR "tele*"[Title/Abstract] OR "welfare tech*"[Title/Abstract] OR "digital health"[Title/Abstract] OR "digital care"[Title/Abstract] OR "smart hom*"[Title/Abstract] OR "smart hea*"[Title/Abstract] OR "mobile health"[Title/Abstract] OR "mhealth"[Title/Abstract] OR "ehealth"[Title/Abstract] OR "robot*"[Title/Abstract]) AND (english[Filter])	319,264
3	("independent living"[MeSH Terms] OR "self help devices"[MeSH Terms] OR "artificial intelligence"[MeSH Terms] OR "telemedicine"[MeSH Terms]) AND ((review[Filter]) AND (english[Filter]))	16,843
4	("aged"[MeSH Terms] OR "aging"[MeSH Terms]) AND ((review[Filter]) AND (english[Filter]))	11,092
5	#1 AND (#2 OR #3 OR #4)	2402

Table 3. SCOPUS (n=3131).

#	Search	Results
1	TITLE-ABS-KEY ((“old* per*”) OR (“old* peo*”) OR (“old* age*”) OR (“old* adu*”) OR (“old* use*”) OR (geriatric) OR (“aged per*”) OR (“aged peo*”) OR (“aged use*”) OR (ag*ing) OR (elder*) OR (senior) OR (retire*) OR (pension*) OR (“later life”))	2,282,529
2	TITLE-ABS-KEY ((ai OR “ag* in place” OR gerontechnology OR “assisted living” OR (“assist* tech”) OR (“assist* device*”) OR tele* OR (“welfare tech*”) OR (“digital* health”) OR (“digital* care”) OR (“smart hom*”) OR (“smart hea*”) OR (“mobile health”) OR mhealth OR ehealth OR robot*))	2,047,409
3	(LIMIT-TO (DOCTYPE, “re”)) AND (LIMIT-TO (LANGUAGE , “English”))	3131

Search

A search consisting of the terms “older people” and “technology for ageing in place” with alternate terms was conducted using Boolean operators and truncation. The search was adapted to the rules for each database.

Selection of Sources of Evidence

The search resulted in a total of 7274 identified studies, that is, 3131 from Scopus, 2402 from PubMed, and 1741 from Web of Science. We used Covidence (Veritas Health Innovation) to organize the review process. After 1827 duplicates were identified and removed, 5447 studies were screened using the eligibility criteria (see Textbox 1). The original list of eligibility criteria contained items 1-7. However, after we identified a retracted paper, we decided to add exclusion criterion 8 “retracted paper.” The title and abstract screening resulted in the exclusion of 4973 studies. The full-text screening resulted in the further exclusion of 130 studies, and the remaining 344 studies were included in the data charting process. Figure 1 illustrates this process.

Textbox 1. Eligibility criteria.

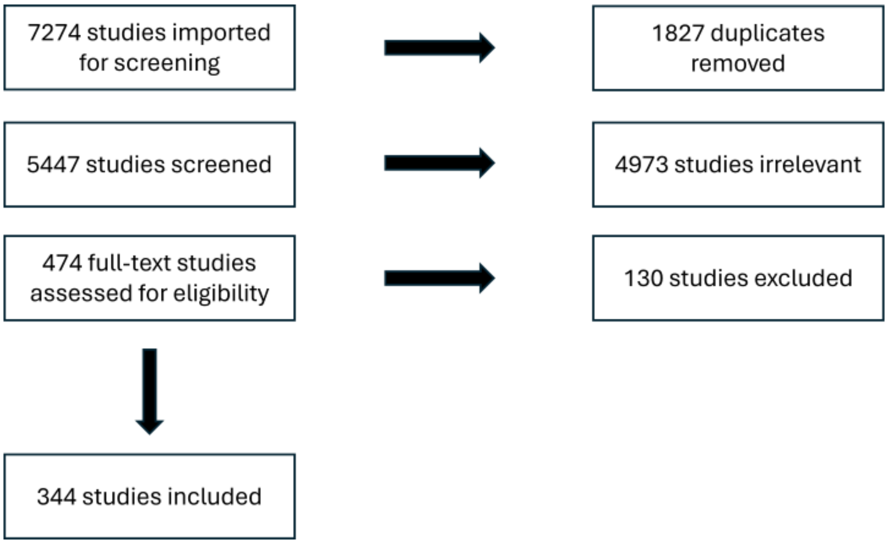
Inclusion criteria

- Literature reviews
- Journal paper
- Peer-reviewed research
- Able to source full text
- Methodologically sound
- About technology for aging in place
- English

Exclusion criteria, with a short label for Covidence

- Not a literature review—Papers that do not review the literature
- Not a journal paper—Anything that is not a paper meaning: book chapters, conference proceedings, protocols, reports, preprints, etc
- Not research—editorials, opinion pieces, press, etc
- Unable to source—currently unable to access full text currently
- Method not described—Reviews that do not clearly describe their methods
- Thematically irrelevant—Not about technology for aging in place
- Not in English
- Retracted paper

Figure 1. Screening process flowchart.



Data Charting Process and Data Items

The data were extracted using the data extraction template feature in Covidence. The extraction of data was organized in line with our objectives and research questions. Tables 4 and 5 provide an overview of the relationship between the research questions and the extracted data.

Table 4. Research questions and charted data that relate to the characteristics of reviews on technologies for aging in place.

Research question	Extracted data
During what years were the reviews published?	Year of publication
In which journals have the reviews been published?	The name of the journal where they are published
Which review methods characterize the reviews?	The named review methods they refer to
Is there an explicit concern with LMICs?[a]	If they refer explicitly to LMICs (yes or no)

[a] LMIC: low- and middle-income countries.

Table 5. Research questions and charted data that relate to the range of evidence in reviews on technologies for aging in place.

Research question	Extracted data
Which populations are they concerned with?	The population specified in the review
Which types of technology are they concerned with?	The technology specified in the review
What type of problems are they concerned with?	The issues of interest specified in the review
What is the relationship between the populations, problems, and technologies the reviews have dealt with	The type of technology and the issues of interest specified in the review

All authors participated in the choice of databases and establishing the search terms and eligibility criteria. EL constructed the search string and conducted the final search. All authors participated in the screening process. The full-text papers were extracted by the authors JMB, MG, and AHE. All authors participated in the data synthesis and presentation of the findings.

Results

Characteristics of Evidence on Technologies for Aging in Place

Multimedia Appendix 3 shows an overview of the data and sources that correspond to this section. The number of reviews of evidence on technology for aging in place has increased dramatically over the past few years (Table 6). The earliest review included in our search was published in 2001 [35]. A total of 20 reviews were published between 2001 and 2010. By comparison, 142 reviews were published between 2015 and 2020. Note that the table only includes reviews published before September 13, 2022, when our search was conducted.

From 2020 to 2021, there was a near doubling in number of reviews. Since our search was conducted at the beginning of September 2022, the figure does not show the full extent of published reviews in 2022. However, it is likely that the trend will continue upwards. The included reviews were published in 183 unique journals. Of those, most journals have only published 1 or 2 reviews since 2001. Only 12 journals have published more than 5 reviews in total since 2001 (Table 7).

Table 6. Number of reviews by year of publication (n=344).

Year of publication	Reviews, n
2001	1
2002	0
2003	0
2004	1
2005	1
2006	0
2007	5
2008	4
2009	6
2010	2
2011	4
2012	8
2013	12
2014	14
2015	6
2016	16
2017	23
2018	23
2019	33
2020	47
2021	88
2022	50

Table 7. Overview of 12 journals that have published 5 or more reviews on technologies for aging in place since 2001.

Journals	Reviews, n
Clinical Interventions in Aging	5
Healthcare	5
Assistive Technology	6
Journal of Telemedicine and Telecare	7
Maturitas	8
JMIR Aging	10
International Journal of Environment Research and Public Health	11
Sensors	11
The Gerontologist	11
Disability and Rehabilitation: Assistive Technology	13
International Journal of Medical Informatics	16
Journal of Medical Internet Research	17

The reviews refer to 15 unique types of review methods. Of these, the most common were systematic reviews (n=144) and scoping reviews (n=60). The third most common review method was to provide a detailed account of the procedures but refrain from referring to a specific type of review method (n=98). While there were only 13 integrative reviews and 6 narrative reviews, the fact that most other review methods only occurred once or twice made the narrative reviews common by comparison (Table 8).

Table 8. Overview of the data analysis methods used in the included reviews.

Data analysis method	Reviews, n
Systematic review	144
Scoping review	60
Integrative review	13
Narrative	6
Mini-review	5
Review of reviews	5
Rapid review	2
Umbrella review	1
Targeted review	1
Meta-interpretive review	1
Focused literature review	1
Descriptive review	1
Clinical review	1
Critical interpretive synthesis	1
Conceptual review	1
Comprehensive review	1
Comparative literature review	1
Reflective review	1
Unspecified	98

Only 1 review referred explicitly to LMICs [36]. This review aimed to identify policy gaps in the delivery and availability of assistive health technology and medical devices for aging populations, particularly in LMICs, and found that practical, life-enhancing support for older people through assistive health technology, medical technology, and related health and social services is a neglected issue.

Range of Evidence on Technologies for Aging in Place

Populations

Multimedia Appendix 4 shows an overview of data and sources that correspond to this section. Some reviews dealt with more than one type of population.

The included reviews dealt with populations in three ways by (1) describing the population in terms of older people or different types of caring roles (n=253), (2) describing the population in terms of a particular health condition or diagnosis (n=73), or (3) not specifying the population (n=43).

Of the included reviews, 253 described the population in terms of people and the roles they play in the context of aging. Of those reviews, an overwhelming majority only included studies on older people (n=220). Of the included reviews, 12 reviews dealt with formal and informal caregivers or combinations of these 3 different populations (Table 9).

Table 9. Overview of the populations in 253 reviews that described the population in terms of people and the roles they play in the context of aging.

Populations	Reviews, n
Older people	220
Formal caregivers	1
Formal caregivers and informal caregivers	2
Informal caregivers	5
Older people and formal caregivers	5
Older people, formal caregivers, and informal caregivers	4
Older people and informal caregivers	16

In total, 73 reviews described the population in terms of older people as well as individuals from other age groups, with a particular diagnosis or health problem. These reviews included studies about people of different age groups with different cognitive impairments exclusively (n=41) or in combination with other health problems (n=2). Notably then, these reviews included evidence based on studies of younger people as well as older people. Table 10 provides an overview of the diagnoses and health problems that these reviews used to conceptualize the populations.

In total, 43 reviews did not specify the population at all. Instead, they referred to the context of aging in place. These reviews were typically concerned with the technical functionality of devices rather than the interplay between what the technology offers and the intended users and their problems.

Table 10. Overview of the diagnoses and health problems used to conceptualize the population in reviews about older people and others with a particular diagnosis or health problem (in total n=73 reviews).

Diagnoses and health problems	Reviews, n
Cancer	1
Cardiovascular diseases	1
Cardiovascular diseases, diabetes, and asthma	1
Chronic conditions	7
Cognitive impairments	41
Cognitive impairments, cardiovascular diseases, and chronic obstructive pulmonary disease	1
Cognitive impairments, neurological disorders, falls, and cardiovascular disease	1
Complex needs	1
Decline in hand grip and dexterity	1
Diabetes	1
Falls	4
Falls and frailty	1
Frailty	6
Frailty and decreased hearing	1
Hip injuries	1
Loneliness and social isolation	2
Mental health	2

Types of Technology

Multimedia Appendix 5 shows an overview of the data and sources that correspond to these results. Some reviews dealt with more than one type of technology.

We identified 69 different types of technology that reviews have been concerned with and 5 substantive strategies that the reviews have used to conceptualize the technology with which they are concerned. Two of the 345 reviews used other strategies for conceptualizing technology. One was about co-designed technologies [37]. The other was about what they termed as consumer technology as well as smart environments [38].

The first and most common strategy (n=140 reviews) is to refer to technology by using descriptive technical terms such as "sensors" [39-48], "artificial intelligence" [49-52], "GPS" [53-55], or "games" [56-60]. The reviews that used this strategy covered 31 different types of technology exclusively or in combination with each other. Most of these reviews were focused on robots or robopets (n=47), information and communication technology (n=23), smart environments (n=17), or sensors (n=10).

The second strategy (n=65) is to conceptualize technology by the purpose of the technology in relation to a disease or type of health challenge that the technology addresses or is believed to be able to address, for instance, by using terms such as "technology for dementia" [61-70], "technologies for social connectedness" [71-75], "technology for frailty" [76-78], "technology for safety" [79], or "technology for falls" [60,80-84]. Most of the reviews that relied on this strategy dealt with assistive technologies (n=28).

The third strategy (n=30 reviews) is to refer to technologies in terms of their intended purpose in caring services or practices that they are part of. Such terms include "teleopthamology" [85], "monitoring technologies" [86,87], "telerehabilitation" [88-93], "technology for home health care" [94,95], or "technology for pain management" [96]. Most reviews that relied on this strategy were concerned with telerehabilitation (n=7) or technology for health information (n=6).

The fourth strategy (n=29 reviews) is to describe the type of technology by using umbrella terms that broadly refer to the use of technology to enable older people to age in place, for instance, by defining the technology of interest in terms of "technology for ageing in place" [11,97-99], "gerontechnology" [100-102], "welfare technology" [103-105], "technology for healthy ageing" [106,107], or "technology for older people" [22,32,108-112].

The fifth strategy (n=75 reviews) is to describe the type of technology the review is concerned with by way of concepts that refer to the use of technology as part of a broad range of caring services, strategies, and practices, such as, for instance, telecare [113-119], telemedicine [120-125], e-interventions [126], or eHealth [127-143]. Most reviews that used this type of concept to describe the technology they are concerned with dealt with mHealth (n=18), eHealth (n=17), or telehealth (n=18).

What Types of Problems Have the Reviews Dealt With?

Multimedia Appendix 6 shows an overview of the corresponding data and sources. Some reviews dealt with more than one type of problem. We identified 49 unique problem topics and 4 principal types of problems.

The first type of problem is related to different types of care services or caring practices (n=60 reviews). Most of these reviews dealt with problems related to the context of home care (n=30), caring practices in nursing homes or other long-term care institutions (n=11), or rehabilitation (n=7). By contrast, other topics occurred only once or twice, that is, problems related to caregiver burden [144,145], dementia care [146], emergency care services [147], informal care [148], and health information services [149,150].

The second type of problem is issues related to the management of health-related issues or diseases in the context of aging in place (n=128 reviews). Of those, most dealt with problems related to cognitive impairments either exclusively (n=61) or in combination with one or several other health problems (n=10), that is, cognitive impairment and mental health [151-155], or cognitive impairment, stroke, cardiovascular disease, and falls [156]. Other problems that were featured relatively frequently included falls and balance–related issues (n=19), frailty (n=8), chronic conditions (n=8), and depression (n=5). Meanwhile, other problems related to the management of other health-related issues and diseases featured only once or twice, despite being common health challenges for older people (for instance, Parkinson’s disease [157,158], malnutrition [159], dental health [160], eye diseases [85], and pain [96,161]).

The third type of problem relates to the experience of aging in place (n=82 reviews). The most common topics in this category were loneliness, including social isolation or connectedness (n=21 reviews), older peoples’ self-care or self-management (n=19 reviews), and active aging (n=16 reviews). Other topics in this category include healthy aging [106,111,137,162-165], information needs [166], quality of life [97,167-173], quality of life and older people’s self-care and self-management [174,175], and activities of daily living exclusively [176-179] or in combination with other topics such as loneliness [180,181], or quality of life [182].

The fourth type of problem relates to the research and development of technology. This was the most common type of problem (n=285 reviews). The overwhelming majority of reviews that dealt with this type of problem were concerned with barriers and drivers of use and acceptability (n=114), the effect or implications of technology (n=86), or the combination of these 2 topics (n=21). Other common topics included uptake or scalability (n=15), user involvement (n=11), ethical considerations (n=14), feasibility (n=10), and cost-effectiveness or use (n=7).

Notably, problems related to home care (n=30), loneliness (n=21), cognitive impairments (n=71), barriers and drivers of use and acceptability (n=114 reviews), and the effect or implications of technology (n=86) have been heavily emphasized. Meanwhile, others such as cost-effectiveness or use of technologies (n=7), health information needs (n=1), malnutrition (n=1), dental health (n=1), eye diseases (n=1), and pain management seem underprioritized by comparison.

What Are the Relationships Between the Problems, Technologies, and Populations That the Reviews Have Dealt With

Multimedia Appendix 7 shows an evidence map that provides an overview of the relationships between problems, technologies, and populations that the reviews have been concerned with. Some reviews deal with more than one population, technology, and type of problem. Multimedia Appendix 8 shows an overview of the corresponding data and sources.

As illustrated in the evidence map (Multimedia Appendix 7), many reviews draw on an evidence base that is not specific to older people or their caregivers.

This is particularly notable in the reviews on the following topics: barriers and drivers of use and acceptability, cognitive impairment, and the effect or implications of technology. The same observation applies to the following types of technology such as assistive technologies, robots, technology for dementia, technology for falls, technology for frailty, telehealth, and technology for Alzheimer disease.

Summary of Evidence

In exploring the range and characteristics of reviews on technology for aging in place, we found that the number of reviews, as well as the pace at which they are published, has increased dramatically over time. While some journals such as *JMIR Aging*, *Disability and Rehabilitation: Assistive Technology*, the *Journal of Medical Internet Research*, and *The Journal of Medical Informatics* have published more reviews on this topic than others, the literature is scattered over 183 unique journals. Most reviews on this topic are systematic reviews (n=144).

In exploring the range of reviews on technology for aging in place, we identified 3 principal ways that reviews have dealt with populations. Specifically, the 3 ways are describing the population in terms of older people or different types of caring roles (n=253), in terms of people affected with a particular health condition or diagnosis (n=73), or not specifying the population (n=43). These may be considered as methods of conceptualizing populations. We identified 88 unique types of technology that the reviews have dealt with. We also found that there are strong tendencies for reviews to synthesize the evidence on broad and unspecific categories of technology such as “ICT” or “robots” rather than to concentrate on a particular device (a notable exception is a review on personal alarms [183]). Moreover, we identified 5 strategies that the reviews draw on to conceptualize technology. Those strategies are to (1) refer to technology by using descriptive technical terms; (2) conceptualize technology by way of the purpose of the technology about a disease or health issue; (3) refer to technologies in terms of their purpose in caring services or practices; (4) use umbrella terms that broadly refer to the use of technology to enable older people to age in place; and (5) use concepts that refer to the technology as part of caring services, strategies, and practices. We also identified 4 principal types of problems and 49 unique subtypes of problems that the reviews have dealt with. The four principal types are problems related to (1) different types of care services or caring practices, (2) the management of health problems or diseases, (3) the experience of aging in place, and (4) the research and development of technology. The evidence map (Multimedia Appendix 6) demonstrates the relationships between the populations, technologies, and problems studied in the reviews and illustrates the gaps. Notably, many of the reviews on the most studied technologies and problems draw on studies that are not specific to older people or the context of aging in place, either by not specifying the population at all or by including studies on patients of all ages, meaning that topics studied only by such reviews should also be considered gaps.

Discussion

Summary of Evidence

Together, these results speak to the need for regularly updated overviews of ongoing debates in the field. However, they are also illustrative of the challenges that such overviews must overcome. For instance, the lack of conceptual hegemony means that any attempt to describe the technologies that the reviews have been concerned with in purely technical terms fails to grasp the diverse ways that technology is understood in this field. A more fruitful approach is to categorize them according to the different ways that they understand and deal with technology. Used as methodological tools, the strategies of defining populations, conceptualizing technology, the typology of problems, and the overview of the relationships presented here can inform the design of future reviews and enable researchers to purposefully identify gaps and publications that are likely to be of relevance to each other despite conceptual differences that may obscure their similarities.

It is notable that only 1 review was explicitly concerned with LMICs, considering that the greatest growth in older people globally will be in LMICs [1], particularly in Africa where the population of 60 years and older is expected to increase by more than 100% by 2050 [184]. Similarly, it is notable that in the included reviews, relatively little attention has been paid to formal and informal caregivers. Both formal and informal caregivers play important roles in the context of technology for aging in place. Both formal and informal caregivers frequently speak and act on behalf of older people, especially older people with cognitive impairments when technology developers seek to identify user needs or evaluate the usefulness of the technology [185-188]. In doing so, they act as gatekeepers who shape what types of technology are developed and offered to older people, and equally important, which are not [109]. Both formal and informal caregivers are often the intended users of technology that is meant to enable older people to age in place. Thus, the politics of their lives and working conditions as well as the quality and type of care they are able to provide to older people are shaped by what the technology affords and prohibits [189-191]. Yet, the purpose of the technology is aimed at the needs of the older person or efficiency-related goals in care organizations rather than the improvement of the care workers' working environment or care burden. Additionally, like all users, both formal and informal caregivers are not just impacted by technologies that enter their lives but they also shape the technology in turn [188,192-199], meaning that the implications that the technology will have in practice are never given beforehand and must always be studied in the context of use [185,187,200,201]. Finally, both informal and formal caregivers must frequently improvise and adapt the technology to render it functional [192,202-205]. Thus, both formal and informal caregivers play important roles in shaping the practices, politics, and services that the technology affords or delimits in the lives of older people who age in place. These roles have been thoroughly described in the literature. Yet, they seem overlooked in reviews on technology for aging in place.

It is problematic that so many reviews concerned with problems related to technologies for aging in place draw on an evidence base that is not specific to older people. Older people frequently have other needs than younger people even when they share a diagnosis because the aging body presents specific challenges, which increase the risk of illnesses, falls, disability, and death [206]. It is therefore unlikely that reviews that do not focus explicitly on older people are able to grasp and address the specificity of the challenges that older people face as part of aging in place. This primarily concerns reviews on the topics of barriers and drivers of use and acceptability, cognitive impairment, and the effect or implications of technology. It also concerns reviews about assistive technologies, robots, technology for dementia, technology for falls, technology for frailty, telehealth, and technology for Alzheimer disease. While these topics and technologies have frequently been addressed, the value that reviews that do not specify their population or that base their arguments on studies of people of all ages (see Multimedia Appendix 6) is limited, and there is a need for more targeted and age-specific syntheses reviews to better address the unique requirements of older individuals and their caregivers. The strong tendency for reviews in this field to concentrate on broad and unspecific categories of technology, such as "ICT" or "robots" means that there is no straightforward way for practitioners to use these reviews as support in decision-making processes regarding the potential usefulness and challenges related to specific devices.

Limitations

Despite the many methodological strengths of the design of a scoping review of reviews, there are some limitations to be considered. These include the potential for bias in the review process, the difficulty ensuring the quality and reliability of the included reviews, and the potential for the review to be influenced by the perspectives and priorities of the researchers conducting the review. Considering the broad eligibility criteria chosen for this review, the results may be considered representative of the characteristics and range of evidence on technologies for aging in place. However, the inclusion of more databases could have expanded the data set even further, and potentially relevant literature that does not use the term aging in place explicitly may have been missed. Moreover, this review has not sought to explore or synthesize the results of the included reviews nor have we considered the quality of the included reviews.

Conclusions

The number of published reviews on this topic in the past few years in combination with the rate at which they are published suggests that redundancies and a lack of fruitful synergies between them are likely. The breadth of variation concerning how reviews have dealt with populations, conceptualizations of types of technology, and problems demonstrates the conceptual differences that must be bridged to remedy this problem.

Together, these results underscore the necessity for improved coordination and collaboration among reviews while also recognizing the potential benefits of more standardized vocabularies.

The insights gained from the methods of dealing with populations, strategies for conceptualizing types of technology, and the types of problems identified in this study may be used methodologically to identify commonalities and connections that may otherwise be obscured by differing conceptual frameworks.

There is an urgent need for an examination of the current state of the art in knowledge regarding technology for aging in place in LMICs. Developing a deeper understanding of the conditions surrounding aging in LMICs, especially in Africa, and the implications those conditions have for the roles that technology may play and not play in the lives of older people and their circles of care should be an essential focus of the research agenda.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA-ScR Checklist.
[DOCX File , 56 KB - aging_v7i1e50286_app1.docx]

Multimedia Appendix 2
Journals to guide the selection of databases.
[PDF File (Adobe PDF File), 116 KB - aging_v7i1e50286_app2.pdf]

Multimedia Appendix 3
Characteristics of evidence on technologies for ageing in place.
[XLSX File (Microsoft Excel File), 68 KB - aging_v7i1e50286_app3.xlsx]

Multimedia Appendix 4
Populations.
[XLSX File (Microsoft Excel File), 62 KB - aging_v7i1e50286_app4.xlsx]

Multimedia Appendix 5
Types of technology.
[XLSX File (Microsoft Excel File), 69 KB - aging_v7i1e50286_app5.xlsx]

Multimedia Appendix 6

Types of problems.
[XLSX File (Microsoft Excel File), 66 KB - aging_v7i1e50286_app6.xlsx]

Multimedia Appendix 7
Evidence map.
[XLSX File (Microsoft Excel File), 71 KB - aging_v7i1e50286_app7.xlsx]

Multimedia Appendix 8
Relationships between problems technologies and populations.
[XLSX File (Microsoft Excel File), 75 KB - aging_v7i1e50286_app8.xlsx]

References

1. Beard JR, Officer A, de Carvalho IA, Sadana R, Pot AM, Michel JP, et al. The world report on ageing and health: a policy framework for healthy ageing. Lancet 2016;387(10033):2145-2154 [FREE Full text] [doi: 10.1016/S0140-6736(15)00516-4] [Medline: 26520231]
2. Bloom DE, Chatterji S, Kowal P, Lloyd-Sherlock P, McKee M, Rechel B, et al. Macroeconomic implications of population ageing and selected policy responses. Lancet 2015;385(9968):649-657 [FREE Full text] [doi: 10.1016/S0140-6736(14)61464-1] [Medline: 25468167]
3. Wilmoth JR, Bas D, Mukherjee S, Hanif N. In: Luchsinger G, editor. World Social Report 2023: Leaving No One Behind in an Ageing World. New York: United Nations Department of Economic and Social Affairs; 2023.
4. Lin SF, Beck AN, Finch BK, Hummer RA, Masters RK. Trends in US older adult disability: exploring age, period, and cohort effects. Am J Public Health 2012;102(11):2157-2163 [FREE Full text] [doi: 10.2105/AJPH.2011.300602] [Medline: 22994192]
5. Freedman VA, Spillman BC. Disability and care needs among older Americans. Milbank Q 2014;92(3):509-541 [FREE Full text] [doi: 10.1111/1468-0009.12076] [Medline: 25199898]
6. Fry AM, Shay DK, Holman RC, Curns AT, Anderson LJ. Trends in hospitalizations for pneumonia among persons aged 65 years or older in the United States, 1988-2002. JAMA 2005;294(21):2712-2719 [FREE Full text] [doi: 10.1001/jama.294.21.2712] [Medline: 16333006]
7. Sudharsanan N, Bloom DE. The demography of aging in low- and middle-income countries: chronological versus functional perspectives. In: Majmundar MK, Hayward MD, editors. Future Directions for the Demography of Aging: Proceedings of a Workshop. Washington, D.C: National Academies Press; 2018.
8. Lee J, Smith JP. Health, economic status, and aging in high-income countries. In: Hayward MD, Majmundar MK, editors. Future directions for the demography of aging : proceedings of a workshop. Washington, DC: National Academies Press; 2018.
9. He W, Goodkind D, Kowal P. An aging world: 2015: international population reports. United States Census Bureau. 2015. URL: https://www.census.gov/content/dam/Census/library/publications/2016/demo/p95-16-1.pdf [accessed 2023-11-18]
10. World report on ageing and health. World Health Organization. 2022. URL: https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1&isAllowed=y [accessed 2023-11-18]
11. Ollevier A, Aguiar G, Palomino M, Simpelaere IS. How can technology support ageing in place in healthy older adults? A systematic review. Public Health Rev 2020;41(1):26 [FREE Full text] [doi: 10.1186/s40985-020-00143-4] [Medline: 33292707]
12. A glossary of terms for community health care and services for older persons. World Health Organization. 2004. URL: https://apps.who.int/iris/handle/10665/68896 [accessed 2023-11-18]
13. Martens CT. Aging in which place? Connecting aging in place with individual responsibility, housing markets, and the welfare state. J Hous Elderly 2017;32(1):1-11 [FREE Full text] [doi: 10.1080/02763893.2017.1393483]
14. Healthy places terminology. Centers for Disease Control and Prevention. 2017. URL: https://www.cdc.gov/healthyplaces/terminology.htm [accessed 2023-11-18]
15. Kim KI, Gollamudi SS, Steinhubl S. Digital technology to enable aging in place. Exp Gerontol 2017;88:25-31 [FREE Full text] [doi: 10.1016/j.exger.2016.11.013] [Medline: 28025126]
16. Borg J, Winberg M, Eide AH, Calvo I, Khasnabis C, Zhang W. On the relation between assistive technology system elements and access to assistive products based on 20 country surveys. Healthcare (Basel) 2023;11(9):1313 [FREE Full text] [doi: 10.3390/healthcare11091313] [Medline: 37174855]
17. Imagine tomorrow: report on the 2nd WHO global forum on innovation for ageing populations. World Health Organization. 2013. URL: https://extranet.who.int/kobe_centre/sites/default/files/GFIAP_report_0.pdf [accessed 2023-11-18]
18. Tun SYY, Madanian S, Mirza F. Internet of Things (IoT) applications for elderly care: a reflective review. Aging Clin Exp Res 2021;33(4):855-867. [doi: 10.1007/s40520-020-01545-9] [Medline: 32277435]
19. Yusif S, Soar J, Hafeez-Baig A. Older people, assistive technologies, and the barriers to adoption: a systematic review. Int J Med Inform 2016;94:112-116 [FREE Full text] [doi: 10.1016/j.ijmedinf.2016.07.004] [Medline: 27573318]

20. Chen YRR, Schulz PJ. The effect of information communication technology interventions on reducing social isolation in the elderly: a systematic review. J Med Internet Res 2016;18(1):e18 [FREE Full text] [doi: 10.2196/jmir.4596] [Medline: 26822073]
21. Ekeland AG, Bowes A, Flottorp S. Effectiveness of telemedicine: a systematic review of reviews. Int J Med Inform 2010;79(11):736-771 [FREE Full text] [doi: 10.1016/j.ijmedinf.2010.08.006] [Medline: 20884286]
22. Khosravi P, Ghapanchi AH. Investigating the effectiveness of technologies applied to assist seniors: a systematic literature review. Int J Med Inform 2016;85(1):17-26 [FREE Full text] [doi: 10.1016/j.ijmedinf.2015.05.014] [Medline: 26216463]
23. Liu P, Li G, Jiang S, Liu Y, Leng M, Zhao J, et al. The effect of smart homes on older adults with chronic conditions: a systematic review and meta-analysis. Geriatr Nurs 2019;40(5):522-530 [FREE Full text] [doi: 10.1016/j.gerinurse.2019.03.016] [Medline: 31029481]
24. Pal D, Triyason T, Funikul S. Smart homes and quality of life for the elderly: a systematic review. 2017 Presented at: 2017 IEEE International Symposium on Multimedia (ISM); December 11-13, 2017; Taichung, Taiwan. [doi: 10.1109/ism.2017.83]
25. Peek STM, Luijkx KG, Vrijhoef HJM, Nieboer ME, Aarts S, van der Voort CS, et al. Understanding changes and stability in the long-term use of technologies by seniors who are aging in place: a dynamical framework. BMC Geriatr 2019;19(1):236 [FREE Full text] [doi: 10.1186/s12877-019-1241-9] [Medline: 31462214]
26. Sokullu R, Akkaş MA, Demir E. IoT supported smart home for the elderly. Internet Things 2020;11:100239 [FREE Full text] [doi: 10.1016/j.iot.2020.100239]
27. Tinker A, Lansley P. Introducing assistive technology into the existing homes of older people: feasibility, acceptability, costs and outcomes. J Telemed Telecare 2005;11(Suppl 1):1-3 [FREE Full text] [doi: 10.1258/1357633054461787] [Medline: 16035974]
28. Chalfont G, Mateus C, Varey S, Milligan C. Self-efficacy of older people using technology to self-manage COPD, hypertension, heart failure, or dementia at home: an overview of systematic reviews. Gerontologist 2021;61(6):e318-e334 [FREE Full text] [doi: 10.1093/geront/gnaa045] [Medline: 32530031]
29. Kunonga TP, Spiers GF, Beyer FR, Hanratty B, Boulton E, Hall A, et al. Effects of digital technologies on older people's access to health and social care: umbrella review. J Med Internet Res 2021;23(11):e25887 [FREE Full text] [doi: 10.2196/25887] [Medline: 34821564]
30. McGarrigle L, Todd C. Promotion of physical activity in older people using mHealth and eHealth technologies: rapid review of reviews. J Med Internet Res 2020;22(12):e22201 [FREE Full text] [doi: 10.2196/22201] [Medline: 33372894]
31. Rocha NP, dos Santos MR, Cerqueira M, Queiros A. Mobile health to support ageing in place: a systematic review of reviews and meta-analyses. Int J E-Health Med Commun 2019;10(3):1-21 [FREE Full text] [doi: 10.4018/ijehmc.2019070101]
32. Silva AG, Caravau H, Martins A, Almeida AMP, Silva T, Ribeiro Ó, et al. Procedures of user-centered usability assessment for digital solutions: scoping review of reviews reporting on digital solutions relevant for older adults. JMIR Hum Factors 2021;8(1):e22774 [FREE Full text] [doi: 10.2196/22774] [Medline: 33439128]
33. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018;169(7):467-473 [FREE Full text] [doi: 10.7326/M18-0850] [Medline: 30178033]
34. DAC list of ODA recipients. OECD. URL: https://www.oecd.org/dac/financing-sustainable-development/development-finance-standards/DAC-List-of-ODA-Recipients-for-reporting-2022-23-flows.pdf [accessed 2023-11-18]
35. Kraskowsky LH, Finlayson M. Factors affecting older adults' use of adaptive equipment: review of the literature. Am J Occup Ther 2001;55(3):303-310 [FREE Full text] [doi: 10.5014/ajot.55.3.303] [Medline: 11723971]
36. Garçon L, Khasnabis C, Walker L, Nakatani Y, Lapitan J, Borg J, et al. Medical and assistive health technology: meeting the needs of aging populations. Gerontologist 2016;56(Suppl 2):S293-S302 [FREE Full text] [doi: 10.1093/geront/gnw005] [Medline: 26994268]
37. Sumner J, Chong LS, Bundele A, Lim YW. Co-designing technology for aging in place: a systematic review. Gerontologist 2021;61(7):e395-e409 [FREE Full text] [doi: 10.1093/geront/gnaa064] [Medline: 32506136]
38. Reeder B, Meyer E, Lazar A, Chaudhuri S, Thompson HJ, Demiris G. Framing the evidence for health smart homes and home-based consumer health technologies as a public health intervention for independent aging: a systematic review. Int J Med Inform 2013;82(7):565-579 [FREE Full text] [doi: 10.1016/j.ijmedinf.2013.03.007] [Medline: 23639263]
39. Baig MM, Afifi S, GholamHosseini H, Mirza F. A systematic review of wearable sensors and IOT-based monitoring applications for older adults - a focus on ageing population and independent living. J Med Syst 2019;43(8):233 [FREE Full text] [doi: 10.1007/s10916-019-1365-7] [Medline: 31203472]
40. Camp N, Lewis M, Hunter K, Johnston J, Zecca M, Di Nuovo A, et al. Technology used to recognize activities of daily living in community-dwelling older adults. Int J Environ Res Public Health 2020;18(1):163 [FREE Full text] [doi: 10.3390/ijerph18010163] [Medline: 33379319]
41. Carver LF, Mackinnon D. Health applications of gerontechnology, privacy, and surveillance: a scoping review. Surveill Soc 2020;18(2):216-230 [FREE Full text] [doi: 10.24908/ss.v18i2.13240]
42. Kim D, Bian H, Chang CK, Dong L, Margrett J. In-home monitoring technology for aging in place: scoping review. Interact J Med Res 2022;11(2):e39005 [FREE Full text] [doi: 10.2196/39005] [Medline: 36048502]

43. Lin Q, Zhang D, Chen L, Ni H, Zhou X. Managing elders’ wandering behavior using sensors-based solutions: a survey. Int J Gerontol 2014;8(2):49-55 [FREE Full text] [doi: 10.1016/j.ijge.2013.08.007]
44. Lussier M, Lavoie M, Giroux S, Consel C, Guay M, Macoir J, et al. Early detection of mild cognitive impairment with in-home monitoring sensor technologies using functional measures: a systematic review. IEEE J Biomed Health Inform 2019;23(2):838-847. [doi: 10.1109/JBHI.2018.2834317] [Medline: 29994013]
45. Pol MC, Poerbodipoero S, Robben S, Daams J, van Hartingsveldt M, de Vos R, et al. Sensor monitoring to measure and support daily functioning for independently living older people: a systematic review and road map for further development. J Am Geriatr Soc 2013;61(12):2219-2227 [FREE Full text] [doi: 10.1111/jgs.12563] [Medline: 24479150]
46. Straiton N, Alharbi M, Bauman A, Neubeck L, Gullick J, Bhindi R, et al. The validity and reliability of consumer-grade activity trackers in older, community-dwelling adults: a systematic review. Maturitas 2018;112:85-93 [FREE Full text] [doi: 10.1016/j.maturitas.2018.03.016] [Medline: 29704922]
47. Vavasour G, Giggins OM, Doyle J, Kelly D. How wearable sensors have been utilised to evaluate frailty in older adults: a systematic review. J Neuroeng Rehabil 2021;18(1):112 [FREE Full text] [doi: 10.1186/s12984-021-00909-0] [Medline: 34238323]
48. Zhong R, Rau PLP. Are cost-effective technologies feasible to measure gait in older adults? A systematic review of evidence-based literature. Arch Gerontol Geriatr 2020;87:103970 [FREE Full text] [doi: 10.1016/j.archger.2019.103970] [Medline: 31743825]
49. Li R, Wang X, Lawler K, Garg S, Bai Q, Alty J. Applications of artificial intelligence to aid early detection of dementia: a scoping review on current capabilities and future directions. J Biomed Inform 2022;127:104030 [FREE Full text] [doi: 10.1016/j.jbi.2022.104030] [Medline: 35183766]
50. Loveys K, Prina M, Axford C, Domènec Ò, Weng W, Broadbent E, et al. Artificial intelligence for older people receiving long-term care: a systematic review of acceptability and effectiveness studies. Lancet Healthy Longev 2022;3(4):e286-e297 [FREE Full text] [doi: 10.1016/S2666-7568(22)00034-4] [Medline: 35515814]
51. Lukkien DRM, Nap HH, Buimer HP, Peine A, Boon WPC, Ket JCF, et al. Toward responsible artificial intelligence in long-term care: a scoping review on practical approaches. Gerontologist 2023;63(1):155-168 [FREE Full text] [doi: 10.1093/geront/gnab180] [Medline: 34871399]
52. Vogan AA, Alnajjar F, Gochoo M, Khalid S. Robots, AI, and cognitive training in an era of mass age-related cognitive decline: a systematic review. IEEE Access 2020;8:18284-18304 [FREE Full text] [doi: 10.1109/access.2020.2966819]
53. Ehn M, Richardson MX, Stridsberg SL, Redekop K, Wamala-Andersson S. Mobile safety alarms based on GPS technology in the care of older adults: systematic review of evidence based on a general evidence framework for digital health technologies. J Med Internet Res 2021;23(10):e27267 [FREE Full text] [doi: 10.2196/27267] [Medline: 34633291]
54. Herrera EP. Location-based technologies for supporting elderly pedestrian in "getting lost" events. Disabil Rehabil Assist Technol 2017;12(4):315-323 [FREE Full text] [doi: 10.1080/17483107.2016.1181799] [Medline: 27377102]
55. Suri A, VanSwearingen J, Dunlap P, Redfern MS, Rosso AL, Sejdić E. Facilitators and barriers to real-life mobility in community-dwelling older adults: a narrative review of accelerometry- and global positioning system-based studies. Aging Clin Exp Res 2022;34(8):1733-1746 [FREE Full text] [doi: 10.1007/s40520-022-02096-x] [Medline: 35275373]
56. Laufer Y, Dar G, Kodesh E. Does a wii-based exercise program enhance balance control of independently functioning older adults? A systematic review. Clin Interv Aging 2014;9:1803-1813 [FREE Full text] [doi: 10.2147/CIA.S69673] [Medline: 25364238]
57. Liu H, Xing Y, Wu Y. Effect of wii fit exercise with balance and lower limb muscle strength in older adults: a meta-analysis. Front Med (Lausanne) 2022;9:812570 [FREE Full text] [doi: 10.3389/fmed.2022.812570] [Medline: 35602499]
58. Martinho D, Carneiro J, Corchado JM, Marreiros G. A systematic review of gamification techniques applied to elderly care. Artif Intell Rev 2020;53(7):4863-4901 [FREE Full text] [doi: 10.1007/s10462-020-09809-6]
59. Suleiman-Martos N, García-Lara R, Albendín-García L, Romero-Béjar JL, Cañadas-De La Fuente GA, Monsalve-Reyes C, et al. Effects of active video games on physical function in independent community-dwelling older adults: a systematic review and meta-analysis. J Adv Nurs 2022;78(5):1228-1244 [FREE Full text] [doi: 10.1111/jan.15138] [Medline: 34935178]
60. Wang YL, Hou HT, Tsai CC. A systematic literature review of the impacts of digital games designed for older adults. Educ Gerontol 2019;46(1):1-17 [FREE Full text] [doi: 10.1080/03601277.2019.1694448]
61. Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C. Involving people with dementia in the development of supportive IT applications: a systematic review. Ageing Res Rev 2013;12(2):535-551 [FREE Full text] [doi: 10.1016/j.arr.2013.01.002] [Medline: 23318684]
62. Dawson A, Bowes A, Kelly F, Velzke K, Ward R. Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. BMC Geriatr 2015;15:59 [FREE Full text] [doi: 10.1186/s12877-015-0053-9] [Medline: 25967742]
63. Holthe T, Halvorsrud L, Karterud D, Hoel KA, Lund A. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. Clin Interv Aging 2018;13:863-886 [FREE Full text] [doi: 10.2147/CIA.S154717] [Medline: 29765211]

64. Huisman C, Huisman E, Kort H. Technological applications contributing to relieve care burden or to sleep of caregivers and people with dementia: a scoping review from the perspective of social isolation. Front Public Health 2022;10:797176 [FREE Full text] [doi: 10.3389/fpubh.2022.797176] [Medline: 35425752]
65. Neal D, van den Berg F, Planting C, Ettema T, Dijkstra K, Finnema E, et al. Can use of digital technologies by people with dementia improve self-management and social participation? A systematic review of effect studies. J Clin Med 2021;10(4):604 [FREE Full text] [doi: 10.3390/jcm10040604] [Medline: 33562749]
66. Neal I, du Toit SHJ, Lovarini M. The use of technology to promote meaningful engagement for adults with dementia in residential aged care: a scoping review. Int Psychogeriatr 2020;32(8):913-935 [FREE Full text] [doi: 10.1017/S1041610219001388] [Medline: 31547900]
67. Neubauer NA, Azad-Khaneghah P, Miguel-Cruz A, Liu L. What do we know about strategies to manage dementia-related wandering? A scoping review. Alzheimers Dement (Amst) 2018;10:615-628 [FREE Full text] [doi: 10.1016/j.dadm.2018.08.001] [Medline: 30456289]
68. Suijkerbuijk S, Nap HH, Cornelisse L, IJsselsteijn WA, de Kort YAW, Minkman MMN. Active involvement of people with dementia: a systematic review of studies developing supportive technologies. J Alzheimers Dis 2019;69(4):1041-1065 [FREE Full text] [doi: 10.3233/JAD-190050] [Medline: 31156158]
69. van Boekel LC, Wouters EJM, Grimberg BM, van der Meer NJM, Luijkx KG. Perspectives of stakeholders on technology use in the care of community-living older adults with dementia: a systematic literature review. Healthcare (Basel) 2019;7(2):73 [FREE Full text] [doi: 10.3390/healthcare7020073] [Medline: 31141999]
70. Whitfield T, McConnell B, Renouf P, Mansour H, Zabihi S, Aguirre E, et al. The effect of remotely delivered lifestyle interventions on cognition in older adults without dementia: a systematic review and meta-analysis. Ageing Res Rev 2021;72:101505 [FREE Full text] [doi: 10.1016/j.arr.2021.101505] [Medline: 34757173]
71. Ibarra F, Baez M, Cernuzzi L, Casati F. A systematic review on technology-supported interventions to improve old-age social wellbeing: loneliness, social isolation, and connectedness. J Healthc Eng 2020;2020:2036842 [FREE Full text] [doi: 10.1155/2020/2036842] [Medline: 32765823]
72. Benoit-Dubé L, Jean EK, Aguilar MA, Zuniga AM, Bier N, Couture M, et al. What facilitates the acceptance of technology to promote social participation in later life? A systematic review. Disabil Rehabil Assist Technol 2023;18(3):274-284 [FREE Full text] [doi: 10.1080/17483107.2020.1844320] [Medline: 33156714]
73. Khosravi P, Rezvani A, Wiewiora A. The impact of technology on older adults' social isolation. Comput Hum Behav 2016;63:594-603 [FREE Full text] [doi: 10.1016/j.chb.2016.05.092]
74. Morris ME, Adair B, Ozanne E, Kurowski W, Miller KJ, Pearce AJ, et al. Smart technologies to enhance social connectedness in older people who live at home. Australas J Ageing 2014;33(3):142-152 [FREE Full text] [doi: 10.1111/ajag.12154] [Medline: 24730370]
75. Wei S, Kang B, Bailey DE, Caves K, Lin Y, McConnell ES, et al. Using technology to measure older adults' social networks for health and well-being: a scoping review. Gerontologist 2022;62(7):e418-e430 [FREE Full text] [doi: 10.1093/geront/gnab039] [Medline: 33754150]
76. Halim I, Umar RZR, Saptari A, Padmanathan V. A review on hand-operated product parameters influencing hand grip of senior citizen. Int J Integr Eng 2020;12(4):191-209 [FREE Full text]
77. Linn N, Goetzinger C, Regnaux JP, Schmitz S, Dessenne C, Fagherazzi G, et al. Digital health interventions among people living with frailty: a scoping review. J Am Med Dir Assoc 2021;22(9):1802-1812.e21 [FREE Full text] [doi: 10.1016/j.jamda.2021.04.012] [Medline: 34000266]
78. Mugueta-Aguinaga I, Garcia-Zapirain B. Is technology present in frailty? Technology a back-up tool for dealing with frailty in the elderly: a systematic review. Aging Dis 2017;8(2):176-195 [FREE Full text] [doi: 10.14336/AD.2016.0901] [Medline: 28400984]
79. Daniel KM, Cason CL, Ferrell S. Emerging technologies to enhance the safety of older people in their homes. Geriatr Nurs 2009;30(6):384-389 [FREE Full text] [doi: 10.1016/j.gerinurse.2009.08.010] [Medline: 19963147]
80. Chan DKY, Chan LKM, Kuang YM, Le MNV, Celler B. Digital care technologies in people with dementia living in long-term care facilities to prevent falls and manage behavioural and psychological symptoms of dementia: a systematic review. Eur J Ageing 2022;19(3):309-323 [FREE Full text] [doi: 10.1007/s10433-021-00627-5] [Medline: 36052197]
81. Chaudhuri S, Thompson H, Demiris G. Fall detection devices and their use with older adults: a systematic review. J Geriatr Phys Ther 2014;37(4):178-196 [FREE Full text] [doi: 10.1519/JPT.0b013e3182abe779] [Medline: 24406708]
82. Griffith L, Sohel N, Walker K, Jiang Y, Mao Y, Hopkins D, et al. Consumer products and fall-related injuries in seniors. Can J Public Health 2012;103(5):e332-e337 [FREE Full text] [doi: 10.1007/BF03404436] [Medline: 23617983]
83. Miranda-Duro MDC, Nieto-Riveiro L, Concheiro-Moscoso P, Groba B, Pousada T, Canosa N, et al. Occupational therapy and the use of technology on older adult fall prevention: a scoping review. Int J Environ Res Public Health 2021;18(2):702 [FREE Full text] [doi: 10.3390/ijerph18020702] [Medline: 33467571]
84. Ward G, Holliday N, Fielden S, Williams S. Fall detectors: a review of the literature. J Assist Technol 2012;6(3):202-215 [FREE Full text] [doi: 10.1108/17549451211261326]
85. Fatehi F, Jahedi F, Tay-Kearney ML, Kanagasingam Y. Teleophthalmology for the elderly population: a review of the literature. Int J Med Inform 2020;136:104089 [FREE Full text] [doi: 10.1016/j.ijmedinf.2020.104089] [Medline: 32044698]

86. Peetoom KKB, Lexis MAS, Joore M, Dirksen CD, De Witte LP. Literature review on monitoring technologies and their outcomes in independently living elderly people. Disabil Rehabil Assist Technol 2015;10(4):271-294 [FREE Full text] [doi: 10.3109/17483107.2014.961179] [Medline: 25252024]
87. Read E, Woolsey C, Donelle L, Weeks L, Chinho N. Passive remote monitoring and aging in place: a scoping review. Can J Aging 2023;42(1):20-32 [FREE Full text] [doi: 10.1017/S0714980822000198] [Medline: 35912590]
88. Fadzil NHM, Shahar S, Rajikan R, Singh DKA, Ludin AFM, Subramaniam P, et al. A scoping review for usage of telerehabilitation among older adults with mild cognitive impairment or cognitive frailty. Int J Environ Res Public Health 2022;19(7):4000 [FREE Full text] [doi: 10.3390/ijerph19074000] [Medline: 35409683]
89. Fakontis C, Iakovidis P, Lytras D, Kasimis K, Kottaras A, Chasapis G. The efficacy of telerehabilitation in older adults after a hip injury: a narrative review. Crit Rev Phys Rehabil Med 2022;34(1):17-28. [doi: 10.1615/critrevphysrehabilmed.2022042895]
90. Reeder B, Chung J, Stevens-Lapsley J. Current telerehabilitation research with older adults at home: an integrative review. J Gerontol Nurs 2016;42(10):15-20 [FREE Full text] [doi: 10.3928/00989134-20160201-02] [Medline: 26870988]
91. Saito T, Izawa KP. Effectiveness and feasibility of home-based telerehabilitation for community-dwelling elderly people in Southeast Asian countries and regions: a systematic review. Aging Clin Exp Res 2021;33(10):2657-2669 [FREE Full text] [doi: 10.1007/s40520-021-01820-3] [Medline: 33765258]
92. Tonga E, Srikesavan C, Williamson E, Lamb SE. Components, design and effectiveness of digital physical rehabilitation interventions for older people: a systematic review. J Telemed Telecare 2022;28(3):162-176 [FREE Full text] [doi: 10.1177/1357633X20927587] [Medline: 32517544]
93. Velayati F, Ayatollahi H, Hemmat M. A systematic review of the effectiveness of telerehabilitation interventions for therapeutic purposes in the elderly. Methods Inf Med 2020;59(2-03):104-109 [FREE Full text] [doi: 10.1055/s-0040-1713398] [Medline: 32629502]
94. Husebø AML, Storm M. Virtual visits in home health care for older adults. ScientificWorldJournal 2014;2014:689873 [FREE Full text] [doi: 10.1155/2014/689873] [Medline: 25506616]
95. Marziali E, Serafini JMD, McCleary L. A systematic review of practice standards and research ethics in technology-based home health care intervention programs for older adults. J Aging Health 2005;17(6):679-696 [FREE Full text] [doi: 10.1177/0898264305281100] [Medline: 16377767]
96. Bhattarai P, Phillips JL. The role of digital health technologies in management of pain in older people: an integrative review. Arch Gerontol Geriatr 2017;68:14-24 [FREE Full text] [doi: 10.1016/j.archger.2016.08.008] [Medline: 27584871]
97. Pani-Harreman KE, Bours GJJW, Zander I, Kempen GIHM, van Duren JMA. Definitions, key themes and aspects of ‘ageing in place’: a scoping review. Ageing Soc 2021;41(9):2026-2059 [FREE Full text] [doi: 10.1017/S0144686X20000094]
98. Peek STM, Wouters EJM, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJM. Factors influencing acceptance of technology for aging in place: a systematic review. Int J Med Inform 2014;83(4):235-248 [FREE Full text] [doi: 10.1016/j.ijmedinf.2014.01.004] [Medline: 24529817]
99. Tsertsidis A, Kolkowska E, Hedström K. Factors influencing seniors' acceptance of technology for ageing in place in the post-implementation stage: a literature review. Int J Med Inform 2019;129:324-333 [FREE Full text] [doi: 10.1016/j.ijmedinf.2019.06.027] [Medline: 31445274]
100. Merkel S, Kucharski A. Participatory design in gerontechnology: a systematic literature review. Gerontologist 2019;59(1):e16-e25 [FREE Full text] [doi: 10.1093/geront/gny034] [Medline: 29788319]
101. Rodeschini G. Gerotechnology: a new kind of care for aging? An analysis of the relationship between older people and technology. Nurs Health Sci 2011;13(4):521-528 [FREE Full text] [doi: 10.1111/j.1442-2018.2011.00634.x] [Medline: 21929580]
102. Sundgren S, Stolt M, Suhonen R. Ethical issues related to the use of gerontechnology in older people care: a scoping review. Nurs Ethics 2020;27(1):88-103 [FREE Full text] [doi: 10.1177/0969733019845132] [Medline: 31113266]
103. Hofmann B. Ethical challenges with welfare technology: a review of the literature. Sci Eng Ethics 2013;19(2):389-406 [FREE Full text] [doi: 10.1007/s11948-011-9348-1] [Medline: 22218998]
104. Zander V, Gustafsson C, Stridsberg SL, Borg J. Implementation of welfare technology: a systematic review of barriers and facilitators. Disabil Rehabil Assist Technol 2021:1-16 [FREE Full text] [doi: 10.1080/17483107.2021.1938707] [Medline: 34129802]
105. Zander V, Johansson-Pajala RM, Gustafsson C. Methods to evaluate perspectives of safety, independence, activity, and participation in older persons using welfare technology. A systematic review. Disabil Rehabil Assist Technol 2020;15(4):373-393 [FREE Full text] [doi: 10.1080/17483107.2019.1574919] [Medline: 30786779]
106. Kim H, Kelly S, Lafortune L, Brayne C. A scoping review of the conceptual differentiation of technology for healthy aging. Gerontologist 2021;61(7):e345-e369 [FREE Full text] [doi: 10.1093/geront/gnaa051] [Medline: 32725147]
107. Ludwig W, Wolf KH, Duwenkamp C, Gusew N, Hellrung N, Marschollek M, et al. Health-enabling technologies for the elderly—an overview of services based on a literature review. Comput Methods Programs Biomed 2012;106(2):70-78 [FREE Full text] [doi: 10.1016/j.cmpb.2011.11.001] [Medline: 22115611]
108. Abdi J, Al-Hindawi A, Ng T, Vizcaychipi MP. Scoping review on the use of socially assistive robot technology in elderly care. BMJ Open 2018;8(2):e018815 [FREE Full text] [doi: 10.1136/bmjopen-2017-018815] [Medline: 29440212]

109. Fischer B, Peine A, Östlund B. The importance of user involvement: a systematic review of involving older users in technology design. Gerontologist 2020;60(7):e513-e523 [FREE Full text] [doi: 10.1093/geront/gnz163] [Medline: 31773145]
110. Hennessy JL, Rodrigues A. Economic impacts of changing technologies on New Zealand homecare delivery. J Enabling Technol 2019:188-200 [FREE Full text] [doi: 10.1108/jet-11-2018-0055]
111. Morato J, Sanchez-Cuadrado S, Iglesias A, Campillo A, Fernández-Panadero C. Sustainable technologies for older adults. Sustainability 2021;13(15):8465 [FREE Full text] [doi: 10.3390/su13158465]
112. Piau A, Campo E, Rumeau P, Vellas B, Nourhashémi F. Aging society and gerontechnology: a solution for an independent living? J Nutr Health Aging 2014;18(1):97-112 [FREE Full text] [doi: 10.1007/s12603-013-0356-5] [Medline: 24402399]
113. Barlow J, Singh D, Bayer S, Curry R. A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. J Telemed Telecare 2007;13(4):172-179 [FREE Full text] [doi: 10.1258/135763307780908058] [Medline: 17565772]
114. Botsis T, Hartvigsen G. Current status and future perspectives in telecare for elderly people suffering from chronic diseases. J Telemed Telecare 2008;14(4):195-203 [FREE Full text] [doi: 10.1258/jtt.2008.070905] [Medline: 18534954]
115. Brownsell S, Aldred H, Hawley MS. The role of telecare in supporting the needs of elderly people. J Telemed Telecare 2007;13(6):293-297. [doi: 10.1258/135763307781644870] [Medline: 17785026]
116. Hvalič-Touzery S, Dolničar V, Prevodnik K. Factors influencing informal carers' acceptance of assistive telecare systems in the pre- and post-implementation phase: a scoping study. Health Soc Care Community 2022;30(5):e1484-e1504 [FREE Full text] [doi: 10.1111/hsc.13840] [Medline: 35574935]
117. Karlsen C, Ludvigsen MS, Moe CE, Haraldstad K, Thygesen E. Experiences of community-dwelling older adults with the use of telecare in home care services: a qualitative systematic review. JBI Database System Rev Implement Rep 2017;15(12):2913-2980 [FREE Full text] [doi: 10.11124/JBISRIR-2017-003345] [Medline: 29219874]
118. Saeed N, Manzoor M, Khosravi P. An exploration of usability issues in telecare monitoring systems and possible solutions: a systematic literature review. Disabil Rehabil Assist Technol 2020;15(3):271-281 [FREE Full text] [doi: 10.1080/17483107.2019.1578998] [Medline: 30794009]
119. Stewart LSP, McKinstry B. Fear of falling and the use of telecare by older people. Br J Occup Ther 2012;75(7):304-312 [FREE Full text] [doi: 10.4276/030802212X13418284515758]
120. Brignell M, Wootton R, Gray L. The application of telemedicine to geriatric medicine. Age Ageing 2007;36(4):369-374 [FREE Full text] [doi: 10.1093/ageing/afm045] [Medline: 17449535]
121. Jamal NE, Abi-Saleh B, Isma'eel H. Advances in telemedicine for the management of the elderly cardiac patient. J Geriatr Cardiol 2021;18(9):759-767 [FREE Full text] [doi: 10.11909/j.issn.1671-5411.2021.09.004] [Medline: 34659382]
122. Haralambous B, Subramaniam S, Hwang K, Dow B, LoGiudice D. A narrative review of the evidence regarding the use of telemedicine to deliver video-interpreting during dementia assessments for older people. Asia Pac Psychiatry 2019;11(3):e12355 [FREE Full text] [doi: 10.1111/appy.12355] [Medline: 31025506]
123. Pang NQ, Lau J, Fong SY, Wong CYH, Tan KK. Telemedicine acceptance among older adult patients with cancer: scoping review. J Med Internet Res 2022;24(3):e28724 [FREE Full text] [doi: 10.2196/28724] [Medline: 35348462]
124. Ramos-Ríos R, Mateos R, Lojo D, Conn DK, Patterson T. Telepsychogeriatrics: a new horizon in the care of mental health problems in the elderly. Int Psychogeriatr 2012;24(11):1708-1724 [FREE Full text] [doi: 10.1017/S1041610212000981] [Medline: 22687259]
125. Sekhon H, Sekhon K, Launay C, Afililo M, Innocente N, Vahia I, et al. Telemedicine and the rural dementia population: a systematic review. Maturitas 2021;143:105-114 [FREE Full text] [doi: 10.1016/j.maturitas.2020.09.001] [Medline: 33308615]
126. Chan JKY, Klainin-Yobas P, Chi Y, Gan JKE, Chow G, Wu XV. The effectiveness of e-interventions on fall, neuromuscular functions and quality of life in community-dwelling older adults: a systematic review and meta-analysis. Int J Nurs Stud 2021;113:103784 [FREE Full text] [doi: 10.1016/j.ijnurstu.2020.103784] [Medline: 33120138]
127. Airola E. Learning and use of eHealth among older adults living at home in rural and nonrural settings: systematic review. J Med Internet Res 2021;23(12):e23804 [FREE Full text] [doi: 10.2196/23804] [Medline: 34860664]
128. Ambrens M, Alley S, Oliveira JS, To Q, Delbaere K, Vandelanotte C, et al. Effect of eHealth-delivered exercise programmes on balance in people aged 65 years and over living in the community: a systematic review and meta-analysis of randomised controlled trials. BMJ Open 2022;12(6):e051377 [FREE Full text] [doi: 10.1136/bmjopen-2021-051377] [Medline: 35688586]
129. Muellmann S, Forberger S, Möllers T, Bröring E, Zeeb H, Pischke CR. Effectiveness of eHealth interventions for the promotion of physical activity in older adults: a systematic review. Prev Med 2018;108:93-110 [FREE Full text] [doi: 10.1016/j.ypmed.2017.12.026] [Medline: 29289643]
130. Preschl B, Wagner B, Forstmeier S, Maercker A. E-health interventions for depression, anxiety disorder, dementia, and other disorders in older adults: a review. J Cyber Ther Rehabil 2011;4(3):371-385 [FREE Full text] [doi: 10.5167/uzh-67320]
131. Robert C, Erdt M, Lee J, Cao Y, Naharudin NB, Theng YL. Effectiveness of eHealth nutritional interventions for middle-aged and older adults: systematic review and meta-analysis. J Med Internet Res 2021;23(5):e15649 [FREE Full text] [doi: 10.2196/15649] [Medline: 33999005]
132. Sanyal C, Stolee P, Juzwishin D, Husereau D. Economic evaluations of eHealth technologies: a systematic review. PLoS One 2018;13(6):e0198112 [FREE Full text] [doi: 10.1371/journal.pone.0198112] [Medline: 29897921]

133. Sülz S, van Elten HJ, Askari M, Weggelaar-Jansen AM, Huijsman R. eHealth applications to support independent living of older persons: scoping review of costs and benefits identified in economic evaluations. J Med Internet Res 2021;23(3):e24363 [FREE Full text] [doi: 10.2196/24363] [Medline: 33687335]
134. Vázquez A, Jenaro C, Flores N, Bagnato MJ, Pérez MC, Cruz M. E-Health interventions for adult and aging population with intellectual disability: a review. Front Psychol 2018;9:2323 [FREE Full text] [doi: 10.3389/fpsyg.2018.02323] [Medline: 30534103]
135. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021;21(1):1556 [FREE Full text] [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]
136. Bastoni S, Wrede C, da Silva MC, Sanderman R, Gaggioli A, Braakman-Jansen A, et al. Factors influencing implementation of eHealth technologies to support informal dementia care: umbrella review. JMIR Aging 2021;4(4):e30841 [FREE Full text] [doi: 10.2196/30841] [Medline: 34623314]
137. Buyl R, Beogo I, Fobelets M, Deletroz C, Van Landuyt P, Dequanter S, et al. e-Health interventions for healthy aging: a systematic review. Syst Rev 2020;9(1):128 [FREE Full text] [doi: 10.1186/s13643-020-01385-8] [Medline: 32493515]
138. Dequanter S, Gagnon MP, Ndiaye MA, Gorus E, Fobelets M, Giguère A, et al. The effectiveness of e-Health solutions for aging with cognitive impairment: a systematic review. Gerontologist 2021;61(7):e373-e394 [FREE Full text] [doi: 10.1093/geront/gnaa065] [Medline: 32525977]
139. Gaspar AGM, Lapão LV. eHealth for addressing balance disorders in the elderly: systematic review. J Med Internet Res 2021;23(4):e22215 [FREE Full text] [doi: 10.2196/22215] [Medline: 33908890]
140. Hirvonen N, Enwald H, Känsäkoski H, Eriksson-Backa K, Nguyen H, Huhta AM, et al. Older adults' views on eHealth services: a systematic review of scientific journal articles. Int J Med Inform 2020;135:104031 [FREE Full text] [doi: 10.1016/j.ijmedinf.2019.104031] [Medline: 31918340]
141. Kwan RYC, Salihu D, Lee PH, Tse M, Cheung DSK, Roopsawang I, et al. The effect of e-health interventions promoting physical activity in older people: a systematic review and meta-analysis. Eur Rev Aging Phys Act 2020;17:7 [FREE Full text] [doi: 10.1186/s11556-020-00239-5] [Medline: 32336996]
142. Lindberg T, Sandström B, Andersson EK, Borg C, Hjelm M, Nilsson L, et al. Older persons' experience of eHealth services in home health care: a meta-ethnography eHealth services in home health care. Health Informatics J 2021;27(4):14604582211059370 [FREE Full text] [doi: 10.1177/14604582211059370] [Medline: 36047741]
143. Marques B, McIntosh J, Valera A, Gaddam A. Innovative and assistive ehealth technologies for smart therapeutic and rehabilitation outdoor spaces for the elderly demographic. Multimodal Technol Interact 2020;4(4):1-21 [FREE Full text] [doi: 10.26686/wgtn.13132970.v1]
144. Marasinghe KM. Assistive technologies in reducing caregiver burden among informal caregivers of older adults: a systematic review. Disabil Rehabil Assist Technol 2016;11(5):353-360 [FREE Full text] [doi: 10.3109/17483107.2015.1087061] [Medline: 26371519]
145. Marston HR, Samuels J. A review of age friendly virtual assistive technologies and their effect on daily living for carers and dependent adults. Healthcare (Basel) 2019;7(1):49 [FREE Full text] [doi: 10.3390/healthcare7010049] [Medline: 30901898]
146. Carswell W, McCullagh PJ, Augusto JC, Martin S, Mulvenna MD, Zheng H, et al. A review of the role of assistive technology for people with dementia in the hours of darkness. Technol Health Care 2009;17(4):281-304 [FREE Full text] [doi: 10.3233/THC-2009-0553] [Medline: 19822946]
147. Shagerdi G, Ayatollahi H, Hemmat M. Emergency care for the elderly: a review of the application of health information technology. Health Policy Technol 2022;11(1):100592 [FREE Full text] [doi: 10.1016/j.hlpt.2021.100592]
148. Sriram V, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. BMC Geriatr 2019;19(1):160 [FREE Full text] [doi: 10.1186/s12877-019-1169-0] [Medline: 31196003]
149. Marschollek M, Mix S, Wolf KH, Effertz B, Haux R, Steinhagen-Thiessen E. ICT-based health information services for elderly people: past experiences, current trends, and future strategies. Med Inform Internet Med 2007;32(4):251-261 [FREE Full text] [doi: 10.1080/14639230701692736] [Medline: 18072003]
150. McLean B, Hossain N, Donison V, Gray M, Durbano S, Haase K, et al. Providing medical information to older adults in a web-based environment: systematic review. JMIR Aging 2021;4(1):e24092 [FREE Full text] [doi: 10.2196/24092] [Medline: 33560228]
151. Mordoch E, Osterreicher A, Guse L, Roger K, Thompson G. Use of social commitment robots in the care of elderly people with dementia: a literature review. Maturitas 2013;74(1):14-20 [FREE Full text] [doi: 10.1016/j.maturitas.2012.10.015] [Medline: 23177981]
152. Moret-Tatay C, Iborra-Marmolejo I, Jorques-Infante MJ, Esteve-Rodrigo JV, Schwanke CHA, Irigaray TQ. Can virtual assistants perform cognitive assessment in older adults? A review. Medicina (Kaunas) 2021;57(12):1310 [FREE Full text] [doi: 10.3390/medicina57121310] [Medline: 34946255]
153. Moyle W, Arnautovska U, Ownsworth T, Jones C. Potential of telepresence robots to enhance social connectedness in older adults with dementia: an integrative review of feasibility. Int Psychogeriatr 2017;29(12):1951-1964 [FREE Full text] [doi: 10.1017/S1041610217001776] [Medline: 28879828]

154. Moyle W, Murfield J, Lion K. The effectiveness of smart home technologies to support the health outcomes of community-dwelling older adults living with dementia: a scoping review. Int J Med Inform 2021;153:104513 [FREE Full text] [doi: 10.1016/j.ijmedinf.2021.104513] [Medline: 34116363]
155. Ong YC, Tang A, Tam W. Effectiveness of robot therapy in the management of behavioural and psychological symptoms for individuals with dementia: a systematic review and meta-analysis. J Psychiatr Res 2021;140:381-394 [FREE Full text] [doi: 10.1016/j.jpsychires.2021.05.077] [Medline: 34144442]
156. Gordon LAN. Assessment of smart watches for management of non-communicable diseases in the ageing population: a systematic review. Geriatrics (Basel) 2018;3(3):56 [FREE Full text] [doi: 10.3390/geriatrics3030056] [Medline: 31011093]
157. Bhidayasiri R, Jitkritsadakul O, Boonrod N, Sringean J, Calne SM, Hattori N, et al. What is the evidence to support home environmental adaptation in Parkinson's disease? A call for multidisciplinary interventions. Parkinsonism Relat Disord 2015;21(10):1127-1132. [doi: 10.1016/j.parkreldis.2015.08.025] [Medline: 26365779]
158. Giannakopoulou KM, Roussaki I, Demestichas K. Internet of things technologies and machine learning methods for Parkinson's disease diagnosis, monitoring and management: a systematic review. Sensors (Basel) 2022;22(5):1799 [FREE Full text] [doi: 10.3390/s22051799] [Medline: 35270944]
159. Marx W, Kelly JT, Crichton M, Craven D, Collins J, Mackay H, et al. Is telehealth effective in managing malnutrition in community-dwelling older adults? A systematic review and meta-analysis. Maturitas 2018;111:31-46 [FREE Full text] [doi: 10.1016/j.maturitas.2018.02.012] [Medline: 29673830]
160. Tan SHX, Lee CKJ, Yong CW, Ding YY. Scoping review: facilitators and barriers in the adoption of teledentistry among older adults. Gerodontology 2021;38(4):351-365 [FREE Full text] [doi: 10.1111/ger.12588] [Medline: 34523172]
161. Dunham M, Bonacaro A, Schofield P, Bacon L, Spyridonis F, Mehrpouya H. Smartphone applications designed to improve older people's chronic pain management: an integrated systematic review. Geriatrics (Basel) 2021;6(2):40 [FREE Full text] [doi: 10.3390/geriatrics6020040] [Medline: 33917697]
162. Backonja U, Chi NC, Choi Y, Hall AK, Le T, Kang Y, et al. Visualization approaches to support healthy aging: a systematic review. J Innov Health Inform 2016;23(3):860 [FREE Full text] [doi: 10.14236/jhi.v23i3.860] [Medline: 28059694]
163. Cicirelli G, Marani R, Petitti A, Milella A, D'Orazio T. Ambient assisted living: a review of technologies, methodologies and future perspectives for healthy aging of population. Sensors (Basel) 2021;21(10):3549 [FREE Full text] [doi: 10.3390/s21103549] [Medline: 34069727]
164. Liu N, Yin J, Tan SSL, Ngiam KY, Teo HH. Mobile health applications for older adults: a systematic review of interface and persuasive feature design. J Am Med Inform Assoc 2021;28(11):2483-2501 [FREE Full text] [doi: 10.1093/jamia/ocab151] [Medline: 34472601]
165. Nilsson MY, Andersson S, Magnusson L, Hanson E. Ambient assisted living technology-mediated interventions for older people and their informal carers in the context of healthy ageing: a scoping review. Health Sci Rep 2021;4(1):e225 [FREE Full text] [doi: 10.1002/hsr2.225] [Medline: 33392394]
166. McSweeney-Feld MH. Assistive technology and older adults in disasters: implications for emergency management. Disaster Med Public Health Prep 2017;11(1):135-139 [FREE Full text] [doi: 10.1017/dmp.2016.160] [Medline: 27866509]
167. Baraković S, Husić JB, van Hoof J, Krejcar O, Maresova P, Akhtar Z, et al. Quality of life framework for personalised ageing: a systematic review of ICT solutions. Int J Environ Res Public Health 2020;17(8):2940 [FREE Full text] [doi: 10.3390/ijerph17082940] [Medline: 32344521]
168. Damant J, Knapp M, Freddolino P, Lombard D. Effects of digital engagement on the quality of life of older people. Health Soc Care Community 2017;25(6):1679-1703 [FREE Full text] [doi: 10.1111/hsc.12335] [Medline: 26919220]
169. Guerra S, Rosa C, Sousa L, Neves A, Pestana G, Hernández MJ, et al. The use of robotic pets by community-dwelling older adults: a scoping review. Int J of Soc Robotics 2022;14(6):1481-1492 [FREE Full text] [doi: 10.1007/s12369-022-00892-z]
170. Kruse C, Fohn J, Wilson N, Patlan EN, Zipp S, Mileski M. Utilization barriers and medical outcomes commensurate with the use of telehealth among older adults: systematic review. JMIR Med Inform 2020;8(8):e20359 [FREE Full text] [doi: 10.2196/20359] [Medline: 32784177]
171. Martínez-Alcalá CI, Pliego-Pastrana P, Rosales-Lagarde A, Lopez-Noguerola JS, Molina-Trinidad EM. Information and communication technologies in the care of the elderly: systematic review of applications aimed at patients with dementia and caregivers. JMIR Rehabil Assist Technol 2016;3(1):e6 [FREE Full text] [doi: 10.2196/rehab.5226] [Medline: 28582258]
172. Siegel C, Dorner TE. Information technologies for active and assisted living-Influences to the quality of life of an ageing society. Int J Med Inform 2017;100:32-45 [FREE Full text] [doi: 10.1016/j.ijmedinf.2017.01.012] [Medline: 28241936]
173. Wong AKC, Bayuo J, Wong FKY, Yuen WS, Lee AYL, Chang PK, et al. Effects of a nurse-led telehealth self-care promotion program on the quality of life of community-dwelling older adults: systematic review and meta-analysis. J Med Internet Res 2022;24(3):e31912 [FREE Full text] [doi: 10.2196/31912] [Medline: 35311680]
174. Choukou MA, Maddahi A, Polyvyana A, Monnin C. Digital health technology for indigenous older adults: a scoping review. Int J Med Inform 2021;148:104408 [FREE Full text] [doi: 10.1016/j.ijmedinf.2021.104408] [Medline: 33609927]
175. Holthe T, Halvorsrud L, Lund A. Digital assistive technology to support everyday living in community-dwelling older adults with mild cognitive impairment and dementia. Clin Interv Aging 2022;17:519-544 [FREE Full text] [doi: 10.2147/CIA.S357860] [Medline: 35464157]

176. D'Onofrio G, Sancarlo D, Ricciardi F, Panza F, Seripa D, Cavallo F, et al. Information and communication technologies for the activities of daily living in older patients with dementia: a systematic review. J Alzheimers Dis 2017;57(3):927-935 [FREE Full text] [doi: 10.3233/JAD-161145] [Medline: 28304297]
177. Gochoo M, Alnajjar F, Tan TH, Khalid S. Towards privacy-preserved aging in place: a systematic review. Sensors (Basel) 2021;21(9):3082 [FREE Full text] [doi: 10.3390/s21093082] [Medline: 33925161]
178. Gokalp H, Clarke M. Monitoring activities of daily living of the elderly and the potential for its use in telecare and telehealth: a review. Telemed J E Health 2013;19(12):910-923 [FREE Full text] [doi: 10.1089/tmj.2013.0109] [Medline: 24102101]
179. Liu L, Stroulia E, Nikolaidis I, Miguel-Cruz A, Rincon AR. Smart homes and home health monitoring technologies for older adults: a systematic review. Int J Med Inform 2016;91:44-59 [FREE Full text] [doi: 10.1016/j.ijmedinf.2016.04.007] [Medline: 27185508]
180. Klimova B, Valis M, Kuca K. Exploring assistive technology as a potential beneficial intervention tool for people with Alzheimer's disease - a systematic review. Neuropsychiatr Dis Treat 2018;14:3151-3158 [FREE Full text] [doi: 10.2147/NDT.S181849] [Medline: 30532546]
181. Ozdemir D, Cibulka J, Stepankova O, Holmerova I. Design and implementation framework of social assistive robotics for people with dementia - a scoping review. Health Technol 2021;11(2):367-378 [FREE Full text] [doi: 10.1007/s12553-021-00522-0]
182. Fares N, Sherratt RS, Elhajj IH. Directing and orienting ICT healthcare solutions to address the needs of the aging population. Healthcare (Basel) 2021;9(2):147 [FREE Full text] [doi: 10.3390/healthcare9020147] [Medline: 33540510]
183. Stokke R. The personal emergency response system as a technology innovation in primary health care services: an integrative review. J Med Internet Res 2016;18(7):e187 [FREE Full text] [doi: 10.2196/jmir.5727] [Medline: 27417422]
184. Nair PS. Population aging in sub-Saharan Africa: present and prospects. Gerontechnology 2014;13(2):266 [FREE Full text] [doi: 10.4017/gt.2014.13.1.009.00]
185. Bergschöld JM. Configuring dementia; how nursing students are taught to shape the sociopolitical role of gerontechnologies. Front Sociol 2018;3(3) [FREE Full text] [doi: 10.3389/fsoc.2018.00003]
186. Bergschöld JM. Frontline Innovation - How Frontline Care Professionals Innovate Welfare Technology And Services. Trondheim: NTNU; 2018.
187. Bergschöld JM, Neven L. DIY gerontechnology: circumventing mismatched technologies and bureaucratic procedure by creating care technologies of one's own. Sociol Health Illn 2020;42(2):232-246 [FREE Full text]
188. Sørenssen IK, Bergschöld JM. Domesticated smartphones in early childhood education and care settings. Blurring the lines between pedagogical and administrative use. Int J Early Years Educ 2021;31(4):874-887 [FREE Full text] [doi: 10.1080/09669760.2021.1893157]
189. Bergschöld JM. When saving time becomes labor: time, work, and technology in homecare. Nord J Work Life Stud 2018;8(1):3-21 [FREE Full text] [doi: 10.18291/njwls.v8i1.104850]
190. Bergschöld JM. Domesticating homecare services; vehicle route problem solver displaced. Nord J Sci Technol Stud 2016;4(2):41-53 [FREE Full text] [doi: 10.5324/njsts.v4i2.2184]
191. Oudshoorn N. Telecare Technologies and the Transformation of Healthcare. Houndmills, Basingstoke, Hampshire, UK: Palgrave Macmillan; 2012.
192. Pols J, Moser I. Cold technologies versus warm care? On affective and social relations with and through care technologies. Alter 2009;3(2):159-178 [FREE Full text] [doi: 10.1016/j.alter.2009.01.003]
193. Stokke R. From "plug" to "play". Inland Norway University of Applied Sciences. 2019. URL: https://www.inn.no/english/ [accessed 2023-11-19]
194. Sørensen KH, Lie M, editors. Making Technology Our Own? Domesticating Technology Into Everyday Life. Oslo: Scandinavian University Press; 1996.
195. Silverstone R, Haddon L. Design and the domesticatoin of information and communication technologies: technical change and everyday life. In: Communication by Design: The Politics of Information and Communication Technologies. Oxford: Oxford University Press; 1996:44-74.
196. Sørensen KH. Domestication: the enactment of technology. In: Berker T, Hartmann M, Punie Y, Ward KJ, editors. Domestication of Media and Technology. Glasgow: Open University Press; 2006:40-62.
197. Berker T, Hartmann M, Punie Y, Ward KJ, editors. Domestication of Media and Technology. Glasgow: Open University Press; 2006.
198. Berker T. Domesticating spaces: sociotechnical studies and the built environment. Sp Cult 2011;14(3):259-268 [FREE Full text] [doi: 10.1177/1206331211412259]
199. Smits M. Taming monsters: the cultural domestication of new technology. Technol Soc 2006;28(4):489-504 [FREE Full text] [doi: 10.1016/j.techsoc.2006.09.008]
200. Maathuis IJH, Oudshoorn N. Technologies of Compliance? Telecare Technologies and Self-management of Chronic Patients. Enschede: University of Twente; 2015.
201. Joyce K, Peine A, Neven L, Kohlbacher F. Aging: the socio-material constitution of later life. In: Miller CA, Smith-Doerr L, Fouche R, Felt U, editors. The Handbook of Science and Technology Studies, Fourth Edition. Cambridge, MA: MIT Press; 2017:915-942.

202. Saborowski M, Kollak I. “How do you care for technology?” – care professionals' experiences with assistive technology in care of the elderly. Technol Forecast Soc Chang 2015;93:133-140 [FREE Full text] [doi: 10.1016/j.techfore.2014.05.006]
203. Gómez DL. Little arrangements that matter. Rethinking autonomy-enabling innovations for later life. Technol Forecast Soc Change 2015;93:91-101 [FREE Full text] [doi: 10.1016/j.techfore.2014.02.015]
204. Nicolini D. The work to make telemedicine work: a social and articulative view. Soc Sci Med 2006;62(11):2754-2767 [FREE Full text] [doi: 10.1016/j.socscimed.2005.11.001] [Medline: 16343724]
205. Styhre A. Tinkering with material resources: operating under ambiguous conditions in rock construction work. Learn Organ 2009;16(5):386-397 [FREE Full text] [doi: 10.1108/09696470910974171]
206. Travers J, Romero-Ortuno R, Bailey J, Cooney MT. Delaying and reversing frailty: a systematic review of primary care interventions. Br J Gen Pract 2019;69(678):e61-e69. [doi: 10.3399/bjgp18X700241] [Medline: 30510094]

Abbreviations

LMIC: low- and middle-income country
mHealth: mobile health
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review
WHO: World Health Organization

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Original Paper

The Prevalence of Missing Incidents and Their Antecedents Among Older Adult MedicAlert Subscribers: Retrospective Descriptive Study

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Abstract

Background: With the population aging, the number of people living with dementia is expected to rise, which, in turn, is expected to lead to an increase in the prevalence of missing incidents due to critical wandering. However, the estimated prevalence of missing incidents due to dementia is inconclusive in some jurisdictions and overlooked in others.

Objective: The aims of the study were to examine (1) the demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering among older adult MedicAlert Foundation Canada (hereinafter MedicAlert) subscribers; and (2) the characteristics and outcomes of the missing incidents.

Methods: This study used a retrospective descriptive design. The sample included 434 older adult MedicAlert subscribers involved in 560 missing incidents between January 2015 and July 2021.

Results: The sample was overrepresented by White older adults (329/425, 77.4%). MedicAlert subscribers reported missing were mostly female older adults (230/431, 53.4%), living in urban areas with at least 1 family member (277/433, 63.8%). Most of the MedicAlert subscribers (345/434, 79.5%) self-reported living with dementia. MedicAlert subscribers went missing most frequently from their private homes in the community (96/143, 67.1%), traveling on foot (248/270, 91.9%) and public transport (12/270, 4.4%), during the afternoon (262/560, 46.8%) and evening (174/560, 31.1%). Most were located by first responders (232/486, 47.7%) or Good Samaritans (224/486, 46.1%). Of the 560 missing incidents, 126 (22.5%) were repeated missing incidents. The mean time between missing incidents was 11 (SD 10.8) months. Finally, the majority of MedicAlert subscribers were returned home safely (453/500, 90.6%); and reports of harm, injuries (46/500, 9.2%), and death (1/500, 0.2%) were very low.

Conclusions: This study provides the prevalence of missing incidents from 1 database source. The low frequency of missing incidents may not represent populations that are not White. Despite the low number of missing incidents, the 0.2% (1/500) of cases resulting in injuries or death are devastating experiences that may be mitigated through prevention strategies.

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KEYWORDS

dementia; Alzheimer disease; memory loss; cognitive impairment; missing incident; wandering; critical wandering; older adults; retrospective design

Introduction

Background

With the population aging, the number of people living with dementia will increase. Currently, approximately 55 million people have dementia globally [1]. With approximately 10 million new diagnoses each year, the total number of cases is expected to rise to 78 million by 2030 [1]. Canada is no exception to this trend, with at least 546,000 people currently living with dementia [2]. By 2030, the number of Canadians with dementia will reach at least 1,712,400 [3].

The disease burden cost associated with dementia is sizable in Canada. It was estimated that the direct costs (eg, long-term care) associated with dementia was CAD $10.4 billion (US $7.52 billion) in 2016, and it is expected to double by 2030 [2]. Half of the global cost of dementia is attributed to informal care (ie, family members and friends) [1]. It is estimated that, on average, care partners spend 26 to 35 hours per week caring for persons with dementia [1,4]. This overwhelming number of caregiving hours is attributed to personal care (ie, personal care such as bathing, feeding, and assisting with toileting) [5] and vigilance as a prevention strategy to prevent unattended exits, ultimately keeping persons living with dementia safe in their homes [6].

With increasing numbers of people living with dementia, the prevalence of missing incidents due to critical wandering is rising as well (refer to section *The Concept of Missingness and Critical Wandering and Its Risk Factors: A Brief Theoretical Background*). However, research on prevalence estimation on missing incidents due to critical wandering is inconclusive in some jurisdictions and overlooked in others. Limitations of the prior literature on this topic exist. First, there is a lack of consistency on reported prevalence [7], leading to disparate statistics; for example, McShane et al [8] reported that 40% of people with dementia become lost, and 5% do so repeatedly. The Alzheimer's Association estimated that 60% of people with Alzheimer disease will wander [3], and a considerably larger set of studies showed that the prevalence of wandering varies from 11% to 60% [9,10]. Second, previous studies included low sample sizes from limited secondary data sources (eg, data not retained for >5 years) [11] such as police data and data obtained from newspaper report or social media [12-15], leading to a limited scope of the statistical analyses. Third, prevalence studies have been completed in the United States [16,17], Japan [18-20], and South Korea [21,22], leaving the prevalence of missing incidents among people with dementia in Canada largely unknown. This is an important gap in our knowledge because Canada has distinct social, health care, and geographic features as well as a harsh climate, making it challenging to extrapolate data from other countries for its unique context. As a result, the prevalence and risk factors of missing incidents due to critical wandering for Canadians living with dementia remain largely unknown.

Objectives

The aims of this study were to examine (1) the demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering among older adult MedicAlert subscribers; and (2) the characteristics and outcomes of the missing incidents. We used a retrospective descriptive design. The sample included 434 older adult MedicAlert subscribers (hereinafter MedicAlert subscribers) involved in 560 missing incidents between January 2015 and July 2021.

The Concept of Missingness and Critical Wandering and Its Risk Factors: a Brief Theoretical Background

Missingness is the phenomenon of going missing [11]. A missing person is an "individual that cannot be found" [23]. A missing person is "an individual whose whereabouts are unknown to members of their familial, social or professional networks where there is concern for either their own safety and wellbeing or that of others" [24]. A person can go missing intentionally or unintentionally. A person who goes missing unintentionally is said to be lost if the person is (1) "confused with current location in respect to finding other locations" and (2) "unable to reorient" [23]. In this research, we analyzed missing incidents related to persons (older adults) who go missing unintentionally. People living with dementia are at risk of unintentionally getting lost due to critical wandering. "Critical wandering" occurs when an individual living with dementia "leaves an institution or home [with or without the consent of their care partner] and is unaware of his or her situation in terms of place and/or time" [7]; the person is lost. Critical wandering is a necessary (but not a sufficient) condition for a missing incident to occur. A missing incident of a person living with dementia can occur when, for instance, this person is left unsupervised for a few minutes and has an episode of critical wandering [25]. Therefore, critical wandering and missing incident are 2 distinct concepts, although the literature in this field acknowledges that the former could lead to the latter [26].

Antecedents or risk factors influence the mechanisms preceding and contributing to missing incidents [11,26,27]. One way to classify antecedents is to determine whether characteristics are intrinsic (demographic and psychopathological or neurocognitive antecedents) or extrinsic (situational or environmental antecedents) to the missing individual. Demographic antecedents comprise sex, gender, age, and ethnicity of the missing individual. Psychopathological or neurocognitive antecedents are manifestations of behaviors related to cognitive or psychological impairment or mental illness, disorders, or distress. Finally, environmental antecedents may include social, cultural, political, economic, and weather conditions [11]. Another way to classify antecedents is to determine whether they are fixed or variable. A fixed antecedent is one that does not vary within individuals over time (eg, ethnicity). Conversely, a variable antecedent changes over time (eg, the age of an individual) [28]. Missing incidents can lead to consequences or outcomes for the missing person and their care partners [26]. For a missing person, these outcomes can range from returning home safely to minor injuries, major injuries, or even death [26].

MedicAlert Service

MedicAlert is a Canadian-based service that can assist first responders and Good Samaritans in identifying an individual who has gone missing and connecting them with their care partners to help them return to their place of residence. The 2 primary tools used in the service are a medical ID object and a personal health information record. The ID object, which is typically in the form of a bracelet, contains key health conditions and a unique MedicAlert ID number specific to the individual. The MedicAlert ID number can then be used by authorized personnel to access a subscriber's personal health information record, which contains extensive details about the subscriber's medical conditions and medications as well as information on previous wandering history if provided by the subscriber or care partner. It is important to recognize that information is self-reported instead of provided by, or confirmed with, health providers, that is, a MedicAlert subscriber or care partners are at liberty to disclose details about the person's situation and medical condition when the person goes missing. This information is relayed via a 24/7 hotline or by direct digital access by police dispatchers. When the missing person is found, the hotline operator or the police dispatcher notifies the care partners about the missing person's location [29]. By linking care partners, first responders, and Good Samaritans, the goal is to safely return the missing person back home.

Methods

Ethical Considerations

The University of Waterloo ethics review board approved this study (43164).

Study Design and Sample

We used a retrospective descriptive design. The sample included 434 older adult MedicAlert subscribers involved in 560 missing incidents between January 2015 and July 2021. Data were obtained from the MedicAlert subscriber and hotline call operators databases and summary notes made by hotline call operators. Both databases are linked through a unique MedicAlert subscriber ID number.

Variables and Measures

We obtained information on the variables described in Textbox 1 (refer to Multimedia Appendix 1 for more details).

Textbox 1. Study variables.

Variable and description

- Demographic antecedents: age, sex at birth, ethnic background, official Canadian languages spoken, province, and primary contact
- Psychopathological antecedents: medical conditions
- Environmental antecedents: domicile (urban vs rural) and living arrangement

Characteristics of the missing incidents: mode of mobility, the time of day and season in which the missing incident occurred, the family care partner's involvement in response to the missing incident, who reported and found the missing person, point last seen or where the person was missing from, location in which the person was found (actual and self-reported), number of missing incidents, repeated missing incident history (actual and self-reported), mean time to the first missing incident (in days), mean time between missing incidents (in days), and survivability

Procedures

Missing Incident Selection Procedure

Detailed information about the missing incidents were obtained from the summary notes made by the MedicAlert hotline operator when a call was received at the MedicAlert call center. These notes are documented by the operator each time a call is received and were in free-text format. We included missing incidents in which the MedicAlert subscribers (1) were aged ≥65 years, (2) went missing unintentionally, and (3) there was clear indication that the subscriber was actually lost (indications of disorientation or confusion or spatial navigation challenges). We excluded missing incidents that (1) were false positive reports (eg, GPS devices were activated and generated a record in the hotline access database, miscommunication between family members, and missing incident calls created for training purposes), (2) were a duplicate missing incident in which several follow-up calls were associated with the same missing incident, or (3) did not contain enough information from which to extract data.

Upon receiving the data set, 8 team members (including the authors) immersed themselves in the data set. Each read 60 different call summary notes and made notes on their contents in relation to the free-text fields in the MedicAlert subscriber database (eg, domicile [urban vs rural]; refer to Multimedia Appendix 1 for more details). Team members shared their observations during 2 subsequent meetings, and these were used to create a preliminary coding framework, including key definitions and the operationalization of each variable (refer to the next subsection for more details). Two team members, hereinafter referred to as analysts, screened, extracted, and coded relevant information from the summary notes made by the MedicAlert hotline operator using the coding framework. The analysts then completed a calibration exercise in which they independently applied the inclusion and exclusion criteria as well as coded 10 included missing incidents. The calibration exercise was conducted as follows: first, 10 cases were selected randomly; next, 2 researchers independently assessed the cases based on the inclusion and exclusion criteria; and, finally, the 2 researchers met and debriefed on the main causes of disagreements. In the calibration process, the team achieved a 90% agreement (ie, percentage of agreement calculated as the number of times a set of ratings is the same divided by the total number of units of observation that are rated). The analysts then screened and coded data for another 100 missing incidents (registries) independently and checked each other's work. The coding framework was revised to improve the clarity of the definitions and the operationalization of the codes. The analysts met weekly to discuss missing incidents that were unclear or required a second opinion and revised the coding framework to increase clarity. When the coding framework was revised, the analysts reviewed the previously coded data against the revised coding framework and recoded as necessary. The analysts also sought feedback from the first author when conflicts arose in their screening and coding. In total, 7045 missing incidents were screened from the hotline access MedicAlert database; after applying the inclusion and exclusion criteria, 6485 (92.5%) incidents were excluded. The 6485 missing incidents were excluded due to false positive reports (n=5093, 78.84%), not enough information from which to extract data (n=1076, 16.66%), no indications of disorientation or confusion or spatial navigation challenges (n=270, 3.8%), and MedicAlert subscribers being aged <65 years (n=46, 0.65%).

Categories Generation and Operationalization of Variables

After the data set was cleaned, variables regarding antecedents to the missing incident were coded categorically based on previous research [30,31] and following Statistics Canada classifications whenever possible [32]. As some variables were stored in the form of free text, categories were generated inductively from the information contained in the free text (refer to the preceding subsection; eg, missing incident notes compiled by the hotline operator). Finally, all variables were operationalized as follows: dichotomous variables were coded as *0* or *1* (eg, MedicAlert subscriber's sex), and each polytomous variable was represented by a set of binary variables, whose values codified each variable category.

Data Analyses

We used descriptive statistics, including mean and SDs, to summarize the central values of distributions for continuous variables. We used the chi-square and Fisher exact—in the case of small, expected counts—tests for comparing categorical variables. Where appropriate, *t* tests (2-tailed) or the Mann-Whitney *U* test (2 independent groups, 2-tailed) and 1-way ANOVA (2-tailed) or the Kruskal-Wallis rank sum test (>2 groups, 2-tailed) were used for determining the difference between groups for continuous variables. Where appropriate, we used Cramer V and Pearson and Spearman ρ to determine correlations or associations between variables. As this was a retrospective descriptive study, each variable was examined separately [31]. Statistical analysis was conducted using SPSS software (version 28.0; IBM Corp). The α was set at .05.

Results

Demographic, Psychopathological, and Environmental Antecedents to Missing Incidents Among MedicAlert Subscribers

Table 1 shows the demographic and environmental antecedents to missing incidents among MedicAlert subscribers. Overall, 434 MedicAlert subscribers were involved in 560 missing incidents between January 2015 and July 2021. Regarding psychopathological or neurocognitive antecedents, in 79.5% (345/434) of the cases, MedicAlert subscribers self-reported living with dementia, and the remaining 20.5% (89/434) self-reported having other medical conditions, the most prevalent being short- and long-term memory loss and mental health issues such as depression, schizophrenia, and anxiety disorder. However, it is important to keep in mind that these data are self-disclosed at the time of subscribing to MedicAlert and thus may underestimate the true prevalence of dementia in this sample. The average age of the MedicAlert subscribers was 82.56 (SD 7.4) years, with a little more than half (230/431, 53.4%) identifying as female. The most prevalent age groups were 75 to 84 years (177/434, 40.8%) and 85 to 94 years (168/434, 38.7%), together representing 79.5% (345/434) of the sample. White older adults represented the vast majority (329/425, 77.4%) of the subscribers. In 55.8% (240/430) of the cases, the subscribers spoke English, with an additional 18.1% (78/430) who spoke another language or other languages in addition to English; notably, 11.6% (50/430) of the subscribers spoke neither of the 2 official Canadian languages, English and French. MedicAlert subscribers primarily resided in Ontario (199/341, 58.3%), British Columbia (57/341, 16.7%), or Quebec (50/341, 14.7%); and a vast majority (331/341, 97.1%) lived in urban areas. Living arrangements included with family (277/433, 64%) and in a facility (90/433, 20.8%), although 13.1% (57/433) reported living alone. Most of the subscribers (309/341, 90.6%) listed family members as their primary contact.

Table 1. Demographics and environmental antecedents of the sample (unit of analysis: MedicAlert subscriber).

Demographic characteristics	Persons without dementia and persons living with dementia	Persons without dementia	Persons living with dementia	Statistical tests (persons without dementia vs persons living with dementia)		*P* value
				F test (*df*)	Chi-square (*df*)	
Age (y), mean (SD; range)	82.56 (7.4; 65-101)	83.90 (7.153; 66-101)	82.21 (7.381; 65-99)	0.93 (1,429)	—[a]	.33[b]
Sex assigned at birth (n=431), n (%)				—	0.9 (1)	.33[c]
Female	230 (53.4)	51 (11.8)	179 (41.5)			
Male	201 (46.6)	37 (8.6)	164 (38.1)			
Age group (y; n=434), n (%)				—	7.8 (3)	.05[c]
65-74	72 (16.6)	9 (2.1)	63 (14.5)			
75-84	177 (40.8)	35 (8.1)	142 (32.7)			
85-94	168 (38.7)	38 (8.8)	130 (29.9)			
95-104	17 (3.9)	7 (1.6)	10 (2.3)			
>105	0 (0)	0 (0)	0 (0)			
Ethnic background (n=425), n (%)				—	3.4 (3)	.34[c]
Black[d]	23 (5.4)	6 (1.4)	17 (4)			
Chinese	20 (4.7)	5 (1.2)	15 (3.5)			
White	329 (77.4)	67 (15.8)	262 (61.6)			
Other[e]	53 (14.3)	6(1.4)	47 (11.1)			
Official Canadian languages spoken (n=430), n (%)				—	6.4 (5)	.27[c]
English only	240 (55.8)	47 (10.9)	193 (44.8)			
English and other	78 (18.1)	11 (2.6)	67 (15.6)			
Neither English nor French	50 (11.6)	10 (2.3)	40 (9.3)			
French only	30 (7)	10 (2.3)	20 (4.7)			
French and English	27 (6.3)	6 (1.4)	21 (4.9)			
French and other	5 (1.2)	2 (0.5)	3 (0.7)			
Province (n=341), n (%)				—	6.6 (7)	.47[c]
Ontario	199 (58.4)	36 (10.6)	163 (47.8)			
British Columbia	57 (16.7)	11 (3.2)	46 (13.5)			
Quebec	50 (14.7)	16 (4.7)	34 (9.9)			
Alberta	18 (5.3)	3 (0.9)	15 (4.4)			
Manitoba	9 (2.6)	2 (0.6)	7 (2.1)			
Nova Scotia	4 (1.2)	0 (0)	4 (1.2)			
Saskatchewan	3 (0.9)	1 (0.3)	2 (0.6)			
New Brunswick	1 (0.3)	0 (0)	1 (0.3)			
Newfoundland and Labrador	0 (0)	0 (0)	0 (0)			
Prince Edward Island	0 (0)	0 (0)	0 (0)			
Nunavut and Northwest Territories	0 (0)	0 (0)	0 (0)			
Yukon	0 (0)	0 (0)	0 (0)			
Population density (n=341), n (%)				—	0.6 (1)	.44[c]

Demographic characteristics	Persons without dementia and persons living with dementia	Persons without dementia	Persons living with dementia	Statistical tests (persons without dementia vs persons living with dementia)		*P* value
				F test (*df*)	Chi-square (*df*)	
Urban	331 (97.1)	66 (19.4)	265 (77.7)			
Rural	10 (2.9)	3 (0.9)	7 (2.1)			
Living arrangement (n=433), n (%)				—	3.2 (3)	.36[c]
With family	277 (64)	53 (12.2)	224 (51.7)			
Facility	90 (20.8)	24 (5.5)	66 (15.2)			
Alone	57 (13.1)	9 (2.1)	48 (11.1)			
Other	9 (2.1)	2 (0.5)	7 (1.6)			
Primary contact (n=341), n (%)				—	3.2 (3)	.37[c]
Family member	309 (90.6)	63 (18.5)	246 (72.1)			
Other	16 (4.7)	5 (1.5)	11 (3.2)			
Health and social care professionals	15 (4.4)	1 (0.3)	14 (4.1)			
Staff of living facility	1 (0.3)	0 (0)	1 (0.3)			

[a] Not applicable.

[b] One-way ANOVA.

[c] Chi-square test.

[d] For example, African, Haitian, Jamaican, or Somali.

[e] Arab or West Asian (eg, Armenian, Egyptian, or Iranian), Latin American, South Asian, Korean, Mediterranean, Aboriginal (eg, Inuit, Métis, or American Indian), Filipino, Caribbean or West Indian (St Lucian or Antiguan), Southeast Asian, and Japanese.

Table 2 shows the history of missing incidents among MedicAlert subscribers. Subscribers self-reported no prior history of missing incidents at the time of subscribing to MedicAlert in 10.4% (45/433) of the cases, while 89.6% (388/433) disclosed having been involved in missing incidents repeatedly. Surprisingly, data from actual repeated missing incidents (ie, data that we accessed using the hotline access database) showed the opposite pattern: most of the subscribers went missing repeatedly in only 16.4% (71/434) of the cases. MedicAlert subscribers self-reported that the most common places to be found were outdoor public spaces (eg, highway or street; 184/308, 59.7%) or indoor public or communal spaces (eg, libraries; 85/308, 27.6%).

Table 2. Missing incidents history (unit of analysis: MedicAlert subscriber).

Missing incidents history	Persons without dementia and persons living with dementia, n (%)	Persons without dementia, n (%)	Persons living with dementia, n (%)	Statistical test (persons without dementia vs persons living with dementia), chi-square (*df*)	*P* value
Missing incident history (self-reported; n=433)				0.9 (2)	.64
None	45 (10.4)	7 (1.6)	38 (8.8)		
Repeated (1[a]-4 times)	327 (75.5)	67 (15.5)	260 (60)		
Habitual (>4 times)	61 (14.1)	14 (3.2)	47 (10.9)		
Repeated missing incident history (actual; n=434)				2.1 (1)	.14
No	363 (83.6)	79 (18.2)	284 (65.4)		
Yes	71 (16.4)	10 (2.3)	61 (14.1)		
Possible locations for the missing person to be found (self-reported; n=308)				4.4 (3)	.22
Outdoor public space[b]	184 (59.7)	34 (11)	150 (48.7)		
Indoor public or communal space[c]	85 (27.6)	18 (5.8)	67 (21.7)		
Private home in the community[d]	32 (10.4)	11 (3.8)	21 (6.8)		
Hospital (day program or day clinic)	7 (2.3)	1 (0.3)	6 (1.9)		

[a] After the first incident.

[b] Highway, street, alley, intersection, park, parking lot, outdoor bus stop, construction, or cemetery.

[c] Grocery store, shopping mall, train station, church, recreation center, library, physician's office, bus, train, police station, or gas station.

[d] House, apartment, condominium, age ≥65 years condominium but without supportive living services.

The statistical tests in Tables 1 and 2 showed that MedicAlert subscribers with dementia and those without who were involved in missing incidents were similar with respect to mean age, ethnic background, official Canadian languages spoken, province of residence, population density, living arrangement, primary contact, possible location to be found during a missing incident (self-reported), missing incident history (self-reported), and repeated missing incident history (actual missing incidents); no statistically significant differences were found between the groups. MedicAlert subscribers with dementia and those without who were involved in missing incidents are significantly different (χ^2_3=7.8; *P*=.05) in terms of age groups. This result means that the prevalence of critical wandering was higher among older age groups of people with dementia, with the peak prevalence between ages 75 and 84 years declining somewhat among the older-aged adults.

Characteristics of the Missing Incidents

Demographic and Psychopathological Antecedents

Missing incidents mostly involved people living with dementia (345/434, 79.6%) and those who were (1) female (230/431, 53.4%); (2) from the age groups 65-74 years (72/434, 16.6%), 75-84 years (177/434, 40.8%), and 85-94 years (168/434, 38.7%); (3) White (329/425, 77.4%); (4) English speaking (345/430, 80.2%); (5) living in an urban area (331/341, 97.1%); (6) mostly from Ontario (199/341, 58.4%), British Columbia (57/341, 16.7%), and Quebec (50/341, 14.7%); and (7) living with a family member (277/433, 64%) or in a facility (90/433, 20.8%).

Locations

Locations were analyzed in terms of point last seen or where the MedicAlert subscribers were missing from and located. MedicAlert subscribers were most frequently missing from private homes in the community (96/143, 67.1%) or residential living facilities (27/143, 18.9%); there were no statistical differences regarding the locations from which MedicAlert subscribers with dementia and those without went missing. Regarding the locations they were found, the most common places (313/382, 82%) were outdoor and indoor public spaces. Importantly, we found a statistically significant difference between point last seen or where the MedicAlert subscribers were missing from and where they were located (χ^2_{25}=42.3; *P*=.02; refer to Table 3 for more details). This result indicates that the MedicAlert subscribers were relatively active, with some degree of mobility. Even more interestingly, we found a moderate positive association between the possible locations to be found (self-reported) and the actual location where the person was found (Cramer V=0.213; *P*=.002).

Table 3. Characteristics of missing incidents. Point last seen or where the person was missing from and location in which the person was found (unit of analysis: missing incidents).

Characteristics of missing incidents (locations)	Persons without dementia and persons living with dementia, n (%)	Persons without dementia, n (%)	Persons living with dementia, n (%)	Statistical test (persons without dementia vs persons living with dementia), chi-square (*df*)	*P* value
Point last seen or where the person was missing from (n=143)				3.4 (5)	.64
Private home in the community	96 (67.1)	20 (14.8)	76 (51.7)		
Residential living facility[a]	27 (18.9)	5 (4)	22 (15.4)		
Indoor public space[b]	8 (5.6)	1 (0.7)	7 (4.7)		
Other	5 (3.5)	2 (1.3)	3 (2.7)		
Hospital (day program or day clinic)	5 (3.5)	0 (0)	5 (3.4)		
Outdoor public space[c]	2 (1.4)	0 (0)	2 (1.3)		
Location in which the person was found (n=382)				10.2 (6)	.12
Outdoor public space	202 (52.9)	42 (11.3)	160 (40.6)		
Indoor public space	111 (29.1)	27 (7.8)	84 (22.6)		
Private home in the community	40 (10.5)	5 (1.3)	35 (8.8)		
Hospital (day program or day clinic)	12 (3.1)	2 (1)	10 (2.5)		
Residential living facility	11 (2.9)	2 (0.5)	9 (8.8)		
Other	4 (1.0)	3 (0.8)	1 (0.3)		
Combination of >1 of the aforementioned locations	2 (0.5)	0 (0)	2 (0.5)		

[a] Long-term care center, assisted living facility, supportive living facility, lodge, or group home.

[b] Grocery store, shopping mall, train station, church, recreation center, library, or physician’s office.

[c] For example, highway, street, alley, intersection, park, or parking lot.

Mode of Mobility

While missing, the most common mode of traveling was on foot (248/270, 91.9%). The second most common mode of mobility was public transportation (12/270, 4.4%; refer to Table 4 for more details).

Table 4. Characteristics of missing incidents. Mode of mobility (unit of analysis: missing incidents; valid cases n=270).

Characteristics of missing incident	Persons without dementia and persons living with dementia, n (%)	Persons without dementia, n (%)	Persons living with dementia, n (%)	Statistical test (persons without dementia vs persons living with dementia), chi-square (*df*)	*P* value
Mode of mobility				2.3 (6)	.89
On foot[a]	248 (91.9)	57 (21.1)	191 (70.7)		
Public transit[b]	12 (4.4)	3 (1.1)	9 (3.3)		
Receiving a ride from someone else[c]	3 (1.1)	1 (0.4)	2 (0.7)		
Driving own car	2 (0.7)	0 (0)	2 (0.7)		
Other	2 (0.7)	0 (0)	2 (0.7)		
Combination of several of the aforementioned modes	2 (0.7)	0 (0)	2 (0.7)		
Long-range or transregional transit[d]	1 (0.4)	0 (0)	1 (0.4)		

[a] Walking.

[b] Bus, light rail transit, subway, or streetcar.

[c] Hitchhiking.

[d] Train, airplane, noncommuter bus, or ferry.

Temporality (Time and Seasonality)

Table 5 shows the temporality of missing incidents in terms of the time of day and season the person was reported missing. In general, missing incidents occurred mostly in the afternoon (262/560, 46.8%) and the evening (174/560, 31.1%), while the most common seasons for these incidents were summer and fall followed by spring (222/560, 39.6%; 154/560, 27.5%; and 113/560, 20.2%, respectively).

No statistical differences for the temporality variable by persons living with dementia and those without were found.

Table 5. Characteristics of missing incidents. Time and seasonality (unit of analysis: missing incidents; n=560).

Missing incident characteristics (time and seasonality)	Persons without dementia and persons living with dementia, n (%)	Persons without dementia, n (%)	Persons living with dementia, n (%)	Statistical test (persons without dementia vs persons living with dementia), chi-square (*df*)	*P* value
Time of day				7.2 (2)	.03
Afternoon (noon to 5:59 PM)	262 (46.8)	61 (11)	201 (35.1)		
Evening (6 PM to 11:59 PM)	174 (31.1)	40 (7.1)	134 (23.3)		
Morning (midnight to 11:59 AM)	124 (22.1)	15 (3.9)	109 (19.2)		
Season				3.3 (3)	.34
Summer (June 1 to August 31)	222 (39.6)	47 (8.4)	175 (31.3)		
Fall (September 1 to November 30)	154 (27.5)	34 (6.1)	120 (21.4)		
Spring (March 1 to May 31)	113 (20.2)	17 (3)	96 (17.1)		
Winter (December 1 to February 28)	71 (12.7)	18 (3.2)	53 (9.5)		

People Involved in the Missing Incident

Table 6 shows the people involved in the missing incidents in terms of the care partner involvement with MedicAlert in response to the missing incident. In the majority of cases (375/518, 72.4%), the family care partner had an involvement in response to the missing incident with MedicAlert, with no statistically significant difference found between the groups (people with dementia and those without). In 96.1% (467/486) of the cases, the MedicAlert subscribers who went missing were located by someone other than the care partner. In most of the cases, either first responders (232/486, 47.7%) or Good

Samaritans (224/486, 46.1%) found the missing person. Again, no statistically significant difference was found between the groups involved in the missing incidents.

Table 6. Characteristics of missing incidents. People involved in the missing incident (unit of analysis: missing incidents).

Missing incident characteristics (people involved in the missing incident)	Persons without dementia and persons living with dementia, n (%)	Persons without dementia, n (%)	Persons living with dementia, n (%)	Statistical test (persons without dementia vs persons living with dementia), chi-square (*df*)	*P* value
Natural care partner involvement in response to incident with MedicAlert (n=518)				0.4 (1)	.54
Yes	375 (72.4)	80 (15.4)	295 (57)		
No	143 (27.6)	27 (5.2)	116 (22.4)		
Who reported and found the missing person (n=486)				1.3 (3)	.72
First responder[a]	232 (47.7)	54 (11.1)	178 (36.6)		
Good Samaritan[b]	224 (46.1)	48 (9.9)	176 (36.2)		
Family member or friend[c]	19 (3.9)	4 (0.8)	15 (3.1)		
Other	11 (2.3)	1 (0.2)	10 (2.1)		

[a] Police, search and rescue member, fire department, or ambulance or paramedic.

[b] The Good Samaritan noticed that something was off with the missing person and called the hotline or was asked by the missing person to call the hotline; they were not formally involved in searching for the missing person.

[c] Informal care partner.

Outcomes of the Missing Incidents

Table 7 shows the outcomes of the missing incidents in terms of the number of missing incidents, repeated missing incidents, mean time to the first missing incident (in days), mean time between missing incidents (in days), and survivability. Overall, 22.5% (113/500) of the missing incidents were repeated missing incidents, with the mean number of missing incidents per MedicAlert subscriber being 1.290 (SD 0.914; range: 1-11). Moreover, the number of missing incidents per MedicAlert subscriber was almost the same for people living with dementia (mean 1.290, SD 0.801) and those without dementia (mean 1.300, SD 1.265). The mean time to the first missing incident (since registering with MedicAlert) was 343.8 (SD 376.2) days (mean 11, SD 11.3 months), whereas the mean time between missing incidents was shorter, that is, 328.0 (SD 366.6) days (mean 11, SD 10.8 months). This is expected because the mean time between missing incidents takes into account repeated missing incidents. In terms of survivability, only a small percentage of cases (46/500, 9%) involved people undergoing harm while missing; even more rare were missing incidents in which MedicAlert subscribers were found deceased (1/500, 0.2%). There was a trend toward adverse outcomes for MedicAlert subscribers living with dementia: they experienced increased repeated missing incidents and injuries (but these results were not statistically significant, *P*=.30), short mean time to the first missing incident (but these results were not statistically significant, *P*=.20), and short mean time between missing incidents (but these results were not statistically significant, *P*=.15). In other words, they went missing more frequently (1 missing incident every 317.08 days) than those subscribers who did not have dementia (1 missing incident every 370.41).

Table 7. Outcomes of the missing incidents.

Missing incident characteristics (outcomes)	Persons without dementia and persons living with dementia	Persons without dementia, n (%)	Persons living with dementia, n (%)	Statistical tests (persons without dementia vs persons living with dementia)			*P* value
				Mann-Whitney *U* test	*z* score	Chi-square (*df*)	
Missing incidents (n=434)	Mean 1.290 (SD 0.914; range 1-11)	1.300 (1.265)	1.290 (0.801)	14,412 (persons without dementia: n=89; persons with dementia: n=345)	−1.386	—[a]	.17[b]
Time (d; n=434), mean (SD)							
MTFI[c] (n=434)	Mean 343.79 (SD 376.20; range 6-2249)	374.82 (410.35)	335.79 (365.09)	14,000 (persons without dementia: n=89; persons with dementia: n=345)	−1.282	—	.20[b]
MTBI[d] (n=434)	Mean 328.02 (SD 366.62; range 6-2249)	370.41 (411.34)	317.08 (354.00)	13,844 (persons without dementia: n=89; persons with dementia: n=345)	−1.429	—	.15[b]
Survivability (n=500), n (%)				—	—	4.9 (4)	.30[e]
No apparent injuries or compromised health	453 (90.6)	94 (18.8)	359 (71.8)				
Injuries or compromised health requiring emergency services and transfer to hospital	35 (7)	8 (1.6)	27 (5.4)				
Minor injuries or health issues requiring some treatment at home[f]	10 (2)	1 (0.2)	9 (1.8)				
Deceased	1 (0.2)	1 (0.2)	0 (0)				
Injuries and concern for health requiring follow-up care[g]	1 (0.2)	0 (0)	1 (0.2)				

[a] Not applicable.

[b] Mann-Whitney *U* test.

[c] MTFI: mean time to the first missing incident.

[d] MTBI: mean time between missing incidents.

[e] Chi-square test.

[e] Getting *Band-Aids*, pain medications, cleaned up, and so on.

[f] Physician visit, walk-in clinic, and so on.

Discussion

Principal Findings

This retrospective descriptive study examined demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering among MedicAlert subscribers, as well as the characteristics and outcomes of these incidents. In doing so, we used a national registry of persons as a secondary data source of information (ie, the MedicAlert database). To date, much of the knowledge about missing individuals with dementia and those without is based on studies with small sample sizes that use social media and newspaper reports from the United States or elsewhere [7,11]. Thus, we aimed to address these limitations by using an extensive secondary data set. To our knowledge, this is the first study that has shed light on the phenomenon of missingness and critical wandering of individuals with dementia and those without in Canada. In addition, we were able to report the prevalence of repeated missing incidents, based on this database, an important figure that has been absent in previous studies.

The demographic characteristics of our study population showed that people involved in missing incidents were mostly older adults (345/434, 79.6%), female older adults (230/431, 53.4%), living in the most populated provinces in Canada (306/341, 89.7%), and living in urban areas with at least 1 family member (309/341, 90.6%). Importantly, the majority of MedicAlert subscribers (345/434, 79.5%) involved in missing incidents self-reported living with dementia. More interestingly, except for age group, we did not find statistically significant differences between the people living with dementia and those without with respect to demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering. In addition, MedicAlert subscribers were most frequently missing from private homes in the community (96/143, 67.1%), as expected; were found in a different place than where they were last seen (313/382, 82%; most commonly outdoor and indoor public spaces); and were traveling on foot (248/270, 91.9%) and by public transportation (12/270, 4.4%), and during the afternoon (262/560, 46.8%) and evening (174/560, 31.1%). Subscribers were located mostly by first responders (232/486, 47.7%) and Good Samaritans (224/486, 46.1%). In terms of outcomes, overall, MedicAlert subscribers were involved in 1 missing incident, with the mean duration between missing incidents being 11 (SD 10.8) months and the time elapsed between subscribing to MedicAlert and the first missing incident being 11 (SD 11.3) months. Finally, the vast majority of MedicAlert subscribers involved in missing incidents were returned home safely (453/500, 90.6%), reports of harm and injuries were very low (46/500, 9.2%), and death was a rare event (1/500, 0.2%).

We found that missing incidents involved mostly older adults (345/434, 79.6%), female older adults (230/431, 53.4%), and White older adults (329/425, 77.4%), with the majority living in urban areas in cities in Ontario, British Columbia, and Quebec provinces (306/341, 89.7%). These demographic results are consistent with previous studies [30,33,34] and can be explained by the fact that these groups were more prevalent in our sample and because our sample was not a representative sample. The higher prevalence of missing incidents among female older adults can be attributed to the higher prevalence of female older adults living with dementia because dementia typically affects people at a 2:1 female-to-male ratio [2]. As there is evidence that demographic characteristics may serve as risk factors for missingness [11,35,36], the next logical step is to determine whether the demographics variables we explored in this study are factors for missingness in this sample. In this study, we did not identify statistically significant differences between people living with dementia and those without with respect to all our variables. The most plausible explanation for this is that these 2 groups of people are essentially the same, that is, they have dementia and memory loss, a risk factor that can lead to critical wandering and, in turn, a missing incident. Another plausible explanation for the lack of between-group differences could be that the individuals (1) had dementia but did not disclose their medical condition at the time of first subscribing to MedicAlert, (2) had dementia but did not know about their diagnosis, or (3) did not have dementia at the time of registration but developed dementia over time or by the time they went missing.

We found that the majority of MedicAlert subscribers involved in missing incidents self-reported living with dementia (345/434, 79.5%). Importantly, among those who were involved in missing incidents but did not self-report living with dementia (89/434, 20.1%), memory loss was self-reported as a medical condition. Our result is aligned with previous studies that found that persons with mental or cognitive disabilities (eg, those with Alzheimer disease or dementia) are more prone to going missing [31,37,38]. The literature reports that neurocognitive deficits from dementia predispose individuals to missing incidents and contribute to the inability to independently return home. These neurocognitive deficits could include memory deficits, such as declarative memory (remembering facts and events), episodic memory (short-term memory for recent events and contexts), and visual agnosia (inability to recognize objects or places). In addition, executive function impairments and disease-related changes to visuospatial and subperceptual processing (especially in unfamiliar locations), which typically manifests as difficulty with navigation, can explain why an individual living with dementia cannot independently return home [26].

The prevalence of MedicAlert subscribers who repeatedly went missing was lower in the hotline database in comparison to repeated missing self-reported variables. This result was anticipated because previous studies suggest that care partners are reluctant to contact emergency services, such as 911 or programs to locate older adults who are having an episode of critical wandering and have gone missing [37]. As a self-reported variable, this result could be attributed to overreporting by care partners. However, more objective explanations can be given. First, care partners often initiate the search within their homes or places last seen, and because many persons with dementia are found near the place that they were last seen, either on their own property or in their own neighborhood, the care partner could locate the missing person before their decision to request assistance from external organizations [31,37]. Second, it is possible that care partners subscribed their family member into the MedicAlert program as a preventative measure. For individuals who repeatedly had episodes of critical wandering in the past, care partners could have implemented their own measures or interventions to avoid missing incidents, including MedicAlert subscriptions. The literature reports that these interventions include avoiding lapses of supervision, whether planned or unplanned, through the use of technology (eg, GPS) to monitor and locate missing older adults with dementia [39]. Finally, it might be possible that care partners chose not to use the MedicAlert hotline to locate missing individuals to avoid attention and stigma associated with a formal search if initiated. Numerous studies have reported that the uses of technologies and programs by people living with dementia and their care partners aiming to reduce the risks of getting lost have highlighted the importance of discreet technologies that are unnoticeable to reduce stigma [40,41].

Our study paves the way for new services and interventions that can be offered by MedicAlert. The services may include implementing preventative strategies to decrease the risk of going missing through threshold alerts in mobile phone apps. According to the literature, a leading feature being implemented in mobile phone apps were alert systems, such as wandering alerts [42]. These apps could send threshold alerts or reminders to care partners when the mean time between missing incidents and the mean time to the first missing incident for a particular MedicAlert subscribers is approaching. The same can be true for common months or the time of day that MedicAlert subscribers tend to go missing. As many MedicAlert subscribers were located mostly by first responders and Good Samaritans, another option to explore is the use of a mobile alert app to engage community volunteers to help locate missing persons with dementia. Community ASAP, a mobile alert system that engages community citizens as volunteers to look for missing persons with dementia, has demonstrated to be an accurate and useful app [43].

For MedicAlert subscribers involved in missing incidents, many were returned home safely (453/500, 90.6%), with few reported harms or injuries (46/500, 9.2%), and death was rare (1/500, 0.2%). Regarding mortality rates when a person with dementia goes missing, the literature shows high variability (between 0.7% and 32%) [44,45]. In this study, the low reports of harm and death can be explained mainly by 2 factors. First, the environmental conditions at the time the MedicAlert subscribers went missing were favorable: subscribers went missing in urban areas while traveling on foot (248/270, 91.9%) or using public transportation (12/270, 4.4%) during the day (262/560, 46.8%) in the warmest months of the year (eg, low chance of severe weather; 358/560, 63.9%). The literature reports that the causes of high mortality rates in people with dementia who go missing include severe weather; driving; and walking near roadways, bodies of water, or in isolated areas [46,47]. These scenarios were very different from what we found in our study. Second, we found that in a high proportion of missing incidents (504/560, 90%), the MedicAlert subscribers were wearing their ID bracelet. We could intuitively affirm that the MedicAlert program prevents injuries and saves lives, but this affirmation would have to be demonstrated in a formal study. Therefore, a next logical step would be to conduct a study to determine whether the MedicAlert program addresses the problem for which it was designed, that is, to help those who are having an episode of critical wandering to return home safely. Our study also shows what some investigators have determined regarding the potential interrelatedness of risk factors for going missing [48]. While most of the outcomes during missing incidents were positive (death was rare), the complex interplay of demographic, psychopathological, and environmental antecedents of MedicAlert subscribers need further exploration.

Study Limitations

Our study has some limitations. Limitations were posed by the MedicAlert data set itself. First, missing incidents are also captured in data held by first responders (police, search and rescue organizations, paramedics, etc), and, because MedicAlert data are subscription-based data, there are inherent self-selection biases. Second, while inquiring about the data entry process at the MedicAlert subscribers' level, we discovered that a high percentage of data were stored raw (free-text fields) and not in analysis-ready format. Consequently, the available information did not allow us to categorize our data with the desired level of granularity. Third, the self-reported nature of the data caused missing data in some variables (eg, the use of de-escalation techniques to avoid missing incidents, whether a MedicAlert subscriber has special needs, and what constitutes a trigger for a missing incident). As the percentage of missing data in these variables was large (ie, >40%), we excluded them from the analyses as recommended in the literature [49]. The missing data will not allow for further comprehensive statistical analysis for these unmeasured confounding variables. Fourth, the database lacked some important outcome variables; for example, we were unable to determine for how long MedicAlert subscribers went missing, the response time (ie, time elapsed between the call to the hotline and the arrival of the first responders to assist a missing person) or the turnaround time of the missing incidents (ie, the time it takes to return a missing person to their residence). In summary, because this study used a secondary data source that had not been compiled for research purposes, we faced the same common limitations reported in other studies that use this kind of data source [50-52]. Notwithstanding these limitations, we believe that the results obtained in this study are very valuable for partially understanding the phenomenon of older adults with dementia and memory loss going missing in Canada. The data set used in this study represents a small portion of people living with dementia in Canada; by virtue of it being a paid subscription service, not everyone uses it. In future research, other sources of data also need to be considered (police and search and rescue data) to get a fuller picture of the prevalence of persons living with dementia who go missing.

Conclusions

In the data set used, missing incidents involved mostly female older adults living with dementia from an urban area (331/341, 97.1%). Overall, the majority of MedicAlert subscribers involved in missing incidents returned home safely (453/500, 90.6%). However, 9.2% (46/500) of the cases resulted in some form of minor or serious injuries and death. Of the 560 missing incidents, 126 (22.5%) were repeated missing incidents. This paves the way to more accurately describe the prevalence of missing incidents and their consequences and outcomes so that we can develop targeted intervention strategies to prevent missing incidents or locate missing persons.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Definitions of variables and measures.

[PDF File (Adobe PDF File), 44 KB - aging_v7i1e58205_app1.pdf]

References

1. Dementia. World Health Organization. 2023 Mar 15. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2024-05-27]
2. Chambers LW, Bancej C, Mcdowell I. Prevalence and monetary costs of dementia in Canada: population health expert panel. The Alzheimer Society of Canada and Public Health Agency of Canada. 2016. URL: https://alzheimer.ca/sites/default/files/documents/Prevalence-and-costs-of-dementia-in-Canada_Alzheimer-Society-Canada.pdf [accessed 2022-11-18]
3. Navigating the path forward for dementia in Canada. Alzheimer Society is Canada. 2022. URL: https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path_Alzheimer-Society-Canada.pdf [accessed 2022-11-18]
4. Unpaid caregiver challenges and supports. Canadian Institute for Health Information. URL: https://www.cihi.ca/en/dementia-in-canada/unpaid-caregiver-challenges-and-supports#wait [accessed 2022-11-18]
5. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci 2009;11(2):217-228 [FREE Full text] [doi: 10.31887/DCNS.2009.11.2/hbrodaty] [Medline: 19585957]
6. Houston AM, Brown LM, Rowe MA, Barnett SD. The informal caregivers' perception of wandering. Am J Alzheimers Dis Other Demen 2011 Dec 31;26(8):616-622 [FREE Full text] [doi: 10.1177/1533317511432731] [Medline: 22296909]
7. Petonito G, Muschert GW, Carr DC, Kinney JM, Robbins EJ, Brown JS. Programs to locate missing and critically wandering elders: a critical review and a call for multiphasic evaluation. Gerontologist 2013 Feb;53(1):17-25 [FREE Full text] [doi: 10.1093/geront/gns060] [Medline: 22565495]
8. McShane R, Gedling K, Kenward B, Kenward R, Hope T, Jacoby R. The feasibility of electronic tracking devices in dementia: a telephone survey and case series. Int J Geriatr Psychiatry 1998 Aug;13(8):556-563. [doi: 10.1002/(sici)1099-1166(199808)13:8<556::aid-gps834>3.0.co;2-6] [Medline: 9733337]
9. Teri L, Larson EB, Reifler BV. Behavioral disturbance in dementia of the Alzheimer's type. J Am Geriatr Soc 1988 Jan;36(1):1-6. [doi: 10.1111/j.1532-5415.1988.tb03426.x] [Medline: 3335725]
10. Hope T, Tilling KM, Gedling K, Keene JM, Cooper SD, Fairburn CG. The structure of wandering in dementia. Int J Geriat Psychiatry 2004 Oct 13;9(2):149-155. [doi: 10.1002/gps.930090209]
11. Ferguson L. Risk factors and missing persons: advancing an understanding of ‘risk’. Humanit Soc Sci Commun 2022 Mar 29;9(1):101. [doi: 10.1057/s41599-022-01113-8]
12. Schonfeld L, King-Kallimanis B, Brown LM, Davis DM, Kearns WD, Molinari VA, et al. Wanderers with cognitive impairment in Department of Veterans Affairs nursing home care units. J Am Geriatr Soc 2007 May 20;55(5):692-699 [FREE Full text] [doi: 10.1111/j.1532-5415.2007.01135.x] [Medline: 17493188]
13. King-Kallimanis B, Schonfeld L, Molinari VA, Algase D, Brown LM, Kearns WD, et al. Longitudinal investigation of wandering behavior in Department of Veterans Affairs nursing home care units. Int J Geriatr Psychiatry 2010 Feb 14;25(2):166-174 [FREE Full text] [doi: 10.1002/gps.2316] [Medline: 19603420]
14. Kiely DK, Morris JN, Algase DL. Resident characteristics associated with wandering in nursing homes. Int J Geriatr Psychiatry 2000 Nov;15(11):1013-1020. [doi: 10.1002/1099-1166(200011)15:11<1013::aid-gps226>3.0.co;2-x] [Medline: 11113981]
15. Volicer L, van der Steen JT, Frijters DH. Involvement in activities and wandering in nursing home residents with cognitive impairment. Alzheimer Dis Assoc Disord 2013;27(3):272-277. [doi: 10.1097/WAD.0b013e31826d012e] [Medline: 22975750]
16. Algase DL, Antonakos C, Beattie ER, Beel-Bates CA, Yao L. Empirical derivation and validation of a wandering typology. J Am Geriatr Soc 2009 Nov 27;57(11):2037-2045 [FREE Full text] [doi: 10.1111/j.1532-5415.2009.02491.x] [Medline: 20121953]
17. Algase DL, Beattie ER, Antonakos C, Beel-Bates CA, Yao L. Wandering and the physical environment. Am J Alzheimers Dis Other Demen 2010 Jun 08;25(4):340-346 [FREE Full text] [doi: 10.1177/1533317510365342] [Medline: 20378834]
18. Kikuchi K, Ijuin M, Awata S, Suzuki T. [A study on the mortality patterns of missing and deceased persons with dementia who died due to wandering]. Nihon Ronen Igakkai Zasshi 2016;53(4):363-373 [FREE Full text] [doi: 10.3143/geriatrics.53.363] [Medline: 27885223]
19. Murata S, Takegami M, Onozuka D, Nakaoku Y, Hagihara A, Nishimura K. Incidence and mortality of dementia-related missing and their associated factors: an ecological study in Japan. J Epidemiol 2021 Jun 05;31(6):361-368 [FREE Full text] [doi: 10.2188/jea.JE20200113] [Medline: 32595183]
20. Okita M, Hanyu H, Hirao K, Shimizu S, Umahara T, Sakurai H. Missing incidents in individuals with dementia attending a memory clinic. J Am Geriatr Soc 2016 Jun 20;64(6):1365-1366. [doi: 10.1111/jgs.14151] [Medline: 27321625]
21. Hong GR, Song JA. Relationship between familiar environment and wandering behaviour among Korean elders with dementia. J Clin Nurs 2009 May 08;18(9):1365-1373. [doi: 10.1111/j.1365-2702.2008.02566.x] [Medline: 19207794]
22. Jeong JG, Song JA, Park KW. A relationship between depression and wandering in community-dwelling elders with dementia. Dement Neurocogn Disord 2016 Mar;15(1):1-6 [FREE Full text] [doi: 10.12779/dnd.2016.15.1.1] [Medline: 30906332]
23. Koester RJ. Lost Person Behavior: A Search and Rescue Guide on Where to Look - For Land, Air and Water. Charlottesville, VA: dbS Productions LLC; 2008.

24. Taylor C, Woolnough PS, Dickens GL. Adult missing persons: a concept analysis. Psychol Crime Law 2018 Oct 05;25(4):396-419. [doi: 10.1080/1068316x.2018.1529230]
25. Puthusseryppady V, Coughlan G, Patel M, Hornberger M. Geospatial analysis of environmental risk factors for missing dementia patients. J Alzheimers Dis 2019;71(3):1005-1013. [doi: 10.3233/JAD-190244] [Medline: 31450494]
26. Rowe M, Houston A, Molinari V, Bulat T, Bowen ME, Spring H, et al. The concept of missing incidents in persons with dementia. Healthcare (Basel) 2015 Nov 10;3(4):1121-1132 [FREE Full text] [doi: 10.3390/healthcare3041121] [Medline: 27417817]
27. Neubauer NA, Liu L. Development and validation of a conceptual model and strategy adoption guidelines for persons with dementia at risk of getting lost. Dementia (London) 2021 Feb 22;20(2):534-555. [doi: 10.1177/1471301219898350] [Medline: 31969006]
28. Kraemer HC, Kazdin AE, Offord DR, Kessler RC, Jensen PS, Kupfer DJ. Coming to terms with the terms of risk. Arch Gen Psychiatry 1997 Apr 01;54(4):337-343. [doi: 10.1001/archpsyc.1997.01830160065009] [Medline: 9107150]
29. Medic-Alert Foundation Canada homepage. Medic-Alert Foundation Canada. URL: https://www.medicalert.ca/ [accessed 2022-11-18]
30. Rowe MA, Greenblum CA, Boltz M, Galvin JE. Missing drivers with dementia: antecedents and recovery. J Am Geriatr Soc 2012 Nov;60(11):2063-2069 [FREE Full text] [doi: 10.1111/j.1532-5415.2012.04159.x] [Medline: 23134069]
31. Bantry White E, Montgomery P. Dementia, walking outdoors and getting lost: incidence, risk factors and consequences from dementia-related police missing-person reports. Aging Ment Health 2015;19(3):224-230. [doi: 10.1080/13607863.2014.924091] [Medline: 24912376]
32. Classifications, variables and statistical units. Statistics Canada. URL: https://www.statcan.gc.ca/en/concepts/definitions/index [accessed 2022-11-18]
33. Tu MC, Pai MC. Getting lost for the first time in patients with Alzheimer's disease. Int Psychogeriatr 2006 Sep 25;18(3):567-570. [doi: 10.1017/S1041610206224025] [Medline: 16867206]
34. Lissemore FM, Shatzman S, Clark N, Nash J, Miller R, Lerner AJ. Dementia reported missing: use of an online search engine to track outcomes in persons with dementia reported missing. Alzheimer Dis Assoc Disord 2019;33(2):142-146. [doi: 10.1097/WAD.0000000000000296] [Medline: 30681433]
35. Cohen IM, McCormick AV, Plecas D. A review of the nature and extent of uncleared missing persons cases in British Columbia. University College of the Fraser Valley. URL: https://ufv.ca/media/assets/ccjr/reports-and-publications/Missing_Persons.pdf [accessed 2024-05-27]
36. Cohen IM, Plecas D, McCormick AV. A comparison of aboriginal and non-aboriginal missing persons in British Columbia where foul play has not been ruled out. University College of the Fraser Valley. 2009. URL: https://ufv.ca/media/assets/ccjr/reports-and-publications/Missing_Aboriginal_Persons.pdf [accessed 2024-05-27]
37. Bowen ME, McKenzie B, Steis M, Rowe M. Prevalence of and antecedents to dementia-related missing incidents in the community. Dement Geriatr Cogn Disord 2011;31(6):406-412. [doi: 10.1159/000329792] [Medline: 21757904]
38. Holmes L, Shalev-Greene K, Clarke C, Pakes F. The impact of living with missing incidents: how the experience and fear of missing incidents affects people with dementia and those who care for them. In: Proceedings of the 25th Alzheimer Europe Conference: Dementia: Putting Strategies and Research Into Practice. 2015 Presented at: 25th Alzheimer Europe Conference; September 2-4, 2015; Ljubljana, Slovenia. [doi: 10.1093/police/paz007]
39. Neubauer NA, Lapierre N, Ríos-Rincón A, Miguel-Cruz A, Rousseau J, Liu L. What do we know about technologies for dementia-related wandering? A scoping review: examen de la portée : que savons-nous à propos des technologies de gestion de l'errance liée à la démence? Can J Occup Ther 2018 Jun 04;85(3):196-208. [doi: 10.1177/0008417418777530] [Medline: 29972049]
40. Neubauer N, Spenrath C, Philip S, Daum C, Liu L, Miguel-Cruz A. Identifying adoption and usability factors of locator devices for persons living with dementia. Dementia (London) 2022 Apr 29;21(3):862-881 [FREE Full text] [doi: 10.1177/14713012211065381] [Medline: 34964391]
41. Peeters MW, Schouten G, Wouters EJ. Wearables for residents of nursing homes with dementia and challenging behaviour: values, attitudes, and needs. Gerontechnology 2021 Jan 01;20(2):1-13. [doi: 10.4017/gt.2021.20.2.7.06]
42. Guo Y, Yang F, Hu F, Li W, Ruggiano N, Lee HY. Existing mobile phone apps for self-care management of people with Alzheimer disease and related dementias: systematic analysis. JMIR Aging 2020 Jan 24;3(1):e15290 [FREE Full text] [doi: 10.2196/15290] [Medline: 32012045]
43. Neubauer N, Daum C, Miguel-Cruz A, Liu L. Mobile alert app to engage community volunteers to help locate missing persons with dementia. PLoS One 2021 Jul 19;16(7):e0254952 [FREE Full text] [doi: 10.1371/journal.pone.0254952] [Medline: 34280219]
44. Woolford MH, Weller C, Ibrahim JE. Unexplained absences and risk of death and injury among nursing home residents: a systematic review. J Am Med Dir Assoc 2017 Apr 01;18(4):366.e1-36.e15. [doi: 10.1016/j.jamda.2017.01.007] [Medline: 28242190]
45. Rowe MA, Bennett V. A look at deaths occurring in persons with dementia lost in the community. Am J Alzheimers Dis Other Demen 2003;18(6):343-348 [FREE Full text] [doi: 10.1177/153331750301800612] [Medline: 14682082]

46. Kibayashi K, Shojo H. Accidental fatal hypothermia in elderly people with Alzheimer's disease. Med Sci Law 2003 Apr 25;43(2):127-131. [doi: 10.1258/rsmmsl.43.2.127] [Medline: 12741656]
47. Hunt LA, Brown AE, Gilman IP. Drivers with dementia and outcomes of becoming lost while driving. Am J Occup Ther 2010;64(2):225-232 [FREE Full text] [doi: 10.5014/ajot.64.2.225] [Medline: 20437909]
48. Kiepal LC, Carrington PJ, Dawson M. Missing persons and social exclusion. Can J Sociol 2012 Mar 21;37(2):137 [FREE Full text] [doi: 10.29173/cjs10114]
49. Jakobsen JC, Gluud C, Wetterslev J, Winkel P. When and how should multiple imputation be used for handling missing data in randomised clinical trials - a practical guide with flowcharts. BMC Med Res Methodol 2017 Dec 06;17(1):162 [FREE Full text] [doi: 10.1186/s12874-017-0442-1] [Medline: 29207961]
50. Johnson EK, Nelson CP. Values and pitfalls of the use of administrative databases for outcomes assessment. J Urol 2013 Jul;190(1):17-18 [FREE Full text] [doi: 10.1016/j.juro.2013.04.048] [Medline: 23608038]
51. Hubbard SL, Fitzgerald SG, Reker DM, Boninger ML, Cooper RA, Kazis LE. Demographic characteristics of veterans who received wheelchairs and scooters from Veterans Health Administration. J Rehabil Res Dev 2006;43(7):831-844 [FREE Full text] [doi: 10.1682/jrrd.2005.11.0174] [Medline: 17436170]
52. Rios A, Miguel Cruz A, Guarín MR, Caycedo Villarraga PS. What factors are associated with the provision of assistive technologies: the Bogotá D.C. case. Disabil Rehabil Assist Technol 2014 Sep;9(5):432-444. [doi: 10.3109/17483107.2014.936053] [Medline: 25007129]

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Original Paper

Toward Safe and Confident Silver Drivers: Interview Study Investigating Older Adults’ Driving Practices

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Abstract

Background: As the aging population in the United States continues to increase rapidly, preserving the mobility and independence of older adults becomes increasingly critical for enabling aging in place successfully. While personal vehicular transport remains a popular choice among this demographic due to its provision of independence and control over their lives, age-related changes may heighten the risk of common driving errors and diminish driving abilities.

Objective: This study aims to investigate the driving practices of older adults and their efforts to maintain safe and confident driving habits. Specifically, we sought to identify the factors that positively and negatively influence older adults’ driving performance and confidence, as well as the existing efforts put into sustaining their driving abilities.

Methods: We recruited 20 adults aged ≥65 years who remained active drivers during the recruitment from the greater New York area. Then, we conducted semistructured interviews with them to examine their perceptions, needs, and challenges regarding safe and confident driving.

Results: Our findings uncovered a notable disparity between older adults’ self-perceived driving skills and the challenges they face, particularly caused by age-related limitations and health conditions such as vision and memory declines and medication routines. Drawing on these findings, we proposed strategies to bridge this gap and empower older adults to drive safely and confidently, including fostering a realistic understanding of their capabilities, encouraging open dialogue regarding their driving, encouraging regular assessments, and increasing awareness of available resources.

Conclusions: This study uncovered a noticeable disparity between the perceived driving competence of older adults and the actual challenges they confront while driving. This divergence underscores a significant need for better support beyond the existing aid available to preserve older adults’ driving skills. We hope that our recommendations will offer valuable insights for practitioners and scholars committed to enhancing the overall well-being and quality of life for older adults as they age in their homes.

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KEYWORDS

older adults; driving; transportation; healthy aging; aging in place; quality of life

Introduction

Background

Due to the culture, lifestyles, and vast geography of the United States, automobiles play a crucial role in enhancing the quality of our daily lives by serving as the key to mobility, freedom, and independence. Driving holds particular significance for older adults in today’s aging society, as it enables them to maintain their socialization, independence, and mobility as they age [1-3]. The absence of driving can lead to isolation and depression among older adults [4], with consequent declines in both their physical and mental health [5-7]. Therefore, it becomes important to ensure that these drivers maintain and prolong their driving skills for independence, healthy aging, and overall quality of life.

According to the American Automobile Association, drivers aged between 60 and 69 years are considered the safest drivers in the United States [8]. Even drivers aged ≥80 years are involved in fewer car accidents per mile driven than younger drivers [9]. Furthermore, drivers in their 70s have lower rates of police-reported crash involvements per capita than middle-aged drivers [9]. Consequently, older adults can significantly contribute to our driving culture as some of the safest drivers. However, age-related changes can adversely affect the driving abilities of older individuals [10,11]. For example, as individuals age, they may experience shifts in reaction time, visual acuity, and cognitive processing, which can impair their capacity to drive safely [12,13]. Therefore, it is crucial for older adults to recognize that aging may increase the risk of safe driving and that they must be vigilant about signs indicating such changes and make efforts to maintain their driving capabilities.

Existing efforts to help maintain older adults' driving capabilities encompass programs focused on driver training, self-assessment tools, and regular health checkups [12,14,15]. However, little is known about the efforts that older drivers exert to cope with their aging-related changes and maintain their driving capabilities, let alone how they use any of these existing programs.

This study seeks to comprehend the current practices associated with daily driving experiences among older adults, providing insights into actionable and empirical implications to help older adults sustain their driving capabilities. Through semistructured interviews with 20 participants aged ≥65 years who were actively driving, we explored their perceptions of their driving abilities, identified the challenges they face while driving, examined strategies for managing these challenges, and assessed the efforts they put into maintaining their driving capabilities, if any.

Our findings revealed a significant disparity between the confident mindset that the participants held regarding their driving abilities and the challenges they encountered while driving. Although most participants expressed no immediate concern or effort about maintaining their driving proficiency and displayed overall confidence in their current capabilities, they acknowledged various challenges that negatively impacted their driving performance and confidence only when prompted about specific driving-related challenges. This highlights a significant disparity between the perceived need for support and the actual assistance required to uphold driving performance among older adults.

In what follows, we describe a review of existing related works, our study procedure, and key findings. We conclude this paper by discussing the implications for supporting the maintenance of older drivers' driving capabilities, along with addressing some limitations of this study.

This study aims to investigate the driving practices of older adults and their efforts to maintain safe and confident driving habits and to explore strategies that help older adults continue driving safely and confidently.

Literature Review

Driving and Quality of Life in Older Adults

The World Health Organization recognizes that maintaining mobility is fundamental to active aging, enabling older adults to remain engaged in various activities [16]. Loss of mobility, often stemming from the inability to operate a vehicle safely, can lead to activity restriction, physical deconditioning, and reduced social participation, significantly affecting an individual's health and overall quality of life [17]. In particular, impaired mobility has been identified as an early predictor of physical disability [18] and is associated with negative outcomes such as falls, loss of independence, institutionalization [19], and even mortality among older adults [20].

Undoubtedly, 1 key aspect of mobility for older adults is maintaining their driving privileges [21]. It is evident that the stage at which individuals change their driving behavior depends on various internal and external factors, such as personal circumstances and declining abilities [22]. Some individuals may abruptly cease driving due to external pressures or sudden events, while others who gradually restrict their driving likely do so in response to internal factors related to their abilities [21,23]. Those who prepare for driving cessation often have a combination of internal and external factors guiding their decision-making [24]. Research also highlights the profound impact of driving cessation on older adults' well-being. Several studies linked driving cessation to increased depressive symptoms [25,26] and identified it as a predictor of mortality risk [27].

Especially for many older adults in rural areas, driving remains critical for maintaining independence [8]. It aids daily living activities, supports familial responsibilities, and promotes community integration [23]. Even when facing physical and cognitive declines that may limit their ability to drive safely, some older adults continue to drive, as it contributes significantly to their self-confidence, well-being, and social connections [23]. As such, the relationship between driving and the quality of life in older adults is a critical aspect of aging, as it directly impacts their ability to lead dynamic and independent lives.

Physical, Cognitive, and Social Factors in Older Adults' Driving Capabilities

The overall physical health has been acknowledged as a crucial factor impacting older adults' ability to drive and respond effectively to unforeseen situations on the road [28]. Numerous studies have documented the correlation between health issues and the driving capabilities of older adults [2,23,29,30]. Generally, the findings indicate that health problems tend to increase with age, placing individuals with various health issues at a heightened risk for diminished driving performance. Specifically, vision impairments and physical limitations are found to be strongly associated with driving performance, albeit to varying degrees [31].

Cognitive abilities, including attention, memory, and executive function, are also critical for quick decision-making and multitasking, both essential for safe driving [28]. Several studies have underscored the crucial role of cognitive and neuropsychological factors in evaluating older adults’ driving capabilities. Factors such as processing speed, divided attention, visuospatial abilities, executive functions, psychomotor speed, and overall cognitive functioning have emerged as pivotal predictors of safe driving among older adults [31-33].

Social factors such as retirement and personal loss have also been found as triggers for driving anxiety among older drivers, thereby influencing their driving behavior [12,34]. These social circumstances can have immediate and long-term impacts on driving capabilities, highlighting the importance of preventive measures and interventions to address them [25].

Although age-related declines occur, older adults may not be aware of these changes or how they affect driving. Some older drivers fail to recognize their declines or overestimate their driving safety [24,25]. In this context, self-regulation and self-awareness play pivotal roles in how older adults adapt to these challenges, ultimately shaping their decisions and behaviors related to driving. Therefore, it is crucial to assist older adults with lower levels of health risk in increasing awareness of their health status concerning driving capabilities and taking preventive actions to maintain their ability to drive safely.

Existing Efforts to Help Maintain Older Adults’ Driving Skills

A systematic review of driver-training interventions for individuals aged ≥55 years, without any health-related impairments that prevent licensure, showed that interventions tailored to individual participants’ health conditions can positively impact driving ability and on-road performance [35]. Compared to the extensive studies on understanding factors that affect older adults’ driving performance, relatively few studies have explored the impact of tailored interventions on sustaining the driving safety of older adults. One exception is a randomized controlled trial that found tailored driving lessons reduced critical driving errors among older adults, acknowledging the need for longer-term follow-up and more extensive trials [28]. In addition, cognitive training, focusing on speed of processing and reasoning skills, demonstrated promising results, with a lower at-fault motor vehicle collision rate observed in older drivers who received training than controls [36]. These findings highlight the potential of personalized training interventions to enhance driving safety, sustain independence, and improve the quality of life for older adults, given the significance of driving mobility and the associated costs of declining driving capabilities.

In addition, driving simulator training has emerged as a useful tool to enhance driving skills in older adults for its effectiveness of attention training [24]. The implications of these interventions are found to be substantial in improving older drivers’ safety on the road [20]. Given the variability in older adults’ driving experiences, skills, and self-awareness, researchers argue that the strategies to help maintain older adults’ driving skills must be customized to address individual strengths and areas for improvement [37].

By delving deeper into the daily driving practices and concerns among older drivers, this research seeks to understand the complex interplay between aging, the challenges associated with driving, and the strategies to maintain mobility and safety. Through this investigation, the study aims to offer insights that can inform future interventions and policies to support older adults’ driving needs.

Methods

Ethical Considerations

The study was approved by the Rutgers Institutional Review Board (Pro2023001102), and informed consent was obtained from all participants before participating in the study. At the end of the interview, each participant was duly compensated with a US $30 Amazon gift card in recognition of their time and willingness to participate in the study.

Participant Recruitment

The recruitment of participants followed a systematic process aimed at ensuring a representative and ethically sound sample. To identify potential participants, the first author visited local libraries, senior centers, and low-income living facilities situated in the vicinity of the greater New York area. During our engagement with these facilities, the study’s objectives and purpose were comprehensively elucidated to the respective managers and supervisors. Upon their explicit approval and support, recruitment flyers were prominently displayed in the facility lobbies and on designated advertising boards.

The eligibility criteria for participant recruitment encompassed 3 primary requirements. First, participants had to be aged >65 years. Second, they needed to possess a valid US driver’s license, demonstrating prior driving experience. Third, they needed to be engaged in driving as part of their daily routine. This methodical recruitment approach ensured that our sample consisted of individuals who met the age criterion, had a documented driving history, and were healthy enough to sustain driving.

We recruited 20 participants, all of whom boasted substantial driving experience and maintained their active status as drivers (mean driving experience 51.1, SD 8.54 years). A gender distribution of approximately 70% (14/20) of female participants and 30% (6/20) of male participants was observed within the sample. The average age of our participants was 71.7 (SD 5.81) years. A breakdown of participant demographics is provided in Table 1 for further insight.

Table 1. Participant demographics and study duration (some participants included their learner’s permit periods in their years of driving experience; N=20).

ID	Age (years)	Gender	Driving experience (years)	Approximate driving frequency	Medical condition
P1	77	Woman	58	2 to 3 times a week	None
P2	65	Woman	50	Every day	None
P3	82	Woman	61	4 to 5 times a week	Cataract surgery
P4	77	Man	59	2 to 3 times a week	None
P5	73	Woman	50	Every day	None
P6	66	Woman	48	Every day	Survivor of breast cancer
P7	76	Woman	59	Every day	None
P8	73	Man	57	5 times a week	None
P9	83	Woman	59	2 to 3 times a week	None
P10	69	Man	52	4 to 5 times a week	Cardiac rehabilitation
P11	68	Man	32	Every day	None
P12	70	Man	52	Every day	None
P13	69	Woman	49	Every day	None
P14	73	Woman	55	Every day	None
P15	65	Woman	30	4 to 5 times a week	None
P16	67	Man	40	2 to 3 times a week	None
P17	74	Man	50	Every day	None
P18	84	Woman	60	5 to 6 times a week	None
P19	74	Woman	37	Twice a week	None
P20	68	Woman	40	Every day	None

Data Collection

The research methodology used in this study was carefully designed to investigate the perspectives that older adults had with their daily driving experiences, as well as the challenges faced by them in maintaining their driving capabilities.

A comprehensive interview protocol was crafted to facilitate in-depth discussions with the study participants. The protocol comprised a series of open-ended interview questions, ensuring a flexible and exploratory approach to data collection. The questions were purposefully designed to elicit a broad range of responses, enabling a comprehensive understanding of the participants’ experiences and perspectives.

The data collection process involved conducting in-person, semistructured interviews with each participant. These interviews were scheduled at a location of the participants’ preference to ensure their comfort and convenience. This approach facilitated candid and open conversations, allowing participants to express their thoughts and experiences freely. In addition to the interview responses, essential demographic information was gathered from each participant. This information encompassed details such as age, gender, prior health issues, and their level of familiarity and experience with technology. These demographic factors were considered in the data analysis to provide a comprehensive context for the study.

To maintain the integrity of the research, great care was taken to avoid any form of bias in the interview process. The questions posed during the interviews were constructed in response to the participants’ narratives and experiences, ensuring that the research did not unduly influence or guide their responses. This approach aimed to collect data that were a true reflection of the participants’ perspectives and challenges.

The duration of each interview session ranged from 30 minutes to 1 hour, depending on the depth and complexity of the participants’ experiences and responses. This flexible approach allowed for comprehensive data collection without imposing undue time constraints on the participants.

To ensure accuracy and a thorough analysis, all interviews were audio recorded. These recordings were later transcribed to create a written record of the interviews, which served as the basis for data analysis and the development of research findings.

Data Analysis

We used thematic analysis to identify and understand patterns across our interview data [38,39]. We began by open coding the data, which involved identifying and labeling key concepts. We then used axial coding to group related concepts into broader categories, which we called phenomena. Phenomena are recurring events, actions, and interactions representing people’s responses to problems and situations. Finally, we used selective coding to assemble the phenomena into a cohesive framework. We iterated all the steps until we achieved data saturation, signifying our thorough exploration of themes and patterns within the interview data. The goal of this step was to understand the relationships between the different phenomena and develop a comprehensive understanding of the interview data.

Results

Overview

The prevailing sentiment among our participants regarding their driving abilities was confidence in their abilities as good drivers. Consequently, a majority did not express any need or support for sustaining their driving proficiency, leading to consent among participants that such support was unnecessary. However, when probed about challenges related to their driving, several health-related issues emerged as factors adversely affecting their driving performance as well as their driving confidence. This dissonance between a confident mindset about driving and the escalating challenges encountered while driving among older drivers contributed to a significant gap between the perceived need for support and the actual assistance required to maintain their driving performance. Next, we first described how our participants perceived their current driving performance and the factors that positively contributed to their confidence in driving. Then, we reported a range of challenges that negatively affected driving performance. Finally, we concluded this section by describing the efforts aimed at maintaining driving capabilities. See Textbox 1 for a summary of our findings.

Textbox 1. A summary of themes and factors.

Factors positively contributing to older adults' driving confidence

- Active and independent driving
- Long-term, adaptive driving experience
- Physical fitness

Challenges older adults face in driving

- Vision challenges
- Memory decline
- Medication routines

Efforts to sustain driving

- Physical exercise
- Technology support: navigation systems
- Keeping focus undistracted while driving

Factors Positively Contributing to Driving Confidence

Active and Independent Driving

All participants reported that they were competent in their current driving skills. Several participants even expressed their pride in engaging in driving actively and regularly:

> *Driving is not a botheration for me at all. I would say 95% of the time, people want me to drive it because they feel I drive well and defensively.* [Participant 17]
>
> *I enjoy driving. It gives independence rights. I can go anywhere.* [Participant 11]

Participants mentioned several factors positively contributing to their belief that they were skilled and capable drivers.

As shown in Table 1, our participants exhibited a consistent trend of active driving, engaging in daily or near-daily driving activities. Daily routines involve driving for various purposes, including grocery shopping, medical appointments, and visits to family and friends. While local travel, covering short to moderate distances, was standard, participants also undertook occasional long-distance drives for special events or trips. Then, they expressed that these regular journeys contributed to their confidence in their driving skills. They attributed their confidence to the notion that by continuously driving, they were continually honing their abilities. The more they drove, the better they perceived themselves to be. For many, having a car and using it as their primary mode of transportation were testaments to their ongoing commitment to maintaining their driving skills:

> *I think driving skills improve on how often you drive. If you don't drive, then you never get improved. If you keep driving, then you will improve, and keep improving.* [Participant 18]
>
> *I have a car, I drive everywhere. And as far as possible, if I have to go anywhere within a certain radius, I prefer to drive rather than take public transportation.* [Participant 17]

Participants proudly emphasized their decades of solo travel on the road. This wealth of experience has undoubtedly contributed to a heightened sense of self-assuredness in their driving capabilities. These experiences, often marked by daily commutes, long-distance journeys, and even the foundational act of obtaining a driver's license, imbued them with a deep-seated belief in their driving proficiency:

> *I live alone. I gotta drive by myself. Driving myself is more accessible than using public transportation.* [Participant 20]

> *I drove from here to Dallas, and then back and forth a couple of times. Earlier, I used to drive for eight hours every day. So, I can drive with no problem.* [Participant 20]

> *When I was working, I used to get up early in the morning have a quick shower, and then drive down to work for the most part in my working career, I drove in excess of 50 miles every day.* [Participant 17]

Participants expressed that their ability to maintain their daily routines, even amid health challenges, reinforced their confidence in their driving skills. Whether running errands or embarking on longer trips, the participants frequently reiterated that they were accustomed to traveling alone. As such, this sense of independence in driving solo, sometimes despite challenges, strengthened their confidence in driving as skilled and independent drivers:

> *I'm good now. Yeah. I mean, I went through eight weeks of radiation. I drove myself every day. And that was not a problem.* [Participant 14]

> *My cataract surgery didn't go well. The doctors didn't correct my eyesight properly in my right eye. I use monocular vision. When the car gets too close, I will switch to my left eye by closing my right, allowing me to continue driving despite the challenge.* [Participant 3]

Long-Term, Adaptive Driving Experience

Our participants have driven for 51 (SD 8.54) years on average. This long-term period of driving contributes to fostering confidence to navigate the road effectively. Furthermore, these experiences have instilled a sense of resilience and adaptability, making them feel that driving in comparatively more spacious and less-congested locations is a breeze. This adaptability also positively contributed to their confidence in driving, as their driving skills are up to par, irrespective of the location:

> *I have traveled alone for the last 40 years.* [Participant 1]

> *I'm 77, and I got my driver's license when I was 18. So, I have been driving for 59 years.* [Participant 18]

> *I came to the United States for my graduate study. That's 1986. And I bought a used car. And I started driving regularly.* [Participant 20]

In particular, extensive driving experiences in different geographical characteristics positively influenced the development of adaptive driving experiences among our participants. Participants shared that they had experienced challenging driving environments throughout their lifelong driving experiences, such as driving along the bustling streets or the narrow and crowded roads of the city countless times. Participants expressed how their initial driving experiences in their countries of origin were marked by traffic congestion, narrow roads, and limited parking spaces. Their proficiency in handling diverse driving environments, from lifelong driving experiences in congested cities to more open rural areas, had bolstered their self-assuredness in driving:

> *Once you overcome that by driving in New York, you feel it's just a cakewalk everywhere driving.* [Participant 6]

> *I have no problem driving anywhere, no matter what kind of place it is, whether it's crowded or not because I have driven in India.* [Participant 16]

> *Driving is okay because you know, in Taiwan, the traffic is so bad. And the roads are so narrow. And the parking space is narrow. Up here all the roads are much bigger, and the parking space is bigger too. So, for me, it's easy.* [Participant 20]

Physical Fitness

The prevailing sentiment among our participants about their health conditions was positive. Participants said that their physical health remained in relatively good shape and did not mention any significant health issues. While some participants mentioned minor challenges in their physical condition, such as feeling weaker or less energetic, all of them said that these challenges did not hinder their driving capabilities much. Only a couple of participants shared specific health concerns, such as vision problems due to unsuccessful cataract surgery, or concerns relating to survivors of cancer or those undergoing cardiac rehabilitation. Unsurprisingly, therefore, we found that participants' good health conditions and physical fitness positively affected their perception of being adept drivers. As such, the absence of health issues and mobility challenges contributed to building a sense of self-confidence about driving skills:

> *At the moment, I feel comfortable driving and I don't have any health conditions. That should not be a problem for me driving.* [Participant 8]

> *I can see that my heart lot better after I retired because doing activities and stuff like that. Before I used to work longer hours and I was always tired. But now I have a lot of energy and I can do myself a lot of different things.* [Participant 15]

In addition, a positive perception of overall health conditions led them to believe that their driving abilities could endure for a considerably prolonged period. They associated good health and overall energy levels with their potential to drive effectively, even after retirement:

> *I think I still can drive for the next 20 years because I always believe we have good genes because my dad's life is 100.* [Participant 20]

> *Serious conditions like diabetes or any other conditions may disturb driving, but regular vision or something muscular isn't stopping driving.* [Participant 3]

Challenges Faced in Driving

Overview

While our participants generally held positive perspectives regarding their driving capabilities, a contrasting reality emerged when we delved into the challenges that they encountered while driving. Participants reported a range of challenges stemming mostly from individuals' health conditions and physical declines due to aging, which echoes much prior work [2,19,20,31,32,40,41].

Vision Challenges

Among the challenges frequently highlighted by the participants, aging-related vision issues emerged as a prevalent concern. These included conditions such as nearsightedness, presbyopia, sensitivity to light and glare, and cataracts. The aging process often introduces visual impairments that might significantly impact safe driving [19,41]. Participants acknowledged the obstacles posed by these aging-related vision issues, even when using corrective eyewear. In particular, night driving emerged as a significant challenge for our participants due to reduced visibility caused by inadequate lighting and distracting glares. This discomfort significantly contributed to having a fear of driving at night among our participants. The disruptive effect of the lights from incoming cars was a recurring theme, with participants describing it as "very difficult" and sometimes "blinding." Consequently, participants stated that they voluntarily restricted their driving activities to daytime hours and, in emergencies, reluctantly ventured out at night:

> *I thought I just needed a new eyeglass prescription (for driving? Or in general?), but apparently, I was starting to develop a cataract, so I'm not comfortable driving at night.* [Participant 10]
>
> *When I drive during the night, it looks like the light from across the car is coming too quickly. It's as if you cannot see, and you are suddenly blinded.* [Participant 15]
>
> *I can see clearly in the morning. Probably my, my eyes are aging for the night. I don't drive at night.* [Participant 13]

While various vision changes can influence driving abilities across different age groups, cataracts were mentioned as a significant concern that is directly connected to aging. Participants mentioned issues relating to the development of cataracts as they aged, often noting that they might not immediately recognize their onset:

> *The only issue I have with driving now is night driving, and it's a curious issue. I had a cataract, and I went for surgery, but it didn't go well.* [Participant 3]

Memory Decline

We confirmed that memory decline in older adults is another critical factor significantly influencing their ability to drive safely and confidently. Participants mentioned how memory decline has negatively impacted their driving experiences and heightened concerns about their safety on the road. They expressed a general feeling of reduced alertness in older age compared to their younger years. Although they lacked quantitative data to confirm a decline in their reaction time, they acknowledged a perceptible change in their level of alertness while driving. This sense of reduced alertness can significantly affect their ability to respond promptly to unexpected events on the road, potentially compromising safety, which echoes prior work [35]:

> *I feel that reaction time is slower. But I haven't tested my reaction time.* [Participant 3]

One recurrent concern regarding memory decline among participants was a diminished awareness of their surroundings, particularly when changing lanes or responding to vehicles approaching from the side. Memory lapses were particularly concerning at intersections and stop signs. Participants admitted to being more forgetful when it came to looking both ways and ensuring that there were no oncoming cars. Such lapses in memory can lead to critical oversights and increased risk at intersections, which are the common sites for accidents:

> *I've become a little less likely to notice a car that's coming up on one side while I'm about to change lanes. Also, when I come to a stop sign, I'm a little bit more forgetful to look both ways and make sure there are no cars coming. I don't have any quantitative evidence that there's a decline in my reaction time, but I just don't feel quite as alert as I did 10 or 20 years ago.* [Participant 8]

Medication Routines

Participants mentioned the increasing need for taking medication in their daily routine as a factor negatively influencing their driving abilities. As they confronted more health issues as they aged, participants relied on a more complex regimen of medications to manage various ailments. In particular, we identified the necessity for our participants to take multiple medications daily, often comprising pills for conditions such as high blood pressure, high cholesterol levels, and heart problems. These medications, while vital for health management, can lead to immediate physical discomfort and limitations. For instance, certain blood pressure medications can cause a significant drop in blood pressure upon ingestion, rendering individuals unfit to drive for a specific period, typically an hour. This medication routine apparently translated into challenges and constraints regarding safe driving and might necessitate meticulous planning around medication schedules, often hindering spontaneous travel. Participants emphasized the importance of understanding these risks and the necessity for stringent precautions to prevent any accidental mishaps on the road:

> *I do have heart problems. I take about six pills in the morning. Because some of them are for blood pressure. And then I take three pills at night. So, when you first take the blood pressure pills, they lower your blood pressure very strongly. So, you're not supposed to drive for like an hour.* [Participant 10]
>
> *I have a friend who takes insulin every day; when insulin is shot, you go into a coma, and you cannot*

> *control that car, then I think you really should be clear about driving.* [Participant 18]

Efforts to Sustain Driving

Overview

The participants highlighted the challenges that adversely affected their driving performance; however, most of them did not exert much effort to overcome or address these challenges. Some participants mentioned that they were not aware of any available resources or support to remedy the challenges, while others expressed the belief that they did not need any assistance:

> *I didn't even know something like the resources existed. So, I never thought of that. Is there anything like that?* [Participant 16]

Only a few participants mentioned that they had adopted efforts to maintain their independence, mobility, and safety on the road. They exhibited resilience and resourcefulness in addressing the obstacles posed by health conditions, medication, and aging-related discomfort. The efforts included doing physical exercise, using technology support for navigation, and keeping undistracted focus while driving.

Physical Exercise

Physical exercise emerged as a crucial strategy among our participants to counteract the physical limitations associated with aging and health issues that negatively influence their driving abilities. Participants emphasized the positive influence of regular physical activity on their overall health and specifically on their driving ability. For them, the incentive to exercise stemmed from health-related wake-up calls, such as heart attacks, muscular pains, and so on. These experiences prompted them to adopt a proactive approach to their well-being. Participants acknowledged that engaging in physical activities, such as doing physical exercises and playing sports, vastly helped maintain their driving capabilities, as it improved reflexes and hand-eye coordination. As such, the connection between physical exercises and driving was emphasized as an avenue for honing the reflexes and cognitive skills required for safe and efficient driving:

> *Many times, the number of games you play helps you to be reflexive, and in my case, I play sports that reflect it. It's hand-eye coordination and also keeps you fit. This helps me to drive better.* [Participant 18]
>
> *That's why I'm trying to do a lot of exercise. That's where my muscles don't get lost and get stronger and stronger. We have a good Senior Center exercise program over there. That helped me a lot.* [Participant 15]

Importantly, some participants found community resources invaluable in their quest for physical fitness. Senior center exercise programs were particularly commended for providing structured and accessible opportunities for exercise. These programs offered guidance, camaraderie, and a supportive environment that motivated older adults to stay active:

> *I'm trying to do a lot of exercise. We have a good exercise program at the senior center. That helped me a lot.* [Participant 15]

Technology Support: Navigation Systems

One of the most remarkable and transformative aids in the driving endeavor has been the adoption of GPS and navigation systems. This technological innovation has become an indispensable tool, significantly enhancing the safety and confidence of not only our participants, older drivers, but all individuals behind the wheel. Participants expressed a heavy reliance on GPS devices and navigation systems to bolster their driving capabilities. Some participants were using traditional stand-alone GPS devices, considering them to be highly reliable, while others were using a mobile navigation app, such as Google Maps:

> *I have a very old navigator. I still use that to navigate. I plug in that older one. It's kind of more reliable.* [Participant 13]
>
> *I can use Google Maps and Waze maps, just to feel confident, and I have GPS on my car also. I always put GPS on my car if I had to go someplace, even my sister's house.* [Participant 15]

Before starting the journeys, participants described their predrive routine, which often includes a preliminary check of routes and traffic conditions using Google Maps or other mobile mapping services. This proactive approach gives them a sense of preparedness and certainty about their route, reducing the stress of driving in unfamiliar locations:

> *Before I drive to a place, I prepare in advance; I use Google Maps at home and on the computer.* [Participant 10]

Participants emphasized that the integration of GPS functionalities into modern vehicles has been a game changer. These systems not only presented navigation instructions and route information but also provided a wealth of supplementary data about the car's performance and its surroundings. This additional information enriched the overall driving experience, addressing sensory limitations by offering extra visual cues and audible directions. For example, signage recognition on the dashboard, even when exterior signs might be challenging to discern, provided an additional layer of safety information and reassurance to our participants:

> *Even though I cannot see the sign outside, I'm able to see it on the map in my dashboard, and then it tells me, like the stop signs, exits.* [Participant 16]
>
> *Now you can get a whole display. And you get so much more information about your car than you ever could before.* [Participant 3]

While these technical innovations are not exclusively advantageous for older drivers, our participants undeniably derived significant benefits from using these technologies, which enhanced their driving performance.

Keeping Focus Undistracted While Driving

For many of our participants, driving has become a singular task that demands their full attention. Since the act of driving itself has its inherent cognitive demands, our participants considered remaining mentally agile crucial for maintaining driving capabilities. Therefore, to focus solely on the road while driving, some participants deliberately minimized distractions by actions such as turning off the radio or refraining from engaging in lengthy conversations with passengers. They consider this a necessity, recognizing that their vigilance on the road is a key factor in their continued safe mobility. This deliberate choice reflects their understanding that maintaining their attention span while driving is crucial for their driving performance and safety:

> *I don't turn the radio on. Attention spans should go to driving. And I have other things like even passengers talking to me. I tell them, you have your conversations. I have mine because I must pay attention to the road.* [Participant 13]
>
> *The more you talk, the more active you are, yeah, otherwise I can fall asleep.* [Participant 16]

Discussion

Principal Findings

Our findings demonstrate a significant disparity between self-perceived driving competence among our participants and the challenges they currently face, which are adversely affecting their driving abilities. Our participants consistently expressed confidence in their driving abilities, either contrasting with or regardless of the actual aging-related difficulties. While it is encouraging that older drivers maintain this confidence, the negative consequences of these perceptual gaps are far-reaching and can directly affect driving safety.

The lack of awareness or denial of their limitations can increase the risk of accidents and compromise overall driving safety [34]. For example, when older adults underestimate the significance of their vision challenges or believe that their adaptability can compensate for memory lapses, they may forego necessary medical evaluations and interventions crucial for their safety on the road [1]. Furthermore, the overreliance on a perception of good health and physical fitness can lead older drivers to disregard the potential effects of aging-related physical changes on their driving skills. This can result in underestimating the risks associated with physical discomfort and the need for medication. Therefore, this gap needs to be addressed adequately to help older adults maintain their ability to drive safely and confidently for longer periods.

The self-assurance of older drivers, often stemming from their extensive driving experience and desire for independence, may cause them to hesitate in recognizing limitations imposed by aging-related health factors that affect their driving abilities. This can result in overconfidence and a delay in taking proactive measures to address their challenges. By bridging the gap between subjective confidence and objective impediments, we can reduce the risk of a false sense of security and promote timely decisions for preventive actions while respecting their need for independence and mobility. While numerous prior works have compared older drivers' self-assessed driving skills to those of drivers in other age groups [22], no study to our knowledge has examined older adults' self-assessed driving skills specifically in light of the challenges they experience while driving, which we believe as a key contribution of our work.

In the following sections, we propose several potential solutions to close this perceptual gap based on our findings on the challenges and practices older drivers might face. These include fostering a realistic understanding of their capabilities, encouraging open dialogue about aging and safe driving, promoting regular assessments, and increasing the awareness of available resources.

Foster a Realistic Understanding of Older Drivers' Capabilities

With age, physiological changes inevitably affect various aspects of driving; however, older drivers may not always recognize these changes or may underestimate their impact on their driving abilities. Therefore, the first step in bridging the gap is to cultivate a realistic understanding among older adults regarding their capabilities and their direct impact on road safety and overall well-being. Understanding their capabilities realistically can allow older drivers to make informed decisions about their driving habits. Furthermore, it empowers them to recognize when adjustments may be necessary, such as limiting driving during certain times of the day or in adverse weather conditions or seeking alternative transportation options when needed. By embracing their limitations and taking proactive steps to address them, older drivers can continue to enjoy the freedom and mobility that driving provides while minimizing the risks associated with age-related changes.

As our findings demonstrated, many older adults may not fully comprehend how age-related changes can directly affect their driving abilities. One way to solve this problem is to provide education tailored specifically for older drivers so that we can emphasize the importance of acknowledging and adapting to age-related changes in a positive and constructive manner. This education can include information about common age-related declines in physical and cognitive functions, such as diminished vision or slower reaction times, and how these changes can affect driving safety.

Encourage Open Dialogue for Aging and Safe Driving

Families and friends serve as invaluable resources for discussing sensitive topics in positive and constructive ways. In this regard, having an open dialogue for safe driving with families and friends can provide a platform for older adults to openly address their concerns, challenges, and experiences related to aging and driving. Family members and friends can play a crucial role in recognizing the changes in driving abilities and discussing potential solutions, such as driving assessment programs or alternative transportation options.

Open dialogue can take place within various settings, such as community groups, senior centers, or health care facilities, and can involve discussions with peers, family members, and health care professionals. By encouraging open communication, older drivers can gain valuable insights, support, and advice from others who may have faced similar situations or challenges. Moreover, open dialogue can help to destigmatize discussions around aging and driving, breaking down barriers that may prevent older drivers from seeking assistance or support. Many older adults may feel reluctant to acknowledge age-related changes in their driving abilities due to fears of losing their independence or being perceived as incapable [22,42]. By fostering an open and supportive environment, older drivers can feel more comfortable expressing their concerns and seeking guidance without judgment.

In addition, open dialogue promotes education and awareness about the importance of safe driving practices as individuals age. This includes discussions about the potential effects of aging on driving abilities, such as changes in vision, hearing, reaction time, and cognitive function. By raising awareness of these issues, older drivers can better understand the importance of regular self-assessment, professional evaluation, and ongoing monitoring of their driving skills.

Encourage Regular Assessments

A structured and standardized approach to providing older drivers with realistic insights into their driving abilities and identifying areas that may require improvement or modification can be achieved through regular assessments. This can include assessments of vision, reaction time, cognitive function, and physical mobility. As individuals age, changes in physical and cognitive abilities can occur, which may impact their driving skills. By undergoing periodic evaluations of their driving abilities, older drivers can stay informed about any changes in their capabilities, address emerging challenges proactively, and continue to enjoy the freedom and mobility that driving provides while ensuring the safety of themselves and others on the road.

Furthermore, regular assessments can empower older drivers to stay informed about any changes in their capabilities, take proactive steps to address any emerging challenges, identify potential areas where they may need to adjust their driving habits, and ensure their safety on the road. For example, if an assessment reveals changes in vision or reaction time, older drivers can take measures such as adjusting their driving habits, seeking additional training or support, or even considering alternative transportation options when necessary. Moreover, regular assessments can provide peace of mind for older drivers and their families, knowing that they are actively monitoring their driving abilities and taking steps to maintain their safety [10]. It can also serve as a preventative measure, helping to identify any potential issues before they escalate into more significant concerns.

Increase the Awareness of Available Resources

There exist useful resources and support tailored to addressing the needs of older drivers with their driving skills and overall health conditions [12,14,15]. For instance, the New York State Office for the Aging has the Older Driver and Pedestrian Safety Project, which offers a handbook for families dealing with the issue of an older driver at risk. The state of New Jersey also provides several resources for older adults who drive, including programs to improve driving skills, assessments to evaluate driving capabilities, and services for drivers with medical conditions. In addition, most other states offer similar programs to support capacity-building initiatives for older drivers. Our findings, however, show limited awareness about available resources and support systems designed to enhance their driving safety and skills. Despite the resources and support systems available for older adults, none of our participants were aware of or had used any of these resources. The lack of awareness about resources can impede their ability to adapt to changing conditions and acquire the knowledge and tools necessary to drive safely as they age.

Increasing the awareness of available resources is crucial for older drivers as it provides them with access to support, information, and services that can enhance their driving safety and overall well-being. Awareness of available resources ensures that older drivers are informed about the various programs and organizations dedicated to promoting safe driving practices among older adults. This includes community-based programs; government agencies; nonprofit organizations; and health care facilities that offer services tailored to the needs of older drivers, such as driver education courses, vehicle safety checks, and mobility assistance programs. By increasing the awareness of these resources, older drivers can proactively seek assistance and support when needed, whether it is addressing age-related changes in their driving abilities, exploring alternative transportation options, or accessing adaptive driving equipment and technologies. This empowers older drivers to take control of their driving safety and make informed decisions that prioritize their well-being.

Moreover, the awareness of available resources helps to combat social isolation and promote social connectedness among older drivers. Many of the resources available to older drivers also provide opportunities for social interaction, peer support, and community engagement, which can have positive effects on mental and emotional well-being. By participating in group activities, support groups, or educational workshops, older drivers can connect with others who share similar experiences and concerns, reducing feelings of isolation and loneliness.

Limitations

Our findings must be evaluated in light of several limitations. First, our sample size was small, and all participants were recruited from the greater New York area. Second, most participants were considerably healthier than average older adults. We believe this is because older adults with health issues that prevent them from daily driving might have been naturally excluded due to an inclusion criterion requiring them to be actively engaged in driving as part of their daily routine at the time of recruitment. However, since we focused on studying older adults who drive daily, having a healthier participant pool was inevitable. Consequently, our participant pool may not accurately represent the broader aging population. While we believe that our findings offer valuable insights into understanding current practices and perspectives on older adults' driving practices, further research is necessary to explore how older adults from different sociocultural-technical backgrounds or residing in other regions (eg, rural areas) might perceive this topic differently.

Conclusions

To many older adults, driving is essential for maintaining mobility and independence for aging in place. The absence of driving can significantly affect the overall quality of life of older adults, which results in declines in both their physical and mental health. Therefore, it is important to ensure that these older drivers prolong their driving skills for independence, healthy aging, and overall quality of later life. This study investigated the daily driving practices of older adults and uncovered a noticeable gap between their perceived confidence in driving abilities and the challenges they encountered on the road. This disparity calls attention to a significant need for support that surpasses the actual assistance currently available to maintain driving performance among older adults. Drawing from our findings, we discussed actionable implications and empirical interventions aimed at sustaining older adults' driving capabilities. We are hopeful that these suggestions are valuable for practitioners and researchers focused on enhancing overall well-being and quality of life in later stages toward facilitating aging in place.

Conflicts of Interest

None declared.

References

1. Baldock MR, Mathias JL, McLean AJ, Berndt A. Self-regulation of driving and its relationship to driving ability among older adults. Accid Anal Prev 2006 Sep;38(5):1038-1045 [FREE Full text] [doi: 10.1016/j.aap.2006.04.016] [Medline: 16725099]
2. Campbell MK, Bush TL, Hale WE. Medical conditions associated with driving cessation in community-dwelling, ambulatory elders. J Gerontol 1993 Jul 01;48(4):S230-S234. [doi: 10.1093/geronj/48.4.s230] [Medline: 8315247]
3. Strogatz D, Mielenz TJ, Johnson AK, Baker IR, Robinson M, Mebust SP, et al. Importance of driving and potential impact of driving cessation for rural and urban older adults. J Rural Health 2020 Jan;36(1):88-93 [FREE Full text] [doi: 10.1111/jrh.12369] [Medline: 31022317]
4. Harrison A, Ragland DR. Consequences of driving reduction or cessation for older adults. Transp Res Rec 2003 Jan 01;1843(1):96-104 [FREE Full text] [doi: 10.3141/1843-12]
5. Bennetts R, Taylor JE. Health and quality of life outcomes of driving cessation for older people are more complex than we thought. Clin Gerontol 2022;45(4):821-832 [FREE Full text] [doi: 10.1080/07317115.2021.1978122] [Medline: 34665997]
6. Chihuri S, Mielenz TJ, DiMaggio CJ, Betz ME, DiGuiseppi C, Jones VC, et al. Driving cessation and health outcomes in older adults. J Am Geriatr Soc 2016 Feb 19;64(2):332-341 [FREE Full text] [doi: 10.1111/jgs.13931] [Medline: 26780879]
7. Fonda SJ, Wallace RB, Herzog AR. Changes in driving patterns and worsening depressive symptoms among older adults. J Gerontol B Psychol Sci Soc Sci 2001 Nov 01;56(6):S343-S351. [doi: 10.1093/geronb/56.6.s343] [Medline: 11682595]
8. Molnar LJ, Eby DW, Zakrajsek JS, Zanier N, Leslie A, Elliott E, et al. Identifying policy approaches to extending the safe mobility of older adults. AAA Foundation for Traffic Safety. 2021. URL: https://aaafoundation.org/identifying-policy-approaches-to-extending-the-safe-mobility-of-older-adults/ [accessed 2024-07-30]
9. Tefft BC. Rates of motor vehicle crashes, injuries and deaths in relation to driver age, United States, 2014-2015. AAA Foundation for Traffic Safety. 2017. URL: https://aaafoundation.org/rates-motor-vehicle-crashes-injuries-deaths-relation-driver-age-united-states-2014-2015/ [accessed 2024-07-30]
10. Karthaus M, Falkenstein M. Functional changes and driving performance in older drivers: assessment and interventions. Geriatrics (Basel) 2016 May 20;1(2):12 [FREE Full text] [doi: 10.3390/geriatrics1020012] [Medline: 31022806]
11. Kowalski K, Jeznach A, Tuokko HA. Stages of driving behavior change within the Transtheoretical Model (TM). J Safety Res 2014 Sep;50:17-25. [doi: 10.1016/j.jsr.2014.01.002] [Medline: 25142357]
12. Stutts JC, Wilkins JW. On-road driving evaluations: a potential tool for helping older adults drive safely longer. J Safety Res 2003;34(4):431-439 [FREE Full text] [doi: 10.1016/j.jsr.2003.09.014] [Medline: 14636665]
13. Taylor JE, Connolly MJ, Brookland R, Samaranayaka A. Understanding driving anxiety in older adults. Maturitas 2018 Dec;118:51-55. [doi: 10.1016/j.maturitas.2018.10.008] [Medline: 30415755]
14. Betz ME, Dickerson A, Coolman T, Schold Davis E, Jones J, Schwartz R. Driving rehabilitation programs for older drivers in the United States. Occup Ther Health Care 2014 Jul 27;28(3):306-317 [FREE Full text] [doi: 10.3109/07380577.2014.908336] [Medline: 24971897]
15. Casutt G, Theill N, Martin M, Keller M, Jäncke L. The drive-wise project: driving simulator training increases real driving performance in healthy older drivers. Front Aging Neurosci 2014 May 13;6:85 [FREE Full text] [doi: 10.3389/fnagi.2014.00085] [Medline: 24860497]
16. Active ageing: a policy framework. World Health Organization. 2002. URL: https://iris.who.int/handle/10665/67215 [accessed 2024-07-30]
17. Yeom HA, Fleury J, Keller C. Risk factors for mobility limitation in community-dwelling older adults: a social ecological perspective. Geriatr Nurs 2008;29(2):133-140 [FREE Full text] [doi: 10.1016/j.gerinurse.2007.07.002] [Medline: 18394514]

18. Hirvensalo M, Rantanen T, Heikkinen E. Mobility difficulties and physical activity as predictors of mortality and loss of independence in the community-living older population. J Am Geriatr Soc 2000 May;48(5):493-498 [FREE Full text] [doi: 10.1111/j.1532-5415.2000.tb04994.x] [Medline: 10811541]
19. Webber SC, Porter MM, Menec VH. Mobility in older adults: a comprehensive framework. Gerontologist 2010 Aug 09;50(4):443-450. [doi: 10.1093/geront/gnq013] [Medline: 20145017]
20. von Bonsdorff M, Rantanen T, Laukkanen P, Suutama T, Heikkinen E. Mobility limitations and cognitive deficits as predictors of institutionalization among community-dwelling older people. Gerontology 2006 Oct 31;52(6):359-365. [doi: 10.1159/000094985] [Medline: 16905887]
21. Curl AL, Stowe JD, Cooney TM, Proulx CM. Giving up the keys: how driving cessation affects engagement in later life. Gerontologist 2014 Jun;54(3):423-433 [FREE Full text] [doi: 10.1093/geront/gnt037] [Medline: 23651920]
22. Huang G, Luster M, Karagol I, Park JW, Pitts BJ. Self-perception of driving abilities in older age: a systematic review. Transp Res Part F Traffic Psychol Behav 2020 Oct;74:307-321 [FREE Full text] [doi: 10.1016/j.trf.2020.08.020]
23. Adler G, Rottunda S. Older adults' perspectives on driving cessation. J Aging Stud 2006 Sep;20(3):227-235. [doi: 10.1016/j.jaging.2005.09.003]
24. Lee HC, Lee AH, Cameron D. Validation of a driving simulator by measuring the visual attention skill of older adult drivers. Am J Occup Ther 2003;57(3):324-328. [doi: 10.5014/ajot.57.3.324] [Medline: 12785671]
25. Freund B, Colgrove LA, Burke BL, McLeod R. Self-rated driving performance among elderly drivers referred for driving evaluation. Accid Anal Prev 2005 Jul;37(4):613-618 [FREE Full text] [doi: 10.1016/j.aap.2005.03.002] [Medline: 15949451]
26. Windsor TD, Anstey KJ. Interventions to reduce the adverse psychosocial impact of driving cessation on older adults. Clin Interv Aging 2006 Aug;1(3):205-211 [FREE Full text] [doi: 10.2147/ciia.2006.1.3.205] [Medline: 18046872]
27. Edwards JD, Perkins M, Ross LA, Reynolds SL. Driving status and three-year mortality among community-dwelling older adults. J Gerontol A Biol Sci Med Sci 2009 Feb;64(2):300-305 [FREE Full text] [doi: 10.1093/gerona/gln019] [Medline: 19181711]
28. Anstey K, Eramudugolla R, Kiely KM, Price J. Effect of tailored on-road driving lessons on driving safety in older adults: a randomised controlled trial. Accid Anal Prev 2018 Jun;115:1-10 [FREE Full text] [doi: 10.1016/j.aap.2018.02.016] [Medline: 29518703]
29. Brayne C, Dufouil C, Ahmed A, Dening TR, Chi LY, McGee M, et al. Very old drivers: findings from a population cohort of people aged 84 and over. Int J Epidemiol 2000 Aug;29(4):704-707. [doi: 10.1093/ije/29.4.704] [Medline: 10922348]
30. Dellinger AM, Sehgal M, Sleet DA, Barrett-Connor E. Driving cessation: what older former drivers tell us. J Am Geriatr Soc 2001 Apr 21;49(4):431-435. [doi: 10.1046/j.1532-5415.2001.49087.x] [Medline: 11347787]
31. De Raedt R, Ponjaert-Kristoffersen I. The relationship between cognitive/neuropsychological factors and car driving performance in older adults. J Am Geriatr Soc 2000 Dec;48(12):1664-1668 [FREE Full text] [doi: 10.1111/j.1532-5415.2000.tb03880.x] [Medline: 11129759]
32. Depestele S, Ross V, Verstraelen S, Brijs K, Brijs T, van Dun K, et al. The impact of cognitive functioning on driving performance of older persons in comparison to younger age groups: a systematic review. Transp Res Part F Traffic Psychol Behav 2020 Aug;73:433-452. [doi: 10.1016/j.trf.2020.07.009]
33. Whelihan WM, DiCarlo MA, Paul RH. The relationship of neuropsychological functioning to driving competence in older persons with early cognitive decline. Arch Clin Neuropsychol 2005 Mar;20(2):217-228. [doi: 10.1016/j.acn.2004.07.002] [Medline: 15770793]
34. Allen HK, Beck KH, Zanjani F. Driving concerns among older adults: associations with driving skill, behaviors, and experiences. Traffic Inj Prev 2019 Feb 04;20(1):45-51 [FREE Full text] [doi: 10.1080/15389588.2018.1528358] [Medline: 30715919]
35. Fausto BA, Adorno Maldonado PF, Ross LA, Lavallière M, Edwards JD. A systematic review and meta-analysis of older driver interventions. Accid Anal Prev 2021 Jan;149:105852. [doi: 10.1016/j.aap.2020.105852] [Medline: 33142161]
36. Ball K, Edwards JD, Ross LA, McGwin GJ. Cognitive training decreases motor vehicle collision involvement of older drivers. J Am Geriatr Soc 2010 Nov;58(11):2107-2113 [FREE Full text] [doi: 10.1111/j.1532-5415.2010.03138.x] [Medline: 21054291]
37. Sangrar R, Mun J, Cammarata M, Griffith LE, Letts L, Vrkljan B. Older driver training programs: a systematic review of evidence aimed at improving behind-the-wheel performance. J Safety Res 2019 Dec;71:295-313 [FREE Full text] [doi: 10.1016/j.jsr.2019.09.022] [Medline: 31862041]
38. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
39. Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin NK, Lincoln YS, editors. Handbook of Qualitative Research. Thousand Oaks, CA: SAGE Publications, Inc; 1994:273-285.
40. Dobbs BM, Wodzin E, Vegega M. Medical Conditions and Driving: A Review of the Literature (1960-2000). Washington, DC: U.S. Department of Transportation. National Highway Traffic Safety Administration; 2005.
41. Ortiz-Peregrina S, Ortiz C, Casares-López M, Castro-Torres JJ, Jiménez Del Barco L, Anera RG. Impact of age-related vision changes on driving. Int J Environ Res Public Health 2020 Oct 12;17(20):7416 [FREE Full text] [doi: 10.3390/ijerph17207416] [Medline: 33053876]

42. Carp FM. Significance of mobility for the well-being of the elderly. In: Transportation in an Aging Society: Improving Mobility and Safety for Older Persons. Washington, DC: National Research Council; 1988:1-20.

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Original Paper

Development of a Dementia Case Management Information System App: Mixed Methods Study

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Abstract

Background: Case managers for persons with dementia not only coordinate patient care but also provide family caregivers with educational material and available support services. Taiwan uses a government-based information system for monitoring the provision of health care services. Unfortunately, scheduling patient care and providing information to family caregivers continues to be paper-based, which results in a duplication of patient assessments, complicates scheduling of follow-ups, and hinders communication with caregivers, which limits the ability of case managers to provide cohesive, quality care.

Objective: This multiphase study aimed to develop an electronic information system for dementia care case managers based on their perceived case management needs and what they would like included in an electronic health care app.

Methods: Case managers were recruited to participate (N=63) by purposive sampling from 28 facilities representing two types of community-based dementia care centers in Taiwan. A dementia case management information system (DCMIS) app was developed in four phases. Phase 1 assessed what should be included in the app by analyzing qualitative face-to-face or internet-based interviews with 33 case managers. Phase 2 formulated a framework for the app to support case managers based on key categories identified in phase 1. During phase 3, a multidisciplinary team of information technology engineers and dementia care experts developed the DCMIS app: hardware and software components were selected, including platforms for messaging, data management, and security. The app was designed to eventually interface with a family caregiver app. Phase 4 involved pilot-testing the DCMIS app with a second group of managers (n=30); feedback was provided via face-to-face interviews about their user experience.

Results: Findings from interviews in phase 1 indicated the DCMIS framework should include unified databases for patient reminder follow-up scheduling, support services, a health education module, and shared recordkeeping to facilitate teamwork, networking, and communication. The DCMIS app was built on the LINE (LY Corporation) messaging platform, which is the mobile app most widely used in Taiwan. An open-source database management system allows secure entry and storage of user information and patient data. Case managers had easy access to educational materials on dementia and caregiving for persons living with dementia that could be provided to caregivers. Interviews with case managers following pilot testing indicated that the DCMIS app facilitated the completion of tasks and management responsibilities. Some case managers thought it would be helpful to have a DCMIS desktop computer system rather than a mobile app.

Conclusions: Based on pilot testing, the DCMIS app could reduce the growing challenges of high caseloads faced by case managers of persons with dementia, which could improve continuity of care. These findings will serve as a reference when the system is fully developed and integrated with the electronic health care system in Taiwan.

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KEYWORDS

case management; dementia; health information systems; mobile apps; user needs; mobile phone

Introduction

The global population of persons living with dementia currently exceeds 55 million. The progressive decline in cognitive impairment and symptoms associated with dementia has a significant impact on the quality of life for patients and families [1] and a global economic cost of US $1.3 trillion [2]. Nearly 50% of the health care costs for persons with dementia stem from informal caregivers such as family members or close friends [2]. Case managers for persons living with dementia who are cared for by informal caregivers provide comprehensive information on medical treatment, caregiving techniques, and social resources, and face additional challenges when providing services for persons with early onset dementia [3]. Case management for these patients involves coordinating assessments, follow-up evaluations, and care, which requires providing caregivers with information about navigating support services available to the patient, as well as the caregiver [3-5].

Taiwan initiated “Long-Term Care 2.0,” which prioritizes dementia care, and within this framework, the focus is on enhancing case management by providing consultations, advice, and support on a regular basis. By 2025, the targeted goal for the percentage of persons living with dementia receiving care facilitated by case managers will exceed 80% [6]. Case management encompasses the coordination and linking of care service resources, which requires case managers to provide regular comprehensive and continuous care services, including monthly consultations, referrals, and service resources, which is based on the severity of dementia, their caregiving needs, and input from caregivers [7]. Currently, each dementia care case manager oversees a caseload with a minimum of 150 patients, which can sometimes exceed 300.

Case managers at community-based dementia care centers use the Dementia Care Service Management System, offered by the Ministry of Health and Welfare, for registration of cases and medical expense reimbursement [7]. However, there is no electronic health care system for managing follow-ups, and integration of health care with health education information is lacking. This leads to duplicate assessments, discontinuities in health education interventions, and the inability to provide timely services. Case managers with no experience or knowledge about certain aspects of dementia care are impacted by the lack of an accessible health education database, requiring them to spend time conducting internet-based searches or reading paper-based health education brochures, which affects their efficiency and confidence [8]. The absence of an established robust information support system that can facilitate data management and easy access to information and education material on dementia care leads to inefficient service and impedes the ability to provide continuous and high-quality case management.

IT in the form of mobile apps, internet-based interventions, and eHealth has been demonstrated to provide support for caregivers of persons with dementia. Mobile apps have been demonstrated to benefit family caregivers of persons living with dementia to help manage their relative’s disruptive behaviors [9] and reduce caregiver burden [10], and an internet-based supportive intervention can reduce caregivers’ depressive symptoms and stress and increase self-efficacy [11]. A systematic review found that eHealth benefited health care staff in long-term care facilities by providing remote consultations for comprehensive assessments and decision-making [12]. Therefore, it should be feasible to facilitate dementia case management with an IT-based support app.

A decision support mobile app for dementia care case managers was designed to increase confidence in their management role. Although overall confidence did not improve compared with a control group, case managers highly recommended the use of the app [8]. This finding and those of studies on caregivers of persons with dementia suggest electronic health care could have significant benefits for dementia care case managers. However, there is no available technology system for case managers in Taiwan. Therefore, this study aimed to develop an IT-based support app to meet the needs of dementia care case managers in Taiwan. We believe the availability of an app that streamlines the organization of case managers’ responsibilities could improve the quality of care provided to persons living with dementia and their family caregivers in Taiwan.

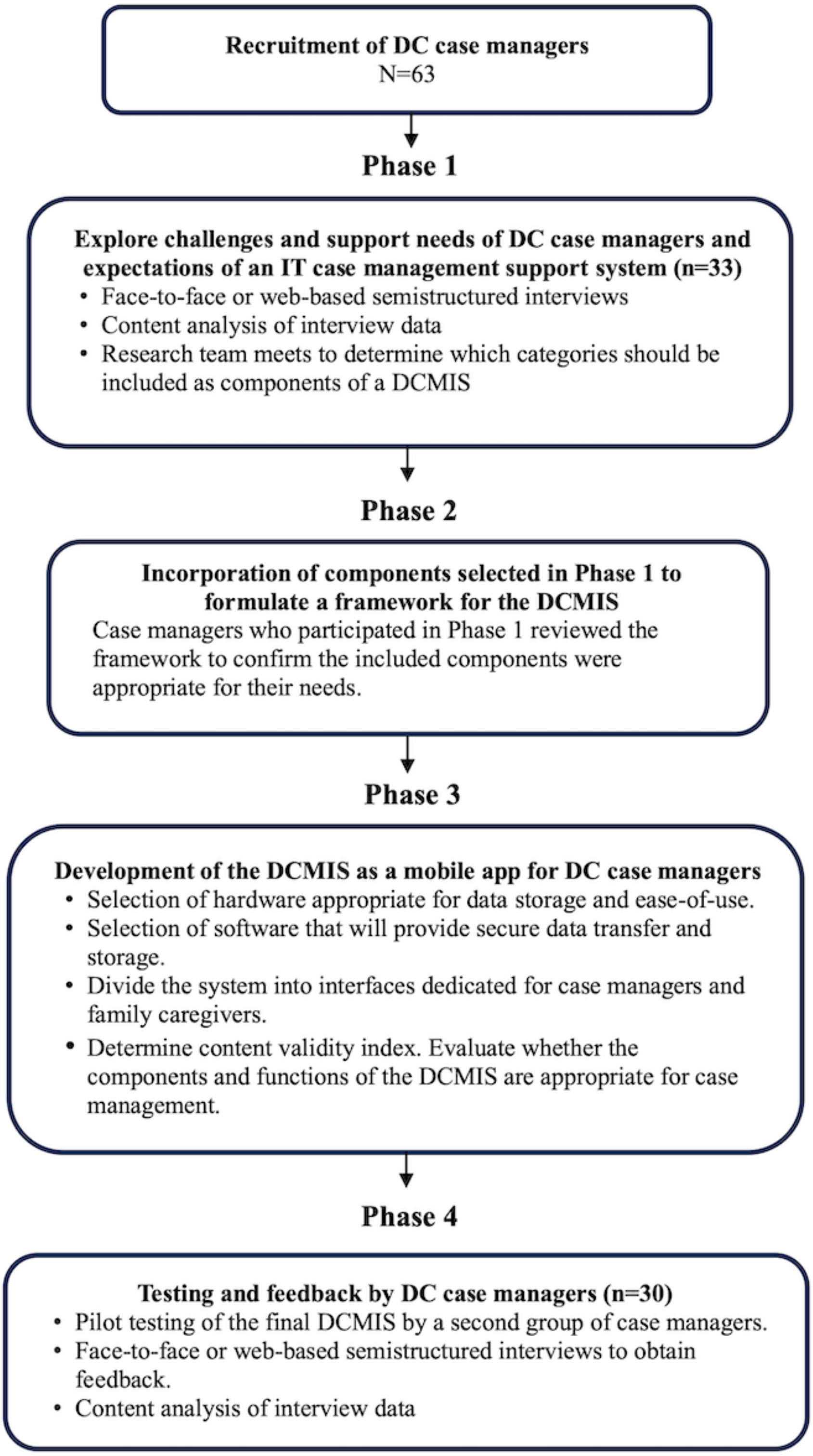
Methods

Study Design

This study was conducted between November 2020 and May 2023. The design of the study was implemented in four phases: phase 1 explored dementia care case managers’ perceived needs and their perspectives about IT support systems for dementia case management; phase 2 formulated the framework of a dementia case management information system (DCMIS) based on the findings of phase 1; phase 3 designed and developed the DCMIS for use as a mobile app and evaluated the validity of the system; and phase 4 pilot-tested the DCMIS app with dementia care case managers (users) and collected user feedback. Figure 1 provides an overview of the study design.

The study is registered at ClinicalTrials.gov (NCT05131789).

Figure 1. Overview of the study design. DC: dementia care; DCMIS: Dementia Case Management Information System.



Recruitment of DC case managers
N=63

Phase 1

Explore challenges and support needs of DC case managers and expectations of an IT case management support system (n=33)

- Face-to-face or web-based semistructured interviews
- Content analysis of interview data
- Research team meets to determine which categories should be included as components of a DCMIS

Phase 2

Incorporation of components selected in Phase 1 to formulate a framework for the DCMIS

Case managers who participated in Phase 1 reviewed the framework to confirm the included components were appropriate for their needs.

Phase 3

Development of the DCMIS as a mobile app for DC case managers

- Selection of hardware appropriate for data storage and ease-of-use.
- Selection of software that will provide secure data transfer and storage.
- Divide the system into interfaces dedicated for case managers and family caregivers.
- Determine content validity index. Evaluate whether the components and functions of the DCMIS are appropriate for case management.

Phase 4

Testing and feedback by DC case managers (n=30)

- Pilot testing of the final DCMIS by a second group of case managers.
- Face-to-face or web-based semistructured interviews to obtain feedback.
- Content analysis of interview data

Participants

Case managers overseeing the coordination of care for persons with dementia at community-based facilities were recruited through purposive sampling from 28 facilities from shared dementia care centers and dementia care community service sites in Taiwan. Case managers were included if they met the following criteria: age 20 years or older, proficient in Mandarin or Taiwanese, and currently employed in one of the above dementia care facilities. There were no exclusion criteria. A total of 63 case managers were recruited to participate.

Development of the DCMIS

Phase 1

During phase 1, semistructured interviews were either face-to-face or internet-based, using Google Meet, based on the preference of each participant. All interviews were conducted with one of two members of the research team (CYK and YLS). Questions followed a semistructured interview guide developed through discussions with members of the research team (Textbox 1). Interviews were recorded and transcribed verbatim. Analysis of interview data was conducted by three members of the research team (CYK, YLS, and HLH) using thematic analysis. Members of the research team met to discuss the findings and determine what identified components were described with the highest frequency by case managers. Any disagreements about what should be included or excluded were discussed and revised until a consensus was reached. Case managers who participated in phase 1 were invited to review the included items to determine whether the components of the DCMIS were relevant to the needs they expressed during the interviews.

Textbox 1. Semistructured interview guide for phase 1: perceived challenges and IT needs of dementia care case managers.

Duration, responsibilities, and experiences of being a case manager

- How long have you been working as a dementia case manager?
- What are the main responsibilities in your role as a case manager?
- How do you feel about the process of performing your duties?

Factors influencing job performance

- What factors influence your performance as a case manager?
- Are there any resources available that could improve your performance as a case manager?

Barriers to fulfilling the responsibilities of a case manager

- Are there any aspects of being a case manager that you find challenging?
- (If yes): What type of assistance would help you navigate the challenge or challenges?

Availability of IT systems

- Do you use any IT system to support your work as a case manager?
- How does this help you with your work?
- Do you feel comfortable or uncomfortable using the system?

IT systems that could improve case management for persons with dementia

- Looking ahead, would you consider using an IT system to assist you in your role?
- Why would you be willing or not willing to use an IT system for support?
- Do you have any suggestions for such a system or the specific type of assistance you would hope would be provided?

Regarding this interview, do you have any other thoughts or ideas you would like to share or discuss?

Phase 2

Phase 2 involved formulating the framework of the DCMIS based on the components identified during phase 1. Dementia care case managers who participated in phase 1 were invited to review the components of the app to confirm whether they were appropriate and functional for case management of persons with dementia.

Phase 3

Phase 3 focused on the development of the DCMIS as a mobile app, which involved an interdisciplinary team comprised of an associate professor from the Department of Computer Science and Information Engineering, two IT engineers, and two experts in dementia care.

The DCMIS operating system was designed to use Microsoft Windows Server 2019 and was based on the LINE (LY Corporation) instant messaging platform. LINE is the most commonly used instant messaging app among Taiwanese, accounting for 77.56% [13]. We used the LINE messaging application programming interface to develop a LINE bot, which requires a webhook URL to receive webhook payloads from the LINE platform. For this purpose, we opted for a secure unified Ingress platform, ngrok [14], which is a proxy server enabling the creation of an HTTP/HTTPS server with a simple command. The ngrok platform was used to establish a secure tunnel with localhost on our local machine, allowing locally running services to be securely accessed over the internet through this tunnel. All responses from the bot server to users are programmed using Python codes stored in an Amazon Elastic Compute Cloud (EC2) virtual machine. The response content can be either text or a hyperlink. It was important that information entered by the users be secure and have cross-platform connectivity; therefore, Hypertext Preprocessor (PHP) scripting language was used, which allows the hyperlink to direct users to a web page where they can securely complete forms such as detailed patient information. The open-source database management system, MySQL, was configured to use the EC2 server for storing user information, patient data, questionnaire items, scoring correspondence tables, and any other needed data. To enhance network security on the EC2 virtual machine, all unnecessary ports were closed and connections for program updates were made using the default remote desktop protocol, which uses a 2048-bit SSH-2 RSA key pair for security. Database security was further enhanced by removing default accounts and using nonroot accounts, applying secure hash algorithm-1 encryption for sensitive data, and scheduling automatic backups.

During this development phase, biweekly meetings were conducted to assess progress, address challenges, and resolve system errors. We also sought consultations with software experts when necessary and feedback from the phase 1 case managers to ensure the DCMIS included all user needs.

Following the development of the DCMIS, four experts in dementia case management were invited to evaluate whether the content of the components and functions of the system were appropriate for case management. Each component was evaluated on a 4-point Likert scale: 1=very inappropriate; 2=inappropriate; 3=appropriate; and 4=highly appropriate. The content validity index (CVI) was calculated as the sum of the scores for each item divided by the number of experts. None of the items had a CVI ≤2, thus none were excluded. Although experts proposed renaming the case management function labeled, “Add/Select Case” to “Case List,” discussions with the research team believed these changes would not impact usability, and no change was made. The CVI for all components was > 0.9, indicating all were acceptable [15,16].

Phase 4

A second group of dementia care case managers participated in using the DCMIS. They then provided feedback on their experiences through face-to-face interviews as described for phase 1, but interviews were guided by a second semistructured interview guide (Textbox 2).

Textbox 2. Semistructured interview guide for phase 4 for case managers’ feedback about using the dementia case management information system (DCMIS) app (n=30).

Experience of using the DCMIS for case management

- What was your overall impression of the app?
- Could you please share your opinions or reactions about the functionality of the components including in the DCMIS?

Impact of the DCMIS on case management

- Do you think the DCMIS with have a positive impact on your work as a case manager?
- Can you tell me more about that?

Changes or modifications needed for the DCMIS

- Do you think there are any additional functions or modifications that should be made to the DCMIS to improve case management?
- Why do you think these are needed?

Other variables about the DCMIS

- Are there any factors that might influence whether you use the DCMIS?
- Could you explain why?

Do you have any other thoughts, ideas, or recommendations about the DCMIS app you would like to share?

Data Collection and Analysis

The collection of interview data and thematic analysis of transcribed interviews were conducted concurrently. Interview data were analyzed with thematic analysis using the method described by Braun and Clark [17]. During phase 1, text was identified to understand the key categories that described case managers’ experiences and perceived needs. During phase 4, text was identified that described the case managers’ experiences of using the DCMIS. For both phases, text was analyzed line-by-line to identify the experiences of the dementia care case managers and coding of the identified text was used to generate the key categories to provide an understanding of the experiences of the case managers [17,18]. The rigor of the interview data was maintained by the credibility of the data, which occurred by allowing other members of the research team to provide feedback about the validity of the analyzed data, and by dependability, which occurred by maintaining an audit trail of the process of data collection and analysis. Confirmability of the findings was provided by peer debriefing sessions; transferability was ensured by comparing the quantitative data with existing research on dementia case management [18].

Ethical Considerations

This study was approved by our institutional review board (phase 1: IRB 202000902B0; phases 2-4: IRB 202100914B0). All case managers were informed of the study’s purpose, procedures, and potential risks before participating. Informed consent was obtained in writing from all participants. The data were anonymized, no personal identifiers were used in the analysis or reporting of the data, and participant confidentiality was strictly maintained. As a token of appreciation, all participants who completed the interview received a US $6 gift voucher.

Results

Participants

A total of 63 case managers were recruited to participate. Phase 1 included 33 case managers with a mean age of 36.7 (SD 10.9; range 23-63) years, most were female (n=29, 88%), and most (n=32, 97%) had a bachelor's degree or higher. The average duration of employment as a dementia care case manager was 28 (SD 19.2; range 6-108) months. Phase 4 included 30 case managers with a mean age of 38.4 (SD 11.5; range 24-62) years, most were female (n=26, 87%), and most had a bachelor's degree. The average duration of employment as a dementia care case manager was 43 (SD 35.6; range 4-156) months.

Phase 1

Overview

Analysis of the interview data indicated that the challenges faced by dementia care case managers were high caseloads and a lack of support services. These were the result of increases in the number of persons with dementia, the time required to enter large amounts of patient data and administrative paperwork, and a lack of support services for themselves, as well as for persons with dementia and their family caregivers. The results of the analysis of the interview data are summarized in Textbox 3. The following information was provided when participants from phase 1 (P1) were asked about what challenges acted as barriers to fulfilling their role as a case manager.

Textbox 3. Challenges and IT needs for case managers (n=33).

Challenges

- High caseload numbers and concomitant increases in paperwork
    - Difficult to keep track of cases
    - Missed follow-ups
- Support services disorganized and complicated to navigate
- Absence of an established health education database
    - Additional time spent searching for material
    - There is no source of material for caregivers
    - No digital database requires carrying large amounts of hard copies
- Little internet-based sources for health education and case management
- Lack of remote data access about patient information

IT needs

- An integrated system with a user-friendly input mechanism
- A comprehensive database of available resources
    - Type and description of dementia care services
    - Type and description of support services
- A detailed health education model
- A communication system to improve patient handover
- A reminder function to identify cases needing assessments or follow-ups
- An itemized list of available dementia education materials for family caregivers

Challenges

One barrier mentioned by nearly all case managers was the significant increase in the size of their caseload. They also mentioned that manpower has not increased accordingly, and therefore, they often miss follow-ups, and the amount of paperwork has increased. Some case managers expressed feelings of powerlessness. One case manager contemplated resigning, saying:

> *Due to the large number of cases, it is impossible to track every case and understand their current status. I feel guilty about this. I have been angry with myself; at one point I considered resigning.* [P1.CM01]

A second barrier mentioned was the absence of a system that lists and describes available support services that address the care needs of persons with dementia. Several case managers mentioned this challenge. The following comment was typical:

> *To be honest, I'm not very familiar with community resources because there are so many types of services.*

> *There are dementia community service sites, long-term care stations, daycare services, small-scale multi-functional services, and respite care services. These things are just too diverse.* [P1.CM16]

Other comments included the following:

> *I'm not familiar with tasks like identification and certification of a disability or hiring a foreign caretaker. I need to study the application procedures and the required documents, which means considerable time spent searching for information.* [P1.CM04]

Case managers also found the lack of a health education database added to their frustration and inability to help patients navigate the system. Case managers described the need to invest additional time searching for health education information for themselves, as well as for patients and family caregivers. Another case manager mentioned family caregivers also found it challenging to obtain relevant information on their own, saying:

> *Some family caregivers don't know where to find these resources and have already begun caring for a family member with dementia (without any information).* [P1.CM26]

The absence of internet-based sources of information about support services and health education material meant that case managers needed to carry large volumes of hard copies. One case manager said:

> *My colleague prints out all the health education materials and case information and puts them in a folder for easy access, but I feel it's inconvenient to carry the folder around for work.* [P1.CM21]

Information Technology Needs

All participants agreed that an IT system would be useful for addressing some of the challenges that were barriers to fulfilling their role as case managers. Making patient data available internet-based would reduce the time required for case management. Although all case managers used the IT systems provided by the government, they expressed frustration that these were not adequate for supporting most of their case management tasks. Some case managers used available software spreadsheets to meet their needs. One participant provided the following description:

> *I believe effective case management requires multiple reminders. These are used as prompts for tracking specific cases on a given day, identify individuals requiring reassessment, and specifying the focus of the current follow-up. I have 20 individuals needing follow-up today. Without the use of an Excel spreadsheet, I would not know which patients will be present.* [P1.CM02]

When asked what should be included in an IT system designed specifically for dementia care case managers, first and foremost was the need for a user-friendly input mechanism. Regarding the components that should be considered, the following were mentioned most frequently: a comprehensive database of resources listing and describing available types of dementia care and support services, a detailed health education module, and a shared platform that would allow communication between team members, which could improve patient handover. Additionally, many case managers emphasized the necessity of reminder functions for efficient case follow-up. One participant explained:

> *At times, due to the demanding nature of our responsibilities, we may overlook pending tasks. With a reminder function, we would be able to identify cases yet to be assessed.* [P1.CM17]

Case managers also believed a health education component should be available, which could be provided to caregivers. Several suggested constructing a needs-specific list of available materials within the areas of dementia care. Case managers could then check a box to indicate materials of interest, which would make it easier to access educational material appropriate for caregivers of their cases. A case manager provided the following example:

> *If a case manager has a client with dementia who is exhibiting behavioral problems, they could check a box next to 'behavioral problems' to generate a list of available educational material that could be provided to the caregiver.* [P1.CM20]

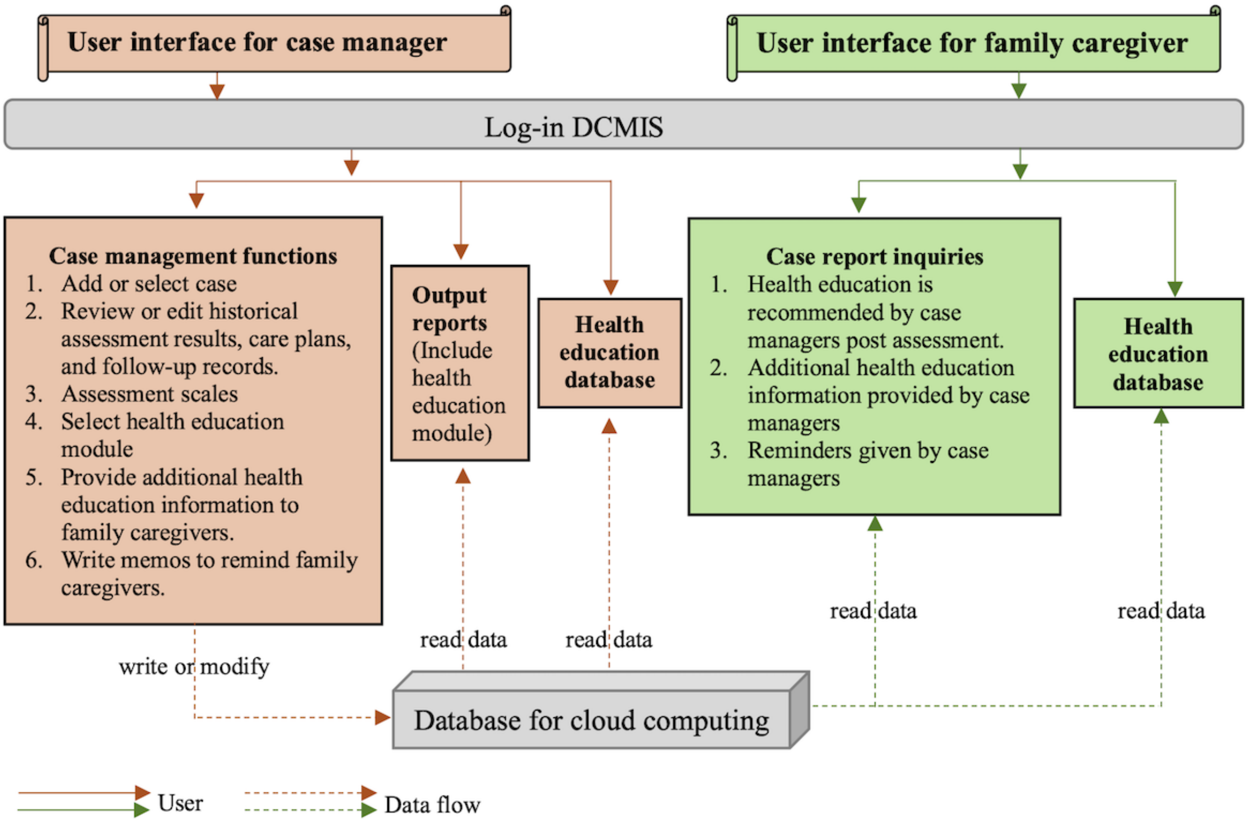
Phase 2

Based on the challenges and needs expressed by dementia care case managers, a framework for the DCMIS was developed. Because interview data showed case managers believed that there should be a component of the DCMIS that could be used by caregivers, the framework included an interface for case managers, as well as one for caregivers. A diagram of the framework of the DCMIS is shown in Figure 2, which includes a schematic of the case manager interface and theoretical interactions with a family caregiver interface.

The case manager interface was comprised of three blocks: case management functions, such as assessments, care plans, and reminders; output reports; and a health education database. The assessment block incorporates comprehensive assessment scales. When conducting case management, case managers can select relevant scales based on the needs of physical and mental assessments for the individuals or caregivers, for example, activities of daily living, brief version, and Chinese version of the Zarit Burden Interview (sCZBI-12). The care management follow-up block incorporates a case management database encompassing patient and family caregiver information, historical assessment results, care plans, and follow-up records. Case managers can review each case, provide care plans, and provide timely reminders for follow-ups. Historical case management data can be exported into reports for review or modification and synchronized with the caregiver interface, which has not yet undergone any clinical trials. The health education database integrates the research findings on dementia [19-24] and existing service resources, which incorporate an introduction to the different stages of dementia, treatments and care, family caregiver support, existing care resources, other chronic disease care, and common health issues. Dementia care case managers can directly select and query the required information from a database. Alternatively, after conducting case assessments, the system automatically and synchronously provides corresponding health education suggestions.

Each block of the case manager interface was designed to facilitate communication with their cases through a family caregiver interface. Although not yet tested with caregivers, the theoretical schematic is included in Figure 2, illustrating how family caregivers will be able to receive health education information, reminders, and follow-up records from the dementia care case managers. Additionally, caregivers will be able to autonomously search for relevant health education content using keywords. Given the prevalence of foreign caregivers hired to provide care for persons with dementia, specific health education materials will include versions in the languages of these caregivers.

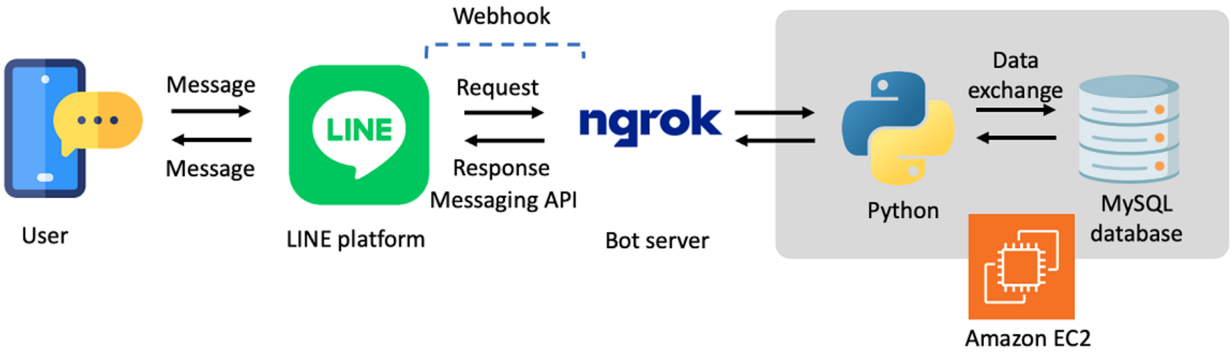
Figure 2. The framework of the DCMIS. DCMIS: Dementia Case Management Information System.



Phase 3

The final architecture of the DCMIS is shown in Figure 3. The use of the LINE mobile app, which is widely used throughout Asia [25], offers portability and freedom from environmental constraints. Case managers download the app to their smartphones, enabling them to perform assessments, health education, and case management. Further clarification and guidance about the use of the app were provided through instructional videos and user manuals.

Figure 3. The final architecture of the DCMIS. API: application programming interface; DCMIS: Dementia Case Management Information System.



Phase 4

Overview

Analysis of interview data with case managers following pilot testing of the DCMIS app indicated that the overall experience was positive because the operation was user-friendly with only a few barriers. Three categories describe case managers' user experiences using the DCMIS app: positive impact, facilitators of use, and barriers to use. Although the focus of pilot testing the DCMIS app was to get feedback about the interface for case managers, when asked if they had anything additional that they would like to share, case managers offered opinions about the caregiver interface, which involved two categories: anticipated benefits and anticipated difficulties. Components of these five categories are summarized in Textbox 4. Some of the specific comments from participants during the phase 4 (P4) interviews are provided below.

Textbox 4. Case managers experiences of pilot testing the dementia case management information system app and their opinions (n=30).

Case managers' experiences

- Positive impact
  - User-friendly operation
  - Enhanced accessibility of patient data
  - Ease of tracking and recording data in real time
  - Simplified interface and logical procedures
  - Reduction in searching for paper-based educational materials
- Facilitators of use
  - Components are time-saving solutions for high caseloads
    - Digital assessment tools
    - Streamlined case management
    - Comprehensive health education database
  - Improved delivery of patient care and availability of information for caregivers
    - Automated reminders enhanced follow-ups
    - Improvements in handovers
    - Comprehensive care information about the trajectory of dementia
- Barriers to use
  - Lack of integration of the DCMIS with the government operating system, which may increase redundancy
  - Availability of the DCMIS as only a mobile app
    - Some case managers preferred using a desktop for data entry; no desktop option
    - Caregivers might view using a mobile app during consultations as impolite or unprofessional

Case managers' opinions about the caregiver interface

- Anticipated benefits
  - Information about the experience of living with dementia
  - A better understanding of caregiving needs for persons living with dementia
  - The ability to access educational material at a time convenient for the caregiver
- Anticipated difficulties
  - Older caregivers might find it challenging to use a mobile app independently
  - Some caregivers prefer being provided with information rather than searching themselves
  - Oral- or paper-based health educational material might be desired by older caregivers

Positive Impact

Incorporating the DCMIS into a mobile app enhanced accessibility to patient data by enabling case managers to seamlessly access and track case information and record data in real-time without temporal or spatial constraints. In addition to the ease of use, the simplified interface and logical procedures were the key factors influencing case managers' readiness to embrace the system. All case managers viewed that eliminating the need to search for supplementary paper-based health education materials reduced their workload considerably. One case manager appreciated being able to perform case management more easily:

> *I feel the app is very convenient. The ability to use my mobile phone with LINE allows me to perform tasks like record keeping and track the status of my cases anywhere, which reduces my workload tremendously. I don't need to bring paper copies with me anymore! Most of my important work as a case manager is away from the office. The app allows to conduct record keeping away from my desk. I think it is very helpful.* [P4.CM11]

Another case manager described why the app was easy to use:

> *The interface is clear, so it's easy to use. Although it took a little time to for me to adjust, when I became familiar with the interface, I understood the logic of it. Once this happened, it was very convenient to use. Including the ADL function is really a time-saver because it calculates the ADL score, which is not always simple.* [P4.CM03]

Facilitators of Use

Case managers reported that the DCMIS would facilitate significant savings in time. They felt the digital assessment tool had a positive impact on work efficiency, which would streamline case management when caseloads were high. The comprehensive health education database was also seen as a time-saving component because it would facilitate searching through stacks of documents and brochures. The generation of corresponding educational modules postassessment content was also considered a time-saver with real-time information delivery to family caregivers ensuring information was received without a delay and the generation of automated reminders from case managers to caregivers would enhance effective case follow-up. One case manager commented on the expectation that the app would improve handovers:

> *I find the presentation format of the output reports very clear. It systematically organizes and presents data and provides a transparent record of actions during the service process.* [P4.CM21]

Another case manager thought that the DCMIS app addressed the complexity of management:

> *Dementia care issues vary at each stage and every condition is unique. This system provides comprehensive care information covering the entire disease trajectory. This includes information that can be shared with family caregivers, which is highly beneficial to our work.* [P4.CM04]

Barriers to Use

One barrier to use that was expressed by some of the case managers was the lack of integration between the government's operating system and the DCMIS. This was a concern because monthly entries into the government system are required for the registration of cases and reimbursements for services delivered. Case managers saw a potential for duplication of efforts if the systems were not integrated. One case manager said:

> *If the DCMIS is not integrated with the Ministry of Health and Welfare's system, my data will need to be entered a second time, which will add redundancy to the system.* [P4.CM28]

The second barrier was that the DCMIS was only available in a mobile version. Some case managers mentioned they preferred a larger desktop system over a small mobile app. Not only was size a consideration, but they also believed that operating a mobile app while simultaneously engaging in clinical responsibilities or having a conversation with a caregiver might have a negative impact on their image as a professional. This was voiced by one case manager, who said:

> *If we are constantly looking at our mobile phones during a consultation, would the family caregivers perceive us as impolite?* [P4.CM13]

Anticipated Benefits for Family Caregiver Users

Case managers mentioned that the DCMIS could enable family caregivers to better understand the experience of dementia for their family members. One case manager said:

> *It could provide family caregivers with information about the current condition of their family member with dementia, which could provide caregivers with a better understanding of the caregiving tasks required.* [P4.CM26]

Another case manager said:

> *Family caregivers can simultaneously access caregiving recommendations or health education information on their mobile phones, which be convenient to reading during their free time.* [P4.CM22]

Anticipated Difficulties for Family Caregiver Users

Some case managers expressed concern that family caregivers might not be able to access and read health education information using an app without the help of someone else. One case manager believed older caregivers might find it challenging to use new technology, saying:

> *I think sometimes family caregivers prefer having information provided to them directly rather than having to do a search themselves, unless they are particularly diligent.* [P4.CM03]

Another case manager had the same concern, although they thought caregivers who were younger would be more willing to use the app:

> *The DCMIS interface may be suitable for younger or middle-aged caregivers familiar with mobile phone use. However, oral- or paper-based health education may be more appropriate for older adult caregivers.* [P4.CM14]

Discussion

Principal Findings

Development of the DCMIS app for dementia care case managers used a multistage process. The framework was designed to meet the needs of case managers, which was guided by the literature on eHealth, as well as qualitative interview data from 33 experienced case managers. The components of the app were examined for content validity and the usability of the app was pilot-tested with hands-on use by 30 case managers. Qualitative interview data provided feedback about functionality and how well the available components aligned with the assistance needed by case managers to benefit their job responsibilities.

The effectiveness and usability of the newly developed eHealth system increases when feedback is obtained from stakeholders who will be the primary users [26-28]. We explored the opinions of case managers regarding not only the type of help the DCMIS should provide but also what they expected in an eHealth app. Firsthand experience of case managers and qualitative interviews following sustained use of the app confirmed the app was feasible for use in a clinical setting.

The incorporation of the LINE messenger app into the system enhanced usability. Most people in Taiwan are already familiar with how to connect to the internet via their mobile phones through LINE messenger, which allows rapid exchange of information and services including text, images and video sharing, and searches [29-31]. This familiarity with LINE further enhanced usability because it was easy for case managers to record, query, and share information. The health education database incorporated into the DCMIS addressed case managers' concern about the problem of time wasted when they needed to manually search through paper-based reports for information on dementia. Finally, the feature of separate interfaces for case managers and family caregivers was designed to allow synchronization of results of assessments and related health education measures allowing caregivers immediate access to patient information before meeting with the case manager. System feedback and individualization are functionalities strongly supported by participants [28,32].

Many of the available platforms have similar functions; however, their applications differ from the DCMIS app for dementia care case managers. Several apps provide support for family caregivers of persons with dementia [9-11,33], video consults and decision support tools to help dementia care nurses and case managers care for persons with dementia in residential care facilities [12], and internet-based training and support for informal dementia carers [28]. An app with similar functions to the DCMIS app is available in Taiwan but its purpose is to provide nurses with tracking information related to location and fall detection for persons with dementia residing in nursing homes [34]. By contrast, the DCMIS app was developed to streamline the work performed by dementia care case managers with a design focused on making it easier to implement dementia case management practices and improving the quality of care for persons with dementia.

The ability of the DCMIS app to help with tracking assessments, care plans, and follow-up reminders, and the inclusion of a health education database will allow integration of the platform with other health systems in Taiwan. Future expansion of the DCMIS to other health care facilities should increase the efficiency of scheduling patient assessments, follow-ups, and receiving test results that require an exchange of information between dementia care case managers and dementia care medical centers, community-based clinics, or home health care providers. Dementia and health care–related assessment tools for behavioral problems, sleep quality, frailty, nutrition, and activities of daily living can be reviewed and associated health education suggestions can be generated. The design of the DCMIS app makes it easier to manage large case numbers by including reminders about when patients need critical assessments or follow-ups so that appointments are not missed. This function will be essential during periods of unexpected reductions in manpower, as occurred during the COVID-19 pandemic. A loss of manpower results in a higher-than-normal caseload, and this reminder function minimizes errors that occur when appointments and follow-ups are paper-based.

The DCMIS app enables case managers to complete multiple tasks on one platform, thus enhancing work efficiency. It is hoped that the system will eventually include an interface with a caregiver app, which will further increase continuity of care. Case managers' concerns that older caregivers of persons with dementia might find it difficult to interact with case managers via an app suggests it will be important to ensure user-friendliness for all ages and abilities when the caregiver app is launched. It is believed this issue will be ameliorated by alterations in the design through interdisciplinary collaborations [35]. Future applications could also include training of current case managers or nursing students.

Limitations

This study had several limitations. First, as mentioned, integrating the DCMIS with the government's operating system to avoid redundancy might not be achievable due to the barriers of integrating the system with Taiwan's IT system, which is based on financial reimbursements. This is in sharp contrast to the DCMIS, which was developed as a tool to improve case management and improve continuity of care. Second, the current DCMIS is only available as an app for mobile phones; it is unclear when it will be available for desktop computers. The convenience of simultaneous assessment and recording was appreciated by some case managers but others were concerned the use of the mobile app might be perceived as disrespectful. Future designs should consider user-friendliness and diversity to align with individual preferences and use habits. Finally, family caregivers were not included in any of the phases for input into their needs or pilot testing of the app and providing feedback, which was due to lack of time and manpower. Future research should include family caregivers to promote better alignment of the DCMIS with their needs.

Conclusions

The growing aging population and increase in the number of persons with dementia present a global challenge to the adequacy of care resources. The availability of a case management app could improve the management of health care for persons with dementia by improving efficiency when managers are faced with high caseloads. Participants who reacted positively to the DCMIS app did so because it was easy to use, and they perceived their caseloads were easier to manage. Our findings suggest that the incorporation of eHealth could enhance efficiency for case managers and improve the quality of care provided to persons with dementia. Our findings can serve as a reference for future research on the development and application of eHealth systems for other case managers. However, a large-scale clinical trial with a larger number of dementia care case managers and multiple health care systems will need to be conducted to quantitatively assess the effectiveness of the DCMIS app on case management outcomes including improvements in patient care and support for family caregivers.

Conflicts of Interest

None declared.

References

1. Gale SA, Acar D, Daffner KR. Dementia. Am J Med 2018 Oct;131(10):1161-1169 [FREE Full text] [doi: 10.1016/j.amjmed.2018.01.022] [Medline: 29425707]
2. Dementia. WHO. 2023. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2024-08-28]
3. Bakker C, Verboom M, Koopmans R. Reimagining postdiagnostic care and support in young-onset dementia. J Am Med Dir Assoc 2022;23(2):261-265 [FREE Full text] [doi: 10.1016/j.jamda.2021.12.008] [Medline: 34951976]
4. Low LF, Gresham M, Phillipson L. Further development needed: models of post-diagnostic support for people with dementia. Curr Opin Psychiatry 2023 Mar;36(2):104-111 [FREE Full text] [doi: 10.1097/YCO.0000000000000848] [Medline: 36705009]
5. Vroomen JM, Bosmans JE, van de Ven PM, Joling KJ, van Mierlo LD, Meiland FJ, et al. Community-dwelling patients with dementia and their informal caregivers with and without case management: 2-year outcomes of a pragmatic trial. J Am Med Dir Assoc 2015 Sep 1;16(9):800.e1-800.e8 [FREE Full text] [doi: 10.1016/j.jamda.2015.06.011] [Medline: 26170035]
6. Dementia prevention and care policy and action plan 2.0. Department of long-term care. Ministry of Health and Welfare. 2023. URL: https://1966.gov.tw/LTC/cp-6572-69818-207.html [accessed 2024-08-28]
7. Dementia-shared care centers, and dementia community service sites reference manual. Ministry of Health and Welfare. 2019. URL: https://1966.gov.tw/LTC/cp-4007-42468-201.html [accessed 2024-08-28]
8. Thoma-Lürken T, Bleijlevens MHC, Lexis MAS, Hamers JPH. Evaluation of a decision support app for nurses and case managers to facilitate aging in place of people with dementia. A randomized controlled laboratory experiment. Geriatr Nurs 2018 Nov;39(6):653-662 [FREE Full text] [doi: 10.1016/j.gerinurse.2018.04.019] [Medline: 29858041]
9. Désormeaux-Moreau M, Michel CM, Vallières M, Racine M, Poulin-Paquet M, Lacasse D, et al. Mobile apps to support family caregivers of people with Alzheimer disease and related dementias in managing disruptive behaviors: qualitative study with users embedded in a scoping review. JMIR Aging 2021 Apr 16;4(2):e21808 [FREE Full text] [doi: 10.2196/21808] [Medline: 33861207]
10. Han SS, White K, Cisek E. A feasibility study of individuals living at home with Alzheimer's disease and related dementias: utilization of visual mapping assistive technology to enhance quality of life and reduce caregiver burden. Clin Interv Aging 2022 Dec 23;17:1885-1892 [FREE Full text] [doi: 10.2147/CIA.S387255] [Medline: 36583148]
11. Leng M, Zhao Y, Xiao H, Li C, Wang Z. Internet-based supportive interventions for family caregivers of people with dementia: systematic review and meta-analysis. J Med Internet Res 2020 Sep 9;22(9):e19468 [FREE Full text] [doi: 10.2196/19468] [Medline: 32902388]
12. Gillam J, Davies N, Aworinde J, Yorganci E, Anderson JE, Evans C. Implementation of eHealth to support assessment and decision-making for residents with dementia in long-term care: systematic review. J Med Internet Res 2022 Feb 3;24(2):e29837 [FREE Full text] [doi: 10.2196/29837] [Medline: 35113029]
13. Taiwan internet report. URL: https://report.twnic.tw/2022/en/index.html [accessed 2024-08-28]
14. ngrok: unified application delivery platform for developers. URL: https://ngrok.com/ [accessed 2024-08-28]
15. Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. Res Nurs Health 2006 Oct 29;29(5):489-497. [doi: 10.1002/nur.20147] [Medline: 16977646]
16. Waltz CF, Strickland OL, Lenz ER. Measurement in Nursing and Health Research. US: Springer Publishing Company; 2005.

17. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
18. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs Health Sci 2013 Sep 15;15(3):398-405 [FREE Full text] [doi: 10.1111/nhs.12048] [Medline: 23480423]
19. Huang HL, Shyu YI, Chen MC, Chen ST, Lin LC. The effectiveness of a community-based caregiver training program for improving the caregiver's preparedness of elders with dementia. Chang Gung Nurs 2003 Mar;14(1):1-10 [FREE Full text] [doi: 10.6386/CGN.200303_14(1).0001]
20. Huang HL, Shyu YI. The effectiveness of a community-based caregiver training program for improving the caregiver's competence of elders with dementia. J Long-Term Care 2003 Jun;7(2):121-134 [FREE Full text] [doi: 10.6317/LTC.200306_7(2).0004]
21. Huang HL, Shyu YI. The community-based caregiver training program of elders with dementia. J Long Term Care 2004 Mar;8(1):89-95 [FREE Full text] [doi: 10.6317/LTC.200403_8(1).0009]
22. Huang HL, Shyu YIL, Chen MC, Chen ST, Lin LC. A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of elders with dementia in Taiwan. Int J Geriatr Psychiatry 2003 Apr;18(4):337-345 [FREE Full text] [doi: 10.1002/gps.835] [Medline: 12673611]
23. Huang HL, Shyu YIL, Chen MC, Huang CC, Kuo HC, Chen ST, et al. Family caregivers' role implementation at different stages of dementia. Clin Interv Aging 2015 Jan 5;10:135-146 [FREE Full text] [doi: 10.2147/CIA.S60574] [Medline: 25584022]
24. Huang HL, Shyu YIL, Huang HL. An investigation on the core competencies of professional dementia caregivers. 2018 Presented at: Sigma 30th International Nursing Research Congress; July 26, 2019; Calgary, AB URL: http://hdl.handle.net/10755/17915
25. Steinberg M. LINE as super app: platformization in East Asia. Soc Media Soc 2020 Jun 19;6(2):205630512093328-205630512093312 [FREE Full text] [doi: 10.1177/2056305120933285]
26. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Q 1989 Sep;13(3):319-340. [doi: 10.2307/249008]
27. Sala-González M, Pérez-Jover V, Guilabert M, Mira JJ. Mobile apps for helping informal caregivers: a systematic review. Int J Environ Res Public Health 2021 Feb 10;18(4):1702 [FREE Full text] [doi: 10.3390/ijerph18041702] [Medline: 33578819]
28. Teles S, Paúl C, Lima P, Chilro R, Ferreira A. User feedback and usability testing of an online training and support program for dementia carers. Internet Interv 2021 Sep;25:100412 [FREE Full text] [doi: 10.1016/j.invent.2021.100412] [Medline: 34401371]
29. LINE's philosophy. LINE Corporation. 2022. URL: https://linecorp.com/zh-hant/company/mission [accessed 2024-08-28]
30. Chang SH, Hsu CH, Kung CC, Chang HY, Chao CL. Combining technology acceptance and task-technology FitModels to explore the effect of nursing staff using social media on job performance. J Healthc Manag 2019 Dec;20(4):267-287 [FREE Full text] [doi: 10.6174/JHM.201912_20(4).267]
31. Darmaastawan K, Sukarsa IM, Buana PW. Line messenger as a transport layer to distribute messages to partner instant messaging. Int J Mod Educ Comput Sci 2019 Mar 8;11(3):1-9 [FREE Full text] [doi: 10.5815/ijmecs.2019.03.01]
32. Hassan AYI. Challenges and Recommendations for the deployment of information and communication technology solutions for informal caregivers: scoping review. JMIR Aging 2020 Jul 29;3(2):e20310 [FREE Full text] [doi: 10.2196/20310] [Medline: 32723720]
33. Kales HC, Gitlin LN, Stanislawski B, Myra Kim H, Marx K, Turnwald M, et al. Effect of the WeCareAdvisor™ on family caregiver outcomes in dementia: a pilot randomized controlled trial. BMC Geriatr 2018 May 10;18(1):113 [FREE Full text] [doi: 10.1186/s12877-018-0801-8] [Medline: 29747583]
34. Lee CW, Chuang HM. Design of a seniors and Alzheimer's disease caring service platform. BMC Med Inform Decis Mak 2021 Nov 16;21(Suppl 10):273 [FREE Full text] [doi: 10.1186/s12911-021-01626-3] [Medline: 34781953]
35. Kuo HL, Chang CH, Ma WF. A survey of mobile apps for the care management of patients with dementia. Healthcare (Basel) 2022 Jul 23;10(7):1173 [FREE Full text] [doi: 10.3390/healthcare10071173] [Medline: 35885700]

Abbreviations

CVI: content validity index
DCMIS: dementia case management information system

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Original Paper

Social Robots and Sensors for Enhanced Aging at Home: Mixed Methods Study With a Focus on Mobility and Socioeconomic Factors

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Abstract

Background: Population aging affects society, with a profound impact on daily activities for those of a low socioeconomic status and with motor impairments. Social assistive robots (SARs) and monitoring technologies can improve older adults' well-being by assisting with and monitoring home activities.

Objective: This study explored the opinions and needs of older adults, including those with motor difficulties and of a low socioeconomic status, regarding SARs and monitoring technologies at home to promote daily activities and reduce sedentary behaviors.

Methods: A mixed methods approach was used, with 31 older adults divided into 3 groups: those of a low socioeconomic status, those with motor difficulties, and healthy individuals. Focus groups were conducted, and they were analyzed using thematic analysis. Perceived mental and physical well-being were assessed using the 12-Item Short Form Health Survey, and attitudes toward robots were evaluated using the Multidimensional Robot Attitude Scale.

Results: The results identified 14 themes in four key areas: (1) technology use for supporting daily activities and reducing sedentary behaviors, (2) perceived barriers, (3) suggestions and preferences, and (4) actual home technology use. Lower perceived physical well-being was associated with higher levels of familiarity, interest, perceived utility, and control related to SARs. Lower perceived psychological well-being was linked to a more negative attitude, increased concerns about environmental fit, and a preference for less variety. Notably, older adults from the low–socioeconomic status group perceived less control over SARs, whereas older adults with motor difficulties expressed higher perceived utility compared to other groups, as well as higher familiarity and interest compared to the low–socioeconomic status group.

Conclusions: Participants indicated that SARs and monitoring technologies could help reduce sedentary behaviors by assisting in the management of daily activities. The results are discussed in the context of these outcomes and the implementation of SARs and monitoring technologies at home. This study highlights the importance of considering the functional and socioeconomic characteristics of older adults as future users of SARs and monitoring technologies to promote widespread adoption and improve well-being within this population.

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KEYWORDS

older adults; motor difficulties; socioeconomic status; social assistive robots; monitoring technologies; mixed methods

Introduction

Background

Population aging is a significant phenomenon with far-reaching implications for both the economy and society. Worldwide, older adults constitute approximately 13% of the population, with this proportion increasing by 3% annually [1], whereas projections for the United Kingdom suggest that, by 2050, a quarter of the population will be aged ≥60 years [2]. This demographic shift introduces new challenges, notably, a heightened need for health and social services [2] as aging is associated with a reduction in physical and cognitive functioning and an increase in frailty conditions [3-5]. Frailty conditions lead to a reduction in an older person's ability to carry out activities required to live independently, known as activities of daily living (ADLs) [6,7]. To counteract this, there is a global increasing interest in age-friendly environments that may include social or technological innovations [8] that support older adults in remaining independent in their daily lives. In this paper, "daily activities" refer to ADLs. These activities can be physical, such as those needed to manage physical needs, or complex, referring to tasks necessary for independent living within the community [8].

The ability to perform ADLs tends to diminish gradually starting from late middle age and during seniority [9,10] due to a reduction in fundamental physical abilities [11-13]. One method of promoting healthy aging and independence in older age is maintaining an active lifestyle [14]; however, older adults often find themselves spending most of their time engaged in sedentary behaviors [15]. Increased sedentary behavior is associated with a higher risk of mortality and adverse health outcomes [16]. In contrast, the performance of daily physical activities is reported to be linked with various indicators of well-being, including improved mental health [17], reduced risk of chronic diseases [18], a reduction in long-term assistance needs [19], reduced hospitalization rates [20], reduced carer burden [21], and reduced mortality [22]. Thus, national and international recommendations suggest decreasing older adults' sedentary time and increasing time spent in physical activities [23].

In addition to declining physical abilities, factors such as lifestyle, health indicators, social isolation, and socioeconomic status—including household income—can affect the ability of older adults to perform daily activities [24]. Within the socioeconomic context, higher socioeconomic status is associated with better health status [25] and decreased frailty conditions [26], and notably, a lower socioeconomic status is linked to a greater need for personal, instrumental, and environmental support [27]. Therefore, individuals of a low socioeconomic status may have specific needs that ought to be considered when designing interventions to promote healthy aging.

There is a current trend of interventions aimed at improving quality of life for older adults consisting of adapting their environment to enable them to live as independently as possible for as long as possible, known as "aging in place" [28]. Aging in place refers to older adults' capacity to remain in their own homes and communities securely, independently, and comfortably irrespective of their age, financial resources, or functional limitations [29]. Through these interventions, support is provided to enhance the well-being and independence of older individuals while reducing health care costs [30,31]. Importantly, because of the high levels of variation among the older population, care provision needs to encompass a wide range of options, with home-based technology serving as a potential tool to reduce the daily burden on primary carers [32]. Within this framework, smart home technologies, such as monitoring systems and social robots, offer promising solutions for helping older adults maintain independence and age in place, particularly in the context of an aging population and a shortage of care workers [33]. The literature indicates that the integration of home modification strategies into smart homes to monitor daily activities and health is viewed as a key factor in enabling successful aging in place [34]. Systems incorporating these technologies use artificial intelligence models to understand older adult users and make informed decisions, with a primary focus on activity assistance and recognition [35].

Social assistive robots (SARs) have proven to be a valid method of supporting older adults and people with clinical conditions [36,37]. The literature indicates a strong interest in understanding the psychological dimensions of human-robot interaction [38]. SARs offer significant potential to improve the quality of life of older adults by providing physical assistance with ADLs [6,39] and carrying out cognitive assessments [40], which are fundamental aspects of supporting "aging in place" solutions [41,42]. The use of these technologies to promote the well-being and healthy behaviors of older adults has increased in recent years. However, it has been noted that their design may not adequately meet the diverse needs and capabilities of all users due to the current limitations in involving individuals with varying characteristics and of various socioeconomic backgrounds in a user-centered design framework [43]. Older adults often embrace robots, sometimes more than their younger counterparts [44]. However, these relationships between older adults and robots are often complex, with the acceptability of robots differing based on financial availability [45], previous experience [46], and perceived usefulness [6]. Discrepancies between the needs of users and the solutions currently provided by SARs have the potential to diminish their adoption [47]; however, acceptability could be improved by tailoring them to users' needs and issues [48].

Alongside SARs, other technologies can be used to detect specific activities taking place within a designated room [49], allowing for the adoption of more specialized care and home adaptation strategies [50]. One strength associated with these technologies is their capacity to provide objective measurements within the domestic environment [51], thus informing decision-making among statutory providers, family carers, and older people. Various types of sensors, both environmental and wearable, have been widely used in the literature to evaluate and recognize older adults' daily activities [52]. Smart home systems have been widely used to assess daily activities. The most common methods involve environmental technologies, with infrared motion sensors and contact sensors being the most frequently used [53]. Data collected from sensors can be used to detect routines, identify deviations from typical daily activities [54], and monitor potential health issues [34]. Given their potential in the assessment of daily activities and various health-related issues, monitoring technologies installed in older adults' homes play a crucial role in the aging-in-place framework [34] and prompt a discussion on the significance of incorporating users' opinions to enhance the design and usability of these sensors [52].

Objectives

This study aimed to understand the perspectives of older adults regarding the use of SARs and monitoring technologies in their domestic environment to reduce sedentary behavior and promote daily physical activities. In addition, through the inclusion of older adults with motor difficulties and those of a low socioeconomic status, this study aimed to recognize the considerable role that these aspects play in influencing individuals' daily activities, needs, and well-being.

Methods

Study Design

This study used a mixed methods approach, with qualitative data gathered during focus groups and quantitative measures collected through the questionnaires described in the Measurements section. This study used a parallel design in which the collection of both quantitative and qualitative data occurred simultaneously but the data were analyzed separately [55]. This design aimed to create distinct sets of data that informed each other and were later integrated to provide a more comprehensive understanding of the overall topic. The questionnaires were web-based, and reporting of these methods and results was in line with the Checklist for Reporting Results of Internet E-Surveys [56] (Multimedia Appendix 1).

Procedure

This study included older adults from the United Kingdom recruited from June 2023 to September 2023. Participants were contacted through social media, email lists and advertisements from charity groups, care homes, and universities. To be eligible for this study, all participants had to be aged ≥65 years. Participants were divided into three groups according to the following criteria: (1) older adults with a relatively low income, as defined by the most recent UK statistics [57], were considered as the *low–socioeconomic status group*; (2) older adults with reported motor difficulties and needing physical support to move were considered as the *motor difficulties group*; and (3) older adults not in relative poverty, without physical difficulties, and able to live independently were considered as the *healthy group*. Participants were asked to complete an online survey at their own pace and then invited to take part in one of the focus groups. The survey collected demographic information, health information, and responses to the questionnaires described in the Measurements section. Focus groups were planned as qualitative data collection that included participants' reported experiences, with ongoing analysis conducted until saturation was achieved [58]. Focus groups were used as a qualitative research technique due to their advantages in fostering interaction to generate ideas and gain deeper insights into participants' beliefs, attitudes, motivations, and perceptions [59]. This approach allows for a shared understanding of daily life and encourages the use of everyday language. The diverse responses provide a richer understanding of the topic, enabling connections to be made and participants' viewpoints to be continually re-evaluated [59]. These methods were used to obtain both qualitative and quantitative data from participants. A total of 40 participants joined the study. In total, 22% (9/40) of the participants withdrew for various reasons, resulting in 31 participants who remained involved.

Ethical Considerations

Before taking part in the study, participants were provided with information regarding the study and asked to sign an informed consent form. This study was approved by Nottingham Trent University Institutional Human Research Ethics Committee (ID 1726544) and was conducted according to the principles established by the Declaration of Helsinki. The participants were reimbursed for their travel expenses. Data were anonymized.

Focus Group Structure

Participants engaged in focus groups comprising 6 to 8 individuals to explore how SARs and monitoring technologies could support older adults in reducing sedentary behavior and enhancing their daily activities. Before the discussion and instructional phase, participants were informed about the focus groups' objectives and discussion rules. A presentation was organized to introduce the 3 main topics: ADLs, SARs, and monitoring technologies. Daily activities could range from the basics to more complex activities, leading to a distinction between basic and instrumental activities [60,61]. For instance, basic daily activities encompass bathing, feeding, or mobility, whereas instrumental activities comprise tasks such as housekeeping or managing medications and finances [62,63]. Basic and instrumental ADLs were presented through a Microsoft PowerPoint presentation, followed by a live demonstration of various SARs, as depicted in Figure 1A. The showcased SARs—NAO, Pepper, MiRo-E, and TurtleBot 4—represented a diverse range of types, functions, dimensions, movements, and characteristics. The rationale for selecting these robots was to provide participants with examples of widely used SARs, showcasing the widest possible range of variations and features. This selection aimed to enable participants to provide concrete ideas and associations related to these technologies during the focus groups. NAO and Pepper were chosen as humanoid robots, both equipped with a variety of sensors and hands capable of gripping objects. However, they differ in dimensions (58 and 120 cm, respectively), types of interaction, and movement style. A key difference is the ability of Pepper to interact using a tablet on its chest, which is not a feature of NAO. Similarly, Pepper has built-in omnidirectional wheels to maneuver itself, whereas NAO is able to walk in a more human fashion due to having legs and feet containing specific motors and joints. MiRo-E was selected to showcase a more minimalistic appearance with an animal-like design. TurtleBot 4 was chosen as an objectlike robot with a design similar to those commonly used at home. It features a differential drive base and sensors for perception, offering versatility. The research team described each SAR's main features and functions, allowing participants to interact with the SARs during the session. Monitoring technologies were explained through a PowerPoint presentation, accompanied by a physical display of various sensor types to participants (Figure 1B), including ultrasonic, light detection and ranging, pressure sensor, and Xsens. The presentation aimed to equip participants with sufficient information to offer coherent suggestions on the topic and provide a more tangible understanding of the current capabilities of SARs and monitoring technologies. The presentations typically lasted between 20 and 30 minutes in total. This segment was followed by the focus group discussion, which took the form of a semistructured interview. Participants were asked about challenges they face in their daily activities, how SARs and monitoring technologies could assist them in reducing sedentary behavior and in daily activities, and their suggestions and concerns regarding the use of SARs and monitoring technologies in the home. The discussions were audio recorded and then transcribed verbatim. The focus groups typically lasted approximately 90 minutes (range 83-101 minutes) with a 15-minute break.

Figure 1. (A) Social assistive robots. From left to right: NAO, MiRo-E, Pepper, and TurtleBot. (B) Monitoring technologies presented to the participants before the discussion. From left to right: light detection and ranging, Xsens, pressure sensor, and ultrasonic sensors.

Measurements

The 12-Item Short Form Health Survey [64], a short form of the Medical Outcomes Study 36-Item Short Form Health Survey [65], is a 12-items questionnaire that assesses people's perception of their general health according to physical and mental health components. A norm-based standardized score is calculated [66] leading to a physical component score and a mental component score.

The Multidimensional Robot Attitude Scale (MdRAS [67]) is a questionnaire developed to assess people's attitudes toward domestic robots investigating 12 dimensions: familiarity, interest, negative attitude, self-efficacy, appearance, utility, cost, variety, control, social support, operation, and environmental fit. The questionnaire is composed of 49 items on a 7-point Likert scale and reflect people's expectations regarding future interactions with real SARs.. Participants were provided with images of SARs before completing the questionnaire.

Thematic Analysis of Focus Groups

The focus groups underwent a comprehensive thematic analysis following an inductive approach [68] using NVivo (QSR International). This method encompasses several key phases, beginning with familiarization with the data followed by the generation of codes, linking these codes to overarching themes, and subsequently reviewing and defining these identified themes. The final step involves compiling a comprehensive report summarizing the outcomes of the analysis. The fit between the codes and statements was reviewed in a series of research team meetings after each focus group during which codes were revised leading to possible changes, splitting, or conceptual expansions [69,70]. The reliability of the codes was then assessed through cross-coding comparison with a small portion of the overall transcripts. To this end, 2 independent research team members who had not previously been involved in the coding processes were introduced to the coding manual and asked to independently code a sample of 10% of the transcripts, indicating strong agreement between the two coders (k=0.81). Codes were then grouped and refined into themes during a series of meetings, and a final report was compiled. Saturation was considered achieved based on a code frequency count approach, with a stopping criterion established as a new information threshold of ≤5% [58].

Statistical Analysis of Questionnaires

The statistical analysis should be interpreted with caution due to the small sample size and further evaluated in future studies. A preliminary Shapiro-Wilk test was conducted, indicating that the data did not follow a normal distribution; therefore, nonparametric techniques were used. To assess differences in scores related to physical (physical component score) and psychological (mental component score) well-being measured using the 12-Item Short Form Health Survey, as well as attitudes toward domestic robots assessed using the MdRAS, the groups were compared using the Kruskal-Wallis test. If a significant result was obtained, pairwise comparisons were then further evaluated using the Dwass-Steel-Critchlow-Fligner test. In addition, Spearman correlations were performed to evaluate associations between the physical and psychological dimensions and the various attitudes toward domestic robots.

Results

After presenting the characteristics of the participants and groups, this section presents the results of the thematic analysis followed by the quantitative statistical results and their joint outcomes.

Participants

A total of 4 focus groups were conducted with 31 participants divided into 3 groups: low–socioeconomic status individuals, individuals with motor difficulties, and healthy individuals. The groups were balanced regarding age (χ^2_2=2.7; P=.25) and sex (P>.99; Fisher exact test). The groups showed no differences regarding psychological well-being (χ^2_2=1.7; P=.43); however, significant differences were found on physical well-being (χ^2_2=19.7; P<.001), where the group with motor difficulties showed lower scores compared to the low–socioeconomic status group (W=−5.34; P<.001) and the healthy group (W=−5.47; P<.001). Group statistics are reported in Table 1.

Table 1. Description of the participants who took part in the focus groups (N=31).

Variable	Healthy group (n=10)	Motor difficulties group (n=10)	Low–socioeconomic status group (n=11)	Statistical test	
				Chi-square (*df*)	*P* value
Sociodemographic characteristics					
Age (y), median (IQR)	75.5 (70.8-80.3)	71.5 (68.3-75.5)	69.0 (68.0-75.5)	2.7 (2)	.25
Sex, n (%)				—[a]	>.99[b]
Male	4 (40)	4 (40)	4 (36)		
Female	6 (60)	6 (60)	7 (64)		
Health-related characteristics					
PCS-12[c] score, median (IQR)[d]	52.8 (50.2-53.7)	31.7 (22.2-35.5)	52.7 (51.0-54.0)	19.7 (2)	<.001
MCS-12[e] score, median (IQR)	58.7 (51.4-59.4)	59.1 (39.9-60.7)	55.7 (49.3-58.3)	1.7 (2)	.43

[a] Not applicable

[b] Fisher exact test.

[c] PCS-12: physical component score of the 12-Item Short Form Health Survey.

[d] The group with motor difficulties had a significantly lower score on the PCS-12 than the other 2 groups.

[e] MCS-12: mental component score of the 12-Item Short Form Health Survey.

Thematic Analysis of Focus Groups

Overview

The thematic analysis resulted in a total of 14 themes divided into 4 key areas: (1) use of technology to support daily activities and reduce sedentary behaviors, (2) perceived barriers, (3) suggestions and preferences, and (4) actual use of technology in the home. Saturation was achieved. For each theme, we report in Table 2 the percentage of related statements made by each group. In the following sections, the type of user who made each comment is indicated in brackets next to the quotes. The full list of comments by participants for each theme is available at the online repository [71]. In addition, for each theme, it is indicated whether it relates to SARs, monitoring technologies, or both.

Table 2. Joint table of qualitative and quantitative results. Percentages and absolute frequencies of a theme are reported for each group. Quantitative dimensions with common concepts are reported for each theme.

Theme	Group, n/N (%)			Quantitative attitude
	Healthy individuals	LSE[a]	MD[b]	
Use of technology to support daily activities and reduce sedentary behaviors				
Managing daily activities	13/36 (36)	11/36 (31)	12/36 (33)	—[c]
Motivating and stimulating older adults	6/26 (23)	8/26 (31)	12/26 (46)	Familiarity[d]
Providing physical assistance	7/33 (21)	3/33 (9)	23/33 (69)	—
Continuous monitoring of health, safety, and activities	15/45 (33)	11/45 (25)	19/45 (42)	—
Perceived barriers				
Social support	9/36 (25)	19/36 (53)	8/36 (22)	Familiarity[d]
Personal factors	17/52 (33)	22/52 (42)	13/52 (25)	Self-efficacy, negative attitude, and social support
Economic factors	5/18 (28)	9/18 (50)	4/18 (22)	Cost
Privacy	5/15 (33)	7/15 (47)	3/15 (20)	—
Spatial issues	2/16 (13)	10/16 (62)	4/16 (25)	Environmental fit
Suggestions and preferences				
Number of devices	6/15 (40)	5/15 (33)	4/15 (27)	—
SAR physical characteristics	21/57 (37)	14/57 (25)	22/57 (38)	Appearance and variety
Personalization and remote control	14/39 (36)	10/39 (26)	15/39 (38)	Control[e] and operation
Monitoring technology use	7/22 (32)	7/22 (32)	8/22 (36)	—
Actual use	13/38 (34)	14/38 (37)	11/38 (29)	Utility[f]

[a] LSE: low socioeconomic status.

[b] MD: motor difficulties.

[c] No common concepts between the quantitative dimensions and the theme.

[d] The MD group showed significantly higher scores than those in the LSE group (*P*=.005).

[e] The LSE group showed significantly lower scores than those in the healthy group (*P*=.02) and the MD group (*P*=.001).

[f] The MD group showed significantly higher scores than those in the healthy group (*P*=.01) and the LSE group (*P*=.003).

Use of Technology to Support Daily Activities and Reduce Sedentary Behaviors

Managing Daily Activities (SARs and Monitoring Technologies)

Participants reported that SARs and monitoring technologies could support older adults in managing their daily activities, which could help in reducing sedentary behaviors through reminders to be active or suggesting specific exercise routines and physical activities:

> *I wouldn't want it to do anything physical...but I think mentally it could be good, you know, as a reminder thing. Like, doing some exercises or something like that, yeah.* [Healthy individual]

> *...well one of the things we could potentially look at doing would be to get a robot doing a kind of exercise routine with people.* [Healthy individual]

Alternatively, they may be a useful reminder of specific events or activities, medications, and maintaining social connections:

> *...a diary and, you know, you wake up in the morning and think "have I got anything today?" you know, you could ask...or press a button, "what's on today?"* [Low–socioeconomic status individual]

> *...It could remind me, you know, "you need to call your aunty" or I think, if you could ask it, as I've said before, like a diary. You'd be able to go out, maybe to your garden, you know, and maybe it would do a conversation. Or "you need to take medicine."* [Individual with motor difficulties]

Motivating and Stimulating Older Adults (SARs)

Participants reported that a possible consequence of using SARs was that they could make people lazier:

> *...the thing that worries me is that it could encourage you to become lazy It would be too easy to do nothing.* [Low–socioeconomic status individual]

However, it was suggested that the way in which SARs are implemented could have the opposite effect:

> *...the other issue, of course, is that they can encourage people to occasionally get up and do something rather than just sit.* [Low–socioeconomic status individual]

The activities suggested by SARs do not necessarily need to be physical but they can also involve other types of tasks:

> *I have a (older adult) friend whose main activity is jigsaw puzzles...I'm wondering whether something like this sat on the table next to him wouldn't actually place the piece for him, but would point out the piece and where it might go.* [Low–socioeconomic status individual]

This may be especially true if motivation to complete daily activities is limited:

> *...sometimes, if I'm not very well I don't always want to get out of bed...but maybe extra support...would help.* [Individual with motor difficulties]
>
> *...to me it would have to, sort of, push you type of thing.* [Individual with motor difficulties]

Providing Physical Assistance (SARs)

Older adults indicated that SARs were suitable aids designed to offer physical support in some scenarios—"...so when you can't walk, it would walk for you, you know, but you'd be inside it or walking with it" (individual with motor difficulties)—or provide assistance in daily tasks requiring more strength than older adults may have, such as shopping, or tasks requiring grip strength—"I can drive in car and fetch shopping but its getting all the bags from the car" (individual with motor difficulties) and "I think the robot is beneficial because they can open things. Things like gripping and holding. That's something that deteriorates with age" (individual with motor difficulties)—which could foster their independence:

> *...maybe it could help to be a bit more independent. I don't need to have another person 24/7, but it could be a device that can help me with some tasks everyday.* [Low–socioeconomic status individual]

Continuous Monitoring of Health, Safety, and Activities (SARs and Monitoring Technologies)

Participants expressed that a strength of SARs and monitoring technologies is that they can support continuous care for older people:

> *...the side of looking after someone who does need 24/7 care, it's a good thing. But there are a lot of things to take on board.* [Low–socioeconomic status individual]

This could assist carers in monitoring older adults' whereabouts:

> *...she can have a tracking device just popped in her bag, and then with a smart phone someone can always know where she is. I think that might be a good idea. I mean, she lives on her own independently, but at least you can keep an eye on them.* [Individual with motor difficulties]

In addition, it could provide peace of mind for carers overnight:

> *I think there are benefits for carers in terms of if you are a carer, say at night time...Because it's actually really difficult if you're a carer. You never really sleep. You're constantly on the alert in case the person you're looking after is needing help.* [Individual with motor difficulties]

According to participants, the monitoring systems should encompass emergencies and risky situations alongside general monitoring for the benefit of both older adults and carers:

> *...you would know that she's just safe. Or if something did happen, you'd know to go over to them.* [Individual with motor difficulties]

Social Support (SARs)

Participants emphasized that loneliness is a significant problem for older adults:

> *...if you're looking at really old people that you're trying to help, they probably wouldn't have a lot of interaction. That's what I find. They don't have an awful lot of interaction.* [Low–socioeconomic status individual]

Consequently, SARs were identified as potential social partners to alleviate loneliness:

> *...you could say, well yeah I want to talk about [this topic] and it already knows about it so it can have a discussion, you see that? That would be very helpful.* [Individual with motor difficulties]

This could also be in addition to other daily tasks:

> *...it could be while you're doing something as well, because it can follow you, so if you're having a conversation, the cameras are pointed at you, so you can keep up with you and stuff.* [Individual with motor difficulties]

However, some participants expressed reservations about SARs replacing human interactions:

> *I don't know if these would ever get to that point...It couldn't ever be human, obviously.* [Individual with motor difficulties]

Moreover, an additional feature reported by participants related to loneliness was supporting older adults' social connections and communication with others:

> *...if we had something like, say, Pepper, which has a screen on it as well. Or like the Turtle one back here that could almost be like a video conferencing robot.* [Low–socioeconomic status individual]
>
> *...we can have an exchange by texting...that's quite a useful thing... [Healthy individual]*

Perceived Barriers

Personal Factors (SARs and Monitoring Technologies)

The discussion highlighted various personal factors among participants that could pose challenges in using technologies and staying active. According to participants, personal motivation emerged as a crucial factor in maintaining activity levels:

> *I think it's a bit dependent on yourself isn't it, really. It's how much you want to keep going.* [Individual with motor difficulties]

Many participants identified physical difficulties as significant barriers that arise with aging and highlighted specific daily challenges:

> *It's the ageing body, it gets harder. Physical activity gets harder, and you have to push yourself more. It's quite easy when you're 20 to go and run, but it's harder when you're old.* [Individual with motor difficulties]
>
> *I have trouble cleaning me windows and that; changing the bed because I get dizzy and lose my balance.* [Individual with motor difficulties]

In addition to physical challenges, participants discussed perceptual issues and cognitive difficulties:

> *Sight deteriorates. Even with glasses, it can still be a problem when you get older.* [Healthy individual]
>
> *I tend to just forget things until someone else tells me that I should do something.* [Low–socioeconomic status individual]

These factors may act as barriers, adding to the difficulties in adapting to and familiarizing themselves with new technologies:

> *Just as we're older, um, we would find it more difficult to understand what we have to do.* [Healthy individual]

Participants also observed that these challenges may lead to stress due to cognitively demanding situations, a possible sense of lack of control, or fears of technology breaking down:

> *I can't handle too many things at once sometimes. I'm afraid it overwhelms me.* [Healthy individual]
>
> *It's got to be under my control.* [Low–socioeconomic status individual]
>
> *I'd be worried if it would break down. I'm always worried that my computer is not going to fire up or something. So I'd certainly been concerned about having one of these in the house.* [Low–socioeconomic status individual]

Participants acknowledged the need for support in using these technologies:

> *I would need help, obviously. Sons, daughters, anybody, but yes I would definitely.* [Healthy individual]

Economic Factors (SARs and Monitoring Technologies)

Participants expressed concerns about the cost of these technologies:

> *...one thing is, well to me, what's the cost of these things going to be?* [Individual with motor difficulties]
>
> *...just how much is it going to cost, I can imagine it would be quite an expensive luxury.* [Low–socioeconomic status individual]

This suggests that the affordability of such technologies is a crucial factor to consider, raising questions about potential financial support or subsidies:

> *...but how would that be financed? Because I mean, a lot of old people, they hardly have money to pay their bills and put food on the table.* [Low–socioeconomic status individual]

Interestingly, participants suggested rental periods as a possible solution, expressing the following idea:

> *...the ideal thing would be able to ring a robot center and say, "oh right, I'm at so-and-so address, send me a robot" and then have it for a day.* [Individual with motor difficulties]

Privacy (SARs and Monitoring Technologies)

The participants' statements underscored significant apprehensions surrounding the privacy implications of SARs and monitoring technologies. Concerns regarded the extent of personal information collected, questioning its storage, custodianship, and the entities involved:

> *...how much personal information, and how much is collected—where is it and who is dealing with it? That's another story, and that's a thought.* [Individual with motor difficulties]

For instance, participants pondered the potential future uses of these data:

> *How is it used in the future? How is your life insurance, health insurance, going to use this?* [Individual with motor difficulties]

The discussion highlighted the importance of consent in the context of tracking individuals, emphasizing that individuals must willingly agree to be tracked:

> *...they have to agree to it. You can't track somebody if they don't want to.* [Healthy individual]

Spatial Issues (SARs)

Older adults emphasized practical considerations and challenges associated with the deployment of these technologies within households, particularly in the context of navigating physical spaces:

> *...you'd have to have the room, like space, as well around your house for it to go in different rooms.* [Low–socioeconomic status individual]

Participants highlighted the need for obstacle detection and avoidance mechanisms to prevent collisions and property damage:

> *...well, it needs to sense, I suppose, where the barriers are...it would need to be able to get over them without tripping or getting stuck in a certain place or whatever. Yeah, so I think that is something you need to consider and think about. And of course, every house is different.* [Individual with motor difficulties]

> *...be able to sense objects around him so that, you know, it doesn't run into tables and break things.* [Healthy individual]

Suggestions and Preferences

Number of Devices (SARs and Monitoring Technologies)

Participants discussed their preferences concerning the number of SARs and monitoring technologies at home. Divergent opinions emerged during the conversation, with some participants expressing a preference for all-encompassing, multitasking SARs or single monitoring sensors:

> *If they're going to get one it's got to do everything.* [Low–socioeconomic status individual]

However, a consensus on this viewpoint was not reached as other participants advocated for a more specialized approach, suggesting different technologies for distinct tasks:

> *I'm not sure it would be a single robot. You know, I think with everything we've got...you can't have one that does everything, and that certain tasks are done by certain pieces of technology, you know.* [Healthy individual]

A nuanced perspective emerged, arguing that the ideal number of SARs and monitoring technologies should be contingent upon an individual's specific circumstances, such as the following:

> *It's like having a sensor in the living room in case you fall. But if you fall in the hallway, you haven't got one, have you? So, depending on how badly you are or how incapable you are of doing things. It would depend on obviously the size of the house or the room. If you're in a one-bedroom flat and it's all on ground level you don't need that much, do you? It depends on the situation of the particular person.* [Healthy individual]

Physical Characteristics (SARs)

Participants expressed a range of opinions regarding the physical characteristics of SARs, demonstrating diverse preferences and considerations. Some participants favored humanoid robots, appreciating the humanlike features:

> *I like that one as well [Pepper]. Its more connected to you as a human. You know, you feel like you could talk to it and it understand you more because it looks at you.* [Healthy individual]

In contrast, others leaned toward nonhumanoid designs, emphasizing their distinct robotlike appearance:

> *...it [TurtleBot] looks more like a robot than the others. It's much more like an object.* [Healthy individual]

Practical considerations emerged as a unifying theme among participants, with agreement that the design of SARs should be task oriented:

> *...well it depends on what the task is its doing, doesn't it? I mean, we assume a robot is in the form of a human being, but a lot of robots aren't.* [Individual with motor difficulties]

> *...the consensus is that they don't need to be humanoid. A box on the decks...could be quite configurable depending on who you are and what you want it to be. But there are limits...that's why there might be a range of robots in a different environment.* [Individual with motor difficulties]

Participants also expressed a preference for smooth movements, emphasizing the importance of versatility in motion:

> *...it would have to move in every direction. Spin round, bend forward, reach up.* [Individual with motor difficulties]

An additional concern raised was discomfort with SARs staring, particularly when not interacting, highlighting the importance of social cues and behaviors in shaping participants' comfort levels:

> *...well it just tends to stare at you a lot, and even when you're not talking to him, his hands and arms and that are moving and it makes you think "oh, well what's he going to do?"* [Low–socioeconomic status individual]

Regarding animal-like SARs, participants expressed the view that, if SARs are to have animal-like characteristics, they should be realistic, featuring fur and tactile qualities:

> *...it would need to have fur, erm, and be a bit more tactile.* [Low–socioeconomic status individual]

However, despite this acknowledgment of realism, participants tended to dislike the animal-like designs:

> *...well just because it's a cute little thing that's all—it's more like a distraction.* [Individual with motor difficulties]

Participants also acknowledged that, while petlike robots could offer more than just the companionship of a dog or cat, they might be perceived more as toys:

> *...it gives them more than just a, you know, dog or cat, so I think there is some good but I think it would be more of a, um, well a toy perhaps.* [Low–socioeconomic status individual]

In fact, a noteworthy trend among older adults was the expressed preference for SAR designs that differed from toys:

> *It sort of looks like a toy [NAO], don't it? I would imagine if that's the same size a pepper, it would be more robotic, a bit more visual that it's a robot more than a toy—only because of its size.* [Individual with motor difficulties]

This characteristic was deemed important as participants expressed the view that SARs should not resemble toys and should not be perceived as such by adults:

> *I think they can be nice, and cute, and not scary for children—they are like toys but they are not to us.* [Individual with motor difficulties]

Personalization and Remote Control (SARs)

The focus groups provided valuable insights into participants' preferences and expectations for the customization of SARs. Participants emphasized the importance of adjustable volume, particularly for individuals with hearing difficulties:

> *...well something where you could turn it up, since I'm a bit deaf. There is those that are hard of hearing.* [Low–socioeconomic status individual]

The participants discussed the idea of customizable voice options, for instance, allowing users to choose between different genders and accents:

> *...yes, and then you can select whether you want a ladies voice or a gent, or a softer voice—American accent, Australian accent.* [Individual with motor difficulties]

This suggestion reflects the importance of the diverse preferences that users may have regarding the characteristics of SARs. In fact, the concept of customizable interactions based on individual preferences was also brought up:

> *I think this is something that can be customized, for some people who really love the interaction and then for those who don't. If you like someone staring into your eyes it can do that but otherwise it can be a bit sideways maybe.* [Healthy individual]

Similarly, a participant stated the following regarding the information used by SARs to enhance user experience:

> *...it would give you information on what's happening. But I suppose you would have to get used to it, wouldn't you—customize him to your way of thinking.* [Individual with motor difficulties]

Participants highlighted the convenience of voice activation over buttons, aligning with the idea of making SARs user-friendly and accessible, allowing for multitasking and seamless interaction:

> *A voice activation would be easier. I'm not good with buttons.* [Individual with motor difficulties]

> *...it allows you to multitask, you know. You could be getting ready for work and you can chat at the same time, you know, "what's the weather today?" you know, and you can still be getting ready.* [Healthy individual]

In addition, some participants raised concerns about batteries and expressed a preference for SARs with the capability to recharge themselves:

> *...if you've got someone with Alzheimer's or limited ability to move, you'd need them to be self-charging.* [Low–socioeconomic status individual]

Use (Monitoring Technologies)

The discussion on monitoring technologies addressed wearable and environmental sensors. Participants highlighted the advantages of wearable sensors, noting that they can be used wherever the person is located:

> *I think it would be useful to wear something because then it doesn't matter where you are, it will pick you up.* [Healthy individual]

However, concerns were raised about the potential for losing these sensors or forgetting to put them on:

> *...you still might lose it somewhere. Might end up wandering into our storage cupboard!* [Low–socioeconomic status individual]

> *I'd probably forget to put it; I don't have a good memory so I'd probably forget to put it on.* [Low–socioeconomic status individual]

In contrast, these concerns did not apply to environmental sensors:

> *Something wearable is always with the person as long as they remember to put it on, but something in the room is always there, you know.* [Healthy individual]

Overall, participants reached a consensus that using both types of sensors would be more beneficial:

> *If you take it off because you've been in the bath and then forget to put it back on, it's not helpful. If you have both, then if you fall or something, it would serve both purposes.* [Healthy individual]

Importantly, participants stressed the need for strategic placement of environmental sensors, prioritizing areas of higher risk for older adults:

> *...the bathroom is a really bad place to fall because there's a lot of hard surfaces and if you slip on a wet patch or something, then you're more likely to injure yourself.* [Individual with motor difficulties]

> *...on the stairs. I think it's a good thing. Because if you, I think you're on that surface, you're more likely to fall.* [Individual with motor difficulties]

Participants also suggested that familiarity with sensor technology could contribute to its acceptance and integration into daily life:

> *I mean, if you've got a burglar alarm in your house, you've got sensors like that. I don't look at mine. Once they're there you should get used to it.* [Low–socioeconomic status individual]

Actual Use (SARs and Monitoring Technologies)

Some participants conveyed both their efforts and enthusiasm to keep up with technology:

> *I always try to keep up to date with technology. I've got two sons who ensure that they do keep up to date with it. Otherwise, there's a gap between the two generations.* [Low–socioeconomic status individual]

> *...yes I would use it, definitely, because I like, you know, I like new technology.* [Individual with motor difficulties]

However, others expressed difficulty in doing so and a reluctance to embrace new technology:

> *I don't think our generation is capable of doing it now. I think we're too old.* [Low–socioeconomic status individual]

The belief in the future prevalence of these technologies was a common sentiment among participants, drawing parallels with other technologies:

> *I think these things are already, kind of, with us and probably are only going to increase as technology, you know, the rate at which technology has happened is, you know, only going to continue along that upward arc, I think.* [Healthy individual]
>
> *I think even if you think about phones. Not that long ago no-one had them and yet now people don't go anywhere without them.* [Individual with motor difficulties]

They also speculated about the integration of SARs and monitoring technologies into health care:

> *...it is something that, you know, in the future, hospitals—doctors, physios, occupational, you know, people—will recommend and prescribe something like this.* [Low–socioeconomic status individual]

Importantly, participants emphasized their willingness to embrace the use of SARs and monitoring technologies if they proved helpful and could be incorporated into daily tasks:

> *...if I needed help I would use it.* [Individual with motor difficulties]
>
> *I'd want a robot to help me with all the things I need to do if I found I couldn't do them myself. I would be reluctant, and probably a bit resistant but I'd want it to help me.* [Healthy individual]
>
> *I could see them being very helpful to lots of people—to be helpful it's got to do the things you want it to do.* [Healthy individual]

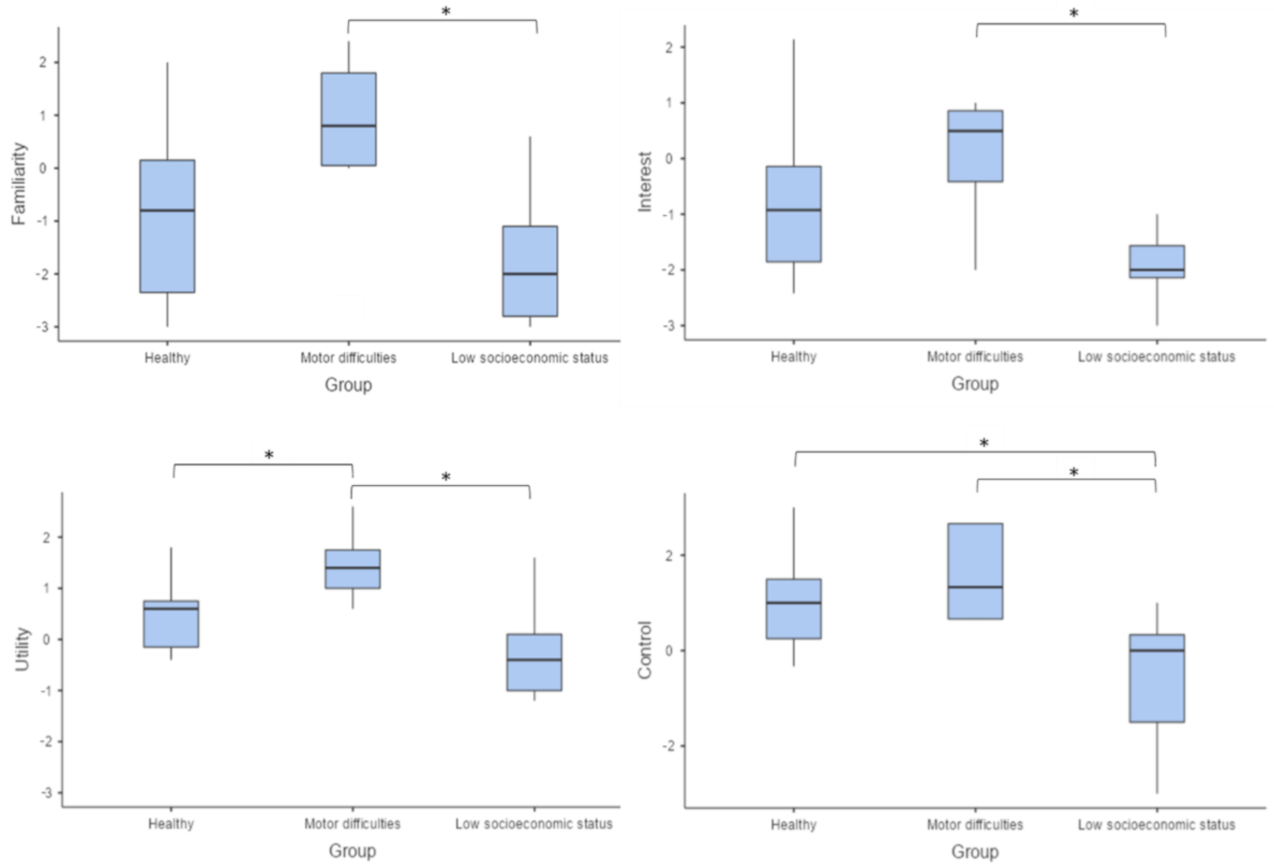
Statistical Analysis of Questionnaires

Spearman correlations indicated that older adults' perceived well-being was associated with attitudes toward domestic robots, assessed using the MdRAS. Specifically, physical well-being was significantly associated with the sense of familiarity with (r=−0.409; P=.02) and interest in (r=−0.381; P=.03) SARs, as well as with perceived utility (r=−0.592; P<.001) and control (r=−0.559; P=.001). This suggests that, as a person perceives lower physical well-being, they report higher levels of familiarity, interest, perceived utility, and control related to SARs. Psychological well-being was significantly associated with a negative attitude toward SARs (r=−0.397; P=.02) and environmental fit (r=−0.394; P=.02), indicating that lower perceived psychological well-being is linked to a higher negative attitude and increased concerns for environmental fit. In addition, psychological well-being was positively associated with variety (r=0.553; P=.001), suggesting that people with lower psychological well-being prefer less variety in domestic SARs.

The group comparison revealed significant differences in the dimensions assessed using the MdRAS: familiarity (χ^2_2=10.8; P=.005), where the group with motor difficulties showed higher perceived familiarity with SARs than the low–socioeconomic status group (W=−4.39; P=.005); interest (χ^2_2=12.0; P=.003), with the group with motor difficulties showing higher interest in SARs than the low–socioeconomic status group (W=−4.60; P=.003); utility (χ^2_2=14.5; P<.001), where the group with motor difficulties showed higher perceived utility of the SARs than the healthy (W=−3.88; P=.01) and low–socioeconomic status (W=−4.69; P=.003) groups; and control (χ^2_2=13.2; P=.001), where the low–socioeconomic status group perceived less control over SARs compared to the healthy group (W=−3.67; P=.02) and the group with motor difficulties (W=−4.91; P=.001). A graphical representation is shown in Figure 2.

Table 2 is a joint table of the qualitative and quantitative analyses. The results show that the group with motor difficulties showed significantly higher scores than the low–socioeconomic status group on the familiarity dimension assessed using the MdRAS, indicating a greater interest in using SARs for the related qualitative themes of motivation and social support. In contrast, participants from the low–socioeconomic status group reported lower perceived control over using SARs at home, highlighting that addressing the needs reported for personalization and remote control features may affect their acceptance. Although participants expressed a willingness to use these technologies if they were beneficial, the utility dimension of the MdRAS indicates that the group with motor difficulties perceived SARs as more useful, suggesting that they may have a higher acceptance of this technology.

Figure 2. Box plot of the groups' scores on the familiarity, interest, utility, and control subscales of the Multidimensional Robot Attitude Scale indicating the groups' attitudes toward domestic social assistive robots. *P<.05.



Discussion

Principal Findings

The aim of this mixed methods study was to understand how healthy older adults, alongside those with motor difficulties and of a lower socioeconomic status, perceive the usefulness of SARs and monitoring technologies in the home to reduce sedentary behavior. This study identified key themes across 4 areas: the use of technology to support daily activities and reduce sedentary behavior, perceived barriers, preferences, and actual home technology use. In terms of using these technologies to assist with daily activities, participants highlighted their potential to help manage tasks, motivate and engage users, provide physical assistance, monitor health, and ensure safety. Perceived barriers included the need for social support, personal and economic limitations, privacy concerns, and spatial constraints. Suggestions focused on preferences for how many technologies they would like at home, desired features for SARs, the need for personalization and remote control, and how monitoring technologies should be used. Importantly, participants indicated that they would adopt these technologies if they effectively addressed their specific needs. These themes reflect how older adults suggest using these technologies to support their daily activities, as well as their preferences and concerns that should be addressed in the design and implementation of these solutions. Importantly, socioeconomic status and motor difficulties influenced perceptions. Older adults from lower socioeconomic backgrounds felt less control over SARs, highlighting the need to carefully consider these factors when designing for this group. In contrast, older adults with motor difficulties found SARs more useful, indicating that this group may have higher expectations and motivation to use such technologies. Notably, lower physical well-being was associated with greater interest in, familiarity with, and control over SARs, whereas lower psychological well-being was linked to more negative attitudes and concerns about environmental fit. Overall, this study underscores the importance of tailoring SARs to the specific needs of older adults to encourage adoption and improve their well-being.

Thematic analysis of the focus groups resulted in 14 themes outlining perceived needs and overall opinions on how these technologies may be used within older adults' domestic environment. Participants indicated that SARs and monitoring technologies could help reduce sedentary behaviors by assisting in the management of daily activities and through providing motivation and stimulation. Many of the suggestions involved providing reminders, establishing routines or programs, and monitoring levels of sedentary behavior. The management of daily living activities poses a challenge for older adults and especially for health care professionals. Enhancing older adults' ability to manage these activities has a significant impact on overall daily living [72].

Motivation is a key element when considering engagement in any physical activities, for instance, through highlighting potential benefits that the activity may entail [73]. When involved in the design of interventions or products to support physical activity, older adults tend to emphasize this motivational aspect [74]. Therefore, designing SARs and monitoring technologies aimed at motivating older adults to participate in physical activities could serve as a viable solution to mitigate sedentary behaviors at home. The combined results indicate that the group with motor difficulties scored significantly higher than the low–socioeconomic status group on the related quantitative measure of Familiarity, suggesting that this specific group has a greater interest in using SARs in relation to activity motivation.

In addition, older adults indicated that they viewed SARs as potential aids in providing physical assistance. Aging is characterized by a reduction in people's physical strength and, thereby, a reduction in their capacity to perform ADLs [11,12]. Technologies could assist older adults with various tasks, catering to a wide range of specific needs such as helping with opening jars (perhaps to support cooking), transporting weights (eg, groceries), or physically assisting older adults (eg, help with walking). This was particularly important for the group with motor difficulties, who made most of the statements related to this theme.

A key perceived benefit offered by these technologies is their ability to monitor older adults' health conditions, safety, and daily activities continuously, including overnight, which can be a particularly stressful time for caregivers. Risky situations such as falls are common in this population, especially in relation to gait during daily activities [75]. Thus, these are important strengths and considerations that monitoring technologies and SARs should address to support older adults at home. It is worth noting that the group with motor difficulties made a slightly higher proportion of statements related to this theme. We can assume that this aspect was of particular interest to them.

Loneliness is a reported issue among older adults [76], with previous work suggesting that socializing and communication are considered important daily activities for older adults [60]. This can be especially prevalent in groups of a low socioeconomic status [77], which was highlighted during our discussions with this group through their ideas of using SARs for social support. Finding solutions to cope with this condition may be challenging [78]; however, it has been suggested that SARs may reduce feelings of loneliness in older adults residing in care facilities [79] or enhance their social interactions [80]. Participants indicated a willingness to interact with SARs to alleviate loneliness or expressed interest in integrated functions that could enhance their social network. Participating in group activities and discussions has been shown to be beneficial for older adults' social [81] and cognitive functioning [82]. Using SARs to facilitate this and as a tool for cognitive stimulation and discussion may be beneficial for older adults experiencing loneliness, which is one of the key future directions for research in this area. In this case, it is important to note that the group with motor difficulties presented significantly higher quantitative scores than the low–socioeconomic status group. This suggests that the group with motor difficulties find SARs more engaging in this role.

Several of the reported barriers to technology use for activity monitoring among the older population were related to personal factors such as personal motivation, with participants underscoring the significance of individual desire in maintaining activity levels regardless of technological intervention. Previously discussed physical challenges associated with aging, such as diminished strength and mobility, were also identified as notable obstacles alongside perceptual issues, such as deteriorating sight, and cognitive difficulties, such as forgetfulness. Moreover, cognitive challenges were expressed in concerns about the capacity to comprehend and effectively use these technologies, which may be perceived as overly complicated. Fear of technology breakdowns and a desire for control over the technology were expressed by many participants, indicating that the design and application of these technologies should be as user-friendly and simple as possible, thus avoiding additional cognitive demands and stress. Using these new technologies will subsequently require a learning process and dealing with issues such as software updates; this can pose cognitive and perceptual challenges to older adults [83], leading to increased stress as individuals adapt to these changes [84]. Participants acknowledged the need for support in using these technologies, suggesting that various forms of support should be considered as potential solutions. Future research should concentrate on addressing these challenges and determining the most effective solutions to facilitate older adults' use of technologies.

When discussing the introduction of new technologies with end users, economic and privacy concerns are often raised [6,85]. Therefore, these should be carefully considered when making decisions about the selection and deployment of SARs and monitoring technologies. There was also a common emphasis on the importance of smooth movement within an environment, with participants also recognizing potential limitations due to physical space availability. This is of increased concern within a domestic environment, which could restrict the movement and subsequent usefulness of SARs. These considerations should be addressed before introducing SARs into the home environment to ensure a suitable fit.

Discussions regarding the number of sensors and SARs to use in one setting were pragmatic, indicating that the number of sensors and SARs should depend on the individual circumstances. This was also true when discussing the preferred characteristics of SARs; however, some similarities emerged, such as the reduced acceptance of animal-like robots and suggestions to avoid SARs that could be perceived as toys. Moreover, a preference for personalizing certain characteristics and being able to control SARs remotely was expressed. In this regard, the quantitative analysis indicated that participants from the low–socioeconomic status group tended to feel that they had less control over the use of SARs at home. This suggests that addressing this need could be a crucial consideration during the design process for this group. Interestingly, participants accepted both environmental and wearable technologies. Despite reporting the common strengths and weaknesses associated with each type of sensor [60], they indicated that using both types would be beneficial. It is important to use sensors in situations or areas in which there is a higher risk for older adults, such as those where falls are more probable. Finally, participants indicated that they would use SARs and monitoring technologies if they were perceived as helpful, confirming previous results [60]. Notably, quantitative results indicated that the group with motor difficulties had a higher perception of the utility of SARs at home, suggesting that they tend to view this technology as more helpful compared to the other groups.

These results align with other evidence suggesting SARs as potential tools to provide coaching, monitoring, and companionship [86] and promote changes in daily routines [87]. In addition to other important key points emerging from the analysis, considering 3 different groups characterized by different socioeconomic levels and physical difficulties further developed our understanding of the perspectives on these technologies within a wider category of older adults. Perceived physical and psychological well-being are associated with various dimensions regarding SARs. When an older adult perceives themselves as more physically impaired, they are more likely to feel a sense of familiarity with and interest in SARs. This perception is coupled with the perceived utility and the ability to control SARs. On the other hand, if an older adult perceives a lower psychological wellness, they may have more reservations about SARs due to a general negative attitude and concerns regarding the environmental fit of the SARs. Interestingly, this was associated with less interest in SAR variety. Several factors, as indicated in the literature, are associated with the intention to use SARs or their acceptability among older adults [88,89]. However, to the best of our knowledge, this is the first study indicating that specific well-being domains—psychological and physical—play a pivotal role in attitudes toward SAR use at home. This is noteworthy considering that most SAR use is related to health [88]. Group comparisons also yielded interesting insights, largely aligning with the associations discussed. The group with motor difficulties perceived SARs as more familiar and expressed greater interest than the low-income group. In addition, the group with motor difficulties considered SARs to be more useful compared to the other groups. On the other hand, participants of a low socioeconomic status indicated less perceived control over SARs compared to the other groups. This aligns with a recent survey indicating that people of a low socioeconomic status are less supportive of technologies and SARs [90]. In this regard, our results suggest a connection with the perceived barriers associated with these technologies as the participants from the low–socioeconomic status group tended to report the highest percentages of statements related to all the perceived barriers identified in the analysis, including personal factors, economic considerations, privacy concerns, and space issues. This suggests that, for this specific category, it may be crucial to demonstrate the usefulness of SARs and monitoring technologies and address older adults' needs. Importantly, older adults with physical difficulties had more positive attitudes toward SARs at home compared to the other groups. These insights highlight their tendency to be more accepting of SARs in their homes for support, aligning with the findings obtained from the thematic analysis.

Limitations

Despite yielding interesting results, this study has certain limitations. The limited sample sizes of the 3 groups for quantitative analysis represent a limitation of the study; thus, the statistical results should be interpreted with caution. Therefore, the results of the quantitative statistical analysis need to be replicated, and future studies should confirm these findings with larger sample sizes. Demographic variations and characteristics specific to older adults may influence their needs and opinions. For instance, our results suggest that psychological well-being significantly influences attitudes toward SARs. Therefore, future studies should encompass older adults with psychological difficulties, such as depression, for a more comprehensive understanding. Cognitive and sensory challenges among participants were not evaluated, which should be considered for future research. This study did not consider other demographic characteristics of older adults, such as gender and ethnicity, which should be included in future studies.

Conclusions

The participants indicated that SARs and monitoring technologies could help reduce sedentary behaviors and assist in the management of daily activities. This study highlights the importance of considering the functional and socioeconomic characteristics of older adults as future users of SARs and monitoring technologies to promote widespread adoption within this population and improve well-being. Older adults with different characteristics and backgrounds may have varying attitudes and needs, which the design and implementation of technologies should take into account.

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Data Availability

The datasets generated during and analyzed during this study are available in the Zenodo repository [71].

Authors' Contributions

RV, MZ, ADN, and DM contributed to conceptualization. Methodology was designed by RV, SM, HM, SFD, and DM. All the authors contributed to formal analysis. Resources were provided by MZ, HM, SFD, ADN, and DM. Data curation was managed by RV and NC. The original draft of the manuscript was written by RV, NC, MS, and KA-B. RV and NC contributed to visualization. Supervision was provided by SM, MZ, ADN, and DM. Project administration was handled by SM, HM, SFD, and DM. Funding was secured by SM, MZ, ADN, HM, SFD, and DM. All the authors contributed to writing, review, and editing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Checklist for Reporting Results of Internet E-Surveys.
[DOCX File , 20 KB - aging_v7i1e63092_app1.docx]

References

1. World population prospects: the 2017 revision. United Nations. URL: https://tinyurl.com/4x3z4mzz [accessed 2024-04-29]
2. Living longer: is age 70 the new age 65? Office for National Statistics. URL: https://tinyurl.com/59vkd475 [accessed 2024-04-29]
3. Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. Lancet 2013 Mar 02;381(9868):752-762 [FREE Full text] [doi: 10.1016/S0140-6736(12)62167-9] [Medline: 23395245]
4. Holland GJ, Tanaka K, Shigematsu R, Nakagaichi M. Flexibility and physical functions of older adults: a review. J Aging Phys Act 2002;10(2):169-206 [FREE Full text] [doi: 10.1123/japa.10.2.169]
5. Hou Y, Dan X, Babbar M, Wei Y, Hasselbalch SG, Croteau DL, et al. Ageing as a risk factor for neurodegenerative disease. Nat Rev Neurol 2019 Oct;15(10):565-581. [doi: 10.1038/s41582-019-0244-7] [Medline: 31501588]
6. Camp N, Di Nuovo A, Hunter K, Johnston J, Zecca M, Lewis M, et al. Perceptions of socially assistive robots among community-dwelling older adults. In: Proceedings of the 14th International Conference on Social Robotics. 2022 Presented at: ICSR '22; December 13-16, 2022; Florence, Italy p. 540-549 URL: https://dl.acm.org/doi/10.1007/978-3-031-24670-8_48 [doi: 10.1007/978-3-031-24670-8_48]
7. Vermeulen J, Neyens JC, van Rossum E, Spreeuwenberg MD, de Witte LP. Predicting ADL disability in community-dwelling elderly people using physical frailty indicators: a systematic review. BMC Geriatr 2011 Jul 01;11(1):33 [FREE Full text] [doi: 10.1186/1471-2318-11-33] [Medline: 21722355]
8. Portegijs E, Lee C, Zhu X. Activity-friendly environments for active aging: the physical, social, and technology environments. Front Public Health 2022;10:1080148 [FREE Full text] [doi: 10.3389/fpubh.2022.1080148] [Medline: 36711401]
9. Dickerson AE, Fisher AG. Age differences in functional performance. Am J Occup Ther 1993 Aug;47(8):686-692. [doi: 10.5014/ajot.47.8.686] [Medline: 8352327]
10. Hayase D, Mosenteen D, Thimmaiah D, Zemke S, Atler K, Fisher AG. Age - related changes in activities of daily living ability. Aus Occup Therapy J 2004 Jun 17;51(4):192-198. [doi: 10.1111/j.1440-1630.2004.00425.x]
11. Candela F, Zucchetti G, Ortega E, Rabaglietti E, Magistro D. Preventing loss of basic activities of daily living and instrumental activities of daily living in elderly: identification of individual risk factors in a holistic perspective. Holist Nurs Pract 2015;29(5):313-322. [doi: 10.1097/HNP.0000000000000106] [Medline: 26263291]
12. Magistro D, Candela F, Brustio PR, Liubicich ME, Rabaglietti E. A longitudinal study on the relationship between aerobic endurance and lower body strength in Italian sedentary older adults. J Aging Phys Act 2015 Jul;23(3):444-451 [FREE Full text] [doi: 10.1123/japa.2013-0215] [Medline: 25341375]
13. Manning KM, Hall KS, Sloane R, Magistro D, Rabaglietti E, Lee CC, et al. Longitudinal analysis of physical function in older adults: the effects of physical inactivity and exercise training. Aging Cell 2024 Jan 08;23(1):e13987 [FREE Full text] [doi: 10.1111/acel.13987] [Medline: 37681737]
14. Bull FC, Al-Ansari SS, Biddle S, Borodulin K, Buman MP, Cardon G, et al. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. Br J Sports Med 2020 Dec;54(24):1451-1462 [FREE Full text] [doi: 10.1136/bjsports-2020-102955] [Medline: 33239350]
15. Harvey JA, Chastin SF, Skelton DA. How sedentary are older people? A systematic review of the amount of sedentary behavior. J Aging Phys Act 2015 Jul;23(3):471-487. [doi: 10.1123/japa.2014-0164] [Medline: 25387160]
16. de Rezende LF, Rey-López JP, Matsudo VK, do Carmo Luiz O. Sedentary behavior and health outcomes among older adults: a systematic review. BMC Public Health 2014 Apr 09;14:333 [FREE Full text] [doi: 10.1186/1471-2458-14-333] [Medline: 24712381]
17. Na L, Streim JE. Psychosocial well-being associated with activity of daily living stages among community-dwelling older adults. Gerontol Geriatr Med 2017;3:2333721417700011 [FREE Full text] [doi: 10.1177/2333721417700011] [Medline: 28540343]

18. Stineman MG, Xie D, Pan Q, Kurichi JE, Saliba D, Streim J. Activity of daily living staging, chronic health conditions, and perceived lack of home accessibility features for elderly people living in the community. J Am Geriatr Soc 2011 Mar;59(3):454-462 [FREE Full text] [doi: 10.1111/j.1532-5415.2010.03287.x] [Medline: 21361881]
19. Kurichi JE, Streim JE, Xie D, Hennessy S, Na L, Saliba D, et al. The association between activity limitation stages and admission to facilities providing long-term care among older Medicare beneficiaries. Am J Phys Med Rehabil 2017 Jul;96(7):464-472 [FREE Full text] [doi: 10.1097/PHM.0000000000000653] [Medline: 28628533]
20. Na L, Pan Q, Xie D, Kurichi JE, Streim JE, Bogner HR, et al. Activity limitation stages are associated with risk of hospitalization among Medicare beneficiaries. PM R 2017 May 21;9(5):433-443 [FREE Full text] [doi: 10.1016/j.pmrj.2016.09.008] [Medline: 27664405]
21. Giebel CM, Sutcliffe C. Initiating activities of daily living contributes to well-being in people with dementia and their carers. Int J Geriatr Psychiatry 2018 Jan;33(1):e94-102. [doi: 10.1002/gps.4728] [Medline: 28467006]
22. Hennessy S, Kurichi JE, Pan Q, Streim JE, Bogner HR, Xie D, et al. Disability stage is an independent risk factor for mortality in Medicare beneficiaries aged 65 years and older. PM R 2015 Dec;7(12):1215-1225 [FREE Full text] [doi: 10.1016/j.pmrj.2015.05.014] [Medline: 26003869]
23. Chastin S, Gardiner PA, Harvey JA, Leask CF, Jerez-Roig J, Rosenberg D, et al. Interventions for reducing sedentary behaviour in community-dwelling older adults. Cochrane Database Syst Rev 2021 Jun 25;6(6):CD012784 [FREE Full text] [doi: 10.1002/14651858.CD012784.pub2] [Medline: 34169503]
24. d'Orsi E, Xavier AJ, Steptoe A, de Oliveira C, Ramos LR, Orrell M, et al. Socioeconomic and lifestyle factors related to instrumental activity of daily living dynamics: results from the English Longitudinal Study of Ageing. J Am Geriatr Soc 2014 Sep;62(9):1630-1639. [doi: 10.1111/jgs.12990] [Medline: 25243677]
25. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. Public Health Rep 2014;129 Suppl 2:19-31 [FREE Full text] [doi: 10.1177/00333549141291S206] [Medline: 24385661]
26. Hayajneh AA, Rababa M. The association of frailty with poverty in older adults: a systematic review. Dement Geriatr Cogn Disord 2021 Dec 20;50(5):407-413 [FREE Full text] [doi: 10.1159/000520486] [Medline: 34929708]
27. Choi NG, McDougall G. Unmet needs and depressive symptoms among low--income older adults. J Gerontol Soc Work 2009;52(6):567-583 [FREE Full text] [doi: 10.1080/01634370802609270] [Medline: 19598039]
28. Chief Medical Officer's annual report 2023: health in an ageing society. Department of Health and Social Care. URL: https://tinyurl.com/yrrxebnv [accessed 2024-04-29]
29. Global strategy and action plan on ageing and health. World Health Organization (WHO). 2017. URL: https://www.who.int/publications/i/item/9789241513500[accessed [accessed 2024-06-10]
30. Prince MJ, Wu F, Guo Y, Gutierrez Robledo LM, O'Donnell M, Sullivan R, et al. The burden of disease in older people and implications for health policy and practice. Lancet 2015 Feb 07;385(9967):549-562. [doi: 10.1016/S0140-6736(14)61347-7] [Medline: 25468153]
31. Zhou W, Oyegoke AS, Sun M. Service planning and delivery outcomes of home adaptations for ageing in the UK. J Hous and the Built Environ 2017 Dec 13;34(2):365-383. [doi: 10.1007/S10901-017-9580-3]
32. Fowler-Davis S, Barnett D, Kelley J, Curtis D. Potential for digital monitoring to enhance wellbeing at home for people with mild dementia and their family carers. J Alzheimers Dis 2020;73(3):867-872 [FREE Full text] [doi: 10.3233/JAD-190844] [Medline: 31884471]
33. Oyibo K, Wang K, Morita PP. Using smart home technologies to promote physical activity among the general and aging populations: scoping review. J Med Internet Res 2023 May 12;25:e41942 [FREE Full text] [doi: 10.2196/41942] [Medline: 37171839]
34. Kim D, Bian H, Chang CK, Dong L, Margrett J. In-home monitoring technology for aging in place: scoping review. Interact J Med Res 2022 Sep 01;11(2):e39005 [FREE Full text] [doi: 10.2196/39005] [Medline: 36048502]
35. Jovanovic M, Mitrov G, Zdravevski E, Lameski P, Colantonio S, Kampel M, et al. Ambient assisted living: scoping review of artificial intelligence models, domains, technology, and concerns. J Med Internet Res 2022 Nov 04;24(11):e36553 [FREE Full text] [doi: 10.2196/36553] [Medline: 36331530]
36. Góngora Alonso S, Hamrioui S, de la Torre Díez I, Motta Cruz E, López-Coronado M, Franco M. Social robots for people with aging and dementia: a systematic review of literature. Telemed J E Health 2019 Jul;25(7):533-540. [doi: 10.1089/tmj.2018.0051] [Medline: 30136901]
37. Vagnetti R, Di Nuovo A, Mazza M, Valenti M. Social robots: a promising tool to support people with autism. a systematic review of recent research and critical analysis from the clinical perspective. Rev J Autism Dev Disord 2024 Feb 29:169 [FREE Full text] [doi: 10.1007/S40489-024-00434-5]
38. Vagnetti R, Camp N, Story M, Ait-Belaid K, Mitra S, Zecca M, et al. Instruments for measuring psychological dimensions in human-robot interaction: systematic review of psychometric properties. J Med Internet Res 2024 Jun 05;26:e55597 [FREE Full text] [doi: 10.2196/55597] [Medline: 38682783]
39. Vagnetti R, Camp N, Story M, Ait-Belaid K, Bamforth J, Zecca M, et al. Robot companions and sensors for better living: defining needs to empower low socio-economic older adults at home. In: Proceedings of the 15th International Conference on Social Robotics. 2023 Presented at: ICSR '23; December 3-7, 2023; Doha, Qata p. 373-383 URL: https://link.springer.com/chapter/10.1007/978-981-99-8715-3_31 [doi: 10.1007/978-981-99-8715-3_31]

40. Varrasi S, Lucas A, Soranzo A, McNamara J, Di Nuovo A. IBM cloud services enhance automatic cognitive assessment via human-robot interaction. In: Carbone G, Ceccarelli M, Pisla D, editors. New Trends in Medical and Service Robotics: Advances in Theory and Practice. Cham, Switzerland: Springer; 2019:169-176.
41. Wiles JL, Leibing A, Guberman N, Reeve J, Allen RE. The meaning of "aging in place" to older people. Gerontologist 2012 Jun;52(3):357-366. [doi: 10.1093/geront/gnr098] [Medline: 21983126]
42. Mayo CD, Kenny R, Scarapicchia V, Ohlhauser L, Syme R, Gawryluk JR. Aging in place: challenges of older adults with self-reported cognitive decline. Can Geriatr J 2021 Jun;24(2):138-143 [FREE Full text] [doi: 10.5770/cgj.24.456] [Medline: 34079607]
43. Palmier C, Rigaud AS, Ogawa T, Wieching R, Dacunha S, Barbarossa F, et al. Identification of ethical issues and practice recommendations regarding the use of robotic coaching solutions for older adults: narrative review. J Med Internet Res 2024 Jun 18;26:e48126 [FREE Full text] [doi: 10.2196/48126] [Medline: 38888953]
44. Arras KO, Cerqui D. Do we want to share our lives and bodies with robots? A 2000-people survey. Swiss Federal Institute of Technology. 2005. URL: http://www2.informatik.uni-freiburg.de/~arras/papers/arrasTR05.pdf [accessed 2024-04-29]
45. Fracasso F, Buchweitz L, Theil A, Cesta A, Korn O. Social robots acceptance and marketability in Italy and Germany: a cross-national study focusing on assisted living for older adults. Int J of Soc Robotics 2022 Jun 02;14(6):1463-1480. [doi: 10.1007/s12369-022-00884-z]
46. Flandorfer P. Population ageing and socially assistive robots for elderly persons: the importance of sociodemographic factors for user acceptance. Int J Popul Res 2012;2012:1-13. [doi: 10.1155/2012/829835]
47. Pino M, Boulay M, Jouen F, Rigaud A. "Are we ready for robots that care for us?" Attitudes and opinions of older adults toward socially assistive robots. Front Aging Neurosci 2015;7:141 [FREE Full text] [doi: 10.3389/fnagi.2015.00141] [Medline: 26257646]
48. Macis D, Perilli S, Gena C. Employing socially assistive robots in elderly care. In: Proceedings of the 30th ACM Conference on User Modeling, Adaptation and Personalization. 2022 Presented at: UMAP '22; July 4-7, 2022; Barcelona, Spain p. 130-138 URL: https://dl.acm.org/doi/10.1145/3511047.3537687 [doi: 10.1145/3511047.3537687]
49. Honda Y, Yamaguchi H, Higashino T. Daily activity recognition based on Markov logic network for elderly monitoring. In: Proceedings of the 16th IEEE Annual Consumer Communications & Networking Conference. 2019 Presented at: CCNC '19; January 11-14, 2019; Las Vegas, NV p. 1-6 URL: https://ieeexplore.ieee.org/document/8651817 [doi: 10.1109/ccnc.2019.8651817]
50. Noury N, Barralon P, Vuillerme N, Fleury A. Fusion of multiple sensors sources in a smart home to detect scenarios of activities in ambient assisted living. Int J E-Health Med Commun 2014;3(3):29-44. [doi: 10.4018/jehmc.2012070103]
51. Stucki RA, Urwyler P, Rampa L, Müri R, Mosimann UP, Nef T. A web-based non-intrusive ambient system to measure and classify activities of daily living. J Med Internet Res 2014 Jul 21;16(7):e175 [FREE Full text] [doi: 10.2196/jmir.3465] [Medline: 25048461]
52. Camp N, Lewis M, Hunter K, Johnston J, Zecca M, Di Nuovo A, et al. Technology used to recognize activities of daily living in community-dwelling older adults. Int J Environ Res Public Health 2020 Dec 28;18(1):163 [FREE Full text] [doi: 10.3390/ijerph18010163] [Medline: 33379319]
53. Lawson L, Mc Ardle R, Wilson S, Beswick E, Karimi R, Slight SP. Digital endpoints for assessing instrumental activities of daily living in mild cognitive impairment: systematic review. J Med Internet Res 2023 Jul 25;25:e45658 [FREE Full text] [doi: 10.2196/45658] [Medline: 37490331]
54. Shahid ZK, Saguna S, Åhlund C. Detecting anomalies in daily activity routines of older persons in single resident smart homes: proof-of-concept study. JMIR Aging 2022 Apr 11;5(2):e28260 [FREE Full text] [doi: 10.2196/28260] [Medline: 35404260]
55. Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. Health Serv Res 2013 Dec;48(6 Pt 2):2134-2156 [FREE Full text] [doi: 10.1111/1475-6773.12117] [Medline: 24279835]
56. Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of internet e-surveys (CHERRIES). J Med Internet Res 2004 Sep 29;6(3):e34 [FREE Full text] [doi: 10.2196/jmir.6.3.e34] [Medline: 15471760]
57. Francis-Devine B. Poverty in the UK: statistics. UK Parliament. URL: https://commonslibrary.parliament.uk/research-briefings/sn07096/[accessed [accessed 2024-04-29]
58. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. Soc Sci Med 2022 Jan;292:114523 [FREE Full text] [doi: 10.1016/j.socscimed.2021.114523] [Medline: 34785096]
59. Litosseliti L. Using Focus Groups in Research. London, UK: Bloomsbury Publishing; 2003.
60. Camp N, Johnston J, Lewis MG, Zecca M, Di Nuovo A, Hunter K, et al. Perceptions of in-home monitoring technology for activities of daily living: semistructured interview study with community-dwelling older adults. JMIR Aging 2022 May 05;5(2):e33714 [FREE Full text] [doi: 10.2196/33714] [Medline: 35511248]
61. Suurmeijer TP, Doeglas DM, Moum T, Briançon S, Krol B, Sanderman R, et al. The Groningen activity restriction scale for measuring disability: its utility in international comparisons. Am J Public Health 1994 Aug;84(8):1270-1273. [doi: 10.2105/ajph.84.8.1270] [Medline: 8059884]
62. Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. Gerontologist 1970;10(1):20-30. [doi: 10.1093/geront/10.1_part_1.20] [Medline: 5420677]

63. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 1969;9(3):179-186. [Medline: 5349366]
64. Ware J, Kosinski M, Keller SD. A 12-item short-form health survey: construction of scales and preliminary tests of reliability and validity. Med Care 1996 Mar;34(3):220-233. [doi: 10.1097/00005650-199603000-00003] [Medline: 8628042]
65. Sherbourne CD, Ware JE. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992 Jun;30(6):473-483. [Medline: 1593914]
66. Ware JE, Kosinski M, Keller SD. SF-12: How to Score the SF-12 Physical and Mental Health Summary Scales. 2nd Edition. Boston, MA: New England Medical Center; 1998.
67. Ninomiya T, Fujita A, Suzuki D, Umemuro H. Development of the multi-dimensional robot attitude scale: constructs of people’s attitudes towards domestic robots. In: Proceedings of the 7th International Conference on Social Robotics.: https://link.springer.com/chapter/10.1007/978-3-319-25554-5_48; 2015 Presented at: ICSR '15; October 26-30, 2015; Paris, France p. 482-491. [doi: 10.1007/978-3-319-25554-5_48]
68. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
69. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? Qual Health Res 2017 Mar;27(4):591-608 [FREE Full text] [doi: 10.1177/1049732316665344] [Medline: 27670770]
70. Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. Qual Health Res 2019 Aug;29(10):1483-1496 [FREE Full text] [doi: 10.1177/1049732318821692] [Medline: 30628545]
71. Vagnetti R, Camp N, Story M, Ait-Belaid K, Suvo M, Fowler-Davis S, et al. Dataset of "social robots and sensors for enhanced ageing at home: a focus on mobility and socioeconomic factors.". Zenodo. 2024. URL: https://doi.org/10.5281/zenodo.10953272 [accessed 2024-04-29]
72. van Het Bolscher-Niehuis MJ, den Ouden ME, de Vocht HM, Francke AL. Effects of self-management support programmes on activities of daily living of older adults: a systematic review. Int J Nurs Stud 2016 Sep;61:230-247. [doi: 10.1016/j.ijnurstu.2016.06.014] [Medline: 27400029]
73. Notthoff N, Klomp P, Doerwald F, Scheibe S. Positive messages enhance older adults' motivation and recognition memory for physical activity programmes. Eur J Ageing 2016 Sep 9;13(3):251-257 [FREE Full text] [doi: 10.1007/s10433-016-0368-1] [Medline: 28804382]
74. Ioannou E, Chen HL, Bromley V, Fosker S, Ali K, Fernando A, et al. The key values and factors identified by older adults to promote physical activity and reduce sedentary behaviour using co-production approaches: a scoping review. BMC Geriatr 2023 Jun 16;23(1):371 [FREE Full text] [doi: 10.1186/s12877-023-04005-x] [Medline: 37328734]
75. Ambrose AF, Paul G, Hausdorff JM. Risk factors for falls among older adults: a review of the literature. Maturitas 2013 May;75(1):51-61. [doi: 10.1016/j.maturitas.2013.02.009] [Medline: 23523272]
76. Dykstra PA. Older adult loneliness: myths and realities. Eur J Ageing 2009 Jun 4;6(2):91-100 [FREE Full text] [doi: 10.1007/s10433-009-0110-3] [Medline: 19517025]
77. Röhr S, Wittmann F, Engel C, Enzenbach C, Witte AV, Villringer A, et al. Social factors and the prevalence of social isolation in a population-based adult cohort. Soc Psychiatry Psychiatr Epidemiol 2022 Oct;57(10):1959-1968 [FREE Full text] [doi: 10.1007/s00127-021-02174-x] [Medline: 34533607]
78. Schoenmakers EC, van Tilburg TG, Fokkema T. Coping with loneliness: what do older adults suggest? Aging Ment Health 2012;16(3):353-360 [FREE Full text] [doi: 10.1080/13607863.2011.630373] [Medline: 22129447]
79. Robinson H, Macdonald B, Kerse N, Broadbent E. The psychosocial effects of a companion robot: a randomized controlled trial. J Am Med Dir Assoc 2013 Sep;14(9):661-667. [doi: 10.1016/j.jamda.2013.02.007] [Medline: 23545466]
80. Sung HC, Chang SM, Chin MY, Lee WL. Robot-assisted therapy for improving social interactions and activity participation among institutionalized older adults: a pilot study. Asia-Pacific Psychiatry 2014 Apr 01;7(1):1-6. [doi: 10.1111/appy.12131]
81. Clare L, Woods RT. Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: a review. Neuropsychological Rehabilitation 2004 Sep;14(4):385-401. [doi: 10.1080/09602010443000074]
82. Gómez-Soria I, Iguacel I, Aguilar-Latorre A, Peralta-Marrupe P, Latorre E, Zaldívar JN, et al. Cognitive stimulation and cognitive results in older adults: a systematic review and meta-analysis. Arch Gerontol Geriatr 2023 Jan;104:104807 [FREE Full text] [doi: 10.1016/j.archger.2022.104807] [Medline: 36116285]
83. Czaja SJ, Lee CC. The impact of aging on access to technology. Univ Access Inf Soc 2006 Dec 8;5(4):341-349. [doi: 10.1007/s10209-006-0060-x]
84. Yagil D, Cohen M, Beer JD. Older adults' coping with the stress involved in the use of everyday technologies. J Appl Gerontol 2016 Feb;35(2):131-149. [doi: 10.1177/0733464813515089] [Medline: 24652919]
85. Pino MC, Vagnetti R, Tiberti S, Valenti M, Mazza M. Involving autism stakeholders in identifying priorities for interventions based on augmented reality. Disabil Rehabil Assist Technol 2024 Apr;19(3):712-720. [doi: 10.1080/17483107.2022.2120103] [Medline: 36074593]
86. Ciuffreda I, Amabili G, Casaccia S, Benadduci M, Margaritini A, Maranesi E, et al. Design and development of a technological platform based on a sensorized social robot for supporting older adults and caregivers: GUARDIAN ecosystem. Int J of Soc Robotics 2023 Sep 06:s12369 [FREE Full text] [doi: 10.1007/s12369-023-01038-5]

87. Cesta A, Cortellessa G, Fracasso F, Orlandini A, Turno M. User needs and preferences on AAL systems that support older adults and their carers. J Ambient Intell Smart Environ 2018 Jan 17;10(1):49-70. [doi: 10.3233/ais-170471]
88. David D, Thérouanne P, Milhabet I. The acceptability of social robots: a scoping review of the recent literature. Comput Human Behav 2022 Dec;137:107419. [doi: 10.1016/j.chb.2022.107419]
89. Heerink M, Kröse B, Evers V, Wielinga B. Assessing acceptance of assistive social agent technology by older adults: the Almere model. Int J of Soc Robotics 2010 Sep 4;2(4):361-375. [doi: 10.1007/s12369-010-0068-5]
90. Thornton N, Horton T, Hardie T, Coxon C. Exploring public attitudes towards the use of digital health technologies and data. The Health Foundation. 2023. URL: https://tinyurl.com/24z38hnj [accessed 2024-02-13]

Abbreviations

ADL: activity of daily living
MdRAS: Multidimensional Robot Attitude Scale
SAR: social assistive robot

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Review

In-Home Positioning for Remote Home Health Monitoring in Older Adults: Systematic Review

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Abstract

Background: With the growing proportion of Canadians aged >65 years, smart home and health monitoring technologies may help older adults manage chronic disease and support aging in place. Localization technologies have been used to support the management of frailty and dementia by detecting activities in the home.

Objective: This systematic review aims to summarize the clinical evidence for in-home localization technologies, review the acceptability of monitoring, and summarize the range of technologies being used for in-home localization.

Methods: The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) methodology was followed. MEDLINE, Embase, CINAHL, and Scopus were searched with 2 reviewers performing screening, extractions, and quality assessments.

Results: A total of 1935 articles were found, with 36 technology-focused articles and 10 articles that reported on patient outcomes being included. From moderate- to high-quality studies, 2 studies reported mixed results on identifying mild cognitive dementia or frailty, while 4 studies reported mixed results on the acceptability of localization technology. Technologies included ambient sensors; Bluetooth- or Wi-Fi–received signal strength; localizer tags using radio frequency identification, ultra-wideband, Zigbee, or GPS; and inertial measurement units with localizer tags.

Conclusions: The clinical utility of localization remains mixed, with in-home sensors not being able to differentiate between older adults with healthy cognition and older adults with mild cognitive impairment. However, frailty was detectable using in-home sensors. Acceptability is moderately positive, particularly with ambient sensors. Localization technologies can achieve room detection accuracies up to 92% and linear accuracies of up to 5-20 cm that may be promising for future clinical applications.

Trial Registration: PROSPERO CRD42022339845; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=339845

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KEYWORDS

gerontology; geriatrics; older adult; elderly; aging; aging-in-place; localization; ambient sensor; wearable sensor; acceptability; home monitor; health monitor; technology; digital health; e-health; telehealth; clinical studies; cognitive impairment; neuro; cognition

Introduction

The proportion of Canadians aged >65 years is growing, from 7 million in 2020 to an estimated 9.5 million (23% of the population) by 2030 [1-3]. With the ratio of adults aged 15-64 years to persons aged 65 years and older halving from 7.2 in 1980 to 3.6 in 2020, the question of how to maintain a sustainable health care system in the face of these changing demographics remains a top priority [1]. Transforming care processes by using digital platforms and remote monitoring tools may be able to address our increasingly older population and lead to higher life expectancies [4]. Smart home and health monitoring technologies have been touted as the future of managing chronic diseases and allowing people to age in place and live within the comfort and familiarity of their own homes for longer [5-8].

Aging is often accompanied by a gradual decrease in physical and mental capacity [9,10]. In-home monitoring technologies have been used to support older adults to age in place by detecting and managing worsening physical and cognitive decline [7,8,11-19]. Wearables, including accelerometers and gyroscopes, have been used to monitor postural transitions [20] and provide yearly gait speed assessments [21], while weight scales and grip balls have been used to monitor changes in weight and grip strength [22]. Actigraphy has been commonly used in cross-sectional studies on physical activity and gait alongside ambient sensors [13] and to monitor behavioral changes such as agitation and aggression [12,16].

In order to identify appropriate interventions for aging in place, technologies need to first identify body postures and positions that can be reliably interpreted as a functional activity of daily living. While actigraphy can give some quantitative idea of the amount of movement happening, it lacks contextual data that could allow for targeted interventions and improved interpretation of activity data [15,23-25]. Localization technologies are key to providing context that helps with reliable interpretation of what activities are being done. Ambient monitors, including infrared sensors and magnetic door contact sensors, can detect which room a resident is in, determine if they are cooking elaborate or simple dishes, or identify if they are doing self-care activities such as mopping or laundry. This context may be a more sensitive factor in the early detection of dementia, cognitive decline, or increased risk of falls among older adults [26-28]. Wearable tags using wireless technologies such as Bluetooth or Wi-Fi can also be used to localize residents in their homes, offering 1.5-5 m, or room-level accuracy that can help with interpreting what activities are being done [29,30]. More modern technologies, such as ultrasound or ultra-wideband (UWB) localization, provide higher level accuracies that are more useful for detecting functional activities. Detection of basic activities of daily living (personal hygiene, grooming, dressing, and toileting) and instrumental activities of daily living (managing finances, food preparation, and housekeeping laundry) are critical for effective functional assessment.

Other systematic reviews on indoor localization have focused on the technical measures of accuracy or the range of technologies that could be used to detect activities with localization techniques [31,32]. The focus of this review is to review currently available localization technologies being used for clinical purposes, including the acceptability of devices and measurement of clinical outcomes or diagnoses.

The primary objective of this study is to systematically review the clinical evidence for indoor localization technologies to support in-home monitoring of older adults. Secondary objectives include the following: to review the acceptability of in-home positioning technologies and to summarize the range of localization technologies being developed.

Methods

Review Registration and Search Strategy

This systematic review protocol was registered with PROSPERO (ID: CRD42022339845) and follows the methodology of the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [33]. The PRISMA checklist can be found in Multimedia Appendix 1.

The search was completed on May 19, 2022, with inclusion criteria displayed in Textbox 1. The search strategy can be found in Multimedia Appendix 2. The search strategy included search terms for the older adult population undergoing in-home positioning or monitoring systems as their intervention. Keywords related to older adults included “Aged,” “Senior,” “Over 65,” or “Aging,” while terms on the setting included their home or house. For the technologies, terms included the purpose of monitoring (“Positioning” or “Localization”) and specific types of technologies, including wireless trackers (Bluetooth, Wi-Fi, UWB, or Zigbee), wearables (accelerometers or gyroscopes), camera, and audio systems. The search did not include comparator groups or outcomes to improve the sensitivity of the search. We included studies that had at least 4 patients to improve the sensitivity of the search. Articles focused on measuring life spaces outside the home (travel to appointments, shopping centers, or recreation centers) were excluded. Studies using wearables were only included if assessed within a home setting.

Textbox 1. Inclusion and exclusion criteria.

Abstract inclusion criteria

- Older adults (65+)
- Monitoring technology
- In-home setting
- Sample size >4 patients

Full-text inclusion criteria

- All abstract inclusion criteria
- Positioning system

Exclusion criteria

- Care centers (assisted living, long-term care, hospital, etc)
- Conference abstracts
- Reviews and study protocols
- Non-English

Study Selection, Extraction, and Quality Assessment

MEDLINE, Embase, CINAHL, and Scopus were searched, and articles were deduplicated. Abstract screening, full-text screening, data extraction, and quality appraisal were completed by 2 reviewers: the first author (AC) and 1 of 4 secondary reviewers (SP, BC, LQ, and JC). Reviewers were trained with 10 test abstracts and full-text articles, and then concordance was reviewed. At each stage, interrater agreement was calculated using the κ coefficient calculated by the following formula:

where Pr(*a*) represents the actual observed agreement and Pr(*e*) represents the chance agreement [34]. Disagreements were resolved by having both reviewers reassess articles for 2 additional rounds, and then the article was discussed to reach a consensus.

Data extraction included article demographics (country and year published), study design (clinical, usability, or technical study), population characteristics (age, gender distribution, clinical diagnoses, and comparators), types of localization interventions (wearable or ambient, data transmission, technology readiness level, and data analytics methods), and outcomes (types of activities monitored, clinical assessments and outcomes, acceptability, and reliability). Data were compiled into summary tables, presenting the population, technological intervention, and clinical outcomes of each study.

To assess risk of bias, the JBI checklist for case series critical appraisal tool was used, as we did not expect any high-quality randomized controlled trials related to in-home monitoring [35]. Criteria for appraisal were predetermined: studies with 7 or more "Yes" ratings were considered high quality, studies with 4-6 "Yes" ratings were considered moderate, and studies with fewer than 5 "Yes" ratings were considered low quality. No meta-analysis was planned, as we did not expect to find high-quality quantitative studies that would allow for heterogeneity to be assessed. Instead, the outcomes from each study were presented individually.

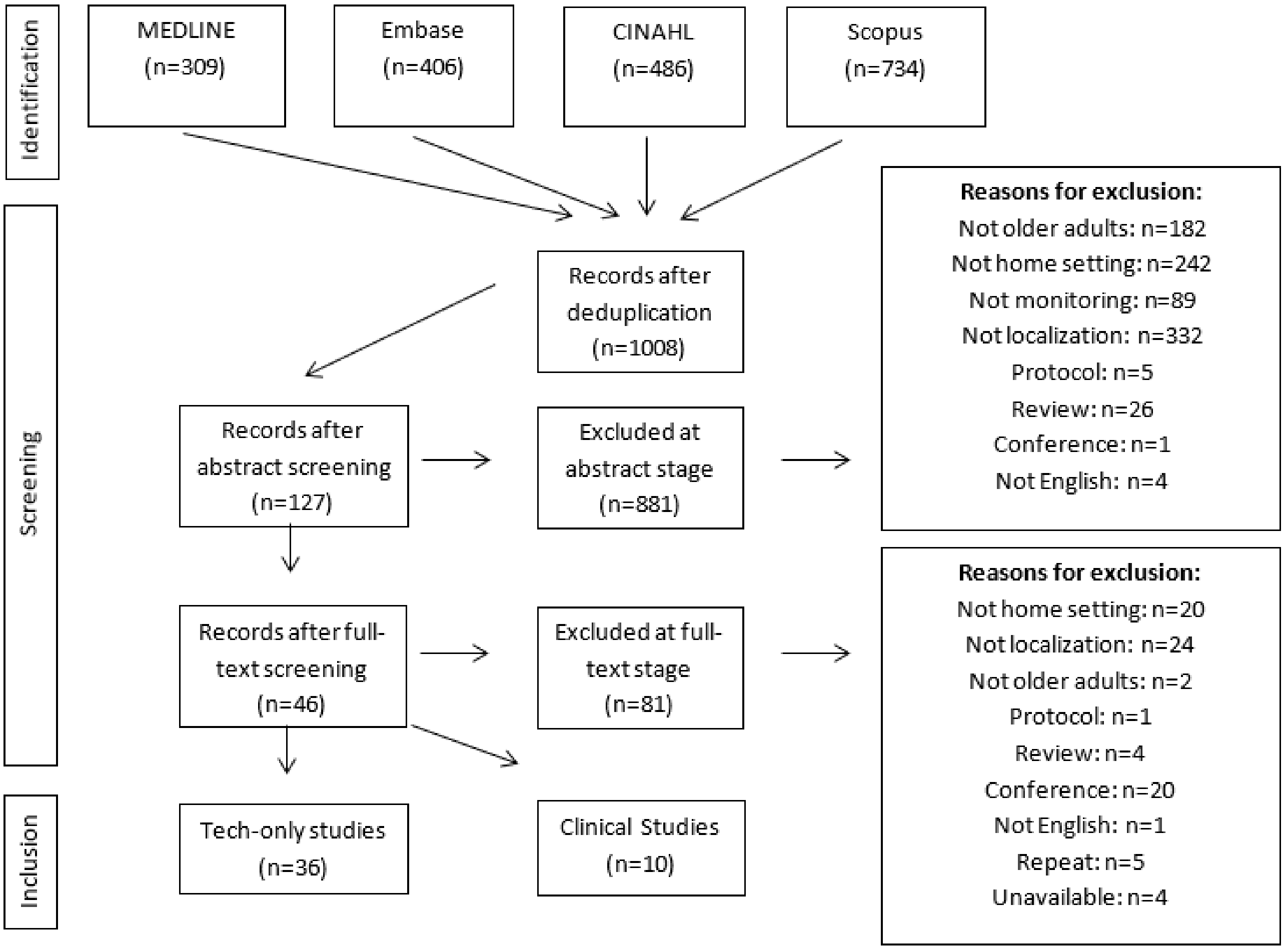
Clinical outcomes were summarized in summary statements, with only moderate- or high-quality studies considered. Evidence was summarized as positive if the majority of studies showed positive results, negative if the majority of studies showed negative results, and mixed if neither had a majority.

Results

Search Results

During the initial search, 1935 articles were found, with 1008 unique articles after deduplication. After abstract screening, 127 articles remained. After full-text screening, 46 articles were included in the final extractions: 36 technology-focused articles and 10 articles that included relevant patient populations. Agreement between reviewers at the abstract screening stage was 94.9% with a κ of 0.77, and agreement for the full-text screening was 95.8% with a κ of 0.71. Quality assessment agreement was 76% with a κ of 0.51. The PRISMA flowchart in Figure 1 maps out the excluded articles.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart showing included clinical studies (n=10) and technology-only studies (n=39).



Studies With Clinical Population

Table 1 displays the baseline characteristic for the 10 papers that included relevant patient populations. In total, 7 studies were conducted since 2019. In total, 5 studies were from North America, 3 from Europe, and 2 from Asia. In total, 2 studies were descriptive studies of the technology, 4 studies had a mixed design and qualitative study design, 2 had qualitative study designs, 1 was a mixed study with qualitative and quantitative outcomes, and 1 focused on quantitative outcomes. Only 1 study had more than 25 participants. In total, 8 studies had more female than male participants.

All studies had patient populations that included older adults, although only 7 specifically reported population characteristics. In total, 4 studies included older adults living at home with nonspecific functional challenges, 2 focused on adults with mild cognitive impairment or dementia, and 1 focused on older adults with frailty. Half of the studies (5/10, 50%) were considered low quality, 3 (30%) were considered moderate quality, and 2 (20%) were considered high quality.

Table 2 shows the technologies and localization methods used in the included studies, their setting, and the duration of monitoring. From a technology perspective, 2 used solely an ambient sensor design, 5 combined ambient sensors with wearables, and 3 used wearable-only designs. Ambient sensors included temperature sensors, magnetic door sensors, infrared motion sensors, light switch sensors, pressure detectors, and lidar sensors. Wearables included inertial measurement units (IMUs), electrocardiograms, heart rate meters, and wearable wireless tags (Wi-Fi or Bluetooth low energy). Of the 10 studies, 7 (70%) included technologies of unknown brand or model (3 only used non-branded devices), while 3 (30%) listed the brands of devices used.

Most studies (7/10, 70%) were done in the home setting, with 2 in a home-like laboratory setting and 1 in a laboratory setting. Studies in the laboratory-home involved monitoring sessions lasting between 1 hour and 7 days [28,29,41], while home-based monitoring ranged from 3 weeks to 18 months.

Table 3 displays the outcomes from studies that included patient populations. In total, 7 included technical outcomes, 6 included usability and acceptability outcomes based on patient or clinician surveys or interviews, and 3 included clinical outcomes. Room detection accuracy ranged from 50% to 88% across 3 studies [27,28,30], while 1 study reported failure rates of >15% for motion detectors and servers installed in the home [36]. One study reported linear accuracies of 1.5-2 m using wireless sensor networks within the home [29].

Table 1. Baseline characteristics from the included clinical papers.

Author (year)	Country	Design type	Participants, n	Female	Age (years), mean (SD; range)	Population	Category of technology	Quality
Hu et al (2016) [36]	United States	Mixed (qualitative + design)	13	62%	69.2 (NR[a]; 54-85)	• Older adults	• Ambient	Low
Rahal et al (2008) [28]	Canada	Descriptive	14	71%	50 (NR; 22-73)	• Mostly older adults	• Ambient	Low
Shin et al (2021) [37]	United States	Mixed (qualitative + design)	23	57%	73 (7.9; 62-89)	• Older adults with difficulty conducting activities of daily living	1. Wearable 2. Ambient 3. Wearable	Moderate
Pais et al (2020) [38]	Switzerland	Qualitative	21	48%	85 (7; 72-96)	• Older adults living at home	1. Ambient 2. Wearable 3. Wearable	High
Lach et al (2019) [27]	United States	Mixed (qualitative + design)	5	100%	86 (5.1; 70-90)	• Older adults living alone in home	1. Wearable 2-5. Ambient	Moderate
Hung et al (2021) [29]	Taiwan	Qualitative	8	60%	68 (NR; 64-77)	• Adults with mild cognitive impairment or dementia	1. Wearable 2-3. Ambient	Moderate
Rawtaer et al (2020) [39]	Singapore	Mixed (qualitative + quantitative)	49	67%	73 (5.3; NR)	1. Older adults who are cognitively healthy 2. Older adults with mild cognitive impairment	1-4. Ambient 5. Wearable	High
Montoliu et al (2020) [30]	Spain	Descriptive	17	NR	62.8 (12; 30-79)	• Older adults	• Wearable	Low
Chen et al (2013) [40]	United States	Mixed (qualitative + design)	4	50%	65 (NR; 46-81)	• Range of diagnoses (polio, multiple sclerosis, spinal cord injury)	• Wearable	Low
Tegou et al 2019 [41]	Greece	Quantitative	271	56%	76.8 (5.2; NR)	1. Older adults who are nonfrail 2. Older adults who are prefrail 3. Older adults who are frail	• Wearable	Low

[a] NR: not reported.

Table 2. Technological setup and technical accuracy of localization devices.

Author (year)	Technology	Brand and model	Localization method	Purpose of monitoring	Setting	Duration	Quality
Hu et al (2016) [36]	1. Temperature, magnetic door sensor (n=2) 2. Motion sensor (n=12)	• Not reported	Motion detection time	Not reported	Home	9-10 weeks	Low
Rahal et al (2008) [28]	1. Motion sensor (n=10) 2. Tactile carpet (n=18) 3. Light switch (n=8) 4. Door contact (n=48) 5. Pressure detectors (n=1)	• Not reported	Motion detection time	Detect walking or preparing sandwich	Home-like laboratory	50 minutes	Low
Shin et al (2021) [37]	1. Wristband: heart rate, electrodermal activity, triaxial accelerometer (n=1) 2. Lidar sensor (n=1) 3. Camera wearable (n=1)	1. Empatica E4 2. FARO Focus S120 3. Not reported	Camera-based	Functional mobility, BADL[a], and IADL[b]	Home	18 months	Moderate
Pais et al (2020) [38]	1. Ambient sensors (not reported) 2. Activity tracker (n=1) 3. Electrocardiogram (n=1)	1. DomoCare 2. Not reported 3. Preventice BodyGuardian	Passive IR[c] sensor	BADL (toilet and fridge usage)	Home	12 months	High
Lach et al (2019) [27]	1. Activity tracker (n=1) 2. Motion detectors (n=3) 3. Bed pressure sensor (n=1) 4. Chair pressure sensor (n=1) 5. Exit sensor (n=1)	1. CamNtech Motion-Watch 8 2. Alarm.com Be-Close	Motion detection time	Functional mobility, BADL (kitchen, bathroom activity), and sleep quality	Home	3 months	Moderate
Hung et al (2021) [29]	1. Bluetooth localizer (n=4) 2. Near-field communication scanner voice-guided exercise 3. Voice questionnaire	• Not reported	Signal intensity	Cognitive training	Laboratory	5 weeks (intermittent) 60-minute sessions	Moderate
Rawtaer et al (2020) [39]	1. Passive infrared sensor (n=4) 2. Proximity tags (n=1) 3. Medication box (n=1) 4. Bed sensor (n=1) 5. Pedometer and heart rate meter (n=1)	1-4. Not reported 5. Microsoft Band	Motion detection	Identify mild cognitive impairment or healthy cognition in community-dwelling older adults	Home	2 months	High
Montoliu et al (2020) [30]	1. Smartwatch (GPS, gyroscope, accelerometer, compass, ambient light sensor; (n=1) 2. Wi-Fi (wireless access point; (n=2) 3. Bluetooth low-energy beacon (n=3) 4. Personal phone (varying)	1. Sony Smart Watch 3 2. Not reported 3. iBKS	Signal intensity (received signal strength indicator)	Localization to detect behavioral changes	Home	2 months	Low
Chen et al (2013) [40]	1. Wi-Fi tag (n=1) 2. Wireless access points (n=3-7) 3. GPS logger	1-2. Ekahau T301A 3. iBlue 860E	Signal intensity (fingerprinting) and GPS	The complete measure of physical activity using various sensors	Home	3-6 weeks	Low
Tegou et al (2019) [41]	1. Smartphone (n=1) 2. Bluetooth beacons (n=5)	1. LG Nexus 5x 2. Sensoro	Signal intensity (received signal strength indicator)	Identify frailty in community-dwelling adults	Home	1-7 days	Low

[a] BADL: basic activities of daily living; refers to personal hygiene, grooming, dressing, and toileting.

[b] IADL: instrumental activities of daily living; refers to managing finances, food preparation, and housekeeping laundry.

[c] IR: infrared.

Table 3. Outcomes from studies that included patient populations.

Author (year)	Category of technology	Outcomes measured	Technical outcomes	Qualitative outcomes	Clinical outcomes	Quality

Hu et al (2016) [36]	Ambient	- Survey: ease of installation, acceptability of sensors, instructions efficiency, device failure rates	- Failure rate:
			  - <15%: motion detectors and temperature sensors
			  - >15%: door sensors, servers, and relays
				- Ease of use: 2.9 out of 4, high
				- Concerns with devices: 1.6 out of 5, low concerns
				- Instructions efficiency: 80.95%, yes
					N/A[a]	Low

Rahal et al (2008) [28]	Ambient	- Localization accuracy	- Combined: 85% room detection accuracy - Accuracy for each device: 1. 88% 2. Not measured 3. 50% 4. 77% 5. Not measured	- N/A	N/A	Low
Shin et al (2021) [37]	Ambient and wearable	- Patient interviews: adaptive behaviors at home	- N/A	- For difficult activities, patients most often give up on them or perform slowly - Home adaptations are rarely implemented due to cost - High fall–risk locations are avoided	N/A	Moderate

Pais et al (2020) [38]	Ambient and wearable	- Survey: satisfaction with devices	- N/A	- Ambient sensors:
				  - Older adults: 81.6% positive
				  - Caregivers: 80% positive
				  - Nurses: 69% positive
				- Wearable sensors:
				  - Older adults: 72.2% positive
				  - Caregivers: 60% positive
				  - Nurses: 49% positive
					N/A	High

Lach et al (2019) [27]	Ambient and wearable	- Measurement of activity levels and sleep duration
		- Patient interviews: Patient experiences with monitoring
			- Activity:
			  - Self-reported activity and sensor activity correlate
			  - Actigraphy did not
			- Sleep:
			  - Self-reported: 492 min
			  - Actigraphy: 524 min
			  - Bed sensor: 435 min
				- Interview: opinions ranged widely on how noticeable and bothersome ambient sensors were
				- Behaviors sometimes changed due to monitoring presence
				- Compromises to data due to the presence of others in the home is a concern
					N/A	Moderate

Author (year)	Category of technology	Outcomes measured	Technical outcomes	Qualitative outcomes	Clinical outcomes	Quality
Hung et al (2021) [29]	Ambient and wearable	• Linear localization accuracy • Patient survey: system usability • Physician survey: availability and quality of system	• 1.5-2 m in 48×32 m space	• Patients: system usability scale: 62.8 SD 11) out of 100 • Physicians: cognitive training more targeted and realistic in patients' home	N/A	Moderate
Rawtaer et al (2020) [39]	Ambient and wearable	• Patient interviews: purpose not specified • Clinical: comparison between healthy cognition and mild cognitive impairment	• N/A	• 83% positive feedback • Improved safety, security, some intrusion where sensors were set up	No behavior difference between healthy cognition and mild cognitive impairment	High
Montoliu et al (2020) [30]	Wearable	• Localization accuracy	• Room detection accuracy: 50.9%-53.8%	• N/A	N/A	Low
Chen et al (2013) [40]	Wearable	• Localization accuracy • Patient interviews: acceptability of system	• Room detection accuracy: 62%-87%	• Lightweight tag: little effort is needed when using tags • The inclusion of GPS is helpful	N/A	Low
Tegou et al (2019) [41]	Wearable	• Clinical: identify frailty in community dwelling adults	• N/A	• N/A	Accuracy in classifying frailty: 80%-87%	Low

[a] N/A: not available.

For studies that included usability and acceptability outcomes, surveys from 3 studies [29,36,38] showed positive results. One study focused on ease of setup of a smart home in a box design and found high ease of use, few concerns with devices, and highly efficient instructions [36]. Another found the highest satisfaction among older adults, followed by caregivers, and the lowest satisfaction with nursing staff [38]. One study found an average system usability scale score of 62.8, indicating below average usability [29]. Interview results from 4 studies [27,37,39,40] found improved safety and security with devices, but there was some perceived physical intrusiveness to ambient devices [39], and some patients changed their behavior due to monitoring [27]. One study found a tag-based system was highly acceptable [40].

Lastly, regarding clinical outcomes, 1 study provided qualitative observations on why patients behaved in certain ways in their home, finding certain activities are performed slower and some areas in the home are avoided, including staircases to avoid falls, depending on their functional level [37]. One study found no difference in behaviors between residents with mild cognitive impairment and those who were cognitively healthy, based on continuous monitoring of sleep and identifying frequency of forgetting to do activities [39], while another study was able to classify patients as frail, prefrail, or nonfrail with 80% to 87% accuracy using machine learning algorithms from Bluetooth-based wearable localization, being monitored for 1-7 days continuously in their own home while doing their own typical activities [41].

Studies on Technology Validation

The primary objective of this systematic review was to review the clinical evidence for in-home localization technologies to support in-home monitoring of older adults. We found 36 articles that reported that their technology would be used for localization of clinical populations. Table 4 is a summary of the characteristics of studies focused on developing and evaluating in-home localization technologies for older adults.

Studies on ambient sensors were from North America (3/6 studies, 50%), wireless tags were most studied in Europe (6/6, 100% for Bluetooth or Wi-Fi and 5/7, 71% for other tags), and wireless tags alongside IMUs were solely studied in Asia (8/8, 100%). The majority (25/36, 69%) of studies were from after 2016. The stated purpose of monitoring was for older adults in a general sense in 27 (75%) out of 36 studies, while older adults with chronic diseases or disabilities were specified in 9 (25%) studies. The purpose of monitoring was mostly for health and safety monitoring (21/36, 58%).

The most common localization mode was to measure signal strength (23/36, 64%), followed by time-based localization (8/36, 22%), which calculates the time that it takes for a signal to travel from a tag to a reference point, and the least common was proximity sensing (5/36, 14%). Received signal strength involves estimating the distance between wearables and reference points based on the strength of the wireless signal. Localization accuracy was most reported as a linear distance (23/36, 64%), followed by classification of activities (13/36, 36%), room or area detection accuracy (6/36, 17%), and lastly accuracy in detecting multiple people in a space (5/36, 14%).

Table 5 summarizes the accuracies of different technologies, organized according to the method of localization and the type of accuracy reporting. Ambient sensors included infrared sensors, radiofrequency transceivers, and video feedback. Devices were primarily used for detecting people passing through spaces, with accuracies of 79% to 98% in differentiating people, and 92% accuracy in detecting presence in a room.

Table 4. Characteristics of studies focused on monitoring technologies.

Category and subcategory	Ambient sensor (video, infrared, magnetic, or pressure), n	Bluetooth or Wi-Fi, n	Localizer tag (RFID[a], UWB[b], Zigbee, or GPS), n	IMU[c] and localizer, n	Other, n	Total, n
Articles	6	6	7	8	9	36
Continent						
Europe	1	6	5	0	1	13
Asia	1	0	1	8	3	13
North America	3	0	0	0	5	8
Oceania	1	0	1	0	0	2
Year						
Before 2010	0	1	0	0	1	2
2010-2016	4	1	0	3	1	9
2016-2022	2	4	7	5	7	25
Target audience						
Older adults	4	4	6	7	6	27
Older adults with chronic disease	2	0	1	1	3	7
Older adults with disabilities	0	2	0	0	0	2
Purpose of monitoring						
Indoor localization	3	0	1	1	0	5
Activity detection	1	0	0	3	2	6
Health or safety monitoring	2	3	5	4	7	21
Self-care	0	3	1	0	0	4
Localization mode						
Signal strength	2	6	5	7	3	23
Proximity sensing	4	1	0	0	3	5
Time-based localization	0	0	2	1	2	8
Accuracy reporting						
Distance	2	3	6	6	6	23
Activity classification	2	0	2	5	4	13
Room or floor or area detection	1	3	0	2	0	6
Multiple tag and person detection	3	0	1	0	1	5

[a] RFID: radio frequency identification.

[b] UWB: ultra-wideband.

[c] IMU: inertial motion unit.

Table 5. Accuracy reporting from localization technologies.

Localization technologies	Distance	Activity classification	Room or floor or area detection	Multiple tag and person detection
Ambient sensors (video, IR[a], magnetic, or pressure; 6 studies)				
Studies, n/N (%)	1/2 (50)	2/2 (100)	1/1 (100)	3/3 (100)
Accuracy	• Thermopile sensor: 12-65 cm [11] • IR sensors: not reported [12]	• RF[b] transceiver [13]: walking: 97%, standing: 95% • Video [14]: sensor placement optimization: 98%	• RF transceiver [13]: room detection: 92%	• RF transceiver [13]: >1 person: 79%-90% • IR and RF transceiver [15]: 2 male individuals: 83% vs 1 male and 1 female individual: 98% • IR doorway sensor [16]: 1 person: 89%, 2 people: 81%
Bluetooth or Wi-Fi (6 studies)				
Studies, n/N (%)	4/4 (100)	—[c]	3/3 (100)	—
Accuracy	• Wireless sensor network: <250 cm [17] • Bluetooth: 60-300 cm [18], 70-240 cm [19], 86 cm [20]	—	• Bluetooth [18]: area accuracy (1 m×1 m): 95%, room detection accuracy [21]: 75%-84% • Wi-Fi [22]: room detection accuracy: 70%-87%	—
Localizer tag (RFID[d], UWB[e], Zigbee, or GPS; 7 studies)				
Studies, n/N (%)	5/6 (83)	2/2 (100)	1/1 (100)	1/1 (100)
Accuracy	• RFID: 17 cm [23], not reported [24] • UWB: 5 cm [25], 5-20 cm [26] • Zigbee [27]: 92 cm • UWB+BLE[f] [28]: 23-100 cm	• UWB [26]: fall detection: sensitivity 99%, specificity 98% • RFID [29]: object identification 88%	• RFID [23]: area accuracy (1.1 m×1.2 m): 90%	• RFID [29]: multitag sensitivity: 76%-90%
IMU[g] and localizer (8 studies)				
Studies, n/N (%)	6/6 (100)	5/5 (75)	2/2 (100)	—
Accuracy	• IMU+UWB: 7.6 cm [30] • IMU+RFID: 10-40 cm in 3.6×2.8 m [31], <50 cm [32] • IMU+Zigbee: 120 cm in 11 m×5.75 m [33], 83-189 cm [34] • IMU+BLE: 47 cm [35]	• IMU+Zigbee: fall detection: 89% [33], unspecified activity: 100% [41] • IMU+RFID: posture recognition: 100% [32] • IMU+BLE: step count within 1 step/minute [35] • IMU+BLE: activity classification: 95% [36]	• IMU+Zigbee: area accuracy (2 m×2 m): 90% [41] • IMU+BLE: room detection accuracy 86.6% [36]	—
Others (9 studies)				
Studies, n/N (%)	5/6 (83)	3/4 (75)	—	0/1 (0)

Localization technologies	Distance	Activity classification	Room or floor or area detection	Multiple tag and person detection
Accuracy	• Triboelectric tracker [38]: at 1.5 m, 20-30 cm • Unspecified doorway sensors: distance traveled error: 10.5%-24% [40] • Android location-based service: not reported [39] • Ultrasound+RF: 11 cm [37] • Floor vibration sensor: 24-61 cm [42] • BLE+Acoustic+Light Fidelity: 20 cm [43]	• IMU+Mic+Wi-Fi: ADL recognition: 92-99% [44] • Unspecified doorway sensors: activity detection: 92% [40] • Ultrasound+RF: gait speed error: 91% [37], distance walked: 92% • Floor vibration sensor: footstep detection: 95%-99% [42] • Ambient+Scales+IMU: not reported [45]	—	• IR+Pressure Pad+RF transceiver: not reported [46]

[a] IR: infrared.

[b] RF: radio frequency.

[c] Not applicable.

[d] RFID: radio frequency identification.

[e] UWB: ultra-wideband.

[f] BLE: Bluetooth low energy.

[g] IMU: inertial measurement unit.

Bluetooth and Wi-Fi technologies can be used with either smartphones or individual tags, reducing the need for extra equipment for localization when compared to stand-alone tags. Accuracies ranged from 70-250 cm, with room detection accuracies of 70% to 87%.

Localizer tags include radio frequency identification (RFID), UWB, Zigbee, and GPS tags. Linear accuracies were superior to Bluetooth or Wi-Fi, ranging from 5 to 100 cm, with area accuracies of 90%. Tags were also used for fall detection and object detection.

Combining localizers with IMUs allowed for a combination of activity classification and localization. Accuracies ranged from 7.6 to 189 cm across 4 modalities (UWB at 7.6 cm, RFID at 10-40 cm, Zigbee at 83-189 cm, and Bluetooth low energy at 47 cm), while activity classification ranged from 89% to 100%, although reporting was not always clear on what activities were being classified. Area classification accuracies were between 86% and 90%.

Lastly, with unique technologies, including sound-based technology, GPS, vibration sensors, pressure pads, and triboelectric sensors, accuracies ranged from 20 to 30 cm with activity recognition at 92% to 99%.

Summary Statements on Clinical Evidence for Localization

From the 5 moderate- to high-quality clinical studies, 4 studies reported on acceptability of in-home localization systems. Results were mixed, with 2 high-quality studies indicating positive acceptability [38,39], 1 finding below average usability [29], and 1 finding a range of concerns over device obtrusiveness [27].

Two studies reported on clinical outcomes from in-home localization systems. One high-quality study showed no difference in behaviors in older adults with healthy cognition compared with those with mild cognitive impairment [39], and 1 moderate-quality study detected adaptive behaviors at home because of limitations to patient function [37].

Discussion

Principal Findings

This systematic review focused on the usage of localization methods to monitor older adults in their homes for any clinical application. While the primary objective was to evaluate the clinical evidence for localization technologies, a survey of technologies for in-home localization was also undertaken to understand upcoming technologies for localization.

Clinical utility of localization was mixed in this study. In the study by Rawtaer et al [39], cognitively healthy older adults (21 participants) and older adults with mild cognitive impairment (28 participants) were monitored and compared over 2 months using a custom set of motion sensors, proximity tags, a bed sensor, and wearables to capture sleep; activity levels; and forgetfulness regarding medications, keys, or wallets. Among typical activities, there was no difference in behaviors [39]. A second study, examining frailty, used in-home localization to detect frailty by measuring number of transitions, speed of transitions, and statistical features through machine learning algorithms, finding a classification accuracy of 82% to 85% when using random forest plots [41]. The model can be used in the future to detect frailty in the general population. The clinical evidence for using localization technology to support care of older adults is currently limited.

From an acceptability perspective, results were moderately positive [27,29,36,38,39]. Pais et al [38] discovered that ambient sensors garner greater acceptance compared to wearables. Moreover, they noted that older adults and caregivers exhibit higher acceptance levels toward both technologies in contrast to nurses. This trend could be attributed to the necessity for monitoring daily performance issues among older adults and their families. The acceptability of home monitoring has been thoroughly studied previously, finding that the trade-offs are critical to consider when developing these technologies [42-45]. These findings align with the present systematic review, with obtrusiveness being a major detractor for these localization technologies balanced by improved safety and security.

Common technologies for localization include ambient sensors; Bluetooth- or Wi-Fi–received signal strength; localizer tags using RFID, UWB, Zigbee, GPS; or IMUs with localizers. This review also found unique localization devices, including triboelectric trackers, ultrasound, floor vibration sensors, and pressure pads. Highest linear accuracies were found with UWB technologies at 5-20 cm compared with greater than 50 cm for most other technologies. UWB uses time-based localization, which involves measuring the time it takes for a signal to travel from a tag to a reference point and then trilateralizing the signal. Room detection accuracies were comparable across technologies, ranging from 75% to 92% using Bluetooth, Wi-Fi, RFID, radio frequency transceivers, or Zigbee with IMUs.

The current literature is limited as it focuses primarily on technical measures of accuracy. The shift needs to be made toward localization for activity identification that can then be used as evidence to provide an intervention. UWB positioning has the potential to make the shift from where a patient is in the home at a room level to a furniture level that can then allow identification of activities. Further exploration and development of algorithms to automatically detect activities are required before broader clinical usage.

Comparison to the Literature

This systematic review fills an important gap by including clinical results, user acceptability, and technological aspects of evaluating localization devices to support older adults to age in place. There remains little evidence for their usage for older adults, a finding that is supported by other systematic reviews. Lenouvel et al [31] reviewed sensors to measure and support activities of daily living for older adults in 2019. While they did not focus on localization, they found that passive and video sensor networks were used to assess activities of daily living across 13 studies out of their search of 10,782 studies, finding that sensors could detect changes in activity patterns but reported no clinical outcomes and that only 1 study assessed the acceptability of devices.

Another systematic review published in 2018 focused solely on technological aspects of human activity recognition supported with indoor localization. Cerón and López [32] described common localization technologies and data fusion methods, reporting accuracy of activity detection and localization accuracies without consideration for age of participants. Human activity recognition accuracy ranged from 72% to 99% across 27 studies, although the exact types of activities were not reported. Localization accuracies ranged from 0.8 to 7 m, depending on the type of technology, although the type of technology was not reported in the review. These values are comparable to this systematic review.

Strengths of This Study and Recommendations for Future Studies

This systematic review had a strong search strategy, covering the major databases and having 2 reviewers screen, extract, and assess the quality of studies. Agreement between reviewers was high across screeners. The JBI quality assessment tool was used with a lower agreement with a κ of 0.51. Agreement was low due to inadequate training for the 10 clinical articles, a lack of specific definitions of how much clinical information was adequate for the study, and how follow-up was defined in the article. Each study was discussed between reviewers according to a standardized definition for the final results of this study.

While the methodology of this review was strong, the findings were not. There is limited clinical evidence for using localization to support monitoring older adults. It was surprising that there were also few studies that evaluated the acceptability of monitoring technologies. The quality of evidence also needs to be improved, with most studies having fewer than 25 participants with a case study design and the quality of studies being mixed.

Still, existing studies on acceptability of localization technologies form a strong basis for further development. Future studies should be located within the homes of participants, with sample sizes greater than 25 to demonstrate scalability and particular use cases in a broad range of home settings. From a study-design perspective, home monitoring as an intervention is a complex intervention that is challenging to capture in a randomized controlled trial. The recent guidelines by the Medical Research Council and National Institute for Health Research in the United Kingdom provide a new framework for assessment that includes considering the context, stakeholders, economics, and uncertainties in an intervention, grounding it in appropriate theory, and iterating to refine the intervention [46]. Nonrandomized designs, hybrid effectiveness-implementation designs, or n-of-1 trials may be more feasible.

Details around patient populations were scarce. Greater detail in medical histories, functional ability, and practical aspects (social supports, living spaces) need to be provided to generate profiles for how monitoring interventions have helped specific residents. A standard battery of activities of daily living needs to be established to allow accuracy in identifying and assessing activities of daily living to be comparable across studies in the range of indoor spaces being localized and the diversity of impairments common to older adults. There needs to be clearer reporting of the spaces being monitored, accuracy of devices, and types of activities of daily living being monitored to allow comparability. Lastly, study outcomes need to be shaped to demonstrate how monitoring technologies lead to clinically and personally relevant interventions that support aging in place. The 2 studies that looked at clinical outcomes in this systematic review focused on detecting dementia or classifying frailty. Perhaps the more important question is how minimally invasive interventions can be used to either prevent decline or intervene to support residents who are having greater challenges doing self-care activities.

The utility of localization techniques for health care is still untapped. While some initial work on detecting cognitive decline and frailty in the home setting has been documented in this review, further development and clinical evaluation of these technologies to determine potential use cases still needs to be undertaken. Development of these technologies requires a multipronged approach that combines understanding the limits of the technology, including the cost, the clinical applicability of localization for health management, and the acceptability of monitoring to enhance wellness. Technologies such as Bluetooth, Wi-Fi, and IMUs are already well established in the market for various quality of life use cases but not for health care.

Localization could be a powerful supporting tool for managing challenges with cognition, with interventions that take into account a user's living patterns and reminders that are tailored to the home environment. Of upcoming technologies, UWB may be the most exciting, offering much higher accuracies than ambient sensors and wireless technologies such as Wi-Fi and Bluetooth. Cognition, mental health, and frailty could be more accurately measured longitudinally, rather than relying on snapshot clinical assessment tools when combined with collecting information on self-care and in-home activity levels. There is great potential for localization technologies to support wellness in the home.

Conclusions

There is no evidence for the usage of in-home localization technologies for any clinical outcomes and mixed evidence for the acceptability of localization technologies among older adults. However, there is a wide range of technologies available that have promising technical accuracy. The technology is ripe for monitoring devices to be tested clinically, providing data that can detect changes in cognition or frailty and drive interventions. Further study on the acceptability of these devices is also warranted to determine the least obtrusive and easier to use modalities that can bring the most benefit for older adults.

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Conflicts of Interest

AC was funded by SmartOne Solutions as part of a Mitacs Accelerate industry partnership grant.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.
[PDF File (Adobe PDF File), 66 KB - aging_v7i1e57320_app1.pdf]

Multimedia Appendix 2
Detailed search strategy for the systematic review.
[PDF File (Adobe PDF File), 112 KB - aging_v7i1e57320_app2.pdf]

References

1. Employment and Social Development Canada. Action for seniors report. Government of Canada. 2016. URL: https://publications.gc.ca/collections/collection_2015/edsc-esdc/Em12-5-2014-eng.pdf [accessed 2022-07-31]
2. Ferrucci L, Giallauria F, Guralnik JM. Epidemiology of aging. Radiol Clin North Am 2008;46(4):643-652 [FREE Full text] [doi: 10.1016/j.rcl.2008.07.005] [Medline: 18922285]
3. Demographic estimates by age and gender, provinces and territories: interactive dashboard. Statistics Canada. 2020. URL: https://www150.statcan.gc.ca/n1/pub/71-607-x/71-607-x2020018-eng.htm [accessed 2022-07-31]
4. Islind AS, Lindroth T, Lundin J, Steineck G. Co-designing a digital platform with boundary objects: bringing together heterogeneous users in healthcare. Health Technol 2019;9(4):425-438. [doi: 10.1007/s12553-019-00332-5]
5. Alam MR, Reaz MBI, Ali MAM. A review of smart homes-past, present, and future. IEEE Trans Syst Man Cybern C 2012;42(6):1190-1203. [doi: 10.1109/TSMCC.2012.2189204]
6. Liu L, Stroulia E, Nikolaidis I, Miguel-Cruz A, Rios Rincon A. Smart homes and home health monitoring technologies for older adults: a systematic review. Int J Med Inform 2016;91:44-59. [doi: 10.1016/j.ijmedinf.2016.04.007] [Medline: 27185508]
7. Narasimhan R, McGlade C. Current state of non-wearable sensor technologies for monitoring activity patterns to detect symptoms of mild cognitive impairment to alzheimer's disease. Int J Alzheimers Dis 2021;2021:2679398 [FREE Full text] [doi: 10.1155/2021/2679398] [Medline: 33628484]

8. Piau A, Wild K, Mattek N, Kaye J. Current state of digital biomarker technologies for real-life, home-based monitoring of cognitive function for mild cognitive impairment to mild Alzheimer disease and implications for clinical care: systematic review. J Med Internet Res 2019;21(8):e12785 [FREE Full text] [doi: 10.2196/12785] [Medline: 31471958]
9. Holliday R. Understanding Ageing. Cambridge, United Kingdom: Cambridge University Press; 1995.
10. Xue QL. The frailty syndrome: definition and natural history. Clin Geriatr Med 2011;27(1):1-15 [FREE Full text] [doi: 10.1016/j.cger.2010.08.009] [Medline: 21093718]
11. Brims L, Oliver K. Effectiveness of assistive technology in improving the safety of people with dementia: a systematic review and meta-analysis. Aging Ment Health 2019;23(8):942-951. [doi: 10.1080/13607863.2018.1455805] [Medline: 29634287]
12. Cote AC, Phelps RJ, Kabiri NS, Bhangu JS, Thomas KK. Evaluation of wearable technology in dementia: a systematic review and meta-analysis. Front Med (Lausanne) 2021;7:501104 [FREE Full text] [doi: 10.3389/fmed.2020.501104] [Medline: 33505979]
13. Dasenbrock L, Heinks A, Schwenk M, Bauer JM. Technology-based measurements for screening, monitoring and preventing frailty. Z Gerontol Geriatr 2016;49(7):581-595. [doi: 10.1007/s00391-016-1129-7] [Medline: 27637581]
14. Gallucci A, Trimarchi PD, Abbate C, Tuena C, Pedroli E, Lattanzio F, et al. ICT technologies as new promising tools for the managing of frailty: a systematic review. Aging Clin Exp Res 2021;33(6):1453-1464. [doi: 10.1007/s40520-020-01626-9] [Medline: 32705589]
15. Godfrey A, Brodie M, van Schooten KS, Nouredanesh M, Stuart S, Robinson L. Inertial wearables as pragmatic tools in dementia. Maturitas 2019;127:12-17. [doi: 10.1016/j.maturitas.2019.05.010] [Medline: 31351515]
16. Khan S, Ye B, Taati B, Mihailidis A. Detecting agitation and aggression in people with dementia using sensors-a systematic review. Alzheimers Dement 2018;14(6):824-832. [doi: 10.1016/j.jalz.2018.02.004] [Medline: 29571749]
17. Mugueta-Aguinaga I, Garcia-Zapirain B. Is technology present in frailty? Technology a back-up tool for dealing with frailty in the elderly: a systematic review. Aging Dis 2017;8(2):176-195 [FREE Full text] [doi: 10.14336/AD.2016.0901] [Medline: 28400984]
18. Teh HY, Kempa-Liehr AW, Wang KI. Sensor data quality: a systematic review. J Big Data 2020;7(1). [doi: 10.1186/s40537-020-0285-1]
19. Vavasour G, Giggins OM, Doyle J, Kelly D. How wearable sensors have been utilised to evaluate frailty in older adults: a systematic review. J Neuroeng Rehabil 2021;18(1):112 [FREE Full text] [doi: 10.1186/s12984-021-00909-0] [Medline: 34238323]
20. Parvaneh S, Mohler J, Toosizadeh N, Grewal GS, Najafi B. Postural transitions during activities of daily living could identify frailty status: application of wearable technology to identify frailty during unsupervised condition. Gerontology 2017;63(5):479-487 [FREE Full text] [doi: 10.1159/000460292] [Medline: 28285311]
21. White DK, Neogi T, Nevitt MC, Peloquin CE, Zhu Y, Boudreau RM, et al. Trajectories of gait speed predict mortality in well-functioning older adults: the health, aging and body composition study. J Gerontol A Biol Sci Med Sci 2013;68(4):456-464 [FREE Full text] [doi: 10.1093/gerona/gls197] [Medline: 23051974]
22. Chkeir A, Novella J, Dramé M, Bera D, Collart M, Duchêne J. In-home physical frailty monitoring: relevance with respect to clinical tests. BMC Geriatr 2019;19(1):34 [FREE Full text] [doi: 10.1186/s12877-019-1048-8] [Medline: 30717696]
23. Hunter SW, Divine A. The effect of walking path configuration on gait in adults with Alzheimer's dementia. Gait Posture 2018;64:226-229. [doi: 10.1016/j.gaitpost.2018.06.118] [Medline: 29940482]
24. Kikkert LHJ, Vuillerme N, van Campen JP, Appels BA, Hortobágyi T, Lamoth CJC. The relationship between gait dynamics and future cognitive decline: a prospective pilot study in geriatric patients. Int Psychogeriatr 2018;30(9):1301-1309. [doi: 10.1017/S1041610217002770] [Medline: 29223180]
25. Persad CC, Jones JL, Ashton-Miller JA, Alexander NB, Giordani B. Executive function and gait in older adults with cognitive impairment. J Gerontol A Biol Sci Med Sci 2008;63(12):1350-1355 [FREE Full text] [doi: 10.1093/gerona/63.12.1350] [Medline: 19126848]
26. Kaye J, Reynolds C, Bowman M, Sharma N, Riley T, Golonka O, et al. Methodology for establishing a community-wide life laboratory for capturing unobtrusive and continuous remote activity and health data. J Vis Exp 2018;137:56942 [FREE Full text] [doi: 10.3791/56942] [Medline: 30102277]
27. Lach HW, Lorenz RA, Palmer JL, Koedbangkham J, Noimontree W. Home monitoring to track activity and sleep patterns among older adults: a feasibility study. Comput Inform Nurs 2019;37(12):628-637. [doi: 10.1097/CIN.0000000000000569] [Medline: 31524691]
28. Rahal Y, Pigot H, Mabilleau P. Location estimation in a smart home: system implementation and evaluation using experimental data. Int J Telemed Appl 2008;2008:142803 [FREE Full text] [doi: 10.1155/2008/142803] [Medline: 18437225]
29. Hung L, Huang W, Shih J, Liu C. A novel IoT based positioning and shadowing system for dementia training. Int J Environ Res Public Health 2021;18(4):1610 [FREE Full text] [doi: 10.3390/ijerph18041610] [Medline: 33567679]
30. Montoliu R, Sansano E, Gascó A, Belmonte O, Caballer A. Indoor positioning for monitoring older adults at home: Wi-Fi and BLE technologies in real scenarios. Electronics 2020;9(5):728. [doi: 10.3390/electronics9050728]
31. Lenouvel E, Novak L, Nef T, Klöppel S. Advances in sensor monitoring effectiveness and applicability: a systematic review and update. Gerontologist 2020;60(4):e299-e308 [FREE Full text] [doi: 10.1093/geront/gnz049] [Medline: 31102436]

32. Cerón J, López DM. Human activity recognition supported on indoor localization: a systematic review. Stud Health Technol Inform 2018;249:93-101. [Medline: 29866962]
33. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Int J Surg 2010;8(5):336-341 [FREE Full text] [doi: 10.1016/j.ijsu.2010.02.007] [Medline: 20171303]
34. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med (Zagreb) 2012;22(3):276-282 [FREE Full text] [Medline: 23092060]
35. Munn Z, Barker TH, Moola S, Tufanaru C, Stern C, McArthur A, et al. Methodological quality of case series studies: an introduction to the JBI critical appraisal tool. JBI Evid Synth 2020;18(10):2127-2133. [doi: 10.11124/JBISRIR-D-19-00099] [Medline: 33038125]
36. Hu Y, Tilke D, Adams T, Crandall A, Cook D, Schmitter-Edgecombe M. Smart home in a box: usability study for a large scale self-installation of smart home technologies. J Reliab Intell Environ 2016;2(2):93-106 [FREE Full text] [doi: 10.1007/s40860-016-0021-y] [Medline: 28936390]
37. Shin J, Her-Xiong Y, Tredinnick R, Ponto K. Toward understanding everyday lives of older adults: a methodological exploration. Gerontologist 2021;61(8):1241-1253. [doi: 10.1093/geront/gnab045] [Medline: 33791751]
38. Pais B, Buluschek P, DuPasquier G, Nef T, Schütz N, Saner H, et al. Evaluation of 1-year in-home monitoring technology by home-dwelling older adults, family caregivers, and nurses. Front Public Health 2020;8:518957 [FREE Full text] [doi: 10.3389/fpubh.2020.518957] [Medline: 33134236]
39. Rawtaer I, Mahendran R, Kua EH, Tan HP, Tan HX, Lee T, et al. Early detection of mild cognitive impairment with in-home sensors to monitor behavior patterns in community-dwelling senior citizens in Singapore: cross-sectional feasibility study. J Med Internet Res 2020;22(5):e16854 [FREE Full text] [doi: 10.2196/16854] [Medline: 32369031]
40. Chen K, Harniss M, Patel S, Johnson K. Implementing technology-based embedded assessment in the home and community life of individuals aging with disabilities: a participatory research and development study. Disabil Rehabil Assist Technol 2014;9(2):112-120. [doi: 10.3109/17483107.2013.805824] [Medline: 23802128]
41. Tegou T, Kalamaras I, Tsipouras M, Giannakeas N, Votis K, Tzovaras D. A low-cost indoor activity monitoring system for detecting frailty in older adults. Sensors (Basel) 2019;19(3):452 [FREE Full text] [doi: 10.3390/s19030452] [Medline: 30678280]
42. Chan A, Cohen R, Robinson K, Bhardwaj D, Gregson G, Jutai JW, et al. Evidence and user considerations of home health monitoring for older adults: scoping review. JMIR Aging 2022;5(4):e40079 [FREE Full text] [doi: 10.2196/40079] [Medline: 36441572]
43. Mann WC, Marchant T, Tomita M, Fraas L, Stanton K. Elder acceptance of health monitoring devices in the home. Care Manag J 2001;3(2):91-98. [Medline: 12455220]
44. Mihailidis A, Cockburn A, Longley C, Boger J. The acceptability of home monitoring technology among community-dwelling older adults and baby boomers. Assist Technol 2008;20(1):1-12. [doi: 10.1080/10400435.2008.10131927] [Medline: 18751575]
45. Pirzada P, Wilde A, Doherty GH, Harris-Birtill D. Ethics and acceptance of smart homes for older adults. Inform Health Soc Care 2022;47(1):10-37. [doi: 10.1080/17538157.2021.1923500] [Medline: 34240661]
46. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ 2021 Sep 30;374:n2061 [FREE Full text] [doi: 10.1136/bmj.n2061] [Medline: 34593508]

Abbreviations

IMU: inertial measurement unit
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RFID: radio frequency identification
UWB: ultra-wideband

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Review

Factors Affecting Clinician Readiness to Adopt Smart Home Technology for Remote Health Monitoring: Systematic Review

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Abstract

Background: The population of older adults worldwide continues to increase, placing higher demands on primary health care and long-term care. The costs of housing older people in care facilities have economic and societal impacts that are unsustainable without innovative solutions. Many older people wish to remain independent in their homes and age in place. Assistive technology such as health-assistive smart homes with clinician monitoring could be a widely adopted alternative to aged-care facilities in the future. While studies have found that older persons have demonstrated a readiness to adopt health-assistive smart homes, little is known about clinician readiness to adopt this technology to support older adults to age as independently as possible.

Objective: The purpose of this systematic review was to identify the factors that affect clinician readiness to adopt smart home technology for remote health monitoring.

Methods: This review was conducted in accordance with the Joanna Briggs Institute methodology for systematic Reviews and followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for reporting.

Results: Several factors affected clinicians' perspectives on their readiness to adopt smart home technology for remote health monitoring, including challenges such as patient privacy and dignity, data security, and ethical use of "invasive" technologies. Perceived benefits included enhancing the quality of care and outcomes.

Conclusions: Clinicians, including nurses, reported both challenges and benefits of adopting smart home technology for remote health monitoring. Clear strategies and frameworks to allay fears and overcome professional concerns and misconceptions form key parts of the Readiness for Adoption Pathway proposed. The use of more rigorous scientific methods and reporting is needed to advance the state of the science.

Trial Registration: PROSPERO International Prospective Register of Systematic Reviews CRD42020195989; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=195989

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KEYWORDS

clinician; provider; health professional; smart home; remote monitoring; technology; readiness; adoption; preparedness

Introduction

Background

The global population is aging, and people are living longer. Adults aged ≥65 years have a high burden of disease, and the current practice of housing and caring for older people in nursing homes is often considered the last resort [1]. With reports of lower-quality care in residential aged-care settings and demands for alternative aging-in-place solutions by a much more technology-savvy baby boomer generation [2,3], health-smart homes (HSHs) are capable of unobtrusive in-home monitoring to support the health and safety of older people. In addition to protecting older adults from unnecessary exposure to communicable diseases such as COVID-19, aging in place has several benefits, including the maintenance of social connectivity and proximity to friends and family [1,4,5]. Furthermore, the ability to age in place supports and maximizes independence, thereby enhancing well-being and quality of life while decreasing the financial burden of residential care costs [1,6,7]. Older adults are a unique population with age-related changes and conditions and yet could remain living in their ancestral homes with the help of HASs, which could also augment public or private home care services. However, while HAS technologies are maturing, to improve wider use of the HAS, gaining an understanding of clinician readiness to use HAS technologies is important because clinicians that make up the multidisciplinary care team constitute important stakeholders [8].

Smart Home Technology for Remote Health Monitoring

The term Internet of Things refers to a collection of “smart” devices that can acquire and connect data or information across environments and act on the information [9], for example, by sending an alert that a person’s overall activity has significantly decreased. Although wearables can be used in an in-home context, there are many different types of wearables for different purposes and that collect different types of data compared with the health-assistive smart home. In addition, wearables usually do not attract some of the privacy concerns associated with remote monitoring using health-assistive smart home technologies. The health-assistive smart home consists of Internet of Things devices such as unobtrusive sensors that are deployed in a home to monitor a person’s routine behaviors and activities of daily living, including movement around the home such as sleeping, eating, steps ambulated, and more without the person having to “wear” a device [10]. The health-assistive smart home can collect and analyze a variety of data with the help of intelligent algorithms. Data can then be used by clinicians to monitor potential changes in health in their older patients [11,12]. Clinicians and the multidisciplinary care team are positioned to be the primary end users of patient data derived from the smart home sensors. Smart devices enable clinicians to unobtrusively monitor their older patients using automated assessment of behaviors that are associated with changes in health, which could support pragmatic, data-driven clinical decision-making [13].

Readiness and Acceptance Models

Readiness and acceptance models have been developed to help integrate computer-based information systems and digital technologies into specific settings, including health care. Researchers have studied the factors that may impact acceptance of and readiness for new technologies for several decades [14,15]. Examples of studies that explore technology readiness and acceptability in clinicians include mobile electronic health records [16], information and communications technologies [17], electronic care plan systems [18], telemedicine readiness [19], and computer-generated nursing care plans [20]. Frameworks and theories have been developed to understand a person’s likelihood of accepting and using health technologies [21]. The technology acceptance model (TAM) is the predominant framework cited in the literature [22-24]. This framework is used to model the behavioral intention that leads people to accept a certain technology [22-24]. In this model, behavioral intention is influenced by the person’s attitude generated from their impression of the perceived usefulness of the technology, which then predicts the actual use of the technology [22-24]. The TAM was expanded to include social influences and cognitive instrumental processes (TAM 2) [22], and later, the TAM 2 was combined with determinants of perceived ease of use to form the TAM 3 [23]. Determinants of perceived ease of use included computer self-efficacy, perception of external control, computer anxiety, computer playfulness, perceived enjoyment, and objective usability [23]. The Unified Theory of Acceptance and Use of Technology was developed from previous work with the aim of explaining end-user intention to and use of IT [24]. Models can help with intentionally integrating computer-based information systems and digital technologies into specific settings, including health care. However, there are larger differences between adopting, for example, an electronic health record and the readiness of clinicians to adopt home health monitoring using smart home technology. Clinician adoption of smart home technology requires clinicians to use and understand a new form of evidence. Accordingly, using the findings of this systematic review, we developed a theoretical model to support clinician readiness for and adoption of HAS technology, which will be discussed at the end of the *Results* section.

Clinician Readiness

The research and development surrounding the health-assistive smart home is maturing, with deployment as part of research studies across a variety of care settings, including private homes, assisted living, residential memory care, and residential care settings such as nursing homes [25-27]. Accordingly, the readiness of clinician end users to adopt smart home technology–generated data for clinical decision-making is important if wider adoption of the health-assistive smart home is desired. Clinicians such as nurses, physicians, and other allied health professionals will play a key role in monitoring older adults living using health-assistive smart home technology. As end users, clinicians will need to use sensor data integrated with other health information and apply clinical judgment to triage information and liaise with the multidisciplinary health care team for early interventions [28,29]. Exploring factors that may impact readiness to adopt, including perceived benefits and challenges, is needed to inform the integration of the HAS into new models of home care and clinical practice. The purpose of this systematic review was to identify and summarize the factors that may impact clinician readiness to adopt smart home technology for remote health monitoring.

Methods

Review Question

What are the factors affecting clinician readiness to adopt smart home technology for remote health monitoring of community-dwelling older adults?

Inclusion Criteria

Participants

A preliminary search showed that, frequently, a variety of clinicians and other stakeholders have been included in studies that examined the phenomenon under review. Accordingly, clinicians aged ≥18 years, such as nurses, registered nurses, clinical nurses, physicians, allied health professionals, and other health care workers, were included. Studies that included nonclinical stakeholders as participants were included if clinicians were also included. Studies were excluded if we were unable to identify clinician participation.

Interventions

Because of the unique data that the health-assistive smart home can generate with the potential to augment clinician decision-making, this review included studies on health-assistive smart home sensor technology embedded or deployed in the home environment (eg, ceilings, walls, furniture, and appliances) to detect motion in persons living in private dwellings in the community, retirement villages, or aged-care homes and residential care homes. Studies focusing on telehealth and remote health monitoring were included if smart home sensors were also embedded in the home. Studies focusing only on wearable sensors or other technologies used for remote monitoring (eg, implanted defibrillators) were beyond the scope of this review and were excluded. Studies that did not provide sufficient information to ascertain whether smart home sensors were embedded or deployed in the home environment were also excluded.

Comparators

This review considered studies that compared the use of smart home technology to usual care. Studies that did not use comparisons such as cohort, case studies or descriptive qualitative studies, were also included. Due to the challenges with the feasibility of implementing the health-assistive smart home in real-world settings, studies that used “mock” or hypothetical health-assistive smart homes to study clinician readiness were included.

Outcomes

The primary outcome of this review was the identification of factors that may impact clinician readiness to adopt smart home technologies. Studies reporting clinician feedback, attitudes, perceptions, and experiences, including barriers, facilitators, and enablers regarding smart home technology, were included. Studies that reported nonclinical stakeholder feedback were included if clinicians were also included in the study.

Types of Studies

This review considered experimental and quasi-experimental studies, randomized controlled trials (RCTs), qualitative studies, case studies, and surveys. Human studies conducted in any geographical area and published in English from database inception to July 2024 were included.

Review Registration

The review protocol was registered with PROSPERO (CRD42020195989) before the commencement of the database searches.

Review Methodology

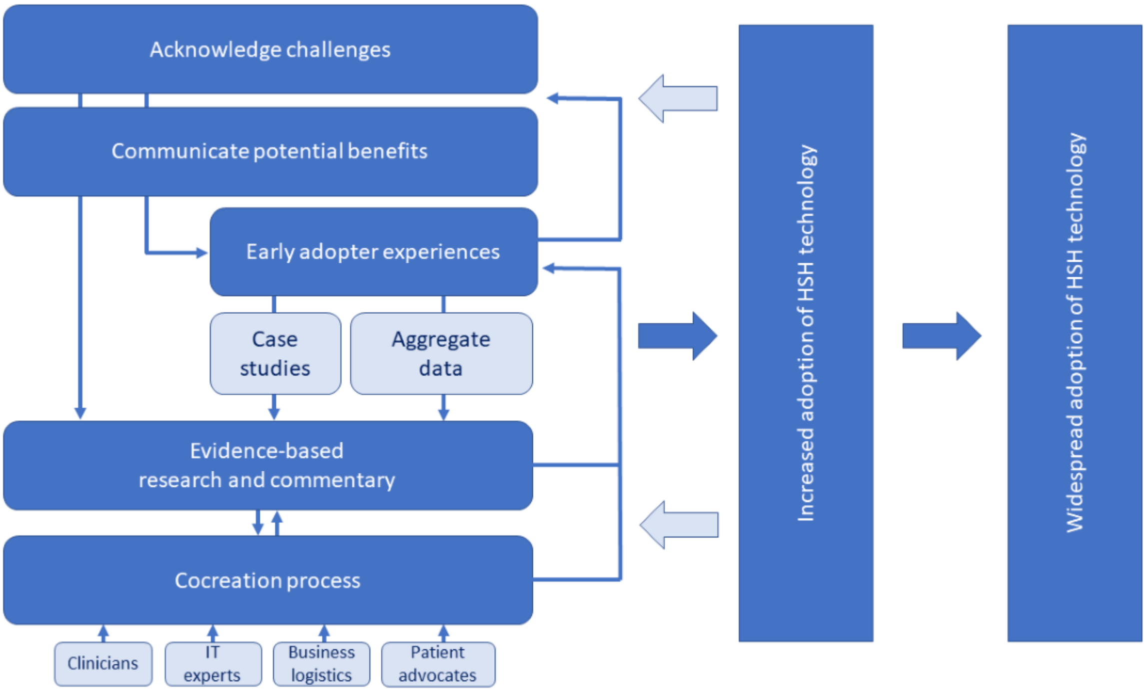
This review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for systematic reviews and followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for reporting.

Search Strategy and Study Selection

The initial search [30] of 12 databases up to July 2024 resulted in 17,204 references. Additional records were identified (n=24) through manual searching, including searching systematic review reference lists. After duplicates were removed, of the 17,228 study titles, a total of 13,423 (77.91%) were assessed. After the title search was completed, a title screen was performed by MD, and abstract screening was performed independently by 4 reviewers (GD, CG, MD, and DW). Full-text screening was performed independently by GD, CG, MD, and DW. A total of 155 full-text articles were comprehensively assessed for inclusion. Disagreements arising between the reviewers were resolved through discussion until consensus was reached. Of the 155 full-text articles, a total of 128 (82.6%) were excluded for the reasons previously stated. A total of 27 papers addressing clinician readiness, perspectives, and attitudes, among other things, regarding smart home technology were included in this systematic review.

The results will inform researchers and clinicians regarding the challenges and perceived benefits of adopting smart home technology for remote health monitoring. Finally, the findings of this review were used to develop a smart home adoption model for clinicians, which is presented in Figure 1.

Figure 1. Model for clinician adoption of smart home technology. HSH: health-smart home.



Assessment of Methodological Quality and Certainty of Findings

Eligible studies were critically appraised, and methodological quality was assessed by independent reviewers (GD, CG, MD, and DW) using the standardized critical appraisal instruments from the JBI [31]. This allowed the reviewers to achieve a greater insight into the methodological strengths and limitations of the selected studies. Blinding treatment groups was not always conceivable given the nature of the intervention; hence, it was not considered a criterion for inclusion. Any incongruities in appraisal that arose between reviewers were discussed and resolved by all authors. The Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach for assessing the certainty of evidence for an effect, summarized in narrative form, was used to assess the overall quality of the findings of each paper [31]. The GRADE assessment evaluates the limitations, indirectness, imprecision, inconsistency, and publication bias of the studies [31]. The overall quality of the evidence was then categorized as high, moderate, low, or very low. In total, 2 reviewers (GD and DW) independently completed the GRADE assessment for each article; there were no disagreements.

Data Extraction

Data were extracted from the studies by 2 independent reviewers (GD and DW) using an adapted version of the JBI standardized data extraction tool. Extracted data included specific details about the populations, study methods, types of smart home technology intervention used, outcomes assessed, and themes relevant to the review objective. Disagreements arising between the reviewers were resolved through team discussions. Both team members' input was equally valued and used when coming to agreements.

Data Synthesis

As the studies included were heterogeneous, the findings of the selected studies were narratively synthesized to examine the barriers, facilitators, enablers, perceptions, and attitudes of clinicians and how these factors may impact the readiness to adopt smart home technology.

Results

Summary of the Search Results

The initial search (Figure 2) of 12 databases resulted in 17,204 references. Additional records were identified (n=24) through manual searching, including searching of systematic review reference lists.

Table 1 presents the comparative characteristics of the studies and the GRADE rating. Table 2 presents the summary of the key factors that may affect clinician readiness to adopt smart home technology, which have been categorized into perceived challenges and perceived benefits. Multimedia Appendix 1 presents descriptive themes and subthemes. The results will inform researchers and clinicians regarding the challenges and perceived benefits of adopting smart home technology for remote health monitoring. Finally, the findings of this review were used to develop a smart home adoption model for clinicians, which is presented in Figure 1.

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.

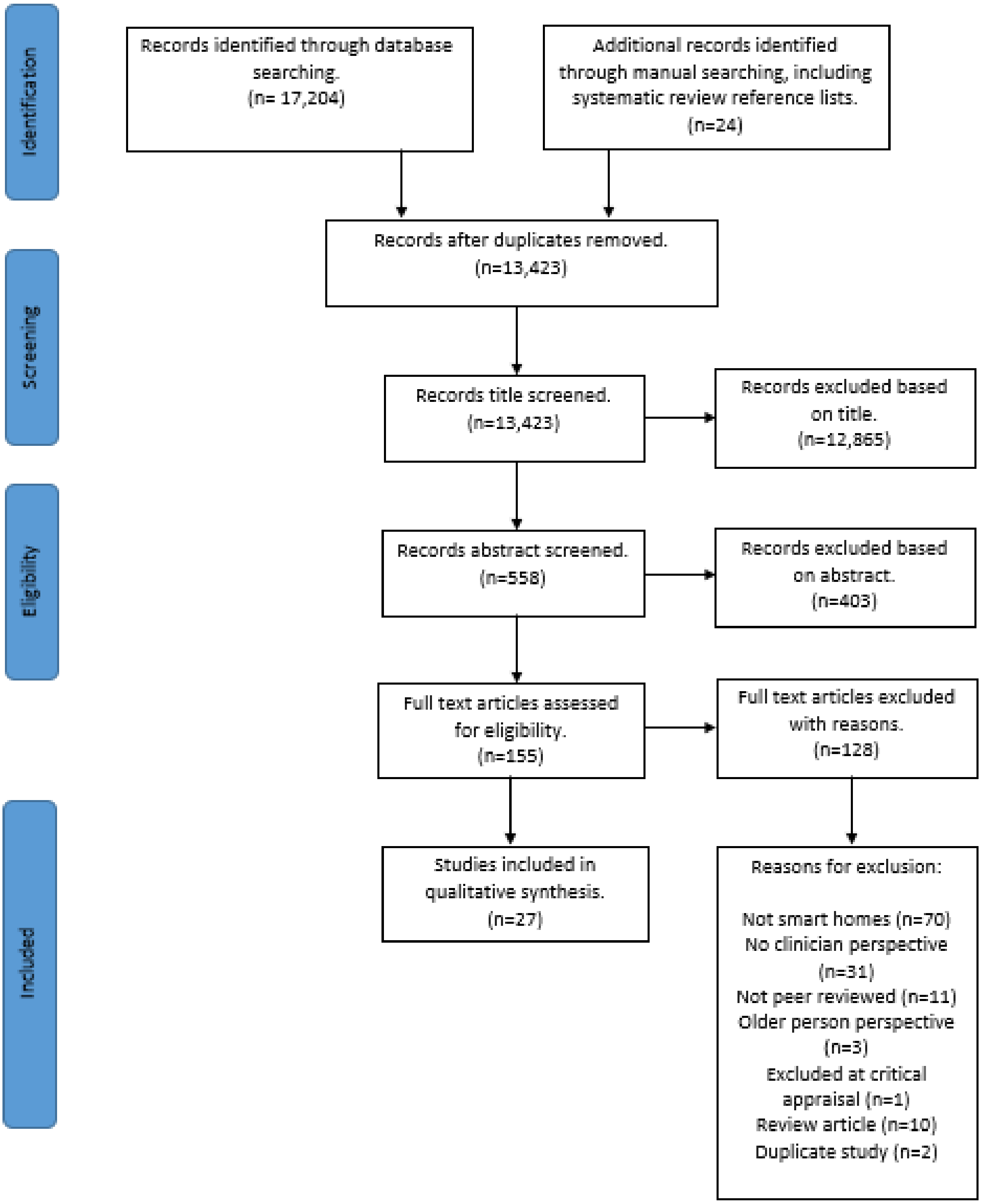


Table 1. Literature review table.

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Beaudin et al [32], United States	Qualitative; to elicit specific feedback from health professionals and lay people on how they might use longitudinal health monitoring data for proactive health and well-being	N=34; 8 health professionals; 26 lay people; professionals in aging and cognition, geriatric nurses, home nurses, cognitive psychologists, and OTs[b]	Developed mock sensor visual displays representing a hypothetical patient in a variety of constructs used to elicit feedback on longitudinal tracking ideas	Reactions to longitudinal monitoring in the ho me; types of behaviors, events, and physiological indicators that participants would be interested in tracking; primary question: can monitoring systems be designed that might be adopted by end consumers for personal use?	Interviews (low)
Brand et al [33], United States	Descriptive; to ask multiple stakeholders to rate their level of concern about the privacy of individuals with disabilities when receiving services via smart homes	N=209; 16 volunteers; 44 direct service professionals; 37 administrators or coordinators; 22 managers; 2 licensed practical nurses; 38 licensed practitioners (eg, psychologists, social workers, and behavior analysts); 18 family members or self; 6 teachers, advocates, or attorneys; 3 counselors-job- coach-trainers; 7 participants with multiple roles listed; 16 not clearly identified or specified; 9.6% aged ≥65 years; 27.3% aged 55-64 years; 25.4% aged 45-54 years; 16.3% aged 35-44 years; 19.1% aged25-34 years; 2.4% aged18-24 years	Participants were shown a short explanatory video that described how smart home technology was used to provide services to individuals with disabilities using video cameras, motion sensors, and remote coaches	Information about levels of concern associated with individual smart home technology; privacy concerns across various aspects of smart homes	Survey (low)
Caprani et al [34], Ireland	Qualitative; to explore HCPs'[c] preferences for using and visualizing sensor data	N=14; phase 1: 9 PTs[d]; phase 2: 0; phase 3: 2 OTs, 2 PTs, and 1 nurse; employment settings: community, nursing home, and community	Developed a mock system design based on clinician feedback consisting of smart home sensors to measure activity, gait, health, and sleep	How sensor technology can support the role of HCPs, technicians, and patients	Interviews (low)
Ding et al [35], United States	Qualitative; to explore the service delivery practices of mainstream smart home technology as assistive technology	N=15; 7 OTs, 6 assistive technology professionals, 4 aging-in-place specialists, 2 speech and language pathologists, 2 certified environmental access consultants, 1 PT, and 1 certified living administrator	Home automation devices to support independence in people with disabilities or older adults	Service delivery practice challenges and perspectives on benefits, limitations, and barriers	Interviews (low)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Cohen et al [36], Switzerland	Descriptive and qualitative; to explore the perception of acceptability among CHNs[e] of an IWSS[f] for use in daily practice for the detection of health issues in home-dwelling older adults receiving home care; secondary analysis of qualitative data from a pilot RCT[g] of IWSS acceptability among home-dwelling older adults	N=17; CHNs were 88% (n=15) female; mean age of 26.4 years; practicing in home care for an average of 5.1 years	IWSS placed in living room, bedroom (time in bed), and refrigerator (tracked refrigerator door opening and closing). An algorithm analyzed and detected changes in behavior patterns regarding refrigerator opening and time in bed. CHNs received alerts via SMS text message followed by email and smart home reminders. The CHN had access to a smart application dashboard to discover the nature of the change in movements or activity patterns.	Perceived usefulness and perceived ease of use of IWSS among CHNs; number of alerts transmitted; relevance of IWSS alerts for CHNs in their daily practice	Survey and focus groups (low)
Delbreil and Zvobgo [37], Switzerland and the United Kingdom	Mixed methods; to examine the health professionals' recognition of sensor technology to enhance the QoL[h] of care recipients with dementia	N=60; comprised RNs[i], medical assistants, PTs, OTs, and social workers; physicians were excluded	WSN[j] technology	Effect of wireless sensor technologies on QoL; confidence of caregivers that wireless sensor technologies will lighten caregiver burden while satisfying end-user needs and QoL aspects; barriers to wireless sensor technology use; value derived in the older adult care sector from using sensor technology	Web-based survey (low-moderate)
Dugstad et al [38], Norway (based on the work by Nilsen et al [39])	Longitudinal case study; to identify facilitators and barriers and explore co-creation practices as an innovation strategy during the implementation of digital monitoring technology in LTC[k] for persons with dementia who were night wanderers	Workshops: n=172 (89 municipal health care service staff members, 8 IT staff members, 30 vendors, 14 research institutions, 3 NGOs[l], 5 other public-sector organizations, 20 innovation and funding organizations, and 3 external experts); interviews: n=16 (13 RNs and 3 HCWs[m]); focus groups:9 HCPs and 4 vendors	On the basis of the Digital Night Surveillance Innovation Project; using monitoring technology for a night surveillance intervention for increasing the safety of PLWD[n] who wander; 67 installations of the monitoring technology were implemented; sensors included door sensors, electronic security blankets on mattresses to monitor bed exit, and SMS text message–mediated alarm	Facilitators of and barriers to monitoring technology in long-term residential aged care; co-creation practices as an innovation strategy	Workshops, interviews, and focus groups (low)
Elavsky et al [40], Czech Republic	Mixed methods; to explore the barriers and concerns related to the adoption of smart technologies among different groups of stakeholders	N=390; qualitative data:12 professional caregivers and 9 experts in aging; cross-sectional survey: 369 older adults attending the University of the Third Age	Smart home technologies in care for older adults; ANUME smart bed system	Barriers to the adoption of smart technologies in the care of older adults; solutions to overcome these barriers	Mixed methods (moderate)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Glasby et al [41], United Kingdom	Qualitative; evaluation of decision-making process and implementation of home-based sensor technology “IndependencePlus”	N=23; 3 decision makers and operational leads; 5 care staff members, care providers, and unpaid carers; 2 technology providers; and 1 regulatory organization	Home-based sensor technology “Independence-Plus” in 3 case study sites (1 care provider and 1 local authority); 1 care home with nursing services (23 clients) and 1 community care setting (9 clients); local authority with urban and rural areas (20-30 clients)	Decision-making process and implementation of “IndependencePlus”; barriers to and facilitators of the use of AI[o] in social care	—[p]
Hall et al [42], United Kingdom	Qualitative; to explore the extent of the ethical considerations of implementing monitoring technologies in 3 dementia specialist care homes	N=24; aged 21-64 years, mean age 39.75 years; managers, clinicians, and support workers (specific numbers for each profession not provided)	Bed sensors, pressure mats, sensors in ceiling, door sensors, RFID[q] location-based system, and accelerometer	Ethical considerations when using monitoring technologies in care homes; equality of access to monitoring technologies	Embedded multiple–case study design; interviews (low)
Hunter et al [43] (research brief) and Hunter et al [44]) original paper, New Zealand	Qualitative; to understand the perspectives of HCWs on the use of technology to provide aging in place to inform the development of a prototype system being tested in older persons’ homes	N=44; community-based care:5 nurses, 11 social workers, 3 PTs, 2 OTs, and 1 clinical coordinator; primary care practice:3 GPs[r], 8 nurses, 3 directors, 1 business manager, 2 clerks, 2 geriatricians, and 1 social worker; predominantly female, with a mean age of 46.6 years	Smart home technologies and home monitoring devices, including technologies that involve interaction among societies, complex infrastructures, and human behavior	Health providers’ perspectives on the use of smart home technologies to provide services to older adults; types of information needs; the type of information that should be collected and transferred; the purpose of the information collected; who should receive the information; ethical concerns	Focus groups (low)
Ienca et al [45], Switzerland, Germany, and Italy	Qualitative; to explore the views and attitudes of health professionals and researchers involved in psychogeriatric care and research on IATs[s] for dementia and older adult care	N=17; 41% female; professionals from gerontology, geriatrics, general practice, neurology, neuropsychology, nursing, nursing home management, and psychiatry	IATs discussed in interviews: distributed systems, robots, mobility and rehabilitation aids, handheld or multimedia, software apps, wearables, and human-machine interfaces	Health professional expectations, needs, and perceptions regarding IATs; practical experience with IATs; perceived effectiveness of IATs; health professional recommendations for improving IAT use for end users	Interviews (low)
Islam et al [46], Australia	Qualitative	N=9; clinicians from different settings involved in the clinical care of people with cardiovascular disease or heart failure; 3 cardiologists, 1 pharmacist, 4 nurses, and 1 GP	Smart home system for heart failure, including sensor-enabled medication monitoring; motion sensors; blood pressure, weight, and fat percentage monitoring; voice activation; wearable for activity; sleep and heart rate monitoring; and educational content, alerts, and messaging	Key HCPs’ perspectives on using smart home system to support self-management and home-based care in people with heart failure; types of technologies useful to support the self-management of patients with heart failure; barriers to and facilitators of uptake	Interviews (low)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Klemets et al [47], Finland	Qualitative; to determine how wireless sensor–collected information about an older adult's physical motion can be used by nurses	N=9; nurses (5 from home care team)	Smart home project–developed prototype wireless infrared sensors placed in each room; monitors in-home physical activity, bathroom visits, physical motion, and time spent in different rooms and outside; data are presented as daily physical motion patterns	Challenges to nurses' existing care provision and whether elementary information about older adults' motion patterns could support their work	Interviews (low)
Klemets et al [48], Finland	Qualitative analysis of a case study; to determine how an in-home monitoring system can be used and integrated into home care nurses' workflows and identify the factors that influence system adoption	N=4; 3 RNs and1 head nurse	IOT[t] architecture with PIR[u] motion sensors to monitor activities of daily living, including bathroom visits and time spent in rooms; sensors were placed in 8 residents' apartments, and nurses captured their thoughts and reflections on the in-home monitoring system in a notebook; they were interviewed on the system's use and usefulness; nurses used the in-home monitoring system 2 times weekly for 4 weeks	Nurses' perspectives on a deployed in-home monitoring system	Focus groups and interviews (low)
Lee and Dey [49], United States	Case study (interviews); to determine how reflecting on sensor data about everyday activities will aid patients and their clinicians in making better informed decisions about their care	N=9; 6 primary care physicians and 1 oncology specialist; case studies of 2 older women (aged 81 and 77 years)	Ubiquitous sensor "dwellSense" system deployed in older adults' homes for 10 months to monitor ODLs[v] using smart pill box, phone sensor, and sensor-augmented coffee maker; relies less on machine learning and more on simple task-based sensors and heuristics applied to common tasks	Patients: support self-reflection, self-awareness, and improvement of their ability to live independently in their home; clinicians: how can clinicians make care plans based on information about patients' ODLs based on data captured by the sensing system	Interviews (low)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Mahoney et al [50], United States	Multiphase mixed methods; to gain an understanding of the needs of independently living residents and whether remote residential monitoring using off-the-shelf wireless sensors might address these concerns	Predevelopment focus groups: n=26 (13 residents: mean age 7 9 years, widowed, and 66% female;4 family members [no details given]; 9 staff members: most were middle aged and female); intervention focus groups: n=29—10 residents, 10 family members, and 9 staff members (residents:60% female, White, mean age 83, range 70-91 years, and most were widowed [n=7]; family members: 60% female, White, mean age 56, range 40-76 years, and married [n=8])	AT EASE[w] remote home monitoring system consisting of motion sensors in each room, water sensors in the bathroom, ability to remotely enable or disable the system, a processing unit with internet connection, and a Zigbee computer interface and custom automation software application; additional sensors available but not desired by participants: contact sensors for doors, pressure sensors for beds and chairs, and appliance on and off sensors	Types of concerns for staff, residents, and families for monitoring independently living residents; potential signal interferences due to density; monitoring system adaptability to the concerns of end users without security breaches and invalid alert notices	Focus groups and questionnaire (low)
Martin et al [51], Ireland and the United Kingdom	Qualitative; to investigate care staff perspectives on an ambient-automated home environment in dementia-specific housing to design a user interface	N=7; 5 care staff members and2 senior management stakeholders employed at the housing scheme	Discrete sensor network to support tenant activity and daily living tasks with minimum staff intrusion; sensors included PIR sensors, door contacts, pressure pads, and water and cooker valves	Staff perspectives on tenant activity had the potential to inform the care process; how this information should be presented on a computer user interface from the data monitor in the staff office	Interviews (low)
Newton et al [52], United Kingdom	Qualitative; to explore the views and experiences of people with dementia and their family carers and GPs regarding accessing information about and use of assistive technologies in dementia care	N=56; 17 GPs (mean age 42 years, including 6 trainees and 5 GPs with a commissioning role [mean age 30 years]), 13 people with dementia (mean age 72 years), and 26 family carers (mean age 61 years)	Photographic images including the following assistive technologies: community alarms and telecare, GPS location monitoring devices, signage, reminiscence tools, clocks to aid orientation, simplified telephones with pictures, and dementia-friendly furniture; personal and practical experience with assistive technologies, such as pendant alarms, fall alarms, door exit sensors, pill dispensers, signage, and easy-to-use telephones	Knowledge and experience of accessing information about and use of assistive technologies in dementia care	Interviews (low)
Nilsen et al [39], Norway	Longitudinal single-embedded case study; to identify and describe forms of resistance to the implementation of night surveillance technology in nursing homes and home care services	N=50 participants with 17 HCPs; network of small to medium-sized technology enterprises and3 municipal health and care services; university research group	Digital night surveillance system with digital communication, sensors on doors, and electronic security blankets on mattresses used during the night	Types of resistance among night care staff to the implementation of the monitoring technologies	Co-creation and implementation process using interviews, focus groups, observations in meetings, and workshops (low)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Offermann-van Heek and Ziefle [53], Germany	Mixed methods; to investigate the PC[x] acceptance of assistive technologies in professional care contexts	N=170; 74.7% female (mean age 36.26, SD 11.23 years); 25.3% working in geriatric care, 22.9% working in medical care, and 51.8% working in care of people with disabilities	Scenario of integration of AAL[y] system, including room sensors, microphones, video cameras, and ultrasonic sensors	PC acceptance of assistive technologies in 3 care contexts: geriatric, medical, and care and support of people with disabilities; PCs' perceptions in different care contexts on AAL technologies, willingness to share care-related data, willingness to be assisted by specific AAL technologies in their daily routines, and which are the main predictor variables for AAL acceptance at a data level	Interviews that informed web-based questionnaire (low)
Pais et al [54], Switzerland	12-month observational study; to evaluate a new in-home monitoring system among home-dwelling older adults, their family caregivers, and nurses for the support of home care	N=46; 13 older adults, 13 family caregivers, and 20 nurses (characteristics of nurses not given)	In-home monitoring system DomoCare using ambient sensors to monitor mobility, sleep habits, refrigerator visits, and door opening and closing; wearable sensors: activity tracking and ECG[z]	Opinion on the usefulness of ambient and wearable sensors; satisfaction of the older adults, family caregivers, and nurses with ambient and wearable sensors; impact of sensors on the relationships among the older adults, family caregivers, and nurses; impact on in-home care practice (integration and barriers)	Observational study (low)
Peek et al [55], the Netherlands	Qualitative, longitudinal field study; to gain insights into the positions of stakeholder groups involved in the implementation of technology for aging in place	N=29; 5 groups of stakeholders in the process of implementing technology for aging in place: 6 older adults, 7 care professionals, 5 home care and social work managers, 6 technology designers and suppliers, and 5 policy makers; mean age 32.55 years	Scenarios that describe aging in place and the need for creative solutions to provide good-quality care	Types of technologies that could support aging in place; feedback on when participants would consider that the use of technology for aging in place is a success; what participants need to be able to successfully implement technology for aging in place; what participants can contribute to achieve successful implementations	Focus groups (low)
Rampioni et al [56], Italy and Romania	Qualitative study; to collect and analyze the perspectives of older adults, family caregivers, and stakeholders in the fields of care and technology on a list of devices that promote healthy aging	N=30; 13 older adults; 8 caregivers; 9 clinical stakeholders, including 1 end-user representative; and 8 psychologists; 6 women and 3 men	A 15-minute video about the European project SAVE[aa] was presented; a storyboard was used to show participants how they would interact with the SAVE system; the SAVE system is a multicomponent platform with multiple smart home and wearable sensors streamed directly to a cloud-based platform to detect behavioral and psychological deviation; location services; telemedicine; thermostat; video communications; antiflooding; smart plug (appliances); gas detector; to-do list	Whether the video or storyboards evoked something in their mind and what (features, services, or suggestions to improve the system); why they found it interesting or otherwise, including added value and pains and gains	1:1 interviews with older adults and caregivers; focus group with clinical stakeholders (low)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Verloo et al [57], Switzerland and France	Qualitative; to examine and understand the perceptions of professional caregivers, informal caregivers, and older adults with cognitive impairment by showing photos of different technologies	n=68 CDOAs[ab] (74% women with a mean age of 82, SD 7.2 years; 60 urban, 35% independent, 34% physically impaired, and 31% cognitively impaired); n=21 IC[ac] (mean age 68, SD 13.8 years, with 76% being women and retired [n=13]); n=32 PCs (mean age 46.7, SD 9.4 years, mostly female, 91%; physicians, 10%; nurses, 34%; social workers, 6%; nursing assistants, 10%; care assistants, 31%; and OTs, 3%)	10 photographs of relevant smart technologies, including light path, fall detector, electronic pill box, robot vacuum cleaner, service robot, GPS bracelet, touchscreen tablet, social network, brain training, and activity sensor	Perceptions of these technologies among CDOAs with physical and cognitive impairment, professional caregivers, and informal caregivers	1:1 interviews, focus groups, and photo elicitation interviews (low)

Study and country	Study design and purpose	Sample size and characteristics	Smart home technology	Outcomes assessed	Measures (GRADE[a])
Warner et al [58], Canada	Qualitative; apply an implementation science framework to explore the multilevel barriers and facilitators that could affect the implementation of passive remote monitoring technology in home care settings from the perspectives of key informant stakeholders from Nova Scotia, Canada	N=20; 4 policy makers, 4 home care managers, 6 direct care providers, 3 resource navigators (registered nurses), and 3 technology providers	Passive remote monitoring technology, including motion sensors, cameras, and medication administration monitoring	Key informant stakeholders’ perceptions of the barriers to and facilitators of implementing passive remote monitoring technology among older home care service recipients	Interviews (low)

[a] GRADE: Grading of Recommendations, Assessment, Development, and Evaluation.

[b] OT: occupational therapist.

[c] HCP: health care professional.

[d] PT: physical therapist.

[e] CHN: community health nurses.

[f] IWSS: intelligent wireless sensor system.

[g] RCT: randomized controlled trial.

[h] QoL: quality of life.

[i] RN: registered nurse.

[j] WSN: wireless sensor.

[k] LTC: long-term care.

[l] NGO: nongovernmental organization.

[m] HCW: health care worker.

[n] PLWD: persons living with dementia.

[o] AI: artificial intelligence.

[p] Not applicable.

[q] RFID: radio frequency identification.

[r] GP: general practitioner.

[s] IAT: intelligent assistive technology.

[t] IOT: Internet of Things.

[u] PIR: passive infrared.

[v] ODL: observation of daily living.

[w] AT EASE: Automated Technology for Elder Assessment, Safety, and Environment.

[x] PC: professional caregivers.

[y] AAL: ambient assistive living.

[a] ECG: electrocardiogram.

[aa] SAVE: Safety of Elderly People and Vicinity Ensuring.

[ab] CDOA: community-dwelling older adults.

[ac] IC: informal caregivers.

Table 2. Summary of key factors that may affect clinician readiness.

Theme and subthemes	Exemplary quotes
Perceived benefits	
Improved clinician-patient relationships	• "...Having the ODL data visually available for both the patient and physician can help remove the confrontational aspect of asking the patient about bad habits. Instead, with a shared objective view, the physician can have a conversation about ODL data similar to how she discusses laboratory results with patients." (Physician; Lee and Dey [49]) • "We wouldn't rely completely [on physical motion information], I'd interview, ask, and listen as well of course." (Nurse; Klemets et al [48]) • "We were hoping it would help them with the assessment process and help them to genuinely understand how people use their homes and therefore what their needs were, so if that person wasn't really showing, for example, that they were making or seeming to be making themselves regular drinks, that's something that we would be able to factor in, because sometimes when you speak to someone and they say 'oh yes I eat very regularly and oh yes I've had no trouble at all making a cup of tea,' but they're either telling you what they think you want to hear or forgetting or fibbing or something, so we felt it would be a useful kind of tool to help a professional really understand the holistic needs of someone in not too intrusive a way." (Case study site 2: Participant 04 [41])
Detection and prediction of health events	• "If they found that a client's feet were swollen, this could be explained by sleeping while sitting in a chair rather than sleeping lying down." (Nurse; Klemets et al [47]) • "...for those that we visit less regularly it would be beneficial, those that are still in good shape. If there is a sudden change, we could find out earlier. Parkinson's and Alzheimer's disease have these degradation phases." (Nurse; Klemets et al [48]) • "Reporting on tenant motion within the apartment was therefore deemed to be a useful activity report. Other activity reports requested were, sleep pattern, water usage, front door activity and general activity within the apartment. Staff opinion was that these could be useful on a daily basis to inform the care requirements of individual tenants." (Dementia care staff member; Martin et al [51]) • "...the record provided a 'suggestion of a problem' that he did not detect from his visit in the office and made him suspicious about patient's 'fishy' situation. If he had seen these data during the patient's last office visit, he would have tried to investigate." (Lee and Dey [49]) • "I think it could help patients because it would make them more independent with their care, make them more responsible, and seeing their signs and symptoms will give them the power to manage [them]...and hopefully prevent hospital admissions." (Participant 4; nurse [46]) • "The patient might be thinking, okay, this shortness of breath is [...] probably usual for them, normal for them, but they are not thinking...this shortness of breath may be worse [than usual]. But if it can be picked up with the smart home system, it can be picked up early stage, which can prevent worsening of HF. Preventative measures can be taken before they become really worse when that patient needs the hospitalization." (Participant 8; cardiologist [46]) • "[Remote monitoring technologies]...allows people to respond faster when something goes wrong." (Key informant 11; home care manager [58]) • "Part of the selling point of IndependencePlus was that, you know, the machine learning would pick up when somebody's daily routine had changed and would alert you to that fact. So, you know, the kit would send a text message to a carer saying 'Usually your mum has five cups of tea by this point and today she's only had one,' you know. 'Do you want to check this out?' or, you know, 'Your mum's usually out of bed by this time; she hasn't got up yet, might be worth going round.'" (Case study site 5: Participant 05 [41])
Facilitation of evidence-based practice	• "I think the environment and the type of dementia care...an individualized care closely dependent on the stage of the disease and as adapted as possible to the personal needs (of the user)." (Psychiatrist; Ienca et al [45]) • "I would say it's patient report, when we're recommending a lot of these things it's about independence, safety, and reduced caregiver burden, so those are kind of the things I'm looking for, and also are they still using it in 6 months when they come back for their re-eval or did they abandon it because it's just too complex." (Practitioner [35]) • "I think patients are not aware [...] as to what they need to know and why so it can be hard to drive compliance. Sometimes you have to educate patients multiple times. You know, one individual session just before the patient is being discharged from the hospital is not enough. You have to repeatedly provide the same information to the patient [and] encourage them to ask questions [...] If something like this can be organised, like even if it's telemonitoring [...] or web monitoring, that would be great." (Participant 1; nurse [46]) • "Within advanced HF, people end up having certain devices implanted, like, cardiac resynchronisation therapy pacemakers. These have different sensors as well as implanted in the heart that give us an idea sometimes of whether the patient is holding on to more fluid and helps doctors adjust things before the patient becomes too symptomatic." (Participant 2; nurse [46]) • "...that client...was supported in his home much longer than anticipated...Because the reason why he would get readmitted [to hospital], have frequent admissions to the hospital, was because he was forgetting to take his medication." (Key informant 4; home care manager [58])

Theme and subthemes	Exemplary quotes
Positive impact on patients, clients, and family caregivers	• "If those devices weren't there, I feel that there were some [home care] clients that...would have been normally removed from their home because of the risk..." (Key informant 4; home care manager [58]) • "...that there's...a few long-term care beds that are open, and it's so difficult to get in. And then seniors often land in the hospital and take up the hospital beds...and I know that there's a great deal of stress in terms of the number of...workers that are available...the homecare business or support has been very much challenged...homecare may be only able to provide you with two hours a day when really that senior requires more than those two hours." (Key informant 20; registered nurse [58])
Peace of mind	• "Something like the smart home system, it's a very [...] efficient module or system, because [...] it helps relax the people at home, the patients themselves and the health personnel. Because they know that they are taking care of the patients, [...] even though if he's very far away, they know that he's safe because you can see all the data." (Participant 3; nurse [46]) • "This allows them...to stay at home with that peace of mind, especially their families to know if they've had a fall. That's a big reason why people end up going to long term care sooner, is if they've had frequent falls, if they're not safe at home." (Key informant 13; direct care provider [58])
Perceived barriers	

Theme and subthemes	Exemplary quotes
Impact on clinicians	• "A presently trained and configured family...doctor would think it was junk. They would go, 'Well, that's interesting, I got 9 more minutes...[of the appointment left].'" (Physician; Beaudin et al [32]) • "Nurses claimed that they were too busy in their daily work and that the many other computer systems they already had to use were too time-consuming." (Nurses; Klemets et al [47]) • "Db6 an oncology specialist, expressed that he (and his office staff) would be too busy to review charts of the ODL data before a visit with the patient because they are already overloaded with tasks to perform." (Physician; Lee and Dey [49]) • "People in the clinics have just a general idea of what can be done, but very few ideas, not so much understanding of what that technologically means." (Psychiatrist; Lenca et al [45]) • "I don't have much knowledge about this. It's true and it makes sense that some training on this wouldn't be bad." (Professional caregiver; Verloo et al [57]) • "It's a lot of trial and errors so often times I have to go back to the assessment part of things after trying 1 device that doesn't work, so it's kind of ongoing throughout the course of treatment." (Practitioner 45) • "Yeah, there still isn't a road map. There are no instructions on how to do this. There's no textbook. And oftentimes while manufacturers may make their products compatible, they don't tell you how to combine them..." (Practitioner 45) • "Our lead domiciliary care provider, they're not geared up to looking at health data and making health judgements based on that, so quite rightly they were saying 'we've got this thing that says heart rate spike, what does that mean, do we have to contact a GP, what's going on?' So there was a lot of confusion around that, and we actually stopped using the system through COVID because of that." (Case study site 4: Participant 01 [41]) • "Because so much of it is health metrics or what would indicate medical problems or something that needs medical attention and support, I think that it needs to be the team that knows the most about that information, it needs to be people who can interpret what normal heart rate data needs to look like and what normal sleep patterns might look like...so it needs people who know what they're looking at, know how to interpret it and are skilled and already knowledgeable about how to take that medical data and turn it into actions. This is when we need to call the GP. This is when we need to call an ambulance. This is when we need to change these meds. This is when we need to—you know, it needs to be the people who will make those medical decisions who are interpreting those data." (Case study site 1: Participant 01 [41])
Impact on clinician identity	• "...worried that if he had been given the ODL data, a jury one day may question his 'interpretation of the dots' in the visualization if the patient had an adverse event related (or even worse, unrelated) to the data in question." (Physician; Lee and Dey [49]) • "I think that these instruments should remain assistive tools and shouldn't replace medical examinations, diagnoses or therapies. I find this a risky trend: if doctor-patient contact is abolished and everything runs via apps...I think this is dangerous..." (Psychiatrist; Lenca et al [45]) • "Some night staff felt that the RFID [location-based tracker] system had been used as a 'Big Brother tool for management' to monitor staff activity." (Health care worker 48) • "I think it's hard to keep up with all the technology changes and I find that as soon as I learn something new, my patients have surpassed me or their family members have heard of something..." (Practitioner 45) • "The problem is people probably want all of it and they can't have all of it, so you need to decide what's your highest priority. Is our highest priority to know when somebody's fallen over so we can go and pick them up and maybe get them to hospital, is that our highest priority? I don't know...Or is our highest priority to have lots of data about people so when we come to review them or assess them, we make better decisions?...Or is our priority something as simple and practical as I want a very good automated meds dispenser for people who are able to take their own medication because overnight that saves me about 500 hours of care a week and, what's that, a lot of money?" (Case study site 4: Participant 02 [41]) • "We're changing the way [we provide] care and that needs some different mindsets and skills or additional to what the care staff have. So the care staff generally have very—they want to be supportive and help people—they're that kind of character generally—some more than others are comfortable around technology." (Case study site 1: Participant 02 [41])
Potential adverse impact on the patient	

Theme and subthemes	Exemplary quotes
	• "These are people that no longer use any technology in their daily life, except for a light switch...very few can use a coffee machine, so it's very difficult to approach..." (Gerontologist; Ienca et al [45]) • "What worries me is situations like this, where the children have even put cameras in the bedroom, not to monitor their parents, but rather to reassure themselves." (Professional caregiver; Verloo et al [57]) • "...there is something about, as I am saying, when I enter a patient room then there is something about what I see and smell and find out how things are as a whole, plus he [the patient] might say that today I would like to watch TV a bit longer...for example." (Health care provider; Nilsen et al [39]) • "...it should be person-centred, and technology isn't person-centred...you've got the technology, but you can't use it until he's capable of accepting [it]...you can't treat everybody the same, and that's where technology falls down, because it'd be too [expensive] to personalise it, and then who'd pay for that?" (Nurse 48) • "...these technologies could like bring on a sense of paranoia or bring on some behavioural and psychological symptoms of dementia for someone...oftentimes people talk about being watched, and we brush that off as being a sign of dementia. When in this case...It would be accurate." (Key informant 12; direct care provider [58]) • "I often explain it that we used to, when we were going out for like IndependencePlus and other technology projects in the past, we used to think what technology's out there and let's go and buy it and now let's look at people that we provide care for and fit them to that technology. That is probably the biggest learning, that that's a mistake. We shouldn't be doing that." (Case study site 4: Participant 01 [41])
Concerns about privacy and data security	• "...there are ethical problems if it's used as a means to monitor the person..." (Professional caregiver; Verloo et al [57]) • "I have no problem displaying what I do at work. I rather think of the user, of...Where did the privacy go? I enter and leave the room and do my job, and am supposed to be professional. But the users shall feel that they have a private life when they enter their flat, that they are not going to be under surveillance, 'cause that is unnatural." (Health care provider; Nilsen et al [39]) • "...we get lots of issues or questions from folks around privacy..." (Practitioner 45) • "...going back to the whole privacy thing as well, that's very important to clients. So educating them about how this technology works..." (Practitioner 45) • "The privacy and confidentiality issue will be very important for the patient, especially when we're talking about clouds and everything and how to protect their privacy." (Participant 6; pharmacist [46]) • "The challenge with this, even as a concept, is this idea of it's all a bit Big Brother-like, it's all a bit you know, sort of a bit 'spying'...The challenge would be to break down some of the stigma that might come with that. I'm not necessarily saying that it's true, that it's like a bit Big Brother-like, but I think that is the perception amongst some people who might be resistant to using the technology, you know. If it's just there forever, recording how many times I use the toilet, you know, it's uncomfortable." (Case study site 2: Participant 03 [41])

Outcomes Targeted

Clinician feedback, attitudes, perceptions, and experiences regarding the use of HAS technology is critical because clinicians are an important end-user group [46,58,59]. Clinicians may use the technology to monitor people living with chronic diseases [46] and use the information in care planning [13]. While the smart technology could optimize clinical care delivery and augment clinical decision-making, certain factors may impact clinicians' readiness to adopt smart home technology for health monitoring.

Populations Included in the Review

Among the 27 studies included, most (n=19, 79%) had a mix of clinical and nonclinical participants, including social workers [32-34,43,44], management [33,35,45,50,51,55,58], policy makers [55,58] or decision makers [41], aging-in-place specialists or experts [35,40,41], older adults [40,42,50,55-57], relatives [42,52], informal caregivers [56,57], and technology designers and suppliers [35,41,55,58]. Table 1 shows that the clinician population recruited was highly variable. Health care workers and care staff and support workers were included in several studies [32-34,37,38,40-42,44,51,53,55,57,58]. The represented clinical disciplines included nursing [33,37,38,40,41,43,44,46-48,58], medicine [32,38,39,43,44,46,49,50,52,53], physiotherapy [34,35,37,43,44], ergotherapy [37], cardiology [46], occupational therapy [35,43,44], psychology [33,56], psychiatry [45], pharmacy [46], gerontology and geriatrics [45], speech and language pathology [35], and neurology and neuropsychology [45,50]. Clinicians worked in a variety of settings in various roles, including in community settings such as home care as direct care providers, navigators, or managers.

Smart Home Technology Use

The studies described a variety of smart home–type technology to monitor specific aspects of activities of daily living. The use of mainstream smart home technology such as home automation devices and smart speakers was described [35], and other studies (n=14, 52%) reported on the use of technologies for remotely monitoring several aspects of activities of daily living, including appliance use [41,55]; use of water [51]; medication adherence [47,49,55,57]; phone and coffee maker and kettle use [41,49]; bathroom and toilet visits [41]; time spent in different rooms and time spent outside [48]; cooking [51]; nighttime monitoring of resident location [38,39,42,52]; general in-home physical motion [57]; resident mobility, including steps ambulated, such as location, activity time, and duration [42]; door use and opening [39,41,42,51,52]; health issues [36,55]; fall detection [34,55,57]; wandering detection [55]; and monitoring of getting in and out of bed [39,42,46]. Several studies (n=6, 22%) included the use of cameras or microphones [33,53], wearables to track activity [46,54], and electrocardiograms to monitor heart rate connected to web-based portals and mobile devices

[39]. Pressure mats [42], smart beds [40], security blankets [39], and alarms [52] were used to monitor residents' activities of daily living, such as sleep and other activities, and remind them to engage in health activities (eg, taking their medication and sleep hygiene). Telecare and remote coaching to facilitate communication were also reported [33,39,52]. Authors described monitoring of task-based resident in-home activities [49] to facilitate residents' independence and emotional connectivity while minimizing staff intrusions [37,51]. For example, in the study by Glasby et al [41], the authors report the implementation of home-based sensors with artificial intelligence capabilities in pilot case study sites. The sensors were placed in key locations of individual homes to remotely monitor opening and closing of doors, kettle use, refrigerator door opening and flushing of the toilet [41].

Notably, 30% (8/27) of the studies did not implement the smart home technologies but investigated health care professionals' predeployment preferences for using smart home technologies [34,43,44,46,56,58], privacy concerns [33], and the issues associated with using smart home and telemonitoring systems [43,44,46]. For example, to obtain clinicians' perspectives, Islam et al [46] provided the clinicians involved in the clinical care of patients with cardiovascular disease with a schematic for a prototype smart home system that included sensor-enabled medication monitoring; blood pressure, weight, and fat percentage monitoring; and a wearable for sleep and heart rate, as well as educational content, alerts, and messaging [46].

In another study, Warner et al [58] explored key stakeholders' perceptions of the barriers to and facilitators of implementing passive remote monitoring technology, including motion sensors, cameras, and medication administration sensors among older home care service recipients [58].

Similarly, the studies by Hunter et al [43,44] investigated the issues that are potentially associated with using smart home and telemonitoring technologies to support older adults. The work by Hunter et al [43,44] was first reported as a research brief [43] and later as a traditional research paper [44]. Another study explored whether sensor-generated motion patterns could support the work of nurses [48] and elicited clinician's views on the sensor-generated data visualization displays. The study by Beaudin et al [32] examined the types of physiological indicators that clinicians would like to monitor for the patients in their care [32]. The study by Rampioni et al [56] examined stakeholder perspectives on how information and communications technologies and sensing technologies could address the needs of older adults for active and healthy aging [56].

Discussion

Principal Findings

Perceived Benefits

Many clinicians in the studies included in this systematic review recognized the benefits of integrating smart home technology to monitor and facilitate care of their patients. First, clinicians perceived that overall quality of care can be enhanced with the use of a variety of patient data collected objectively and over time by the sensor technology [32,34,43,45,47-49,54]. For example, previously difficult-to-obtain data such as nighttime behaviors can provide accurate information about a patient's well-being that may otherwise not be included in clinical decision-making [47]. In addition, there is often a mismatch between what patients report and what is actually happening in the home. Understanding the actual holistic needs of patients as unobtrusively as possible was considered helpful for health professionals [41]. Second, clinicians perceived that adopting smart home technology for remote health monitoring could lead to feeling more informed by real-time and just-in-time data [34,46-49]. Provision of just-in-time data can facilitate timely patient transitions [34], allow for appropriate clinical responses [34,47,48], and enable clinicians to act quickly in response to data that could forecast clinical emergencies [46,53,58]. Third, clinicians recognized that the combination of access to real-time, objectively collected data can facilitate clinicians' understanding of patients' needs and risks and tailoring of care approaches accordingly [46,53,58].

Fourth, clinicians perceived that access to data about activities of daily living collected in the context of the patients' environment was beneficial because it could empower clinicians to identify early patterns of decline [32,34,47,48] and changes in cognitive and functional capacity [34,47-49], forecast future health events [46,47], and enable clinicians to tailor appropriate actions to address health concerns [32,49]. In addition, in-context sensor data [32] were considered more reflective of a patient's health, which could empower clinicians to implement and evaluate tailored care approaches and identify and act upon any issues quickly [32,34,48]. Importantly, contextually collected smart home sensor data case studies could be useful to promote adoption of a specific intervention or care approach [49,58].

A final benefit perceived by clinicians was the potential for enhancing clinician-patient relationships and the ensuing positive psychosocial impact on patients. Clinicians recognized the potential of smart home technology to streamline clinical visits, saving clinicians and patients time [43,58] and reducing health care costs [45,50]. Importantly, clinicians could present the collected data to patients in the form of a visual summary [49], which could facilitate meaningful discussions with patients or family members about their care [32,51,58], enabling patient-centered, informed care decisions [48]. Smart home technology–enabled patient-centered care could support clinicians in addressing numerous dimensions of care concerns, such as respect for the values, preferences, and needs of patients; coordination of care and integration of services; communication and accurate, timely, and appropriate information; enhanced physical comfort and emotional support; involvement of family and friends; and transition and continuity of care [58,60]. Addressing these dimensions of care can lead to strong clinician-patient relationships, which can empower patients to feel more involved in their care [61,62] and self-management [46,56]. Consequently, contrary to perceived threats of smart home technology resulting in disconnection between clinicians and patients [39,57], many clinicians reported that the use of smart home technology for remote health monitoring could strengthen clinician-patient relationships and enhance patient motivation [32,50] and social relations [45].

Perceived Challenges

Clinicians perceived several factors that were challenges to the adoption of smart home technology for remote health monitoring. Chief concerns included privacy, data security, and the ethical and moral use of potentially "invasive" technology and the clinicians' capacity to learn how to use the smart home technology and the generated data. First, nearly half (11/27, 41%) of the reviewed studies highlighted clinician concerns about the privacy and dignity of patients and the security of their data [32-35,39,42-44,46,47,51,53,57]. Brand et al [33] provided insight into the privacy concerns of a mix of stakeholders, including nonclinicians. Survey respondents emphasized the importance of both patient privacy and the secure storage of personal data. They were particularly concerned with the use of video cameras with visual fields that included bedroom and bathroom entrances [33]. While such locations within the home are essential for establishing and monitoring important patient norms regarding activities of daily living [63] and well-being [64], in contrast, Nilsen et al [39] acknowledged that monitoring using a digital night surveillance system with digital communication, sensors on doors, and electronic security blankets made it possible to monitor the patient without disturbing them [39]. These findings suggest that clinicians may perceive sensor technology as less intrusive than video cameras. In addition, clinicians who experienced using the smart home technology highlighted that physically entering a patient's room was also an invasion of privacy [39]. Concerns were also raised regarding the privacy and ethical use of sensor-collected data by Peek et al [55] and Islam et al [46]. These authors emphasized the importance of confidentiality and protecting patients' privacy via clear privacy policies when such technology is used. This suggests that both clear policies and a working knowledge of the available smart home sensor technology will be important for its successful adoption by clinicians.

Second, clinicians expressed concerns regarding their capacity to successfully adopt smart home technology, highlighting the demands required to master software and build the requisite competency [35,43,54] and the perceived time required to view and interpret data [47,54]. A lack of familiarity with sensor technology was a clear challenge [39], highlighted by clinicians citing the effort required to "get used to the system deployed" and "understand and interpret graphs" [47]. Notably, Ienca et al [45] reported a lack of clinician technical skills and digital resources as perceived causes of suboptimal care. While clinicians perceived the need to gain competency regarding smart home technology and the interpretation of smart home sensor data as a challenge, clinicians have been described as capable of understanding the depth of information derived from smart home technology over time [47].

In addition, while older adults enjoyed using smart home technology [55], clinicians expressed concerns about patient readiness to adopt complex smart home technology [44]. Similarly, Ding et al [35] explored the service delivery practices of mainstream smart home technology as assistive technology and found that there were concerns about lack of instructions or manufacturer guidelines on the compatibility and interoperability of devices.

Subsequently, the use of mainstream smart technology in combination with other health-related smart home technology may encounter barriers to adoption by clinicians. Clinicians may need to anticipate substantial education and knowledge gaps, especially among patients who may have concerns about Big Brother–type intrusion into their private life [43,58]. The potential deficits (skills and resources) of both clinicians and patients will need to be addressed for broad adoption. Deployment of a user-friendly and easily navigated system [51,55] could facilitate successful adoption and ensure optimal provision of care.

The perceived negative impact of smart home technology on patient well-being is another important factor that could impact clinician readiness to adopt from psychosocial, quality of care, and equity perspectives. Clinicians reported perceptions that smart home technology could be harmful to patients [58,65]. For example, patients may incorrectly interpret their sensor data assuming causation rather than correlation between behaviors and changes in health [32]. This could lead to self-directed lifestyle changes to the potential detriment of their overall health and quality of life [32,39]. In another example, Warner et al [58] found that patients may experience paranoia because of monitoring devices in the home.

Similarly, clinicians recognized that potential evidence of a decline in health could lead to depression or have a negative self-fulfilling effect on a patient's self-perception [32], exacerbating their physical and mental conditions. Clinicians also raised concerns that remote monitoring may create real or imagined distance between themselves and their patients, which could have a negative impact on the health of the patient [39,57]. For example, many patients placed a high value on nurse-patient interactions [60]. Conversely, the question of equity of access was also raised by some clinicians, posing a social justice challenge to adoption wherein some patients may benefit from access to the technology while it remains inaccessible to others [39], thereby making it inequitable for clinicians to adopt smart home technology for certain segments of the population (eg, those who can afford it). All these factors regarding the well-being of patients expressed by clinicians need to be considered because they could impact clinicians' readiness to adopt smart home technology [55].

Finally, some clinicians in the reviewed studies perceived the use of smart home technology as a threat to their professional culture, highlighting both logistic concerns and misconceptions about this technology [39,42,45,57]. In contrast to the perceived benefits of deploying smart home technology, some clinicians raised concerns that it may replace the role of some allied health professionals and create distance with patients [34]. Others expressed concern about the clash of professional cultures [39], emphasizing that technology cannot replace human-delivered person-centered care [39,42,45,57]. Some participants voiced concerns about potential incongruity between health care and IT and business priorities [39,42,45]. Such views highlight an important misconception and knowledge gap regarding smart home technology—that it is deployed to *replace* clinician contact with patients. However, the opposite is true if smart home technology can *enhance* clinician-patient communication [32,51] and enable clinicians to better understand their patients' needs [49] and quickly respond [32,34,47]. Previous negative experiences with technology may exacerbate such misconceptions, highlighting the need for clinician-driven technology showcases and peer-reviewed evidence to establish the credibility, system reliability, and clinical validity of smart home technology [45].

A well-designed co-creation process involving key professional stakeholders can help address negative experiences, the incongruity between health care and IT priorities, and reported logistical concerns regarding time and money cost [35,39,58]. Theoretical models to help advance clinician readiness for smart home adoption could provide strategies that address or mitigate challenges that negatively impact the readiness for adoption. The findings of this systematic review suggest that there are several factors that impact clinician readiness to adopt smart home technology. The factors related to using smart technology and interventions for remotely monitoring patient health and well-being were categorized into perceived challenges and benefits.

If widespread adoption of health smart homes is the goal, a model is needed to facilitate the co-design of technology use, support its implementation, and ensure its ethical use. Figure 1 is a proposed theoretical model that could enable clinicians to weigh the benefits and challenges, including potential ethical issues of smart home implementation.

The first step in the model is to provide clinicians with opportunities to acknowledge both the challenges and potential benefits of smart home technology for remote health monitoring. Discussing potential benefits alone is not nor should be sufficient to convince clinicians to adopt smart home technology. For widespread adoption, potential challenges will need to be practically discussed and addressed. For example, the use of remotely collected sensor data on activities of daily living is a new form of evidence that clinicians will need to learn to use for evidence-based practice. Clinicians will need to have confidence that they will receive training on how to optimize their clinical decision-making using their patients' sensor–collected smart home data [56].

Second, the experiences of early adopters [66] with smart home technology could be useful for clinicians because early adopters can acknowledge challenges, provide education on potential misconceptions, and affirm that clinicians are patient advocates. Early adopters can present the benefits of adopting this technology by showcasing the findings and lessons learned of real-world small- or larger-scale smart home technology implementation. Third, researchers [8] have an important role in facilitating clinician adoption through the co-creation process with clinicians, IT experts, business logistics professionals, patients, and patient advocates that includes the development or refinement of smart home technology, conduct of studies, development of policies, and creation of new smart home technology–enabled care paradigms. The dissemination of small- and large-scale implementation study findings and the presentation of data-driven case studies can collectively provide valuable, pragmatic evidence; critical evaluation; and commentary in peer-reviewed manuscripts. The dissemination of such evidence is useful to enhance clinician readiness and would support eventual widespread adoption of smart home technology for remote health monitoring as a standard of care for older adults who wish to age in place. Finally, reports of experiences of the co-creation process, such as that proposed by Nilsen et al [39] and Islam et al [46] and exemplified by the study by Glasby et al [41], are invaluable as they signpost a practical pathway to adoption and validate the clinical relevance of the purpose of smart home technology to support older adults.

Implications for Clinicians

More studies are showing that both older adults and family caregivers are open to adopting smart homes to facilitate and support aging in place [34,54,67]. It will be important for the members of the multidisciplinary health team to become knowledgeable of smart home technology and how it can be used to augment traditional care models by remotely monitoring health and well-being and supporting efficient and effective care coordination for the older person [51,59]. Although several different health disciplines were part of the studies in this review, it is clear that there are major differences in clinician expectations of the HAS. For example, home health nurses may be interested in smart home data to ensure that the older person is performing their usual daily routines, whereas a primary care physician may be more interested in certain data points that could help with early identification of a change in health. In addition, very little is known about how the different disciplines may envision the integration of the HAS into their clinical practice and the changes needed in the current systems and processes for the translation of the HAS to support the health and wellness of older adults living at home.

To benefit clinical care, clinicians will need to learn some technical and practical aspects of how to use the data collected by the smart home system that may be deployed in the homes of clients whom they are caring for. Accordingly, it is conceivable that the ever-evolving roles of clinicians will include leading change in the digital health space [50]. It is likely that workloads will be impacted; however, more knowledge is needed to understand how to integrate the smart home system into new "smart" models of care and how to use the sensor data to support clinical decision-making. The cost-benefit of this technology as a health care solution, including impacts on staffing shortages and care delivery in rural and remote locations, also needs to be investigated. Finally, for clinicians to embrace the artificial intelligent agent as a new member of the health care team, and to optimize the smart homes' capability, clinicians need to be offered training specifically focused on the use of smart home technology and sensor data interpretation. Tertiary education frameworks need to include these monitoring technologies as a core competency.

Limitations

This review demonstrates that the scientific understanding of clinician readiness to adopt smart home technology is progressing. The studies reviewed were varied and all studies included a range of stakeholders with relatively small sample sizes, making it challenging to synthesize the findings for specific clinical disciplines. The diversity in study populations, which often included multiple types of clinicians and other stakeholders, makes it difficult to extract findings that are directly applicable to any single clinical discipline.

Only English-language papers were included; however, during our search, we did not encounter non–English-language papers. While qualitative studies with relatively small sample sizes are often ranked lower in traditional evidence hierarchies compared with RCTs, which are considered the "gold standard," qualitative research provides essential insights into user experiences that are crucial for designing effective, user-centered technologies and the policies and procedures needed for implementation. Dismissing these contributions in favor of a rigid adherence to RCTs overlooks critical aspects of practical implementation and user acceptance that determine the real-world success of interventions. Moreover, the rapid pace of technological development necessitates timely research to keep up with innovations, suggesting that waiting for large-scale RCTs (or waiting for the funding to execute such studies) might render findings obsolete by the time they are applied or indeed stifle implementation in new models of care. The integration of smart home technology into models of care for older adults has been challenging, requiring researchers to partner with a variety of clinical and nonclinical professionals, such as technologists, designers, clinicians, and business and industry professionals, to study various aspects of co-design, acceptability, and implementation. This could explain why researchers have used a more pragmatic approach for their studies, including nonprobability sampling, purposive and convenience sampling, case studies, and multiple sources of data.

Another major drawback to synthesizing the literature is the incongruence of the definitions used for smart home technology and the fact that most studies included a mix of clinicians and nonclinicians. As clinicians represent a major end-user group, they need to be more involved in smart home co-design and implementation studies. More studies that focus on specific clinician groups (eg, nurses and physicians) are needed to determine the specific factors that could potentially undermine the success of smart home monitoring for patients at home. Finally, the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines should be used to report comprehensive qualitative findings. While the conduct of RCTs may not be sufficiently pragmatic for this field, the use of mixed methods could yield more generalizable findings. The studies by Delbreil and Zvobgo [37], Elavsky et al [40], and Offerman-van Heek and Ziefle [53] are all good examples of providing readers with greater depth of knowledge regarding clinicians' readiness.

Conclusions

This systematic review synthesized the literature on clinician readiness to adopt HAS technology for remote health monitoring—a key determinant for the future successful adoption of such technologies. The review identified several factors that may impact readiness for adoption among clinicians, highlighting both challenges and perceived benefits of smart home technology. The ensuing proposed theoretical model outlines the steps and key roles that early adopting clinicians, researchers, and cocreating stakeholders will have if widespread clinician adoption of smart home technologies for health monitoring occurs. Importantly, an incongruence in the terminology used in the limited body of literature to date reinforces the need for standardized reporting when discussing smart home technology to develop a clear and consistent body of credible evidence. Future research should continue to evolve this body of literature, evidencing the credibility, reliability, and clinical validity of smart home technology through a combination of peer-reviewed case studies, well-designed research trials, and commentaries. Continuing to reflect, act, and report on clinician's experiences of smart home technology will help identify and overcome challenges to adoption and simultaneously affirm and embrace its benefits. Doing so can establish the professional acceptability and clinical validity of this technology, underpinning its widespread adoption in clinical practice.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Themes and subthemes.
[DOCX File , 28 KB - aging_v7i1e64367_app1.docx]

Multimedia Appendix 2
Prisma checklist.
[PDF File (Adobe PDF File), 85 KB - aging_v7i1e64367_app2.pdf]

References

1. The desire to age in place among older Australians. Australian Institute of Health and Welfare. 2013 Apr. URL: https://www.aihw.gov.au/getmedia/69a6b0b9-6f86-411c-b15d-943144296250/15141.pdf [accessed 2024-09-20]
2. Beals RK. This is how boomers are reinventing retirement living. Market Watch. 2019 Aug 04. URL: https://www.marketwatch.com/story/

boomers-are-reinventing-retirement-housing-imagine-galleries-walkability-and-multi-age-communities-2019-05-22 [accessed 2019-11-13]

3. Crul S. Smart home care for our second adulthood. Freedom Lab. 2019 Sep 30. URL: https://www.freedomlab.com/posts/smart-home-care-for-our-second-adulthood [accessed 2019-11-12]
4. Stepler R. Smaller share of women ages 65 and older are living alone. Pew Research Center. 2016 Feb 18. URL: https://www.pewresearch.org/social-trends/2016/02/18/smaller-share-of-women-ages-65-and-older-are-living-alone/ [accessed 2024-09-20]
5. Wiles JL, Allen RE, Palmer AJ, Hayman KJ, Keeling S, Kerse N. Older people and their social spaces: a study of well-being and attachment to place in Aotearoa New Zealand. Soc Sci Med 2009 Feb;68(4):664-671. [doi: 10.1016/j.socscimed.2008.11.030] [Medline: 19110361]
6. Older Australians. Australian Institute of Health and Welfare. 2024 Jul 02. URL: https://www.aihw.gov.au/reports/older-people/older-australians/contents/health/health-status-and-functioning [accessed 2024-09-11]
7. National overview of the retirement village sector. Property Council of Australia. 2014. URL: https://www.propertycouncil.com.au/?s=national+overview+of+the+retirement+sector [accessed 2024-09-20]
8. Dermody G, Mikus J, Porock D, Sugarman D, Janjua NK, How C, et al. Perspectives on wider integration of the health-assistive smart home. J Ageing Longev 2022 Jun 16;2(2):140-152. [doi: 10.3390/jal2020013]
9. Marikyan D, Papagiannidis S, Alamanos E. A systematic review of the smart home literature: a user perspective. Technol Forecast Soc Change 2019 Jan;138:139-154 [FREE Full text] [doi: 10.1016/j.techfore.2018.08.015]
10. Cook DJ, Crandall AS, Thomas BL, Krishnan NC. CASAS: a smart home in a box. Computer (Long Beach Calif) 2013 Jul;46(7):10.1109/MC.2012.328 [FREE Full text] [doi: 10.1109/MC.2012.328] [Medline: 24415794]
11. Cook DJ, Krishnan NC, Rashidi P. Activity discovery and activity recognition: a new partnership. IEEE Trans Cybern 2013 Jun;43(3):820-828. [doi: 10.1109/tsmcb.2012.2216873]
12. Cook D, Das SK. Smart Environments: Technology, Protocols, and Applications. Hoboken, NJ: John Wiley & Sons; 2004.
13. Fritz RL, Wilson M, Dermody G, Schmitter-Edgecombe M, Cook DJ. Automated smart home assessment to support pain management: multiple methods analysis. J Med Internet Res 2020 Nov 06;22(11):e23943 [FREE Full text] [doi: 10.2196/23943] [Medline: 33105099]
14. Keen PG. Information systems and organizational change. Commun ACM 1981 Jan 01;24(1):24-33. [doi: 10.1145/358527.358543]
15. Dwivedi YK, Rana NP, Chen H, Williams MD. A meta-analysis of the unified theory of acceptance and use of technology (UTAUT). In: Proceedings of the International Working Conference on Transfer and Diffusion of IT. 2011 Presented at: TDIT 2011; September 22-24, 2011; Hamburg, Germany. [doi: 10.1007/978-3-642-24148-2_10]
16. Kuo KM, Liu CF, Ma CC. An investigation of the effect of nurses' technology readiness on the acceptance of mobile electronic medical record systems. BMC Med Inform Decis Mak 2013 Aug 12;13:88 [FREE Full text] [doi: 10.1186/1472-6947-13-88] [Medline: 23938040]
17. Melas CD, Zampetakis LA, Dimopoulou A, Moustakis VS. An empirical investigation of technology readiness among medical staff based in Greek hospitals. Eur J Inf Syst 2017 Dec 19;23(6):672-690. [doi: 10.1057/ejis.2013.23]
18. Ho KF, Chang PC, Kurniasari MD, Susanty S, Chung MH. Determining factors affecting nurses' acceptance of a care plan system using a modified technology acceptance model 3: structural equation model with cross-sectional data. JMIR Med Inform 2020 May 05;8(5):e15686 [FREE Full text] [doi: 10.2196/15686] [Medline: 32369033]
19. Kowitlawakul Y. The technology acceptance model: predicting nurses' intention to use telemedicine technology (eICU). Comput Inform Nurs 2011 Jul;29(7):411-418. [doi: 10.1097/NCN.0b013e3181f9dd4a] [Medline: 20975536]
20. Dharmarajan B, Gangadharan K. Applying technology acceptance (TAM) model to determine the acceptance of nursing information system (NIS) for computer generated nursing care plan among nurses. Int J Comput Trends Technol 2013;V4(8):2625-2629.
21. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Manag Sci 1989 Aug 01;35(8):982-1003 [FREE Full text] [doi: 10.1287/mnsc.35.8.982]
22. Venkatesh V, Davis FD. A theoretical extension of the technology acceptance model: four longitudinal field studies. Manag Sci 2000 Feb 1;46(2):186-204 [FREE Full text] [doi: 10.1287/mnsc.46.2.186.11926]
23. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Q 2003 Sep;27(3):425-478 [FREE Full text] [doi: 10.2307/30036540]
24. Venkatesh V, Bala H. Technology acceptance model 3 and a research agenda on interventions. Decis Sci 2008 May 09;39(2):273-315 [FREE Full text] [doi: 10.1111/j.1540-5915.2008.00192.x]
25. Rantz M, Lane K, Phillips LJ, Despins LA, Galambos C, Alexander GL, et al. Enhanced registered nurse care coordination with sensor technology: impact on length of stay and cost in aging in place housing. Nurs Outlook 2015;63(6):650-655. [doi: 10.1016/j.outlook.2015.08.004] [Medline: 26463735]
26. Rantz M, Popejoy LL, Galambos C, Phillips LJ, Lane KR, Marek KD, et al. The continued success of registered nurse care coordination in a state evaluation of aging in place in senior housing. Nurs Outlook 2014;62(4):237-246. [doi: 10.1016/j.outlook.2014.02.005] [Medline: 24731918]

27. Sprint G, Cook DJ, Schmitter-Edgecombe M. Unsupervised detection and analysis of changes in everyday physical activity data. J Biomed Inform 2016 Oct;63:54-65 [FREE Full text] [doi: 10.1016/j.jbi.2016.07.020] [Medline: 27471222]
28. Williams JA, Cook DJ. Forecasting behavior in smart homes based on sleep and wake patterns. Technol Health Care 2017;25(1):89-110 [FREE Full text] [doi: 10.3233/THC-161255] [Medline: 27689555]
29. Dawadi PN, Cook DJ, Schmitter-Edgecombe M. Automated cognitive health assessment from smart home-based behavior data. IEEE J Biomed Health Inform 2016 Jul;20(4):1188-1194. [doi: 10.1109/jbhi.2015.2445754]
30. Gough D, Thomas J, Oliver S. Clarifying differences between review designs and methods. Syst Rev 2012 Jun 09;1:28 [FREE Full text] [doi: 10.1186/2046-4053-1-28] [Medline: 22681772]
31. The Joanna Briggs Institute reviewers' manual 2015 methodology of JBI scoping reviews. The Johanna Briggs Institute. 2015. URL: https://reben.com.br/revista/wp-content/uploads/2020/10/Scoping.pdf [accessed 2024-09-20]
32. Beaudin JS, Intille SS, Morris ME. To track or not to track: user reactions to concepts in longitudinal health monitoring. J Med Internet Res 2006;8(4):e29 [FREE Full text] [doi: 10.2196/jmir.8.4.e29] [Medline: 17236264]
33. Brand D, DiGennaro Reed FD, Morley MD, Erath TG, Novak MD. A survey assessing privacy concerns of smart-home services provided to individuals with disabilities. Behav Anal Pract 2019 Jan 7;13(1):11-21 [FREE Full text] [doi: 10.1007/s40617-018-00329-y] [Medline: 32231963]
34. Caprani N, Doyle J, Komaba Y, Inomata A. Exploring healthcare professionals' preferences for visualising sensor data. In: Proceedings of the 2015 British HCI Conference. 2015 Presented at: British HCI '15; July 13-17, 2015; Lincoln, UK. [doi: 10.1145/2783446.2783564]
35. Ding D, Morris L, Messina K, Fairman A. Providing mainstream smart home technology as assistive technology for persons with disabilities: a qualitative study with professionals. Disabil Rehabil Assist Technol 2023 Oct;18(7):1192-1199. [doi: 10.1080/17483107.2021.1998673] [Medline: 34752169]
36. Cohen C, Kampel T, Verloo H. Acceptability among community healthcare nurses of intelligent wireless sensor-system technology for the rapid detection of health issues in home-dwelling older adults. Open Nurs J 2017 Apr 17;11:54-63 [FREE Full text] [doi: 10.2174/1874434601711010054] [Medline: 28567170]
37. Delbreil E, Zvobgo G. Wireless sensor technology in dementia care: caregiver perceptions, technology take - up and business model innovation. EuroMed J Bus 2013;8(1):79-97. [doi: 10.1108/EMJB-05-2013-0019]
38. Dugstad J, Eide T, Nilsen ER, Eide H. Towards successful digital transformation through co-creation: a longitudinal study of a four-year implementation of digital monitoring technology in residential care for persons with dementia. BMC Health Serv Res 2019 Jun 10;19(1):366 [FREE Full text] [doi: 10.1186/s12913-019-4191-1] [Medline: 31182093]
39. Nilsen ER, Dugstad J, Eide H, Gullslett MK, Eide T. Exploring resistance to implementation of welfare technology in municipal healthcare services - a longitudinal case study. BMC Health Serv Res 2016 Nov 15;16(1):657 [FREE Full text] [doi: 10.1186/s12913-016-1913-5] [Medline: 27846834]
40. Elavsky S, Knapova L, Janiš K, Cimler R, Kuhnova J, Cernicky T. Multiple perspectives on the adoption of SMART technologies for improving care of older people: mixed methods study. J Med Internet Res 2024 Feb 07;26:e45492 [FREE Full text] [doi: 10.2196/45492] [Medline: 38324345]
41. Glasby J, Litchfield I, Parkinson S, Hocking L, Tanner D, Roe B, et al. New and emerging technology for adult social care - the example of home sensors with artificial intelligence (AI) technology. Health Soc Care Deliv Res 2023 Jun;11(9):1-64. [doi: 10.3310/HRYW4281] [Medline: 37470136]
42. Hall A, Brown Wilson C, Stanmore E, Todd C. Moving beyond 'safety' versus 'autonomy': a qualitative exploration of the ethics of using monitoring technologies in long-term dementia care. BMC Geriatr 2019 May 24;19(1):145 [FREE Full text] [doi: 10.1186/s12877-019-1155-6] [Medline: 31126240]
43. Hunter I, Elers P, Lockhart C, Whiddett D, Guesgen H, Singh A. Technology to assist aging in place: the perspective of health organizations. Stud Health Technol Inform 2019 Aug 21;264:1688-1689. [doi: 10.3233/SHTI190598] [Medline: 31438294]
44. Hunter I, Elers P, Lockhart C, Guesgen H, Singh A, Whiddett D. Issues associated with the management and governance of sensor data and information to assist aging in place: focus group study with health care professionals. JMIR Mhealth Uhealth 2020 Dec 02;8(12):e24157 [FREE Full text] [doi: 10.2196/24157] [Medline: 33263551]
45. Ienca M, Lipps M, Wangmo T, Jotterand F, Elger B, Kressig RW. Health professionals' and researchers' views on intelligent assistive technology for psychogeriatric care. Gerontechnology 2018;17(3):139-150 [FREE Full text] [doi: 10.4017/gt.2018.17.3.002.00]
46. Islam SM, Halooq A, Dening J, Uddin R, Laranjo L, Chow CK, et al. Healthcare providers' perspectives on using smart home systems to improve self-management and care in people with heart failure: a qualitative study. Int J Med Inform 2022 Nov;167:104837 [FREE Full text] [doi: 10.1016/j.ijmedinf.2022.104837] [Medline: 36126353]
47. Klemets J, Määttälä J, Hakala I. Integration of an in-home monitoring system into home care nurses' workflow: a case study. Int J Med Inform 2019 Mar;123:29-36. [doi: 10.1016/j.ijmedinf.2018.12.006] [Medline: 30654901]
48. Klemets J, Määttälä J, Jansson J, Hakala I. Nurses' perspectives on in-home monitoring of elderlies's motion pattern. Stud Health Technol Inform 2017;235:23-27. [Medline: 28423748]
49. Lee ML, Dey AK. Sensor-based observations of daily living for aging in place. Pers Ubiquit Comput 2014 Sep 7;19:27-43. [doi: 10.1007/s00779-014-0810-3]

50. Mahoney DF, Mahoney EL, Liss E. AT EASE: automated technology for elder assessment, safety, and environmental monitoring. Gerontechnology 2009 Jan;8(1):11-25 [FREE Full text] [doi: 10.4017/gt.2009.08.01.003.00]
51. Martin S, Nugent C, Wallace J, Kernohan G, McCreight B, Mulvenna M. Using context awareness within the ‘smart home’ environment to support social care for adults with dementia. Technol Disabil 2007 Apr 13;19(2-3):143-152. [doi: 10.3233/TAD-2007-192-311]
52. Newton L, Dickinson C, Gibson G, Brittain K, Robinson L. Exploring the views of GPs, people with dementia and their carers on assistive technology: a qualitative study. BMJ Open 2016 May 13;6(5):e011132 [FREE Full text] [doi: 10.1136/bmjopen-2016-011132] [Medline: 27178978]
53. Offermann-van Heek J, Ziefle M. They don't care about us! Care personnel's perspectives on ambient assisted living technology usage: scenario-based survey study. JMIR Rehabil Assist Technol 2018 Sep 24;5(2):e10424 [FREE Full text] [doi: 10.2196/10424] [Medline: 30249592]
54. Pais B, Buluschek P, DuPasquier G, Nef T, Schütz N, Saner H, et al. Evaluation of 1-year in-home monitoring technology by home-dwelling older adults, family caregivers, and nurses. Front Public Health 2020;8:518957 [FREE Full text] [doi: 10.3389/fpubh.2020.518957] [Medline: 33134236]
55. Peek ST, Wouters EJ, Luijkx KG, Vrijhoef HJ. What it takes to successfully implement technology for aging in place: focus groups with stakeholders. J Med Internet Res 2016 May 03;18(5):e98 [FREE Full text] [doi: 10.2196/jmir.5253] [Medline: 27143097]
56. Rampioni M, Mo oi AA, Rossi L, Moraru SA, Rosenberg D, Stara V. A qualitative study toward technologies for active and healthy aging: a thematic analysis of perspectives among primary, secondary, and tertiary end users. Int J Environ Res Public Health 2021 Jul 14;18(14):7489 [FREE Full text] [doi: 10.3390/ijerph18147489] [Medline: 34299940]
57. Verloo H, Kampel T, Vidal N, Pereira F. Perceptions about technologies that help community-dwelling older adults remain at home: qualitative study. J Med Internet Res 2020 Jun 04;22(6):e17930 [FREE Full text] [doi: 10.2196/17930] [Medline: 32496197]
58. Warner G, Weeks LE, Chen YT, Hiebert B, Ledoux K, Donelle L. Key informant perceptions of challenges and facilitators to implementing passive remote monitoring technology for home care clients. Gerontechnology 2023;22(1):1-13. [doi: 10.4017/gt.2023.22.1.834.09]
59. Fritz RL, Dermody G. A nurse-driven method for developing artificial intelligence in "smart" homes for aging-in-place. Nurs Outlook 2019;67(2):140-153 [FREE Full text] [doi: 10.1016/j.outlook.2018.11.004] [Medline: 30551883]
60. Delbanco T, Gerteis M. A patient-centered view of the clinician-patient relationship. UpToDate. 2020 Oct 2. URL: https://stax.broadwaygynecology.com/A-patient-centered-view-of-the-clinician-patient-relationship-UpToDate.pdf [accessed 2024-09-20]
61. Carey T, Mullan R. Patients taking the lead. A naturalistic investigation of a patient led approach to treatment in primary care. Counselling Psychol Q 2007 Mar 14;20(1):27-40. [doi: 10.1080/09515070701211304]
62. McCarley P. Patient empowerment and motivational interviewing: engaging patients to self-manage their own care. Nephrol Nurs J 2009;36(4):409-413. [Medline: 19715108]
63. Rogers WA, Meyer B, Walker N, Fisk AD. Functional limitations to daily living tasks in the aged: a focus group analysis. Hum Factors 1998 Mar;40(1):111-125. [doi: 10.1518/001872098779480613] [Medline: 9579107]
64. Zisberg A, Zysberg L, Young HM, Schepp KG. Trait routinization, functional and cognitive status in older adults. Int J Aging Hum Dev 2009;69(1):17-29. [doi: 10.2190/AG.69.1.b] [Medline: 19803338]
65. Conchar M. An integrated framework for the conceptualization of consumers' perceived-risk processing. J Acad Marketing Sci 2004 Oct 01;32(4):418-436. [doi: 10.1177/0092070304267551]
66. Rogers EM, Singhal A, Quinlan MM. Diffusion of innovations. In: An Integrated Approach to Communication Theory and Research. Milton Park, UK: Routledge; 2008.
67. Dermody G, Fritz R, Glass C, Dunham M, Whitehead L. Family caregiver readiness to adopt smart home technology to monitor care-dependent older adults: a qualitative exploratory study. J Adv Nurs 2024 Mar;80(2):628-643. [doi: 10.1111/jan.15826] [Medline: 37614010]

Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
GRADE: Grading of Recommendations, Assessment, Development, and Evaluation
HAS: health-smart home
JBI: Joanna Briggs Institute
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: randomized controlled trial
TAM: technology acceptance model

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Improving How Caregivers of People Living With Dementia Are Identified in the Electronic Health Record: Qualitative Study and Exploratory Chart Review

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Abstract

Background: Family and unpaid caregivers play a crucial role in supporting people living with dementia; yet, they are not systematically identified and documented by health systems.

Objective: The aims of the study are to determine the extent to which caregivers are currently identified and documented in the electronic health record (EHR) and to elicit the perspectives of caregivers and clinical staff on how to best identify, engage, and support caregivers of people living with dementia through the EHR.

Methods: People with dementia were identified based on *International Classification of Diseases, Tenth Revision* (*ICD-10*) codes or dementia medications in the EHR. A chart review of people with dementia characterized how caregiver information was documented and whether caregivers had shared access to the patient portal. Caregivers of eligible people with dementia were then recruited through mailed letters and follow-up calls to the homes of people with dementia. We conducted semistructured interviews with caregivers, clinicians, and staff involved in the care of people with dementia within 2 health systems in Maryland and Colorado. Transcripts were analyzed using a mixed inductive and deductive approach.

Results: Caregivers of people with dementia (N=22) were usually identified in the “contact information” or “patient contacts” tab (n=20, 91%) by their name and relation to the people with dementia; this tab did not specify the caregiver’s role. Caregivers were also mentioned, and their roles were described to a varying degree in clinical notes (n=21, 96%). Of the 22 caregivers interviewed, the majority (n=17, 77%) reported that the people with dementia had additional caregivers. The presence of multiple caregivers could be gleaned from most charts (n=16, 73%); however, this information was not captured systematically, and caregivers’ individual contributions were not explicitly recorded. Interviews with 22 caregivers and 16 clinical staff revealed two major themes: (1) caregiving arrangements are complex and not systematically captured or easy to locate in the EHR and (2) health systems should develop standardized processes to obtain and document caregiver information in the EHR.

Conclusions: This exploratory chart review and qualitative interview study found that people with dementia frequently have multiple caregivers, whose roles and needs are captured inconsistently in the EHR. To address this concern, caregivers and clinical staff suggested that health systems should develop and test workflows to identify caregivers, assess their needs at multiple touchpoints, and record their information in extractable EHR fields.

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KEYWORDS

dementia; dementia care; caregivers; electronic health record; patient record; aging; geriatrics; memory

Introduction

The engagement of family and unpaid caregivers is critical for improving care for people living with dementia [1]. More than 11 million family members and other unpaid caregivers provide an estimated 18 billion hours of care to people living with dementia [2]. Caregivers assist with daily activities, cope with behavioral symptoms, schedule and attend medical visits, manage medications, and make medical decisions [3]. Health systems lack systematic and proactive processes to identify and engage with caregivers, meaning that they remain largely invisible [4,5].

The electronic health record (EHR) is a promising tool to enable timely, accurate, bidirectional information exchange and communication between caregivers and health care teams through applications such as the patient portal. Despite the nearly universal adoption of the EHR [6], its application to dementia care remains limited. Developing a feasible approach to identify caregivers of people living with dementia in the EHR would enable health systems to reach them equitably and at scale, include them in decisions, provide support, and recruit them for research that would benefit them [7]. As little is known about how best to achieve this, we conducted an exploratory chart review and qualitative study with caregivers and clinical staff to characterize how caregivers are currently identified and documented in the EHR in 2 health care systems and elicit perspectives on how best to identify, engage, and support caregivers of people living with dementia through the EHR. Qualitative methods are ideal for this purpose, as they can provide a deep understanding of caregivers' lived experiences and of caregiver and staff interactions with the EHR and generate hypotheses about how health systems can better use the EHR as a tool to support caregivers.

Methods

Study Design

This analysis was done as part of a study designed to develop a tool to identify caregivers of people living with dementia through the EHR for pragmatic trials related to medication management. Caregivers of people living with dementia and clinical staff from 2 health systems in Maryland and Colorado were recruited from March to May 2022. Research staff screened the EHR to identify patients aged 65 years or older with dementia (based on *International Classification of Diseases, Tenth Revision* [*ICD-10*] codes or dementia medications; Multimedia Appendix 1) and polypharmacy (defined as taking 5+ medications), who received care at primary care or memory clinics. The dementia diagnosis was confirmed by reviewing clinic notes. Our approach was designed to be pragmatic to characterize the real-world caregiving arrangements of people with dementia. For this reason, we sought to include caregivers regardless of how much time they spent caring for the people living with dementia. To maximize generalizability, we used broad eligibility criteria for caregivers and allowed them to self-identify. Recruitment letters addressed to "family members or friends" were mailed to the homes of eligible people living with dementia. We then called the people living with dementia to identify a caregiver interested in participating. Staff who provided ambulatory care to people living with dementia were identified through lists provided by clinics and recommendations of clinic administrators. They were recruited by email. We stopped recruitment once no new themes were emerging in interviews.

Chart review of people living with dementia whose caregivers participated focused on characterizing whether caregiver identities, contact information, and roles were documented in the EHR (and if so, where) and whether caregivers had registered for proxy access to the patient portal. We developed a chart abstraction form in Microsoft Excel. Two research coordinators (RQR and AED) reviewed charts in the EHR and recorded their findings. These data were discussed with the principal investigator (ARG) during team meetings to identify and adjudicate discrepancies. We conducted semistructured interviews with 22 caregivers and 16 clinical staff (eg, clinicians, nurses, medical assistants, and practice managers). An interview guide was developed based on the research questions. We asked caregivers about their roles and caregiving arrangements and compared this with the information that was documented in the EHR. We also asked whether the patient's health care team ever routinely asked them about caregiving roles and responsibilities and, if so, when. We asked staff how they currently identify caregivers and record their information. Both groups were asked about challenges related to this process and how it could be improved. All participants were also asked for demographic information. Four research team members (RQR, AED, KSG, and TETM) experienced in qualitative research conducted the interviews via phone or videoconference; all interviews were conducted in private locations. Two coders (KSG and TETM) developed an initial codebook based on the Consolidated Framework for Implementation Research and the study aims. Three study team members then refined the codebook by reading transcripts from 5 caregivers and 5 staff. Open coding allowed inductive identification of new themes in addition to deductive coding guided by the Consolidated Framework for Implementation Research. The entire team met to discuss and finalize the codebook. Using this version, a single team member coded approximately 25% (n=8) of the remaining transcripts, which were reviewed by another coder. Discrepancies were discussed at study team meetings until 100% agreement was reached. The remaining transcripts were then coded by a single coder, and the study team met weekly to discuss emerging themes.

Ethical Considerations

The Johns Hopkins University School of Medicine Institutional Review Board (IRB) served as the single IRB and approved this research (IRB protocol 00297952); the Kaiser Permanente Colorado IRB ceded. All participants provided verbal consent. Caregivers at both health systems and clinical staff in Maryland received a US $25 gift card for participating; clinical staff in Colorado volunteered without compensation, as company policy did not allow it. All interviews were audio recorded and transcribed verbatim.

Results

Overview

Participant characteristics are described in Table 1. People with dementia (n=22) had a mean age of 84.1 (SD 6.5) years. Most were male (n=15, 68%) and White (n=15, 68%) and had a mean of 8 (SD 3.5) medications.

Table . Demographic characteristics of participants.

	People with dementia[a] (n=22)	Caregiver[b] (n=22)	Staff[b] (n=16)
Age (years), mean (SD)	84.1 (6.5)	63 (12.6)	48 (9.3)[c]
Sex, n (%)			
Female	7 (32)	21 (96)	12 (75)
Male	15 (68)	1 (5)	2 (13)
Other or unknown	0 (0)	0 (0)	2 (13)
Race, n (%)			
Asian	0 (0)	0 (0)	3 (19)
Black or African American	5 (23)	5 (23)	0 (0)
White	15 (68)	16 (73)	9 (56)
Other	1 (4.5)	1 (5)	1 (6)
Unknown or not reported	1 (5)	0 (0)	3 (19)
Ethnicity, n (%)			
Hispanic or Latino	1 (5)	1 (5)	1 (6)
Not Hispanic or Latino	20 (91)	21 (96)	15 (94)
Unknown or not reported	1 (5)	—[d]	—
Total number of medications, mean (SD)	8 (4)	—	—
Confidence filling out medical forms, n (%)	—		—
Extremely		16 (73)	
Quite a bit		5 (23)	
Somewhat		1 (5)	
A little bit		0 (0)	
Not at all		0 (0)	
Relationship to people with dementia [c], n (%)	—		—
Spouse or partner		9 (41)	
Adult child		9 (41)	
Other (friend or other relative)		4 (18)	
Lives with the people with dementia, n (%)	—	14 (64)	—
Occupation, n (%)	—	—	
Physician			4 (25)
Physician assistant			2 (13)
Medical assistant			2 (13)
Nurse (LPN[e], RN[f], NP[g])			6 (38)
Practice manager			2 (13)
People with dementia identified via, n (%)		—	—
Dementia diagnosis on problem list	19 (86)		
Dementia medication on medication list	10 (46)		

[a] Data based on chart review.

[b] Data based on interviews.

[c] Three staff members did not provide their ages.

[d] These questions were not asked of both groups.

[e] LPN: licensed practical nurse.

[f] RN: registered nurse.

[g] NP: nurse practitioner.

Caregivers had a mean age of 63 (SD 12.6) years. The majority were female (n=21, 96%) and White (n=16, 73%). Most were the spouse, partner, or adult child of the people with dementia (n=18,82%) and lived with the people with dementia (n=14, 64%). Only 1 caregiver had proxy access to the patient portal. As shown in Table 2, caregiver names and their relation to the people with dementia were usually recorded in the “contact information” or “patient contacts” tab of the chart (n=20, 91%). Caregivers were frequently mentioned in clinical notes (n=21, 96%), where their relations and roles were described with a varying degree of detail (eg, patient lives independently and son helps). One of the health systems had a “lay caregiver” field that was used inconsistently (n=3, 27%). Most people with dementia (n=13, 59%) had an advance directive in the chart that named a medical decision maker. When an advance directive was present, it identified the same caregiver as interviewed only slightly more than half of the time (n=12, 55%). Of the 22 caregivers interviewed, the majority (n=17, 77%) reported that the people with dementia had additional caregivers. Most charts (n=16, 73%) contained documentation implying the presence of multiple caregivers; this information was recorded unsystematically in various locations throughout the chart, and caregivers’ individual contributions were not explicitly described. Two major themes emerged from interviews (described with illustrative quotations in Table 3).

Table . Results of chart review and interviews related to caregiver identification in the EHR[a] (N=22).

Category	Values, n (%)
Interviewed caregiver identified multiple caregivers[b]	17 (77)
Chart review identified multiple caregivers	16 (73)
Locations where caregivers were identified[c] in the EHR	
Contact information[d]	20 (91)
Clinical notes	21 (96)
"Lay caregiver" field	3 (27)[e]
People with dementia had patient portal access	
Yes	18 (82)
No	1 (5)
Inactive	3 (14)
Caregiver had proxy access to the patient portal	
Yes	1 (5)
No	19 (86)
Unknown (patient deceased)	2 (9)
People with dementia had an advance directive (ie, living will or medical durable power of attorney) in the chart that named a medical decision maker	
Yes	13 (59)
No	7 (32)
Unknown (patient reported having advance directive but copy not in chart)	2 (9)
If an advance directive was present, it identified the same caregiver as interviewed	
Yes	12 (55)
No	1 (5)
Unknown (patient reported having advance directive but copy not in chart)	2 (9)

[a] EHR: electronic health record.

[b] Data obtained from the interview; all other data in the table were obtained from chart review.

[c] Fields were not mutually exclusive.

[d] Caregivers were identified in various fields within the "Demographics" or "Snapshot" tabs, depending on the health system, such as "permanent comments," "patient contacts," "additional info," and "alternate contact person."

[e] This field only existed at 1 health system; denominator=11.

Table . Key themes and illustrative quotations.

Participant	Quote
Theme 1: complexity of caregiving arrangements not systematically captured or easy to locate in the EHR[a]	
Caregiver	"We'll spread it out...I am the one that goes to the appointments. If...she needs to be on something new, I work with the doctor and then talk to my sister about it.... I generally will have the current list or whoever has been at the last few doctors' appointments."
Medical assistant	"[The problem list] shows dementia...but there's not any real information in regard to who the caregiver is."
Nurse case manager	"It's a lot of time devoted to...detective work – trying to peel the layers back to figure out who would be an appropriate person to truly get good information from."
Physician	"We don't have a system.... So I do it my way. Another doctor does it their way. A third person does it their way.... In my initial new patient assessment, I put it in my note, but you need to know where to find it."
Theme 2: health systems should develop standardized processes to obtain and document caregiver information in the EHR	
Caregiver	"No one seemed to know what the correct procedure was [to register for shared access in the patient portal].... I was told to fill out this form. Later I found out 'No, that was not the form you were supposed to fill-out.' ...I drove over to the medical clinic 45 minutes each way to get this done."
Caregiver	"I'd like, somehow, when [clinicians] sign into [the EHR] that it's apparent that she has dementia and that her daughter-in-law is the caregiver and that there's a banner there right away so I don't always have to explain myself.... It's necessary [that] I be with her because she is incapable of giving them the information they need.... Somehow, in My Chart, that information would be...a quick blip on the page."
Caregiver	"Every now and then, just ask me how I'm doing.... It's kind of hard to answer with him sitting there."
Nurse case manager	"[The EHR should include] what services they provide, [do] they grocery shop for [the PLWD], prepare meals for them, provide transportation, medication management – all the big things that you're concerned with a memory-impaired person – who can be relied on to help."
Clinic medical director	"I think it would be helpful if [the caregiver information] was a banner that went across [the EHR], so that it's highlighted. So, if a patient has an active health care agent right now, when you open the chart, it's a banner, and it has the name and the number listed. And every time you go within that patient's chart, even every single note that you bring up, has that banner.… But, otherwise, everything else would get lost, the information that was collected."
Physician	"If we can also add [caregiver information] into Epic [so] that we don't need to dig...the problem is you need to know it and you always need to look. There [are] so many scanned papers, but if they can add...the contact information [to a] box...[the] primary caregiver and...the other caregivers, that would be useful."

[a] EHR: electronic health record.

Complexity of Caregiving Arrangements Not Systematically Captured or Easy to Locate

Interviews revealed that most people living with dementia had multiple people who helped them, including family, friends, and community members. Some people who provided instrumental support did not view themselves as caregivers, complicating health system efforts to identify them. Caregivers said that their needs (eg, skills or resources needed for caregiving) were rarely assessed or recorded by the health system. Staff said caregiver information was not collected systematically and that caregiver roles, such as which caregiver helps with medical decision-making and daily activities, including medication administration, were usually described in clinical notes rather than readily accessible fields. This often made it time-consuming and difficult to identify the appropriate caregiver to contact for information exchange. Even when a caregiver was identified by name or relation to the patient, it was often not easy to determine if that caregiver was the relevant person for a particular clinical decision, such as a medication change.

Health Systems Should Develop Standardized Processes to Obtain and Document Caregiver Information

Caregivers expressed a desire to be identified and have their needs routinely assessed and addressed. Clinical staff recommended developing workflows to identify caregivers and assess their needs at multiple touchpoints, including standardized questions in the waiting room, the patient portal, and during scheduling. Staff said that it would be useful to collect information on what tasks caregivers perform and suggested adding a caregiver tab to the EHR to standardize what information is collected and where it is recorded. Caregivers and staff suggested that proxy access to patient portals could facilitate improved identification, engagement, and support of caregivers. However, the complicated proxy enrollment process, which requires downloading and completing forms and providing proof of legal representative status if the patient lacks decision-making capacity, was seen as a barrier.

Discussion

Principal Findings

This exploratory chart review and qualitative study found that people living with dementia frequently have multiple caregivers, whose roles and needs are inconsistently captured in the EHR. Our findings were similar in both health systems. Caregivers emphasized the importance of having their needs routinely evaluated and addressed. Clinical staff suggested creating processes to identify caregivers and assess their needs at various points, such as using standardized questions in the clinic waiting room, through the patient portal, and during appointment scheduling. Participants recommended simplifying the process of obtaining proxy access to patient portals, particularly for caregivers of people living with dementia.

Similar to our findings, a previous study of 211 people living with dementia that did not involve interviews or determine whether people living with dementia had multiple caregivers found that 89% of charts identified caregivers; however, “an extensive search through individual notes” was required to locate caregiver information; few charts documented caregiver needs [8]. These findings have important implications. Caregiver engagement and support are essential components of high-quality dementia care. Patients with poorly supported caregivers face a heightened risk for inappropriate medication use [9], hospitalization, and burdensome treatments [10]. Pragmatic trials may exclude people with dementia when there is no documentation of a caregiver, limiting generalizability [11].

Earlier research has shown that patient portals can be a valuable resource for supporting patients with serious illness and their caregivers [12]. This is illustrated by the fact that patient portal use, such as secure messaging, tends to increase following a dementia diagnosis, reflecting the substantial need for information and communication of people living with dementia and their caregivers [13]. In a pilot study, caregivers of people living with dementia perceived that they received more information about resources from the doctor after completing a caregiver wellness questionnaire in the patient’s EHR [14]. Another study tested an EHR-driven process to identify veterans with unpaid caregivers based on receipt of home- and community-based referrals; however, the process was inefficient [4]. Shared access to the patient portal would facilitate the identification and enable the engagement of multiple caregivers, reflecting the reality of caregiving arrangements for people living with dementia [15]. However, health systems should simplify the complicated proxy enrollment process, which is a barrier [16,17]. To address the concerns identified in our study, health systems should develop and test workflows to identify caregivers, assess their needs at multiple touchpoints, and record their roles and contact information in standardized, clearly defined, and readily extractable fields. These workflows could include fielding caregiver questions as part of the Medicare Annual Wellness Visit, creating a communication plan at the time of dementia diagnosis, and testing different modes of outreach to people living with dementia and caregivers [15,16].

Limitations

This study has some limitations. The small sample from 2 health care systems may not be generalizable to other practice settings. In addition, caregivers who could be identified during recruitment and who agreed to participate may be more likely to be engaged and identified in the EHR. Our broad inclusion criteria may have resulted in people who only spent a few hours caregiving being classified as caregivers. Although both health systems used the Epic EHR, the tabs and fields were different in each system, and the locations where we found caregiver information may not be generalizable. As a qualitative study, this work is designed to be exploratory. However, it is valuable because it provides an in-depth understanding of caregiving arrangements for people living with dementia and of the lived experiences of dementia caregivers in their interactions with the EHR. In so doing, the study generates important hypotheses about how health systems can better support caregivers. Finally, we did not seek to interview paid caregivers, who may be responsible for the day-to-day care of the people living with dementia and accompany them to medical appointments [18].

Conclusions

This qualitative study and exploratory chart review found that caregivers of people living with dementia are identified inconsistently in the EHR. If their roles and needs are documented, this information is not easy to locate. Future studies could develop and test workflows to identify caregivers, assess their needs, and record their information in extractable EHR fields.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

International Classification of Diseases, Tenth Revision (*ICD-10*) codes and medications used to identify people living with dementia.

[DOCX File, 22 KB - aging_v7i1e59584_app1.docx]

References

1. Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division. In: Schulz R, Eden J, editors. Families Caring for an Aging America: National Academies Press; 2016.
2. Alzheimer's Association. 2023 Alzheimer's disease facts and figures. Alz Dement 2023 Apr;19(4):1598-1695. [doi: 10.1002/alz.13016]
3. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. Health Aff (Millwood) 2015 Oct;34(10):1642-1649. [doi: 10.1377/hlthaff.2015.0536] [Medline: 26438739]
4. Ma JE, Grubber J, Coffman CJ, et al. Identifying family and unpaid caregivers in electronic health records: descriptive analysis. JMIR Form Res 2022 Jul 18;6(7):e35623. [doi: 10.2196/35623] [Medline: 35849430]
5. Wolff JL, Freedman VA, Mulcahy JF, Kasper JD. Family caregivers' experiences with health care workers in the care of older adults with activity limitations. JAMA Netw Open 2020 Jan 3;3(1):e1919866. [doi: 10.1001/jamanetworkopen.2019.19866] [Medline: 31977063]
6. Office of the National Coordinator for Health IT. Office-based physician electronic health record adoption. Health IT Quick-Stat. URL: https://www.healthit.gov/data/quickstats/office-based-physician-electronic-health-record-adoption [accessed 2024-08-15]
7. Fail RE, Bowman BA, Meier DE. Improving dementia care: getting started. Center to Advance Palliative Care. URL: https://www.capc.org/documents/download/567 [accessed 2024-08-15]
8. Davis ML, Hendrickson J, Wilson N, Shrestha S, Amspoker AB, Kunik M. Taking care of the dyad: frequency of caregiver assessment among veterans with dementia. J Am Geriatr Soc 2019 Aug;67(8):1604-1609. [doi: 10.1111/jgs.15882] [Medline: 31002403]
9. Thorpe JM, Thorpe CT, Kennelty KA, Gellad WF, Schulz R. The impact of family caregivers on potentially inappropriate medication use in noninstitutionalized older adults with dementia. Am J Geriatr Pharmacother 2012 Aug;10(4):230-241. [doi: 10.1016/j.amjopharm.2012.05.001] [Medline: 22683399]
10. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. N Engl J Med 2009 Oct 15;361(16):1529-1538. [doi: 10.1056/NEJMoa0902234]
11. Shi S, Largent EA, McCreedy E, Mitchell SL. Design considerations for embedded pragmatic clinical trials of advance care planning interventions for persons living with dementia. J Pain Symptom Manage 2023 Feb;65(2):e155-e163. [doi: 10.1016/j.jpainsymman.2022.11.009] [Medline: 36423803]
12. Portz JD, Powers JD, Baldwin M, et al. Patient portal use near the end-of-life. J Gen Intern Med 2021 Jan 27. [doi: 10.1007/s11606-020-06333-9] [Medline: 33506403]
13. Gleason KT, Wu MMJ, Wec A, et al. Use of the patient portal among older adults with diagnosed dementia and their care partners. Alzheimers Dement 2023 Dec;19(12):5663-5671. [doi: 10.1002/alz.13354] [Medline: 37354066]
14. Kokorelias KM, Danieli E, Dunn S, Feldman S, Ryan DP, Sadavoy J. The DWQ-EMR embedded tool to enhance the family physician-caregiver connection: a pilot case study. Geriatrics 2021;6(1):29. [doi: 10.3390/geriatrics6010029]
15. Wolff JL, DesRoches CM, Amjad H, et al. Catalyzing dementia care through the learning health system and consumer health information technology. Alzheimers Dement 2023 May;19(5):2197-2207. [doi: 10.1002/alz.12918] [Medline: 36648146]
16. Wolff JL, Dukhanin V, Burgdorf JG, DesRoches CM. Shared access to patient portals for older adults: implications for privacy and digital health equity. JMIR Aging 2022 May 4;5(2):e34628. [doi: 10.2196/34628] [Medline: 35507405]
17. Salmi L, Peereboom D, Dorr DA, Graham LR, Wolff JL, DesRoches CM. Patient portals fail to collect structured information about who else is involved in a person's care. J Med Internet Res 2024 Jun 27;26:e49394. [doi: 10.2196/49394] [Medline: 38935963]

18. Reckrey JM, Watman D, Tsui EK, et al. “I am the home care agency”: the dementia family caregiver experience managing paid care in the home. Int J Environ Res Public Health 2022 Jan 25;19(3):1311. [doi: 10.3390/ijerph19031311] [Medline: 35162335]

Abbreviations

EHR: electronic health record
***ICD-10*:** *International Classification of Diseases, Tenth Revision*
IRB: institutional review board

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An Evidence-Based IT Program With Chatbot to Support Caregiving and Clinical Care for People With Dementia: The CareHeroes Development and Usability Pilot

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Abstract

Background: There are numerous communication barriers between family caregivers and providers of people living with dementia, which can pose challenges to caregiving and clinical decision-making. To address these barriers, a new web and mobile-enabled app, called CareHeroes, was developed, which promotes the collection and secured sharing of clinical information between caregivers and providers. It also provides caregiver support and education.

Objective: The primary study objective was to examine whether dementia caregivers would use CareHeroes as an adjunct to care and gather psychosocial data from those who used the app.

Methods: This paper presents the implementation process used to integrate CareHeroes into clinical care at 2 memory clinics and preliminary outcome evaluation. Family caregivers receiving services at clinics were asked to use the app for a 12-month period to collect, track, and share clinical information with the care recipient's provider. They also used it to assess their own mental health symptoms. Psychosocial outcomes were assessed through telephone interviews and user data were collected by the app.

Results: A total of 21 caregivers enrolled in the pilot study across the 2 memory clinics. Usage data indicated that caregivers used many of the features in the CareHeroes app, though the chatbot was the most frequently used feature. Outcome data indicated that caregivers' depression was lower at 3-month follow-up (t_{11}=2.03, P=.03).

Conclusions: Recruitment and retention of the pilot study were impacted by COVID-19 restrictions, and therefore more testing is needed with a larger sample to determine the potential impact of CareHeroes on caregivers' mental health. Despite this limitation, the pilot study demonstrated that integrating a new supportive app for caregivers as an adjunct to clinical dementia care is feasible. Implications for future technology intervention development, implementation planning, and testing for caregivers of people living with dementia are discussed.

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KEYWORDS

Alzheimer disease; artificial intelligence; caregivers; chatbot; dementia; mobile applications; conversational agent; design; apps

Introduction

Overview

Caregiving and clinical care for the 7 million Americans with Alzheimer disease or a related dementia (ADRD) is complex and expensive, with projected medical costs for this population increasing to just under $1 trillion in 2050 [1]. Further complicating care for people living with dementia are communication barriers among patients, their family caregivers (eg, spouses and adult children), and providers (eg, physicians and nurses), which may negatively impact the collection of information that is needed to make clinical decisions and create additional challenges for caregivers [2,3]. Health IT (HIT) interventions have been identified as having potential for overcoming these communication challenges [4,5]. While there has been an increase in the development and testing of HIT for this purpose, little remains known about how to effectively integrate new HIT into practice to support provider-caregiver communication. In this study, a multidisciplinary team developed a new multifunctional application, called CareHeroes, and conducted a pilot study to evaluate usage and preliminary outcomes for caregivers receiving services at 2 memory clinics. This paper presents findings from the project as well as the extensive implementation process that the team underwent to develop and integrate the app into care. Implications for technology development and testing in dementia care are discussed.

Caregiver-Provider Communication in Dementia Care

Prior research has found that some barriers to caregiver-provider communication stem from caregivers, who have reported that they sometimes have difficulty remembering all of the information they planned to discuss with the care recipient's provider or they become too upset during the medical visit to adequately share information [6]. Other research has reported that caregivers with lower levels of health literacy or who experience anxiety when discussing difficult topics may not effectively communicate with providers [7]. There are also communication barriers stemming from providers and service systems. For example, lack of time to collect sufficient information during the medical visit, insufficient sharing of clinical information across care settings [8], and lack of access to community-based resources for dementia care [9,10].

Poor communication between caregivers and providers may contribute to a number of negative outcomes. For caregivers, the difficulties of health management for people living with dementia place them at increased risk of poor mental and physical health [1]. Communication challenges can also impede clinical decision-making by providers, which can have a negative impact on patient care and outcomes [10]. There are also disparities in experiences with health care providers. For example, African American caregivers are more likely than white caregivers to report that they lacked knowledge about ADRD before their loved one's diagnosis and greater dissatisfaction with the interactions they have with providers regarding dementia care [11], which contribute to disparities in outcomes. For example, while African American and Latino/a populations are at higher risk of ADRD compared to their non-Latino/a White counterparts, they are more likely to go undiagnosed or misdiagnosed [12,13]. Caregivers living in rural communities may face additional barriers to interacting with providers due to the inaccessibility of services [14].

Opportunities and Limitations of IT and AI Apps for Dementia Caregiving and Care

Over the past decade, there has been increased attention on how IT and artificial intelligence (AI) may be used to overcome challenges in dementia care and caregiving [15,16]. An increasing number of studies have examined how tech-based platforms may support caregivers of people living with dementia, though many of the interventions that have been reported in the research literature have not reflected advancements in technology, such as smartphone apps or AI tools [15]. For commercially available smartphone apps targeting caregivers, reviews of existing technologies have shown that they are limited in function, compared to the demands of caregiving; are underresearched, especially with underserved populations; and are not designed to be integrated within clinical care settings [15-17]. Hence, there is a need for increased research that develops an evidence base for advanced technology tools that support this population.

Developing the CareHeroes App

In response, our interdisciplinary team (social work, nursing, physical therapy, geriatric psychiatry, neurology, and computer science) developed CareHeroes, a web-based application that was designed with ongoing input from caregivers and providers, including those from underserved populations [18]. CareHeroes supports caregiver-provider communication through several functions. First, it supports caregiver health literacy through text and video caregiver educational resources about dementia and caregiving. It also supports education through an educational chatbot. CareHeroes also improves the collection and sharing of clinical information about the care recipient between the caregiver and provider. The app includes validated clinical assessment tools, such as the Revised Memory and Behavioral Problem Checklist [19] and ADL/IADL assessments [20], that the caregiver can complete in real time, and the algorithm can create a color-coded table of the responses that can be tracked over time and shared with the provider.

CareHeroes also supports caregivers through self-assessments of depression (Patient Health Questionnaire for Depression and Anxiety (PHQ-2) [21], burden (Zarit Caregiver Burden Inventory) [22], and positive aspects of caregiving [23] and provides the caregiver with feedback based on the results of their responses. A full description of CareHeroes, its design, and features has been reported elsewhere [18,24]. All features on CareHeroes, except for the chatbot, are available in Spanish [25]. There are future plans to translate the chatbot into Spanish.

Preliminary Work to Maximize Potential Adoption in Real-World Settings

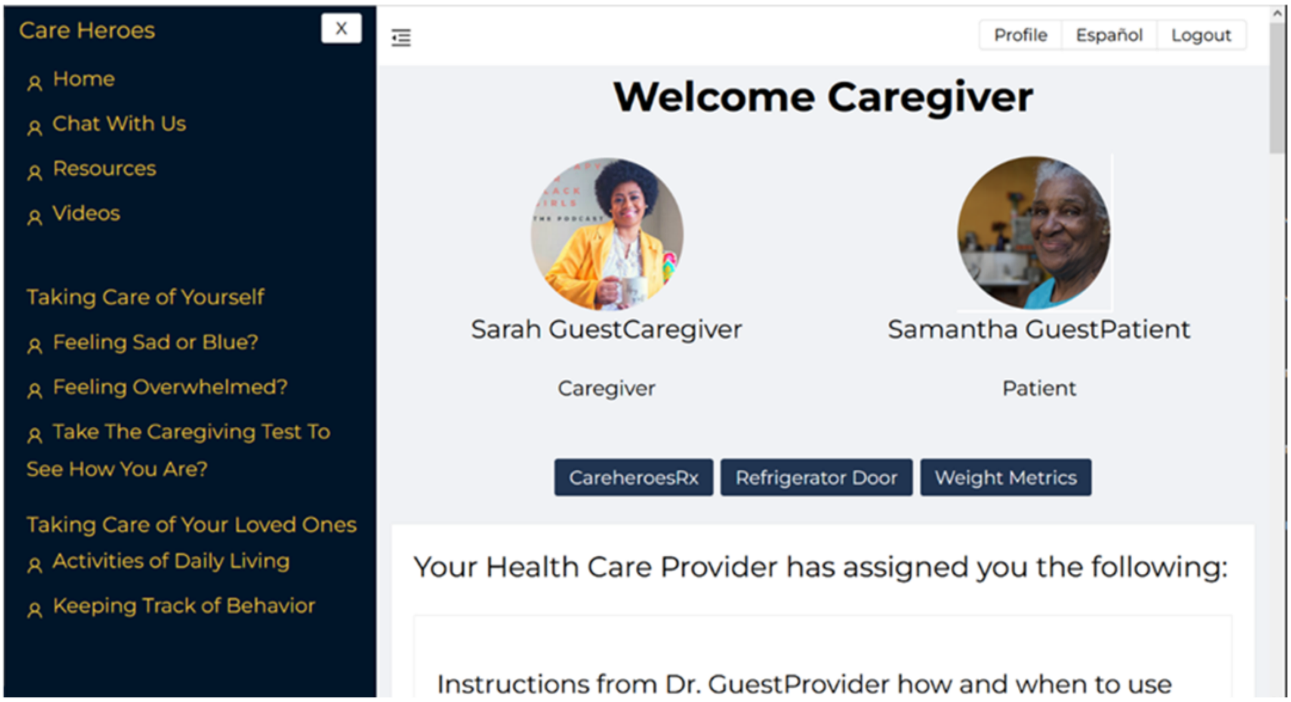
The ultimate goal for CareHeroes was to develop an app that could be integrated into clinical care in real-world settings, and therefore the research team took several initial steps in developing the app to maximize its potential for adoption by providers and caregivers as end users [26]. Early on, the research team conducted needs assessments with stakeholders, which identified potential features of CareHeroes that caregivers and providers though would be beneficial. Surveys were conducted with geriatric home care workers to learn more about communication needs in dementia care [27] and late-life depression care [28]. These studies found that there was little communication between in-home care and primary care providers about older patients' mental health and that home care workers' observations about patients' mental health are not easily shared with other providers. The team also analyzed HIT policy for its potential impact on the app and identified logical ways of fostering interoperability and security for information sharing [29].

After developing an initial prototype of the app, the interdisciplinary team conducted a small beta-testing study in Miami, Florida, where triads of caregivers, geriatric home care managers, and primary care providers used CareHeroes for 11 weeks [18]. The study determined that it was feasible to share information through CareHeroes and that caregivers found it useful and easy to use, though it was found that adoption of the app in real-world settings would be more feasible for dyads of caregivers and primary care providers without the involvement of home health care because it reduced the administrative barriers associated with. These findings informed revisions of the app code. This revised version then underwent alpha testing with 36 caregivers, most of whom were from caregiver populations that have historically been underserved by HIT (eg, African Americans, rural dwelling) [6,30]. The team also conducted focus groups with staff at 2 collaborating memory clinics [31] to gain feedback on the design, capacity, and potential adoption of CareHeroes. This helped the team develop a clinical workflow plan (eg, which clinic staff member collects information caregivers enter in the app, deciding how the information gets to the patient's record). The team also worked with HIT security administrators at both clinics to make sure that information sharing followed HIPAA (Health Insurance Portability and Accountability Act) and organizational policies.

CareHeroes Code Development

The CareHeroes application was developed using a hybrid of agile and unified software development processes [32]. Figure 1 shows the caregiver's home page in the CareHeroes application. CareHeroes was developed based on the requirements of 3 stakeholders. These stakeholders include the health care provider, the caregiver, and the people living with dementia. The requirements included 32 use cases, with 17 caregiver use cases, 5 provider use cases, and 9 use cases focusing on the security of the system. The CareHeroes architectural design is based on a 4-tiered architecture consisting of a client tier (web-based and mobile—to be implemented), a presentation layer, a business logic layer, and the data store layer. The database structure consists of 5 parts. One part each for the user, survey, prescription, and reminder services. The final part of the database is the correlation database, which stores the keys needed to encrypt and decrypt the protected information of people living with dementia.

Figure 1. CareHeroes home page for the caregiver.



Welcome Caregiver

Sarah GuestCaregiver

Caregiver

Samantha GuestPatient

Patient

Your Health Care Provider has assigned you the following:

Instructions from Dr. GuestProvider how and when to use

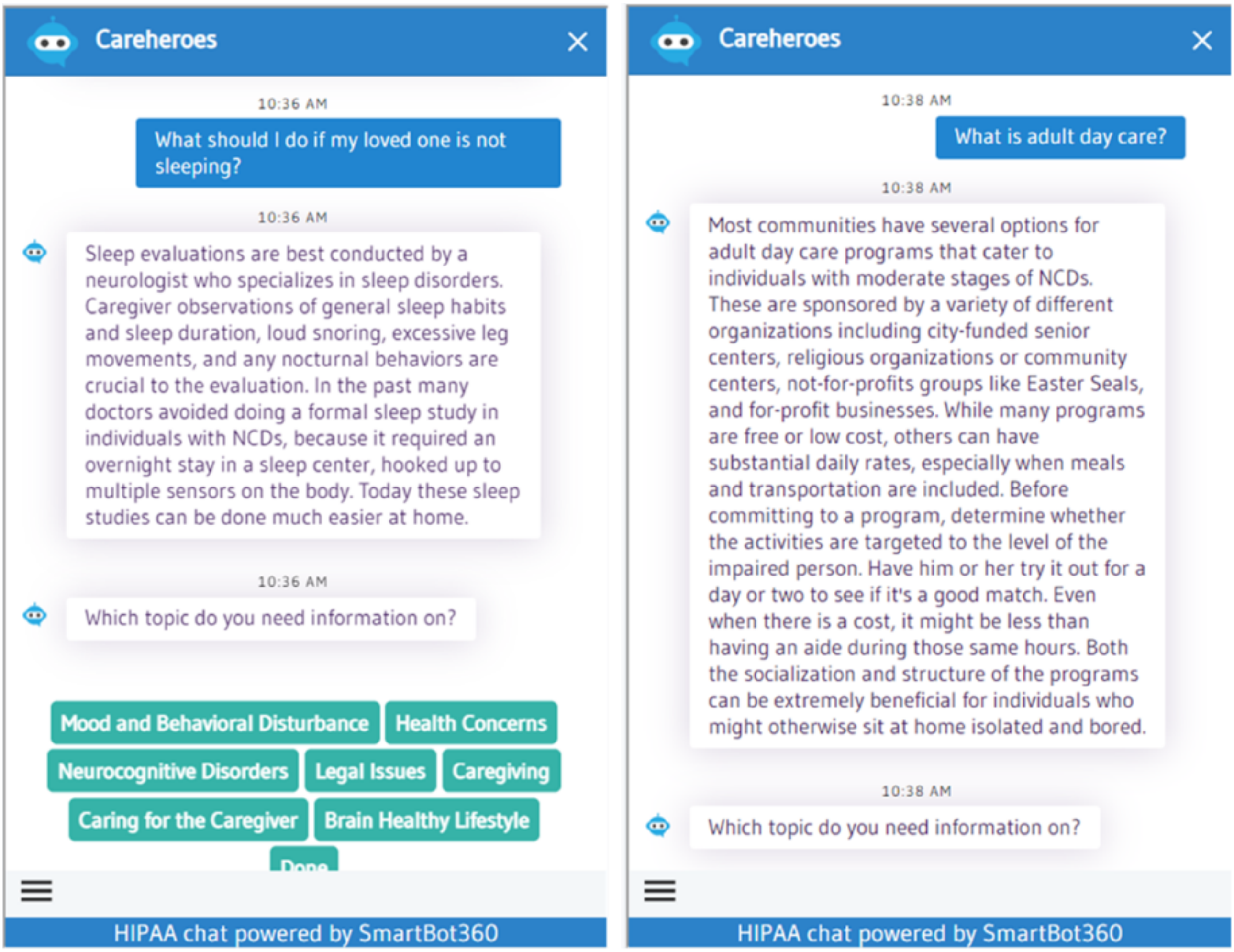
The implementation of CareHeroes security protocols follows the HIPAA security rule as specified in the Federal Register [33]. CareHeroes uses a role-based authentication system to ensure that only certain users with specific roles can perform certain operations within the system. All electronic communication with the CareHeroes system is encrypted, and all HTTP requests are encrypted using the Secure Sockets Layer protocol [34]. The security protocol is implemented using the database structure previously described.

Chatbot Programming

One of the more novel features of CareHeroes. Compared to existing apps for caregivers of people living with dementia, this is an educational chatbot. For Carehereos, the chatbot was programmed to respond to predetermined topics selected by the user (eg, mood and behavioral disturbances) and to recognized text from user questions (eg, How do I help my father eat?). The topics and content that were programmed into the chatbot and the responses it provided to users were from the book, *The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer's Disease and Other Neurocogntive Disorders* [35] by geriatric psychiatrist, Dr Marc E. Agronin. The book's focus is guiding caregivers through caring for the people living with dementia and themselves. Minor edits were made to simplify language and to shorten responses. See Figure 2 for screenshots of the CareHeroes Chatbot with example text.

Chatbots are programmed to respond to user input (eg, questions, comments) with text or verbal language responses and have become increasingly popular in health care, especially for patient education in other health care settings [36]. For *CareHeroes*, the chatbot was programmed to respond to predetermined topics selected by the user (eg, mood and behavioral disturbances) and to recognize text from user questions (eg, How do I help my father eat?). Specifically, the user could first pick a topic, and then type in free text a question. The chatbot uses text embedding methods to perform semantic matching between the user's question and the list of stored questions.

Figure 2. Screenshots of chatbot on the CareHeroes platform demonstrating its answers to potential caregiver questions. HIPAA: Health Insurance Portability and Accountability Act.



10:36 AM

What should I do if my loved one is not sleeping?

10:36 AM

Sleep evaluations are best conducted by a neurologist who specializes in sleep disorders. Caregiver observations of general sleep habits and sleep duration, loud snoring, excessive leg movements, and any nocturnal behaviors are crucial to the evaluation. In the past many doctors avoided doing a formal sleep study in individuals with NCDs, because it required an overnight stay in a sleep center, hooked up to multiple sensors on the body. Today these sleep studies can be done much easier at home.

10:36 AM

Which topic do you need information on?

10:38 AM

What is adult day care?

10:38 AM

Most communities have several options for adult day care programs that cater to individuals with moderate stages of NCDs. These are sponsored by a variety of different organizations including city-funded senior centers, religious organizations or community centers, not-for-profits groups like Easter Seals, and for-profit businesses. While many programs are free or low cost, others can have substantial daily rates, especially when meals and transportation are included. Before committing to a program, determine whether the activities are targeted to the level of the impaired person. Have him or her try it out for a day or two to see if it's a good match. Even when there is a cost, it might be less than having an aide during those same hours. Both the socialization and structure of the programs can be extremely beneficial for individuals who might otherwise sit at home isolated and bored.

10:38 AM

Which topic do you need information on?

Methods

Recruitment

CareHeroes was implemented at 2 memory clinics: (1) The Frank C. and Lynn Scaduto MIND Institute at Miami Jewish Health in Miami, Florida, and (2) the Memory Disorder Clinic at the University of Alabama at Birmingham in Birmingham, Alabama. Both clinics provide a variety of services to people living with dementia and their caregivers, many of which are from underserved communities (eg, African American, Latino/a, rural dwelling). IRB approval was obtained from all institutions involved in this project before initiating the study. Recruitment took place between February 2021 and April 2022. In most cases, caregivers were recruited during telehealth visits with providers at either clinic. To be eligible for the study, caregivers had to: have regular access to the internet (via computer or smartphone); be 21 years old or older; provide caregiving activities for at least 2 hours or more per day on average of direct assistance or supervision for a person living with dementia; and have the ability to speak and understand English or Spanish. During the telehealth session, the provider would tell the caregiver about the study and ask if they were interested in more information about the project. In addition, clinic staff reached out to caregivers who were listed on existing caregiver support groups and research participant pools to inform them about the study. Those who reported interest in the study were referred to the research team, which would follow up with the caregiver to determine eligibility and enroll those who were eligible and interested in participating in the study.

Data Collection

Interview Data and Measures

The data collection plan included telephone or Zoom interviews with caregivers at baseline, 3-month, 6-month, and 12-month time points. Each interview lasted between 45 and 60 minutes. The interviewer would record responses using a Qualtrics form. Interview guides included several validated psychosocial measures, and the baseline interview included a demographic questionnaire. To minimize burden, some measures were only scheduled to be included in the baseline and 12-month follow-up interviews.

Communication With Providers

A 3-item scale developed by Lorig et al [37] was used to measure caregiver communication with providers. Each item used a 6-point scale (0=never to 5=always) and measures frequency of which the respondent prepares a list of questions for a physician; asks questions regarding the physician and regarding things the respondent does not know; and discusses personal problems related to the illness with a physician.

Depression

The PHQ-4 is a brief 4-item validated tool to assess overall psychological distress and screen for both anxiety and depressive disorders [21]. The measure includes the 2-item depression screen (PHQ-2) and the 2-item screen for anxiety disorders (Generalized Anxiety Disorder 2 item [GAD-2]). The 4-item response options are scored from 0 to 3, 0=not at all, 1=several days, 2=more than half the day, and 3=nearly every day. The total PHQ-4 score is computed by adding together the 4 items; the overall psychological distress score range is from 0 - 12 (normal: 0 - 2; mild: 3 - 5; moderate: 6 - 8; severe 9 - 12). A total score for the 2 depression items (depressed mood, anhedonia) of 3 or greater indicates depression and a total score of 3 or more for the 2 anxiety items (feeling anxious, uncontrolled worry) indicates anxiety. The PHQ-4 properties have been established for Spanish-speaking Hispanic Americans [38].

Health Literacy About Alzheimer Disease

The Alzheimer's Disease Knowledge Scale (ADKS) is a validated 30-item true or false tool that is used to evaluate the participants knowledge on aspects of Alzheimer disease [39]. This short survey takes approximately 5 - 10 minutes to complete, where each item includes a statement about Alzheimer disease, including risk factors, diagnosis, assessment and symptoms, prognosis, effects on caregiving, and management of the disease.

Caregiver Burden

The Zarit Burden Interview used is a 22-item survey to collect information on caregiver burden, including items relating to dependence in activities of daily living, and assess the frequency of any problem behaviors [40]. The items are answered as never (0), rarely (1), sometimes (2), quite frequently (3), or nearly always (4). A total score ranges 0 - 88, with 0 - 21 identified as no to mild burden, 21 - 40 as mild to moderate burden, 41 - 60 as moderate to severe burden, and scores 61 or above identified as severe burden.

User Data

CareHeroes was also programmed to automatically collect anonymized user data from the app. The program tracked several activities for those using the app, including (1) dates and times for Log-in and log-out; (2) dates and times for clicks on links for educational resources and videos; (3) outcome scores for the care recipient clinical assessments; (4) outcome scores for caregiver self-assessments; and (5) date and time when a caregiver entered a reminder.

Data Analysis

Interview data were entered into an SPSS (IBM SPSS Statistics Developer) database. Data management and analyses were conducted in Stata (version 17) [41]. Because of missing data, the sample was restricted to participants with observations at baseline and the 3-month follow-up, yielding a final sample of 13. Descriptive statistics and bivariate analyses including analysis of variance and paired-sample 1-tailed *t* tests.

Ethical Considerations

The design and procedures for this study received approval from the University of Alabama Institutional Review Board, protocol #19-06-2486, and other involved institutions approved reliance for this protocol approval. Participants were required to electronically sign a consent form using Docusign (DocuSign Inc); they received US $25 for each interview they completed and the data were de-identified.

Results

A total of 21 caregivers initially enrolled in the study (n=13 at the Frank C. and Lynn Scaduto MIND Institute at Miami Jewish Health and n=8 at the University of Alabama at Birmingham). For one caregiver, interviews were conducted in Spanish. Overall, participants were most likely to be a non-Latina white woman caring for a parent or spouse, though the sample was diverse, with 14.3% identifying as African American or Afro Caribbean caregivers and 23.8% identifying Latino/a. Caregivers tended to have moderate to higher incomes and more than two-thirds (68.2%) had a bachelor's or graduate degree. Most participants lived in urban (40.9%) or suburban (50%) communities. Table 1 provides detailed information about the demographics of participating caregivers. A bivariate analysis with outcome variables demonstrated that burden was associated with caregiver income at baseline, but this relationship disappeared at 3-month follow-up (t_{20}=8.42, *P*<.001). No other relationships were found between demographic and outcome variables.

Of the 21 caregiver participants completing the PHQ-4 at baseline, 66.6% (n=7) were classified as having normal psychological distress, 47.5% (n=10) mild, 9.5% (n=2) moderate, and 9.5% (n=2) severe distress. All 21 caregivers reported burden, where 2 (9.6%) scored in the mild range, 5 (23.9%) scored in the moderate range, and the remainder (n=14, 66.5%) reported high levels of burden.

Baseline data also demonstrated that many caregivers who enrolled in the project had high health literacy and were active in care management. The average score for caregivers on the ADKS at baseline was 25.71 (SD 2.31, range 21 - 28), indicating that many caregivers in the sample were knowledgeable (accuracy approaching 90%) about dementia when they enrolled in the study. In terms of communication with providers, on average caregivers reported that they *fairly often* prepare a list of questions for providers (mean 3.67, SD 1.35), *fairly often* discuss any personal problems that may be related to their loved one’s condition (mean 3.43, SD 1.66) and *very often* ask questions about the things they want to know and the things they do not understand about their loved one’s treatment (mean 4.62, SD 0.74).

A missingness analysis was conducted to determine if there were any relationships between participant demographics and attrition at follow up. An independent samples 1-tailed *t* test examining the mean differences between those who completed the Zarit and PHQ-4 at baseline and the 3-month follow-up with those who didn’t complete them at follow-up did not show any significant differences in their scores for either outcome variable. However, a χ^2 test with Fisher exact test was conducted to examine the demographic characteristics of those who completed both baseline and 3-month follow-up assessments on the PHQ-4 total score, anxiety, and depression. It showed that those who identified as Hispanic or Latino/a were more likely to be lost at follow-up than those who did not. This result suggests that the sample might not be entirely representative, as certain demographic groups (in this case, Hispanic participants) might be underrepresented in the group with complete data.

Table . Demographic characteristics of the caregiver participants and bivariate analysis with Zarit at baseline.

Characteristics	Participants, n (%)	Baseline (N=21)		
		Mean (SD)	*t*/*F* test (*df*)	*P* value
Gender			–1.26 (19)	.22
Female	18 (85.7)	21.22 (8.14)		
Male	3 (14.3)	14.67 (10.07)		
Average age (range 43 ‐ 80 years)	—[a]	65.32 (10.66)		
Race			–0.66 (19)	.52
White or Caucasian	18 (85.7)	19.78 (8.73)		
African American or Afro-Caribbean	3 (14.3)	23.33 (7.51)		
Ethnicity			0.09 (19)	.93
Hispanic or Latino/a	5 (23.8)	21.26 (6.22)		
Not Hispanic or Latino/a	16 (76.2)	23.33 (14.83)		
Household income (US $)			8.42 (19)	<.001
Less than 20,000	1 (4.8)	37.00 (0)		
20,000-34,999	2 (9.5)	5 (1)		
35,000-49,999	3 (14.3)	22 (4)		
50,000-74,999	3 (14.3)	29 (4)		
75,000-99,000	5 (23.8)	17 (3)		
100,000 or greater	7 (33.3)	20 (6)		
Educational attainment			0.56 (20)	.65
Some college, no degree	3 (13.6)	14.00 (5.00)		
Associate’s degree	4 (18.2)	22.00 (9.00)		
Bachelor’s degree	8 (36.4)	21.00 (11.00)		
Graduate or professional degree	7 (31.8)	21.00 (7.00)		
Community setting			—	—
Rural	2 (9.1)	—		
Suburban	11 (50)	—		
Urban	9 (40.9)	—		
Relationship to care recipient			—	—
Wife	11 (50)			
Husband	3 (13.6)			
Daughter	5 (22.7)			
Daughter-in-law	3 (13.6)			
Average length of time caregiving (range)	5.45 (0.5- 18) years	—	—	—
Living situation			—	—
Lives with care recipient	18 (77.3)	—		
Does not live with care recipient	3 (22.7)	—		
Self-rated computer skills (n=21)			—	—

Characteristics	Participants, n (%)	Baseline (N=21)		
		Mean (SD)	*t*/*F* test (*df*)	*P* value
Beginner	1 (4.7)	—		
Average	12 (57.1)	—		
Advanced	7 (33.3)	—		
Expert	1 (4.7)	—		

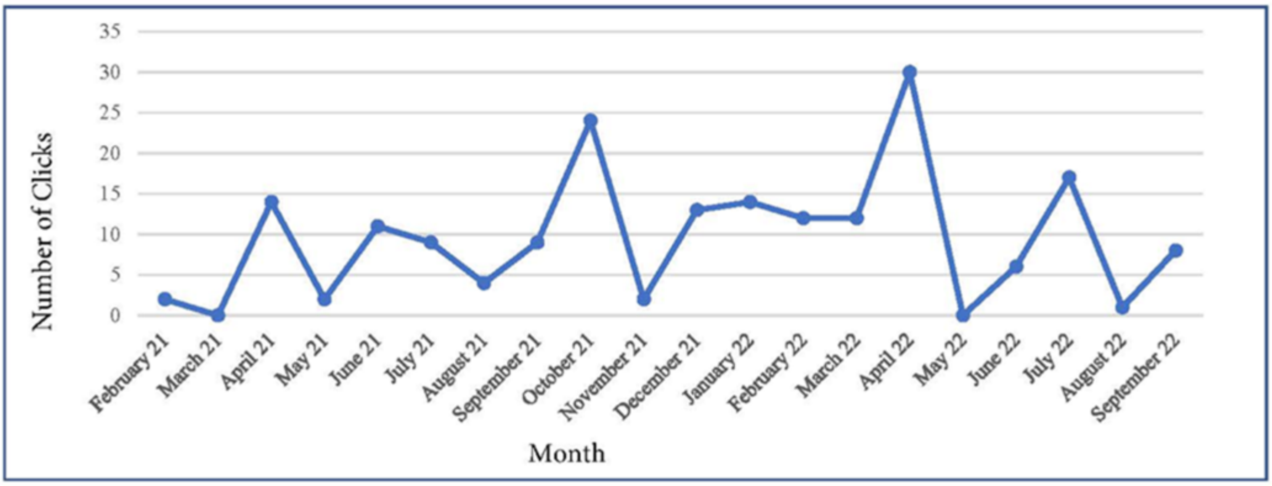
[a] Not applicable.

Usage Data Findings

Usage data were collected between February 2021 and September 2022. Figure 3 shows the user activity for *CareHeroes* over time. It should be noted that recruitment took place over a 14-month period, and throughout the project, enrollment ranged from 2 to 12 caregivers at any given time point. However, enrollment peaked between December 2021 and August 2022, which is reflected in the data. Overall, there were 169 actions that caregivers made on *CareHeroes* (eg, link clicks). Participants most often accessed: the chatbot (44 sessions), resource links (30 clicks), the Zarit Caregiver Burden Inventory (22 submissions), and the Revised Memory and Behavior Problem Checklist (19 submissions). Fewer caregivers access the reminder feature (8 entries) and PHQ-2 assessment (13 submissions).

For the chatbot data, caregivers accessed the chatbot 44 times over the course of the study. The most common topics that caregivers explored on the chatbot were how to manage the depression of the care recipient (n=5 total chats), sleep problems experienced by the care recipient (n=4 total chats), and about living wills (n=4 total chats).

Figure 3. CareHeroes usage data over time.



Interview Outcome Data

The outcome measure for knowledge about Alzheimer disease was only scheduled to be assessed at baseline and at the 12-month follow-up. The sample of caregivers who completed 12-month interviews was too small to evaluate this outcome. However, there was enough data to assess outcomes for burden, depression, and anxiety.

Among the 21 caregivers with baseline data, 12 completed the PHQ-4 and 13 completed the Zarit CBI at the 3-month follow-up. At follow-up, it was found that there was a decrease in total scores for the PHQ-4, though this relationship was not statistically significant (t_{11}=1.56, *P*=.15). However, when an 1-tailed *t* test was performed with the separate subscales for the PHQ-4, it was found that caregivers reported significantly lower levels of depression at the 3-month follow-up (mean 1.08, SD 1.08) than they did at baseline (mean 1.67, SD 1.48; t_{11}=2.03; *P*=.03; see Table 2). There was no difference in scores for anxiety during the same time period (t_{11}=1.0667, *P*=.15).

Table . Paired samples 1-tailed *t* test for burden, anxiety, and depression.

	Mean (SD)	*t* test (*df*)	*P* value
Zarit (n=13)		–0.07 (12)	.95
Baseline	21.85 (6.38)		
3-month	21.92 (7.89)		
2 Anxiety items [a] **(n=12)**		1.0667 (12)	.15
Baseline	2.25 (1.48)		
3 Months	1.75 (1.29)		
2 Depression items [a] **(n=12)**		2.03 (12)	.03
Baseline	1.67 (1.32)		
3 Months	1.08 (1.08)		

[a] Patient Health Questionnaire for Depression and Anxiety (PHQ-4) was administered, and from the PHQ-4 items, the 2-item measure of depression (PHQ-2) and the 2-item measure of anxiety (the Generalized Anxiety Disorder-2 scale [GAD-2]) were analyzed.

Discussion

Principal Findings

Over the past decade, the development and research of new technologies to support people living with dementia and their caregivers has increased significantly. However, little remains known about how such technologies can be integrated into clinical care to facilitate caregiver support and secure clinical information sharing. In this pilot study, we were able to demonstrate that caregivers did use *CareHeroes* for education and support. We also demonstrated that new HIT can be integrated into care for secure sharing of patient information in real time. Although outcome data suggests that there was a decrease in caregiver depression at the 3-month follow-up, more research is needed to fully assess the potential impact of using *CareHeroes* on psychosocial outcomes.

Potential of Chatbots for Caregiver Support

Overall, this pilot study recruited a smaller sample than initially planned, and attrition of caregivers in the study was high, which created limits to assessing outcome variables. However, user data indicated that caregivers accessed a variety of features on the app, though the most used feature on the app was the educational chatbot. This was notable because very few chatbots have been developed to support people living with dementia and their caregivers [17]. Chatbots have grown in popularity over the past decade and have become a familiar technology to many through popular chatbots like Apple’s Siri and Amazon’s Alexa [42]. Chatbots offer benefits over other types of information technologies for health education and support in that they may be programmed so they are tailored to the user’s needs. Also, recent advances in chatbots based on large language models, such as ChatGPT, have the potential to significantly improve the responsiveness to caregivers’ support needs.

In a recent study, ChatGPT and Google were evaluated on their ability to respond to common questions that caregivers have [43]. ChatGPT was found to produce results that were more closely aligned with what the question was asking, though it did not provide sources or how old the information was. Both ChatGPT and Google were found to provide responses that were written at a higher reading level than what is recommended for general health education. Similar to other AI chatbot tools, the bot’s responses to the user’s input require regular training. As a result, the quality and availability of information is dependent on how often the chatbot is trained and the content used to train it. As earlier discussed, the chatbot in the *CareHeroes* app is programmed with expert feedback to common questions that caregivers have about dementia and caregiving [35]. Hence, while a Google search of similar questions may result in an overwhelmingly large number of search results that are irrelevant, the *CareHeroes* chatbot is able to provide more direct responses to the questions caregivers often have. In other health settings, it has been found that chatbots can be an effective way of promoting health education, treatment management, and moral support [44,45]. It has also been suggested that chatbots may be an ideal platform for collecting patient-related information [46]. Moving forward, the implementation of *CareHeroes* may be more successful if more features were offered in a chatbot format.

Limitations and Future Research

Like many studies during this time period, the COVID-19 pandemic posed significant challenges to recruiting and retaining caregivers. Initially, the research team thought the increase in telehealth during the pandemic would possibly lead to more caregivers wanting to participate in the study. However, anecdotally, many caregivers reported to the clinic staff that they were overwhelmed by the pandemic and its associated increased need for telecommunication. In such cases, caregivers expressed that learning another new technology was too burdensome. Among the caregivers who enrolled in the study, some reported to interviewers at the 12-month follow-up that they wished they had used the app more because they thought the features would have helped them, but it was difficult to fit using the app within their daily care activities during the pandemic. Similarly, the clinic staff reported that understaffing during the pandemic made it difficult for them to log onto *CareHeroes* regularly. While this pilot study provides direction for future research, more research is needed under more typical circumstances to generate strong evidence about the potential of HIT as an adjunct to clinical care for people living with dementia and their caregivers.

One challenge in the study stemming from the pandemic was that the research team was unable to meet with caregivers in person when they enrolled in the study to orient them with the technology when it was first introduced. This may have impacted their familiarity with using the app, since they were only given instructions over the telephone or Zoom. Future research should identify best practices in training caregivers to use new HIT so that they gain the maximum benefit that the technology has to offer. Similarly, how best to provide ongoing support to caregivers should be identified. For example, examining the effectiveness of embedding instructional videos in the software design on maintaining caregiver engagement with the technology. In this study, caregivers were provided with a helpline that they could call when they encountered a problem with *CareHeroes*. However, it is possible that some caregivers experienced challenges that they did not report to the helpline and stopped using the app when they could not resolve the issue themselves.

Another limitation to this study is that the caregiver participants who enrolled in the study were very experienced and very knowledgeable about ADRD at baseline, which may be associated with their access to specialized memory care, as opposed to primary care. It is suspected that newer caregivers would interact with and learn from the *CareHeroes* app differently. However, the findings from the study's implementation evaluation and outcome assessment provide future researchers with insight on developing tech-focused interventions.

In addition, future studies should also examine how to better integrate new information technologies into clinical care so that they are easily adopted by providers. For example, designing new technologies so that they can be integrated into existing secure systems, like electronic medical records, rather than offering additional programs that require new log-ins can minimize the burden on providers who have to navigate multiple secure software programs on a regular basis. Similarly, more research is needed on technologies that can encourage triadic communication between people living with dementia, their caregivers, and providers. While *CareHeroes* was designed to empower caregivers of patients with dementia, the research team recognizes that more should be done to empower these patients to promote person-centered care.

Conclusion

There has been growing interest in the development of technologies that support people living with dementia and their caregivers. While the features and functions of new technologies will impact their adoption, this paper highlights the importance of implementation planning in order to maximize success in tech adoption, particularly by caregivers. While these findings may provide future direction for researchers involved in developing technologies for dementia care and caregiving, they are also relevant to commercial technology developers who are interested in integrating similar technologies within real-world contexts. Though this research experienced several limitations stemming from the COVID-19 pandemic, the research team credits the early work done to overcoming these challenges and successfully implementing *CareHeroes*.

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Conflicts of Interest

VH is the founder of SmartBot360, which is a health care chatbot company. ELB, PJC, and NR are co-owners of Person First Technology LLC (PFT), which develops and tests technologies for people with dementia and their families. PFT was formed after this research was completed and was not involved with the study.

References

1. Alzheimer's Association. 2023 Alzheimer's disease facts and figures. Alz Dem 2023 Apr;19(4):1598-1695. [doi: 10.1002/alz.13016]
2. Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. J Gen Intern Med 2007 Nov;22(11):1487-1492. [doi: 10.1007/s11606-007-0317-y] [Medline: 17823840]
3. Wolff JL, Freedman VA, Mulcahy JF, Kasper JD. Family caregivers' experiences with health care workers in the care of older adults with activity limitations. JAMA Netw Open 2020 Jan 3;3(1):e1919866. [doi: 10.1001/jamanetworkopen.2019.19866] [Medline: 31977063]

4. Vedel I, Akhlaghpour S, Vaghefi I, Bergman H, Lapointe L. Health information technologies in geriatrics and gerontology: a mixed systematic review. J Am Med Inform Assoc 2013;20(6):1109-1119. [doi: 10.1136/amiajnl-2013-001705] [Medline: 23666776]
5. Zulman DM, Piette JD, Jenchura EC, Asch SM, Rosland AM. Facilitating out-of-home caregiving through health information technology: survey of informal caregivers' current practices, interests, and perceived barriers. J Med Internet Res 2013 Jul 10;15(7):e2472. [doi: 10.2196/jmir.2472] [Medline: 23841987]
6. Ruggiano N, Brown EL, Li J, et al. Communicating with providers for dementia care: Perspectives from caregivers and the potential role for information technology. J Aging Soc Change 2019;9(3). [doi: 10.18848/2576-5310/CGP/v09i03/25-38]
7. Wittenberg E, Kerr AM, Goldsmith J. Exploring family caregiver communication difficulties and caregiver quality of life and anxiety. Am J Hosp Palliat Care 2021 Feb;38(2):147-153. [doi: 10.1177/1049909120935371]
8. Brown EL, Raue PJ, Klimstra S, Mlodzianowski AE, Greenberg RL, Bruce ML. An intervention to improve nurse-physician communication in depression care. Am J Geriatr Psychiatry 2010 Jun;18(6):483-490. [doi: 10.1097/JGP.0b013e3181bf9efa] [Medline: 21217559]
9. Brown EL, Friedemann ML, Mauro AC. Use of adult day care service centers in an ethnically diverse sample of older adults. J Appl Gerontol 2014 Mar;33(2):189-206. [doi: 10.1177/0733464812460431] [Medline: 24652954]
10. Riffin C, Wolff JL, Estill M, Prabhu S, Pillemer KA. Caregiver needs assessment in primary care: views of clinicians, staff, patients, and caregivers. J Am Geriatr Soc 2020 Jun;68(6):1262-1270. [doi: 10.1111/jgs.16401] [Medline: 32167573]
11. Fabius CD, Wolff JL, Kasper JD. Race differences in characteristics and experiences of Black and White caregivers of older Americans. Gerontologist 2020 Sep 15;60(7):1244-1253. [doi: 10.1093/geront/gnaa042] [Medline: 32400881]
12. Gianattasio KZ, Prather C, Glymour MM, Ciarleglio A, Power MC. Racial disparities and temporal trends in dementia misdiagnosis risk in the United States. Alzheimers Dement (N Y) 2019;5(1):891-898. [doi: 10.1016/j.trci.2019.11.008] [Medline: 31890853]
13. Lin PJ, Daly AT, Olchanski N, et al. Dementia diagnosis disparities by race and ethnicity. Med Care 2021 Aug 1;59(8):679-686. [doi: 10.1097/MLR.0000000000001577] [Medline: 34091580]
14. Abner EL, Jicha GA, Christian WJ, Schreurs BG. Rural-urban differences in Alzheimer's disease and related disorders diagnostic prevalence in Kentucky and West Virginia. J Rural Health 2016 Jun;32(3):314-320. [doi: 10.1111/jrh.12155] [Medline: 26515331]
15. Ruggiano N, Brown EL, Li J, Scaccianoce M. Rural dementia caregivers and technology: what is the evidence? Res Gerontol Nurs 2018 Jul 1;11(4):216-224. [doi: 10.3928/19404921-20180628-04] [Medline: 30036405]
16. Brown EL, Ruggiano N, Li J, Clarke PJ, Kay ES, Hristidis V. Smartphone-based health technologies for dementia care: opportunities, challenges, and current practices. J Appl Gerontol 2019 Jan;38(1):73-91. [doi: 10.1177/0733464817723088] [Medline: 28774215]
17. Ruggiano N, Brown EL, Roberts L, et al. Chatbots to support people with dementia and their caregivers: available applications, opportunities, and challenges. J Med Internet Res (JMIR) 2021;23(6):e25006. [Medline: 34081019]
18. Brown EL, Ruggiano N, Page TF, et al. CareHeroes Web and Android™ apps for dementia caregivers: a feasibility study. Res Gerontol Nurs 2016;9(4):193-203. [doi: 10.3928/19404921-20160229-02] [Medline: 29977440]
19. Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, Vitaliano PP. Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. Psychol Aging 1992 Dec;7(4):622-631. [doi: 10.1037//0882-7974.7.4.622] [Medline: 1466831]
20. Johnson N, Barion A, Rademaker A, Rehkemper G, Weintraub S. The Activities of Daily Living Questionnaire: a validation study in patients with dementia. Alzheimer Dis Assoc Disord 2004;18(4):223-230. [Medline: 15592135]
21. Kroenke K, Spitzer RL, Williams JBW, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. Psychosomatics 2009;50(6):613-621. [doi: 10.1176/appi.psy.50.6.613] [Medline: 19996233]
22. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. Gerontologist 2001 Oct;41(5):652-657. [doi: 10.1093/geront/41.5.652] [Medline: 11574710]
23. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D. Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving. Res Aging 2004;26(4):429-453.
24. Ruggiano N, Brown E, Clarke P, et al. Examining the Clinical Workflow and Outcomes of Integrating Health IT to Educate and Support Dementia Caregivers (Final Report). : Agency for Healthcare Research and Quality (AHRQ); 2023.
25. Ruggiano N, Brown E, Hristitis V, Clarke P. Expanding health information technology to support hispanic caregivers and improve dementia care. Presented at: Paper presentation for the Gerontological Society of America's 69th Annual Scientific Meeting; Nov 2016; New Orleans, LA.
26. Nilsen P. Making sense of implementation theories, models and frameworks. Implement Sci 2015 Apr 21;10:53. [doi: 10.1186/s13012-015-0242-0] [Medline: 25895742]
27. Ruggiano N, Shtompel N, Hristidis V, Roberts L, Grochowski J, Brown EL. Need and potential use of information technology for case manager–physician communication in home care. Home Health Care Manag Pract 2012 Dec;24(6):292-297. [doi: 10.1177/1084822312459615]

28. Brown EL, Raue PJ, Mlodzianowski AE, Meyers BS, Greenberg RL, Bruce ML. Transition to home care: quality of mental health, pharmacy, and medical history information. Int J Psychiatry Med 2006;36(3):339-349. [doi: 10.2190/6N5P-5CXH-L750-A8HV] [Medline: 17236701]
29. Ruggiano N, Brown EL, Hristidis V, Page TF. Adding home health care to the discussion on health information technology policy. Home Health Care Serv Q 2013;32(3):149-162. [doi: 10.1080/01621424.2013.813884] [Medline: 23937673]
30. Ruggiano N, Brown EL, Shaw S, et al. The potential of information technology to navigate caregiving systems: perspectives from dementia caregivers. J Gerontol Soc Work 2019;62(4):432-450. [doi: 10.1080/01634372.2018.1546786] [Medline: 30422754]
31. Ruggiano N, Brown EL, Clarke P. Integrating health IT into clinical workflow for dementia care: provider and caregiver perspectives. Presented at: Poster presentation at the Annual Scientific Meeting of the Gerontological Society of America; Nov 2019; Austin, TX.
32. Braude EJ, Bernstein ME. Software Engineering: Modern Approaches. : Waveland Press; 2016.
33. Department of Health and Human Services. 45 CFR Parts 160 and 164. Fed Regist 2013 Jan 25;78(17).
34. Akram M, Barker W, Clatterbuck R, et al. Securing Web Transactions: TLS Server Certificate Management. : National Institute of Standards and Technology; 2020.
35. Agronin ME. The Dementia Caregiver: A Guide to Caring for Someone With Alzheimer’s Disease and Other Neurocognitive Disorders: Rowman & Littlefield; 2015.
36. Laranjo L, Dunn AG, Tong HL, et al. Conversational agents in healthcare: a systematic review. J Am Med Inform Assoc 2018 Sep 1;25(9):1248-1258. [doi: 10.1093/jamia/ocy072] [Medline: 30010941]
37. Lorig K, Stewart A, Ritter P, González V, Laurent D, Lynch J. Outcome Measures for Health Education and Other Health Care Interventions: SAGE; 1996.
38. Mills SD, Fox RS, Pan TM, Malcarne VL, Roesch SC, Sadler GR. Psychometric evaluation of the Patient Health Questionnaire–4 in Hispanic Americans. Hisp J Behav Sci 2015 Nov;37(4):560-571. [doi: 10.1177/0739986315608126]
39. Carpenter BD, Balsis S, Otilingam PG, Hanson PK, Gatz M. The Alzheimer’s Disease Knowledge Scale: development and psychometric properties. Gerontologist 2009 Apr;49(2):236-247. [doi: 10.1093/geront/gnp023] [Medline: 19363018]
40. Yu J, Yap P, Liew TM. The optimal short version of the Zarit Burden Interview for dementia caregivers: diagnostic utility and externally validated cutoffs. Aging Ment Health 2019 Jun;23(6):706-710. [doi: 10.1080/13607863.2018.1450841] [Medline: 29553806]
41. StataCorp. Stata Statistical Software: Release 17. : StataCorp LLC; 2021.
42. Dale R. The return of the chatbots. Nat Lang Eng 2016 Sep;22(5):811-817. [doi: 10.1017/S1351324916000243]
43. Hristidis V, Ruggiano N, Brown EL, Ganta SRR, Stewart S. ChatGPT vs Google for queries related to dementia and other cognitive decline: comparison of results. J Med Internet Res 2023 Jul 25;25:e48966. [doi: 10.2196/48966] [Medline: 37490317]
44. Piau A, Crissey R, Brechemier D, Balardy L, Nourhashemi F. A smartphone Chatbot application to optimize monitoring of older patients with cancer. Int J Med Inform 2019 Aug;128:18-23. [doi: 10.1016/j.ijmedinf.2019.05.013] [Medline: 31160007]
45. Vaidyam AN, Wisniewski H, Halamka JD, Kashavan MS, Torous JB. Chatbots and conversational agents in mental health: a review of the psychiatric landscape. Can J Psychiatry 2019 Jul;64(7):456-464. [doi: 10.1177/0706743719828977] [Medline: 30897957]
46. Fadhil A, Gabrielli S. Addressing challenges in promoting healthy lifestyles: the al-chatbot approach. 2017 Presented at: PervasiveHealth ’17: Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare; May 23-26, 2017; Barcelona Spain p. 261-265.

Abbreviations

ADKS: Alzheimer’s Disease Knowledge Scale
ADRD: Alzheimer disease and related dementias
AI: artificial intelligence
GAD-2: Generalized Anxiety Disorder 2 item
HIPAA: Health Insurance Portability and Accountability Act
HIT: health IT
PHQ: Patient Health Questionnaire for Depression and Anxiety

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Internet-Based Supportive Interventions for Family Caregivers of People With Dementia: Randomized Controlled Trial

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Abstract

Background: As dementia progresses, patients exhibit various psychological and behavioral symptoms, imposing a significant burden on families and society, including behavioral and psychological symptoms of dementia. However, caregivers lack professional care knowledge and skills, making it difficult for them to effectively cope with the diverse challenges of caregiving. Therefore, it is necessary to provide caregivers with professional knowledge and skills guidance.

Objective: This study aimed to analyze the impact of internet-based training on behavioral and psychological symptoms of dementia in patients, and explore how this training model affects the caregiving abilities and caregiving burden of the family caregivers of patients with dementia.

Methods: Using a consecutive enrollment method, the Department of Geriatrics at Zhejiang Hospital (Zhejiang, China) recruited 72 informal caregivers of patients with dementia. These caregivers were randomly divided into an intervention group and a control group, with 36 participants in each group. The intervention group underwent caregiver skill training via a web-based platform, whereas the control group initially received face-to-face follow-up guidance and was subsequently offered web-based training after 6 months. To assess the effectiveness of the intervention program, we used the Neuropsychiatric Inventory Questionnaire (NPI-Q), the Chinese version of the Zarit Burden Interview (CZBI), and the Sense of Competence in Dementia Care Staff Scale (SCIDS) for evaluations conducted before the intervention, 3 months after the intervention, and 6 months after the intervention.

Results: Between July 2019 and December 2020, a total of 66 patients successfully completed the intervention and follow-up. After 6 months of intervention, the NPI-Q score of the intervention group was 3.18 (SD 3.81), the CZBI score was 10.97 (SD 5.43), and the SCIDS score was 71.88 (SD 4.78). The NPI-Q score of the control group was 8.09 (SD 8.52), the CZBI score was 30.30 (SD 13.05), and the SCIDS score was 50.12 (SD 9.10). There were statistically significant differences in NPI-Q (*P*=.004), CZBI (*P*<.001), and SCIDS scores (*P*<.001) between the intervention group and the control group. Repeated measures analysis of variance showed that compared with before the intervention, there were statistically significant differences in CZBI (*P*<.001) and SCIDS (*P*<.001) scores 3 months after the intervention, while the difference in NPI-Q (*P*=.11) scores was not significant. The total scores of NPI-Q (*P*<.001), CZBI (*P*<.001), and SCIDS (*P*<.001) were significantly improved 6 months after the intervention. In addition, the results of the covariance analysis showed that after excluding the time effect, the web-based training intervention significantly reduced the NPI-Q score (−2.79, 95% CI −4.38 to −1.19; *P*<.001) of patients with dementia and the CZBI score (−13.52, 95% CI −15.87 to −11.16; *P*<.001) of caregivers, while increasing the SCIDS score (12.24, 95% CI 9.02-15.47; *P*<.001).

Conclusions: Internet-based training could significantly reduce the level of behavioral symptoms in older patients with dementia and alleviate the burden on caregivers, enhancing their caregiving abilities. Our results confirmed the effectiveness and feasibility of web-based training, which was of great significance in providing caregiving knowledge training for informal caregivers of persons with dementia.

Trial Registration: Chinese Clinical Trial Registry ChiCTR2200057858; https://www.chictr.org.cn/showproj.html?proj=136442

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KEYWORDS

dementia; family caregiver; web-based training; care burden; care ability; caregivers; carer; caregiving; informal care; RCT; controlled trial; randomized; gerontology; geriatric; older adult; elder; elderly; older person; older people; ageing; aging; dementia care; randomized controlled trial; internet-based training

Introduction

Dementia care remains a major public health challenge for global health systems. According to a recent nationwide cross-sectional study [1], 15.07 million individuals older than 60 years experienced dementia in China. A person with dementia, particularly one with moderate-to-severe dementia, has extensive health and social care needs. The annual total treatment costs of patients with Alzheimer disease in China are predicted to reach US $507.49 billion in 2030 and US $1.89 trillion in 2050 [2]. Dementia severity is an important driver of cost and the proportion of mild, moderate, and severe dementia cases living in a country can influence the cost estimates. In China, 70% of patients with dementia live at home and are cared for by their spouses, children, or other relatives. According to a survey conducted by Alzheimer Disease Chinese [3], there are 3 major difficulties faced by the families of patients with dementia, which mainly are insufficient care capacity, a lack of care resources, and single treatment services. According to the research report [3], 65.43% of caregivers have no hope of treatment and feel intense psychological pressure, 68.69% of caregivers report that their health has been affected, and 78.39% of caregivers said that their social life is often affected.

Behavioral and psychological symptoms of dementia (BPSD) may occur at any stage of the disease progression, with patients exhibiting at least one type of BPSD. BPSD is highly correlated with caregiver burden. Caregiver factors are some of the causes and triggers of BPSD, and insufficient interaction between caregivers and care recipients may lead to the occurrence or exacerbation of BPSD. For family caregivers, caring for people with dementia is perceived as one of the most stressful experiences. During the long-term progression of the disease, the patient's independence will decline, which requires more responsibility and supervision time from informal caregivers. Long-term problems of continuously managing activities of daily living [4,5], behavioral and psychological symptoms [6], and providing emotional, spiritual, and social support place considerable burdens on the family, which can result in mental health problems such as depression. The burden of care can put caregivers at risk of physical and psychological ailments, as well as negatively affect their quality of life, so effective and practical support is essential. Training and supporting family caregivers, especially in the proper management of BPSD, to enhance their ability to cope with BPSD, may help break this vicious cycle [7].

In 2019, informal dementia caregivers spent over 89 billion hours providing support with activities of daily living about 5 hours per day per person with dementia [8]. As the most direct contact and participant, the competence of the caregiver has a direct impact on the outcome of BPSD. However, due to the ongoing COVID-19 pandemic, many support services for dementia caregivers have been reduced, delayed, or even withdrawn, which has substantially increased interest in web-based health services [9]. It is important to create a digital platform that offers invaluable and usable information to caregivers of people living with dementia [10]. In the face of these significant challenges, the WHO developed "iSupport," an evidence-based e-health intervention designed to help dementia caregivers provide good care and take care of themselves [11]. Internet-based supportive interventions can provide convenient and efficient support and education to potentially reduce the physical and psychological burden associated with providing care. Internet-based supportive interventions for family caregivers of people with dementia have been reported in the United Kingdom [11], India [12], the Netherlands [13], Brazil [14], Germany [15], and other countries, but they are rare in China.

This manuscript presents the findings of a randomized controlled trial examining the implementation of internet-based supportive interventions for home care among patients with dementia in China. The trial is an innovative web-based support program that was developed to advance the skills, knowledge, and practice of caregivers, in order to enhance self-care skills in individuals with dementia and simultaneously provide invaluable assistance to their caregivers. The experiment also aims to assess the effectiveness of the web-based support program, and to explore its impact on the caregiving burden and caregiving abilities of dementia caregivers, compared with dementia caregivers who receive routine caregiving interventions after discharge. The primary outcomes of this study consisted of evaluating the severity of neuropsychiatric symptoms in patients with dementia, assessing the burden on caregivers, and gauging the capability of caregivers. We hypothesized that internet-based supportive interventions would lead to greater improvement in primary outcomes than routine caregiving interventions after discharge.

Methods

Study Design

The trial was designed, planned, and executed by the Department of Geriatrics of Zhejiang Hospital (Zhejiang China). A randomized controlled trial design was used to study the feasibility and effectiveness of a nurse-led multidisciplinary team web-based training and support program. A total of 72 caregivers of patients with dementia were recruited from the Geriatric Department of Zhejiang Hospital from July 2019 to December 2020. The recruitment strategy included posting flyers and posters in the geriatric ward. During the patient's hospitalization, the geriatric nurse proposed this protocol to the family caregivers of the patient with dementia. Interested participants were provided with a flyer containing contact information for the research and filled out a contact form. The geriatric nurse confirmed the inclusion criteria and collected the signed informed consent. The control group intervention measures included regular face-to-face follow-up interviews with caregivers to provide education on dementia care knowledge and skills. These measures were conducted every 3 months after the patient's discharge. All participants were assessed at baseline (T0) and postintervention (T1, 3 months after T0; T2, 6 months after T0). Once enrolled, participants had access to the web-based program or follow-up interview for more than 6 months.

Ethical Considerations

All procedures were in accordance with the Helsinki Declaration, and the study was approved by the Ethics Review Committee of Zhejiang Hospital (2019 pretrial case number: 23K). It was registered at the Chinese Clinical Trial Registry (ChiCTR-2200057858). A written informed consent form was sought from each participant.

Inclusion and Exclusion Criteria

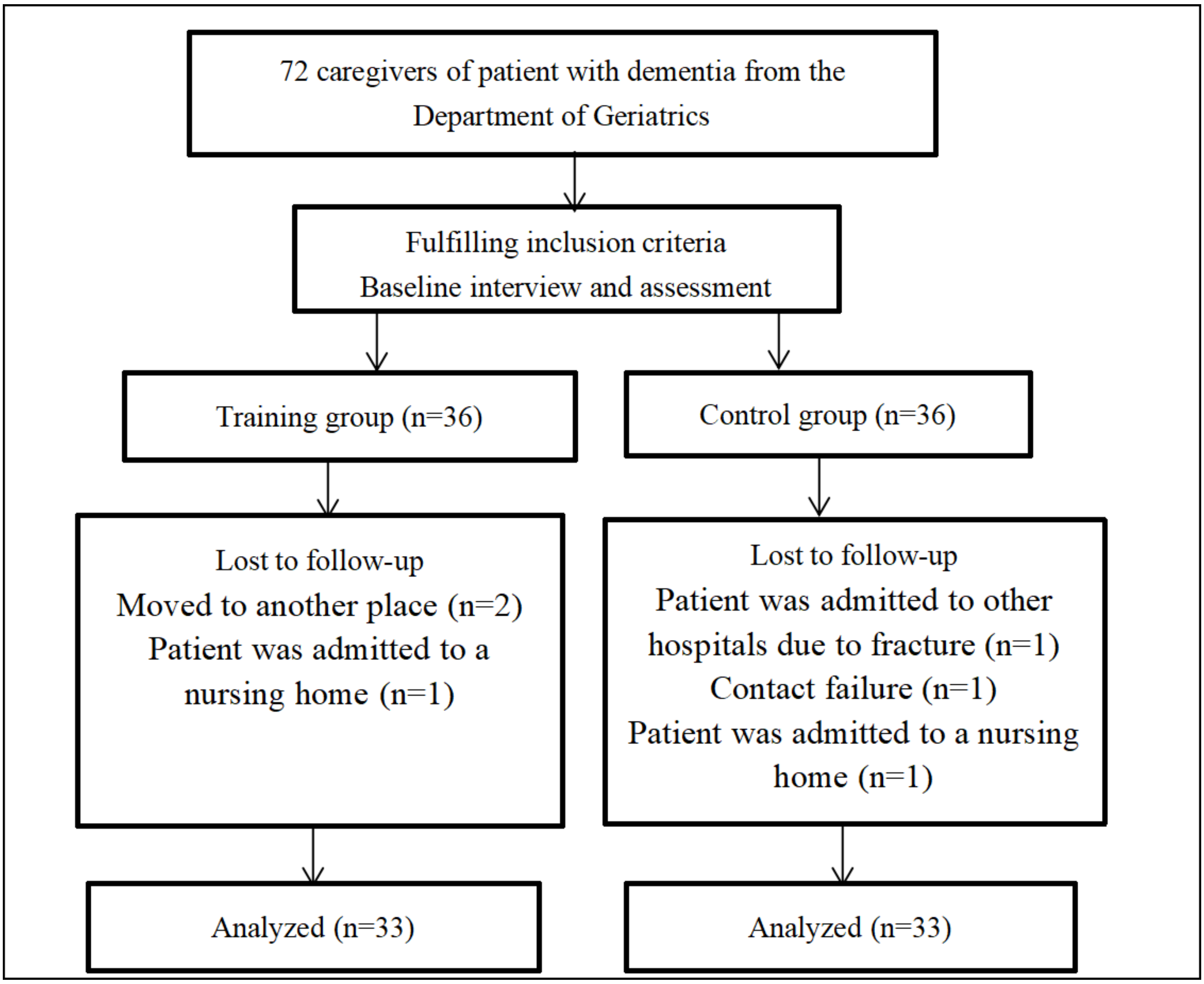
Selection criteria included the following: (1) being a primary, informal caregiver aged at least 18 years; (2) caring for individuals with dementia while living together at home for a minimum of 6 months; (3) having internet access via computers or iPads; and (4) could read, understand Chinese, and following instructions. Participants were excluded if they had severe visual or hearing impairment that was incompatible with participation as assessed by the study staff.

Recruitment, Consent, and Baseline Data Collection

Between July 2019 and December 2020, 72 informal primary caregivers of people with dementia of all subtypes and stages were recruited via the Department of Geriatrics, Zhejiang Hospital. Caregivers meeting the eligibility criteria were informed of initial details about the study and provided with a subject information sheet. Once potential participants decided to participate, they were asked to sign the informed consent form and were informed of their rights. Baseline information was collected by trained interviewers from participants through the completing standardized questionnaires. During the interviews, trained interviewers were blinded to the group allocations. Participants were randomly allocated on a 1:1 ratio assigned to either the intervention or a waiting list control group after baseline assessment. Randomization was carried out using a random number generator.

In the follow-up period, 3 patients in the intervention group and the control group were lost to follow-up, respectively. In the intervention group, 2 caregivers accompanied the patients with dementia when they relocated to a different city, and another caregiver returned to her hometown after the patient with dementia was admitted to a nursing home. In the control group, one caregiver of a patient with dementia accompanied the patient for emergency hospital admission due to a fracture, another caregiver failed to continue contact despite repeated appointments, and one caregiver accompanied the patient to a nursing home (Figure 1).

Figure 1. Flowchart of study participants.



Sample Size Calculation

The experiment was conducted as a parallel-group randomized controlled trial study design, and repeated measures were used. Sample size calculation was based on the primary outcome of the Chinese version of the Zarit Burden Interview (CZBI) at 6 months after baseline. The detection power was set at 90%, and α (2-tailed) was set at .05. Preliminary experiments showed that the CZBI of dementia family caregivers was 21.55, with an SD of 9.89, and an auto-correlation between adjacent measurements on the same individual was 0.70. By providing web-based knowledge and skills training through the internet, the preliminary trial showed that the average CZBI had decreased by 12.5. Using PASS software (version 16.0; National Council on Social Studies), the minimum sample size for each group was identified as 27. Considering a potential 10% loss of samples during the study, the final sample size was determined to be 36 individuals per group.

Intervention

The platform aims to provide opportunities for support, education, and sharing experiences among users across Zhejiang province. In order to provide users with convenient access to the course at any time and place, the platform was designed to operate on any internet-enabled device. In the intervention group, we instructed the informal caregivers of persons with dementia to log in to the platform web page and taught them about the knowledge and skills relevant to home care via the internet. The content on the platform was divided into 5 different themes, which were: computer cognitive training, language training, reality-oriented therapy, daily life rehabilitation, and care skills training. Computer cognitive training includes concentration (picture-text matching), memory (vocabulary memorization), calculation (simulated shopping), and reaction training (fruit picking). Each training time was 20 minutes and was conducted 3 times a week. Language training aims to improve communication by focusing on vocalization, recognition, and the application of words. Reality orientation therapy focuses on presenting patients with facts about the time, date, and current environment. The primary objective for daily life rehabilitation is to increase self-care ability. The 4 themes (cognitive training, language training, reality-oriented therapy, and daily life rehabilitation) have been evaluated in a prior study with pending results and this paper focuses mainly on the fifth theme. The latter theme consisted of 18 lessons (270 min) aimed at improving caregiver care skills (Table 1). In order to encourage participants to complete the web-based course training, the web-based active screen time was calculated. Once participants completed at least 80% of the training sessions (216 min), they would be sent a book (“Long-term Care for Dementia”).

The control-comparison group would receive an educational booklet on caring for patients with dementia provided by the research team. In addition to this education, the control group would also receive face-to-face follow-up guidance and have the option to receive the same intervention after 6 months. The research team’s helpline would also be available 24 hours a day to the control group for caregiver assistance.

Table . Overview of intervention modules.

Theme	Curriculum content
Recognition of dementia	• The concept of dementia • The overview of dementia care • Types and causes of dementia
Physical care for dementia	• Nutritional care for dementia • Excretory care for dementia • Nonpharmacologic interventions for sleep disorders in dementia • BPSD[a] and response strategies
Physical activity maintenance	• Accompany shopping • Accompany outdoor activities • Preventing and delaying the onset of dementia BPSD syndrome
Good memories: cognitive facilitation of care	• Memory training: vocabulary memorization • Computational skill training: calculation (simulated shopping) • Manual activities: reaction training (fruit picking) • Music therapy: this module includes 100 Chinese revolutionary and nostalgic songs, and encourages family caregivers to customize personalized music playlists for the elderly, put them in the proper order, and play them at specific times or activities, such as when they wake up in the morning, at lunchtime, or during evening relaxation time • Spatial orientation training: the platform displays the date, day, weather, season, and holiday. The platform provides prompts to guide the patient in answering questions related to the direction of time • Language training: identifying and describing objects from pictures, finding the correct word, and idiomatic solitaire
Safe harbor: health promotion care	• Safety risks and prevention in home care for older people with dementia: improving the living environment; arranging for special care; setting up reminders such as “Watch out for slipping” and “CAUTION//Hot Water”; avoiding the use of dangerous items such as knives and matches; conducting regular checkups • Emergency response plan for patients with dementia with sudden incidents (stray, fall, and choking) • Sharing family care experience of dementia

[a] BPSD: behavioral and psychological symptoms of dementia.

Measurement Instruments

Due to the in-person meeting restrictions imposed by the COVID-19 pandemic, caregivers participated in two 10-minute web-based self-assessed surveys through Questionnaire Star at 3 and 6 months. The primary outcome measures were the Neuropsychiatric Inventory Questionnaire (NPI-Q), CZBI, and the Sense of Competence in Dementia Care Staff Scale (SCIDS).

The NPI-Q [16] is an observer rating scale that was used to evaluate participants’ neuropsychiatric symptoms across 12 different areas, including delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/emotional lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances. Each symptom was evaluated with a basic screening question (to which participants responded). If a positive answer is given to the screening question, a more detailed exploration of specific areas will be conducted. The neurobehavioral manifestations within a domain are collectively rated by caregivers based on frequency (1 to 4) and severity (1 to 3), resulting in a composite domain score (frequency × severity), with higher scores indicating greater severity of symptoms. The total NPI-Q score is defined as the sum of scores from 12 symptom evaluations, with a maximum score of 144. The Cronbach α coefficient of the NPI-Q was .82, and the test-retest coefficients ranged from .66 to .98 ($P<.001$) [17].

The caregiver burden was measured using the CZBI [18]. CZBI consists of 22 items that require a Likert-type response ranging from 0 (never) to 4 (almost always), with a total score ranging from 0 to 88. A higher score indicates an increased caregiver burden. The internal consistency value, established by Cronbach α coefficient, was .89 and the intraclass correlation coefficient for test-retest reliability of the total score was 0.88.

SCIDS is designed to evaluate the level of competency among caregivers in providing care for individuals with dementia [19]. The scale consists of 17 items across 4 subscales: professionalism, relationship-building, care challenges, and sustaining personhood. SCIDS has acceptable to good internal consistency (Cronbach α=.91) and moderate to substantial test-retest reliability (0.74). The total score on the scale ranges from 17 to 68 points, with higher scores indicating that staff members have a better awareness of dementia care abilities.

Statistical Analysis

Outliers were identified using boxplots, and data distribution was assessed by the Shapiro-Wilk test. Data were tested for normal distribution or variance homogeneity using appropriate tests before statistical analysis with SPSS statistical software (version 20.0; IBM Corp). Continuous variables that followed a normal distribution were expressed as mean and SD and were compared using an independent *t* test between the 2 groups. Categorical variables were expressed as frequencies and proportions and compared using a chi-square test between groups. In repeated measures analysis of variance (ANOVA), when the assumption of sphericity was violated (evaluated using the Mauchly test), the degrees of freedom value for testing the *F*-ratio was adjusted using the Greenhouse-Geisser correction. If there was no interaction effect between time and treatment factors in the repeated measures ANOVA results, the main effects test was used to evaluate the treatment effect. If there was an interaction effect, separate analyses were performed: the within-group effect was evaluated using a one-way repeated measures ANOVA, and the between-group effect was evaluated using a multivariate ANOVA. Bonferroni correction was used for posthoc multiple pairwise comparisons.

Results

Sample Characteristics

The patients in the control and intervention groups were comparable in terms of their baseline data such as sex, education level, marital status, age, BMI, number of children, number of diseases, and number of long-term medications (Table 2). In this study, caregivers averaged 57.74 years old (SD 3.93; range 48-66) and the majority (57/66, 86%) were female. Caregivers were most frequently the patients' distant relatives from the countryside (42/66, 64%) and children (13/66, 20%); the remainder were spouses (11, 16%). Table 2 presents the demographic characteristics of the sample. Among the study groups, demographic and clinical characteristics did not differ significantly.

Table . Sample characteristics.

Category		Intervention group (n=33)	Control group (n=33)
Caregiver age (years), mean (SD); range		58.79 (4.08); 48 - 66	56.70 (3.47); 50 - 64
Sex, n (%)			
	Male	3 (9)	5 (16)
	Female	30 (91)	27 (84)
Caregiver relationship, n (%)			
	Spouse	5 (15)	6 (18)
	Distant relatives from the country-side	22 (67)	20 (61)
	Son or daughter (-in law)	6 (18)	7 (21)
Education level, n (%)			
	Illiterate or primary school	21 (64)	19 (58)
	Junior school	5 (15)	4 (12)
	High school or above	7 (21)	10 (30)
Outcome variables at baseline, mean (SD)			
	NPI-Q[a]	5.97 (6.14)	4.45 (5.43)
	CZBI[b]	24.48 (10.77)	19.85 (11.55)
	SCIDS[c]	59.64 (5.63)	59.76 (7.36)

[a] NPI-Q: Neuropsychiatric Inventory Questionnaire.

[b] CZBI: Chinese version of the Zarit Burden Interview.

[c] SCIDS: Sense of Competence in Dementia Care Staff Scale.

Findings

According to the results of repeated measures ANOVA, as shown in Table 3, it was found that intervention and time had significant statistical effects on the NPI-Q, CZBI, and SCIDS (*P*<.05), and the significant interaction effects of group × time in primary outcome indicators were also found (*P*<.05). Since there were significant differences (group × time effect) in the primary outcome measure, analyses of the individual effects of intervention and time were performed. To verify the significance of intervention effects, multiple comparisons were subjected to the Bonferroni correction for adjustment. The comparison of various data between the intervention group and the control group at different time points is shown in Table 4. After 6 months of intervention, the NPI-Q of caregivers in the intervention group was significantly lower than that of in the control group ($t=-3.020$, $P=.004$); at 3 and 6 months after intervention, the care burden (CZBI) of caregivers in the intervention group was significantly lower than that of in the control group ($t_{3\text{month}}=-2.939$, $P=.005$; $t_{6\text{month}}=-7.858$, $P<.001$). The caregiving ability (SCIDS) of caregivers was significantly higher than that of the control group ($t_{3\text{month}}=6.138$, $P<.001$; $t_{6\text{month}}=12.16$, $P<.001$).

Using the Sidak method to conduct multiple comparisons for the individual effects of time on the primary outcome measure (NPI-Q, CZBI, and SCIDS), the results are shown in Table 5. In the intervention group, the NPI-Q score showed a decrease over time (mean $\text{difference}_{T2\text{-}T1}=-1.39$, mean $\text{difference}_{T3\text{-}T1}=-2.79$), while the comparison group showed a significant increase at the 3- and 6-month follow-up compared with baseline, with statistically significant differences (mean $\text{difference}_{T2\text{-}T1}=1.46$, mean $\text{difference}_{T3\text{-}T1}=3.64$). According to the research results, the severity of NPI-Q in patients with dementia tends to worsen over time. However, this study showed that caregiver knowledge and skills training through an information platform significantly delayed the progression of NPI-Q symptoms in patients with dementia, indicating the effectiveness of this training method.

The intervention group's CZBI scores showed a significant decrease over time (mean $\text{difference}_{T2\text{-}T1}=-7.70$, mean $\text{difference}_{T3\text{-}T1}=-13.52$), while the control group experienced a significant increase (mean $\text{difference}_{T2\text{-}T1}=4.49$, mean $\text{difference}_{T3\text{-}T1}=10.45$). The study revealed that internet-based supportive interventions providing dementia caregivers with knowledge and skills training led to a significant reduction in caregiving burden and were proved to be highly effective.

In terms of caregiving ability (SCIDS), the performance of the intervention group's caregivers significantly improved in the 3- and 6-month follow-ups, with statistically significant differences compared with before intervention (mean $\text{difference}_{T2\text{-}T1}=5.79$, mean $\text{difference}_{T3\text{-}T1}=12.24$). Conversely, the caregiving ability of the control group's caregivers declined during the same period (mean $\text{difference}_{T2\text{-}T1}=-6.70$, mean $\text{difference}_{T3\text{-}T1}=-8.64$). This result indicated that providing knowledge and skills training to informal caregivers of persons with dementia through information technology platforms can effectively enhance their caregiving skills.

Table . Comparison of 3 scores between 2 randomly assigned groups with key outcomes that vary over time.

Measure		NPI-Q[a]	CZBI[b]	SCIDS[c]
Baseline				
	Intervention group	5.97 (6.14)	24.48 (10.77)	59.64 (5.63)
	Control group	4.45 (5.43)	19.85 (11.55)	59.76 (7.36)
3 months after intervention				
	Intervention group	4.58 (4.95)	16.79 (8.05)	65.42 (6.15)
	Control group	5.91 (6.44)	24.33 (12.35)	52.06 (10.89)
6 months after intervention				
	Intervention group	3.18 (3.81)	10.97 (5.43)	71.88 (4.78)
	Control group	8.09 (8.52)	30.30 (13.05)	50.12 (9.09)
F **intergroup effect**		1.282	9.009	61.86
	P value	.26	.004	<.001
	Partial η^2	0.02	0.123	0.491
F **time effect**		0.516	3.469	3.205
	P value	.58	.05	.05
	Partial η^2	0.008	0.051	0.048
F **interaction effect**		23.856	151.706	63.03
	P value	<.001	<.001	<.001
	Partial η^2	0.272	0.703	0.492

[a] NPI-Q: Neuropsychiatric Inventory Questionnaire.

[b] CZBI: Chinese version of the Zarit Burden Interview.

[c] SCIDS: Sense of Competence in Dementia Care Staff Scale.

Table . Comparison of 3 scores between the 2 groups at different time points.

Scale		Intervention group, mean (SD)	Control group, mean (SD)	*t*	*P* value
NPI-Q [a]					
	Baseline	5.97 (6.14)	4.45 (5.43)	1.062	.29
	3 months	4.58 (4.95)	5.91 (6.44)	−0.943	.35
	6 months	3.18 (3.81)	8.09 (8.52)	−3.020	.004
CZBI [b]					
	Baseline	24.48 (10.77)	19.85 (11.55)	1.687	.10
	3 months	16.79 (8.05)	24.33 (12.35)	−2.939	.005
	6 months	10.97 (5.43)	30.30 (13.05)	−7.858	<.001
SCIDS [c]					
	Baseline	59.64 (5.63)	58.76 (7.36)	0.545	.59
	3 months	65.42 (6.15)	52.06 (10.89)	6.138	<.001
	6 months	71.88 (4.78)	50.12 (9.10)	12.160	<.001

[a] NPI-Q: Neuropsychiatric Inventory Questionnaire.

[b] CZBI: Chinese version of the Zarit Burden Interview.

[c] SCIDS: Sense of Competence in Dementia Care Staff Scale.

Table . Time for multiple comparisons of the individual effects of the Neuropsychiatric Inventory Questionnaire (NPI-Q), Chinese version of the Zarit Burden Interview (CZBI), and Sense of Competence in Dementia Care Staff Scale (SCIDS).

Measure		T2-T1		T3-T1		T3-T2	
		Mean difference (95% CI)	Adjusted *P* value	Mean difference (95% CI)	Adjusted *P* value	Mean difference (95% CI)	Adjusted *P* value
Intervention group							
	NPI-Q	−1.39 (−2.99 to 0.20)	.11	−2.79 (−4.38 to −1.19)	<.001	−1.39 (−2.99 to 0.20)	.11
	CZBI	−7.70 (−10.05 to −5.34)	<.001	−13.52 (−15.87 to −11.16)	<.001	−5.82 (−8.17 to −3.46)	<.001
	SCIDS	5.79 (2.56 to 9.02)	<.001	12.24 (9.02 to 15.47)	<.001	6.46 (3.23 to 9.68)	<.001
Control group							
	NPI-Q	1.46 (−0.14 to 3.05)	.09	3.64 (2.04 to 5.23)	<.001	2.18 (0.59 to 3.78)	.004
	CZBI	4.49 (2.13 to 6.84)	<.001	10.45 (8.10 to 12.81)	<.001	5.97 (3.62 to 8.32)	<.001
	SCIDS	−6.70 (−9.92 to −3.47)	<.001	−8.64 (−11.86 to −5.41)	<.001	−1.94 (−5.17 to 1.29)	.38

Discussion

Principal Findings

The restrictions of the COVID-19 pandemic have had profound effects on patients with dementia and their caregivers. This study shows that internet-based support and education have a positive impact on family caregivers. The intervention can reduce the NPI-Q scores of patients with dementia, enhance the dementia care skills of informal caregivers, and ease the care burden for caregivers. With the progression of dementia, caregivers not only have to deal with many behavioral, daily living, and safety issues but also lack the professional knowledge and skills to address diverse caregiving challenges. This not only causes them to experience anxiety and depression but also brings care and financial burdens to their families and society. Web-based interventions based on internet technology are highly flexible and suitable for family caregivers, as their schedules are largely consumed by caregiving and they may not have time to attend in-person learning sessions (due to travel and time constraints).

Patients diagnosed with dementia often struggle with a gradual deterioration of emotional regulation and an increased likelihood of displaying behavioral and psychological symptoms. This is closely linked to the decline in cognitive function associated with the condition. Research on caregiver burden indicated that BPSD are strongly correlated with caregiver burden [20]. The prevalence of dementia in Chinese society is expected to increase in the next 40 years. Family members remain the primary caregivers and bear a heavy burden. BPSD not only has a significant impact on the health and quality of life of patients but also brings enormous physical and psychological burdens to caregivers. In this study, the intervention group had significantly lower NPI-Q scores than the control group after 6 months of intervention. The results indicated that internet-based supportive interventions for dementia caregivers can effectively improve BPSD symptoms in patients with dementia. This result is consistent with those of previous studies [21,22]. BPSD symptoms are a prevalent issue among older individuals with dementia. These symptoms often occur repeatedly and can present at varying stages of the disease. Previous research [23] has demonstrated that the emergence of BPSD symptoms is associated with an increased risk of accelerated progression of dementia, reduced cognitive function, and a quicker decline in cognitive abilities in individuals with dementia. Our research has to some extent reduced the incidence and severity of behavioral and emotional symptoms. The meta-analysis results of Leng et al [24] also show that internet-based supportive interventions have potential benefits for the neurological and psychiatric symptoms of patients with dementia.

The research results showed that after 6 months of intervention, the total score of caregiving ability for the intervention group caregivers was significantly higher than that of the control group ($P<.05$), indicating that web-based supportive intervention for dementia informal caregivers can significantly improve their caregiving ability. Providing care for patients with dementia is an incredibly difficult task, and caregivers may struggle with a lack of essential resources, including knowledge, skills, and social support. In this context, the development of knowledge and skills to support family caregivers is essential. The web-based caregiver training intervention plan for dementia caregivers in this project covers the basic knowledge that caregivers should possess. It systematically explains the causes, clinical manifestations, and progression of dementia, promoting caregivers' understanding. Mastering knowledge is a prerequisite for improving skill levels [25]. In caring for patients with dementia, knowing about the disease can help caregivers better care for patients. Only when caregivers have a correct understanding of the illness can they truly empathize with patients and provide them with appropriate care. This study adopted web-based training to enhance caregivers' caregiving skills from 4 aspects: knowledge, skills, self-emotional management, interpersonal relationships, and resource use. In terms of intervention form, web-based knowledge and skills training is more flexible in terms of time, allowing caregivers to choose their free time to increase their participation. The result is similar to the study by Teles et al [26].

After comparing the CZBI scores of the 2 groups of caregivers at different time points, we concluded that within 6 months after the intervention, the CZBI scores of caregivers in the intervention group were significantly lower than those in the control group ($P<.05$). The findings demonstrated that the internet-based supportive intervention had a significant impact on alleviating the burden of care for dementia. This result is consistent with those of 2 studies [26,27]. The meta-analysis carried out by Egan et al [28] and the systematic review conducted by Pleasant et al [29] have also demonstrated web-based training programs' supportive intervention for informal caregivers of persons with dementia were highly effective in reducing their burden. When informal caregivers have mastered basic care knowledge and skills, their confidence in caring for patients is enhanced, uncertainty is reduced, and understanding of patients is improved. This knowledge and skills can reduce the burden on caregivers and enable them to care for patients more effectively. Using home care resources could help maintain health status, minimize symptom relief, and reduce avoidable hospitalizations [30]. This study offers a solution to the challenges faced by informal caregivers by providing them with training through web-based programs. They gain knowledge and skills that allow them to adjust their caregiving schedules flexibly to accommodate the needs of individuals with dementia. This approach not only empowered informal caregivers but also optimized the use of home care resources, making care provision more effective.

Limitations

This study has limitations. First, due to time constraints, the effects of the intervention program in this study were evaluated for only 6 months, and long-term follow-up will be conducted in the future. Second, since manpower, funding, and time constraints prevented long-term research, this study was conducted with a small sample size only. Third, we measured outcomes and exposures using self-reported questionnaires, so reporting errors was possible. Despite these limitations, our plan is still noteworthy because it is one of the few web-based interventions that have a significant impact on fostering positive emotions towards caregiving and reducing the burden on informal caregivers of persons with patients with dementia. Bastoni et al's [31] research has found that monitoring devices are rapidly developing and are seen as promising technologies. This includes monitoring health and safety in homes, as well as providing outdoor location identification for patients with dementia. In the future, we will conduct in-depth research on integrating wearable devices and other mobile information collection terminals into this information platform to achieve real-time monitoring of the health status of patients with dementia.

Conclusions

The long-term care system in China predominantly relies on informal family care. Family caregivers are the mainstay of elderly care at present in China, and their caregiving capacity directly affects the quality of family care. The lack of caregiver competence affects the quality of care because family caregivers lack basic knowledge and relevant skills in caregiving. The Chinese eldercare system relies heavily on informal care provided by family members due to filial piety. China has many patients with dementia due to its huge population base. Family caregivers are the mainstay of elderly care in China currently [32], and their ability to provide care directly affects the quality of home-based care. Caregivers for patients with dementia often face the reality of inadequate caregiving skills and a desire for support. As a family caregiver, one needs to possess a variety of knowledge and skills. This comprises an understanding of the ailment in question, being adept at solving problems creatively, and possessing techniques for maintaining psychological well-being. Informal caregivers play a crucial role in the care of individuals with dementia. Therefore, it is imperative to have interventions in place that not only support them but also alleviate their burden. Major technological advancements should be leveraged to optimize the time and effectiveness of the dementia care workforce [33]. As a cost-effective, convenient, and accessible intervention, web-based solutions have emerged to support informal caregivers. The advantage of web-based support training lies in breaking the limitations of time and space and providing a feasible solution for the popularization of support services. During the COVID-19 pandemic, our research project provided digital resources through web-based support and training to informal caregivers of persons with dementia, which improved the caregivers' skills and alleviated their burden.

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Conflicts of Interest

None declared.

Checklist 1
CONSORT-EHEALTH (V 1.6.1).
[PDF File, 9465 KB - aging_v7i1e50847_app1.pdf]

References

1. Jia L, Du Y, Chu L, et al. Prevalence, risk factors, and management of dementia and mild cognitive impairment in adults aged 60 years or older in China: a cross-sectional study. Lancet Public Health 2020 Dec;5(12):e661-e671. [doi: 10.1016/S2468-2667(20)30185-7] [Medline: 33271079]
2. Jia J, Wei C, Chen S, et al. The cost of Alzheimer's disease in China and re-estimation of costs worldwide. Alzheimers Dement 2018 Apr;14(4):483-491. [doi: 10.1016/j.jalz.2017.12.006] [Medline: 29433981]
3. Report on the family survival status of Alzheimer's disease patients in China. Alzheimer's Disease Chinese, 2020-1. 2019. URL: http://weixin.moreedge.cn/bps_2019/index.php [accessed 2023-06-23]
4. Drummond N, McCleary L, Garcia L, et al. Assessing determinants of perceived quality in transitions for people with dementia: a prospective observational study. Can Geriatr J 2019 Mar;22(1):13-22. [doi: 10.5770/cgj.22.332] [Medline: 31501679]
5. Spigelmyer PC, Schreiber JB. A pilot study: resistive behavior in the context of informal caregiver-assisted activities of daily living. Geriatr Nurs 2019 Aug;40(4):399-404. [doi: 10.1016/j.gerinurse.2019.01.005] [Medline: 30878279]
6. Baharudin AD, Din NC, Subramaniam P, Razali R. The associations between behavioral-psychological symptoms of dementia (BPSD) and coping strategy, burden of care and personality style among low-income caregivers of patients with dementia. BMC Public Health 2019 Jun 13;19(Suppl 4):447. [doi: 10.1186/s12889-019-6868-0] [Medline: 31196141]
7. Lu X, Ye R, Wu J, Rao D, Liao X. Comparing behavioral and psychological symptoms of dementia and caregiver distress caused between older adults with dementia living in the community and in nursing homes. Front Psychiatry 2022 May;13:881215. [doi: 10.3389/fpsyt.2022.881215] [Medline: 35651819]
8. Global status report on the public health response to dementia. World Health Organization. 2021. URL: www.who.int/publications/i/item/9789240033245 [accessed 2023-03-08]
9. Ramirez M, Duran MC, Pabiniak CJ, et al. Family caregiver needs and preferences for virtual training to manage behavioral and psychological symptoms of dementia: interview study. JMIR Aging 2021 Feb 10;4(1):e24965. [doi: 10.2196/24965] [Medline: 33565984]
10. Fan Q, DuBose L, Ory MG, et al. Financial, legal, and functional challenges of providing care for people living with dementia and needs for a digital platform: interview study among family caregivers. JMIR Aging 2023 Sep 5;6:e47577. [doi: 10.2196/47577] [Medline: 37526513]
11. Windle G, Flynn G, Hoare Z, et al. Effects of an e-health intervention "isupport" for reducing distress of dementia carers: protocol for a randomised controlled trial and feasibility study. BMJ Open 2022 Sep 21;12(9):e064314. [doi: 10.1136/bmjopen-2022-064314] [Medline: 36130751]

12. Baruah U, Varghese M, Loganathan S, et al. Feasibility and preliminary effectiveness of an online training and support program for caregivers of people with dementia in India: a randomized controlled trial. Int J Geriatr Psychiatry 2021 Apr;36(4):606-617. [doi: 10.1002/gps.5502] [Medline: 33491811]
13. Christie HL, Dam AEH, van Boxtel M, Köhler S, Verhey F, de Vugt ME. Lessons learned from an effectiveness evaluation of inlife, a web-based social support intervention for caregivers of people with dementia: randomized controlled trial. JMIR Aging 2022 Dec 7;5(4):e38656. [doi: 10.2196/38656] [Medline: 36476485]
14. Ottaviani AC, Monteiro DQ, Ferreira Campos CR, et al. Isupport-Brasil: preliminary results of the usability and acceptability assessment by caregivers of people who have dementia. Front Med (Lausanne) 2022 Aug;9:981748. [doi: 10.3389/fmed.2022.981748] [Medline: 36059826]
15. Meichsner F, Theurer C, Wilz G. Acceptance and treatment effects of an internet-delivered cognitive-behavioral intervention for family caregivers of people with dementia: a randomized-controlled trial. J Clin Psychol 2019 Apr;75(4):594-613. [doi: 10.1002/jclp.22739] [Medline: 30597537]
16. Kaufer DI, Cummings JL, Ketchel P, et al. Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. J Neuropsychiatry Clin Neurosci 2000;12(2):233-239. [doi: 10.1176/jnp.12.2.233] [Medline: 11001602]
17. Wang T, Xiao S, Li X, et al. Reliability and validity of the Chinese version of the neuropsychiatric inventory in Mainland China. Int J Geriatr Psychiatry 2012 May;27(5):539-544. [doi: 10.1002/gps.2757] [Medline: 21769938]
18. Ko KT, Yip PK, Liu SI, Huang CR. Chinese version of the Zarit caregiver burden interview: a validation study. Am J Geriatr Psychiatry 2008 Jun;16(6):513-518. [doi: 10.1097/JGP.0b013e318167ae5b] [Medline: 18515696]
19. Schepers AK, Orrell M, Shanahan N, Spector A. Sense of competence in dementia care staff (SCIDS) scale: development, reliability, and validity. Int Psychogeriatr 2012 Jul;24(7):1153-1162. [doi: 10.1017/S104161021100247X] [Medline: 22340666]
20. Chen YJ, Su JA, Chen JS, et al. Examining the association between neuropsychiatric symptoms among people with dementia and caregiver mental health: are caregiver burden and affiliate stigma mediators? BMC Geriatr 2023 Jan 16;23(1):27. [doi: 10.1186/s12877-023-03735-2] [Medline: 36646996]
21. Birkenhäger-Gillesse EG, Achterberg WP, Janus SIM, Kollen BJ, Zuidema SU. Effects of caregiver dementia training in caregiver-patient dyads: a randomized controlled study. Int J Geriatr Psychiatry 2020 Nov;35(11):1376-1384. [doi: 10.1002/gps.5378] [Medline: 32662184]
22. Gharavi Y, Stringer B, Hoogendoorn A, Boogaarts J, Van Raaij B, Van Meijel B. Evaluation of an interaction-skills training for reducing the burden of family caregivers of patients with severe mental illness: a pre-posttest design. BMC Psychiatry 2018 Mar 27;18(1):84. [doi: 10.1186/s12888-018-1669-z] [Medline: 29587690]
23. Eikelboom WS, van den Berg E, Singleton EH, et al. Neuropsychiatric and cognitive symptoms across the Alzheimer disease clinical spectrum: cross-sectional and longitudinal associations. Neurology 2021 Sep 28;97(13):e1276-e1287. [doi: 10.1212/WNL.0000000000012598] [Medline: 34413181]
24. Leng M, Zhao Y, Xiao H, Li C, Wang Z. Internet-based supportive interventions for family caregivers of people with dementia: systematic review and meta-analysis. J Med Internet Res 2020 Sep 9;22(9):e19468. [doi: 10.2196/19468] [Medline: 32902388]
25. Farran CJ, McCann JJ, Fogg LG, Etkin CD. Developing a measurement strategy for assessing family caregiver skills: conceptual issues. Alzheimers Care Today 2009;10(3):129-139. [doi: 10.1097/ACQ.0b013e3181b15d82] [Medline: 20179779]
26. Teles S, Ferreira A, Paúl C. Feasibility of an online training and support program for dementia carers: results from a mixed-methods pilot randomized controlled trial. BMC Geriatr 2022 Mar 1;22(1):173. [doi: 10.1186/s12877-022-02831-z] [Medline: 35232389]
27. Shadarevian J, Chan C, Berndt A, et al. Creating a toolkit with stakeholders for leveraging tablet computers to support person-centred dementia care in hospitals. J Rehabil Assist Technol Eng 2020 Jan;7:2055668320960385. [doi: 10.1177/2055668320960385] [Medline: 33282336]
28. Egan KJ, Pinto-Bruno Á, Bighelli I, et al. Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. J Am Med Dir Assoc 2018 Mar;19(3):200-206. [doi: 10.1016/j.jamda.2017.10.023] [Medline: 29306605]
29. Pleasant M, Molinari V, Dobbs D, Meng H, Hyer K. Effectiveness of online dementia caregivers training programs: a systematic review. Geriatr Nurs 2020 Nov;41(6):921-935. [doi: 10.1016/j.gerinurse.2020.07.004] [Medline: 32703628]
30. Næss G, Kirkevold M, Hammer W, Straand J, Wyller TB. Nursing care needs and services utilised by home-dwelling elderly with complex health problems: observational study. BMC Health Serv Res 2017 Sep 12;17(1):645. [doi: 10.1186/s12913-017-2600-x] [Medline: 28899369]
31. Bastoni S, Wrede C, da Silva MC, et al. Factors influencing implementation of eHealth technologies to support informal dementia care: umbrella review. JMIR Aging 2021 Oct 8;4(4):e30841. [doi: 10.2196/30841] [Medline: 34623314]
32. Krings MF, van Wijngaarden JDH, Yuan S, Huijsman R. China's elder care policies 1994-2020: a narrative document analysis. Int J Environ Res Public Health 2022 May 18;19(10):6141. [doi: 10.3390/ijerph19106141] [Medline: 35627677]
33. 2023 Alzheimer's disease facts and figures. Alzheimers Dement 2023 Apr;19(4):1598-1695. [doi: 10.1002/alz.13016] [Medline: 36918389]

Abbreviations

ANOVA: analysis of variance
BPSD: behavioral and psychological symptoms of dementia
CZBI: Chinese version of the Zarit Burden Interview
NPI-Q: Neuropsychiatric Inventory Questionnaire
SCIDS: Sense of Competence in Dementia Care Staff Scale

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mHealth Apps for Dementia Caregivers: Systematic Examination of Mobile Apps

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Abstract

Background: Informal caregivers of persons living with dementia are increasingly using mobile health (mHealth) apps to obtain care information. mHealth apps are seen as promising tools to better support caregivers' complex and evolving information needs. Yet, little is known about the types and quality of dementia care information that these apps provide. Is this information for caregivers individually tailored; if so, how?

Objective: We aim to address the aforementioned gaps in the literature by systematically examining the types and quality of care-related information provided in publicly available apps for caregivers of persons living with dementia as well as app features used to tailor information to caregivers' information wants and situations.

Methods: In September 2023, we used a multistage process to select mobile apps for caregivers of persons living with dementia. The final sample included 35 apps. We assessed (1) types of dementia care information provided in the apps, using our 3-item Alzheimer disease and related dementias daily care strategy framework, which encompasses educational information, tangible actions, and referral information; (2) quality of apps' care information, using the 11 indicators recommended by the National Library of Medicine; and (3) types of tailoring to provide personalization, feedback, and content matching, which are common tailoring strategies described in the literature.

Results: Educational information was the most prevalent type of information provided (29/35 apps, 83%), followed by information about tangible actions (18/35, 51%) and referrals (14/35, 40%). All apps presented their objectives clearly and avoided unrealistic or emotional claims. However, few provided information to explain whether the app's content was generated or reviewed by experts (7/35, 20%) or how its content was selected (4/35, 11%). Further, 6 of the 35 (17%) apps implemented 1 type of tailoring; of them, 4 (11%) used content matching and the other 2 (6%) used personalization. No app used 2 types of tailoring; only 2 (6%) used all 3 types (the third is feedback).

Conclusions: Existing dementia care apps do not provide sufficient high-quality, tailored information for informal caregivers. Caregivers should exercise caution when they use dementia care apps for informational support. Future research should focus on designing dementia care apps that incorporate quality-assured, transparency-enhanced, evidence-based artificial intelligence–enabled mHealth solutions for caregivers.

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KEYWORDS

dementia; informal care; mobile health applications; tailoring; information quality; mobile phone

Introduction

Background

Alzheimer disease and related dementias (ADRD) present a critical public health concern; in 2023, a total of 55 million individuals were estimated to live with dementia worldwide, with an increase of nearly 10 million expected each year [1]. Often, the care for these persons living with dementia falls on *informal caregivers*—family members, friends, neighbors, or others (hereafter, "caregivers"). In the United States, more than 11 million caregivers were estimated to have provided approximately 18 billion hours of care to people living with dementia in 2022, valued at over US $330 billion [2].

Caregivers of persons living with dementia often lack formal training [2,3] or have little to no knowledge about dementia care [4], representing a substantial information gap [5,6], and they have health information wants (HIWs)—"health information that one would like to have and use to make important health decisions that may or may not be directly related to diagnosis or standard treatment" [7]. Centered around health consumer's perspective, the ADRD HIWs framework suggests seven types of information that caregivers typically want for dementia care: (1) information about treatment or prevention, (2) characteristics of the patient's health condition, (3) daily care strategies for patients at home, (4) practical information about care transition and coordination and end-of-life care, (5) psychosocial aspects of caregiving, (6) resources or scientific updates, and (7) legal, financial, or insurance-related information [8]. Unmet HIWs often lead to a severe care burden and increased stress for caregivers [9,10].

Given the anticipated increase in the number of persons living with dementia and the unlikelihood of a cure in the near future, numerous interventions have been developed to equip caregivers with necessary competencies to fulfill their HIWs (see review by Whitlatch and Orsulic-Jeras [11]). However, the feasibility of most currently available face-to-face interventions is limited due to the demanding nature of caregiving, challenges in finding alternative care for persons living with dementia to attend the programs, and the scarcity of caregiver services, especially in rural or underdeveloped areas [12]. Consequently, internet-based interventions such as web-based courses [13,14], or web-based programs [15,16] have emerged as a potentially efficient alternative, providing information and support to caregivers, as evidenced by the volume of systematic reviews and meta-analyses on this topic [17-19].

According to the review by Boots et al [17], internet-based interventions can be effective in supporting caregivers if they are tailored to the individual needs. For caregivers, timely and personally tailored information is important [20]. It improves their knowledge and enables them to develop coping abilities, so that they can provide competent care throughout the disease trajectory [21,22]. A recent meta-analysis of 17 randomized controlled trials of internet-based interventions has demonstrated improvements in dementia-related knowledge and care skills among caregivers [23]. Not surprisingly, it was discovered that personalized interventions are more beneficial than interventions that are not personalized. Despite these findings, a national caregiver survey in the United States reported that caregivers use health-related internet resources less frequently than the general public [24], which limits the reach and effectiveness of these programs for caregivers at large. Additionally, challenges such as the web layout's inherent limitations and infrequent updates of features further hinder the delivery of tailored information [25,26], thus diminishing the potential effectiveness of internet-based interventions for caregivers. These findings underscore the need to explore more innovative technological solutions to better support caregivers' complex and evolving HIWs.

The Need of This Study

As of 2023, there has been a substantial increase in smartphone uptake among US adults aged 65 years or older, with adoption rates rising from 13% to 76% over the preceding decade [27,28]. Consequently, the use of mobile health (mHealth) apps to support caregivers has attracted much attention recently [29,30]. These internet-based applications, installed on mobile devices (eg, smartphones, wireless tablets), have become important tools for accessing health information and providing real-time feedback, even without computer and network connectivity [31]. They are now the most prevalent technological solutions [32] and have been used to support health education and the care across a wide range of chronic health conditions [33], and have also been tested among different age groups, including older adults [34].

Nevertheless, research on mHealth app–based interventions for caregivers is still at an early stage [29,35]. Recent literature reviews searched available apps, describing most apps as information resources for caregivers [36-38]. While these reviews acknowledged caregiving-related information as one of the most critical components of the apps, none of the studies systematically examined the quality of this information. Moreover, the extent to which these apps provide care-related information tailored to caregivers' HIWs remains unclear. As Brodaty and Donkin [39] have noted, the success of caregiver interventions depends greatly on "the extent to which they are tailored to the needs of the individual and address issues to do with subjective burden." Thus, it is critical to systematically examine mHealth apps for their information provision and tailoring, as a first step in assessing their effectiveness for the support of caregivers.

In the use of mHealth apps to tailor support [40,41], three strategies for tailoring are common: (1) *Personalization*—strategies that convey "explicitly or implicitly, that the communication is designed specifically" for an individual [42]. This is typically carried out by drawing on personally identifiable information, making clear that the messages are designed specifically for the individual, and situating the messages within the individual's specific context. (2) *Feedback*—the provision of "messages to users about their psychological or behavioral states" that reflect user updates [41]. (3) *Content matching*, which entails providing content suitable for individuals' stages of changes [40,42]. Reviews of mHealth apps for caregivers have not considered these strategies as components of tailoring [36,43]. In our study, we therefore systematically examine whether these tailoring strategies have been implemented in existing mHealth apps for caregivers of persons living with dementia, and if so, how they have been implemented.

Context of This Study and Objectives

This study is an essential component of a larger project titled "Tailoring Responses to ADRD Caregivers' InfOrmation wants (TRACO) through Human-machine Collaboration" (R56AG075770). The primary goal of the project is to develop an artificial intelligence (AI)–based system with a mobile app interface that help caregivers in obtaining high-quality, relevant information tailored to their specific HIWs and unique caregiving contexts. While mHealth apps and AI tools can provide tailored information, their full tailoring potential has been underused [44-47]. Hence, this study is designed to systematically examine how mHealth apps provide information and serve as a foundational exploration to better support the development of the TRACO system.

Specifically, this study aims to understand more about the characteristics and the delivery of these apps. Therefore, the following research questions are identified:

1. What types of information do current mHealth apps offer to caregivers of persons living with dementia?
2. What is the quality of information presented in these mHealth apps?
3. How do current mHealth apps tailor their information to support caregivers of persons living with dementia?

Methods

Study Design

Following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [48] and the procedures used in a previous systematic review of mHealth apps [49], we performed 3 rounds of screening to select relevant apps for examination. First, using keywords, we searched Apple's App Store for iOS and Google's Play Store for Android devices. Next, we screened the app store pages, using inclusion and exclusion criteria. Then we downloaded or attempted to download the apps to ensure their accessibility. Finally, using our criteria, we assessed the included apps in order to answer our research questions.

Ethical Considerations

This study did not involve human participants, human data, or any form of intervention with individuals, and therefore did not require approval from an institutional review board or ethics committee. According to the Office for Human Research Protections, research that does not include human participants falls outside the scope of institutional review board review [50]. As no human participants were involved in the research, no ethical concerns related to human subject research were applicable.

App Selection

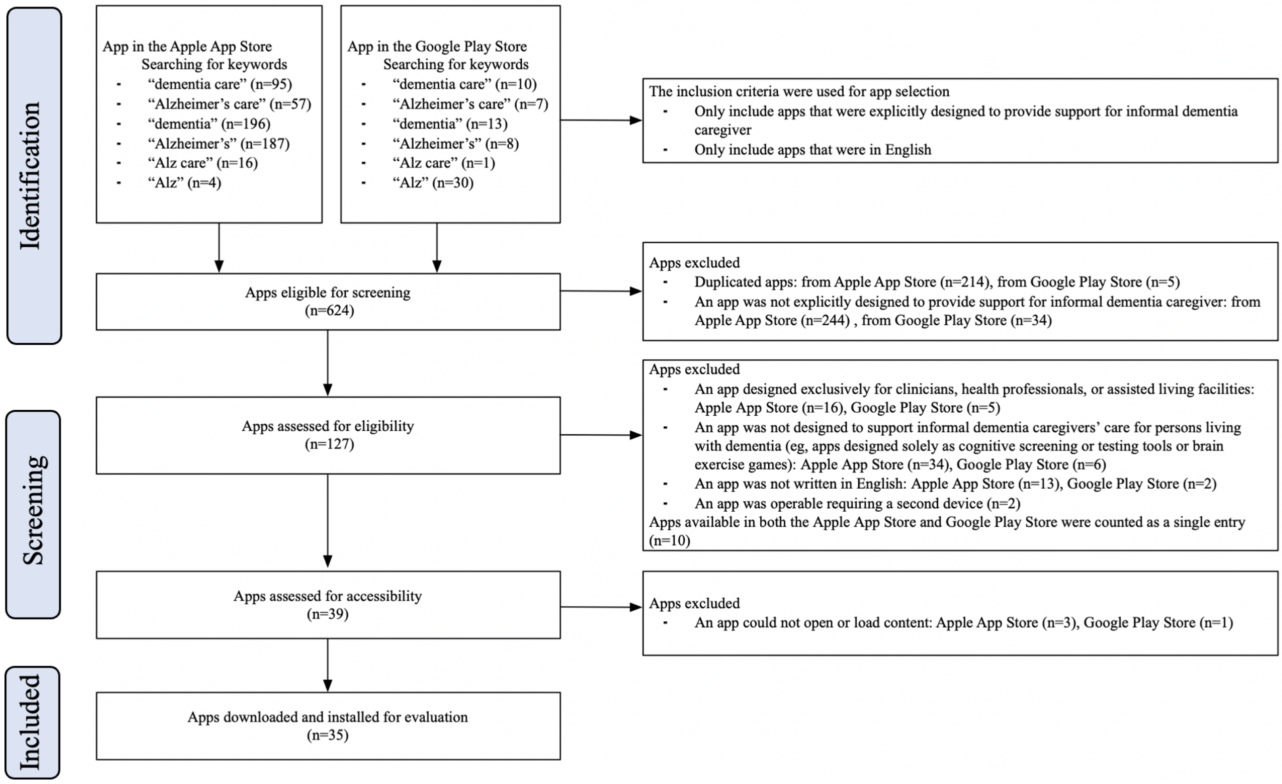
Consistent with prior reviews [36,37,51], our search keywords included the following: "dementia care," "dementia," "Alzheimer's care," and "Alzheimer's." During initial screening, we realized that several apps' titles used the abbreviation "Alz" instead of "dementia" or "Alzheimer's"; we therefore expanded the search to include "Alz." Our initial searches, performed in September 2023, yielded a total of 624 apps from Apple's App Store for iOS and from Google's Play Store for Android devices. We noted from the app store descriptions that many apps cater to various caregiver groups, not solely caregivers of persons living with dementia. These included caregivers of children with cognitive disorders or individuals with Ataxia, among others. Given our study's specific aim to investigate mHealth apps exclusively for caregivers of persons living with dementia, we excluded apps not explicitly designed for dementia care at this stage. After removing duplicates, 127 apps remained.

We then screened the 127 apps for inclusion. Consistent with the scope of this study, we included only apps developed specifically to support caregivers. Apps that did not directly support the care of persons living with dementia were excluded. Specifically, we exclude (1) apps designed to support other dementia care stakeholders, such as health professionals, clinicians, or residential care facilities; (2) apps developed solely as cognitive screening and testing tools or brain exercise games, as they did not focus on caregiving for persons living with dementia. We also excluded (3) apps not in English to maintain consistency with the larger project as stated in the introduction, and (4) those that required the use of second device (eg, smartwatch or wearable gadget). The adoption of such devices typically involves interactions with multiple stakeholders, not just caregivers [52], which is beyond the scope of this study. Both free and paid apps were included.

The research team first discussed a randomly selected subset of 10 out of the 127 apps during weekly team meetings between September and October, 2023, using the established inclusion and exclusion criteria. Any disagreements were resolved through discussions. Subsequently, based on the agreed-upon criteria, 1 researcher (NZ) continued the screening process, ultimately including a total of 39 apps for further assessment. Then, 2 researchers (NZ and BX) independently reviewed a randomly selected sample of these 39 apps (n=13, representing 33% of the total). The agreement rate between the 2 reviewers was high (92.3%), and any differences were resolved through further discussions.

Finally, we downloaded or attempted to download each of the 39 apps to an iPhone and an Android phone for further examination. During this step, we excluded 4 more apps that could not be opened or downloaded, for a final sample of 35 apps: 20 were iOS-only; 5 were Android-only; and 10 were available for both iOS and Android systems. App selection, including the numbers of apps excluded at each step, is illustrated in Figure 1.

Figure 1. App selection process.



Measures

The ADRD Daily Care Strategy Framework to Evaluate Types of Information Provided

To assess the types of dementia care information provided in the apps, we used the ADRD Daily Care Strategy Framework developed in our earlier work [53]. We selected this framework because the types of information it encompasses have been proven in our prior work to be evidence-based care strategies that effectively match the responses to caregivers' HIWs. This framework includes 3 types of information about care strategies: educational information, tangible actions that caregivers can take; and referrals for caregivers to seek help beyond the patient-caregiver dyad (Table 1). Each type of information found in the app was assigned a score of 1, and its absence was scored as 0; scores thus ranged from 0 to 3. Higher scores indicated more types of care information present in the apps.

Table . The Alzheimer disease and related dementias daily care strategy framework.

Types of information provided	Operational definition
Educational information	Provides education about the behavior or situation in question; education about what caregivers could do on their own in response to challenges encountered; focus on caregivers' own knowledge, preparation, and adjustments, not on others'
Tangible actions	Provides information about specific things caregivers can do (on their own) to address situations
Referral information	Provides referral information so that caregivers can seek help beyond the patient-caregiver dyad, for example, peer caregivers, health care professionals, financial advisors, an attorney for elder law, other family members, community organizations, and long-term care facilities

The National Library of Medicine's Criteria for Evaluating the Quality of Web-Based Health Information

The National Library of Medicine (NLM)'s tutorial on evaluating web-based health information offers a comprehensive checklist for assessing the quality of web-based health information [54].

Although the Mobile App Rating Scale [55] is commonly used to evaluate mHealth apps for caregivers [38,51], its criteria for assessing the quality of information—ensuring the app content is correct, well-written, and relevant to the goal or topic of the app—appear too vague for comprehensively evaluating the care-related information provided by the apps. Drawing on the success of previous empirical research that used the NLM's criteria to assess information quality in mHealth apps for cardiovascular disease [49], we adopted the NLM criteria and developed definitions for the context of dementia care to operationalize the NLM’s criteria (Table 2). These included 11 indicators of information quality; the presence of each indicator was recorded as 1, and each absence was recorded as 0 (scoring range: 0 - 11). Higher scores indicated higher information quality.

Table . National Library of Medicine’s criteria for information quality and our operational definitions.

Evaluation criteria	Operational definition
Providing information on who is managing the app	Provides information that could help users understand who oversees the app (eg, information about the app provider’s name). Such information is typically found via the *About Us* button in the app or on the app’s store page.
Providing information about why the app is being provided	Provides information that could help users understand the app’s purpose, intended users, and functionalities. Such information is typically found on the app’s store page or via the *About this app* or *About us* button in the app (eg, indicating that the app is developed for dementia caregivers, or to provide dementia care-related information, or to provide tailored support to dementia caregivers).
Providing the app provider’s contact information	Provides information about the physical address, a contact number or email address for the app developer or administrator, or an option for users to submit questions or comments.
Providing information on the source of the content	Provides information that could help users understand where the dementia care information used by the app comes from (eg, an article or book with authors’ names; or for web-based information, the website from which the information was retrieved).
Providing information on how the content was selected	Provides a logical explanation for how the app’s information was selected (eg, information selected from peer-reviewed journals).
The content that goes on the app is reviewed by an expert	Provides information to make clear that information presented in the app has been reviewed by qualified health care professionals.
Does not use unbelievable or emotional claims	Whether or not the app makes claims that are too good to be true or are based on emotions instead of scientific facts.
Content is up to date	The original National Library of Medicine guidelines do not specify what time frame would be considered up to date; in our study, we operationalized this indicator as app content updated in the past 12 months.
Financial disclosure	Provides information on where the money to support an app comes from (eg, government agencies, nonprofit organizations, or professional service companies). This information can help users understand whether an app’s providers have financial motives that users should be aware of (eg, the sale of courses or consultation services).
Does not have advertisements	Whether or not an app contains advertisements. Note: if a treatment option mentioned in an app was a part of scientific results (eg, reported in a research article), then it was not considered an advertisement.
Personal data privacy disclosure	Whether or not an app asks users to submit personal information (eg, name, phone number, or email address) and personal health indicators (eg, health status or medical history) in order to use certain app features. If asked, whether an app provides information on how users’ personal data will be used.

Types of Tailoring Strategies for Evaluating Apps’ Information Tailoring

We examined whether apps provided the 3 types of tailoring strategies commonly reported in the literature: personalization, feedback, and content matching [40,42]. Our operational definitions for these 3 types of tailoring are provided in Table 3. The presence of each type of tailoring was recorded as 1, and each absence was recorded as 0 (scoring range: 0 - 3). Higher scores indicate more types of tailoring.

Table . Information tailoring strategies and our operational definitions.

Evaluation criteria	Operational definitions
Personalization	App’s output contains personal information (based on the user’s input, for example, the person living with dementia is the user’s grandmother) to make clear that the output was designed specifically for the user and places the messages in the user’s specific context.
Feedback	App’s output contains information acknowledging the user’s specific situation (based on the user’s input) to convey to the user that the system is aware of the user’s situation.
Content matching	App’s output contains relevant responses to the types of health information wants expressed in a user’s input.

Data Analysis

We assessed (1) types of dementia care information provided in the apps, using our 3-item ADRD Daily Care Strategy Framework; (2) quality of dementia care information provided in the apps, using the 11 indicators recommended by the NLM; and (3) types of tailoring provided, using the 3 common tailoring strategies reported in the literature. Further, 2 members of the research team (NZ and BX) initially evaluated 7 randomly selected apps from the final sample according to these measures. For any items with a recorded disagreement, the 2 reviewers met to discuss and reach a consensus. Later, researcher NZ continued and completed the evaluation of the remaining apps. Discussions were consistently held between researchers NZ and BX to address any ambiguities that arose during the evaluation process. The ratings for each measure were entered into a Microsoft Excel spreadsheet, and we used descriptive statistics to analyze each rating.

Results

Overview

Of the 35 apps in our final sample, 10 (29%) were developed between 2012 and 2017. Among them, only 1 (3%) was still having regular updates at the time of our study. Further, 6 (17%) of the apps had actively received updates, for an average duration of 5 (SD 1.55) years before stopping any further updates; 3 had not been updated at all since their initial release. The other 25 (71%) apps were developed between 2018 and 2023. Additionally, 13 (37%) were actively receiving updates by 2023; 7 (20%) had not received any updates since their release; and another 5 (14%) stopped receiving updates after an average of 2.4 (SD 1.95) years.

In total, 15 (43%) apps were created by for-profit companies such as corporations providing health care services or consulting firms; 8 (23%) were developed by nonprofit health care organizations or charities; another 8 (23%) were developed by academic institutions; and the remaining 4 (11%) did not disclose any affiliation of app developers. Most apps were free (28/35; 80%); 5 (14%) were free with in-app purchases; only 2 (6%) were paid apps (requiring US $2.99 and US $3.99, respectively). The largest number of apps (15/35, 43%) were from the United States; 8 (23%) from the United Kingdom; 4 (11%) from Australia, 3 (9%) from Canada, and 1 (3%) from India. The 4 (11%) apps that provided no developer information also provided no information about where they were developed.

Types of Information

In total, 16 (46%) of the apps offered only 1 type of information. Among them, 12 (75%) provided educational information; 2 (13%) offered information about tangible actions, and 2 (13%) offered referral information. Further, 12 (34%) apps offered 2 types of information: 7 (58%) of them offered both educational information and information about tangible actions; 3 (25%) provided both educational information and referral information; and 2 (13%) provided both information about tangible actions and referral information. Only 7 (20%) apps in our final sample offered all 3 types of information. Of the reviewed apps, if an app attempted to offer more than one type of information, its content frequently remained broad and merely basic, in contrast to apps that specialized in providing only a specific type of information. Overall, educational information was the most commonly offered type of information (29/35, 83%), followed by information about tangible actions (18/35, 51%). Information about referrals (14/35, 40%) was the least common type of information provided in the apps.

Information Quality

Of the 35 apps, 17% (6 apps) met 3 - 4 of the NLM’s criteria for web-based health information quality. Another 34% (12 apps) met 5 - 6 criteria, and 40% (14 apps) met 7 - 9 criteria. Only 11% (4 apps) met 10 of the NLM’s criteria, and none met all 11 criteria. Notably, the 4 apps that met 10 criteria were all developed by academic institutions, nonprofit health care organizations, or charities. In contrast, all 6 apps meeting only 3 or 4 criteria were developed by for-profit companies or developers of unknown origin. Apps available on both iOS and Android systems scored higher on average (mean 7.9, SD 2.28, 95% CI 7.14-8.66) than those available exclusively on iOS (mean 6.6, SD 1.73, 95% CI 6.03-7.17) or Android (mean 4, SD 1.41, 95% CI 3.53-4.47). All apps met 2 of the NLM criteria: they clearly stated the purpose of developing the app and avoided making unbelievable or emotional claims. Few explained whether the app’s content was reviewed by experts (7/35, 20%); and even fewer stated how the content was selected (4/35, 11%; Table 4).

Table . National Library of Medicine's information quality indicators covered by the apps.

Information quality indicator	Apps, n (%)
Provided information about why the app is being provided	35 (100)
Does not use unbelievable or emotional claims	35 (100)
Provided information on who is managing the app	30 (86)
Does not have advertisements	29 (83)
Provided the app provider's contact information	25 (71)
Personal information use disclosure	22 (63)
Provided information on the source of the content	18 (51)
Content is up to date	15 (43)
Financial disclosure	13 (37)
The content that goes on the app is reviewed by an expert	7 (20)
Providing information on how the content was selected	4 (11)

Information Tailoring

In total, 6 of the 35 (17%) apps implemented 1 type of tailoring strategy; of them, 4 (11%) used content matching and the remaining 2 (6%) used personalization. The specific content matching strategies varied among the 4 apps. Further, 2 of the apps used web-based discussion forums to deliver responses from platform-verified experts or peer caregivers. The other 2 offered a list of behavioral problems along with possible causes, allowing caregivers to choose, and, on the basis of the caregivers' choice, the app tailored a list of care strategies to address the specific problem expressed by the caregiver.

Of the 2 apps that entailed personalization, each used a unique approach to collect and use personal information. However, neither app successfully delivered tailored support. The first app gathered detailed information on the person living with dementia, such as disease stage and health conditions. The second app surveyed caregivers' stress levels and the person living with dementia's behavioral issues. Despite collecting such personal information, both apps failed to tailor the content depending on user input and provided the same responses regardless of the user data provided. This lack of customization and transparency about how personal information affected content raises concerns about the apps' effectiveness and credibility for offering personalized support.

No app used 2 types of tailoring strategies; 2 (6%) used all 3 tailoring strategies. Both apps used generative AI-enabled intelligent assistants to provide tailored responses. These platforms allowed caregivers to input any queries and provided personalized answers. One of these apps explicitly stated that it used ChatGPT for this purpose; the other did not specify what AI tool it used or how its intelligent assistant was developed.

Discussion

Principal Findings

Previous reviews have found that dementia care apps mainly offer educational content along with generic care tips for coping [36,37]. In our study, we have examined the extent to which care-related information in the apps includes not only educational information but also information about tangible actions and referrals. Tangible action and referral information were underrepresented in the apps. As these 2 types of information can vary greatly depending on caregivers' specific situations [56,57], it may be challenging for apps to provide such information. Current dementia care apps primarily provide extensive static educational information, and so they cannot meet caregivers' specific HIWs [36,38]. Future dementia care apps should consider including elements designed to capture caregivers' specific HIWs, which can evolve as the disease progresses [8].

Recent reviews have primarily used the Mobile App Rating Scale [55] to evaluate apps and have found that the quality of information in dementia care apps falls below minimum acceptable scores [38,51]. Going beyond statistical validation of this known issue regarding poor information quality [36], we have adapted the NLM's information quality evaluation criteria to examine specific attributes that affect information quality. Apps developed by academic institutions or nonprofit health care organizations appeared to align more closely with the NLM's quality indicators. Nevertheless, the lack of indicators for expert-reviewed content and content selection remains a problem. Given the critical role of health care providers in ensuring the accuracy and reliability of information [49,58], further research is needed to explore how to design features that integrate dementia care professionals within information assessment and selection [58,59]. Implementing these improvements will enhance the credibility and reliability of caring-related information and potentially improve caregivers' information-seeking and, ultimately, the apps' adoption rates [60].

Commonly recommended tailoring has yet to be successfully implemented in dementia care apps. By and large, apps' tailoring merely replicates approaches found in web-based discussion forums [61,62]. Yet, there is potential for dementia care apps to provide more tailored, personally relevant learning [36]. The AI-enabled intelligent assistants found in 2 of the reviewed apps may represent a promising approach for delivering tailored information. Recent research suggests ChatGPT's capability to generate high-quality responses to meet dementia caregivers'

HIWs [63]. Nonetheless, recent studies have raised concerns regarding ChatGPT's use in health care, particularly its tendency to conceal its information sources and provide inappropriate references [64]; its outputs may require cautious human oversight to ensure quality [65].

These concerns echo our findings for apps' lack of explanation regarding information selection, including a lack of information about whether their content had been reviewed by health care professionals. If unaddressed, these issues are likely to persist in AI-enabled mHealth apps for caregivers. More rigorous efforts are needed in dementia care research and practice to investigate AI-enabled mHealth tools. There is a need to explore comprehensive frameworks that involve health care professionals in content validation, as well as advancements to streamline these technological processes.

Limitations and Future Directions

Limitations of this study include the following. App evaluation was carried out by researchers with professional expertise in the subject matter; no evaluation was performed by caregivers. Our evaluation relied on guidelines designed from a top-down perspective, reflecting what health care professionals would view as important for evaluating an app's information quality. This approach might not fully align with caregivers' perspectives, and the insights derived might differ from those of caregivers. Given the importance of user-centered design in developing mHealth technology for dementia caregiving [66], future research will benefit from caregivers' evaluation of such technology. User-centered evaluation would ensure that apps meet caregivers' actual needs and preferences. This study only included mHealth apps that were available in English, thus, there could be apps available in other languages that provide high-quality information to caregivers of persons living with dementia. This study did not consider app design or usability when evaluating the type and quality of information provided. Given that academic institutions and nonprofits produced mHealth apps with higher information quality, future developments could include collaborations with for-profit organizations to design tailored apps that meet the needs of caregivers of persons living with dementia.

Conclusion

Tailoring and the quality of care information is limited in current mHealth apps for caregivers. Caregivers should use current dementia care apps with caution when they seek information about caregiving and support. Although mHealth may potentially be effective in meeting caregivers' HIWs, future research is needed in order to develop quality-assured, transparency-enhanced, evidence-based AI-enabled mHealth solutions for caregivers.

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Conflicts of Interest

None declared

References

1. Dementia. World Heath Organization. 2023. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2023-11-02]
2. 2023 Alzheimer's disease facts and figures. Alzheimers Dement 2023 Apr;19(4):1598-1695. [doi: 10.1002/alz.13016]
3. Spillman BC, Wolff J, Freedman VA, Kasper JD. Informal caregiving for older americans:an analysis of the 2011 national study of caregiving. US Department of Health and HumanServices. 2014. URL: https://aspe.hhs.gov/reports/informal-caregiving-older-americans-analysis-2011-national-study-caregiving [accessed 2024-10-10]
4. Peterson K, Hahn H, Lee AJ, Madison CA, Atri A. In the information age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. BMC Geriatr 2016 Sep 23;16(1):164. [doi: 10.1186/s12877-016-0338-7] [Medline: 27662829]
5. McCabe M, You E, Tatangelo G. Hearing their voice: a systematic review of dementia family caregivers' needs. Gerontologist 2016 Oct;56(5):e70-e88. [doi: 10.1093/geront/gnw078] [Medline: 27102056]
6. Soong A, Au ST, Kyaw BM, Theng YL, Tudor Car L. Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. BMC Geriatr 2020 Feb 14;20(1):61. [doi: 10.1186/s12877-020-1454-y] [Medline: 32059648]
7. Xie B. Older adults' health information wants in the internet age: implications for patient-provider relationships. J Health Commun 2009 Sep;14(6):510-524. [doi: 10.1080/10810730903089614] [Medline: 19731124]
8. Wang Z, Zou N, Xie B, et al. Characterizing dementia caregivers' information exchange onsocial media: exploring an expert-machine co-development process. In: Toeppe K, Yan H, Chu SKW, editors. Diversity, Divergence, Dialogue: 16th International Conference, iConference2021 Proceedings Part I: Springer Nature Switzerland; 2021:47-67. [doi: 10.1007/978-3-030-71292-1_6]

9. Ruggiano N, Brown EL, Shaw S, et al. The potential of information technology to navigate caregiving systems: perspectives from dementia caregivers. J Gerontol Soc Work 2019;62(4):432-450. [doi: 10.1080/01634372.2018.1546786] [Medline: 30422754]
10. Hargreaves S, Sbaffi L, Ford N. Information seeking amongst informal caregivers of people with dementia: a qualitative study. JD 2023 Mar 6;79(2):281-300. [doi: 10.1108/JD-03-2022-0066]
11. Whitlatch CJ, Orsulic-Jeras S. Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. Gerontologist 2018 Jan 18;58(suppl_1):S58-S73. [doi: 10.1093/geront/gnx162] [Medline: 29361068]
12. Cheng ST, Au A, Losada A, Thompson LW, Gallagher-Thompson D. Psychological interventions for dementia caregivers: what we have achieved, what we have learned. Curr Psychiatry Rep 2019 Jun 6;21(7):59. [doi: 10.1007/s11920-019-1045-9] [Medline: 31172302]
13. Blom MM, Zarit SH, Groot Zwaaftink RBM, Cuijpers P, Pot AM. Effectiveness of an internet intervention for family caregivers of people with dementia: results of a randomized controlled trial. PLoS ONE 2015;10(2):e0116622. [doi: 10.1371/journal.pone.0116622] [Medline: 25679228]
14. Hattink B, Meiland F, van der Roest H, et al. Web-based STAR E-learning course increases empathy and understanding in dementia caregivers: results from a randomized controlled trial in the Netherlands and the United Kingdom. J Med Internet Res 2015 Oct 30;17(10):e241. [doi: 10.2196/jmir.4025] [Medline: 26519106]
15. Torkamani M, McDonald L, Saez Aguayo I, et al. A randomized controlled pilot study to evaluate a technology platform for the assisted living of people with dementia and their carers. J Alzheimers Dis 2014;41(2):515-523. [doi: 10.3233/JAD-132156] [Medline: 24643137]
16. Kales HC, Gitlin LN, Stanislawski B, et al. Effect of the WeCareAdvisor™ on family caregiver outcomes in dementia: a pilot randomized controlled trial. BMC Geriatr 2018 May 10;18(1):113. [doi: 10.1186/s12877-018-0801-8] [Medline: 29747583]
17. Boots LMM, de Vugt ME, van Knippenberg RJM, Kempen GIJM, Verhey FRJ. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. Int J Geriatr Psychiatry 2014 Apr;29(4):331-344. [doi: 10.1002/gps.4016] [Medline: 23963684]
18. Christie HL, Bartels SL, Boots LMM, Tange HJ, Verhey FJJ, de Vugt ME. A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. Internet Interv 2018 Sep;13:51-59. [doi: 10.1016/j.invent.2018.07.002] [Medline: 30206519]
19. Hopwood J, Walker N, McDonagh L, et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: systematic review. J Med Internet Res 2018 Jun 12;20(6):e216. [doi: 10.2196/jmir.9548] [Medline: 29895512]
20. van der Roest HG, Meiland FJM, Jonker C, Dröes RM. User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness. Aging Ment Health 2010 May 1;14(4):461-470. [doi: 10.1080/13607860903311741]
21. Bressan V, Visintini C, Palese A. What do family caregivers of people with dementia need? A mixed-method systematic review. Health Soc Care Community 2020 Nov;28(6):1942-1960. [doi: 10.1111/hsc.13048] [Medline: 32542963]
22. Kokorelias KM, Gignac MAM, Naglie G, et al. A grounded theory study to identify caregiving phases and support needs across the Alzheimer's disease trajectory. Disabil Rehabil 2022 Apr;44(7):1050-1059. [doi: 10.1080/09638288.2020.1788655] [Medline: 32687722]
23. Leng M, Zhao Y, Xiao H, Li C, Wang Z. Internet-based supportive interventions for family caregivers of people with dementia: systematic review and meta-analysis. J Med Internet Res 2020 Sep 9;22(9):e19468. [doi: 10.2196/19468] [Medline: 32902388]
24. Kim H. Understanding internet use among dementia caregivers: results of secondary data analysis using the US caregiver survey data. Interact J Med Res 2015;4(1):e1. [doi: 10.2196/ijmir.3127]
25. Gaugler JE, Reese M, Tanler R. Care to Plan: an online tool that offers tailored support to dementia caregivers. Gerontologist 2016 Dec;56(6):1161-1174. [doi: 10.1093/geront/gnv150] [Medline: 26603183]
26. Kabir ZN, Leung AYM, Grundberg Å, et al. Care of family caregivers of persons with dementia (CaFCa) through a tailor-made mobile app: study protocol of a complex intervention study. BMC Geriatr 2020 Aug 26;20(1):305. [doi: 10.1186/s12877-020-01712-7] [Medline: 32847495]
27. Faverio M. Share of those 67 and older who are tech users has grown in the past decade. Pew Research Center. 2022. URL: https://www.pewresearch.org/short-reads/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/ [accessed 2024-05-26]
28. Mobile fact sheet. Pew Research Center. 2024. URL: https://www.pewresearch.org/internet/fact-sheet/mobile/ [accessed 2024-10-10]
29. Brown EL, Ruggiano N, Li J, Clarke PJ, Kay ES, Hristidis V. Smartphone-based health technologies for dementia care: opportunities, challenges, and current practices. J Appl Gerontol 2019 Jan;38(1):73-91. [doi: 10.1177/0733464817723088] [Medline: 28774215]

30. Faieta J, Sheehan J, DiGiovine C. Mhealth interventions to improve health and quality of life related outcomes for informal dementia caregivers: a scoping review. Assist Technol 2022 May 4;34(3):362-374. [doi: 10.1080/10400435.2020.1829174] [Medline: 33006526]
31. Zhang MWB, Chan S, Wynne O, et al. Conceptualization of an evidence-based smartphone innovation for caregivers and persons living with dementia. Technol Health Care 2016 Sep 14;24(5):769-773. [doi: 10.3233/THC-161165] [Medline: 27129032]
32. Rivera-Romero O, Gabarron E, Ropero J, Denecke K. Designing personalised mHealth solutions: an overview. J Biomed Inform 2023 Oct;146:104500. [doi: 10.1016/j.jbi.2023.104500] [Medline: 37722446]
33. Kelley MM, Powell T, Camara D, et al. Mobile health apps, family caregivers, and care planning: scoping review. J Med Internet Res 2024 May 23;26:e46108. [doi: 10.2196/46108] [Medline: 38781588]
34. Changizi M, Kaveh MH. Effectiveness of the mHealth technology in improvement of healthy behaviors in an elderly population-a systematic review. mHealth 2017;3:51. [doi: 10.21037/mhealth.2017.08.06] [Medline: 29430455]
35. Lorca-Cabrera J, Grau C, Martí-Arques R, Raigal-Aran L, Falcó-Pegueroles A, Albacar-Riobóo N. Effectiveness of health web-based and mobile app-based interventions designed to improve informal caregiver’s well-being and quality of life: a systematic review. Int J Med Inform 2020 Feb;134:104003. [doi: 10.1016/j.ijmedinf.2019.104003] [Medline: 31790857]
36. Wozney L, Freitas de Souza LM, Kervin E, Queluz F, McGrath PJ, Keefe J. Commercially available mobile apps for caregivers of people with Alzheimer disease or other related dementias: systematic search. JMIR Aging 2018 Dec 7;1(2):e12274. [doi: 10.2196/12274] [Medline: 31518255]
37. Choi SK, Yelton B, Ezeanya VK, Kannaley K, Friedman DB. Review of the content and quality of mobile applications about Alzheimer’s disease and related dementias. J Appl Gerontol 2020 Jun;39(6):601-608. [doi: 10.1177/0733464818790187] [Medline: 30049239]
38. Werner NE, Brown JC, Loganathar P, Holden RJ. Quality of mobile apps for care partners of people with Alzheimer disease and related dementias: mobile app rating scale evaluation. JMIR mHealth uHealth 2022 Mar 29;10(3):e33863. [doi: 10.2196/33863] [Medline: 35348467]
39. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci 2009;11(2):217-228. [doi: 10.31887/DCNS.2009.11.2/hbrodaty] [Medline: 19585957]
40. Noar SM, Grant Harrington N, Van Stee SK, Shemanski Aldrich R. Tailored health communication to change lifestyle behaviors. Am J Lifestyle Med 2011 Mar;5(2):112-122. [doi: 10.1177/1559827610387255]
41. Kamel Ghalibaf A, Nazari E, Gholian-Aval M, Tara M. Comprehensive overview of computer-based health information tailoring: a systematic scoping review. BMJ Open 2019 Jan 9;9(1):e021022. [doi: 10.1136/bmjopen-2017-021022] [Medline: 30782671]
42. Hawkins RP, Kreuter M, Resnicow K, Fishbein M, Dijkstra A. Understanding tailoring in communicating about health. Health Educ Res 2008 Jun;23(3):454-466. [doi: 10.1093/her/cyn004] [Medline: 18349033]
43. Kim E, Baskys A, Law AV, Roosan MR, Li Y, Roosan D. Scoping review: the empowerment of Alzheimer’s disease caregivers with mHealth applications. NPJ Digit Med 2021 Sep 7;4(1):131. [doi: 10.1038/s41746-021-00506-4] [Medline: 34493819]
44. de Jongh T, Gurol-Urganci I, Vodopivec-Jamsek V, Car J, Atun R. Mobile phone messaging for facilitating self-management of long-term illnesses. Cochrane Database Syst Rev 2012 Dec 12;12(12):CD007459. [doi: 10.1002/14651858.CD007459.pub2] [Medline: 23235644]
45. Kannisto KA, Koivunen MH, Välimäki MA. Use of mobile phone text message reminders in health care services: a narrative literature review. J Med Internet Res 2014 Oct 17;16(10):e222. [doi: 10.2196/jmir.3442] [Medline: 25326646]
46. Nhavoto JA, Gronlund A. Mobile technologies and geographic information systems to improve health care systems: a literature review. JMIR mHealth uHealth 2014;2(2):e21. [doi: 10/2196/mhealth.3216]
47. Househ M. The role of short messaging service in supporting the delivery of healthcare: an umbrella systematic review. Health Informatics J 2016 Jun;22(2):140-150. [doi: 10.1177/1460458214540908] [Medline: 25038203]
48. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. J Clin Epidemiol 2009 Oct;62(10):e1-34. [doi: 10.1016/j.jclinepi.2009.06.006] [Medline: 19631507]
49. Nie L, Xie B, Yang Y, Shan YM. Characteristics of chinese m-Health applications for diabetes self-management. Telemed J E Health 2016 Jul;22(7):614-619. [doi: 10.1089/tmj.2015.0184] [Medline: 27171016]
50. 45 CFR 46. US Department of Health and Human Services. 2016. URL: https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html [accessed 2024-09-27]
51. Castillo LIR, Tran V, Hadjistavropoulos T. Are mobile apps meeting the needs of caregivers of people living with dementia? An evaluation of existing apps for caregivers. Aging Ment Health 2024 Apr;28(4):577-586. [doi: 10.1080/13607863.2023.2177832] [Medline: 36775643]
52. Zou N, Chi Y, He D, Xie B, Wang Z. Together they shall not fade away: opportunities and challenges of self-tracking for dementia care. Inf Process Manag 2022 Sep;59(5):103024. [doi: 10.1016/j.ipm.2022.103024]
53. Zou N, Ji Y, Xie B, He D, Luo Z. Mapping dementia caregivers’ comments on social media with evidence-based care strategies for memory loss and confusion. 2023 Mar 19 Presented at: 2023 Conference on Human Information Interaction

and Retrieval; Mar 19-23, 2023; Austin TX USA p. 362-367 URL: https://dl.acm.org/doi/proceedings/10.1145/3576840 [doi: 10.1145/3576840.3578313]

54. Evaluating internet health information: a tutorial from the national library of medicine. MedlinePlus. 2023. URL: https://medlineplus.gov/webeval/EvaluatingInternetHealthInformationTutorial.pdf [accessed 2024-10-11]
55. Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR mHealth uHealth 2015;3(1):e27. [doi: 10.2196/mhealth.3422] [Medline: 25760773]
56. Cha J, Peterson CM, Millenbah AN, et al. Delivering personalized recommendations to support caregivers of people living with dementia: mixed methods study. J Aging 2022 May 3;5(2):e35847. [doi: 10.2196/35847] [Medline: 35503650]
57. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. Gerontologist 2015 Apr;55(2):210-226. [doi: 10.1093/geront/gnu123] [Medline: 26035597]
58. Berridge C, Demiris G, Kaye J. Domain experts on dementia-care technologies: mitigating risk in design and implementation. Sci Eng Ethics 2021 Feb 18;27(1):14. [doi: 10.1007/s11948-021-00286-w] [Medline: 33599847]
59. Gagnon MP, Ngangue P, Payne-Gagnon J, Desmartis M. m-Health adoption by healthcare professionals: a systematic review. J Am Med Inform Assoc 2016 Jan;23(1):212-220. [doi: 10.1093/jamia/ocv052] [Medline: 26078410]
60. Rutkowski RA, Ponnala S, Younan L, Weiler DT, Bykovskyi AG, Werner NE. A process-based approach to exploring the information behavior of informal caregivers of people living with dementia. Int J Med Inform 2021 Jan;145:104341. [doi: 10.1016/j.ijmedinf.2020.104341] [Medline: 33242761]
61. Rupert DJ, Gard Read J, Amoozegar JB, et al. Peer-generated health information: the role of online communities in patient and caregiver health decisions. J Health Commun 2016 Nov;21(11):1187-1197. [doi: 10.1080/10810730.2016.1237592] [Medline: 27805496]
62. Wasilewski MB, Stinson JN, Cameron JI. Web-based health interventions for family caregivers of elderly individuals: a scoping review. Int J Med Inform 2017 Jul;103:109-138. [doi: 10.1016/j.ijmedinf.2017.04.009] [Medline: 28550996]
63. Aguirre A, Hilsabeck R, Smith T, et al. Assessing the quality of ChatGPT responses to dementia caregivers. Quest Qual Anal JMIR Aging 2024;7:e53019. [doi: 10.2196/53019] [Medline: 38722219]
64. Whiles BB, Bird VG, Canales BK, DiBianco JM, Terry RS. Caution! AI bot has entered the patient chat: ChatGPT has limitations in providing accurate urologic healthcare advice. Urology 2023 Oct;180:278-284. [doi: 10.1016/j.urology.2023.07.010] [Medline: 37467806]
65. Spallek S, Birrell L, Kershaw S, Devine EK, Thornton L. Can we use ChatGPT for mental health and substance use education? Examining its quality and potential harms. JMIR Med Educ 2023 Nov 30;9:e51243. [doi: 10.2196/51243] [Medline: 38032714]
66. Thorpe JR, Rønn-Andersen KVH, Bień P, Özkil AG, Forchhammer BH, Maier AM. Pervasive assistive technology for people with dementia: a UCD case. Healthc Technol Lett 2016 Dec;3(4):297-302. [doi: 10.1049/htl.2016.0057] [Medline: 28008366]

Abbreviations

ADRD: Alzheimer disease and related dementias
AI : artificial intelligence
HIW: health information want
mHealth: mobile health
NLM: National Library of Medicine
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
TRACO: Tailoring Responses to Alzheimer Disease and Related Dementias Caregivers' Information

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Original Paper

Refining Cultural Adaptations of a Behavioral Intervention for Latino Caregivers of People Living With Dementia: Qualitative Interview Study in Washington State

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Abstract

Background: In the United States, Latino caregivers of individuals with dementia face unique challenges and an elevated risk of adverse health outcomes. Despite the increasing prevalence of Alzheimer disease and related dementias among Latino adults, few evidence-based interventions are tailored to their cultural context. To address this gap, we examined the cultural adaptations required for the STAR caregivers (STAR-C) virtual intervention, an evidence-based intervention that educates family caregivers to manage behavioral and psychological symptoms of dementia. While STAR-C has shown effectiveness, neither the original in-person nor the virtual intervention considered the distinct experiences of Latino caregivers, who often bring culturally significant values into caregiving interactions.

Objective: This study's objective was to test and refine the preliminary cultural adaptations of the STAR-C web-based training modules for Latino caregivers of people living with dementia.

Methods: Through qualitative interviews with 15 Latino caregivers in Washington State, we identified key adaptations to enhance the cultural relevance of the web-based training modules.

Results: The interviews highlighted 4 main themes for adaptation: the delivery of the STAR-C web-based training modules, comprehensive dementia education, simplified problem-solving strategies, and prioritizing caregiver well-being.

Conclusions: This study's findings informed the development of culturally adapted STAR-C web-based training modules that aim to provide tailored support to Latino caregivers. While further research is needed to assess the efficacy of these adaptations, our work contributes to bridging the gap in dementia caregiving for Latino families, potentially reducing health disparities and enhancing health care services for this population.

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KEYWORDS

caregivers; caregiver; caregiving; carer; carers; STAR-C; STAR caregiver; internet; web-based; online; educational; education; family care; family; families; informal care; adaptation; adaptations; cultural; culturally; module; modules; training; Hispanic; Hispanics; Spanish; Latin; Latina; Latinas; Latinos; Latinx; Latino; dementia; qualitative research; Alzheimer disease; qualitative; Alzheimer; experience; experiences; attitude; attitudes; opinion; perception; perceptions; perspective; perspectives; aging; older adults; old age; mental health; neuro; ageing; geriatrics; gerontology; geriatric; interview; eHealth; digital health; alzheimers; memory; memory loss; care giving; Hispanic or Latino; mobile phone

Introduction

Latino caregivers of people living with dementia are at an increased risk of experiencing adverse health impacts due to caregiving, yet few evidence-based interventions have been developed to support Latino families [1]. In the United States, Latino adults are 1.5 times more likely to develop Alzheimer disease and related dementias (ADRD) compared to non-Latino

White adults [2]. The disparity is due in large part to the health conditions (eg, cardiovascular disease, diabetes, high blood pressure, and obesity) and socioeconomic factors (eg, chronic exposure to economic and social adversity, lower levels and quality of education, and discrimination) that are more prevalent in Latino populations and are associated with cognitive decline [2,3]. The number of Latino people living with dementia is expected to increase to 3.5 million by 2060, leading to a rise in Latino adults caring for family members with ADRD [4]. Although evidence-based caregiver interventions exist, they often fall short in meeting the unique cultural needs of Latino families [1,5,6]. There is an urgent need to develop culturally appropriate evidence-based interventions that address the unique challenges faced by Latino caregivers of people living with dementia and consider the sociocultural context in which they provide care.

STAR caregivers (STAR-C) is an in-home intervention that involves training health professionals to teach family caregivers strategies to manage behavioral and psychological symptoms of dementia (BPSD) [7,8]. Caregivers learn to monitor symptoms, identify possible environmental or interpersonal triggers, and develop effective responses. They also learn strategies for communicating with people living with dementia in a way that supports positive affect and prevents or minimizes problems, increasing pleasant events to improve mood, and improving the support caregivers receive from informal and formal networks. STAR-C is demonstrated to reduce the frequency and severity of BPSD, as well as improve burden, depression, and reactivity to symptoms in caregivers [7]. Recently, STAR-C was reconfigured as a virtual intervention to facilitate large-scale implementation in clinical settings. The virtual intervention, coined STAR-C Virtual Training and Follow-up is being tested in an ongoing trial at Kaiser Permanente Washington [9,10]. For 6-8 weeks, caregivers complete 6 web-based training modules asynchronously and have six 30-minute weekly telephone check-ins with a coach (ie, master's-level social worker or mental health counselor). In addition, support from coaches is provided, as needed, via secure messaging in the Kaiser Permanente Washington patient portal for up to 6 months.

The STAR-C virtual intervention was timely given the COVID-19 pandemic, which shed light on the urgent need for digital health strategies that offer support virtually [11]. Many social and health care services for older adults and their family caregivers shifted from in-person to digital platforms to expand reach during the pandemic [12]. Neither the in-person or virtual STAR-C interventions, however, were developed with explicit consideration of the experience of Latinos providing care to a family member living with ADRD. Caregiver interventions for Latinos need cultural adaptations because cultural values and beliefs, such as *familismo* (dedication and commitment to family) and *respeto* (respect) play a pivotal role in shaping caregiving interactions with people living with dementia, experiences, and perceptions of support [13]. The goal of performing cultural adaptations to evidence-based interventions such as STAR-C is to promote more favorable experiences with the intervention and alleviate the health disparities associated with dementia caregiving among vulnerable populations.

To address the gap in the lack of culturally appropriate evidence-based interventions for Latino caregivers, we sought to culturally adapt the content of the web-based training modules of the STAR-C virtual intervention for Latino caregivers. In our previous study, we identified what cultural adaptations to the STAR-C web-based training modules are needed for Latino caregivers and we designed preliminary adaptations [14]. Preliminary adaptations included expanding the content of the web-based training modules to improve understanding of dementia; revising language that was viewed as stigmatizing, offensive, or culturally inappropriate; and adding cultural examples to reflect the range of family involvement in caring for people living with dementia and multigenerational living [14]. It is unknown, however, whether these modifications sufficiently align with the intended goals of cultural adaptation [15]. In addition, it is unknown whether there are additional opportunities to further enhance the cultural relevance of the STAR-C web-based training modules for Latino families. Therefore, the objective of this study was to test and refine the preliminary cultural adaptations of the STAR-C web-based training modules for Latino caregivers of people living with dementia.

Methods

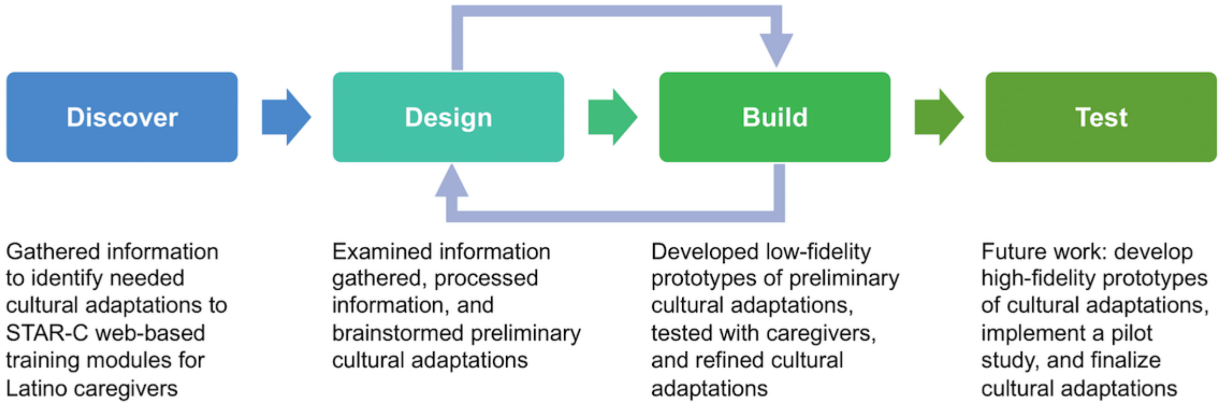
Ethical Considerations

This study was granted approval by the institutional review board at the University of Washington (STUDY00009534). Participants in this study gave their verbal or written consent for their involvement. All the data we collected from participants was labeled with a unique study identification number and not the participants' name or any other information that could identify participants. The contact information of participants was kept in a password-protected file and computer. All data collected from participants were kept confidential and accessible only by our study team. We did not use participants' names in reports of study findings, REDCap (Research Electronic Data Capture; Vanderbilt University) surveys, or audio recordings of interviews. Instead, we labeled everything with this study's identification number. We destroyed data that identified participants when we finished recruitment.

Overview of This Study's Design

Figure 1 [16] illustrates our approach to the cultural adaptation of the STAR-C web-based training modules within the context of the Discover, Design + Build, Test framework. In our previous study, we conducted a qualitative study to gather information about needed cultural adaptations to the web-based training modules for Latino caregivers (the "Discover" phase) [14]. We then used the findings from the qualitative study to brainstorm ideas for preliminary cultural adaptations (the "Design" phase). In this study, we developed low-fidelity prototypes of the culturally adapted STAR-C web-based training modules and tested the prototypes with Latino caregivers (the "Build" phase).

Figure 1. The cultural adaptation of STAR-C web-based training modules within the context of the Discover, Design + Build, and Test Framework. STAR-C: STAR caregiver.



Gathered information to identify needed cultural adaptations to STAR-C web-based training modules for Latino caregivers

Examined information gathered, processed information, and brainstormed preliminary cultural adaptations

Developed low-fidelity prototypes of preliminary cultural adaptations, tested with caregivers, and refined cultural adaptations

Future work: develop high-fidelity prototypes of cultural adaptations, implement a pilot study, and finalize cultural adaptations

Participant Selection

We carried out semistructured qualitative interviews in Washington State with 15 Latino caregivers of people living with dementia who spoke Spanish or English. Caregivers were considered eligible if they self-identified as Hispanic or Latino, were aged 21 years or older, were a child, spouse, or partner, or close friend of someone diagnosed with dementia, lived with the diagnosed individual or within a 5-mile radius, and provided a minimum of 8 hours of weekly care. Our recruitment strategy involved 3 approaches. Initially, we identified potential participants through the electronic health record system at University of Washington Medicine. Additionally, we circulated flyers in both Spanish and English across various locations, including a UW Medicine specialty clinic, a primary care practice-based research network, the Alzheimer Association Washington State Chapter, and local *tiendas* in Latino communities. Lastly, we used media platforms like local Spanish and English radio stations and newspapers to discuss the impact of dementia on the Latino population and publicize this study.

A member of this study's team screened for eligibility the individuals who showed interest in joining this study and arranged interviews for those who met the eligibility requirements. Caregivers received a compensation of US $45 for taking part in this study.

Description of the Low-Fidelity Prototypes

In the STAR-C Virtual Training and Follow-up intervention, caregivers receive 1 web-based training module per week for a period of 6-8 weeks. Textbox 1 describes the topics of the web-based training modules. The core components of the intervention include dementia education, strategies for effective communication, Activators-Behaviors-Consequences (ABC) problem-solving, pleasant events, and caregiver support.

Textbox 1. Topics of STAR caregivers (STAR-C) web-based training module.

Week 1: Understanding dementia, realistic expectations about behavioral treatments for behavioral and psychological symptoms of dementia, and strategies for effective communication.

Week 2: Activator, Behavior, Consequence (ABC) approach to problem-solving, including rationale and development of an ABC plan for target behaviors that caregivers identify.

Week 3: Review of ABC plan (revise if needed).

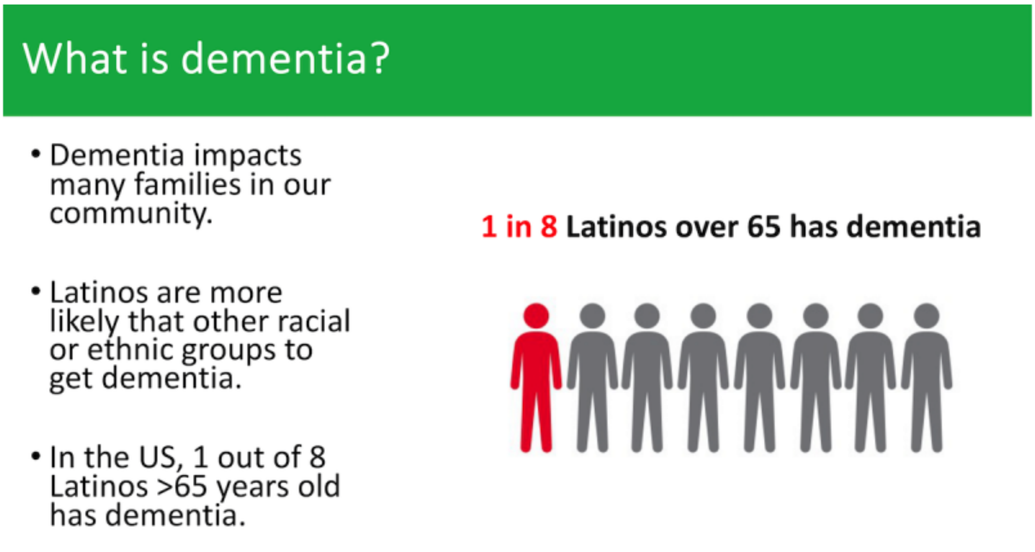
Week 4: Pleasant events and managing negative thinking.

Week 5: Review of ABC plan and pleasant events schedule (revise if needed).

Week 6: Caregiver support strategies for coping with caregiving and maintaining gains.

We created 3 low-fidelity prototypes of the culturally adapted STAR-C web-based training modules in both English and Spanish for testing among study participants. The low-fidelity prototypes were in the form of videos of recorded presentations with images, text, and voice-over. The videos featured short excerpts from various STAR-C web-based training modules. The first video consisted of educating Latino family caregivers on dementia and problem-solving using the ABC approach. This video explained the STAR-C program, dementia, its causes, walked through each step of the ABC approach for problem-solving in dementia, and concluded with a caregiving example of the ABC approach. The second video featured some modifications, including the addition of information about dementia stages, common behaviors exhibited by people living with dementia, and importance of self-care. We also enhanced the visual aesthetics and design of the lessons to make them more visually appealing and added humor. In the third video, we maintained the core content from the previous versions but incorporated interactive images and examples to increase engagement and interactivity. Figures 2 and 3 provide an example of the low-fidelity prototypes.

Figure 2. Culturally adapted STAR-C web-based training module—understanding Alzheimer and related dementias, with a focus on disproportionate impact on Latinos. STAR-C: STAR caregiver.

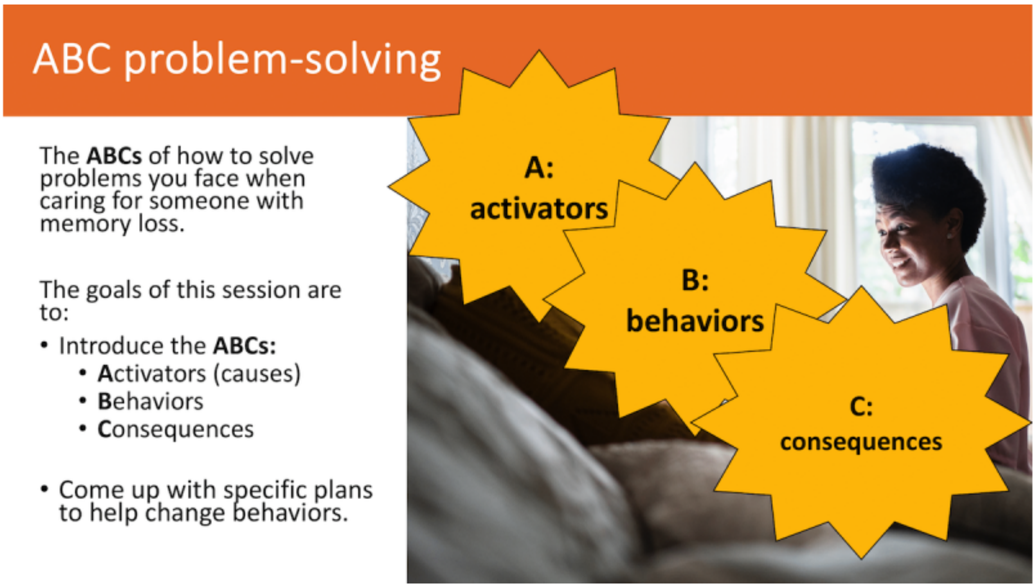


What is dementia?

- Dementia impacts many families in our community.
- Latinos are more likely that other racial or ethnic groups to get dementia.
- In the US, 1 out of 8 Latinos >65 years old has dementia.

1 in 8 Latinos over 65 has dementia

Figure 3. Culturally adapted STAR-C web-based training module—ABC acronym. ABC: Activators-Behaviors-Consequences; STAR-C: STAR caregiver.



ABC problem-solving

The **ABCs** of how to solve problems you face when caring for someone with memory loss.

The goals of this session are to:

- Introduce the **ABCs:**
  - **A**ctivators (causes)
  - **B**ehaviors
  - **C**onsequences
- Come up with specific plans to help change behaviors.

Data Collection

Study participants received the low-fidelity prototypes (ie, videos) via text message, WhatsApp Messenger, or email, depending on their preference, and were asked to watch the video at home on their own time prior to the scheduled qualitative interview. A bilingual or bicultural staff member trained in qualitative research techniques conducted interviews from January to August 2022. These interviews were held virtually, and they took place in either Spanish or English based on the participant's choice. Each interview spanned 30 to 60 minutes in length and was audio recorded and transcribed verbatim by a professional service.

The staff member used semistructured interview guides. For the first 5 interviews, the interview guide asked general questions pertaining to likes and dislikes, queries about the program's dementia content, examination of the ABC problem-solving strategy, assessment of the provided caregiving example, and a series of questions delving into video accessibility, design, and duration. For the subsequent 5 interviews, we revised the interview guide by adding questions focused on participant preferences, such as whether they preferred watching or listening to the video content, their favored method of receiving the videos, and their ideal video length. Finally, after another subsequent 5 interviews, we revised the interview guide again by incorporating additional inquiries centered around evaluating the images within the videos and improving viewer engagement.

Data Analysis

We analyzed the transcripts in their original languages, either Spanish or English, using the qualitative data analysis techniques described by Saldaña [17]. We began by reading through all the transcripts and writing analytic memos to reflect on the content—noting insights, thoughts, and emerging patterns. We then applied deductive codes from a pre-established codebook to the interview transcripts ("protocol coding" [17]). The pre-established codebook was used in a prior qualitative study of STAR-C and was composed of codes representing components of the cultural treatment adaptation framework [14,18]. As an illustration, the codebook contained codes like "Materials and Semantics," "Cultural Examples and Themes," and "Therapeutic Framework" to capture cultural adaptations that were needed in the delivery of the intervention. In the next step, we applied inductive second-order codes to capture the details of participants' feedback ("subcoding" [17]). For example, one of the inductive subcodes under "Materials and Semantics" was "Different BPSD examples" since multiple participants had suggested including in the intervention materials problem-solving examples for different BPSD. Afterward, we grouped the deductive and inductive codes into a smaller number of candidate themes that represented opportunities to improve the cultural adaptations of STAR-C ("pattern coding" [17]). We examined the interrelationship across and within the candidate themes and made refinements to ensure that excerpts within themes cohered and that each final theme was distinct from the others. Finally, we developed a statement to describe each of themes, which are presented in the following section. To manage this coding process, we used Dedoose (version 8.1.8; SocioCultural Research Consultants, LLC).

Results

Overview

Table 1 provides the characteristics of Latino caregivers who participated in this study and a description of their caregiving situation. The average age of caregivers was 48.9 (SD 11.1) years, 13 (87%) identified as women, 7 (47%) were the adult children of the people living with dementia, and 12 (80%) provided 35 hours or more of care per week.

Table 1. Characteristics of family caregivers and description of the caregiving situation.

Characteristics	Family caregivers (N=15), n (%)
Age (years), mean (SD)	48.9 (11.1)
Mexican, Mexican American, or Chicano	15 (100)
Gender	
Woman	13 (87)
Man	2 (13)
Occupational status	
Retired	1 (7)
Employed	5 (33)
Unemployed	1 (7)
Homemaker	5 (33)
Other	3 (20)
Highest level of educational attainment, mean (SD)	
Less than high school	4 (27)
High school	5 (33)
Vocational or technical training	2 (13)
Some college	1 (7)
College graduate	2 (13)
Postgraduate	1 (7)
Devices owned	
Smartphone	14 (93)
Tablet	5 (33)
Laptop	7 (47)
Computer	6 (40)
Owns any device	15 (100)
Caregiver’s relationship to person living with dementia, mean (SD)	
Adult child (eg, daughter)	7 (46.7)
Spouse or partner	5 (33.3)
Other relative	3 (20)
Care provided per week (hours)	
35 or more	12 (80)
5-14	3 (20)
Number of years providing care, mean (SD)	3.7 (2.4)
Caregiver and person living with dementia living together, mean (SD)	10 (66.7)

The qualitative analysis revealed adaptations that were needed in the (1) delivery of the STAR-C virtual intervention, (2) “dementia education” core component, (3) “ABC Problem-Solving” core component, and (4) “caregiver support strategies” core component. The sections below describe the need for these adaptations from the perspective of caregivers, as well as the changes that were made to the STAR-C web-based training modules in response to caregiver feedback.

Theme 1: Adaptations to the Delivery of the STAR-C Virtual Intervention

Design Videos to be Accessible via Audio Only

Latino caregivers reported that they liked that the STAR-C videos combined visuals with narration. They reported that the narration helped to reinforce the visual content and vice versa. They said this combination of visuals and narration was engaging because it helped to hold their attention and made it easier for them to learn the content. For example, 1 Spanish-speaking caregiver said:

> *The thing is that audio and seeing the image are also easier in this type of application. It became more practical and easier for me to learn and understand compared to just reading and seeing it without any—well, at least in my opinion, my brain doesn't work the same way, I believe, but I liked the idea that you can see it, like imagine it, and create that idea.*

However, while the ideal would be to watch the STAR-C videos, some caregivers mentioned that this may not always be practical. They said that they were often occupied with errands, household, and caregiving work, and that it would be nice in these circumstances to be able to listen to the video. For that reason, the caregivers suggested that the videos be designed to be accessible via audio only. Further, 1 Spanish-speaking caregiver stated:

> *Since sometimes one doesn't have much time to sit down and take the time to be looking at the screen. So, I put everything in the background while I do my daily tasks.*

In response to caregivers' feedback, we modified the narration script to ensure that it was independent of visuals and accessible via audio only. The narration focused on providing clear and descriptive explanations of the visual content. Instead of relying on visuals to convey information, the narration script described the key elements, actions, and visuals present in the video. This approach would enable caregivers to form a mental image and grasp the content without needing to see the visuals.

Make Videos Accessible on Multiple Platforms

Latino caregivers expressed a preference for having various methods of accessing the STAR-C videos, including phone applications such as Facebook Messenger, WhatsApp Messenger, YouTube, and other platforms. Caregivers desired video access through platforms they used regularly and were easily accessible on their preferred devices. For example, 1 Spanish-speaking caregiver stated:

> *No, but I hardly use my email. I do check my email, but almost all the information I receive, I receive it through WhatsApp. And then, I can see it right away without any problem.*

A few caregivers encountered technical difficulties when attempting to access the videos such as lack of Wi-Fi access in their homes or limited storage on their phones, requiring troubleshooting. For example, 1 caregiver said she could not view the videos initially because her phone's storage was full. Once the caregiver emptied her phone's storage, she was able to view the videos. In addition, while the caregiver could view the videos on her computer, she did not have Wi-Fi at home and would need to connect the computer to her phone's hotspot.

In response to caregivers' feedback, we considered various options to accommodate preferences and technology access, to ensure optimal accessibility to the STAR-C videos. We would offer caregivers the option to receive the STAR-C videos on phone applications like Facebook Messenger, WhatsApp Messenger, and YouTube, as these are commonly used platforms for communication and information exchange. We would also optimize the video formats to reduce file sizes. Finally, we would offer troubleshooting support to assist caregivers who may face technical challenges while trying to view the videos.

Enable Caregivers to Easily Share Videos With Family Members

According to caregivers, the content in the STAR-C videos had a positive impact on communication and information sharing among caregivers and other family members who assist with caregiving. For that reason, caregivers expressed a strong desire to share the video content with their extended family, including siblings and other relatives involved in caregiving responsibilities. Sharing the videos empowered caregivers to improve their caregiving practices. For example, 1 Spanish-speaking caregiver explained:

> *Moreover, right away, I allowed myself—I don't know if it was allowed, but I sent that information to my sisters-in-law and they were like, "Wow, wait, so I'm going to treat my dad like this, so I can stop this. So, I got irritated by this." My sisters said, "I got it now," because we truly are alone, there really isn't much of a tool at hand that leads you to something like this, and even though it might seem small, a few minutes of video, it was truly very good. So, I can't imagine everything that's going to come [in the future with STAR-C]. Really, I appreciate it, truly.*

Another Spanish-speaking caregiver highlighted the need for education and support at the individual level. They indicated that the program's benefits extended beyond their immediate family, potentially benefiting other caregivers in similar situations. The caregiver explained:

> *I believe what we were missing was educating ourselves more about this… It could be the entire family, because it was in Mexico where my mom, the rest of my siblings, and I were. We were all taking care of dad, and sometimes, even then, we couldn't manage. We were like five adults and my dad.*

In response to caregivers' feedback, we decided that it would be appropriate to encourage Latino caregivers participating in the research study to share the STAR-C videos with other family members if they wished, regardless of whether the other family members were also enrolled in the research study. In addition, we decided to welcome other family members within the same family to enroll as study participants if they were interested and met the eligibility criteria. The program's content could serve as a catalyst for discussion, knowledge exchange, and support among primary caregivers and their extended network of caregivers.

Theme 2: Adaptations to the "Dementia Education" Core Component

Expand Content to Improve Caregiver Understanding of Dementia

Latino family caregivers expressed the need for expanded content in the "Dementia Education" core component to enhance their understanding of dementia. They highlighted the importance of delving deeper into the nature of the disease, its progression, and the various stages it entails.

> *[The video] was very practical, the basics, what [dementia] is, the essentials, but at the beginning, yes, to know a little more about what that type of illness it is, like videos on how it forms in the brain and the stages, that it goes deeper because it progresses in stages and increases day by day. That's what I think.*

Several caregivers identified common misconceptions about Alzheimer disease and memory loss in the Latino community, expressing surprise at the late stages of dementia when physical limitations manifest. They stressed the necessity of detailed information to comprehend the evolving challenges faced by people living with dementia. Caregivers emphasized the significance of incorporating this expanded content to enhance their knowledge and foster a more holistic understanding of dementia.

> *But that part surprised me a lot, which is that the body itself forgets its needs. And it's the final stage. And I would like it if they did include the stages of Alzheimer's or dementia. Because for most people, if you tell them, it's like “oh, they forgot things or put something in the wrong place or they get lost.” But the final stage is the one that very few people know about, it's what happens when your body, even if it gives signals, you don't recognize them. It's like a baby who can't tell you they’re thirsty, they’re hungry, their stomach hurts, and things like that. So, that's when it gets complicated and obviously, the end is near.*

In response to caregivers’ feedback, we further expanded the content of the first video focused on teaching caregivers about ADRD. Our goal was to provide a comprehensive understanding of dementia, untangling its root causes and distinguishing it from the natural aging process. We describe the different stages of dementia to offer Latino caregivers a better understanding about types of cognitive, emotional, and behavioral changes to expect in their family member with dementia as the disease progresses.

Encourage Caregivers to Empathize With Person Living With Dementia

Latino caregivers expressed the importance of fostering empathy toward individuals living with dementia. They highlighted the need to understand and acknowledge the unique challenges faced by both the caregivers and the person with dementia.

A Spanish-speaking caregiver found the examples provided in the program to be highly relatable, acknowledging the frustrations experienced by both themselves and their patients. They said:

> *I loved the examples they provided because they're very real, of diagnosing changes for oneself, the patient or client, or the family. Why? Because it's not the same; it's frustrating for them, as much as for us, because they don't understand us, and we don't understand them. So, we can't say that one is normal, because, to be honest, none of us are normal [laughter]. But yes, we can understand that diagnosis, put ourselves in the shoes of that person, or think about how I would feel if I see that the person taking care of me is frustrated by something I don't even know about, or I'm not comprehending.*

Caregivers also expressed the need to put themselves in the shoes of the person with dementia. Further, 1 Spanish-speaking caregiver said:

> *The only thing is that it would also be good to mention how it's frustrating for them and for us. We should put ourselves in their shoes, how would we like to be treated if we were the ones sick, how would we want to be treated? In terms of frustration or reactions... They won't react the way we would want them to or how we would like them to react, because they have a condition, we don't.*

In response to caregivers’ feedback, we integrated content into the STAR-C videos that would remind caregivers to be empathetic and to consider the perspective of people living with dementia. The added content emphasizes the importance of understanding the frustrations experienced by both caregivers and people living with dementia and the need to approach interactions with empathy and compassion.

Provide Education on how to Reduce Risk of Developing Dementia

Caregivers indicated the need for comprehensive education on reducing their own risk of developing dementia. They highlighted the importance of understanding the impact of dementia while also learning about strategies to combat it. A Spanish-speaking caregiver said:

> *The thing is, for example, I'm looking at my husband's case and I think about myself, and I think, “Well, what can I do to prevent what happened to my husband from happening to me?” Because what will happen if I develop dementia? What will happen to both of us? So, I would like to have more information. What can I do to avoid this? Because I am his caregiver.*

Another Spanish-speaking caregiver, after learning about the prevalence of dementia among Hispanics in the STAR-C video, expressed the need for more information on prevention and early signs. They said:

> *That's really good [the information in the module]. I was genuinely surprised when it said that one in every eight Hispanics has or will develop, right? So, it's a bit alarming, and I think, wow, I don't know, I would like to know more about whether there would be any way to prevent it. It would be great to have more information about prevention or the signs—as it says there, some forgetfulness is normal, certain forgetfulness, right? Like now, being busy with a thousand things, I forgot, and believe me, it happens to me, but I know it's because I have a lot on my plate and I try to do them all. But I would really like if there was information about whether there's any way to prevent this condition.*

Caregivers’ feedback confirmed our previous findings about the need to modify the STAR-C content to include comprehensive education on dementia. In response to caregivers' feedback, we will also be providing caregivers with information on reducing their own risk of developing the condition. By providing caregivers with guidance and knowledge on prevention strategies, STAR-C can empower them to take proactive steps in safeguarding their cognitive health and that of their loved ones.

Theme 3: Adaptations to the "ABC Problem-Solving" Core Component

Simplify the "ABC" Problem-Solving Acronym in Spanish

The "ABC" problem-solving approach in the STAR-C program was regarded as helpful by some Latino caregivers, who found the provided examples to be effective and relatable. However, it was acknowledged that understanding the acronym ("Activators, Behaviors, Consequences") could be a bit challenging for others. Further, 1 Spanish-speaking caregiver explained why she liked the ABC problem-solving approach:

> *So, I found the video to be very original, very realistic. It was done very well because I felt identified. The three ways they presented it, in A, B, and C, personally, it felt very real to me, I loved it, almost perfect, because these are situations that do happen and changes that we do need to make. From the beginning, we don't know how to do it, but with this video or the app that they're going to develop, it seems very practical to me because it will provide a lot of tools and strategies to people who have no idea how to go about it. Like us in the beginning, we were learning as we went through each day.*

Another Spanish-speaking caregiver initially faced challenges in understanding the ABC acronym but gained clarity once the video explained it further.

> *Yes, some of those words were a bit difficult for me to understand, but later on, it was explained what each of them meant.*

Further, 1 Spanish-speaking caregiver reported that while they could understand the content, including the ABC acronym, well due to their extensive Spanish language skills, they acknowledged that a person with limited education might struggle to understand it clearly.

> *I can understand it perfectly, but I think I can understand because I have a very good Spanish. I was a Spanish teacher for many years, so my language and vocabulary are quite extensive. However, I believe that if the same video had to be heard by someone with limited education, they probably wouldn't understand it, at least not clearly.*

These quotes highlight the caregivers' perspective on the need to simplify the "ABC" problem-solving acronym in Spanish. While some caregivers found the explanations of each letter in the acronym helpful, others reported that individuals with limited education may potentially face challenges in understanding the acronym. In response to caregivers' feedback, we simplified the ABC acronym to enhance comprehension and accessibility for a wider range of caregivers. Initially, the ABC acronym was translated as A for "activadores" (activators), B for "comportamiento" (behavior), and C for "consecuencias" (consequences). However, based on the feedback received, we took an additional step to simplify it entirely in Spanish, resulting in the revised form as "las 3 Cs" (the 3 Cs) representing C for "causas" (causes), C for "comportamiento" (behavior), and C for "consecuencias" (consequences).

Add More Problem-Solving Examples With Different BPSDs

Caregivers conveyed a strong desire for the STAR-C program to incorporate a greater variety of problem-solving examples that cover different BPSDs. While some caregivers appreciated the existing examples, they emphasized the importance of including a more extensive range of stories and behaviors to address the diverse challenges encountered in dementia care. For example, 1 Spanish-speaking caregiver stated:

> *I liked everything, the only thing is that I would like them to add a bit more different stories, with different behaviors.*

Another Spanish-speaking caregiver shared their personal experience with their mother's behavior and the importance of addressing such situations.

> *Yes, my mom experiences a lot of panic episodes, and I didn't see that in the video, so in my own way, I handled panic situations in her illness, like waking up at night in a panic: "Where am I? Who am I? Where are we?" So, I didn't see in the video strong things like that, like screaming, situations where you don't know what to do as a family member, so you just hug them. I hugged my mom, I hugged her, I hugged her, and I said, "Calm down, we're okay. I'm your daughter, we're here." I mentioned the house, the surroundings, everything. But she has those night panics out of fear very often.*

These quotes underscore the caregivers' interest in having a more extensive selection of problem-solving examples that address various BPSDs, such as aggression and panic attacks. In response to caregiver's feedback, we will include a broader range of scenarios and behaviors, so that caregivers can gain invaluable insights and strategies to effectively manage the diverse challenges associated with BPSDs.

Demonstrate Problem-Solving With Real People

Latino caregivers reported a desire for more realistic and relatable problem-solving examples in the STAR-C program. They suggested incorporating videos featuring real interactions between caregivers and persons living with dementia to enhance the learning experience. Further, 1 Spanish-speaking caregiver explained:

> *Perhaps, in the example—I mean, I don't know how much of the video or program is left [to be developed], but maybe, I don't know, perhaps the depiction of two people acting out the situation, maybe it would look much more professional or*

> *more—you know, I understand that this requires investment and it requires many things.*

Another Spanish-speaking caregiver reported interest in observing caregiving interactions to better understand effective communication strategies.

> *Perhaps some of this information would be clearer in a video format or as an interaction between two people. Yes, specifically with an Alzheimer's patient. Because if they're [the program] going to be incorporating strategies on how to talk, how to interact, it would be very useful to see the behavior live; how it's happening, how one can communicate with that person.*

Incorporating videos of real people and interactive caregiving scenarios in the STAR-C program can provide caregivers with tangible and relatable examples of problem-solving techniques. Based on caregivers' feedback, future adaptations of STAR-C should demonstrate the app of the problem-solving techniques with real people. These demonstrations may enhance caregivers' experience with the program by presenting solutions in a dynamic and engaging manner.

Theme 4: Adaptations to the "Caregiver Support Strategies" Core Component

Latino caregivers emphasized the importance of seeking assistance and support to alleviate the burdens of caregiving. Many highlighted the value of reaching out to family members or friends when feeling fatigued or overwhelmed, recognizing the need for rest and self-care. A Spanish-speaking caregiver described how the STAR-C program needed to encourage caregivers to take care of their own health and well-being. The caregiver said:

> *[For caregivers] to be well-rested. That's why I mention seeking help in some way, even from family or friends, you can say "I need—" when you feel tired or stressed, very stressed, you need to be able to call someone and say, "Can you take care of my mom for a while? Can you take care of my dad or my wife? I need a break." Because if you're not well-rested or already feeling overwhelmed—I say this because, for example, my sister, when she was taking care of my mom, my sister wasn't emotionally well. She had her own problems, so when it was her turn to care for my mom, there were almost always issues because she didn't have enough patience.*

Participants collectively acknowledged the importance of supporting caregivers themselves, not just the care recipients. They emphasized the need for caregivers to take regular breaks and engage in activities that promote mental well-being. For example, a Spanish-speaking caregiver stated:

> *I just wanted to mention that also the people--sometimes the people who care for others also need to be taken care of, to take a break or do something different in order to continue, to be mentally well enough to keep taking care of our loved ones.*

This comment highlights the importance of recognizing the caregiver's mental and emotional health as it directly impacts their ability to provide effective care. In response to caregivers' feedback, we integrated content throughout the various modules (not just the last module) about the importance of caregiver health and well-being. The content emphasizes the need for caregiver rest, support, and self-care, so that caregivers can be better equipped to provide optimal care to their loved ones.

Discussion

Principal Results

This study's objective was to test and refine the preliminary cultural adaptations to the STAR-C web-based training modules for Latino caregivers. Our qualitative analysis identified key adaptations required in (1) the delivery of STAR-C, (2) the "dementia education" core component, (3) the "ABC problem-solving" core component, and (4) the "caregiver support strategies" core component. Caregivers expressed a desire for STAR-C videos to be accessible through audio-only formats, and they highlighted the importance of making the videos available on various platforms, including those commonly used in their community. They also emphasized the need for the videos to be easily shareable with family members to enhance communication and caregiving practices. In response, we tailored the narration script to facilitate audio-only access and optimized video formats for widespread accessibility. Moreover, caregivers requested comprehensive education on dementia prevention and understanding the disease's stages, advocating for expanded content within the "Dementia Education" core component. This resulted in additional content aimed at enhancing caregivers' understanding of dementia progression and challenges. To further foster empathy, caregivers suggested highlighting the importance of viewing the world from the perspective of individuals living with dementia. Consequently, we incorporated elements emphasizing empathy into the program. Caregivers also sought to incorporate strategies for reducing the risk of developing dementia, leading to the inclusion of content addressing preventive measures. Within the "ABC Problem-Solving" core component, caregivers expressed a need to simplify the "ABC" acronym in Spanish and expand problem-solving examples. We responded by simplifying the acronym and incorporating more problem-solving scenarios to cater to diverse challenges. Additionally, caregivers desired realistic problem-solving examples featuring real interactions between caregivers and persons with dementia. Lastly, caregivers emphasized the importance of caregiver well-being, prompting us to underscore self-care, rest, and seeking support to ensure caregivers' mental and emotional health is prioritized. These adaptations collectively refine the STAR-C web-based training modules for Latino caregivers and provide a culturally tailored, evidence-based intervention to support dementia caregiving in this community.

Comparison With Prior Work

Our study identified several key adaptations needed to enhance the cultural relevance and effectiveness of the STAR-C web-based training modules for Latino caregivers. Notably, caregivers expressed a strong desire for videos to be accessible through audio-only formats, a finding that aligns with a study conducted among Hispanic participants from Spain [19], where a similar preference for audio accessibility was observed. The importance of making videos available on various platforms, as highlighted in our study, is also consistent with research where caregivers expressed openness to learning caregiving information from diverse sources and settings [20].

The cultural adaptations identified in this study to enhance the relevance and effectiveness of the STAR-C web-based training modules for Latino caregivers may have applicability to caregivers from other racial and ethnic minority groups as well. For example, collectivist and familism values tend to be strong in Asian cultures that emphasize family and community interdependence [21,22]. As such, making the STAR-C videos easily shareable with family members to facilitate communication and coordinated caregiving practices may also resonate with Asian caregivers.

Furthermore, our study aligns with prior research by emphasizing the need for comprehensive education on dementia prevention and understanding the disease's stages [20,23]. In a study conducted among various ethnic groups, including Hispanic or Latinos, African Americans, and Asian Americans, it was found that a common lack of knowledge about the early signs of Alzheimer disease existed [23]. This knowledge gap underscores the importance for comprehensive dementia education, a point that resonates with our study's findings. Additionally, another study similarly stressed the importance of greater education regarding the diversity and spectrum of dementia-related symptoms [20].

Caregivers also strongly advocated for simplifying the ABC acronym in Spanish, adding more problem-solving examples, and demonstrating problem-solving with real individuals. These adaptations align with a study assessing Spanish language health information via videos [24], which found that participants preferred videos featuring increased actor participation, as it enhanced their ability to relate the content to real-life situations.

Limitations

Our study has limitations worth noting. First, the low-fidelity prototypes of the STAR-C web-based training modules (ie, videos) we used in this study lacked the realistic appearance and comprehensiveness of the full virtual STAR-C program. This may have limited our ability to obtain accurate perceptions and feedback, as caregivers might not have fully understood or engaged with the low-fidelity prototypes as they would have with a higher-fidelity version of the full STAR-C program. As a next step in this research, we plan to pilot test high-fidelity prototypes of the STAR-C web-based training modules. Second, caregivers' feedback about STAR-C is influenced by their personal preferences and experiences, which may result in us inadvertently prioritizing features or solutions that appeal to the specific subgroup of Latino caregivers participating in this study rather than broader populations of Latino caregivers. We tried to address this limitation by interviewing a diverse group of caregivers including both male and female caregivers (most Latino caregivers tend to be women), caregivers of different ages and family roles (ie, spouse vs child caregiver), and caregivers with different educational backgrounds.

Conclusions

This study addresses a critical gap in the field of dementia caregiving, particularly for Latino caregivers who face unique challenges and disparities in health outcomes. The culturally adapted version of the virtual STAR-C program represents a significant step forward in bridging this gap. Our findings highlight the importance of tailoring interventions to meet the specific needs of Latino caregivers, considering cultural values and beliefs that shape caregiving interactions and experiences. The key adaptations we needed to make to the STAR-C web-based training modules, including accessibility improvements, expanded dementia education, enhanced problem-solving strategies, and a focus on caregiver well-being, underscore the importance of cultural adaptation of evidence-based caregiver interventions for Latino families. While further research is needed to assess the efficacy of these adaptations, we believe that the virtual STAR-C intervention has the potential to improve health care services and health outcomes for Latino people living with dementia and their family caregivers. By addressing the pressing need for culturally adapted evidence-based interventions, we aim to promote more favorable experiences with the intervention and ultimately reduce the health disparities associated with dementia caregiving in this community. This work contributes to the broader mission of advancing health care services for older adults by using technological innovations, serving the interest of health professionals and family caregivers of older adults.

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Conflicts of Interest

None declared.

References

1. Dessy A, Zhao AJ, Kyaw K, Vieira D, Salinas J. Non-pharmacologic interventions for hispanic caregivers of persons with dementia: systematic review and meta-analysis. J Alzheimers Dis 2022;89(3):769-788. [doi: 10.3233/JAD-220005] [Medline: 35938246]
2. Alzheimer's disease facts and figures. Alzheimer's Association. 2023. URL: https://www.alz.org/alzheimers-dementia/facts-figures [accessed 2023-12-15]

3. Lines LM, Sherif NA, Wiener JM. Racial and ethnic disparities among individuals with Alzheimer’s disease in the United States: a literature review. RTI Press. 2014. URL: https://www.rti.org/rti-press-publication/racial-and-ethnic-disparities-among-individuals-alzheimers-disease-united-states-literature-review [accessed 2023-12-15]
4. Wu S, Vega WA, Resendez J, Haomiao J. Latinos and Alzheimer's disease: new numbers behind the crisis. USC Edward R. Roybal Institute on Aging and the LatinosAgainstAlzheimer's Network. 2016. URL: https://www.usagainstalzheimers.org/sites/default/files/Latinos-and-AD_USC_UsA2-Impact-Report.pdf [accessed 2023-12-15]
5. Vila-Castelar C, Fox-Fuller JT, Guzmán-Vélez E, Schoemaker D, Quiroz YT. A cultural approach to dementia—insights from US Latino and other minoritized groups. Nat Rev Neurol 2022;18(5):307-314 [FREE Full text] [doi: 10.1038/s41582-022-00630-z] [Medline: 35260817]
6. Hepburn K, Siegel EO. New directions to advance family caregiving research. Gerontologist 2020;60(Suppl 1):S1-S4 [FREE Full text] [doi: 10.1093/geront/gnz182] [Medline: 32057079]
7. Teri L, McCurry SM, Logsdon R, Gibbons LE. Training community consultants to help family members improve dementia care: a randomized controlled trial. Gerontologist 2005;45(6):802-811 [FREE Full text] [doi: 10.1093/geront/45.6.802] [Medline: 16326662]
8. McCurry SM, Logsdon RG, Mead J, Pike KC, La Fazia DM, Stevens L, et al. Adopting evidence-based caregiver training programs in the real world: outcomes and lessons learned from the STAR-C oregon translation study. J Appl Gerontol 2017;36(5):519-536. [doi: 10.1177/0733464815581483] [Medline: 25873454]
9. Kaiser P. STAR Caregivers—Virtual Training and Follow-up (STAR-C-VTF). clinicaltrials.gov, Clinical trial registration NCT04271046. 2022. URL: https://clinicaltrials.gov/study/NCT04271046 [accessed 2023-08-15]
10. Ramirez M, Duran MC, Pabiniak CJ, Hansen KE, Kelley A, Ralston JD, et al. Family caregiver needs and preferences for virtual training to manage behavioral and psychological symptoms of dementia: interview study. JMIR Aging 2021;4(1):e24965 [FREE Full text] [doi: 10.2196/24965] [Medline: 33565984]
11. Fagherazzi G, Goetzinger C, Rashid MA, Aguayo GA, Huiart L. Digital health strategies to fight COVID-19 worldwide: challenges, recommendations, and a call for papers. J Med Internet Res 2020;22(6):e19284 [FREE Full text] [doi: 10.2196/19284] [Medline: 32501804]
12. Berridge C, Parsey CM, Ramirez M, Freitag C, Johnson IM, Allard SW. Caring for Washington's older adults in the COVID-19 pandemic: interviews with organization leaders about the state of social and healthcare services. LTC Responses to COVID-19. 2020. URL: https://ltccovid.org/wp-content/uploads/2020/12/CARING-FOR-WASHINGTONS-OLDER-ADULTS-IN-THE-COVID-19-PANDEMIC.pdf [accessed 2023-08-17]
13. Parker LJ, Marx KA, Nkimbeng M, Johnson E, Koeuth S, Gaugler JE, et al. It's more than language: cultural adaptation of a proven dementia care intervention for Hispanic/Latino caregivers. Gerontologist 2023;63(3):558-567 [FREE Full text] [doi: 10.1093/geront/gnac120] [Medline: 35951488]
14. Ramirez M, Duran MC, Penfold RB, Pabiniak CJ, Hansen KE, Ornelas IJ. STAR-caregivers virtual training and follow-up: a cultural adaptation for Latino caregivers of people with dementia. Transl Behav Med 2023;13(9):625-634. [doi: 10.1093/tbm/ibad028] [Medline: 37130336]
15. Barrera M, Castro FG, Strycker LA, Toobert DJ. Cultural adaptations of behavioral health interventions: a progress report. J Consult Clin Psychol 2013;81(2):196-205 [FREE Full text] [doi: 10.1037/a0027085] [Medline: 22289132]
16. Lyon AR, Munson SA, Renn BN, Atkins DC, Pullmann MD, Friedman E, et al. Use of human-centered design to improve implementation of evidence-based psychotherapies in low-resource communities: protocol for studies applying a framework to assess usability? JMIR Res Protoc 2019;8(10):e14990 [FREE Full text] [doi: 10.2196/14990] [Medline: 31599736]
17. Saldaña J. The Coding Manual for Qualitative Researchers, 3rd Edition. London: Sage Publications Ltd; 2021.
18. Chu J, Leino A. Advancement in the maturing science of cultural adaptations of evidence-based interventions. J Consult Clin Psychol 2017;85(1):45-57. [doi: 10.1037/ccp0000145] [Medline: 28045287]
19. Molinari-Ulate M, Guirado-Sánchez Y, Platón L, van der Roest HG, Bahillo A, Franco-Martín M. Cultural adaptation of the iSupport online training and support programme for caregivers of people with dementia in Castilla y León, Spain. Dementia (London) 2023;22(5):1010-1026 [FREE Full text] [doi: 10.1177/14713012231165578] [Medline: 36942726]
20. Peterson K, Hahn H, Lee AJ, Madison CA, Atri A. In the information age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. BMC Geriatr 2016;16(1):164 [FREE Full text] [doi: 10.1186/s12877-016-0338-7] [Medline: 27662829]
21. Miyawaki CE. A review of ethnicity, culture, and acculturation among Asian caregivers of older adults (2000-2012). Sage Open 2015;5(1):1-18 [FREE Full text] [doi: 10.1177/2158244014566365] [Medline: 26229736]
22. Krys K, Vignoles VL, de Almeida I, Uchida Y. Outside the "cultural binary": understanding why Latin American collectivist societies foster independent selves. Perspect Psychol Sci 2022;17(4):1166-1187 [FREE Full text] [doi: 10.1177/17456916211029632] [Medline: 35133909]
23. Mahoney DF, Cloutterbuck J, Neary S, Zhan L. African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia: cross-cultural similarities and differences. Gerontologist 2005;45(6):783-792 [FREE Full text] [doi: 10.1093/geront/45.6.783] [Medline: 16326660]

24. De Alba Rosales A, Schober D, Johansson P. Examining perceptions of Spanish language health information among Hispanics living in the United States: a qualitative study assessing videos, brochures, and websites. Health Promot Pract 2021;22(3):385-394 [FREE Full text] [doi: 10.1177/1524839920950029] [Medline: 32820963]

Abbreviations

ABC: Activators-Behaviors-Consequences
ADRD: Alzheimer disease and related dementias
BPSD: behavioral and psychological symptoms of dementia
REDCap: Research Electronic Data Capture
STAR-C: STAR caregiver

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Original Paper

Expectation, Attitude, and Barriers to Receiving Telehomecare Among Caregivers of Homebound or Bedridden Older Adults: Qualitative Study

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Abstract

Background: In recent years, telehomecare has become an increasingly important option for health care providers to deliver continuous care to their patients.

Objective: This study aims to explore the expectations, attitudes, and barriers to telehomecare among caregivers of homebound or bedridden older adults.

Methods: This qualitative study used semistructured interviews to explore caregivers' perspectives on telehomecare for homebound or bedridden older adults. The study adhered to the SRQR (Standards for Reporting Qualitative Research) guidelines. Participants were selected using convenience sampling from caregivers of homebound or bedridden older adults with experience in both in-person home visits and telehomecare services provided by the Department of Family Medicine at Chiang Mai University, in an urban area of Chiang Mai Province in Northern Thailand. Semistructured interviews were conducted. The interviews were audio recorded with participant consent and transcribed verbatim. The framework method was used, involving multiple readings of transcripts to facilitate familiarization and accuracy checking. The study used the technology acceptance model and comprehensive geriatric assessment as the analytical framework.

Results: The study included 20 caregivers of older adult patients. The patients were predominantly female (15/20, 75%), with an average age of 86.2 years. Of these patients, 40% (n=8) of patients were bedridden, and 60% (n=12) of patients were homebound. Caregivers expressed generally positive attitudes toward telehomecare. They considered it valuable for overall health assessment, despite recognizing certain limitations, particularly in physical assessments. Psychological assessments were perceived as equally effective. While in-person visits offered more extensive environmental assessments, caregivers found ways to make telehomecare effective. Telehomecare facilitated multidisciplinary care, enabling communication with specialists. Caregivers play a key role in care planning and adherence. Challenges included communication issues due to low volume, patient inattention, and faulty devices and internet signals. Some caregivers helped overcome these barriers. The loss of information was mitigated by modifying signaling equipment. Technology use was a challenge for some older adult caregivers. Despite these challenges, telehomecare offered advantages in remote communication and resolving scheduling conflicts. Caregivers varied in their preferences. Some preferred in-person visits for a broader view, while others favored telehomecare for its convenience. Some had no strong preference, appreciating both methods, while others considered the situation and patient conditions when choosing between them. Increased experience with telehomecare led to more confidence in its use.

Conclusions: Caregivers have positive attitudes and high expectations for telehomecare services. Although there may be barriers to receiving care through this mode, caregivers have demonstrated the ability to overcome these challenges, which has strengthened their confidence in telehomecare. However, it is important to enhance the skills of caregivers and health care teams to overcome barriers and optimize the use of telehomecare.

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KEYWORDS

telehomecare; telemedicine; telehealth; caregivers; older adults; attitudes

Introduction

Thai society has come to recognize the challenge of the aging society and that there is a rapid growth in the number of homebound or bedridden older adult patients with chronic diseases [1]. Homebound refers to a state in which one's life space is limited to their residence, yet they retain the ability to move within their home. On the other hand, being bedridden is a condition in which a person has experienced significant physical weakness and can no longer move about freely, thus being confined to their bed. These 2 statuses are typically caused by the patient's comorbidities and often result in the need for comprehensive care and caregiver [2-4]. As a result, coordinated health care services are essential for these individuals, and home health care services have been found to be effective in improving patient outcomes. A long-term care policy has been implemented to provide home care and social support for this population [1,5]. These services are particularly useful for doctors to assess a patient's living conditions and have been shown to decrease hospitalization, improve physical and psychosocial health, and enhance the overall quality of life for older adults [6,7].

Telemedicine has emerged as a potential solution to bridge the gap between homebound or bedridden patients and health care services [8]. By allowing health care providers to connect with patients remotely, telemedicine can reduce travel costs, provide convenience, and help control the spread of the pandemic [9]. However, there are also disadvantages and challenges associated with this technology, such as the lack of face-to-face communication between doctors and patients and the need for patients to have the technical skills to use these devices [1]. These factors may make the home visit system unsustainable [10].

Over the past 3 years, the COVID-19 pandemic has further highlighted the need for telemedicine, as in-person home visits have been interrupted and transformed into telehomecare for patients requiring continuous health care at home [11-13]. Telehomecare is a form of telemedicine that combines videoconferencing and health monitoring between homebound or bedridden patients and home health care providers [14]. In order to conduct telehomecare for homebound or bedridden older adult care, the caregiver has the main role of helping monitor the patient and to communicate all information to health care team. Therefore, if the caregivers are also older adults and are not proficient with technology, this can pose a barrier, especially for patients living in remote areas [15].

Prior studies on the perception or perspective of the use of telemedicine in caring for older adults have primarily focused on the viewpoints of physicians [16,17] and older adult patients [18,19], rather than caregivers. Physicians have also reported perceiving advantages in the use of telemedicine for older adults, including the reduction of postponed care, the promotion of timely care, enhanced physician efficiency, improved communication with both patients and caregivers, the alleviation of patient travel burdens, and the facilitation of health outreach and educational efforts [17]. The use of technology for health care in older adults could be influenced by their age and the complexity of diseases they face [19], impacting their acceptance of technology [20] and use behavior [21]. It has been noted that the technological acceptance of patients and providers appears to have positive effects on patient outcomes, including self-management and readmissions. The literature also indicates that family caregivers play a vital role in assisting the patient's decision to adopt and engage with technology [22]. Physicians are aware that caregivers have a role in deciding whether to use telehealth services [16]. Overall, it is important to assess caregivers' genuine perspectives and suggestions.

A recent study from the United States has explored family caregivers' perceived benefits and barriers to telemedicine visits for community-dwelling older adults with chronic diseases [23]. Caregivers reported effectiveness in increasing access and continuity of care, but they also expressed concerns about their older relatives' ability to access and use the technology independently and difficulty in establishing patient-provider rapport. However, these results could be different in Thailand and among families of older adults with more limited capacity, such as the homebound or bedridden population. Thus, this study aims to investigate the expectations, attitudes, and barriers concerning telehomecare among caregivers of homebound or bedridden older adults. Specifically, it will explore caregivers' expectations regarding the perceived usefulness of the service in delivering comprehensive care for older adults with limited mobility; the barriers that affect the perceived ease of using the service; and their overall attitudes toward the care provided, including their preferences. The results of this study will provide useful insights for the creation of effective care plans for homebound or bedridden older adult patients and their caregivers.

Methods

Study Design

This study was a qualitative study, using semistructured interviews to investigate the perspectives of using telehomecare for homebound or bedridden older adults, as perceived by their caregivers. The study was reported according to the SRQR (Standards for Reporting Qualitative Research) guidelines [24].

Ethical Considerations

Ethical approval was obtained through the Medical Ethical Committee of Chiang Mai University, Chiang Mai, Thailand

(227/2021). Informed consent was obtained from all participants. The privacy and confidentiality of human participants were rigorously protected throughout this study. Data were either anonymized or deidentified, as applicable, to safeguard the identity of participants. Participants in the study received a monetary compensation of 100 (US $2.7) for their participation.

Recruitment

Participants were selected using convenience sampling from caregivers of homebound or bedridden older adult patients who had experience with both in-person home visits and telehomecare services provided by the Department of Family Medicine at Chiang Mai University. The samples were selected from a list of families of older adults who had received care within the past 2 months. Research assistants reached out to these families via phone calls until the total expected sample size was achieved. The study was conducted in an urban area of Chiang Mai Province in Northern Thailand. Inclusion criteria were that participants must be the primary caregiver and speak Thai, while caregivers with communication difficulties were excluded. The researchers expected to recruit at least 20 participants to achieve data saturation, based on similar qualitative studies [25].

Data Collection

Semistructured in-depth interviews were conducted between November 2021 and March 2022. There were two parts to data collection as follows: (1) participant characteristics and (2) in-depth interviews about the perspectives of using telehomecare for homebound or bedridden older adults. The patient interviews were conducted in Thai by a single researcher (PO) who was trained in the interview method and interview questions by the qualitative researchers (KP and WJ). Each interview was conducted in a private counseling room to help ensure comfort and confidentiality. Each interview was audio recorded with the participant’s consent, followed by verbatim transcription. PO and KP subsequently reviewed the audio record, and any issues that needed further exploration were discussed. Participant characteristics including sex, age, occupation, relationship with the patient, and the duration of care as the caregiver were recorded. Patient diagnoses and homebound or bedridden status were also gathered. Open-ended interview guides were designed and then piloted to make sure that participants were allowed to share their thoughts freely. The interview guide was described in Textbox 1.

Textbox 1. The interview guide.

- How long has your family been receiving home care and telehomecare?
- What was the main reason for switching from in-person care to telehomecare?
- Do you perceive telehomecare as useful for your family?
- As a caregiver for an older adult patient, do you feel confident about receiving care for the patient through telehomecare?
- Can you compare the effectiveness of care between in-person home visits and telehomecare for older adult patients?
- Are you satisfied with these services? Which one do you prefer and why?
- What do you see as potential barriers or concerns regarding the use of telehomecare for caring for older adult patients?

Data Analysis

We followed the framework method for the analysis of qualitative data [26]. Each transcript was read multiple times by the 2 researchers (PO and KP) to aid familiarization and to check the accuracy of each transcript. The key elements of the technology acceptance model and comprehensive geriatric assessment for older adult patient care were used as the analytical framework to help identify key issues, concepts, and themes. The study aimed to address the 2 main research questions, which align with the technology acceptance model in the context of providing care for older adults from the perspective of caregivers. The technology acceptance model is the theory that suggests the predictors toward the acceptance and rejection to use technology. These predictors include (1) perceived usefulness and (2) perceived ease of use which are influenced by, for example, technology anxiety or experience, subjective norms, expectations, trust, cultural diversities, and technology characteristics [27]. These factors, in turn, shape attitudes toward using telehomecare services.

The first question focused on perceived usefulness (expectation), incorporating comprehensive geriatric assessment to determine whether telehomecare is suitable for providing comprehensive home-based care for older adults. Comprehensive geriatric assessment is usually carried out while providing care for older adults at home to increase the understanding of an older person’s care needs and preferences and to help in finding common goals of care [28,29]. Its three key elements include (1) comprehensiveness (physical, psychological, and environmental issues); (2) multidisciplinarity; and (3) person - centered goal setting. The second question concentrated on the perceived ease of use of telehomecare for caregivers caring for older adults. This encompassed concerns and perceived barriers.

To explore our research questions, we adopted the framework method, which used a combined approach, incorporating both deductive and inductive elements for the analysis [26]. The deductive approach was applied to the preexisting theories, specifically the technology acceptance model and comprehensive geriatric assessment. Meanwhile, the inductive approach was used to analyze the expectations, attitudes, and barriers associated with telehomecare among caregivers of homebound or bedridden older adults.

The researchers compared the identified codes and discussed the similarities and differences until they reached a consensus on the emergent themes and subthemes. Then, the preliminary results were interpreted with WJ and CA. All authors read and contributed to the manuscript. NVivo (version 12; QSR International) was used for data analysis. Descriptive analysis was used to describe participant characteristics, including frequency, percentage, mean, and SD. The results were presented to caregivers to receive their feedback.

Results

Sociodemographic Data of Caregivers

A total of 20 caregivers were recruited, of which 25% (n=5) were male and 75% (n=15) were female, with an average age of 59.5 (SD 14.27) years. Fourteen (70%) of the caregivers were identified as the children of the patients, 15 (75%) caregivers had at least a bachelor's degree or equivalent level of education, and the average duration of patient care was 3.3 (SD 2.9) years. Table 1 provides a summary of the general information about the caregivers. The average interview duration was 28.45 minutes, ranging from 20 to 47 minutes.

Table 1. Sociodemographic data of caregivers (N=20).

Item	Value
Sex, n (%)	
Male	5 (25)
Female	15 (75)
Age (years)	
Mean (SD)	59.5 (14.27)
Range	26-87
Relation to patient, n (%)	
Spouse	2 (10)
Siblings	1 (5)
Child	14 (70)
Grandchild	3 (15)
Highest education, n (%)	
Primary school	2 (5)
Secondary school	3 (15)
Bachelor's degree and higher	15 (75)
Duration of receiving home health care (years)	
Mean (SD)	3.3 (2.9)
Range	1.5-15

Health Status of Older Adult Patients

The majority (15/20, 75%) of patients were female, with an average age of 86.2 (range 66-95) years. Among these patients, 8 (40%) patients were bedridden and 12 (60%) patients were homebound. The most common comorbidities included hypertension (15/20, 75%), dyslipidemia (7/20, 35%), dementia (7/20, 35%), and stroke (6/20, 30%). Additionally, 45% (n=9) of patients reported needing assistance for using technology, while 40% (n=8) of patients indicated that they were unable to use technology.

Caregivers' Expectations, Attitudes, and Barriers Toward Telehomecare

Overview

Based on the interviews, it was found that caregivers of older adult patients have specific attitudes and expectations toward taking care of the older adult by using telehomecare. They see it as a valuable service for overall health assessment, although they acknowledge limitations in certain aspects. Communication and device usability challenges were noted, but there is a clear advantage to telehomecare in specific cases compared with in-person visits. Confidence in this service is widespread, yet individual preferences are influenced by family circumstances and situations. Multimedia Appendix 1 shows the framework matrix. The details are provided in the following sections.

It is a Service That Provides an Overall Assessment of a Patient's Health, but Some Aspects May Be Limited

When surveying caregivers' perceived usefulness toward telehomecare for older adult patients within the comprehensive geriatric assessment framework, differing attitudes emerged. Overall, caregivers displayed a favorable attitude toward telehomecare, despite some limitations in specific areas.

Physical Assessment

With regard to the physical assessment of the patients, telehomecare can be more limited than in-person home visits. However, caregivers can mitigate this by providing clearer information through photos and videos.

> *Similar to the case of my mother's mole which turned into a malignant tumor, it was not noticed clearly through VDO call.* [Participant 019]
>
> *It doesn't affect me. If grandma has a pain or where there is any wound, the doctor will ask to take pictures or ask her to walk around to observe the symptom through video call.* [Participant 014]

Psychological Assessment

Caregivers believe that psychological assessments yield similar outcomes through both telehomecare and in-person visits, as doctors can ask questions and provide privacy for patients during an assessment session.

> *It's not different. The doctor asks the same questions, such as "Are you worried about anything?" or "Would you like me to help you with anything?"* [Participant 017]

Environmental Assessment

In-person visits offer a broader environmental assessment experience compared with telehomecare, leading to more precise advice on home environment modification. However, caregivers have found ways to use telehomecare effectively, such as walking around with the device.

> *If the doctor was to visit in person, they would be able to see the home environment and provide advice on how to improve it. If it is stuffy, smelly, unsightly, not suitable for the patient, then the doctor can suggest more than a VDO call. This is because sometimes we don't show the home environment as much.* [Participant 013]

Multidisciplinary Care

Telehomecare facilitates engagement with specialists such as dieticians and physiotherapists, thus enhancing patient care.

> *The telehomecare allows us to have more knowledge from other members of the health care team, especially about how to do physical therapy and how to manage the diet for the patient.* [Participant 015]

Goal of Care and Care Planning

Caregivers play a key role in facilitating communication and treatment plan adherence during telehomecare, ensuring patients follow prescribed plans effectively.

> *We're able to keep up with the treatment plan even during telehomecare because when the doctor has a video call with my grandma, I always listen and take notes, and then I go over what the doctor has told her. I take notes of it all.* [Participant 002]

Communication and Device and Usability Limitations Are Also Challenges

In telehomecare, despite the content, care processes, and follow-ups remaining the same, challenges still arise. The main barriers are related to communication and issues with the equipment, but most caregivers are capable of handling these challenges.

Communication

Challenges include low volume from either the patient or health care worker, low patient inattention, and faulty devices, leading to unclear communication. Caregiver presence during sessions can help overcome these barriers.

> *Grandma's voice is quite soft. She can't speak loud making it difficult for the doctor to hear* [Participant 002]
>
> *During telehomecare, if mother is sitting and trying to listen, it may be necessary for a caregiver to be present to help explain things, as she may have a reduced ability to listen and understand due to her age and weakening internal systems.* [Participant 015]

Technologies and Signaling Systems

Loss of information may occur in telehomecare, but some caregivers have modified or changed the signaling equipment and environment to enhance it, resolving this issue.

> *The sound is a bit lacking, but it's probably my Internet. After changing the Wifi, it's better. My mother's room lacks internet signal.* [Participant 007]
>
> *Barriers? There are some when we use VDO call. Because the phone is old, and we changed the area where we put the phone, so we received a call late. We don't use Wifi.* [Participant 018]

Ability to Use Technology

Older caregivers may encounter difficulties due to their unfamiliarity with technology, affecting their ability to use telehomecare equipment.

> *I am not good at using the smartphone. Sometimes they ask me to take pictures of this and that area and I don't really know how to shoot and am not very proficient in using the device.* [Participant 013]

There is an Obvious Advantage of Telehomecare in Limited Cases Rather Than In-Person Home Visits

Despite some challenges and difficulties, telehomecare offers a clear advantage by providing a means of communication in remote areas.

Scheduling Conflicts

Telehomecare can resolve scheduling conflicts caused by caregiver appointments, enabling remote participation when in-person visits are not possible.

> *There are times when the older adult patient is not at home during the appointment time. Recently, Grandma was at the center. But we communicated through Line in this group. And then we turn on the*

> *camera and talk from 3 different places: the center, the hospital and the office. I can even participate in the call while at work.* [Participant 020]

Inconvenient Home Settings

Telehomecare is convenient when the patient’s home is not suitable for visits, for example, the home space is not suitable for the health care team to visit, or traveling to the home of the patient is inconvenient. It is especially effective when assessments rely on the caregiver alone, as outcomes remain similar without the need for travel.

> *It’s convenient. We don't have to prepare anything. It’s the same. The appointment time doesn’t need to be made, just only when she is unable to sleep.* [Participant 017]

Limited Participation of the Patient

It is also effective when assessments rely solely on the caregiver, for example, when the patient has limited participation in conversation, as outcomes remain similar without the need for travel.

> *...I think it's convenient for both parties. Maybe the patient is taking a nap when the team visit, so eventually the doctor didn't talk to grandma anyway but to me.* [Participant 016]

Everyone is Confident About This Type of Service, but Their Preference Depends on the Family Circumstance and Situation

Overview

When asked about transitioning from in-person home visits to telehomecare, all participants (100%) expressed confidence in receiving telehomecare. Caregivers believed it was similar to in-person visits and met their expectations for health care services. For instance, suggestions about how to reduce health risk behaviors, providing physical therapy advice, managing diet, and offering psychological support for both patients and caregivers.

> *I feel confident because if we have any problems, we can ask just like how we did when the doctor came, but the disadvantage is that the doctor does not see the patient in person but everything else is the same* [Participant 016]

The preference of individual caregivers toward the in-person home visit versus the telehomecare service model is due to personal experiences and all aspects gained during both forms of services. These can be divided into 3 categories.

Preference for In-Person Home Visit

Some caregivers prefer in-person visits because they provide a broader view. These visits allow for a more comprehensive understanding of the patient’s living conditions, environment, evolving symptoms, and overall well-being. In addition, from the direct experience of caregivers, it is easier to identify additional abnormalities during in-person visits that may require treatment. Eight caregivers preferred in-person home visits because they could see more of the overall picture of the patient and the environment.

> *Because the last time the doctor and the nurse came to visit the house, they gave me notice and later, mother had discovered a mole that protruded into a malignant tumor, we didn't know it. We thought it was a normal wart. Here, in-person home visits are very helpful. because sometimes caregiver doesn't know what it is.* [Participant 019]

Preference of Telehomecare

Two caregivers prefer telehomecare over in-person visits because it is more convenient as they require less preparation. Often, during home visits, the patient may be sleeping and most of the communication is with the caregiver.

> *She prefers a VDO call because it is convenient for both doctor and patient. Sometimes the patient will be taking a nap. Most of the patients as old as grandma start napping a lot. If the doctor comes and grandma is not talking to him anymore, she’ll take a nap. This is a waste of the doctor’s time.* [Participant 016]

Preference for Both Methods

Five caregivers had similar preferences for both forms of services. They appreciated that both approaches provided an equivalent level of service and treatment, meeting their expectation and goals of health care services during examinations and treatment processes.

> *I like both. I had no problems with both of them, Through VDO calls, we also get what we need for patient care - medicines and lab results. For me, I don’t have a preference for either method because the specific advantages are different.* [Participant 003]

Additionally, some of the caregivers had no preference between in-person home visits and telehomecare as they found advantages in both methods depending on the situation, such as the current pandemic situation and the patient’s condition.

> *It can be both. But now the doctor says that during the COVID pandemic, he still needs to communicate through VDO call as it is good for both sides. As for the in-person home visit, it provides a visual interaction, but during A VDO call, we still have talking, interviewing, asking questions, providing the health care process which is similar kind of work as well.* [Participant 014]

Discussion

Principal Findings

The study discovered that telehomecare is not the same as in-person visits. It may present certain difficulties and barriers, particularly in the aspects of assessment, interaction, and technology use. Despite these barriers, it has the potential to fulfill requirements and bolster trust among those caregivers who provide care to older adults at home to a similar extent as a face-to-face visit. The majority of patients prefer both forms of care, but it is important to adapt use to fit specific circumstances and conditions.

Comparison With Prior Work

The caregivers of homebound or bedridden older adults expressed positive attitudes toward telehomecare and are prepared to familiarize themselves with this service, comprehending its limitations and the need for its use instead of in-person visits. The previous scope review for patients receiving the telehomecare service at home found that patients desire telehomecare as a supplementary channel, offering easier access to health services from the health care team. This can enhance symptom management and encourage greater self-care [30]. Additionally, 1 study shows that telehomecare patients have greater expectations of telehomecare for the quality and efficiency of patient care, a positive relationship with the team, reduced travel costs [31], and a sense of continuous health monitoring and reassurance from their health care team [32]. If these concerns are addressed in patient care, it will heighten the confidence and satisfaction of both patients and their families.

Moreover, previous studies have found that the majority of participants with a negative attitude toward telehomecare services need more face-to-face health checks than those monitored by telehomecare. This is because they did not have a sense of touch as in in-person visits and were not familiar with using devices. This caused barriers. Conversely, those who are already comfortable with the technology tend to have a more favorable view and see telehomecare as a convenient option, eliminating the need for physically transporting patients to a hospital [8]. These findings align with the results of this study.

Recommendations for Enhancing Telehomecare Services

Based on these results, there are 4 recommendations for enhancing telehomecare services as provided in the following sections.

The Provider Should Enhance the Patients' or Caregivers' Skills to Do Self-Health Assessment

Our study results revealed that it is possible to conduct an overall assessment of a patient's health through telehomecare, but there may be limitations in assessing certain aspects, such as physical assessment. Telehomecare's limitations make it hard to conduct comprehensive videoconferencing or telephone-based health checks, leading to potential medical errors. To ensure effective patient care, family members and caregivers must be involved [33]. Educating them on symptom recognition and initial assessments can help detect abnormalities early, leading to prompt notification for further assessment by the health care team [23]. It is important to provide training and education to caregivers on how to effectively use telemedicine services, as it can improve their skills in self-observing symptoms and mental health management. Telehomecare can also be used to educate and promote self-care, which can lead to better health outcomes for patients. Various channels, such as phone calls, websites, apps, or chats, can be used to provide additional health care skills to caregivers [34,35].

The Health Care Team Should Enhance Their Skills on Telehomecare Services for Patients at Home

A technical problem has been reported as an issue. Therefore, it is crucial for the health care team to possess the necessary skills in telehomecare services to assist patients and their families when they encounter such problems in order to enhance ease of use. It has been suggested that health care teams possess the following skills when delivering telehomecare services [36]: (1) determining when to use telemedicine and assessing the ability of patients and caregivers to use it; (2) proficiency in assessing and caring remotely for patients; (3) effective communication and relationship-building with patients, caregivers, and families; (4) professionalism; (5) basic understanding of information technology; (6) knowledge of laws and privacy protection; (7) ethical considerations; (8) awareness of patient's safety; and (9) awareness of accessibility and service culture. All of these knowledge and skills required by the health care team impact the provision of effective services which are of utmost importance. In some countries, such as the Netherlands, core competencies have been defined for nurses to ensure the effective implementation of telehealth [37].

The key findings from this study suggest that the health care team should know how to assess the situation and select the appropriate service models, whether it could be in-person home visits or telehomecare based on the experience. Although service users have different preferences, circumstances and necessities should be considered. According to the study by Doraiswamy et al [38], it was noted that telehomecare services had previously been used for noncommunicable diseases. However, during the current pandemic, they have become increasingly important for diagnosis, symptom monitoring, rehabilitation physiotherapy, and reducing the spread of pathogens as well [38]. Despite these advantages once the outbreak situation improves, telehomecare services should only be provided in appropriate cases. Patients with positive attitudes toward telehomecare services; who have used technology and have previously received in-person medical treatment; and have difficulties traveling to the hospital due to distance, finances, or health issues are typically considered suitable for telehomecare services. In addition, the content discussed during the telehomecare services should not be of a sensitive nature, particularly in the case of relationships with the caregiver [39]. It is important to ensure that the patient has a suitable place to receive telehomecare services without distractions and can provide the necessary information to the health care team.

The preferences of patients and their families are a crucial factor in choosing the right telehomecare service. It is important for the physician to consider various aspects, including the patient's health, family preferences on service models, and the current social situation. Health care providers should engage in conversations with older adult patients and their caregivers regarding the advantages and disadvantages of telehealth, enabling patients to make informed choices between in-person and telemedicine options [23]. This is to make an informed decision and ensure patient satisfaction with the chosen service in the future.

The Barriers, Especially Those That Are Fundamental to Providing Telehomecare Services, Should Be Removed as Much as Is Feasibly Possible

In our study, we found that barriers to telehomecare can originate from patients themselves, including soft speaking voices or inadequate communication devices. Technology-related barriers, such as poor signal quality or connectivity issues, may also occur. To mitigate these issues, providers and recipients may need to invest in proper equipment, use a microphone that can absorb speech well, and place equipment in the right position to optimize the internet signal [33]. Additionally, the financial aspect of the service should also be considered, it may be useful to have a system to restore certain devices from the service provider but must be weighed against the expenses of the service provider side as well.

Some caregivers struggle to use communication devices, which can cause interruptions in telehomecare services. Patients may also feel incapable of learning to use these devices, according to a study by Huang et al [8]. Thus, telehomecare teams should be knowledgeable about the devices used, inquire about any concerns, and provide assistance to build confidence in using them. To ensure accessibility to all areas, it is recommended to develop strong internet signal towers to support telehomecare for the national benefit.

Interestingly, this study found that the majority of caregivers for older adult patients were highly educated children, with great potential to use technology better than the patient. However, they may still have limitations in using communication devices and technology [40]. Health care providers should not judge their ability based on age or education, and even frail older adults can be trained with help from nurses and caregivers [41]. Each family should be evaluated on a case-by-case basis, and appropriate assistance provided.

Services Should Also Be Provided to Meet Expectations Regarding the Management of Health Problems

Caregivers of older adult patients often have specific expectations from their health care providers, such as recommendations to enhance the patient’s overall health, psychological support, and reducing transportation costs. Our findings support that caregivers perceive telehomecare as useful and prefer it when their expectations are met during the service delivery. Offering services that meet the expectations of patients and their caregivers helps improve the health care aspect and engage in service involvement, which leads to a reduction in hospitalization rates [41,42]. The health care team should strive to meet these expectations to maintain the trust of patients and their families in the telehomecare health care service to the same extent as in an in-person home visit.

Strengths

The strength of this study is that the study involved caregivers with experience in both in-person home visit and telehomecare, allowing for comparison of both services. The study also focused on in-depth aspects related to caring for the bedridden older adults who may have limitations in receiving services.

Limitations

However, there are also limitations to this study. For instance, the information obtained through interviews by health care teams or personnel from the hospital may be biased. To mitigate this, the researchers took measures to ensure that the interviewer was not involved in the treatment of any of the patients and caregivers interviewed. The interview process for participants using convenience sampling may involve selecting individuals who are readily available or easy to reach, potentially leading to a sampling bias. However, the data reach its saturation. Additionally, the sex of participants was 75% (n=15) female, which may yield different insights compared with settings with varying sex ratios among caregivers. However, in Thailand, the majority of caregivers for older adults are female, with a prevalence ranging from 70% to 90% [43-45]. This ratio is similar to that in our study. Given the slight tendency for male individuals to hold slightly more favorable attitudes toward technology use than female individuals, although not substantially [46], it is important to note that this sex imbalance among caregivers should not significantly impact the study’s results. The participants of this study were mainly caregivers of older adults with stable chronic illnesses. Caregivers of patients with more complicated illnesses or the terminally ill may have different attitudes or expectations. We did not include the attitudes of the medical service team with regard to this aspect. These attitudes may affect the outcomes of services and treatment as well, which may be subject to further study. Last, conducting a study comparing telehomecare with no care would underscore the significance of home-delivered care. However, since our initial aims did not include a comparison of these 2 populations, we did not collect data from individuals who have not received the service. It may be worthwhile to consider further research involving families of older adults with health conditions that limit their function but are unable to obtain home care services. Nevertheless, obtaining information about this population could be challenging.

Conclusion

In conclusion, telehomecare is a viable option to supplement in-person home visits. It has the potential to provide quality health care services to patients and allow health care teams to offer treatment and advice remotely. Caregivers have shown a positive attitude toward telehomecare, which is comparable in effectiveness to in-person visits. Despite potential challenges, telehomecare can be a useful alternative in situations where in-person visits are not possible. However, it is important to enhance the skills of caregivers and health care teams to overcome barriers and optimize the use of telehomecare.

Acknowledgments

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Data Availability

The data sets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Framework matrix.
[DOCX File , 25 KB - aging_v7i1e48132_app1.docx]

References

1. Suriyanrattakorn S, Chang CL. Long-term care (LTC) policy in Thailand on the homebound and bedridden elderly happiness. Health Policy Open 2021;2:100026 [FREE Full text] [doi: 10.1016/j.hpopen.2020.100026] [Medline: 37383491]
2. Ko Y, Noh W. A scoping review of homebound older people: definition, measurement and determinants. Int J Environ Res Public Health 2021;18(8):3949 [FREE Full text] [doi: 10.3390/ijerph18083949] [Medline: 33918712]
3. Bekdemir A, Ilhan N. Predictors of caregiver burden in caregivers of bedridden patients. J Nurs Res 2019;27(3):e24 [FREE Full text] [doi: 10.1097/jnr.0000000000000297] [Medline: 30431539]
4. Schirghuber J, Schrems B. Being wheelchair-bound and being bedridden: two concept analyses. Nurs Open 2023;10(4):2075-2087 [FREE Full text] [doi: 10.1002/nop2.1455] [Medline: 36336822]
5. Klein S, Hostetter M, McCarthy D. An overview of home-based primary care: learning from the field. Issue Brief (Commonw Fund) 2017;15:1-20. [Medline: 28591975]
6. Kim CO, Jang SN. Home-based primary care for homebound older adults: literature review. Ann Geriatr Med Res 2018;22(2):62-72 [FREE Full text] [doi: 10.4235/agmr.2018.22.2.62] [Medline: 32743249]
7. Ergin E, Akin B, Kocoglu-Tanyer D. Effect of home visits by nurses on the physical and psychosocial health of older adults: a systematic review and meta-analysis. Iran J Public Health 2022;51(4):733-745 [FREE Full text] [doi: 10.18502/ijph.v51i4.9234] [Medline: 35936539]
8. Huang KTL, Lu TJ, Alizadeh F, Mostaghimi A. Homebound patients' perspectives on technology and telemedicine: a qualitative analysis. Home Health Care Serv Q 2016;35(3-4):172-181. [doi: 10.1080/01621424.2016.1264341] [Medline: 27897466]
9. Kong DC, Chauhan A, Leung ATA, Chin M. Telemedicine in the context of COVID-19- a qualitative study of cancer patients and clinicians. Research Square. Preprint posted online on February 1, 2021 :1-22 [FREE Full text] [doi: 10.21203/rs.3.rs-149380/v1]
10. Radhakrishnan K, Xie B, Jacelon CS. Unsustainable home telehealth: a Texas qualitative study. Gerontologist 2016;56(5):830-840 [FREE Full text] [doi: 10.1093/geront/gnv050] [Medline: 26035878]
11. Sethi BA, Sethi A, Ali S, Aamir HS. Impact of coronavirus disease (COVID-19) pandemic on health professionals. Pak J Med Sci 2020;36(COVID19-S4):S6-S11 [FREE Full text] [doi: 10.12669/pjms.36.COVID19-S4.2779] [Medline: 32582306]
12. Khoshrounejad F, Hamednia M, Mehrjerd A, Pichaghsaz S, Jamalirad H, Sargolzaei M, et al. Telehealth-based services during the COVID-19 pandemic: a systematic review of features and challenges. Front Public Health 2021;9:711762 [FREE Full text] [doi: 10.3389/fpubh.2021.711762] [Medline: 34350154]
13. Pinyopornpanish K, Nantsupawat N, Buawangpong N, Pliannuom S, Vaniyapong T, Jiraporncharoen W. Concerns of home isolating COVID-19 patients while receiving care via telemedicine during the pandemic in the Northern Thailand: a qualitative study on text messaging. Int J Environ Res Public Health 2022;19(11):6591 [FREE Full text] [doi: 10.3390/ijerph19116591] [Medline: 35682177]
14. Finkelstein SM, Speedie S, Hoff M, Demiris G. Tele-homecare: telemedicine in home health care. 1999 Presented at: 1999 IEEE Engineering in Medicine and Biology 21st Annual Conference and the 1999 Annual Fall Meeting of the Biomedical Engineering Society; October 13-16, 1999; Atlanta, GA, USA p. 13-16. [doi: 10.1109/iembs.1999.803836]
15. Phuthong T, Mangsungnoen N. Factors influencing the elderly intention to use and adopt mobile health services. Veridian E-Journal Silpakorn University 2017;10(2):548-566.
16. Wardlow L, Roberts C, Archbald-Pannone L. Perceptions and uses of telehealth in the care of older adults. Telemed J E Health 2023;29(8):1143-1151 [FREE Full text] [doi: 10.1089/tmj.2022.0378] [Medline: 36493377]
17. Goldberg EM, Lin MP, Burke LG, Jiménez FN, Davoodi NM, Merchant RC. Perspectives on telehealth for older adults during the COVID-19 pandemic using the quadruple aim: interviews with 48 physicians. BMC Geriatr 2022;22(1):188 [FREE Full text] [doi: 10.1186/s12877-022-02860-8] [Medline: 35260091]

18. Bowles KH, Baugh AC. Applying research evidence to optimize telehomecare. J Cardiovasc Nurs 2007;22(1):5-15 [FREE Full text] [doi: 10.1097/00005082-200701000-00002] [Medline: 17224692]
19. Mangin D, Parascandalo J, Khudoyarova O, Agarwal G, Bismah V, Orr S. Multimorbidity, eHealth and implications for equity: a cross-sectional survey of patient perspectives on eHealth. BMJ Open 2019;9(2):e023731 [FREE Full text] [doi: 10.1136/bmjopen-2018-023731] [Medline: 30760515]
20. Shin HR, Um SR, Yoon HJ, Choi EY, Shin WC, Lee HY, et al. Comprehensive senior technology acceptance model of daily living assistive technology for older adults with frailty: cross-sectional study. J Med Internet Res 2023;25:e41935 [FREE Full text] [doi: 10.2196/41935] [Medline: 37036760]
21. Ma Q, Chan AHS, Teh PL. Insights into older adults‘ technology acceptance through meta-analysis. Int J Hum Comput Interact 2021;37(11):1049-1062. [doi: 10.1080/10447318.2020.1865005]
22. Cook EJ, Randhawa G, Guppy A, Sharp C, Barton G, Bateman A, et al. Exploring factors that impact the decision to use assistive telecare: perspectives of family care-givers of older people in the United Kingdom. Ageing Soc 2018;38(9):1912-1932. [doi: 10.1017/S0144686X1700037X]
23. Raj M, Iott B, Anthony D, Platt J. Family caregivers' experiences with telehealth during COVID-19: insights from Michigan. Ann Fam Med 2022;20(1):69-71 [FREE Full text] [doi: 10.1370/afm.2760] [Medline: 35074770]
24. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014;89(9):1245-1251 [FREE Full text] [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
25. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Med Res Methodol 2018;18(1):148 [FREE Full text] [doi: 10.1186/s12874-018-0594-7] [Medline: 30463515]
26. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013;13:117 [FREE Full text] [doi: 10.1186/1471-2288-13-117] [Medline: 24047204]
27. Marangunić N, Granić A. Technology acceptance model: a literature review from 1986 to 2013. Univ Access Inf Soc 2015;14(1):81-95. [doi: 10.1007/s10209-014-0348-1]
28. Chadborn NH, Goodman C, Zubair M, Sousa L, Gladman JRF, Dening T, et al. Role of comprehensive geriatric assessment in healthcare of older people in UK care homes: realist review. BMJ Open 2019;9(4):e026921 [FREE Full text] [doi: 10.1136/bmjopen-2018-026921] [Medline: 30962238]
29. Stoop A, Lette M, van Gils PF, Nijpels G, Baan CA, de Bruin SR. Comprehensive geriatric assessments in integrated care programs for older people living at home: a scoping review. Health Soc Care Community 2019;27(5):e549-e566 [FREE Full text] [doi: 10.1111/hsc.12793] [Medline: 31225946]
30. Steindal SA, Nes AAG, Godskesen TE, Dihle A, Lind S, Winger A, et al. Patients' experiences of telehealth in palliative home care: scoping review. J Med Internet Res 2020;22(5):e16218 [FREE Full text] [doi: 10.2196/16218] [Medline: 32369037]
31. Chang JY, Chen LK, Chang CC. Perspectives and expectations for telemedicine opportunities from families of nursing home residents and caregivers in nursing homes. Int J Med Inform 2009;78(7):494-502. [doi: 10.1016/j.ijmedinf.2009.02.009] [Medline: 19345640]
32. Husebø AML, Storm M. Virtual visits in home health care for older adults. ScientificWorldJournal 2014;2014:689873 [FREE Full text] [doi: 10.1155/2014/689873] [Medline: 25506616]
33. Fageir S, Osman O, Addison C. A closer look at dementia patients' barriers to telemedicine utilization during the COVID-19 pandemic. Eur J Env Public Hlt 2023;7(4):em0146 [FREE Full text] [doi: 10.29333/ejeph/13408]
34. Graven LJ, Glueckauf RL, Regal RA, Merbitz NK, Lustria MLA, James BA. Telehealth interventions for family caregivers of persons with chronic health conditions: a systematic review of randomized controlled trials. Int J Telemed Appl 2021;2021:3518050 [FREE Full text] [doi: 10.1155/2021/3518050] [Medline: 34093704]
35. Kruse C, Betancourt J, Ortiz S, Luna SMV, Bamrah IK, Segovia N. Barriers to the use of mobile health in improving health outcomes in developing countries: systematic review. J Med Internet Res 2019;21(10):e13263 [FREE Full text] [doi: 10.2196/13263] [Medline: 31593543]
36. Galpin K, Sikka N, King SL, Horvath KA, Shipman SA, AAMC Telehealth Advisory Committee. Expert consensus: telehealth skills for health care professionals. Telemed J E Health 2021;27(7):820-824 [FREE Full text] [doi: 10.1089/tmj.2020.0420] [Medline: 33236964]
37. van Houwelingen CTM, Moerman AH, Ettema RGA, Kort HSM, Cate OT. Competencies required for nursing telehealth activities: a Delphi-study. Nurse Educ Today 2016;39:50-62 [FREE Full text] [doi: 10.1016/j.nedt.2015.12.025] [Medline: 27006033]
38. Doraiswamy S, Abraham A, Mamtani R, Cheema S. Use of telehealth during the COVID-19 pandemic: scoping review. J Med Internet Res 2020;22(12):e24087 [FREE Full text] [doi: 10.2196/24087] [Medline: 33147166]
39. Sturesson L, Groth K. Clinicians' selection criteria for video visits in outpatient care: qualitative study. J Med Internet Res 2018;20(11):e288 [FREE Full text] [doi: 10.2196/jmir.9851] [Medline: 30401661]

40. Rojanasumapong A, Jiraporncharoen W, Nantsupawat N, Gilder ME, Angkurawaranon C, Pinyopornpanish K. Internet use, electronic health literacy, and hypertension control among the elderly at an urban primary care center in Thailand: a cross-sectional study. Int J Environ Res Public Health 2021;18(18):9574 [FREE Full text] [doi: 10.3390/ijerph18189574] [Medline: 34574499]
41. Finkelstein SM, Speedie SM, Zhou X, Potthoff S, Ratner ER. Perception, satisfaction and utilization of the VALUE home telehealth service. J Telemed Telecare 2011;17(6):288-292. [doi: 10.1258/jtt.2011.100712] [Medline: 21844178]
42. Bowles KH, Hanlon AL, Glick HA, Naylor MD, O'Connor M, Riegel B, et al. Clinical effectiveness, access to, and satisfaction with care using a telehomecare substitution intervention: a randomized controlled trial. Int J Telemed Appl 2011;2011:540138 [FREE Full text] [doi: 10.1155/2011/540138] [Medline: 22187551]
43. Pinyopornpanish K, Wajatieng W, Niruttisai N, Buawangpong N, Nantsupawat N, Angkurawaranon C, et al. Violence against caregivers of older adults with chronic diseases is associated with caregiver burden and depression: a cross-sectional study. BMC Geriatr 2022;22(1):264 [FREE Full text] [doi: 10.1186/s12877-022-02950-7] [Medline: 35354435]
44. Pinyopornpanish K, Soontornpun A, Wongpakaran T, Wongpakaran N, Tanprawate S, Pinyopornpanish K, et al. Impact of behavioral and psychological symptoms of Alzheimer's disease on caregiver outcomes. Sci Rep 2022;12(1):14138 [FREE Full text] [doi: 10.1038/s41598-022-18470-8] [Medline: 35986203]
45. Sanprakhon P, Chaimongkol N, Hengudomsub P. Relationships between caregiving stress and sleep quality among family caregivers of older adults with dementia in Thailand. Belitung Nurs J 2022;8(3):229-234 [FREE Full text] [doi: 10.33546/bnj.2106] [Medline: 37547117]
46. Cai Z, Fan X, Du J. Gender and attitudes toward technology use: a meta-analysis. Comput Educ 2017;105:1-13 [FREE Full text] [doi: 10.1016/j.compedu.2016.11.003]

Abbreviations

SRQR: Standards for Reporting Qualitative Research

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Original Paper

A Web-Based Intervention Based on Acceptance and Commitment Therapy for Family Caregivers of People With Dementia: Mixed Methods Feasibility Study

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Abstract

Background: Acceptance and commitment therapy (ACT), as an empirically based third-wave cognitive behavioral therapy, has shown promise in enhancing well-being and functioning across diverse populations. However, in the context of caregiving, the effect size of available ACT interventions remains at best moderate, sometimes accompanied by high dropout rates, highlighting the need for more effective and feasible intervention designs.

Objective: The objective of our study was to evaluate the feasibility and acceptability of a fully online ACT program designed for family caregivers of people with dementia. This study aimed to boost psychological flexibility and support caregivers, enabling them to realize and prioritize their own life values alongside their caregiving responsibilities.

Methods: A mixed methods feasibility study using an uncontrolled pretest-posttest design was conducted. This intervention included a 9-week web-based self-help program based on ACT incorporating collaborative goal setting and weekly web-based motivational coaching for family caregivers of people with dementia. This study involved 30 informal caregivers recruited through memory clinics and social media platforms in the Netherlands and received approval from the Medical Ethics Committee of the Maastricht University Medical Center+ (NL77389.068.21/metc21-029).

Results: A total of 24 caregivers completed the postintervention assessment, indicating a high adherence rate (24/29, 83%). Caregivers reported positive feedback regarding collaborative goal setting, but some found challenges in implementing new skills due to their own habitual responses or the unpredictable context of dementia caregiving. Personalizing the intervention based on individual value preferences was highlighted as beneficial.

Conclusions: Compared to other web-based self-help ACT interventions for family caregivers, this intervention showed a high adherence and sufficient level of feasibility, which underscores the use of personalization in delivering web-based interventions. Moreover, the potential of this ACT-based intervention for family caregivers of people with dementia was demonstrated, suggesting that further research and a larger-scale controlled trial are warranted to validate its effectiveness.

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KEYWORDS

acceptance and commitment therapy; ACT; psychological flexibility; behavior change; theory-guided eHealth; web-based intervention; supported self-help; family caregivers; dementia

Introduction

Background

The number of people with dementia is predicted to double every 20 years, which will lead to a corresponding rapid increase in the number of family caregivers [1]. Family care increases the quality of life of people with dementia and reduces formal care costs, thus making a substantial contribution to dementia care management. This is noteworthy as most people with dementia rely on a range of crucial and unpaid support from family caregivers [2]. Although the experience of caregiving might be fulfilling and positive, research also shows that, with advancing dementia, the need for care can become increasingly time-intensive, stressful, and more complex, posing a risk to the overall well-being of caregivers. In the context of dementia, family caregivers may experience inevitable and long-lasting changes due to the progressive nature of the condition and the increasing dependence of the person with dementia on their caregivers.

Importantly, the adverse effects of caregiving can be addressed and improved through a wide range of psychological interventions [3-6]. However, the long-term care situation and associated (inevitable) changes in caregivers' lives underscore the importance of acceptance-based interventions that focus on developing skills to effectively address the management of maladaptive thoughts and emotions and acceptance of ongoing changes [7]. Specifically, the ways through which caregivers perceive and respond to internal (ie, thoughts and feelings) and external (ie, environmental) stressors are significant predictors of negative outcomes in this population [8,9]. Subsequently, acceptance and commitment therapy (ACT), as an empirically based third-wave cognitive behavioral therapy, might be particularly noteworthy due to its scalable focus on promoting psychological flexibility [10]. From the ACT perspective, psychological flexibility refers to efficient functioning in the presence of difficult experiences and is achieved via 6 interrelated core processes. These processes include openness to internal experiences (ie, acceptance), defusing from thoughts (ie, cognitive defusion), being in the present moment and aware of oneself and others (ie, mindfulness), having a distinct perspective on internal experiences (ie, self as context), identifying meaningful action qualities that can be connected with bringing purpose and motivation (ie, values), and active engagement and behavioral action aligned with values (ie, committed action) [11]. Hundreds of randomized controlled trials (RCTs) have demonstrated the effectiveness of ACT in improving overall well-being in the general population and in people with mental or somatic health problems [6,12].

ACT for Family Caregivers of People With Dementia

In the context of dementia caregiving, ACT shows promise in promoting acceptance of change and increasing willingness to take meaningful actions, leading to improved psychological flexibility and better overall functioning in caregivers [13-15]. Several RCTs have demonstrated that face-to-face individual ACT interventions provided by trained therapists result in a significant reduction in depression and anxiety in family caregivers of people with dementia compared to control groups [13,15,16]. Furthermore, non-RCT ACT studies have also shown promise in supporting family caregivers of people with dementia through modalities such as telephones [17], videoconferencing [18], group settings [19], or web-based self-help modules [20,21].

eHealth Adaptations for Family Caregivers

In recent years, technological advancements have facilitated the development and adaptation of a wide range of acceptable and promising psychological programs, from face-to-face to eHealth (ie, the use of internet to promote well-being) [4,22,23]. In particular, web-based self-help interventions are cost-effective and accessible approaches that reduce the significant involvement of health care professionals, allowing caregivers to complete the intervention on their own time using computers, tablets, or mobile devices. Web-based self-help interventions provide materials such as modules, text, and videos, enabling users to navigate the program at their own pace [24].

However, the effect sizes of the available interventions are still at best moderate [3] with a high dropout rate [20], indicating the need for more effective intervention designs [15]. Furthermore, in the context of caregiving, family caregivers of people with dementia are often older adults. The potential lower digital literacy and preference for traditional face-to-face psychological support, coupled with implementation limitations, make them the subgroup of caregivers who most frequently report challenges related to accessing and using eHealth interventions [4]. Thus, in the context of eHealth, guided self-help interventions including "minimal contact" might be a promising approach for this population. In a "minimal contact" approach, health care professionals (eg, coaches) are involved for nontherapeutic purposes and mainly for periodic check-ins, teaching participants how to use the digital tools, and provision of initial rationales [23,25].

Personalizing Self-Help Interventions From the ACT Perspective

Personalizing interventions is an important and effective strategy to increase adherence and prevent dropout rates, making trials, including RCTs, more feasible, acceptable, and effective [26]. One effective and efficient approach to personalization is collaborative goal setting, in which individuals, together with health care professionals, set specific goals based on their own needs and resources before the intervention, leading to increased motivation and, ultimately, behavior change [27]. From the ACT perspective, there is a distinction between goals and value-based choices and their impact on (long-term) behavior change. Goals are typically external and have a clear end point that can be achieved or completed. In contrast, values are meaningful qualities that cannot be obtained or finished but rather help set meaningful goals and guide long-term patterns of behavior. Thus, acknowledging personal values and nesting specific goals underneath them is more likely to drive effective behavior change in the long term [11]. Engaging in value-based activities in the context of caregiving has a positive association with emotional well-being [28] and a negative association with distress [16].

To our knowledge, collaborative goal setting based on caregivers' values has not yet been explored within the context of web-based ACT self-help interventions. Gaining further insights into the feasibility of web-based ACT interventions for family caregivers of people with dementia might contribute to decisions related to the implementation of ACT interventions in clinical practice, facilitating intervention refinements and, ultimately, leading to the design and development of more acceptable, effective, and sustainable interventions for future large-scale controlled trials.

This Study

Despite the growing literature on ACT and the efficacy of eHealth interventions in family caregivers, there is a limited focus on understanding the specific challenges and opportunities of web-based self-help interventions for this population [29]. To date, few studies have used supported or personalized self-help ACT to address the specific needs of family caregivers. The aforementioned studies, although promising [21], showed a high dropout rate [20], or the intervention did not prove highly effective [30]. Therefore, in response to the need for a more efficient intervention design for family caregivers of people with dementia, this pilot trial aimed to use a mixed methods assessment approach (qualitative and quantitative data) to examine the feasibility and acceptability of the ACT for informal caregivers of people with dementia intervention. This web-based guided intervention is designed for community-based family caregivers of people with dementia through web-based ACT modules, collaborative goal setting based on individuals' personal values before the intervention, and minimal-contact motivational coaching during the intervention. Subsequently, this study aimed to address the following research question: what are the practical and conceptual barriers and facilitators influencing the feasibility and acceptability of this guided web-based intervention?

Methods

Overview

This study was a pilot trial with a mixed methods approach, a baseline assessment, a 9-week web-based intervention embedded with web-based weekly motivational coaching, and a postintervention assessment. This study was reported according to the guidelines presented in the CONSORT (Consolidated Standards of Reporting Trials) checklist [31]. The CONSORT checklist is presented in Multimedia Appendix 1 [32]. The complete design is described in the protocol [33], and the methodological details relevant to this feasibility and acceptability study are presented in the following sections.

Participants

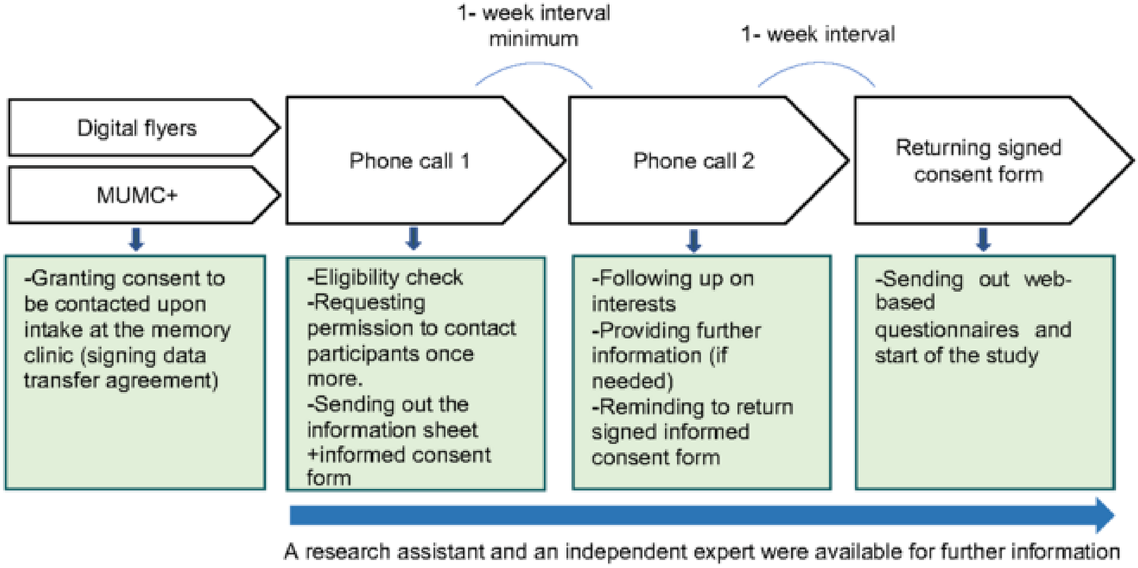
A sample size of 30 participants is considered to be sufficient to enable a reasonable calculation of the key factors relevant to feasibility (eg, attrition rates) and provide useful information required for recommending a larger controlled trial [34,35]. Therefore, 30 family caregivers of people with dementia were recruited for this study.

Eligible family caregivers were recruited sequentially from May 2022 to June 2023. The following inclusion criteria were applied: (1) adult caregivers (aged ≥18 y), (2) self-identified primary family caregivers of a person with a diagnosis of dementia, (3) caring for the care recipient for at least 3 hours per week for at least 3 months, (4) internet and tablet or computer accessibility in the household, and (5) consent to participate. Family caregivers were excluded if (1) they indicated cognitive difficulties or disorders in their medical record (based on self-report) or (2) they had undergone psychotherapy or psychopharmacological treatment during the previous 3 months.

Recruitment Procedure and Screening

Family caregivers were recruited from referrals by clinicians (eg, psychiatrists or psychologists) at the memory clinic of the Maastricht University Medical Center+ in the Netherlands. Furthermore, recruitment took place using printed or web-based flyers and website posts by patient and caregiver support organizations in the Netherlands, the Dutch Alzheimer Association, and local mental health institutions. Information about the study as well as a self-addressed stamped envelope for returning the informed consent form were provided to all the participants via post. When the research team received the signed informed consent form (in paper format), the study officially started. The process of screening and recruitment is shown in Figure 1, and further details on the recruitment procedure can be found in the study protocol [33].

Figure 1. Recruitment procedure. MUMC+: Maastricht University Medical Center+.



Intervention

Overview

The guided web-based intervention followed a written protocol [33]. As a general structure, each week, participants first completed a web-based module and then received a telephone or video call from a motivational coach. Participants were instructed to complete consecutive steps, including (1) a 50-minute web-based video call at baseline with a motivational coach for value-based goal setting, (2) 9 self-help web-based ACT modules (20-30 min each), and (3) an approximately 20-minute weekly web-based video call with a motivational coach for 9 weeks. In addition, participants had the flexibility to extend the duration of the intervention and complete the 9 modules and coaching sessions in 12 weeks. Contact with the coach took place in individual sessions.

Collaborative Goal Setting

Collaborative goal setting [36] was chosen to personalize the guided web-based intervention. During the individual value-based goal-setting session with the motivational coach, each participant set one value-based personalized goal that was specific, measurable, attainable, realistic, and time-orientated (SMART) [37]. Individuals could select from a predefined list of value-based actions or write goals in their own words (Multimedia Appendix 2). The list was prepared based on the ACT model and an adapted version of the valued living questionnaire for dementia caregiving [28,29,38]. Specific value-based actions with clear steps were defined during the collaborative goal-setting session and were embedded into future activities within the intervention. The steps of collaborative goal setting are shown in Multimedia Appendix 3.

Web-Based Self-Help Modules

Details about the intervention can be found elsewhere [33]; in brief, caregivers focused on 1 of the 6 ACT components (ie, acceptance, cognitive defusion, mindful attention, self as context, value, or committed action) in each module, gradually covering all the core principles of psychological flexibility. The 9 self-help web-based modules were released weekly consisting of a standard structure including a brief introductory text, a short video, an ACT-related metaphor, and content-oriented assignments. Module 1 provided a short introduction to ACT and a program overview. In module 2, “Creative Hopelessness” was introduced to reflect on the dysfunctionality of avoidance strategies for difficult thoughts and feelings in life. Modules 3 to 8 reviewed each of the 6 ACT components in detail. Finally, session 9 was a recap of all ACT components incorporating strategies for relapse prevention in everyday life (Multimedia Appendix 4). In addition, ACT metaphors were embedded in the content of the modules. For example, the boomerang metaphor was used for avoiding unpleasant feelings. The concept is that the more one attempts to throw the metaphorical boomerang away, the more forcefully it will eventually return [39].

After completing a module, caregivers received an automated email notification from the website reminding them of the availability of the next module. Access to the modules was sequential, requiring completion in a specific order rather than allowing access to all modules at once. Further details on the content of the website are presented in Table 1.

Table 1. Overview of the 9 modules included in the intervention.

Module	Title	ACT[a] strategy	Example of the exercise
1	Introduction	The introduction of ACT and the content of the program consists of modules with videos explaining ACT components accompanied by metaphorical images and exercises to enhance personal resilience.	“You are now invited to answer these two questions for yourself: Where do you want to go with your life (as a person, privately and in your work)? What stands in your way?”
2	Creative hopelessness	Exploring creative hopelessness strategies among informal caregivers for navigating unpleasant thoughts and feelings.	“Share three personal examples of how you prevent unpleasant feelings, employing strategies like prevention, avoidance, and reduction. This exercise fosters self-awareness about your functioning in challenging situations.”
3	Acceptance	Recognizing caregivers’ potential struggles with negative emotions, this module involves fostering acceptance by making room for unpleasant feelings.	“This exercise encourages reflection on personal pain, strategies for coping, and resulting suffering. Identify specific instances of pain, whether thoughts, feelings, physical sensations, or situations.”
4	Defusion	Addressing the tendency of individuals to take their thoughts seriously, the focus is on defusion—encouraging individuals to distance themselves from difficult thoughts.	“Write a negative self-view, e.g., ‘I’m not good enough,’ then rephrase it as ‘I have the thought that I am not good enough.’ Notice the difference between directly identifying with the thought and acknowledging it as a passing idea.”
5	Self as context	Acknowledging the tendency of individuals to define their self-image based on perceived expectations, the emphasis is on the self as context—creating room for individuals to be themselves and fostering flexibility in their self-image to alleviate stress.	“In ACT, your self-image is like wearing a tailor-made suit that may not fit your current feelings. Reflect on times this felt restrictive and consider less uncomfortable suits you’ve worn. Explore a more flexible approach and think of the benefits of taking them off for a moment.”
6	Mindfulness	Recognizing that excessive focus on the past or future may not always be helpful, the emphasis is on the here and now—encouraging individuals to pay sufficient attention to the present moment, the only time when we can truly live, act, and experience.	“Reflecting on past and future often overshadows the present; embracing the moment enhances life satisfaction. Losing the present in thoughts might result in missing the richness of the present experience. Try to recognize an example of this in your own life.”
7	Value	Recognizing the significance of acknowledging what truly matters in one’s life, the focus is on values—actively encouraging individuals to ask whether their values are sufficiently present in their lives and put them into practice.	Value-sorting task: “Identify core life values using a set of cards, categorizing them as ‘Very Important,’ ‘Important,’ or ‘Not Important,’ and then prioritizing the top 10 values to actively invest in.”
8	Committed action	Emphasizing the facilitation of a more meaningful life, the focus is on committed action—encouraging individuals to define concrete and feasible actions toward their values, actively invest in them, and translate them into value-based actions.	“Take practical steps and reflect on each significant value and ask, ‘What is the smallest, easiest step I can take in the next 24 hours to align my life with that value?’ Ensure specificity and feasibility in these actions for practical implementation.”
9	Psychological flexibility	The concluding module highlights that cultivating psychological flexibility through the practice of the 6 core skills enables individuals to address problems differently and with greater flexibility, enriching their lives in ways that hold personal value.	“You were introduced to all the different ACT components. We invite you to answer the initial questions from Module One again: Where do you want to go with your life (as a person, privately and in your work)? What stands in your way?”

[a] ACT: acceptance and commitment therapy.

Weekly Coaching

A trained research assistant with experience in intervention coaching was appointed from Maastricht University to fulfill the role of the motivational coach. As part of the weekly coaching process, participants were encouraged to complete the weekly module before scheduling a video call. During the weekly coaching, the coach inquired about the participants’ overall experience with the web interface (ie, whether any technical or other issues occurred), how goal attainment was progressing (ie, value-based actions defined during the collaborative goal setting), and whether they experienced a (positive or negative) change in their motivation (Multimedia Appendix 5). Weekly coaching was not intended as a therapeutic function but rather to provide technical support and motivate participants to follow the web-based self-help modules (ie, adherence) and stay engaged with their value-based goals. Thus, goal attainment and module completion were not mandatory before coaching took place.

Sampling and Intervention Quality

Data were collected using the Castor web-based platform provided by Maastricht University. Intervention integrity was monitored independently by experts. Several types of monitoring visits were conducted by the Clinical Trial Center Maastricht for the purpose of quality and control at the beginning of the study (ie, site initiation visit); during the course of the study (ie, interim monitoring visits); and at the end of the study, when participants had completed the study and all data had been collected (close-out visit) [33].

Quantitative and qualitative data were used to inform the feasibility and acceptability of the intervention for the participants and coach. The number of referrals, number of eligible participants willing and not willing to take part, reasons for declined participation or dropout after signing the informed consent form and before starting the intervention (if provided), and amount of time spent on recruiting 30 participants were monitored during recruitment. Quantitative and qualitative data on the intervention procedure were collected to inform use logs and interaction with the web-based modules. Barriers (eg, technical problems or difficulties) to user engagement were qualitatively collected during weekly coaching. To distinguish between intervention rejections and dropouts, we defined dropout as attrition following the start of the intervention (ie, those participants who attended at least one session of the intervention but discontinued it) [26]. Reasons for dropout after starting the intervention (if provided), attrition rate of weekly coaching sessions, and ACT module completion were also recorded.

Assessment

Overview

This study specifically focused on feasibility and acceptability aspects. The preliminary efficacy and changes in psychological outcomes will be reported elsewhere. Further details on the measures of preliminary efficacy are described elsewhere [33].

End-of-Module Questionnaire

Following the previous study, the research team developed the end-of-module questionnaires [40] with the goal of gaining additional insights into the feasibility and acceptability of each module. Subsequently, content comprehension was assessed directly after completion of each module via a feedback questionnaire. This questionnaire included 3 items (ie, “I found today’s module useful,” “I have experienced the content of the modules as stressful,” and “I can apply the content of today’s modules in my daily life”) rated on a Likert scale ranging from 1=*strongly disagree* to 7=*strongly agree* on perceived usefulness, stressfulness, and applicability of each module to one’s daily life.

Goal Attainment

The level of goal achievement, as well as qualitative feedback on the feasibility and acceptability of goal achievement, was collected on a weekly basis during coaching. Goal attainment scaling was mapped on a prespecified ordinal scale, and the number of attainment levels ranged from −3 to +2. Each SMART goal was set at different layers as an “action list” including different levels of goal attainment. Level “0” was set as the “expected” level, and the rest of the levels were defined by a possible change in goal attainment. Any progress from the “expected level” was scored with “+1” as the “better than expected” level or “+2” as the “much better than expected” level. Deterioration in goal attainment was scored with “−1” as the “improvement but less than expected” level. The “−2” score was assigned to the “current” level and addressed “no change” from the goal-setting day, and “−3” referred to the “much less than expected” level in goal attainment. Setting an in-between “−2” score as the “current” level was considered to prevent floor effect and capture deterioration from the “current” individuals’ state [37]. During collaborative goal setting at baseline, each caregiver defined and clarified 5 layers of their SMART goals (from −3 to +2).

The Program Participation Questionnaire

Further insights into the usability, clarity, and acceptability of the intervention for family caregivers was obtained during a postintervention semistructured interview using the Program Participation Questionnaire (PPQ) [40]. The PPQ consisted of 26 items scored on a Likert scale ranging from 1=*strongly disagree* to 7=*strongly agree* focusing on 3 main areas, including the applicability of the intervention in everyday life, feasibility, usability, acceptability, and content quality and quantity (Multimedia Appendix 6). Furthermore, the number of log-ins to the modules and feature use were collected and compared with self-reported data. The feasibility and perceived experience of the coach was evaluated using a brief 6-item coach questionnaire focusing on the intervention’s usability and relevance for the coach, general perceived experience, the program’s positive and negative aspects, and suggestions for improvements (Multimedia Appendix 7).

Demographic Information

During the baseline assessment, family caregivers completed a demographics questionnaire providing information about their age, sex, level of education, living situation (ie, whether the caregiver and the person with dementia lived together or independently), hours of caregiving per week, type of kin relationship with the person with dementia, years since diagnosis, and dementia type.

Data Analysis

The PPQ was analyzed quantitatively and qualitatively. Due to the lack of external criteria to properly define feasibility [41], median scores as a conventional strategy were defined as determinants of the overall feasibility, usability, and acceptability [40,42]. This approach to evaluating feasibility was also previously used in a Delphi study [43]. The overall PPQ scores ranged from 26 to 182. The median score of 130 was deemed as the cutoff and, thus, “acceptable feasibility” [40]. Mean item scores (range 1-7) of <5 (“slightly agree”) were considered as having potential for improvement. Participants further reflected qualitatively on their scores, and their reflections were audio recorded and transcribed verbatim. The deductive content analysis was conducted by authors GLA and RVK using field notes to interpret the quantitative scores on the PPQ [42,44]. In addition, to evaluate whether the intervention components aligned with the specific needs of the target group [45], field notes were classified and deductively coded into four main categories to address the intervention components: (1) overall experience and suggestions, (2) goal setting and value identification, (3) web-based self-help ACT modules, and (4) coaching. Furthermore, the self-report acceptability questionnaires at the end of each module were summarized in SPSS (IBM Corp) using descriptive statistics. Finally, web feature use and the number of log-ins were collected and subsequently compared with self-reported data. Data from the weekly coaching sessions were incorporated to complement the log data and the postintervention semistructured interviews.

Ethical Considerations

The study was approved by the Medical Ethics Committee of the Maastricht University Medical Center+ (NL77389.068.21/metc21-029). All participants provided informed consent, and the rigorous protection of privacy and confidentiality of participants was safeguarded throughout the study. Data were anonymized when applicable to safeguard participant identities. As a token of appreciation, participants received a €25 (US $27.13) gift card for their involvement.

Results

Overview

A total of 33 family caregivers were deemed eligible to participate in the study, of whom 30 (91%) provided informed consent and 24 (73%) completed the postintervention assessment (Figure 2).

In total, 3 eligible caregivers declined to sign the informed consent form citing the extra burden on their caregiving responsibilities (n=2, 67%) and the admission of the person with dementia to a nursing home (n=1, 33%) as reasons for their decision. Of the 29 participants who initiated the intervention, 4 (14%) decided to leave prematurely. Thus, based on the definition of dropout in this study, an adherence rate of 83% (24/29) was recorded, including 1 withdrawal and 4 dropouts.

Of the 30 caregivers who signed the informed consent form, 1 (3%) did not continue the baseline assessment due to difficulties in arranging an electronic device, such as a laptop or tablet, to continue the study. In addition, of the remaining 29 caregivers, 1 (3%) withdrew due to the death of the person with dementia, and 4 (14%) dropped out citing concerns that the study was too time-consuming or emotionally challenging or added an extra burden to their existing caregiving responsibilities. Examples of reasons for dropout included the following:

> *I wasn't that fond of it. It makes you depressed, all that thinking about the past and stuff. It's not what I expected.* [ACT-IC015; aged 63 years; male]
>
> *I don't want to dwell on it, don't want to learn to think differently either, I find that scary.* [ACT-IC018; aged 51 years; female]

No differences were identified between caregivers who dropped out and those who completed the study. Of the 24 participants who completed the study, most were female (18/24, 75%), and the hours of caregiving were often reported to be >15 per week, ranging from 3 to 20. The duration of dementia (ie, time since diagnosis) was, on average, 4.1 (SD 2.7) years, with a higher prevalence of Alzheimer (12/24, 50%) followed by vascular dementia (6/24, 25%). Further sociodemographic characteristics of the caregivers are shown in Table 2.

Figure 2. Participant flow.

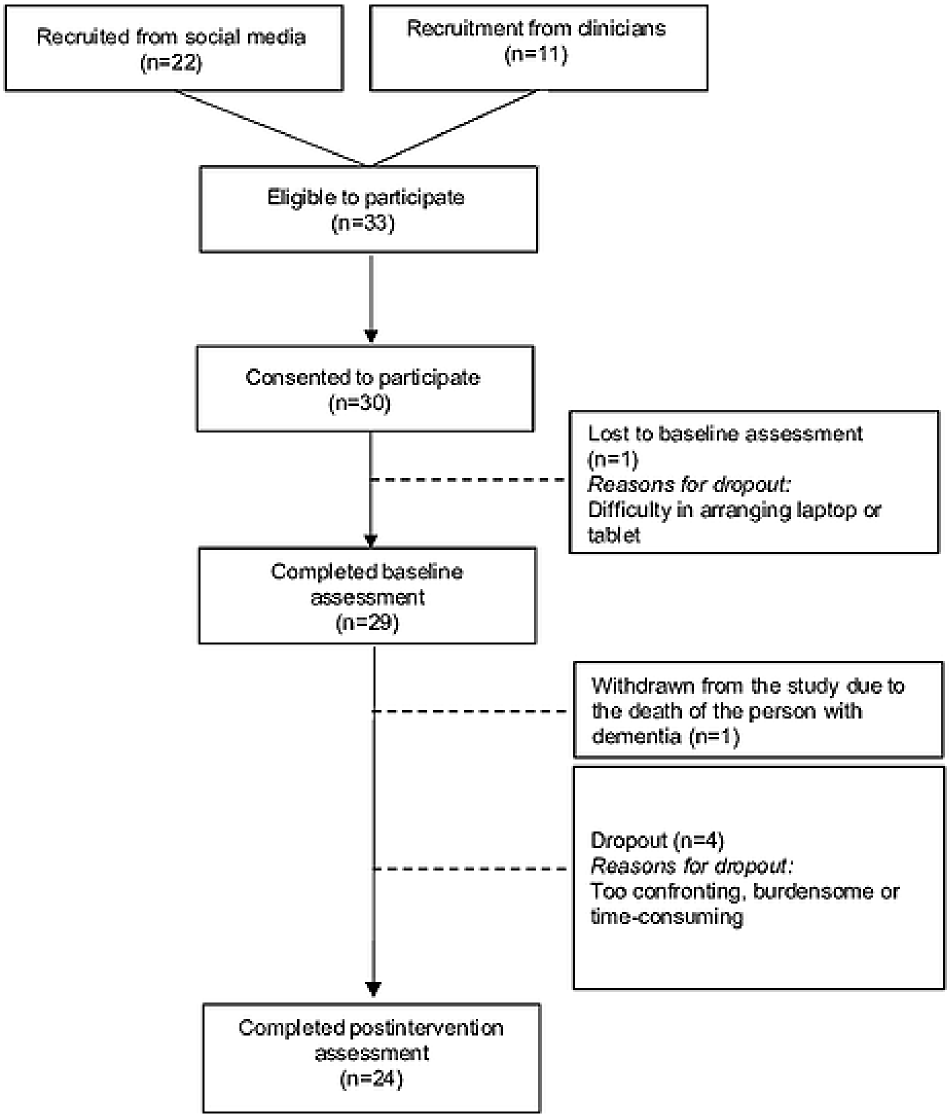


Table 2. Overview of the sample characteristics (N=24).

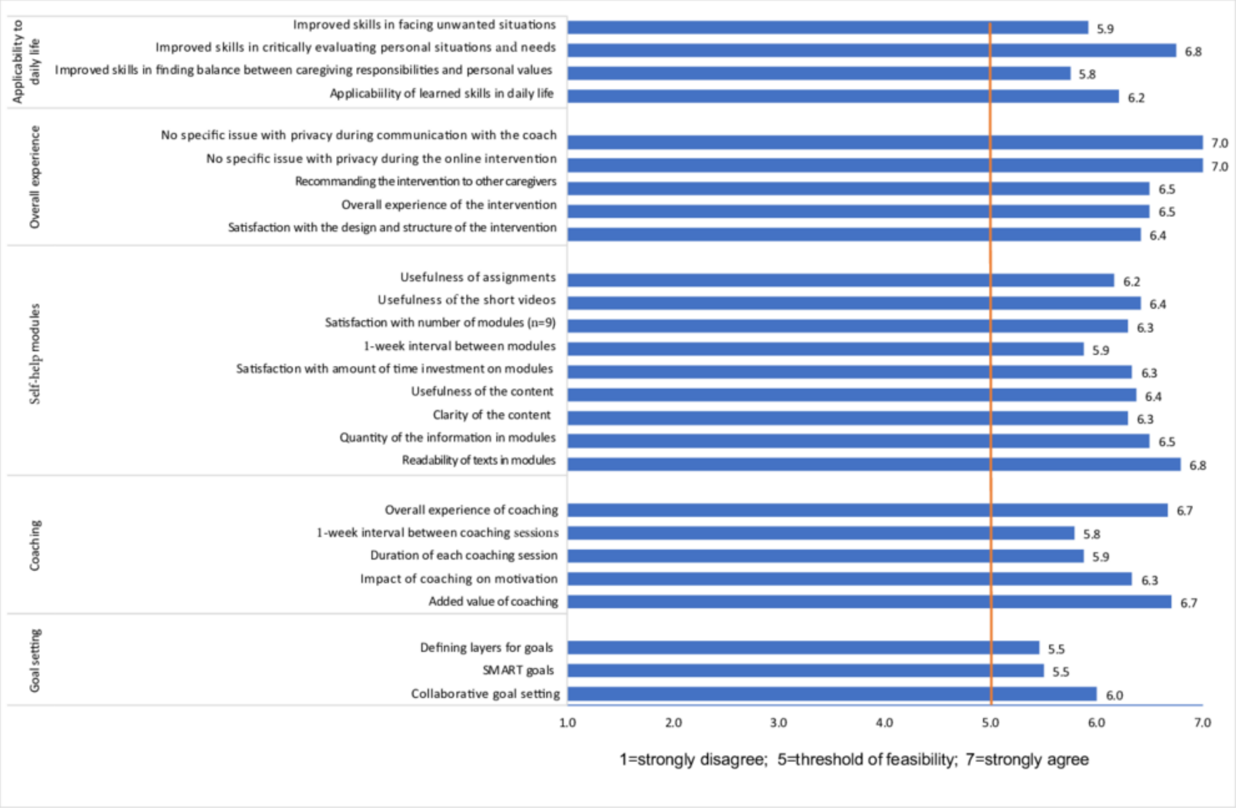
Characteristic	Values
Age (y), mean (SD)	62.5 (13.1)
Sex, n (%)	
Female	18 (75)
Male	6 (25)
Kin relationship, n (%)	
Spouse	14 (58)
Child	9 (38)
Ethnicity, n (%)	
Non-Hispanic White	24 (100)
Education, n (%)	
Completed college	15 (62)
Employment status, n (%)	
Currently employed	10 (42)
Living arrangement, n (%)	
Living with care recipient	17 (71)
Hours of caregiving per week, n (%)	
≥15	15 (62)
Dementia diagnosis, n (%)	
Alzheimer disease	12 (50)
Vascular	6 (25)
Young onset dementia	1 (4)
Frontotemporal	1 (4)
Parkinson disease	2 (8)
General (diagnosed, not specified)	2 (8)
Duration of dementia (y), mean (SD)	4.1 (2.7)

Results of PPQ

Overview

The total score on the PPQ ranged from 90 to 182. The average total score on the PPQ of the 24 caregivers who completed the intervention was 163.4 (SD 22.3). On average, family caregivers gave all items a score of at least 5 (mean 6.29, SD 0.46), with a total median score of 172, indicating high perceived feasibility and acceptability (Figure 3).

Figure 3. Average scores on each item of the Program Participation Questionnaire. SMART: specific, measurable, attainable, realistic, and time-orientated.



The quantitative results of the PPQ on intervention feasibility and acceptability were consistent with postmodule self-report acceptability as well as with deductive qualitative content analysis of the field notes.

Qualitative feedback informed the feasibility and acceptability of the intervention components, specifically (1) overall experience, (2) goal setting and value identification, (3) web-based self-help ACT modules, and (4) coaching. In addition, a semistructured interview was conducted with the motivational coach to gain more insights into study feasibility for the interventionist.

Overall Experience

Overall, participants found the intervention's design comprehensive, logically structured, and strongly interconnected, "like a string of chain," emphasizing that removing a single component would disrupt the functionality of the intervention. Enhanced adaptability to the caregiving role and improved ability to focus on meaningful life values while providing care for people with dementia were noted as valuable components in addressing the balance between caregiving and self-care. Caregivers reported that their enhanced psychological flexibility, achieved through ACT principles, supported their resilience and also positively influenced people with dementia, describing it as a "win-win" situation:

> *It was aligned, enriching, confronting, and educational. Without a coach, it would have been easier to let things slip. Providing care becomes much more sincere and high quality by being mindful. You can only do that if you have space for it, so you have to let go of your need for control. It starts with yourself, and you can apply it everywhere, that is a relaxing feeling. I learned to deal with myself in a different way. I could respond more calmly. I wasn't overwhelmed and overstimulated; it had such a positive effect on the person with dementia.* [ACT-IC 002; aged 47 years; male]

Caregivers suggested the inclusion of a psychoeducational module specifically addressing the application of ACT to the unique challenges caregivers face in dementia care. Such a module may support contextualizing ACT and enhance the understanding of the metaphors used within the intervention, making it more relevant and applicable to the unpredictable and progressive nature of the condition. In addition, some caregivers expressed the desire to have ongoing access to the modules or receive a printed booklet containing all the modules, allowing them to reference the material even after the study. While acknowledging that the intervention was confronting and required more time than initially anticipated, participants still expressed their recommendation of the intervention to other caregivers.

Goal Setting and Value Identification

Family caregivers expressed that setting goals before participating in the intervention was essential for their engagement with the program and establishing a road map toward desired behavior change. Formulating SMART goals made the process more tangible for participants and stimulated a sense of purpose during the intervention, which led individuals to plan and adapt self-management and personal values to their caregiving responsibilities. Most caregivers often emphasized the importance of receiving guidance in value identification, prioritizing goals, breaking value-based actions down into manageable steps, and adjusting goals when necessary:

> *Providing guidance is important because then I receive a kind of confirmation that I should do it as well. Otherwise, it remains so open-ended. The coach allowed me the freedom to set my own goals and provided guidance when needed. Setting goals and timeframes helped me avoid feeling guilty about taking time for myself.* [ACT-IC012; aged 65 years; female]

Goal Attainment

Participants had mixed experiences when it came to engaging with the action list, which included layers of goal attainment, as well as when they were asked to self-report their progress on their goals during meetings with the coach. Some caregivers found the action list to be beneficial for adapting their goals to better align with the changing demands of caregiving, enhancing their ability to navigate through personal values and caregiving responsibilities effectively. Nonetheless, some caregivers encountered challenges in both accomplishing their goals and accurately assessing their level of achievement. Furthermore, a desire to modify their goals was also noted among some participants. Factors that influenced the attainment of goals primarily included caregiving demands such as the inability to leave the care recipient alone, their own health conditions (eg, physical pain), and time limitations. These factors often resulted in adjustments to the goals throughout the intervention. In addition, a shift in focus to a different set of values was another factor that influenced goal adjustment.

Reduced engagement with the action list or failure to attain goals at a desirable level for some caregivers caused feelings of anxiety or increased burden when reporting to the coach:

> *I had the tendency to give socially desirable answers when the coach asked if I had worked on my goals. I would be asked if I had gone cycling, but I can't leave my partner alone. So, I do want to take more time for myself, but the situation doesn't always allow me to engage in outdoor activities.* [ACT-IC 009; aged 74 years; female]

According to the coach, using the SMART framework for goal setting was valuable for structuring collaborative goal-setting sessions. However, adjusting goals to account for comorbidities and caregiving demands presented challenges at times in providing guidance, particularly within limited time frames.

Web-Based Self-Help ACT Modules

Content

The content of the web-based self-help ACT modules was reported mainly as "easy to follow" and helped caregivers in adapting their coping strategies, acquiring new skills to navigate challenges, cultivating mindfulness of the present moment, and reframing their perspective to align with their life values. According to caregivers, following ACT principles in parallel with goals empowered them to gain more insights into psychological flexibility, enabling them to take practical steps toward living in accordance with their values:

> *I went out of my comfort zone...I usually think that if you want something, you'll just do it, but it (i.e., ACT) was truly an eye-opener. I was constantly realising I need to do this, oh yes, I need to pay attention to that as well, of course. Those moments of realisation, I found them very valuable.* [ACT-IC 004; aged 52 years; female]

After completing each module, participants provided self-report feedback and rated the usefulness, stressfulness, and applicability of the content on a Likert scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). All participants (24/24, 100%) completed all modules along with the self-report questionnaires. According to their feedback, the web-based self-help modules were generally perceived as useful, with a mean score of 5.6 (SD 0.2; range 5.4-6.1), and applicable to daily life, with a mean score of 5.2 (SD 0.5; range 4.4-5.9). The stressfulness of the content was rated with a mean score of 3.5 (SD 0.8; range 2.4-4.4). Among the various components, the "self as a context" component was identified as the most useful yet one of the most stressful modules after "Acceptance" (Multimedia Appendix 8).

Overall, participants expressed that the ACT modules enabled them to "change attitude," which was necessary for openness and developing skills that are "potentially applicable" in everyday life. However, taking perspective did not always result in actual changes in behavior in everyday life for some (older) caregivers. The most frequently reported barrier to applying new skills "in the situation" was the role of habits. Caregivers often highlighted that implementing new ACT skills took time to "sink in," particularly due to habitized responses to specific cues that developed through years of repetition:

> *You've been doing things your whole life, often unconsciously, and now you're becoming aware of things. Becoming aware and then changing your behavior takes time.* [ACT-IC001; aged 65 years; female]
>
> *In difficult situations, it's not so easy to implement everything you know. You know it now, but it can still be challenging to apply in the situations.* [ACT-IC006; aged 71 years; female]
>
> *With a certain age and lifestyle, it's a significant adjustment, not easy, but the adaptations are necessary.* [ACT-IC011; aged 79 years; male]

According to the coach, extending the completion time frame to 12 weeks allowed caregivers more time and space to learn the materials. However, given the time required to acquire new skills, extending the time frame to >12 weeks could also be beneficial.

Format

Most participants found 1 module per week to be suitable, with some suggesting that 2-week intervals could also work. In total, 29% (7/24) of the caregivers required >9 weeks to complete all 9 modules. Caregivers found the web-based format beneficial as it eliminated the need for additional travel time, making it convenient to integrate the intervention into their daily routines. In addition, the convenience of the self-help modules was appreciated, which allowed caregivers to review the material and take notes at their own pace, offering an opportunity to consider personal preferences:

> *I have difficulty remembering certain things (concerning the intervention material). I have to reread things to apply them properly.* [ACT-IC001; aged 65 years; female]

All participants (24/24, 100%) completed the intervention using computers or laptops with internet access. Regarding the experience of the web-based format, caregivers expressed that the presence of a coach supported them with navigating through the web setup. The combination of video, text, and assignments was expressed as useful to comprehend ACT exercises and metaphors. However, some caregivers chose to review the material either by accessing the web application on their mobile phones or offline by printing the material rather than logging into their accounts via their computers:

> *I printed it out so I could read it and write down my thoughts and notes. I prefer paper over online, which might have to do with my age.* [ACT-IC006; aged 71 years; female]

According to the coach, addressing technical difficulties provided the necessary support for participants with lower digital literacy and prevented dropout due to technical issues.

Coaching

Overall, participants found the coaching sessions aligned, enriching, and constructive. The supportive listening, availability of the coach through multiple channels (video call, phone call, and email) during coaching, technical support for the web-based module, feeling safe with privacy on the web, and flexible rather than fixed coaching appointments were particularly appreciated. Caregivers reported that receiving personal feedback enhanced their active engagement with the entire intervention. This engagement, in turn, increased their motivation to learn new perspectives presented by the ACT modules and strengthened their commitment to achieving their goals. The contact with the coach through digital means was mentioned as added "accountability" and a suitable modality, particularly for those who preferred direct contact with health care professionals.

From the Coach's Perspective

The weekly coaching sessions revealed several prominent barriers faced by caregivers, including technological, intrinsic, and extrinsic challenges. Technological barriers centered on issues related to digital literacy, limited access to digital devices, and a lack of self-efficacy in technology use. The coach addressed these concerns by offering supplementary guidance, providing the option to print materials for offline use, and enabling access to the intervention through a mobile-friendly web application. Intrinsic obstacles included motivational struggles, physical discomfort, and reduced sensory abilities, which influenced the caregivers' willingness to implement new ACT strategies or attain their goals. The coach navigated these barriers through motivational conversations, supportive listening, and adaptable goal setting to accommodate individual preferences and limitations. Extrinsic barriers included time constraints, demanding caregiving responsibilities, and the evolving condition of the care recipient, leading to fluctuations in the caregivers' schedules and diaries.

Regarding the nontherapeutic nature of the coaching, the coach expressed that "caregivers just needed to be heard." However, providing motivation without knowing the context was often not possible, resulting in the duration of sessions exceeding the planned 20 minutes. Although the longer calls were still feasible for the coach, providing flexible availability was not always easy to adjust to daily work responsibilities. Furthermore, the coach noted that conducting data collection fully over the web and providing technical support posed occasional challenges that sometimes required contacting third parties and could result in delays.

Discussion

Principal Findings

This feasibility study was conducted in response to the demand for interventions that are both more scalable and personalized for family caregivers of people with dementia. The findings of this study revealed that caregivers acknowledged the beneficial impact of psychological flexibility. This recognition resulted in perceived positive effects not only in self-management and caregiving quality but also in the applicability of ACT in noncaregiving situations in daily life. This outcome is in line with that of previous research that ACT can be transdiagnostic in addressing psychological flexibility in a heterogeneous sample of caregivers who provided care for individuals at various stages and with various types of conditions, including dementia [46,47]. The findings of this study revealed a high adherence rate of 83% (24/29) at the postintervention measurements, which exceeded the average adherence rate of 57% found in self-guided ACT interventions [48], 73% found in self-help interventions [24], and 69% found in internet-based treatments for the general population [49]. High adherence and overall satisfaction are particularly important findings as family caregivers of people with dementia have the highest dropout rates and reported problems with access and usability of eHealth interventions [4].

The aim of this guided web-based intervention was to broaden the evidence base by exploring practical and conceptual barriers and facilitators influencing feasibility and acceptability. This investigation provides additional insights for refining future interventions and potentially facilitates the implementation of effective controlled trials on a larger scale. This web-based self-help intervention was designed for family caregivers of people with dementia and integrated ACT modules with collaborative goal setting based on personal values and weekly nontherapeutic coaching.

Personalizing ACT Interventions Through Goal Setting

In line with previous research, our findings showed that collaborative goal setting based on caregivers' values holds promise as an approach to address the specific needs of caregivers and personalize interventions [36]. In addition, collaborative reflections and guidance played a crucial role in the process of value, need, and resource identification when setting SMART goals as well as adjusting goals or timings throughout the intervention. This adaptability was perceived as necessary due to the continuously changing care demands and concurrent circumstances for caregivers. Multiple participants who set goals consistent with their originally selected values changed their goals focusing on a different value domain. Consistent with previous research, our findings underscore the significance of maintaining flexibility in future intervention designs, allowing for the selection of personally relevant values and value-focused exercises [50].

From the ACT perspective, values are meaningful qualities that cannot be obtained or finished but rather guide long-term patterns of behavior [11]. Subsequently, acknowledging personal values and nesting specific goals underneath them is more likely to drive effective behavior change in the long term [51]. Thus, the shift in focus to a different value domain may represent a potential intervention effect, enhancing caregivers' motivation to align their lives with their values. Further investigation is also warranted to closely examine the factors that drive caregivers to modify their value-based goals following their involvement in a value-based intervention. Such an exploration will shed light on whether these changes in goals are motivated by a genuine desire of caregivers to align their lives with their core values.

In the context of personalizing ACT interventions, facilitating skill building and modifying behavioral responses in older adults with regard to potential concurrent challenging circumstances (eg, health conditions) might be especially important [52]. Moreover, technology offers opportunities to personalize future interventions by providing real-time feedback or guidance (eg, using experience sampling methodology and "just-in-time" interventions), promoting engagement with and managing multiple goals over time, simplifying complex goals, and facilitating collaborative or interactive reflections [53]. Personalizing eHealth interventions for future studies is particularly noteworthy as person-centered (family) care emerges as a crucial scope of research in the path of global dementia care [54].

Utility of ACT for Behavior Change in Caregivers

Our findings suggest that ACT contributes to an increase in perceived psychological flexibility and perspective taking. For some caregivers, increased psychological flexibility might enable them to prioritize focusing on personal growth and self-care as well as embracing challenges over acquiring high goal attainment scores or external validations and motivation (eg, those provided by the coach) [55]. However, perspective taking for some caregivers did not lead to a reported change in behavior.

For some caregivers, defining an appropriate goal or putting goals into action was challenging due to concurrent circumstances (eg, comorbidities). Family caregivers noted that, despite their change in attitude through practicing ACT, reconfiguring their habitual responses based on the new insights from ACT remained challenging in certain situations. It was difficult to adopt a new mindset and avoid reacting impulsively, especially in response to the unpredictable symptoms of the person with dementia. This suggests that behaviors may be triggered by contextual cues rather than being solely the result of mindful attention or personal willpower [56].

This finding is in line with that of previous research highlighting that habits might impact the relationship between attitudes and behavior, resulting in the regulation of desirable behavior change in the long term. Therefore, a change in attitude in caregivers, although crucial for behavior change, might be influenced by situational factors (eg, behavioral symptoms of the person with dementia), potentially making them less reliable predictors of behavior [56]. Addressing habit formation in the context of dementia caregiving is particularly noteworthy as behavioral symptoms and the deteriorative nature of dementia might lead to an unstable, impulsive, unpredictable, and stressful context for caregivers.

Future design of behavior change interventions can target habit formation and the interplay between attitudes and habits for the consolidation of effective upskilling and long-term behavior change in caregivers. This effort may involve developing ACT interventions with additional modules, such as behavior modification strategies for managing disruptive behaviors [13], tailored mindfulness, or habit reversal training [57]. In this endeavor, specific attention to discovering intervention mechanisms may benefit from the use of experience sampling methodology as a quantitative approach [58].

In addition, several participants in this study suggested the inclusion of an explicit module addressing the specific context of dementia and dementia caregiving. Accordingly, a module designed to incorporate ACT principles and provide guidance on managing dementia-specific challenges, such as effectively managing repetitive questions from people with dementia, could significantly enhance the applicability of ACT to their unique situation. This result is in line with those of previous research highlighting that caregiving itself is a natural value for caregivers [59]. The future development of ACT interventions for caregivers can be centered on values associated with caregiving (ie, maintaining care and improving the relationship with the person with dementia) while allowing for variations among different caregiver profiles based on their individual value preferences [28]. Further empirical research is now needed for further evidence-based understanding of the impact of value commitment on caregiver and care recipient outcomes.

Guided Self-Help Interventions for Caregivers

In the context of caregiving, adhering to web-based self-help interventions and incorporating them into everyday life commitments is thought to be improved by embedding more personal retention approaches (eg, telephone calls), provision of flexibility, personalization, scalability, and guidance [4,14,23]. Our study showed that a web-based self-help ACT intervention with synchronous motivational coaching was highly feasible and acceptable for family caregivers, suggesting that ACT and skill building can be learned through self-help [24].

It is important to recognize the coach's significant role in enhancing adherence, motivation, and confidence in technology use as well as fostering a willingness to adopt eHealth among family caregivers of people with dementia. In line with previous research, our findings suggest that providing training on technological features and access to troubleshooting might be beneficial for caregivers with lower digital literacy as, this way, they might be less likely to perceive eHealth as difficult, incompatible, or ineffective. Furthermore, including dedicated coaches for guidance and offering technical support might more likely generate a positive attitude toward eHealth [29].

Although this study provided insights into the role of coaching in maintaining intervention adherence, providing resource-heavy support does not reflect how ACT-based programs are often used at a broader scale and outside the research context [48]. Future designs of personalized and guided eHealth interventions can explore how technology can provide additional support to health care professionals as providers to reduce personal resources and also facilitate the design of effective and implementable interventions on a large scale. Subsequently, guided self-help interventions for family caregivers can evaluate the effects of varying degrees of contact, allowing for the realization of what is the minimum amount of contact that should accompany self-help to obtain the maximum benefit [60]. To support effective, acceptable, and sustainable interventions, future approaches could involve caregivers in the process of designing interventions to capture both the context and dementia-specific needs of caregivers to be tested in larger samples [9].

Adapting ACT to a Web-Based Format for Older Adults

Although websites are the most common way of delivering web-based ACT interventions and are typically more feasible for researchers to build [61], our results showed the preference of some participants to use the intervention via their mobile phones (web application). Considering that mobile apps are more accessible and are the most commonly accessed method of self-help, future research can consider ACT-based apps for family caregivers to address the discrepancy between the ACT literature and real-world practice [48]. This technological development is noteworthy for bridging the gap to make therapy available, accessible, and affordable for larger populations of family caregivers who do not need heavy support [62]. Implementing interventions in the real world is essential for caregivers as, despite the need for behavior change interventions, most feasible and effective eHealth interventions for family caregivers of people with dementia are not yet ready for implementation and, thus, not implemented in the real world [63].

Strengths and Limitations

This study introduced a blended intervention to address the crucial need for effective interventions in dementia caregiving by exploring the feasibility of a web-based ACT intervention tailored for this population. The strengths of this study lie in its contribution to the need for further evidence-based interventions in the area of ACT and family care, paving the way for future controlled trials and intervention refinement. Additional strengths include high adherence rates, flexibility in delivering the intervention to a diverse population of caregivers of people with dementia, and shedding light on barriers and facilitators that family caregivers experienced over the course of the guided web-based self-help intervention. The mixed methods approach combined quantitative adherence rates and qualitative caregiver feedback for a comprehensive understanding of the intervention.

Nevertheless, this study might be influenced by potential biases, and when interpreting the findings, it is crucial to acknowledge its limitations. Although conducting feasibility studies before an RCT can ensure the design of studies with a higher likelihood of success, the small sample size in this study necessitates caution when generalizing the results to a larger population of caregivers of people with dementia. The study sample size was relatively small (N=30), which may limit the generalizability of the findings. Larger samples are required to draw more robust conclusions and account for potential individual differences among caregivers. In addition, the study duration was 9 weeks, and it lacked a control group, which made it challenging to determine whether the observed positive outcomes were solely due to the intervention or whether other factors may have contributed to the results. Conducting larger studies with long follow-up assessments and including a control group would provide a better basis for assessing this guided web-based intervention.

Participation in the study was voluntary and occurred over the web. Thus, individuals who chose to participate may not constitute a fully representative sample, potentially skewing toward those who are more technologically savvy with higher levels of education and greater familiarity with technology. It is crucial to acknowledge this selection bias and consider generalizability concerns when interpreting the findings. ACT principles underscore that individuals do not always have the autonomy to select the content of any given situation. To convey this concept, ACT uses metaphors that may necessitate intellectual engagement and abstract reasoning [10]. Considering the above-average level of education among the study participants and the availability of a trained coach for questions, our findings may not be broadly generalizable to caregivers with lower digital literacy or a lower educational background.

We used a guided ACT-based intervention blended with other non-ACT complementary techniques (eg, goal setting) and components (eg, weekly coaching), which might have had therapeutic effects. Specifically, some caregivers received more than the anticipated 20 minutes of coaching, leading to an unequal distribution of coaching among participants. This variability, as well as the use of self-report questionnaires, could potentially influence the generalizability of the study findings. In addition, most caregivers were at an early stage of caregiving and cared mainly for people with Alzheimer disease, limiting the understanding of how the intervention works across different contexts and stages of dementia caregiving.

Conclusions

This study was conducted to evaluate the feasibility and acceptability of a guided web-based self-help ACT intervention for family caregivers of people with dementia. The high adherence rate and positive feedback from caregivers indicate the intervention's feasibility and acceptability. The findings suggest that family caregivers can learn ACT principles and use them to enhance their psychological flexibility through self-help. Moreover, personalizing the intervention through collaborative goal setting based on individuals' values was found to be promising for addressing the specific needs of caregivers. The findings also suggest that ACT can be adapted to a web-based format, increasing accessibility and scalability for a diverse and large sample of caregivers. However, the absence of a control group and small sample size limit the drawing of definitive conclusions. Some caregivers faced challenges in translating new skills into behavior change due to habitual responses. Larger controlled trials are needed to validate the feasibility in a more diverse caregiver sample and determine the effectiveness of ACT-based interventions in this population. This study highlights the need for future interventions to address habit formation and the interplay between attitudes and habits in unpredictable and continuously changing caregiving contexts. In addition, exploration of the impact of value-based behavior on caregiver and care recipient outcomes should be considered in further research. It is hoped that the results of this feasibility study will pave the way for future effective controlled trials and the implementation of evidence-based research in real-world settings.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth) checklist V 1.6.1.
[PDF File (Adobe PDF File), 1088 KB - aging_v7i1e53489_app1.pdf]

Multimedia Appendix 2
An overview of family caregivers' potential personal values.
[DOCX File , 15 KB - aging_v7i1e53489_app2.docx]

Multimedia Appendix 3
Steps of collaborative goal setting.
[DOCX File , 531 KB - aging_v7i1e53489_app3.docx]

Multimedia Appendix 4
The interface of the website used to deliver the intervention.
[DOCX File , 2291 KB - aging_v7i1e53489_app4.docx]

Multimedia Appendix 5
An overview of the weekly coaching questions.
[DOCX File , 17 KB - aging_v7i1e53489_app5.docx]

Multimedia Appendix 6
An overview of the Program Participation Questionnaire.
[DOCX File , 25 KB - aging_v7i1e53489_app6.docx]

Multimedia Appendix 7
Semistructured interview with the coach.
[DOCX File , 20 KB - aging_v7i1e53489_app7.docx]

Multimedia Appendix 8
An overview of the acceptability of the self-help modules.
[DOCX File , 19 KB - aging_v7i1e53489_app8.docx]

References

1. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 08;396(10248):413-446 [FREE Full text] [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
2. Coe NB, Konetzka RT, Berkowitz M, Blecker E, Van Houtven CH. The effects of home care provider mix on the care recipient: an international, systematic review of articles from 2000 to 2020. Annu Rev Public Health 2021 Apr 01;42(1):483-503 [FREE Full text] [doi: 10.1146/annurev-publhealth-090419-102354] [Medline: 33395544]
3. Cheng S, Au A, Losada A, Thompson LW, Gallagher-Thompson D. Psychological interventions for dementia caregivers: what we have achieved, what we have learned. Curr Psychiatry Rep 2019 Jun 06;21(7):59 [FREE Full text] [doi: 10.1007/s11920-019-1045-9] [Medline: 31172302]
4. Sin J, Henderson C, Spain D, Cornelius V, Chen T, Gillard S. eHealth interventions for family carers of people with long term illness: a promising approach? Clin Psychol Rev 2018 Mar;60:109-125 [FREE Full text] [doi: 10.1016/j.cpr.2018.01.008] [Medline: 29429856]
5. Walter E, Pinquart M. How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. Gerontologist 2020 Nov 23;60(8):609-619. [doi: 10.1093/geront/gnz118] [Medline: 33226434]
6. ACBS, 2019 A. ACT randomized controlled trials since 1986. Association for Contextual Behavioral Science. 2019. URL: https://contextualscience.org/ACT_Randomized_Controlled_Trials [accessed 2024-02-21]
7. Márquez-González M, Romero-Moreno R, Losada A. Caregiving issues in a therapeutic context: new insights from the acceptance and commitment therapy approach. In: Pachana N, Laidlaw K, Knight B, editors. Casebook of clinical geropsychology: International Perspectives on Practice. Oxford, UK: Oxford University Press; 2010:33-53.
8. Jackson MA, Fauth EB, Geiser C. Comparing the neuropsychiatric inventory and the revised memory and behavior problems checklist for associations with caregiver burden and depressive symptoms. Int Psychogeriatr 2014 Jun;26(6):1021-1031. [doi: 10.1017/S1041610213002421] [Medline: 24423578]
9. Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. Annu Rev Psychol 2020 Jan 04;71(1):635-659 [FREE Full text] [doi: 10.1146/annurev-psych-010419-050754] [Medline: 31905111]
10. Hayes SC, Strosahl KD, Wilson KG. Acceptance and Commitment Therapy: The Process and Practice of Mindful Change. New York, NY: The Guilford Press; 2011.
11. Hayes SC, Villatte M, Levin ME, Hildebrandt MJ. Open, aware, and active: contextual approaches as an emerging trend in the behavioral and cognitive therapies. Annu Rev Clin Psychol 2011;7:141-168. [doi: 10.1146/annurev-clinpsy-032210-104449] [Medline: 21219193]
12. A-Tjak JG, Davis ML, Morina N, Powers MB, Smits JA, Emmelkamp PM. A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. Psychother Psychosom 2015;84(1):30-36. [doi: 10.1159/000365764] [Medline: 25547522]
13. Márquez-González M, Romero-Moreno R, Cabrera I, Olmos R, Pérez-Miguel A, Losada A. Tailored versus manualized interventions for dementia caregivers: the functional analysis-guided modular intervention. Psychol Aging 2020 Feb;35(1):41-54. [doi: 10.1037/pag0000412] [Medline: 31985248]
14. Atefi GL, de Vugt ME, van Knippenberg RJ, Levin ME, Verhey FR, Bartels SL. The use of Acceptance and Commitment Therapy (ACT) in informal caregivers of people with dementia and other long-term or chronic conditions: a systematic review and conceptual integration. Clin Psychol Rev 2023 Nov;105:102341 [FREE Full text] [doi: 10.1016/j.cpr.2023.102341] [Medline: 37776577]
15. Losada A, Márquez-González M, Romero-Moreno R, Mausbach BT, López J, Fernández-Fernández V, et al. Cognitive-behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for dementia family caregivers with significant depressive symptoms: results of a randomized clinical trial. J Consult Clin Psychol 2015 Aug;83(4):760-772. [doi: 10.1037/ccp0000028] [Medline: 26075381]
16. Romero-Moreno R, Márquez-González M, Gallego-Alberto L, Cabrera I, Vara-García C, Pedroso-Chaparro MD, et al. Guilt focused intervention for family caregivers. Preliminary results of a randomized clinical trial. Clin Gerontol 2022 Mar 14;45(5):1304-1316. [doi: 10.1080/07317115.2022.2048287] [Medline: 35286236]
17. Fowler NR, Judge KS, Lucas K, Gowan T, Stutz P, Shan M, et al. Feasibility and acceptability of an acceptance and commitment therapy intervention for caregivers of adults with Alzheimer's disease and related dementias. BMC Geriatr 2021 Feb 16;21(1):127 [FREE Full text] [doi: 10.1186/s12877-021-02078-0] [Medline: 33593296]
18. Han A, Yuen HK, Jenkins J. The feasibility and preliminary effects of a pilot randomized controlled trial: videoconferencing acceptance and commitment therapy in distressed family caregivers of people with dementia. J Health Psychol 2023 May 02;28(6):554-567 [FREE Full text] [doi: 10.1177/13591053221141131] [Medline: 36591636]
19. Gallego-Alberto L, Losada A, Cabrera I, Romero-Moreno R, Pérez-Miguel A, Pedroso-Chaparro MD, et al. "I feel guilty". Exploring guilt-related dynamics in family caregivers of people with dementia. Clin Gerontol 2022 Jun 04;45(5):1294-1303. [doi: 10.1080/07317115.2020.1769244] [Medline: 32496935]
20. Fauth EB, Novak JR, Levin ME. Outcomes from a pilot online acceptance and commitment therapy program for dementia family caregivers. Aging Ment Health 2022 Aug 07;26(8):1620-1629. [doi: 10.1080/13607863.2021.1942432] [Medline: 34233133]

21. Kishita N, Gould RL, Farquhar M, Contreras M, Van Hout E, Losada A, et al. Internet-delivered guided self-help acceptance and commitment therapy for family carers of people with dementia (iACT4CARERS): a feasibility study. Aging Ment Health 2022 Oct;26(10):1933-1941 [FREE Full text] [doi: 10.1080/13607863.2021.1985966] [Medline: 34617489]
22. Taylor HO, Strauss C, Cavanagh K. Can a little bit of mindfulness do you good? A systematic review and meta-analyses of unguided mindfulness-based self-help interventions. Clin Psychol Rev 2021 Nov;89:102078. [doi: 10.1016/j.cpr.2021.102078] [Medline: 34537665]
23. French KR, Golijani-Moghaddam N, Schröder T. What is the evidence for the efficacy of self-help acceptance and commitment therapy? A systematic review and meta-analysis. J Contextual Behav Sci 2017 Oct;6(4):360-374 [FREE Full text] [doi: 10.1016/j.jcbs.2017.08.002]
24. Cavanagh K, Strauss C, Forder L, Jones FW. Can mindfulness and acceptance be learnt by self-help?: a systematic review and meta-analysis of mindfulness and acceptance-based self-help interventions. Clin Psychol Rev 2014 Mar;34(2):118-129 [FREE Full text] [doi: 10.1016/j.cpr.2014.01.001] [Medline: 24487343]
25. Boots LM, de Vugt ME, van Knippenberg RJ, Kempen GI, Verhey FR. A systematic review of internet-based supportive interventions for caregivers of patients with dementia. Int J Geriatr Psychiatry 2014 Apr;29(4):331-344. [doi: 10.1002/gps.4016] [Medline: 23963684]
26. Ong CW, Lee EB, Twohig MP. A meta-analysis of dropout rates in acceptance and commitment therapy. Behav Res Ther 2018 May;104:14-33. [doi: 10.1016/j.brat.2018.02.004] [Medline: 29477890]
27. Wade DT. Goal setting in rehabilitation: an overview of what, why and how. Clin Rehabil 2009 Apr 17;23(4):291-295. [doi: 10.1177/0269215509103551] [Medline: 19293289]
28. Vara-García C, Romero-Moreno R, Barrera-Caballero S, Pedroso-Chaparro MD, Cabrera I, Márquez-González M, et al. Personal values profiles in dementia family caregivers: their association with ambivalent feelings and anxious and depressive symptoms. Aging Ment Health 2021 Nov;25(11):2160-2168. [doi: 10.1080/13607863.2020.1821169] [Medline: 32954792]
29. Wilson KG, Sandoz EK, Kitchens J, Roberts M. The valued living questionnaire: defining and measuring valued action within a behavioral framework. Psychol Rec 2017 Jun 30;60(2):249-272. [doi: 10.1007/bf03395706]
30. Han A, Yuen HK, Lee HY, Zhou X. Effects of acceptance and commitment therapy on process measures of family caregivers: a systematic review and meta-analysis. J Contextual Behav Sci 2020 Oct;18:201-213. [doi: 10.1016/j.jcbs.2020.10.004]
31. Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, PAFS consensus group. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ 2016 Oct 24;355:i5239 [FREE Full text] [doi: 10.1136/bmj.i5239] [Medline: 27777223]
32. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of web-based and mobile health interventions. J Med Internet Res 2011 Dec 31;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]
33. Atefi GL, van Knippenberg RJ, Bartels SL, Verhey FR, de Vugt ME. Blended intervention based on acceptance and commitment therapy for informal caregivers of people with dementia (ACT-IC): protocol of a mixed-methods feasibility study. BMJ Open 2023 Sep 13;13(9):e070499 [FREE Full text] [doi: 10.1136/bmjopen-2022-070499] [Medline: 37709305]
34. Arain M, Campbell MJ, Cooper CL, Lancaster GA. What is a pilot or feasibility study? A review of current practice and editorial policy. BMC Med Res Methodol 2010 Jul 16;10:67 [FREE Full text] [doi: 10.1186/1471-2288-10-67] [Medline: 20637084]
35. Thabane L, Ma J, Chu R, Cheng J, Ismaila A, Rios LP, et al. A tutorial on pilot studies: the what, why and how. BMC Med Res Methodol 2010 Jan 06;10:1 [FREE Full text] [doi: 10.1186/1471-2288-10-1] [Medline: 20053272]
36. Vermunt NP, Harmsen M, Westert GP, Olde Rikkert MG, Faber MJ. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. BMC Geriatr 2017 Jul 31;17(1):167 [FREE Full text] [doi: 10.1186/s12877-017-0534-0] [Medline: 28760149]
37. Bovend'Eerdt TJ, Botell RE, Wade DT. Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. Clin Rehabil 2009 Apr;23(4):352-361. [doi: 10.1177/0269215508101741] [Medline: 19237435]
38. Romero-Moreno R, Gallego-Alberto L, Márquez-González M, Losada A. Psychometric properties of the valued living questionnaire adapted to dementia caregiving. Aging Ment Health 2017 Sep 02;21(9):983-990. [doi: 10.1080/13607863.2016.1191055] [Medline: 27253426]
39. Jansen G, Batink T. Time to ACT!: het basisboek voor professionals. Amsterdam, The Netherlands: Thema; 2014.
40. Boots LM, de Vugt ME, Withagen HE, Kempen GI, Verhey FR. Development and initial evaluation of the web-based self-management program "partner in balance" for family caregivers of people with early stage dementia: an exploratory mixed-methods study. JMIR Res Protoc 2016 Mar 01;5(1):e33 [FREE Full text] [doi: 10.2196/resprot.5142] [Medline: 26932438]
41. Caregiving in the U.S. 2004 appendix a: detailed methodology. National Alliance for Caregiving and AARP. 2004. URL: http://assets.aarp.org/rgcenter/il/us_caregiving.pdf [accessed 2015-09-15]
42. Bruinsma J, Peetoom K, Bakker C, Boots L, Millenaar J, Verhey F, et al. Tailoring and evaluating the web-based 'partner in balance' intervention for family caregivers of persons with young-onset dementia. Internet Interv 2021 Sep;25:100390 [FREE Full text] [doi: 10.1016/j.invent.2021.100390] [Medline: 33996507]

43. Campbell SE, Azuara-Blanco A, Campbell MK, Francis JJ, Greene AC, Ramsay CR, et al. Developing the specifications of an open angle glaucoma screening intervention in the United Kingdom: a Delphi approach. BMC Health Serv Res 2012 Dec 05;12(1):447 [FREE Full text] [doi: 10.1186/1472-6963-12-447] [Medline: 23216983]
44. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115. [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]
45. Morgan DL. Pragmatism as a paradigm for social research. Qual Inq 2014 Feb 03;20(8):1045-1053. [doi: 10.1177/1077800413513733]
46. Dindo L, Van Liew JR, Arch JJ. Acceptance and commitment therapy: a transdiagnostic behavioral intervention for mental health and medical conditions. Neurotherapeutics 2017 Jul;14(3):546-553 [FREE Full text] [doi: 10.1007/s13311-017-0521-3] [Medline: 28271287]
47. Han A, Yuen HK, Jenkins J. Acceptance and commitment therapy for family caregivers: a systematic review and meta-analysis. J Health Psychol 2021 Jan 10;26(1):82-102. [doi: 10.1177/1359105320941217] [Medline: 32659142]
48. Klimczak KS, San Miguel GG, Mukasa MN, Twohig MP, Levin ME. A systematic review and meta-analysis of self-guided online acceptance and commitment therapy as a transdiagnostic self-help intervention. Cogn Behav Ther 2023 May 27;52(3):269-294. [doi: 10.1080/16506073.2023.2178498] [Medline: 36847182]
49. Melville KM, Casey LM, Kavanagh DJ. Dropout from Internet-based treatment for psychological disorders. Br J Clin Psychol 2010 Nov;49(Pt 4):455-471. [doi: 10.1348/014466509X472138] [Medline: 19799804]
50. Firestone J, Cardaciotto L, Levin ME, Goldbacher E, Vernig P, Gambrel LE. A web-based self-guided program to promote valued-living in college students: a pilot study. J Context Behav Sci 2019 Apr;12:29-38. [doi: 10.1016/j.jcbs.2019.01.004]
51. Chase JA, Houmanfar RA, Hayes SC, Ward TA, Vilardaga JC, Follette VM. Values are not just goals: online ACT-based values training adds to goal setting in improving undergraduate college student performance. J Contextual Behav Sci 2013 Oct;2(3-4):79-84. [doi: 10.1016/j.jcbs.2013.08.002]
52. Petkus AJ, Wetherell JL. Acceptance and commitment therapy with older adults: rationale and considerations. Cogn Behav Pract 2013 Feb;20(1):47-56 [FREE Full text] [doi: 10.1016/j.cbpra.2011.07.004] [Medline: 26997859]
53. Agapie E, Areán PA, Hsieh G, Munson SA. A longitudinal goal setting model for addressing complex personal problems in mental health. Proc ACM Hum Comput Interact 2022 Nov 11;6(CSCW2):1-28. [doi: 10.1145/3555160]
54. Monnet F, Dupont C, Pivodic L. In global approaches to dementia research, do not forget care. Nat Med 2023 Jul 26;29(7):1595. [doi: 10.1038/s41591-023-02356-x] [Medline: 37237048]
55. O'hora D, Maglieri KA. Goal statements and goal-directed behavior. J Organ Behav Manage 2006 Nov 07;26(1-2):131-170. [doi: 10.1300/j075v26n01_06]
56. Verplanken B, Orbell S. Attitudes, habits, and behavior change. Annu Rev Psychol 2022 Jan 04;73(1):327-352. [doi: 10.1146/annurev-psych-020821-011744] [Medline: 34587780]
57. Crosby JM, Dehlin JP, Mitchell PR, Twohig MP. Acceptance and commitment therapy and habit reversal training for the treatment of trichotillomania. Cogn Behav Pract 2012 Nov;19(4):595-605. [doi: 10.1016/j.cbpra.2012.02.002]
58. Bartels SL, van Knippenberg RJ, Viechtbauer W, Simons CJ, Ponds RW, Myin-Germeys I, et al. Intervention mechanisms of an experience sampling intervention for spousal carers of people with dementia: a secondary analysis using momentary data. Aging Ment Health 2022 Feb 09;26(2):294-304. [doi: 10.1080/13607863.2020.1857692] [Medline: 33291998]
59. Losada A, Marquez-Gonzalez M, Knight BG, Yanguas J, Sayegh P, Romero-Moreno R. Psychosocial factors and caregivers' distress: effects of familism and dysfunctional thoughts. Aging Ment Health 2010 Mar;14(2):193-202. [doi: 10.1080/13607860903167838] [Medline: 20336551]
60. Scott AJ, Webb TL, Rowse G. Self-help interventions for psychosis: a meta-analysis. Clin Psychol Rev 2015 Jul;39:96-112 [FREE Full text] [doi: 10.1016/j.cpr.2015.05.002] [Medline: 26046501]
61. Stawarz K, Preist C, Coyle D. Use of smartphone apps, social media, and web-based resources to support mental health and well-being: online survey. JMIR Ment Health 2019 Jul 12;6(7):e12546 [FREE Full text] [doi: 10.2196/12546] [Medline: 31301126]
62. Bennett CB, Ruggero CJ, Sever AC, Yanouri L. eHealth to redress psychotherapy access barriers both new and old: a review of reviews and meta-analyses. J Psychother Integr 2020 Jun;30(2):188-207. [doi: 10.1037/int0000217]
63. Christie HL, Martin JL, Connor J, Tange HJ, Verhey FR, de Vugt ME, et al. eHealth interventions to support caregivers of people with dementia may be proven effective, but are they implementation-ready? Internet Interv 2019 Dec;18:100260 [FREE Full text] [doi: 10.1016/j.invent.2019.100260] [Medline: 31890613]

Abbreviations

ACT: acceptance and commitment therapy
CONSORT: Consolidated Standards of Reporting Trials
PPQ: Program Participation Questionnaire
RCT: randomized controlled trial
SMART: specific, measurable, attainable, realistic, and time-orientated

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Original Paper

The Olera.care Digital Caregiving Assistance Platform for Dementia Caregivers: Preliminary Evaluation Study

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Abstract

Background: The increasing prevalence of Alzheimer disease and Alzheimer disease–related dementia in the United States has amplified the health care burden and caregiving challenges, especially for caregivers of people living with dementia. A web-based care planning tool, Olera.care, was developed to aid caregivers in managing common challenges associated with dementia care.

Objective: This study aims to preliminarily evaluate the quality and usability of the Olera.care platform and assess the preferences of using the technology and interests in learning about different older adult care services among caregivers.

Methods: For interview 1, we aim to understand caregiving needs and let the participants start engaging with the platform. After they engage with the platform, we schedule the second interview and let the participants complete the Mobile Application Rating Scale. The survey also included sociodemographic characteristics, caregiving experiences, communication preferences in technology adoption, and older adult care service use and interests. Descriptive statistics were used to describe the quality and usability of the platform and characteristics of the participants. We conducted 2-sample 2-tailed *t* tests to examine the differences in the Mobile Application Rating Scale evaluation scores by caregiver characteristics.

Results: Overall, 30 adult caregivers in Texas completed the evaluation. The majority were aged ≥50 years (25/30, 83%), women (23/30, 77%), White (25/30, 83%), and financially stable (20/30, 67%). The Olera.care platform evaluation showed high satisfaction, with an overall mean rating of 4.57 (SD 0.57) of 5, and scored well in engagement (mean 4.10, SD 0.61), functionality (mean 4.46, SD 0.44), aesthetics (mean 4.58, SD 0.53), and information quality (mean 4.76, SD 0.44) consistently across all participants. A statistically significant difference (P=.02) was observed in functionality evaluation scores by duration of caregiving, with caregivers dedicating more hours to care rating it higher than those providing less care (mean 4.6, SD 0.4 vs mean 4.2, SD 0.5). In addition, caregivers with less caregiving experience reported significantly higher evaluation scores for aesthetics (P=.04) and information quality (P=.03) compared to those with longer years of caregiving. All participants expressed a willingness to recommend the app to others, and 90% (27/30) rated the app overall positively. Most of the participants (21/30, 70%) favored anonymous interactions before receiving personalized feedback and preferred computer browsers over mobile apps. Medical home health services were the most used, with a diverse range of services being used. Caregiver support groups, medical providers, memory care, meal services, and adult day care were among the most desired services for future exploration.

Conclusions: The Olera.care web-based platform is a practical, engaging, easy-to-use, visually appealing, and informative tool for dementia caregivers. Future development and research are essential to enhance the platform and comprehensively evaluate it among a broader population.

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KEYWORDS

evaluation; usability; family caregiver; Alzheimer disease; dementia; digital health; mobile phone

Introduction

Background

With the population of Americans living with Alzheimer disease (AD) and AD-related dementia projected to grow from 6.7 million to 13.8 million by 2060, there is a need for effective and innovative solutions to address the increasing health care burden, particularly with caregivers of people living with dementia [1,2]. Oftentimes, these caregivers are unpaid or informal family members or friends who provide care mostly related to activities of daily living [3,4]. Due to the variability in disease progression and the caregiver's personal needs, family caregivers encounter diverse unmet needs, including challenges related to the physical and emotional deterioration of the people living with dementia [5-7]. Particularly, caregivers of people living with dementia report difficulties related to assisting the care recipient with activities of daily living, identifying the right older adult living services, navigating the financial and legal aspects of caregiving for people living with dementia, and finding relevant and concise information on dementia and dementia caregiving [5-7]. Due to the multifaceted and individualized burdens that caregivers of people living with dementia face, they are particularly susceptible to experiencing emotional, physical, and financial challenges that increase with disease progression [3,6,7].

To aid informal caregivers with challenges related to dementia care, many digital technologies have been developed that focus on either the needs of the caregiver or of the people living with dementia [8]. These solutions range from web-based training to web-based forums and caregiving groups, psychological and educational forums, and videoconferencing technologies [9,10]. Despite the many digital interventions to aid caregivers and their care recipients, these solutions do not adequately address the individual needs of caregivers of people living with dementia, leading to limited adoption of technologies outside of pilot studies [5,11]. Previous studies have shown that, despite the availability of digital interventions, the unique and individual needs of caregivers of people living with dementia are not always adequately addressed, leading to limited technology adoption and potentially contributing to sustained or increased emotional, physical, and financial burdens associated with caregiving [6,9]. To increase the use of technology that aids caregivers of people living with dementia, technology development should involve caregivers' feedback on usability and align with caregivers' expectations and needs [7,12,13]. However, not many studies have investigated the usability and usefulness of technology interventions for dementia care or involved caregivers of people living with dementia in the development process to accurately address caregivers' needs [10,12,14-16].

With the plethora of digital technologies available today to aid in dementia caregiving, there is a need for an evidence-based, engaging, adaptable, and preference-based platform for informal caregivers of people living with dementia to aid them in identifying resources and education on dementia relevant to their and their care recipient's needs [5,7,11,17]. Previously, our qualitative study reported that caregivers are looking for several features in such a web-based navigation and resource platform: "(1) a comprehensive database of commonly needed professional services, (2) mental health and caregiver support groups, (3) educational resources on dementia and caregiving, [and] (4) a platform that is easy to use, aesthetic, reliable, and interactive" [5]. Some current solutions that function as resource finders or navigators include the Community Resource Finder by AARP and the Alzheimer's Association, the Alzheimer's Navigator by the Alzheimer's Association, and CareNav by the Family Caregiver Alliance. While these web-based tools provide databases and tips for locating resources and education on dementia and caregiving, they do not provide categorized recommendations or resources tailored to the stage of dementia of the people living with dementia and based on caregiver characteristics and preferences.

The overall performance rating of a digital app by users is greatly affected by several behavioral factors according to the theory of planned behavior, which states that an individual's intention to use or adopt technologies is greatly influenced by their attitude toward the technologies [18,19]. Thus, the more favorably a caregiver views a technological intervention, the more likely they will be to adopt and use the product. In addition, an individual's adoption of a technological intervention is greatly influenced by their perception of technology self-efficacy, which is defined as an individual's confidence in applying a technology to perform a task [20-23]. The more positive an individual's attitude and initial experience, the more likely they are to use the technology as their perceived self-efficacy increases [24]. The Mobile Application Rating Scale (MARS) is a widely used tool to test the performance of health mobile apps and digital platforms based on the functionality, design, information quality, engagement, and subjective quality of the digital apps [25].

Objectives

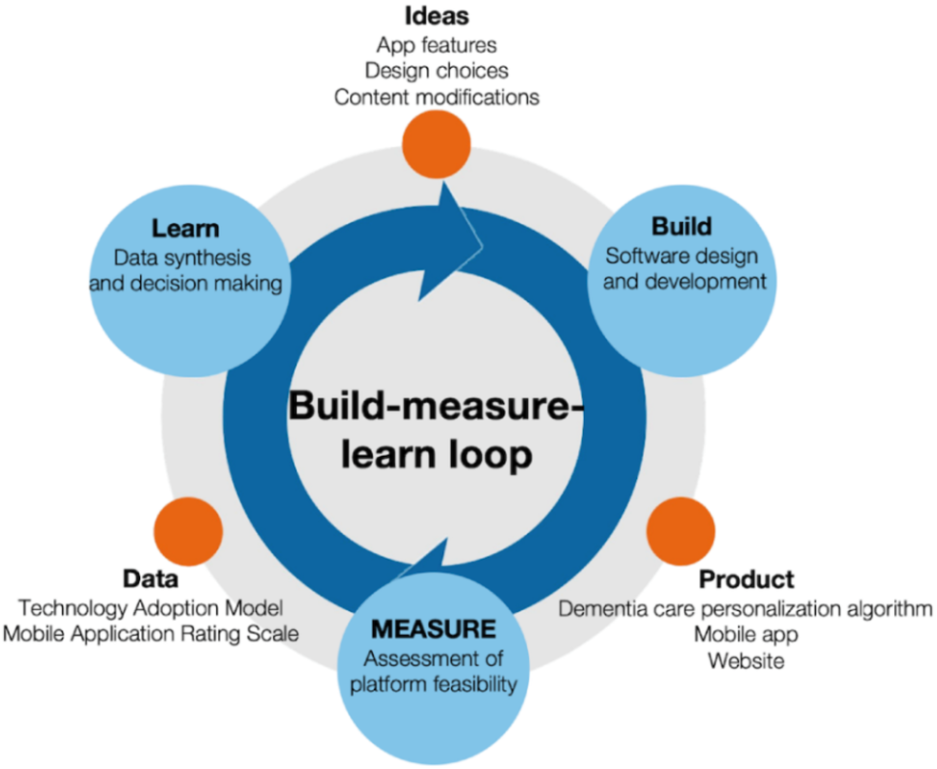
To address caregivers' needs and expectations of a web-based platform to assist them in the care of their care recipient, we developed a web-based care planning tool, Olera.care, that assists caregivers in navigating common challenges by supplying personalized recommendations and curated sets of resources (eg, care services, products, and professionals) as well as education on dementia and caregiving for people living with dementia. This pilot study aims to evaluate the functionality and usability of the initial Olera.care platform for caregivers of people living with dementia in addressing their needs with personalized education and resource matching.

Methods

Overview

This pilot study was conducted to support the development and evaluation of the usability of the Olera.care digital platform. The development and testing of the platform adopt an iterative “build-measure-learn” approach (Figure 1) that places caregivers at the forefront of design and development, ensuring that our platform continually evolves to meet their evolving needs and expectations [26]. This framework ensures that our platform iteratively evolves through an ongoing process of design and development, incorporating frequent touch points with family caregivers to assess the usability and functionality of a given prototype and align subsequent development with caregiver wishes and expectations for digital assistance technology. Participants in the study were engaged in 2 rounds of Zoom (Zoom Video Communications, Inc) or telephone interviews from January 2022 to May 2022 to (1) understand their caregiver needs, (2) engage with the platform, and (3) complete a technology survey assessment, including the modified MARS, via a Qualtrics (Qualtrics International Inc) web-based form. Each MARS item used a 5-point scale to assess the engagement, functionality, aesthetics, and information quality of the Olera.care digital platform among unpaid caregivers of people living with dementia in Texas.

Figure 1. The build-measure-learn approach used to research and develop Olera.care.

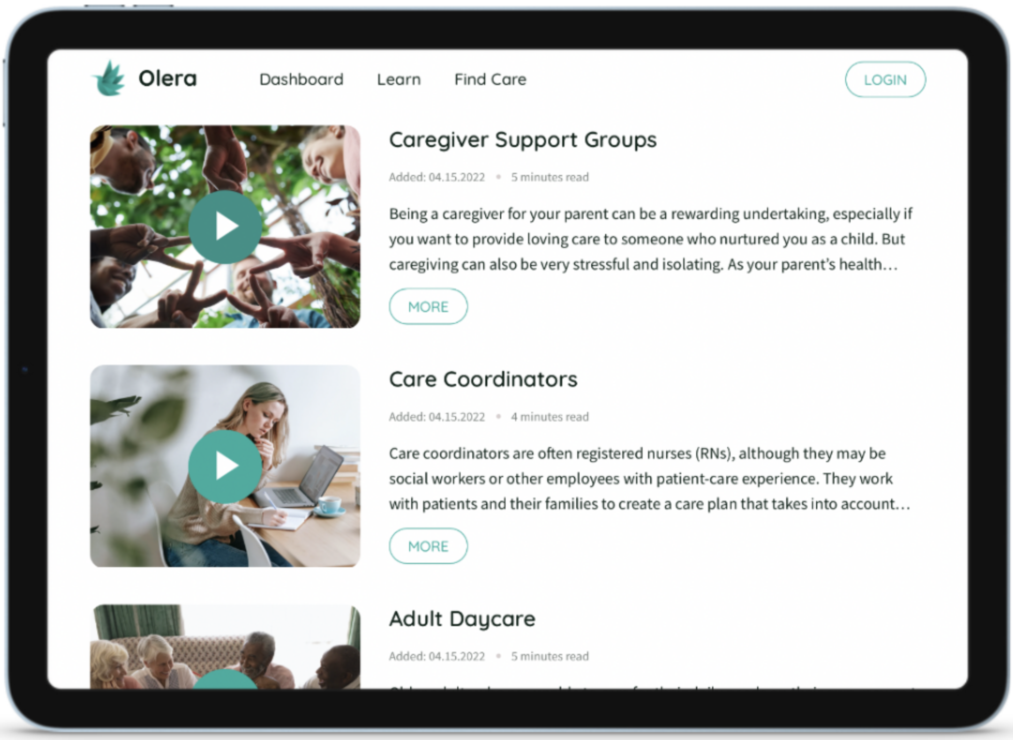


Platform Development and Testing

Development of a Digital Platform Capable of Providing Personalized Information on the Legal, Financial, and Estate Planning Aspects of Caregiving for Dementia, Including Information on Local Resources Most Relevant to Caregivers

We developed a robust web application that provides tailored educational videos and articles on topics associated with the most prominent challenges and struggles that caregivers of people living with dementia face as evidenced by our previous work identifying common pain points in the caregiving journey [5]. Personalized information is curated based on answers to a caregiving questionnaire and an algorithm developed to sift through a data repository and present the most relevant information pertaining to a user’s circumstances. Our growing content repository currently hosts 66 original articles and video postings that cover various topics, including legal, financial, and estate planning. In addition to personalized education, the developed web application can present tailored listings of relevant professionals in the legal, financial, home care, older adult living, and older adult care coordination industry (Figure 2). Credentialed professionals are presented in a personalized directory that is curated based on our algorithm’s assessment of caregivers’ current professional needs, preferences, and geographic location.

Figure 2. Content repository example of the Olera.care platform.



Caregiver Support Groups

Added: 04.15.2022 • 5 minutes read

Being a caregiver for your parent can be a rewarding undertaking, especially if you want to provide loving care to someone who nurtured you as a child. But caregiving can also be very stressful and isolating. As your parent's health…

Care Coordinators

Added: 04.15.2022 • 4 minutes read

Care coordinators are often registered nurses (RNs), although they may be social workers or other employees with patient-care experience. They work with patients and their families to create a care plan that takes into account…

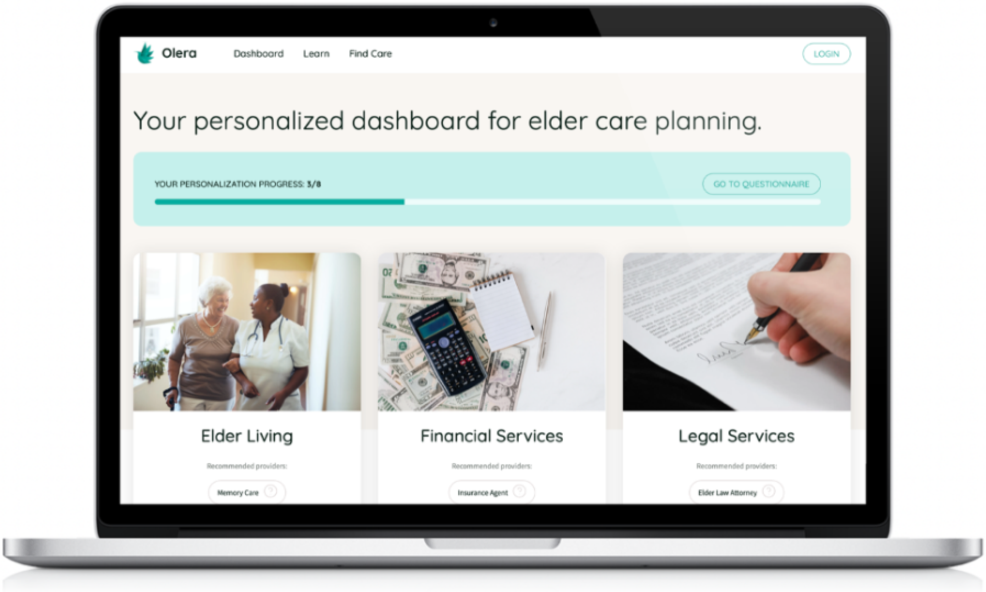
Adult Daycare

Added: 04.15.2022 • 5 minutes read

Compilation and Management of Relevant Financial, Legal, and Estate Planning Resources Available in Our Target Area

We have created a repository database that includes information on >22,000 professional service providers and 66 original educational articles or videos. This database is integrated with our web application's user interface to allow users to sort through it quickly and effortlessly for information most relevant to their current needs (Figure 3). Of note, relevant service providers included in our database are certified financial planners, Medicare insurance agents, older adult law attorneys, older adult care planners, older adult housing facilities (memory care and assisted or independent living), rehabilitation centers, hospice or palliative care agencies, and in-home professional caregivers as well as home health services. These services have been included because of direct commentary noted on interviewing current dementia caregivers about their service needs when providing AD and AD-related dementia family caregiving for a loved one [5].

Figure 3. Personalized dashboard for older adult care planning on the Olera.care platform.



Your personalized dashboard for elder care planning.

YOUR PERSONALIZATION PROGRESS: 3/8

Elder Living

Recommended providers: Memory Care

Financial Services

Recommended providers: Insurance Agent

Legal Services

Recommended providers: Elder Law Attorney

Preliminary Assessments of the Usability and Functionality of the Technology Using Techniques Such as End-User Surveys and Real-Time Monitoring

We evaluated the usability and functionality of our caregiver support platform with a pilot panel of 30 current family caregivers of persons living with dementia who met our eligibility criteria. Participants interacted with the web application in a test environment. They were asked to use the main functions and rate the usability and functionality on a modified MARS, which is a well-established instrument used as a benchmark for digital health apps. In addition, real-time monitoring during participation helped researchers identify areas for improvement in the user experience.

Participant Eligibility and Recruitment

Participants were recruited through academic and community networks, such as the Texas A&M University Center for Community Health and Aging and the Brazos Valley Area Agency on Aging. We used both traditional and digital channels to reach out to potential participants. These included printed materials such as physical or electronic flyers, outreach emails, and social media platforms (eg, Facebook, Instagram, and Twitter) as well as engagement with web-based forums such as local caregiver support group meetings.

Individuals expressing interest in participating in the study were provided 2 options to complete the eligibility screening: participants could access a web-based form by following the recruitment materials' QR code or web link; alternatively, they could contact the Olera.care team via telephone to obtain information about the study and take the eligibility screening survey over the telephone.

The eligibility screening survey collected relevant information to examine whether interested individuals met the following inclusion criteria: (1) be aged ≥18 years; (2) be a nonpaid caregiver of a person living with dementia; (3) be the adult child, spouse or partner, other family member, or legal guardian of a person living with dementia; (4) be engaged in making legal or financial, older adult living, or medical decisions for a person living with dementia; (5) be seeking older adult care services in Texas; and (6) have access to a smartphone or computer with internet access.

After the eligibility screening process, participants who met the inclusion criteria were asked to provide their full name, contact information, preferred mode of contact (ie, telephone or email), and preferred day and time for subsequent outreach by the research team.

Ethical Considerations

Ethics approval was obtained from the Texas A&M University Institutional Review Board (2021-0943D). The study personnel asked all participants to provide electronic informed consent in the screening survey. Upon the completion of the eligibility screening survey, participants were presented with an informed consent document. This document provided instructions on how to convey their consent to participate in the study and their willingness to be recorded and followed up via the Qualtrics platform. The consent form covered important information, including the rationale for inclusion; the research objectives; the voluntariness of participation with the option to withdraw at any point; the anticipated participation duration and procedures; the potential risks, benefits, and costs of participation; and how participant confidentiality would be protected.

Assessments and Measurements

Evaluating the Quality of the Olera.care Platform Using the MARS

We used the MARS as a robust assessment tool to evaluate the quality of the Olera.care platform among the caregiver participants. The MARS provides a multidimensional assessment of the engagement, functionality, aesthetics, information quality, and overall subjective quality of the Olera.care platform. To tailor the assessment to our study's specific context, we selected 13 items from the MARS questionnaire that were directly relevant to the Olera.care platform. Our methodology for adapting the MARS questionnaire was 2-pronged: first, we evaluated and retained items based on their relevance to our platform's functions, omitting nonapplicable elements such as gestural design; and second, we modified the wording of the retained items to better reflect our platform's unique features. These items were adapted and modified for our assessment objectives while retaining the original item classification across the 5 dimensions. The modified items and responses, while maintaining the integrity of the MARS, ensure an effective evaluation of our digital platform. Participants provided ratings for each MARS item using a 5-point scale (1=inadequate, 2=poor, 3=acceptable, 4=good, and 5=excellent), with each response tailored to the content of the respective item. An overall subjective quality rating of ≥3.6 was set as the threshold to indicate good usability and quality of the Olera.care platform according to past literature [27], allowing us to effectively report the platform's overall quality from assessment among the caregiver users.

Assessing Willingness, Self-Efficacy, and Communication Preferences in Technology Adoption

To understand the willingness and preference for technology use, we further assessed participants' intention to use the Olera.care platform, self-efficacy for using the technology, and preferences for web-based communication and platform format. The participants were asked whether they would like to use the technology in the future, with the response options being "yes," "maybe," and "no." They were also asked about their confidence level in using the technology, with the response options being "uncertain," "neither certain nor uncertain," "somewhat confident," and "very confident." In addition, participants were asked about their preference for anonymity when seeking information on the internet and whether they would consider sharing personal information for receiving individualized answers. The net promoter score, which was created in 2003 and has been used in a variety of industries such as insurance, technology services, communications, and health care [28], was used to evaluate the willingness of participants and provide insights for user experience management. Responses on a scale ranging from 0=strongly disagree to 10=strongly agree were used. Scores from 0 to 6 were classified as *detractor*, scores of

7 and 8 were categorized as *passive*, and scores of 9 and 10 were designated as *promoter*. Participants were also asked whether they preferred a website-based format or a mobile app format.

Assessing the Use of, and Interests in, Older Adults Care Services Among Caregivers

To gain a deeper understanding of our targeted population's preferences and needs for planning older adult care and to continually enhance and optimize our platform, we assessed the level of interests in older adult care services among caregivers. Caregivers were presented with 21 types of older adult care services (eg, home health, hospice care, memory care, caregiver support group, and assisted living), and they were asked to select ≥1 of the following responses: "currently using," "have used before," "would like to learn more," and "would never use." This assessment allowed us to gather valuable insights into caregivers' engagement and interests in various older adult care options, informing our efforts to better serve their needs.

Sociodemographic and Caregiving Characteristics of Caregivers

We collected the sociodemographic and caregiving characteristics of participants to understand how representative our study population was for the Texas caregiver profile and whether the major platform evaluation outcomes differ by the background characteristics of participants. The caregiver characteristics collected included age, sex, race, ethnicity, the highest level of education completed, employment status, general financial status, caregiving role, and length of providing care.

Analysis

Descriptive statistics were used to describe the engagement, functionality, aesthetics, information quality, and subjective quality of the platform and caregiver characteristics and responses. Mean scores and SDs were calculated for each MARS item. We conducted 2-sample 2-tailed *t* tests to compare the differences in the major MARS evaluation scores by caregiver characteristics. All analyses were conducted using Stata (version 17.0; StataCorp LLC).

Results

Participants' Characteristics

Of the initial 822 respondents who completed the prescreening surveys, 150 (18.2%) met the eligibility criteria, of whom, after excluding 115 (76.7%) individuals for not being available to attend interviews, 35 (23.3%) were enrolled into the study. Of these 35 enrolled individuals, 30 (86%) interacted with the platform and completed the study survey of technology evaluation and caregiving needs (Figure 4). The sociodemographic and caregiving characteristics of participants are summarized in Table 1.

Of the 30 participants, the majority were aged ≥50 years (n=25, 83%), women (n=23, 77%) , White (n=25, 83%), non-Hispanic (n=27, 90%), had bachelor's or graduate degrees (n=22, 73%), and were employed for wages (n=12, 40%) or retired (n=12, 40%). Financially, 67% (20/30) had surplus funds at the end of each month, while 30% (9/30) just about managed to meet their expenses or faced deficits. Most of the participants were recruited via email invitations (13/30, 43%) or web-based advertisements (11/30, 37%), with some also recruited through in-person presentations and personal connections (5/30, 17%). In terms of caregiving characteristics, the majority of the participants identified themselves as primary caregivers (20/30, 67%), reported to have provided care for at least 1 year (28/30, 93%), and dedicated at least 20 hours weekly to caregiving in the past 3 months (21/30, 70%).

Figure 4. Study flow diagram.

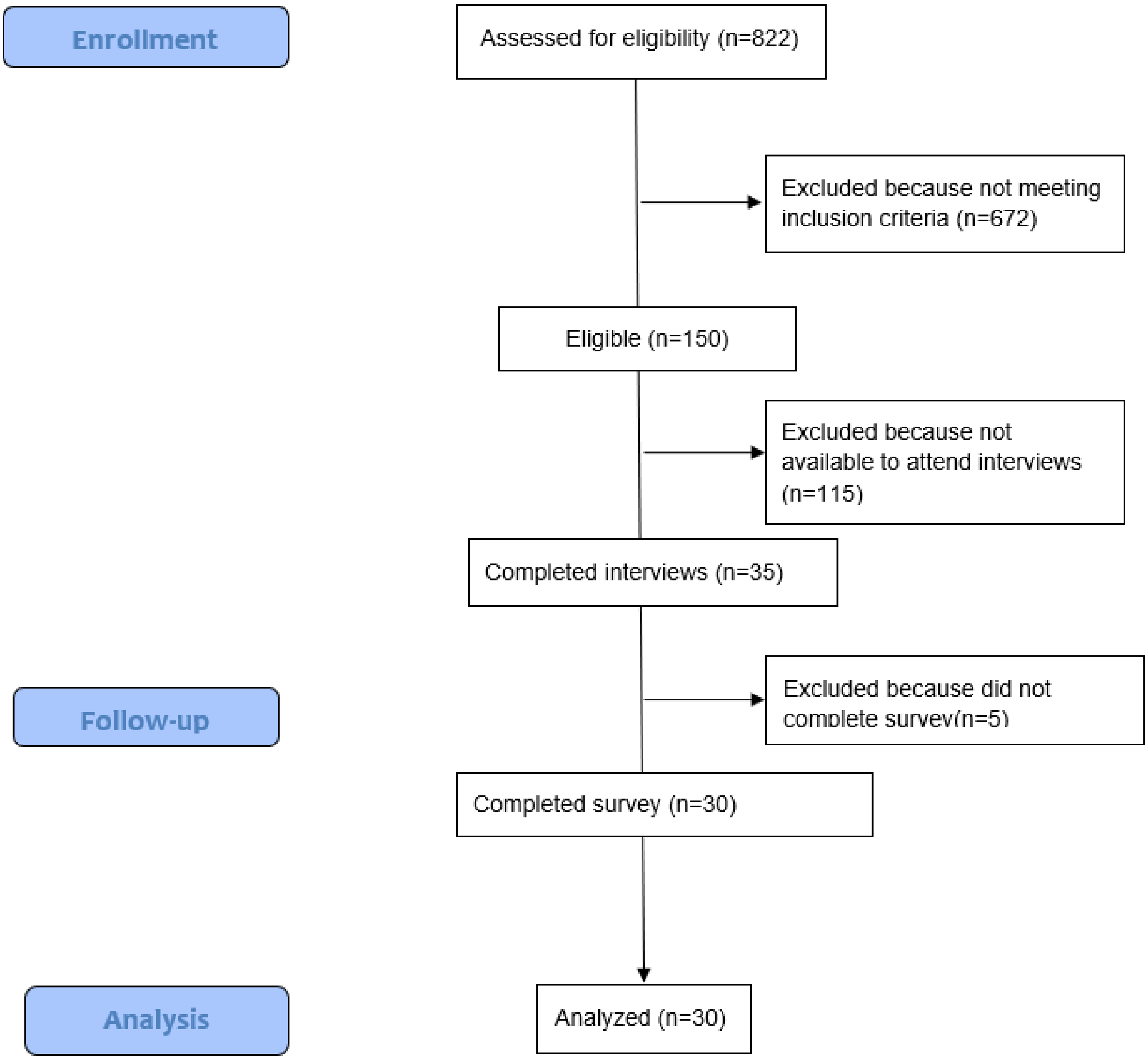


Table 1. Sociodemographic and caregiving characteristics of participants (n=30).

Characteristics	Participants, n (%)
Age (y)	
35-49	5 (17)
50-64	12 (40)
≥65	13 (43)
Sex	
Male	7 (23)
Female	23 (77)
Race	
American Indian or Alaska Native	1 (3)
Asian, Native Hawaiian, or Pacific Islander	1 (3)
Black or African American	2 (7)
White	25 (83)
Multiracial	1 (3)
Ethnicity	
Spanish, Hispanic, or Latinx origin or descent	3 (10)
Other	27 (90)
Highest level of education completed	
Some college but no degree	5 (17)
Associate degree	3 (10)
Bachelor’s degree	8 (27)
Graduate degree	14 (47)
Employment status	
Employed for wages	12 (40)
Homemaker or self-employed	4 (13)
Unemployed or unable to work	2 (7)
Retired	12 (40)
General financial status at the end of the month	
End up with some money left over	20 (67)
Have just enough to make ends meet	7 (23)
Not have enough money to make ends meet	2 (7)
Do not know	1 (3)
Caregiving role in providing care for ≥1 adults aged >50 y	
Participant is the primary caregiver	20 (67)
Someone else is the primary caregiver	4 (14)
The participant shared caregiving responsibilities about equally with someone else	5 (17)
Unknown	1 (3)
How long has the participant been providing care or assistance for the care recipients? (y)	
0.5 to <1	2 (7)
1 to <5	14 (47)
5 to <10	8 (27)
≥10	6 (20)
Over the past 3 months, about how many h/wk has the participant provided some form of care for ≥1 adults aged >50 y?	

Characteristics	Participants, n (%)
<20	9 (30)
20-40	9 (30)
>40	12 (40)
Recruitment channel	
Online advertisement (Facebook, LinkedIn, etc)	11 (37)
Email invitation	13 (43)
In-person presentation	2 (7)
Personal connection	3 (10)
Other	1 (3)

Quality Assessment of the Olera.care Platform

Overview

The descriptive statistics of the Olera.care platform evaluation by the MARS dimensions and items are presented in Table 2.

The mean overall satisfaction rating of the Olera.care platform among the participants was 4.57 (SD 0.57) of 5. Mean scores for engagement, functionality, aesthetics, and information quality were 4.10 (SD 0.61), 4.46 (SD 0.44), 4.58 (SD 0.53), and 4.76 (SD 0.44), respectively.

Table 2. Modified Mobile Application Rating Scale items and responses of participants.

Dimensions, items, questions, and response items	Participants, n (%)	Score, mean (SD)
Engagement		4.10 (0.61)
Entertainment: compared to other older adult care finders, websites, or alternative resources for older adult care information you may have used, do you think this app is fun to use?		3.67 (0.80)
Highly entertaining	5 (17)	
Fun	11 (37)	
OK, fun enough	13 (43)	
Mostly dull	1 (3)	
Dull	0 (0)	
Interestingness: compared to other older adult care finders, websites, or alternative resources for older adult care information you may have used, does this app present its content in an interesting way?		4.53 (0.57)
Very interesting	17 (57)	
Interesting	12 (40)	
Slightly interesting	1 (3)	
Mostly uninteresting	0 (0)	
Not interesting	0 (0)	
Functionality		4.46 (0.44)
Performance: how well do the app's features, components, and buttons work?		4.57 (0.57)
Works perfectly	18 (60)	
Very functional	11 (37)	
App works overall	1 (3)	
Some functions work	0 (0)	
App is broken	0 (0)	
Ease of use: how easy is it to learn how to use the app?		4.57 (0.50)
Very simple	17 (57)	
Easy to learn	13 (43)	
Usable	0 (0)	
Somewhat confusing	0 (0)	
Very confusing	0 (0)	
Navigation: does moving between pages make sense?		4.28 (0.59)
Moving between pages is perfectly logical, easy, clear and intuitive	10 (33)	
Moving between pages is easy to understand and navigate	17 (57)	
Moving between pages is understandable after some time and effort	2 (7)	
Moving between pages is understandable after a lot of time and effort	0 (0)	
Moving between pages is difficult	0 (0)	
Missing	1 (3)	
Aesthetics		4.58 (0.53)
Visual appeal: how good does the app look?		4.53 (0.63)
Very visually appealing	18 (60)	
High-level visual appeal	10 (33)	
Some visual appeal	2 (7)	
Little visual appeal	0 (0)	
No visual appeal	0 (0)	
Graphics: how high is the quality of graphics, buttons, and content?		4.53 (0.63)

Dimensions, items, questions, and response items	Participants, n (%)	Score, mean (SD)
Very high quality	18 (60)	
High quality	10 (33)	
Moderate quality	2 (7)	
Low quality	0 (0)	
Very poor quality	0 (0)	
Layout: how would you rate the design? Are the arrangement and size of buttons and content on the screen appropriate?		4.67 (0.61)
Very professional	22 (73)	
Mostly professional	6 (20)	
Satisfactory	2 (7)	
Bad design	0 (0)	
Very bad design	0 (0)	
Information		4.76 (0.44)
Accuracy of app description: after reviewing the home page, does the app contain what is advertised and described?		4.79 (0.41)
Highly accurate	23 (77)	
Mostly accurate	6 (20)	
Somewhat accurate	0 (0)	
Slightly misleading	0 (0)	
Very misleading	0 (0)	
Missing	1 (3)	
Quality of information: is the content in the app relevant to helping with older adult care planning?		4.76 (0.44)
Highly relevant	22 (73)	
Relevant	7 (23)	
Moderately relevant	0 (0)	
Barley relevant	0 (0)	
Irrelevant content	0 (0)	
Missing	1 (3)	
Quality of visual information: are images, videos, and graphics clear and easily understandable?		4.73 (0.45)
Perfectly clear	22 (73)	
Mostly clear	8 (27)	
Somewhat clear	0 (0)	
Mostly unclear	0 (0)	
Completely unclear	0 (0)	
Subjective quality		4.15 (0.51)
Stimulates repeat use: how many times do you think you would use this app in the next 12 months if it was relevant to you?		3.77 (0.86)
>50	6 (20)	
10-50	13 (43)	
3-10	9 (30)	
1-2	2 (7)	
None	0 (0)	
Worth recommending: would you recommend this app to people who might benefit from it?		4.27 (0.14)
I would recommend this app to everyone	13 (43)	

Dimensions, items, questions, and response items	Participants, n (%)	Score, mean (SD)
There are many people I would recommend this app to	12 (40)	
There are several people I would recommend it to	5 (17)	
There are a few people I would recommend this app to	0 (0)	
I would not recommend this app to anyone	0 (0)	
Overall satisfaction rating: what is your overall star rating of the app? (1 star=poor; 5 stars=excellent)		4.57 (0.57)
5	17 (57)	
4	10 (33)	
3	1 (3)	
2	0 (0)	
1	0 (0)	
Missing	2 (7)	

Engagement

Participants reported high levels of engagement with the Olera.care platform, with 97% (29/30) describing it highly entertaining or fun or fun enough, and 97% (29/30) expressing that it was interesting to interact with.

Functionality

In terms of functionality, the majority of the participants assessed the Olera.care platform positively, with 60% (18/30) perceiving it as working perfectly and 37% (11/30) rating it as very functional. Moreover, 57% (17/30) found it very simple to learn to use, and 43% (13/30) considered it easy to learn. An impressive 90% (27/30) of the participants reported that it was easy to navigate between pages.

Aesthetics

The aesthetics of the platform received favorable feedback from participants, with 93% (28/30) expressing that it was visually appealing, highlighting the high quality of graphics, buttons, and content. The design and layout of the content were described as professional.

Information

In terms of information quality, nearly all participants (29/30, 97%) noted that the app contained relevant and clear information. A substantial 73% (22/30) found the information highly relevant for older adult care planning, while 23% (7/30) considered it relevant. Visual information was deemed perfectly clear by 73% (22/30) of the participants and mostly clear by 27% (8/30).

Subjective Quality

Participants expressed a strong inclination to use the app in in the next 12 months, with 20% (6/30) planning to use it >50 times and 43% (13/30) aiming to use it between 10 and 50 times. Importantly, all participants indicated their willingness to recommend the app to those who may benefit from it. In terms of overall satisfaction, most of the participants rated the Olera.care platform positively, with 57% (17/30) rating it as excellent and 33% (10/30) as very good.

Intention to Use the Olera.care Platform, Self-Efficacy of Technology Use, and Platform Preference

In this study, a substantial proportion of the participants expressed a positive intention to use the Olera.care platform (Table 3), with 90% (27/30) indicating a definite willingness ("yes"), while the remaining 10% (3/30) expressed a more tentative interest ("maybe"). In terms of self-efficacy in using technology, 40% (12/30) of the participants reported feeling "very confident," 57% (17/30) indicated a moderate level of confidence ("somewhat confident"), and 3% (1/30) expressed uncertainty. In the context of online communication with a representative, 70% (21/30) of the participants favored remaining anonymous before sharing contact information. Furthermore, 43% (13/30) of the participants expressed willingness to share personal information to receive personalized assistance. In terms of platform preference, most of the participants (22/30, 73%) preferred the computer browser format, 10% (3/30) preferred to use a mobile app, and 17% (5/30) did not have a preference. This preference for computer browser format directly ties into overall user satisfaction, which is a critical determinant in the net promoter score categorization. Focusing on optimizing this platform could lead to higher user satisfaction and thus more promoters.

Table 3. Intention to use, self-efficacy of use, and preferences for communication and platform.

Questions and response items	Participants, n (%)
Intention to use the app	
Would you use this app?	
Yes	27 (90)
Maybe	3 (10)
No	0 (0)
Self-efficacy to use technology	
When it comes to your confidence in the use of technology, which of the following best describes you?	
Uncertain	1 (3)
Neither certain nor uncertain	0 (0)
Somewhat confident	17 (57)
Very confident	12 (40)
Preferences when asking a representative	
When researching older adult services on the web, I'd appreciate the ability to ask a representative a question anonymously before sharing my contact information (0=strongly disagree; 10=strongly agree).	
9-10 (promoter)	21 (70)
7-8 (passive)	3 (10)
0-6 (detractor)	6 (20)
When researching older adult services online, I would consider sharing personal information (contact information, etc) with a representative to better determine my loved one's fit for the service (0=strongly disagree; 10=strongly agree).	
9-10 (promoter)	13 (43)
7-8 (passive)	6 (20)
0-6 (detractor)	11 (36)
Preference for platform	
When searching online for information on older adult care planning, would you prefer to use a computer browser or download a mobile app?	
Computer browser	22 (73)
Mobile app I can download to my phone	3 (10)
No preference	5 (17)

Caregivers' Use of, and Interests in, Older Adult Care Services

We also examined the current and past use of, as well as interests in, different types of older adult care services among the caregiver participants (Table 4). Among the participants, 63% (19/30) were currently using medical home health services, 33% (10/30) used hospice care, and 30% (9/30) employed certified financial planners. In addition, 27% (8/30) relied on house maintenance service, and 23% (7/30) engaged insurance agents and older adult law attorneys and participated in public and free older adult programs. Memory care, nonmedical home aid, and adult day care each had a 20% (6/30) use rate, while services such as assisted living, independent living, transportation, skilled nursing, medical providers, and rehabilitation facilities were used by 7% (2/30) to 13% (4/30) of the participants. Older adult living referral agents, caregiver support groups, and yard services were used by 3% (1/30) of the participants. The results suggest the diverse range of older adult care services currently being used, with medical home health being the most used service.

Table 4. Caregivers' use of, and interests in, older adult care services (n=30).

Older adult care services	Participants, n (%)
Using currently	
Home health	19 (63)
Hospice care	10 (33)
Certified financial planner	9 (30)
House maintenance	8 (27)
Insurance agent	7 (23)
Older adult law attorney	7 (23)
Public and free older adult programs	7 (23)
Adult day care	6 (20)
Memory care	6 (20)
Professional home caregivers	6 (20)
Have used before	
Professional home caregivers	13 (43)
Older adult law attorney	10 (33)
Rehabilitation facility	10 (33)
Insurance agent	9 (30)
Certified financial planner	7 (23)
Older adult living referral agent	7 (23)
Hospice care	7 (23)
Transportation services	7 (23)
Skilled nursing	6 (20)
Home health	6 (20)
Public and free older adult programs	6 (20)
Would never use	
Yard services	8 (27)
Certified financial planner	7 (23)
House maintenance service	7 (23)
Care manager	7 (23)
Insurance agent	5 (17)
Independent living	5 (17)
Assisted living	4 (13)
Meal service	4 (13)
Memory care	3 (10)
Rehabilitation facility	3 (10)
Older adult living referral agent	3 (10)
Would like to learn more	
Caregiver support group	24 (80)
Medical providers	23 (77)
Memory care	19 (63)
Meal service	19 (63)
Adult day care	19 (63)
Older adult living referral agent	18 (60)

Older adult care services	Participants, n (%)
Transportation services	18 (60)
Care manager	18 (60)
Skilled nursing	17 (57)
Assisted living	17 (57)
Public and free older adult programs	17 (57)

Regarding past use, 43% (13/30) had previously used nonmedical home aid, and 33% (10/30) had engaged older adult law attorneys and used rehabilitation facilities. Insurance agents were consulted by 30% (9/30) of the participants, and 23% (7/30) had used certified financial planners and older adult living referral agents, as well as hospice care and transportation services. Skilled nursing, medical home health, and public and free older adult programs were previously used by 20% (6/30) of the participants, while independent living and adult day care had a use rate of 17% (5/30). Memory care, assisted living, meal services, and yard services were used by 13% (4/30), while house maintenance, care managers, and medical providers were used by 7% (2/30). Caregiver support groups were attended by 3% (1/30) of the participants.

In terms of preferences for further exploration, 80% (24/30) expressed interest in learning more about care support groups, while 77% (23/30) were interested in understanding medical providers better. In addition, 63% (19/30) showed interest in memory care, meal services, and adult day care. Furthermore, 60% (18/30) were interested in older adult living referral agents, transportation services, and care managers. An additional 57% (17/30) desired to learn more about skilled nursing, assisted living, and public and free older adult programs. Interestingly, all older adult care services were mentioned as areas of interest by participants.

For services that would never be considered, some of the participants (18/30, 60%) indicated reluctance toward specific services, with yard services (8/30, 27%), certified financial planners (7/30, 23%), and house maintenance (7/30, 23%) being among those mentioned, while none expressed a definitive refusal to consider nonmedical home aid or hospice care.

Platform Feature Evaluation Results by Participants' Characteristics

We conducted 2-sample *t* tests to assess variances in platform feature evaluation results based on caregivers' characteristics, providing mean scores and SDs for reporting (Multimedia Appendix 1). The evaluation results for the Olera.care platform, spanning engagement, functionality, aesthetics, information quality, and overall satisfaction, were notably consistent across all caregiver groups. However, a statistically significant difference (*P*=.02) was observed in the functionality evaluation scores, with caregivers dedicating at least 20 hours to care (mean 4.6, SD 0.4) rating it higher than those providing less care (mean 4.2, SD 0.5). In addition, caregivers with <5 years of caregiving experience reported significantly higher evaluation scores for aesthetics (mean 4.7, SD 0.4 vs mean 4.3, SD 0.7; *P*=.04) and information quality (mean 4.8, SD 0.2 vs mean 4.6, SD 0.3; *P*=.03) compared to those with a minimum of 5 years of caregiving experience.

Discussion

Principal Findings

This research lays the foundation for the development of digital tools tailored to the needs of caregivers. The principal findings involve the quality and usability of the Olera.care platform, a web-based care planning tool designed to assist caregivers of people living with dementia in addressing their legal and financial needs and enable them to access functional care services. The results suggest that the Olera.care web tool is a practical, engaging, easy-to-use, visually appealing, and informative digital platform designed to provide resources that address common challenges faced by family caregivers of people living with dementia [5]. The study assessed caregivers' intentions to use the Olera.care platform, their expectations for caregiving educational content, and their preferences for web-based information delivery. These aspects are crucial in our iterative build-measure-learn framework of research and development, which underpins our commitment to caregiver-centric product design.

The results indicate that the tested Olera.care web tool can distinguish itself not only in terms of practicality and user-friendliness but also in the quality of its content and its degree of personalization. We acknowledge existing solutions such as the Community Resource Finder by AARP and the Alzheimer's Association, the Alzheimer's Navigator by the Alzheimer's Association, and CareNav by the Family Caregiver Alliance. These platforms offer valuable databases and guidance for dementia caregiving. However, our Olera.care platform differentiates itself by providing recommendations and resources that are not only categorized but also personalized and tailored to the caregiver's specific characteristics and preferences. This unique aspect of Olera.care addresses a gap in current offerings and stands in contrast to many currently available web-based information tools such as static web pages, resource directories, or learning modules, which can be inadequate in addressing certain needs due to their lack of user engagement, personalization, relevance, and adoptability [29,30]. By contrast, the Olera.care platform attempts to involve users in the design of the platform and address these issues effectively, and the platform stands out for its interactivity, visual appeal, personalization capabilities, and informative content, making it a valuable resource for family caregivers of people living with dementia.

One noteworthy finding is that participants who devoted more weekly hours to caregiving and had limited cumulative caregiving experience tended to rate the Olera.care platform more favorably. This suggests that the platform offers specific support and benefits to caregivers with heavier caregiving workloads and those with limited prior caregiving experience. This insight underscores the importance of tailoring digital tools to the specific needs of caregivers in different situations, considering their experience and time commitment [29,30]. Such findings are integral to the build-measure-learn framework, guiding the iterative development of the platform to better align with the specific needs of caregivers. Furthermore, the relevance of the Olera.care platform is heightened in the context of the COVID-19 pandemic, which significantly disrupted family caregiving arrangements, as evidenced by more than half of these arrangements being affected [31]. This disruption led to heightened psychological burdens on caregivers, including increased depression, anxiety, and loneliness [31,32]. The pandemic also exacerbated the shortage of professional caregivers, further challenging the support systems for older adult care. Studies highlight the increased stress levels among caregivers, particularly those caring for individuals with severe dementia [33], and the overall strain on mental health resources for both caregivers and patients [34]. With the increasing social and support needs of caregivers, internet-based tools are crucial to help caregivers to access information and gain support [35].

Another significant finding pertains to the use of, and demand for, older adult care services. Many caregivers reported using or intending to use services such as home health, hospice care, insurance agents, older adult law attorneys, and financial planners. However, there is notable interest in exploring other services, such as caregiver support groups, medical providers, skilled nursing, memory care, public and free older adult programs, meal services, adult day care, and various older adult living alternatives. The data indicate that these services are often underused, potentially leading to unmet needs among older adults and their caregivers [36]. This underuse may stem from a lack of awareness about the availability of older adult care services among caregivers [37]. This insight has prompted a shift in our database curation strategy, and we are focusing now on underused yet high-demand care services and programs to make them more readily available to caregivers through our platform.

The high engagement, functionality, aesthetics, and information quality of the Olera.care digital platform can be attributed to several underlying principles and strategies. First, the platform's unique approach of involving caregivers in the design process has proven highly effective. We demonstrated that technology interventions developed with input from the target population will increase overall satisfaction with, and preference for, the product. Second, the curated content and resources of the Olera.care platform, informed by leading experts, have been rated highly relevant by the participants, with 73% (22/30) reporting the content as highly relevant with a mean MARS score of 4.76 (SD 0.44) of 5. This demonstrates the significance of expert guidance in creating a resource that resonates with the target audience [26]. The curated content and resources on the Olera.care platform can be further improved through the incorporation of artificial intelligence and large language models, allowing for improved and personalized recommendations based on an existing recommendation system [38]. Large language models can process large data sets across numerous relevant variables (eg, specific needs, geographic location, and financial constraints) to provide the most appropriate care solutions. To increase the accuracy of the large language model, the data would have to undergo rigorous quality control and standardization. Industry experts that we are currently working with to inform our curated content could also validate the model through feedback on its accuracy and quality. The model's recommendations can also be consistently improved through the input of new data, further increasing the accuracy of its recommendations.

Limitations and Future Research and Practice

It is important to acknowledge the limitations of this pilot study, which we view as opportunities for further learning and refinement within our build-measure-learn framework. First, the small sample size and lack of racial and ethnic diversity among the participants may limit the generalizability of the findings, pushing us to expand our research scope. The participants in this study were also mostly technology savvy and well educated. However, the demographic characteristics of the caregiver participants in this study aligned well with the caregiver profile in the United States (ie, the majority were women: 23/30, 77%; aged ≥50 years: 25/30, 83%; and non-Hispanic White: 25/30, 83%) [39]. The study populations also represented some diversity in financial levels and caregiving experiences. Future research should aim to include a more racially and ethnically diverse study population to ensure a broader representation of caregiver experiences and preferences. Second, all acceptability and usability metrics in this study were self-reported, which could introduce self-report bias. However, we used a validated tool, the MARS [25], which was adapted according to platform features. Third, given the limited sample size and insufficient statistical power in the subgroup analyses, both significant and nonsignificant *t* test results should be interpreted cautiously. Furthermore, the study's short duration of interaction with the digital platform also limits our understanding of the platform's long-term usability and usefulness for caregivers of people living with dementia.

A future study should be conducted with a larger and more diverse group of caregivers, allowing for a more comprehensive assessment of the platform's long-term perceived usability and ease of use, thus enabling us to continually learn and refine the platform. For future practice, we are focused on enhancing the accessibility and visibility of our web application for family caregivers by integrating it into the existing care delivery framework through strategic digital marketing, primarily using organic search engine optimization. This strategy ensures that our platform aligns with user search behaviors, making it easily discoverable by those in need of caregiving resources. Simultaneously, we are committed to maintaining universal accessibility, opting for a broader reach via effective search engine optimization strategies over direct integration into health plans. Our platform, designed more as a comprehensive digital health tool than a conventional medical device, provides holistic care planning support for family caregivers. Financially, we have chosen a sustainable business-to-business revenue model, focusing on advertising and commission-based referral fees from businesses serving our caregiver community, which allows us to offer our services free of charge to families. This approach is underpinned by the older adult care industry's potential for low-cost client acquisition, enabling us to provide much-needed support to families without financial burden and ensuring that our platform remains accessible to all caregivers in need.

Conclusions

The Olera.care platform, characterized by its practicality, interactivity, ease of use, visual appeal, and informativeness, shows promise as a valuable tool for dementia caregivers. With the pilot group of caregivers' engagement and feedback, the platform provides tailored support to meet the specific challenges of dementia caregiving. Future development and research are essential to enhance the platform and comprehensively evaluate its efficacy in supporting caregivers and alleviating caregiving burdens across broader and more diverse populations.

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Authors' Contributions

TF, LD, SL, and MGO contributed to study design. LD, TF, MNH, JV, and QF contributed to study implementation and data collection. QF contributed to data analysis. QF, MNH, MGO, and LD contributed to data interpretation. SL and MGO contributed to supervision. QF, MNH, and LD contributed to the original draft writing. All authors contributed to critical revision of the manuscript.

Conflicts of Interest

LD is an executive and owner of Olera, Inc.

Multimedia Appendix 1

Results of the 2-sample 2-tailed t tests for platform feature evaluation by participants' characteristics.

[DOCX File , 377 KB - aging_v7i1e55132_app1.docx]

References

1. 2023 Alzheimer's disease facts and figures. Alzheimers Dement 2023 Apr 14;19(4):1598-1695. [doi: 10.1002/alz.13016] [Medline: 36918389]
2. Radue R, Walaszek A, Asthana S. Neuropsychiatric symptoms in dementia. Handb Clin Neurol 2019;167:437-454. [doi: 10.1016/B978-0-12-804766-8.00024-8] [Medline: 31753148]
3. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A national profile of family and unpaid caregivers who assist older adults with health care activities. JAMA Intern Med 2016 Mar;176(3):372-379 [FREE Full text] [doi: 10.1001/jamainternmed.2015.7664] [Medline: 26882031]
4. Plöthner M, Schmidt K, de Jong L, Zeidler J, Damm K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatr 2019 Mar 13;19(1):82 [FREE Full text] [doi: 10.1186/s12877-019-1068-4] [Medline: 30866827]
5. Fan Q, DuBose L, Ory MG, Lee S, Hoang M, Vennatt J, et al. Financial, legal, and functional challenges of providing care for people living with dementia and needs for a digital platform: interview study among family caregivers. JMIR Aging 2023 Sep 05;6:e47577 [FREE Full text] [doi: 10.2196/47577] [Medline: 37526513]
6. Connors MH, Seeher K, Teixeira-Pinto A, Woodward M, Ames D, Brodaty H. Dementia and caregiver burden: a three-year longitudinal study. Int J Geriatr Psychiatry 2020 Feb 10;35(2):250-258. [doi: 10.1002/gps.5244] [Medline: 31821606]
7. Block L, Gilmore-Bykovskyi A, Jolliff A, Mullen S, Werner NE. Exploring dementia family caregivers' everyday use and appraisal of technological supports. Geriatr Nurs 2020;41(6):909-915 [FREE Full text] [doi: 10.1016/j.gerinurse.2020.06.019] [Medline: 32665095]
8. Bhargava Y, Baths V. Technology for dementia care: benefits, opportunities and concerns. J Glob Health Rep 2022;6:e2022056. [doi: 10.29392/001c.39606]
9. Wójcik D, Szczechowiak K, Konopka P, Owczarek M, Kuzia A, Rydlewska-Liszkowska I, et al. Informal dementia caregivers: current technology use and acceptance of technology in care. Int J Environ Res Public Health 2021 Mar 19;18(6):3167 [FREE Full text] [doi: 10.3390/ijerph18063167] [Medline: 33808644]

10. Astell AJ, Bouranis N, Hoey J, Lindauer A, Mihailidis A, Nugent C, TechnologyDementia Professional Interest Area .... Technology and dementia: the future is now. Dement Geriatr Cogn Disord 2019;47(3):131-139 [FREE Full text] [doi: 10.1159/000497800] [Medline: 31247624]
11. Kinchin I, Edwards L, Adrion E, Chen Y, Ashour A, Leroi I, et al. Care partner needs of people with neurodegenerative disorders: what are the needs, and how well do the current assessment tools capture these needs? A systematic meta-review. Int J Geriatr Psychiatry 2022 May 24;37(7) [FREE Full text] [doi: 10.1002/gps.5764] [Medline: 35665539]
12. Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M, Damant J. Technology-based tools and services for people with dementia and carers: mapping technology onto the dementia care pathway. Dementia 2019 Feb;18(2):725-741. [doi: 10.1177/1471301217691617] [Medline: 28178858]
13. McCabe M, You E, Tatangelo G. Hearing their voice: a systematic review of dementia family caregivers' needs. Gerontologist 2016 Oct;56(5):e70-e88. [doi: 10.1093/geront/gnw078] [Medline: 27102056]
14. Garcia-Ptacek S, Dahlrup B, Edlund AK, Wijk H, Eriksdotter M. The caregiving phenomenon and caregiver participation in dementia. Scand J Caring Sci 2019 Jun;33(2):255-265 [FREE Full text] [doi: 10.1111/scs.12627] [Medline: 30488971]
15. Ambegaonkar A, Ritchie C, de la Fuente Garcia S. The use of mobile applications as communication aids for people with dementia: opportunities and limitations. J Alzheimers Dis Rep 2021;5(1):681-692 [FREE Full text] [doi: 10.3233/ADR-200259] [Medline: 34632304]
16. Martínez-Alcalá CI, Pliego-Pastrana P, Rosales-Lagarde A, Lopez-Noguerola JS, Molina-Trinidad EM. Information and communication technologies in the care of the elderly: systematic review of applications aimed at patients with dementia and caregivers. JMIR Rehabil Assist Technol 2016 May 02;3(1):e6 [FREE Full text] [doi: 10.2196/rehab.5226] [Medline: 28582258]
17. Chelberg GR, Neuhaus M, Mothershaw A, Mahoney R, Caffery LJ. Mobile apps for dementia awareness, support, and prevention - review and evaluation. Disabil Rehabil 2022 Aug;44(17):4909-4920. [doi: 10.1080/09638288.2021.1914755] [Medline: 34034601]
18. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process 1991 Dec 01;50(2):179-211. [doi: 10.1016/0749-5978(91)90020-T]
19. Acikgoz F, Elwalda A, De Oliveira MJ. Curiosity on cutting-edge technology via theory of planned behavior and diffusion of innovation theory. Int J Inf Manage Data Insights 2023 Apr;3(1):100152. [doi: 10.1016/j.jjimei.2022.100152]
20. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977 Mar;84(2):191-215. [doi: 10.1037//0033-295x.84.2.191] [Medline: 847061]
21. An F, Xi L, Yu J, Zhang M. Relationship between technology acceptance and self-directed learning: mediation role of positive emotions and technological self-efficacy. Sustainability 2022 Aug 20;14(16):10390 [FREE Full text] [doi: 10.3390/su141610390]
22. Rahman MS, Ko M, Warren J, Carpenter D. Healthcare Technology Self-Efficacy (HTSE) and its influence on individual attitude: An empirical study. Comput Human Behav 2016 May;58:12-24. [doi: 10.1016/j.chb.2015.12.016]
23. Pan X. Technology acceptance, technological self-efficacy, and attitude toward technology-based self-directed learning: learning motivation as a mediator. Front Psychol 2020 Oct 27;11:564294 [FREE Full text] [doi: 10.3389/fpsyg.2020.564294] [Medline: 33192838]
24. Laganà L, Oliver T, Ainsworth A, Edwards M. Enhancing computer self-efficacy and attitudes in multi-ethnic older adults: a randomised controlled study. Ageing Soc 2011 Aug;31(6):911-933 [FREE Full text] [doi: 10.1017/S0144686X10001340] [Medline: 25512679]
25. Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR Mhealth Uhealth 2015 Mar 11;3(1):e27 [FREE Full text] [doi: 10.2196/mhealth.3422] [Medline: 25760773]
26. Blank S. The Four Steps to the Epiphany: Successful Strategies for Products That Win. Hoboken, NJ: John Wiley & Sons; 2020.
27. Mandracchia F, Llauradó E, Tarro L, Valls RM, Solà R. Mobile phone apps for food allergies or intolerances in app stores: systematic search and quality assessment using the mobile app rating scale (MARS). JMIR Mhealth Uhealth 2020 Sep 16;8(9):e18339 [FREE Full text] [doi: 10.2196/18339] [Medline: 32936078]
28. Hamilton DF, Lane JV, Gaston P, Patton JT, MacDonald DJ, Simpson AH, et al. Assessing treatment outcomes using a single question. Bone Joint J 2014 May;96-B(5):622-628. [doi: 10.1302/0301-620x.96b5.32434]
29. Sztramko R, Levinson AJ, Wurster AE, Jezrawi R, Sivapathasundaram B, Papaioannou A, et al. Online educational tools for caregivers of people with dementia: a scoping literature review. Can Geriatr J 2021 Dec;24(4):351-366 [FREE Full text] [doi: 10.5770/cgj.24.506] [Medline: 34912490]
30. Petrovic M, Gaggioli A. Digital mental health tools for caregivers of older adults-a scoping review. Front Public Health 2020;8:128 [FREE Full text] [doi: 10.3389/fpubh.2020.00128] [Medline: 32411643]
31. Truskinovsky Y, Finlay JM, Kobayashi LC. Caregiving in a pandemic: COVID-19 and the well-being of family caregivers 55+ in the United States. Med Care Res Rev 2022 Oct;79(5):663-675. [doi: 10.1177/10775587211062405] [Medline: 35001714]

32. Hughes MC, Liu Y, Baumbach A. Impact of COVID-19 on the health and well-being of informal caregivers of people with dementia: a rapid systematic review. Gerontol Geriatr Med 2021;7:23337214211020164 [FREE Full text] [doi: 10.1177/23337214211020164] [Medline: 34104687]
33. Cohen G, Russo MJ, Campos JA, Allegri RF. Living with dementia: increased level of caregiver stress in times of COVID-19. Int Psychogeriatr 2020 Nov;32(11):1377-1381 [FREE Full text] [doi: 10.1017/S1041610220001593] [Medline: 32729446]
34. Penteado CT, Loureiro JC, Pais MV, Carvalho CL, Sant'Ana LF, Valiengo LC, et al. Mental health status of psychogeriatric patients during the 2019 new coronavirus disease (COVID-19) pandemic and effects on caregiver burden. Front Psychiatry 2020;11:578672 [FREE Full text] [doi: 10.3389/fpsyt.2020.578672] [Medline: 33312138]
35. Newman K, Wang AH, Wang AZ, Hanna D. The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: a scoping review. BMC Public Health 2019 Nov 09;19(1):1495 [FREE Full text] [doi: 10.1186/s12889-019-7837-3] [Medline: 31706294]
36. Fabius CD, Wolff JL, Willink A, Skehan ME, Mulcahy J, Kasper J. Community-based long-term services and supports: are the needs of older adults and their caregivers being met? The Commonwealth Fund. 2021 Oct. URL: https://www.commonwealthfund.org/publications/issue-briefs/2021/oct/community-based-long-term-services-and-supports-are-needs-older [accessed 2023-11-16]
37. Gaugler JE, Kane RL, Kane RA, Newcomer R. Early community-based service utilization and its effects on institutionalization in dementia caregiving. Gerontologist 2005 Apr;45(2):177-185. [doi: 10.1093/geront/45.2.177] [Medline: 15799982]
38. Zhang Q, Lu J, Jin Y. Artificial intelligence in recommender systems. Complex Intell Syst 2020 Nov 01;7(1):439-457. [doi: 10.1007/s40747-020-00212-w]
39. National Alliance for Cargiving, American Association of Retired Persons. Caregiving in the United States 2020. American Association of Retired Persons. 2020 May 14. URL: https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html [accessed 2023-11-16]

Abbreviations

AD: Alzheimer disease
MARS: Mobile Application Rating Scale

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Review

The Use of Digital Technologies in the Promotion of Health Literacy and Empowerment of Informal Caregivers: Scoping Review

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Abstract

Background: Informal caregivers (IC) play an important role in the community as health care providers for people who are dependent on self-care. Health literacy contributes to empowerment, better care, and self-management of one’s own health and can be developed using digital technologies.

Objective: This study aims to map scientific evidence about the use of digital technologies to promote health literacy and the empowerment of ICs.

Methods: We conducted a scoping review following the Joanna Briggs Institute methodology. The CINAHL, MEDLINE, Scopus, and PubMed databases were searched to find primary studies on the theme. Inclusion criteria were based on the Population, Concept, and Context logic. To be selected for analysis, studies must have involved informal or family caregivers aged ≥18 years who provide care to dependent persons and who have access to the internet and digital devices (computer, smartphone, and tablet). A total of 2 independent researchers (SS and LVH) performed the screening process. This study is part of a main project that was approved by the Ethics Committee for Health of the Regional Health Administration of Lisbon and Tagus Valley (reference 058/CES/INV/2022).

Results: A total of 9 studies were included in the review. The analysis of the studies showed that ICs use digital tools, such as computers and smartphones, with smartphones being the preferred tool. ICs use the internet to access information; manage home tasks; communicate with relatives, their peers, and health care professionals; and take part in forums. Due to difficulties in leaving their houses, forums are highly valued to preserve human connections.

Conclusions: The use of digital technologies to convey clear, objective, reliable, and accessible information is a strategic action for promoting health literacy and for contemplating the variable care needs of ICs. By working with ICs in the development of new technologies, researchers are building a new tool that meets ICs’ needs.

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KEYWORDS

health literacy; empowerment; digital technology; informal caregiver; family caregiver

Introduction

Background

Population aging is a social challenge worldwide. As life expectancy increases, the incidence of chronic and incapacitating diseases also increases [1]. The high levels of dependence and the complex management of health status raise awareness of the increasingly relevant role of informal caregivers (ICs) in terms of care and health promotion of their relatives [2]. The ICs, defined as *someone who provides nonremunerated care to a person with a long-term illness, disability or other health need, or long-term care, outside a professional or formal framework*, are considered essential both to the care of people in the community and to the economy of European Union countries [3]. ICs are more and more important to patients as well as to health care professionals [4]. They play a central role in the planning, training, and provision of services to people with care needs [2,3]. In practical terms, ICs collaborate in providing health care at home to people who show an impairment in self-care, activities of daily living, and instrumental activities of daily living. The needs change over time, as does the level of dependency of the person cared for [5].

In most situations, ICs are not prepared to play this role. This transition in caregivers' lives brings out feelings of insecurity due to the unknown and the lack of knowledge and skills to ensure that the person cared for is given proper care [5]. This way, ICs' existing and acquired knowledge is extremely important and becomes necessary for the implementation of interventions destined to promote the development of skills and the involvement of relatives in patient trajectories to improve patient outcomes [2-4].

A vital point in health policies is the investment in the health literacy (HL) of ICs. HL is central to empowering people, their families, and communities, promoting greater control over decisions and actions affecting their health [6]. HL is defined as the ability to access, understand, evaluate, and apply information about health care, disease prevention, and health promotion to maintain and promote quality of life during the life course [7].

Through HL development, conditions are created for individuals to gain knowledge and skills, make informed decisions, and feel motivated to adopt a behavior that improves their health status and well-being [8].

Considering that HL is a health determinant, mediator, and moderator, it is important to ensure that citizens access reliable, useful, and updated health information to help them make the best decisions about their personal health, their family's health, and the community's health [9-11]. Proper access to information allows to promote and increase citizen empowerment so that they participate in their health care, leading to shared responsibility and informed decision-making [12].

As an agent, the health care professional plays a central role in effective communication and in conveying reliable information to the population. User-relative–health care professional communication significantly affects health outcomes and user satisfaction concerning health services [13]. Digital technologies have created an opportunity for health professionals and health organizations to directly communicate with many people in real time. This digital revolution in communication allows to customize information, help people set health targets, and interact in real time [1].

Information and Communication Technologies (ICTs) is the set of technologies and equipment that, in an integrated manner, allow working and communicating information, including computers and the respective applications, the internet, and telecommunications [14]. They are part of the citizens' routine, with an increasing use of educational platforms. The internet is considered a privileged means of interaction with the population that needs health care [1].

ICTs improve the quality of life of older adults and their caregivers and their access to quality care, contributing to improving the social lives of caregivers and decreasing their isolation via social activities and intergenerational relationships [15]. These aspects contribute to balanced physical, mental, and emotional health and to a decrease in depressive symptoms and sadness. Digital technologies are considered *a key component and facilitator of sustainable health systems and universal health coverage* [16]. Digital technology is a strategy that can promote accessibility to health care for all citizens. Digital means can be used to increase access to reliable, useful information and to strategies that meet the needs of the highest possible number of ICs, whether in real time or not [1]. However, accessing and handling these technologies requires digital literacy, which is one of the barriers identified by studies in certain groups considered vulnerable, such as older adults. Digital HL is the ability of citizens to use digital platforms to manage their health, validate web-accessible health information, and communicate with health professionals [17].

Objectives

In Portuguese literature, there are only a few scientific studies conducted by nurses that refer to the use of digital technologies as a resource to empower dependent people and family caregivers [1]. The need to know if dependent people and their ICs have access to digital technologies and use them when they have health needs gave rise to the following research question: "Which digital technologies are used for promoting Health Literacy and empowering the Informal Caregiver?" For the mapping, we used the following guiding questions: "Do the Informal Caregivers have access to digital technology?" and "Do the Informal Caregivers use digital technologies to improve their health literacy and empowerment concerning the care of the person cared for?" To answer these questions, this review aims to map the scientific evidence regarding the use of digital technologies to promote HL and empower ICs.

Methods

Overview

This is a scoping review conducted according to the methodology recommended by the Joanna Briggs Institute (JBI) [18]. Scoping reviews are used to identify knowledge gaps, enhance knowledge described in the literature, clarify concepts, or investigate research conduct [19].

The theme was searched in the JBI Database of Systematic Reviews, CINAHL, MEDLINE, Scopus, and PubMed, and no systematic review was found for this same theme. The inclusion criteria were based on the Population, Concept, and Context logic: the Population included all informal or family caregivers aged ≥18 years who provide care to dependent persons and who have access to the internet and digital devices (computer, smartphone, and tablet).

The search was conducted from April 4 to 18, 2022, and included primary qualitative and quantitative studies and mixed method studies in English, Portuguese, French, and Spanish, during 5-year period between January 2017 and December 2021, to obtain the most recent studies published on this theme. Key terms and inclusion criteria were used as a strategy to identify papers that were relevant to the search.

Study Selection, Data Extraction, and Analysis

According to the JBI's recommendations, the search strategy was performed in 2 steps [18]. There was an initial search of the electronic platform EBSCO, in particular, MEDLINE and CINAHL, with the natural keywords informal caregiver; family caregiver; health literacy; empower; digital technology; and community, following the search for the indexing term MH "Empowerment." Subsequently, we carried out an analysis of the words used in the title, the abstract, and the terms indexed as well as the keywords presented in the description of each searched article. We then carried out a second survey in which the indexing terms and keywords were searched in MEDLINE (PubMed), CINAHL (via EBSCO), MEDLINE (via EBSCO), and Scopus (Textbox 1).

A total of 2 independent reviewers (SS and LVH) analyzed the relevance of papers using the information included in the title and abstract, considering that the study population must be defined and the goal must be associated with digital tools.

It was necessary to retrieve the papers after reading the abstract. Full papers were obtained for all studies with the inclusion criteria. A table was filled with the defined criteria, considering the goals and the results of the study that would answer the research question. After reading the full text, 2 papers showed a divergent opinion. This situation was discussed and resolved without the need to speak to a third reviewer.

The screening process identified 442 studies. Of the 442 studies, 77 (17.4%) were duplicated and so were excluded. Of the remaining 365 studies, 320 (87.7%) were excluded for their titles and 25 (6.8%) for their abstracts, based on the inclusion criteria that had determined their eligibility. In the second step, there were 20 papers for full-text review. Of the 20 papers, 11 (55%) were eliminated because of the following reasons: 4 (20%) because their goals did not relate to the technological needs of ICs but to the person cared for; 4 (20%) because they were about another type of nontechnological experience; and 3 (15%) because they were about behavioral therapies and coping strategies. Figure 1 [20] shows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart for the identification and selection of the studies.

A data collection instrument was made to extract information from the selected studies, including the following items: author, country, year of publication, study goal, study type and methodology used, population, sample, types of interventions, main results, and conclusions. The results were analyzed based on their content and organized according to the research question and goals.

Textbox 1. Search strategy according to database searched.

MEDLINE (via PubMed)

- (((informal caregivers) OR (family caregivers) AND (community) AND ((“health literacy”) OR (empowerment) OR ((digital education) OR (digital technology) OR (digital era) OR (digital platforms) OR (digital sources) OR (Information and communication technology))) in the last 5 years

CINAHL complete (via EBSCO)

- S1 informal caregivers
- S2 family caregivers
- S3 S1 OR S2
- S4 community
- S5 health literacy
- S6 empowerment
- S7 MH“empowerment”
- S8 empower*
- S9 digital technology
- S10 digital era
- S11 digital health literacy
- S12 digital sources
- S13 digital education
- S14 digital platforms
- S15 Information Communication Technology
- S16 S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15
- S17 S3 AND S4 AND S16

MEDLINE (via EBSCO)

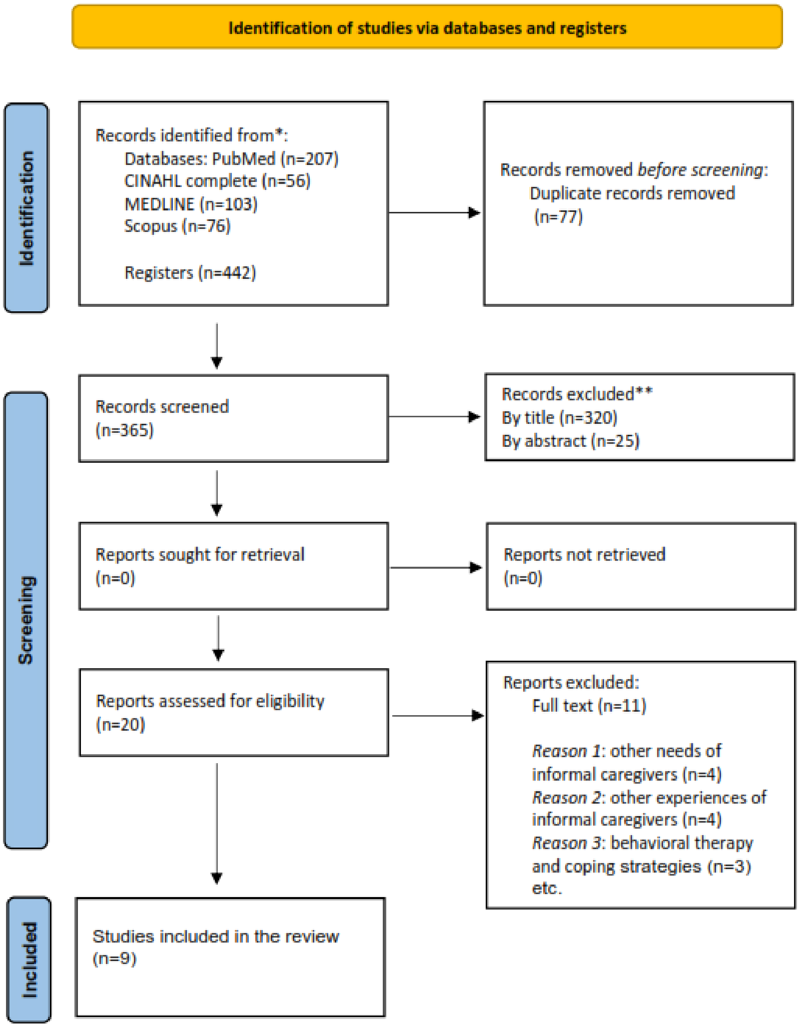
- S1 informal caregivers
- S2 family caregivers
- S3 S1 OR S2
- S4 community
- S5 health literacy
- S6 empowerment
- S7 MH“empowerment”
- S8 empower*
- S9 digital technology
- S10 digital era
- S11 digital health literacy
- S12 digital sources
- S13 digital education
- S14 digital platforms
- S15 Information Communication Technology
- S16 S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15
- S17 S3 and S4 and S16

Scopus

-

(TITLE-ABS-KEY [“informal caregivers”] AND PUBYEAR>2016) OR (TITLE-ABS-KEY [“family caregivers”] AND PUBYEAR>2016 AND PUBYEAR<2023) (TITLE-ABS-KEY [community] AND >2016 AND PUBYEAR<2023) (TITLE-ABS-KEY [“health literacy”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY (“empower*”) AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“empowerment”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [mh “empowerment”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“digital technology”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“digital era”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“digital sources”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“digital health literacy”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“digital education”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“digital platforms”] AND PUBYEAR>2016 AND PUBYEAR<2023) OR (TITLE-ABS-KEY [“information and communication technology”] AND PUBYEAR>2016AND PUBYEAR<2023) (TITLE-ABS-KEY (*#3* AND *#4* AND *#16*) AND PUBYEAR> *2016* AND PUBYEAR< *2023* AND (LIMITTO [LANGUAGE, *“English”*] OR LIMIT TO [LANGUAGE, *“Spanish”*] OR LIMIT TO [LANGUAGE, *“French”*] OR LIMIT TO [LANGUAGE, *“Portuguese”*])

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) flowchart.



Ethical Considerations

This study is part of a main project that was approved by the Ethics Committee for Health of the Regional Health Administration of Lisbon and Tagus Valley (reference 058/CES/INV/2022).

Results

Studies Characteristics

In total, 9 studies were included in this review after the search. According to the JBI’s guidelines, after the selection, the studies were organized based on their research question and goals (Tables 1 and 2).

Table 1. Summary of study characteristics.

Paper title	Authors, country, and year	Goal	Type of study and methodology	Population and sample
What is “care quality” and can it be improved by information and communication technology? A typology of family caregivers’ perspective	Leslie et al [21], Canada, 2020	• To determine how ICTs[a] can support family caregivers who play the caregiver role	• Qualitative study • Method • Focus group	• FC[b] of older people • Sample: 25
Effect of an innovative model of complexity care on family caregiver experience: qualitative study in family practice	Nickell et al [22], Canada, 2020	• To learn about the experiences of FC of older people with complex needs, using the Interprofessional Model of Practice for Aging and Complex Treatments	• Qualitative study • Method • Individual interviews	• FC of older people with complex needs • Sample: 20
Building a Research Roadmap for Caregivers Innovation: Finding from a Multi-Stakeholder Consultation and Evaluation	Egan et al [23], Scotland, 2021	• To explore a future roadmap for innovation from IC[c] participation	• Mixed study • Method • Interview • Questionnaire	• ICs • Sample: 112 • Professionals and researchers • Sample: 62
The care capacity goals of family carers and the role of technology in achieving them	Leslie et al [24], Canada, 2020	• To identify the goals of FC when caring for older adults and how technology can help achieve those goals	• Mixed study • Method • Focus group • Questionnaire	• FCs • Sample: 25
Mobile Support for Older Adults and Their Caregivers: Dyad Usability Study	Quinn et al [25], United States, 2019	• To determine the usability of a mobile app within the older population and in their relationship with ICs	• Observational study • Method • Questionnaires	• Older people and ICs • Sample: 24 (dyad 12)
Preferences for using a Mobile App in Sickle cell Disease Self-management: descriptive Qualitative study	Mayo-Gamble et al [26], Canada, 2020	• To explore health preferences for using an app in the process of facilitating the self-management of adults with sickle cell disease and their caregivers who live in urban and rural communities	• Qualitative study • Method • Focus group	• Adults with sickle cell disease and caregivers • Sample: 43
A Digital Mobile Community App for Caregivers in Singapore: predevelopment and Usability Study	Lwin et al [27], Singapore, 2021	• To provide a clear understanding of the implementation along with a usability study to gauge user opinion of the “Caregiver’s circle” app within Singapore	• Qualitative study • Method • In-person interviews • Questionnaire	• ICs • Sample: 103
Improving the Quality of Life of Family Caregivers of People with Alzheimer’s Disease through Virtual Communities of Practice: A Quasiexperimental Study	Romero-Mas et al [28], Spain, 2021	• To describe the relation between the quality of life of ICs of people with Alzheimer disease and their participation in a VCoP[d] (virtual community with the exchange of knowledge and an emotional support and collaboration culture) • To determine the impact of ICs’ HL[e] in the quality of life and involvement in the VCoP	• Quasiexperimental study • Method • Phone calls and in-person contact • Focus group • Evaluation scales • Control group with and without VCoP intervention • Questionnaire	• ICs of people with Alzheimer disease • Sample: 38 before the test and 37 after the test
Patient Portals as a Tool for health Care Engagement: A Mixed-Method Study of older Adults with Varying Levels of Health Literacy and Prior Patient Portal Use	Irizarry et al [29], United States, 2017	• To explore attitudes in relation to choosing the portal and its utility as a tool to involve health care with different levels of HL	• Mixed-methods study • Method • Phone interview • Focus group	• Older people • Sample: 100

[a] ICT: Information and Communication Technology.

[b] FC: family caregiver.

[c] IC: informal caregiver.

[d] VCoP: virtual community of practice.

[e] HL: health literacy.

Table 2. Summary of study results.

Types of interventions	Main findings	Conclusion
Intervention made with 10 focus groups from May 2017 to August 2018. Each session took 2 hours. Bottom-up approach with thematic content analysis.	Technologies that are only focused on the task can lose their value as they lose the capacity to provide information that is relevant to caregivers' needs. ICTs[a], as the intermediary for an improvement in quality of life and as providers of relevant information that are enabled with knowledge and caregiver needs' change. Smartphones can be an extension of access to software.	ITC product development supported by ICs[b] should focus on human relationships and expand a facilitating communication, allowing their participation in decision-making and allowing them to express their concerns and goals. Technology appears as a support to receive information that is relevant to caregivers' needs and to establish human connections.
Individual interviews with 13 family caregivers about the caregiver role and their (physical and emotional) well-being. The patient and the caregiver are encouraged to play a more active role in the process of their disease by raising questions and discussing actions.	Caregivers reported that they no longer felt lonely in this role because they were given basic information about the disease as well as existing resources and equipment. They felt recognized and heard; they were able to express their uncertainties, stories, and suggestions, increasing their commitment to caregiving. They searched the internet.	Involving ICs as part of the multiprofessional team increases their perception and understanding of the caregiver role and their trust in their ability to perform this role and facilitates their empowerment.
A mixed approach was used: A 10-minute multisector consultation from June 15, 2020, to September 30, 2020. Web-based questionnaire on social media.	In total, 108 of the 112 (96%) ICs use digital technology. The hybrid approach (both in person and web based) can work for caregivers. The experience of ICs in collaborating with universities to work via multiple communication channels should be valued. Deep knowledge of needs and existing gaps allows one to contribute to technological innovation to overcome existing technological barriers and learn what the facilitating mechanisms are. The ICs mentioned the need for improved financial, emotional, psychological, training, and educational support.	A technological approach in the following areas is required for the health and well-being of ICs: information, monitoring technology, and communication with other ICs and professionals. The experience of ICs in collaborating with universities to identify priorities and actions that speed up searches and future political decisions about significant and innovative solutions should be valued.
Sequential method, focus group, and web-based questionnaire. In total, 10 focus groups with 25 family caregivers. The intervention took place from May 2017 to August 2018. First part: discussion of targets and technological solutions. In what they think technology can help them. Second part: web-based questionnaire about 7 fields: physical health, mental health, well-being, social connection, education, employment, and finances.	Technology maintains the ability to care and allows ICs to develop coping strategies, guide themselves, and socialize. Technology is an intermediary that connects ICs to information support and other caregivers. Key targets for ICs are to reinforce and preserve their ability to provide care.	Technology is well positioned to find the best self-care to facilitate the connections needed for a social life. Technological targets and suggestions should imply that the understanding of care as a source of overload was transformed into a more resilient, sustainable caregiving model. Technology can help promote such resilience but can be limited to the role of an intermediary that connects family caregivers to information supports and peers.

Types of interventions	Main findings	Conclusion
• Participants completed a skill evaluation questionnaire and downloaded an app to their smartphones or computers that was used for a month. • Then, participants completed 2 questionnaires that evaluated app features and esthetics and their relationship with the app. • App features: user profile, family health history, health information, receiving studies based on their health profile, and establishing a relationship with their caregivers.	• Study results showed normal levels of digital competence for the older adults and high levels for the ICs. Older adults use their smartphones to make calls (9/12, 75%) and read emails (7/12, 58%). They access the internet (4/12 33%) but on their computers. ICs use their smartphones for calls, SMS text messages, emails, and the internet equally (11/12, 92%). They access the internet via their phones. • This study concluded that 50% (6/12) of ICs want to use the app to manage the appointments and clinical information of the person cared for and to access specific information that allows them to share and discuss to commit to the caregiving; they believe that the app’s esthetic dimension is important.	• Technologically experienced caregivers play an essential role in showing the benefits of technology for supporting care provision for older adults. • There were high levels of use of technology among the older adults and caregivers, but there was only an average use of the mobile app. Additional training is recommended for the older adults and caregivers, including behaviors directed toward keeping digital health records.
• In total, 5 community listening sessions were made with 1 urban and 1 rural community. Each session took 2 hours. A questionnaire about demographics and access to technology was applied. • Where they searched for information about self-care in relation to the SCD[c] and what was their satisfaction level with the search for and support about management and resources. A total of 7 aspects were evaluated: self-management information, such as receiving information, which information they wish to receive, changes in disease management, support types, barriers to and facilitators for the use of apps, and mobile app preferences.	• Participants are receptive to using the app to self-manage the disease. A mobile app reduces the information access barrier. In rural communities, the app increases ICs’ access to resources. • The internet is the reported source to learn about self-management techniques and receive information, reinforcing the importance of reliable websites. ICs want emotional support, information support from the family, and follow-up from health care professionals. Positive feedback about the app included easy configuration and a good interface. • Barriers: participants were not comfortable using the internet because they struggled to identify relevant, reliable information. The notification system, information trackers, and the fact that they can communicate with their health care professionals and caregivers were aspects valued by patients.	• The results can be used to develop a patient-centered health app that is easy to use to facilitate disease self-management, thereby increasing access to resources by relatives that live in rural communities.
• A predevelopment survey was made about the following issues: care, support provided, and what they would like in a caregiving mobile app. Identifying the needs of ICs and the gaps in web community networks. • Demographics about the health of the person cared for and about the ICs’ physical and mental health. • What is the level of use of digital means when searching for information and support. • A total of 32 caregivers completed a web-based questionnaire and in-person interviews, followed by a usability test.		• Caregivers enjoyed the “Caregivers’ Circle” and were confident that this app could help them improve their quality of life. • Including many resources that caregivers need daily in 1 app can help save time and help them live without problems.

Types of interventions	Main findings	Conclusion
	- ICs said they liked using the app. They said it was useful, easy to use, and helpful to improve the quality of life because they included multiple resources: a public forum for discussions with the community and other ICs in the same region without ever leaving home and a market to purchase and sell material and equipment required for caregiving. Including many resources that caregivers need daily in an easy-to-use app allowed them to save time and helped browse without any issues. - The use of smartphones created an opportunity for the caregiving community to use technology in a useful way. - The app included caregivers' ideas, which created an app that facilitated caregiving. - As to concerns about safety and security, trust would increase if the app were supported by a renowned organization. - ICs have suggested that the app should include a resource that would help with mental health, namely, relaxation techniques, motivational quotes, and guides that would remind them to take care of themselves.	
- The study took place between July 2017 and April 2018. - Previous contact was made with the AFMADO[d] association, and explanatory sessions were held (individual and group). In total, 2 groups were created, 1 with and 1 without health care professionals. Intervention: developing an app based on the CoP[e] theory, with space for chatting and a member file with information about each member. - The following aspects were evaluated before and after the VCoP[f] intervention: quality of life, HL, and the Barthel scale associated with the Spanish population.	- QoL[g] was 66.6 and increased to 69.5. - There was no discrepancy between sexes for the QoL. Age was the only sociodemographic criterion that affected the quality of life; older adults increased their QoL to 74.6. Young people went from 66.7 to 67.85. Spouses said that the app had a positive impact on their QoL. - Regarding HL[h], the average rate of 26.10 (in 40) increased to 30.68. Internet interventions can help caregivers meet their needs, which is a positive experience. - Allowed to get to know their peers and to feel less lonely.	- Caregivers can benefit from the VCoP because it enables interaction and knowledge sharing between caregivers and helps them meet their needs. - VCoP's impact is governed by age and relationship with the person cared for. It was positive for the caregivers' quality of life, at a physical level, when the functional condition of the person with Alzheimer disease worsened. - The VCoP was considered a useful tool. - HL had a positive impact on the physical area of the QoL of caregivers.
- First contact made by phone (data collection: demographics, health, "Deficit of quality-of-life technology" questionnaire, and CREATE[i]). - Classified participants according to their HL level and portal use. This classification resulted in 4 groups (group 1: high HL, yes portal; group 2: high HL, no portal; group 3: low HL, yes portal; and group 4: low HL, no portal). - Second contact made with 4 focus groups (N=75) aimed at analyzing participants' attitudes. Sessions took 1 hour, were recorded, and used NVS[j].		- The study concluded that there should be more research focused on the attitudes and experiences of ICs of older adults as substitute users for the older adults. - Health organizations should connect people to technology by adopting the following strategies: campaign to disclose the benefits of technology and how they meet people's needs; offer specific training so that they can use technological tools in a secure, trustful way; include ICs in the campaign and training; and create workflows where people can communicate to update data, exchange information, and clarify any doubts that validate their knowledge. This would create a tool designed for support and commitment.

Types of interventions	Main findings	Conclusion
	- Participants with the higher HL who use the portal struggle to solve issues without the digital support and feel more pressured to use these methods. - Those who do not use the portal say they do not feel safe using it due to the risk of sharing personal data and prefer to use the phone. People with low HL who do not use the portal do not have experience using computers, are not trained, and do not have internet access at their homes, but those who use the portal say they are more interested in learning and training with new technologies. - People who are more familiar with accessing health information using the internet might be more willing to participate in research related to digital technology. The study revealed that HL was a factor that contributed to trust when accessing digital health information. However, it was not directly related to the motivation to get involved in health care. If portal users understand the benefits, this would be a motivation for portal use. Specific technology training is required to gain trust. ICs play a potential role in improving access to portal use for older adults who cannot access portals.	

[a] ICT: Information and Communication Technology.

[b] IC: informal caregiver.

[c] SCD: sickle cell disease.

[d] AFMADO: Osona's Association of Alzheimer's Family Caregivers.

[e] CoP: community of practice.

[f] VCoP: virtual community of practice.

[g] QoL: quality of life.

[h] HL: health literacy.

[i] CREATE: Center for Research and Education on Accessible Technology and Experiences.

[j] NVS: Newest Vital Sign.

Main Findings

Table 2 shows the main findings and conclusions of the studies described in the papers.

Regarding the year of publication, the studies were published in year 2017 (1/9, 11%); year 2019 (1/9, 11%); year 2020 (4/9, 44%); and year 2021 (3/9, 33%). They were conducted in the following countries: Canada (4/9, 44%), the United States (2/9, 22%), Scotland (1/9, 11%), Singapore (1/9, 11%), and Spain (1/9, 11%). Of the 9 studies, 3 (33%) followed a qualitative approach, 4 (44%) followed a mixed approach, 1 (11%) was observational, and 1 (11%) was a quasi-experiment.

The results of the studies enabled us to address the guiding questions. On the question "Does the Informal Caregiver have access to digital technology?" the studies show that ICs have access to and use digital technology [23,25]. They describe which types of technological resources are used more frequently by them: smartphones with mobile apps or internet access. The internet is the source of choice for accessing health information and learning about self-management techniques, with the importance of reliable websites being emphasized [22,25,26]. Smartphones are used to make calls, send SMS text messages and emails, and access the internet [25]. Apps are used to manage the appointments and medical information of the person cared for and to access specific information that allows ICs to share and discuss to commit to the caregiving relationship [25]. The esthetic dimension, ease of configuration, and nice interface are app features that are valued by ICs [25,26].

Privacy and security issues seem to be a factor that limits the use of technologies because users feel insecure due to the risk of sharing personal information [19,27]. Struggling to identify relevant and reliable information is also a factor that causes apprehension when it comes to internet use [26]. The degree of trust when accessing digital information seems to be related to the HL level of users [29]. Users with low HL levels who did not use the technology that was being analyzed had little experience using computers, no training, and no internet access at home. Those who used the portal showed increased interest in learning and practicing with the new technologies [29]. This fact reinforces the need for specific training on the use of digital technologies to gain trust [29].

Regarding the question “Does the Informal Caregiver use digital technology to improve their HL and their training in caring for the person cared for?” the studies show that the use of digital technology can benefit the population as well as caregivers [21,25-27,29].

ICTs lower information access barriers and provide relevant information that is enabled when there is a need to gain new knowledge [21,26]. ICTs are perceived as giving ICs the opportunity to guide themselves and interact with other caregivers, which allows them to get to know their peers and feel less lonely [24,28].

Caregivers say that by using digital technologies, they can obtain basic information about the disease, such as symptoms and treatment options, and about existing resources and equipment, which makes them feel less lonely in this role [21-23]. With the support of digital tools, caregivers felt recognized and heard and could express their uncertainties, stories, and suggestions, which increased their commitment to care provision [22]. Technology also maintains their caring ability and allows them to develop coping strategies [24].

The use of technology is also referred to as an intermediary for an improved quality of life [21,28]. This perception of the improvement of the quality of life is boosted when the technology that is used includes multiple resources, such as the fact that there is a public forum for community discussion with other ICs in the same region without having to leave home, a market to purchase and sell materials and equipment that is needed for providing care, and an alert system or information trackers [26,27]. The integration of the multiple resources that are needed by caregivers daily in an app that is easy to use allows them to save time and provide help to browse without problems [27].

Another aspect referred to by the studies concerns suggestions or factors that can improve the experience of ICs when using digital technologies. One study described that new technologies that are only focused on the task can lose their value as they lose the capacity to provide information that is relevant to caregivers’ needs [21]. It is important that ICs collaborate in the development of technologies because their deep knowledge of the needs and existing gaps contribute to technological innovation, which allows them to overcome the existing technological barriers and learn facilitator mechanisms [23].

The expectations of ICs as to digital technologies also seemed to be an important aspect to consider because they can increase the technology used. ICs hope that technologies can provide emotional and psychological support, informative support from the family, training and education, and health care follow-up [23,26]. In a more practical way, ICs suggested that there should be resources that help them with their mental health, namely, relaxation techniques and motivational quotes and guides that would help them remember to take care of themselves [27].

Discussion

Informal Caregivers’ Role in the Health Care System

According to the studies that were analyzed, demographic changes are leading to an increasing need for long-term care, which results in people informally caring for their relatives. Being an informal or family caregiver brings uncertainties, isolation, and overload [21,27]. Studies have shown that the involvement of the caregiver in the care plan is essential. The active involvement of ICs as a member of the interprofessional care team results in an improved experience, increased caregiver capacity, and the appreciation of the caregiver role [22,24].

These results are in accordance with the literature where ICs are considered “one of the elements of the sustainability of social and health systems” [30]. This emphasizes how important it is for health care professionals to work with ICs to find the strategies that are most adequate for effective empowerment [30]. The empowerment of ICs should be “a priority in health care organizations and the nurse assumes a major, dynamic, empowering role when it comes to the most adequate response to meet those needs” [31].

The World Health Organization (WHO) has defined a long-term strategy for the expansion and use of digital health, emphasizing the positive impact that it can have on health care access and provision as well as on the health and well-being of the population and caregivers [23]. According to the literature, health technology is “one of the strategies used by the health care professional to empower citizens to use it in a secure way” [32].

The Use of Digital Technologies Supporting Caregivers

The studies revealed that low HL was a barrier to accessing digital information and the correct use of technological tools. Lack of training makes browsing difficult and results in user insecurity [26,29]. The initial findings of a European survey on population HL carried out by the WHO Action Network on Measuring Population and Organizational Health Literacy indicate that 22% to 58% of the population find it challenging to access and interpret digital health information [33]. By contrast, the European data report shows that, in 2019, in European countries such as Finland, the Netherlands, the United Kingdom, and Germany, 75% of the active population had basic digital skills [34].

Promoting HL improves safety in caregiving and decreases the risk associated with this activity [32].

Using digital technology in the health field can benefit the caregivers and the general population [21,25-27,29].

Questions about privacy and security when using these digital tools are an important factor for users. Although there is an increasing concern about what is the best way to develop emerging web-based technologies (eg, ethical data use), the results show that a hybrid model with a web-based and in-person approach can work well for caregivers in rural areas [23]. The model that includes digital technology and an in-person approach is pointed out as a more reliable model for the ICs.

These results are in line with the American study that described that ICs use the internet (77.5%) to access health information for themselves (73%), for others (67.5%), and to communicate with the physician [35].

The results highlight that ICs intend to use digital tools to establish communication relationships with people cared for, their family members, the peers, and health care professionals [21,23,24,27,28].

Principal Findings

The text highlights privacy concerns limiting technology use, underscoring the impact of low HL on users' digital engagement. ICs benefit from digital tools by experiencing empowerment, recognition, and an improved quality of life. The integration of multiple resources in one technological tool supports caregiving, saving time and facilitating daily tasks. The collaboration of ICs in technology development is crucial for innovation and overcoming barriers, emphasizing the need for user-driven solutions.

Limitations

As for the analysis of the included studies, it was not possible to use a tool to evaluate study quality. In the papers that were analyzed, it was not possible to identify references about improvement opportunities arising from the research process. The fact that the samples in the presented studies are small does not allow us to extrapolate data to the population.

The included papers were published in English, French, Spanish, and Portuguese, and the inclusion of articles in other languages could have brought more relevant information to this review. However, searching in 4 databases allowed us to expand the search comprehensiveness.

Comparison With Previous Work

In Portugal, there are few scientific studies carried out by nurses that refer to the use of digital technologies as a resource to train people with dependence and ICs.

Conclusions

Evidence found in studies revealed that ICTs such as digital platforms, portals, and web-based community groups were preferentially used by informal caregivers via mobile apps and that computers were used more by the people cared for. Studies showed that ICs had access to and used digital technology not only to meet the needs of the person cared for but also to meet their own needs. Studies have shown that digital technology is an accessible tool for empowering ICs. However, there were concerns regarding privacy, security, and the use of these tools, which should be considered by health care professionals and researchers. It is also important to highlight the necessity of providing digital training for both ICs and the individuals under their care.

ICs play a key role in the provision of quality care to the dependent people to whom they commit. It is crucial to understand how digital tools can be effectively and beneficially used to empower ICs.

The participation of ICs is essential when it comes to developing digital tools (platforms, mobile apps, and portals) because they can contribute to developing tools that meet users' needs (ICs and the people cared for). The use of digital technologies can guarantee access to knowledge, thereby empowering caregivers when it comes to making a decision and sharing care provision with health care professionals. It is important to emphasize the significance of digital empowerment in enhancing the digital health literacy of both ICs and those they care for. Digital technology allows accessible, targeted, and effective communication. Health care professionals and researchers should guarantee information reliability, security, and clarity and optimize existing resources.

Authors' Contributions

SS contributed to the design of the paper; contributed to the collection, analysis, and interpretation of the data; and drafted the paper. LVH contributed to the interpretation of the data, drafted the paper, and substantively revised it. MFF contributed to the design of the paper and the collection, analysis, and interpretation of the data. AH contributed to the design of the paper and the interpretation of the data. GC contributed to the interpretation of the data and substantively revised it. ASC contributed to the design of the paper and the interpretation of the data and drafted and substantively revised the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA-ScR checklist.
[PDF File (Adobe PDF File), 350 KB - aging_v7i1e54913_app1.pdf]

References

1. Lumini MJ, Freire R. As novas tecnologias no processo de cuidar. In: Morim AR, editor. A Pessoa Dependente & O Familiar Cuidador. Porto, Portugal: Escola Superior de Enfermagem do Porto; 2016.

2. Hassan AY. Challenges and recommendations for the deployment of information and communication technology solutions for informal caregivers: scoping review. JMIR Aging 2020 Jul 29;3(2):e20310 [FREE Full text] [doi: 10.2196/20310] [Medline: 32723720]
3. The 10 steps towards carer-friendly societies across Europe. Euro Carers. URL: https://eurocarers.org/strategy/ [accessed 2022-03-11]
4. Berthelsen CB, Kristensson J. The content, dissemination and effects of case management interventions for informal caregivers of older adults: a systematic review. Int J Nurs Stud 2015 May;52(5):988-1002. [doi: 10.1016/j.ijnurstu.2015.01.006] [Medline: 25661314]
5. Araújo F, Martins T. Avaliação dos cuidadores – Considerações e orientações para a prática. In: Morim A, Gomes B, Martins C, Araújo F, Bastos F, Petronilho F, et al, editors. A Pessoa Dependente e o Familiar Cuidador. Porto, Portugal: Lusodidacta, Lda; 2016:29-39.
6. Health promotion glossary of terms 2021. World Health Organization. 2021 Dec 6. URL: https://www.who.int/publications/i/item/9789240038349 [accessed 2022-04-14]
7. Sørensen K. Uma visão para a literacia em saúde na Europa. In: Lopes C, Almeida CV, editors. Literacia Em Saúde Na Prática. Lisboa, Portugal: Edições ISPA; 2019:27-32.
8. Health promotion glossary. World Health Organization. 1998 Jun 16. URL: https://www.who.int/publications-detail-redirect/health-promotion-glossary [accessed 2022-03-10]
9. Níveis de literacia em saúde - Portugal. Associação Portuguesa de Nutrição. 2021 Sep 10. URL: https://www.apn.org.pt/noticia/publicacao-dgs-niveis-de-literacia-em-saude-portugal [accessed 2024-03-25]
10. Estratégia nacional para a qualidade na saúde 2015-2020. Direção-Geral da Saúde. URL: https://www.dgs.pt/qualidade-e-seguranca/estrategia-nacional-para-a-qualidade-na-saude.aspx [accessed 2022-01-20]
11. Nutbeam D. From health education to digital health literacy – building on the past to shape the future. Glob Health Promot 2021 Oct 31;28(4):51-55. [doi: 10.1177/17579759211044079]
12. Promoting health in the SDGs: report on the 9th Global conference for health promotion, Shanghai, China, 21–24 November 2016: all for health, health for all. World Health Organization. 2017 May 10. URL: https://www.who.int/publications/i/item/promoting-health-in-the-sdgs [accessed 2022-01-20]
13. King A, Hoppe RB. "Best practice" for patient-centered communication: a narrative review. J Grad Med Educ 2013 Sep;5(3):385-393. [doi: 10.4300/JGME-D-13-00072.1] [Medline: 24404300]
14. Nunes P. TIC (Tecnologias de Informação e Comunicação). Knoow.net. 2016. URL: https://knoow.net/cienceconempr/gestao/tic-tecnologias-de-informacao-e-comunicacao/ [accessed 2022-04-14]
15. Carretero S, Stewart J, Centeno C. Information and communication technologies for informal carers and paid assistants: benefits from micro-, meso-, and macro-levels. Eur J Ageing 2015 Jan 24;12(2):163-173. [doi: 10.1007/s10433-015-0333-4]
16. Draft global strategy on digital health 2020–2024. World Health Organization. 2020. URL: https://www.who.int/docs/defaultsource/documents/gs4dh0c510c483a9a42b1834a8f4d276c6352.pdf [accessed 2022-03-12]
17. Levy H, Janke AT, Langa KM. Health literacy and the digital divide among older Americans. J Gen Intern Med 2015 Mar;30(3):284-289 [FREE Full text] [doi: 10.1007/s11606-014-3069-5] [Medline: 25387437]
18. Aromataris E, Munn Z. JBI Manual for Evidence Synthesis. Adelaide, Australia: Joanna Briggs Institute; 2020.
19. Munn Z, Peters MD, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol 2018 Nov 19;18(1):143 [FREE Full text] [doi: 10.1186/s12874-018-0611-x] [Medline: 30453902]
20. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021 Mar 29;372:n71 [FREE Full text] [doi: 10.1136/bmj.n71] [Medline: 33782057]
21. Leslie M, Gray RP, Khayatzadeh-Mahani A. What is 'care quality' and can it be improved by information and communication technology? A typology of family caregivers' perspectives. Scand J Caring Sci 2021 Mar 13;35(1):220-232. [doi: 10.1111/scs.12837] [Medline: 32168399]
22. Nickell LA, Tracy CS, Bell SH, Upshur RE. Effect of an innovative model of complexity care on family caregiver experience: qualitative study in family practice. Can Fam Physician 2020 Mar;66(3):194-200 [FREE Full text] [Medline: 32165470]
23. Egan KJ, McMillan KA, Lennon M, McCann L, Maguire R. Building a research roadmap for caregiver innovation: findings from a multi-stakeholder consultation and evaluation. Int J Environ Res Public Health 2021 Nov 23;18(23):12291 [FREE Full text] [doi: 10.3390/ijerph182312291] [Medline: 34886044]
24. Leslie M, Gray RP, Eales J, Fast J, Magnaye A, Khayatzadeh-Mahani A. The care capacity goals of family carers and the role of technology in achieving them. BMC Geriatr 2020 Feb 27;20(1):52 [FREE Full text] [doi: 10.1186/s12877-020-1455-x] [Medline: 32102654]
25. Quinn CC, Staub S, Barr E, Gruber-Baldini A. Mobile support for older adults and their caregivers: dyad usability study. JMIR Aging 2019 May 23;2(1):e12276 [FREE Full text] [doi: 10.2196/12276] [Medline: 31518271]
26. Mayo-Gamble TL, Quasie-Woode D, Cunningham-Erves J, Rollins M, Schlundt D, Bonnet K, et al. Preferences for using a mobile app in sickle cell disease self-management: descriptive qualitative study. JMIR Form Res 2021 Nov 30;5(11):e28678 [FREE Full text] [doi: 10.2196/28678] [Medline: 34851295]

27. Lwin MO, Sheldenkar A, Panchapakesan C. A digital mobile community app for caregivers in Singapore: predevelopment and usability study. JMIR Nurs 2021;4(2):e25679 [FREE Full text] [doi: 10.2196/25679] [Medline: 34345796]
28. Romero-Mas M, Ramon-Aribau A, de Souza DL, Cox AM, Gómez-Zúñiga B. Improving the quality of life of family caregivers of people with Alzheimer's disease through virtual communities of practice: a quasiexperimental study. Int J Alzheimers Dis 2021;2021:8817491 [FREE Full text] [doi: 10.1155/2021/8817491] [Medline: 33884204]
29. Irizarry T, Shoemake J, Nilsen ML, Czaja S, Beach S, DeVito Dabbs A. Patient portals as a tool for health care engagement: a mixed-method study of older adults with varying levels of health literacy and prior patient portal use. J Med Internet Res 2017 Mar 30;19(3):e99 [FREE Full text] [doi: 10.2196/jmir.7099] [Medline: 28360022]
30. Melo L. Literacia em Saúde, um Desafio Emergente - O Poder e a Dimensão do Cuidador Informal no Sistema de Saúde. Coimbra, Portugal: Centro Hospitalar e Universitário de Coimbra; 2021.
31. Andrade A. A ação dos enfermeiros deve estar dirigida/centrada na capacitação do Cuidador Informal. In: Literacia em Saúde, um Desafio Emergente - O Poder e a Dimensão do Cuidador Informal no Sistema de Saúde. Coimbra, Portugal: Centro Hospitalar e Universitário; 2021:11-13.
32. Santos C. A Literacia em Saúde enquanto fator determinante para a promoção do bem-estar da pessoa cuidada. In: Literacia em Saúde, um Desafio Emergente - O Poder e a Dimensão do Cuidador Informal no Sistema de Saúde. Coimbra, Portugal: Centro Hospitalar e Universitário; 2021:9-10.
33. Digital health literacy for Europe's digital future. EuroHealthNet Annual Seminar. 2021. URL: https://eurohealthnet.eu/wp-content/uploads/publications/2022/220225_digital_health_literacy_seminar_final_event_report.pdf [accessed 2024-01-17]
34. Skills matter: additional results from the survey of adult skills. Organisation for Economic Co-operation and Development. 2019. URL: https://www.oecd.org/skills/piaac/publications/Skills_Matter_Additonal_Results_from_the_Survey_of_Adult_Skills_ENG.pdf [accessed 2024-03-25]
35. Shaffer KM, Chow PI, Cohn WF, Ingersoll KS, Ritterband LM. Informal caregivers' use of internet-based health resources: an analysis of the health information national trends survey. JMIR Aging 2018 Dec 18;1(2):e11051 [FREE Full text] [doi: 10.2196/11051] [Medline: 31518244]

Abbreviations

HL: health literacy
IC: informal caregiver
ICT: Information and Communication Technology
JBI: Joanna Briggs Institute
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis
WHO: World Health Organization

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Original Paper

Digital Adoption by an Organization Supporting Informal Caregivers During COVID-19 Pandemic Showing Impact on Service Use, Organizational Performance, and Carers' Well-Being: Retrospective Population-Based Database Study With Embedded User Survey

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Abstract

Background: The COVID-19 pandemic has catalyzed a move from face-to-face to digital delivery of services by hospitals and primary care. However, little is known about the impact of digital transformation on organizations supporting unpaid caregivers. Since the start of the COVID-19 pandemic, the value of care provided by such informal caregivers is estimated to be £111 billion (US$ 152.7 billion) in England.

Objective: This study aims to analyze service uptake patterns (including digital service options) over the pandemic period in an English caregivers' support organization covering a population of 0.98 million; measure changes in organizational performance, service efficiency, and quality; and identify the views of caregivers on service provision and future digital delivery.

Methods: This was a retrospective analysis of the use of digital versus nondigital support services (January 2019 to June 2021) by caregivers in city and rural geographic areas. We compared organizational performance and service quality indicators for 2 financial years (2019-2020 and 2020-2021). A survey was conducted to identify barriers and facilitators to digital service uptake, the computer proficiency of caregivers (the Computer Proficiency Questionnaire, 12-item version), and preferences for future digital service provision. Quantitative data were analyzed using Stata 13 (StataCorp LLC). Thematic analysis was used for open-text survey responses.

Results: The number of caregivers registered with the organization rose from 14,817 in 2019 to 20,237 in 2021. Monthly contacts rose from 1929 to 6741, with remote contacts increasing from 48.89% (943/1929) to 86.68% (5843/6741); distinctive patterns were observed for city versus rural caregivers. There was an increase in one-to-one contacts (88.8%) and caregiver assessments (20.9%), with no expansion in staffing. Service quality indicators showed an improvement in 5 of 8 variables (all $P<.05$). The 152 carers completing the survey had similar demographics to all registered caregivers. The Computer Proficiency Questionnaire, 12-item version, mean score of 25.61 (SD 4.40) indicated relatively high computer proficiency. The analysis of open-text responses identified a preference for the organization to continue to offer face-to-face services as well as web-based options. The digital services that were the most highly rated were carers’ well-being assessments, support needs checks, and peer support groups.

Conclusions: Our findings show that staff in the caregiver support organization were agile in adapting their services to digital delivery while dealing with increased numbers of registered clients and higher monthly contacts, all without obvious detriment to service quality. Caregivers indicated a preference for blended services, even while recording high computer proficiency. Considering the economic importance of unpaid caregivers, more attention should be given to organizations funded to provide support for them and to the potential for technology to enhance caregivers’ access to, and engagement with, such services.

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KEYWORDS

digital adoption; COVID-19; informal caregivers; carer support organization; organization performance; integrated care systems; care systems; health policy; aging in place; digital divide

Introduction

Background

During the COVID-19 pandemic, social distancing policies limiting physical contact transformed how people were able to access health and care services and sped up digital transformation in many sectors. In the United Kingdom, traditional hospital services rapidly moved from face-to-face to digital services, from simple websites to web-based platforms, to reduce the chance of infection transmission [1]. In primary care, general practitioners (GPs) also adopted a *digital first* approach for consultations [2]. However, how those organizations that are contracted to support unpaid caregivers adapted their services is not known [3]. Such organizations are not part of the National Health Service (NHS) but are instead contracted by local government [4]. Before the pandemic, expenditure on the services these organizations provided was reduced by 11% over the 6-year period from 2015 to 2021 [5], while 36,000 more carers were directed to their services [5]. It is recognized that unpaid carers play a crucial role in providing essential care worldwide [6]. Bearing these facts in mind, the absence of research on how these organizations moved to web-based delivery, what impact this had on service delivery, their ability to do this without affecting service quality, and the response of client caregivers are noteworthy.

Before the pandemic, an NHS report on the *Widening Digital Participation Programme* identified that organizations supporting the well-being of carers had largely been forgotten [7]. Currently, many countries are introducing policies of *active aging*, supporting older people to live independently in the community rather than entering expensive long-term residential care [8,9]. As a result, while the number of staff employed by care homes has remained unchanged from 2012 to 2022 in England, there has been a 27% increase in domiciliary care workers who support people in their own homes [10]. The pressures on unpaid carers have inevitably increased. Currently, the care provided by unpaid carers in England is estimated to be equivalent to that provided by 3.2 million full-time paid care workers [11,12], nearly 6 times the size of the paid workforce of 510,000 domiciliary care workers [13]. In addition, the continuity of care provided by family carers is becoming increasingly important in the context of a high annual turnover of domiciliary care staff (31.5% in England) [13].

Across the world, countries are developing integrated long-term care strategies to support their aging populations as recommended by the World Health Organization [14]. England has established 42 new integrated care systems (ICSs) to underpin integration between health and care services in these geographic areas [15]. Proposals for joining up care include the idea of *wrap-around services* for care recipients plus their caregivers, but there is no mention of organizations that provide support for unpaid caregivers. Although the national ICS strategy incorporated a digital plan, this currently excludes mention of organizations that support informal carers [16]. Such services are typically provided by charities or not-for-profit organizations that themselves may have limited expertise in digital transformation [17]. In this context, it is important to better understand the experiences of such carer support organizations during the pandemic and the response of the caregivers they support.

Objectives

This study aims to provide evidence to address this important research gap. The research has 3 main objectives: to analyze changes in service use patterns (including services accessed and the uptake of digital options); to assess any impact on organizational performance, service efficiency, and key quality indicators; and to identify user clients’ preference for future digital services.

Methods

Overview

We analyzed data collected by an organization providing support for 20,237 caregivers, covering city and rural geographic areas. Data were downloaded and fully anonymized. The uptake of digital and traditional services was examined over a 30-month period from January 2019 (before the pandemic) to June 2021 (after COVID-19–related restrictions were lifted). Service-level performance and proxy quality indicators were constructed and compared for the prepandemic financial year (2019-2020) and through the following initial lockdowns (2020-2021). The analysis of a user feedback survey undertaken at the end of this period (September 2021) explored barriers and facilitators to digital service uptake, the computer proficiency of caregivers, and views on future digital service provision. The organization’s digital preparedness before the pandemic was assessed.

Ethical Considerations

This retrospective study using fully anonymized existing data received ethics approval from the Coventry University Ethics service (P163079).

Organizational Setting

The study was undertaken at the Carers Trust Heart of England (CTHE). The organization operates in the complex UK sector that provides support for unpaid carers [4]. The CTHE is contracted to provide carer assessments and caregiver well-being services in 2 separate geographic areas: city area (Coventry) and rural area (Warwickshire, including towns and villages). The 2 areas have a total population of 0.98 million, and they are covered by a single ICS. Services provided include an assessment of a caregiver's needs, information on health and care services, benefit entitlement, assistive technologies, and peer support. Before the pandemic, the CTHE had made a number of changes to its IT systems, moving everything to a single cloud platform so that databases could be accessed from anywhere. Laptop computers and mobile phones had been provided to all frontline staff, all of which greatly facilitated home working. Job descriptions were also adapted to mention hybrid working. Throughout the observation period, the number of CTHE staff providing direct support to adult carers remained relatively constant at 14 well-being advisers, 3 administrators, 3 specialist roles (ethnic minority support worker, mental health worker, and carer trainer), and a manager for each area. A separate team provided support for young carers; this activity was excluded from our study. The CTHE is a member of a network of 124 Carers Trust partners across England, Scotland, and Wales. Members work within a national framework of policies, procedures, and internal quality assurance programs.

Longitudinal Data and Analysis

Overview

CTHE staff downloaded select activity data routinely collected for adult carers registered with the service (Multimedia Appendix 1). Young carers (aged <18 y) were excluded. Data were fully anonymized before being provided to the research team for analysis. Data cleaning and analysis were conducted on the imported raw data using reproducible coding files. Statistical analysis used Stata 13 (StataCorp LLC). The hypothesis was that there would be an increase in the use of web-based methods, although it was unclear whether digital levels would be sustained, what the impact on service delivery levels and quality would be, or what views client carers might have on a future digital service.

Service Use Patterns

Descriptive statistics were used to examine service use patterns and changes in the means of accessing services (ie, in person vs digital) [18]. Monthly contacts handled by the service were the primary variable used to explore use patterns over the 30-month period (January 2019 to June 2021). This covered two 15-month pre- and postpandemic periods, with the first national lockdown occurring midway in March 2020. The levels of service use by city versus rural carers were examined, together with the primary reasons for contacting the CTHE.

Service Performance Levels and Quality Indicators

Four key activity measures reported to commissioners each financial year were extracted from the data downloads. These included the number of carers supported, the number of one-to-one contacts, the number of carers' assessments completed, and numbers of carers attending group activities. The CTHE also collected structured feedback from the client after every contact (Multimedia Appendix 1). Five proxy quality indicators routinely reported to the funder were also extracted. A further 3 proxy quality indicators were constructed from the raw data to identify whether a contact had *reduced stress*, *increased control of personal life*, or *increased confidence*. Changes in all 8 quality indicators were compared for the 2 financial years 2019-2020 and 2020-2021, with P values for percentage changes estimated using the Pearson chi-square test of association between the characteristic variables and the corresponding totals [19].

Survey of Client Caregivers

Registered adult carers were invited by the CTHE to complete a feedback questionnaire in September 2021 to review provision and help plan future services (Multimedia Appendix 2). Responses were fully anonymized before being provided to the research team, with a minimum target of 60 responses set for analysis. Closed questions requested information on the use of digital services, barriers and facilitators to access, and satisfaction with the services accessed, while open-text comment boxes enabled people to expand on their responses. Respondents were also invited to complete the Computer Proficiency Questionnaire, 12-item version (CPQ-12) to assess their computer proficiency [20]. As well as being made available on the web, feedback questionnaires were also mailed by the CTHE to carers. The characteristics of respondents were compared to those of adult carers on the register where possible. Open-text responses were analyzed for content using thematic analysis and cross-referenced to gain an understanding of the underlying reasoning behind the views expressed [21].

Results

Longitudinal Data Analysis

Registered Carer Characteristics

Data on registered carers (Multimedia Appendix 1) were analyzed over the 30-month period from January 2019 to July 2021. During this time, the total number of carers registered with the organization increased from 14,817 to 20,237 (Table 1). Those living in the rural area rose from 1685 to 4778 (183.6% increase), while those in the city showed a more modest rise from 13,132 to 15,459 (17.7% increase). Overall, the proportion of rural caregivers increased from 1 in 10 (1685/14,817, 11.37%) to 1 in 4 (4778/20,237, 23.61%).

Table 1. Demographics of registered caregivers and survey respondents.

Characteristics	Caregivers, n (%)
Rural caregivers	
January 2019[a]	1685 (11.37)
January 2020[b]	3035 (17.63)
July 2021[c]	4778 (23.61)
Registered caregivers (n=17,641; March 2020)[d]	
Race and ethnicity	
Black (Caribbean or African)	406 (2.3)
South Asian	2382 (13.5)
White	13,972 (79.2)
Sex (female)	11,467 (65)
Aged ≥65 years	9067 (51.4)
Employment status	
Retired or gave up work to care	7868 (44.59)
Working or in training	3369 (19.1)
Unemployed	1270 (7.2)
Survey respondents (n=152; September 2021)	
Rural caregivers[e]	80 (56.3)
Sex (female)	97 (63.8)
Employment status	
Retired or gave up work to care[f]	33 (59)
Working or in training[f]	18 (32)
Unemployed[f]	2 (3)

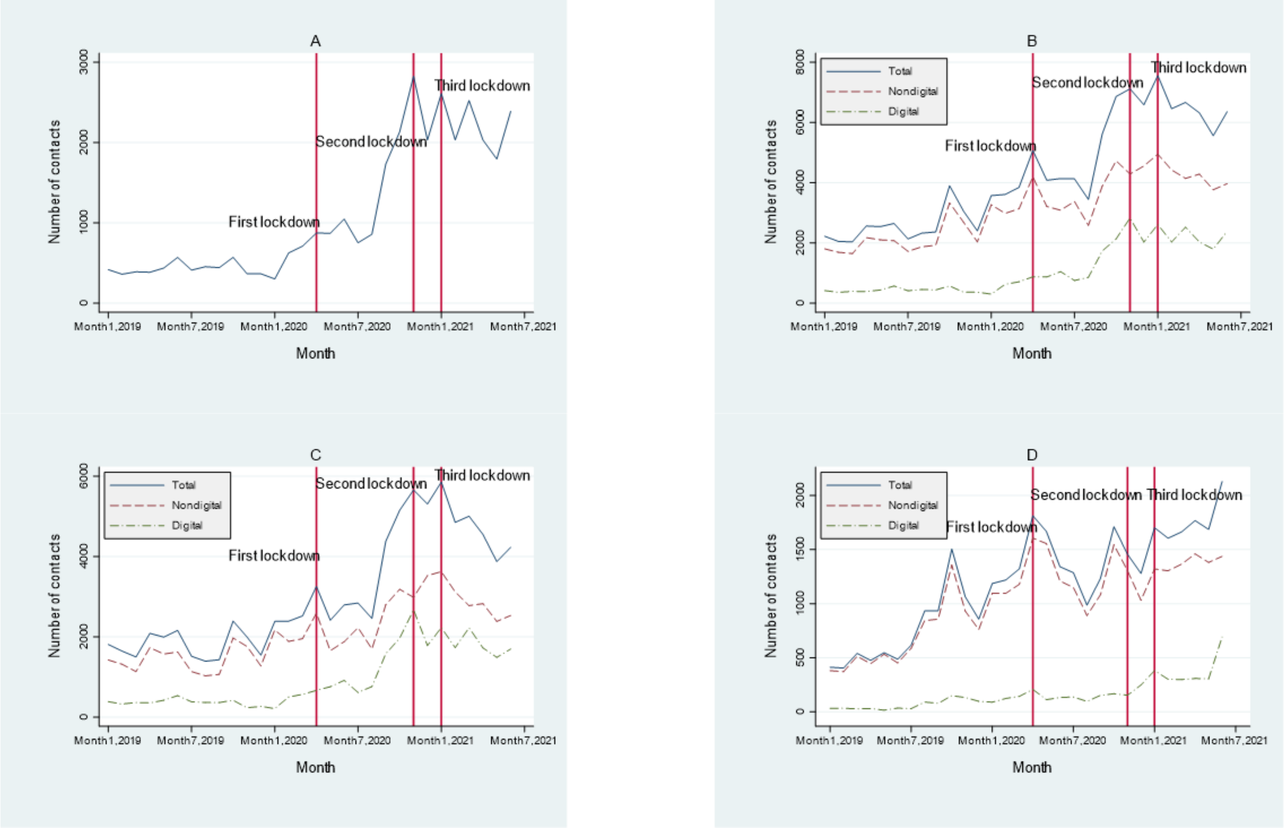
[a] Total registered carers: 14,817.
[b] Total registered carers: 17,246.
[c] Total registered carers: 20,237.
[d] Midway through the study period.
[e] 142 respondents provided information on their location.
[f] 56 respondents provided information on their employment status.

The demographic characteristics of registered carers were analyzed based on data recorded midway through the observation period from January 2019 to March 2020 (Table 1). The age and sex breakdown is comparable to national figures for carers [12]. Two-thirds (11,467/17,641, 65%) of the respondents were female carers; approximately half (9067/17,641, 51.4%) were aged ≥65 years; and over three-quarters (13,972/17,641, 79.2%) were White. In terms of their employment status, nearly half (7868/17,641, 44.59%), the largest group, were retired or had given up work to care, with only 1 in every 5 (3369/17,641, 19.1%) working or in training.

Service Use Patterns

Over the 30-month period (January 2019 to July 2021), digital services were provided alongside face-to-face services. The former included the use of email, SMS text messaging, Zoom, WhatsApp, and Microsoft Teams, as well as web-based group sessions. Use patterns were analyzed over time (Figure 1). The 3 vertical lines indicate the time points at which major national COVID-19–related restrictions were applied (ie, lockdown periods). From 2019 to 2021, monthly carer contacts with the well-being support service rose from 1929 to 6741, with telephone contacts rising from 818 to 3071 per month, and digital contacts from 125 to 2772 per month. A separate analysis of digital contacts during this period (Figure 1A) shows that, alongside a near–5-fold overall increase in the monthly rate, there were peaks coinciding with the national lockdowns. A separate analysis of digital versus nondigital contacts (Figure 1B) uncovers a clear change in the balance between the two, with digital contacts rising from 6.48% (125/1929) to 41.12% (2772/6741) of all contacts by the end of the period.

Figure 1. Number and types of contacts. (A) Digital contacts (all carers). (B) Breakdown of digital and nondigital contacts (all carers). (C) City carers (breakdown of digital and nondigital contacts). (D) Rural carers (breakdown of digital and nondigital contacts).

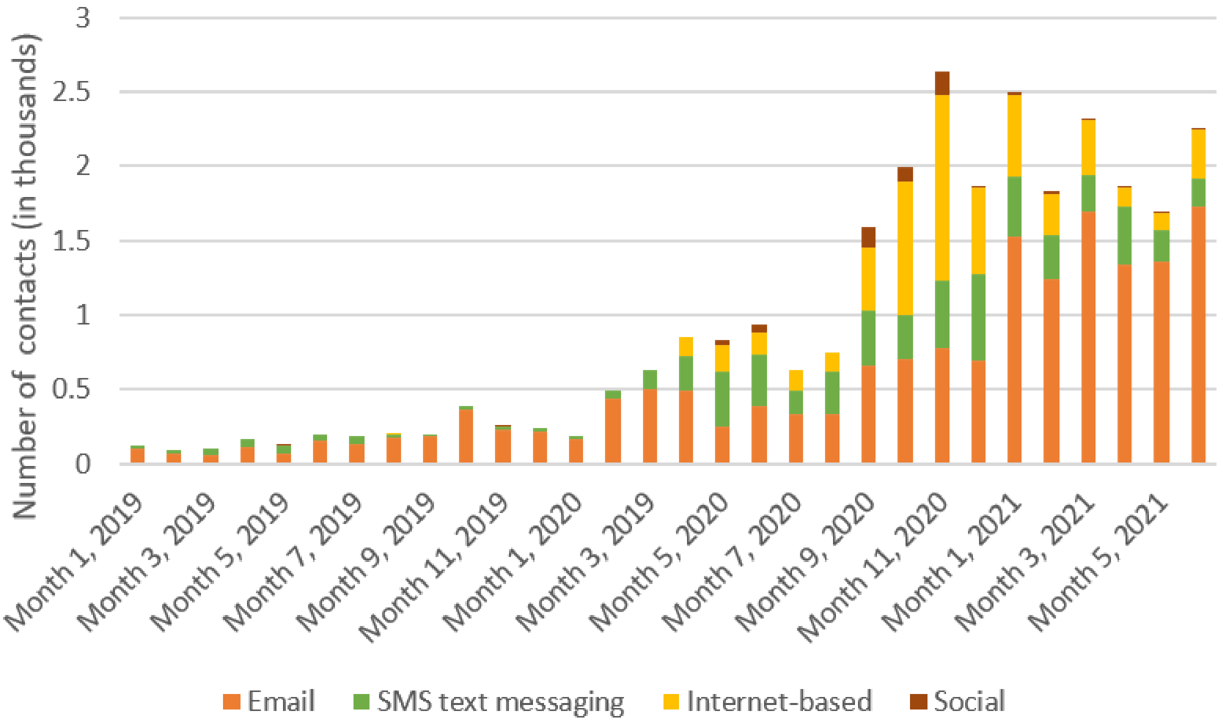


A separate examination of rural and city caregivers uncovers distinctly different patterns. For city carers (Figure 1C), digital contacts started to climb steadily from the start of the pandemic, almost reaching parity with face-to-face contacts around the time of the second lockdown. They then started to tail off toward the end of the 30-month observation period. Rural carers (Figure 1D) demonstrated a much slower initial uptake, with the rate of digital adoption only really starting to pick up after the second and third lockdowns. However, unlike in the case of city carers, rates were continuing to rise at the end of the observation period.

Types of Digital Contacts Used

Digital contacts were categorized into 4 broad groups. Two represented more flexible asynchronous methods (ie, email and SMS text messaging), whereas 2 represented fixed-time synchronous methods (ie, internet-based communication using Zoom, WhatsApp, and Microsoft Teams) and social digital group activities. Before the pandemic, only asynchronous methods were used, and rates were very low (Figure 2). With the first national lockdown (month 15), the use of other digital methods started to be added. Over time, the use of internet-based communication increased, overtaking SMS text messaging, although email remained the principal form of contact. “Social” groups were the least used form of digital contact used, possibly due to greater difficulties in arranging and delivering these. Their use peaked between September 2020 and January 2021 (ie, between the second and third lockdowns).

Figure 2. Number of digital contacts per month versus type of remote access.

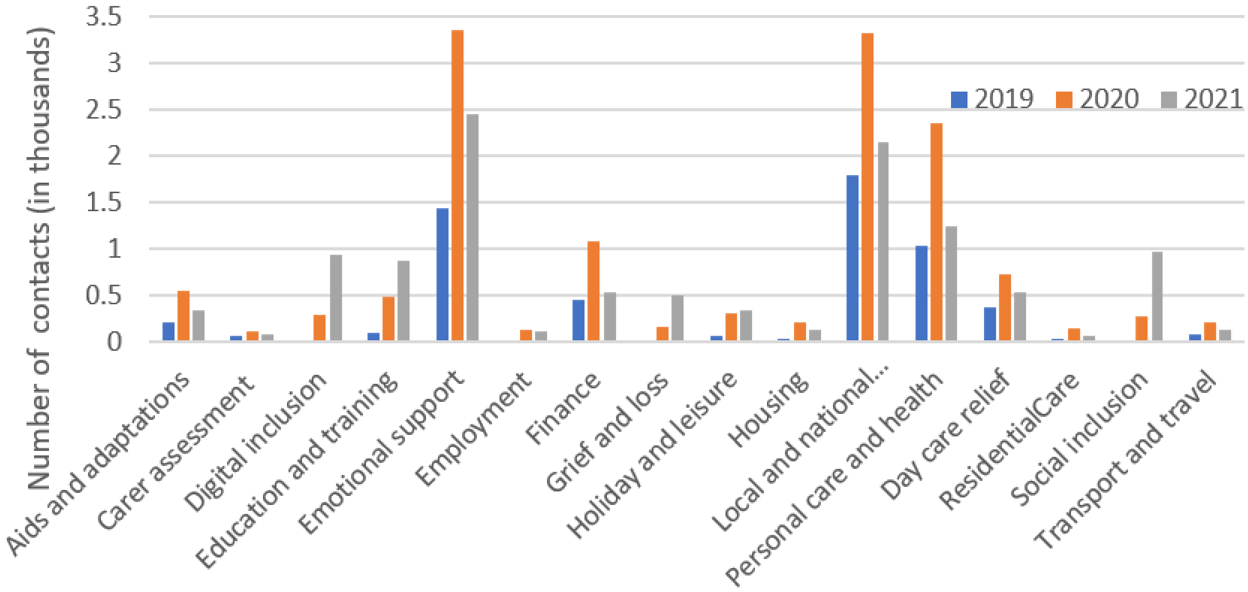


Types of Services Accessed

Well-being services available to carers at the start of the pandemic were mostly delivered via carers center appointments, home visits, and various outreach activities. During the pandemic, carers center appointments ceased after the first lockdown, with home visits and outreach activities significantly reduced. The well-being services provided were information and advice on aids and adaptations, carers' assessment, education and training (including digital), emotional support, local and national health and social care services, personal care and health, residential care and day care (for cared-for persons), and social inclusion and interests (including links to local and national groups). Other services included peer support and emergency planning. During the pandemic, additional services were introduced to address specific needs: a *grief and loss* service, *employment support* working collaboratively with employers, and *finance support* to reduce carer hardship.

Analysis of the reasons for contacting the well-being service over the 3-year period from 2019 to 2021 indicated that, irrespective of the year, the 3 most common reasons were *emotional support*, *local and national information*, and *personal care and health* (Figure 3). All 3 reasons peaked in 2020 (early pandemic period), as did information on *day care relief* and *aids and adaptations*. Advice related to *digital inclusion* and *social inclusion* were unusual in showing a steep rise in the final 6 months, from a base where both were 0 in 2019. *Education and training* showed a similar pattern, possibly partly related to digital training needs. The most frequently new service accessed was *finance*, with the *grief and loss* service reaching a similar level in the final 6 months.

Figure 3. Pattern of carer support services contacted over time.



Service Performance and Quality

Activity levels demonstrated an increase of 88.8% over 2 years in the numbers of one-to-one contacts and an increase of 20.9% in individual carer assessments (Table 2). At the same time, there was a decrease of 70.6% in numbers attending group activities. Among the 5 proxy quality indicators routinely reported to the funder, those critical to well-being all showed an improvement (ie, *feeling less alone*, *making it easier to cope with caring role*, and *helping improve physical health*), as did the extra 3 indicators constructed (ie, *reduced stress*, *increased control of personal life*, and *increased confidence*). Improvements ranged from 13% for reduced stress (*P*=.001) to 1% for others (*P*>.05). The only measure to show a significant decrease was *help dealing with health and social care professionals* (*P*=.001). This may, in part, be due to pressures experienced by health and social care staff during the pandemic.

Table 2. Change in carer contact type and quality indicators (from 2019-2020 to 2020-2021).

	2019-2020	2020-2021	Change (%)	*P* value[a]
Carer contact type				
One-to-one contacts with carers, n	7344	13,868	+88.8	<.001
Carers supported on one-to-one basis, n	3021	4463	+47.7	<.001
Carer assessments completed, n	234	283	+20.9	.03
Carers attending group activities, n	670	197	−70.6	<.001
Registered caregivers, n	14,817[b]	17,641[c]	+19.1	N/A[d]
Benefits reported after contact				
Helped me feel less alone in my caring role				
Contacts, n	2249	5217	+131.0	<.001
Contacts (%)	33	36	+9.0	N/A
Caregivers expressing this, n	1134	2410	+112.5	<.001
Helped me reduce my stress				
Contacts, n	1771	4378	+147.2	<.001
Contacts (%)	18	31	+72.2	N/A
Caregivers expressing this, n	948	2410	+154.2	<.001
Made it easier to cope with my caring role				
Contacts, n	825	1319	+59.9	<.001
Contacts (%)	8	9	+12.5	N/A
Caregivers expressing this, n	597	879	+47.2	.95
Helped me improve my physical health				
Contacts, n	465	1278	+174.8	<.001
Contacts (%)	5	9	+80.0	N/A
Caregivers expressing this, n	293	660	+125.3	<.001
Helped me improve my financial position				
Contacts, n	692	804	+16.2	<.001
Contacts (%)	7	6	−14.3	N/A
Caregivers expressing this, n	469	513	+9.4	<.001
Helped me deal with health and social care professionals				
Contacts, n	342	250	−26.9	<.001
Contacts (%)	3	2	−33.3	N/A
Caregivers expressing this, n	230	174	−24.3	<.001
Helped me increase control of my personal life				
Contacts, n	305	638	+109.2	.15
Contacts (%)	3	4	+33.3	N/A
Caregivers expressing this, n	218	350	+60.6	.35
Helped me increase my confidence				
Contacts, n	205	417	+103.4	.39
Contacts (%)	2	3	+50.0	N/A
Caregivers expressing this, n	144	272	+89.9	.02

[a] Pearson chi-square test.

[b] January 2019.

[c] March 2020.

[d] N/A: not applicable.

Survey of Client Caregivers

Respondents

A total of 152 caregivers completed the survey. Personal characteristics (age and sex) were largely comparable to those of all caregivers registered with the CTHE (Table 1). Ethnicity was not recorded in the survey. In terms of employment, the 2 largest groups were those who had retired or people who had given up work to care and those in work or training. The survey respondents included a higher percentage of rural caregivers than the carer register (85/142, 59.9% vs 4778/20,237, 23.61%); of the 152 respondents, 10 (6.6%) did not provide information on their location. Information provided in the survey showed that nearly half of these respondents (70/152, 46.1%) were caring for a husband, wife, or partner and 27.6% (42/152) for a parent, whereas the remaining 26.3% (40/152) had *another relationship*. Nearly one-third (41/148, 27.7%) of people providing more detailed information were caring for someone who was living on their own, and in 78.9% (112/142) of responses, care was provided solely by the unpaid caregiver. Where there was access to support from domiciliary carers, this averaged 19.5 (SD 30.7; range 2-40) hours per week. The CPQ-12 Questionnaire was completed by 94 (61.8%) of the 152 respondents. Respondents achieved a mean score of 25.61 (SD 4.40), with city and rural carers exhibiting similar proficiencies (Multimedia Appendix 3 [20,22]).

Prepandemic Use of Services and Main Barriers

Historically, respondents reported using a broad range of services (Table 3). Reasons for not accessing a particular service were provided by 82.2% (125/152) of the respondents; the remainder (27/152, 17.8%) reported only registering with the CTHE after the first lockdown. Two barriers to use were timing and travel distances, but far more respondents, from 28.6% (30/105) to 39.6% (40/101), perceived lack of awareness of a service as a barrier to its use. A further 33% (30/90) to 44.6% (45/101) stated that, before the pandemic, they had no need for a particular service. During the pandemic, some respondents had stopped using community outreach sites (14/114, 12.3%) and carers centers (19/114, 16.7%); a very small percentage (from 2/114, 1.8% to 4/114, 3.5%) had started to use these services. With cessation of home visits, 21.9% (25/114) reported that they had started to use telephone support during the pandemic.

Table 3. Carers' use of services before the pandemic and perceived barriers to use.

Service	Used 1-12 times (2019), n/N (%)	Barriers to use of a service, n/N (%)			
		Timing not suitable	Too far to travel	Not aware of service	Not needed
Carers center (drop-in visit)	23/116 (19.8)	12/105 (11.4)	5/105 (4.8)	30/105 (28.6)	37/105 (35.2)
Carers center (appointment visit)	16/117 (13.7)	8/101 (7.9)	5/101 (5)	32/101 (31.7)	42/101 (41.6)
Home visits	16/112 (14.3)	9/101 (8.9)	2/101 (2)	30/101 (29.7)	45/101 (44.6)
Outreach (eg, community site)	14/114 (12.3)	4/101 (4)	5/101 (5)	40/101 (39.6)	36/101 (35.6)
Telephone support	48/122 (39.3)	4/88 (4.5)	0/88 (0)	28/88 (31.8)	34/88 (38.6)
Group activities	34/121 (28.1)	11/90 (12.2)	7/90 (7.8)	26/90 (28.9)	30/90 (33.3)

Which Digital Services Were Used During the Pandemic?

Three-quarters (114/152, 75%) of the respondents identified (from a predefined list) which digital support services they used during the pandemic. Email (58/114, 50.9%), Zoom or Microsoft Teams (32/114, 28.1%), and WhatsApp, SMS text messaging, or video (10/114, 8.8%) were most commonly used, mirroring data presented in Figure 2. No respondent had used Skype or FaceTime. The most valued digital support services were carers' well-being assessments, support needs checks, and peer support groups. When asked to indicate which web-based group activities they had experienced (respondents could tick as many as appropriate), 28.8% (34/118) replied. Those carers who provided a response most frequently accessed web-based training and resilience courses (14/24, 58%), virtual yoga sessions or quizzes (10/23, 43%), virtual cafes (9/22, 40%), and "carers evening chat" (4/16, 25%).

A total of 102 comments were entered by participants. These were analyzed for thematic content and commonalities. Three superordinate themes were identified (Textbox 1). These included 8 subthemes (2-3 subthemes emerged for each superordinate theme). A selection of comments relating to each subtheme were extracted. The first theme, how to help carers use digital services in the future, highlighted aspects such as a need for more publicity, activities provided at different times and in different formats, and technical help for persons who are digitally excluded. The second theme, offering a selection of well-being services, contained 2 strong subthemes. One was the view that digital services are invaluable and the second was that face-to-face services are essential for certain functions and for those who are digitally excluded because of their age or for financial reasons. The third and final theme emerging from users was the need to tailor future digital services to meet individual caregivers' needs. This might include, for example, not only addressing the practical elements of caring or issues of isolation and confidentiality but also acknowledging that "people need more than their problems fixing" and not losing the personal service previously provided, which is highly valued.

Textbox 1. Themes from qualitative analysis of responses.

Theme 1: things to help me use digital services in future

- The need for more publicity and better communications
- “I was not aware of the online services, more information/publicity would be helpful.”
- “Better information of services you can use.”
- “Old fashioned ‘come join us’ flyer through the post. My elderly parents need constant encouragement and they don’t read emails and my repeating them...or reading them out does not have the same impact.”
- Technical help and digital inclusion
- “[C]an’t use a computer, [need] help to set up Zoom.”
- “I am not comfortable using online services.”
- “Not everyone is online so cannot avail themselves to online forums...also the cost of broadband needed to use Zoom etc. which requires higher speed etc. is quite prohibitive if you are living on a fixed income.”
- Activities at different times and in different formats
- “They just don’t fit in as they are at times when I’m caring for my mother.”
- “Due to work pattern [I am] not always available.”
- “A wider range of subjects for the online service. Perhaps short podcasts of interesting places in the world e.g. videos of museums around the world or tourist destinations or cultures and traditions or other countries.”
- “A blend of online and face-to-face better. Also, a brief catch-up call if you can’t make a session as guilt can set in for me if I’m overloaded and I feel unable to continue.”

Theme 2: offering a selection of well-being services, including on the web

- Web-based services are invaluable
- “Online saves time travelling and you can access it whilst still caring for the patient in your own home.”
- “Living through COVID has been like being relocated to the moon, no contact with anyone. At a time when in person is still beset with logistical problems the online equivalent is a lifeline.”
- Face-to-face services still necessary
- “It (digital) was a necessary substitute during lockdown but nothing replaces face-to-face interaction.”
- “Nothing is as helpful as face-to-face help, especially where counselling and support services are concerned. Many carers, especially those caring for someone with dementia are elderly and not used to computers.”

Theme 3: tailoring future services

- Practical elements of caring
- “A list of possible areas to look at and their contact details e.g. home cleaners, meals on wheels etc.”
- “I have as a parent, many worries about what will happen when I can’t ‘go on’...Legal advice for preparations for the outcome.”
- “Recommended places approved by members experiences. Where to get...Equipment, grants assistance etc. positive recommendations for work carried out for adaptations by local companies.”
- Addressing isolation and confidentiality
- “I feel very isolated as a carer and being able to go to meetings/events/social gathering and see and speak to people normally I feel is very important, both for me as a carer, and my husband who has mixed dementia.”
- “I feel it is of great importance that you can discuss on a one-to-one level in person or telephone on the day. Not every carer can talk freely about what is going on for themselves and especially if the cared for is listening.”
- Addressing changing times and loss of personal service
- “Go back 15 years and the carers center was a place where you could turn up to have a chat with whoever was on the desk. With the move to the library the feel changed— interactions more like ‘please state the nature of your problem’ than ‘how are you, how are things going?’ People need more than their problems fixing...it is more the emotional and community support. That’s it—emotional support as well as practical support.”

Discussion

Principal Findings

To our knowledge, this is the first large-scale study to analyze the impact of the COVID-19 pandemic on the provision of well-being services for unpaid caregivers. The longitudinal analysis of >20,000 rural and city carers identified, as expected, a move away from face-to-face to web-based service access. The shift observed mirrors those reported by researchers for other services during the pandemic, such as GP practices [2]. However, over the period from January 2019 to June 2021, the number of monthly contacts handled by the carer support organization more than tripled, with no significant changes in staffing levels. Before the pandemic, digital contacts were exclusively by email or SMS text messaging. During the pandemic, additional options were introduced, including Zoom, WhatsApp, and Microsoft Teams, with new web-based group sessions also offered to carers.

Within the context of a 37% increase in the number of carers registered, the organization managed to increase the number of one-to-one contacts by 88.8%. This increase was particularly evident in rural areas, with the ratio of such carers on the register rising from 1 in 10 carers to 1 in 4 carers by the end of the observation period. Rural carers demonstrated slightly different behaviors, showing much slower initial digital adoption rates. In terms of carers' rating of the service received, 6 of the 8 quality indicators showed an improvement, and the other two showed only a minor, nonsignificant decrease. The largest improvement was observed in reduced stress, consistent with the findings of a systematic review of caregiver web-based interventions [23]. Our survey identified a high level of computer proficiency among carers, at or above that reported for other older populations [20,22]. Even so, respondents expressed a preference for the organization to continue to offer face-to-face services as well as web-based options to meet a carer's preferences and the type of well-being support required.

Comparison With Prior Work

Before the pandemic, researchers reported that the uptake of web-based services by older adults in the United Kingdom remained relatively low, despite their potential benefits [24]. A European examination of web-based services available to support informal carers also found a lack of reliability and usability [25]. A qualitative study of the views of caregivers on suitable technologies to assist their caregiving identified similar themes to this larger study, in particular that digital technology needs to be tailored to users' needs in order to ensure adoption [26]. Although it is acknowledged that there may be a huge potential to use such tools to support unpaid carers, it is recognized that wholesale adoption may risk inadvertently exacerbating existing support through digital exclusion [27]; for example, the testing of digital tools in a real-world setting has identified a *digital inverse care law*, with those most in need of support least likely to engage with digital health platforms [28]. In addition, a review of eHealth interventions to support caregivers of older adults also highlights the importance of using appropriate language and text, as well as helping caregivers learn how to use the intervention [29].

Our research shows that, during a crisis such as the COVID-19 pandemic, an organization providing support for the well-being of caregivers was able to successfully implement remote service provision using a mix of traditional and digital tools without a detrimental impact on the reported quality of individual contacts and in the context of an increased workload. Systematic reviews of internet-based interventions to support caregivers have to date reported mixed results and called for more high-quality studies [30,31]. A recent review of factors influencing the implementation of eHealth to support informal care found a gap in knowledge regarding success factors and limited focus on the well-being of the unpaid carer, with the focus being principally on the person receiving care [32]. Similarly, studies of telecare that focus on conditions such as dementia usually do not differentiate the caregivers' needs, instead usually considering the caregiver and the older person or care recipient as a dyad [33-35]. Early in the pandemic, there were some calls to move "carers from the back of the queue" when considering digital services [36]. However, a recent research study of digital interventions for carers of people with dementia still considers need in terms of the dyad, with caregivers in a secondary role [37]. In the United Kingdom, the 2019 report for government on preparing the health care workforce for the digital future recommended that the NHS should work with carer organizations to prioritize the education of patients and caregivers alongside the health care workforce [38].

It is important to consider the indicator that showed a significant deterioration in our study. This was associated with support in accessing health care and social care services, both presumably disrupted by the COVID-19 pandemic. A review of carer support has identified that the ability to coordinate access to such services is particularly valuable, with the integration of home care and community care able to improve outcomes for older people [39,40]. This seems to be particularly important for carers of people with a mental health condition [41]. In Australia, the integration of digital care and clinical care is being assessed to coordinate mental health teams, caregivers, and service users as active partners [42]. The potential for appropriate digital technology to provide support and reassurance is recognized as a benefit for both the caregiver and the person for whom they care [43]. In some parts of the world, volunteers are also being integrated into care to help caregivers use custom-built apps [44].

Investment in innovation to provide optimum support services for informal caregivers could be highly cost-effective. The workforce of unpaid carers represents approximately 6% of the UK population and, together with the 1.3 million registered carers who receive a small carer's allowance, informal caregivers are widely acknowledged as a crucial component in care delivery [12,45]. Furthermore, since the start of the pandemic, the value of unpaid care provided in England is estimated to be £111 billion (US$ 152.7 billion) [46] and in the United States >US $450 billion annually [47]. The UK government has recently set out a range of policies aimed at empowering unpaid carers, with a dedicated, although small, £25 million (US $26.72 million) budget for this purpose [46]. The danger is that the initiatives will once again focus on caregivers rather the sector that supports them. Thus, the opportunity to integrate organizations such as the one in this study into the wider community-based care system will be missed. This study also questions the stereotype of low digital capability among older carers, with CPQ-12 scores demonstrating high computer proficiency. Even so, survey responses indicate that large-scale naïve digital transformation is unlikely to be effective. Instead of a “one-size-fits-all” approach, there is a need for person-centered support (face-to-face as well as web-based options) as part of the service, together with training for those who need it. Meanwhile, there are emerging indications of a move toward providing solely web-based support, with some suppliers looking ahead to younger and more digitally engaged carers who are assumed not to require face-to-face services [48]. The lower cost of web-based support services may make this seem an attractive option for commissioners in the United Kingdom. A similar situation has occurred in primary care with disruptive innovators entering the NHS market to provide web-based GP services, with the evaluation reporting mixed findings and providers withdrawing from some NHS contracts [49]. For any caregiver support service evaluation, as well as delivery costs, there will need to be a careful consideration of utility (ie, quality and effectiveness from the user perspective) [50]. Although this study was set in England, the findings will be relevant for other countries where digital services to support the well-being of informal caregivers are in use or are being developed.

Limitations

There are a number of limitations to this study that need to be acknowledged. First, it is unclear how representative, in terms of its digital readiness, the organization studied is of the whole sector. There are no national audits of such carer support organizations, although it is known that >60% of care homes still use internet connections that will not support full digital transformation [16]. Second, the cohort excluded young carers, which inevitably limits generalizability to the wider population of carers [51]. In addition, an important subgroup (working caregivers) could not be identified due to limitations in the data. A quarter of older workers in England currently have caring responsibilities, and this percentage is expected to increase as the population ages [52]. Third and last, although we identified a high level of computer proficiency in survey respondents, this may not be fully representative because most of the respondents (136/152, 89.5%) completed the survey on the web. Further research is needed to provide evidence on these subgroups before drawing any final conclusions about web-based support services.

Conclusions

Looking to the future, the integration of health care and care services to meet the complex care needs of a country’s aging population is recognized as a global challenge [53]. Considering the importance of unpaid carers, more attention needs to be given in all national strategies to organizations that support this important *free* workforce. Our study highlights a number of issues worthy of further consideration and study that have implications for the design of future cost-effective digital initiatives. These include the lack of any audits of the digital readiness of organizations that provide support for caregivers; the need for a better understanding of rural carers; evidence of the cost-effectiveness as well as the use of different forms of support for caregivers; and the potential for collaboration among different partners within ICSs to better support unpaid caregivers, enhancing their access to, and engagement with, support services after the COVID-19 pandemic.

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Authors' Contributions

MC and SW developed the original concept. MC, DW, and AS jointly developed the analysis plan for the study. AJK and SN undertook data analyses. AS wrote the first draft of the article, and all authors critically revised the paper for important aspects. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Metrics and outcomes recorded for adult carers registered with the well-being service.
[DOCX File , 21 KB - aging_v7i1e46414_app1.docx]

Multimedia Appendix 2
Caregivers’ feedback questionnaire.
[PDF File (Adobe PDF File), 242 KB - aging_v7i1e46414_app2.pdf]

Multimedia Appendix 3
Computer Proficiency Questionnaire, 12-item.
[DOCX File , 18 KB - aging_v7i1e46414_app3.docx]

References

1. Webster P. Virtual health care in the era of COVID-19. Lancet 2020 Apr 11;395(10231):1180-1181 [FREE Full text] [doi: 10.1016/S0140-6736(20)30818-7] [Medline: 32278374]
2. Access to GP appointments and services. Nuffield Trust. 2023 Dec 14. URL: https://www.nuffieldtrust.org.uk/resource/access-to-gp-services [accessed 2024-03-06]
3. Chan EY, Gobat N, Kim JH, Newnham EA, Huang Z, Hung H, et al. Informal home care providers: the forgotten health-care workers during the COVID-19 pandemic. The Lancet 2020 Jun;395(10242):1957-1959 [FREE Full text] [doi: 10.1016/s0140-6736(20)31254-x]
4. Fenney D, Thorstensen-Woll C, Bottery S. Caring in a complex world: perspectives from unpaid carers and the organisations that support them. The King's Fund. 2023 May 26. URL: https://www.kingsfund.org.uk/publications/unpaid-carers-caring-complex-world [accessed 2023-07-17]
5. Paddison C, Crellin N. Falling short How far have we come in improving support for unpaid carers in England? Nuffield Trust. 2022 Oct. URL: https://www.nuffieldtrust.org.uk/files/2022-10/nuffield-trust-unpaid-carers-web-final.pdf [accessed 2022-10-15]
6. Cotis JP. Population ageing: facing the challenge: ageing will make it hard for governments to deal with mounting financial pressures. It may be time to rethink our policies towards work. OECD Publications and Information Centre. 2003 Sep. URL: https://go.gale.com/ps/i.do?id=GALE%7CA110739426&sid=googleScholar&v=2.1&it=r&linkaccess=abs&issn=00297054&p=AONE&sw=w&userGroupName=anon%7E2e3388c9&aty=open-web-entry [accessed 2020-10-15]
7. Stone E, Nuckley P, Shapiro R. Digital inclusion in health and care: lessons learned from the NHS widening digital participation programme (2017-2020). Social Care Institute for Excellence. 2020. URL: https://www.goodthingsfoundation.org/wp-content/uploads/2021/04/DigitalInclusioninHealthandCare-LessonslearnedfromtheNHSWideningDigitalParticipationProgramme2017-2020.pdf [accessed 2024-03-06]
8. Walker A. Commentary: the emergence and application of active aging in Europe. J Aging Soc Policy 2009;21(1):75-93. [doi: 10.1080/08959420802529986] [Medline: 19197609]
9. Aging in place: growing older at home. National Institutes of Health National Institute on Aging. URL: https://www.nia.nih.gov/health/aging-place/aging-place-growing-older-home#:~:text=Staying%20in%20your%20own%20home,requires%20careful%20consideration%20and%20planning [accessed 2024-03-05]
10. The state of the adult social care sector and workforce in England. Skills for Care. URL: https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx [accessed 2022-11-09]
11. Bottery S, Ward D. Social care 360. The King's Fund. 2021 May. URL: https://assets.kingsfund.org.uk/f/256914/x/609306b60e/social_care_360_2021.pdf [accessed 2023-06-20]
12. Foley N, Powell A, Kennedy S, Powell T, Roberts N, Harker R, et al. Informal carers. House of Commons Library, United Kingdom Government. URL: https://researchbriefings.files.parliament.uk/documents/CBP-7756/CBP-7756.pdf [accessed 2021-10-24]
13. Domiciliary care services in the adult social care sector. Skills for Care. URL: https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/Summary-of-domiciliary-care-services-2022.pdf [accessed 2022-06-15]
14. Rudnicka E, Napierała P, Podfigurna A, Męczekalski B, Smolarczyk R, Grymowicz M. The World Health Organization (WHO) approach to healthy ageing. Maturitas 2020 Sep;139:6-11 [FREE Full text] [doi: 10.1016/j.maturitas.2020.05.018] [Medline: 32747042]
15. Joining up care for people, places and populations. Department of Health and Social Care, United Kingdom Government. 2022 Feb 9. URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1055688/joining-up-care-for-people-places-and-populations-print-version.pdf [accessed 2022-03-09]
16. A plan for digital health and social care. United Kingdom Government. 2022 Jun 29. URL: https://www.gov.uk/government/publications/a-plan-for-digital-health-and-social-care/a-plan-for-digital-health-and-social-care [accessed 2024-03-06]

17. Support where you live. Carers UK. URL: https://www.carersuk.org/help-and-advice/get-support/local-support [accessed 2022-10-10]
18. Cooksey RW. Descriptive statistics for summarising data. In: Illustrating Statistical Procedures: Finding Meaning in Quantitative Data. Singapore, Singapore: Springer; 2020:61-139.
19. McHugh ML. The chi-square test of independence. Biochem Med (Zagreb) 2013;23(2):143-149 [FREE Full text] [doi: 10.11613/bm.2013.018] [Medline: 23894860]
20. Boot WR, Charness N, Czaja SJ, Sharit J, Rogers WA, Fisk AD, et al. Computer proficiency questionnaire: assessing low and high computer proficient seniors. Gerontologist 2015 Jun;55(3):404-411 [FREE Full text] [doi: 10.1093/geront/gnt117] [Medline: 24107443]
21. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs Health Sci 2013 Sep;15(3):398-405. [doi: 10.1111/nhs.12048] [Medline: 23480423]
22. Ratanjee-Vanmali H, Swanepoel DW, Laplante-Lévesque A. Digital proficiency is not a significant barrier for taking up hearing services with a hybrid online and face-to-face model. Am J Audiol 2020 Dec 09;29(4):785-808 [FREE Full text] [doi: 10.1044/2020_AJA-19-00117] [Medline: 32997504]
23. Hu C, Kung S, Rummans TA, Clark MM, Lapid MI. Reducing caregiver stress with internet-based interventions: a systematic review of open-label and randomized controlled trials. J Am Med Inform Assoc 2015 Apr;22(e1):e194-e209. [doi: 10.1136/amiajnl-2014-002817] [Medline: 25125686]
24. Bentley CL, Powell LA, Orrell A, Mountain GA. Making telecare desirable rather than a last resort. Ageing Soc 2018;38(5):926-953. [doi: 10.1017/s0144686x16001355]
25. Papa R, Efthymiou A, Lamura G, Piccinini F, Onorati G, Papastavrou E, et al. Review and selection of online resources for carers of frail adults or older people in five european countries: mixed-methods study. JMIR Mhealth Uhealth 2020 Jun 17;8(6):e14618 [FREE Full text] [doi: 10.2196/14618] [Medline: 32554378]
26. Xiong C, D'Souza A, El-Khechen-Richandi G, Mihailidis A, Cameron JI, Astell A, et al. Perceptions of digital technology experiences and development among family caregivers and technology researchers: qualitative study. JMIR Form Res 2022 Jan 28;6(1):e19967 [FREE Full text] [doi: 10.2196/19967] [Medline: 35089150]
27. Mistry P, Jabbal J. Moving from exclusion to inclusion in digital health and care. The King's Fund. 2023 Mar 8. URL: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/exclusion-inclusion-digital-health-care [accessed 2023-03-17]
28. Hutchings R, Sherlaw-Johnson C. Supporting patient engagement with digital health care innovations: lessons from the Care City test bed. Nuffield Trust. 2022 May 5. URL: https://tinyurl.com/4pp9bvpm [accessed 2024-03-06]
29. Garnett A, Northwood M, Ting J, Sangrar R. mHealth interventions to support caregivers of older adults: equity-focused systematic review. JMIR Aging 2022 Jul 08;5(3):e33085 [FREE Full text] [doi: 10.2196/33085] [Medline: 35616514]
30. Boots LM, de Vugt ME, van Knippenberg RJ, Kempen GI, Verhey FR. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. Int J Geriatr Psychiatry 2014 Apr;29(4):331-344. [doi: 10.1002/gps.4016] [Medline: 23963684]
31. Hopwood J, Walker N, McDonagh L, Rait G, Walters K, Iliffe S, et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: systematic review. J Med Internet Res 2018 Jun 12;20(6):e216 [FREE Full text] [doi: 10.2196/jmir.9548] [Medline: 29895512]
32. Bastoni S, Wrede C, da Silva MC, Sanderman R, Gaggioli A, Braakman-Jansen A, et al. Factors influencing implementation of eHealth technologies to support informal dementia care: umbrella review. JMIR Aging 2021 Oct 08;4(4):e30841 [FREE Full text] [doi: 10.2196/30841] [Medline: 34623314]
33. Cook EJ, Randhawa G, Guppy A, Sharp C, Barton G, Bateman A, et al. Exploring factors that impact the decision to use assistive telecare: perspectives of family care-givers of older people in the United Kingdom. Ageing Soc 2018;38(9):1912-1932. [doi: 10.1017/S0144686X1700037X]
34. Balasubramanian GV, Beaney P, Chambers R. Digital personal assistants are smart ways for assistive technology to aid the health and wellbeing of patients and carers. BMC Geriatr 2021 Nov 15;21(1):643 [FREE Full text] [doi: 10.1186/s12877-021-02436-y] [Medline: 34781881]
35. Killin LO, Russ TC, Surdhar SK, Yoon Y, McKinstry B, Gibson G, et al. Digital support platform: a qualitative research study investigating the feasibility of an internet-based, postdiagnostic support platform for families living with dementia. BMJ Open 2018 Apr 12;8(4):e020281 [FREE Full text] [doi: 10.1136/bmjopen-2017-020281] [Medline: 29654028]
36. Egan K. Digital technology, health and well-being and the Covid-19 pandemic: it's time to call forward informal carers from the back of the queue. Semin Oncol Nurs 2020 Dec;36(6):151088 [FREE Full text] [doi: 10.1016/j.soncn.2020.151088] [Medline: 33229183]
37. Knapp M, Shehaj X, Wong G. Digital interventions for people with dementia and carers: effective, cost-effective and equitable? Neurodegener Dis Manag 2022 Oct;12(5):215-219 [FREE Full text] [doi: 10.2217/nmt-2022-0025] [Medline: 35833456]
38. Topol E. Preparing the healthcare workforce to deliver the digital future. National Health Service. 2019 Feb. URL: https://topol.hee.nhs.uk/wp-content/uploads/HEE-Topol-Review-2019.pdf [accessed 2024-03-06]
39. Strobel NA, Adams C. Best practice in caring for carers. Sax Institute. 2015. URL: https://api.research-repository.uwa.edu.au/ws/portalfiles/portal/22162169/Best_practice_in_caring_for_carers_1_.pdf [accessed 2021-11-09]

40. Low LF, Yap M, Brodaty H. A systematic review of different models of home and community care services for older persons. BMC Health Serv Res 2011 May 09;11:93 [FREE Full text] [doi: 10.1186/1472-6963-11-93] [Medline: 21549010]
41. Batchelor R, Gulshan S, Shritharan H, Williams E, Henderson C, Gillard S, et al. Perceived acceptability and experiences of a digital psychoeducation and peer support intervention (COPe-support): interview study with carers supporting individuals with psychosis. J Med Internet Res 2022 Feb 02;24(2):e27781 [FREE Full text] [doi: 10.2196/27781] [Medline: 35107439]
42. LaMonica HM, Iorfino F, Lee GY, Piper S, Occhipinti JA, Davenport TA, et al. Informing the future of integrated digital and clinical mental health care: synthesis of the outcomes from project synergy. JMIR Ment Health 2022 Mar 09;9(3):e33060 [FREE Full text] [doi: 10.2196/33060] [Medline: 34974414]
43. Technologies to make life easier. Carers UK. URL: https://www.carersuk.org/help-and-advice/technology-and-equipment/technologies-to-make-life-easier [accessed 2022-10-30]
44. Wilding C, Davis H, Rasekaba T, Hamiduzzaman M, Royals K, Greenhill J, et al. Volunteers' support of carers of rural people living with dementia to use a custom-built application. Int J Environ Res Public Health 2021 Sep 20;18(18):9909 [FREE Full text] [doi: 10.3390/ijerph18189909] [Medline: 34574832]
45. Family resources survey. United Kingdom Government. 2010 Jun 1. URL: https://www.gov.uk/government/collections/family-resources-survey--2 [accessed 2022-09-14]
46. People at the heart of care: adult social care reform white paper. Department of Health and Social Care, United Kingdom Government. 2021 Dec 1. URL: https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper [accessed 2021-12-02]
47. Reinhard SC, Feinberg LF, Houser A, Choula R, Evans M. Valuing the invaluable: 2019 update. AARP Public Policy Institute. 2019 Nov. URL: https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf [accessed 2022-06-14]
48. Lessons from lockdown: what next for online carer support? Mobilise. 2021 Jul. URL: https://tinyurl.com/yuru3dv8 [accessed 2024-03-06]
49. Oliver D. David Oliver: lessons from the Babylon health saga. BMJ 2019 Jun 05;365:l2387. [doi: 10.1136/bmj.l2387] [Medline: 31167923]
50. Turner HC, Archer RA, Downey LE, Isaranuwatchai W, Chalkidou K, Jit M, et al. An introduction to the main types of economic evaluations used for informing priority setting and resource allocation in healthcare: key features, uses, and limitations. Front Public Health 2021 Aug 25;9:722927 [FREE Full text] [doi: 10.3389/fpubh.2021.722927] [Medline: 34513790]
51. Aldridge J. Where are we now? Twenty-five years of research, policy and practice on young carers. Crit Soc Policy 2018;38(1):155-165. [doi: 10.1177/0261018317724525]
52. Living longer: caring in later working life. Office for National Statistics. 2019 Mar 15. URL: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15#overview [accessed 2020-10-26]
53. Pin S, Spini D. Meeting the needs of the growing very old population: policy implications for a global challenge. J Aging Soc Policy 2016;28(3):218-231. [doi: 10.1080/08959420.2016.1181972] [Medline: 27110727]

Abbreviations

CPQ-12: Computer Proficiency Questionnaire, 12-item version
CTHE: Carers Trust Heart of England
GP: general practitioner
ICS: integrated care system
NHS: National Health Service

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Original Paper

Sentiment Dynamics Among Informal Caregivers in Web-Based Alzheimer Communities: Systematic Analysis of Emotional Support and Interaction Patterns

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Abstract

Background: Alzheimer disease and related dementias (ADRD) are a growing global health challenge. ADRD place significant physical, emotional, and financial burdens on informal caregivers and negatively affects their well-being. Web-based social media platforms have emerged as valuable sources of peer support for these caregivers. However, there has been limited investigation into how web-based peer support might influence their mental well-being.

Objective: This study aims to examine the dynamics of sentiment scores, a major indicator of mental well-being, among informal ADRD caregivers, specifically how their sentiment changes as they participate in caregiving experience discussions within 2 ADRD web-based communities.

Methods: We collected data from 2 large web-based ADRD caregiving communities, ALZConnected (from November 2011 to August 2022) and TalkingPoint (from March 2003 to November 2022). Using the Valence Aware Dictionary for Sentiment Reasoning and Linguistic Inquiry and Word Count, we calculated sentiment scores for each post and evaluated how the initial sentiment score of a topic initiator evolves within a discussion thread. Structured topic modeling and regression analysis were used to identify the primary topics consistently associated with sentiment changes within these threads. We investigated longitudinal sentiment trends to identify patterns of sentimental stability or enhancement due to prolonged engagement in web-based communities by plotting linear interpolation lines of the sentiment values of each individual user.

Results: The ALZConnected dataset comprised 532,992 posts, consisting of 57,641 topic threads and 475,351 comments. The TalkingPoint dataset was composed of 846,344 posts, consisting of 81,068 topic threads and 765,276 comments. Our research revealed that topic initiators experienced a notable increase in sentiment as they engaged in subsequent discussions within their threads, with a significant uptick in positivity in the short term. This phenomenon is part of a broader trend of steadily rising positive sentiment among ADRD caregivers. Using structured topic modeling, we cataloged a diverse range of topics that included both emotional aspects, such as family emotions, and practical concerns, such as diagnosis and treatment and everyday care practices. We observed that sentiment scores were positively aligned with discussions about family and daily routines life (coefficient=3.53; *P*<.001), while topics related to illness (coefficient=–1.37; *P*<.001) and caregiving facilities (coefficient=–1.98; *P*<.001) tended to correlate with lower sentiment scores. This evidence highlights the significant impact that both the time of participation and the posting content have on the sentiment changes of caregivers.

Conclusions: This study identifies sentiment changes among informal ADRD caregivers through their interactions in 2 extensive web-based communities. These findings emphasize the importance of early emotional support within a topic thread and demonstrate a predominantly positive sentiment in these communities over time. These further highlight the value of web-based peer support and its potential to enhance the emotional well-being of informal ADRD caregivers.

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KEYWORDS

informal caregivers; Alzheimer disease; dementias; web-based community; sentiment analysis; topic modeling; caregiving; carers; family care; support group; peer support; gerontology; geriatrics; aging; attitudes; opinion; perceptions; perspectives; sentiment; cognitive; web-based communities; Linguistic Inquiry and Word Count; machine learning; Valence Aware Dictionary for Sentiment Reasoning

Introduction

Alzheimer disease (AD) is the most common cause of dementia, a clinical syndrome that severely impairs a person's memory, language, and judgment and planning abilities [1]. AD and related dementias (ADRD) are increasingly prevalent health issues all over the world [2]. The responsibility of caring for people living with ADRD falls primarily on the unpaid informal caregivers, typically the family members and friends of the people living with ADRD [3,4]. These informal caregivers face a wide range of physical, emotional, and financial challenges that can cause significant stress and negatively affect their health and well-being [5]. Notably, many informal ADRD caregivers claim to have emotional exhaustion that manifests in caregivers as a result of prolonged emotional stress and the constant demands of caregiving. [6].

Understanding the emotional challenges informal ADRD caregivers face and offering appropriate support to enhance their well-being is of vital importance. Prior investigations into these issues have primarily relied upon traditional offline strategies, such as surveys [7,8] and interventions [9]. Additionally, the primary support for ADRD caregivers mainly comes from local, offline resources like charities and community support groups, with efforts like those of Meyers et al [10], who are committed to advancing ADRD research through collaborating with funded researchers and communities. The study by Robinson et al [11] uses existing cross-sectional survey data from the National Institute of Nursing Research–funded National Caregiver Training Project to examine differences between users and nonusers of community services among caregivers of persons with dementia. While these methodologies play an important role in studying and assisting informal ADRD caregivers' needs, they come with inherent challenges. Caregivers may face hurdles in accessing offline support due to geographic constraints [12], resource limitations [13], and individual preferences. As for researchers, offline studies demand financial and human resources and can introduce potential geographical and demographic biases in the collected data.

Recognizing the limitations of offline support, social media platforms have emerged as a valuable, convenient resource for caregivers to gain informational and emotional support that may not be easily obtained in traditional offline face-to-face interactions [14,15]. A recent survey indicated that web-based communities could provide informal caregivers with a sense of understanding, empowerment, support, and belongingness, thus reducing social isolation and improving the emotional well-being of these caregivers [16]. Despite the potential benefits of web-based support, there is a lack of research examining whether informal ADRD caregivers receive positive emotional feedback when discussing their caregiving experience or challenges in web-based communities. This is important because an improved sentiment change observed from posts on web-based platforms may indicate a positive impact of web-based peer support on a caregiver's emotional well-being [17].

In this study, we investigate the changes in the sentiment exhibited by informal ADRD caregivers through their published posts on web-based platforms in 2 large web-based communities, ALZConnected and TalkingPoint. ALZConnected is a web-based community powered by the Alzheimer's Association for any person affected by ADRD in North America, while TalkingPoint is a web-based ADRD community organized by the UK Alzheimer's Society. The selection of these platforms was based on their substantial user base, which provides a rich dataset for analysis, and their focus on ADRD, ensuring that the study's insights are directly applicable to this group. Web-based peer support has been shown to offer a wide range of benefits, including informational and emotional support [18,19], which should also be valuable for caregivers facing the complex challenges of ADRD. Therefore, we hypothesize that the sentiment of informal ADRD caregivers revealed in their published posts will be improved after interacting with other caregivers in web-based communities. Specifically, we investigated the following 3 research questions (RQs) to test this hypothesis.

- RQ1: How did the sentiment of the topic initiator change within a topic thread?
- RQ2: What topics in initial posts were associated with sentiment change?
- RQ3: How did the sentiment of a web-based caregiver change over time within the community?

To investigate these questions, we apply sentiment analysis and statistical methods to determine whether engaging in web-based communities can provide emotional benefits to informal ADRD caregivers.

Methods

For context, there are several key terms that we rely upon in this paper. Web-based communities generally structure discussions into disparate topic threads. Each thread is defined as an initial post followed by several subsequent comments, where these comments contribute to the ongoing discussion initiated by the original post. We refer to the user who initiates a topic thread as the "topic initiator" of the topic thread. The comments published by topic initiators within their own topic threads are called "self-comments."

Data Collection and Preprocessing

We collected data from two large, representative web-based communities that create a unique environment for ADRD caregiving discussions: (1) ALZConnected and (2) TalkingPoint. ALZConnected was established by the Alzheimer's Association [20] as the first and the largest web-based community for any person affected by ADRD in North America. TalkingPoint, on the other hand, is a web-based community organized by the Alzheimer's Society [21] in the United Kingdom for people living with ADRD or their caregivers to share information, advice, and support with one another.

We focused our analysis on a specific subset of forums that are dedicated to ADRD caregivers who share caregiving experiences, seek assistance, and engage in caregiving discussions. To ensure relevance and coherence, we conducted a preliminary selection process, manually reviewing the top 20 most viewed or commented posts within each relevant forum to assess their alignment with caregiving topics. This selection process was designed to retain the vast majority of relevant posts while excluding those that were not relevant to our study, such as posts from individuals with ADRD themselves or from forum administrators. In TalkingPoint, we focused on users with a label of a registered user or new member. In ALZConnected, we focused on users who self-identified as ADRD caregivers. The selection criteria varied between forums due to differences in their search functionalities and user engagement metrics.

We gathered all publicly accessible data from these 2 communities using a web crawler built with the *BeautifulSoup* package of Python (version 4.11; Python Software Foundation). We removed punctuation, special characters, and emojis, and converted the text to lowercase.

Ethical Considerations

Our study received an exemption from human participants research by the institutional review board at Vanderbilt University Medical Center (IRB 221732). Informed consent was waived due to the study's exempt status. To ensure participant privacy and confidentiality, all quoted texts have been paraphrased to prevent user identification. No compensation was provided to participants, as the research involved minimal risk and did not require direct interaction.

Sentiment Evaluation

To mitigate measurement bias that can result from applying off-the-shelf models to our dataset, we applied 2 popular sentiment analysis tools, specifically, Valence Aware Dictionary for Sentiment Reasoning (VADER) [22] and Linguistic Inquiry and Word Count (LIWC) [23], to calculate the sentiment scores of web-based communications to quantify the overall sentiment expressed. These tools were chosen for their ability to consistently analyze large volumes of text data, making them suitable for our study. While they do not have traditional performance metrics like accuracy or F_1-score, they have been validated in numerous studies for their reliability in sentiment analysis.

VADER is a module of The Natural Language Toolkit [24] that provides sentiment ratings based on the words used. It operates as a rule-based sentiment analyzer, where terms are categorized as positive or negative based on their semantic orientation. In this study, we selected the VADER compound score, calculated by summing the valence scores of each word in the lexicon and then normalizing it to a range between –1=most extreme negative and +1=most extreme positive as the sentiment evaluation score.

LIWC calculates the percentage of words in each linguistic category by mapping the words of a given text into a predefined word list of that category [25]. This tool has been widely adopted in social media content–based research [26]. In this study, we focused on the tone category in LIWC, which summarizes the 2 dimensions of positive and negative emotions into a single variable. The LIWC tone score ranged from 0% to 100%, with higher scores indicating a more positive emotional tone. The delineation occurred at 50%, where scores above (below) indicated a positive (negative) tone. In this study, we standardized the LIWC tone score to a range of –1 to 1 to align it with the VADER score range.

The sentiment score, as calculated by VADER and LIWC, reflects the emotional tone inferred from the text and serves as a proxy for emotional support in our study. For example, the post "Hi kids! I want to take a moment to thank all the veterans and their families on this forum..." received a predominantly positive sentiment (VADER 0.94, LIWC tone 0.98), while the post "My mother has lived with my husband and me for a year and I have always felt frustrated and resentful towards her..." was evaluated as predominantly negative (VADER –0.96, LIWC tone –0.84). "Emotional support" is defined here as the presence of supportive feedback inferred from positive shifts in sentiment scores following responses to a user's posts, which will guide our analysis of the changes in sentiment throughout the subsequent research questions.

RQ1: Sentiment Changes of Topic Initiators

To measure a topic initiator's sentiment score changes within a topic thread, we focused on the topic initiators who published at least M (M>0) self-comments with a topic thread. This threshold ensures that the topic initiator contributes sufficient conversational involvement. In this study, M was set to a value that ensured at least 95% of the users posted at most M self-comments.

For each topic thread with at least M self-comments, we define an array, , to represent the sentiment scores of the initial post and the following M self-comments in chronological order. As such, S_0 is the sentiment score of the initial post, while the S_i where i ∊ {1,...,M} is the sentiment score of the ith self-comment. We defined sentiment change, S_Δ, as the difference between the average sentiment score of m self-comments and the initial post's sentiment score: , where , and $m \leq M$. We analyzed the sentiment score changes and generated distributions of these changes with a 95% CI.

To address potential bias from highly active users who contributed a large number of topic threads, we repeated the comparison by randomly selecting a group of P ∊ {5%,10%,25%,50%} of the total number of topic threads in each community. We conducted a pairwise 2-tailed t test to evaluate the difference between and , where N represents the number of selected topic threads in each comparison. We examined the difference at the significance level of α=.05/4 with Bonferroni correction. This adjustment ensures that the error rate remains at the conventional 5% level across all 4 testing groups.

RQ2: Association Between Sentiment Changes and Initial Post Topics

We used the structural topic model (STM) [27] to infer the topics that were communicated in the initial posts, with the subsequent goal of exploring their correlation with sentiment changes. STM is an advanced modeling technique that allows for the incorporation of document-level metadata to inform the discovery of topics within textual data. This unsupervised machine learning approach is particularly adept at handling large, unstructured datasets by identifying latent thematic structures without the need for preassigned labels. This capability makes it an excellent tool for exploring the vast and varied content found in web-based caregiver discussions, where topics may not be clearly defined in advance. Next, we applied ordinary least squares regression, as implemented in the Python package *statmodels* (version 0.14.0), to investigate what kinds of topics in the initial posts are associated with sentiment change.

Before applying topic modeling on the initial posts, we removed stop words and special symbols and discarded words that occurred less than 10 times in the dataset. Since STM is an unsupervised machine learning strategy, we rely on 2 metrics—exclusivity and semantic coherence—to determine the appropriate number of generated topics. Exclusivity refers to the uniqueness of the most frequent words in a topic, while semantic coherence [28] quantifies the co-occurrence of words in a topic in a general context or all the posts. We assess STM for topic numbers ranging from 5 to 30 and select the optimal number K of topics for further analysis [14].

Subsequently, we rank the topics by their prevalence across all documents, a process that involves examining the expected proportion of words in each document attributed to each topic. We calculate the expected topic proportions (ETP) using the *estimateEffect* function in the *STM* package. With this distribution, we conducted a regression analysis where the topic proportions served as independent variables, and the changes in sentiment scores, which were calculated by VADER compound scores or LIWC tone changes, served as the dependent variable. In this regression, we only considered the topics that held an ETP greater than the mean ETP of K topics. For instance, in a model with 20 topics, we would expect an ETP of 5% per topic (1%/20 or 100%/20) on average and only include topics that exceeded 5% in the regression analysis for each initial post.

RQ3: Temporal Changes of Caregiver Sentiment

We defined the active time of a web-based caregiver in the community, up to the point of writing a specific post, as the duration from their account registration to the posting date of that particular post. We analyzed sentiment changes over various fixed time intervals, as 1 week, 2 weeks, 1 month, 3 months, 6 months, 1 year, 3 years, 5 years, and 10 years. For each time interval, we selected posts from active users who had contributed within the designated time frame (0 to the specific interval) and continued to post at least once after that period. For example, to assess sentiment changes for active users within 1 year, we only consider users who have published at least 2 posts (either initial posts or comments) within a year and still have at least 1 post beyond the 1-year period. As such, we ensure that every user included in a time-period analysis is still active in contributing posts. We focused on time intervals where at least half of the users remained active.

To quantify the change in sentiment for active users over time, we plotted linear interpolation lines with 95% CIs to analyze trends in the sentiment values of each individual user. We calculated the Spearman coefficient of correlation [29] to analyze similarities in trends across communities, as well as to validate results across different sentiment analysis tools.

Results

Basic Statistics

We collected data from ALZConnected from November 14, 2011, to August 6, 2022, and TalkingPoint from March 31, 2003, to November 3, 2022. Table 1 provides basic statistics for both datasets. The different time periods for each dataset reflect the respective forum's establishment dates and the availability of their archival data, with no intercommunity comparison being made.

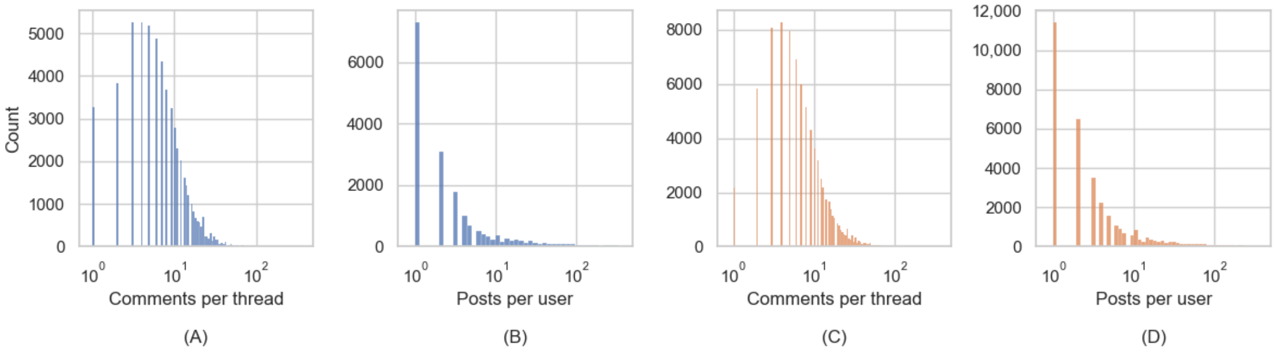
Table 1. Summary statistics for the datasets in this study.

Community	Total posts, n	Topic threads, n	Comments, n	Authors, n	Topic initiators, n	Commentors, n	Time period
ALZConnected	532,992	57,641	475,351	18,569	12,590	14,964	From November 14, 2011, to August 6, 2022
TalkingPoint	846,344	81,068	765,276	34,551	27,907	26,651	From March 31, 2003, to November 3, 2022

The ALZConnected dataset covers 532,992 posts, consisting of 57,641 topic threads and 475,351 comments. It involves 18,569 unique users, 12,590 (68%) of which are topic initiators and 14,964 (80.1%) are commenters, indicating that a nontrivial proportion of users engage in both creating and discussing content. The TalkingPoint dataset covers 846,344 posts, consisting of 81,068 topic threads and 765,276 comments. It involves 34,551 unique users, 27,907 (81%) of which are topic initiators and 26,651 (77.1%) are commenters.

Both datasets exhibit a long-tailed distribution with respect to the number of comments per topic thread (Figures 1A and 1C). For example, most topic threads contain around 10 comments while a few inspire extensive dialogue. Similarly, the distribution of posts per user (Figures 1B and 1D) indicates that, although many users occasionally participate, a small subset of highly active users contribute the majority of the content. These phenomena hold true in both ALZConnected and TalkingPoint. The consistency in posting and user activity patterns across both communities highlights common behaviors in user engagement within social media caregiving forums.

Figure 1. (A,C) The distribution of the number of comments per topic thread and (B,D) the number of posts per user in the ALZConnected and TalkingPoint web-based communities. The plots show the log-scaled x-axis for ease of viewing.

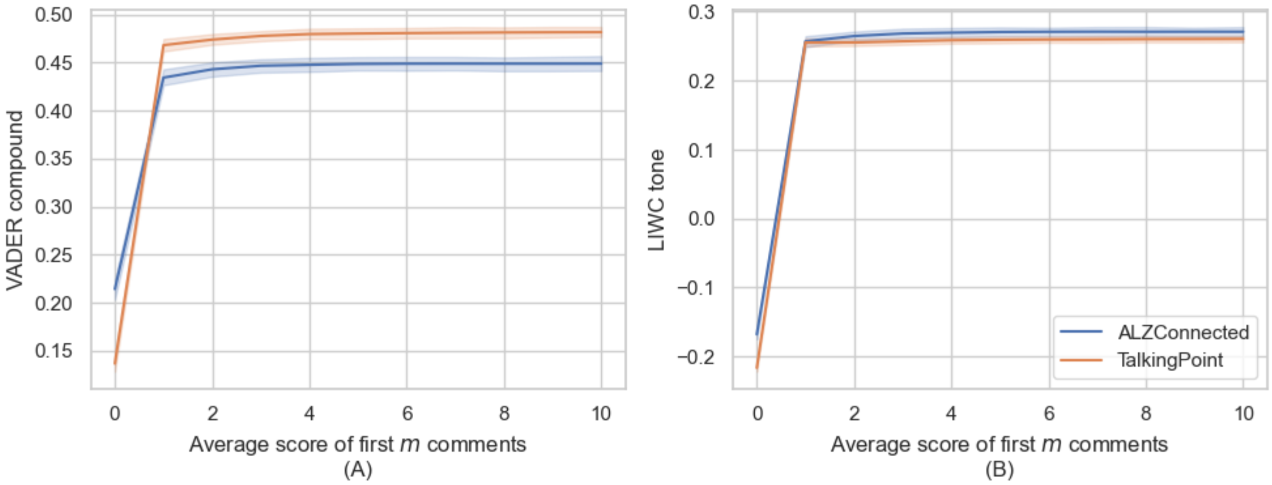


RQ1: Sentiment Change of Topic Initiator

After removing threads lacking self-comments, 30,739 (53.3%) out of 57,641 topic threads from ALZConnected and 53,995 (67%) out of 81,068 topic threads from TalkingPoint remained, comprising 79,869 and 181,049 self-comments, respectively. In ALZConnected, 95% of the topic initiators have fewer than 6 self-comments, while in TalkingPoint, 95% of the topic initiators have fewer than 8 self-comments. To minimize the influence of highly active users, we focused on measuring sentiment changes for the first M=10 self-comments, encompassing 30,209 (98.3%) out of 30,739 and 52,370 (97%) out of 53,995 topic threads, respectively, in ALZConnected and TalkingPoint.

Figure 2 shows how the sentiment score changes within a 95% CI, in terms of VADER compound (Figure 2A) and LIWC tone (Figure 2B), throughout the count of self-comments m. The m=0 on the x-axis corresponds to the initial sentiment score S_0 while m>0 corresponds to the average score of the first m self-comments. For example, a post in ALZConnected stated, "I am overwhelmed with sadness. This entire week, my husband's condition has worsened, leaving him fixated on repetitive thoughts that I cannot divert…[rephrased]" with initial sentiment scores (VADER –0.85, LIWC –0.88). After receiving comments from 3 users, the caregiver's follow-up post showed, "Thank you for your response...My husband, diagnosed with early onset Alzheimer's 5 years ago, isn't physically ill, yet we face immense challenges. [rephrased]" with sentiment scores improving to (VADER 0.54, LIWC –0.48). Thus, it is evident that initial engagement in web-based community discussions is associated with a notable increase in sentiment scores, suggesting prompt emotional support for topic initiators (RQ1). Both VADER and LIWC indicate a substantial increase in the sentiment score as the number of self-comments m grows from 0 to 1. This is followed by a slow, gradual increase as the number of self-comments further increases. This suggests that web-based community interactions effectively provide prompt emotional support to topic initiators. However, these positive changes in sentiment do not escalate rapidly with the frequency of topic initiators' activities within the web-based communities.

Figure 2. Sentiment changes as a function of the number of self-comments. The x-axis indicates the count of self-comments. For example, m=2 represents the average sentiment of the first 2 self-comments under each author's thread. LIWC: Linguistic Inquiry and Word Count; VADER: Valence Aware Dictionary for Sentiment Reasoning.



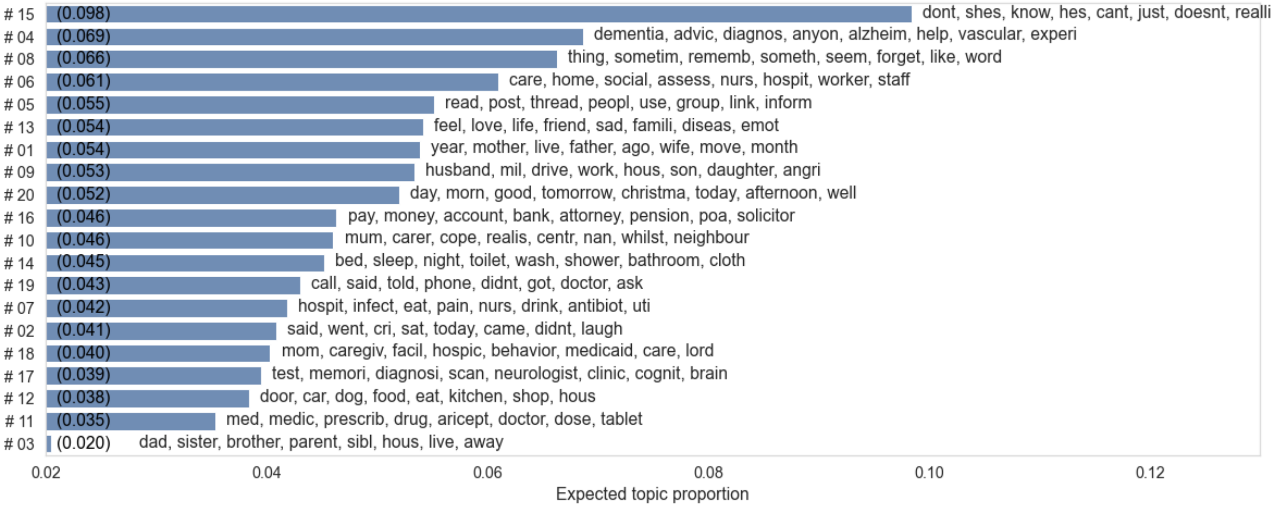
VADER and LIWC show different patterns of changes in sentiment scores. Notably, the VADER compound score indicates a higher initial sentiment in ALZConnected compared to TalkingPoint. However, when the number of self-comments exceeds 1, the sentiment value in TalkingPoint surpasses that of ALZConnected. Conversely, the LIWC tone score shows an opposite trend, though the differences between the 2 communities are less distinct. This dissimilarity might arise from variations in the training corpora used by VADER and LIWC.

We investigated whether the initial sentiment significantly differed from the average sentiment across the first 10 self-comments. The results indicated statistically significant differences between the 2 sentiment values in both web-based communities for all test groups, with *P* values approaching 0, significantly lower than the significance level of α=.0125 (Bonferroni-corrected from α=.05/4). These findings emphasize that web-based interactions have a prompt and noticeable impact on the sentiment of caregivers in web-based communities.

RQ2: Sentiment Changes Correlates with Initial Post Topics

In determining the ideal number of topics for our STM, we evaluated metrics of exclusivity and semantic coherence across a spectrum ranging from 5 to 30 topics. The analysis indicated that a set of 20 topics achieved an optimal balance between word distinctiveness and thematic relevance. Thus, we retrained STM on this number of topics. Figure 3 visualizes this topic modeling, showing the most representative words for each topic and indicating the relative topic proportions, which quantitatively reflect the prevalence of each topic across all analyzed documents.

Figure 3. Topics generated by structural topic modeling, sorted in decreasing order of expected topic proportions. The proportion of each topic is shown to the right of each bar, while the top 8 most representative words in the topic are shown to the right.



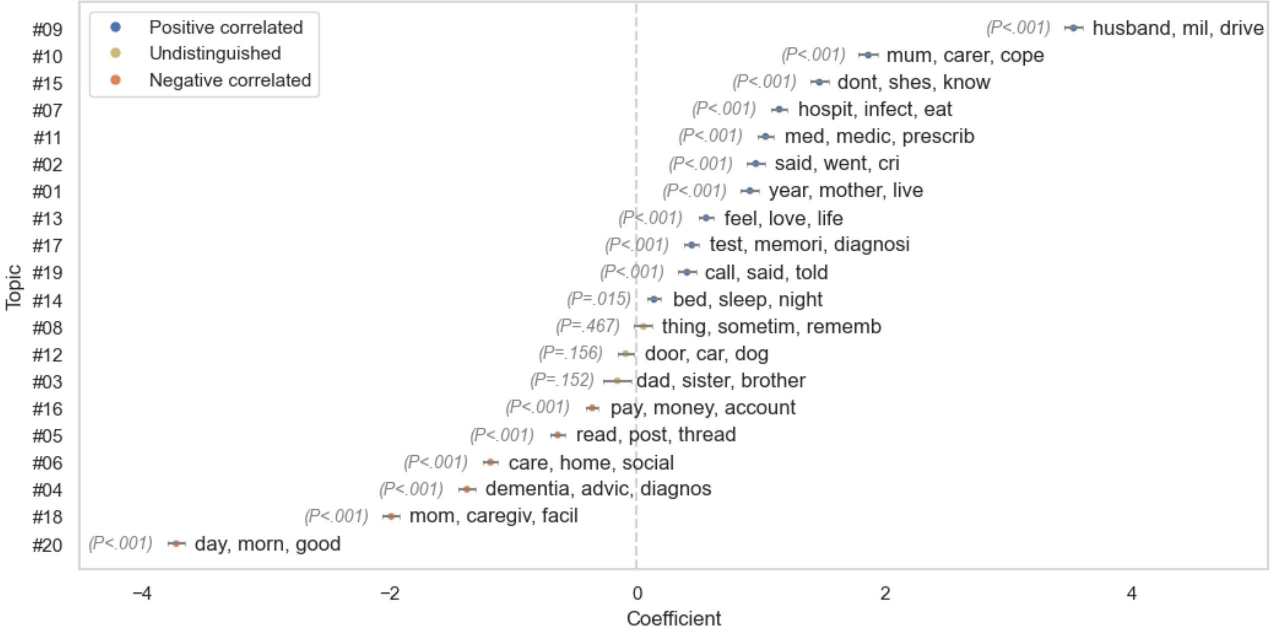
From Figure 3, it was evident that several topics were related to sentiment. For instance, topic #13, which is about "family members feelings," is characterized by frequent words like "feel," "love," and "sad." The ETP of this topic is 5.4%, which stands out as notably high when considering an even distribution across 20 topics would average 5% per topic. This suggests that discussions related to family members' feelings are more prevalent in the dataset than what would be expected by chance.

The following posts are representative examples of this topic: "Sadly, I am letting you all know that my poor mother has left this earth; she passed away peacefully surrounded by her family [rephrased]" and "I miss my husband every day, he is getting further away from us...This disease has taken away his mind, I feel exhausted, and life is not fun at all [rephrased]." These topics are related to sentimental changes and offer insights into the deeply personal and heartfelt experiences of community members. Additionally, we identified topics that convey specific emotional actions. For example, topic #2 contains the keywords "cries" and "laughter," reflecting the diverse sentimental landscape caregivers are facing. A typical initial post from this topic is "When I was a little boy, I often dropped my spoon, and now my old man does the same thing, which makes me laugh and cry at the same time [rephrased]."

In addition to sentiment-related topics, we identified other commonly discussed topics. For example, topic #4 (dementia, advic, diagnos) delved into information related to diagnosis and treatment, providing a relatively objective description. Topic #14 (bed, sleep, shower) centered around caring for people living with ADRD's daily life, while topic #16 (pay, money, account) was about financial matters. Notably, topic #1 (mother, father, wife) and topic #09 (husband, son, daughter) specifically addressed personal relationships such as those with spouses or adult children. Those topics align with previous studies, which have shown that spousal caregivers and adult-child caregivers make up a significant portion of informal ADRD caregivers [30].

To clarify the relationship between the content of initial posts and subsequent changes in sentiment scores, as outlined in RQ2, we present in Figure 4 the influence of each topic on the VADER compound sentiment scores. Blue (positive) and orange (negative) dots represent correlation, each topic's *P* value is displayed beside its associated keywords. This analysis indicates that most topics are statistically significant (*P*<.001), indicating that various topics are significantly linked to sentiment changes within the topic threads.

Figure 4. The coefficients of each topic with VADER compound sentiment changes: blue (positive) and orange (negative) dots indicate correlation, while yellow dots indicate undistinguished features where *P*>.05. VADER: Valence Aware Dictionary for Sentiment Reasoning.



When considering specific topics, topic #9 (husband, mil, drive), exhibits the highest positive correlation with changes in the VADER compound score. This topic talks about family relationships and daily life. This suggests that many users of web-based platforms find comfort in sharing their daily experiences and connecting with others. As a result, emotions tend to become more positive as individuals engage in such sharing and communication. By contrast, the most negatively related topic is topic #20 (day, morn, good), which is primarily related to time. This topic illustrates how, as time progresses, the sentiments expressed by caregivers tend to become more negative, possibly due to the progressive nature of dementia. For example, a representative initial post on this topic starts optimistically, "Good morning, we are already halfway through March...enjoy the day, it's looking good [rephrased; VADER compound of 0.97]." However, as the thread continues, the same author later expresses increasing despair: "Hi [name], not a very good afternoon... Every year I try to finish it by February, but time flies so fast... Things are getting worse for [name]. I hope there is no reincarnation because things are going to be terrible here in a hundred years [rephrased; VADER compound –0.96]."

This transition from a positive to a negative tone, marked by the significant shift in VADER scores, reflects the worsening symptoms over time and the understandable decline in caregivers' moods.

Furthermore, topics directly tied to sentiment, such as topic #2 (said, went, cri) and topic #13 (feel, love, life), exhibit strong positive associations with sentiment changes. In topic #2, discussions often begin with sentiments of sorrow, as seen in posts like, "My mom has not gotten better...I understand why they call it a long goodbye [rephrased]" and typically conclude with acknowledgments of support, "Thank you so much for your support...I know I am not alone. [rephrased]."

Similarly, topic #13 features initial expressions of emotional turmoil, "This is hard to explain but I've been having a weird feeling of loss today...[rephrased]" which transitions into expressions of gratitude, "This is great advice [name]...thank you for staying with me [rephrased]." This indicates that the forum effectively caters to individuals seeking to express their emotional experiences.

Topic initiators may receive positive emotional support, likely due to the compassionate and empathetic nature of users in web-based communities; while topics closely related to illness and caregiving facility, such as topic #4 (dementia, advic, diagnostics) and topic #18 (mom, caregiv, facil), display a negative emotional correlation, underscoring the stress and difficulties that caregivers encounter.

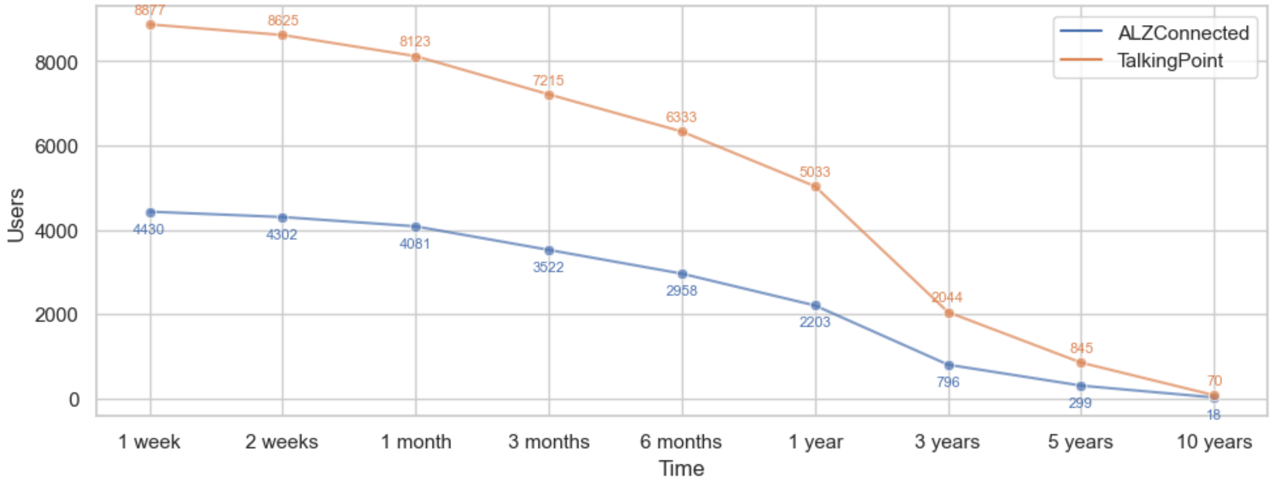
It is worth noting that the performance of LIWC tone scores closely mirrors that of the VADER compound hence we did not present the figure here.

RQ3: Temporal Changes in Caregiver Sentiment

Next, we computed the changes in sentiment according to the VADER compound score and LIWC tone over time. We partitioned users into different timespan groups (from 1 week to 10 years) based on their active time and displayed the sentiment trends in each phase.

Figure 5 shows the number of users active in each timespan, revealing a notable drop in the number of users active for more than a year. For instance, in the ALZConnected community, out of 4430 users who were active for over a week, only 796 (18%) were active for over 3 years, while only 299 (7%) were active for over 5 years. Interestingly, there is a small fraction of users, 18 (0.4%) out of 4430 users in ALZConnected and 70 (0.8%) out of 8877 in TalkingPoint, who remain active for over 10 years. Due to the substantial reduction in active users after the 1-year mark, our subsequent sentiment trend analysis concentrates on the 1-week to 1-year timespan, capturing a more representative (50%) sample of the community's active users.

Figure 5. The number of users that are active in each timespan in the 2 web-based communities.



This analysis examines the trajectory of sentiment scores among caregivers over time to understand the effect of sustained participation in web-based communities. To improve the readability of the figure, we used linear regression lines, along with linear interpolation and its 95% CI, for the data points in each subplot. Figures 6 and 7 provide a comprehensive view of the VADER compound and LIWC tone sentiment changes, respectively, in the web-based communities. Each subplot demonstrates the trend of sentiment change for eligible users in various timespans.

Figure 6. VADER compound sentiment score temporal trend via active time separated into certain time spans. VADER: Valence Aware Dictionary for Sentiment Reasoning.

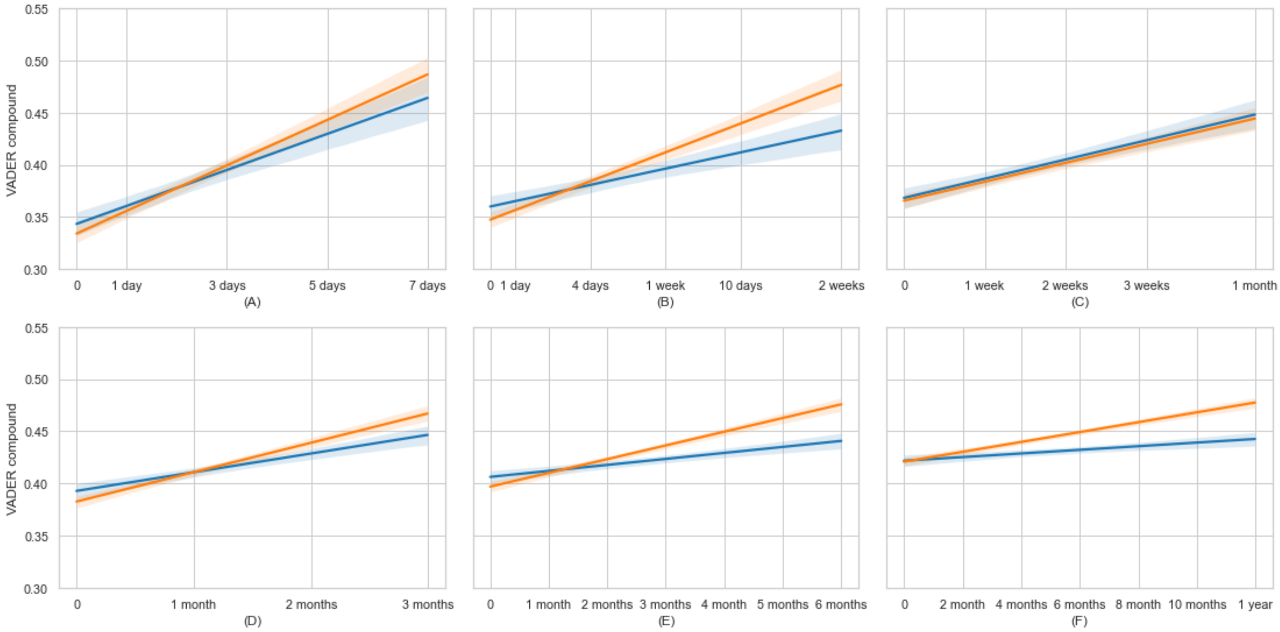
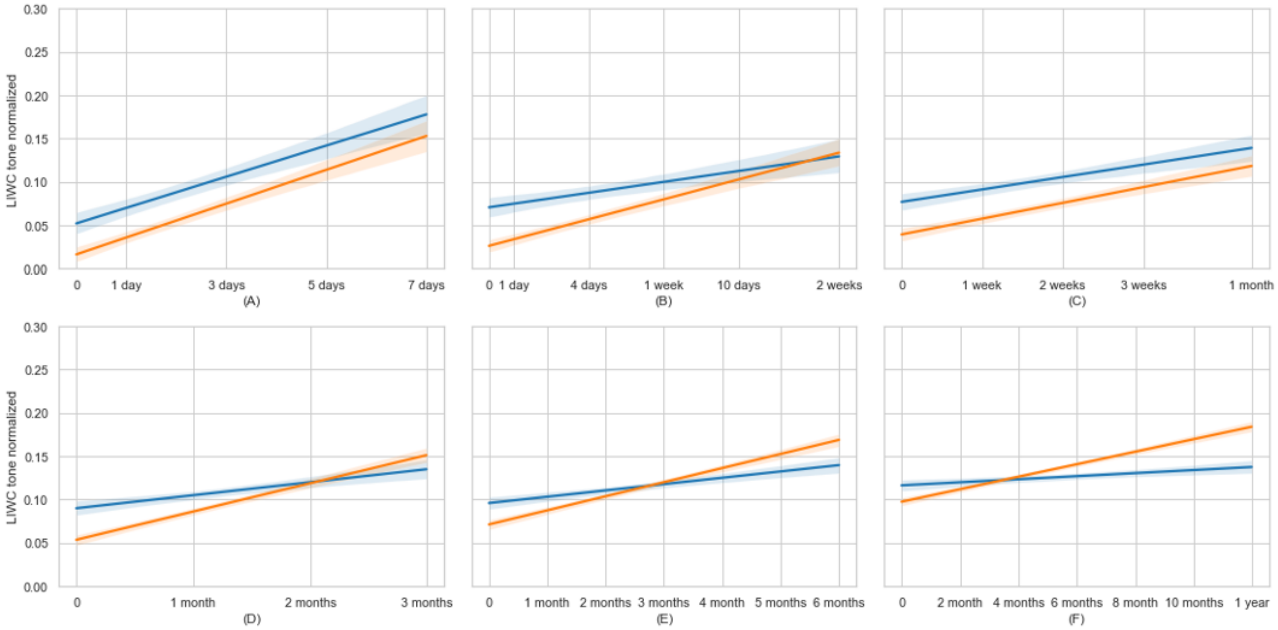


Figure 7. LIWC tone sentiment score temporal trend via active time separated into certain time spans. LIWC: Linguistic Inquiry and Word Count.



The analysis reveals an overall positive sentiment trend in both web-based communities, suggesting that engagement in these forums is generally associated with positive emotional expression. Notably, as the active time interval grows, the increase in sentiment weakens. The Spearman rank-order correlation between the VADER compound score and active time within 1 week, 1 month, and 1 year are 0.062, 0.038, and 0.021 (all statistically significant at *P*<.001), respectively. This finding suggests that participation in the web-based community increases a user's sentiment. However, the effect becomes less pronounced as users spend more time in the web-based community. Third, in both sentiment score measures, there is no substantial difference between ALZConnected and TalkingPoint, showing that both communities provide an environment for ADRD caregivers to express their feelings, supporting the validity of analyzing sentiment changes in ADRD caregivers in either community.

Discussion

Principal Findings

This study illustrates patterns related to the sentiment score changes of informal ADRD caregivers within 2 large web-based communities, shedding light on the role of web-based peer support in enhancing their emotional well-being.

Our investigation into the sentiment changes of topic initiators revealed a prompt elevation in sentiment scores compared with their first self-comment. For example, within a TalkingPoint thread spanning 2 years with 8264 comments, the topic initiator initially expressed frustration, stating, “Fed up to the back teeth today. Had a bad night and all day, Mum talking to the clock and asking her Mum to come and get her [VADER –0.36, LIWC –0.22].”

However, after receiving responses from 3 other commenters, one of which is “wish I could draw I had a great image in my head...OK I’ll stop. I just wanted to make you laugh—that’s the best I can come up with [VADER 0.75, LIWC 0.80],” the tone of the conversation shifted positively, as indicated by the first self-comment, “Haha, I feel better now, coming here is like taking a tonic. Thanks, my TP friends. Gotta go, mom has to go to the bathroom so I got the cat out [VADER 0.93, LIWC 0.98].”

This initial boost was followed by a gradual yet continuous improvement as the number of self-comments increased, emphasizing the efficacy of web-based communities in delivering prompt and ongoing peer support to caregivers. Jenkins et al [31] found that web-based support can significantly contribute to well-being, suggesting a similar benefit for ADRD caregivers who actively participate in web-based communities.

Moreover, the continuously increasing trend in sentiment score suggests that web-based peer support is effective in increasing social inclusion [32], which helps to maintain an emotional balance. A plausible explanation is that long-term caregivers in web-based communities who have years of caring experiences, when becoming more capable of caring for people living with ADRD through learning from web-based peers, may sustain stable sentiments. This assumption can be proved by the same example thread as mentioned above, which includes the topic initiator’s 1064 self-comments. As the self-comments progressed from learning new caregiving skills (“Learned a new way to talk to my mom”) to sharing resources (“Same thing happened to me, [name], I recommend you read this book [title], it really helped me”), a strong sense of community and mutual support was ultimately fostered. The last self-comment we collected from a topic initiator was “Hi ladies, hope you all had a great Christmas break, and everyone had a blast. I miss you all and hope the new year is just as great. Big hugs [VADER 0.97, LIWC 0.98].”

As long-term caregivers in web-based communities progressively enhance their caregiving skills through continued engagement with the community [33], their increased proficiency makes their caregiving responsibilities more manageable [34], thus improving their overall quality of life.

However, the sentiment trends of long-term users exhibited a slower sentiment improvement rate compared to short-term users. One possible reason could be that the trajectory of caregiver burdens is highly dynamic and complex due to increased behavioral impairment and decline in functional status in people living with ADRD [35]. This complexity makes it unrealistic to remove all the stressors in this long-term caregiving journal. In other words, informal caregivers will be in stressful situations, and an upper limit of their emotional well-being may exist even when receiving support from other peers in web-based communities. Cultural complexity in caregiving, which includes diverse cultural norms, values, and caregiver expectations, further influences these experiences. It is reflected in the findings of Ajrouch et al [36] that, although often overlooked in research and service delivery, the role of cultural complexity in ADRD care has been recognized.

Furthermore, our topic modeling analysis identified various ADRD caring topics, including those discussing diagnosis, treatment, daily care, and financial matters. We found that topics discussing personal and heartfelt caregiving experiences exhibited a significant positive correlation with sentiment improvement. For example, an initial post in topic #9 aligned with this trend: “My husband has been taking [drug] for anger for about [specific] days now, but it’s not working. Nothing he’s tried seems to work. It drives me crazy [rephrased].” In response, subsequent commentators provided valuable support, sharing experiences with this drug or offering emotional support through sympathy and comfort. These interactions contributed to a more positive sentiment score in the self-comments.

However, our topic analysis also revealed that posts associated with ADRD, and caregiving facilities were correlated with lower sentiment scores, which might be due to the inherent challenges of ADRD caregiving related to these topics. The complexity of ADRD poses significant emotional and psychological challenges for caregivers [37]. For instance, an indicative initial post from topic #4 reads, “Hi, I am a full-time carer for my [age]-year-old husband who has vascular dementia and is profoundly deaf. Is there anyone on the forum who is in a similar situation? Thank you [rephrased].” The responses to this post included, “Hi [topic initiator name], my [age]-year-old husband has vascular dementia but without the added complication of being deaf. He lives so much in his own world most of the time that he often seems to be deaf, though. It doesn’t feel nice [rephrased].” These interactions led to the topic initiator’s self-comment, “Thank you all for your responses. It seems to be totally deaf, and dementia is quite uncommon. You are right—I do often feel lonely and isolated, as he must as well. I feel very sad [rephrased].” This is a typical example of negative sentiment change resulting from communication with other users of web-based platforms in the community. ADRD caregivers often witness their loved ones struggling with a loss of identity and independence. As caregivers provide care and support for individuals with ADRD, they often experience feelings of sadness, frustration, and helplessness [38]. In this situation, the decrease in sentiment may be caused by the continued narrative of their negative caregiving experience. However, sharing these challenging experiences with other web-based peers may foster a sense of belongingness among caregivers [39,40], which may lead to a long-term sentiment improvement, as shown in our sentiment temporal trends analysis.

Limitations and Future Works

While sentiment analysis tools provide valuable insights, they may not fully capture the intricate nuances and complexity of human emotions within the ADRD caregiving context. Future analyses may consider combining supervised machine learning for more precise sentiment classification. Although our study identified a correlation between topic initiators and positive sentiment change within threads, it is important to delve deeper into understanding whether web-based interactions directly cause sentiment changes. Our future research will expand the analysis to include all comments within a thread, thus offering a more comprehensive view of the community's support structure. This approach will allow us to better understand the overall sentiment dynamics and support mechanisms across the platform, addressing the skewed perspective that may arise from focusing solely on self-comments.

The use of STM in our analysis, while powerful for identifying dominant themes from large text corpora, can also present challenges. These models may generate overlapping themes that do not distinctly separate different but related caregiving aspects, due to the unsupervised nature of the topic generation process. This overlap can sometimes obscure the clarity of how specific topics impact caregiver sentiment. Future studies might explore refined modeling techniques that can more effectively differentiate closely related topics or apply hierarchical models to capture nested thematic structures.

Also, our study only examined the registered users who actively write posts on web-based platforms. Since both web-based communities are open to anyone, the data primarily reflect the experiences of active contributors, potentially overlooking the perspectives of passive users or those who may face barriers to participation. This selective participation may concentrate the content creation among a small subset of highly active users, which might narrow the findings to this more vocal group. Additionally, the lack of demographic data on participants limits the generalizability of our findings across diverse caregiver populations, which could result in an unrepresentative sample. It will be interesting to investigate how discussions on web-based platforms, as collective knowledge, can influence the emotional well-being of all caregivers, including those who only observe interactions without contributing directly. Such findings will help to expand the impact of web-based peer support, which is unique to open web-based communities.

Conclusions

To the best of our knowledge, this is the first study to investigate how sentiment changes among informal ADRD caregivers within 2 open, large, existing web-based communities using computational methods. We observed improved sentiment score trends at both the topic thread and community levels, highlighting the positive impact of web-based peer support for both short-term and long-term caregivers on web-based communities. However, we did find some topics that are negatively associated with sentiment improvement, which reflects the complexity of some caregiving burdens that might not be easily solved at the emotional level. Overall, our findings indicate that peer support in web-based communities can be powerful in assisting informal ADRD caregivers.

Conflicts of Interest

None declared.

References

1. Arvanitakis Z, Bennett DA. What is dementia? JAMA 2019;322(17):1728 [FREE Full text] [doi: 10.1001/jama.2019.11653] [Medline: 31688886]
2. Kessler EM. Dementia worries and cognitive complaints in a long-life society. GeroPsych 2021;34(1):1-3. [doi: 10.1024/1662-9647/a000257]
3. Manzini CSS, do Vale FAC. Emotional disorders evidenced by family caregivers of older people with Alzheimer's disease. Dement Neuropsychol 2020;14(1):56-61 [FREE Full text] [doi: 10.1590/1980-57642020dn14-010009] [Medline: 32206199]
4. Sajwani Z. Challenges of caregivers of patients with Alzheimer's disease. Innov Aging. 2020 2020;4:149. [doi: 10.1093/geroni/igaa057.486]
5. Williamson HJ, Begay AB, Dunn DJ, Bacon R, Remiker M, Garcia Y, et al. "We Live on an Island": perspectives on rural family caregivers for adults with Alzheimer's disease and related dementias in the United States. Qual Rep 2022;27(10):2343-2358 [FREE Full text] [doi: 10.46743/2160-3715/2022.5193] [Medline: 36425903]
6. Burgdorf JG, Reckrey J, Russell D. "Care for Me, Too": A novel framework for improved communication and support between dementia caregivers and the home health care team. Gerontologist 2023;63(5):874-886. [doi: 10.1093/geront/gnac165] [Medline: 36317266]
7. Lancashire L, Biggar V, Comer M, Frangiosa T, Gage A, Paulsen R, et al. Caring for dementia caregivers: understanding caregiver stress during the COVID-19 pandemic. Gerontol Geriatr Med 2023;9:23337214231185664 [FREE Full text] [doi: 10.1177/23337214231185664] [Medline: 37426770]
8. McCarthy MJ, Hustead MLR, Garcia YE. Development and validation of a community assessment survey for diverse rural family caregivers of people with Alzheimer's disease and related dementias. Fam Community Health 2021;3(44):126-135. [doi: 10.1097/fch.0000000000000297]
9. Cheng ST, Li KK, Losada A, Zhang F, Au A, Thompson LW, et al. The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychol Aging 2020;35(1):55-77. [doi: 10.1037/pag0000401] [Medline: 31985249]
10. Meyers EA, Amouyel P, Bovenkamp DE, Carrillo MC, de Buchy GD, Dumont M, et al. Commentary: global Alzheimer's disease and Alzheimer's disease related dementia research funding organizations support and engage the research community throughout the COVID-19 pandemic. Alzheimers Dement 2022;18(5):1067-1070 [FREE Full text] [doi: 10.1002/alz.12472] [Medline: 34596318]

11. Robinson KM, Buckwalter K, Reed D. Differences between dementia caregivers who are users and nonusers of community services. Public Health Nurs 2013;30(6):501-510. [doi: 10.1111/phn.12041] [Medline: 24579710]
12. Orth J, Flowers D, Betz G, Cagle JG. A systematic review of specialty dementia care units in long-term care settings. Int J Geriatr Psychiatry 2023;38(4):e5907 [FREE Full text] [doi: 10.1002/gps.5907] [Medline: 36971436]
13. Wang N, Albaroudi A, Chen J. Decomposing urban and rural disparities of preventable ED visits among patients with alzheimer's disease and related dementias: evidence of the availability of health care resources. J Rural Health 2021;37(3):624-635 [FREE Full text] [doi: 10.1111/jrh.12465] [Medline: 32613666]
14. Ni C, Malin B, Song L, Jefferson A, Commiskey P, Yin Z. “Rough Day … Need a Hug”: learning challenges and experiences of the Alzheimer’s disease and related dementia caregivers on Reddit. In: ICWSM. 2022 Presented at: 16th International AAAI Conference on Web and Social Media (AAAI ICWSM 2022); June 6-9, 2022; Atlanta, GA p. 711-722. [doi: 10.1609/icwsm.v16i1.19328]
15. Chan MS, Cheng C. Explaining personality and contextual differences in beneficial role of online versus offline social support: a moderated mediation model. Comput Hum Behav 2016;63:747-756. [doi: 10.1016/j.chb.2016.05.058]
16. Oser TK, Oser SM, Parascando JA, Hessler-Jones D, Sciamanna CN, Sparling K, et al. Social media in the diabetes community: a novel way to assess psychosocial needs in people with diabetes and their caregivers. Curr Diab Rep 2020;20(3):1-10. [doi: 10.1007/s11892-020-1294-3] [Medline: 32080765]
17. Sun V, Raz DJ, Kim JY. Caring for the informal cancer caregiver. Curr Opin Support Palliat Care 2019;13(3):238-242. [doi: 10.1097/SPC.0000000000000438] [Medline: 31157656]
18. Liu Y, Huang W, Luo D. The reception of support in peer-to-peer online networks: network position, support solicitation, and support provision in an online asthma caregivers group. Health Informatics J 2021;27(5):14604582211066020 [FREE Full text] [doi: 10.1177/14604582211066020] [Medline: 34910594]
19. Setoyama Y, Yamazaki Y, Nakayama K. Comparing support to breast cancer patients from online communities and face-to-face support groups. Patient Educ Couns 2011;85(2):e95-100. [doi: 10.1016/j.pec.2010.11.008] [Medline: 21159482]
20. Jack CR, Albert MS, Knopman DS, McKhann GM, Sperling RA, Carrillo MC, et al. Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 2011;7(3):257-262 [FREE Full text] [doi: 10.1016/j.jalz.2011.03.004] [Medline: 21514247]
21. Prince M, Knapp M, Guerchet M. Dementia UK: Second Edition - Overview. Alzheimer’s Society. 2014. URL: https://eprints.lse.ac.uk/59437/1/Dementia_UK_Second_edition_-_Overview.pdf [accessed 2024-10-29]
22. Hutto C, Gilbert E. VADER: A parsimonious rule-based model for sentiment analysis of social media text. 2014 Presented at: 18th International AAAI Conference on Web and Social Media (AAAI ICWSM 2024); June 3-6, 2024; Buffalo, NY p. 216-225. [doi: 10.1609/icwsm.v8i1.14550]
23. Pennebaker JW, Boyd RL, Jordan K, Blackburn K. The development and psychometric properties of LIWC2015 [dissertation].: University of Texas at Austin; 2015. URL: https://repositories.lib.utexas.edu/server/api/core/bitstreams/b0d26dcf-2391-4701-88d0-3cf50ebee697/content [accessed 2024-10-29]
24. Bird S, Klein E, Loper E. Natural Language Processing with Python. Sebastopol, CA: O'Reilly Media, Inc; 2009:330-332.
25. Chung C, Pennebaker J. Linguistic Inquiry and Word Count (LIWC): pronounced “Luke”,… and other useful facts. In: McCarthy PM, Boonthum-Denecke C, editors. Applied Natural Language Processing: Identification, Investigation and Resolution. Hershey, PA: Information Science Reference; 2012:206-229.
26. Saha K, Yousuf A, Boyd RL, Pennebaker JW, de Choudhury M. Social media discussions predict mental health consultations on college campuses. Sci Rep 2022;12(1):123 [FREE Full text] [doi: 10.1038/s41598-021-03423-4] [Medline: 34996909]
27. Roberts ME, Stewart BM, Tingley D. stm: An R package for structural topic models. J. Stat. Soft 2019;91(2):1-40. [doi: 10.18637/jss.v091.i02]
28. Mimno D, Wallach H, Talley E, Leenders M, McCallum A. Optimizing semantic coherence in topic models. 2011 Presented at: Proceedings of the 2011 Conference on Empirical Methods in Natural Language Processing; July 27-31, 2011; Edinburgh, United Kingdom p. 262-272.
29. Hauke J, Kossowski T. Comparison of values of Pearson's and Spearman's correlation coefficients on the same sets of data. Quaestiones Geographicae 2011;30(2):87-93. [doi: 10.2478/v10117-011-0021-1]
30. Statz TL, Peterson CM, Birkeland RW, McCarron HR, Finlay JM, Rosebush CE, et al. "We Moved Her Too Soon": navigating guilt among adult child and spousal caregivers of persons living with dementia following a move into residential long-term care. Couple Family Psychol 2021;11(4):300-314 [FREE Full text] [doi: 10.1037/cfp0000150] [Medline: 36743783]
31. Jenkins C, Oyebode J, Bicknell S, Webster N, Bentham P, Smythe A. Exploring newly qualified nurses' experiences of support and perceptions of peer support online: a qualitative study. J Clin Nurs 2021;30(19-20):2924-2934. [doi: 10.1111/jocn.15798] [Medline: 33870599]
32. Sheldon KM, Lyubomirsky S. How to increase and sustain positive emotion: the effects of expressing gratitude and visualizing best possible selves. J Posit Psychol 2006;1(2):73-82. [doi: 10.1080/17439760500510676]
33. Ni C, Song Q, Malin B, Song L, Commiskey P, Stratton L, et al. Examining online behaviors of adult-child and spousal caregivers for people living with Alzheimer disease or related dementias: comparative study in an open online community. J Med Internet Res 2023;25:e48193 [FREE Full text] [doi: 10.2196/48193] [Medline: 37976095]

34. Jutkowitz E, Gaugler JE, Trivedi AN, Mitchell LL, Gozalo P. Family caregiving in the community up to 8-years after onset of dementia. BMC Geriatr 2020;20(1):216 [FREE Full text] [doi: 10.1186/s12877-020-01613-9] [Medline: 32560701]
35. Clare L. We'll fight it as long as we can: coping with the onset of Alzheimer's disease. Aging Ment Health 2002;6(2):139-148. [doi: 10.1080/13607860220126826] [Medline: 12028882]
36. Ajrouch KJ, Webster NJ, Zahodne LB, Antonucci TC. Introduction to ADRD care in context. J Gerontol B Psychol Sci Soc Sci 2023;78(Suppl 1):S1-S3 [FREE Full text] [doi: 10.1093/geronb/gbac181] [Medline: 36477194]
37. Cheng ST, Au A, Losada A, Thompson LW, Gallagher-Thompson D. Psychological interventions for dementia caregivers: what we have achieved, what we have learned. Curr Psychiatry Rep 2019;21(7):59 [FREE Full text] [doi: 10.1007/s11920-019-1045-9] [Medline: 31172302]
38. Gibson A, Walsh J, Brown LM. A perfect storm: challenges encountered by family caregivers of persons with Alzheimer's disease during natural disasters. J Gerontol Soc Work 2018;61(7):775-789. [doi: 10.1080/01634372.2018.1474158] [Medline: 29781774]
39. Greenwood N, Habibi R, Mackenzie A, Drennan V, Easton N. Peer support for carers: a qualitative investigation of the experiences of carers and peer volunteers. Am J Alzheimers Dis Other Demen 2013;28(6):617-626 [FREE Full text] [doi: 10.1177/1533317513494449] [Medline: 23813790]
40. Newman K, Wang AH, Wang AZY, Hanna D. The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: a scoping review. BMC Public Health 2019;19(1):1495 [FREE Full text] [doi: 10.1186/s12889-019-7837-3] [Medline: 31706294]

Abbreviations

AD: Alzheimer disease
ADRD: Alzheimer disease and related dementias
ETP: expected topic proportions
LIWC: Linguistic Inquiry and word count
RQ: research question
STM: structural topic modeling
VADER: Valence Aware Dictionary for Sentiment Reasoning

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Original Paper

The Implementation Outcomes and Population Impact of a Statewide IT Deployment for Family Caregivers: Mixed Methods Study

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Abstract

Background: In 2022, the US Department of Health and Human Services released the first National Strategy to Support Family Caregivers, identifying actions for both government and the private sector. One of the major goals is to expand data, research, and evidence-based practices to support family caregivers. While IT tools are widely deployed in health care settings, they are rarely available at scale in community agencies. In 2019, the state of California recognized the importance of a statewide database and a platform to serve caregivers remotely by enhancing existing service supports and investing in a web-based platform, CareNav. Implementation commenced in early 2020 across all 11 California Caregiver Resource Centers.

Objective: This paper describes the implementation strategies and outcomes of the statewide implementation of CareNav, a web-based platform to support family caregivers.

Methods: The Consolidated Framework for Implementation Research (CFIR), including a recent addendum, guided this mixed methods evaluation. Two major approaches were used to evaluate the implementation process: in-depth qualitative interviews with key informants (n=82) and surveys of staff members (n=112) and caregivers (n=2229). We analyzed the interview transcripts using qualitative descriptive methods; subsequently, we identified subthemes and relationships among the ideas, mapping the findings to the CFIR addendum. For the surveys, we used descriptive statistics.

Results: We present our findings about implementation strategies, implementation outcomes (ie, adoption, fidelity, and sustainment), and the impact on population health (organizational effectiveness and equity, as well as caregiver satisfaction, health, and well-being). The platform was fully adopted within 18 months, and the system is advancing toward sustainment through statewide collaboration. The deployment has augmented organizational effectiveness and quality, enhanced equity, and improved caregiver health and well-being.

Conclusions: This study provides a use case for technological implementation across a multisite system with diverse community-based agencies. Future research can expand the understanding of the barriers and facilitators to achieving relevant outcomes and population impact.

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KEYWORDS

web-based assessment; caregiver; technology implementation; Consolidated Framework for Implementation Research; CFIR; information technology; IT; family caregivers; eHealth

Introduction

Background

Family caregiving is gaining visibility as an important public health issue, with 1 in 5 families engaged in long-term care for older adults and persons with disabilities often lacking adequate resources and supports [1]. The complexity and intensity of caregiving for older adults and persons with disabilities is increasing as the population ages, and more individuals live longer with physical, cognitive, and mental health challenges. Family caregivers enable family members and friends to live with chronic conditions in their environments of choice, assist with navigating acute health crises and hospitalizations, and provide comfort and support at the end of life. More than half of all family caregivers provide complex care, including medical or nursing tasks previously performed in inpatient settings, delivering most of the care after discharge from hospitals [2]. State-level data reveal that in California, at least 4.4 million family caregivers assist individuals aged >18 years; of these caregivers, more than half (56%) are employed while providing care. These individuals provide an estimated US $81 billion worth of unpaid care each year [3].

Caregivers remain relatively invisible in the health care system, to their employers, and in their communities; yet, they bear the brunt of delivering most of the long-term care for the aging population. Caregivers report a lack of knowledge regarding the best caregiving practices, often learn how to deliver care on their own, and are worried about making mistakes [2]. Most caregivers are employed, but their income is often compromised by the caregiving role [3]. While family caregivers report positive aspects of caregiving, they also experience strain, depression, and loneliness; moreover, they neglect their own health-related conditions because of the caregiving role [2]. There is evidence of health disparities in caregiving demands, supports, and resources among diverse populations by race or ethnicity and socioeconomic status [4]. Recent systematic reviews have concluded that caregivers require information and skills training, tools to improve coping with the physical and emotional burden of caregiving, paid and unpaid help, effective communication with the person in their care, and support to address barriers as they navigate the health care system [5,6].

In 2022, the US Department of Health and Human Services released the first National Strategy to Support Family Caregivers, identifying actions for both government and the private sector [7]. One of the major goals is to expand data, research, and evidence-based practices to support family caregivers. While IT tools are widely deployed in health care settings, they are rarely available at scale in community-based agencies. Clinical settings use consumer-facing features such as secure internet portals that enable individual access to the electronic health record and facilitate secure email messaging between the person and the health care provider, as well as internet-based resources for education, information, advice, and peer support [8]. IT tools could be highly beneficial for community-based caregiver assessment, service delivery, and the evaluation of a broad range of interventions, increasing access and convenience. To date, most projects examining innovative IT tools focus on feasibility and acceptance with studies of limited sample sizes [9-11].

The California Caregiver Resource Center System

Established in 1984 by the Comprehensive Act for Families and Caregivers of Brain-Impaired Adults to support caregivers and care recipients, the California Caregiver Resource Center (CRC) system includes 11 sites with catchment areas covering the entire state. Staffed with administrators, family consultants, and educators, the CRCs respond to caregiver inquiries or referrals by conducting a short intake followed by a structured standardized assessment should the caregiver want to proceed. Before 2020, these assessments were completed on paper, either in person or by telephone. In 2020, the CRCs conducted 6126 intakes, with 4299 proceeding to full assessment. In some cases, caregivers have a simple query that is satisfied with the initial contact; others seek longer-term support. After the assessment, family consultants develop recommendations for community-based services and supports based on caregiver priorities and needs, including appropriate referrals for respite, counseling, financial or legal consultation, education, and support services. The CRCs do not address the health care needs of the care recipient; instead, they recommend follow-up with health care providers.

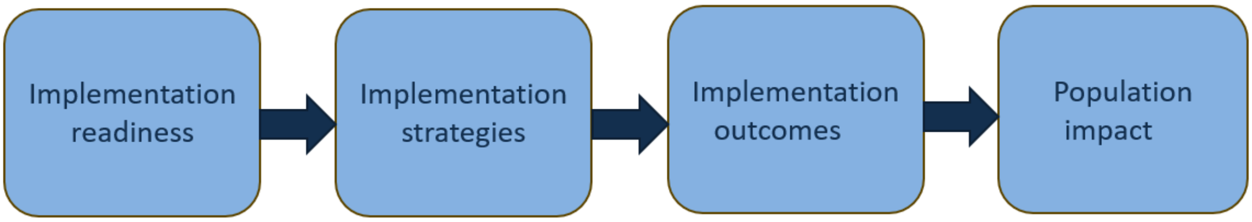
The Implementation of a Statewide Caregiver Database

Recognizing the importance of a statewide database and a platform to serve caregivers virtually, in 2019, the California Department of Health and Community Services invested in a web-based platform, CareNav, across the existing support network, the California CRC system. The Department of Health and Community Services committed to funding expanded caregiver services and the deployment of CareNav over 3 years (2019-2022). In essence, the deployment of CareNav converted a manual record system to an electronic system with expanded functionality to manage client services and supports. The proprietary software platform CareNav was developed by the San Francisco Bay Area CRC, Family Caregiver Alliance, in collaboration with software developer Quality Process [12]. CareNav enables standardized caregiver self-assessment, a web-based record of client information and encounters, secure communications, and the ability to create a care plan as well as tailored information and resource content. Clients may complete the assessment either on the web or by contacting staff members who administer and document the assessment in the electronic record. The system includes administrative functionality for tracking service authorizations and contracts, generating aggregate profiles, and producing management reports on staff activities.

Led by the Family Caregiver Alliance, statewide CareNav implementation included related training for all CRC sites on platform use, data quality improvement, and change management. The University of California Davis Family Caregiving Institute was engaged to evaluate the implementation process. A previous publication described the implementation process and early outcomes [13]. The Consolidated Framework for Implementation Research (CFIR) guided our evaluation [14]. Early findings indicated that leadership, communication, the harmonization of processes across sites, and motivation to serve clients using technology were critical elements of success.

The aim of this paper is to describe further progress, including implementation readiness, implementation strategies, and subsequent implementation outcomes and population impact of the web-based resource IT tool or platform (CareNav) at the 11 California CRCs. A recent addendum to the CFIR went beyond evaluating the outer setting, the inner setting, the intervention characteristics, staff characteristics, and the process of implementation by augmenting the original model with implementation outcomes and population impact [15]. The dynamic sustainability framework [16] informed the interpretation of the sustainability of implementation outcomes. The conceptual model for this study incorporated both the CFIR addendum and the dynamic sustainability framework, adapted from the work of Damschroder et al [15] and Chambers et al [16], and is depicted in Figure 1.

Figure 1. Consolidated Framework for Implementation Research addendum.



Methods

We used a mixed methods sequential triangulation design to examine the implementation process and outcomes, including focused interviews with CRC staff members and leaders and surveys of both staff members and caregiver clients.

Ethical Considerations

The study was determined as exempt research and approved by the University of California Davis Institutional Review Board (IRB ID: 1561379-2). No identifying information was collected from participants in the focused interviews and surveys. Participants were informed of the study's purpose and the voluntary nature of participation. In the focus interviews, participants provided oral consent to participate and to be recorded. In the surveys, participants provided assent by completing the survey.

Recruitment

We recruited participants from the 11 California CRC sites. For focused interviews, we sent an email invitation to all leaders and clinical staff members as well as the implementation team. All current leaders and staff members of the 11 CRCs were eligible to participate in the focus group interviews. For the staff survey, we sent email invitations to all CRC staff members to complete. The survey was administered electronically between July and September 2023. For caregiver surveys, the sites distributed surveys quarterly to all caregivers served in the past quarter (4 quarters during the year between July 2022 and June 2023). Caregivers were given the option to complete the survey electronically or on paper, mailing the response to the sites, whose staff members entered the data in an electronic database.

Focused Interviews

We conducted within-site focus group interviews with leaders and staff members of each site (22 focus groups in total) and interviewed 2 key informants from the implementation team. After obtaining consent to participate and be recorded, we used a semistructured interview guide to explore the CareNav implementation process, challenges and facilitators, anticipated system and client outcomes, satisfaction with the process, and training activities. The interviews were conducted over Zoom (Zoom Video Communications, Inc) in March and April 2022 and audio recorded. The duration of the interviews ranged from 45 to 60 minutes.

Surveys

The Readiness Survey

The readiness survey is a tool assessing staff preparation and confidence regarding the implementation process and self-efficacy using a 5-point scale (1 represents the most negative response and 5 the most positive response) [13]. The readiness survey also assessed knowledge about CareNav, caregiver support to use CareNav, and implementation outcomes encompassing CareNav adoption and developmental phases (fidelity). Six items addressing developmental phases rated current CareNav use and willingness to expand CareNav use according to functionalities previously identified in the focused interviews. These items were tailored to either clinical or administrative staff, depending on role. Clinical staff responded to 15 items focused on using CareNav to guide assessment and encouraging clients to access CareNav. Administrative support staff responded to 14 items focused on using CareNav data to make decisions. Open-ended questions identified benefits and concerns about CareNav, as well as suggestions for improvement.

The Caregiver Satisfaction Survey

The caregiver satisfaction survey assessed satisfaction with services, confidence in caregiving, knowledge, caregiver stress, and experiences with the web-based platform and technology. The surveys included items rated on a 5-point scale. Scores range from 1 (*strongly disagree*) to 5 (*strongly agree*), with 5 indicating the most positive impact. The survey also invited comments from caregivers in an open-ended format. Surveys were translated into Spanish and back translated into English and clients could select either English or Spanish versions.

To encourage caregivers to participate in the satisfaction survey in a safe environment and minimize social desirability bias, the surveys were anonymous, and associated demographic data were not collected.

Data Analysis

The recordings of the focus group interviews were transcribed, audited, and then imported into Dedoose qualitative data analysis software (SocioCultural Research Consultants, LLC). We used qualitative descriptive methods to analyze the transcripts and open-ended responses to the surveys [17,18] and established a 3-phase protocol for analysis. In the first phase, 3 members of the research team reviewed the transcripts and developed initial codes and definitions. In the second phase, 2 team members coded the transcripts, meeting weekly with the third member to discuss coding decisions; refine code definitions; reach consensus about the coding; and identify themes, subthemes, and relationships among the ideas. In the third phase, we mapped the themes to the CFIR addendum and the dynamic sustainability framework. We documented analysis notes, codes, and refinements in an audit trail.

Quantitative data from both surveys were analyzed using SPSS software (version 27.0; IBM Corp) to generate descriptive statistics. Mixed methods data analysis was performed after the completion of separate analyses of the survey and focused interview data. During this phase, we integrated quantitative and qualitative results and interpreted the findings in relation to the CFIR addendum and the dynamic sustainability framework.

Results

Participants

Across 11 CRC sites, 80 members of the staff (clinical staff members [family consultants or social workers]: n=43, 54%; administrative support staff members: n=10, 13%; and leaders [directors, clinical directors, and managers]: n=27, 34%) participated in 22 site-specific focus group interviews, with between 2 (2%) and 15 (19%) participants per site. In addition, we conducted 2 individual interviews with key informants from the implementation team.

For the readiness survey, there were responses from 118 staff members, of whom 112 (94.9%) completed at least 80% (12/15 for clinical staff and 13/14) of the readiness survey responses, and 105 (89%) submitted a demographic survey. Most of the participating staff members served in clinical roles (70/112, 62.5%), and the remaining (42/112, 37.5%) were in administrative roles.

All samples were diverse across age and racial identity, with most of the participants being female (60/82, 73% in the focused interviews and 85/105, 80.9% in the readiness survey). Demographic characteristics of the samples are presented in Table 1.

For the caregiver satisfaction survey, of the 5782 caregivers served during fiscal year 2022-2023, a total of 2229 (38.55%) responded. In addition to responding to the survey items, caregivers were invited to make comments about the services. Caregivers provided 1210 comments about the services, of which 40 (3.31%) were in Spanish. While we did not collect demographic data in these anonymous surveys, we present the characteristics of the population of caregivers who completed assessments between July 2022 and June 2023 with the CRC sites (n=5782) in Multimedia Appendix 1.

We present survey results and major themes from the qualitative data that reflect major components of our conceptual model: implementation readiness, implementation strategies, implementation outcomes, and population impact.

Table 1. Demographic characteristics of staff members participating in the focused interviews and readiness survey.

Participant characteristics	Interviews (n=82), n (%)	Readiness survey (n=105)[a], n (%)
Age (y)		
≤25	8 (9.8)	1 (1)
26-35	30 (36.6)	39 (37.1)
36-45	11 (13.4)	27 (25.7)
46-55	12 (14.6)	11 (10.5)
56-65	11 (13.4)	13 (12.4)
>65	4 (4.9)	6 (5.7)
Declined to answer	6 (7.3)	8 (7.6)
Sex		
Female	60 (73.2)	85 (81)
Male	16 (19.5)	13 (12.4)
Other	1 (1.2)	3 (2.9)
Declined to answer	5 (6.1)	4 (3.8)
Racial and ethnicity[b]		
African American or Black	4 (4.9)	5 (4.8)
Asian or Pacific Islander	12 (14.6)	17 (16.2)
Hispanic or Latinx	34 (41.5)	39 (37.1)
Native American	2 (2.4)	2 (1.9)
White	30 (36.6)	37 (35.2)
Other	1 (1.2)	2 (1.9)
Declined to answer	5 (6.1)	10 (9.6)

[a] Of the 118 survey respondents, 105 (89%) submitted demographic surveys.

[b] Percentages may not total 100 because respondents could select multiple racial identities.

Implementation Readiness

We assessed the implementation readiness of staff members with the readiness survey. Overall, participants had very positive attitudes toward the implementation of CareNav, with a mean total readiness score of 4.3 (SD 0.5) on a scale of 1 to 5, where 5 represents the most positive response. Average responses to all items were in the positive range (Table 2).

Table 2. Readiness survey responses 3 years after implementation launch (n=112).

Item	Score, mean (SD)
Knowledge and beliefs about CareNav	
CareNav improves the ability to record services	4.4 (0.8)
CareNav provides tailored and accessible information for caregivers	3.8 (1.0)[a]
Clients should be given a range of service delivery options to ensure they select one that works best for them	4.8 (0.5)
Self-efficacy	
Prepared to use CareNav	4.3 (0.7)[a]
Confident to use CareNav	4.4 (0.7)
Capable to use CareNav	4.5 (0.7)[b]
Readiness for change	
Positive regarding the expansion of CRC[c] services	4.4 (0.8)[b]
Positive regarding using CareNav	4.1 (0.9)[a]
Willing to do new things	4.4 (0.7)
Know where to obtain help	3.5 (1.3)
Total readiness score	4.3 (0.5)
Developmental phases of CareNav implementation	
Use CareNav data to understand the needs of diverse clients	3.7 (1.3)
Clinical support	
Use CareNav to guide assessments and enter data in real time	4.3 (1.0)
Encourage clients to access CareNav through the portal	3.1 (1.2)
Would like to expand use of CareNav to coordinate client support	3.8 (1.0)
Administration	
Use CareNav data to make decisions regarding the CRC site and its programs	3.6 (1.0)
Would like to expand use of CareNav	4.3 (1.0)

[a] n=111.

[b] n=109.

[c] CRC: Caregiver Resource Center.

Implementation Strategies

Overview

The implementation process entailed iterative, continuous, and long-term activities using real-time analysis of client data with adaptation and refinement. Focus group participants and key informants described 3 main strategies used: data harmonization and quality, training and technical support, and group learning. Figure 2 summarizes the implementation strategies.

Figure 2. Implementation strategies.

Data Harmonization and Quality

The goal of creating a statewide database and service management system carried several important assumptions, including standardizing the assessment, adopting common workflows around services and referrals, and agreeing to shared metrics for success. CRC site staff members and the Quality Process technology team engaged in data harmonization and quality, facilitated by the evaluation team. During the early part of the project, the design team engaged in deep learning at each site to understand the local conditions and to map the technology implementation path. The overall approach to initial deployment was to optimize the common elements and to minimize customization. The philosophy of designing and scaling CareNav necessitated balancing the unique data collection and integration needs of each site, with the goal of creating a state-level decision support and resource provision system to expand services for California caregivers. Thoughtful decisions were made regarding the extent of the site-level flexibility that the system could support for each CareNav feature without compromising uniformity.

The evaluation team conducted extensive analysis of CareNav data, including variables collected at intake, assessment, and reassessment, providing rapid-cycle feedback to the CRC sites when data discrepancies were identified. The evaluation team also raised issues around data quality and integrity to the CRC directors and clinical directors for discussion and consensus building. Implementation involved data harmonization—the integration of data sources and structures from the 11 sites—requiring processes to ensure data quality and consistency. There were 2 major issues in the implementation of a standardized assessment: mapping previous data to the appropriate fields in CareNav and coming to consensus on variable definitions to reconcile diverse interpretations of specific data points.

Several threats to data quality had to be resolved through consensus building. First, staff members held diverse beliefs about data accuracy and quality, which led to different practices in collection and entry; for example, staff members varied in how they conducted and recorded assessments, ranging from the majority of consultants administering the standardized assessment and completing data fields in a systematic way into the electronic record to consultants at 1 site using the standardized assessment as a general guide for conversation and later entering their interpretation of the client's narrative as data. At this site, consultants conducted guided interviews, after which another staff member entered the data. Data integrity was further threatened because staff members interpreted the meaning of data fields differently and subsequently recorded with this bias. These issues were compounded when staff members conducted the interviews in languages other than English (the only language currently supported by CareNav), then translated and entered data. Complex concepts, such as spirituality or loneliness, carry different cultural meanings and are subject to linguistic inaccuracy across translation. Finally, site leaders varied in their commitment to ensuring data quality and in their ability to provide guidance to their teams to achieve consensus and accuracy.

Training and Technical Support

Technology deployment requires extensive training and technical support. Users begin with different levels of technical and data understanding; therefore, leaders must customize training to establish shared foundational knowledge and skills and to address site- and person-specific learning needs. Furthermore, CareNav features a client portal, necessitating the preparation of caregivers—both in general digital access and specific coaching—to use the program. The implementation team advanced training and support in several ways, with site-specific education sessions, statewide web-based training, and site and individual technical support, as well as assisting staff members to support caregivers [13].

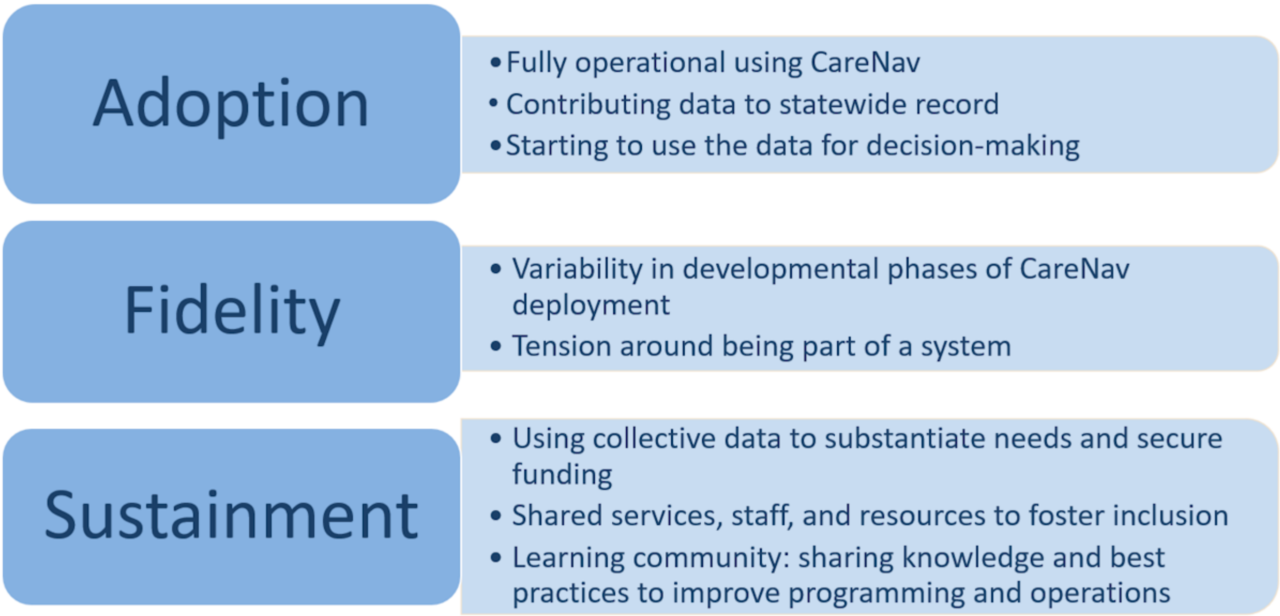
Group Learning

The statewide deployment of CareNav offered the CRC sites new opportunities for collaboration and group learning. Several subgroups were formed, including those focused on clinical, leadership, and data management issues. Within these subgroups, members across the state engaged with one another in lessons learned and shared educational materials and best practices among the sites. A statewide education committee was formed to identify and develop collective resources for both staff members and clients. The collective also focused on cross-site marketing efforts, including a central website with links to all sites, enhancing the general visibility of caregiver resources and improving the ability of clients to find the appropriate support.

Implementation Outcomes

Implementation outcomes (adoption, fidelity, and sustainment) were assessed using qualitative and survey data gathered from staff members and clients. Figure 3 summarizes the main themes encompassing implementation outcomes.

Figure 3. Implementation outcomes.



Adoption

By fiscal year 2021-2022 (approximately 2 years after launching CareNav at all California CRC sites), all CRCs had adopted the new platform and were fully operational, using CareNav and contributing data to the statewide record. A year later, in 2023, most of the staff survey participants (101/112, 90.1%) agreed (somewhat or strongly) that everyone on staff regularly used CareNav.

CareNav Functionality

Participants described the most significant features of CareNav: the standardized assessment, reports, and the client portal. The CRC sites use these CareNav features for 2 primary purposes: as client records to facilitate serving individual clients and for consultant- or site-level management of the client population. Table 3 summarizes CareNav features and their use, along with more detailed description.

Table 3. Standardized assessment, report generation and a client portal are CareNav features.

Functionality	Standardized assessment	Report generation	Client portal
Client level			
Client records	Data collection and service history	Client use and web-based resource use	Self-administration of intake and assessment
Case management and decision support	Access to client records for all staff members on the team	Aggregate client data and units of service	Messaging clients and assigning resources
Staff-client interaction and service provision	Generating tailored resources	Client engagement and units of service	Asynchronous access and communication
Consultant, site, and system levels			
Caseload management to support efficiency	Navigation features (search, sort, and filter)	Clinical staff caseload	—[a]
Outreach and diversity, equity, and inclusion	Ease of access for diverse clients	Outreach and service for target populations	Convenient access to services
State-level planning	Aggregate summary of client needs	Populations served and service provision	—

[a] Not applicable.

The most common and universal use of CareNav is for client data collection. The sites described the advantages of having streamlined longitudinal records that are accessible in real time. CareNav provides ready access across staff, facilitating the continuity of client service and support, as well as case management along the service trajectory. CareNav improves team capability, facilitating care coordination among staff members, streamlining client communication, and building trust. Clinical directors and administrators use aggregate client data to manage and assign caseloads for staff members and guide outreach and program planning priorities. At the system level, standardized data collection has enabled the first-ever comprehensive view of caregiver needs in California, populations served, a comparison of clients to other caregivers in state or national databases, and service provision. CRC directors identified the power of this information to guide strategy, resource allocation, and policy:

> *One of the things I love as a director, is how we can look at the data and what we can do with the data...I'm able to look at our numbers and look at sort of our demographics, look at the profile of who we're serving, and I've been able to take that information and talk to county funders about...who are the caregivers in...County that your funding has to serve?...We were able...to look at the difference between what's going on with our folks in rural areas and what's going on in nonrural areas. And it was a surprise to people that, it's the same... And that was really awesome, because we were expecting our rural folks to be faring probably, I think worse because they were more isolated...So we can use that internally as well...And we looked at...our need to be more accessible to our diverse populations...I was able to...look at...some of our rural areas, and...we haven't really served our Indian population, our tribal communities, as well as I think that we should.* [Director]

The client portal is a major innovation for CRC service delivery, providing clients with continuous access to the CRCs to post queries, complete assessments, review tailored resources, receive service vouchers, and communicate with CRC clinical staff members asynchronously. The adoption of this feature is a multifaceted process that requires the involvement of clinical staff members and clients. The clinical staff members reported that some clients prefer self-administration of the intake and assessment because it is faster and more convenient than an interview, while others prefer engaging with staff members for the assessment. CRC clients reported that they appreciate the convenience of choosing a time to complete the assessment, the privacy compared to speaking on the telephone, and the ability to complete part of the assessment and return to it later:

> *We appreciate having the access to be able to do the assessment and the reassessment online and to be able to compare especially...an old reassessment to what we're doing now, so you can see side by side...so I can see the changes and that helps generate a little bit more conversation...if we see a bigger change...we can have that conversation of what happened, how has that impacted you as a caregiver? And...being able to offer a little bit different resources, then maybe...I wouldn't have been able to do before, just because I wasn't able to see the change.* [Staff]

The client satisfaction survey collected information about caregiver experiences with the web-based platform. Of the 2125 respondents, most were offered web-based services (n=1734, 82%), and a quarter of the respondents (n=533, 25%) indicated having used the CareNav system. Most of the caregivers who used CareNav were satisfied with the experience (extremely satisfied: 255/533, 47.8%; somewhat satisfied: 170/533, 31.9%). Those who did not use CareNav were asked about the reasons for not engaging with the web-based program. The largest barrier to use was awareness about the program (439/1390, 31.58%), followed by the impression that the caregiver did not need CareNav (265/1390, 19.06%) and a lack of technology experience (192/1390, 13.81%). Access to the internet (55/1390, 3.96%) and finding the platform too confusing (21/1390, 1.51%) were minimal barriers.

Staff members at sites offer varied levels of expertise and motivation in supporting clients, with some unable or unwilling to provide the necessary technological support and education to enable client self-administration. Some sites took a proactive approach, having a dedicated staff member to monitor clients who start a record and to reach out to offer support, as well as to send invitations to sign up and complete the web-based intake form before an appointment with a family consultant. A third of the clinical support staff members (23/70, 33%) in the survey reported encouraging clients to access CareNav through the portal.

Fidelity

Site-level analysis of CareNav use revealed that while all CRC sites now use CareNav for daily operations, individual sites represent different dynamic stages of the operational integration of CareNav, outreach approaches, and expansion of services, as well as diversity, equity, and inclusion efforts. The sites were categorized as *early phase* or *advanced phase* for each of the 6 dimensions. We categorized sites as *early phase* if they focused on more technical, basic, and passive actions and as *advanced phase* when they presented a more strategic approach and more use of data- and outcome-oriented operations. Table 4 depicts the developmental phases of the implementation of the platform across the 11 sites.

Table 4. Fidelity: the developmental phases of implementation by site.

Dimension	Developmental phase description		Site-level developmental phase (sites: N=11)											
	EP[a]	AP[b]	1	2	3	4	5	6	7	8	9	10	11	AP sites, n (%)
CareNav functionality	Client level: data collection and documentation	Client level: case management and decision support; consultant, site, and system levels: caseload management	EP	AP	AP	AP	AP	AP	AP	AP	AP	AP	AP	10 (91)
CareNav feature: standardized assessment	Asynchronous and selected fields; dedicated technical staff members entering paper data	Synchronous, comprehensive data collection; staff members or clients enter electronic data in real time	EP	AP	EP	EP	AP	AP	AP	EP	AP	EP	AP	6 (55)
CareNav feature: report generation	Predefined templates for reports	Flexible reports run by sites as needed; use reports for decision support	EP	AP	EP	AP	AP	AP	AP	EP	EP	AP	EP	6 (55)
CareNav feature: client portal	Passive approach	Active approach: staff members encourage and support clients to use client portal	EP	AP	AP	AP	EP	EP	EP	AP	AP	EP	AP	6 (55)
Outreach approach	Historical relationships and referral sources	Using data to guide and evaluate selective outreach	EP	AP	EP	EP	EP	EP	EP	EP	AP	EP	AP	3 (27)
Diversity, equity, and inclusion	Translation of materials and focusing on specific local ethnic groups	Broad definition of diversity (race and ethnicity, geography, LGBTQ[c] identities, and income) and using data to identify opportunities for inclusion	EP	AP	EP	EP	AP	EP	EP	AP	AP	AP	EP	5 (45)

[a] EP: early phase.

[b] AP: advanced phase.

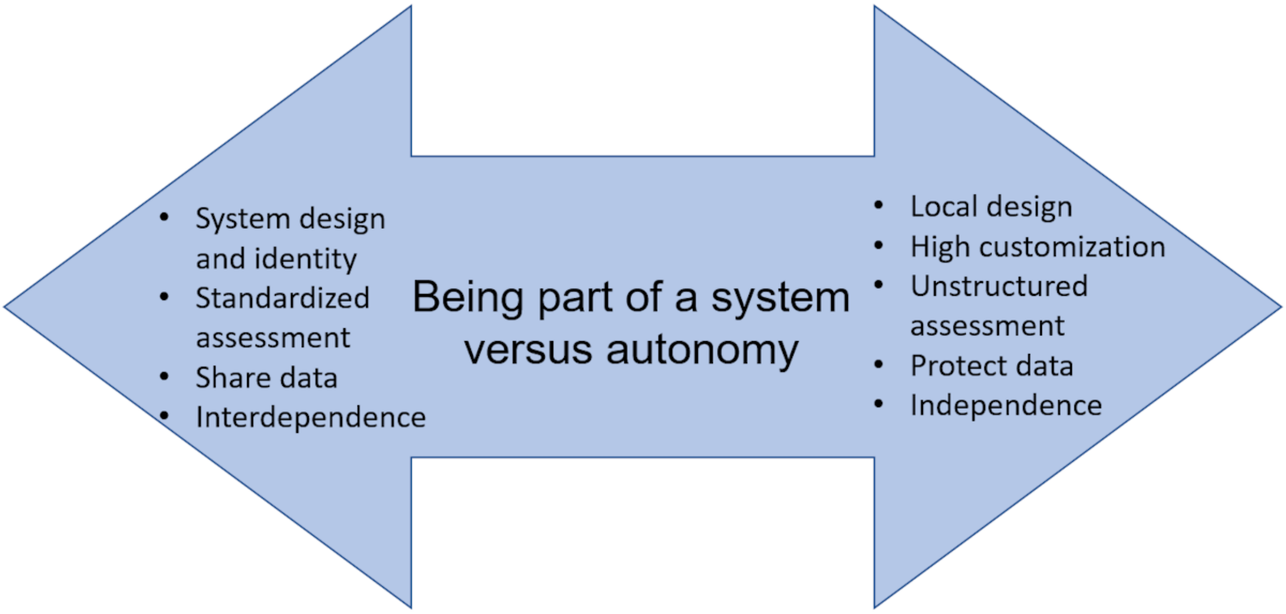
[c] LGBTQ: lesbian, gay, bisexual, transgender, and queer.

As can be seen in Table 4, the sites are in different phases of implementation depending on the dimension: of the 11 sites, 1 (9%) is operating at an advanced level across all dimensions, and 1 (9%) is at an early level across all dimensions. The most advanced dimension across sites is data collection and documentation, while the dimension with the lowest advancement, with only 3 (27%) of the 11 sites at advanced level, involves using data to create strategies for outreach:

> *Learning a new system. It just requires...time and patience and flexibility. And one thing came up...about CareNav in particular...there's a lot of functionality built into it. We can do a lot of things with CareNav. And so right now we're doing, maybe we're only using a certain percentage of all of the tools that are built into it, and really learning how.* [Staff]

The developmental phases were shaped by the baseline systems in place at each site and their unique local conditions and relationships. A major interview theme related to the developmental phase was how each site weighed the benefits of incorporation into the CRC system alongside the benefits of autonomy as an individual CRC (Figure 4). For some sites, CareNav implementation involved a shift in service philosophy, in addition to implementing new technology; for example, this shift triggered a tension between a professional philosophy valuing open-ended interviewing and the standardization of the intake and assessment processes, an important feature of incorporation into a larger system with a uniform database. Most of the tension around being part of a system centered on standardized assessment, coupled with the ability to customize reports to meet local needs. This tension was most acute when a site had a previous data management system in place, requiring adaptation and harmonization. Another area of tension related to the extent to which sites are proactive in reaching the population of the region versus being more reactive and relying on established referral sources. As a statewide system with a commitment to expand services, advanced sites are using data to identify unmet needs in the region and designing strategies to connect with underresourced communities and to tailor programs to meet cultural and linguistic requirements. Furthermore, they are collaborating with one another to leverage resources across regions.

Figure 4. The tension between being part of a system and being autonomous.



The readiness survey results (Table 2) illustrate the overall extent to which CRC staff members and leaders integrated CareNav and service expansion dimensions into their operations and future plans. The highest-rated items (mean 4.3, SD 1.0) were using CareNav to guide assessments and enter data in real time and a desire to expand the use of the platform. The lowest-rated item was encouraging clients to use the portal (mean 3.1, SD 1.2). Most of the participants with clinical support roles (56/70, 80%) used CareNav to guide assessments and enter data in real time, and two-thirds (43/70, 61%) would like to expand the use of CareNav to coordinate client support. Only a third of the clinical staff members (23/70, 33%) agreed that they encourage clients to access CareNav through the portal.

A little more than half of the participants with administrative roles (23/42, 55%) used CareNav for decision-making regarding the CRC site and its programs (eg, targeted outreach and program offerings), and more than two-thirds (30/42, 71%) were willing to expand the use of CareNav (eg, generating new reports, using data for program improvement, and making decisions). Two-thirds of the participants (69/112, 61.6%) used CareNav data to understand the needs of diverse clients (eg, in terms of race, ethnicity, geography, sexual orientation, gender identity, and income). They reported using these data to implement various strategies, including collecting demographic data, targeting grant funding and outreach based on a comparison between intake data and census demographics, improving linguistic access, training staff, and expanding the resources available in CareNav.

Sustainment

The focused interview participants highlighted having a shared identity and mission, sharing data and collaborating as critical elements to actualize the potential of a system of delivery for California's caregivers and to promote sustainability. The most commonly discussed system outcome was the statewide identity across the sites that has created various opportunities for current and future partnerships. Several expressed pride in being part of a system that is a model for the nation and has a goal to support all caregivers in California. Both staff members and leaders identified the creation of new structures supporting long-term collaboration between the sites and the use of the CareNav statewide comprehensive database as a path to sustainability. They recognized the power of working together and using their collective data to better serve clients and to substantiate client care needs toward the goal of securing funding for sustainability.

CRC leaders also identified system-level outcomes that benefit clients directly. They recognized the potential of shared services, staff, and resources to foster greater inclusion across race or ethnicity and language groups. This has particular impact for service to smaller or more geographically dispersed populations. The statewide shared calendar of virtual events is a prime example of the wide and efficient dissemination of useful culturally and linguistically appropriate resources across the entire state.

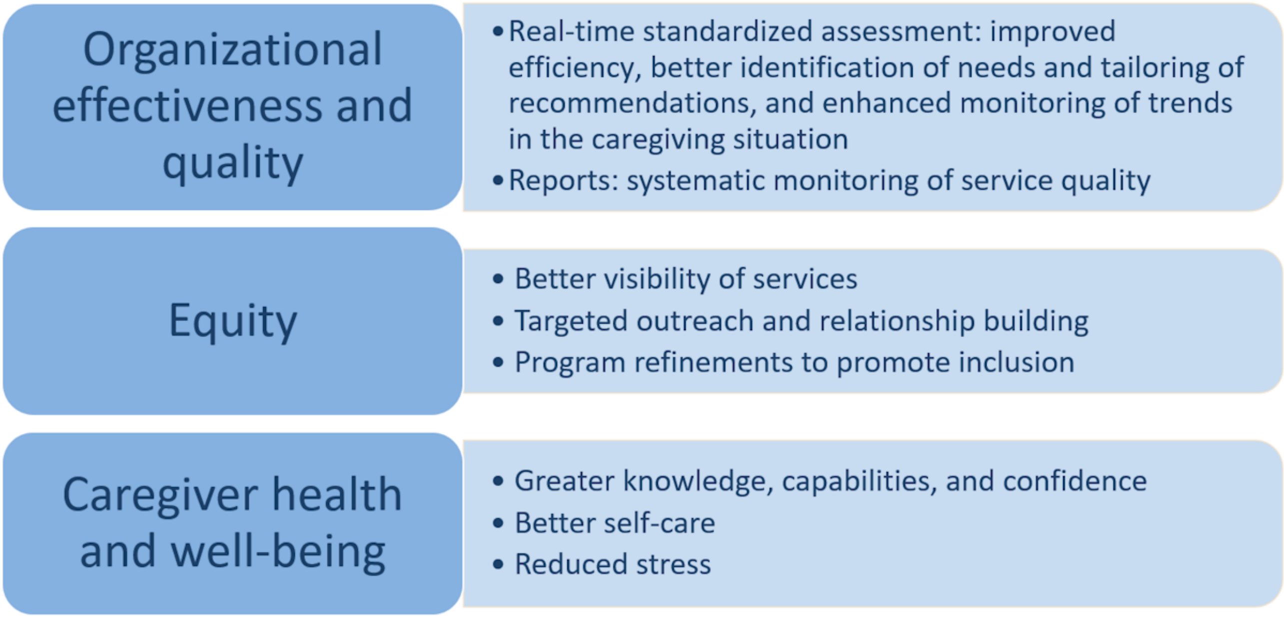
The CRC leaders have formed a learning community with one another, sharing best practices and knowledge to improve the quality of their programming and operations. Directors and clinical directors have developed system-wide clinical policies and engaged in cross-site marketing efforts. Several statewide meetings involving directors, clinical directors, supervisors, and education coordinators are building collective momentum. The statewide education committee enriches site-level effectiveness and creates shared resources, as a director explains:

> *Since we've gone forward with CareNav, our entire Caregiver Resource Center system has really gone through a massive enhancement. And I think a lot of it is the work that the directors and the staff have done. So we're getting together on a regular basis. We're meeting. We are developing, you know, policies with the clinical side, the staff, they're getting together and they're coming up with policies. We've created a marketing campaign. Through Zoom, we're now sharing education events statewide and collecting data statewide. So again, CareNav is critical tool. But I think the driving force behind everything has been this kind of movement of the Caregiver Resource Centers coming back together, working with lobbyists, legislators, leveraging money to come in and support our efforts.* [Director]

Population Impact

The impact on the population manifested in 3 major ways: achieving organizational effectiveness and quality, promoting equity, and enhancing caregiver health and well-being. Figure 5 depicts the population impact.

Figure 5. The population impact.



Organizational Effectiveness and Quality

Leaders described greater operational effectiveness and responsiveness as well as improved quality of services. The real-time standardized assessment assured better identification of needs and tailoring of recommendations for clients. With the documentation of repeat encounters, staff members were able to monitor the caregiving trajectory and augment resources as needed. The web-based platform enabled better communication among staff members and greater efficiency in serving clients as a team. Site leaders valued the ability to monitor the quality of service and to use data to guide decision-making around staff assignments and program priorities. The client portal facilitated timely and consistent communication with clients at convenient times for them as well as a central repository of individualized resources and services.

The most reported impact of CareNav on serving clients was the ability to provide more resources for more people in a faster and more convenient way. Many staff members noted improved client-provider relationships because CareNav allows a transparent means to provide services, accessible to both staff members and clients, fostering a more collaborative relationship. The virtual messaging tools enable timely and consistent communication. Web-based statewide resources provide more options to clients than a small regional program can offer, providing more opportunities for caregivers to access educational and support group resources from any site.

Equity

CareNav promotes equity by targeted subgroup analysis to better understand the experiences and priorities of diverse caregivers, enabling more thoughtful tailoring of both outreach and programs. The aggregate profiles of clients served by each CRC provided information about the reach of the programs and the gaps in service for subpopulations in the region. Synthesis of the data identified opportunities for developing new partnerships in the community to promote visibility to, and acceptability for, underserved caregivers. The data also provide guidance for strategic planning around program enhancement to achieve cultural congruence and to promote inclusion. Leaders have forged new shared services, staff, and resources to foster inclusion. A statewide shared calendar of virtual events, such as educational resources in various languages, has increased access for all regions. Several sites have collaborated to match staff members to their regional linguistic diversity, enabling the provision of consultation in the preferred language of the caregiver. Some staff members expressed concern about the digital divide disproportionately affecting certain client populations because of cost, internet access, or technological literacy. To accomplish digital equity, staff members recognize that full client engagement will require further tools and education to prepare clients to use the CareNav platform.

Caregiver Health and Well-Being

All parties identified benefits for caregivers, including improved health and well-being. Specifically, clients appreciated having a centralized resource that records precise identification of both care recipient and caregiver needs, coupled with tailored resources. Overall, staff members reported that CareNav has improved their ability to identify and respond to client needs and has changed the way they engage with clients:

> *[T]hat [the results of the assessment] gives you room to have a conversation...No wonder you're feeling so overwhelmed. Look at, this is what you just told us. We're not guessing you're overwhelmed. You just told us you were overwhelmed, right, by answering these questions in that way. So, having the questions you ask in CareNav, sort of be the structure for that, the clinical interview...but taking that information and using it for developing the care plan...You said you don't have your financial...documents in order, so...perhaps that should be on your care plan, right? Is that something that you can commit to do?...you're feeling overwhelmed and isolated, perhaps one of our support groups might work, right?...what we ask in the assessment tells you, sort of, informs the conversation with the client.* [Staff]

Caregivers, staff members, and leaders highlighted the positive impact on caregiver health and well-being. The assessment followed by a tailored care plan prioritizing the most pressing concerns resulted in positive outcomes for clients. Caregivers reported gaining confidence, knowledge and awareness of community resources, better understanding of the care recipient's situation, and better ability to manage the care they provide:

> *The family consultant is such a valuable resource...Helping us to connect to different resources, helping us to remember [that] we, as caregivers, shouldn't forget to take care of our mental, emotional, and physical well-being. I am grateful they can help us to organize and make a plan to help ourselves to be there for our care receivers.* [Caregiver]

The caregiver satisfaction survey explored the impact of CareNav and services on the lives of the caregivers (mean scores are presented in Table 5). The results indicate strong impact in confidence and ability to manage care, increased knowledge and awareness, better access to community resources, enhanced understanding of the disease or disability and issues, improved self-care for their physical and mental health, and reduced feelings of stress.

Table 5. Caregiver satisfaction survey scores: the impact of CareNav and services on caregiver lives (n=2254).

Item	Score, mean (SD)
More confident as a caregiver	4.2 (0.8)
Better able to manage care	4.2 (0.8)
More knowledge and awareness	4.3 (0.8)
Understand the disease, disability, or problem better	4.1 (0.9)
Taking better care of self	4.1 (0.9)
Less stressed	3.9 (1.0)

Discussion

Principal Findings

This paper describes a rigorous evaluation of a complex implementation of a statewide web-based platform to enhance services provided to family caregivers. We presented findings about implementation strategies, implementation outcomes (ie, adoption, fidelity, and sustainment), and the impact on population health (ie, organizational effectiveness and equity as well as caregiver satisfaction, health, and well-being). The platform was fully adopted within 18 months, and the system is advancing toward sustainment through statewide collaboration. The deployment has augmented organizational effectiveness and quality, enhanced equity, and improved caregiver health and well-being.

The CFIR addendum and the dynamic sustainability framework provided a useful approach to explore cross-site variability and the driving forces for implementation and sustainability. A deeper consideration of outcomes can drive meaningful evaluation that includes both implementation and innovation outcomes as well as a consideration of the indicators of sustainability and impact on the population served [19].

The implementation of CareNav occurred during a unique time in history marked by rapid advances in technology in all sectors of society, changing expectations among caregivers as younger generations assumed this role, and a global pandemic. In many ways, these forces accelerated and aided the implementation process. In other ways, these collective changes deepened the divide between those who accept and embrace change and those who prefer to retain the status quo. Early implementation findings suggested that some of the sites, particularly those embedded within larger health systems, experienced a tension between harmonizing workflows with the other CRC sites and also retaining compatibility with the workflows and technologies of partner organizations [13].

Although tension around adapting individual site workflows remained a theme in this longitudinal view of implementation, site-specific technology support and training helped to address logistical barriers, and group learning provided opportunities to build consensus around which modifications were the most important. With the complexity of CRC operations, from client engagement and outreach to creating business efficiencies, it is not surprising that the sites manifest variable patterns of implementation phases across CareNav and service expansion dimensions. As has been suggested previously [20], local contextual factors drive the priority of various strategies to accomplish implementation, an observation amplified across the 11 sites in this evaluation. The variability in developmental implementation patterns is expected across a diverse network of organizations. The tendency to focus on individual client data before engaging in more advanced analytical processes provides evidence for a nonlinear implementation course of a multicomponent health IT adoption. It was helpful to the evaluation to establish the developmental phases of the implementation to consider both site-specific attainment of minimal progress and overall evolution.

The leaders of this initiative used an iterative, continuous, and long-term implementation strategy that advanced the full adoption of CareNav in daily operations. The effort was accelerated by providing appropriate training and technical support and fostering a learning community. The relatively high scores we identified across items on the readiness survey persisted over time, suggesting that these support efforts have helped to prepare CRC staff members effectively for implementation and ongoing operations.

The client adoption rates of approximately 25% exceeded the reported rates of patient portal adoption in health care systems. In a study conducted in the Netherlands, 20% of older adults who were hospitalized activated a patient portal account. The participation rate decreased with age, with approximately 50% more patients aged >76 years declining to create an account compared to those who activated one [21]. Similarly, in a community-based sample of ethnically diverse patients with low-income status attending a rural clinic in the United States, 20.5% reported using their patient portal, with greater odds of engagement for those having higher education and social support coupled with frequent internet use [22]. In the case of CareNav, the most important barrier was a lack of awareness of the opportunity to use a web-based portal. This finding contrasts with a systematic review of patient portal and electronic personal health record use, where the major barriers were privacy and security, access to the internet, and the ability to use technology [23]. Together, these findings suggest that caregiver clients are using the system at a level slightly higher than health system portals and that increasing awareness could be the most important strategy to increase engagement.

The CareNav implementation process fostered statewide system identity and created structures that had a significant role in promoting the sustainability of the implementation. Future efforts should focus on achieving sustainment and realizing population impact. Data-driven strategic decisions have the potential to realize operational efficiencies while prioritizing the most effective efforts of staff members. The system has the potential to support the documentation of population impact and cost-effectiveness as a persuasive strategy to procure sustainable funding for vital programs. Going forward, with a goal of achieving advanced implementation across all sites, training and technical support could focus more attention on enhancing site- and system-level functions and optimizing the use of data to drive both client-level and system-level decisions and priorities.

On the basis of data about the population served and gaps in program offerings, both staff members and leaders articulated the need for broader cultural adaptation of the service model for specific communities, including the linguistic translation of assessment and educational materials. Beyond language, several CRC leaders and staff members recognized the importance of a broader cultural adaptation approach for specific communities (eg, caregivers from tribal communities, underresourced racial or ethnic groups, the LGBTQ+ [lesbian, gay, bisexual, transgender, queer, and similar minority] community; and rural settings) to assure the congruence of programming with client needs and to advance equity. Several leaders cited the dearth of evidence about the best approaches to serve certain underrepresented communities and shared the hope that evaluation of their efforts will contribute to this important knowledge base.

For clients, digital equity occurs at multiple levels, from the availability of internet service in certain communities and the affordability of service to technological literacy. CRC staff members play a vital role in encouraging clients to use the web-based program and providing technical support as they navigate the system, and some of the sites are more effective at promoting web-based engagement than others. Full deployment requires overcoming these barriers and ensuring access to all caregivers who desire to participate in this way.

The limitations of this study included reliance on self-report from staff members and caregivers regarding implementation progress. This limitation was partially offset by the triangulation of actual data entered into CareNav that was analyzed by the evaluation team to identify quality and integrity issues. With the iterative process of engagement among the evaluation team and the sites implementing the program, we were able to identify progress and barriers associated with implementation in real time. The implementation occurred in a state that is more diverse demographically than many other US states, limiting generalizability to all states but providing valuable information related to equity.

Conclusions

The study identified individual and site-level factors related to the CareNav implementation process. Future longitudinal studies should explore long-term adoption trajectories to inform continuous implementation planning, particularly to guide implementation efforts in complex health or social care systems, where one size does not fit all. Further research could examine longer-term outcomes, particularly in the areas of impact on clients served. Finally, the question of the extent to which automating social service processes and using artificial intelligence expands capacity is a vital consideration with the growth of the older adult population and the need for new solutions to increase capacity.

While electronic records are common in health systems and in a variety of industries, community-based agencies have lagged behind in adoption. Advancement in technology in this sector is essential to realize the integration of health and social services for the betterment of population health and to address the growing demand for services. The results of the efforts of the California CRCs provide a compelling use case for the successful implementation and adoption of technology in community-based agencies. Going forward, the California CRCs will grapple with important questions about being a statewide system, advancing technological capacity for clients and staff members, and solving vital equity issues to provide services and supports to all caregivers in need.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics of caregivers served by the California Caregiver Resource Centers (n=5782).
[DOCX File , 25 KB - aging_v7i1e63355_app1.docx]

References

1. Schulz R, Eden J. Families Caring for an Aging America. Washington, DC: The National Academies Press; 2016.
2. Reinhard S, Young HM, Levine C, Kelly K, Choula R, Accius J. Home alone revisited: family caregivers providing complex care. AARP Public Policy Institute. 2019 Apr 17. URL: https://www.aarp.org/pri/topics/ltss/family-caregiving/home-alone-family-caregivers-providing-complex-chronic-care/ [accessed 2024-11-01]
3. Reinhard SC, Caldera S, Houser A, Choula R. Valuing the invaluable 2023 update: strengthening supports for family caregivers. AARP Public Policy Institute. 2023 Mar 8. URL: https://www.aarp.org/pri/topics/ltss/family-caregiving/valuing-the-invaluable-2015-update/ [accessed 2024-11-02]
4. Whitney RL, Bell JF, Kilaberia TR, Link BM, Choula RB, Reinhard SC, et al. Diverse demands and resources among racially/ethnically diverse caregivers. Ethn Health 2023 Aug 01;28(6):912-931. [doi: 10.1080/13557858.2023.2179022] [Medline: 36858966]
5. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. J Clin Nurs 2009 May 08;18(10):1379-1393. [doi: 10.1111/j.1365-2702.2008.02405.x] [Medline: 18624779]
6. Garvelink MM, Emond J, Menear M, Brière N, Freitas A, Boland L, et al. Development of a decision guide to support the elderly in decision making about location of care: an iterative, user-centered design. Res Involv Engagem 2016 Jul 19;2(1):26 [FREE Full text] [doi: 10.1186/s40900-016-0040-0] [Medline: 29062524]
7. National strategy to support family caregivers. National Association of Counties. 2024 Jan. URL: https://www.naco.org/sites/default/files/2024-01/Natl-Strategy-Support-Fam-Caregivers.pdf [accessed 2024-11-02]
8. Ricciardi L, Mostashari F, Murphy J, Daniel JG, Siminerio EP. A national action plan to support consumer engagement via e-health. Health Aff (Millwood) 2013 Feb;32(2):376-384. [doi: 10.1377/hlthaff.2012.1216] [Medline: 23381531]
9. Demiris G, Iribarren SJ, Sward K, Lee S, Yang R. Patient generated health data use in clinical practice: a systematic review. Nurs Outlook 2019 Jul;67(4):311-330 [FREE Full text] [doi: 10.1016/j.outlook.2019.04.005] [Medline: 31277895]
10. Sun V, Raz DJ, Kim JY. Caring for the informal cancer caregiver. Curr Opin Support Palliat Care 2019 Sep;13(3):238-242 [FREE Full text] [doi: 10.1097/SPC.0000000000000438] [Medline: 31157656]

11. Lobo EH, Frølich A, Kensing F, Rasmussen LJ, Livingston PM, Grundy J, et al. mHealth applications to support caregiver needs and engagement during stroke recovery: a content review. Res Nurs Health 2021 Feb 20;44(1):213-225. [doi: 10.1002/nur.22096] [Medline: 33341958]
12. Family Caregiver Alliance. URL: https://www.caregiver.org/ [accessed 2024-11-02]
13. Young HM, Bell JF, Tonkikh O, Kilaberia TR, Whitney RL, Mongoven JM, et al. Implementation of a statewide web-based caregiver resource information system (CareNav): mixed methods study. JMIR Form Res 2022 Jul 13;6(7):e38735 [FREE Full text] [doi: 10.2196/38735] [Medline: 35830234]
14. Keith RE, Crosson JC, O'Malley AS, Cromp D, Taylor EF. Using the Consolidated Framework for Implementation Research (CFIR) to produce actionable findings: a rapid-cycle evaluation approach to improving implementation. Implement Sci 2017 Feb 10;12(1):15 [FREE Full text] [doi: 10.1186/s13012-017-0550-7] [Medline: 28187747]
15. Damschroder LJ, Reardon CM, Opra Widerquist MA, Lowery J. Conceptualizing outcomes for use with the Consolidated Framework for Implementation Research (CFIR): the CFIR outcomes addendum. Implement Sci 2022 Jan 22;17(1):7 [FREE Full text] [doi: 10.1186/s13012-021-01181-5] [Medline: 35065675]
16. Chambers DA, Glasgow RE, Stange KC. The dynamic sustainability framework: addressing the paradox of sustainment amid ongoing change. Implement Sci 2013 Oct 02;8(1):117 [FREE Full text] [doi: 10.1186/1748-5908-8-117] [Medline: 24088228]
17. Bradshaw C, Atkinson S, Doody O. Employing a qualitative description approach in health care research. Glob Qual Nurs Res 2017 Nov 24;4:2333393617742282 [FREE Full text] [doi: 10.1177/2333393617742282] [Medline: 29204457]
18. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health 2000 Aug;23(4):334-340. [doi: 10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g] [Medline: 10940958]
19. Schroeder D, Luig T, Finch TL, Beesoon S, Campbell-Scherer DL. Understanding implementation context and social processes through integrating Normalization Process Theory (NPT) and the Consolidated Framework for Implementation Research (CFIR). Implement Sci Commun 2022 Feb 09;3(1):13 [FREE Full text] [doi: 10.1186/s43058-022-00264-8] [Medline: 35139915]
20. Waltz TJ, Powell BJ, Fernández ME, Abadie B, Damschroder LJ. Choosing implementation strategies to address contextual barriers: diversity in recommendations and future directions. Implement Sci 2019 Apr 29;14(1):42 [FREE Full text] [doi: 10.1186/s13012-019-0892-4] [Medline: 31036028]
21. Wildenbos GA, Maasri K, Jaspers M, Peute L. Older adults using a patient portal: registration and experiences, one year after implementation. Digit Health 2018 Sep 02;4:2055207618797883 [FREE Full text] [doi: 10.1177/2055207618797883] [Medline: 30186619]
22. Arcury TA, Quandt SA, Sandberg JC, Miller DPJ, Latulipe C, Leng X, et al. Patient portal utilization among ethnically diverse low income older adults: observational study. JMIR Med Inform 2017 Nov 14;5(4):e47 [FREE Full text] [doi: 10.2196/medinform.8026] [Medline: 29138129]
23. Sakaguchi-Tang DK, Bosold AL, Choi YK, Turner AM. Patient portal use and experience among older adults: systematic review. JMIR Med Inform 2017 Oct 16;5(4):e38 [FREE Full text] [doi: 10.2196/medinform.8092] [Medline: 29038093]

Abbreviations

CFIR: Consolidated Framework for Implementation Research
CRC: Caregiver Resource Center
LGBTQ+: lesbian, gay, bisexual, transgender, queer, and similar minority

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Original Paper

The CareVirtue Digital Journal for Family and Friend Caregivers of People Living With Alzheimer Disease and Related Dementias: Exploratory Topic Modeling and User Engagement Study

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Abstract

Background: As Alzheimer disease (AD) and AD-related dementias (ADRD) progress, individuals increasingly require assistance from unpaid, informal caregivers to support them in activities of daily living. These caregivers may experience high levels of financial, mental, and physical strain associated with providing care. CareVirtue is a web-based tool created to connect and support multiple individuals across a care network to coordinate care activities and share important information, thereby reducing care burden.

Objective: This study aims to use a computational informatics approach to thematically analyze open text written by AD/ADRD caregivers in the CareVirtue platform. We then explore relationships between identified themes and use patterns.

Methods: We analyzed journal posts (n=1555 posts; 170,212 words) generated by 51 unique users of the CareVirtue platform. Latent themes were identified using a neural network approach to topic modeling. We calculated a sentiment score for each post using the Valence Aware Dictionary and Sentiment Reasoner. We then examined relationships between identified topics; semantic sentiment; and use-related data, including post word count and self-reported mood.

Results: We identified 5 primary topics in users' journal posts, including descriptions of specific events, professional and medical care, routine daily activities, nighttime symptoms, and bathroom/toileting issues. This 5-topic model demonstrated adequate fit to the data, having the highest coherence score (0.41) among those tested. We observed group differences across these topics in both word count and semantic sentiment. Further, posts made in the evening were both longer and more semantically positive than other times of the day.

Conclusions: Users of the CareVirtue platform journaled about a variety of different topics, including generalized experiences and specific behavioral symptomology of AD/ADRD, suggesting a desire to record and share broadly across the care network. Posts were the most positive in the early evening when the tool was used habitually, rather than when writing about acute events or symptomology. We discuss the value of embedding informatics-based tools into digital interventions to facilitate real-time content delivery.

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KEYWORDS

caregiving; dementia; social support; technology; intervention; Alzheimer disease; family; care network; elder; CareVirtue; open text; online platform; digital journaling tool; computational informatics; thematic analysis; topic modeling; neurodegeneration; gerontology; sentiment analysis

Introduction

Background

Nearly 7 million people in the United States currently live with Alzheimer disease (AD) or AD-related dementias (ADRD), a number that is projected to double by 2050 [1]. AD/ADRD generally progresses slowly; however, as disease symptomology worsens, most people living with AD/ADRD require support from informal caregivers (ie, unpaid family or friends) [1-5]. Recent estimates suggest these caregivers provide roughly 16 billion hours of unpaid care labor annually in the United States. Caring for people living with AD/ADRD is highly complex and has broad psychological, physical, and economic consequences [1,4,6]. Care partners are often underresourced and unsupported [5-8], which has been associated with high levels of care partner stress, burden, burnout, depression, morbidity, and isolation [2,3,9]. The national plan to address AD highlights the need to expand support for people with AD/ADRD and their families [10]. This research aimed to explore the use of a novel care support platform, CareVirtue, by AD/ADRD caregivers, particularly focusing on specific aspects of use for the platform's care journal feature.

Caregiving for Individuals Living With AD/ADRD

AD/ADRD can present with a broad set of behavioral and medical symptoms across an extended time period, contributing to the challenges of caregiving [1,11,12]. Yet, caregivers often remain underresourced and overburdened due to the complexity of AD/ADRD care [7]. Compared with caregivers of people living with other chronic conditions, AD/ADRD caregivers report higher levels of burden, characterized by greater financial, emotional, and physical strain associated with care, aiding with a larger number of activities of daily living, and more difficulty maintaining their own health and well-being [1,7]. Further, a recent review found that many behavioral symptoms of AD/ADRD (eg, sleep disturbances, aggression, and care recipient depression) were directly associated with higher levels of caregiver burden [2]. Not surprisingly, and important to this study, higher levels of perceived burden are associated with increased unplanned hospitalization and poorer quality of life for caregivers [1,2,13,14].

Alleviating suboptimal outcomes (eg, caregiver burden) associated with the progressively changing needs of people living with AD/ADRD often requires a network of multiple care partners including extended family, friends, respite providers, and paid in-home care [4,6,9,15,16]. These care networks engage with and support care partners and the person living with AD/ADRD [4,6,8,9,16-18]. Previous research has advanced a foundational understanding of AD/ADRD care networks demonstrating that (1) many AD/ADRD care partners distribute caregiving in a heterogeneous care network [17]; (2) network members have varying levels of contributions that influence the person living with AD/ADRD and other care partners [8,9,17]; and (3) care networks are currently under supported, leading to factors associated with increased caregiver burden, including role conflict and ambiguity among care network members, communication and coordination challenges, and increased task demands on care partners [4-6,16-21].

Technology Interventions to Support Caregivers

Overview

Systematically connecting and activating care networks through technology interventions is a critical area of need for improving caregiver outcomes [8,22]. As rates of AD/ADRD, and associated need for care, are expected to significantly increase in coming decades, there are increasing calls for scalable interventions to support caregivers, particularly those enabled by technology. There is growing evidence that internet-based tools are an effective and appropriate tool for delivering interventions for older adults, including individuals with some cognitive impairment [23,24]. Further, novel informatics-based tools offer potential capacity as a design feature of internet-based interventions, allowing for real-time participant monitoring and modification to meet user's unique needs in the moment. That is, by embedding certain tools into the design of such interventions, processes for delivering content can be automated to occur in real time [25]. However, to date, there is less research related to technology-based network interventions for AD/ADRD caregivers.

The CareVirtue Platform

CareVirtue is a web-based platform designed to connect a care network of AD/ADRD caregivers around the care of a person living with AD/ADRD [22]. CareVirtue is designed with features for documenting, communicating, and coordinating care needs. CareVirtue's central feature is the care journal in which caregivers can create posts about their daily caregiving experiences, create posts about caregiving updates and logistics, and ask questions that are shared with their care network. Results from a recent feasibility test of CareVirtue indicated that AD/ADRD care networks use CareVirtue's journal feature to document and share information, acquire information, cocreate strategies, and lend support to the care partner [22]. We also found that care networks used the journal to give and receive logistic, social, and emotional support [26]. Additionally, posting in the journal provided individual benefits to caregivers, including the ability to process emotions through posting in the care journal [26].

Given that the initial feasibility results indicate that journaling in CareVirtue has benefits for AD/ADRD caregivers [22], an important next step is to glean design requirements from actual use patterns that can be used to support and sustain engagement with the care journal. Therefore, this study first sought to apply exploratory topic modeling to identify primary themes among journal posts. We then explored relationships between these computer-generated themes and certain post characteristics (ie, word count and text sentiment score). Finally, we explored potential differences in care journal post characteristics based on time of day and caregiver mood, self-reported at the time of posting.

Methods

Ethical Considerations

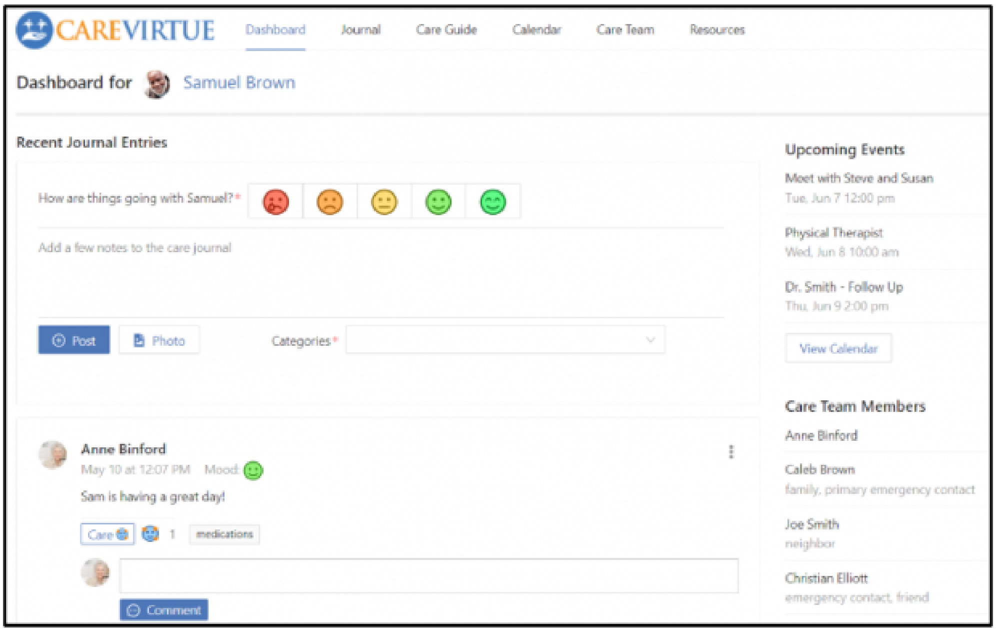
This study is a secondary analysis of the CareVirtue feasibility study (R41AG069607), which was approved by the University of Wisconsin-Madison Institutional Review Board. All participants provided informed consent. Participants were provided compensation via e-gift card for completing each stage of the trial (totaling US $150). All data was deidentified prior to analysis, with personally identifying information removed. To protect participant information, any names or proper nouns represented in text are pseudonyms.

Study Design and Primary Study Procedures

The primary study enrolled 51 caregivers and their network members to use CareVirtue for 60 days. Details of the primary study and its findings are provided elsewhere [22].

Care partners who were enrolled in the primary study first created an account on CareVirtue and then invited their chosen care network members to join their CareVirtue account. Care network members included family members and friends who were involved in the care of the person living with AD/ADRD, wanted information about the daily care of the person living with AD/ADRD, or provided social support to the care partner. Care network members can also include paid care partners such as respite care providers and in-home aides and nurses. Features of the CareVirtue platform include a personal care guide, calendar, geolocated resources, and the care journal [22,26]. As noted, this study focused specifically on CareVirtue's care journal feature. A typical CareVirtue user uses the care journal feature to document and share their daily caregiving experiences and the status of the person living with AD/ADRD with their care network, as well as to communicate with care network members. In addition to posting content using the journal, users are prompted with each post to provide a mood rating using faces as depicted in Figure 1, as well as to assign a relevant "Categories" tag that labels the post for easier search and filter (eg, medication management, behavior related, activities, and hobbies). Journal posts are displayed in the dashboard and shared with all care network members. Anyone in the care network can comment on the journal posts and respond to other network member comments.

Figure 1. CareVirtue journal.



Sam is having a great day!

Participants

Participants for this research (n=51) were AD/ADRD caregivers, recruited to participate in a feasibility study for the CareVirtue care platform. Participants were recruited for this study through flyers distributed by community partners in Wisconsin and California and through the Wisconsin Alzheimer Disease Research Center.

Data Collection

Data were collected in the feasibility study in three parts: the enrollment interview, 60-day use period, and postuse interview. During the enrollment interview, a research team member met with the participant; obtained informed consent; and oriented the participant to CareVirtue, including creating an account, inviting a care network member, and making a journal post. Care network members received an invitation email once an invitation was made in the CareVirtue system that oriented them to the study and electronically obtained informed consent. At the end of the enrollment interview, the participant completed a demographic survey via electronic survey link and then the use period began. To capture actual use, participants were instructed to use CareVirtue as they would like during the use period but were asked to log in at least once per day. At the end of 60 days, a research team member met with the participant to conduct an interview focused on acceptability. Participants were provided compensation via e-gift card for completing each stage of the trial (totaling US $150). For this study, we examine user data generated within the platform (ie, journal entries) across the trial period.

Analysis

Overview

Descriptive statistics for participant demographics were calculated. All journal posts made by enrolled care partners were then exported verbatim to .csv files for analysis. Each journal post represented a separate row in the file, with columns of relevant data including user ID, full post text, time of day, and self-reported mood rating.

Bidirectional Encoder Representations From Transformers Topic Modeling Tool

Bidirectional encoder representations from transformers topic modeling tool (BERTopic) uses a neural network approach to topic modeling. Unlike other established unsupervised topic modeling algorithms and tools such as latent Dirichlet allocation, BERTopic does not approximate topics within data using probabilities alone. Indeed, BERTopic's calculation considers pretrained embeddings from one of many transformer models. These transformer models represent a type of neural network architecture where text entries fed through the program are compared against large-scale language data to better approximate content and meaning. For each entry (ie, journal post), BERTopic then calculates an embedding that converts unstructured language data into a fixed-length and continuous vector. These vectors are then further distilled to generate latent topics for a dataset and other natural language processing (NLP) operations, including semantic meaning, sentiments, and relationships.

Principal Components Analysis and Visualization

Embeddings and vectors calculated using BERTopic are complex and often difficult to interpret. As such, we can apply dimensionality reduction techniques to better interpret the data while retaining its constituent parts. This study used a principal components analysis for this task. Principal components analysis is commonly applied for NLP analyses. This analysis allowed us to extract a range of possible clusters, or topics, and visualize them accordingly. Once we reduced the dimensionality of our vectors, we applied hierarchical density-based spatial clustering of applications with noise, to identify and name our latent clusters. We used CountVectorizer to tokenize each topic and class term frequency–inverse document frequency to extract topic words for each cluster. These additional analyses allowed us to generate various visualizations for our data to help us identify the relative similarities and differences across our topics.

Valence Aware Dictionary and Sentiment Reasoner

Valence Aware Dictionary and Sentiment Reasoner (VADER) is a rule-based lexicon and web-based dictionary that measures the polarity, or sentiment, of words, phrases, and similar text entries. VADER assumes that most words in the English language can be triaged into either positive, negative, or neutral categories. VADER also assumes that certain words may have higher or lower polarity than others, which implicates a wide range of positivity or negativity, such as the word "horrible" being inherently more negative than the word "bad." Text fed through the VADER lexicon receives a score based on the presence or absence of negatively and positively charged words. Negative VADER values (–0.99 to –0.01) largely reflect lower sentiment, mood, and affect. Positive VADER values (0.01 to 0.99) largely reflect higher sentiment, mood, and affect.

Other Measures

User Mood

User mood was measured using a 5-point, self-report item completed at the time of posting. Moods were visually represented with colorful emoji-style pictures (Figure 1), ranging from a red angry face to a green smiling face.

Time of Day

We extracted the time of day at submission for each post to the CareVirtue Journal, which were recorded as Universal Time Coordinated values. We first converted each time to local time based on user's location at the time of posting. We then assigned posts to 1 of 4 categories as follows: Morning (6 AM-12 PM), Afternoon (12 PM-5 PM), Evening (5 PM-10 PM), and Overnight (10 PM-6 AM).

Procedure

We analyzed posts generated by caregivers who used CareVirtue between March and May 2021 using an iterative BERTopic analysis in Python. We first preprocessed our data to remove names, numbers, and dates, which we determined would harm the interpretability of our topic model. Once data were preprocessed, we then iteratively applied the neural network NLP tool (ie, BERTopic) to identify prominent topics within journal entries beginning with 5 topics and concluding with 25 topics, in increments of 5 topics. We calculated coherence scores for each of the iterations as a metric of model fit, selecting the model with the highest overall score for final analysis.

All posts in the dataset were then sorted into groups, based on the topic with which they most closely corresponded. Using computer-generated topics as a grouping variable, we then explored differences in word count and post sentiment (ie, VADER scores). We further explored differences in post word count and VADER sentiment, grouped by caregiver mood and the time of day, respectively. Due to violations of normality assumptions in two outcome variables (word count and VADER sentiment score, Shapiro-Wilk test, $P<.05$), group differences were examined using nonparametric Kruskall-Wallace omnibus tests, with Dunn post hoc procedures to test for individual group differences.

Results

Participant Demographics

We first calculated descriptive statistics for participant sociodemographics. Table 1 below provides a detailed summary of this information.

Table 1. Caregiver sociodemographics.

Characteristic	Primary caregivers (n=51)
Gender (women), n (%)	38 (74.5)
Age (years), mean (SD)	60.3 (9.8)
Race and ethnicity, n (%)	
Asian	2 (3.9)
Black or African American	1 (2.0)
Hispanic or Latinx	2 (3.9)
Native American or American Indian	1 (2.0)
Not reported	1 (2.0)
White	44 (86.2)
Marital status, n (%)	
Married or domestic partnership	37 (72.5)
Divorced	11 (21.6)
Single or never married	2 (3.9)
Widowed	1 (2.0)
Education, n (%)	
Postcollege education	19 (37.2)
4-year college	17 (33.3)
Technical school, vocational training, or community college	10 (19.6)
High school diploma or equivalent	5 (9.8)
Employment, n (%)	
Full-time	21 (41.2)
Retired	19 (37.3)
Part-time	7 (13.7)
Not working	4 (7.8)
Income (US $), n (%)	
>100,000	18 (35.3)
40,000-60,000	8 (15.7)
Do not wish to answer	8 (15.7)
80,000-100,000	6 (13.7)
60,000-80,000	4 (11.8)
20,000-40,000	2 (3.9)
<20,000	1 (2.0)
Location, n (%)	
Wisconsin	29 (56.9)
California	19 (37.2)
Illinois	2 (3.9)
Virginia	1 (2.0)
Location type, n (%)	
Urban	42 (82.3)
Rural	9 (17.7)
Relationship of caregiver to person living with AD/ADRD[a], n (%)	
Child	28 (54.9)

Characteristic	Primary caregivers (n=51)
Spouse/partner	20 (39.2)
Other relative	3 (5.9)
Distance to person living with AD/ADRD, n (%)	
In household	34 (66.7)
<20 min	12 (23.5)
>2 h	3 (5.9)
20-60 min	2 (3.9)

[a] AD/ADRD: Alzheimer disease or Alzheimer disease–related dementias.

Topic Modeling

The final dataset comprised the CareVirtue Journal entries (n=1555 posts; 170,212 words) of 51 AD/ADRD caregivers. The optimal model from our analyses suggested 5 latent topics within the corpus. This model was selected after iterative generation of multiple solutions via BERTopic as it had the highest overall coherence score (0.41), indicating adequate fit to the data. After review, we determined the overarching themes to be general content about individual events, professional and medical care, routine daily activities, nighttime symptoms, and bathroom/toileting issues. Table 2 provides further detail about the composition of each topic, including the number of posts (and percentage of the total sample) associated with each topic, mean VADER sentiment score, keywords, and exemplar posts that reflect each topic. Figure 2 is a topic similarity matrix, wherein darker blue colors indicate highly correlated topics; within our data, the 5 latent topics had limited similarity to each other, indicating distinct topics. Figure 3 offers visualization of our findings through an intertopic distance map; intertopic distance maps reflect relative salience and conceptual relationships between topics. Each circle represents a latent topic in the corpus, with larger circles indicating more salient topics. Further, topics are spatially situated such that highly correlated topics will overlap, while conceptually different topics will be arranged further from each other. In our model, no topics overlap, suggesting minimal collinearity between topics. As seen in Figure 2, the topics are loosely clustered, with topics 1 and 2 (individual events and medical care) on one side, and topics 3-5 (routine daily activities, nighttime symptoms, and toileting) clustered together on the other. We discuss each broad cluster in turn below.

On the left of the intertopic distance map, the two largest topics in the corpus were conceptually linked. The largest overall topic (topic 1), with the most associated posts, was related to a broad swath of specific, individual events; this topic was qualitatively the most diverse with respect to overall content. Messages assigned to this topic generally centered on individual (ie, one-time) activities, with particular emphasis on outings or conversations, and included specific details. As such, this topic was largely defined by breaks in standard routine, with many posts focused on conversations or events that were memorable for a novel or specific reason (eg, learned a new tip, spoke to a new person, and tried a new activity). The second most common topic written about by caregivers on the platform is related to various forms of professional and medical care. These included posts about interactions with in-home health aids and nurses, as well as professional care settings (eg, doctors' offices, nursing homes, assisted living, and memory care). For those discussing in-home professional care, posts were commonly about new instructions for care or updates on patient conditions. Another common subtheme in this topic was the sharing of updates or results from doctor visits, both specific to AD/ADRD (eg, neurologists) and not (eg, dermatologists and dentists).

Figure 2. Similarity matrix demonstrating bivariate relationships between topics.

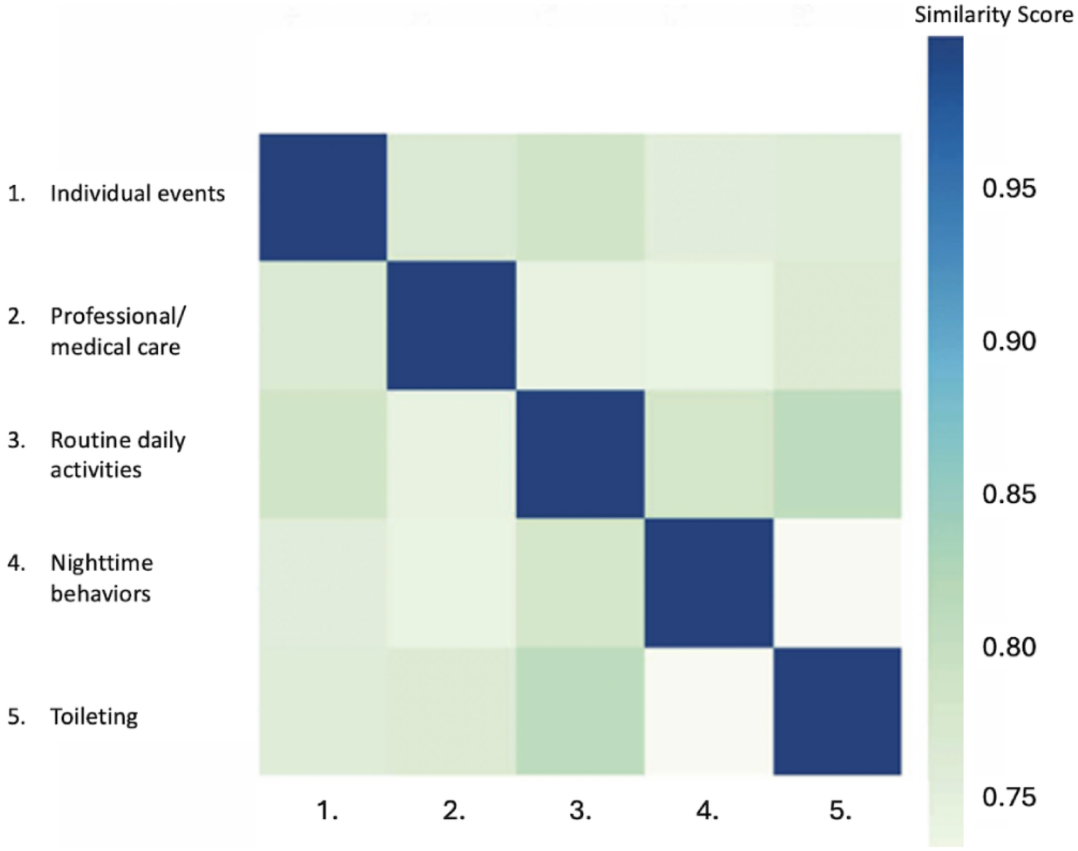


Figure 3. Intertopic distance map visualizing relatedness and relative size of topics observed.

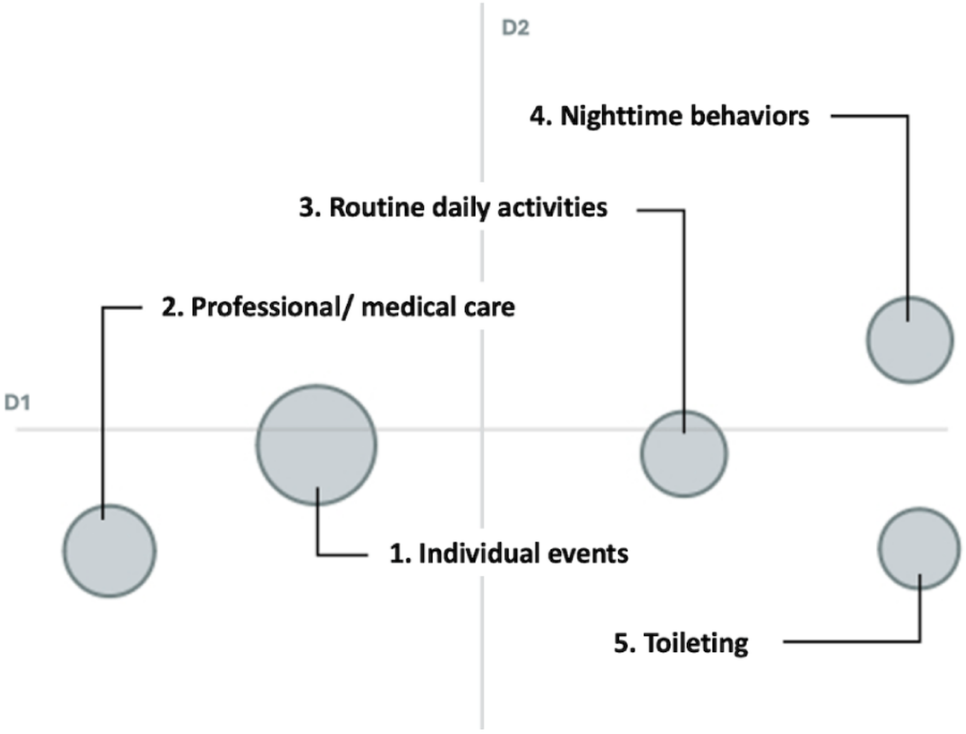


Table 2. Topic model solution for CareVirtue Journal.

Topic ID	Topic name	Post count (n=1555), n (%)	Keywords	Excerpts
1	Individual events	506 (32.75)	Busy, Pastor, Talking, Didn't, Evening, Banging, Day, Told, Work, Doesn't	• I still try to do things like we did a year ago, but the minute I get there I realize it is hard to get back to the old ways. I keep trying Flea markets, but I can't keep up with him. He wants to buy everything and talk to everyone, and I always want to leave the minute we get there. I also realized that my friends don't want to be with him, and I probably have the wrong friends because he is too sweet and good to them. • A very interesting day. The one good thing that happened, the small pot turned up. I found it when I went to make popcorn. She would say she never touched it. • [She] was hesitant at first, but really got into the painting zoom session with [others]. She was able to visualize the correct colors to use based on the image of the final product. Her control of the paint brushes was good. Lisa plans to offer more sessions in the future.
2	Professional/medical care	296 (19.16)	Aunt, Appointment, Mother, Doctor, Nurse, Care, CAN, Hospice Bed	• Was notified by [Name], a caregiver accidentally OVER medicated mom with medication that was NOT hers (Divalproex 125mg in applesauce)! This is the 5th time in 4 months that a medication error has occurred due to caregiver incompetence. Hospice nurse was called and she is being monitored by staff. • I called and spoke with [Name] (a CNA in Memory Care) where my Mom resides. She said my Mom is "tooling around" in her wheelchair. She ate all her dinner last night (fish, asparagus, etc), which is great to hear. Her behavior has been good the past couple days. • Granny has a new primary care "doctor" — [Name], NP, and she's great! She is going to do regular home checkups. In her initial visit she completed a basic memory assessment, the first I think that Granny has ever had, and also ordered a visit with a neurologist—something I've been trying to make happen for years! I am adding [the NP's] contact info to the resources tab. Her next visit is scheduled for 5/20.
3	Routine daily activities	258 (16.70)	Nap, Slept Breakfast, Woke, Morning, Lunch Tired, Bed, Sleep Laundry	• Friday we did not do showers, so the morning was enjoyable. We went to Walmart to buy dirt for the flower beds. We had lunch, naps and devotions and enjoyed the afternoon as well. [She] ate a good supper, we watched our favorite shows and she went to bed without problem. She slept through the nite with waking up only when I got her up to go to the bathroom. • Not much to report. We walked Sunday and Monday and expect to do same daily for the rest of this week. We did Zoom church on Sunday and I played music in the afternoon. Today I played tennis in the morning; [Name] handled laundry. I need to turn on the machine every now and then for her. At dinner she asked four times what was planned for tomorrow, which is very little, pickleball for me. I am waiting for a warmer day, which won't be this week, apparently, so we can go outside for lunch somewhere, maybe the Cupcake place, which has outdoor picnic tables. The TV experiment isn't working […]as she can't figure out the remote. • Tuesday, March 30th ~ Today was [dog]'s grooming appointment. Mom was not sure yesterday if she wanted to go with me to have him groomed. She said she was not feeling well and could I go alone. Today, she was ready when I called to say I was coming to pick him up. She had her cash, her keys and the dog ready. We dropped him off and I took her to Walmart for the two items she had on her list. She liked looking at the Easter Candy and decorations. I kept the trip short and then we drove through McDonalds for her chicken sandwich, one of the only foods that I know she will eat, besides sweet pastries and cookies. Everything went well, she likes [pet]'s grooming, and was happy to get out of the house to get groceries. She called at her 7 PM bedtime and said she was checking all the locks again because it was too quiet outside. I assured her it was all okay and she was safe here in this town.

Topic ID	Topic name	Post count (n=1555), n (%)	Keywords	Excerpts
4	Nighttime behaviors	257 (16.63)	Bedtime, Slept, Restless, Sleep, Sleeping, Morning, Agitated, Woke	• I had to get up every hour to handle [name]. I need to get steady sleep to function well all day. • Up last night for a few hours. She was cold even with electric blanket and extra covers. • Last evening until 2 AM this morning, [name] exhibited Sundowners Syndrome symptoms more than ever before. From when she initially went to bed at 5 PM, she was restless, anxious, fearful and attempted to shadow my every movement. Neither one of us slept much until 2 AM. I'm going to give her her bedtime meds later in the hope she will go to bed later in the evening and sleep better from that point forward.
5	Toileting	228 (14.76)	Nurse, Toilet, Doctor, Poop, Bathroom, Walk, Pee, Care, Bed, Change	• He has diaper rash back in right groin. put something on it that burned?? arthritis cream? anything in a tube he will use. doesn't wash well, just took a shower and doesn't smell good. told him to get in shower and wash off then put on a and d [sic] ointment. will he do?? why is he wearing depends all day? has to go right now! he says. urine the problem? but been in bathroom a lot too for #2 ?? • Came home from Grocery store at 8:15 on Sat and the smell of poop reeked throughout the house. [They] tried to clean up the toilet seat but things were smeared. I tried to look in and ask about it but she locked the door! I got in and she was asleep. I didn't wake her. • Well the past 24 hours have been a poop fest. Dad went from being constipated to having loose stools that have been filling his pants. Lots of showers and laundry. I finally had to put a diaper on him this morning. I hope this ends soon but not with constipation again.

The other three topics (ie, topics 3-5) were clustered together to the right of the intertopic distance map. Topic 3 generally outlined daily routines and common activities; spatially, this topic was situated between topic 0 (relating to specific events) and the two final topics related to AD/ADRD behavioral symptomology (ie, topic 4 [nighttime behaviors] and topic 5 [toileting]). Posts associated with topic 3 (routine daily activities) often included a full walkthrough of the caregivers' day, including any minor events happening throughout the day. This differed from topic 1 in that these posts did not offer details about any single event but tended to be more general in form. Topics 4 and 5 discussed two common challenges associated with AD/ADRD symptomology: nighttime challenges and toileting issues, respectively. In topic 4, caregivers often discussed "sundowning," which is a state of confusion that often occurs in the late afternoon or early evening and can lead to a disrupted sleep schedule [27]. Users also frequently noted that care recipients would wake often throughout the night, sometimes noting confusion or agitation upon waking. The final topic related to bathroom and toileting issues. Journal entries on this topic often described challenges with incontinence, including secondary infections, dirty laundry, or hesitation around the use of disposable underwear. Some posts also related to challenges with constipation or the care recipient's refusal to ask for help in toileting.

Group Differences in Text by Topic, User Mood, and Time of Day

Overview

After exploring topics present in user journals, we then sought to better understand group differences in text features (ie, length of post and VADER sentiment score) associated with topic, users' self-reported mood, and the time of day. Across the whole sample, we found an average of 110.15 (SD 153.41) words per post, with a slightly positive mean VADER sentiment score of 0.23 (SD 0.57).

Differences by Topic

Significant group differences across topics were observed with respect to both word count (χ^2_4=826.11, *P*<.001) and VADER sentiment score count (χ^2_4=212.37, *P*<.001). Descriptive statistics by topic are presented in Table 3. With respect to word count, all groups were significantly different from each other.

With respect to VADER sentiment, topic 3 about routine daily activities had higher average scores than all other groups. A middle tier, including topics 2 and 5 (professional/medical care and toileting) had the next highest sentiment scores, but did not differ from each other. The lowest tier of scores related to topics 1 and 4 (individual events and nighttime behaviors), which did not significantly differ from each other, but were significantly different from all other groups.

Table 3. Descriptive statistics of word count and sentiment score by topic.

Topic	Word count, mean (SD)	VADER[a] score, mean (SD)
1	33.11 (31.34)	0.11 (0.46)
2	71.97 (60.81)	0.24 (0.52)
3	163.88 (82.34)	0.61 (0.53)
4	46.22 (39.09)	0.07 (0.51)
5	341.93 (258.25)	0.27 (0.57)

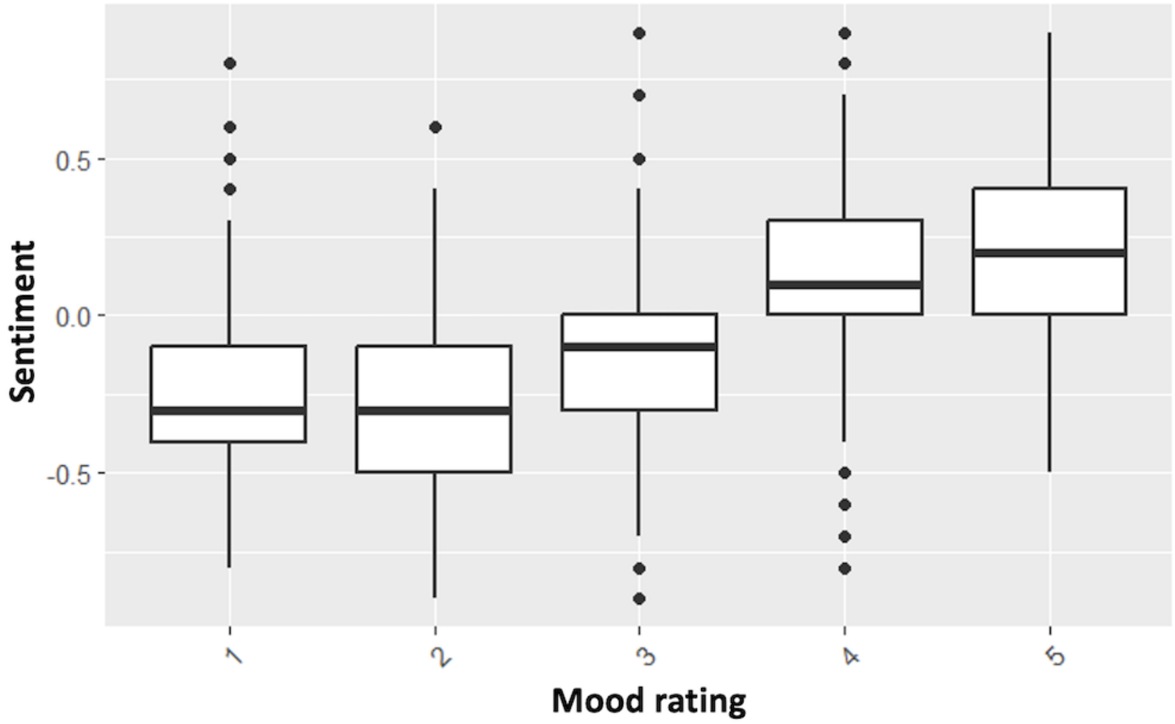
[a] VADER: Valence Aware Dictionary and Sentiment Reasoner.

Differences by User Mood

Mood ratings were self-reported using nonnumbered emojis at the time of posting (Figure 1). For analysis, mood ratings were numbered from 1 to 5, with 1 representing the worst mood state (angry, red face) and 5 representing the best (happy, green face). We observed differences in both word count (χ^2_4=46.15, P<.001) and sentiment (χ^2_4=516.93, P<.001), when grouped by mood rating. The longest overall posts were found in groups 3 (mean 117.71) and 4 (mean 126.55), which were significantly longer than all other groups, but not significantly different from each other. Word count for groups 1 (mean 91.84), 2 (mean 72.11), and 5 (mean 85.61), did not significantly differ from each other.

Text sentiment (ie, VADER scores) also differed between mood groups, following a roughly linear pattern wherein low user mood posts had the low sentiment scores, while higher user reported mood posts had the highest sentiment scores. This can be seen in Figure 4. The only groups that did not differ significantly from each other were groups 1 and 2.

Figure 4. Box-and-whisker plot showing group differences in user sentiment by self-reported mood rating.

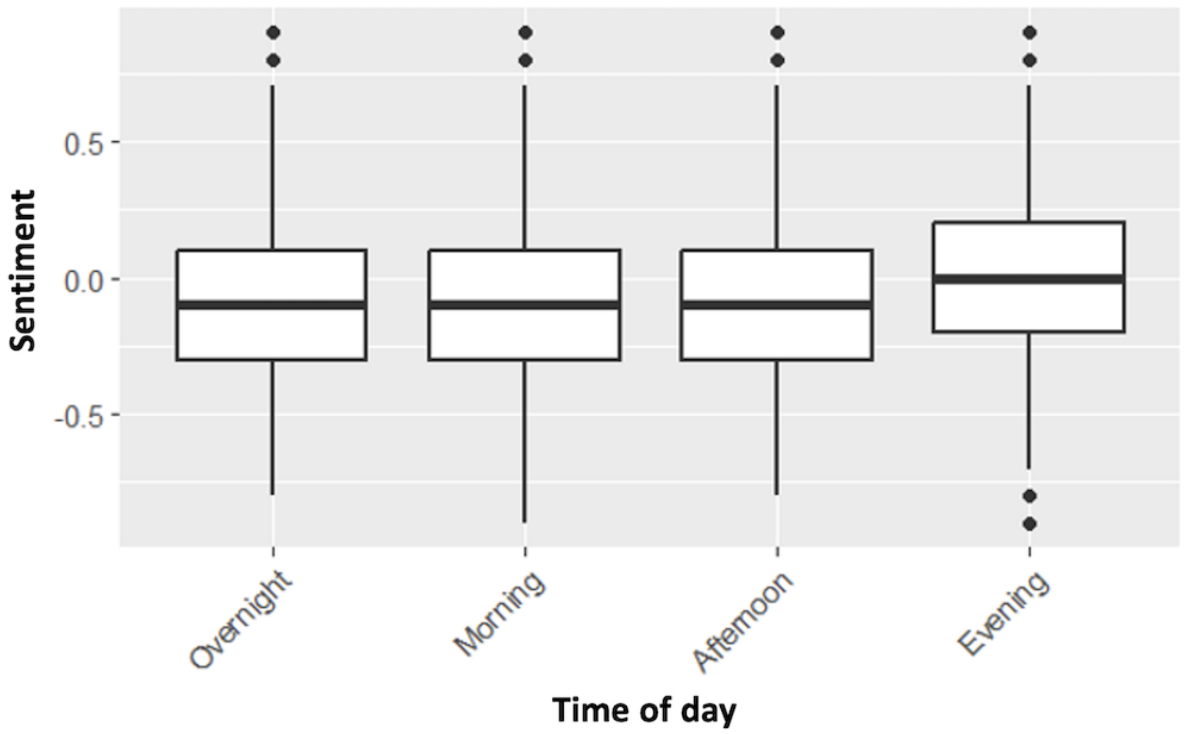


Differences by Time of Day

Finally, we examined differences in word count and sentiment score at different times of day. We again observed significant group differences with respect to both word count (χ^2_3=56.99, P<.001) and sentiment score (χ^2_3=35.71, P<.001). Posts made in the evening (mean 131.05) were statistically significantly longer than all other groups, followed by posts made in the afternoon (mean 110.60) and morning (mean 94.28), which did not significantly differ from each other. Posts made overnight were significantly shorter than all other groups (mean 46.70).

VADER sentiment scores also differed by time of day (Figure 5). Posts made in the evening had significantly higher sentiment than those made at any other time. There were no observed differences in sentiment between other time groups.

Figure 5. Box-and-whisker plot showing group differences in user sentiment by time of day.



Discussion

Principal Findings

This study sought to understand the use of the CareVirtue Journal by caregivers of people living with AD/ADRD [22,26], identifying salient topics within the data and exploring patterns related to the topic of discussion, user mood, and time of day. Using an iterative computational approach to identify the optimal topic modeling solution, we identified 5 primary themes in caregivers' journals. Broadly, these topics related to descriptions of individual events or conversations, professional or medical care, daily activity routines, nighttime symptoms, and toileting behaviors. Across the corpus of posts, users portrayed a generally positive tone, as indicated by a mean VADER score above zero. However, there was a wide deviation in sentiment scores, suggesting there was a variety of content present, including posts that were both highly positive and negative in nature. However, there was a wide deviation in VADER scores, suggesting a wide variety of sentiments across posts in the corpus, including some that were either highly positive or highly negative in nature. In examining post characteristics by time of day, we found posts written in the evening were the most linguistically positive and were longer than posts in all other groups, suggesting a more routine journaling practice at the end of the day. In contrast, the lower sentiment scores and word counts found at other times of day may reflect acute incidents users felt needed to be documented in the moment, or an attempt to fit journal writing into smaller windows of available free time. Broadly, our findings help identify key needs and salient thoughts of AD/ADRD caregivers. These findings have important implications related to increasing support for and improving the well-being of caregivers.

Based on emergent topics in the data, we identified two primary ways users communicated about care tasks and experiences using the Journal feature. These divergent patterns reflect differing approaches or use cases of the Journal feature. The first was defined by sharing information across the care network (ie, much like a social media feed) [17,26], while the other was more individually focused, operating much like a traditional journal for recording personal thoughts and experiences [28,29]. Posts in topic 1 tended to reflect the more social use case of the Journal, often describing a specific event or conversation that was memorable or had useful implications for care. For example, one user wrote, "we did the exersize [sic] class together and [he] was able to participate some of the time. He couldn't answer the question that they asked him about what he is happy about. I guess he is losing his verbal skills."

In this case, description of this event, and particularly the loss of verbal skill, would be of value to others across the care network as it may influence future interactions with the care recipient. These posts also often reflected somewhat more traditional journaling purposes, where users wrote down their experiences, thoughts, and emotions—engaging in real-time reflection or planning for changes in care practices within the post itself. Likely related to their specificity around a particular need or AD/ADRD-related event, these posts were the shortest in length and had the lowest average sentiment score of any topic.

A second latent topic in our data (ie, topic 3) included generalized discussion around care activities, with users describing an entire day or more of activities [18,29]. Posts in this topic reflected the second use case described above, with users treating the tool much like a traditional written journal. These posts generally offered limited detail about any specific activity; rather, posts on this topic seemed to serve the purpose of cataloging daily routines. Posts on this topic did not generally have specific relevance to care and would likely be of limited use to others in the care network [17]. Broadly, the primary use of these posts by other users would be in day-over-day comparisons of daily activities or symptoms. For example, one post said, “Had a busy day yesterday getting ready for a weekend visitor. Went shopping, dropped things off at recyclers, made use of great weather for a walk. [NAME] was pretty worn out by the end of the day. She went to bed early right after supper. Could not remember eating breakfast or lunch.”

These recap-style posts did not generally include the reflection elements common in topic 1, but rather provided the list of activities without further comment. Despite being among the lengthiest posts in the corpus, this topic had the highest average sentiment score, reflecting a lack of symptom-specific or other negative language that may drive down scores in other topic areas.

Caregivers also used the journal to discuss medical care and other professional assistance related to AD/ADRD care (topic 2) [26]. Posts on this topic were diverse in topic and tone, reflected by the wide deviation in VADER score across the topic. Here, there were posts relaying updates from doctors specifically related to AD/ADRD (eg, neurologists) and other medical providers (eg, dentists and general practitioners). This underscores the nature of AD/ADRD caregiving, which is not limited to a single domain, but often requires many hours per day for a wide range of support tasks [4,5]. Additionally, within this topic, users sometimes discussed individual instances related to professional care settings, including mishaps (eg, missed diagnoses and errors in medication management) and praise for individual providers.

Implications for Practice

This work has important implications for organizations seeking to provide support for AD/ADRD caregivers. First, our exploratory findings suggest two distinct use cases for the CareVirtue Journal—one for personal journaling and one for shared communication across the care network—in which users engaged roughly equally. Future refinement of care coordination platforms may provide unique space for each, with clearer instruction related to their different purposes [30]. Given the documented importance of care networks in diffusing caregiver burden and the mental health benefits associated with private journaling [17,26,28], we suggest the maintenance of both functionalities. However, due to time constraints associated with care provision, caregiver support interventions should be tailored to achieve specific tasks in a clear and efficient manner. Relatedly, our findings point to the value of both routinized and as-needed engagement with the Journal. We noted that users often posted longer messages, with a more positive sentiment, in the evening likely as part of a daily routine. By contrast, posts made at odd hours were shorter, more negative, and likely related to an acute instance. Again, however, users seemed to value both capacities of the platform. Future intervention development may consider cues to complete routine posts/engagement, while also providing additional tools to maximize use flexibility (eg, mobile optimization) [31].

In reviewing the content posted to users’ Journals, we found a broad set of general topics. However, some AD/ADRD symptomologies were particularly common among posts; specifically, users often posted about sleep and toileting issues [11,12,32]. There was also a unique topic related to professional medical care, both from physicians and in assisted or long-term care facilities. The frequency with which these topics were discussed may indicate particular stress points for caregivers [4]. This is perhaps, not surprising, as these symptoms less likely to be managed by respite or temporary caregivers, who are not with the care recipient after hours or overnight. Prior research has also found that caregivers often face challenges in determining the appropriate timing to move their care recipient into a long-term care facility [33]. Caregiver interventions and organizations may, therefore, focus efforts on creating novel mechanisms for managing these symptoms and making these determinations. For example, digital care coordination platforms like CareVirtue may nudge local, secondary caregivers in the network to explore options for providing overnight care. Broadly, our findings suggest primary caregivers of people living with AD/ADRD experience myriad, complex emotions and challenges associated with care. Novel technology-based interventions are needed to reduce burden and improve caregiver well-being [26].

One important contribution of this work was to demonstrate the capacity to use large language and machine learning tools in understanding user behavior for digital health tools. A prior study used traditional qualitative content analysis to explore the use of the CareVirtue Journal tool [26]. In that study, primary themes that emerged from the data related to caregivers’ information acquisition, information sharing, strategy development, and information feedback. While similar themes emerged in the current analysis, by using computational tools, we were able to derive additional themes and quantitatively relate these themes to user behavior. This is consistent with prior research suggesting the additive value of such methods in understanding and contextualizing large datasets of unstructured text [34,35].

Beyond uses for retrospective data analysis, the informatics-based tools here could be used within the intervention itself to automate processes for delivering real-time content across the care network [36,37]. For example, embedding a calculation of semantic sentiment score (ie, VADER) at the time of posting, given its significant relationship with user mood, could allow for the identification of caregiver stress in real time. This data could be used to then trigger in-program responses, including curated content for the caregiver related to stress reduction strategies, as well as notifications to others in the care network prompting them to reach out to the principal care provider. This is consistent with other digital health interventions, which have begun to embed artificial intelligence and other informatics-based approaches into digital interventions, including artificial intelligence–enabled chatbots [38,39]. Such applications of these tools are increasingly common, given their relatively low cost to implement and high capacity to make digital tools more immediately responsive to user needs [40].

Limitations and Future Directions

As with all research, this work had certain limitations that limit generalizability and should be noted for consideration. First, this study analyzed the free text responses of AD/ADRD caregivers, who were not given particular prompts or instructions for their use of the Journal tool. As such, individual users perceived differing uses for the CareVirtue Journal feature. While this lack of clarity provided interesting and novel insights for the design process, future research may seek to examine each use case independently. Additionally, those individuals willing to post to the shared Journal space may have certain characteristics (eg, extroversion), which may limit the generalizability of findings to all caregivers. Further, this study was completed with a relatively small sample of predominantly White, female caregivers and may not be generalizable to all caregiving situations. Readers should exercise caution in drawing broad conclusions from this work. Future research may seek to examine Journal use among larger and more diverse samples.

Conclusions

This study examined the use of a novel tool, the digital CareVirtue Journal, by caregivers of people living with AD/ADRD. Using a computational, informatics approach, we identified 5 salient themes in users' free-text journal posts. Two related broadly to the caregiving experience, but with unique use cases: a more traditional journaling approach wherein users chronicled daily routines, and a second approach for recording acute or specific events with relevance for others across the care network. Further, caregivers often journaled about professional medical care and two specific symptomologies of AD/ADRD (ie, sleep disturbance and toileting challenges). We found that users who routinely engage the platform in the evening and who reported a better overall mood also tended toward longer and more semantically positive posts. By contrast, users who engaged in off-hours or who reported poor mood tended to write shorter, semantically negative posts. Taken together, these findings suggest multiple, valuable uses for the CareVirtue Journal tool, which offers AD/ADRD caregivers space to reflect and organize their thoughts, as well as to share important care-related information across their networks.

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Authors' Contributions

JJB, CE, MZ, and NEW conceptualized the larger study and contributed to data collection. ACP, DV, PL, and LAW conducted data analysis. ACP, DV, and NEW drafted the original manuscript, which was reviewed and edited by all authors.

Conflicts of Interest

CE is the founder and chief executive officer of Whiplash Technology and the developer of CareVirtue. MZ is the Customer Service Implementation Manager for Whiplash Technology and supports the development of CareVirtue; is an Associate for HFC, which is a 501(c)3 with a mission of bringing light to Alzheimer; and sits on the Board of Directors for that National Adult Day Services Association (NADSA).

References

1. 2024 Alzheimer's disease facts and figures. Alzheimer's Association. URL: https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf [accessed 2024-12-10]
2. Abdollahpour I, Nedjat S, Noroozian M, Salimi Y, Majdzadeh R. Caregiver burden: the strongest predictor of self-rated health in caregivers of patients with dementia. J Geriatr Psychiatry Neurol 2014;27(3):172-180. [doi: 10.1177/0891988714524627] [Medline: 24614200]
3. Anderson JG, Hundt E, Dean M, Rose KM. "A Fine Line That We Walk Every Day": self-care approaches used by family caregivers of persons with dementia. Issues Ment Health Nurs 2019;40(3):252-259. [doi: 10.1080/01612840.2018.1499156] [Medline: 30422041]
4. Jutkowitz E, Mitchell LL, Bardenheier BH, Gaugler JE. Profiles of caregiving arrangements of community-dwelling people living with probable dementia. J Aging Soc Policy 2022;34(6):860-875 [FREE Full text] [doi: 10.1080/08959420.2021.1927613] [Medline: 34003081]
5. Jutkowitz E, Gaugler JE, Trivedi AN, Mitchell LL, Gozalo P. Family caregiving in the community up to 8-years after onset of dementia. BMC Geriatr 2020;20(1):216 [FREE Full text] [doi: 10.1186/s12877-020-01613-9] [Medline: 32560701]
6. Gaugler JE, Anderson KA, Leach CRWCR, Smith CD, Schmitt FA, Mendiondo M. The emotional ramifications of unmet need in dementia caregiving. Am J Alzheimers Dis Other Demen 2004;19(6):369-380 [FREE Full text] [doi: 10.1177/153331750401900605] [Medline: 15633946]

7. Werner NE, Stanislawski B, Marx KA, Watkins D, Kobayashi M, Kales H, et al. Getting what they need when they need it. Appl Clin Inform 2017;26(01):191-205. [doi: 10.4338/aci-2016-07-ra-0122]
8. Werner NE, Campbell NL, Boustani M, Ganci A, Holden RJ. Helping the Helpers - A research protocol for user-centered technology to aid caregiver management of medications for people with Alzheimer's disease and related dementias. Res Social Adm Pharm 2022;18(9):3680-3686 [FREE Full text] [doi: 10.1016/j.sapharm.2022.03.014] [Medline: 35396151]
9. Cheng ST. Dementia caregiver burden: a research update and critical analysis. Curr Psychiatry Rep 2017;19(9):64 [FREE Full text] [doi: 10.1007/s11920-017-0818-2] [Medline: 28795386]
10. National plan to address Alzheimer's disease. Assistant Secretary for Planning and Evaluation. URL: https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plan [accessed 2024-10-20]
11. Allegri RF, Sarasola D, Serrano CM, Taragano FE, Arizaga RL, Butman J, et al. Neuropsychiatric symptoms as a predictor of caregiver burden in Alzheimer's disease. Neuropsychiatr Dis Treat 2006;2(1):105-110 [FREE Full text] [Medline: 19412452]
12. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. Front Neurol 2012;3:73. [doi: 10.3389/fneur.2012.00073] [Medline: 22586419]
13. Brodaty H, Connors MH, Xu J, Woodward M, Ames D. Predictors of institutionalization in dementia: a three year longitudinal study. JAD 2014;40(1):221-226. [doi: 10.3233/jad-131850]
14. Coen RF, Swanwick GRJ, O'Boyle CA, Coakley D. Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. Int J Geriat Psychiatry 1997;12(3):331-336. [doi: 10.1002/(sici)1099-1166(199703)12:3<331::aid-gps495>3.3.co;2-a]
15. Esandi N, Nolan M, Alfaro C, Canga-Armayor A. Keeping things in balance: family experiences of living with Alzheimer's disease. Gerontologist 2018;58(2):e56-e67. [doi: 10.1093/geront/gnx084] [Medline: 28633376]
16. Ajrouch KJ, Webster NJ, Zahodne LB, Antonucci TC. Introduction to ADRD care in context. J Gerontol B Psychol Sci Soc Sci 2023;78(Suppl 1):S1-S3 [FREE Full text] [doi: 10.1093/geronb/gbac181] [Medline: 36477194]
17. Friedman EM, Kennedy DP. Typologies of dementia caregiver support networks: a pilot study. Gerontologist 2021;61(8):1221-1230 [FREE Full text] [doi: 10.1093/geront/gnab013] [Medline: 33585929]
18. Bachmann P. Caregivers' experience of caring for a family member with Alzheimer's disease: a content analysis of longitudinal social media communication. Int J Environ Res Public Health 2020;17(12):4412 [FREE Full text] [doi: 10.3390/ijerph17124412] [Medline: 32575455]
19. Miranda-Castillo C, Woods B, Galboda K, Oomman S, Olojugba C, Orrell M. Unmet needs, quality of life and support networks of people with dementia living at home. Health Qual Life Outcomes 2010;8(1):132 [FREE Full text] [doi: 10.1186/1477-7525-8-132] [Medline: 21073721]
20. Pickett AC, Valdez D, Sinclair KL, Kochell WJ, Fowler B, Werner NE. Social media discourse related to caregiving for older adults living with Alzheimer disease and related dementias: computational and qualitative study. JMIR Aging 2024;7:e59294 [FREE Full text] [doi: 10.2196/59294] [Medline: 38896462]
21. Jacobs MT, Broese van Groenou MI, Aartsen MJ, Deeg DJH. Diversity in older adults' care networks: the added value of individual beliefs and social network proximity. J Gerontol B Psychol Sci Soc Sci 2018;73(2):326-336. [doi: 10.1093/geronb/gbw012] [Medline: 26912490]
22. Boutilier JJ, Loganathar P, Linden A, Scheer E, Noejovich S, Elliott C, et al. A web-based platform (CareVirtue) to support caregivers of people living with Alzheimer disease and related dementias: mixed methods feasibility study. JMIR Aging 2022;5(3):e36975 [FREE Full text] [doi: 10.2196/36975] [Medline: 35925654]
23. Ploeg J, McAiney C, Duggleby W, Chambers T, Lam A, Peacock S, et al. A web-based intervention to help caregivers of older adults with dementia and multiple chronic conditions: qualitative study. JMIR Aging 2018;1(1):e2. [doi: 10.2196/aging.8475] [Medline: 31518230]
24. Vanoh D, Ishak IH, Shahar S, Manaf ZA, Ali NM, Noah SAM. Development and assessment of a web-based intervention for educating older people on strategies promoting healthy cognition. Clin Interv Aging 2018;13:1787-1798 [FREE Full text] [doi: 10.2147/CIA.S157324] [Medline: 30271134]
25. Chávez A, Borrego G, Gutierrez-Garcia JO, Rodríguez LF. Design and evaluation of a mobile application for monitoring patients with Alzheimer's disease: a day center case study. Int J Med Inform 2019;131:103972. [doi: 10.1016/j.ijmedinf.2019.103972] [Medline: 31563010]
26. Linden A, Jolliff A, Gonzalez D, Loganathar P, Elliott C, Zuraw M, et al. "It made me feel like I wasn't alone in the darkness": exploring dementia care network communication and coordination through a digital health platform. J Am Med Inform Assoc 2022;29(12):2003-2013. [doi: 10.1093/jamia/ocac172] [Medline: 36166717]
27. Canevelli M, Valletta M, Trebbastoni A, Sarli G, D'Antonio F, Tariciotti L, et al. Sundowning in dementia: clinical relevance, pathophysiological determinants, and therapeutic approaches. Front Med (Lausanne) 2016;3:73. [doi: 10.3389/fmed.2016.00073] [Medline: 28083535]
28. Butcher HK, Gordon JK, Ko JW, Perkhounkova Y, Cho JY, Rinner A, et al. Finding meaning in written emotional expression by family caregivers of persons with dementia. Am J Alzheimers Dis Other Demen 2016;31(8):631-642 [FREE Full text] [doi: 10.1177/1533317516660611] [Medline: 27574336]

29. Davidsson R, Baker D, Chintakrindi S, Lee J, Kinser P, Ozkaynak M, et al. Exploring the multidimensionality of home-based dementia caregiving and related challenges based on digital journaling and interviews. Int J Older People Nurs 2024;19(2):e12600. [doi: 10.1111/opn.12600]
30. Javahery H, Deichman A, Seffah A, Taleb M. Human-centered software engineering: software engineering models, patterns and architectures for HCI. In: Seffah A, Vanderdonckt J, Desmarais MC, editors. A User-Centered Framework for Deriving A Conceptual Design From User Experiences: Leveraging Personas and Patterns to Create Usable Designs. London, United Kingdom: Springer; 2009.
31. Kumar S. Optimization Issues in Web and Mobile Advertising: Past and Future Trends. New York, NY: Springer; 2015.
32. Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioral and psychological symptoms of dementia. BMJ 2015;350(mar02 7):h369-h369 [FREE Full text] [doi: 10.1136/bmj.h369] [Medline: 25731881]
33. Atefi GL, de Vugt ME, van Knippenberg RJ, Levin ME, Verhey FR, Bartels SL. The use of acceptance and commitment therapy (ACT) in informal caregivers of people with dementia and other long-term or chronic conditions: a systematic review and conceptual integration. Clin Psychol Rev 2023;105:102341 [FREE Full text] [doi: 10.1016/j.cpr.2023.102341] [Medline: 37776577]
34. Valdez D, Soto-Vásquez AD, Montenegro MS. Geospatial vaccine misinformation risk on social media: online insights from an English/Spanish natural language processing (NLP) analysis of vaccine-related tweets. Soc Sci Med 2023;339:116365 [FREE Full text] [doi: 10.1016/j.socscimed.2023.116365] [Medline: 37984184]
35. Valdez D, Pickett AC, Goodson P. Topic modeling: latent semantic analysis for the social sciences. Soc Sci Q 2018;99(5):1665-1679. [doi: 10.1111/ssqu.12528]
36. Warner D, Sale J. Intervention informatics - healing with information. In: Interactive Technology and the New Paradigm for Healthcare. Amsterdam, the Netherlands: IOS Press; 1995:399-405.
37. Figueroa CA, Aguilera A, Chakraborty B, Modiri A, Aggarwal J, Deliu N, et al. Adaptive learning algorithms to optimize mobile applications for behavioral health: guidelines for design decisions. J Am Med Inform Assoc 2021;28(6):1225-1234 [FREE Full text] [doi: 10.1093/jamia/ocab001] [Medline: 33657217]
38. Gudala M, Ross MET, Mogalla S, Lyons M, Ramaswamy P, Roberts K. Benefits of, barriers to, and needs for an artificial intelligence-powered medication information voice chatbot for older adults: interview study with geriatrics experts. JMIR Aging 2022;5(2):e32169 [FREE Full text] [doi: 10.2196/32169] [Medline: 35482367]
39. Boucher EM, Harake NR, Ward HE, Stoeckl SE, Vargas J, Minkel J, et al. Artificially intelligent chatbots in digital mental health interventions: a review. Expert Rev Med Devices 2021;18(sup1):37-49 [FREE Full text] [doi: 10.1080/17434440.2021.2013200] [Medline: 34872429]
40. Laymouna M, Ma Y, Lessard D, Schuster T, Engler K, Lebouché B. Roles, users, benefits, and limitations of chatbots in health care: rapid review. J Med Internet Res 2024;26:e56930 [FREE Full text] [doi: 10.2196/56930] [Medline: 39042446]

Abbreviations

AD: Alzheimer disease
ADRD: Alzheimer disease–related dementias
BERTopic: bidirectional encoder representations from transformers topic modeling tool
NLP: natural language processing
VADER: Valence Aware Dictionary and Sentiment Reasoner

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Evaluating the Prognostic and Clinical Validity of the Fall Risk Score Derived From an AI-Based mHealth App for Fall Prevention: Retrospective Real-World Data Analysis

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Abstract

Background: Falls pose a significant public health concern, with increasing occurrence due to the aging population, and they are associated with high mortality rates and risks such as multimorbidity and frailty. Falls not only lead to physical injuries but also have detrimental psychological and social consequences, negatively impacting quality of life. Identifying individuals at high risk for falls is crucial, particularly for those aged ≥60 years and living in residential care settings; current professional guidelines favor personalized, multifactorial fall risk assessment approaches for effective fall prevention.

Objective: This study aimed to explore the prognostic validity of the Fall Risk Score (FRS), a multifactorial-based metric to assess fall risk (using longitudinal real-world data), and establish the clinical relevance of the FRS by identifying threshold values and the minimum clinically important differences.

Methods: This retrospective cohort study involved 617 older adults (857 observations: 615 of women, 242 of men; mean age 83.3, SD 8.7 years; mean gait speed 0.49, SD 0.19 m/s; 622 using walking aids) residing in German residential care facilities and used the LINDERA mobile health app for fall risk assessment. The study focused on the association between FRS at the initial assessment (T1) and the normalized number of falls at follow-up (T2). A quadratic regression model and Spearman correlation analysis were utilized to analyze the data, supported by descriptive statistics and subgroup analyses.

Results: The quadratic model exhibited the lowest root mean square error (0.015), and Spearman correlation analysis revealed that a higher FRS at T1 was linked to an increased number of falls at T2 ($\rho=0.960$, $P<.001$). Subgroups revealed significant strong correlations between FRS at T1 and falls at T2, particularly for older adults with slower gait speeds ($\rho=0.954$, $P<.001$) and those using walking aids ($\rho=0.955$, $P<.001$). Threshold values revealed that an FRS of 45%, 32%, and 24% corresponded to the expectation of a fall within 6, 12, and 24 months, respectively. Distribution-based minimum clinically important difference values were established, providing ranges for small, medium, and large effect sizes for FRS changes.

Conclusions: The FRS exhibits good prognostic validity for predicting future falls, particularly in specific subgroups. The findings support a stratified fall risk assessment approach and emphasize the significance of early and personalized intervention. This study contributes to the knowledge base on fall risk, despite limitations such as demographic focus and potential assessment interval variability.

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KEYWORDS

falls; older adults; mHealth; prognostic tool; clinical validity; AI; mobile health; artificial intelligence

Introduction

Falls represent a major health risk, with a profound impact on both individuals and society, particularly for those aged ≥60 years [1]. They are inherently linked to adverse effects on mobility, concurrent care risks, increased disease burden, and increased mortality rates [2-5]. Falls are the second leading cause of unintentional injury deaths globally, with an estimated 684,000 fatalities annually [6]. The number of falls and their related injuries are estimated to likely increase in the upcoming years [7]. This occurrence can be attributed in part to increasing life expectancy [8] and a rising prevalence of fall risk factors, including but not limited to multimorbidity, polypharmacy, and frailty [7]. Fall-related injuries often lead to severe consequences [9], including hip fractures [10] and head trauma [11], which can increase the risk of death, disability, and institutional care, as well as impose substantial economic strain on the health care system [12]. Falls can also have a significant impact on quality of life. Fear of falling can lead to social isolation, reduced physical activity, and loss of independence [13]. These psychosocial consequences can further exacerbate the risk of falls by creating a vicious cycle.

Identifying individuals at elevated risk of falling constitutes a critical aspect of preventing falls. An individualized approach to screening, assessment, and intervention is highlighted in professional guidelines, exemplified by practices outlined in the German nursing expert standards for fall and fracture prevention [14] and in the World guidelines for fall prevention for older adults [1]. Although no unanimous agreement exists on the precise selection of fall risk assessment methods [15], an emphasis on an individualized, multifactorial, and comprehensive assessment of fall risk is consistent across professional guidelines [1,14], allowing for the development of tailored multifactorial measures to address fall risk. In accordance with these guidelines, a comprehensive assessment should encompass various domains, including mobility, sensory function, activities of daily living, cognitive function, autonomic function, disease history, medication history, nutrition history, and environmental risk. This personalized approach can enable the efficient identification of older adults at risk of falling, facilitating the implementation of targeted interventions to mitigate this risk.

At present, methods for predicting falls in older adults mostly depend on single assessments [15]. These assessments, being singular tools, may lack the scalability and real-time capabilities necessary for widespread multifactorial fall prevention efforts [1,15]. To embrace a multifactorial approach in fall prevention, the incorporation of technology, such as wearables and mobile health (mHealth) technologies, could prove beneficial. These technological tools possess the capability to capture diverse data types, thereby offering the potential for implementing a comprehensive strategy for multifactorial fall prevention. Some mHealth tools have been developed to implement multifactorial fall risk assessments and have focused on validating both their mobile technology (eg, validation of their inertial measurement units against gold standard technologies) and their application in real-world environments (eg, retirement communities) [16]. Most published research related to fall risk assessments has focused on the ability to discriminate between fallers and nonfallers, determining cutoffs, and assessing their sensitivity and specificity [16,17]. Although this is relevant for identifying individuals at an increased risk of falls, the provision of minimal clinically important differences (MCIDs) is missing [16-21]. Such metrics are crucial for identifying responsiveness to fall prevention programs in effectiveness trials using multifactorial risk assessments as a measure of fall risk.

Many of the available mHealth tools use a combination of functional assessments and questionnaires to gather additional risk factors as part of the multifactorial approach to fall risk assessment [16]. For instance, the Steady app incorporates a health history questionnaire alongside a progressive postural stability test, which informs a weighted algorithm to determine the fall risk [22,23]. Similarly, the Kinesis Balance app enables measurements of standing balance, supplemented by a questionnaire addressing further fall risk factors [24]. Another app, the Aachen Falls Prevention App, is based on the Aachen Falls Prevention Scale and evaluates fall risk through a series of questionnaires and a single balance task [25]. The app developed by Taheri-Kharameh and colleagues assesses fall risk based on the Stopping Elderly Accidents, Deaths, and Injuries framework and incorporates a Timed Up and Go test to categorize individuals regarding their fall risk [26]. Most available apps primarily focus on balance assessments and do not incorporate gait-related information, which is relevant for understanding fall risk [15,27]. Although some apps include a Timed Up and Go test [26,28], it focuses solely on the time taken to complete the test, lacking insight into gait parameters. For instance, among other factors, step length, gait speed, and dynamic trunk sway [29-31] have been identified as parameters contributing to fall risk. To the best of our knowledge, the LINDERA Mobility Analysis (LINDERA GmbH) mHealth app uniquely incorporates gait parameters derived from the smartphone camera, and also includes a questionnaire addressing supplementary fall risk factors, providing a multifactorial approach for fall risk assessment.

The LINDERA Mobility Analysis mHealth app comprehensively captures intrinsic (such as comorbidities, incontinence, fear of falling, and prior falls) and extrinsic (including mobility aids, environmental barriers, and home footwear) factors. These factors, recognized as contributors to the risk of falling [1], are seamlessly integrated into the mHealth app's calculation of the Fall Risk Score (FRS). The FRS has been previously detailed and evaluated to ascertain its discriminatory efficacy in distinguishing between fallers and nonfallers within a cross-sectional study design [32]. The FRS exhibits performance metrics that are comparable to those of established assessments commonly used for the evaluation of fall risk [32]. Through this, the mHealth app can provide personalized assessments of fall risk and recommendations for fall prevention [32,33]. However, the prognostic value of the FRS has yet to be reported. This study aimed to investigate the prognostic validity of the FRS based on longitudinal real-world data. It is hypothesized that the FRS serves as a prognostic indicator, suggesting an association with future falls within a predetermined time interval. As a secondary goal, this research aims to establish the clinical relevance of the FRS by identifying threshold values and the MCIDs.

Methods

Study Design

This is an observational, retrospective cohort study in older adults undergoing fall prevention assessment.

Setting

This study focused on nursing facilities for older adults within Germany. These institutions, tailored to the distinctive needs of older adults, adhere to routine fall prevention practices mandated by German legislation. Furthermore, these facilities have incorporated LINDERA into their fall prevention assessment strategy, conducting fall prevention assessments approximately every 3 months, contingent upon the absence of any reported falls.

Participants

Data acquisition involved retrieving data in August 2023 from the LINDERA database. Prior to participant data selection, precise criteria were delineated to identify and incorporate the data relevant to the investigation.

Inclusion criteria were defined as follows: (1) participants should have completed more than one fall risk prevention assessment and (2) participants should be aged 60 years or older. Assessments were exclusively accepted if captured through a uniform app version (versions 10.0.6 to 10.17.0), ensuring consistency in the used FRS calculation, questionnaire version, and gait parameters calculation. Additionally, assessments were considered if they exhibited an interval between 45 and 180 days, corresponding to an initial assessment (T1) and a subsequent follow-up assessment (T2). Repeated assessments (observations) for the same individual were also considered. As the app involved a video-based fall risk assessment, all participants were required to be capable of walking at least 6 meters.

After data retrieval, assessments were included in the analysis only if the gait videos showed the presence of older adults, meaning real human measurements had been collected. To guarantee a dependable documentation of fall history, the analysis focused solely on residents from residential care settings. The study's final sample size comprised 617 older adults (857 observations), with data collected between June 2021 and July 2023.

Description of mHealth App

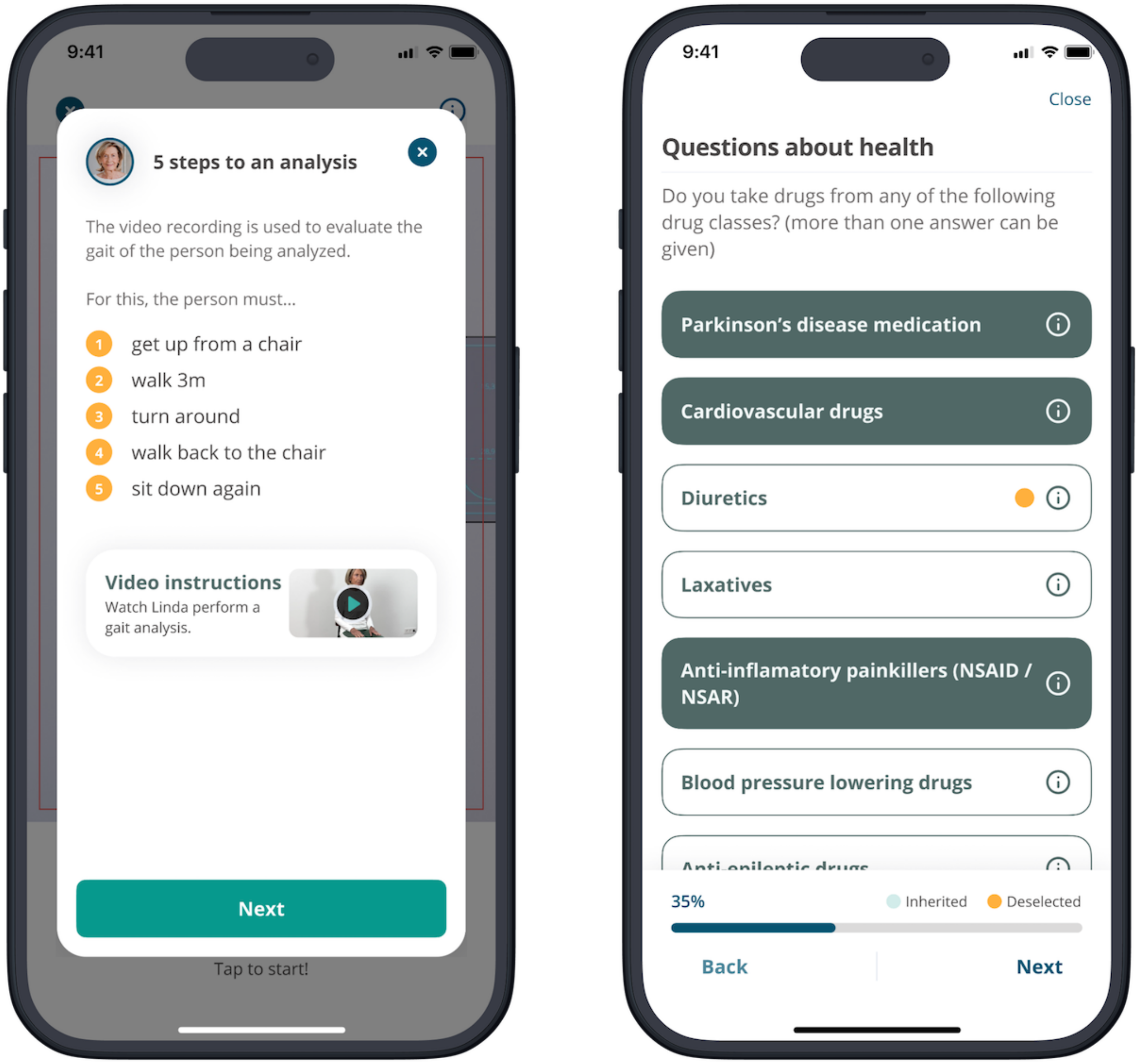
The mHealth app (English version: Figure 1; German version: Multimedia Appendix 1) was used for the evaluation of fall risk among the study participants through the computation of an FRS, as described elsewhere [32]. Briefly, to complete a fall risk assessment, two procedures are required: (1) recording the participants' gait via smartphone-based video to evaluate the gait pattern through a computer vision algorithm [34] and (2) the collection of additional fall risk factors through a standardized questionnaire integrated within the mHealth app.

For the video procedure, participants were required to perform a 3-meter walking test involving the sequence of standing up from a chair, walking approximately 3 meters toward the camera, executing a 180-degree turn, returning to the starting point, and sitting down. Participants were permitted to utilize assistive mobility devices (eg, a cane, crutch, or walker) during the video capture process. The video was recorded by a caregiver, such as a nurse, who simultaneously ensured patient safety. The underlying computer vision algorithm is based on a modular system consisting of a video tester, a skeleton estimator (skeleton estimator 2D, skeleton estimator 3D, skeleton optimization 3D), and processing of mobility parameters [34]. The modular artificial intelligence–based algorithm detects gait cycles during the walking segment of the assessment and computes gait parameters such as step length and gait speed. The accuracy of this algorithm has been previously evaluated through comparison with the GAITRite walkway system elsewhere [34], with reported intraclass correlation coefficient values exceeding 0.90, indicating excellent agreement, as detailed in prior research. Following video capture, immediate quality checks are conducted to confirm that the video complies with the predefined quality criteria (eg, exposure, camera movement). If necessary, a new video recording is requested.

Following the video procedure, participants were required to complete a questionnaire comprised of a maximum of 58 questions that encompassed person-related risk factors and environmental risk factors. Participants had the option to fill out the questionnaire either independently or, if they preferred, with the help of caregivers. Additionally, if cognitive limitations prevent a participant from completing the questionnaire, an alternative version is triggered for external assessment by the caregiver. Nevertheless, the same risk factors are collected.

Assessments were analyzed only if the 2 procedures were carried out and uploaded.

Figure 1. Screenshots depicting the mobile health app during the initialization phase of a new fall prevention assessment.



9:41

5 steps to an analysis

The video recording is used to evaluate the gait of the person being analyzed.

For this, the person must...

1. get up from a chair
2. walk 3m
3. turn around
4. walk back to the chair
5. sit down again

Video instructions
Watch Linda perform a gait analysis.

Next

Tap to start!

9:41

Close

Questions about health

Do you take drugs from any of the following drug classes? (more than one answer can be given)

- Parkinson's disease medication
- Cardiovascular drugs
- Diuretics
- Laxatives
- Anti-inflamatory painkillers (NSAID / NSAR)
- Blood pressure lowering drugs
- Anti-epileptic drugs

35% ● Inherited ● Deselected

Back Next

Variables Extracted From the mHealth App

Fall Risk Score

Utilizing these 2 procedures (video and questionnaire) inherent to the mHealth app, fall risk factors were systematically and automatically gathered. The recorded video exclusively allows an analysis of the gait pattern, which includes key characteristics such as step length and gait speed. The questionnaire screens for a range of additional fall risk factors, including dizziness and visual and acoustic impairments, among others, which are relevant for a comprehensive assessment of fall risk [32]. There are no overlaps between the risk factors derived from the video and those obtained from the questionnaire; each risk factor is exclusively captured from 1 of these 2 sources.

Each risk factor identified through these methods is considered in the FRS calculation, which is quantified on a scale ranging from 0-100 points. A score of 0 indicates the absence of fall risk factors, while a score of 100 represents the complete presence of all identified fall risk factors. The higher the FRS, the more fall risk factors are present. According to established fall-risk models with demonstrated diagnostic accuracy [35,36], such as St. Thomas's Risk Assessment Tool in Falling Elderly Inpatients, the Hendrich II Fall Risk Model, and the Downton Fall Risk Assessment, 9 specific risk factors are assigned double weighting. These factors include limited mobility, dizziness, visual and auditory impairments, medication use, cognitive impairment, depression, urge incontinence, a history of falls, and restlessness. Additional risk factors are assigned single weighting. These include comorbidities that limit mobility, foot disorders, conditions that can cause syncope, fear of falling, the use of walking aids, and environmental hazards.

Number of Falls at Follow-Up Assessment

The number of falls recorded at follow-up, T2, was self-reported by the senior using the mHealth app. Participants responded to a specific inquiry presented in the mHealth app, detailing how often falls occurred since the last analysis. It is noteworthy to highlight that, owing to the nature of the setting being stationary residential, the number of falls is meticulously documented in this environment. Caregivers have ready access to this documented information when conducting the fall risk prevention assessment.

To standardize these reported values and account for variable observation periods, a normalization process was implemented where the number of reported falls was divided by the corresponding number of days covered by the analysis (T1 to T2).

Bias

To address potential biases inherent in the study design [37] that could potentially introduce confusion and affect the precision of association estimates, a series of methodological strategies were implemented to enhance the internal validity of the study findings.

Statistical Analysis

Overview

Descriptive statistics were calculated as mean and standard deviation for continuous data and counts for categorical data. For all statistical evaluations, the significance level was set at α=.05. RStudio (R version 4.3.1; Posit PBC, irr package) and Python (version 3.9; Python Software Foundation) were used to process, analyze, and visualize all data. Specifically for Python, NumPy (version 1.25.2), Pandas (version 2.03), and scikit-learn (version 1.3.0) libraries were used.

Regression Analysis

To determine the relationship between the FRS at T1 and the number of falls at T2, a correlation analysis was performed, with a 3-step approach. First, to enhance data smoothing and establish a more consistent data representation, a running average was computed. This running average utilized the FRS as a grouping parameter, with a window size equivalent to 2% of the FRS value, resulting in the derivation of an average number of falls at T2 for each FRS. Second, multiple regression models were created to identify the function that best fits the data points. To assess the performance of the fitted function, root mean square error (RMSE) was reported. The model exhibiting the lowest RMSE value was selected as the most appropriate. Finally, in the third step, the Spearman rank correlation coefficient was used to evaluate the strength and direction of the monotonic relationships between FRS at T1 and number of falls at T2, both extracted from the running average. This nonparametric test was selected for its ability to handle ordinal data and nonlinear relationships. Correlation coefficients and corresponding *P* values were computed to assess the statistical significance of these associations. This analysis was also conducted in multiple subgroups to identify stronger associations within specific variables. Specifically, the following variables were investigated: time interval (60, 90, or 120 days); number of reported diseases (cancer, arthritis, osteoarthritis, stroke, Parkinson disease, multiple sclerosis, chronic pain, heart disease, lung disease, kidney disease, liver disease, HIV, osteoporosis, dementia, anemia); age (<65, 65-74, 74-85, or >85 years old); gait speed (above or below 0.6 m/s); dementia (with or without); gait speed and dementia (above 0.6 m/s and without dementia, below 0.6 m/s and with dementia); fall history (yes or no); and use of walking aids (yes or no). The subgroups were selected based on risk factors previously mentioned as associated with increased risk of a fall [1,15,38-43]. For each subgroup explored, the RMSE, Spearman correlation coefficients, *P* values, and sample size are reported.

Threshold Values

Following this process, threshold values were determined based on the obtained regression model for the main sample size. The corresponding model’s equation was used to estimate the average number of falls per week. To estimate the threshold values over longer periods—such as 6, 12, and 24 months—the average number of falls per week was multiplied by the corresponding number of weeks in those periods (26, 52, and 104, respectively). This approach enabled the calculation of fall risk thresholds over extended time frames.

Determination of MCID

To determine the MCID for the FRS, a distribution-based approach was used, in accordance with [44]. Consequently, the distribution-based MCID was computed using the following formula: effect size × SD pooled, where the effect size assumes values of 0.2, 0.5, and 0.8, representing small, medium, and large effect sizes, respectively, in accordance with [45]. The pooled standard deviation (SDpooled) is determined as the square root of [(SD baseline)^2 + (SD follow-up)^2/ 2] in [44,46]. The 95% CIs were estimated using bootstrapping methodology. The MCID range was estimated by considering values that span from smaller to larger, as derived from these calculations.

Ethical Considerations

Data acquisition involved retrieving data in August 2023 from the LINDERA database, encompassing participants who had provided informed consent for the collection and utilization of their data for research purposes. Participants were not compensated for their participation. LINDERA adheres to the European Union General Data Protection Regulation, and all data incorporated into the study were pseudonymized. The study was approved by the local ethics committee at Charité - Universitätsmedizin Berlin (EA4/009/21).

Results

Participants

A detailed participant inclusion flowchart before exclusion is provided in Figure 2, illustrating the selection process. Initially, 4577 patients (3146 women and 1431 men) who provided consent to use their data for research purposes were considered for inclusion. The average age of these participants was 81.1 (SD 12.1) years. Among them, 1192 (25.8%) had dementia and 3235 (70.7%) used walking aids.

The details of the full sample at T1 are displayed in Table 1. The FRS for the observations of the full sample size was 29.7 (SD 11.8%; range 1 - 71) at T1 and 29.2 (SD 11.5%; range 4 - 77) at T2. The average time interval between T1 and T2 was 108.5 (SD 31.6) days.

At T1, a total of 190 patients (with a total of 277 observations) could not self-report the fall risks collected through the questionnaire and required an external assessment. Comparisons between this group and the self-reported group showed no statistically significant differences in gender (*P*=.31) and fallers at T1 (*P*=.40). However, statistically significant differences were found for age (*P*<.001), gait speed (*P*=.03), and walking aid usage (*P*<.001). Specifically, the self-reported assessment group was older and slower and had a higher proportion of individuals using walking aids (464/580 observations, 80%) compared to the external assessment group (158/277 observations, 57%).

Figure 2. Participant inclusion flowchart.

Table . Demographic and anthropometric data at initial assessment (T1) for the full sample, the self-reported fall risk questionnaire sample, and the externally assessed fall risk questionnaire sample.

Initial assessment characteristic	Full sample	Self-reported questionnaire	Externally assessed questionnaire
Participants, n	617	427	190
Observations, n	857	580	277
Gender, n	615 women, 242 men	423 women, 157 men	192 women, 85 men
Age (years), mean (SD)	83.3 (8.7)	84.0 (8.8)	81.8 (8.4)
Dementia, n	277	0	277
Fallers, n	125	80	45
Gait speed (m/s), mean (SD)	0.49 (0.19)	0.48 (0.19)	0.52 (0.20)
Using walking aids, n	622	464	158

Regression Analysis

Figure 3A presents a scatter plot illustrating the relationship between the normalized number of falls at T2 and the FRS at T1. The mean (SD) normalized number of falls per week at T2 for the full sample was 0.02 (SD 0.05). A running average was calculated using the FRS as a grouping parameter, with a window size equivalent to 2% of the FRS value. Figure 3B displays the resultant points of this running average computation, revealing a nonlinear relationship in the data.

Multiple regression models were computed to determine the best-fitting function. Three sequential models were tested: linear, quadratic, and exponential, introduced in ascending order of complexity. Among the models, the quadratic model (Figure 3B) was selected as it exhibited the lowest RMSE (0.015). The corresponding quadratic regression model's equation is as follows, where FRS represents the average Fall Risk Score at T1:

$$\text{avg number of falls per week} = 2.9745\times10^{-5}\times FRS^{2} + 3.4612\times10^{-5}\times FRS - 2.4251\times10^{-3}$$

The linear and exponential models exhibited corresponding RMSE values of 0.017 and 0.016, respectively.

Spearman correlation analysis, using the moving average data as the basis, revealed a strong, positive correlation between FRS at T1 and falls at T2 (ρ=0.960, *P*<.001). Subgroup analysis, using the moving average as the basis, was conducted to explore the impact of various variables on the relationship between FRS at T1 and falls at T2. The outcomes of the subgroup analysis are summarized in Table 2.

Table 2 reveals that significant strong correlations were found for the subgroup using walking aids (ρ=0.955, *P*<.001), with a gait speed below 0.6 m/s (ρ=0.954, *P*<.001), and with a time interval of 120 days (ρ=0.934, *P*<.001), indicating robust associations. Moderate yet significant correlations were observed for the subgroup aged 65 - 74 years (ρ=0.437, *P*=.002) and with no diseases (ρ=0.504, *P*=.002). Weak and nonsignificant correlations were found for groups such as those with 3 diseases and gait speed above 0.6 m/s, suggesting no substantial relationship. The results obtained using the raw data are presented in Multimedia Appendix 2.

Figure 3. (A) Scatter plot of the FRS at T1 and normalized number of falls per week at T2. (B) Resultant values for the running average computation for the FRS at T1 and normalized number of falls per week at T2, including of the quadratic model in the resultant values of the running average computation. FRS: Fall Risk Score.

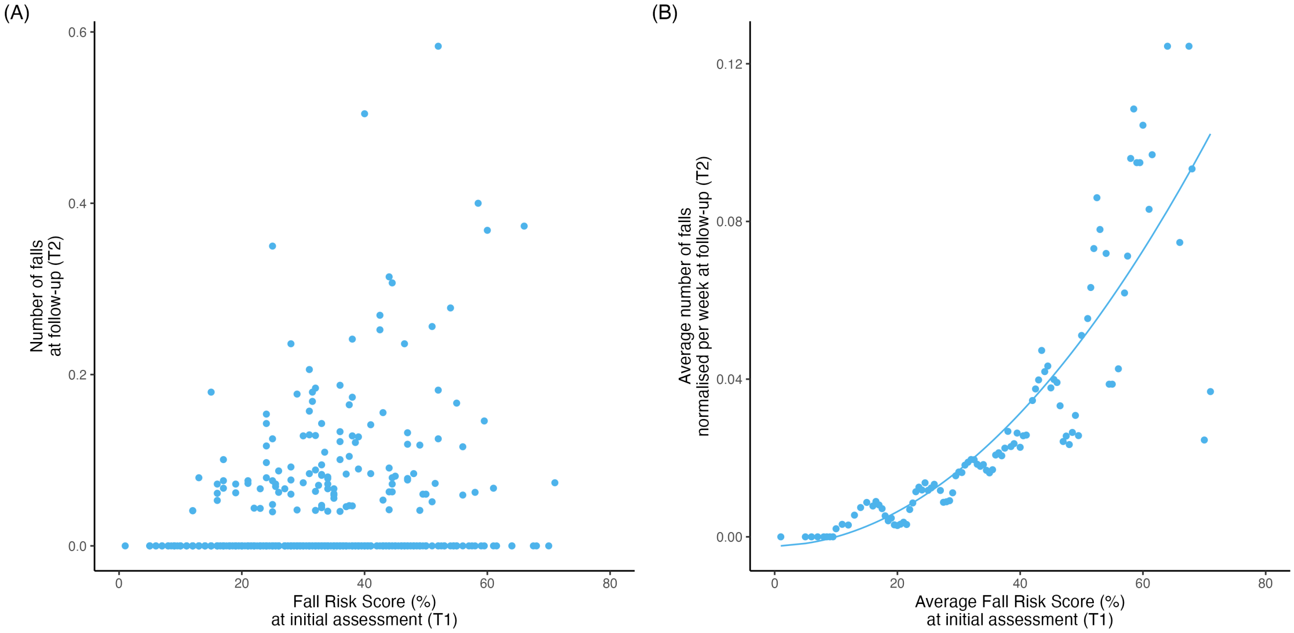


Table . Performance metrics of the models evaluated (running average–based; root mean square error) and Spearman correlation analysis to predict number of falls at T2 based on Fall Risk Score values at T1 for subgroups.[a,b]

Subgroups explored at T1		Root mean square error	Spearman correlation coefficient	*P* value	Fall Risk Score at T1, mean (SD)	Observations, n
Time interval between T1 and T2						
	60 days	0.08	0.739	<.001	28.5 (13.7)	36
	90 days	0.03	0.833	<.001	30.6 (12.9)	268
	120 days	0.02	0.934	<.001	30.0 (12.1)	611
Diseases, n						
	0	0.01	0.504	<.001	21.0 (9.9)	107
	1	0.05	0.807	<.001	26.2 (11.1)	221
	2	0.04	0.800	<.001	29.7 (11.1)	223
	3	0.03	0.166	.19	32.8 (10.5)	167
	≥4	0.02	0.719	<.001	37.9 (10.4)	139
Age (years)						
	<65	0.03	0.167	.38	24.4 (9.4)	47
	65 - 74	0.03	0.437	.002	27.4 (12.0)	93
	74 - 85	0.03	0.778	<.001	29.2 (12.4)	324
	>85	0.02	0.760	<.001	31.2 (11.3)	393
Gait speed (m/s)						
	≥0.6	0.02	0.130	.32	21.9 (9.5)	215
	<0.6	0.02	0.954	<.001	32.3 (11.4)	642
Dementia						
	Yes	0.04	0.719	<.001	29.2 (11.1)	242
	No	0.02	0.748	<.001	29.8 (12.1)	615
Gait speed (m/s) and dementia						
	≥0.6 and without dementia	0.01	0.019	.90	21.9 (10.3)	140
	<0.6 and with dementia	0.04	0.666	<.001	32.4 (10.8)	167
Fall history						
	Yes	0.05	0.729	<.001	40.2 (12.0)	125
	No	0.02	0.571	<.001	29.7 (11.8)	857
Use of walking aids						
	Yes	0.02	0.955	<.001	32.4 (11.3)	622
	No	0.03	0.664	<.001	22.3 (9.8)	235

[a] T1: initial assessment.

[b] T2: follow-up assessment.

Threshold Values

The threshold values obtained from the quadratic model revealed the corresponding FRS values as follows: an expectation of 1 fall within the next 6 months aligns with an FRS value starting at 45%, while an anticipation of 1 fall within the next 12 months corresponds to an FRS value starting at 32%. Additionally, individuals expecting 1 fall in the upcoming 24 months exhibited an associated FRS value starting at 24%.

MCID Values

Table 3 reports the distribution-based MCID (95% CI) values for the FRS change from T1 to T2.

Table . Distribution-based MCID values for the Fall Risk Score change from T1 to T2.[a,b,c]

Effect size	Distribution-based MCID (95% CI) for Fall Risk Score
Small (effect size=0.2)	2.3 (2.2-2.4)
Medium (effect size=0.5)	5.8 (5.6-6.1)
Large (effect size=0.8)	9.3 (8.9-9.8)

[a] MCID: minimal clinically important difference.

[b] T1: initial assessment.

[c] T2: follow-up assessment.

Discussion

Principal Findings

The study confirms the multifaceted nature of fall risk for older adults from several long-term care facilities (inpatient caregiving) as represented by the FRS. The main findings highlight the prognostic significance of the FRS across different time intervals. Individuals with an FRS exceeding 45% had an increased risk of falling within 6 months, emphasizing the importance of early intervention for those identified at this threshold. The graded risk spectrum, with FRS values of 32% and 24% corresponding to expected falls over 12 and 24 months, respectively, provides a nuanced framework for risk stratification and tailoring of preventive strategies over different time horizons. Additionally, establishing MCID values for FRS offers a robust metric to evaluate the clinical impact of FRS measurement and its corresponding fall prevention programs. By providing MCIDs for small (effect size=0.2), medium (effect size=0.5), and large (effect size=0.8) effect sizes, a framework for interpreting the observed changes in fall risk scores was established, which will help in understanding the results of future prospective studies by evaluating whether observed changes in fall risk scores are meaningful.

Subgroup analyses broaden the understanding of the FRS's contextual applicability, revealing that the use of walking aids, slower gait speed, and the time interval between assessments are important contributing factors influencing fall risk. In contrast, faster gait speeds and a combination of faster gait speeds and no dementia (indicating higher functional levels) do not appear to be significant contributing factors to fall risk. These insights into FRS dynamics underscore the need for a multifactorial approach to fall risk assessment and management, incorporating clinical, behavioral, and environmental factors for optimal outcomes for people exposed to fall risks.

Overall, the study aimed to assess the prognostic validity of the FRS based on longitudinal fall risk assessment data acquired in real-world conditions. The study hypothesis posited that the FRS operates as a prognostic indicator, suggesting an association with future falls within a predetermined time interval. The study's main finding was that the FRS, when assessed at T1 and used in a quadratic model to predict the number of falls at T2, demonstrates a good predictive performance. This is supported by the significant strong correlations detected between the FRS at T1 and falls at T2 ($\rho=0.960$, $P<.001$).

Prognostic Validity of the Fall Risk Score

The best-fitting regression model, characterized by the lowest RMSE, depicted a nonlinear relationship between the FRS and number of falls. These results seemed to be consistent with previous research. Notably, alternative models for predicting falls rely on objective metrics such as gait speed. Quach and colleagues [47] identified a nonlinear, U-shaped relationship between gait speed and the frequency of falls in community-dwelling older adults. Both faster and slower gait speeds were associated with the highest risk of falls. Subsequent subgroup analyses in this investigation revealed that variations in gait speed may influence the magnitude of the association between FRS and fall frequency, as significant, strong correlations were detected for slower walkers (gait speed below 0.6 m/s), in agreement with findings from [47]. Moreover, the mean FRS values of slower walkers (mean 32.3, SD 11.4%) exceeded the threshold indicative of distinguishing fallers from nonfallers (27.5%), as previously determined [32]. In contrast, the mean FRS values of faster walkers (mean 21.9, SD 9.5%) did not surpass this threshold, underscoring the relevance of gait speed in the predictive model.

Spearman correlation analysis revealed differing strengths of correlation across different subgroups. It was most effective for predicting falls among older individuals with slower gait speeds, using walking aids, and with a time interval between fall risk assessments of 120 days. On the other hand, the correlations were weaker among individuals with different disease counts and those with a combination of gait speed and dementia status. These results indicate that, while the predictive model is robust in certain contexts, it may require additional refinement or consideration of other factors to improve its predictive power across all subgroups. For instance, in the disease group with 3 conditions (n=3), the observed low Spearman correlation can be attributed to the presence of observations with high FRS and zero falls (Multimedia Appendix 3). These observations disrupt the rank-order relationship, leading to a reduction in the Spearman correlation coefficient. Nonetheless, the low RMSE indicates that the quadratic model performed well overall for most data points within this subgroup. Individuals with multiple diseases exhibited a descriptively higher fall risk (Table 2), with an even greater fall risk observed in those over 85 years of age (Multimedia Appendix 4). Health care professionals may be more vigilant in monitoring these individuals, paying closer attention to their health conditions, environmental hazards, and behaviors that could contribute to falls. Such heightened awareness has been previously reported to influence their decisions and actions to prevent falls [48], which may help explain the lack of a statistically significant association between the variables in this subgroup.

An increasing number of mHealth solutions are contributing to the growing body of evidence that supports the validity of using this technology for fall risk screening [49]. For example, the Aachen Falls Prevention Scale, a self-assessment tool that combines a short questionnaire with a balance test, has been found to significantly correlate with users' self-reported history of falls [25]. In addition, Ozinga and Alberts [50] evaluated postural stability assessments captured by a tablet, comparing their results to those obtained through a 3D motion analysis system. Their findings indicate that tablet sensors can quantify postural stability with sufficient accuracy. A more recent review also evaluated several digital apps developed for fall risk assessment [16]. The accumulating body of evidence supporting mHealth use for assessing fall risk holds significant potential to optimize fall prevention efforts by not only identifying individuals at high risk but also delivering targeted interventions tailored to the specific needs identified. This opens avenues for older adults to assess their individual fall risk, a crucial step in determining the appropriate type of fall prevention treatment. However, the majority of mHealth tools assessed in the literature only provide support and integration with isolated parts of fall risk assessment and fail to incorporate a multifactorial, multimodal approach.

MCID Findings

The results from the quadratic model established threshold values for the FRS that correlated with the expectation of falls over different time frames, resulting in risk stratification. The calculation of MCID for FRS changes from T1 to T2, with varying effect sizes, enabled clinicians to understand the magnitude of change in FRS that would be considered clinically significant. Subgroup analysis further refined the understanding of how various characteristics influenced the FRS and the implementation of recommendations, highlighting the complex interplay of factors such as disease presence, age, gait speed, dementia status, fall history, and the use of walking aids in fall risk and response to interventions. These findings underscore the importance of personalized approaches in managing fall risk among different populations, which was not part of the real-world usage of the device.

The distribution-based approach allowed for the interpretation of the MCID while taking into consideration its inherent variability [51]. This method informed the estimation of the MCID by incorporating descriptive statistics derived from the observed scores across the sample's distribution [52]. The magnitude of effect sizes varied with the clinical condition under consideration, with small effect sizes holding potential significance for patients with severe disease, while moderate to large effect sizes become relevant for patients with milder conditions [44]. Among distribution-based methods, the standard deviation between participants is one of the most widely accepted [51,53], and both the variability at initial and follow-up assessments should be considered [46].

Distribution-based approaches are validated methods to derive MCIDs [53,54]. These studies support the use of distribution-based MCID methods, demonstrating accuracy and reliability in deriving MCIDs. In this study, distribution-based methods to derive MCIDs from real world baseline data were effectively applied. In the results, the MCID was divided into 3 categories: small change of approximately 2.3 points, medium change of approximately 5.8 points, and large change of approximately 9.3 points. These MCID numbers can be used to evaluate whether the changes in FRS after an intervention (eg, an exercise program) are large enough to be meaningful. If a participant's FRS drops by more than the MCID, it is likely that the program was beneficial. As a result, the distribution-based approach yielded appropriate differences for a meaningful clinical interpretation of FRS changes.

Usage of Real-World Data

Regulatory organizations are progressively acknowledging the utility of real-world data (RWD) in forming real-world evidence. A systematic literature review was recently undertaken to examine the use of RWD for interpreting outcomes from trials lacking control groups [55]. The study examined major regulatory and health technology assessment bodies and underscored the necessity for enhanced guidance on methodological considerations from these bodies. The systematic review articulated essential directives for generating real-world evidence that is appropriate for its intended benefits. The application of RWD is particularly pertinent in areas where randomized clinical trials are not viable, such as in oncology, rare diseases, or nursing homes [56,57]. Here, controls may be derived from historical data and observational studies. Finally, the paper advocated for the exchange of experiences among stakeholders (eg, sponsors and regulatory bodies) to promote learning and refine the application of RWD-derived evidence, aiming to enhance patient care.

Limitations

Study Group

This study included the physical and demographic characteristics of older adults, providing valuable insights for aging populations. However, its focus on older individuals, gender imbalance, and lack of specific details regarding dementia and fall circumstances could limit its generalizability. Notably, there are indications that gender could have a significant influence on fall risk factors [58] and fall awareness behavior should be emphasized among older females to address gender-specific factors that might be crucial in mitigating fall risk in this demographic [59]. Furthermore, variable assessment intervals may affect the reliability of longitudinal comparisons.

Study Type

The study relies on preexisting, retrospective data, which may have limitations in accuracy, completeness, and consistency. There is also a risk of selection bias, as the data might not have been collected with the current research questions in mind (eg, without a control group, it is harder to attribute changes in fall risk solely to the digital interventions studied). This limits the ability to establish cause-and-effect relationships. Although RWD are valuable for their practical relevance, they can introduce confounding factors and variability.

Statistical Methods

The study suggests that, while there were associations between FRS and fall frequency, there were nonlinear relationships, with variable correlations across different subgroups. The prognostic model was most reliable for predicting falls among older individuals with slower gait speeds and those using walking aids. However, its predictive power was less consistent among individuals with different disease counts and those with a combination of gait speed and dementia status. These results indicate that, while the FRS is robust in certain contexts, it may require additional refinement or consideration of other factors to improve its predictive power across all subgroups.

Bias Reduction

Specifically, eligibility criteria were preestablished to ensure consistency in participant selection and minimize the impact of selection bias on the study outcomes. Additionally, quality criteria were defined for both video capture and data collection processes. For video capture, to optimize the reliability of gait parameter calculations from video recordings, predetermined quality criteria—encompassing aspects such as exposure and camera movement—were systematically implemented. After video capture, this quality assurance process was executed to verify adherence to the predefined criteria, ensuring the integrity of the captured data. For the data collection process, to guarantee caregivers' proficiency in utilizing the mHealth app, a regimen of regular and standardized training sessions was administered by the LINDERA Customer Success Team. Finally, to ensure the reliability of the dataset included, a comprehensive review of all videos associated with the analyses was conducted to confirm the presence of older adults in the video recordings.

In summary, the study utilized the FRS as a predictive tool and the MCID for managing individual fall risk. The FRS could screen fall risks among older adults in nursing care, with its real-world application underscoring its practical utility in clinical settings. The MCID enhanced the study's findings, while translating statistical shifts in FRS into meaningful, patient-centric outcomes. This approach can be used to personalize care plans and also offers an objective measure for evaluating the efficacy of fall prevention strategies. The deduction of MCID sets a practical standard in geriatric care research and practice, emphasizing its value in assessing the effectiveness of interventions in fall risk management.

Conclusions

This study investigated the complex nature of falls and fall risk, encapsulated by the FRS and its prognostic value. Elevated FRS values corresponded to an increased risk of falls and future falls. This, along with the obtained threshold, offers a stratified approach to risk assessment and the formulation of preventative strategies tailored to risk projections of falls. The deduction of MCID values for FRS changes provides a metric for assessing the clinical significance of interventions across a spectrum of effect sizes. Despite the stated limitations, the study's insights are a valuable addition to the existing literature on fall risk, suggesting the FRS as a predictive tool that may benefit from further refinement for broader applications in clinical and nursing settings. The fall risk assessment method utilized in this study identified specific fall risk factors for each individual. By targeting the individual fall risk profile with distinct fall risk factors—such as mobility limitations or environmental hazards—this method enables the delivery of tailored and person-centered fall prevention strategies. These strategies are designed to manage and mitigate the fall risks identified by addressing the particular needs and vulnerabilities of each individual based on a holistic, multifactorial fall risk assessment. Future research should focus on evaluating the effectiveness of such fall prevention strategies derived from a comprehensive and multifactorial fall risk assessment among individuals in residential care settings.

Acknowledgments

All authors developed the study concept and contributed to the study design. ST, SAA, and AB processed and analyzed all the data. SAA wrote the first draft of the manuscript under the supervision of AB. SM contributed to the statistical analysis processes. SAA, ST, SM, MK, WP, SW, JZ, and AB had a role in the preparation of the manuscript, overall data analysis and interpretation of data, and critical revision of the manuscript. SAA, ST, SM, MK, WP, SW, JZ, and AB gave final approval of the version to be published. The authors would like to thank all study participants. Additionally, thanks to Menia Ettrich for her support in manuscript coordination and to Peter Woodcraft for proofreading the final draft.

Conflicts of Interest

SAA, ST, SM, and MK are employees of LINDERA GmbH, which is involved in the development of technologies relevant to the study. Author WP has received consulting fees in the past from LINDERA GmbH. AB has served as a consultant for LINDERA GmbH regarding the market access application of the mHealth app. WP and AB did not receive honoraria for participation in advisory meetings related to the scope of this research. JZ and SW declare no conflicts of interest.

Multimedia Appendix 1

Screenshots depicting the mobile health app (German version) during the initialization phase of a new fall prevention assessment.

[DOCX File, 546 KB - aging_v7i1e55681_app1.docx]

Multimedia Appendix 2

Spearman correlation analysis to predict number of falls at T2 based on Fall Risk Score values at T1 for subgroups.
[DOCX File, 25 KB - aging_v7i1e55681_app2.docx]

Multimedia Appendix 3
Scatter plot of resultant values for the running average of the Fall Risk Score at T1 and normalized number of falls per week at T2 for different combinations of number of diseases. The solid line refers to the quadratic model.
[DOCX File, 105 KB - aging_v7i1e55681_app3.docx]

Multimedia Appendix 4
Spearman correlation analysis to predict number of falls at T2 based on Fall Risk Score values at T1 for subgroups of individuals aged over 85 years.
[DOCX File, 26 KB - aging_v7i1e55681_app4.docx]

References

1. Montero-Odasso M, van der Velde N, Martin FC, et al. World guidelines for falls prevention and management for older adults: a global initiative. Age Ageing 2022 Sep 2;51(9):afac205. [doi: 10.1093/ageing/afac205] [Medline: 36178003]
2. Rubenstein LZ. Falls in older people: epidemiology, risk factors and strategies for prevention. Age Ageing 2006 Sep;35 Suppl 2:ii37-ii41. [doi: 10.1093/ageing/afl084] [Medline: 16926202]
3. Masud T, Morris RO. Epidemiology of falls. Age Ageing 2001 Nov;30 Suppl 4:3-7. [doi: 10.1093/ageing/30.suppl_4.3] [Medline: 11769786]
4. Karinkanta S, Heinonen A, Sievanen H, Uusi-Rasi K, Kannus P. Factors predicting dynamic balance and quality of life in home-dwelling elderly women. Gerontology 2005;51(2):116-121. [doi: 10.1159/000082196] [Medline: 15711078]
5. Haagsma JA, Olij BF, Majdan M, et al. Falls in older aged adults in 22 European countries: incidence, mortality and burden of disease from 1990 to 2017. Inj Prev 2020 Oct;26(Supp 1):i67-i74. [doi: 10.1136/injuryprev-2019-043347] [Medline: 32111726]
6. Falls. World Health Organization. 2021. URL: https://www.who.int/news-room/fact-sheets/detail/falls [accessed 2023-11-16]
7. Montero-Odasso MM, Kamkar N, Pieruccini-Faria F, et al. Evaluation of clinical practice guidelines on fall prevention and management for older adults: a systematic review. JAMA Netw Open 2021 Dec 1;4(12):e2138911. [doi: 10.1001/jamanetworkopen.2021.38911] [Medline: 34910151]
8. Khow KSF, Visvanathan R. Falls in the aging population. Clin Geriatr Med 2017 Aug;33(3):357-368. [doi: 10.1016/j.cger.2017.03.002] [Medline: 28689568]
9. James SL, Lucchesi LR, Bisignano C, et al. The global burden of falls: global, regional and national estimates of morbidity and mortality from the Global Burden of Disease Study 2017. Inj Prev 2020 Oct;26(Supp 1):i3-i11. [doi: 10.1136/injuryprev-2019-043286] [Medline: 31941758]
10. Abolhassani F, Moayyeri A, Naghavi M, Soltani A, Larijani B, Shalmani HT. Incidence and characteristics of falls leading to hip fracture in Iranian population. Bone 2006 Aug;39(2):408-413. [doi: 10.1016/j.bone.2006.01.144] [Medline: 16510325]
11. Stevens JA, Adekoya N. Brain injury resulting from falls among elderly persons. JAMA 2001 Dec 5;286(21):2665-2666. [doi: 10.1001/jama.286.21.2665] [Medline: 11730427]
12. Haddad YK, Bergen G, Florence CS. Estimating the economic burden related to older adult falls by state. J Public Health Manag Pract 2019;25(2):E17-E24. [doi: 10.1097/PHH.0000000000000816] [Medline: 29757813]
13. Schoene D, Heller C, Aung YN, Sieber CC, Kemmler W, Freiberger E. A systematic review on the influence of fear of falling on quality of life in older people: is there a role for falls? Clin Interv Aging 2019;14:701-719. [doi: 10.2147/CIA.S197857] [Medline: 31190764]
14. Blumenberg P, Büscher A, Krebs M, Stehling H. 2. Aktualisierung. In: Expertenstandard Sturzprophylaxe in Der Pflege [Book in German]: Deutsches Netzwerk für Qualitätsentwicklung in der Pflege; 2022.
15. Beck Jepsen D, Robinson K, Ogliari G, et al. Predicting falls in older adults: an umbrella review of instruments assessing gait, balance, and functional mobility. BMC Geriatr 2022 Jul 25;22(1):615. [doi: 10.1186/s12877-022-03271-5] [Medline: 35879666]
16. Hsieh KL, Chen L, Sosnoff JJ. Mobile technology for falls prevention in older adults. J Gerontol A Biol Sci Med Sci 2023 May 11;78(5):861-868. [doi: 10.1093/gerona/glac116] [Medline: 35640254]
17. Tiedemann A, Lord SR, Sherrington C. The development and validation of a brief performance-based fall risk assessment tool for use in primary care. J Gerontol A Biol Sci Med Sci 2010 Aug;65(8):896-903. [doi: 10.1093/gerona/glq067] [Medline: 20522529]
18. Lee V, Appiah-Kubi L, Vogrin S, Zanker J, Mitropoulos J. Current cut points of three falls risk assessment tools are inferior to calculated cut points in geriatric evaluation and management units. Muscles 2023;2(3):250-270. [doi: 10.3390/muscles2030019]
19. Hayashi C, Okano T, Toyoda H. Development and validation of a prediction model for falls among older people using community-based data. Osteoporos Int 2024 Oct;35(10):1749-1757. [doi: 10.1007/s00198-024-07148-8] [Medline: 38879613]

20. Mishra AK, Skubic M, Despins LA, et al. Explainable fall risk prediction in older adults using gait and geriatric assessments. Front Dig Health 2022;4:869812. [doi: 10.3389/fdgth.2022.869812] [Medline: 35601885]
21. Ong MF, Soh KL, Saimon R, Myint WW, Pawi S, Saidi HI. Falls risk screening tools intended to reduce fall risk among independent community-dwelling older adults: a systematic review. Int J Nurs Pract 2023 Aug;29(4):e13083. [doi: 10.1111/ijn.13083] [Medline: 35871775]
22. Hsieh KL, Fanning JT, Rogers WA, Wood TA, Sosnoff JJ. A fall risk mHealth app for older adults: development and usability study. JMIR Aging 2018 Nov 20;1(2):e11569. [doi: 10.2196/11569] [Medline: 31518234]
23. Hsieh KL, Fanning JT, Sosnoff JJ. A smartphone fall risk application is valid and reliable in older adults during real-world testing. Gerontechnology 2019 Apr 15;18(1):29-35. [doi: 10.4017/gt.2019.18.1.003.00]
24. Greene BR, McManus K, Ader LGM, Caulfield B. Unsupervised assessment of balance and falls risk using a smartphone and machine learning. Sensors (Basel) 2021 Jul 13;21(14):4770. [doi: 10.3390/s21144770] [Medline: 34300509]
25. Rasche P, Mertens A, Bröhl C, et al. The “Aachen Fall Prevention App” - a smartphone application app for the self-assessment of elderly patients at risk for ground level falls. Pat Saf Surg 2017;11:14. [doi: 10.1186/s13037-017-0130-4] [Medline: 28503199]
26. Taheri-Kharameh Z, Malmgren Fänge A, Ekvall Hansson E, et al. Development of a mobile application to screen and manage fall risks in older people. Disabil Rehabil Assist Technol 2022 Apr;17(3):362-367. [doi: 10.1080/17483107.2020.1785562] [Medline: 32608287]
27. Espy DD, Yang F, Bhatt T, Pai YC. Independent influence of gait speed and step length on stability and fall risk. Gait Posture 2010 Jul;32(3):378-382. [doi: 10.1016/j.gaitpost.2010.06.013] [Medline: 20655750]
28. Singh DKA, Goh JW, Shaharudin MI, Shahar S. A mobile app (FallSA) to identify fall risk among Malaysian community-dwelling older persons: development and validation study. JMIR mHealth uHealth 2021 Oct 12;9(10):e23663. [doi: 10.2196/23663] [Medline: 34636740]
29. Rodríguez-Molinero A, Herrero-Larrea A, Miñarro A, et al. The spatial parameters of gait and their association with falls, functional decline and death in older adults: a prospective study. Sci Rep 2019 Jun 19;9(1):8813. [doi: 10.1038/s41598-019-45113-2] [Medline: 31217471]
30. Lindemann U, Lundin-Olsson L, Hauer K, Wengert M, Becker C, Pfeiffer K. Maximum step length as a potential screening tool for falls in non-disabled older adults living in the community. Aging Clin Exp Res 2008 Oct;20(5):394-399. [doi: 10.1007/BF03325143] [Medline: 19039279]
31. Lee SW, Verghese J, Holtzer R, Mahoney JR, Oh-Park M. Trunk sway during walking among older adults: norms and correlation with gait velocity. Gait Posture 2014 Sep;40(4):676-681. [doi: 10.1016/j.gaitpost.2014.07.023] [Medline: 25155693]
32. Rabe S, Azhand A, Pommer W, Müller S, Steinert A. Descriptive evaluation and accuracy of a mobile app to assess fall risk in seniors: retrospective case-control study. JMIR Aging 2020 Feb 14;3(1):e16131. [doi: 10.2196/16131] [Medline: 32130111]
33. Strutz N, Brodowski H, Kiselev J, Heimann-Steinert A, Müller-Werdan U. App-based evaluation of older people’s fall risk using the mHealth app Lindera Mobility Analysis: exploratory study. JMIR Aging 2022 Aug 16;5(3):e36872. [doi: 10.2196/36872] [Medline: 35972785]
34. Azhand A, Rabe S, Müller S, Sattler I, Heimann-Steinert A. Algorithm based on one monocular video delivers highly valid and reliable gait parameters. Sci Rep 2021 Jul 7;11(1):14065. [doi: 10.1038/s41598-021-93530-z] [Medline: 34234255]
35. da Costa BR, Rutjes AWS, Mendy A, Freund-Heritage R, Vieira ER. Can falls risk prediction tools correctly identify fall-prone elderly rehabilitation inpatients? A systematic review and meta-analysis. PLoS One 2012;7(7):e41061. [doi: 10.1371/journal.pone.0041061] [Medline: 22815914]
36. Park SH. Tools for assessing fall risk in the elderly: a systematic review and meta-analysis. Aging Clin Exp Res 2018 Jan;30(1):1-16. [doi: 10.1007/s40520-017-0749-0] [Medline: 28374345]
37. Taur SR. Observational designs for real-world evidence studies. Perspect Clin Res 2022;13(1):12-16. [doi: 10.4103/picr.picr_217_21] [Medline: 35198423]
38. Chantanachai T, Sturnieks DL, Lord SR, Payne N, Webster L, Taylor ME. Risk factors for falls in older people with cognitive impairment living in the community: systematic review and meta-analysis. Ageing Res Rev 2021 Nov;71:101452. [doi: 10.1016/j.arr.2021.101452] [Medline: 34450352]
39. Schoene D, Wu SMS, Mikolaizak AS, et al. Discriminative ability and predictive validity of the timed up and go test in identifying older people who fall: systematic review and meta-analysis. J Am Geriatr Soc 2013 Feb;61(2):202-208. [doi: 10.1111/jgs.12106] [Medline: 23350947]
40. Mortaza N, Abu Osman NA, Mehdikhani N. Are the spatio-temporal parameters of gait capable of distinguishing a faller from a non-faller elderly? Eur J Phys Rehabil Med 2014 Dec;50(6):677-691. [Medline: 24831570]
41. Peeters G, Cooper R, Tooth L, van Schoor NM, Kenny RA. A comprehensive assessment of risk factors for falls in middle-aged adults: co-ordinated analyses of cohort studies in four countries. Osteoporos Int 2019 Oct;30(10):2099-2117. [doi: 10.1007/s00198-019-05034-2] [Medline: 31201482]
42. Jehu DA, Davis JC, Falck RS, et al. Risk factors for recurrent falls in older adults: a systematic review with meta-analysis. Maturitas 2021 Feb;144:23-28. [doi: 10.1016/j.maturitas.2020.10.021] [Medline: 33358204]

43. Kearney FC, Harwood RH, Gladman JRF, Lincoln N, Masud T. The relationship between executive function and falls and gait abnormalities in older adults: a systematic review. Dement Geriatr Cogn Disord 2013;36(1-2):20-35. [doi: 10.1159/000350031] [Medline: 23712088]
44. Jehu DA, Davis JC, Madden K, Parmar N, Liu-Ambrose T. Establishing the minimal clinically important difference of the EQ-5D-3L in older adults with a history of falls. Qual Life Res 2022 Nov;31(11):3293-3303. [doi: 10.1007/s11136-022-03231-x] [Medline: 35999431]
45. Cohen J. Statistical Power Analysis for the Behavioral Sciences: Routledge; 1988.
46. Lin KC, Hsieh YW, Wu CY, Chen CL, Jang Y, Liu JS. Minimal detectable change and clinically important difference of the Wolf Motor Function Test in stroke patients. Neurorehab Neural Repair 2009 Jun;23(5):429-434. [doi: 10.1177/1545968308331144]
47. Quach L, Galica AM, Jones RN, et al. The nonlinear relationship between gait speed and falls: the Maintenance of Balance, Independent Living, Intellect, and Zest in the Elderly of Boston Study. J Am Geriatr Soc 2011 Jun;59(6):1069-1073. [doi: 10.1111/j.1532-5415.2011.03408.x] [Medline: 21649615]
48. Takase M. Falls as the result of interplay between nurses, patient and the environment: using text-mining to uncover how and why falls happen. Int J Nurs Sci 2023 Jan;10(1):30-37. [doi: 10.1016/j.ijnss.2022.12.003] [Medline: 36860705]
49. Hamm J, Money AG, Atwal A, Paraskevopoulos I. Fall prevention intervention technologies: a conceptual framework and survey of the state of the art. J Biomed Inform 2016 Feb;59:319-345. [doi: 10.1016/j.jbi.2015.12.013] [Medline: 26773345]
50. Ozinga SJ, Alberts JL. Quantification of postural stability in older adults using mobile technology. Exp Brain Res 2014 Dec;232(12):3861-3872. [doi: 10.1007/s00221-014-4069-8] [Medline: 25150554]
51. Guyatt GH, Osoba D, Wu AW, Wyrwich KW, Norman GR, Clinical Significance Consensus Meeting Group. Methods to explain the clinical significance of health status measures. Mayo Clin Proc 2002 Apr;77(4):371-383. [doi: 10.4065/77.4.371] [Medline: 11936935]
52. Revicki D, Hays RD, Cella D, Sloan J. Recommended methods for determining responsiveness and minimally important differences for patient-reported outcomes. J Clin Epidemiol 2008 Feb;61(2):102-109. [doi: 10.1016/j.jclinepi.2007.03.012] [Medline: 18177782]
53. Mouelhi Y, Jouve E, Castelli C, Gentile S. How is the minimal clinically important difference established in health-related quality of life instruments? Review of anchors and methods. Health Qual Life Outcomes 2020 May 12;18(1):136. [doi: 10.1186/s12955-020-01344-w] [Medline: 32398083]
54. Watt JA, Veroniki AA, Tricco AC, Straus SE. Using a distribution-based approach and systematic review methods to derive minimum clinically important differences. BMC Med Res Methodol 2021 Feb 26;21(1):41. [doi: 10.1186/s12874-021-01228-7] [Medline: 33637039]
55. Curtis LH, Sola-Morales O, Heidt J, et al. Regulatory and HTA considerations for development of real-world data derived external controls. Clin Pharmacol Ther 2023 Aug;114(2):303-315. [doi: 10.1002/cpt.2913] [Medline: 37078264]
56. Corrao G, Franchi M, Mancia G. Knocking on heaven's door: the gap between health institutions and academies in generating knowledge utilizing real-world data. Front Public Health 2022;10:1002910. [doi: 10.3389/fpubh.2022.1002910] [Medline: 36388354]
57. Wieseler B, Neyt M, Kaiser T, Hulstaert F, Windeler J. Replacing RCTs with real world data for regulatory decision making: a self-fulfilling prophecy? BMJ 2023 Mar 2;380:e073100. [doi: 10.1136/bmj-2022-073100] [Medline: 36863730]
58. Gale CR, Westbury LD, Cooper C, Dennison EM. Risk factors for incident falls in older men and women: the English longitudinal study of ageing. BMC Geriatr 2018 May 16;18(1):117. [doi: 10.1186/s12877-018-0806-3] [Medline: 29769023]
59. Goh JW, Singh DKA, Mesbah N, Hanafi AAM, Azwan AF. Fall awareness behaviour and its associated factors among community dwelling older adults. BMC Geriatr 2021 Apr 6;21(1):226. [doi: 10.1186/s12877-021-02122-z] [Medline: 33823808]

Abbreviations

FRS: Fall Risk Score
MCID: minimal clinically important differences
RMSE: root mean square error
RWD: real-world data
T1: initial assessment
T2: follow-up assessment

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Original Paper

Sleep Duration and Functional Disability Among Chinese Older Adults: Cross-Sectional Study

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Abstract

Background: The duration of sleep plays a crucial role in the development of physiological functions that impact health. However, little is known about the associations between sleep duration and functional disability among older adults in China.

Objective: This study aimed to explore the associations between sleep duration and functional disabilities in the older population (aged≥65 years) in China.

Methods: The data for this cross-sectional study were gathered from respondents 65 years and older who participated in the 2018 survey of the China Health and Retirement Longitudinal Study, an ongoing nationwide longitudinal investigation of Chinese adults. The duration of sleep per night was obtained through face-to-face interviews. Functional disability was assessed according to activities of daily living (ADL) and instrumental activities of daily living (IADL) scales. The association between sleep duration and functional disability was assessed by multivariable generalized linear models. A restricted cubic-spline model was used to explore the dose-response relationship between sleep duration and functional disability.

Results: In total, 5519 participants (n=2471, 44.77% men) were included in this study with a mean age of 73.67 years, including 2800 (50.73%) respondents with a functional disability, 1978 (35.83%) with ADL disability, and 2299 (41.66%) with IADL disability. After adjusting for potential confounders, the older adults reporting shorter (≤4, 5, or 6 hours) or longer (8, 9, or ≥10 hours) sleep durations per night exhibited a notably increased risk of functional disability compared to that of respondents who reported having 7 hours of sleep per night (all $P<.05$), which revealed a U-shaped association between sleep duration and dysfunction. When the sleep duration fell below 7 hours, increased sleep duration was associated with a significantly lower risk of functional disability (odds ratio [OR] 0.85, 95% CI 0.79-0.91; $P<.001$). When the sleep duration exceeded 7 hours, the risk of functional disability associated with a prolonged sleep duration increased (OR 1.16, 95% CI 1.05-1.29; $P<.001$).

Conclusions: Sleep durations shorter and longer than 7 hours were associated with a higher risk of functional disability among Chinese adults 65 years and older. Future studies are needed to explore intervention strategies for improving sleep duration with a particular focus on functional disability.

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KEYWORDS

sleep duration; functional disability; activity of daily living disability; instrumental activity of daily living; older population

Introduction

The issue of disability in the older population has garnered significant attention and interest in recent decades [1-3]. Disability—as defined by the International Classification of Functioning, Disability, and Health—encompasses the combined effects of impairments, activity limitations, or participation restrictions [4]. Functional disability is a significant measure of restrictions in activities, specifically referring to challenges in performing basic activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) [5,6]. ADLs are widely recognized as essential tasks for maintaining independence in one's own residence, such as dressing, bathing, and eating. IADLs refer to more complex tasks that require a higher level of independence and cognitive ability, such as managing financial matters, engaging in shopping activities, and preparing meals [7].

According to the World Health Organization (WHO) survey of 2022, 46.1% of adults 60 years and older worldwide are living with a disability, and this figure is increasing in tandem with the rapid global aging phenomenon [8]. China has one of the highest proportions of older citizens globally, with over 14% of individuals living in China classified as older people (ie, 65 years and older) [8]. This proportion is expected to increase to 30% by 2050, along with a massive drop in the elderly support ratio (defined as the number of people of "working age" [15-64 years] divided by those aged ≥65 years) from 9 in 2010 to 3 in 2050, which is comparable to that of the United States and Germany [9]. A meta-analysis conducted in 2022 reported that the cumulative prevalence of functional disability in China exceeds 30 million [10]. Moreover, the WHO projects that by 2050, the number of older adults living with a functional disability in China will increase to 66 million [11]. Given the high and rising prevalence of functional disabilities among the growing older adult population, exploring the key factors influencing the risk of functional disabilities is crucial to establish appropriate prevention and intervention strategies.

Duration of sleep plays a crucial role in the development of physiological functions that impact health, showing correlations with an increased risk of cognitive decline, depression, cardiovascular diseases, osteoporosis, and stroke [12-17]. However, a consensus has yet to be reached about the association between the duration of sleep and potential risk of functional disability.

In 2016, the National Survey of Midlife Development in the United States presented evidence that insufficient sleep is an independent and important factor contributing to physiological function disability [18]. A cohort study conducted in China with 1798 individuals 90 years or older demonstrated that sleep duration of 8 to 10 hours was associated with the lowest risk of experiencing an ADL disability, whereas a sleep duration exceeding 12 hours was associated with a heightened risk of experiencing ADL disability [19]. However, there is limited knowledge about the correlations of sleep duration with IADL disability. A US study with 136 participants, predominantly comprising older (aged≥65 years) Black individuals from low-income households, revealed a significant correlation between extended sleep duration surpassing 7.5 hours and worse IADL performance [20]. Similarly, evidence from the National Health Interview Survey spanning 2000 to 2015 showed that an extended sleep duration (≥9 hours) was associated with a higher risk of IADL disability [21]. In addition, owing to interactions with historical, ethnic, economic, and sociocultural factors, the association between sleep duration and functional disability may be heterogeneous across different countries and regions [22,23]. Therefore, the aim of this study was to examine the association between sleep duration and functional disability in China using a nationally representative sample of adults 65 years and older.

Methods

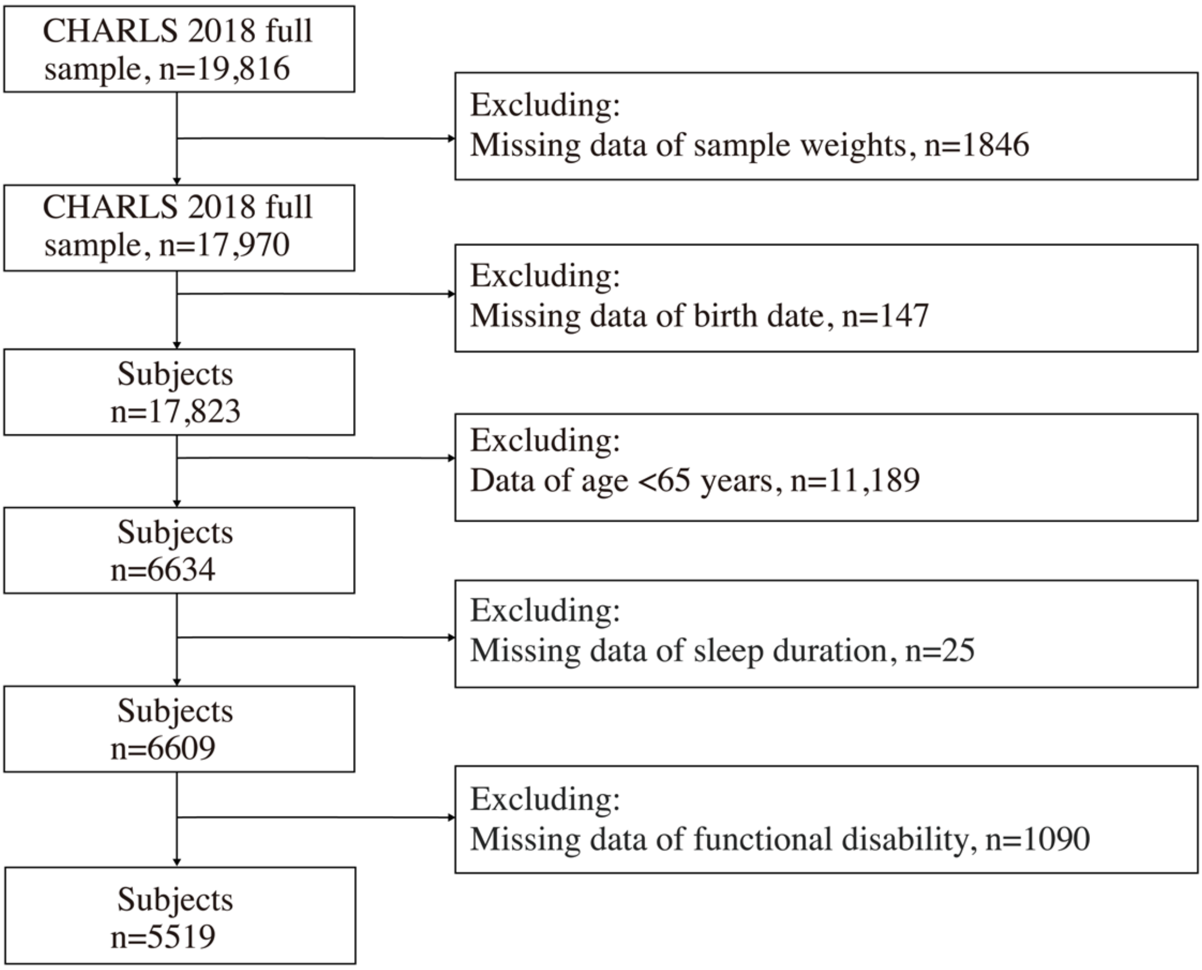
Design and Study Population

This study used data from the China Health and Retirement Longitudinal Study (CHARLS), a comprehensive longitudinal data set designed to provide a representative sample of individuals aged ≥45 years residing in mainland China [3]. The baseline survey of the CHARLS involved a multistage, stratified, probability proportional to sampling method to recruit participants across 150 counties or districts and 450 villages or urban areas throughout the country. Face-to-face interviews were used to obtain the data. A relative or caregiver was asked to complete the survey on behalf of the older adult if assistance was needed. Additional details regarding the CHARLS data set are available elsewhere [3].

The data analyzed in this study were taken from the most recent wave of the CHARLS in 2018, with a sample size of 19,816 participants, to investigate the potential correlation between sleep duration and functional disability. We included only observations without missing values from Chinese older adults aged ≥65 years. The schematic flow of the study sample is depicted in Figure 1. The total sample consisted of 5519 individuals, both with and without functional disability.

This cross-sectional study followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) reporting guideline [24].

Figure 1. Flowchart of the study sample inclusion process. CHARLS: China Health and Retirement Longitudinal Study.



Ethical Considerations

The protocols followed in the CHARLS were aligned with the principles of the Declaration of Helsinki [25]. This study obtained ethical approval from the Institutional Review Board at Peking University (IRB00001052-11015, IRB00001052-11014) [3]. All participants in the CHARLS provided written informed consent. The participants received a physical examination report for their participation. The data were deidentified and treated for confidentiality by anonymization and coding.

Sleep Duration

The self-reported data on sleep duration were obtained from a question about the average number of hours participants slept per night over the course of the previous month. Based on previous research experience of the CHARLS on sleep [26,27], we divided respondents into seven sleep duration groups (≤4, 5, 6, 7, 8, 9, and ≥10 hours per night) in the analyses. In addition to assessing sleep duration, we also explored daytime napping habits and established four distinct groups based on napping duration: 0, <30, 30-90, and >90 minutes [28].

Functional Disability

Functional disability was evaluated by asking participants about their ability to perform several domains of routine tasks included in the ADL and IADL questionnaires without special equipment [29]. The response of each item was categorized into four levels: “No, I do not encounter any problem”; “I experience difficulty but am still able to perform the task”; “Yes, I encounter trouble and require assistance”; and “I am unable to perform the task.” According to previous studies [30-32], respondents were recorded as having a functional disability if they reported any challenge in any of the six ADLs (dressing, bathing, eating, getting in and out of bed, using the toilet, and managing urination and defecation) or the five IADLs (household chores, cooking, shopping, paying bills or managing assets, and taking medications) [29,33].

Covariates

The CHARLS structured questionnaire was completed using in-person interviews to gather participants’ demographic characteristics as covariates, including age (years), gender (man or woman), tobacco use (never and current use), alcohol consumption (never and current use), education level (illiterate, primary or middle school, and high school or higher), residential location (urban or rural area), marital status (married or cohabiting and other statuses), afternoon napping habits, chronic disease status, sampling weights, and depression status. The 10-item Center for Epidemiological Studies Depression Scale was used to differentiate between individuals with and without depression according to a cut-off score of 10 [34-36]. The chronic illness condition of participants was assessed using self-reported noncommunicable diseases (NCDs), including hypertension, diabetes, dyslipidemia, heart issues, stroke, liver diseases, renal diseases, lung diseases, arthritis, and stomach disorders. Based on a recent analysis of CHARLS data on sleep duration [37], individuals were divided into three chronic disease groups: "none" (no NCD), "mild" (1-2 NCDs), or "severe" (more than 3 NCDs). Sampling weights were incorporated based on sets of cross-sectional individual weights that included adjustments for nonresponse by individuals and households.

Statistical Analysis

Participants' characteristics are summarized as numbers and percentages for categorical variables and as mean and SD values for continuous variables and were divided according to the functional disability status (including ADL and IADL disability). Missing baseline data were handled by a multiple-imputation method, which is a widely used approach to compensate for missing data via generating predictions for each missing value multiple times, resulting in a data set containing no missing values [38]. Multivariable generalized linear models (GLMs) were established using a binomial family and log-link functions to investigate the associations between sleep duration and functional disability status. Restricted cubic-splines analyses with four specific knots located at the 5th, 25th, 75th, and 95th centiles of the exposure distribution were performed to assess dose-response relationships between sleep duration and functional disability. The GLM and restricted cubic-spline models were adjusted for potential confounders, including age, gender, education, marital status, tobacco and alcohol use, afternoon napping, residential location, depression status, chronic disease condition, and sampling weights. All analyses accounting for the complex survey design of the CHARLS were conducted using Stata version 14.0 (Stata Corp). Statistically significant findings were defined by a two-sided *P* value below .05.

Results

Sample Characteristics

A total of 5519 participants (2471 men and 3048 women) were included in this analysis with a mean age of 73.67 years, including 2800 (50.73%) participants with a functional disability, 1978 (35.83%) with an ADL disability, and 2299 (41.66%) with an IADL disability.

Table 1 provides a summary of the baseline characteristics of the participants according to disability status. The average sleep duration was 6.04 hours for the total sample, with the majority of respondents reporting sleep durations less than 7 hours. Moreover, individuals with functional disability exhibited an average reduction in sleep duration in comparison to that of individuals without functional disability (5.80 vs 6.28 hours). A similar pattern emerged among individuals with ADL and IADL disabilities. Notably, older participants; women; nonsmokers; alcohol abstainers; those who are single; rural inhabitants; as well as those with lower educational attainment, depression, and a higher burden of chronic illnesses had greater rates of functional disability.

Table 1. Baseline characteristics of participants according to functional disability status.

Characteristics	Total sample (N=5519)	Functional disability		ADL[a] disability		IADL[b] disability	
		Yes (n=2800)	No (n=2719)	Yes (n=1978)	No (n=3541)	Yes (n=2299)	No (n=3220)
Sleep duration per night (hours), mean (SD)	6.04 (2.41)	5.80 (2.64)	6.28 (2.12)	5.73 (2.72)	6.21 (2.20)	5.78 (2.71)	6.23 (2.15)
Hours of sleep per night, n (%)							
≤4	1418 (25.69)	900 (32.14)	518 (19.05)	678 (34.28)	740 (20.90)	755 (32.84)	663 (20.59)
5	792 (14.35)	411 (14.68)	381 (14.01)	273 (13.80)	519 (14.66)	345 (15.01)	447 (13.88)
6	995 (18.03)	450 (16.07)	545 (20.04)	302 (15.27)	693 (19.57)	364 (15.83)	631 (19.60)
7	695 (12.59)	259 (9.25)	436 (16.04)	182 (9.20)	513 (14.49)	199 (8.66)	496 (15.40)
8	885 (16.04)	392 (14.00)	493 (18.13)	268 (13.55)	617 (17.42)	311 (13.53)	574 (17.83)
9	315 (5.71)	145 (5.18)	170 (6.25)	109 (5.51)	206 (5.82)	111 (4.83)	204 (6.34)
≥10	419 (7.59)	243 (8.68)	176 (6.47)	166 (8.39)	253 (7.14)	214 (9.31)	205 (6.37)
Age (years), mean (SD)	73.67 (6.41)	74.79 (6.79)	72.53 (5.76)	74.83 (6.87)	73.03 (6.04)	75.16 (6.93)	72.62 (5.78)
Gender, n (%)							
Man	2 471 (44.77)	1099 (39.25)	1372 (50.46)	790 (39.94)	1681 (47.47)	883 (38.41)	1588 (49.32)
Woman	3048 (55.23)	1701 (60.75)	1347 (49.54)	1188 (60.06)	1860 (52.53)	1416 (61.59)	1632 (50.68)
Education, n (%)							
Illiterate	2067 (37.45)	1230 (43.93)	837 (30.78)	857 (43.33)	1210 (34.17)	1058 (46.02)	1009 (31.34)
Primary or middle school	3132 (56.75)	1464 (52.29)	1668 (61.35)	1050 (53.08)	2082 (58.80)	1156 (50.28)	1976 (61.37)
High school or above	320 (5.80)	106 (3.79)	214 (7.87)	71 (3.59)	249 (7.03)	85 (3.70)	235 (7.30)
Tobacco use[c], n (%)							
Never	3158 (57.93)	1677 (60.61)	1481 (55.18)	1163 (59.58)	1995 (57.02)	1379 (60.62)	1779 (56.01)
Current	2293 (42.07)	1090 (39.39)	1203 (44.82)	789 (40.42)	1504 (42 98)	896 (39.38)	1397 (43.99)
Alcohol use, n (%)							
Never	3959 (71.73)	2120 (75.71)	1839 (67.64)	1479 (74.77)	2480 (70.04)	1787 (77.73)	2172 (67.45)
Current	1560 (28.27)	680 (24.29)	880 (32.36)	499 (25.23)	1061 (29.96)	512 (22.27)	1048 (32.55)
Married or cohabiting, n (%)	3754 (68.02)	1780 (63.57)	1974 (72.60)	1248 (63.09)	2506 (70.77)	1434 (62.37)	2320 (72.05)
Area of residence[d], n (%)							
Rural	4337 (78.65)	2304 (82.34)	2033 (74.85)	1635 (82.70)	2702 (76.39)	1901 (82.72)	2436 (75.75)
Urban	1177 (21.35)	494 (17.66)	683 (25.15)	342 (17.30)	835 (23.61)	397 (17.28)	780 (24.25)
Depression[e], n (%)	2131 (38.61)	1312 (46.86)	819 (30.12)	968 (48.94)	1163 (32.84)	1083 (47.11)	1048 (32.55)
Daytime napping (minutes), n (%)							
None	1972 (35.73)	1016 (36.29)	956 (35.16)	713 (36.05)	1259 (35.55)	1576 (39.51)	1126 (34.97)
≤30	417 (9.22)	244 (8.71)	227 (8.35)	167 (8.44)	304 (8.59)	359 (9.00)	259 (8.04)
31-90	2058 (37.29)	995 (35.54)	1063 (39.10)	706 (35.69)	1352 (38.18)	1385 (34.72)	1271 (39.47)
≥90	1018 (18.45)	545 (19.46)	473 (17.40)	392 (19.82)	626 (17.68)	669 (16.77)	564 (17.52)
Chronic disease condition, n (%)							
None	2679 (48.54)	1174 (41.93)	1505 (55.35)	805 (40.70)	1874 (52.92)	945 (41.10)	1734 (53.85)
Mild	2389 (43.29)	1333 (47.61)	1056 (38.84)	951 (48.08)	1438 (40.61)	1099 (47.80)	1290 (40.06)

Characteristics	Total sample (N=5519)	Functional disability		ADL[a] disability		IADL[b] disability	
		Yes (n=2800)	No (n=2719)	Yes (n=1978)	No (n=3541)	Yes (n=2299)	No (n=3220)
Severe	451 (8.17)	293 (10.46)	158 (5.81)	222 (11.22)	229 (6.47)	255 (11.09)	196 (6.09)

[a] ADL: activity of daily living.

[b] IADL: instrumental activity of daily living.

[c] Missing data for 139 (1.11%) participants.

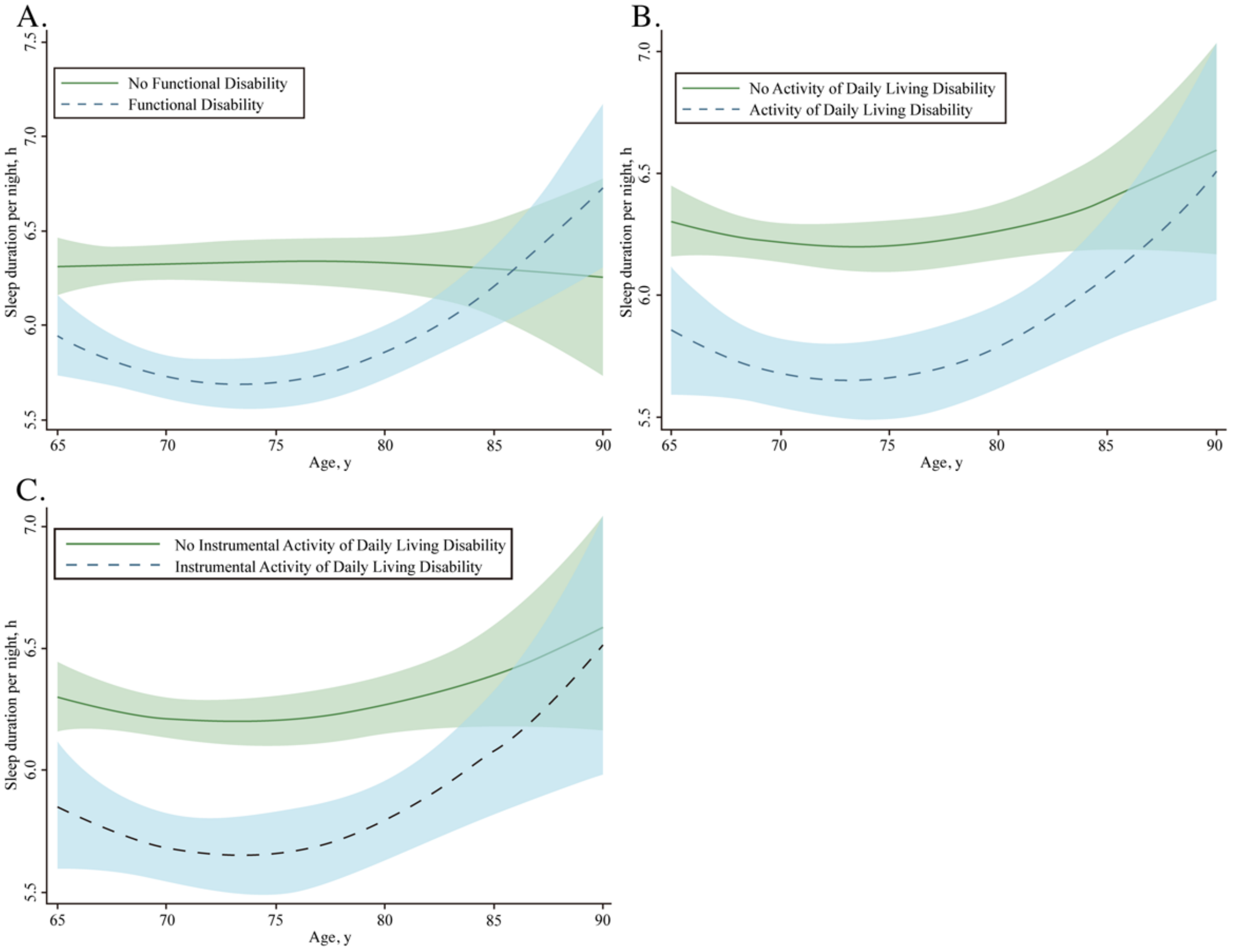
[d] Missing data for 17 (0.14%) participants.

[e] Defined as a score of 10 or greater on the 10-item Center for Epidemiologic Studies Depression scale.

Trajectories for Sleep Duration According to Functional Disability Status

The trajectories of sleep duration for groups classified according to different types of functional disability are depicted in Figure 2. The sleep duration of respondents with no functional disability followed a flat curve, whereas there was a U-shaped association between sleep duration and age among respondents with functional disability (Figure 2A). Individuals in the age range of 65 and 75 years with any functional disability had a substantially shorter sleep duration than those 75 years and older (mean 6.11, SD 2.22 vs mean 5.98, SD 2.43). Respondents with functional disability showed an increasing trend in sleep duration after the age of 75 years (mean change per 1 age point later in life of 0.09 hours). Respondents with ADL disability showed a rapid decline in sleep duration between the ages of 65 and 75 years, which increased after the age of 75 years (Figure 2B). Similar patterns are illustrated in Figure 2C, showing that for respondents with IADL disability, the sleep duration trajectories took on a U shape with age, and the shortest sleep duration was evident around the age of 75 years.

Figure 2. Trajectories of sleep duration across individuals according to functional disability status. Graphs display analog values (lines) of the sleep duration with 95% CIs (shaded areas) for any functional disability (A), activity of daily living disability (B), and instrumental activity of daily living disability (C).



Associations Between Sleep Duration and Functional Disability

Table 2 presents the association between sleep duration and functional disability status. In the unadjusted model (model 1), both individuals reporting shorter sleep durations (≤4, 5, and 6 hours) and those reporting longer sleep durations (8, 9, and ≥10 hours) per night exhibited a significantly increased risk of functional disability compared to the reference group (7 hours of sleep/night). The same trend was observed in the relationship between different sleep durations and IADL. Correspondingly, participants reporting shorter sleep durations (≤4 and 5 hours) or longer sleep durations (9 and ≥10 hours) demonstrated a significantly higher odds of ADL disability compared to the reference group.

After adjusting for other potential confounding factors (model 2), the significant associations between shorter sleep durations (≤4, 5, and 6 hours) or longer sleep durations (8, 9, and ≥10 hours) and functional disability persisted, whereas the association of a longer sleep duration (9 hours) to IADL disability dissipated and the association of a longer sleep duration (8 hours) to ADL disability emerged (Table 2).

Table 2. Associations between sleep duration and functional disability status in participants from the 2018 China Health and Retirement Longitudinal Study.

Sleep duration per night (hours)	Functional disability		ADL[a] disability		IADL[b] disability	
	OR[c] (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Model 1[d]						
≤4	2.92 (2.42-3.52)	<.001	2.58 (2.12-3.14)	<.001	2.84 (2.34-3.44)	<.001
5	1.81 (1.48-2.23)	<.001	1.48 (1.19-1.85)	.001	1.92 (1.55-2.38)	<.001
6	1.39 (1.14-1.69)	.001	1.23 (0.98-1.52)	.06	1.44 (1.16-1.77)	.001
7	Reference	—[e]	Reference	—	Reference	—
8	1.34 (1.09-1.63)	.005	1.22 (0.98-1.52)	.07	1.35 (1.09-1.67)	.006
9	1.43 (1.09-1.88)	.009	1.49 (1.12-1.98)	.006	1.36 (1.02-1.80)	.04
≥10	2.32 (1.81-2.97)	<.001	1.85 (1.43-2.39)	<.001	2.60 (2.02-3.34)	<.001
Model 2[f]						
≤4	2.65 (2.08-3.38)	<.001	2.16 (1.68-2.78)	<.001	2.48 (1.94-3.19)	<.001
5	1.78 (1.34-2.37)	<.001	1.39 (1.04-1.88)	.03	1.82 (1.36-2.46)	<.001
6	1.67 (1.29-2.15)	<.001	1.26 (0.96-1.66)	.09	1.69 (1.29-2.20)	<.001
7	Reference	—	Reference	—	Reference	—
8	1.51 (1.18-1.94)	.001	1.33 (1.02-1.74)	.04	1.48 (1.14-1.93)	.003
9	1.57 (1.12-2.21)	.01	1.66 (1.16-2.38)	.006	1.37 (0.96-1.96)	.09
≥10	2.23 (1.60-3.09)	<.001	1.64 (1.17-2.29)	.004	1.91 (1.57-2.32)	<.001

[a] ADL: activity of daily living.

[b] IADL: instrumental activity of daily living.

[c] OR: odds ratio.

[d] Model 1 was unadjusted.

[e] Not applicable.

[f] Model 2 was adjusted for age, gender, education, marital status, tobacco use, alcohol use, afternoon napping, residence, depression, chronic disease status, and sampling weights.

Subgroup Analyses

The findings of subgroup analyses by gender and age are shown in Figure 3 and Figure 4, respectively, where significant effects specific to gender and age were noted. Compared to men, women who slept for shorter durations (≤4, 5, and 6 hours) or longer durations (8, 9, and ≥10 hours) per night were more likely to experience functional disability (Figure 3). Regarding age-specific effects, participants in the older group (75 years and older) who slept for fewer than 6 hours or more than 8 hours were more likely to develop a functional disability than the younger group (74 years and younger) (Figure 4).

Figure 3. Gender-specific effect of sleep duration on functional disability.

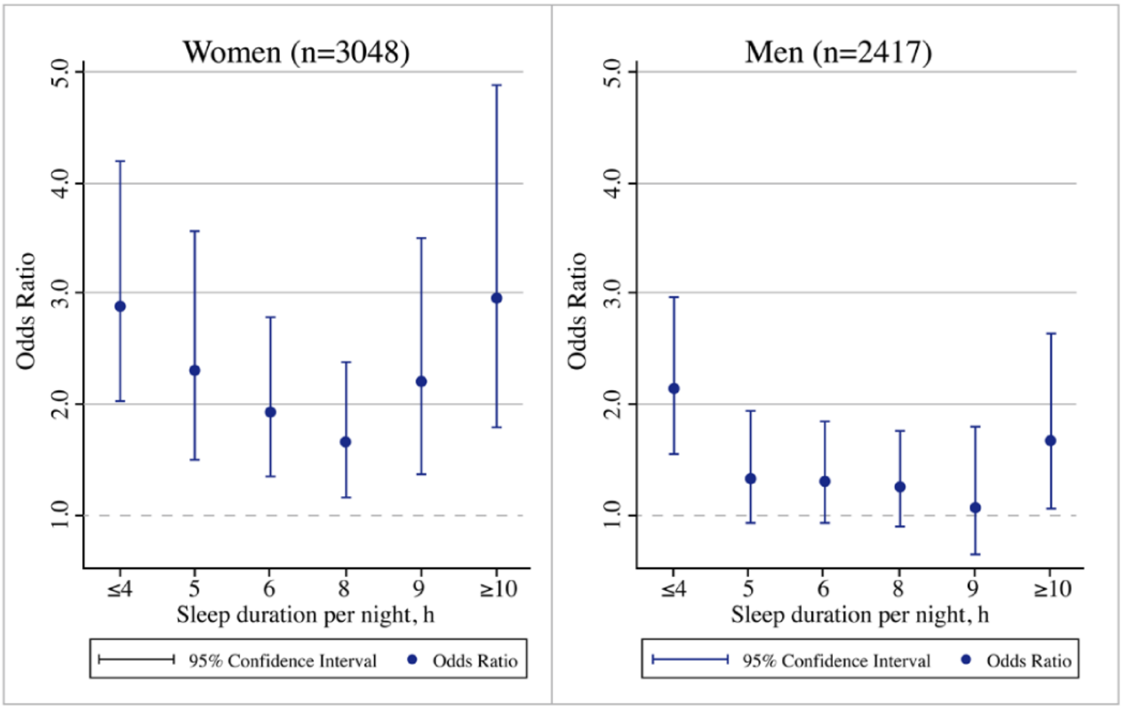
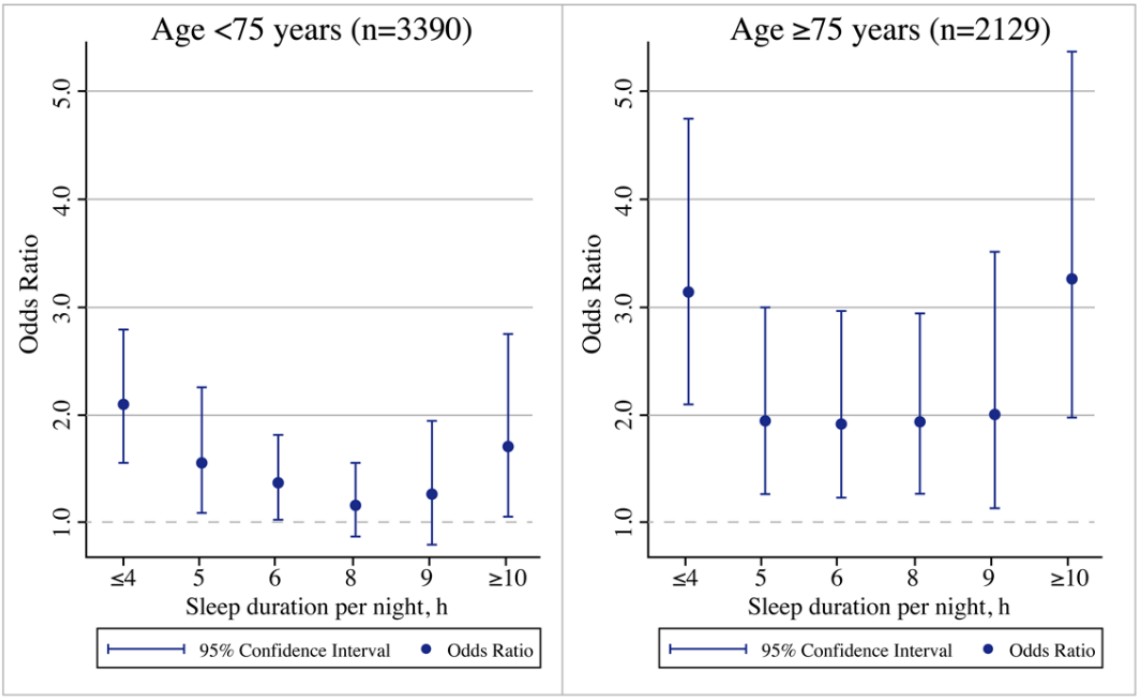


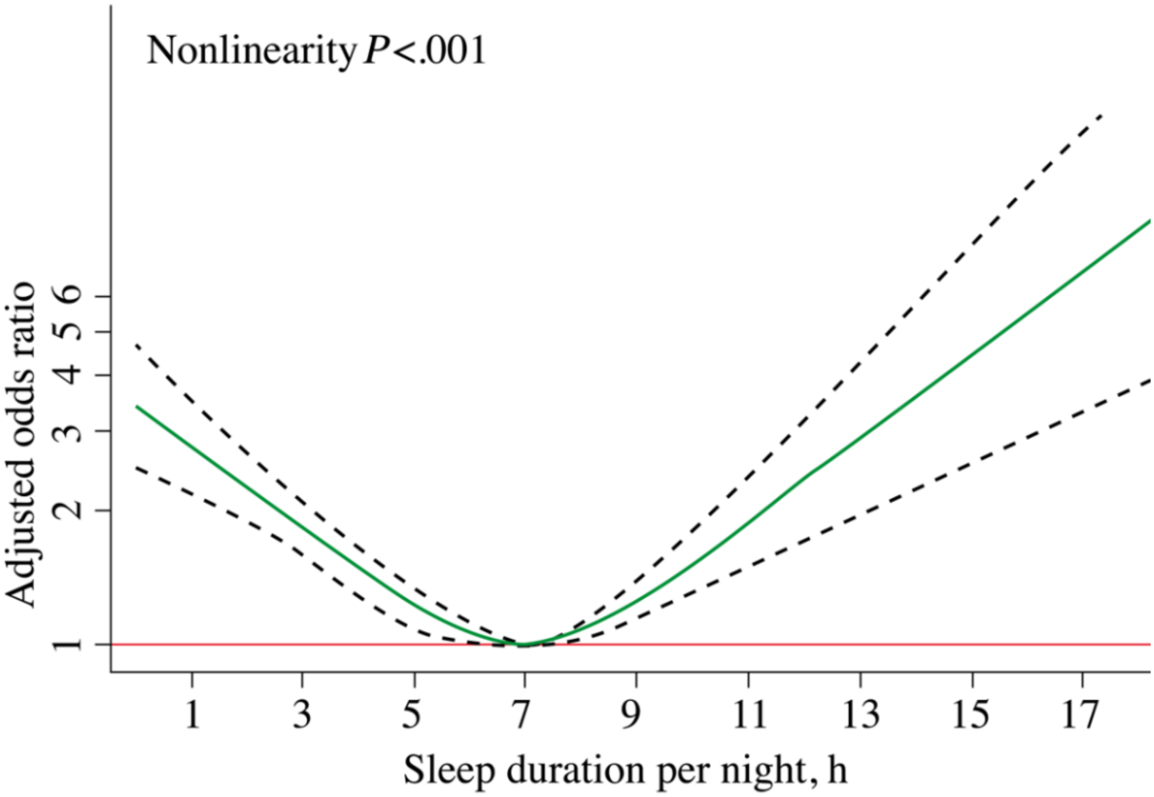
Figure 4. Age-specific effect of sleep duration on functional disability.



Nonlinear Relationship Between Sleep Duration and Functional Disability

Restricted cubic-splines analyses were conducted to visually represent the associations between the duration of sleep and functional disability. We found a U-shaped relationship between sleep duration and functional disability, even after accounting for confounding factors. As shown in Figure 5, the risk of functional disability was negatively correlated with sleep duration until it bottomed out at 7 hours (odds ratio [OR] 0.85, 95% CI 0.79-0.91; *P*<.001). Nevertheless, there was a substantial increase in the risk of functional disability when the duration of sleep exceeded 7 hours (OR 1.16, 95% CI 1.05-1.29; *P*<.001).

Figure 5. Nonlinear relationship of sleep duration and functional disability status. The adjusted odds ratio is presented accounting for potentially confounding factors (green solid line) in the relationship of sleep duration with 95% CIs (dotted lines) for functional disability. The red solid line is the reference line for the association at an odds ratio of 1.0.



Discussion

Principal Results

Our findings obtained from a nationally representative sample of 5519 participants 65 years and older in China indicated that shorter or longer sleep durations are associated with a higher risk of functional disability, including limitations in ADLs and IADLs. In the case of the older population, a minimum risk of 7 hours of sleep is associated with a reduced likelihood of experiencing functional disability. Based on previous studies highlighting functional disability as a notable risk factor for sleep disorders in the older population [39], the findings of this study suggest that the association between sleep and functional disability can exhibit a bidirectional nature.

Limitations

Our study has several limitations. First, the data of sleep duration and functional disability assessment were collected via self-report by participants, which could be subject to information bias. Second, the sample for this study comprised individuals from China who were 65 years of age or older. This particular demographic characteristic may limit the generalizability of the findings to different age cohorts, geographical areas, or ethnic backgrounds. Third, this study adopted a cross-sectional design, which limits the ability to show a causal association. It is plausible to consider that older adults with functional disability may require prolonged periods of sleep and a reduced duration of sleep could potentially serve as an initial indication of dysfunction. Therefore, it is necessary to conduct further comprehensive cohort studies to validate these findings.

Comparison With Prior Work

Functional ability refers to an individual’s capacity to engage in daily living and social activities according to their own intentions and preference. However, it is discouraging that the prevalence of functional disability was determined to be 41% across the entire sample in China [40]. The aging process is commonly accompanied by disturbances in sleep patterns, which have been linked to notable alterations in brain function and a decline in overall quality of life [41]. Moreover, various population-based studies [42-44], including both cross-sectional and longitudinal study designs, have demonstrated that the prevalence of cognitive decline may be linked to an increased risk of experiencing functional disability. Epidemiological research has also documented a U-shaped association between sleep duration and cognitive decline, indicating a significant trend in the association between sleep duration and functional disability [45-47]. Nevertheless, a definitive consensus has not yet been attained and there is still a dearth of studies examining the association between sleep duration and functional disability.

Despite previous investigations into the association between sleep duration and self-care function, the majority of these studies have primarily concentrated on a single form of functional disability. One study involving nightshift workers in the United States found that individuals with a shorter sleep duration (<7 hours/day) had the highest prevalence of sleep problems (61.8%) and the highest prevalence of an impaired ADL score (24.8%) [48], revealing a correlation between shorter sleep duration and higher risk of ADL disability. Another study focusing on patients with dementia discovered that a longer sleep duration was associated with ADL disability [49].

Similarly, a cross-sectional study that recruited 1798 participants older than 90 years found that a long sleep duration (≥12 hours) may be associated with an increased risk of ADL disability for this population [19]. Peng et al [50] found that after accounting for potential confounders such as age and gender, both longer and shorter sleep durations were linked to a heightened risk of IADL disability, which was consistent with the results of this study. Furthermore, instead of solely focusing on the relationship between shorter or longer sleep duration and functional disability among different sample sets, we simultaneously explored the impact of both shorter and longer sleep durations on functional disability within the same sample group. Additionally, concerning functional disability, we separately explored the associations between sleep duration and ADL and IADL disabilities, demonstrating that both shorter and longer sleep durations have an influence on functional health among the older population.

Implications and Contribution

The mechanism that accounts for the association between sleep duration and functional disability has yet to be fully explained; however, several hypotheses have been proposed. Luo et al [51] demonstrated that inadequate and excessive sleep durations were associated with an increased likelihood of hypertension among Chinese individuals. The increased susceptibility to cardiovascular illnesses associated with this elevated risk can have a direct influence on the overall well-being and functional abilities of older adults. Another recent study revealed that both insufficient and excessive sleep durations are associated with an increased risk of late-life dementia, a condition that significantly impairs the ability of older individuals to perform their daily tasks [52]. Other relevant studies indicated that sleep was correlated with changes in epigenetic mechanisms such as DNA methylation and histone modifications, which can also lead to cognitive dysfunctions such as learning and memory disruption [53-55]. This evidence has provided a new avenue for exploring the mechanism underlying the relationship between sleep duration and functional disability. Interventions aimed at good sleep hygiene may have the capacity to yield favorable outcomes in terms of improving physiological function among older adults. As evidenced by the empirical findings of this study, maintenance of the recommended sleep duration (7 hours) might play a crucial role in the health of older adults.

Our subgroup analyses suggested that women and older adults aged ≥75 years with shorter sleep durations (≤4, 5, and 6 hours) or longer sleep durations (8, 9, and ≥10 hours) per night were more likely to experience functional disability. Gender differences in sleep duration among the older population cannot be ignored. With changes in biological life cycles and the extreme hormonal fluctuations occurring with advancing age, women are at an increased risk for sleep disturbances (including insomnia and hypersomnia) [56]. Further, the sleep disturbances occurring during menopause can be an independent risk factor associated with arterial stiffness, which can result in a higher incidence of osteoarthritis that is in turn highly related to dysfunction [57]. With respect to age-specific effects, changes in sleep duration are a part of the normal aging process and also may enhance cellular aging in the later years of life [58]. According to the findings from an umbrella review [59], extreme sleep durations (including shorter and longer sleep durations) were more likely to be associated with an elevated risk of all-cause mortality, cognitive disorders, and type 2 diabetes in the general population. The circadian oscillations that alter body functions, including sleep, become less pronounced in older age, which can increase the risk of functional disability [60]. Collectively, these results emphasize the importance of addressing the complex needs of the population experiencing functional disabilities, particularly among women and older adults.

Conclusions

In conclusion, more attention should be paid to older individuals with shorter or longer sleep durations than recommended (7 hours). The precise mechanisms underlying the association between sleep duration and functional disability in the older population require further investigation.

Acknowledgments

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Data Availability

The data sets presented in this study can be found in online repositories of the China Health and Retirement Longitudinal Study [61]. The data sets generated and analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

HR and YF had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. ML, YD, BF, and XZ contributed to the hypothesis and study design and interpreted the results. HL and CL analyzed the data. ML wrote the manuscript. HR and YF revised the manuscript. All authors contributed to the article and approved the submitted version.

Conflicts of Interest

None declared.

References

1. Beard JR, Officer A, de Carvalho IA, Sadana R, Pot AM, Michel JP, et al. The world report on ageing and health: a policy framework for healthy ageing. Lancet 2016 May 21;387(10033):2145-2154 [FREE Full text] [doi: 10.1016/S0140-6736(15)00516-4] [Medline: 26520231]
2. Global issues: aging. The United Nations. URL: https://www.un.org/en/global-issues/ageing [accessed 2024-01-25]
3. Zhao Y, Hu Y, Smith JP, Strauss J, Yang G. Cohort profile: the China Health and Retirement Longitudinal Study (CHARLS). Int J Epidemiol 2014 Feb;43(1):61-68 [FREE Full text] [doi: 10.1093/ije/dys203] [Medline: 23243115]
4. International Classification of Functioning, Disability and Health (ICF). World Health Organization. 2018. URL: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health [accessed 2024-01-25]
5. Wang X, Chen P. Population ageing challenges health care in China. Lancet 2014 Mar 08;383(9920):870. [doi: 10.1016/S0140-6736(14)60443-8] [Medline: 24607099]
6. Papaioannou EC, Räihä I, Kivelä SL. Self-neglect of the elderly. An overview. Eur J Gen Pract 2012 Sep;18(3):187-190. [doi: 10.3109/13814788.2012.688019] [Medline: 22640528]
7. Millán-Calenti JC, Tubío J, Pita-Fernández S, González-Abraldes I, Lorenzo T, Fernández-Arruty T, et al. Prevalence of functional disability in activities of daily living (ADL), instrumental activities of daily living (IADL) and associated factors, as predictors of morbidity and mortality. Arch Gerontol Geriatr 2010;50(3):306-310. [doi: 10.1016/j.archger.2009.04.017] [Medline: 19520442]
8. Global report on health equity for persons with disabilities. World Health Organization. URL: https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/global-report-on-health-equity-for-persons-with-disabilities [accessed 2024-01-25]
9. World Population Prospects 2022: Summary of Results. UN DESA/POP/2022/TR/NO. 3. United Nations Department of Economic and Social Affairs. 2022. URL: https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/wpp2022_summary_of_results.pdf [accessed 2024-01-25]
10. Zheng P, Guo Z, Du X, Yang H, Wang Z. Prevalence of disability among the Chinese older population: a systematic review and meta-analysis. Int J Environ Res Public Health 2022 Jan 31;19(3):1656 [FREE Full text] [doi: 10.3390/ijerph19031656] [Medline: 35162679]
11. China country assessment report on ageing and health. World Health Organization. URL: https://www.who.int/publications/i/item/9789241509312 [accessed 2024-01-25]
12. Moradi S, Shab-Bidar S, Alizadeh S, Djafarian K. Association between sleep duration and osteoporosis risk in middle-aged and elderly women: a systematic review and meta-analysis of observational studies. Metabolism 2017 Apr;69:199-206. [doi: 10.1016/j.metabol.2017.01.027] [Medline: 28162775]
13. Wang C, Bangdiwala SI, Rangarajan S, Lear SA, AlHabib KF, Mohan V, et al. Association of estimated sleep duration and naps with mortality and cardiovascular events: a study of 116 632 people from 21 countries. Eur Heart J 2019 May 21;40(20):1620-1629 [FREE Full text] [doi: 10.1093/eurheartj/ehy695] [Medline: 30517670]
14. Zhou L, Yu K, Yang L, Wang H, Xiao Y, Qiu G, et al. Sleep duration, midday napping, and sleep quality and incident stroke: the Dongfeng-Tongji cohort. Neurology 2020 Jan 28;94(4):e345-e356. [doi: 10.1212/WNL.0000000000008739] [Medline: 31827003]
15. Titova OE, Michaëlsson K, Larsson SC. Sleep duration and stroke: prospective cohort study and Mendelian randomization analysis. Stroke 2020 Nov;51(11):3279-3285 [FREE Full text] [doi: 10.1161/STROKEAHA.120.029902] [Medline: 32895015]
16. da Silva AA, de Mello RGB, Schaan CW, Fuchs FD, Redline S, Fuchs SC. Sleep duration and mortality in the elderly: a systematic review with meta-analysis. BMJ Open 2016 Feb 17;6(2):e008119 [FREE Full text] [doi: 10.1136/bmjopen-2015-008119] [Medline: 26888725]
17. Ren Y, Miao M, Yuan W, Sun J. Sleep duration and all-cause mortality in the elderly in China: a population-based cohort study. BMC Geriatr 2020 Dec 30;20(1):541 [FREE Full text] [doi: 10.1186/s12877-020-01962-5] [Medline: 33380318]
18. Friedman EM. Self-reported sleep problems prospectively increase risk of disability: findings from the survey of midlife development in the United States. J Am Geriatr Soc 2016 Nov;64(11):2235-2241 [FREE Full text] [doi: 10.1111/jgs.14347] [Medline: 27626617]
19. Wang Z, Ni X, Gao D, Fang S, Huang X, Jiang M, et al. The relationship between sleep duration and activities of daily living (ADL) disability in the Chinese oldest-old: a cross-sectional study. PeerJ 2023;11:e14856 [FREE Full text] [doi: 10.7717/peerj.14856] [Medline: 36815994]
20. Okoye SM, Szanton SL, Perrin NA, Nkimbeng M, Schrack JA, Han H, et al. Objectively measured sleep and physical function: associations in low-income older adults with disabilities. Sleep Health 2021 Dec;7(6):735-741 [FREE Full text] [doi: 10.1016/j.sleh.2021.09.001] [Medline: 34602384]

21. Seixas AA, Chung DP, Richards SL, Madhavaram S, Raghavan P, Gago J, et al. The impact of short and long sleep duration on instrumental activities of daily living among stroke survivors. Neuropsychiatr Dis Treat 2019;15:177-182 [FREE Full text] [doi: 10.2147/NDT.S177527] [Medline: 30655670]
22. Chen T, Wu Z, Shen Z, Zhang J, Shen X, Li S. Sleep duration in Chinese adolescents: biological, environmental, and behavioral predictors. Sleep Med 2014 Nov;15(11):1345-1353 [FREE Full text] [doi: 10.1016/j.sleep.2014.05.018] [Medline: 25277663]
23. Liu X, Zhao Z, Jia C, Buysse DJ. Sleep patterns and problems among chinese adolescents. Pediatrics 2008 Jun;121(6):1165-1173. [doi: 10.1542/peds.2007-1464] [Medline: 18519486]
24. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, STROBE Initiative. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol 2008 Apr;61(4):344-349. [doi: 10.1016/j.jclinepi.2007.11.008] [Medline: 18313558]
25. Goodyear MDE, Krleza-Jeric K, Lemmens T. The Declaration of Helsinki. BMJ 2007 Sep 29;335(7621):624-625 [FREE Full text] [doi: 10.1136/bmj.39339.610000.BE] [Medline: 17901471]
26. Ma Y, Liang L, Zheng F, Shi L, Zhong B, Xie W. Association between sleep duration and cognitive decline. JAMA Netw Open 2020 Sep 01;3(9):e2013573 [FREE Full text] [doi: 10.1001/jamanetworkopen.2020.13573] [Medline: 32955572]
27. Rong H, Wang X, Lai X, Yu W, Fei Y. Associations between sleep duration and sensory impairments among older adults in China. Front Aging Neurosci 2022;14:910231 [FREE Full text] [doi: 10.3389/fnagi.2022.910231] [Medline: 35754970]
28. Johns MW. A new method for measuring daytime sleepiness: the Epworth sleepiness scale. Sleep 1991 Dec;14(6):540-545. [doi: 10.1093/sleep/14.6.540] [Medline: 1798888]
29. Katz S. Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. J Am Geriatr Soc 1983 Dec;31(12):721-727. [doi: 10.1111/j.1532-5415.1983.tb03391.x] [Medline: 6418786]
30. Qiao Y, Liu S, Li G, Lu Y, Wu Y, Shen Y, et al. Longitudinal follow-up studies on the bidirectional association between ADL/IADL disability and multimorbidity: results from two national sample cohorts of middle-aged and elderly adults. Gerontology 2021;67(5):563-571. [doi: 10.1159/000513930] [Medline: 34182559]
31. Guo L, An L, Luo F, Yu B. Social isolation, loneliness and functional disability in Chinese older women and men: a longitudinal study. Age Ageing 2021 Jun 28;50(4):1222-1228. [doi: 10.1093/ageing/afaa271] [Medline: 33352582]
32. Ferrucci L, Guralnik JM, Simonsick E, Salive ME, Corti C, Langlois J. Progressive versus catastrophic disability: a longitudinal view of the disablement process. J Gerontol A Biol Sci Med Sci 1996 May;51(3):M123-M130. [doi: 10.1093/gerona/51a.3.m123] [Medline: 8630705]
33. Silverstein M, Gong CH, Kendig H. Perceived availability of future care and depressive symptoms among older adults in China: evidence from CHARLS. BMC Geriatr 2020 Jan 30;20(1):31 [FREE Full text] [doi: 10.1186/s12877-020-1435-1] [Medline: 32000708]
34. Lei X, Sun X, Strauss J, Zhang P, Zhao Y. Depressive symptoms and SES among the mid-aged and elderly in China: evidence from the China Health and Retirement Longitudinal Study national baseline. Soc Sci Med 2014 Nov;120:224-232 [FREE Full text] [doi: 10.1016/j.socscimed.2014.09.028] [Medline: 25261616]
35. Luo H, Li J, Zhang Q, Cao P, Ren X, Fang A, et al. Obesity and the onset of depressive symptoms among middle-aged and older adults in China: evidence from the CHARLS. BMC Public Health 2018 Jul 24;18(1):909 [FREE Full text] [doi: 10.1186/s12889-018-5834-6] [Medline: 30041632]
36. Zhou L, Ma X, Wang W. Relationship between cognitive performance and depressive symptoms in Chinese older adults: The China Health and Retirement Longitudinal Study (CHARLS). J Affect Disord 2021 Feb 15;281:454-458. [doi: 10.1016/j.jad.2020.12.059] [Medline: 33360747]
37. Sun Y, Shi L, Bao Y, Sun Y, Shi J, Lu L. The bidirectional relationship between sleep duration and depression in community-dwelling middle-aged and elderly individuals: evidence from a longitudinal study. Sleep Med 2018 Dec;52:221-229. [doi: 10.1016/j.sleep.2018.03.011] [Medline: 29861378]
38. Sterne JAC, White IR, Carlin JB, Spratt M, Royston P, Kenward MG, et al. Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls. BMJ 2009 Jun 29;338:b2393 [FREE Full text] [doi: 10.1136/bmj.b2393] [Medline: 19564179]
39. Lee Y, Kong D, Lee YH, Lin C, Liu C, Chang Y. Functional disabilities and changes in sleep quality and duration among older adults: results from a longitudinal study in China, 2005-2014. Eur Geriatr Med 2022 Aug;13(4):967-975. [doi: 10.1007/s41999-022-00619-3] [Medline: 35191012]
40. Deting Y. The comparing study on individual factors about elder’s ability of caring for themselves. J Beijing Admin College 2017;1:86. [doi: 10.19879/j.cnki.1005-5304.202305064]
41. Romanella SM, Roe D, Tatti E, Cappon D, Paciorek R, Testani E, et al. The sleep side of aging and Alzheimer's disease. Sleep Med 2021 Jan;77:209-225 [FREE Full text] [doi: 10.1016/j.sleep.2020.05.029] [Medline: 32912799]
42. Solfrizzi V, Scafato E, Lozupone M, Seripa D, Giannini M, Sardone R, Italian Longitudinal Study on Aging Working Group. Additive role of a potentially reversible cognitive frailty model and inflammatory state on the risk of disability: the Italian Longitudinal Study on Aging. Am J Geriatr Psychiatry 2017 Nov;25(11):1236-1248. [doi: 10.1016/j.jagp.2017.05.018] [Medline: 28689645]

43. Shimada H, Makizako H, Lee S, Doi T, Lee S, Tsutsumimoto K, et al. Impact of cognitive frailty on daily activities in older persons. J Nutr Health Aging 2016;20(7):729-735 [FREE Full text] [doi: 10.1007/s12603-016-0685-2] [Medline: 27499306]
44. Feng L, Zin Nyunt MS, Gao Q, Feng L, Yap KB, Ng T. Cognitive frailty and adverse health outcomes: findings from the Singapore Longitudinal Ageing Studies (SLAS). J Am Med Dir Assoc 2017 Mar 01;18(3):252-258 [FREE Full text] [doi: 10.1016/j.jamda.2016.09.015] [Medline: 27838339]
45. Goodkin K, Evering TH, Anderson AM, Ragin A, Monaco CL, Gavegnano C, et al. The comorbidity of depression and neurocognitive disorder in persons with HIV infection: call for investigation and treatment. Front Cell Neurosci 2023;17:1130938 [FREE Full text] [doi: 10.3389/fncel.2023.1130938] [Medline: 37206666]
46. Suh SW, Han JW, Lee JR, Byun S, Kwon SJ, Oh SH, et al. Sleep and cognitive decline: a prospective nondemented elderly cohort study. Ann Neurol 2018 Mar;83(3):472-482. [doi: 10.1002/ana.25166] [Medline: 29394505]
47. Kawada T. Sleep duration and mortality. Am J Med 2019 Jan;132(1):e26. [doi: 10.1016/j.amjmed.2018.08.023] [Medline: 30573218]
48. Yong LC, Li J, Calvert GM. Sleep-related problems in the US working population: prevalence and association with shiftwork status. Occup Environ Med 2017 Feb;74(2):93-104. [doi: 10.1136/oemed-2016-103638] [Medline: 27609325]
49. Akada K, Koyama N, Miura Y, Takahashi K, Aoshima K. Nationwide database analysis of risk factors associated with decreased activities of daily living in patients with Alzheimer's disease. J Alzheimers Dis 2023;94(4):1465-1475. [doi: 10.3233/JAD-230106] [Medline: 37393499]
50. Peng Y, Bu J, Dai N, Huang C, Liu Y, Yang H, et al. Association of nocturnal sleep duration and nocturnal sleep changes with instrumental activities of daily living disability among middle-aged and elderly Chinese. Sleep Med 2023 Sep;109:90-97. [doi: 10.1016/j.sleep.2023.06.017] [Medline: 37423024]
51. Luo SY, Ye YX, Sun MY, Shen JC, Chen NX, Jia S, et al. Relationship of quality and duration of sleep with hypertension among adults in Guangzhou. Zhonghua Yu Fang Yi Xue Za Zhi 2021 Jul 06;55(7):853-859. [doi: 10.3760/cma.j.cn112150-20210204-00125] [Medline: 34304422]
52. Ohara T, Honda T, Hata J, Yoshida D, Mukai N, Hirakawa Y, et al. Association between daily sleep duration and risk of dementia and mortality in a Japanese community. J Am Geriatr Soc 2018 Oct;66(10):1911-1918. [doi: 10.1111/jgs.15446] [Medline: 29873398]
53. Webb CA, Cui R, Titus C, Fiske A, Nadorff MR. Sleep disturbance, activities of daily living, and depressive symptoms among older adults. Clin Gerontol 2018;41(2):172-180. [doi: 10.1080/07317115.2017.1408733] [Medline: 29272210]
54. Meguro K, Ueda M, Kobayashi I, Yamaguchi S, Yamazaki H, Oikawa Y, et al. Sleep disturbance in elderly patients with cognitive impairment, decreased daily activity and periventricular white matter lesions. Sleep 1995 Feb;18(2):109-114. [doi: 10.1093/sleep/18.2.109] [Medline: 7792490]
55. Gaine ME, Chatterjee S, Abel T. Sleep deprivation and the epigenome. Front Neural Circuits 2018;12:14 [FREE Full text] [doi: 10.3389/fncir.2018.00014] [Medline: 29535611]
56. Tandon VR, Sharma S, Mahajan A, Mahajan A, Tandon A. Menopause and sleep disorders. J Midlife Health 2022;13(1):26-33 [FREE Full text] [doi: 10.4103/jmh.jmh_18_22] [Medline: 35707298]
57. Pehlivan S, Karadakovan A, Pehlivan Y, Onat AM. Sleep quality and factors affecting sleep in elderly patients with rheumatoid arthritis in Turkey. Turk J Med Sci 2016 Jun 23;46(4):1114-1121. [doi: 10.3906/sag-1506-82] [Medline: 27513413]
58. Gulia KK, Kumar VM. Sleep disorders in the elderly: a growing challenge. Psychogeriatrics 2018 May;18(3):155-165. [doi: 10.1111/psyg.12319] [Medline: 29878472]
59. Li J, Cao D, Huang Y, Chen Z, Wang R, Dong Q, et al. Sleep duration and health outcomes: an umbrella review. Sleep Breath 2022 Sep;26(3):1479-1501. [doi: 10.1007/s11325-021-02458-1] [Medline: 34435311]
60. Liu F, Chang H. Physiological links of circadian clock and biological clock of aging. Protein Cell 2017 Jul;8(7):477-488 [FREE Full text] [doi: 10.1007/s13238-016-0366-2] [Medline: 28108951]
61. China Health and Retirement Longitudinal Study (CHARLS) data repository. URL: https://charls.charlsdata.com/index/en.html [accessed 2024-05-24]

Abbreviations

ADL: activity of daily living
CHARLS: China Health and Retirement Longitudinal Study
GLM: generalized linear model
IADL: instrumental activity of daily living
NCD: noncommunicable disease
OR: odds ratio
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
WHO: World Health Organization

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Original Paper

Factors Influencing Malnutrition Among Older Adult Residents in the Western Region of Saudi Arabia: Sex Differential Study

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Abstract

Background: The global population of older adults is on the rise. As people age, their physical functions gradually decline, leading to a decrease in the overall functioning of different organ systems. Due to these changes, older individuals are at a higher risk of encountering various adverse health outcomes and complications, such as malnutrition.

Objective: This study aims to investigate the prevalence of malnutrition and its associated factors among older adults dwelling in the western region of Saudi Arabia. We have analyzed these factors separately for both men and women to understand any potential sex differences.

Methods: A nonrandomized cross-sectional study was conducted for older adults aged ≥60 years in the western region of Saudi Arabia. Personal information was obtained through a closed questionnaire. The Mini Nutritional Assessment Short Form was used to determine the malnutrition status of older adults. Consequently, the individuals were divided into 2 groups: normal and malnourished. To assess the risk factors related to malnutrition, the odds ratio (OR) and 95% CI were determined using a binary logistic regression.

Results: The prevalence of malnutrition in men and women was around 7% and 5%, respectively. Potential risk factors related to malnutrition in men were higher age (OR 1.263, 95% CI 1.086-1.468; *P*=.002), being widowed (OR 8.392, 95% CI 1.002-70.258; *P*=.049), and having dental problems (OR 9.408, 95% CI 1.863-47.514; *P*=.007). On the other hand, risk factors associated with malnutrition in women were lower BMI (OR 0.843, 95% CI 0.747-0.952; *P*=.006) and being disabled (OR 18.089, 95% CI 0.747-0.952; *P*=.006).

Conclusions: The findings of this study provide important insights into the risk factors for malnutrition among older adults in the western region of Saudi Arabia. While the overall prevalence of malnutrition was relatively low, the analysis revealed distinct risk factors for older men and women. Interventions developed based on the identified risk factors may prove effective in addressing the issue of malnutrition within this population.

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KEYWORDS

Elderly; Makkah; Malnutrition; Mini Nutritional Assessment Short Form; Risk factors

Introduction

The global population of older adults, aged 60 years and older, is considerably large. According to the World Health Organization, the global population of individuals aged 60 years and older was approximately 1 billion in 2019. It is projected to reach 1.4 billion by 2030 and further increase to 2.1 billion by 2050 [1]. Older adults in Saudi Arabia are expected to increase from 5.6% in 2017 to 23% by 2050 [2]. This rapid growth emphasizes the importance of the country to prepare and adapt to the changing demographics.

The process of aging involves a gradual decline in physiological functions, resulting in a decrease in the functional abilities of various organ systems and a reduced ability to cope with physical, cognitive, and mental stressors [3]. The impact of these changes can have a profound effect on the overall well-being of individuals. Additionally, as aging progresses, the prevalence of chronic diseases and multiple chronic conditions increases substantially, placing significant burdens on both individuals and the health care system. Older adults face greater risks of experiencing adverse health outcomes and complications, including malnutrition [4].

The prevalence of malnutrition among older adults is substantial and varies across different countries, ranging from an estimated 13% to 54% globally [5]. According to a recent study conducted in Nepal, the occurrence of malnutrition among a group of 320 older adults was found to be 11.6% [6]. The earlier study found that malnutrition was more common among women (15%) compared to men (9.3%). However, malnutrition is a complex condition influenced by various factors that can vary between countries and even different cities within the same country [3]. Therefore, this study specifically focuses on the western region of Saudi Arabia to examine the prevalence of malnutrition and its associated factors among older adults, taking into account the variations based on sex.

Methods

Participants

This study was conducted in the western region of Saudi Arabia (Makkah, Jeddah, Al-Taif, and Al-Madinah) as a community-based, nonrandomized, cross-sectional study, and was conducted between the periods of October 2022 and December 2022. To be included in the study, participants had to be older adults aged <60 years and living in the western region of Saudi Arabia. However, hospitalized older adults were excluded from the study. Out of 883, 623 were included; 2 were missing data, and 258 were out of the recruited age. As per the latest data from the General Authority for Statistics Report in the Kingdom of Saudi Arabia (KSA), there are approximately 400,000 older adults residing in the western region. The sample size was calculated using the Raosoft website. Based on specific parameters, including a 5% accepted margin of error, a 95% CI, and a 50% response distribution, the minimum required sample size for the study was determined to be 384 older adults.

Study Design

A web-based questionnaire was submitted to eligible participants. Informed consent was meticulously drafted in simple Arabic language to ensure understanding, and it was obtained directly from the older adults or through their immediate family members, as outlined in the procedural instructions prior to questionnaire completion. Personal information was obtained by a closed questionnaire, including age, height (cm), weight (kg), BMI (kg/m^2), nationality, city, social status, educational level, family income, living status, and health status. The Mini Nutritional Assessment (MNA) Short Form was used to determine the malnutrition status of older adults [7]. The MNA Short Form questionnaire includes 6 sections: food intake declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties, weight loss during the last 3 months, mobility, experiencing psychological stress or acute disease in the past 3 months, neuropsychological problems, and BMI (kg/m^2). Each answer to the previous questions is assigned a score, and the total value is the MNA score. Based on this score, we divided the sample into 2 categories: normal (MNA score ranging from 8 to 14), and malnourished (MNA score ≤7 points).

Statistical Analysis

To analyze the data statistically, we applied IBM-SPSS statistics (version 23). We considered a P value less than .05 as statistically significant. For continuous variables, we represented them as the mean and SD. On the other hand, category variables were compared using a chi-squared test to examine their frequencies. The Mann-Whitney test was used to compare the mean ranks between the 2 groups when the distribution was not normal. To evaluate the risk factors associated with malnutrition, we conducted a multivariate binary logistic regression separately for men and women. This analysis allowed us to determine the odds ratio (OR) along with the corresponding 95% CI.

Ethical Considerations

This study was approved by the Ethical Committee of Umm Al-Qura University (approval number AMSEC-6-954-2022), following the Declaration of Helsinki. All participants in the study volunteered and provided informed consent at the beginning. The data collected was made anonymous and did not include any identifiable information. As a token of appreciation, all participants who completed the questionnaire received a US $25 gift voucher.

Results

The findings of this study are presented in Tables 1-3. Table 1 presents the sociodemographic characteristics of the participants in relation to malnutrition in both sexes. Tables 2 and 3 present the findings of logistic regression analysis, which was used to assess the probability of malnutrition occurrence based on the presence or absence of various risk factors in men and women, respectively. As shown in Table 1, of the total sample size (n=623), 36.5% were male and 55.5% were female. The majority of participants (95.3%) were of Saudi Arabian nationality. The prevalence of malnutrition was observed to be slightly higher among men (≈7%) compared to women (≈5%). Age was identified as a non-modifiable risk factor (a trait that cannot be altered or changed) that showed a positive association with malnutrition in older men. This suggests that as men get older, they are more likely to experience malnutrition (OR 1.263; 95% CI 1.086-1.468; P=.002; Table 2). However, no such association was observed among women (Table 3).

As opposed to the positive association detected between malnutrition and age, a negative correlation was observed between malnutrition and BMI in women. Specifically, the incidence of malnutrition was found to be more prevalent among women with a lower BMI compared to those with a higher BMI (mean BMI 25.5, SD 8.1 vs mean 29.4, SD 7; P=.04; Table 1). Logistic regression analysis further supported this finding, indicating that older women with a higher BMI had a 16% lower probability of experiencing malnutrition compared to those with a lower BMI (OR 0.843, 95% CI 0.747-0.952; *P*=.006), as depicted in Table 3.

As presented in Table 1, additional factors were found to be associated with the nutritional status of both male and female older adults. These factors include educational level, social status, and health status. Specifically, individuals with higher levels of education exhibited better health outcomes across both sexes. For instance, a significant proportion of older men (76.3%) who held bachelor's or postgraduate degrees were not affected by malnutrition, whereas only 35% experienced malnutrition (*P*=.001). Similarly, 62.9% of women, with bachelor's or postgraduate degrees did not experience malnutrition, while only 29.4% were malnourished (*P*=.02) (Table 1). Furthermore, malnutrition was less prevalent among financially independent individuals of both sexes. Notably, 93.8% of financially independent men were not malnourished, whereas only 6.2% of them experienced malnutrition (*P*<.001). Likewise, among financially independent women, 79% were not malnourished, while 21% of them exhibited malnutrition (*P*=.005).

Regarding social status, being married was associated with a more favorable nutritional status, with 90.7% of married men not affected by malnutrition. Additionally, the presence of a spouse and children in the household was linked to a significantly lower prevalence of malnutrition among older adults. Around 96% of men living with their wives and children were not affected by malnutrition, while only 3.9% experienced malnutrition (*P*=.006; Table 1). Conversely, being widowed was identified as a risk factor for malnutrition in older men. Interestingly, according to the logistic regression analysis, widowed men had an approximately 8-fold higher likelihood of experiencing malnutrition compared to their married counterparts (95% CI 1.002-70.258; *P*=.049), as depicted in Table 2. However, this association was not evident among women (Table 3).

In terms of health status, the prevalence of malnutrition was observed to be high among men with chronic health conditions. Compared to healthy older men, malnutrition was notably more prevalent among individuals diagnosed with diabetes (15% vs 85%, *P*=.006), hypertension (20% vs 80%, *P*=.007), and heart disease (40% vs 60%, *P*=.001; Table 1). An additional noteworthy factor linked to the likelihood of developing malnutrition in older men was the presence of dental problems. Specifically, older men with dental problems exhibited a significantly higher probability of experiencing malnutrition, approximately 9-fold higher than those without dental problems (95% CI 1.863-47.514; *P*=.007; Table 2). As for women, disability was found to be strongly associated with malnutrition. The probability of experiencing malnutrition in older women with a disability was approximately 18-fold higher compared to their counterparts without a disability (95% CI 2.605-125.626; *P*=.003; Table 3).

Table 1. Relationship between malnutrition and participants' characteristics based on sex.

Variable	Men (n=277)		*P* value	Women (n=346)		*P* value
	Malnutrition			Malnutrition		
	Yes (n=20)	No (n=257)		Yes (n=17)	No (n=329)	
Age (years), mean (SD)	73.1 (7.6)	65.3 (4.9)	*<.001* [a]	66.6 (5.7)	64.3 (5.3)	*.03*
Height (cm), mean (SD)	178.9 (5.9)	171.7 (7)	.08	157.4 (7.5)	159.3 (7)	.37
Weight (kg), mean (SD)	84.8 (26)	84.1 (15.9)	.57	62.8 (18.7)	74.4 (17.7)	.15
BMI (kg/m^2), mean (SD)	26.5 (8.1)	28.4 (5.4)	.05	25.5 (8.1)	29.4 (7)	*.04*
MNA[b] score, mean (SD)	5.2 (1.5)	12.5 (1.6)	*<.001*	6 (1.1)	12.1 (1.8)	*<.001*
Nationality, n (%)			.30			.51
Saudi	18 (90)	244 (94.9)		16 (94.1)	316 (96)	
Non-Saudi	2 (10)	13 (5.1)		1 (5.9)	13 (4)	
Residence, n (%)			.19			.34
Makkah	11 (55)	127 (49.4)		12 (70.6)	220 (66.9)	
Jeddah	5 (25)	99 (38.5)		3 (17.6)	83 (25.1)	
Al-Taif	3 (15)	12 (4.7)		0 (0)	13 (4)	
Al-Madinah	1 (5)	19 (7.4)		2 (11.8)	13 (4)	
Social status, n (%)			*<.001*			*.007*
Married	9 (45)	233 (90.7)		4 (23.5)	202 (61.4)	
Single or divorced	2 (10)	11 (4.3)		6 (35.3)	51 (15.5)	
Widowed	9 (45)	13 (5)		7 (41.2)	76 (23.1)	
Education level, n (%)			*.001*			*.009*
Illiterate or elementary	5 (25)	14 (5.4)		5 (29.4)	56 (17)	
Middle school	2 (10)	8 (3.1)		4 (23.5)	19 (5.8)	
High school	6 (30)	39 (15.2)		3 (17.6)	47 (14.3)	
Bachelor's degree	4 (20)	132 (51.4)		3 (17.6)	178 (54.1)	
Postgraduate degree	3 (15)	64 (24.9)		2 (11.8)	29 (8.8)	
Income (SAR[c]), n (%)			*.04*			*.02*
<5000	6 (30)	24 (9.3)		11 (64.7)	99 (30.1)	
5001-10,000	4 (20)	55 (21.4)		2 (11.8)	81 (24.6)	
10,001-20,000	5 (25)	99 (38.5)		2 (11.8)	117 (35.6)	
>20,000	5 (25)	79 (30.7)		2 (11.8)	32 (9.7)	
Describe your financial status, n (%)			*<.001*			*.005*
Dependent	8 (40)	16 (6.2)		9 (52.9)	69 (21)	
Independent	12 (60)	241 (93.8)		8 (47.1)	260 (79)	
Living status, n (%)			*.01*			*.008*
Alone	4 (20)	10 (3.9)		8 (47.1)	60 (18.2)	
With wife, husband, or children	16 (80)	247 (96.1)		9 (52.9)	269 (81.8)	
Diabetes, n (%)			*.006*			.10
Yes	17 (85)	140 (54.5)		10 (58.8)	131 (39.8)	
No	3 (15)	117 (45.5)		7 (41.2)	198 (60.2)	
Hypertension, n (%)			*.007*			.47
Yes	16 (80)	127 (49.4)		9 (52.9)	161 (48.9)	

Variable	Men (n=277)		*P* value	Women (n=346)		*P* value
	Malnutrition			Malnutrition		
	Yes (n=20)	No (n=257)		Yes (n=17)	No (n=329)	
No	4 (20)	130 (50.6)		8 (47.1)	168 (51.1)	
Heart disease, n (%)			*.001*			.18
Yes	12 (60)	62 (24.1)		4 (23.5)	42 (12.8)	
No	8 (40)	195 (75.9)		13 (76.5)	287 (87.2)	
Disability, n (%)			*<.001*			*.001*
Yes	12 (60)	13 (5.1)		4 (23.5)	7 (2.1)	
No	8 (40)	244 (94.9)		13 (76.5)	322 (97.9)	
Dental problem, n (%)			*<.001*			.19
Yes	18 (90)	112 (43.6)		12 (70.6)	186 (56.5)	
No	2 (10)	145 (56.4)		5 (29.4)	143 (43.5)	
Smoking, n (%)			.12			.40
Yes	6 (30)	72 (28)		1 (5.9)	34 (10.3)	
Ex-smoker	5 (25)	118 (45.9)		16 (94.1)	271 (82.4)	
No	9 (45)	67 (26.1)		0 (0)	24 (7.3)	

[a] The *P* values presented in italics are considered statistically significant at $P<.05$.

[b] MNA: Mini Nutritional Assessment.

[c] SAR: Saudi Riyals (SAR 1=US $0.27).

Table 2. Potentially significant predictors related to malnutrition for men.

Variable	Odds ratio	95% CI	*P* value
Age	1.263	1.086-1.468	*.002* [a]
Social status			
Married	1[b]	—[c]	—
Single or divorced	1.603	0.063-40.822	.78
Widowed	8.392	1.002-70.258	*.049*
Education level			
Illiterate or elementary	3.931	0.176-87.737	.39
Middle school	1.774	0.047-66.967	.76
High school	7.023	0.368-134.086	.20
Bachelor's degree	0.804	0.073-8.874	.86
Postgraduate degree	1	—	—
Income (SAR[d])			
<5000	3.893	0.182-83.176	.38
5001-10,000	0.287	0.012-6.945	.44
10,001-20,000	1.443	0.128-16.266	.77
>20,000	1	—	—
Describe your financial status			
Dependent	0.462	0.052-4.12	.49
Independent	1	—	—
Living status			
Alone	4.299	0.258-71.566	.31
With wife, husband, or children	1	—	—
Diabetes			
Yes	0.544	0.07-4.233	.56
No	1	—	—
Hypertension			
Yes	1.84	0.304-11.128	.51
No	1	—	—
Heart disease			
Yes	3.048	0.52-17.851	.22
No	1	—	—
Disability			
Yes	6.666	0.741-59.986	.09
No	1	—	—
Dental problem			
Yes	9.408	1.863-47.514	*.007*
No	1	—	—

[a] Italic values are considered statistically significant.

[b] Reference values.

[c] Not applicable.

[d] SAR: Saudi Riyals (SAR 1=US $0.27).

Table 3. Potentially significant predictors related to malnutrition for women.

Variable	Odds ratio	95% CI	*P* value
Age	1.017	0.925-1.118	.73
BMI	0.843	0.747-0.952	*.006* [a]
Social status			
Married	1[b]	—[c]	—
Single or divorced	3.099	0.456-21.082	.25
Widowed	2.653	0.492-14.303	.26
Education level			
Illiterate or elementary	0.703	0.036-13.776	.82
Middle school	1.371	0.071-26.494	.84
High school	0.479	0.027-8.492	.62
Bachelor’s degree	0.457	0.047-4.431	.50
Postgraduate degree	1	—	—
Income (SAR[d])			
<5000	1.284	0.114-14.451	.84
5001-10,000	0.357	0.024-5.214	.45
10,001-20,000	0.37	0.039-3.538	.39
>20,000	1	—	—
Describe your financial status			
Dependent	1.749	0.468-6.546	.41
Independent	1	—	—
Living status			
Alone	1.76	0.422-7.336	.44
With wife, husband, or children	1	—	—
Disability			
Yes	18.089	2.605-125.626	*.003*
No	1	—	—

[a] Italic values are considered statistically significant.

[b] Reference value.

[c] Not applicable.

[d] SAR: Saudi Riyals (SAR 1=US $0.27).

Discussion

Principal Findings

This study explored the prevalence of malnutrition among older men and women in the Saudi Arabian community in the western province, with an emphasis on its associated risk factors. The study revealed that the occurrence of malnutrition was approximately 7% among men and 5% among women. This is comparable to the findings of studies conducted in the region. For instance, a study conducted in Jeddah city reported that the prevalence of malnutrition among older adults was 5.3% [8]. Another study conducted in Al Madinah Al Munawarah reported a lower prevalence of malnutrition among older adults, accounting for 3.5% [9]. One possible reason for this difference in the prevalence of geriatric malnutrition could be attributed to the different support and health programs provided in each district.

However, a study involving participants from Makkah and Jeddah cities found a higher prevalence of malnutrition among older adults, reaching approximately 13% [10]. This elevated prevalence could be linked to the study's recruitment strategy, which involved recruiting individuals from public places as well as health care clinics. This suggests that the study cohort may have had preexisting health conditions or chronic illnesses that could impact their nutritional status. This is consistent with a further study conducted in Jeddah city, which included hospitalized patients and reported a higher prevalence of geriatric malnutrition, reaching 27% [11].

The association between malnutrition and chronic disease is well established in the literature [12]. This is also confirmed by the findings of this study, which found that the prevalence of malnutrition was higher among older men with chronic health conditions (ie, diabetes, hypertension, and heart disease), which could be attributed to several factors. For instance, symptoms associated with chronic diseases, such as fatigue, pain, or shortness of breath, can impact appetite and food intake, leading to malnutrition [13]. Furthermore, medications used to manage chronic diseases can have side effects that reduce appetite, alter taste perception, or impair nutrient absorption, leading to malnutrition [14]. Therefore, regular monitoring of the old individual's nutritional status as well as any signs of malnutrition is recommended in order to identify and address any deficiencies or imbalances early on.

The significant association between chronic disease and malnutrition observed in men, but not in women, could be partially explained by the higher prevalence of chronic conditions in the male subsample compared to the female subsample. Specifically, the prevalence of diabetes was 85% in men versus 58.8% in women, the prevalence of hypertension was 80% in men versus 52.9% in women, and the prevalence of heart disease was 60% in men versus 23.5% in women. This disparity in chronic disease burden between sexes may have contributed to the stronger link between chronic conditions and malnutrition risk observed in the male participants. The higher underlying chronic disease prevalence in the male group could make them more susceptible to the detrimental effects of chronic illness on nutritional status, leading to the significant association found in the regression analysis. However, further investigation into the complex interplay of sex, chronic disease burden, and nutritional status in this population would be valuable to elucidate the factors contributing to the divergent findings.

Not only were chronic health conditions associated with the prevalence of malnutrition in the participated sample, but disability was also a strong predictor, especially among women. In this study, women with disabilities were 18 times more likely to experience malnutrition compared to healthy individuals. This is consistent with a study conducted in the KSA, which reported that physically dependent older adults had higher scores of malnutrition compared to their independent counterparts [15]. This could be explained by the fact that disability adversely affects the potential to access and consume nutritious food, leading to poor nutritional intake [16]. In contrast to the adverse impact of disability on nutritional status, mobility in older patients was associated with 90% lower cases of malnutrition compared to being bed-bound, as shown by a recent study conducted in the KSA [11]. This is probably because older adults with better mobility are more likely to be independent in performing their daily activities, including shopping, cooking, and eating. This independence allows them to have greater autonomy in their food choices and meal preparation, leading to a higher likelihood of consuming a balanced and nutritious diet [17].

Contrary to the significant negative association observed between disability and nutritional status among women, this study did not detect a comparable adverse effect of physical impairment on the nutritional profile of men. This difference may be partly explained by the slightly higher prevalence of disability among women (46.7%) compared to men (41.5%) in the KSA, based on openly available data from 2015 to 2020 [18]. Another potential explanation for the significant impact of disability on women, compared with the absence of such an association in men, may lie in the social context. For instance, physical impairment might be linked with social isolation and depression [19], which could diminish appetite and subsequently lower nutritional intake, resulting in malnutrition [20]. According to the World Health Organization, rates of depression are higher among women (6%) compared to men (4%) [21]. This discrepancy may elucidate the observed sex differences in the relationship between disability and nutritional status.

According to the findings of this study, dental problems were also identified as a risk factor for geriatric malnutrition. The likelihood of experiencing malnutrition in older men was approximately 9 times higher in participants experiencing dental problems compared to their counterparts who had good dental health. This is in line with the findings of a recent study conducted in Riyadh (central region, KSA), which reported that malnutrition was greater in patients with higher scores of oral health problems compared to those with lower scores [22]. This is expected, as dental and oral problems in older adults could be associated with malnutrition due to difficulties in chewing, pain, and discomfort while eating, leading to poor nutrient intake.

In this study, we investigated the relationship between malnutrition among older adults and BMI as a continuous variable, rather than focusing on a specific weight status category such as underweight or overweight. It is important to note that obesity is prevalent in the KSA [23]; however, there are limited data regarding the associations between weight status and malnutrition among older adults in the country. While low BMI is often used to identify the presence of malnutrition [24], we sought to explore the associations between an individual's BMI, across its entire range, and the likelihood of being malnourished. The analysis took into account the complex interplay of factors that can contribute to malnutrition risk. This allowed us to assess the independent effect of BMI, treated as a continuous measure, on malnutrition, while controlling for other potential confounding variables. It was found that a higher BMI is considered a protective factor against malnutrition in the participated older women. This is in alignment with the findings of several studies conducted in Kuwait [25], Lebanon [26], and Iran [27]. The reduced risk of malnutrition among older adults with a higher BMI could be explained by the fact that a higher BMI implies larger energy reserves and nutrient stores, which can help buffer against periods of reduced food intake or increased nutrient requirements that may occur in situations of illness or decreased appetite [28]. However, a recent review highlighted the absence of comprehensive research on anthropometric cutoffs for older adults in Saudi Arabia, which hampers the development of evidence-based guidelines. Thus, further studies are needed to establish anthropometric cutoffs that align with the Saudi Vision 2030 [29]. This is important for enabling health care professionals to accurately assess and manage the nutritional needs of older adults.

According to the study findings, being married and living with family emerged as potential protective factors against malnutrition in older men. This is expected and could be attributed to the positive influence of social interaction and companionship during mealtimes, which could enhance appetite and enjoyment of food. In contrast, being widowed in men was associated with 8 times greater likelihood of experiencing malnutrition compared to being married. This is in line with the findings of a systematic review and meta-analysis of 40 observational studies, which confirmed that social status is a predictor of geriatric malnutrition [30]. The adverse influence of spouse loss on malnutrition in older adults might be due to a lack of emotional support and companionship, which can contribute to a decline in appetite and skipping meals, leading to poor nutritional status [31,32].

It is worth mentioning that the absent probability of experiencing malnutrition in women compared to men, in this study, might be explained by cultural norms and sex roles. In many societies, traditional sex roles have assigned women the primary responsibility for food preparation, cooking skills, and attention to the nutritional value of food. This has resulted in women having a greater understanding of nutrition and being less prone to malnutrition compared to men who may rely on their wives for meal preparation [33].

The preceding sections discussed the findings of this study in terms of the prevalence of geriatric malnutrition in the KSA and its associated risk factors. This section will briefly discuss the potential solutions to address this pressing issue. It is recommended to consider comprehensive interventions that encompass a range of strategies aimed at mitigating malnutrition among older adults. These strategies may include social support, dietary modifications, nutritional supplementation, meal delivery programs, and nutrition education or counseling [34-36]. Moreover, it is important to consider cultural factors during the development of the intervention, as they play a crucial role in shaping dietary habits, attitudes towards food, and health-seeking behaviors in older adults [37]. By designing an intervention that aligns with the cultural norms, values, and preferences of the target population, the effectiveness and acceptability of the intervention are likely to be enhanced [38]. Therefore, it is recommended to develop culturally tailored interventions that tackle barriers including traditional food practices, religious beliefs, and social norms, as they are likely to have the potential to enhance nutrition outcomes.

Furthermore, it is recommended to leverage the advantages offered by modern technology and widespread internet usage, along with the proliferation of handheld devices. These factors could facilitate intervention delivery to older adults. This is supported by the findings of a systematic review of 70 studies, which indicated that eHealth interventions using mobile apps could be deemed effective in enhancing health outcomes in older adults [39]. Nevertheless, that review underscored heterogeneity in terms of intervention duration, targeted health outcomes, and populations. Therefore, additional research endeavors are warranted in this domain to establish robust evidence concerning the optimal approaches for addressing geriatric malnutrition.

Limitations

It is important to note that this study has a cross-sectional design, which limits its scope. Moreover, older adults were only recruited from certain regions in the KSA, so the findings of this study cannot be generalized to the entire older adults in the KSA. Another limitation of the study involved the self-reported nature of the data. The researchers relied on self-reported information from the participants, which may be subject to recall bias or social desirability bias. This could potentially affect the accuracy of the data collected, particularly regarding factors such as weight loss, food intake, and health status. However, a key strength of the study is that, to the best of our knowledge, it is the first to investigate the sex-based differences in the prevalence and associated risk factors of malnutrition among older adults in the KSA. This represents an important contribution to the limited existing literature on this topic in the KSA.

Conclusions

The findings of this study indicate that malnutrition affects both older men and women in the western region of Saudi Arabia. Importantly, the study identified various risk factors associated with malnutrition in this population. These findings hold significance for informing the development of targeted interventions aimed at addressing malnutrition among older adults. By identifying the specific risk factors, health care providers and policy makers can tailor strategies and interventions to effectively meet the distinct needs and challenges faced by both sexes. Furthermore, understanding the impact of malnutrition on older men and women allows for the consideration of sex-specific factors in the planning and implementation of interventions. This recognition enables the design of interventions that account for the unique circumstances, social dynamics, and cultural norms that may influence nutritional health differently for men and women. In addition, future research is recommended to evaluate the efficacy of digital interventions in mitigating malnutrition within the Saudi Arabian population, considering the potential benefits of technology-based approaches to addressing this issue.

Conflicts of Interest

None declared.

References

1. WHO. Ageing and health. 2024. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2024-06-01]

2. Alshanberi AM. Frailty in Kingdom of Saudi Arabia—prevalence and management, where are we? Healthcare (Basel) 2023 Jun 12;11(12):1715 [FREE Full text] [doi: 10.3390/healthcare11121715] [Medline: 37372833]
3. Norman K, Haß U, Pirlich M. Malnutrition in older adults—recent advances and remaining challenges. Nutrients 2021 Aug 12;13(8):2764 [FREE Full text] [doi: 10.3390/nu13082764] [Medline: 34444924]
4. Khoja AT, Aljawadi MH, Al-Shammari SA, Mohamed AG, Al-Manaa HA, Morlock L, et al. The health of Saudi older adults; results from the Saudi National Survey for Elderly Health (SNSEH) 2006-2015. Saudi Pharm J 2018 Feb;26(2):292-300 [FREE Full text] [doi: 10.1016/j.jsps.2017.11.008] [Medline: 30166931]
5. Krishnamoorthy Y, Vijayageetha M, Kumar S, Rajaa S, Rehman T. Prevalence of malnutrition and its associated factors among elderly population in rural Puducherry using mini-nutritional assessment questionnaire. J Family Med Prim Care 2018;7(6):1429-1433 [FREE Full text] [doi: 10.4103/jfmpc.jfmpc_22_18] [Medline: 30613537]
6. Chataut J, Jonche S, Ghimire M, Tamrakar D, Singh Bhandari MS. Prevalence of malnutrition among elderly people living in a rural area of Nepal. JNMA J Nepal Med Assoc 2021 Feb 28;59(234):146-151 [FREE Full text] [doi: 10.31729/jnma.6013] [Medline: 34506457]
7. Rubenstein LZ, Harker JO, Salvà A, Guigoz Y, Vellas B. Screening for undernutrition in geriatric practice: developing the short-form mini-nutritional assessment (MNA-SF). J Gerontol A Biol Sci Med Sci 2001 Jun;56(6):M366-M372. [doi: 10.1093/gerona/56.6.m366] [Medline: 11382797]
8. Alzahrani SH, El Sayed IA, Alshamrani SM. Prevalence and factors associated with geriatric malnutrition in an outpatient clinic of a teaching hospital in Jeddah, Saudi Arabia. Ann Saudi Med 2016;36(5):346-351 [FREE Full text] [doi: 10.5144/0256-4947.2016.346] [Medline: 27710987]
9. Shikieri ABE, Saeed WMM, Alharbi A, Badhawi B, AlAwfi J, Alrwaythi M, et al. Nutritional status and associated risk factors amongst older adults in Al Madinah Al Munawarah. EC Nutr 2019;14(9):1-9 [FREE Full text]
10. Althaiban MA, Aljefree NM, Almoraie NM, Shatwan IM. Malnutrition is associated with increased disease risk in older people in the Makkah region of Saudi Arabia: a cross-sectional study. Front Public Health 2023;11:1149739 [FREE Full text] [doi: 10.3389/fpubh.2023.1149739] [Medline: 37077189]
11. Naaman RK, Bakhsh MA, Alsherebi RK, Sultan RM. Prevalence and recognition of malnutrition in elderly patients admitted to a university hospital in Jeddah, Saudi Arabia. Top Clin Nutr 2023;38(4):318-326. [doi: 10.1097/TIN.0000000000000344]
12. Leij-Halfwerk S, Verwijs MH, van Houdt S, Borkent JW, Guaitoli P, Pelgrim T, MaNuEL Consortium. Prevalence of protein-energy malnutrition risk in European older adults in community, residential and hospital settings, according to 22 malnutrition screening tools validated for use in adults ≥65 years: a systematic review and meta-analysis. Maturitas 2019 Aug;126:80-89. [doi: 10.1016/j.maturitas.2019.05.006] [Medline: 31239123]
13. Jaime-Lara RB, Koons BC, Matura LA, Hodgson NA, Riegel B. A qualitative metasynthesis of the experience of fatigue across five chronic conditions. J Pain Symptom Manage 2020 Jun;59(6):1320-1343 [FREE Full text] [doi: 10.1016/j.jpainsymman.2019.12.358] [Medline: 31866485]
14. White R. Drugs and nutrition: how side effects can influence nutritional intake. Proc Nutr Soc 2010 Nov;69(4):558-564. [doi: 10.1017/S0029665110001989] [Medline: 20678294]
15. Al Turki M, Al Sibaie N, Al Otaibi H, Al Ammari G, Al Otaibi R. Prevalence of geriatric malnutrition in long term care center in Riyadh/Saudi Arabia: a cross sectional study. Act Sci Nutr 2021;5(2):11-17. [doi: 10.31080/asnh.2020.05.0807]
16. Khattab HAH, Al-Saadoun ET. Nutritional assessment of institutionalized elderly in Makkah region, Saudi Arabia. Biosci Res 2016;13(1):43-64 [FREE Full text]
17. Lim EJ. Factors influencing mobility relative to nutritional status among elderly women with diabetes mellitus. Iran J Public Health 2018 Jun;47(6):814-823 [FREE Full text] [Medline: 30087866]
18. UNFPA. Country profile: the rights and wellbeing of older persons in Saudi Arabia. 2024. URL: https://arabstates.unfpa.org/sites/default/files/pub-pdf/country_profile_-_saudia_27-10-2021.pdf [accessed 2024-06-03]
19. Mohd Shahrin FI, Lim ZY, Omar N, Zakaria NF, Daud ZAM. Association of socio-demographic characteristics, nutritional status, risk of malnutrition and depression with quality of life among elderly haemodialysis patients. Mal J Nutr 2019;25(1):1-11. [doi: 10.31246/mjn-2018-0101]
20. Mohamed Khalifa AF, Ahmed Hussamuldin AB, Alkhathran RM, Alghamdi AA, Rifaey AA, Alabdullah AM, et al. PHQ-9 to screen for depression in Riyadh, Saudi Arabia. Med Sci 2023;27(135):1-7. [doi: 10.54905/disssi/v27i135/e204ms2974]
21. WHO. Depressive disorder (depression). 2024. URL: https://www.who.int/news-room/fact-sheets/detail/depression [accessed 2024-06-03]
22. Alghofaili AA, Aladel AI, Alsoghier AM, Othman F, Shoqeair MM, Alqahtani SM, et al. Association of Oral and General Health with nutritional status of older adults attending two medical centers in Riyadh, Saudi Arabia: a cross-sectional study. Nutrients 2023 Sep 18;15(18):4032 [FREE Full text] [doi: 10.3390/nu15184032] [Medline: 37764815]
23. Al-Othaimeen AI, Al-Nozha M, Osman AK. Obesity: an emerging problem in Saudi Arabia. Analysis of data from the National Nutrition Survey. East Mediterr Health J 2007;13(2):441-448 [FREE Full text] [Medline: 17684864]
24. Budzyński J, Szukay B. BMI as a biomarker in patients‘ nutritional assessment. In: Biomarkers in Nutrition. USA: Springer International Publishing; 2022:1-35.
25. Alkazemi DU, Zadeh MH, Zafar TA, Kubow SJ. The nutritional status of adult female patients with disabilities in Kuwait. J Taibah Univ Med Sci 2018 Jun;13(3):238-246 [FREE Full text] [doi: 10.1016/j.jtumed.2018.01.002] [Medline: 31435330]

26. Hallit S, Daher M, Hallit R, Hachem D, Kheir N, Salameh P. Correlates associated with mental health and nutritional status in Lebanese older adults: a cross-sectional study. Arch Gerontol Geriatr 2020;87:103879. [doi: 10.1016/j.archger.2019.05.004] [Medline: 31160065]
27. Hoseinzadeh-Chahkandak F, Rahimlou M, Salmani F, Ansarifar E, Moodi M, Sharifi F, et al. Nutrition assessment and geriatric associated conditions among free living elderly people in Birjand, East of Iran: a cross-sectional study. BMC Geriatr 2021 Oct 30;21(1):612 [FREE Full text] [doi: 10.1186/s12877-021-02518-x] [Medline: 34717587]
28. Chan HTH. The Nutrition Source. 2024. URL: https://www.hsph.harvard.edu/nutritionsource/healthy-weight/measuring-fat/ [accessed 2023-12-23]
29. Noorwali EA, Aljaadi AM. A review of anthropometric measurements for Saudi adults and elderly, directions for future work and recommendations to establish Saudi guidelines in line with the Saudi 2030 Vision. Healthcare (Basel) 2023 Jul 08;11(14):1982 [FREE Full text] [doi: 10.3390/healthcare11141982] [Medline: 37510422]
30. Besora-Moreno M, Llauradó E, Tarro L, Solà R. Social and economic factors and malnutrition or the risk of malnutrition in the elderly: a systematic review and meta-analysis of observational studies. Nutrients 2020 Mar 11;12(3):737 [FREE Full text] [doi: 10.3390/nu12030737] [Medline: 32168827]
31. Islam MZ, Disu TR, Farjana S, Rahman MM. Malnutrition and other risk factors of geriatric depression: a community-based comparative cross-sectional study in older adults in rural Bangladesh. BMC Geriatr 2021 Oct 18;21(1):572 [FREE Full text] [doi: 10.1186/s12877-021-02535-w] [Medline: 34663237]
32. Senee A, Bye Ishnoo Y, Jeewon R. An analysis of the contributors and factors influencing dietary patterns among the elderly population. Curr Res Nutr Food Sci 2022;10(3):895-903. [doi: 10.12944/crnfsj.10.3.7]
33. Storz MA, Beckschulte K, Brommer M, Lombardo M. Current sex distribution of cooking and food shopping responsibilities in the United States: a cross-sectional study. Foods 2022 Sep 14;11(18):2840 [FREE Full text] [doi: 10.3390/foods11182840] [Medline: 36140974]
34. Fakoya OA, McCorry NK, Donnelly M. Loneliness and social isolation interventions for older adults: a scoping review of reviews. BMC Public Health 2020 Feb 14;20(1):129 [FREE Full text] [doi: 10.1186/s12889-020-8251-6] [Medline: 32054474]
35. Taylor J, Walsh S, Kwok W, Pinheiro MB, de Oliveira JS, Hassett L, et al. A scoping review of physical activity interventions for older adults. Int J Behav Nutr Phys Act 2021 Jun 30;18(1):82 [FREE Full text] [doi: 10.1186/s12966-021-01140-9] [Medline: 34193157]
36. Volkert D, Beck AM, Cederholm T, Cereda E, Cruz-Jentoft A, Goisser S, et al. Management of malnutrition in older patients—current approaches, evidence and open questions. J Clin Med 2019 Jul 04;8(7):974 [FREE Full text] [doi: 10.3390/jcm8070974] [Medline: 31277488]
37. Noack AL, Pouw NRM. A blind spot in food and nutrition security: where culture and social change shape the local food plate. Agric Hum Values 2014;32(2):169-182. [doi: 10.1007/s10460-014-9538-y]
38. Watkins R, Goodwin VA, Abbott RA, Backhouse A, Moore D, Tarrant M. Attitudes, perceptions and experiences of mealtimes among residents and staff in care homes for older adults: a systematic review of the qualitative literature. Geriatr Nurs 2017;38(4):325-333. [doi: 10.1016/j.gerinurse.2016.12.002] [Medline: 28089317]
39. Robert C, Erdt M, Lee J, Cao Y, Naharudin NB, Theng Y. Effectiveness of eHealth nutritional interventions for middle-aged and older adults: systematic review and meta-analysis. J Med Internet Res 2021 May 17;23(5):e15649. [doi: 10.2196/15649] [Medline: 33999005]

Abbreviations

KSA: Kingdom of Saudi Arabia
MNA: Mini Nutritional Assessment
OR: odds ratio

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Original Paper

Interrelationships Among Individual Factors, Family Factors, and Quality of Life in Older Chinese Adults: Cross-Sectional Study Using Structural Equation Modeling

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Abstract

Background: China's rapidly aging population necessitates effective strategies for ensuring older adults' quality of life (QOL). While individual factors (IF) and family factors (FF) are known to influence QOL, existing research often examines these factors in isolation or focuses on specific subpopulations, overlooking potential interactions and mediating pathways.

Objective: This study aims to examine both direct and indirect pathways connecting IF and FF to older adults' QOL, focusing on the mediating roles of health risks (HR) and health care service demand (HSD).

Methods: This study uses structural equation modeling (SEM) to analyze cross-sectional data from 8600 older participants in the 2015 China Health and Retirement Longitudinal Study (CHARLS), a nationally representative study using a multistage probability proportional to size sampling method.

Results: Among the 8600 participants, the majority (5586/8502, 65.7%) were aged 60-70 years, with a near-equal distribution of males and females at around 50%. The average PCS score was 76.77, while the MCS score averaged 59.70. Both IF (β=0.165, *P*<.001) and FF (β=0.189, *P*<.001) had a direct positive effect on QOL. Furthermore, the indirect effects of IF (β=0.186, *P*<.001) and FF (β=0.211, *P*<.001) through HR and HSD were also significant. In the direct model, IF and FF had a greater impact on MCS (β=0.841) than on PCS (β=0.639). However, after including the 2 mediating factors, HR and HSD, the influence of IF and FF on MCS (β=0.739) became consistent with that on PCS (β=0.728). Subgroup analyses revealed that the direct effect of IF on QOL was significant in the 60-70 age group (β=0.151, *P*<.001) but not in those over 70 years old (β=0.122, *P*=.074). Comorbidity status significantly influenced the pathway from HR to HSD, with older adults having 2 or more chronic diseases (β=0.363) showing a greater impact compared to those with fewer than 2 chronic diseases (β=0.358).

Conclusions: Both IF (education, per capita disposable income, and endowment insurance) and FF (satisfaction with a spouse and children) directly impact the QOL in older people. Meanwhile, IF and FF have equal influence on QOL through the mediating role of HR and HSD. Recognizing the interplay among these factors is crucial for targeted interventions to enhance the well-being of older adults in China.

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KEYWORDS

quality of life; older adults; individual factor; family factor; structural equation modeling (SEM)

Introduction

Since China transitioned into an aging society around 2000, the aging process has accelerated steadily [1]. It is projected that by 2040, the population aged 60 years and older in China will reach 402 million, with an aging rate exceeding 28%, marking the country's transition into a deeply aging society [2]. The increased number of older adults will inevitably lead to a substantial rise in national financial pressure and family care burden [3,4]. Ensuring a dignified and high quality of life (QOL) for older adults during their later years has evolved into a pivotal focal point within the sphere of social development.

QOL refers to an individual's overall well-being and satisfaction with various aspects of their life [5]. It is directly correlated with overall health outcomes, health care use, and the effectiveness of health interventions. QOL serves as a pivotal benchmark illuminating the living standards of older adults, forming the cornerstone for the implementation of strategies promoting healthy and active aging. The health status of older individuals is a key determinant of their overall physical and mental well-being. While considerable research has been devoted to exploring the risk factors affecting the health status of older adults [6-8], comprehensive studies integrating various sociodemographic factors, such as individual and family factors, which broadly impact their QOL, remain limited. Individual factors (IFs) include socioeconomic and demographic characteristics [9]. In this study, IF is represented by education level [10], per capita disposable income [11], and endowment insurance [12]. Family factors (FFs) include interactions among family members and the broader family environments [13]. In this study, FF is represented by measures of spouse satisfaction [14] and children satisfaction [15].

Existing literature has extensively examined the impact of various individual and family factors on the QOL of older adults, highlighting the importance of maintaining healthy lifestyles and fostering strong social connections to enhance QOL in later life [16,17]. For example, studies by Zhang et al [18] in Shanxi, China, and Chen et al [19] in Hainan, China, delved into the influence of socioeconomic status, health behaviors, and family relationships on the QOL of older adults. However, these studies often either focus on the impact of a single factor or target subgroups with specific characteristics, such as empty nesters and the oldest-old population. This overlooks the potential mutual interactions between variables and the interactive effects on outcomes, potentially resulting in partial and nongeneralizable research conclusions.

Furthermore, previous studies indicated that IFs, such as education and income, impact dietary habits, smoking and alcohol consumption, physical activity levels [20,21], and access to health insurance in older adults [22]. Similarly, FFs, such as marital status and parent-child relationships, affect health risks (HR) and mental well-being in older adults [23,24]. In turn, HR can influence health care service demand (HSD) [25]. Both HR and HSD are known to be associated with QOL [26]. Nevertheless, only a few studies have addressed the potential mediating role of HR and HSD in the relationship between individual or familial factors and QOL. For example, Zhang et al [18] demonstrated the indirect effects of socioeconomic status and family relationships on QOL through health behaviors among empty nesters. Similarly, studies emphasized the importance of addressing health-related issues and improving access to health care services to enhance QOL among older adults in Zhejiang province and Shanghai [27,28]. However, these studies focus on specific regions or populations, and most studies rely on cross-sectional designs, hindering the establishment of causal relationships. There is a need for more comprehensive frameworks that integrate a broader range of personal, familial, and environmental factors and examine their complex interactions and potential mediating roles to provide a holistic understanding of QOL among older adults.

This study uses structural equation modeling (SEM) to analyze the direct and indirect effects of individual and family factors on QOL among individuals aged 60 years and older that cover the entire scope of China. We consider the mediating roles of HR and HSD in the relationship between individual or family factors and QOL. By examining these complex relationships, this study aims to provide valuable insights for policy making and interventions to improve the well-being of older adults in China.

Methods

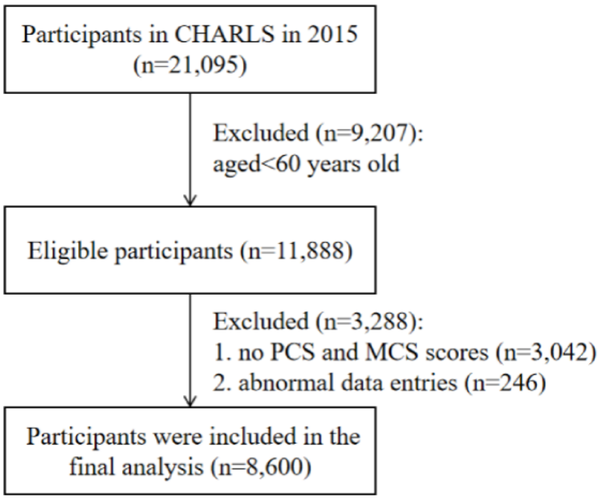
Data Source and Participants

This study used data from the China Health and Retirement Longitudinal Study (CHARLS), the details of which have been documented previously [29]. Briefly, the CHARLS project aims to gather high-quality microdata representing households and individuals aged 45 years and older in China, promoting interdisciplinary aging research. The national baseline survey of CHARLS was conducted in 2011 using a multistage probability proportional to size sampling method. The sample encompassed 450 villages, 150 counties, and 28 provinces, comprising over 17,000 individuals from approximately 10,000 households. CHARLS is an ongoing survey, with assessments conducted every 2-3 years. Participants were interviewed face-to-face in their homes using computer-assisted personal interviewing technology. The survey comprehensively covered basic demographic information of respondents and their families, intrafamily transfer payments, health status, medical care and insurance, employment, income, expenditure, assets, and more. Additionally, CHARLS included 13 physical measurements and collected blood samples. To date, CHARLS has released data from 5 waves: the national baseline survey (Wave 1, 2011), first follow-up survey (Wave 2, 2013), second follow-up survey (Wave 3, 2015), third follow-up survey (Wave 4, 2018), and fourth follow-up survey (Wave 5, 2020) [30]. The CHARLS datasets can be downloaded at the CHARLS home page [30]. The CHARLS survey project received approval from the Biomedical Ethics Committee of Peking University, and all participants have provided informed consent.

This study used data from the third wave of the CHARLS, collected in 2015, with a sample size of 21,095. We excluded 12,495 individuals due to (1) age <60 years (n=9207); (2) missing information on physical component summary (PCS) and mental component summary (MCS) scores (n=3042); and

(3) abnormal data entries (n=246), resulting in a final analytic sample of 8600 participants for this cross-sectional analysis. The detailed flowchart of the sample selection process is shown in Figure 1.

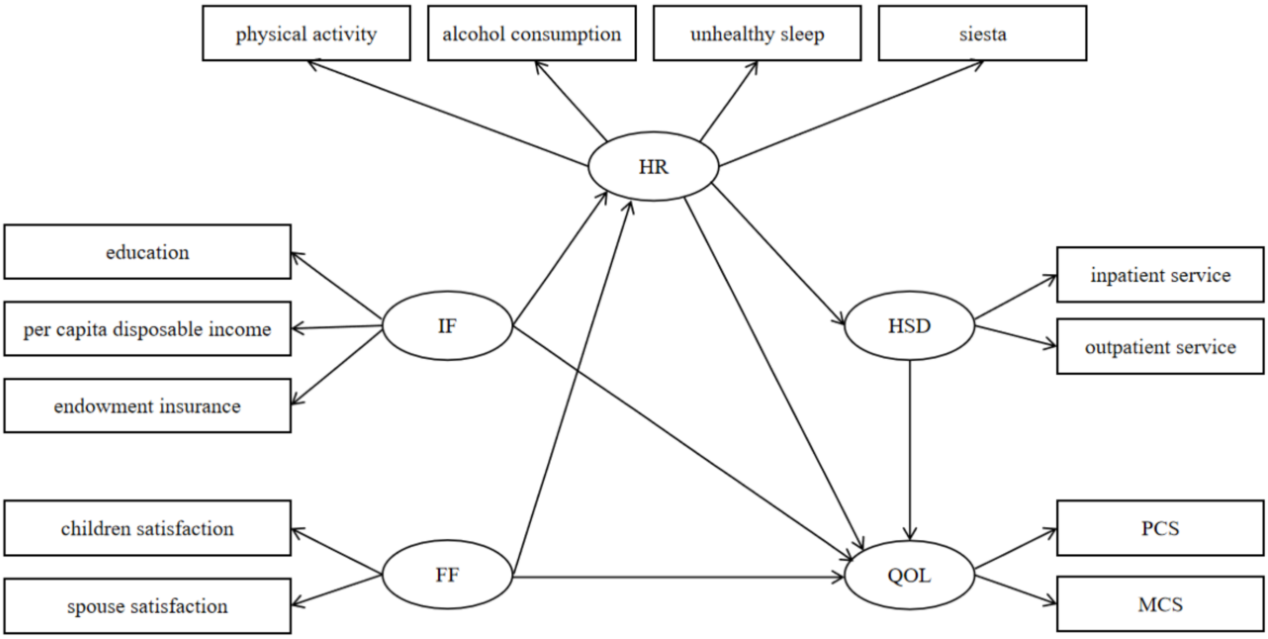
Figure 1. The flowchart of participants through the study. CHARLS: China Health and Retirement Longitudinal Study; PCS: physical component summary; MCS: mental component summary.



Conceptual Framework

Building upon a review of the literature [16,26-30] and informed by medical context, the core components of the conceptual framework in this study include: (1) IF is associated with education [10], per capita disposable income [11], and endowment insurance [12], which directly influence QOL. (2) FF is associated with spouse satisfaction [14] and children satisfaction [15], which directly influence QOL. (3) Individual and family factors indirectly influenced QOL via HR. The reason is that health plays a pivotal role in overall well-being [18]. IFs, such as education and income, also impact dietary habits, smoking and alcohol consumption, and physical activity levels in older adults [31]. Similarly, FFs, such as marital status and parent-child relationships, affect health risks and mental well-being in older adults [23,24]. HR encompasses physical activity, alcohol consumption, unhealthy sleep, and siesta. (4) IF and FF indirectly influenced QOL via HR and HSD. HSD involves both inpatient service and outpatient service. Previous studies have found that HR can influence HSD [25]. Both HR and HSD are known to be associated with QOL [26]. (5) Assessing the QOL through the metrics of PCS and MCS, which is accessed by Short Form 36 (SF-36) [32]. The multiple pathways from IF and FF to QOL and the statistical analysis strategy are shown in Figure 2.

Figure 2. Research framework. IF: individual factors; FF: family factors; HR: health risk; HSD: health services demand; PCS: physical component summary; MCS: mental component summary; QOL: quality of life.



Measures

This study introduced a novel scale construction from variables derived from both SF-36 and the CHARLS questionnaire to measure QOL in older Chinese adults. This scale's development emanated from the 8 dimensions within the SF-36, while we curated pertinent CHARLS variables to appraise these dimensions, encompassing physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality, social functioning (SF), role-emotional (RE), and mental health (MH). PF, RP, BP, and GH were computed as PCS, while vitality, SF, RE, and MH were computed as MCS (Multimedia Appendix 1). Each dimension score was converted to a range from 0 to 100, with a high score indicating better levels of functioning. The SF-36 score was obtained from the average of the 8 dimensions. Consequently, higher SF-36 scores indicate better QOL [32].

Drawing on methodologies applied in pertinent literature, the development of this scale mirrored approaches using Cronbach α coefficient to assess reliability between SF-36 and CHARLS variables. Overall, the scale demonstrated robust reliability across dimensions, registering α values exceeding 0.6 for all except vitality (α=0.34) [33]. At both the item (I-CVI) and scale (S-CVI) levels, the content validity index (CVI) was assessed, with I-CVI surpassing 0.83 and an S-CVI reaching 0.94 [33]. These findings suggest that the scale exhibited commendable reliability and validity and has already been used in related research [34].

Demographic characteristics included sex (male or female) and age groups (60-70 years and 70 years or older). We defined comorbidity as the presence of ≥2 chronic diseases [35]. IF was accessed by 3 variables: education [10], per capita disposable income [11], and endowment insurance [12]. The specific definition of each variable is added in Multimedia Appendix 2. It is important to note that per capita disposable income, presented as a continuous variable, was extracted from the 2015 Gotohui data [36], takes into account deductions, such as personal income tax, social insurance contributions, and removes essential living expenses to measure individuals' actual disposable income within an economy [37]. The following 2 variables accessed FF: spouse satisfaction [14] and children satisfaction [15]. HR was accessed by 4 variables: physical activity [38], alcohol consumption [39], unhealthy sleep, and siesta [40,41]. Thereby, HSD was accessed using 2 variables: inpatient service and outpatient service [42].

SEM and the Theory of Inferred Causation

First, SEM allows for constructing latent variables using other observable variables and models causal relationships between latent and observed variables [43]. Second, within SEM, causal paths are explicitly represented as directed arrows between variables in a path diagram [44]. These paths represent hypothesized causal relationships based on theory or prior research [44]. Finally, SEM evaluates how well the specified model fits the observed data to evaluate the validity of hypothesized causal relationships [45]. A well-fitting model indicates that the hypothesized causal relationship model can effectively explain or predict the observed variability in the data [44]. Additionally, the magnitude of each path parameter signifies the strength and direction of the causal paths between variables [43]. In cases of poor model fit, researchers can refine models based on empirical data and theoretical insights, enhancing the accuracy of causal inferences [44].

Statistical Analysis

Continuous variables are presented as mean and SD, and categorical variables are presented as frequencies and percentages. Scores of QOL are presented as mean and SD. Pearson correlation analysis is used to examine the correlations among the IF, FF, HR, HSD, and QOL variables. The missing data were imputed using nonparametric missing value imputation based on the random forest procedure in R. Detailed missing rates for the essential factors used in this study are provided in Multimedia Appendix 3.

To verify the suitability of the SF-36 scale based on the CHARLS database for the construction of SEM, we performed confirmatory factor analysis (CFA) [46]. In CFA, CR is used to demonstrate composite reliability, and average variance extracted (AVE) is used to establish the convergent validity of the model. The model exhibits strong internal consistency and convergent validity, as indicated by the CR exceeding 0.7 and the AVE surpassing 0.5, and the AVE between 0.36 and 0.5 is also acceptable [47].

SEM was used to ascertain the direct and indirect effects among outcome, observed, and latent variables. Among them, the observed variable refers to a variable that can be directly observed with specific values. In contrast, the latent variable is a variable that cannot be directly observed and requires inference through other variables. The total effect represents the sum of direct and indirect effects, mathematically expressed as follows [48]: $c = c' + ab$, where c = total effect, c' = direct effect, ab = indirect effect. Subsequently, bias-corrected bootstrapping (using 2000 bootstrap samples) was used to gauge the statistical significance of both direct and indirect effects within each pathway of the SEM. Various modification indices were used to refine and adjust the model, aiming to achieve the optimal fit [49], including the comparative fit index (CFI), incremental fit index (IFI), standardized root-mean-square residual (SRMR), goodness of fit index (GFI), adjusted goodness of fit index (AGFI), and the root-mean-square error of approximation (RMSEA). The RMSEA and SRMR ≤ 0.08, CFI, IFI, GFI, and AGFI > 0.90 indicated an acceptable model [50]. Due to the sensitivity of chi-square values to large sample sizes, they were excluded from the analysis [50]. Main effect values are presented by β, representing standardized regression coefficients. $P< .05$ indicated statistical significance. In addition, given that approximately 50% of the data on physical activity were missing, we conducted an additional sensitivity analysis to assess the robustness of the results by excluding participants with missing physical activity data.

Finally, we conducted subgroup analyses to examine the applicability of the model across gender, age, and comorbidity groups and to assess whether there were significant differences in the β values of different paths among the subgroups. In subgroup analyses, an absolute critical ratio for a difference of more than 1.96 was considered to indicate a significant difference between the groups [51]. $P<.05$ for β indicates its statistical significance. All data were analyzed using the statistical software IBM SPSS Statistics (version 26.0; IBM Corp), IBM SPSS Amos (version 26.0), and R (version 4.3.2; R Foundation for Statistical Computing).

Ethical Considerations

This study used secondary data from CHARLS. The agency responsible for the survey is Peking University.

Results

Participant Characteristics

Table 1 summarizes the results of descriptive statistics. Among the 8600 samples, the gender distribution was nearly equal. Participants aged 60-70 years outnumbered those aged over 70 years (n=5586 vs n=2916). Concerning comorbidity, a modest proportion (3171/8600, 36.9%) of the participants had more than 2 chronic diseases. Most participants reported their educational attainment as less than the secondary level and did not have endowment insurance. The mean annual per capita disposable income in the study population was ¥ 17,715.97 (SD ¥ 10,131.80; US $2852.27, per the 2015 average annual exchange rate). A significant number of participants reported satisfaction with their spouses and children.

Table 1. Descriptive statistics of the variables at baseline.

Variables	Overall, n (%)
Age (years), (n=8502)	
60-70	5586 (65.7)
≥70	2916 (34.3)
Gender, (n=8599)	
Male	4297 (50.0)
Female	4302 (50.0)
Comorbidity, (n=8600)	
Fewer than 2 chronic diseases	5429 (63.1)
Having 2 or more chronic diseases	3171 (36.9)
Education, (n=8598)	
Below secondary education	7912 (92.0)
High school and vocational training	534 (6.2)
Higher education	152 (1.8)
Endowment insurance, (n=8550)	
Having endowment insurance	1097 (12.8)
No endowment insurance	7453 (87.2)
Spouse satisfaction, (n=6939)	
Satisfied with spouse	6355 (91.6)
Dissatisfied with spouse	584 (8.4)
Children satisfaction, (n=8494)	
Satisfied with children	8080 (95.1)
Dissatisfied with children	414 (4.9)
Alcohol consumption, (n=8596)	
Drinking alcoholic beverages in the past year	6403 (74.5)
Not drinking alcoholic beverages in the past year	2193 (25.5)
Physical activity, (n=4259)	
Engaging in any physical activity in the past week	2990 (70.2)
Have not engaged in any strenuous physical activity in the past week	1269 (29.8)
Unhealthy sleep, (n=7915)	
Sleep less than 5 hours or more than 9 hours per night	3084 (39.0)
Sleep duration is within 6-8 hours	4831 (61.0)
Siesta, (n=7982)	
Having a habit of taking midday naps	4606 (57.7)
Absence of the habit of taking midday naps	3376 (42.3)
Outpatient services, (n=8588)	
Received outpatient or home care services in the past month	1767 (20.6)
Not attending outpatient or home health services in the past month	6821 (79.4)
Inpatient services, (n=8588)	
Inpatient service use in the past year	1436 (16.7)
No inpatient service use in the past year	7152 (83.3)

In terms of lifestyle factors, most participants engaged in physical activity and reported alcohol consumption in the past year. Healthy sleep patterns were prevalent. More than half of the individuals indicated good sleep quality and had regular siestas. Health care use patterns indicated that only a minority of the participants had received inpatient services in the past year and used outpatient or home care services within the past month during the baseline period.

Status Quo of the Older Chinese Adults' QOL

Table 2 displays the total scores and dimensional scores of SF-36. Among the 8600 participants, the PCS score averaged 76.77, and the MCS score averaged 59.70. Among the 4 dimensions of PCS, role physical obtained the highest score, followed by bodily pain and physical functioning. The general health dimension had the lowest score. In the realm of MCS, vitality, role emotional, and mental health scores were similar, all above 70.00, while social functioning scored lower.

Table 2. Scores for quality of life (n=8600).

Dimensions	Scores, mean (SD)
PCS[a]	76.77 (14.50)
PF[b]	85.54 (17.61)
RP[c]	94.99 (13.70)
BP[d]	87.90 (22.80)
GH[e]	38.66 (26.08)
MCS[f]	59.70 (17.83)
Vitality	77.29 (27.05)
SF[g]	13.18 (13.63)
RE[h]	72.35 (31.66)
MH[i]	75.97 (23.51)

[a] PCS: physical component summary.

[b] PF: physical functioning.

[c] RP: role-physical.

[d] BP: bodily pain.

[e] GH: general health.

[f] MCS: mental component summary.

[g] SF: social functioning.

[h] RE: role-emotional.

[i] MH: mental health.

Correlation Between Variables

The correlation analysis results between IF, FF, HR, HSD, and QOL variables are detailed in Multimedia Appendix 4. The results indicate that the observed IF, FF, HR, and HSD variables significantly correlate with the outcome indicators. Meantime, the significant correlation coefficients between each observed variable ranged from –0.007 to 0.307, which did not meet the standard of strong correlation [52].

CFA Results

The detailed results of the CFA performed to assess the suitability of the SF-36 scale based on the CHARLS database for the construction of SEM are presented in Table 3. According to the results, the standardized regression coefficients, ranging from 0.132 to 0.839, were statistically significant in the 2-factor model. The CR and AVE of the PCS and MCS were within the acceptable range. These findings indicate that the model exhibited excellent reliability and validity, rendering it suitable for SEM analysis. The fit indexes for the entire sample model, as shown in Table 4, suggest a good model fit.

Table 3. Standardized regression coefficient, composite reliability, and convergent validity of the CFA[a].

Path	β[b]	*P* value	CR[c]	AVE[d]
PCS [e]		<.001	0.726	0.412
PCS→physical function	0.831			
PCS→role-physical	0.692			
PCS→bodily pain	0.526			
PCS→general health	0.448			
MCS[f]		<.001	0.704	0.419
MCS→vitality	0.650			
MCS→social functioning	0.132			
MCS→role-emotional	0.738			
MCS→mental health	0.839			

[a] CFA: confirmatory factor analysis.

[b] β: standardized regression coefficient.

[c] CR: composite reliability.

[d] AVE: average variance extracted.

[e] PCS: physical component summary.

[f] MCS:mental component summary.

Table 4. Model-fit index of CFA[a] and SEM[b] (n=8600).

Inspected Fit Indices	Acceptable Fit	CFA Fit Indices	Direct SEM Fit Indices	Multiple intermediary SEM Fit Indices
SRMR[c]	≤0.08	0.060	0.017	0.031
RMSEA[d]	≤0.08	0.091	0.018	0.038
GFI[e]	>0.9	0.958	0.998	0.985
AGFI[f]	>0.9	0.921	0.996	0.977
CFI[g]	>0.9	0.926	0.995	0.917
IFI[h]	>0.9	0.926	0.995	0.917

[a] CFA: confirmatory factor analysis.

[b] SEM: structural equation model.

[c] SRMR: standard root-mean-square residual.

[d] RMSEA: root-mean-square error of approximation.

[e] GFI: goodness of fit index.

[f] AGFI: adjusted goodness of fit index.

[g] CFI: comparative fit index.

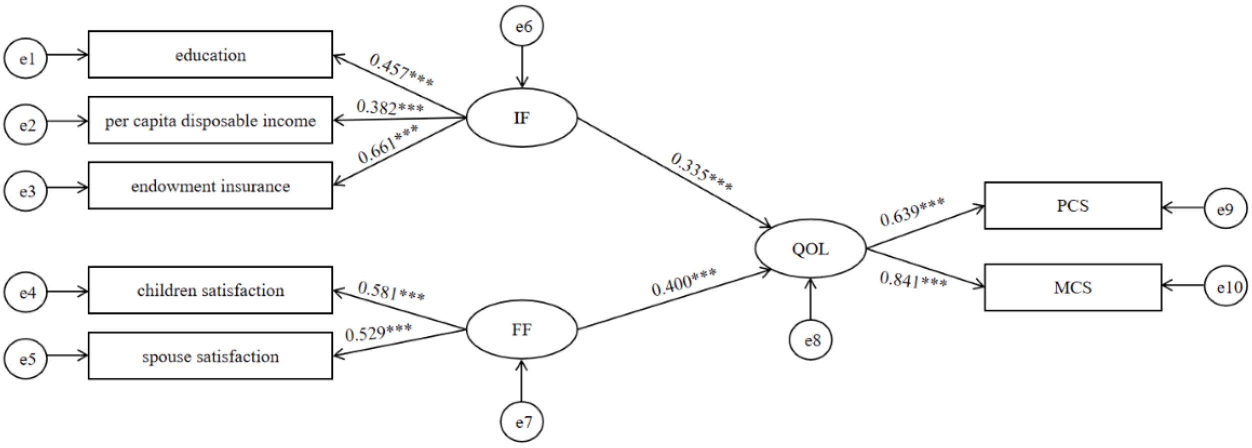
[h] IFI: incremental fit index.

SEM Results

Direct Effects Model

Before analyzing the intermediary effects model, we used a total direct model to assess the effect of IF and FF on the QOL (Figure 3). The fit index of the direct model is acceptable (Table 4). In the direct effects model of individual and family factors on the QOL of older adults, IF and FF have significant positive direct effects on MCS and PCS, thereby promoting an improvement in QOL. It is worth noting that the impact of FF on QOL is greater than that of IF (0.400 vs 0.335; Figure 3). Moreover, the β value of endowment insurance to QOL in IF is much higher than the β values of education and per capita disposable income (0.661 vs 0.457 and 0.382). Additionally, in QOL, the β value of MCS is greater than the β value of PCS (0.841 vs 0.639), indicating that the direct impact of individual and family factors on MCS is greater than that on PCS (Figure 3).

Figure 3. The direct effects of IF and FF on QOL. IF: individual factors; FF: family factors; PCS: physical component summary; MCS: mental component summary; QOL: quality of life.



Multiple Indirect Effects Model

Second, we formulated a multiple intermediary effects model to explore how IF and FF influence the QOL among older adults through mediators—specifically, HR and HSD (Figure 4 and Multimedia Appendix 5). Table 4 illustrates the detailed information on model fit indices, revealing an acceptable fit for the multiple mediation mode. Table 5 further presents the total, direct, and indirect effects of IF and FF on QOL and their corresponding 95% CI.

Figure 4. Multiple mediation model between IF, FF, and QOL with HR and HSD as mediators. IF: individual factors; FF: family factors; HR: health risk; HSD: health services demand; PCS: physical component summary; MCS: mental component summary; QOL: quality of life.

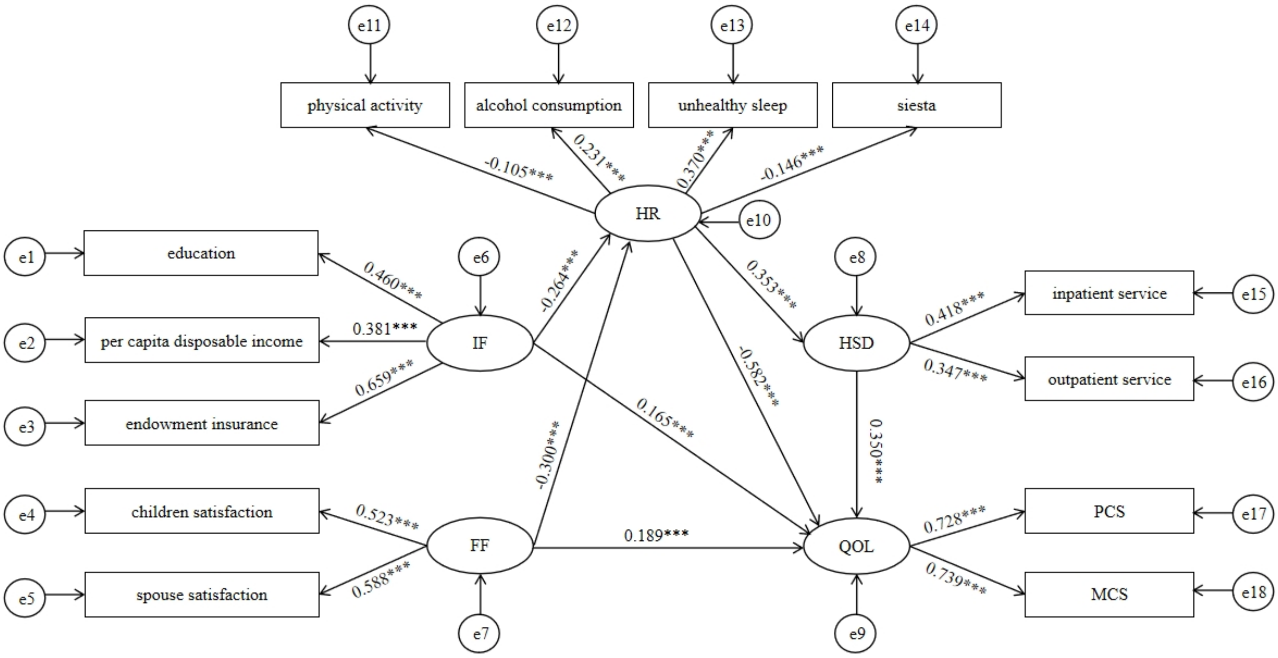


Table 5. Standardized total, direct, and indirect effects of the variables on QOL[a].

Mediation Effect	β[b]	Lower[c]	Upper[d]	Ratio of indirect to total effect, %	Ratio of direct to total effect, %
IF[e]→HR[f]→QOL	0.154	0.104	0.219	44	—[g]
IF→HR→HSD[h]→QOL	0.033	0.023	0.048	9	—
Total indirect effects: IF→QOL	0.186	0.128	0.254	53	—
Direct Effects: IF→QOL	0.165	0.100	0.219	—	47
Total Effects: IF→QOL	0.351	0.321	0.381	—	—
FF[i]→HR→QOL	0.174	0.119	0.240	44	—
FF→HR→HSD→QOL	0.037	0.025	0.054	9	—
Total Indirect Effects: FF→QOL	0.211	0.150	0.282	53	—
Direct Effects: FF→QOL	0.189	0.112	0.258	—	47
Totally Effects: FF→QOL	0.400	0.359	0.443	—	—

[a] QOL: quality of life.

[b] β: standardized regression weights.

[c] Lower: lower limit of confidence interval.

[d] Upper: upper limit of confidence interval.

[e] IF: individual factors.

[f] HR: health risk.

[g] Not applicable.

[h] HSD: health services demand.

[i] FF: family factors.

Specifically, the indirect effects of IF and FF on QOL mediated by HR accounted for a similar proportion of the total effect, both approximately 44%. Similarly, the proportions of the total effect attributed to the indirect effects mediated by HR and HSD were also comparable, around 9%. The CIs corresponding to each mediation path did not include 0, indicating that the multiple mediating effects between IF, FF, and QOL were valid. Additionally, the β values for PCS and MCS were similar in the multiple indirect effects model compared with the direct model (0.728 and 0.739 vs 0.639 and 0.841). This suggests that the impacts of IF and FF on PCS were strengthened following the inclusion of the mediation effect, gradually aligning with the effect observed for MCS. In conclusion, the indirect effects of IF and FF on QOL play equally significant roles as the direct effects, and the indirect effect through HR surpasses that through both HR and HSD. This indicates the pivotal role of HR in mediating the impact of IF and FF on QOL.

Subgroup Analyses

The model fit indices for subgroup analysis are presented in Multimedia Appendix 6. All fit indices across different subgroups fall within the acceptable range, indicating that the model is equally applicable across different genders, age groups, and comorbidities.

The detailed results of the subgroup analysis are presented in Table 6. In the gender subgroup analysis, all path coefficients (β values) are significant, and the absolute values of critical ratios for difference are all below 1.96, indicating no significant differences in the paths across different gender groups. In the age subgroup analysis, the absolute values of critical ratios for difference are all less than 1.96, indicating no significant differences in other paths across different age groups. It is worth noting that in terms of the effect of IF on QOL, the β value in the 60-70 age group was significant, and the β value in the group older than 70 years was not significant, indicating that for older adults aged 60-70 years, IF has a direct impact on QOL, but for older adults older than 70 years, IF has no direct effect on QOL. In the comorbidity subgroup analysis, the absolute value of the critical ratio for difference (–3.011) for the path from HR to HSD is greater than 1.96, indicating a significant difference in comorbidity for the HR to HSD path. Specifically, the effect of HR on HSD for older adults with 2 or more chronic diseases (0.363) is greater than for those with fewer than 2 chronic diseases (0.358). However, the absolute values of critical ratios for difference for other paths are all less than 1.96, demonstrating no differences in β values among paths due to comorbidity status.

Sensitivity Analysis

Due to the high missingness in physical activity data, we conducted an additional sensitivity analysis to evaluate the robustness of our findings. A total of 4259 participants with physical activity data were included in the analysis. The results indicate that the model fit indices are within acceptable ranges, and all path coefficients of the structural model are significant, suggesting that the missing physical activity data have minimal impact on the overall robustness of the multiple indirect effects model. Detailed results can be found in Multimedia Appendices 7 and 8.

Table 6. Standardized regression coefficients (β) with *P* values for the components of subgroup analyses.

Path	Gender			Age			Comorbidity		
	Male	Female	Critical ratios for difference	60-70 years old	≥70 years old	Critical ratios for difference	≥2 chronic diseases	<2 chronic diseases	Critical ratios for difference
IF[a]→HR	–0.215[b]	–0.154[b]	–0.903	–0.269[b]	–0.404[b]	0.100	–0.235[b]	–0.288[b]	0.221
FF[c]→HR	–0.251[b]	–0.293[b]	0.620	–0.283[b]	–0.326[b]	–0.006	–0.232[b]	–0.344[b]	–1.258
HR[d]→HSD[e]	0.401[b]	0.353[b]	–1.376	0.368[b]	0.175[f]	–0.319	0.363[b]	0.358[b]	–3.011
IF→QOL[g]	0.235[b]	0.170[b]	1.090	0.151[b]	0.122 (0.074)	1.225	0.194[b]	0.131[h]	0.112
FF→QOL	0.225[b]	0.207[b]	–0.413	0.161[b]	0.243[b]	–0.852	0.272[b]	0.118[f]	0.530
HR→QOL	–0.469[b]	–0.519[b]	–1.258	–0.631[b]	–0.514[b]	–0.012	–0.535[b]	–0.639[b]	–0.321
HSD→QOL	–0.381[b]	–0.366[b]	–0.460	–0.354[b]	–0.386[b]	–1.040	–0.329[b]	–0.357[b]	–1.263

[a] IF: individual factors.

[b] *P*<.001.

[c] FF: family factors.

[d] HR: health risk.

[e] HSD: health services demand.

[f] *P*<.05.

[g] QOL: quality of life.

[h] *P*<.01.

Discussion

Principal Findings

To our knowledge, this study is the first to comprehensively assess the impact of IF and FF on QOL in a representative Chinese population aged 60 years and older. We used latent variable modeling to estimate the combined effects of various factors on QOL among older adults. Additionally, we investigated potential mediating pathways beyond the direct effects of IF and FF on QOL. Our findings indicate that both IF and FF have a positive direct impact on QOL. FF showed a greater influence on QOL than IF. Notably, endowment insurance emerged as a significant determinant of QOL among IF. Moreover, indirect effects mediated by HR and HSD were found equally significant as direct effects, with HR playing a pivotal role among the mediators. While individual and family factors had a notably greater direct impact on MCS compared to PCS, their influence converged when considering mediators. Furthermore, we identified differential effects among subgroups with different age and comorbidity status.

Our study aligns with previous studies identifying factors influencing QOL, including education, income, and family relationships [19,28]. However, previous studies often focused on the impact of individual or family factors in isolation or on specific subgroups, such as solitary older adults [27] and community-dwelling older adult populations [53]. In contrast, our study uses structural equation modeling to consider the interactions between variables and their mutual influences on outcomes. Additionally, our study encompasses a nationwide sample of older adults aged 60 years and above in China, enhancing the representativeness and generalizability of the findings. Furthermore, we compared the combined effects of individual and family factors on QOL and found that FF has a greater direct influence than IF. Notably, our study is the first to investigate the impact of pension insurance on the QOL of older adults, highlighting its significance among personal factors. Consistent with the findings of Zhang et al [18], our study incorporates HR and showed its substantial impact on QOL. We further introduce HSD, enriching the mediating pathways through which individual and family factors influence QOL. Our findings underscore the moderating effects of HR and HSD, demonstrating that the indirect effects of individual and family factors on QOL are equally important as their direct effects. Moreover, the influence on mental and physical health exhibits a similar trend across variables.

Our study found that endowment insurance plays a significant role in IF. Endowment insurance may enhance the QOL among older adults through various aspects, such as providing economic security, medical coverage, fostering social engagement, and enhancing psychological well-being [54]. Additionally, endowment insurance could potentially reduce older adults' financial dependence on their children, improve family relationships, and elevate their social status and self-esteem, thus influencing their physical and mental health and enhancing their QOL [55,56]. Our study offers valuable insights for policy makers and social welfare institutions for improving the survival and well-being of older adults.

HR is an important mediating factor for the QOL in older adults. Individual and family factors can indirectly influence the QOL of older adults by moderating HR [54]. Higher education and income levels promote easier access to nutritious food and health care services for older adults, leading to the adoption of healthier lifestyles, thus reducing their HR and enhancing their QOL [18]. Strong family relationships can provide emotional and social support for older adults, helping them cope with stress and challenges, lowering their HR and improving their QOL [57].

The impact of HSD on the QOL of older adults is relatively minor. While QOL can assist older adults in accessing necessary medical services, it cannot eliminate the influence of HR. This may be attributed to the natural decline in physiological functions as individuals age, where certain diseases or health issues may result in permanent physical damage or functional decline, thus potentially affecting the physical and mental well-being of older adults [58]. Furthermore, HSD may also be influenced by individual and family factors such as economic status and medical insurance [59]. Additionally, there may be a lag effect in the impact of HR on HSD, meaning that the influence of HR may take some time to manifest in terms of HSD [60].

In direct effect analysis, we observed the direct impacts of individual and family factors on MCS, which are significantly greater than those on PCS. This may be attributed to the multifaceted influences on MCS, including personal, social, and environmental factors [61], with these factors more likely to directly affect MCS than PCS, when not considering related intermediary effects such as health risks [62]. For instance, factors such as educational attainment and family satisfaction are more closely associated with MCS [63]. Tense family relationships, economic pressures, social discrimination, and similar factors may also contribute to MCS [64]. In contrast, PCS is more influenced by biological factors and is relatively less susceptible to direct impacts from the social environment [65]. However, incorporating HR and HSD as mediators, the impact of individual and family factors on MCS and PCS tends to converge. This could be explained by the moderating role of HR and HSD in individual and family factors and mental or physical health [66]. For instance, unhealthy dietary habits, lack of physical activity, smoking, and other health risk factors, as well as accessibility and use of medical services, which all substantially impact MCS and PCS [67]. This finding contributes to a deeper understanding of how individual and family factors affect the mental and physical health in older adults.

The subgroup analysis indicated that the influence of IF on the QOL in older adults may vary with age. This variation may be associated with increased reliance on family and social support, declining health conditions, and changes in values and life goals among older adults. First, with advancing age, older adults may experience a decline in economic and social resources, leading to increased reliance on family and social support, thereby the impact of IF on QOL declined [68,69]. Second, deteriorating health conditions in old age are characterized by a higher prevalence of chronic diseases and physical impairments, which negatively influence their QOL [70]. Although the influence of IF on health conditions may persist, the overall decline in health status might diminish the significance of IF on QOL [71]. Third, as individuals age, their values and life goals may change [72]. In the age group of 60-70 years, older adults may still have an active lifestyle and self-actualization, thus making the impact of IF on QOL more pronounced. However, in the age group of 70 years and above, older adults may prioritize family and social relationships, leading to a relatively diminished impact of IF on QOL. Consequently, to enhance the QOL among older adults, tailored policies and interventions need to be devised based on the characteristics of different age groups. For individuals aged 60-70 years, efforts can be focused on enhancing their personal capabilities and social resources, such as providing education and training and increasing employment opportunities. For those aged 70 years and older, emphasis can be placed on providing family and social support, such as establishing comprehensive older adult care systems and strengthening community-based older adult care services.

Additionally, within the context of considering comorbidity status, we found that older adults with 2 or more chronic disease conditions tend to require a greater HSD compared to those without such conditions. This may be attributed to the fact that older adults with multiple chronic diseases tend to bear a greater burden of health risks compared to those who are relatively healthy [25]. The Health Belief Model proposes that individuals are most likely to take preventive actions when they perceive a health risk as a serious threat to their own health [73]. Moreover, older adults with a greater number of chronic diseases tend to experience comparatively poorer overall physical conditions, thereby resulting in a heightened HSD [74]. Based on this, it is imperative to emphasize the cultivation of self-management awareness of comorbidities and implement additional health interventions for older adults with multiple chronic diseases. This may involve tailored health education initiatives aimed at enhancing healthy behavior and disease prevention, thereby reducing health risks and enhancing overall QOL. Furthermore, communities should develop comprehensive care service systems that cope with the varying health conditions of older adults, ultimately improving QOL.

Strengths and Limitation

A strength of this study is the use of a large sample covering different regions of China to explore the associations between individual and family factors and QOL in older people. Furthermore, the statistical analysis was conducted using SEM based on a conceptual framework, which is an advanced statistical approach to estimate direct and indirect effects from exposure to outcome, including latent variables. This is the first study using SEM to analyze the pathways from individual and family factors to QOL via HR and HSD over the entire older adult population in China. The findings suggest potential avenues for policy and intervention to improve the QOL among older individuals.

The limitations of the study must be taken into account when interpreting the results. First, the data used in this study is from a cross-sectional survey; although the hypotheses of this study are supported by theory, experience, and statistical data, caution is still warranted in inferring causal relationships. Future research using prospective, longitudinal cohorts is needed to further validate these findings. Second, due to the constraints of the CHARLS database, there are limitations regarding the selection of variables for constructing individual and family factors, and the relevant data on the personal income data of older adults in the database are missing, so we chose per capita disposable income at the city level as a substitute, which may cause bias in the results. Third, for the physical activity data, there is a 50% missing data rate, and our sample does not include individuals with disabilities. Although sensitivity analyses indicated that the absence of physical activity data did not affect the robustness of the model, caution is advised when extrapolating conclusions to individuals with disabilities. Finally, this study included all older adults with spouses and children, caution is needed when extrapolating the conclusions to older individuals who are unmarried or without children.

Conclusions

Both IF (education, per capita disposable income, and endowment insurance) and FF (satisfaction with a spouse and children) directly impact the QOL in older people. Meanwhile, IF and FF have equal influence on QOL through the mediating role of HR and HSD. Therefore, it is imperative to enhance social support and prioritize home care for older adults in future interventions. Enhanced access to financial and emotional support can mitigate health risks and facilitate access to quality health care, thereby improving QOL for older adults.

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Data Availability

Please contact CHARLS (China Health and Retirement Longitudinal Study) for data requests.

Authors' Contributions

YTW, CG, and LFP contributed equally to designing the study, collecting and analyzing the data, and writing the manuscript. MXZ verified data and contributed to data analysis. WFL and YMW revised the manuscript, provided valuable suggestions for study design and data analysis, conceived the project and provided overall supervision. WFL and YMW are recognized as co-corresponding authors.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Corresponding variables in the CHARLS (China Health and Retirement Longitudinal Study) data.
[DOCX File , 12 KB - aging_v7i1e59818_app1.docx]

Multimedia Appendix 2
Definition of variables in structural equation model.
[DOCX File , 13 KB - aging_v7i1e59818_app2.docx]

Multimedia Appendix 3
The percentages of participants with missing data.
[DOCX File , 12 KB - aging_v7i1e59818_app3.docx]

Multimedia Appendix 4
Correlation matrix of the variables (N=8,600).
[DOCX File , 16 KB - aging_v7i1e59818_app4.docx]

Multimedia Appendix 5
The detailed impact pathways of IF and FF on the QOL.
[DOCX File , 15 KB - aging_v7i1e59818_app5.docx]

Multimedia Appendix 6
Model fit indices of subgroup analysis.
[DOCX File , 13 KB - aging_v7i1e59818_app6.docx]

Multimedia Appendix 7
The detailed impact pathways of individual factors and family factors on the quality of life in sensitivity analyses (N=4259).
[DOCX File , 15 KB - aging_v7i1e59818_app7.docx]

Multimedia Appendix 8
Model-ft index of sensitivity analyses.
[DOCX File , 12 KB - aging_v7i1e59818_app8.docx]

References

1. Chen R, Xu P, Song P, Wang M, He J. China has faster pace than Japan in population aging in next 25 years. Biosci Trends 2019 Sep 17;13(4):287-291 [FREE Full text] [doi: 10.5582/bst.2019.01213] [Medline: 31434814]
2. The Lancet. Population ageing in China: crisis or opportunity? Lancet 2022 Nov 26;400(10366):1821. [doi: 10.1016/S0140-6736(22)02410-2] [Medline: 36436518]
3. Liu W, Yang C, Chen Z, Lei F, Qin JJ, Liu H, et al. Global death burden and attributable risk factors of peripheral artery disease by age, sex, SDI regions, and countries from 1990 to 2030: results from the global burden of disease study 2019. Atherosclerosis 2022 Apr;347:17-27. [doi: 10.1016/j.atherosclerosis.2022.03.002] [Medline: 35299057]
4. Wang W, Hu M, Liu H, Zhang X, Li H, Zhou F, et al. Global burden of disease study 2019 suggests that metabolic risk factors are the leading drivers of the burden of ischemic heart disease. Cell Metab 2021 Oct 5;33(10):1943-1956.e2 [FREE Full text] [doi: 10.1016/j.cmet.2021.08.005] [Medline: 34478633]
5. NA. The WorAd Health Organization Quality of Life assessment (WHOQOL): development and general psychometric properties. Soc Sci Med 1998 Jun;46(12):1569-1585. [doi: 10.1016/s0277-9536(98)00009-4] [Medline: 9672396]
6. Yu Y, Cai J, She Z, Li H. Insights into the epidemiology, pathogenesis, and therapeutics of nonalcoholic fatty liver diseases. Adv Sci (Weinh) 2018 Nov 12;6(4):1801585 [FREE Full text] [doi: 10.1002/advs.201801585] [Medline: 30828530]
7. Zhang X, Liu YM, Lei F, Huang X, Liu W, Sun T, et al. Association between questionnaire-based and accelerometer-based physical activity and the incidence of chronic kidney disease using data from UK biobank: a prospective cohort study. EClinicalMedicine 2023 Nov 20;66:102323 [FREE Full text] [doi: 10.1016/j.eclinm.2023.102323] [Medline: 38024479]
8. Zhang X, Tao J, Lei F, Sun T, Lin L, Huang X, et al. Association of the components of ambient fine particulate matter (PM) and chronic kidney disease prevalence in China. J Environ Manage 2023 Aug 1;339:117885. [doi: 10.1016/j.jenvman.2023.117885] [Medline: 37086641]
9. Banda A, Hoffman J, Roos V. Individual and community-contextual level factors associated with wellbeing among older adults in rural Zambia. Int J Public Health 2024 Feb;69:1606571 [FREE Full text] [doi: 10.3389/ijph.2024.1606571] [Medline: 38440080]
10. Antonoplis S. Studying socioeconomic status: conceptual problems and an alternative path forward. Perspect Psychol Sci 2023 Mar;18(2):275-292 [FREE Full text] [doi: 10.1177/17456916221093615] [Medline: 35981108]
11. Calixto OJ, Anaya JM. Socioeconomic status. The relationship with health and autoimmune diseases. Autoimmun Rev 2014 Jun;13(6):641-654. [doi: 10.1016/j.autrev.2013.12.002] [Medline: 24418307]
12. Hou FR, Yang Y, Yan LQ, Gao YY, Zhang X, Dai XM, et al. Analysis on the health-related quality of life and influencing factors among the older generation of migrant workers in Chengdu City. Sichuan Da Xue Xue Bao Yi Xue Ban 2020 May;51(3):383-387. [doi: 10.12182/20200560105] [Medline: 32543147]
13. Liu X, Liu J, Flores DD, McDonald CC. Family factors related to adolescent screen media use and mental health outcomes: a systematic review and recommendation for practices. J Adolesc 2024 Jun 25. [doi: 10.1002/jad.12367] [Medline: 38922966]
14. Ren Y, Jin Y. Family factors and people's desired fertility: implications to improving family policies in the context of low ferity society. Journal of Shandong Women's University. 2024. URL: https://tinyurl.com/2536s4yj [accessed 2024-08-02]
15. Peltz JS, Rogge RD, Sturge-Apple ML. Transactions within the family: coparenting mediates associations between parents' relationship satisfaction and the parent-child relationship. J Fam Psychol 2018 Aug;32(5):553-564. [doi: 10.1037/fam0000413] [Medline: 29927285]
16. Mugomeri E, Chatanga P, Khetheng T, Dhemba J. Quality of life of the elderly receiving old age pension in lesotho. J Aging Soc Policy 2017;29(4):371-393. [doi: 10.1080/08959420.2017.1328952] [Medline: 28535113]
17. Polku H, Mikkola TM, Rantakokko M, Portegijs E, Törmäkangas T, Rantanen T, et al. Hearing and quality of life among community-dwelling older adults. J Gerontol B Psychol Sci Soc Sci 2018 Mar 2;73(3):543-552. [doi: 10.1093/geronb/gbw045] [Medline: 27154962]
18. Zhang C, Cai Y, Xue Y, Zheng X, Yang X, Lu J, et al. Exploring the influencing factors of quality of life among the empty nesters in Shanxi, China: a structural equation model. Health Qual Life Outcomes 2021 May 28;19(1):156 [FREE Full text] [doi: 10.1186/s12955-021-01793-x] [Medline: 34049560]
19. Chen C, Liu GG, Shi QL, Sun Y, Zhang H, Wang MJ, et al. Health-related quality of life and associated factors among oldest-old in China. J Nutr Health Aging 2020;24(3):330-338 [FREE Full text] [doi: 10.1007/s12603-020-1327-2] [Medline: 32115616]
20. Mackenbach JP, Stirbu I, Roskam AJR, Schaap MM, Menvielle G, Leinsalu M, European Union Working Group on Socioeconomic Inequalities in Health. Socioeconomic inequalities in health in 22 European countries. N Engl J Med 2008 Jun 5;358(23):2468-2481 [FREE Full text] [doi: 10.1056/NEJMsa0707519] [Medline: 18525043]
21. Siahpush M, McNeill A, Hammond D, Fong GT. Socioeconomic and country variations in knowledge of health risks of tobacco smoking and toxic constituents of smoke: results from the 2002 International Tobacco Control (ITC) four country

survey. Tob Control 2006 Jun;15 Suppl 3(Suppl 3):iii65-iii70 [FREE Full text] [doi: 10.1136/tc.2005.013276] [Medline: 16754949]

22. Marmot M, Friel S, Bell R, Houweling TAJ, Taylor S, Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. Lancet 2008 Nov 8;372(9650):1661-1669. [doi: 10.1016/S0140-6736(08)61690-6] [Medline: 18994664]
23. Han KT, Park EC, Kim JH, Kim SJ, Park S. Is marital status associated with quality of life? Health Qual Life Outcomes 2014 Aug 8;12:109 [FREE Full text] [doi: 10.1186/s12955-014-0109-0] [Medline: 25104276]
24. Li Q, Dong JH, Zhang X. The effects of children's quantity and quality on parental subjective wellbeing. Journal of East China Normal University (Philosophy and Social Sciences) 2021;53(4):150-165. [doi: 10.16382/j.cnki.1000-5579]
25. Zhong Y, Qin G, Xi H, Cai D, Wang Y, Wang T, et al. Prevalence, patterns of multimorbidity and associations with health care utilization among middle-aged and older people in China. BMC Public Health 2023 Mar 21;23(1):537 [FREE Full text] [doi: 10.1186/s12889-023-15412-5] [Medline: 36944960]
26. Sun BC. Quality-of-life, health service use, and costs associated with syncope. Prog Cardiovasc Dis 2013;55(4):370-375. [doi: 10.1016/j.pcad.2012.10.009] [Medline: 23472773]
27. Chen Y, Hicks A, While AE. Quality of life and related factors: a questionnaire survey of older people living alone in mainland China. Qual Life Res 2014 Jun;23(5):1593-1602. [doi: 10.1007/s11136-013-0587-2] [Medline: 24293059]
28. Zhou B, Chen K, Wang J, Wang H, Zhang S, Zheng W. Quality of life and related factors in the older rural and urban Chinese populations in Zhejiang Province. J Appl Gerontol 2010 Feb 16;30(2):199-225. [doi: 10.1177/0733464810361346]
29. Zhao Y, Hu Y, Smith JP, Strauss J, Yang G. Cohort profile: the China health and retirement longitudinal study (CHARLS). Int J Epidemiol 2014 Feb;43(1):61-68 [FREE Full text] [doi: 10.1093/ije/dys203] [Medline: 23243115]
30. National school of development, peking university. China Health and Retirement Longitudinal Study (CHARLS). URL: https://charls.pku.edu.cn/en/ [accessed 2024-07-11]
31. Adler NE, Newman K. Socioeconomic disparities in health: pathways and policies. Health Aff (Millwood) 2002;21(2):60-76. [doi: 10.1377/hlthaff.21.2.60] [Medline: 11900187]
32. Ware JE, Gandek B. Overview of the SF-36 health survey and the international quality of life assessment (IQOLA) project. J Clin Epidemiol 1998 Nov;51(11):903-912. [doi: 10.1016/s0895-4356(98)00081-x] [Medline: 9817107]
33. Hao X, Yang Y, Gao X, Dai T. Evaluating the effectiveness of the health management program for the elderly on health-related quality of life among elderly people in China: findings from the China health and retirement longitudinal study. Int J Environ Res Public Health 2019 Jan 3;16(1):113 [FREE Full text] [doi: 10.3390/ijerph16010113] [Medline: 30609852]
34. Jia Z, Gao Y, Zhao L, Han S. Longitudinal relationship between cognitive function and health-related quality of life among middle-aged and older patients with diabetes in China: digital usage behavior differences. Int J Environ Res Public Health 2022 Sep 29;19(19):12400 [FREE Full text] [doi: 10.3390/ijerph191912400] [Medline: 36231699]
35. World health organization. Obesity and Overweight. URL: https://www.who.int/news-room/fact-sheets/detail/obesity-and-overweight [accessed 2024-07-11]
36. Gotohui. Gotohui Data. URL: https://www.gotohui.com/ [accessed 2024-07-11]
37. Yang G, Zhang L. Relationship between aging population, birth rate and disposable income per capita in the context of COVID-19. PLoS One 2023 Aug 9;18(8):e0289781 [FREE Full text] [doi: 10.1371/journal.pone.0289781] [Medline: 37556431]
38. Vagetti GC, Barbosa Filho VC, Moreira NB, Oliveira VD, Mazzardo O, Campos WD. Association between physical activity and quality of life in the elderly: a systematic review, 2000-2012. Braz J Psychiatry 2014;36(1):76-88 [FREE Full text] [doi: 10.1590/1516-4446-2012-0895] [Medline: 24554274]
39. Chen CY, Storr CL. Alcohol use and health-related quality of life among youth in Taiwan. J Adolesc Health 2006 Nov;39(5):752.e9-716.e9 [FREE Full text] [doi: 10.1016/j.jadohealth.2006.04.019] [Medline: 17046514]
40. Ohayon MM, Reynolds CF, Dauvilliers Y. Excessive sleep duration and quality of life. Ann Neurol 2013 Jun;73(6):785-794 [FREE Full text] [doi: 10.1002/ana.23818] [Medline: 23846792]
41. Shen K, Cho Y, Pascoe EM, Hawley CM, Oliver V, Hughes KM, et al. The SIESTA trial: a randomized study investigating the efficacy, safety, and tolerability of acupressure versus sham therapy for improving sleep quality in patients with end-stage kidney disease on hemodialysis. Evid Based Complement Alternat Med 2017;2017:7570352 [FREE Full text] [doi: 10.1155/2017/7570352] [Medline: 28316636]
42. Sahoo U, Akhtar S. Utilization of inpatient and outpatient health services and associated cost for chronic diseases among older adults in India: evidences from longitudinal ageing survey in India 201-2018. Handbook of Aging, Health and Public Policy: Perspectives from Asia 2023 Sep 6:1-26. [doi: 10.1007/978-981-16-1914-4_106-1]
43. Kline RB, Little TD. Principles and Practice of Structural Equation Modeling, Fourth Edition. New York, United States: Guilford Press; 2015.
44. Neuberg LG. Causality: models, reasoning, and inference, by Judea pearl, cambridge university press, 2000. Econ Theory 2003;19(4):675-685. [doi: 10.1017/s0266466603004109]
45. Byrne BM. Structural Equation Modeling With AMOS Basic Concepts, Applications, and Programming, Third Edition. New York: Routledge; 2016:460.

46. Karmakar M, Elhai JD, Amialchuk AA, Tietjen GE. Do personality traits mediate the relationship between childhood abuse and migraine? An exploration of the relationships in young adults using the add health dataset. Headache 2018 Feb;58(2):243-259. [doi: 10.1111/head.13206] [Medline: 29027200]
47. Fornell C, Larcker DF. Evaluating structural equation models with unobservable variables and measurement error. Journal of Marketing Research 1981 Feb;18(1):39-50. [doi: 10.1177/002224378101800104]
48. VanderWeele TJ. Mediation analysis: a practitioner's guide. Annu Rev Public Health 2016;37:17-32. [doi: 10.1146/annurev-publhealth-032315-021402] [Medline: 26653405]
49. Browne MW, Cudeck R. Alternative ways of assessing model fit. Sociological Methods & Research 1992 Nov;21(2):230-258. [doi: 10.1177/0049124192021002005]
50. Schermelleh-Engel K, Moosbrugger H, Müller H. Evaluating the fit of structural equation models: tests of significance and descriptive goodness-of-fit measures. Methods of Psychological Research. 2003. URL: https://www.researchgate.net/publication/251060246 [accessed 2024-07-11]
51. Kim E, Sok SR, Won CW. Factors affecting frailty among community-dwelling older adults: a multi-group path analysis according to nutritional status. Int J Nurs Stud 2021 Mar;115:103850. [doi: 10.1016/j.ijnurstu.2020.103850] [Medline: 33418448]
52. Mukaka MM. Statistics corner: a guide to appropriate use of correlation coefficient in medical research. Malawi Med J 2012 Sep;24(3):69-71 [FREE Full text] [Medline: 23638278]
53. Chen Z, Zhu M, Zheng L, Xie X. Personal wisdom and quality of life among Chinese older adults. J Health Psychol 2022 Jun;27(7):1646-1658. [doi: 10.1177/1359105321999093] [Medline: 33752460]
54. Yu L, Xia Z. The impact of China’s endowment insurance system on health behavior. Journal of Chinese Governance 2024;9(2):279-302. [doi: 10.1080/23812346.2024.2309597]
55. Chen X, Eggleston K, Sun A. The impact of social pensions on intergenerational relationships: comparative evidence from China. J Econ Ageing 2018 Nov;12:225-235 [FREE Full text] [doi: 10.1016/j.jeoa.2017.04.001] [Medline: 30534523]
56. Ma X, Oshio T. The impact of social insurance on health among middle-aged and older adults in rural China: a longitudinal study using a three-wave nationwide survey. BMC Public Health 2020 Dec 1;20(1):1842 [FREE Full text] [doi: 10.1186/s12889-020-09945-2] [Medline: 33261609]
57. Zhang C, Zhu R, Lu J, Xue Y, Hou L, Li M, et al. Health promoting lifestyles and influencing factors among empty nesters and non-empty nesters in Taiyuan, China: a cross-sectional study. Health Qual Life Outcomes 2018 May 25;16(1):103 [FREE Full text] [doi: 10.1186/s12955-018-0936-5] [Medline: 29801495]
58. López-Otín C, Blasco MA, Partridge L, Serrano M, Kroemer G. The hallmarks of aging. Cell 2013 Jun 6;153(6):1194-1217 [FREE Full text] [doi: 10.1016/j.cell.2013.05.039] [Medline: 23746838]
59. Finkelstein A, Taubman S, Wright B, Bernstein M, Gruber J, Newhouse JP, Oregon Health Study Group. The oregon health insurance experiment: evidence from the first year. Q J Econ 2012 Aug;127(3):1057-1106 [FREE Full text] [doi: 10.1093/qje/qjs020] [Medline: 23293397]
60. McWilliams JM, Meara E, Zaslavsky AM, Ayanian JZ. Health of previously uninsured adults after acquiring medicare coverage. JAMA 2007 Dec 26;298(24):2886-2894. [doi: 10.1001/jama.298.24.2886] [Medline: 18159058]
61. World health organization. Mental health. URL: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response [accessed 2024-07-11]
62. Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. Arch Gen Psychiatry 2005 Jun;62(6):593-602. [doi: 10.1001/archpsyc.62.6.593] [Medline: 15939837]
63. Lorant V, Deliège D, Eaton W, Robert A, Philippot P, Ansseau M. Socioeconomic inequalities in depression: a meta-analysis. Am J Epidemiol 2003;157(2):98-112 [FREE Full text] [doi: 10.1093/aje/kwf182] [Medline: 12522017]
64. Umberson D, Montez JK. Social relationships and health: a flashpoint for health policy. J Health Soc Behav 2010;51 Suppl(Suppl):S54-S66 [FREE Full text] [doi: 10.1177/0022146510383501] [Medline: 20943583]
65. Plomin R, DeFries JC, Knopik VS, Neiderhiser JM. Top 10 replicated findings from behavioral genetics. Perspect Psychol Sci 2016 Jan;11(1):3-23 [FREE Full text] [doi: 10.1177/1745691615617439] [Medline: 26817721]
66. Adler NE, Stewart J. Health disparities across the lifespan: meaning, methods, and mechanisms. Ann N Y Acad Sci 2010 Feb;1186:5-23. [doi: 10.1111/j.1749-6632.2009.05337.x] [Medline: 20201865]
67. Rechel B, Grundy E, Robine JM, Cylus J, Mackenbach JP, Knai C, et al. Ageing in the european union. Lancet 2013 Apr 13;381(9874):1312-1322. [doi: 10.1016/S0140-6736(12)62087-X] [Medline: 23541057]
68. Litwin H. Social networks and well-being: a comparison of older people in mediterranean and non-mediterranean countries. J Gerontol B Psychol Sci Soc Sci 2010 Sep;65(5):599-608 [FREE Full text] [doi: 10.1093/geronb/gbp104] [Medline: 20008485]
69. Zaninotto P, Falaschetti E, Sacker A. Age trajectories of quality of life among older adults: results from the English longitudinal study of ageing. Qual Life Res 2009 Nov;18(10):1301-1309. [doi: 10.1007/s11136-009-9543-6] [Medline: 19806468]

70. Wu F, Guo Y, Kowal P, Jiang Y, Yu M, Li X, et al. Prevalence of major chronic conditions among older Chinese adults: the study on global AGEing and adult health (SAGE) wave 1. PLoS One 2013 Sep 17;8(9):e74176. [doi: 10.1371/journal.pone.0074176] [Medline: 24069278]
71. Ćwirlej-Sozańska AB, Wiśniowska-Szurlej A, Wilmowska-Pietruszyńska A, Sozański B. Factors associated with disability and quality of life among the oldest-old living in community in Poland - a cross-sectional study. Ann Agric Environ Med 2020 Dec 22;27(4):621-629 [FREE Full text] [doi: 10.26444/aaem/115020] [Medline: 33356070]
72. Lang FR, Carstensen LL. Time counts: future time perspective, goals, and social relationships. Psychol Aging 2002 Mar;17(1):125-139. [doi: 10.1037/0882-7974.17.1.125] [Medline: 11931281]
73. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the health belief model. Health Educ Q 1988;15(2):175-183. [doi: 10.1177/109019818801500203] [Medline: 3378902]
74. Li C, Zhou R, Yao N, Cornwell T, Wang S. Health care utilization and unmet needs in Chinese older adults with multimorbidity and functional impairment. J Am Med Dir Assoc 2020 Jun;21(6):806-810. [doi: 10.1016/j.jamda.2020.02.010] [Medline: 32222351]

Abbreviations

AVE: average variance extracted
AGFI: adjusted goodness of fit index
BP: bodily pain
CFA: confirmatory factor analysis
CFI: comparative fit index
CHARLS: China Health and Retirement Longitudinal Study
CR: composite reliability
CVI: content validity index
FF: family factor
GFI: goodness of fit index
GH: general health
HR: health risk
HSD: health services demand
I-CVI: item content validity index
IF: individual factor
IFI: incremental fit index
MCS: mental component summary
MH: mental health
PCS: physical component summary
PF: physical functioning
QOL: quality of life
RE: role-emotional
RMSEA: root-mean-square error of approximation
RP: role-physical
S-CVI: scale content validity index
SEM: structural equation modeling
SF: social functioning
SF-36: Short Form 36
SRMR: standardized root-mean-square residual

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Identifying Predictive Risk Factors for Future Cognitive Impairment Among Chinese Older Adults: Longitudinal Prediction Study

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Abstract

Background: The societal burden of cognitive impairment in China has prompted researchers to develop clinical prediction models aimed at making risk assessments that enable preventative interventions. However, it is unclear what types of risk factors best predict future cognitive impairment, if known risk factors make equally accurate predictions across different socioeconomic groups, and if existing prediction models are equally accurate across different subpopulations.

Objective: This paper aimed to identify which domain of health information best predicts future cognitive impairment among Chinese older adults and to examine if discrepancies exist in predictive ability across different population subsets.

Methods: Using data from the Chinese Longitudinal Healthy Longevity Survey, we quantified the ability of demographics, instrumental activities of daily living, activities of daily living, cognitive tests, social factors and hobbies, psychological factors, diet, exercise and sleep, chronic diseases, and 3 recently published logistic regression–based prediction models to predict 3-year risk of cognitive impairment in the general Chinese population and among male, female, rural-dwelling, urban-dwelling, educated, and not formally educated older adults. Predictive ability was quantified using the area under the receiver operating characteristic curve (AUC) and sensitivity-specificity curves through 20 repeats of 10-fold cross-validation.

Results: A total of 4047 participants were included in the study, of which 337 (8.3%) developed cognitive impairment 3 years after baseline data collection. The risk factor groups with the best predictive ability in the general population were demographics (AUC 0.78, 95% CI 0.77-0.78), cognitive tests (AUC 0.72, 95% CI 0.72-0.73), and instrumental activities of daily living (AUC 0.71, 95% CI 0.70-0.71). Demographics, cognitive tests, instrumental activities of daily living, and all 3 recreated prediction models had significantly higher AUCs when making predictions among female older adults compared to male older adults and among older adults with no formal education compared to those with some education.

Conclusions: This study suggests that demographics, cognitive tests, and instrumental activities of daily living are the most useful risk factors for predicting future cognitive impairment among Chinese older adults. However, the most predictive risk factors and existing models have lower predictive power among male, urban-dwelling, and educated older adults. More efforts are needed to ensure that equally accurate risk assessments can be conducted across different socioeconomic groups in China.

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KEYWORDS

cognitive impairment; China; prediction; predictions; predict; predictor; predictors; risk; risks; population; demographic; demographics; gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; MCI; cognitive; cognition; machine learning; variable; variables; model; models; mild cognitive impairment

Introduction

China's aging population has led to cognitive impairment becoming increasingly burdensome to society [1,2]. In 2020, more than 68 million Chinese older adults had mild cognitive impairment, dementia, or Alzheimer disease [3]. The economic and social burden of cognitive impairment has led to calls for improving risk assessments and prioritizing early diagnoses [1,3]. Given China's limited number of geriatric psychiatrists, researchers have turned to developing prediction models to identify older adults at risk of cognitive impairment for preventative interventions [4-8]. However, no study has compared the predictive ability of known risk factors side by side, and our understanding of which factors are the most useful for developing prediction models is limited. Furthermore, population characteristics vary widely across China, but it is unknown which risk factors are the most predictive in different socioeconomic groups, and existing prediction models have primarily been tested in the general population alone. To understand how to best predict future cognitive impairment and to develop more targeted prediction models for population subgroups, the predictive ability of known risk factors and existing prediction models must be quantified and compared across different subsets of the Chinese population.

A plethora of modifiable and nonmodifiable risk factors that are associated with cognitive impairment among Chinese older adults have been identified. Previous studies have found that increased age, limited functional independence, alcohol consumption, hypertension, and depression are significantly associated with cognitive impairment [3,9-12]. Protective factors have also been identified, namely, good sleep quality, sleeping sufficiently for many hours per night, exercise, and increased social participation [3,9,13-17]. It is also known that the prevalence of cognitive impairment in China differs across population subsets such as male and female individuals, rural and urban dwellers, and older adults with different levels of education [3]. Explanations for such discrepancies include different social patterns and literacy rates across the sexes and across regions with varying degrees of rurality, rates of depression in rural areas, and levels of education [3]. More years of education has also been associated with a greater cognitive reserve, which protects against future impairment [3]. Nevertheless, it is unclear which risk factors are the most useful for predicting future cognitive impairment across different subpopulations in China. Although we have a reasonable understanding of which characteristics make a person more likely to develop cognitive impairment, our understanding of which parts of a person's health profile most accurately predict their risk of developing cognitive impairment is limited.

In addition to known risk factors, it is unclear if existing prediction models for future cognitive impairment are equally accurate across different socioeconomic groups in China. Several published models have reported areas under the receiver operating characteristic curve (AUCs) greater than 0.80 in their development cohorts [5,7,8], but each model has only been tested on the general population. Nearly all existing models make predictions by leveraging measures of cognition, age, and education. Additional covariates vary from model to model and include factors such as instrumental activities of daily living (IADL), hobbies such as gardening and watching television, marital status, and others. Examining the predictive ability of existing models across population subsets would allow us to identify where more efforts are needed to improve risk assessments for cognitive impairment, further our understanding of which subpopulations are more difficult to conduct risk assessments within, and provide a more thorough evaluation of existing prediction models than has been reported previously.

In this study, we quantified the ability of 9 risk factor groups and 3 existing models to predict future cognitive impairment among Chinese older adults. We examined how well demographics, IADL, activities of daily living (ADL), cognitive tests, social factors and hobbies, psychological factors, diet, exercise and sleep, chronic diseases, and 3 recently published models predict future cognitive impairment in the general population and among male, female, rural-dwelling, urban-dwelling, educated, and not formally educated older adults. To our knowledge, this study is the first to comprehensively compare the ability of known risk factors to predict future cognitive impairment and the first seeking to identify which subsets of the Chinese population need greater attention to improve the accuracy of risk assessments.

Methods

Data Source and Study Design

The Chinese Longitudinal Healthy Longevity Survey (CLHLS) is a prospective cohort study of Chinese older adults that contains information on demographics, cognitive function, lifestyle factors, chronic diseases, and more [18,19]. The CLHLS began in 1998, and follow-up surveys have been conducted every 2-3 years since. The data include older adults from 23 of China's provinces that together make up 85% of the country's total population.

We used the 2011 and 2014 CLHLS waves in our study. Baseline characteristics were gathered from the 2011 survey and used to predict if an individual became cognitively impaired by 2014. CLHLS participants younger than the age of 60 years or those with cognitive impairment at baseline were excluded. Sample size calculations were conducted following the methodology for multivariable prediction models by Riley et al [20]. This study is presented following the TRIPOD (Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis) guidelines where appropriate [21,22].

Ethical Considerations

The CLHLS received ethics approval from the Duke University Institutional Review Board (Pro00062871) and Peking University's Biomedical Ethics Committee (IRB00001052–13,074). Written informed consent was given by all participants prior to the survey interviews. This study secondarily analyzed anonymized data from the CLHLS.

Measuring Cognitive Function

Cognition was assessed through the Chinese-language version of the Mini Mental State Examination (MMSE) [23]. MMSE scores range from 0 to 30, with lower scores indicating worse cognitive function. We adopted education-specific cutoffs that have been previously validated in the Chinese older adult population to indicate cognitive impairment [24]. Those with no formal education and MMSE scores less than 18 were labeled as cognitively impaired, as were those with 1-6 years of education with scores less than 21 and those with more than 6 years of education with scores less than 25 [24].

Risk Factor Groups

Overview

A total of 9 groups containing known risk factors for cognitive impairment were considered in this study: demographics, ADL, IADL, cognitive tests, social factors and hobbies, psychological factors, exercise and sleep, diet, and chronic diseases. The risk factor groups were chosen by selecting parts of a person's health profile previously found to be associated with developing cognitive impairment [9]. Each group is briefly described below, and a complete list of the variables in each group can be found in Multimedia Appendix 1.

Demographics Group

The demographics group contained each individual's age, sex, years of education, household income, marital status, and residence location (city, town, or rural area).

ADL Group

The ADL group included each person's ability to bathe, get dressed, use the toilet, get in and out of bed, control urination and bowel movements, and eat food.

IADL Group

The IADL group covered tasks that require thinking, organizational, and physical independence. The IADL group included an older adult's ability to visit neighbors, go shopping, cook, wash clothes, walk continuously for 1 km, lift a bag of groceries, crouch and stand up, and take public transportation.

Cognitive Tests Group

The cognitive tests group included scores from each subsection of the MMSE: orientation, naming, registration, calculation, attention, recall, and language. Scores from each section were included as separate variables.

Social Factors and Hobbies Group

The social factors and hobbies group included whether a person grows vegetables, gardens, reads newspapers and books, looks after pets or animals, plays cards or mahjong, and participates in social activities.

Psychological Factors Group

The psychological factors group included the following factors that primarily relate to depression and anxiety: whether a person is generally optimistic, keeps their belongings organized, is generally anxious, is often lonely, makes decisions independently, feels useless with age, was happier when they were younger, and felt sad for more than 2 consecutive weeks over the past year.

Exercise and Sleep Group

The exercise and sleep group included whether someone currently exercises, whether they used to exercise, as well as the self-reported duration and quality of sleep.

Diet Group

The diet group contained information on each person's staple food; if they eat fresh fruits and vegetables; the main flavor of the dishes they cook; how frequently they consume meat, fish, eggs, sugar, and tea; if they consume alcohol; the type of alcohol they consume; and the frequency of alcohol consumption.

Chronic Diseases Group

The chronic diseases group included the presence or absence of hypertension, diabetes, heart disease, blood disease, and cardiovascular disease.

Recreating Existing Prediction Models

Prediction models were selected based on the following criteria: the model was developed for use in China, was reproducible using the CLHLS, and had an AUC of >0.75 during development. We selected 3 models published in Zhou et al [8], Hu et al [5], and Wang et al [7]. Each model was developed for use in the general Chinese population and showed excellent predictive performance (AUC>0.80) during development. All the models we recreated were based on logistic regression, which returns predictions by summing weighted values of each covariate before the sum is passed through the logistic function to produce predicted probabilities between 0 and 1. The logistic regression model recreated from Zhou et al [8] included age, a functional independence score based on ADL, baseline MMSE score, chewing ability, visual function, history of stroke, whether the participant watches TV or listens to the radio, and whether the participant grows flowers or raises pets. From Hu et al [5], the recreated model included age, marital status, IADL, and baseline MMSE score. Lastly, the model from Wang et al [7] included age; education; sex; ADL; baseline MMSE; and whether the participant gardens, reads newspapers or books, plays mahjong or cards, watches TV, or listens to the radio.

Statistical Analysis

All analyses were performed using the R Statistical Software (version 4.0.5; R Foundation for Statistical Computing), and all code required to reproduce the analyses presented herein can be found on the web [25]. Predictive ability was quantified using AUC, sensitivity, and specificity. We assessed the predictive ability of each risk factor group using logistic regression models evaluated through 20 repeats of 10-fold cross validation, which has been recommended to obtain optimism-corrected performance metrics for prediction models [26]. This resulted in 200 training sets and 200 validation sets. All "I don't know" or "refused" responses in the CLHLSs were set to missing, ordinal variables were integer encoded, and nonordinal categorical variables were dummy encoded. Missing values were imputed on each training and validation set separately using *k*-nearest neighbors imputation [27]. During each iteration of cross-validation, the data were split into training and validation sets before 9 logistic regression models, each containing all covariates in 1 particular risk factor group, were fit to the training data. Thereafter, each model was used to make predictions on the validation set for the general population and 6 subpopulations: male, female, rural-dwelling, urban-dwelling, educated, and not formally educated older adults. The same procedure was also followed for evaluating the prediction models from Zhou et al [8], Hu et al [5], and Wang et al [7]. Average AUCs and accompanying 95% CIs were calculated across the 200 validation-set AUCs for each model in this study. Sensitivity and specificity curves, 1 from each validation set, were also plotted for the risk factor group models.

Results

Given a binary outcome, a population-level prevalence of 0.20, a conservatively estimated Cox-Snell R^2 of 0.09, and 24 predictors in the largest risk factor group, the sample size required for this study was determined to be 1065 with 213 events to minimize the risk of overfitting, reduce the chance of overly optimistic performance metrics, and ensure that the models have sufficient data to estimate the overall risk of cognitive impairment in our sample. After excluding CLHLS participants with cognitive impairment at baseline and those younger than the age of 60 years, a cohort of 4047 Chinese older adults were included, of which 337 (8.3%) developed cognitive impairment. The average age of the cohort was 79.8 (SD 9.4) years, and 2037 (50%) were male. The group that developed cognitive impairment was older at baseline (89.1 vs 79.0 years) with a lower average baseline MMSE score (25.1 vs 27.7). A full description of the cohort's characteristics can be found in Table 1, and the distribution of variables in each risk factor group can be found in Multimedia Appendix 2.

Table . Baseline cohort characteristics.

Characteristics		All participants (N=4047)	Developed cognitive impairment	
			Yes (n=337)	No (n=3710)
Age (y), mean (SD)		79.8 (9.4)	89.1 (9.8)	79.0 (8.9)
Sex, n (%)				
	Male	2037 (50.3)	130 (38.6)	1907 (51.4)
	Female	2010 (49.7)	207 (61.4)	1803 (48.6)
Years of schooling, mean (SD)		2.8 (3.7)	1.8 (3.2)	2.9 (3.7)
Household income (CN ¥; CN ¥1=US $0.14), mean (SD)		24,483.8 (25,778.6)	22,942.1 (23,198.5)	24,623.1 (25,997.7)
Marital status, n (%)				
	Married and living with spouse	2033 (50.3)	83 (24.6)	1950 (52.7)
	Married but not living with spouse	89 (2.2)	4 (1.2)	85 (2.3)
	Divorced	8 (0.2)	0 (0)	8 (0.2)
	Widowed	1862 (46.1)	246 (73)	1616 (43.7)
	Never married	46 (1.1)	4 (1.2)	42 (1.1)
Residential status, n (%)				
	City	665 (16.4)	57 (16.9)	608 (16.4)
	Town	1241 (30.7)	89 (26.4)	1152 (31.1)
	Rural area	2141 (52.9)	191 (56.7)	1950 (52.6)
Baseline MMSE[a] score, mean S(D)		27.5 (2.8)	25.1 (3.6)	27.7 (2.6)
Follow-up MMSE score, mean (SD)		26.2 (5.2)	12.8 (6.1)	27.5 (2.8)

[a] MMSE: Mini Mental State Examination.

As shown in Figure 1A and Table 2, demographics had the best predictive ability in the general population (AUC 0.78, 95% CI 0.77-0.78), followed by cognitive tests (AUC 0.72, 95% CI 0.72-0.73) and IADL (AUC 0.71, 95% CI 0.70-0.71). Social factors and hobbies had a moderate predictive ability (AUC 0.67, 95% CI 0.66-0.68), whereas diet, psychological factors, exercise and sleep, ADL, and chronic diseases all had average AUCs less than 0.60. Demographics, cognitive tests, and IADL also had the best sensitivity and specificity tradeoffs, as shown in Figure 2. By contrast, the sensitivity and specificity curves for the chronic diseases group showed that such risk factors only sometimes resulted in better-than-random predictions.

Figure 1. Average AUC by predictor group and target population. ADL: activities of daily living; AUC: area under the receiver operating characteristic curve; IADL: instrumental activities of daily living.

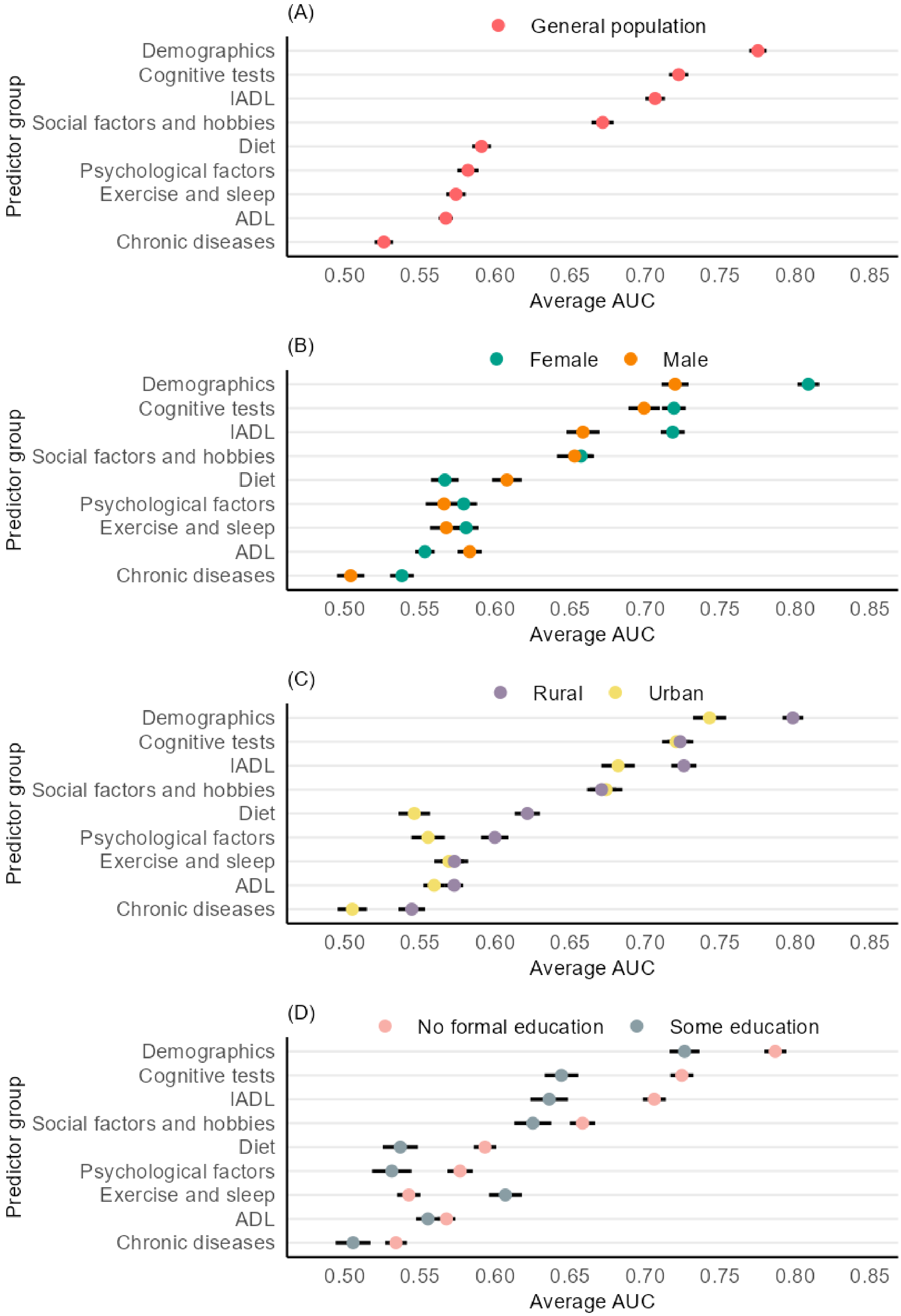
(A)
● General population
Predictor group
Demographics
Cognitive tests
IADL
Social factors and hobbies
Diet
Psychological factors
Exercise and sleep
ADL
Chronic diseases
0.50
0.55
0.60
0.65
0.70
0.75
0.80
0.85
Average AUC
(B)
● Female
● Male
Predictor group
Demographics
Cognitive tests
IADL
Social factors and hobbies
Diet
Psychological factors
Exercise and sleep
ADL
Chronic diseases
0.50
0.55
0.60
0.65
0.70
0.75
0.80
0.85
Average AUC
(C)
● Rural
● Urban
Predictor group
Demographics
Cognitive tests
IADL
Social factors and hobbies
Diet
Psychological factors
Exercise and sleep
ADL
Chronic diseases
0.50
0.55
0.60
0.65
0.70
0.75
0.80
0.85
Average AUC
(D)
● No formal education
● Some education
Predictor group
Demographics
Cognitive tests
IADL
Social factors and hobbies
Diet
Psychological factors
Exercise and sleep
ADL
Chronic diseases
0.50
0.55
0.60
0.65
0.70
0.75
0.80
0.85
Average AUC

Table . Predictive ability by target population.

Model	Target population, AUC[a] (95% CI)						
	General population	Male	Female	Rural	Urban	No formal education	Some education
Demographics	0.78 (0.77-0.78)	0.72 (0.71-0.73)	0.81 (0.80-0.82)	0.80 (0.79-0.81)	0.74 (0.73-0.75)	0.79 (0.78-0.79)	0.73 (0.72-0.74)
Cognitive tests	0.72 (0.72-0.73)	0.70 (0.69-0.71)	0.72 (0.71-0.73)	0.72 (0.71-0.73)	0.72 (0.71-0.73)	0.72 (0.72-0.73)	0.64 (0.63-0.66)
IADL[b]	0.71 (0.70-0.71)	0.66 (0.65-0.67)	0.72 (0.71-0.73)	0.73 (0.72-0.73)	0.68 (0.67-0.69)	0.71 (0.70-0.71)	0.64 (0.62-0.65)
Social factors and hobbies	0.67 (0.66-0.68)	0.65 (0.64-0.66)	0.66 (0.65-0.67)	0.67 (0.66-0.68)	0.67 (0.66-0.68)	0.66 (0.65-0.67)	0.63 (0.61-0.64)
Diet	0.59 (0.58-0.60)	0.61 (0.60-0.62)	0.57 (0.56-0.58)	0.62 (0.61-0.63)	0.55 (0.54-0.56)	0.59 (0.59-0.60)	0.54 (0.53-0.55)
Psychological factors	0.58 (0.57-0.59)	0.57 (0.55-0.58)	0.58 (0.57-0.59)	0.60 (0.59-0.61)	0.56 (0.54-0.57)	0.58 (0.57-0.59)	0.53 (0.52-0.54)
Exercise and sleep	0.57 (0.57-0.58)	0.57 (0.56-0.58)	0.58 (0.57-0.59)	0.57 (0.56-0.58)	0.57 (0.56-0.58)	0.54 (0.53-0.55)	0.61 (0.60-0.62)
ADL[c]	0.57 (0.56-0.57)	0.58 (0.58-0.59)	0.55 (0.55-0.56)	0.57 (0.57-0.58)	0.56 (0.55-0.57)	0.57 (0.56-0.57)	0.56 (0.55-0.56)
Chronic diseases	0.53 (0.52-0.53)	0.50 (0.49-0.51)	0.54 (0.53-0.55)	0.54 (0.54-0.55)	0.50 (0.50-0.51)	0.53 (0.53-0.54)	0.51 (0.49-0.52)
Wang et al [7]	0.80 (0.80-0.81)	0.78 (0.77-0.78)	0.82 (0.81-0.82)	0.82 (0.81-0.83)	0.78 (0.77-0.79)	0.81 (0.81-0.82)	0.75 (0.74-0.76)
Zhou et al [12]	0.80 (0.80-0.81)	0.78 (0.77-0.79)	0.82 (0.81-0.82)	0.82 (0.81-0.83)	0.78 (0.77-0.79)	0.82 (0.81-0.83)	0.75 (0.74-0.76)
Hu et al [5]	0.80 (0.80-0.81)	0.77 (0.77-0.78)	0.82 (0.81-0.83)	0.82 (0.81-0.83)	0.78 (0.77-0.79)	0.82 (0.81-0.82)	0.75 (0.74-0.76)

[a] AUC: area under the receiver operating characteristic curve.

[b] IADL: instrumental activities of daily living.

[c] ADL: activities of daily living.

Figure 2. Sensitivity and specificity curves for predictions made in the general population. ADL: activities of daily living; IADL: instrumental activities of daily living.

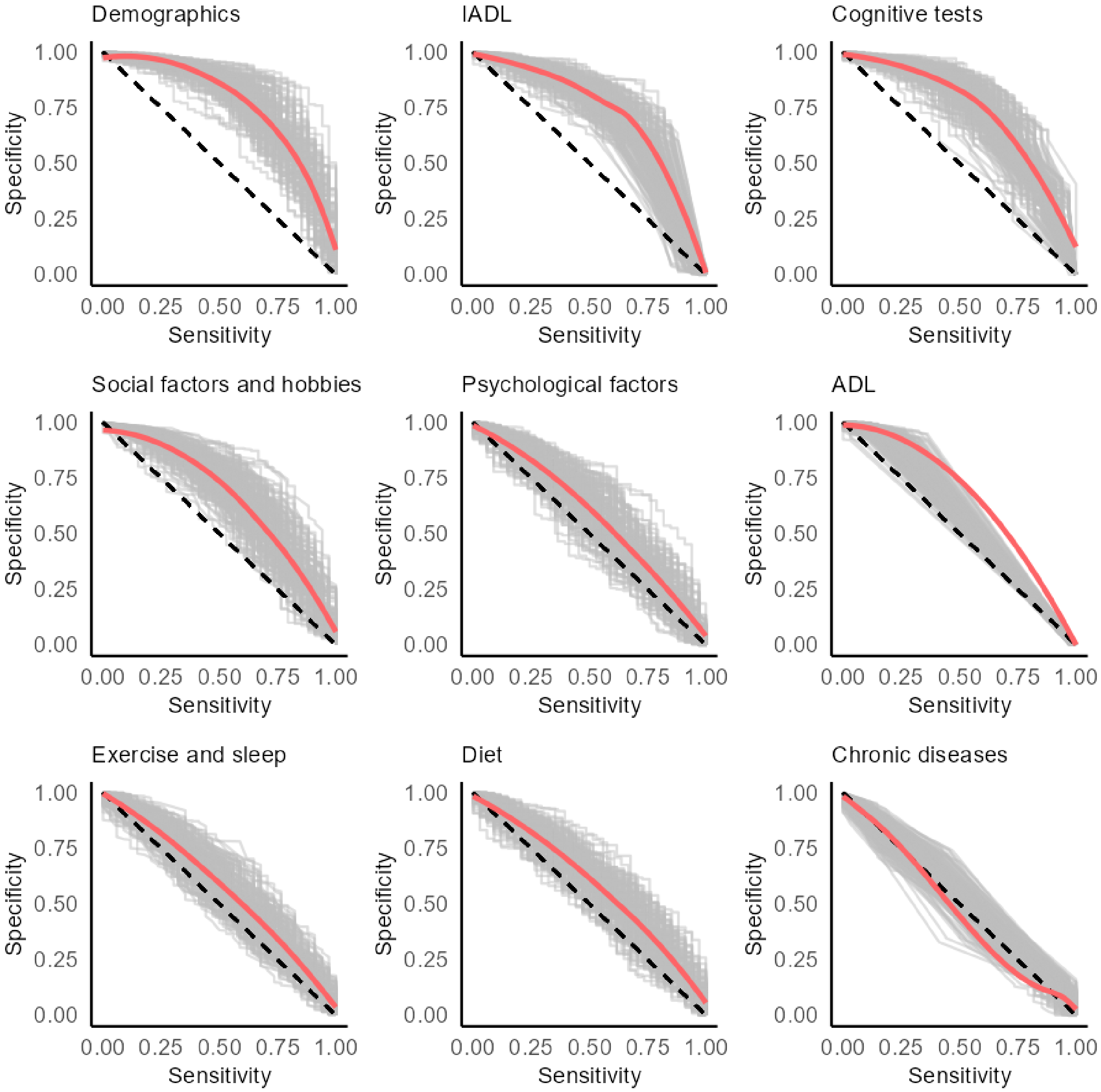

Figure 1D shows that most risk factor groups had significantly higher AUCs when making predictions among older adults with no formal education compared to those with some education. The only exceptions were the ADL and exercise and sleep groups. Among those with no formal education, demographics, cognitive tests, and IADL had AUCs of 0.79 (95% CI 0.78-0.79), 0.72 (95% CI 0.72-0.73), and 0.71 (95% CI 0.70-0.71), respectively. When making predictions among those with some education, demographics, cognitive tests, and IADL had average AUCs of 0.73 (95% CI 0.72-0.74), 0.64 (95% CI 0.63-0.66), and 0.64 (95% CI 0.62-0.65), respectively.

The existing prediction models recreated in this study all had good predictive ability in the general population. Each model had an average AUC of 0.80 (95% CI 0.80-80.1). However, each model had significantly higher AUCs when making predictions in female individuals compared to male individuals, in rural dwellers compared to urban dwellers, and in those with no formal education compared to those with some education. Complete results can be found in Table 2 and Figure 3. The TRIPOD checklist for this study can be found in Checklist 1.

Demographics had a significantly better predictive ability when making predictions among rural dwellers (AUC 0.80, 95% CI 0.79-0.81) compared to urban dwellers (AUC 0.74, 95% CI 0.73-0.75). Similarly, IADL showed a higher average AUC among rural dwellers (AUC 0.73, 95% CI 0.72-0.73) compared to urban dwellers (AUC 0.68, 95% CI 0.67-0.69). As shown in Figure 1C and Table 2, significantly higher AUCs among rural dwellers were also observed for the diet, psychological factors, and chronic diseases groups.

Demographics, cognitive tests, and IADL also had the highest average AUCs when making predictions for male and female individuals, although the predictive ability varied between the

2 sexes. The demographics group had a higher average AUC when making predictions in female individuals compared to male individuals (0.81, 95% CI 0.80-0.82 vs 0.72, 95% CI 0.71-0.73), as did the IADL group (0.72, 95% CI 0.71-0.73 vs 0.66, 95% CI 0.65-0.67) and the cognitive tests group (0.72, 95% CI 0.71-0.73 vs 0.70, 95% CI 0.69-0.71). The dietary group had a significantly higher AUC when making predictions among male individuals (0.61, 95% CI 0.60-0.62) compared to female individuals (0.57, 95% CI 0.56-0.58). No significant differences were observed for the social factors and hobbies group, and all other remaining groups has AUCs less than 0.60 for both male and female individuals. Full results can be found in Figure 1B and Table 2.

Figure 3. Predictive ability of existing models [5,7,8]. AUC: area under the receiver operating characteristic curve.

Discussion

Principal Findings

In this study, we quantified the ability of 9 risk factor groups and 3 prediction models to predict future cognitive impairment in the general Chinese population and 6 population subsets: male, female, rural-dwelling, urban-dwelling, educated, and not formally educated older adults. In the general population, the risk factor groups with the best predictive ability were demographics (AUC 0.78, 95% CI 0.77-0.78), cognitive tests (AUC 0.72, 95% CI 0.72-0.73), and IADL (AUC 0.71, 95% CI 0.70-0.71). The most predictive risk factors and the existing models performed inconsistently across socioeconomic groups and had significantly higher AUCs when making predictions for female individuals and older adults with no formal education compared to male individuals and older adults with some education.

Our study showed that the 3 existing prediction models had significantly lower AUCs when predicting future cognitive impairment among male, urban-dwelling, and educated Chinese older adults compared to female, rural-dwelling, and not formally educated older adults. Despite the only shared risk factors in all 3 models being age and baseline MMSE score, significant differences in predictive ability were consistent across every model. One explanation is that risk factor differences between those who developed cognitive impairment and those who did not were larger among the groups where more accurate predictions were made. For example, the difference in average age between female older adults who did and did not become cognitively impaired was 11.8 years, whereas for male older adults, it was 7.0 years. Similarly, among those with no formal education, the difference in baseline MMSE score between those with and without cognitive impairment at follow-up was 2.67 compared to 1.45 among those with some education. In addition, the prevalence of cognitive impairment in our sample was higher among female, rural-dwelling, and not formally educated older adults, meaning that the models had more events to learn from. Indeed, previous studies using nationally representative data have also reported higher prevalence estimates among these groups [3]. Our results indicate that targeted prediction models for specific socioeconomic groups are needed in China to make equally accurate risk assessments across sex, residential status, and education level. Several studies have called for such models [28,29], but as of this writing, none have been developed in China.

Out of the 9 risk factor groups, we found that demographics, cognitive tests, and IADL best predict future cognitive impairment in the general Chinese population and across sex, residential status, and education level. Demographics are often included in prediction models for cognitive impairment [28,30-32], and we suggest that they continue to be leveraged because of their predictive power and ease to collect. Associations between chronic diseases, ADL, psychological factors, and diet with cognitive impairment among Chinese older adults have been established [13,33-39], but such factors showed moderate predictive ability in our study. To our knowledge, dietary factors have not been incorporated into existing prediction models in China, but they had higher AUCs than commonly used risk factors such as psychological factors, ADL, and chronic diseases. In fact, chronic diseases did not make significantly better than random predictions among male (AUC 0.50, 95% CI 0.49-0.51), urban-dwelling (AUC 0.50, 95% CI 0.50-0.51), and not formally educated (AUC 0.51, 95% CI 0.49-0.52) older adults. Hence, in addition to providing a ranking of the most predictive risk factor groups, our study is the first to show that dietary factors warrant consideration when predicting future cognitive impairment among Chinese older adults.

Many risk factor groups had significantly different AUCs across population subsets. Similar to the existing models we recreated, our study revealed that the most predictive risk factors (demographics, cognitive tests, and IADL) had significantly higher AUCs when making predictions among female and not formally educated older adults compared to male and educated older adults. As was the case with the recreated models, this likely resulted from the distributions of risk factors being more separable between those who developed cognitive impairment and those who did not in the groups where more accurate predictions were made. Given the lack of available evidence, it is unclear whether the discrepancies in predictive ability found in our study generalize outside of China, and future work may seek to perform similar analyses elsewhere.

Limitations

Our study has several limitations. The source code was not available for the models we selected to recreate in this study, but we explicitly followed all preprocessing, variable derivation, and model creation procedures described in the original papers during the model replication process. The AUCs of each model in the general population in this study were consistent with the reported AUCs in the original papers, suggesting that the models were properly recreated from scratch. To facilitate future research, we have further made our code publicly available. Second, the CLHLS is not nationally representative, although it does include older adults from 23 of China’s provinces. The exercise and sleep group did not include objective measurements of physical activity and sleep. Self-reported exercise and sleep are often inaccurate, and we suggest that the results be interpreted with caution for the exercise and sleep group. Lastly, the data used in this study were from 2011 to 2014. Future studies may wish to collect new data and further validate the results presented herein.

Conclusions

Out of the 9 risk factor groups, our study found that demographics, cognitive tests, and IADL best predicted future cognitive impairment among Chinese older adults and had significantly better predictive ability among female and not formally educated older adults compared to male and educated older adults. Similarly, every existing model we recreated made significantly better predictions among female, rural-dwelling, and not formally educated older adults. Our study suggests that more targeted predictions models for cognitive impairment are needed to make equally accurate risk assessments across different socioeconomic groups in China and provides foundational evidence that can support variable selection for such models.

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Authors' Contributions

CS, XL, and JL designed the study. CS and TL performed the statistical analyses. CS and XL wrote the manuscript with additional input from JL.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Predictors in each risk factor group and prediction model.
[DOCX File, 21 KB - aging_v7i1e53240_app1.docx]

Multimedia Appendix 2
Cohort characteristics for each covariate from every risk factor group.
[DOCX File, 65 KB - aging_v7i1e53240_app2.docx]

Checklist 1
TRIPOD (Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis) checklist.
[DOCX File, 26 KB - aging_v7i1e53240_app3.docx]

References

1. Fang EF, Scheibye-Knudsen M, Jahn HJ, et al. A research agenda for aging in China in the 21st century. Ageing Res Rev 2015 Nov;24(Pt B):197-205. [doi: 10.1016/j.arr.2015.08.003] [Medline: 26304837]
2. Fang EF, Xie C, Schenkel JA, et al. A research agenda for ageing in China in the 21st century (2nd edition): focusing on basic and translational research, long-term care, policy and social networks. Ageing Res Rev 2020 Dec;64:101174. [doi: 10.1016/j.arr.2020.101174] [Medline: 32971255]
3. Jia L, Du Y, Chu L, et al. Prevalence, risk factors, and management of dementia and mild cognitive impairment in adults aged 60 years or older in China: a cross-sectional study. Lancet Public Health 2020 Dec;5(12):e661-e671. [doi: 10.1016/S2468-2667(20)30185-7] [Medline: 33271079]
4. Gao F, Lv X, Dai L, et al. A combination model of AD biomarkers revealed by machine learning precisely predicts Alzheimer's dementia: China Aging and Neurodegenerative Initiative (CANDI) study. Alzheimers Dement 2022 Jun 6;19(3):749-760. [doi: 10.1002/alz.12700] [Medline: 35668045]
5. Hu M, Shu X, Yu G, Wu X, Välimäki M, Feng H. A risk prediction model based on machine learning for cognitive impairment among Chinese community-dwelling elderly people with normal cognition: development and validation study. J Med Internet Res 2021 Feb 24;23(2):e20298. [doi: 10.2196/20298] [Medline: 33625369]
6. Pu L, Pan D, Wang H, et al. A predictive model for the risk of cognitive impairment in community middle-aged and older adults. Asian J Psychiatr 2023 Jan;79:103380. [doi: 10.1016/j.ajp.2022.103380] [Medline: 36495830]
7. Wang S, Wang W, Li X, et al. Using machine learning algorithms for predicting cognitive impairment and identifying modifiable factors among Chinese elderly people. Front Aging Neurosci 2022 Aug 11;14:977034. [doi: 10.3389/fnagi.2022.977034] [Medline: 36034140]
8. Zhou J, Lv Y, Mao C, et al. Development and validation of a nomogram for predicting the 6-year risk of cognitive impairment among Chinese older adults. J Am Med Dir Assoc 2020 Jun;21(6):864-871. [doi: 10.1016/j.jamda.2020.03.032] [Medline: 32507532]
9. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 8;396(10248):413-446. [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
10. Yang J, Zhang Y, Shen S, et al. Instrumental activities of daily living trajectories and risk of mild cognitive impairment among Chinese older adults: results of the Chinese Longitudinal Healthy Longevity Survey, 2002-2018. Front Public Health 2023 May 3;11:1165753. [doi: 10.3389/fpubh.2023.1165753] [Medline: 37206872]
11. Han L, Jia J. Long-term effects of alcohol consumption on cognitive function in seniors: a cohort study in China. BMC Geriatr 2021 Dec 15;21(1):699. [doi: 10.1186/s12877-021-02606-y] [Medline: 34911450]

12. Zhou L, Ma X, Wang W. Relationship between cognitive performance and depressive symptoms in Chinese older adults: the China Health and Retirement Longitudinal Study (CHARLS). J Affect Disord 2021 Feb 15;281:454-458. [doi: 10.1016/j.jad.2020.12.059] [Medline: 33360747]
13. Jia J, Zhao T, Liu Z, et al. Association between healthy lifestyle and memory decline in older adults: 10 year, population based, prospective cohort study. BMJ 2023 Jan 25;380:e072691. [doi: 10.1136/bmj-2022-072691] [Medline: 36696990]
14. Li M, Wang N, Dupre ME. Association between the self-reported duration and quality of sleep and cognitive function among middle-aged and older adults in China. J Affect Disord 2022 May 1;304:20-27. [doi: 10.1016/j.jad.2022.02.039] [Medline: 35176346]
15. Zhang Q, Wu Y, Liu E. Longitudinal associations between sleep duration and cognitive function in the elderly population in China: a 10-year follow-up study from 2005 to 2014. Int J Geriatr Psychiatry 2021 Dec;36(12):1878-1890. [doi: 10.1002/gps.5615] [Medline: 34378823]
16. Lü J, Fu W, Liu Y. Physical activity and cognitive function among older adults in China: a systematic review. J Sport Health Sci 2016 Sep;5(3):287-296. [doi: 10.1016/j.jshs.2016.07.003] [Medline: 30356530]
17. Zhou Y, Chen Z, Shaw I, et al. Association between social participation and cognitive function among middle- and old-aged Chinese: a fixed-effects analysis. J Glob Health 2020 Dec;10(2):020801. [doi: 10.7189/jogh.10.020801] [Medline: 33110597]
18. Zeng Y. Towards deeper research and better policy for healthy aging --using the unique data of Chinese Longitudinal Healthy Longevity Survey. China Economic J 2012 Feb 15;5(2-3):131-149. [doi: 10.1080/17538963.2013.764677] [Medline: 24443653]
19. Yi Z. Introduction to the Chinese Longitudinal Healthy Longevity Survey (CLHLS). In: Yi Z, Poston DL, Vlosky DA, et al, editors. Healthy Longevity in China: Springer; 2008:23-38. [doi: 10.1007/978-1-4020-6752-5_2]
20. Riley RD, Snell KI, Ensor J, et al. Minimum sample size for developing a multivariable prediction model: part II - binary and time-to-event outcomes. Stat Med 2019 Mar 30;38(7):1276-1296. [doi: 10.1002/sim.7992] [Medline: 30357870]
21. Collins GS, Reitsma JB, Altman DG, Moons KGM. Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis (TRIPOD): the TRIPOD statement. BMC Med 2015 Jan 6;13(1):1. [doi: 10.1186/s12916-014-0241-z] [Medline: 25563062]
22. Moons KGM, Altman DG, Reitsma JB, et al. Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis (TRIPOD): explanation and elaboration. Ann Intern Med 2015 Jan 6;162(1):W1-73. [doi: 10.7326/M14-0698] [Medline: 25560730]
23. Katzman R, Zhang MY, Qu OY, et al. A Chinese version of the Mini-Mental State Examination; impact of illiteracy in a Shanghai dementia survey. J Clin Epidemiol 1988;41(10):971-978. [doi: 10.1016/0895-4356(88)90034-0] [Medline: 3193141]
24. Li H, Jia J, Yang Z. Mini-Mental State Examination in elderly Chinese: a population-based normative study. J Alzheimers Dis 2016 May 7;53(2):487-496. [doi: 10.3233/JAD-160119] [Medline: 27163822]
25. Sakal C. CLHLS-cognitive-impairment-prediction. GitHub. URL: https://github.com/CollinSakal/CLHLS-Cognitive-Impairment-Prediction [accessed 2024-03-18]
26. Smith GCS, Seaman SR, Wood AM, Royston P, White IR. Correcting for optimistic prediction in small data sets. Am J Epidemiol 2014 Aug 1;180(3):318-324. [doi: 10.1093/aje/kwu140] [Medline: 24966219]
27. Beretta L, Santaniello A. Nearest neighbor imputation algorithms: a critical evaluation. BMC Med Inform Decis Mak 2016 Jul 25;16(Suppl 3):74. [doi: 10.1186/s12911-016-0318-z] [Medline: 27454392]
28. Hou XH, Feng L, Zhang C, Cao XP, Tan L, Yu JT. Models for predicting risk of dementia: a systematic review. J Neurol Neurosurg Psychiatry 2019 Apr;90(4):373-379. [doi: 10.1136/jnnp-2018-318212] [Medline: 29954871]
29. Chen Y, Qian X, Zhang Y, et al. Prediction models for conversion from mild cognitive impairment to Alzheimer's disease: a systematic review and meta-analysis. Front Aging Neurosci 2022 Apr 7;14:840386. [doi: 10.3389/fnagi.2022.840386] [Medline: 35493941]
30. Stephan BCM, Pakpahan E, Siervo M, et al. Prediction of dementia risk in low-income and middle-income countries (the 10/66 study): an independent external validation of existing models. Lancet Glob Health 2020 Apr;8(4):e524-e535. [doi: 10.1016/S2214-109X(20)30062-0] [Medline: 32199121]
31. Calvin CM, Wilkinson T, Starr JM, et al. Predicting incident dementia 3-8 years after brief cognitive tests in the UK Biobank prospective study of 500,000 people. Alzheimers Dement 2019 Dec;15(12):1546-1557. [doi: 10.1016/j.jalz.2019.07.014] [Medline: 31619348]
32. You J, Zhang YR, Wang HF, et al. Development of a novel dementia risk prediction model in the general population: a large, longitudinal, population-based machine-learning study. EClinicalMedicine 2022 Sep 23;53:101665. [doi: 10.1016/j.eclinm.2022.101665] [Medline: 36187723]
33. Xiao S, Shi L, Zhang J, et al. The role of anxiety and depressive symptoms in mediating the relationship between subjective sleep quality and cognitive function among older adults in China. J Affect Disord 2023 Mar 15;325:640-646. [doi: 10.1016/j.jad.2023.01.048] [Medline: 36657496]
34. Zhou S, Wang Q, Zhang J, et al. Depressive symptoms and cognitive decline among Chinese rural elderly individuals: a longitudinal study with 2-year follow-up. Front Public Health 2022 Jul 13;10:939150. [doi: 10.3389/fpubh.2022.939150] [Medline: 35910927]

35. Li XX, Li Z. The impact of anxiety on the progression of mild cognitive impairment to dementia in Chinese and English data bases: a systematic review and meta-analysis. Int J Geriatr Psychiatry 2018 Jan;33(1):131-140. [doi: 10.1002/gps.4694] [Medline: 28240415]
36. Guo M, Kang K, Wang A, et al. Association of diabetes status with cognitive impairment in two Chinese rural communities. J Neurol Sci 2020 Aug 15;415:116894. [doi: 10.1016/j.jns.2020.116894] [Medline: 32446011]
37. Lv YB, Zhu PF, Yin ZX, et al. A U-shaped association between blood pressure and cognitive impairment in Chinese elderly. J Am Med Dir Assoc 2017 Feb 1;18(2):193.e7-193.e13. [doi: 10.1016/j.jamda.2016.11.011] [Medline: 28126139]
38. Zhao Z, Li B, Wei C, Sha F. Alcohol consumption and cognitive impairment among Chinese older adults: 8-year follow-up of Chinese Longitudinal Healthy Longevity Study. Alzheimer’s & Dementia 2021 Dec 31;17(S10):e057651. [doi: 10.1002/alz.057651]
39. Lee ATC, Richards M, Chan WC, Chiu HFK, Lee RSY, Lam LCW. Lower risk of incident dementia among Chinese older adults having three servings of vegetables and two servings of fruits a day. Age Ageing 2017 Sep 1;46(5):773-779. [doi: 10.1093/ageing/afx018] [Medline: 28338708]

Abbreviations

ADL: activities of daily living
AUC: area under the receiver operating characteristic curve
CLHLS: Chinese Longitudinal Healthy Longevity Survey
IADL: instrumental activities of daily living
MMSE: Mini Mental State Examination
TRIPOD: Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis

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Exploring the Perspectives of Older Adults Living With HIV on Virtual Care: Qualitative Study

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Abstract

Background: As the population of individuals with HIV ages rapidly due to advancements in antiretroviral therapy, virtual care has become an increasingly vital component in managing their complex health needs. However, little is known about perceptions of virtual care among older adults living with HIV.

Objective: This study aimed to understand the perceptions of older adults living with HIV regarding virtual care.

Methods: Using an interpretive, qualitative, descriptive methodology, semistructured interviews were conducted with 14 diverse older adults living with HIV. The participants lived in Ontario, Canada, self-identified as HIV-positive, and were aged 50 years or older. Efforts were made to recruit individuals with varying experience with virtual health care. Reflexive thematic analysis was conducted with the interview transcripts to identify prevalent themes.

Results: The identified themes included (1) the importance of relationships in virtual care for older adults living with HIV; (2) privacy and confidentiality in virtual care; and (3) challenges and solutions related to access and technological barriers in virtual care. These themes highlight the perceptions of diverse older adults living with HIV concerning virtual care, emphasizing the fundamental role of trust, privacy, and technology access.

Conclusions: By embracing the unique perspectives and experiences of this population, we can work toward building more inclusive and responsive health care systems that meet the needs of all individuals, regardless of age, HIV status, or other intersecting identities.

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KEYWORDS

HIV; human immunodeficiency virus; perspective; telemedicine; telehealth; virtual care; virtual health; virtual medicine; qualitative; gerontology; geriatrics; older adult; older people; aging

Introduction

The increased uptake in virtual care in response to the COVID-19 pandemic represents a shift in health care delivery worldwide [1-4]. This expansion of virtual care necessitated numerous assessments of its efficacy and suitability for patients with different disease states and demographics [5,6]. Among these studies, the emerging and concerning trend of older individuals lacking access to health care, including timely care, became notable [7], presenting a potential added risk of morbidity and mortality [7]. In contrast, the use of virtual care has continued to be advocated for following the pandemic to provide options and to increase the availability and accessibility of health care services for older adults [7,8]. We define virtual care as "the interaction between patients and/or members of their circle of care, occurring remotely, using any forms of communication or information technologies with the aim of facilitating and maximizing the quality and effectiveness of patient care," in accordance to the Canadian Women's College Hospital Institute for Health System Solutions and Virtual Care [9]. Virtual care can encompass various modalities, including teleconsultation, remote monitoring, and mobile health applications, among others [10,11].

Older adults represent a patient demographic with distinct health care needs and challenges who might benefit from virtual care [12]. As individuals age, they often experience age-related health conditions, chronic diseases, and functional limitations that necessitate frequent interactions with the health care system [13,14]. Moreover, older adults may face logistical obstacles, such as transportation challenges, lack of time, mobility limitations, and caregiver responsibilities, which can impede their access to in-person health care services [15-18]. Virtual care interventions tailored to older adults can offer numerous advantages, including improved access to care [19-21], enhanced convenience for homebound older adults [22] and those who live in rural and remote areas [23,24], cost-effectiveness [22], and the potential for early detection and intervention of clinically adverse events [25]. Thus, virtual care for specialized populations is valuable, as it increases access to specialists who might otherwise be inaccessible.

Older adults living with HIV are accessing virtual care services more commonly [26,27]. As the population of individuals with HIV ages, their complex health needs require specialized management [28]. The intersection of HIV and aging poses unique health care challenges [29-32], and as this population grows rapidly due to advancements in antiretroviral therapy, virtual care has become an increasingly vital component in managing their complex health needs [32]. However, little is known about the experiences and perceptions of older adults living with HIV regarding virtual care [26,33]. Addressing this knowledge gap may inform improvements to virtual care delivery by highlighting the unique health care needs of this population [26].

The goal of this study was to understand the perceptions of diverse older adults living with HIV regarding virtual care. Specifically, we aimed to explore the perceptions of diverse older adults living with HIV on (1) how virtual care supported age-related conditions experienced by older adults living with HIV; (2) perceived obstacles, pathways, and needs encountered in virtual care; and (3) recommendations for improving virtual care to support diverse older adults living with HIV.

Methods

Ethical Considerations

The study received ethics approval from the Mount Sinai Hospital Research Ethics Board (REB: 23-0106E).

Methodology

We used an interpretive qualitative descriptive methodology for this study [34]. This methodology was selected as it is geared toward generating knowledge applicable to clinical practice, which aligns with our objectives [34].

This work was part of a broader research program[35] that involved a diverse advisory team of 10 individuals working within nonprofit community-based organizations, clinical settings, with lived and living experience, and working within policy, and research sectors. As such, an integrated knowledge translation approach was applied throughout this study [34]. This collaborative effort aimed to generate relevant and practical knowledge aligned with our study objectives. The advisory committee played a key role in identifying participants, analyzing data, reviewing the manuscript, and disseminating findings. Our team includes academic researchers and clinicians from geriatric, social work, and infectious disease programs, as well as partners from community organizations, lived experience of HIV, and policy sectors. Some individuals informed this project through their dual roles as researchers and lived experience representatives.

Participants

The participants were not known to our research team in any personal, professional, or academic capacity before the study. All interactions with participants were strictly limited to the context of the research project. To be eligible, individuals had to self-identify as HIV-positive, be 50 years of age or older, and reside in Ontario. This geographic specificity facilitated a targeted examination of health care resources available to older persons living with HIV in this province.

Recruitment

Our advisory committee's websites and social media platforms were used to promote the study. We also recruited through HIV clinics, geriatric clinics, and other health care facilities catering to older individuals living with HIV, to engage potential participants already involved in health care services in Ontario. Representation was purposively sought across various areas to ensure diversity in perspectives [36], including sex and gender, age, ethnicity and race, socioeconomic status, prior usage of virtual-geriatric care, geographical location (rural vs urban), non-English first language, and level of educational attainment. This involved targeted recruitment from community-based organizations, including churches, mosques, temples, shelters, community centers, senior groups, health centers, libraries, and senior living buildings [37]. At these community-based locations, organizational staff posted flyers and circulated newsletters regarding the purpose of the study. Interested participants reached out to the research team via email or telephone. After the principal investigator or the research coordinator contacted interested persons to determine eligibility and to confirm interest via voluntary verbal consent, the participants were provided a written consent form and scheduled a time and location for the interview. The participants were given the option of an in-person, Zoom for Healthcare, or telephone interview. The participants were also offered the opportunity to bring a support person to the interview.

Data Collection

Individual interviews (n=14) were conducted by a trained research assistant (n=10) or a peer researcher with lived experience (n=4) to enhance participants' comfort in expressing their candid thoughts and opinions about virtual care. Interviews were guided using a semistructured interview guide that was developed by the research team in consultation with an advisory committee and took place between November 2023 and April 2024.

The semistructured interview guide (Table S1 in Multimedia Appendix 1) explored participants' experiences with virtual care, including obstacles, pathways, and needs encountered in virtual care. Interview questions also examined their reasons for choosing or avoiding virtual care, the types of health care providers and conditions they consulted in their virtual appointments, and their overall care experiences during and after the COVID-19 pandemic when much care shifted to virtual formats.

The participants also had the option of completing an optional demographic form, either before, during, or after the interview.

Recruitment continued until data saturation was achieved [38]. Data saturation was determined through an ongoing review of the interviews by the research team to ensure no new data themes emerged [38]. The participants received a CAD $25 (US$ 17.80) gift card honorarium as a token of appreciation for their time. All interviews were recorded, professionally transcribed, and reviewed for accuracy by a research assistant.

Data Analysis

Transcripts were analyzed and organized using NVivo 12 software [39]. The reflexive thematic analysis process outlined by Braun and Clarke was followed [40]. The research assistants and principal investigator read each transcript thoroughly, coded the data, and collaborated regularly with the co-investigators to develop and fine-tune the coding scheme. This involved recursive coding and theme development, including immersion in the data, review of relevant literature, and deep reflection [40]. Quality and reporting were guided by checklists provided by Braun and Clarke [41], including Braun and Clarke's 15 questions for evaluating thematic analysis papers for publication (see Table S2 in Multimedia Appendix 1 [42,43]), and the Standards for Reporting Qualitative Research [44].

The sociodemographic characteristics of the participants were summarized using descriptive statistics.

Rigor

To ensure methodological rigor, several strategies were used. These included building rapport with participants, seeking feedback on the interview guide, presenting direct quotes, engaging in team discussions to interpret data, and maintaining reflective notes throughout the analysis process. In addition, a collaborative and inclusive approach was maintained with participants, prioritizing open discussions and considering practical constraints such as scheduling, arranging interviews through a modality convenient to the participant, and the duration of interviews. This approach facilitated authentic exchanges, contributing to enhanced data quality.

Results

Overview

A total of 14 participants participated in this study. Of this, 4 identified as women and 10 as men. The participants were 63 years old on average (SD 10). Overall, 9 participants resided in urban settings, 2 in suburban settings, and 3 in rural settings. In total, 9 participants identified as low income (CAD $0-$29,999). Further details on participants are given in Table 1. Additional details are provided in Table S3 in Multimedia Appendix 1.

Table . Participant demographics.

Demographic characteristics	Participants (N=14), n (%)
Age group (years)	
50 - 54	4 (29)
55 - 59	4 (29)
60 - 64	0 (0)
64 - 69	3 (21)
70 - 74	0 (0)
75 - 79	1 (7)
80+	2 (14)
Gender	
Men	10 (71)
Women	4 (29)
Nonbinary	0 (0)
Two-spirit	0 (0)
English as first language	
Yes	8 (57)
No	6 (43)
Access to a computer	
Yes	9 (64)
No	1 (7)
No response	4 (29)
Access to a smartphone	
Yes	9 (64)
No	1 (7)
No response	4 (29)
Access to internet connectivity	
Yes	9 (64)
No	1 (7)
No response	4 (29)
Require assistance with internet use	
Yes	3 (21)
No	7 (50)
Prefer not to say	4 (29)
No response	0 (0)

Theme 1: Importance of Relationships in Virtual Care for Older Adults Living With HIV

Privacy and data security emerged as key factors influencing the acceptance of virtual geriatric care, with some participants appreciating the privacy of virtual consultations while others preferred in-person visits to ensure confidentiality. Access to technology and internet connectivity were identified as significant obstacles, and participants noted the need for technology training and mutual understanding between patients and health care providers. Stigma associated with registering for age-related virtual care services was also a concern, with suggestions to integrate these services into existing health care frameworks to mitigate this issue. The findings are highlighted using participant quotes cited by the study participant ID, gender of the participant, and age.

All participants described experiencing unique health care challenges that intersect with both aging (eg, memory loss and frailty) and their HIV status (eg, stigma and risk of infection), making supportive and trustworthy relationships with health care providers crucial. The participants noted that the same health care providers should be accessible through virtual care to build effective communication, trust, and a sense of security. The participants who described having strong, positive relationships with their health care providers resulted in them being more likely to engage in open communication about their health concerns and feel supported in managing their condition(s). For example, one participant shared how trust in her relationship with her family physician allowed her to be tested for HIV:

> *I could finally be honest of what was happening in all areas of my life and trusted [family doctor] enough to finally go and get tested anonymously* [Participant 09, woman, 70 years]

On the other hand, when participants lacked a trusting relationship with their health care provider, they seldom adhered to their treatment or appointment schedule. One participant shared:

> *It's hard to want to go to the doctor when you feel like they are judging. The stories and stuff I have been told by doctors. Why would I ever go back and show up? Maybe I should put my pride aside, but it's enough to make you rather be sick* [Participant 11, male, 52 years]

The participants recognized feelings of discomfort during their interactions with new health care providers. One participant shared that he disliked having to "break in new doctors," when discussing his experiences living with HIV (Participant 02, Man, 57 y old). The participants, therefore, emphasized that one of the critical aspects of building strong relationships in virtual health care is the consistency of health care providers. In addition to clinical discussions, the participants emphasized the importance of exploring social and emotional needs with their virtual health care provider. However, the participants who had experience with virtual care of any kind before the interview noted that the physical distance and lack of face-to-face interaction in virtual care made them feel disconnected from their care team, and sometimes challenged the trust that they had in their health care provider, questioning whether the health care provider was truly engaged in their care. One participant shared, "why would I just go and disclose all this to someone I never met and get their judgement" (participant 02, man, 57 years), highlighting the importance of consistent health care providers for discussing personal and sensitive health issues.

The participants noted that if they received care from a consistent health care provider, whether a physician or nurse, they would be willing to access other virtual care services (eg, from a geriatrician or therapist). Adding additional services and health care providers was often accompanied by discussions about who should be involved in a health care team. The integration of various health care providers into a patient's care team emerged throughout the interviews, as the participants noted that they had some trusted health care professionals that they would continue to interact with in-person (eg, pharmacists), even if they saw the same or new health care providers virtually. The participants noted that other members of the care team need to be managed thoughtfully to support trusting relationships between patients and their health care providers.

> *You can tell when a doctor really cares about me. Like when they just know me and actually remember things. So if I had a doctor who I knew actually cared, I'd be more open to using virtual services because I know they would tell me if I needed to come in. They care enough to be honest, not whatever is easiest for them. But like would I go to everyone virtually? Probably not.* [Participant 06, female, 57 years]

Theme 2: Privacy and Confidentiality in Virtual Care

Privacy emerged as a key theme that influenced participants' acceptance of and preference for virtual care. Some participants noted that they would prefer virtual care, particularly phone consultations, over in-person care, as they would not have to see the care provider and thus, privacy and some degree of anonymity could be maintained. For example, one participant said:

> *sometimes, I worry about them knowing me. So if I could just call someone with a question, maybe I'd appreciate it.* [Participant 09, woman, 70 years]

These participants noted that they appreciated the enhanced privacy that virtual care could provide, such as the ability to discuss sensitive issues like menopause and sexual health, from the comfort and security of their own homes, without the risk of being overheard or recognized in a clinical setting. On the other hand, other participants, particularly those who spoke about living in close proximity with others (eg, partner or family members), noted that they preferred in-person appointments to ensure that their privacy and confidentiality were maintained from others in their lives. One participant shared:

> *Even if you live with a partner you trust, there are things you want to say alone* [Participant 01, man, 55 years]

In relation, some participants noted distrust in virtual care platforms as they were skeptical that these platforms could keep their information secure and private. These participants often shared that they heard from friends or family that companies sometimes sold patient health data. For others, despite being aware of the confidentiality and security measures in place for virtual care across Canada, the participants still harbored concerns that they could not ascertain what a provider would discuss with other health care providers.

Subtheme: Stigma of Registration

A few participants expressed that actively registering for a new virtual geriatric care service could heighten their sensitivity to stigma, as it marked them as individuals with an age-related issue, even if they did not see themselves as older. One participant noted:

> *Bad enough they call the doctors infectious doctors, and now I have to see an old person doctor* [Participant 10, man, 79 years]

To mitigate this, the participants suggested integrating the virtual clinic seamlessly with other primary health care services that they were already receiving. They proposed that all individuals living with HIV should be able to register for a virtual clinic, alongside other existing health care services, allowing them to be able to speak to someone about age-related concerns in a private manner.

Theme 3: Access and Technological Barriers in Virtual Care: Challenges and Solutions

Almost all the participants reported that the COVID-19 pandemic had discouraged them from seeking or attending in-person health care, with less than half of the participants noting that they used virtual care. Despite this, most participants noted that they could access a telephone or computer to access virtual care, even if they had to share the technology with other individuals. For many participants, virtual care allowed them to reduce the time taken off from work to attend appointments and associated costs of appointments, such as gas and parking costs. Other participants, expressed that not having a strong internet connection or personal devices presented an obstacle to virtual care. The participants, without the appropriate technology to access virtual care, noted concerns about accessing a secure location to connect to virtual appointments. These participants also spoke to challenges associated with virtual care due to poor internet connectivity, audio problems, and outdated technology, particularly affecting those in rural areas or without access to high-speed internet. One participant explained:

> *People need to think on a spectrum. Sometimes I may have Wi-Fi, sometimes I may not, sometimes I can't afford my phone bill and that will be turned off. We need to consider something that can always be there.* [Participant 14, man, 50 years]

Subtheme: Technology Training That Goes Both Ways

The participants expressed mixed feelings about the use of technology to access geriatric care. Some highlighted difficulties due to limited technological literacy and hoped health care providers could help them navigate virtual care and electronic health information. However, others were concerned that health care providers might assume they lacked technological skills based solely on their age or HIV status. They also expressed a need for guidance on effectively communicating relevant information to health care providers in virtual settings, especially without nearby support or written instructions. One participant said:

> *My English isn't great so I don't even know how to ask for help. Sometimes in person I can write it down, but online, I don't know.* [Participant 04, male, 82 years]

Despite these concerns, the participants acknowledged that virtual care could play a role in educating health care providers about HIV. They believed that while virtual care might help facilitate this education, sharing personal experiences and knowledge in person was often more effective due to fewer distractions and a more direct communication channel. One participant emphasized this point, stating:

> *They [physicians] can't know everything, even if they read it in a textbook. They need to listen to people like us who are aging and who have HIV and sometimes a lot more* [Participant 03, woman, 74 years]

This reflects a preference for in-person interactions when discussing complex, lived experiences, despite recognizing the potential benefits of virtual care.

Discussion

Principal Findings

The study examined the perceptions of diverse older adults living with HIV regarding virtual care, focusing on supporting age-related conditions and identifying obstacles and pathways. Key findings highlighted the importance of consistent and trustworthy relationships with health care providers, emphasizing the need for continuity in virtual care to build rapport. Privacy was a significant concern, with preferences for virtual or in-person care varying based on individual privacy needs and concerns about data security. Access to technology was another critical issue, with obstacles including poor connectivity, audio problems, and outdated devices, particularly affecting rural participants. The participants also highlighted the need for technological assistance and the opportunity to educate geriatric care providers about the intersection of aging and HIV. The study emphasizes that older adults living with HIV can offer valuable insights to enhance virtual care, helping to overcome obstacles such as distance, mobility, and transportation. Our themes, while addressing important aspects of virtual care, highlight that many issues transcend age demographics and are more specifically related to the virtual aspect of care itself rather than being uniquely tied to geriatric care.

Many of the themes uncovered in this study resonate with findings from prior research conducted among the general older adult population. Other studies with older adults have noted that the potential advantages reported by participants included enhanced convenience, and the ability to conduct consultations within the familiar setting of patients' homes, supporting their comfort [45-47]. Similarly, studies noted that older adults have privacy concerns about the use of their health data [46,48,49]. Moreover, some older adults noted challenges due to a lack of technology and/or technological literacy [24,28]. While our study aligns with previous research on the general older adult population, it offers unique insights by focusing specifically on older adults living with HIV. As such, their perspectives on the importance of privacy and trust-building with health care providers during virtual care may differ from those of the general older adult population. Therefore, health care providers offering virtual care to this population must prioritize strategies to ensure the privacy and confidentiality of patient information, thereby fostering a sense of trust and confidence among older adults living with HIV. In practice, health care organizations offering virtual care should implement policies and protocols designed to safeguard patient privacy and promote trust-building between health care providers and patients, such as allowing additional time for visits and follow-up, and communicating with older adults where the provider is situated during calls [50]. These efforts strive to ensure that virtual care delivery is respectful, nonjudgmental, and tailored to the unique circumstances of each patient.

The study participants expressed a strong desire for consistency in their health care providers, underscoring the importance of trust and familiarity in managing their health conditions. This finding aligns with existing literature, which highlights that continuity of care is crucial for building patient-provider relationships, improving patient satisfaction, and enhancing health outcomes, especially for older adults with complex health needs [51-53]. However, given the scarcity of geriatricians [54,55], relying solely on geriatricians for consistent care is impractical. Older adults living with HIV can benefit from receiving care from specialized geriatric interprofessional teams [55], but the success of such care hinges on the establishment of trust and rapport between patients and health care providers. As a viable alternative, a system of "soft handovers" can be implemented. Soft handovers involve a thorough and empathetic transition process between health care providers, ensuring the new provider is well-informed about the patient's history, preferences, and needs [56]. This approach can minimize disruption and maintain continuity of care, addressing the gap caused by the limited number of geriatric specialists. Implementing soft handovers can ensure that older adults living with HIV receive consistent and comprehensive care, despite the limited availability of specialized geriatricians. However, prior to the handoff, fostering trusting relationships between patients and members of the geriatric interprofessional team, including geriatricians, nurses, social workers, and other specialists, is essential. To build trust, geriatric interprofessional teams must prioritize patient-centered care, empathy, and cultural sensitivity [57,58]. This involves actively listening to patients' concerns, respecting their autonomy, and involving them in decision-making regarding their care [59]. In addition, health care providers should be knowledgeable about the unique needs and experiences of older adults living with HIV, including the physical, psychological, and social dimensions of aging with a chronic illness [60]. By demonstrating competence and understanding in addressing these needs, health care providers can establish credibility and foster trust with their patients in a virtual space.

Numerous studies document how stigma associated with HIV can deter individuals from seeking care or disclosing their condition, leading to disparities in health care utilization and outcomes [61]. Moreover, research on age-related stigma highlights how societal perceptions of aging can influence individuals' self-perception and willingness to engage with services tailored for older adults [62,63]. Strategies proposed by the participants in this study, such as integrating virtual clinics with existing health care services to reduce the visibility of age-related concerns, align with recommendations from previous studies in the realm of mental health aimed at destigmatizing health care access [64]. By incorporating virtual care into comprehensive health care delivery models, health care providers can create inclusive environments where individuals feel comfortable addressing their health needs without fear of judgment or discrimination. However, it is important to recognize that challenges to access may persist, particularly for the most marginalized populations. Individuals facing intersecting forms of stigma and discrimination, such as older adults living with HIV, may still encounter challenges in accessing virtual care services due to systemic inequalities, digital divides, and social determinants of health [65]. Future research should prioritize understanding efforts to address stigma and discrimination within health care settings to be integrated into virtual care initiatives, ensuring that all individuals, regardless of their background or health status, feel valued and respected in their interactions with health care providers. Collaborative partnerships between researchers, health care providers, policymakers, and community organizations are essential for identifying and codesigning solutions that address these obstacles effectively, ultimately advancing equity and accessibility in virtual care delivery.

Limitations

Despite the valuable insights gained from this study, several limitations should be acknowledged. First, the sample consisted of older adults living with HIV in Ontario, which may limit the transferability of the findings to other geographic locations or populations with different health care systems. Another limitation is that all participants had access to technology for virtual care. In addition, most were younger than 60 years, and the majority had been living in Canada for over 10 years. These factors may not be representative of the older adult living with HIV population. In addition, the recruitment strategy primarily relied on community-based organizations and health care facilities, potentially introducing selection bias toward individuals already engaged in health care services. Despite challenges, such as participant availability and interest, efforts were made to encompass diverse perspectives in this study, although our sample may limit the transferability of the findings to other contexts. Furthermore, the study did not explore the perspectives of health care providers or other stakeholders involved in the delivery of virtual care, which could provide complementary insights and perspectives. Finally, the study did not assess the long-term impact of virtual care on health outcomes or health care utilization, which warrants further investigation to fully understand the effectiveness and feasibility of virtual care for this population.

Conclusion

In conclusion, this study illuminates the perceptions of diverse older adults living with HIV concerning virtual care, emphasizing the pivotal role of trust, privacy, and technology access. Using an interpretive qualitative descriptive methodology, we gleaned nuanced insights into participants' preferences and experiences, offering actionable implications for practice and policy. Our findings underscore the imperative of cultivating trusting relationships between health care providers and older adults living with HIV in virtual care settings, necessitating strategies to ensure patient privacy, confidentiality, and cultural competence. Moreover, equitable access to technology emerges as a crucial consideration, with efforts needed to address obstacles such as poor connectivity and technological literacy. Moving forward, collaboration between health care providers and policymakers is essential to develop inclusive virtual care models that meet the diverse needs of this population, ensuring continuity of care, providing technological support, and integrating virtual care seamlessly into existing health care services. While the study's findings provide valuable insights, limitations such as sample scope and generalizability underscore the need for further research to comprehensively understand the long-term impact of virtual care on health outcomes and health care utilization among older adults living with HIV. By embracing the unique perspectives and experiences of this population, we can work toward building more inclusive and responsive health care systems that meet the needs of all individuals, regardless of age, HIV status, or other intersecting identities.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables.
[DOCX File, 23 KB - aging_v7i1e65730_app1.docx]

References

1. Wosik J, Fudim M, Cameron B, et al. Telehealth transformation: COVID-19 and the rise of virtual care. J Am Med Inform Assoc 2020 Jun 1;27(6):957-962. [doi: 10.1093/jamia/ocaa067] [Medline: 32311034]
2. Glazier RH, Green ME, Wu FC, Frymire E, Kopp A, Kiran T. Shifts in office and virtual primary care during the early COVID-19 pandemic in Ontario, Canada. CMAJ 2021 Feb 8;193(6):E200-E210. [doi: 10.1503/cmaj.202303] [Medline: 33558406]
3. Murphy RP, Dennehy KA, Costello MM, et al. Virtual geriatric clinics and the COVID-19 catalyst: a rapid review. Age Ageing 2020;49(6):907-914. [doi: 10.1093/ageing/afaa191]
4. Budak JZ, Scott JD, Dhanireddy S, Wood BR. The impact of COVID-19 on HIV care provided via telemedicine-past, present, and future. Curr HIV/AIDS Rep 2021 Apr;18(2):98-104. [doi: 10.1007/s11904-021-00543-4] [Medline: 33616811]
5. Wise J, Abrahamyan L, Stefanescu A, Horlick E. A Canadian perspective on patient experience using virtual care during COVID-19. J Undergrad Life Sci 2022;16(1):1. [doi: 10.33137/juls.v16i1.38930]
6. Dallison AE. Applying a Health Equity Lens to Virtual Primary Care for Socially Vulnerable Groups During the Covid-19 Pandemic [Thesis]: Royal Roads University; 2023. URL: https://www.viurrspace.ca/items/31e6a5ad-9e33-4963-a770-d788a996247d [accessed 2024-11-26]
7. Doraiswamy S, Jithesh A, Mamtani R, Abraham A, Cheema S. Telehealth use in geriatrics care during the COVID-19 pandemic-a scoping review and evidence synthesis. Int J Environ Res Public Health 2021 Feb 11;18(4):1755. [doi: 10.3390/ijerph18041755] [Medline: 33670270]
8. Angelopoulou E, Papachristou N, Bougea A, et al. How telemedicine can improve the quality of care for patients with Alzheimer's disease and related dementias? A narrative review. Medicina (Kaunas) 2022 Nov 22;58(12):1705. [doi: 10.3390/medicina58121705] [Medline: 36556907]
9. Jamieson T, Wallace R, Armstrong K, et al. Virtual Care: a Framework for a Patient-Centric System: Women's College Hospital Institute for Health Systems Solutions and Virtual Care; 2015:11.
10. Li CZ, Borycki EM, Kushniruk AW. Connecting the world of healthcare virtually: a scoping review on virtual care delivery. Healthcare (Basel) 2021 Oct 5;9(10):1325. [doi: 10.3390/healthcare9101325] [Medline: 34683005]
11. Shepherd L, McConnell A, Watling C. Good for patients but not learners? Exploring faculty and learner virtual care integration. Med Educ 2022 Dec;56(12):1174-1183. [doi: 10.1111/medu.14861] [Medline: 35732194]
12. Patterson PB, Roddick J, Pollack CA, Dutton DJ. Virtual care and the influence of a pandemic: Necessary policy shifts to drive digital innovation in healthcare. Healthc Manage Forum 2022 Sep;35(5):272-278. [doi: 10.1177/08404704221110084] [Medline: 35775144]
13. Cheng Y, Goodin AJ, Pahor M, Manini T, Brown JD. Healthcare utilization and physical functioning in older adults in the United States. J Am Geriatr Soc 2020 Feb;68(2):266-271. [doi: 10.1111/jgs.16260] [Medline: 31755551]
14. Ploeg J, Matthew-Maich N, Fraser K, et al. Managing multiple chronic conditions in the community: a Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers. BMC Geriatr 2017 Jan 31;17(1):40. [doi: 10.1186/s12877-017-0431-6] [Medline: 28143412]
15. Fitzpatrick AL, Powe NR, Cooper LS, Ives DG, Robbins JA. Barriers to health care access among the elderly and who perceives them. Am J Public Health 2004 Oct;94(10):1788-1794. [doi: 10.2105/ajph.94.10.1788] [Medline: 15451751]
16. Sorkin DH, Murphy M, Nguyen H, Biegler KA. Barriers to mental health care for an ethnically and racially diverse sample of older adults. J Am Geriatr Soc 2016;64(10):2138-2143. [doi: 10.1111/jgs.14420]
17. Syed ST, Gerber BS, Sharp LK. Traveling towards disease: transportation barriers to health care access. J Community Health 2013 Oct;38(5):976-993. [doi: 10.1007/s10900-013-9681-1] [Medline: 23543372]
18. Carrillo JE, Carrillo VA, Perez HR, Salas-Lopez D, Natale-Pereira A, Byron AT. Defining and targeting health care access barriers. J Health Care Poor Underserved 2011 May;22(2):562-575. [doi: 10.1353/hpu.2011.0037] [Medline: 21551934]

19. Liu L, Goodarzi Z, Jones A, Posno R, Straus SE, Watt JA. Factors associated with virtual care access in older adults: a cross-sectional study. Age Ageing 2021 Jun 28;50(4):1412-1415. [doi: 10.1093/ageing/afab021] [Medline: 33625475]
20. Abdallah L, Stolee P, Lopez KJ, Whate A, Boger J, Tong C. The impact of COVID-19 on older adults' perceptions of virtual care: qualitative study. JMIR Aging 2022 Oct 20;5(4):e38546. [doi: 10.2196/38546] [Medline: 36054599]
21. Hung L. Using virtual care interventions to provide person-centred care to hospitalised older people with dementia. Nurs Older People 2023;35(5). [doi: 10.7748/nop.2020.e129]
22. Husebø AML, Storm M. Virtual visits in home health care for older adults. Sci World J 2014;2014:689873. [doi: 10.1155/2014/689873] [Medline: 25506616]
23. Lum HD, Nearing K, Pimentel CB, Levy CR, Hung WW. Anywhere to anywhere: use of telehealth to increase health care access for older, rural veterans. Pub Policy Aging Rep 2020 Jan 31;30(1):12-18. [doi: 10.1093/ppar/prz030]
24. Liu L, Goodarzi Z, Jones A, Posno R, Straus S, Watt J. Factors associated with access to virtual care in older adults: a cross-sectional study. medRxiv. Preprint posted online on Oct 4, 2020. [doi: 10.1101/2020.10.01.20205302]
25. van den Berg N, Schumann M, Kraft K, Hoffmann W. Telemedicine and telecare for older patients—a systematic review. Maturitas 2012 Oct;73(2):94-114. [doi: 10.1016/j.maturitas.2012.06.010] [Medline: 22809497]
26. Kokorelias KM, Wasilewski MB, Flanagan A, et al. Co-creating socio-culturally-appropriate virtual geriatric care for older adults living with HIV: a community-based participatory, intersectional protocol. Int J Qual Methods 2023 Oct;22:16094069231205189. [doi: 10.1177/16094069231205189]
27. Walsh JL, Quinn KG, Hirshfield S, et al. Acceptability, feasibility, and preliminary impact of 4 remotely-delivered interventions for rural older adults living with HIV. AIDS Behav 2024 Apr;28(4):1401-1414. [doi: 10.1007/s10461-023-04227-5] [Medline: 38170275]
28. Pu D, Palmer V, Greenstock L, et al. Identifying public healthcare priorities in virtual care for older adults: a participatory research study. Int J Environ Res Public Health 2023 Feb 23;20(5):4015. [doi: 10.3390/ijerph20054015] [Medline: 36901031]
29. Emlet CA, Brennan DJ, Brennenstuhl S, Rueda S, Hart TA, Rourke SB. The impact of HIV-related stigma on older and younger adults living with HIV disease: does age matter? AIDS Care 2015;27(4):520-528. [doi: 10.1080/09540121.2014.978734] [Medline: 25397643]
30. Johnson Shen M, Freeman R, Karpiak S, Brennan-Ing M, Seidel L, Siegler EL. The intersectionality of stigmas among key populations of older adults affected by HIV: a thematic analysis. Clin Gerontol 2019;42(2):137-149. [doi: 10.1080/07317115.2018.1456500] [Medline: 29617194]
31. Shippy RA, Karpiak SE. The aging HIV/AIDS population: Fragile social networks. Aging Ment Health 2005 May;9(3):246-254. [doi: 10.1080/13607860412331336850]
32. Guaraldi G, Milic J, Mussini C. Aging with HIV. Curr HIV/AIDS Rep 2019 Dec;16(6):475-481. [doi: 10.1007/s11904-019-00464-3] [Medline: 31823125]
33. Smith E, Badowski ME. Telemedicine for HIV care: current status and future prospects. HIV AIDS (Auckl) 2021;13:651-656. [doi: 10.2147/HIV.S277893] [Medline: 34140812]
34. Thorne S. Interpretive Description: Qualitative Research for Applied Practice: Routledge; 2016. [doi: 10.4324/9781315545196]
35. Kokorelias KM, Wasilewski MB, Flanagan A, et al. Co-creating socio-culturally-appropriate virtual geriatric care for older adults living with HIV: a community-based participatory, intersectional protocol. Int J Qual Methods 2023 Sep 29;22:16094069231205189.
36. Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? J Adv Nurs 1997 Sep;26(3):623-630. [doi: 10.1046/j.1365-2648.1997.t01-25-00999.x] [Medline: 9378886]
37. Casado BL, Negi NJ, Hong M. Culturally competent social work research: methodological considerations for research with language minorities. Soc Work (Stell) 2012 Jan 1;57(1):1-10. [doi: 10.1093/sw/swr002]
38. Aldiabat K, Le Navenec CL. Data saturation: the mysterious step in grounded theory method. TQR 2018;23(1):245-261. [doi: 10.46743/2160-3715/2018.2994]
39. Edhlund B, McDougall A. NVivo 12 Essentials: Lulu Press, Incorporated; 2018.
40. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019 Aug 8;11(4):589-597. [doi: 10.1080/2159676X.2019.1628806]
41. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qual Res Psychol 2021 Jul 3;18(3):328-352. [doi: 10.1080/14780887.2020.1769238]
42. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
43. Fearnley CJ. Mind mapping in qualitative data analysis: managing interview data in interdisciplinary and multi‐sited research projects. Geography and Environment 2022 Jan;9(1):e00109 [FREE Full text] [doi: 10.1002/geo2.109]
44. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014 Sep;89(9):1245-1251. [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
45. Bhatia R, Gilliam E, Aliberti G, et al. Older adults' perspectives on primary care telemedicine during the COVID-19 pandemic. J Am Geriatr Soc 2022 Dec;70(12):3480-3492. [doi: 10.1111/jgs.18035] [Medline: 36169152]

46. Ware P, Bartlett SJ, Paré G, et al. Using eHealth technologies: interests, preferences, and concerns of older adults. Interact J Med Res 2017 Mar 23;6(1):e3. [doi: 10.2196/ijmr.4447] [Medline: 28336506]
47. Ladin K, Porteny T, Perugini JM, et al. Perceptions of telehealth vs in-person visits among older adults with advanced kidney disease, care partners, and clinicians. JAMA Netw Open 2021 Dec 1;4(12):e2137193. [doi: 10.1001/jamanetworkopen.2021.37193] [Medline: 34870680]
48. Boise L, Wild K, Mattek N, Ruhl M, Dodge HH, Kaye J. Willingness of older adults to share data and privacy concerns after exposure to unobtrusive in-home monitoring. Gerontechnology 2013;11(3):428-435. [doi: 10.4017/gt.2013.11.3.001.00] [Medline: 23525351]
49. Pool J, Akhlaghpour S, Fatehi F, Gray LC. Data privacy concerns and use of telehealth in the aged care context: An integrative review and research agenda. Int J Med Inform 2022 Apr;160:104707. [doi: 10.1016/j.ijmedinf.2022.104707] [Medline: 35131698]
50. Pardasani M, Moreno CL, Forge NR. Cultural competence and HIV. In: Handbook of HIV and Social Work: Principles, Practice, and Populations: John Wiley & Sons; 2010:41-58.
51. Kamimura A, Higham R, Rathi N, Panahi S, Lee E, Ashby J. Patient–provider relationships among vulnerable patients: the association with health literacy, continuity of care, and self-rated health. J Patient Exp 2020 Dec;7(6):1450-1457. [doi: 10.1177/2374373519895680] [Medline: 33457601]
52. Williams-Roberts H, Abonyi S, Kryzanowski J. What older adults want from their health care providers. Patient Exp J 2018;5(3):81-90. [doi: 10.35680/2372-0247.1307]
53. Murray B, McCrone S. An integrative review of promoting trust in the patient-primary care provider relationship. J Adv Nurs 2015 Jan;71(1):3-23. [doi: 10.1111/jan.12502] [Medline: 25113235]
54. Lester PE, Dharmarajan TS, Weinstein E. The looming geriatrician shortage: ramifications and solutions. J Aging Health 2020 Oct;32(9):1052-1062. [doi: 10.1177/0898264319879325] [Medline: 31583940]
55. Flaherty E, Bartels SJ. Addressing the community-based geriatric healthcare workforce shortage by leveraging the potential of interprofessional teams. J Am Geriatr Soc 2019 May;67(S2):S400-S408. [doi: 10.1111/jgs.15924] [Medline: 31074849]
56. Abraham J, Kannampallil TG, Patel VL. Bridging gaps in handoffs: a continuity of care based approach. J Biomed Inform 2012 Apr;45(2):240-254. [doi: 10.1016/j.jbi.2011.10.011] [Medline: 22094355]
57. Mavronicolas HA, Laraque F, Shankar A, Campbell C. Understanding the drivers of interprofessional collaborative practice among HIV primary care providers and case managers in HIV care programmes. J Interprof Care 2017 May;31(3):368-375. [doi: 10.1080/13561820.2016.1270921] [Medline: 28388286]
58. Pinto RM, Witte SS, Filippone PL, Baird KL, Whitman WR. Factors that influence linkages to HIV continuum of care services: implications for multi-level interventions. Int J Environ Res Public Health 2017 Nov 7;14(11):1355. [doi: 10.3390/ijerph14111355] [Medline: 29112126]
59. Epstein RM, Street RL. The values and value of patient-centered care. Ann Fam Med 2011;9(2):100-103. [doi: 10.1370/afm.1239] [Medline: 21403134]
60. O'Brien KK, Solomon P, Trentham B, et al. Evidence-informed recommendations for rehabilitation with older adults living with HIV: a knowledge synthesis. BMJ Open 2014 May 14;4(5):e004692. [doi: 10.1136/bmjopen-2013-004692] [Medline: 24833687]
61. Abdulai MA, Marable JK, Wadus A, Asante KP. A qualitative analysis of factors influencing health-seeking behavior of people living with HIV, hypertension and diabetes in an urban area of Ghana. J Multimorb Comorb 2022;12:26335565221092664. [doi: 10.1177/26335565221092664] [Medline: 35586035]
62. Policek N, Mendão L. Tackling ageism in the healthcare system: a community perspective. HIV Med 2023 Dec;24(12):1172-1175. [doi: 10.1111/hiv.13589] [Medline: 38012853]
63. Brown MJ, Adeagbo O. HIV and aging: double stigma. Curr Epidemiol Rep 2021;8(2):72-78. [doi: 10.1007/s40471-021-00265-6] [Medline: 33728256]
64. Altaf Dar M, Maqbool M, Ara I, Zehravi M. The intersection of technology and mental health: enhancing access and care. Int J Adolesc Med Health 2023 Oct 30;35(5):423-428. [doi: 10.1515/ijamh-2023-0113]
65. Social determinants of health among adults with diagnosed HIV infection, 2019. Centers for Disease Control and Prevention. 2019. URL: https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-27-2.pdf [accessed 2024-10-30]

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Understanding Older Adults’ Experiences With a Digital Health Platform in General Practice: Qualitative Interview Study

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Abstract

Background: In our aging population, primary care is under pressure to remain accessible to all. Effective use of digital health care could potentially lower general practitioners’ (GPs) workload. Some general practices are already implementing a digital health platform as a primary method to contact their patients. However, it is unknown how older people experience this novel way to communicate with their GP.

Objective: The aim of this study was to study the experiences of patients aged 65 years and older in general practices who use digital health as a primary communication tool. The secondary aims were to identify barriers and facilitators for the use of digital health care and whether a practice focus on digital health influences older patients’ choice to enlist.

Methods: We invited all patients aged 65 years and older at 2 general practices in Amsterdam that work with a novel digital health platform. We used purposive sampling to select a heterogeneous group of patients in terms of age, sex, level of education, digital literacy, and experiences with the digital app of their general practice. We conducted 18 semistructured interviews from May through July 2023. All interviews were audio-recorded, transcribed, coded, and thematically analyzed.

Results: We generated three themes: (1) experiences of older people with digital health care in general practice, (2) impact of individual factors on digital health experiences, and (3) reasons for choosing a digitally oriented general practice. Participants reported both positive and negative experiences. The main perceived advantages of the digital health platform were increased accessibility, direct GP contact without an intermediary, and saving time through asynchronous communication. The disadvantages mentioned were log-in difficulties and problems with the automated explanatory questionnaire. Individual factors such as age, digital literacy, and expectations of general practice care seemed to impact people’s experiences and could act as barriers or facilitators for using digital health. Reasons for older patients to enlist at a general practice were mainly practical. The digital orientation of the practice hardly played a role in this choice.

Conclusions: Older patients in general practice see benefits to using a digital health platform that offers 2-way chat-based communication between the patient and GP. We found that individual factors such as skills, norms and values, attitudes toward digitalization, and expectations of general practice care impacted older patients’ experiences with digital health care. For many older participants, the digital profile of the general practice did not play a role in their choice to enlist. Further improvement of digital health platforms will be necessary to ensure digital health for all in general practice.

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KEYWORDS

digital health care; digital health platform; general practice; qualitative research; older adults; primary care; mobile phone

Introduction

Primary care is under pressure. The population in Europe is aging, and the prevalence of multimorbidity rises, which will increase the demand on primary care services [1-3]. These developments will be difficult to address by the current capacity of health care professionals. Compared with 2015, British general practitioners (GPs) in 2023 already had to care for 19% more patients [4]. In a Dutch representative survey among GPs in 2022, a total of 82% of participants reported that the current workload was too high [5]. Digital health care is often mentioned as a possible solution to meet increased demand and reduce high workload [6,7].

Digital health can be defined as “the proper use of technology to improve the health and wellbeing of people, as well as enhancing the care of patients, through intelligent processing of data” [8,9]. In 2022, the majority of Dutch general practices already used digital platforms for written e-consults and reorders of medication, with similar use in urban and rural areas [10,11]. Digital health has the potential to improve both efficiency and quality of health care. However, there are risks and challenges in using digital health through these platforms. The main concern is digital inequity since digital health is less accessible for people with lower digital skills, lower (health) literacy, and lower financial status [7,8,10,12-17]. By transforming primary care without regard for digital inequity, we risk further increasing health inequity in society [8,12,13,18]. Older people, aged 65 years and older, relatively often require general practice care while they are less likely to use the internet [19,20]. Issues such as lower digital device skills, difficulties evaluating the quality of information on the internet, and concerns about privacy have been reported as barriers for older people to use digital health [10,13,21]. In designing new digital health platforms for primary care, it is therefore vital to understand and address the difficulties older patients face.

In Swedish primary care, digital health platforms that allow 2-way (asynchronous) chat-based communication between the patient and GP, (synchronous) video communication, and self-registration of patient data using automated questions have been researched in recent years [22-26]. Although proper implementation represents many challenges, these digital health platforms improve accessibility across time and space and are seen as a useful addition to current practice both by patients and GPs [22-26]. However, these studies have not specifically focused on the experiences of older adults with this novel way of communication between patients and GPs.

Recently, a few general practices in the Netherlands have started using a similar digital health platform that offers 2-way chat-based communication. To our knowledge, no scientific studies have been conducted to assess this novel form of digital health in the Netherlands. Our main aim in this study was to investigate the experiences of older patients with this digital health platform. Secondary aims were assessing barriers and facilitators for the use of the app and investigating if a practice focus on digital health influences older patients' choice to enlist.

Methods

Study Design

A qualitative study was performed using semistructured interviews to get an in-depth understanding of the experiences of older people with a novel digital health platform in Dutch general practice. We followed the COREQ (Consolidated Criteria for Recording Qualitative Research) to conduct this study (Checklist 1).

Setting

We performed this study in 2 general practices in Amsterdam, Doccs Slotervaart and Doccs Amstel III. As is common in Dutch general practice, enlisting in these practices as a patient is only possible for people who live in the same postal code area. Both practices have worked with a digital health platform (doccs app; doccs BV) since their start in 2021. The doccs app allows 2-way (asynchronous) chat-based communication between the patient and GP and is designated to be the primary way for patients to contact the GPs. The app is solely a communication tool in which patients can chat with their GP, make appointments, or order repeat medications. The app does not have an automated role in the diagnostic or treatment process and is not linked with the electronic patient record. The app has a 2-factor authentication log-in process and is secured with end-to-end encryption to comply with the General Data Protection Regulations. The app can be used on a smartphone or tablet. The patient starts a chat conversation with the GP through the app when they want to make an appointment or ask a question. The patient is automatically asked several explanatory questions about the complaint (shown in Multimedia Appendix 1) that help the GP provide an answer to the patient's question or prepare for a face-to-face consultation. It is possible for patients to skip these questions. Within practice hours, one of the GPs of the practice will review and provide a direct answer within 1 hour. To ensure accessibility for all, it is made clear to patients that use of the app is not required to enlist as a patient because appointments can also be made by telephone or by visiting the practice.

Recruitment of Participants

At the time of recruitment, the total number of patients in the practices was 5055. We approached all patients aged 65 years and older in both practices (N=163) by postal mail. We sent the first invitation on May 19, 2023, and a reminder letter on June 8, 2023. Both letters contained an invitation, study information, and an informed consent form. In total, 54 (33%) patients responded that they wanted to participate. We called all respondents and used purposive sampling to select a group that was heterogeneous in age, sex, level of education, digital literacy, and experiences with the digital health platform. The level of education was assessed according to the Dutch Statistical Office [27]. Perceived digital literacy was assessed by using the eHealth Literacy Scale (eHEALS) questionnaire, which is validated for use in older Dutch adults [28-30]. All respondents provided written informed consent. Within reflexive thematic analysis, the term data saturation is deemed less useful since there are always new theoretical insights possible when data continue to be collected [31]. Regarding the breadth of our research questions and pragmatic considerations, we hypothesized that we would need to conduct 10 - 20 interviews. The final sample size was determined in the process of data collection and reviewing data quality. Recruitment continued until the research team agreed that the data set contained enough richness and complexity to address the research questions.

Interviews

All interviews were performed in Dutch from May through July 2023. We compiled the topic list based on discussions within the research team and previous research [8,10]. During the interviews, the interviewer constantly revisited the topic list and added items when relevant (final topic list in Multimedia Appendix 2). Most interviews took place at the patient's home or the general practice, 1 interview took place at the Amsterdam University Medical Centers. The interviews lasted 22 to 66 minutes. The lead author (HRK) performed all interviews. She explained to patients beforehand that she was not linked to the doccs general practice and guaranteed patients that their audiotape would be deleted after transcription. All interviews were audiotaped and transcribed verbatim.

Analysis

We used a reflexive thematic analysis approach according to Braun and Clarke [32-34]. After reading the transcripts several times, the data were coded by 2 authors (HRK and HTNN) with an inductive orientation. At the time, HRK was a medicine master student in her final year of training, and HTNN was a general practice resident and PhD student. HRK had an open view toward digital health for older adults in general practice but was mindful of the dangers it may pose to the accessibility of care, especially for older patients. HTNN shared those concerns, but as a PhD candidate who researched the implementation of a web-based treatment for chronic dizziness in general practice, she also had a lot of positive experiences with older patients using digital health. HRK and HTNN separately coded the first 2 transcripts and then reflected together on the story within the data. After their discussion, HRK continued coding the other transcripts to further analyze the data. Next, HRK assigned codes to generate initial themes and subthemes which were visualized in a mind map. This preliminary analysis was discussed in a meeting with HRK, HTNN, and VAvV. Afterward, HRK continued analyzing the data, also performing selective coding, in which she conceptualized each theme further, searched for relations across cases, and analyzed variation within and between the cases. She visualized this in mind maps, code matrices, and code-relation matrices to gain insight into the spectrum of different factors influencing patients' experiences. The final results were discussed with the project team (HRK, VAvV, and ORM). Interviews were analyzed in Dutch using MAXQDA (version 2022; Verbi Software). After completion, all themes, subthemes, codes, and quotes were translated into English by the authors.

Ethical Considerations

The study received institutional research board approval by the medical ethics committee of the VU University Medical Center (2023.0001). The study was conducted in accordance with the ethical standards of the responsible committee. All participants included in the study provided written informed consent. Data were deidentified after collection and handled in accordance with the Amsterdam Public Health research institute code of conduct, following General Data Protection Regulation rules. Participants received no financial compensation to participate, but travel costs, when applicable, were reimbursed.

Results

Overview

We conducted and analyzed a total of 18 interviews with older patients before the research team agreed the data set was rich and complex enough to answer the research questions. Characteristics of participants are described in Table 1.

Table . Participant characteristics.

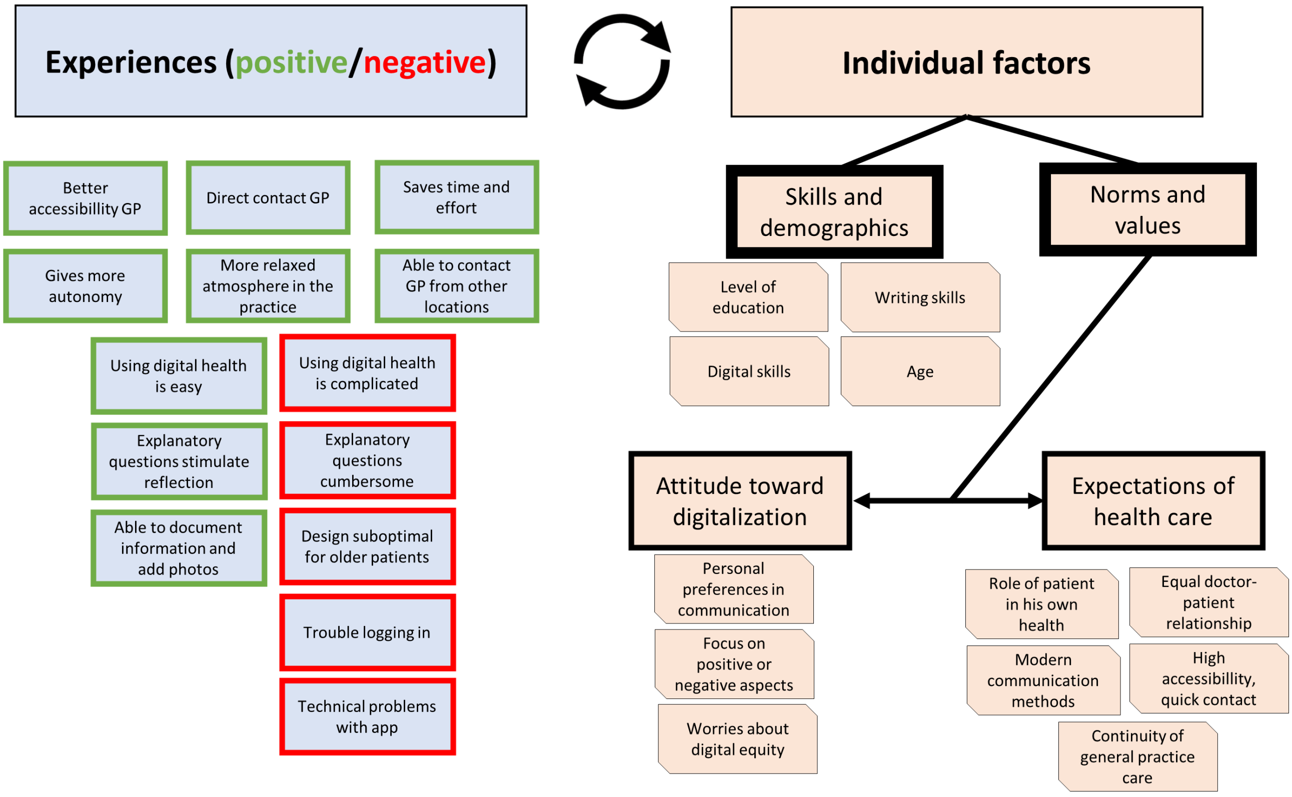
Participant	Sex	Age (years)	Digital literacy[a]	Level of education[b]
A	Male	69	29	High
B	Female	68	39	High
C	Male	77	31	High
D	Female	69	40	High
E	Female	70	36	High
F	Male	70	30	High
G	Female	69	33	High
H	Female	71	26	Intermediate
I	Female	84	14	High
J	Female	79	27	Intermediate
K	Male	71	32	High
L	Male	68	35	Intermediate
M	Female	69	27	Intermediate
N	Male	73	29	Intermediate
O	Female	71	33	Low
P	Male	83	22	Low
Q	Female	68	29	Intermediate
R	Female	89	18	Intermediate

[a] eHealth Literacy Scale score is used to measure digital literacy. Range 8 - 40 points; a higher score indicates better perceived digital literacy [28-30].

[b] Level of education is divided into low, intermediate, and high in accordance with the national Dutch Statistical Office [27].

We generated three main themes: (1) experiences of older people with digital health care in general practice, (2) impact of individual factors on digital health experiences, and (3) reasons for choosing a digitally oriented general practice. The first theme is divided into (1a) positive experiences with digital health care and (1b) negative experiences with digital health care. The second theme is divided into (2a) skills and demographics and (2b) norms and values. In Figure 1, we show a graphical overview of themes 1 and 2 with their subthemes.

Figure 1. Digital health for older patients in general practice. GP: general practitioner.



Theme 1: Experiences of Older People With Digital Health Care in General Practice

Subtheme 1a: Positive Experiences With Digital Health Care

Several participants had good experiences with the digital health platform of their general practice. They found the app easy to navigate and user-friendly. The speed with which they came into contact with a GP was one of the main advantages.

> *Because, I have to say, when I send a message, they respond almost immediately.* [Participant B]

Several participants found having more direct contact with their GP (without an intermediary) beneficial. Participants value the time and effort that they save by having digital asynchronous contact instead of calling or visiting the practice.

> *I don’t always have to call, do I? So I can just ask questions and get answers. Yes, I like that very much. [Interviewer: And why do you prefer this instead of calling?] That takes too long. Then I first get an assistant, and either the GP is busy, or he is talking to someone else. That’s nice, I believe all that, but I have a question. And now I can ask him and I will get an answer. So I like that.* [Participant L]

Other positive experiences were mainly due to opportunities that are specific for using a digital health platform to communicate with the practice, such as sending photos for dermatological issues, easily coming into contact with a GP when on holiday, and experiencing autonomy by making appointments and viewing laboratory results on the web. In addition, a few participants liked to have some time to reflect before they reply to a doctor, which is harder during a physical consultation. By chatting digitally, they have the opportunity to ask questions that would not always come to mind during a consult. A few participants liked the explanatory questions upfront because it helped them reflect on why exactly they contact the GP and activated them in their own health as well. A few participants experienced a more relaxed atmosphere in these general practices compared with other practices, due to an empty waiting room, the doctor being on time, and not constantly hearing ringing phones and assistants talking on the phone.

Subtheme 1b: Negative Experiences With Digital Health Care

Some participants experienced the app as complicated, and a few participants found the app too difficult to use at all. The main issue was logging in with different passwords and using a 2-factor authentication process. One of the other things that some participants experienced negatively is the automated explanatory questionnaire that they were asked to fill out at the start of each new contact with the practice. Participants found it either not relevant to their question (eg, they wanted to ask for test results and first had to answer questions like “at which moments do you experience your symptoms?”) or cumbersome because of the number of questions.

> *I just find it a bit cumbersome....I’m not just going to ask nonsense.* [Participant L]

Some minor issues also impacted participants’ experiences negatively. A few participants would prefer the app to open with a clear menu with different options instead of a direct question “how can we help you?”. In addition, a few participants experienced some technical hiccups, mainly when the practice just started. Furthermore, a few participants suggested the design of the app should be better suited to older patients, with big font size, buttons in the middle of the screen rather than in the corners, and multiple-choice options for ordering medication instead of typing. In addition, a few participants would have liked the possibility to use the digital app on a computer rather than a smartphone or tablet, so it is easier for older people to type longer messages.

Theme 2: Impact of Individual Factors on Digital Health Experiences

Subtheme 2a: Skills and Demographics

Perceived digital skills seemed to play an important role in experiences with digital health. The eHEALS questionnaire can produce scores between 8 and 40, with higher scores representing higher self-perceived digital literacy [28-30]. The digital literacy of participants varied much, with eHEALS scores ranging from 14 to 40. One participant did not use a smartphone or other digital devices and therefore did not use the app at all.

> *I don’t use the app myself....Then I should need to know how to make contact in the first place, therefore I need a password and, oh well... [Wife: he is a computer illiterate, and this is way too complicated for him.]* [Participant P]

One participant, who scored 29 points relatively high on the eHEALS scale, was afraid that he could not keep up with the speed of digitalization.

> *Because the speed of electronics and stuff, it goes so fast and so quick. And as long as we can follow it, through the apps and iPad and iPhone, I think it’s fine, very well. But it’s something that frightens me, that the moment may come when I can no longer keep up.* [Participant N]

Next to digital skills, also reading and writing skills determined people’s experiences, as using the digital health platform mainly consists of reading and writing messages. None of the participants had difficulty reading, but a few had difficulties putting their symptoms into words while typing in the app.

> *Well I think, you have to be able to clarify, as a patient. You have to...Yes, actually be able to clearly tell...what you have and what you want. But I think in that situation, I would call the front desk receptionist, if I really couldn’t figure it out, I would call.* [Participant G]

Finally, we saw that few participants who were the oldest (age 79 years and older) more often reported bad experiences or did not use the app at all. In younger participants (younger than 78 years), the experiences differed, but all of them used the app (to some extent). Next to that, we observed that the people with a high level of education had predominantly more positive experiences than negative ones. In contrast, participants with a lower level of education more often had negative experiences with the app.

Subtheme 2b: Norms and Values

Attitude Toward Digitalization

Personal preferences in communication seemed to be a factor in experiences with digital health. Many participants considered chat-based communication to be of added value because it is fast, they can do it in their own time (asynchronous communication), and it is accessible. However, several participants preferred contact via telephone or face-to-face. These communication methods were more familiar to them and were viewed as more personal. In contrast, a few participants stated chat-based communication was something they would participate in with family and friends but not with a doctor. Many of the participants thought video calling was not of added value; however, some saw it as an added value for situations in which they are immobilized. Furthermore, participants’ attitude toward digitalization in society and health care appeared important. Almost half of the participants liked digitalization because it makes information more accessible and improves communication. Some people focused on disadvantages, for example, dangers in privacy and a more individualized society. Some participants simply found it redundant.

> *Well I don’t think it’s necessary. It’s more, the nonsense...You are often talked into needs. You have to do this now, you have to do that now.* [Participant D]

A few participants worried that in digital interaction, relevant emotions such as fear are lost. Opinions on the topic of searching for digital health information varied. Most participants seek information to some degree, but a few do not, mostly because digital health information can scare them. Opinions about receiving digital health information from their GP varied as well. Some liked it because it is efficient and easy, while others found it the GP’s task to inform the patient instead of sending information.

> *Do I have to read what he studied for? Come on...* [Participant J]

A factor that impacted some participants’ experiences is problems with accessibility, leading to digital inequity. To several participants, it did not impact their own experiences, but it did worry them that other older adults might not be able to access care if communication would be (solely) digital. Participants mentioned different forms of possible digital inequity. Two of those are the difficulty of digital apps (discussed in Subtheme 1b) and the level of digital skills (discussed in Subtheme 2a). Other concerns that were mentioned were that assistance with using digital health care is hard to arrange, learning and remembering new things are harder for older patients, the use of digital tools can be complicated by medical issues, and certain monitors (eg, blood pressure monitor) needed for home measurement may not be affordable or easy to use by all patients. However, some participants also mentioned that to them accessibility was increased by digital care due to easier contact, the possibility to have contact while abroad, and having insight into their own test results.

Expectations of Health Care

Participants' expectations of health care in general also affected how they viewed digital health care. Some participants mentioned that they expect their GPs to apply modern communication methods.

> *At the previous general practitioner, prescriptions were still sent to the pharmacy by fax. And...you couldn't email, you couldn't chat. You were purely like "there are so many people waiting in front of you" on a landline phone. So yeah, their way of doing things was a little outdated, if you know how things are here.* [Participant F]

Many participants said that they expect their GP to listen carefully, take them seriously, and provide solutions. Some participants talked about valuing an equal doctor-patient relationship, in which a doctor empowers a patient by involving them in the diagnosis and decisions. They found that the app increased empowerment because when chatting, both patients and GPs use first names, the GP sends information for the patient to read themselves and involves them with different options for the next steps (eg, come to practice, wait, try lifestyle changes, and try medication). In the general practices, messages by patients were answered by the team of GPs, depending on who worked that day, to ensure each question in the app was answered as soon as possible. Some participants who valued continuity of care found it a disadvantage that the messages were not always answered by their own regular GP. However, other participants who valued accessibility and logistics more did not see this as a problem.

> *[Interviewer: what is important to you in contact with your GP?] Accessibility. For this the app is fantastic because they don't have to be open at all....As long as they respond. Right? Well, they do within 24 hours. What else do you want? Well, I think it's great.* [Participant D]

The way older participants viewed self-management of health varied. A few participants mentioned they did not want to play an active role in their own health management. They preferred to let the GP decide which actions were needed and preferred to have all measurements conducted in the practice. However, many participants preferred an active role in their health in some way. For instance, they were open to perform measurements at home and send them to the GP via the app. One participant stated that he saw his health as his own responsibility.

> *Yes exactly! Yes, it's my health. And I think it's great that I can talk to a doctor about that. Not only can, but sometimes must....But it's still my thing.* [Participant C]

Theme 3: Reasons for Choosing a Digitally Oriented General Practice

For many participants, the digital health platform of these practices did not play a role in their choice of practice. Most participants chose their practice because of practical reasons (location of practice, room to enlist new patients, and partner joined the practice) or because they were unsatisfied with their previous GP. Some participants chose these practices because they wanted a more modern practice (different ways of communication and young doctors) or they wanted more accessible communication. For some participants, however, the presence of digital tools was one of the reasons to enlist.

> *To me it is easier to write something down if I have something, than to go to the doctor right away. So now I am more in contact with the doctor than I would have if I had to go to a normal doctor.* [Participant M]

The reasons for choosing the digitally oriented general practices did seem to affect patients' experiences. Participants for whom the digital tools did not play a role in their choice or who chose the practices because of different reasons (eg, the partner enlisted so they joined) were slightly more negative about the digital health platform and mainly found it complicated. In contrast, participants who enlisted in these practices because they had bad experiences with their previous GP or wanted an improvement in communication had predominantly positive experiences with the digital health platform. The same applies for participants who enlisted in these practices specifically because they wanted to use more digital health tools.

Discussion

Principal Results

Our main aim in this study was to investigate the experiences of older patients in general practice with a digital health platform that offers 2-way chat-based communication between the patient and GP. As expected, participants reported both positive and negative experiences with the digital app. The most important advantages of the digital health platform were described by participants as increased accessibility of the general practice for different health complaints, direct contact with the GP without an intermediary, and saving time because of asynchronous communication between the patient and GP. Disadvantages were that for some participants, use of the platform was complicated, logging in with 2-step authentication was difficult, and filling out the automated explanatory questionnaire was found to be cumbersome or irrelevant to their care request.

Our secondary aims were to assess barriers and facilitators for the use of the app and investigate if a practice focus on digital health impacted older patients' choice to enlist. Our findings suggest that many different individual factors impacted people's experiences with digital health care. Barriers to the use of the digital health platform in general practice appeared to be low digital and writing skills, higher age, and a low level of education. Negative attitudes toward digitalization in general, a preference for face-to-face contact with the GP, and a wish for all health questions to be handled by their own regular GP were also seen as barriers to use the app in its current form. There were also some app-related barriers in details of design and user-friendliness such as small font size. Facilitators for using the digital health platform were being digitally skilled, being highly educated, having a preference for an equal patient-GP relationship, the good accessibility of a GP, and a wish to unburden the GP. Surprisingly, for many older participants, the special focus of the practice on digital health (which was also advertised on the website) did not play a role in their choice to enlist. Logistical reasons or bad experiences with their previous GP were the main reasons to switch to their current general practice.

Strengths and Limitations

Our study has several strengths. First, to find a representative sample of older patients who used the digital health platform, we invited all patients aged 65 years and older who were enlisted in the general practices. To find a more heterogeneous sample, we conducted a second invitation round so we were able to select more patients who were relatively old, less digitally skilled, and less educated. In the end, by using purposive sampling and continuing until the research team decided the data set was rich and complex enough, we were therefore able to attain various samples in terms of age, sex, level of education, and digital literacy. Second, all interviews were performed by the same interviewer, and the interview location was chosen by the participant. This assured that there was no interrater difference and helped participants speak freely during the interviews.

There were also some limitations. First, some participants did not use the digital app but answered how they think they would experience the functions of the digital health platform. Therefore, not all participants were able to comment on all aspects of the digital health platform. However, because expectations of experiences of older patients with digital health may help guide the development of future digital health platforms, we decided to also describe these hypothetical experiences separately. Second, our conclusions on the digital literacy of our participants should be interpreted with care. Digital literacy is a complex concept to measure. We chose to use the eHEALS because this is the only widely used questionnaire that is validated for use in Dutch older adults [28-30]. However, the eHEALS only focuses on perceived literacy as stated by patients and misses questions about skills like logging in with passwords. For future studies, we would consider complementing the eHEALS questionnaire with another established questionnaire such as the Mobile Device Proficiency Questionnaire to measure digital literacy more accurately [29,35].

Interpretation of the Results and Comparison With Prior Work

As far as we know, this is the first study to assess the experiences of older patients with a digital health platform that offers 2-way chat-based communication in Dutch general practice. The willingness for older patients to digitally communicate with their doctor has been often described [10,15,36]. The advantages of digital health platforms mentioned by our older participants, such as increased accessibility of the general practice [37], direct contact with the GP without an intermediary [38], and time-saving because of asynchronous communication [37-39], were also found in previous studies. The problems participants in our sample experienced with logging in are considered a barrier for many digital health platforms [40]. Our participants mentioned that at a high age, it is already hard to remember passwords, while a 2-step authentication is even more complicated. However, for data security reasons, this 2-step authentication is legally obligated by the Dutch General Data Protection Regulations [41]. Although the importance of privacy of health care data cannot be overstated, current requirements limit accessibility of digital health for older patients and may therefore increase digital inequity [40]. Developing methods to ease the log-in process for end users, while still attaining adequate data security, will be essential to ensure digital health for all in the future. Swedish studies that evaluated the GP perspective of a digital health platform with 2-way chat-based communication were very positive about using automated questionnaires to better triage and prepare visits to the general practice [24,42]. This could be an important tool in reducing workload in general practice. However, in our study, some participants experienced the automated questionnaire as cumbersome or not relevant. Explaining to patients why these questions matter and attempting to keep this questionnaire as succinct and to the point as possible will be necessary to achieve broad implementation.

In our study, we found potential barriers and facilitators for the use of digital health by older patients in general practice. Because this is a qualitative study, no inferences can be made about the prevalence of phenomena, and further quantitative research will be necessary to further explore these findings [43]. However, the impact of age, digital literacy, and level of education on digital health has been often described in previous studies and implies a digital divide in which people have unequal access to important parts of society [15-17,44]. A more novel finding in our study is the way how expectations of older patients from general practice care affected their experience with digital health. We found that valuing an equal doctor-patient relationship that causes patient empowerment may be a facilitator. However, patients who wanted all health questions to be handled by one regular GP were less happy with the current form of the digital health platform. This is an important finding because personal continuity of care is a core value of general practice and offers multiple benefits to both patients and GPs [45]. When general practices use a digital health platform, choices have to be made when handling care requests. The digital health platform we assessed allowed all care requests to be primarily answered by a GP who was on duty, even when this was not the patient's regular GP. This ensured that questions that request immediate care could also be asked digitally but limited personal continuity of general practice care. The value of personal continuity of care in general practice has been well demonstrated for both patients and GPs [46,47]. However, the optimal way to achieve personal continuity in a digital health context is still mostly unknown and deserves further study [37,48]. Early in development, future digital health platforms in general practice should view improving personal continuity of care as an essential feature.

By focusing on strengthening this core value of general practice, the introduction of digital health can change from a threatening development to a protective factor. Our study showed that the reasons for older patients to enlist in a practice were mostly practical. Surprisingly, for most older participants, the option of digital health care did not influence their choice for the practice. This is at odds with previous studies that stated that digitally oriented practices attract only digitally minded, young, and skilled patients [37,38,49]. This is further confirmation that digital health platforms for general practice should be designed to be accessible to all to reduce the risk of increased health disparities by the digital divide.

Implications for Research and Practice

For Practice

This research shows that a digital health platform in general practice with 2-way chat-based communication can offer benefits to older patients, but nondigital routes remain important. When developing digital health platforms, it is important to think of details that improve user-friendliness for older patients. An automated explanatory questionnaire may help make the GP work efficiently, but for patients, it should be succinct and to the point, and its importance should be explained clearly. When general practices consider implementing digital health platforms, it is good to know that for older patients this aspect may not play a role in enlisting in a practice.

For Research

To ensure digital health for all, future studies should focus on other patient groups who may struggle with the use of digital health platforms in general practice. Interviewing younger patients with a low socioeconomic position, low level of education, or low (digital) literacy could complement our findings. Furthermore, we found several potential barriers and facilitators for older people in using digital health. Large-scale quantitative research could be helpful to further assess the effects of these factors in daily practice. Finally, continuing scientific work on the effects of digital health platforms on the core value of personal continuity of care will be essential to ensure that digital health can be sustainably implemented in general practice.

Conclusions

This qualitative study showed both positive and negative experiences of older patients in general practice with a digital health platform that offers 2-way chat-based communication between patients and GPs. In assessing barriers and facilitators for the use of the app, we found that individual factors impacted older patients' experiences with digital health care such as skills, norms and values, attitudes toward digitalization, and expectations of general practice care. For many older participants, the digital profile of the general practice did not play a role in their choice to enlist. Further improvement of digital health platforms will be necessary to ensure digital health for all in general practice.

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Authors' Contributions

VAvV conceived and designed this study. HRK included the participants and collected the data. HRK and HTNN performed the data analysis. HRK drafted the first version of the manuscript, HTNN, VAvV, and ORM provided feedback and input.

Conflicts of Interest

HRK, HTNN, and ORM have no competing interests to disclose. VAvV is employed both as a researcher at the Amsterdam UMC and as a general practitioner in one of the general practices where the digital health platform was tested. He was not involved in the primary development process of the digital health platform.

Multimedia Appendix 1
Automated explanatory questionnaire.
[DOCX File, 184 KB - aging_v7i1e59168_app1.docx]

Multimedia Appendix 2
Topic list.
[DOCX File, 187 KB - aging_v7i1e59168_app2.docx]

Checklist 1
COREQ (Consolidated Criteria for Recording Qualitative Research) checklist.
[DOCX File, 192 KB - aging_v7i1e59168_app3.docx]

References

1. Infographic impact of ageing. RIVM: Dutch National Institute for Public Health and the Environment. 2019. URL: https://www.rivm.nl/documenten/infographic-impact-van-vergrijzing [accessed 2023-05-16]
2. Blokstra A, Verschuren WMM, Baan CA, et al. Vergrijzing en toekomstige ziektelast: prognose chronische ziektenprevalentie 2005-2025 [Article in Dutch]. 2007. URL: https://www.rivm.nl/bibliotheek/rapporten/260401004.pdf [accessed 2023-05-16]
3. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet 2012 Jul;380(9836):37-43. [doi: 10.1016/S0140-6736(12)60240-2]
4. Pressures in general practice data analysis. British Medical Association. 2023. URL: https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis [accessed 2023-06-28]
5. Flinterman L, Vis E, Keuper J, Schaaijk A, Batenburg R. De arbeidsmarkt van de nederlandse huisartsenzorg in 2022: toelichting en samenvatting van het onderzoek- en de regionale factsheets [Article in Dutch]. Nivel: Nederlands instituut voor onderzoek van de gezondheidszorg. 2023. URL: https://www.nivel.nl/nl/publicatie/de-arbeidsmarkt-van-de-nederlandse-huisartsenzorg-2022-toelichting-en-samenvatting-van [accessed 2023-08-31]
6. Elbert NJ, van Os-Medendorp H, van Renselaar W, et al. Effectiveness and cost-effectiveness of eHealth interventions in somatic diseases: a systematic review of systematic reviews and meta-analyses. J Med Internet Res 2014 Apr 16;16(4):e110. [doi: 10.2196/jmir.2790] [Medline: 24739471]
7. Kickbusch I, Piselli D, Agrawal A, et al. The Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world. Lancet 2021 Nov;398(10312):1727-1776. [doi: 10.1016/S0140-6736(21)01824-9]
8. van der Kleij R, Kasteleyn MJ, Meijer E, et al. SERIES: eHealth in primary care. Part 1: concepts, conditions and challenges. Eur J Gen Pract 2019 Oct;25(4):179-189. [doi: 10.1080/13814788.2019.1658190] [Medline: 31597502]
9. Fatehi F, Samadbeik M, Kazemi A. What is digital health? Review of definitions. Stud Health Technol Inform 2020 Nov 23;275:67-71. [doi: 10.3233/SHTI200696] [Medline: 33227742]
10. Ware P, Bartlett SJ, Paré G, et al. Using eHealth technologies: interests, preferences, and concerns of older adults. Interact J Med Res 2017 Mar 23;6(1):e3. [doi: 10.2196/ijmr.4447] [Medline: 28336506]
11. Keuper JJ, Tuyl LHD. Digitale middelen hebben structurele plek in de huisartsenpraktijk. Resultaten meting 2022. Organisatie van zorg op afstand [Article in Dutch]. Nivel. 2023. URL: https://www.nivel.nl/sites/default/files/bestanden/1004518.pdf [accessed 2024-08-12]
12. Boers SN, Jongsma KR, Lucivero F, et al. SERIES: eHealth in primary care. Part 2: exploring the ethical implications of its application in primary care practice. Eur J Gen Pract 2020 Dec;26(1):26-32. [doi: 10.1080/13814788.2019.1678958] [Medline: 31663394]
13. Yao R, Zhang W, Evans R, Cao G, Rui T, Shen L. Inequities in health care services caused by the adoption of digital health technologies: scoping review. J Med Internet Res 2022 Mar 21;24(3):e34144. [doi: 10.2196/34144] [Medline: 35311682]
14. The Lancet Digital Health. Digital technologies: a new determinant of health. Lancet Digit Health 2021 Nov;3(11):e684. [doi: 10.1016/S2589-7500(21)00238-7] [Medline: 34711372]
15. Fjellså HMH, Husebø AML, Storm M. eHealth in care coordination for older adults living at home: scoping review. J Med Internet Res 2022 Oct 18;24(10):e39584. [doi: 10.2196/39584] [Medline: 36256831]
16. Gell NM, Rosenberg DE, Demiris G, LaCroix AZ, Patel KV. Patterns of technology use among older adults with and without disabilities. Gerontologist 2015 Jun;55(3):412-421. [doi: 10.1093/geront/gnt166] [Medline: 24379019]
17. Goedhart N. Social inclusion in digitizing societies. Vrije Universiteit Amsterdam. 2021. URL: https://research.vu.nl/en/publications/social-inclusion-in-digitizing-societies-starting-from-the-lifewo [accessed 2023-08-24]
18. Lu X, Yao Y, Jin Y. Digital exclusion and functional dependence in older people: findings from five longitudinal cohort studies. EClinicalMedicine 2022 Dec;54:101708. [doi: 10.1016/j.eclinm.2022.101708] [Medline: 36353265]
19. Bähler C, Huber CA, Brüngger B, Reich O. Multimorbidity, health care utilization and costs in an elderly community-dwelling population: a claims data based observational study. BMC Health Serv Res 2015 Jan 22;15:23. [doi: 10.1186/s12913-015-0698-2] [Medline: 25609174]
20. van Boekel LC, Peek ST, Luijkx KG. Diversity in older adults' use of the internet: identifying subgroups through latent class analysis. J Med Internet Res 2017 May 24;19(5):e180. [doi: 10.2196/jmir.6853] [Medline: 28539302]
21. Garcia Reyes EP, Kelly R, Buchanan G, Waycott J. Understanding older adults' experiences with technologies for health self-management: interview study. JMIR Aging 2023 Mar 21;6:e43197. [doi: 10.2196/43197] [Medline: 36943333]
22. Eldh AC, Sverker A, Bendtsen P, Nilsson E. Health care professionals' experience of a digital tool for patient exchange, anamnesis, and triage in primary care: qualitative study. JMIR Hum Factors 2020 Dec 14;7(4):e21698. [doi: 10.2196/21698] [Medline: 33315014]
23. Cajander Å, Larusdottir M, Hedström G. The effects of automation of a patient-centric service in primary care on the work engagement and exhaustion of nurses. Qual User Exp 2020 Dec;5(1). [doi: 10.1007/s41233-020-00038-x]
24. Entezarjou A, Bolmsjö BB, Calling S, Midlöv P, Milos Nymberg V. Experiences of digital communication with automated patient interviews and asynchronous chat in Swedish primary care: a qualitative study. BMJ Open 2020 Jul 23;10(7):e036585. [doi: 10.1136/bmjopen-2019-036585] [Medline: 32709650]

25. Nilsson E, Sverker A, Bendtsen P, Eldh AC. A human, organization, and technology perspective on patients' experiences of a chat-based and automated medical history-taking service in primary health care: interview study among primary care patients. J Med Internet Res 2021 Oct 18;23(10):e29868. [doi: 10.2196/29868] [Medline: 34661544]
26. Frennert S, Erlingsdóttir G, Muhic M, Rydenfält C, Milos Nymberg V, Ekman B. Embedding and integrating a digital patient management platform into everyday primary care routines: qualitative case study. JMIR Form Res 2022 Feb 22;6(2):e30527. [doi: 10.2196/30527] [Medline: 35191845]
27. Education level. CBS: Dutch Central Statistical Office. URL: https://www.cbs.nl/en-gb/news/2023/48/satisfaction-high-in-caribbean-nl-in-spite-of-low-material-well-being/education-level [accessed 2023-08-29]
28. Norman CD, Skinner HA. eHEALS: the eHealth Literacy Scale. J Med Internet Res 2006 Nov 14;8(4):e27. [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
29. Oh SS, Kim KA, Kim M, Oh J, Chu SH, Choi J. Measurement of digital literacy among older adults: systematic review. J Med Internet Res 2021 Feb 3;23(2):e26145. [doi: 10.2196/26145] [Medline: 33533727]
30. van der Vaart R, van Deursen AJ, Drossaert CH, Taal E, van Dijk JA, van de Laar MA. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. J Med Internet Res 2011 Nov 9;13(4):e86. [doi: 10.2196/jmir.1840] [Medline: 22071338]
31. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
32. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qual Res Sport Exerc Health 2021 Mar 4;13(2):201-216. [doi: 10.1080/2159676X.2019.1704846]
33. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019 Aug 8;11(4):589-597. [doi: 10.1080/2159676X.2019.1628806]
34. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. In: Liamputtong P, editor. Handbook of Research Methods in Health Social Sciences: Springer; 2019. URL: https://doi.org/10.1007/978-981-10-5251-4_103 [accessed 2024-08-26] [doi: 10.1007/978-981-10-5251-4]
35. Roque NA, Boot WR. A new tool for assessing mobile device proficiency in older adults: the mobile device proficiency questionnaire. J Appl Gerontol 2018 Feb;37(2):131-156. [doi: 10.1177/0733464816642582] [Medline: 27255686]
36. Abdi S, Spann A, Borilovic J, de Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO International Classification of Functioning, Disability and Health Framework (ICF). BMC Geriatr 2019 Jul 22;19(1):195. [doi: 10.1186/s12877-019-1189-9] [Medline: 31331279]
37. Van Der Burg L, Bruinsma J, Crutzen R, Cals J. Onderzoek naar de effectiviteit van digitale zorgtoepassingen in de huisartsenzorg [Article in Dutch]. Maastricht University. 2023. URL: https://open.overheid.nl/documenten/ronl-f863258b48575bff34e8f5b0e23df988c14cab7b/pdf [accessed 2023-06-28]
38. Atherton H, Brant H, Ziebland S, et al. The potential of alternatives to face-to-face consultation in general practice, and the impact on different patient groups: a mixed-methods case study. Health Serv Deliv Res 2018;6(20):1-200. [doi: 10.3310/hsdr06200]
39. Atherton H, Pappas Y, Heneghan C, Murray E. Experiences of using email for general practice consultations: a qualitative study. Br J Gen Pract 2013 Nov;63(616):e760-e767. [doi: 10.3399/bjgp13X674440] [Medline: 24267859]
40. Palacholla RS, Fischer N, Coleman A, et al. Provider- and patient-related barriers to and facilitators of digital health technology adoption for hypertension management: scoping review. JMIR Cardio 2019 Mar 26;3(1):e11951. [doi: 10.2196/11951] [Medline: 31758771]
41. Digitale toegang in de zorg | Digitale toegang | Gegevensuitwisseling in de zorg [Article in Dutch]. Dutch Ministry of Health Welfare and Sport. URL: https://www.gegevensuitwisselingindezorg.nl/digitale-toegang/achtergrond [accessed 2023-09-01]
42. Johansson A, Larsson M, Ivarsson B. General practitioners' experiences of digital written patient dialogues: a pilot study using a mixed method. J Prim Care Community Health 2020;11:2150132720909656. [doi: 10.1177/2150132720909656] [Medline: 32133905]
43. Neale J, Miller P, West R. Reporting quantitative information in qualitative research: guidance for authors and reviewers. Addiction 2014 Feb;109(2):175-176. [doi: 10.1111/add.12408] [Medline: 24422609]
44. van Middelaar T, Beishuizen CRL, Guillemont J, et al. Engaging older people in an internet platform for cardiovascular risk self-management: a qualitative study among Dutch HATICE participants. BMJ Open 2018 Jan 21;8(1):e019683. [doi: 10.1136/bmjopen-2017-019683] [Medline: 29358447]
45. Winkel MTT, Slottje P, de Kruif AJ, et al. General practice and patient characteristics associated with personal continuity: a mixed-methods study. Br J Gen Pract 2022 Nov;72(724):e780-e789. [doi: 10.3399/BJGP.2022.0038] [Medline: 36192355]
46. Barker I, Steventon A, Deeny SR. Association between continuity of care in general practice and hospital admissions for ambulatory care sensitive conditions: cross sectional study of routinely collected, person level data. BMJ 2017 Feb 1;356:j84. [doi: 10.1136/bmj.j84] [Medline: 28148478]
47. Pereira Gray D, Sidaway-Lee K, Johns C, Rickenbach M, Evans PH. Can general practice still provide meaningful continuity of care? BMJ 2023 Nov 14;383:e074584. [doi: 10.1136/bmj-2022-074584] [Medline: 37963633]

48. Ladds E, Khan M, Moore L, Kalin A, Greenhalgh T. The impact of remote care approaches on continuity in primary care: a mixed-studies systematic review. Br J Gen Pract 2023 May;73(730):e374-e383. [doi: 10.3399/BJGP.2022.0398] [Medline: 37105731]
49. Salisbury C, Quigley A, Hex N, Aznar C. Private video consultation services and the future of primary care. J Med Internet Res 2020 Oct 1;22(10):e19415. [doi: 10.2196/19415] [Medline: 32812887]

Abbreviations

COREQ: Consolidated Criteria for Recording Qualitative Research
eHEALS: eHealth Literacy Scale
GP: general practitioner

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Sociodigital Determinants of eHealth Literacy and Related Impact on Health Outcomes and eHealth Use in Korean Older Adults: Community-Based Cross-Sectional Survey

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Abstract

Background: eHealth literacy is an essential skill for pursuing electronic health information, particularly for older people whose health needs increase with age. South Korea is now at the intersection of a rapidly digitalizing society and an increasingly aged population. eHealth literacy enables older people to maximize the effective use of emerging digital technology for their health and quality of life. Understanding the eHealth literacy of Korean older adults is critical to eliminating the gray digital divide and inequity in health information access.

Objective: This study aims to investigate factors influencing eHealth literacy in older Korean adults and its impact on health outcomes and eHealth use.

Methods: This was a cross-sectional survey. Community-dwelling older adults 65 years and older in 2 urban cities in South Korea were included. eHealth literacy was measured by the eHealth Literacy Scale. Ordinal logistic regression was used to analyze factors associated with eHealth literacy and multivariate ANOVA for the impact of eHealth literacy on health outcomes and eHealth use.

Results: In total, 434 participants were analyzed. A total of 22.3% (97/434) of participants had high eHealth literacy skills. Increasing age, higher monthly income, and time spent on the internet were significantly associated with eHealth literacy ($P<.001$), and social media users were 3.97 times (adjusted odds ratio 3.97, 95% CI 1.02 - 15.43; $P=.04$) more likely to have higher skill. Higher eHealth literacy was associated with better self-perceived health and frequent use of digital technologies for accessing health and care services ($P<.001$).

Conclusions: Disparity in socioeconomic status and engagement on the internet and social media can result in different levels of eHealth literacy skills, which can have consequential impacts on health outcomes and eHealth use. Tailored eHealth interventions, grounded on the social and digital determinants of eHealth literacy, could facilitate eHealth information access among older adults and foster a digitally inclusive healthy aging community.

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KEYWORDS

eHealth literacy; eHEALS; electronic health information; eHealth information; health literacy; health education; eHealth education; health training; eHealth training; digital health; digital technology; digital intervention; digital interventions; gray digital divide;

healthy aging; gerontology; geriatric; geriatrics; older adult; older adults; older person; older people; aging; aging; eHealth Literacy Scale

Introduction

Declining fertility rates and longer life expectancy primarily contribute to the demographic transition into an aging population worldwide. This transition is more prominent in Asia, where Japan, South Korea, China, and Singapore entered the aged society within a period of 20 years. In 2021, South Korea hosted 8.71 million people aged 65 years and older (16.8% of the total population), and the proportion increased by 5.1% compared to 2020 [1]. The rapid increase in the older population underscores the importance of an age-friendly environment in which older people can think or do what they value and age in a place to which they are attached.

Nowadays, with technological integration in every aspect of life, digital inclusiveness has become a basic component of an age-friendly environment. Traditional health promotion and long-term care systems could be upgraded into more productive and efficient systems with the diffusion of technology and digital devices. Gerontechnology, an emerging scientific field applying technological advances in the aging sector, is now used to improve health and social connections among older adults [2]. It is more evident in the COVID-19 pandemic, where physical distancing was inevitable. Digital health promotion activities and exercise videos were used to maintain over 20-year-old community exercise programs in Japan and preserve older people's functional mobility [3]. The application of robotic technology for social connections of residents also showed better engagement and positive user perception in long-term care facilities compared to conventional methods such as telephone communication [4]. Additionally, older adults have a positive attitude toward using digital technology and are willing to use it for health purposes and to maintain activities of daily living [5,6].

Although older people have a positive attitude and are willing to use digital health interventions and devices, they face challenges and limitations when adopting digital technology. First, having access to digital devices and networks is the initial step in adopting digital technology and its associated interventions [7]. Aged countries, such as Japan, South Korea, and Singapore, prioritized digitalization and promoted and implemented policies for digital inclusiveness [8]. Due to government efforts, the gap in access to digital devices and the internet has narrowed. In 2022, the digitization level reached 76.2% among South Korea's vulnerable populations (older people, low-income individuals, people with disabilities, fishermen, and farmers), and digital access was as high as 96% of the total population [9]. Regarding older people, 69.9% had access to digital information in 2022, increasing from 69.1% in 2021 [9]. Ownership of digital devices and access to the internet do not guarantee the actual application of digital technology for health. Another barrier for older adults to fully embrace the benefits of technology is not knowing how to acquire and use information obtained in the digital context to make effective health decisions [10].

According to Norman and Skinner [11], eHealth literacy is defined as "the ability to seek, discover, evaluate and appraise eHealth information and apply the acquired knowledge to solve health problems." Older adults often see eHealth literacy as a barrier to successfully using electronically delivered health information and interventions [10]. Due to technological advancements, health information is one-click away, and older adults are faced with information overload, in which misleading information could be exposed physically and digitally. On the other hand, internet use for health-related searches by older American adults increased from 24.8% in 2009 to 43.9% in 2018 [12]. Due to the prevalence of chronic diseases and age-related disorders in older age, there are pros of searching health information on the web. However, older adults could be harmed by fake information on the web if they lack adequate skills to identify the correct source and facts. Therefore, being eHealth literate is essential, and exploring the factors associated with older adults' eHealth literacy is crucial.

Extensive research has shown that age, sex, level of education, marital status, economic conditions, and social support contribute to the eHealth literacy of older adults [13]. Arcury et al [14] stated that internet use is positively associated with eHealth literacy. Little published data exist on the relationship between social media and eHealth literacy, especially in older populations. In addition, having a good command of eHealth literacy skills enhances the physical, mental, and social well-being of older people [15]. Higher eHealth literacy skill is a protective factor against cognitive decline and is positively associated with health-promoting behaviors and better health outcomes [16,17]. There have been few attempts to investigate the impact of eHealth literacy on perceived health status and the use of digital devices and the internet for health, particularly in the older population. The need for scientific literature in this field is more urgent in South Korea, which is becoming a super-aged society, and the proportion of older adults is expected to be as high as 44% in 2050 [18]. Additionally, the Ministry of Health and Welfare in South Korea started a pilot project to use artificial intelligence and the Internet of Things to improve the health care of older adults [19]. Advanced technology is readily diffused into the daily lives of older Korean adults, and knowledge of embracing eHealth information becomes inevitable. Therefore, this study aims to fill the gap by exploring the factors associated with eHealth literacy in community-dwelling older Korean adults and the impact of eHealth literacy on health-related outcomes and digital technology use for health purposes.

Methods

Participants, Setting, and Data Collection

It is a community-based survey conducted in 2 urban cities of the Republic of Korea, Wonju-si and Yeoju-si, in 2022. This cross-sectional study is part of the digitally inclusive healthy aging communities study, a cross-cultural study in 4 rapid aging countries: Japan, the Republic of Korea, Singapore, and Thailand [20]. After obtaining ethics approval, participation in the study was announced in the study area. It was accomplished through the cooperation of local senior welfare centers and senior citizen centers. Community-dwelling older adults aged 65 years and older, both male and female adults with ongoing health promotion activities in residing communities, were included in the study.

The sample size was calculated by 1 sample estimation of proportion in Stata SE (version 16.0; Stata Corp) based on the proportion of internet use among older adults in South Korea. The calculated sample size was inflated by 20% for nonresponses. A sample of 444 participants responded to the questionnaire, and 434 were analyzed after excluding 10 participants who were younger than 65 years.

Ethical Considerations

The Juntendo University Ethical Committee (approval E22-0057-M01) and Yonsei University Institutional Review Board (approval 1041849 - 202304SB-073-02) approved the ethics of the digitally inclusive healthy aging communities study. Participation in the study was completely voluntary. The study’s purposes and procedures were thoroughly explained, and written informed consent was obtained. Data were collected using a structured questionnaire in the participants’ native language (Korean). The data were anonymized and identifiable features were not included. The participants were compensated with a financial incentive equivalent to US $10 for answering the questionnaire.

Measures

Demographic Characteristics

Demographic characteristics of age, sex, education, living arrangements, and financial status were investigated. Age was described as a continuous variable for distribution and divided into 4 categories (65-70, 71-75, 76-80, and >80 years) for eHealth distribution and regression analysis. Education was asked for the highest level of completed education, with 4 groups (did not go to school, primary school completed, junior high school completed, and high school and above). For living arrangements, the participants were asked whether they lived alone or with someone and categorized into living alone, living only with a spouse, and living only with children or grandchildren. Financial status included average income per month based on the 4 income quartiles in South Korea, which is divided into 2 groups of low (less than or equal to 1 million Won; a currency exchange rate of ₩ 1=US $0.0008 is applicable) and high (more than 1 million Won) and a dichotomous question on receiving a pension of any type.

Internet Use and Social Media Use

We determined internet use by a dichotomous question about the internet use derived from the internet environment and digital devices used to access the internet. The frequency is then determined by number of hours per day and number of days per week spent on the internet. Negative responses in the dichotomous question, 0 hours and 0 days of using the internet, were defined as internet nonusers. Positive responses in the dichotomous question, more than 0 hours and 0 days of using the internet, were defined as internet users. Engagement in 1 or more social media platforms prevalent in South Korea determined social media use.

Health-Related Outcomes and eHealth Use

Self-perceived health status was measured using a single-item 4-point Likert scale (1=very healthy to 4=not healthy at all). A single-item 4-point scale has been used to reflect the subjective health status of community-dwelling older adults in longitudinal and cross-sectional studies and to predict mortality, health outcomes, and digital use among older adults [21-24]. Annual medical checkup was measured using a 5-point Likert scale ranging from 1=never to 5=always, and the participants were asked how frequently they participated in regular medical checkups. The technology used in health was measured by how often participants used the internet and digital technology to improve eating habits and access health care and long-term care services. The scale was a 5-point Likert scale ranging from 1=never to 5=always. For analysis, annual medical checkups, digital technology, and internet use for health purposes were regrouped according to their participation and frequency of use as never or nonuser, low participation or low user, and frequent participation or frequent user.

eHealth Literacy

eHealth literacy was measured by an 8-item 5-pointed eHealth Literacy Scale (eHEALS) developed by Norman and Skinner [25]. The scale was developed using the Lily model of eHealth literacy, which consisted of 6 aspects (healthy, traditional, information, scientific, media, and computer literacy). The scale tends to measure perceived skill and comfort with eHealth rather than the actual skill itself [25]. Although eHEALS was primarily developed for using computers for health purposes, it has been validated with the use of mobile devices and social media and shows good reliability [26,27]. In this study, the scale has a Cronbach α reliability coefficient of 0.99, which indicates high internal consistency and reliability. For distribution, eHealth literacy is categorized into 3 groups: lack of eHealth literacy (eHEALS 8 - 15.9), low to moderate eHealth literacy (eHEALS 16 - 31.9), and high eHealth literacy (eHEALS 32 - 40) [28].

Statistical Analysis

The statistical analysis was done by using Stata SE (version 16.0; StataCorp). Sociodemographic characteristics, the use of the internet and social media, eHealth literacy, self-perceived health, annual medical checkups and eHealth use for improving eating habits, and access to health care services and long-term care services were described by descriptive statistics. Frequency and percentage were used to describe categorical data and mean and SD for continuous data. The normality of the data was checked by using the Shapiro-Wilk test. The distribution of eHealth literacy across sociodemographic factors, internet, and social media use were described by descriptive statistics. A Kruskal Wallis H test and Mann-Whitney *U* tests analyzed the difference in mean scores.

Ordinal logistic regression was used to identify factors influencing eHealth literacy. Univariate ordinal logistic regression treated eHealth literacy as the dependent variable and age, sex, education, monthly income, pension receiving status, living arrangement, internet use, and social media use as independent variables. The statistically significant variables (*P*<.2) and conceptually relevant variables were included in the multivariate analysis. Association was reported as an adjusted odds ratio (aOR) and 95% CI. Statistical significance is defined as a *P* value ≤.05 with a 95% CI. Age, sex, income, and education were included as covariates in the multivariate analysis.

Furthermore, multivariate analysis of variance was applied to assess the difference in health-related outcomes such as perceived health status, annual medical checkup, and eHealth use to improve eating habits, access to health care, and long-term care services among the different orders of eHealth literacy. The covariates for the impact of eHealth literacy on health outcomes and eHealth use were age and sex.

Results

Overview

The mean age was 76.8 (SD 6.6) years, and participants 80 years and older occupied 30% (131/432) of the total sample. Of the total sample (N=434), 315 (72.6%) were female, and 192 (44%) participants of the sample had primary school education or lower. A total of 136 (31.5%) older people lived alone, 341 (78.6%) had monthly income lower than or equal to 1 million Won, and 385 (88.7%) received a pension (Table 1). Regarding digital technology use (N=434), 208 (47.9%) participants used the internet, and 184 (42.4%) engaged in social media. The mean days of internet use in a week were 2.4 (SD 2.9), and the mean hours of internet use in a day were 0.8 (SD 1.4). Over one-third of the sample population spent more than 3 days a week (142/404, 35.2%) and 1 - 2 hours a day (155/404, 38.4%) on the web. The mean of the eHEALS score was 15.4 (SD 10.8). Over half of the participants (289/434, 66.6%) lacked eHealth literacy, and 97 (22.4%) had high eHealth literacy (Table 2).

Regarding health-related outcomes, almost every participant had an annual medical checkup (n=423, 97.9%). Over half of the participants (n=242, 55.8%) reported not being in good health. Regarding eHealth use, 353 (81.3%) participants did not have experience using digital technology to improve eating habits. A total of 350 (80.6%) and 370 (85.3%) users did not use digital technology to access health care services or long-term care services, respectively (Table 2).

Table 3 shows the distribution of eHealth literacy across different groups of sociodemographic factors and digital technology use. The results showed significant differences in mean eHEALS scores across all variables except for receiving pension. The level of eHealth literacy descends with older age and ascends with daily time spent on the web (Figure 1).

Table . Sociodemographic characteristics and digital technology use in older Korean adults (N=434).

		Values, n (%)	Mean (SD)
Age (years)			76.8 (6.6)
	65 - 70	94 (22)	
	71 - 75	108 (25)	
	76 - 80	99 (23)	
	>80	131 (30.3)	
Sex			—[a]
	Male	119 (27.4)	
	Female	315 (72.6)	
Education			—
	Did not go to school	70 (16)	
	Primary school	124 (28.6)	
	Secondary school	93 (21)	
	High school and above	147 (33.8)	
Living arrangements			—
	Living alone	136 (31.5)	
	Living with spouse	241 (55.8)	
	Living with a child or grandchild	55 (13)	
Monthly income[b]			—
	Less than or equal to 1 million Won	341 (78.6)	
	More than 1 million Won	93 (21)	
Pension receiving status			—
	Not receiving	49 (11)	
	Receiving pension	385 (88.7)	
Internet use			—
	Nonuser	226 (52.1)	
	User	208 (47.9)	
Days of internet use per week			2.4 (2.9)
	0 days	223 (55.2)	
	1 to 3 days	39 (10)	
	More than 3 days	142 (35.2)	
Hours of internet use per day			0.8 (1.4)
	0 hours	219 (54.2)	
	1 hour	92 (23)	
	2 hours	63 (15)	
	3 hours and above	30 (7)	
Social media use			—
	Nonuser	250 (57.6)	
	User	184 (42.4)	

[a] Not applicable.

[b] A currency exchange rate of ₩ 1=US $0.0008 is applicable.

Table . eHealth literacy, health-related outcomes, and eHealth use distribution in older Korean adults (N=434).

		Values, n (%)	Mean (SD)
eHealth Literacy Scale			15.4 (10.8)
	Lack of eHealth literacy (8 - 15.9)	289 (66.6)	
	Low to moderate eHealth literacy (16 - 31.9)	48 (11.1)	
	High eHealth literacy (32-40)	97 (22.3)	
Perceived health status			—[a]
	Very healthy	65 (15)	
	Moderately healthy	127 (29.2)	
	Not very healthy	150 (34.6)	
	Unhealthy	92 (21.2)	
Annual medical checkup			—
	Never	9 (2.1)	
	Low participation	36 (8.3)	
	Frequent participation	389 (89.6)	
Digital technology and the internet use to improve eating habits			—
	Nonuser	353 (81.3)	
	Low user	53 (12.2)	
	Frequent user	28 (6.5)	
Digital technology and the internet use to access health care			—
	Nonuser	350 (80.6)	
	Low user	55 (12.7)	
	Frequent user	29 (6.7)	
Digital technology and the internet use to access long-term care services			—
	Nonuser	370 (85.3)	
	Low user	53 (12.2)	
	Frequent user	11 (2.5)	

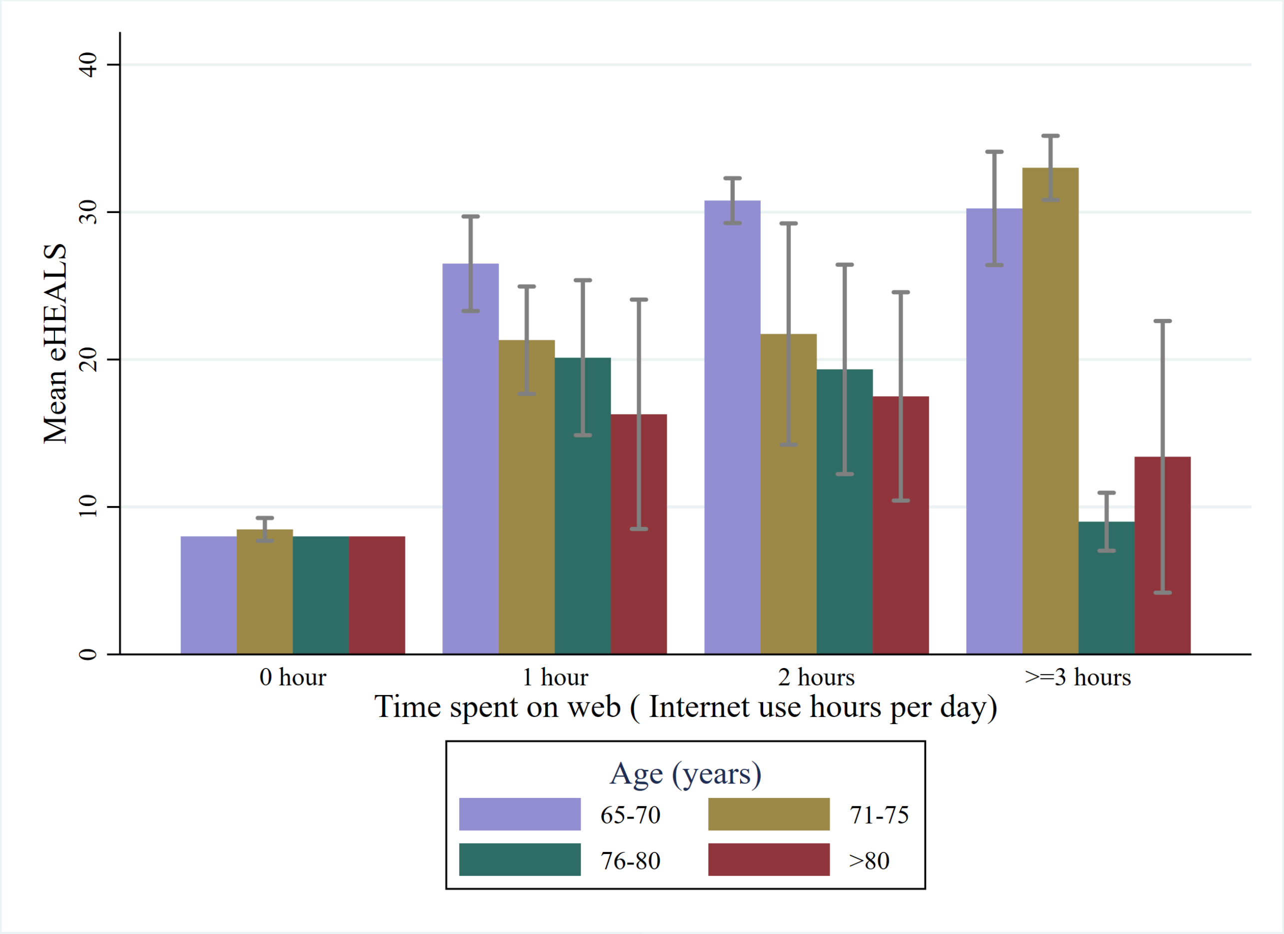
[a] Not applicable.

Table . eHealth literacy distribution across sociodemographic factors, internet use and social media use in older Korean adults (N=434).

		eHealth Literacy Scale score, mean (SD)	*P* value
Age (years)			<.001
	65 - 70	26.9 (9.7)	
	71 - 75	16.6 (11.3)	
	76 - 80	11.8 (8.3)	
	>80	9.2(4.5)	
Sex			.002
	Male	18.1 (11.7)	
	Female	14.5 (10.4)	
Education			<.001
	Did not go to school	11.2 (7.7)	
	Primary school	10.4 (6.7)	
	Secondary school	13.6 (9.8)	
	High school and above	23.0 (11.5)	
Living arrangement			.002
	Living alone	12.8 (9.1)	
	Living only with spouse	17.0 (11.6)	
	Living only with child or grandchild	14.6 (10.3)	
Monthly income[a]			<.001
	Less than or equal to 1 million Won	14.3 (10.2)	
	More than 1 million Won	19.8 (12.1)	
Pension receiving status			.97
	Yes	15.5 (10.9)	
	No	15.2 (10.2)	
Internet use			<.001
	Nonuser	8.3 (2.7)	
	User	23.2 (11.1)	
Days of internet use per week			<.001
	0 days	8.3 (2.4)	
	1 to 3 days	23.2 (9.6)	
	More than 3 days	24.7 (10.8)	
Hours of internet use per day			<.001
	0 hours	8.1 (1.1)	
	1 hour	22.6 (10.7)	
	2 hours	26.1 (9.9)	
	3 hours and above	25.4 (11.2)	
Social media use			<.001
	Nonuser	8.6 (3.2)	
	User	24.9 (10.6)	

[a] A currency exchange rate of ₩ 1=US $0.0008 is applicable.

Figure 1. Level of eHealth literacy of different age groups by different categories of daily time spent on the web among older Korean adults. eHEALS: eHealth Literacy Scale.



Social and Digital Determinants of eHealth Literacy

Ordinal logistic regression predicted eHealth literacy from sociodemographic factors and the use of digital technology. eHealth literacy was associated with age, income, internet use, and social media use, while other variables were controlled. Compared to the 65 - to 70-year age group, the odds of having high eHealth literacy were decreased by 76% (aOR 0.24, 95% CI 0.1 - 0.6) for the 76 - to 80-year age group and 88% (aOR 0.12, 95% CI 0.03 - 0.42) for the >80-year age group. A monthly income of more than 1 million Won per month increased the odds of having a higher eHealth literacy 2.8 times (aOR 2.8, 95% CI 1.35 - 5.8) than a monthly income of less than or equal to 1 million Won. Univariate analysis showed that internet users had significantly higher eHealth literacy (odds ratio 108.57, 95% CI 42.63 - 276.54; *P*<.001). In multivariable analysis, hours spent on the web daily were significantly associated with eHealth literacy. Users who spent an hour per day had 19.2 times (aOR 19.2, 95% CI 2.33 - 158.81; *P*=.006), 2 hours per day had 25.7 times (aOR 25.72, 95% CI 2.83 - 233.47; *P*=.004), and 3 hours and more had 35.3 times (aOR 35.39, 95% CI 3.70 - 338.63; *P*=.002) higher eHealth literacy than nonusers of the internet. Social media users had 3.9 times (aOR 3.97, 95% CI 1.02 - 15.43; *P*=.04) higher eHealth literacy than nonusers (Table 4).

Table . Univariate and multivariable analysis of factors associated with eHealth literacy in older Korean adults (n=400)[a].

Independent variables		Univariate analysis, OR[b] (95% CI)	Multivariable analysis, aOR[c] (95% CI)
Age (65 - 70 as reference)			
	71 - 75	0.18[d] (0.11 - 0.32)	0.53 (0.24 - 1.17)
	76 - 80	0.06[d] (0.03 - 0.12)	0.24[f] (0.09 - 0.59)
	>80	0.02[d] (0.009 - 0.04)	0.12[f] (0.03 - 0.42)
Sex (male as reference)			
	Female	0.52[d] (0.34 - 0.78)	0.61 (0.32 - 1.18)
Education (did not go to school as reference)			
	Primary school	0.78 (0.34 - 1.79)	0.39 (0.09 - 1.60)
	Secondary	2.01 (0.91 - 4.41)	0.99 (0.26 - 3.76)
	High school and above	11.12[d] (5.44 - 22.73)	1.46 (0.39 - 5.47)
Income (less than or equal to 1 million Won as reference)[e]			
	More than 1 million Won	2.66[d] (1.70 - 4.16)	2.8[f] (1.35 - 5.81)
Pension receiving status (receiving pensions as reference)			
	No	1.01 (0.56 - 1.82)	—[g]
Living status (living alone as reference)			
	Living with spouse	2.28[d] (1.44 - 3.61)	1.22 (0.61 - 2.44)
	Living with child and grandchild	1.49 (0.77 - 2.93)	1.02 (0.35 - 2.91)
Internet use (nonuser as reference)			
	User	108.57[d] (42.63 - 276.54)	7.3 (0.59 - 89.67)
Days of internet use per week (0 days as reference)			
	1 to 3 days	108.4[d] (37.99 - 309.31)	1.52 (0.26 - 8.74)
	More than 3 days	157.93[d] (60.25 - 413.95)	1.45 (0.26 - 7.94)
Hours of internet use per day (0 hours as reference)			
	1 hour	251.88[d] (59.01 - 1075.19)	19.23[f] (2.33 - 158.81)
	2 hours	530.87[d] (119.98 - 2348.9)	25.72[f] (2.83 - 233.47)
	3 hours and above	589.94[d] (120.99 - 2876.56)	35.39[f] (3.7 - 338.63)
Social media use (nonuser as reference)			
	User	87.34[d] (42.56 - 179.26)	3.97[h] (1.02 - 15.43)

[a] Model parameter: likelihood ratio (LR) $\chi2_{17}$= 390.6 (P<.001), pseudo r^2=0.35, LR test of proportionality of odds=199.07 (P=.78).

[b] OR: odds ratio.

[c] aOR: adjusted odds ratio.

[d] P<2.

[e] A currency exchange rate of ₩ 1=US $0.0008 is applicable.

[f] P<.01.

[g] Not applicable.

[h] P<.05.

Impacts of eHealth Literacy on Health-Related Outcomes and eHealth Use

Self-perceived health was significantly better in participants with higher mean eHealth literacy scores (very healthy groups: mean 22.2, SD 12.0 and unhealthy groups: mean 11.6, SD 8.1; *P*<.001). Participants with higher mean eHealth literacy scores attended annual medical checkups frequently. Regarding the use of digital technology for health, frequent users had a statistically significant higher mean in all 3 measures: the use of the internet and digital technology for improving eating habits (mean 25.4, SD 11.8; *P*<.001), access to health care services (mean 28.4, SD 10.4; *P*<.001), and long-term care services (mean 23.3, SD 14.1; *P*=.004; Table 5).

The influence of eHealth literacy on health-related outcomes was analyzed using multivariate ANOVA (Table 6). The result showed eHealth literacy had an effect at the multivariate level on self-perceived health status, digital technology, and internet use to improve eating habits to access health care and long-term care (*P*<.001). In multivariate analysis, the eHealth literacy level did not significantly influence participation in annual medical checkups.

Table . eHealth Literacy Scale (eHEALS) and different levels of health outcomes and digital technology use for health in older Korean adults (N=434).

Health outcomes and eHealth use		eHEALS score, mean (SD)	*P* value
Perceived health status			<.001
	Very healthy	22.2 (12.0)	
	Moderately healthy	18.8 (11.6)	
	Not very healthy	12.1 (8.8)	
	Unhealthy	11.6 (8.1)	
Annual medical checkup			.004
	Never	9.9 (4.4)	
	Low participation	10.0 (6.0)	
	Frequent participation	16.1 (11.1)	
Use of digital technology and the internet to improve eating habits			<.001
	Nonuser	14.3 (10.4)	
	Low user	17.9 (10.6)	
	Frequent user	25.4 (11.8)	
Use of digital technology and the internet to access health care			<.001
	Nonuser	14.3 (10.4)	
	Low user	16.4 (9.6)	
	Frequent user	28.4 (10.4)	
Use of digital technology and the internet to access long-term care			.004
	Nonuser	14.8 (10.6)	
	Low user	18.4 (10.9)	
	Frequent user	23.1 (14.1)	

Table . The influence of eHealth literacy on health outcomes and eHealth use in older Korean adults (n=430).

	Self-perceived health status	Annual medical check-up	Digital technology use to improve eating habits	Digital technology use to access health care services	Digital technology use to access Long-term care services
eHealth literacy (β)	−0.018[a]	0.001	0.016[a]	0.019[a]	0.008[a]
95% CI	−0.027 to −0.008	−0.003 to 0.004	0.01 to 0.02	0.013 to 0.025	0.004 to 0.013

[a] *P*<.001.

Discussion

Principal Findings

Competent in eHealth literacy skills is a characteristic of older people with healthy behaviors and those with better health knowledge and attitudes [15]. This study fills the gaps in eHealth literacy evidence by identifying social and digital determinants of eHealth literacy in community-dwelling Korean older adults and its consequential impact on subjective health status and digital technology application for lifestyle improvement and health needs.

In this study, older age, monthly income of lower or equal to 1 million Won, internet nonusers, and those not engaged in social media have a higher risk of having poor eHealth literacy (Table 4). Furthermore, the findings indicated that eHealth literacy has a significant effect on self-perceived health and eHealth use. It was also associated with lifestyle behaviors using digital resources for promoting health (Tables 5 and 6), such as improving healthy eating habits. Using smartwatches in physical activity promotion is an ideal recent example globally [29]. Additionally, eHealth literacy enabled older persons to seek health care services digitally and access long-term care services digitally (Tables 5 and 6). Integrating all these findings, we can highlight the significant influence of eHealth literacy upon general well-being, self-care, and opportunity to use health and social care services and health promotion through multiple evidence. The findings in other recent publications agreed with our findings [30,31].

The eHealth literacy of community-dwelling older Korean adults is relatively low, and 66.6% (n=289) need support and facilitation to improve their skills (Table 2). Since eHealth literacy is a predictor of eHealth information seeking, the disparity could result in inequity in health information access. Incompetency in eHealth literacy skills in older adults reflects lower self-efficacy in the effective use of electronically delivered information and services and the risk of exclusion from these services [10]. Therefore, regarding the country's high-paced demographic and digital transition, urgent interventions in eHealth literacy promotion targeting high-risk groups should be prioritized to ensure older adults' healthy and inclusive aging.

The effect of age on eHealth literacy varies among different age groups (Table 4). The skill increases with age in young and middle-aged adults and declines with age in older adults [32,33]. Younger older adults are more likely to have better eHealth literacy than those who are older. This may be due to an age-related decline in physiological and cognitive ability to access eHealth information. A qualitative study stated that younger older adults adopt digital technology considering literacy, benefits, and support from relatives and families, while those who are older are more likely to adopt with support from friends and relatives [34]. Therefore, older adults are not homogenous, and improving eHealth literacy in older adults should consider age-specific interventions tailored to the needs of different older adults.

Previous studies have stated that economic status has a significant association with eHealth literacy, which is concurrent with this study [35]. Older adults with higher incomes are more likely to adopt digital devices and have more autonomy in internet use [36]. Lower-income older adults may face poor access to digital technology, leading to skill disparity. As South Korea ranked highest in old age poverty among Organization for Economic Co-operation and Development countries [37], the relationship between financial security, social support for older adults, and eHealth literacy needs in-depth investigations to prevent the potential loss of the silver economy in a digitalized society.

Regarding other socioeconomic factors, there is inconsistency in the relationship between sex and eHealth literacy, and this study did not find any significant differences among different sex (Table 4). Level of education is a significant predictor of eHealth literacy in several studies [33,38]. However, this study did not find favorable relationships between education level and eHealth literacy, except that those with a high school education or above were more likely to have higher eHealth literacy in univariate analysis (Table 4).

Internet and social media use had a strong association with eHealth literacy. The frequency and time spent on the internet lead to different levels of eHealth literacy among older people, and those spending 3 hours or more have 35 times higher eHealth literacy than nonusers (Table 4). The internet penetration of older people is around 90% of the general population [39] in South Korea, which means that Korean older adults have favorable environmental access to the internet, and they are more likely to adopt digital devices [40]. In addition, having confidence in using the internet promotes the use of the internet for seeking health information and thus improves eHealth usability [41]. Therefore, comprehensive internet coverage serving as a foundation, boosting older adults' self-efficacy with digital technology and comfortability with eHealth skills, is a promising way to narrow the usability gap.

The eHEALS was developed before the widespread use of social media, and there were few studies regarding the validity of eHEALS on social media use. This study showed that social media users had 3.97 times higher eHealth literacy than nonusers (Table 4), which is concurrent with Tennant et al's [42] findings. The diffusion of social media into people's daily lives has become a channel to distribute health information and promote health, especially during the COVID-19 pandemic. South Korea and China have effectively used social media for disease notification, updating health information, and promoting preventive behaviors [43,44]. People who use social media frequently are more likely to keep abreast with updated health information, have better eHealth literacy, and be able to adopt healthy behaviors.

This study also found that eHealth literacy significantly impacts the self-perception of health (Table 6). Better levels of eHealth literacy are related to better-perceived health through access to quality health information and prompt and adequate health-related decisions [45,46]. Healthy behavior, such as participation in annual medical checkups, is not associated with eHealth literacy in this study population. The study population's participation in annual medical checkups is 90% (Table 2), higher than the national level of 80.3% in the group older than 40 years [47]. Due to the well-established health screening programs and high participation, this study could not find a significant impact of eHealth literacy on participation in health screening programs.

In addition, this study found that eHealth literacy influences digital technology use for health and care purposes (Table 6). People with better eHealth literacy can navigate the required information correctly, whereas people with poor eHealth literacy skills lack eHealth self-efficacy and pose a barrier to the adoption of eHealth services. Moreover, a higher eHealth literacy level increases the positive impact on perceived usefulness and ease of use in technology and facilitates the adoption of digital health technology [45]. Recently, a municipality in South Korea has introduced an artificial intelligence–featured call to prevent social isolation in the older population [46]. Such development affirmed that digital technology would narrow the unmet needs of health care and long-term care services in the future, provided that the users have the proper knowledge and self-efficacy in eHealth. Therefore, promoting eHealth literacy for the older population is fundamental in expanding eHealth services and eliminating the gray digital divide.

Limitations

Due to the demographics and aging rate of the sample population and the location of the study site, generalizing the findings may underestimate internet use in the older Korean population. In addition, eHEALS measures perceived eHealth skills rather than the actual performance of using digital technology. The possible gap between perceived skill and actual application of eHealth literacy could not be excluded.

Conclusions

eHealth literacy is an essential skill in the rapidly digitalizing world. It is important to learn about the factors associated with eHealth literacy in community-dwelling Korean older adults and the impact of eHealth literacy on health-related outcomes and digital technology use for health purposes. With the application of the results from this study, interventions to improve the eHealth literacy skills of older adults can be tailored to high-risk populations and narrow the gap in the usability of eHealth services by older adults.

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Authors' Contributions

MNA, MYK, MY, and YK conceptualized the research. MYK and MNA performed the formal analysis and visualization and were involved in writing the original draft. MNA contributed toward using the software. MNA, MY, SM, and TNNA supervised the project. MNA and MY were responsible for funding acquisition. MNA, YK, EWN, MY, HKCM, and TNNA administered the project, and MYK, MNA, YK, SM, TNNA, EWN, HL, and HKN were responsible for validation. All authors were responsible for investigation, methodology, writing, reviewing, and editing of the manuscript.

Conflicts of Interest

None declared.

References

1. Population and housing census (register-based census). Statistics Korea. 2021. URL: https://kostat.go.kr/board.es?mid=a20108070000&bid=11747 [accessed 2024-07-25]
2. Huang G, Oteng SA. Gerontechnology for better elderly care and life quality: a systematic literature review. Eur J Ageing 2023 Jun 22;20(1):27. [doi: 10.1007/s10433-023-00776-9] [Medline: 37347277]
3. Aung MN, Yuasa M, Koyanagi Y, et al. Sustainable health promotion for the seniors during COVID-19 outbreak: a lesson from Tokyo. J Infect Dev Ctries 2020 Apr 30;14(4):328-331. [doi: 10.3855/jidc.12684] [Medline: 32379708]
4. Hung L, Hu G, Wong J, et al. Telepresence robots in long-term care settings in British Columbia during the COVID-19 pandemic: analyzing the experiences of residents and family members. Gerontol Geriatr Med 2023 Apr 4;9:23337214231166208. [doi: 10.1177/23337214231166208] [Medline: 37033088]
5. Begde A, Jain M, Goodwin M, et al. Exploring factors influencing willingness of older adults to use assistive technologies: evidence from the Cognitive Function and Ageing Study II. Inf Commun Soc 2024 Jan 25;27(2):368-385. [doi: 10.1080/1369118X.2023.2205915]
6. Ienca M, Schneble C, Kressig RW, Wangmo T. Digital health interventions for healthy ageing: a qualitative user evaluation and ethical assessment. BMC Geriatr 2021 Jul 2;21(1):412. [doi: 10.1186/s12877-021-02338-z] [Medline: 34215209]
7. Van Dijk JA. Digital divide: impact of access. In: The International Encyclopedia of Media Effects: Wiley Blackwell; 2017:1-11. [doi: 10.1002/9781118783764]
8. Mulati N, Aung MN, Field M, et al. Digital-based policy and health promotion policy in Japan, the Republic of Korea, Singapore, and Thailand: a scoping review of policy paths to healthy aging. Int J Environ Res Public Health 2022 Dec 17;19(24):16995. [doi: 10.3390/ijerph192416995] [Medline: 36554873]
9. MSIT announces 2022 survey result on digital divide. Ministry of Science and ICT. 2023. URL: https://www.msit.go.kr/eng/bbs/view.do?sCode=eng&mId=4&mPid=2&pageIndex=&bbsSeqNo=42&nttSeqNo=782&searchOpt=ALL&searchTxt= [accessed 2024-07-25]
10. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021 Aug 17;21(1):1556. [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]

11. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. J Med Internet Res 2006 Jun 16;8(2):e9. [doi: 10.2196/jmir.8.2.e9] [Medline: 16867972]
12. Hung LY, Lyons JG, Wu CH. Health information technology use among older adults in the United States, 2009–2018. Curr Med Res Opin 2020 May;36(5):789-797. [doi: 10.1080/03007995.2020.1734782] [Medline: 32096650]
13. Jung SO, Son YH, Choi E. E-health literacy in older adults: an evolutionary concept analysis. BMC Med Inform Decis Mak 2022 Jan 31;22(1):28. [doi: 10.1186/s12911-022-01761-5] [Medline: 35101005]
14. Arcury TA, Sandberg JC, Melius KP, et al. Older adult internet use and eHealth literacy. J Appl Gerontol 2020 Feb;39(2):141-150. [doi: 10.1177/0733464818807468] [Medline: 30353776]
15. Xie L, Zhang S, Xin M, Zhu M, Lu W, Mo PKH. Electronic health literacy and health-related outcomes among older adults: a systematic review. Prev Med 2022 Apr;157:106997. [doi: 10.1016/j.ypmed.2022.106997] [Medline: 35189203]
16. Li SJ, Yin YT, Cui GH, Xu HL. The associations among health-promoting lifestyle, eHealth literacy, and cognitive health in older Chinese adults: a cross-sectional study. Int J Environ Res Public Health 2020 Mar 27;17(7):2263. [doi: 10.3390/ijerph17072263] [Medline: 32230935]
17. Kim SH, Son YJ. Relationships between eHealth literacy and health behaviors in Korean adults. Comput Inform Nurs 2017 Feb;35(2):84-90. [doi: 10.1097/CIN.0000000000000255] [Medline: 27258808]
18. South Korea’s population shift: challenges and opportunities. Lancet Reg Health West Pac 2023 Jul;36(100865). [doi: 10.1016/j.lanwpc.2023.100865] [Medline: 37621310]
19. Kim DJ, Lee YS, Jeon ER, Kim KJ. Present and future of AI-IoT-based healthcare services for senior citizens in local communities: a review of a South Korean government digital healthcare initiatives. Healthcare (Basel) 2024 Jan 22;12(2):281. [doi: 10.3390/healthcare12020281] [Medline: 38275561]
20. Aung MN, Koyanagi Y, Nagamine Y, et al. Digitally inclusive, healthy aging communities (DIHAC): a cross-cultural study in Japan, Republic of Korea, Singapore, and Thailand. Int J Environ Res Public Health 2022 Jun 7;19(12):6976. [doi: 10.3390/ijerph19126976] [Medline: 35742230]
21. Wuorela M, Lavonius S, Salminen M, Vahlberg T, Viitanen M, Viikari L. Self-rated health and objective health status as predictors of all-cause mortality among older people: a prospective study with a 5-, 10-, and 27-year follow-up. BMC Geriatr 2020 Mar 30;20(1):120. [doi: 10.1186/s12877-020-01516-9] [Medline: 32228464]
22. Bombak AE. Self-rated health and public health: a critical perspective. Front Public Health 2013 May 20;1:15. [doi: 10.3389/fpubh.2013.00015] [Medline: 24350184]
23. Kouvonen A, Kemppainen L, Ketonen EL, Kemppainen T, Olakivi A, Wrede S. Digital information technology use, self-rated health, and depression: population-based analysis of a survey study on older migrants. J Med Internet Res 2021 Jun 14;23(6):e20988. [doi: 10.2196/20988] [Medline: 34125069]
24. Yang H, Deng Q, Geng Q, et al. Association of self-rated health with chronic disease, mental health symptom and social relationship in older people. Sci Rep 2021 Jul 19;11(1):14653. [doi: 10.1038/s41598-021-94318-x]
25. Norman CD, Skinner HA. eHEALS: the eHealth Literacy Scale. J Med Internet Res 2006 Nov 14;8(4):e27. [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
26. James DCS, Harville C. eHealth literacy, online help-seeking behavior, and willingness to participate in mHealth chronic disease research among African Americans. Prev Chronic Dis 2016 Nov 17;13:E156. [doi: 10.5888/pcd13.160210] [Medline: 27854421]
27. Burzyńska J, Rękas M, Januszewicz P. Evaluating the psychometric properties of the eHealth Literacy Scale (eHEALS) among Polish social media users. Int J Environ Res Public Health 2022 Mar 29;19(7):4067. [doi: 10.3390/ijerph19074067] [Medline: 35409753]
28. Ghazi SN, Berner J, Anderberg P, Sanmartin Berglund J. The prevalence of eHealth literacy and its relationship with perceived health status and psychological distress during COVID-19: a cross-sectional study of older adults in Blekinge, Sweden. BMC Geriatr 2023 Jan 4;23(1):5. [doi: 10.1186/s12877-022-03723-y] [Medline: 36597040]
29. Martinato M, Lorenzoni G, Zanchi T, et al. Usability and accuracy of a smartwatch for the assessment of physical activity in the elderly population: observational study. JMIR Mhealth Uhealth 2021 May 5;9(5):e20966. [doi: 10.2196/20966] [Medline: 33949953]
30. De Santis KK, Mergenthal L, Christianson L, Zeeb H. Digital technologies for health promotion and disease prevention in older people: protocol for a scoping review. JMIR Res Protoc 2022 Jul 21;11(7):e37729. [doi: 10.2196/37729] [Medline: 35862187]
31. Zhang Y, Lee EWJ, Teo WP. Health-seeking behavior and its associated technology use: interview study among community-dwelling older adults. JMIR Aging 2023 May 4;6:e43709. [doi: 10.2196/43709] [Medline: 36996003]
32. Yang E, Chang SJ, Ryu H, Kim HJ, Jang SJ. Comparing factors associated with eHealth literacy between young and older adults. J Gerontol Nurs 2020 Aug 1;46(8):46-56. [doi: 10.3928/00989134-20200707-02] [Medline: 32936926]
33. Lee J, Tak SH. Factors associated with eHealth literacy focusing on digital literacy components: a cross-sectional study of middle-aged adults in South Korea. Digit Health 2022 Jan;8:20552076221102765. [doi: 10.1177/20552076221102765] [Medline: 35615270]
34. Weck M, Afanassieva M. Toward the adoption of digital assistive technology: factors affecting older people’s initial trust formation. Telecomm Policy 2023 Mar;47(2):102483. [doi: 10.1016/j.telpol.2022.102483]

35. Guo Z, Zhao SZ, Guo N, et al. Socioeconomic disparities in eHealth literacy and preventive behaviors during the COVID-19 pandemic in Hong Kong: cross-sectional study. J Med Internet Res 2021 Apr 14;23(4):e24577. [doi: 10.2196/24577] [Medline: 33784240]
36. Hargittai E, Piper AM, Morris MR. From internet access to internet skills: digital inequality among older adults. Univ Access Inf Soc 2019 Nov;18(4):881-890. [doi: 10.1007/s10209-018-0617-5]
37. Kang J, Park J, Cho J. Inclusive aging in Korea: eradicating senior poverty. Int J Environ Res Public Health 2022 Feb 14;19(4):2121. [doi: 10.3390/ijerph19042121] [Medline: 35206309]
38. Cherid C, Baghdadli A, Wall M, et al. Current level of technology use, health and eHealth literacy in older Canadians with a recent fracture—a survey in orthopedic clinics. Osteoporos Int 2020 Jul;31(7):1333-1340. [doi: 10.1007/s00198-020-05359-3] [Medline: 32112118]
39. Jun W. A study on the current status and improvement of the digital divide among older people in Korea. Int J Environ Res Public Health 2020 Jun 1;17(11):3917. [doi: 10.3390/ijerph17113917] [Medline: 32492861]
40. Lee H, Choi JY, Kim SW, et al. Digital health technology use among older adults: exploring the impact of frailty on utilization, purpose, and satisfaction in Korea. J Korean Med Sci 2024 Jan 8;39(1). [doi: 10.3346/jkms.2024.39.e7] [Medline: 38193326]
41. Lee OK, Kim DH, Beum KA. Factors affecting information and communication technology use and eHealth literacy among older adults in the US and South Korea. Educ Gerontol 2020 Sep 1;46(9):575-586. [doi: 10.1080/03601277.2020.1790162]
42. Tennant B, Stellefson M, Dodd V, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. J Med Internet Res 2015 Mar 17;17(3):e70. [doi: 10.2196/jmir.3992] [Medline: 25783036]
43. Li X, Liu Q. Social media use, eHealth literacy, disease knowledge, and preventive behaviors in the COVID-19 pandemic: cross-sectional study on Chinese netizens. J Med Internet Res 2020 Oct 9;22(10):e19684. [doi: 10.2196/19684] [Medline: 33006940]
44. You J. Lessons from South Korea’s COVID-19 policy response. Am Rev Public Adm 2020 Aug;50(6-7):801-808. [doi: 10.1177/0275074020943708]
45. Kim S, Chow BC, Park S, Liu H. The usage of digital health technology among older adults in Hong Kong and the role of technology readiness and eHealth literacy: path analysis. J Med Internet Res 2023 Apr 12;25:e41915. [doi: 10.2196/41915] [Medline: 37043274]
46. Seoul to start AI service for senior single households. Seoul Metropolitan Government. 2022 Apr 20. URL: https://world.seoul.go.kr/seoul-to-start-ai-service-for-senior-single-households/ [accessed 2024-07-25]
47. Park SY, Shin YJ. A multi-level analysis of factors affecting participation in health screenings in Korea: a focus on household and regional factors. J Prev Med Public Health 2022 Mar;55(2):153-163. [doi: 10.3961/jpmph.21.268] [Medline: 35391527]
48. Digitally inclusive, healthy ageing communities (DIHAC): a cross-cultural study in Japan, Republic of Korea, Singapore and Thailand. KAKEN. URL: https://kaken.nii.ac.jp/grant/KAKENHI-PROJECT-21H00795 [accessed 2024-07-25]

Abbreviations

aOR: adjusted odds ratio
eHEALS: eHealth Literacy Scale

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Three Perspectives on Older Adults' Daily Performance, Health, and Technology Use During COVID-19: Focus Group Study

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Abstract

Background: During COVID-19 lockdowns, older adults' engagement in daily activities was severely affected, causing negative physical and mental health implications. Technology flourished as a means of performing daily activities in this complex situation; however, older adults often struggled to effectively use these opportunities. Despite the important role of older adults' social environments—including their families and health professionals—in influencing their technology use, research into their unique perspectives is lacking.

Objective: This study aimed to explore the daily activity performance, health, and technology use experiences of healthy independent Israeli adults (aged ≥65 years) during COVID-19 from a 3-dimensional perspective: older adults, older adults' family members, and health professionals.

Methods: Nine online focus groups, averaging 6-7 participants per group, were conducted with older adults, family members, and health professionals (N=59). Data were analyzed using thematic analysis and constant comparative methods.

Results: The intertwining of daily activity performance and health emerged as a central theme, with differences between the groups. Older adults prioritized their self-fulfilling routines based on motivation and choice, especially in social-familial activities. In contrast, family members and health professionals focused on serious physical and mental health COVID-19–related consequences. A consensus among all three groups revealed the meaningful role of technology use during this period in bridging functional limitations. Participants delved into technology's transformative power, focusing on the need for technology to get engaged in daily activities.

Conclusions: This study illustrates the profound interplay between daily activity performances, physical and mental health, and technology use, using a 3-dimensional approach. Its focus on technology's uses and benefits sheds light on what older adults need to increase their technology use. Interventions for improving digital activity performance can be tailored to meet older adults' needs and preferences by focusing on motivational and preference-related activities.

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KEYWORDS

daily activity; health; technology use; older adult; qualitative study; focus group; COVID-19

Introduction

Background

Occupational scientist Ann Wilcock [1] claimed that "occupation and health are inseparable," meaning that a person's ability to function and perform in daily activities and occupations, especially meaningful ones, directly affects their health [2]. Previous studies have emphasized the substantial role of daily activity performance in maintaining and enhancing older adults' health. More information should be gathered to explore the unique daily experiences of older adults during a crisis such as the COVID-19 pandemic, since they cope with specific age-related changes, including physical, psychological, and social factors [3].

Although COVID-19 presented additional major challenges to older adults' daily activity performance and health, some remained active, most notably by using technology [4,5]. Since technology has become integral to modern life, it is essential to understand technology use among older adults in terms of their daily activity performance and health [6]. One major factor affecting older adults' success in daily functioning and adopting technology is their social environment [7,8], including family and health professionals [9]. For example, family members can support technology challenges (choosing suitable devices and introducing basic functions), and health professionals can suggest appropriate technology [8]. Thus, a deep understanding of daily activity performance and technology use necessitates consideration of family members' and health professionals' experiences.

Nevertheless, previous studies focused almost entirely on older adults' perspectives regarding daily activity performance. For example, Israeli studies of activity performance during the COVID-19 pandemic focused on adults (18 years and older) in general without addressing the specific needs and experiences of older adults (65 years and older) [5,10]. It remains unclear how older adults adjusted their daily activity performance in the face of the COVID-19 outbreak. Similarly, a study conducted among family members and health professionals regarding technology use did not specifically address the needs of older adults in terms of using technology to promote health in times of crisis [11]. Therefore, it is necessary to gain greater insight into Israeli older adults' experiences of their daily activity performance and technology use during COVID-19 through the various perspectives of older adults, family members, and gerontology health professionals. In this study, technology is considered with daily activity performance. Hence, the term technology refers to devices that adults already own (eg, mobile phones, computers, and tablets) for carrying out these activities.

Prior Studies

Older Adults' Daily Activity Performance and Health During the COVID-19 Pandemic

Globally, people are living longer, with more options to discover new interests, such as education or professional training. Alternatively, they might contribute positively to their families and society by caring for their grandchildren or volunteering for various charitable activities. Despite this empowering perspective, a central aspect—health—strongly influences their ability to engage in daily activities [12].

Extraordinary circumstances such as the COVID-19 pandemic present a substantial concern for older individuals' health. Worldwide, they reported restrictions on daily activities, such as banking, shopping, hiking [13], and leisure activities [14]. These changes negatively affected their physical and mental health [15,16]. Hence, exploring older adults' daily experiences during the COVID-19 pandemic can provide insight into their needs.

The occupational perspective, which provides an in-depth view of human doing, highlights the contribution of daily activity performance to health. This perspective further emphasizes the impact of the activities' context, time, and role in doing, being, becoming, and belonging [17]. Situations like COVID-19 may negatively affect older adults' ability to function (doing) and their sense of self (being). It can present obstacles to achieving future goals (becoming) and particularly affect older adults' ability to participate socially (belonging) [18]. The occupational perspective can demonstrate how humanity adapted to COVID-19 changes by adapting activities to what was available at the time.

Studies in numerous global regions showed that older adults adjusted to the COVID-19–related activity changes in various ways. They may have acquired a new skill or knowledge (eg, learning a foreign language), modified the nature of their activities, or adjusted the time allocated to each activity. Thus, they might have engaged in social, leisure, physical, and educational activities throughout the pandemic—but in new ways. Maintaining routines and participating in such meaningful activities regularly facilitated individuals maintaining their mental health [19,20].

Israeli Society's Distinctive Characteristics

Previous cross-sectional studies among Israeli adults (18 years and older) during COVID-19 highlighted the importance of maintaining daily routines. Their findings showed that Israeli adults discontinued some activities and modified their environment, often opting for solitude or staying home [5,10]. Cultural influences greatly determine how older adults navigate daily activities and use technology [21], thus requiring insight into their experiences. Despite the earlier studies, Israeli older adults' experiences of their performance in daily activities during crises still require clarification.

Technology-Supported Daily Activity Performance During the COVID-19 Pandemic

Previous studies focused mainly on older adults' self-reports on their technology use [4,19-26]. However, because social support, often provided by family members or health professionals, can overcome gaps between technology and barriers to using it [8], it is also vital to explore the person's social environment. The studies that were conducted among family members and health professionals focused on issues like assistive technology [27], robots allowing aging in place [28], technology for care services [11], strategies and barriers for communication technologies [29], and accepting personal alerting devices [30]. None directly addressed the older adults' specific needs for using technology in meaningful daily activities to promote health in crisis periods.

This Study's Goal

This study aimed to fill the literature gaps by exploring daily activity performance and technology use experiences among healthy, independent, older Israeli adults during COVID-19 using a 3-dimensional perspective (including older adults, their family members, and health professionals).

Methods

Overview

This study is part of a larger project, Empathic Platform to Personally Monitor, Stimulate, Enrich, and Assist Elders and Children in Their Environment (ESSENCE). The ESSENCE used opportunities arising during the COVID-19 pandemic to study vulnerable populations, including older adults and children. This paper provides the results of focus groups exploring older adults' daily activity performance experiences with technology in the COVID-19 pandemic context. The focus groups provided a multi-perspective window through diverse daily communication, allowing us to learn more about human experiences, desires, and concerns.

Ethics Approval

This study was approved by the University of Haifa Faculty Ethics Committee (086/21).

Procedures

Recruitment

We recruited participants using snowball sampling and social media. Participants received information about the study, signed online consent forms, and completed a short demographic questionnaire. We honored their willingness to share their experiences with gift certificates.

Data Collection

The data were collected between February 2021 and July 2022 (Israel was in lockdown part of this time). Using three types of focus groups (older adults, family members, and health professionals) allowed for triangulation, strengthening the results' validity [31].

The 9 focus group sessions were conducted by the first and third authors. We calculated the focus group size (6-7 participants each) according to Krueger and Casey's [32] guidelines. The moderators created a relaxed and friendly environment, encouraging participant interaction and continued data collection until the main issues were repeated and theoretical saturation was reached [33].

Participants

The 9 focus groups comprised 3 clusters. The clusters were:

1. Older adults (65 years and older) living independently at home and able to use a computer and Zoom software (n=20)
2. Family members of older adults deeply familiarized with the older adults' routines (n=19)
3. Health professionals with at least 5 years of experience working with older adults (n=20)

Table 1 presents each group's sociodemographic characteristics.

Table . Sociodemographic characteristics of study participants.

Characteristic		Older adults (n=20)	Family members (n=19)	Health professionals (n=20)
Gender, n (%)				
	Female	10 (50)	16 (84)	18 (90)
	Male	10 (50)	3 (16)	2 (10)
Level of family closeness, n (%)				
	First-degree family links	—[a]	15 (78)	—
	Second-degree family links	—	4 (21)	—
Health profession, n (%)				
	Doctor	—	—	2 (10)
	Nurse	—	—	4 (20)
	Occupational therapy	—	—	6 (30)
	Physiotherapy	—	—	3 (15)
	Social worker	—	—	3 (15)
	Day care director	—	—	2 (10)
Age (years), mean (SD)				
	Mean (SD)	70.8 (3.81)	39.16 (10.52)	49.85 (11.75)
	Range	66-80	21-55	33-70
Education (years), mean (SD)		15.7 (2.45)	16.5 (3.29)	—
Experience working with older adults (years)				
	Mean (SD)	—	—	17.95 (9.49)
	Range	—	—	5-35
Marital status, n (%)				
	Single	0 (0)	3 (16)	—
	Separated or divorced	3 (15)	4 (21)	—
	Married	14 (70)	12 (63)	—
	Widowed	3 (15)	0 (0)	—
Employment status, n (%)				
	Full-time	1 (5)	10 (53)	—
	Part-time	2 (10)	9 (47)	—
	Retired	17 (85)	0 (0)	—

[a] Not applicable.

Each focus group lasted approximately 60-70 minutes. They were conducted via Zoom videoconferencing software, video- and audio-recorded in Hebrew, and stored on the researchers' password-protected computers. The recordings were transcribed without details that could identify the participants. Once transcribed, the original records were deleted to maintain anonymity and confidentiality.

The researchers wrote reflective comments capturing verbal and nonverbal interactions during each focus group. Because the groups were conducted online, particular attention was paid to the older participants' needs. For instance, we offered support for difficulties in using technology. Support included help setting up an internet connection in another room and repeating the conversation issues. The broad perspective on older adults' use of technology during the focus group further enhanced the study's credibility.

Research Tools

The moderator's questions were customized for each group. However, the session structure, developed based on findings in the relevant literature [34], was similar for all three focus group types. It was designed to create a relaxing environment where participants felt free to share their experiences and thoughts. We invited the participants to introduce themselves and asked a general opening question to encourage active participation in the discussion: "What is your most enjoyable activity in your free time?" Additional questions were asked related to older adults' general daily function and routines, for example, "Would you be able to summarize your ordinary day, starting from the moment you wake up to the moment you go to sleep,” daily activity performance during the COVID-19 period (“How has the COVID-19 affected your daily activity performance in comparison to the routine before the COVID-19?”), and technology (“Which technology devices do you use and how do you use them?” and “How has the use of technology changed since the COVID-19?”).

Data Analysis

The data were analyzed according to thematic analysis and the constant comparative method [35] using Word (Microsoft Corporation) and Excel (Microsoft Corporation) worksheets. The researchers repeatedly reread the transcripts and reflective comments to familiarize themselves with the data and used the Office software to create memos related to the text. The data were then sorted, highlighted, and categorized by cases, and comparisons were made. Comprehensive coding was conducted to produce themes, and selective coding was performed to fit the theme precisely. Last, the quotations were rearranged into new categories and translated into English. We paid particular attention to the similarities and differences between participants’ experiences in each group and between the three groups [33,34,36,37]. In-depth discussions of any disagreements among the researchers were held in a series of research meetings with a researcher in the field and a qualitative researcher [38], improving the findings’ trustworthiness [36].

Results

Overview

We identified two main themes, with two subthemes each:

- Daily activity performance and health are intertwined.
    - Changes in daily activity performance affect health.
    - Meaningful activities shape a healthy routine.

Whereas older adults described how they adapted during the pandemic and used it for self-fulfillment, the family members and health professionals discussed its devastating effect, especially relative to physical and mental health.

- Technology use bridges functional limitations.
    - “It forced them to use technology.”
    - Opportunities to engage in daily activities.

While the COVID-19 pandemic was underway, technology allowed solutions to some challenges older adults faced. Thus, this extended period provided a window into their technology needs.

Daily Activity Performance and Health Are Intertwined

Changes in Daily Activity Performance Affect Health

Miriam (a 69-year-old female participant) illustrated the older adults’ changing daily activity performance during the lockdown period when they were required to stay home:

> *My previous routine included the whole culture thing. And I miss it very much...I live in a private house in Israel, and we saw the grandchildren. We were careful...We were restricted from going for a walk. Now, we can do a little more. It is very lacking, and it greatly affects my mood that I can’t go to the theater or plays or concerts. It is a central part of my life.*

Although she met with others, Miriam’s inability to participate in cultural activities, which she considered vital, affected her mood.

Racheli exemplified the family members’ descriptions of emotional reactions, changes in daily activity performance, and concerns about their older family members:

> *The Corona interrupted [my mother’s] blossom and somewhat stole the joy of her retirement...It was also very frustrating for her...It seems we cared more about her than she cared about herself...And suddenly, all the classes and everything moved to Zoom...It was also hard for her to follow, so [she lost] all her fun from “brain strength” or [other] kinds of things...She was keeping herself, feeling that she was suddenly deteriorating, and she struggled terribly with it—with this feeling and with trying not to be a burden on us, not expressing her loneliness so that we didn’t feel it, too.*

Racheli portrayed her mother’s frustration during this crisis period, in which activities were reduced, compared to her earlier delight in retirement. Although the situation and her loneliness affected Racheli’s mother, she did not share her feelings with the family.

The professional therapists’ perspectives added to this dimension while foregrounding the health-related implications. One physiotherapist referred to medical treatment, stating, “I don’t think we’ve even talked about all the medical treatments that people forgo in order not to go to, I don’t know what, hospitals, even dental treatments.”

A family therapist expounded, “I think the last year brought death closer to older people in a very present way,...and they are very busy with their physical health and fears that were not there before.”

The professional therapists included physical health alongside the fear, exemplifying how this crisis affected both physical and mental health and how they intertwine. A geriatrician described how the mental state caused stressful reactions:

> *I saw terrible examples of loneliness and anxiety...In the beginning, it really was all of us, even the children who, every day before Corona, would come in and hug their parents, and parents, as usual, would get along. Here, they came to the door of the house because they said it was forbidden to enter and it was forbidden to meet, and they left the food for them—left it for them. Rang the bell, but it wasn’t enough. I had terrible examples of people who were afraid, all the time using alcohol gel, and came [to me] with wounds on their hands and all kinds of terrible anxiety.*

Meaningful Activities Shape a Healthy Routine

Lea's (66-year-old woman) words illustrated how the older adults described adaptations that helped them cope with challenges in the COVID-19 period:

> *I also had a difficult time when everything was closed. In the more serious lockdowns, the children refused to come. I told them, "Come, I'm right at the limit in terms of age," but they didn't agree. On Passover, they came and put something for me by the door. And they told me, "We left something for you by the door." Flower...It was really...wow. On the other hand, I had a dog, so I would go for walks. So it helped because the dog took me for a walk in a way, so that was good. The garden saved me. The garden and the dog, and that's it; some phones.*

Daily meaningful outdoor activities such as walking her dog and tending her garden supported Lea during this challenging period. Similarly, Rebecca (a 70-year-old woman) demonstrated adaptation to the new situation to the point where she enjoyed it:

> *Compared to before? Obviously, I haven't left the house since the end of February. I was at home. And I'm telling you the truth, I really enjoyed it. I picked up, arranged, got to a lot of things that I hadn't gotten to in years...I adapted myself to the thought that this is what there is.*

The health professionals' focus groups discussed reasons for the shift in activities and their meaning. A paramedic described:

> *Until now, they were really assisted. First, their day would have been filled with grandchildren who would come,...you know, there would be a reason to go to the kitchen and make the meatballs this child loves...There was this thing, now, because of the whole last year that was not created, so they simply look for the meaning in other forms.*

According to that paramedic, these circumstances forced older adults to find solutions to their difficulties and continuity in routine, such as preparing meals for grandchildren, which supported their coping.

Technology Use Bridges Functional Limitations

"It Forced Them to Use Technology"

The COVID-19 pandemic restrictions required individual adjustments in daily activity performance. One prominent change was how technology was used in daily life. Michel (a 67-year-old man) described needing technology to perform social and leisure activities:

> *I don't know how I would have gotten through this period without technology. I started taking a course that stopped due to the Coronavirus. But during all these periods, there are, of course, Zooms and all kinds of lectures, even WhatsApp conversations between groups of friends.*

Rebecca described keeping her life active with technology while learning new skills:

> *This (virus) is unknown...It has stopped the whole world, and [we] just wait for it to pass and learn how to behave afterward. I was very active every day. And even now in Corona, I participate in Zoom, learning new things. There is nothing to be done; you must realize that this is the situation, and that is what there is.*

She described COVID-19 as a period of inactivity but also emphasized the need to acquire new skills, especially those related to technology.

The family members' and health professionals' groups also demonstrated how technology use became a necessity during COVID-19. Olivia, the daughter of an older adult, explained:

> *My father retired a short time before the Coronavirus, and then the Coronavirus started, and it really worried us; it was huge. And we said, "Okay, even this [retirement] transition, which seemed difficult for him, and then Corona." And it seemed way too much. But surprisingly—maybe because it was something worldly—my father really found himself. Like maybe because there was no alternative, and everyone was now in some kind of madness, so he really surprised us for the better. As if he really found himself. He is not a technological person, but he really found himself in Zooms, one after the other, such as lectures and all. Even to the extent that they hang up on us because they now have some Zoom.*

Olivia's quote shows that even though her father apparently had no knowledge of technology before the COVID-19 pandemic, he learned to use it because it was necessary and there was no alternative. The restrictions and lockdowns decreased communications with the outside world. A gerontology social worker noted technology use as a communication issue to consider:

> *We knew this even before the Coronavirus. There was a lot of work in this area, but obviously, during the Coronavirus, [digital literacy] jumped by hundreds of percent. And it was a sudden realization that it's something almost existential,...that it's nice fun, and it's enriching. You need a real existence for connection with the world.*

A nurse added, "It forced them to use [technology] because, otherwise, there is no option to communicate with the world." The social worker and the nurse emphasized that technology use becomes a virtual requirement for not only engaging in meaningful activities but also staying connected with the outside world.

Opportunities to Engage in Daily Activities

The older adult participants depicted their technology use according to their desires for meaningful activities, divided into three main domains: instrumental activities of daily living (IADL), leisure, and social activities.

Aharon (a 66-year-old man) described how COVID-19 affected IADL, especially shopping:

> *A notable thing that changed is a funny thing: Yes, shopping in the supermarket has become the whole of the Corona only through the Internet. It...yes, continues with it, almost never physically visiting the store.*

Jacob (a 79-year-old man) described technology use for leisure activities:

> *We tried to compensate (which was not possible in the pre-Corona period) during the Corona period...We play bridge online; there is an online option to play bridge with opponents from all over the world who enter the table and open and play for an hour or so...In the game of bridge, both partners play but do not see the cards each has. We arranged the two computers, so we sit back-to-back and don't see the partner's cards, and that's how we play, and it's very nice. Sometimes, when you lose, you get quite frustrated, but that's the game.*

Although Jacob played the game on an online platform, it seemed to provide the same experience as regular gaming. It made him feel he was compensating for activities he could not perform.

The availability of technology seemed to provide older adults more opportunities to participate in lessons than they were used to. Shira (69-year-old woman) described:

> *The timing of Corona was good for me. I felt I was already very tired when this rest came to me, and what helped me with Corona was Zoom. I am alone at home, and I have a son who lives with his partner. It helped me overcome this period. From morning to evening, on Zoom all the time. You don't have to sit in front of the screen; you also listen to the lectures.*

Shira described the benefits of the COVID-19 period, bringing her opportunities to rest and interact using Zoom.

Emma, a daughter of an older adult, added:

> *Now, during the Corona period, we bought [my mother] a smartphone that she didn't have before, and this made it very accessible for us to share with her...Every time she would send pictures by email, and when everyone is on WhatsApp and presses a button and forwards to everyone, then an email is already something a little more like sending a letter by post with a stamp. And she didn't always understand: "What's so hard for you? Well, send." The phone was a gift from us. We bought it for her birthday, but it gave us the option to share with her more and gave her another tool to help her orient herself.*

Communicating through advanced technology apparently provided Emma's mother opportunities to not only stay in touch with family but also feel a sense of belonging.

The health professionals described opportunities for older adults' remote health care. A paramedic explained:

> *They receive remote medical treatments...like they were sitting in front of doctors once upon a time. Who thought of it? So, coming from a generation connected with a wire to the wall, like a curled phone, everything was so terrible when talking face-to-face. Suddenly, they learned the whole young generation of today, and they are inside it. And I say up to higher studies, which is beautiful...They know how to use a computer at such a level as the Open University.*

The paramedic exemplified the incredible changes in the older population receiving health care during COVID-19, adjusting their habits to the realities of the COVID-19 period when people were required or encouraged to stay home.

Discussion

Principal Findings

COVID-19 had a substantial impact on people's health. Technology use supported the daily lives of Israeli older adults (65 years and older) and affected their health during the pandemic. Findings based on a 3-dimensional perspective (older adults, family members, and health professionals) highlight the overlaps and differences between perspectives and provide explanations of these findings. Overall, the findings point to older adults' need to stay active as a factor motivating their technology use.

Older Adults: Meaningful Activities Shape Healthy Routines

The participants described changes in daily activity performance, emphasizing COVID-19 constraints as causing emotional difficulties. Their descriptions demonstrate the effects of time and context on their activities and how *doing* and *being* interrelate from an occupational perspective [17]. Older Japanese adults described similar pain and fear emotions regarding their daily activity limitations [39]. The aging process alone includes substantial changes in routine (like retirement) and in the ability to engage in some activities due to biological, psychological, and social changes [3,40]. These aging characteristics, magnified in a crisis, underscore the importance of offering emotional support to older adults with daily activity performance limitations resulting from varying causes.

Despite limitations preventing them from reaching their aspirations and *becoming*, older adults seek adaptions and opportunities to remain active. They become involved in new activities, gain new skills, and find alternative methods (like using technology) to carry out their daily tasks. In line with previous research [19,20], this study's participants describe how staying engaged in leisure, educational, and outdoor activities (eg, gardening and walking) supported their daily routines during COVID-19.

Interestingly, the older adult participants tend to emphasize engaging in *secondary routines*, associated with preference and motivation (eg, leisure and social activities) rather than *primary routines*. *Primary routines* are behaviors vital for survival (eg, sleep and personal hygiene) and establish the general pattern of daily life [41,42]. The participants stressed the benefits of meaningful activities of pleasure, social interaction, and mental health, which motivate them to participate [43].

Specifically, older Israeli adults frequently mentioned social activities with family members, including religious rituals. The activities perceived as meaningful vary across cultures [21]. Older adults in Brazil, Italy, Portugal, and the United States viewed their social environment, including family and friends, and religious rituals as coping mechanisms. They underlined the crucial role of the family as a support system during the COVID-19 pandemic [13]. Somewhat differently, the older Israeli adults in this study often referred to activities with their families, indicating that maintaining contact with their relatives was paramount and composed a substantial part of their daily routines. Even with cultural differences, the value of the family to older adults in times of crisis is cross-cultural.

Family Members: Close Social Environments and Caring for a Loved One

Like the older participants, the family members described changes they noticed in their daily activity performance, including leisure, educational, and social activities. However, they exhibited greater concern for the older members of their families, prioritizing their loved ones' safety and emotional support. For instance, they worried about the older adults' increased vulnerability to the virus, the potential consequences to their health [7], and particularly their loneliness and unwillingness to share their struggles. Witnessing their loved ones' health deterioration and accelerated aging while experiencing their own COVID-19 challenges could increase the family members' mental burdens. Since they are a source of support for older adults [7], professional involvement is warranted in supporting both older adults and their family members during times of crisis.

Health Professionals: Health Implications

Similarly, to older adults and family members, health professionals outlined changes in meaningful activities. However, they added a main focus on ensuring the health and safety of older adults, drawing upon their expertise and knowledge [44]. Notably, the professional participants represented a wide range of fields; several were older than 60 years, allowing for valuable and unique insights. They assessed the situation accurately and objectively from a medical perspective, being equipped with knowledge of the aging process, and addressed health consequences, including mental and physical implications. They particularly noted loneliness, anxiety, and physical health symptoms associated with COVID-19 in older adults and stressed the importance of maintaining meaningful activities to enhance older adults' health. Consideration of these factors can contribute to older adults' health and well-being whenever they are faced with similar situations.

Focus Group Consensus: Technology Use Promotes Health

All focus groups agreed on technology's necessity. The need for technology during the COVID-19 pandemic might have played a role in the rise of older adults adopting and using technology [21]. Technology is indispensable for motivating them and meeting their needs in routine and crisis periods. During the COVID-19 pandemic, older adults had to cope with an unknown situation requiring them to use technology. Adapting to unfamiliar situations and using technology effectively require higher-order cognitive abilities of executive functions (eg, inhibition, working memory, cognitive flexibility, planning, and problem-solving) [45]. Although possibly the first affected by the cognitive dysfunction associated with aging, executive functions have a remarkable ability to maintain physical and mental health [46,47]. Therefore, it is vital to leverage the COVID-19 period by creating opportunities for older individuals to engage in unfamiliar digital activities, which could benefit executive functions and improve physical and mental health.

Technology benefits include opportunities for daily activities, especially IADL (eg, shopping and receiving remote health care), education, leisure, and social activities. As in previous research, this study's participants described how engaging in digital activities fostered a sense of belonging [48]. Focusing on technology's uses and benefits sheds light on older adults' needs, allowing them to increase their use of technology.

Limitations and Future Research

It is important to acknowledge this study's limitations. First, participation in online focus groups requires high functional abilities. Thus, the study might present a limited perspective on digital activity performance because potential participants with less technology proficiency were not included. Further, most participants in all groups were female, possibly introducing gender bias and limiting the diversity of perspectives represented in the study. Finally, the snowball sampling method increased the likelihood that some participants, particularly health professionals, had preexisting relationships.

Future studies should include participants with a more diverse range of technological proficiency and gender. Because participating in digital technology is vital to physical and mental health among the older adult population, further research should be conducted in both a qualitative and quantitative manner exploring technology's downsides, including its disadvantages and challenges for older adults. This could identify key principles for interventions to promote older adults' technology use.

Conclusion

This study illustrates the profound interplay between daily activities, physical and mental health, and technology use among Israeli older adults (65 years and older) using a 3-dimensional approach. Specifically, it delves into the perspectives of older adults, their family members, and health professionals. In light of an occupational perspective, older adults emphasize family connection activities as a significant aspect of their lives. Thus, when activities are restricted, it is imperative to provide emotional support to them and their families. All three groups emphasize the importance of digital activities for coping with changes in routines and activities and promoting emotional and physical health during crises. These findings apply to various circumstances that older adults may encounter, ranging from health conditions to crises. Whether facing personal challenges such as the loss of a loved one or coping with social upheavals like war, their daily lives may be affected. The focus on technological uses and benefits during COVID-19 sheds light on what older adults need to increase their technology use. Interventions for improving digital activity performance can be tailored to meet their needs and preferences by focusing on their secondary routines.

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Authors' Contributions

OCE contributed to data collection and analysis and writing the original draft. SR contributed to project administration, conceptualization, methodology, validation, analysis, writing, reviewing, and editing. MTC contributed to data collection and analysis. SM contributed to conceptualization, data collection, analysis, and editing. SF contributed to supervision, project administration, conceptualization, and funding acquisition. ND contributed toward conceptualization, data collection and analysis, validation, writing, reviewing, editing, and visualization.

Conflicts of Interest

None declared.

References

1. Wilcock AA. An Occupational Perspective of Health: Slack; 2006.
2. Law M, Cooper B, Strong S, Stewart D, Rigby P, Letts L. The Person-Environment-Occupation Model: a transactive approach to occupational performance. Can J Occup Ther 1996 Apr;63(1):9-23. [doi: 10.1177/000841749606300103]
3. Chalise HN. Aging: basic concept. Am J Biomed Sci Res 2019 Jan;1(1):8-10. [doi: 10.34297/AJBSR.2019.01.000503]
4. Greenwood-Hickman MA, Dahlquist J, Cooper J, et al. “They're Going to Zoom It”: a qualitative investigation of impacts and coping strategies during the COVID-19 pandemic among older adults. Front Public Health 2021 May 19;9:679976. [doi: 10.3389/fpubh.2021.679976] [Medline: 34095079]
5. Lipskaya-Velikovsky L. COVID-19 isolation in healthy population in Israel: challenges in daily life, mental health, resilience, and quality of life. Int J Environ Res Public Health 2021 Jan 23;18(3):999. [doi: 10.3390/ijerph18030999] [Medline: 33498662]
6. Hošnjak AM, Pavlović A. Older adults knowledge about using smart technology during the COVID-19 crisis: a qualitative pilot study. IFAC Pap OnLine 2021 Nov;54(13):675-679. [doi: 10.1016/j.ifacol.2021.10.529] [Medline: 38620852]
7. Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. Annu Rev Psychol 2020 Jan 4;71(1):635-659. [doi: 10.1146/annurev-psych-010419-050754]
8. Lee C, Coughlin JF. Perspective: older adults’ adoption of technology: an integrated approach to identifying determinants and barriers. J Product Innov Manag 2014 Jun 3;32(5):747-759. [doi: 10.1111/jpim.12176]
9. International Classification of Functioning, Disability and Health (ICF). World Health Organization. 2001. URL: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health [accessed 2024-05-10]
10. Segev-Jacubovski O. Changes in daily occupations patterns, optimism, and positive affect during COVID-19 lockdown. Can J Occup Ther 2023 Jun;90(2):152-160. [doi: 10.1177/00084174231166260] [Medline: 36987704]
11. Deusdad B, Riccò I. Professional stakeholders’ views of the use of digital technologies in Spanish long-term care. Hum Technol 2018;14:382-403. [doi: 10.17011/ht/urn.201811224839]
12. Ageing and health. World Health Organization. 2022. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2024-05-10]
13. Gonçalves AR, Barcelos JLM, Duarte AP, et al. Perceptions, feelings, and the routine of older adults during the isolation period caused by the COVID-19 pandemic: a qualitative study in four countries. Aging Ment Health 2022 May;26(5):911-918. [doi: 10.1080/13607863.2021.1891198] [Medline: 33645345]
14. Teramura A, Kimura Y, Hamada K, Ishimoto Y, Kawamori M. COVID-19-related lifestyle changes among community-dwelling older adult day-care users: a qualitative study. Int J Environ Res Public Health 2021 Dec 27;19(1):256. [doi: 10.3390/ijerph19010256] [Medline: 35010515]
15. Freedman VA, Hu M, Kasper JD. Changes in older adults’ social contact during the COVID-19 pandemic. J Gerontol B Psychol Sci Soc Sci 2022 Jul 5;77(7):e160-e166. [doi: 10.1093/geronb/gbab166] [Medline: 34529083]
16. Bailey L, Ward M, DiCosimo A, et al. Physical and mental health of older people while cocooning during the COVID-19 pandemic. QJM 2021 Nov 13;114(9):648-653. [doi: 10.1093/qjmed/hcab015] [Medline: 33471128]
17. Njelesani J, Tang A, Jonsson H, Polatajko H. Articulating an occupational perspective. J Occup Sci 2014 Apr 3;21(2):226-235. [doi: 10.1080/14427591.2012.717500]

18. Carlsson G, Granbom M, Fristedt S, et al. A hundred days in confinement: doing, being, becoming, and belonging among older people in Sweden during the COVID-19 pandemic. J Occup Sci 2022 Jul 3;29(3):402-416. [doi: 10.1080/14427591.2022.2057572]
19. Cruyt E, De Vriendt P, De Letter M, et al. Meaningful activities during COVID-19 lockdown and association with mental health in Belgian adults. BMC Public Health 2021 Mar 30;21(1):622. [doi: 10.1186/s12889-021-10673-4] [Medline: 33785029]
20. Finlay JM, Kler JS, O'Shea BQ, Eastman MR, Vinson YR, Kobayashi LC. Coping during the COVID-19 pandemic: a qualitative study of older adults across the United States. Front Public Health 2021 Apr 7;9:643807. [doi: 10.3389/fpubh.2021.643807] [Medline: 33898379]
21. Elimelech OC, Ferrante S, Josman N, et al. Technology use characteristics among older adults during the COVID-19 pandemic: a cross-cultural survey. Technol Soc 2022 Nov;71:102080. [doi: 10.1016/j.techsoc.2022.102080] [Medline: 35991080]
22. Cosco TD, Fortuna K, Wister A, Riadi I, Wagner K, Sixsmith A. COVID-19, social isolation, and mental health among older adults: a digital catch-22. J Med Internet Res 2021 May 6;23(5):e21864. [doi: 10.2196/21864] [Medline: 33891557]
23. Garcia KR, Rodrigues L, Pereira L, et al. Improving the digital skills of older adults in a COVID-19 pandemic environment. Educational Gerontology 2021 May 4;47(5):196-206. [doi: 10.1080/03601277.2021.1905216]
24. Murciano-Hueso A, Martín-García AV, Cardoso AP. Technology and quality of life of older people in times of COVID: a qualitative study on their changed digital profile. Int J Environ Res Public Health 2022 Aug 22;19(16):10459. [doi: 10.3390/ijerph191610459] [Medline: 36012093]
25. Abdallah L, Stolee P, Lopez KJ, Whate A, Boger J, Tong C. The impact of COVID-19 on older adults' perceptions of virtual care: qualitative study. JMIR Aging 2022 Oct 20;5(4):e38546. [doi: 10.2196/38546] [Medline: 36054599]
26. Desai S, McGrath C, McNeil H, Sveistrup H, McMurray J, Astell A. Experiential value of technologies: a qualitative study with older adults. Int J Environ Res Public Health 2022 Feb 16;19(4):2235. [doi: 10.3390/ijerph19042235] [Medline: 35206435]
27. van Heek J, Ziefle M, Himmel S. Caregivers' perspectives on ambient assisted living technologies in professional care contexts. Presented at: 4th International Conference on Information and Communication Technologies for Ageing Well and e-Health; Mar 22 to 23, 2018; Funchal, Madeira, Portugal. [doi: 10.5220/0006691400370048]
28. Bedaf S, Draper H, Gelderblom GJ, Sorell T, de Witte L. Can a service robot which supports independent living of older people disobey a command? The views of older people, informal carers and professional caregivers on the acceptability of robots. Int J Soc Robotics 2016 Jan 18;8(3):409-420. [doi: 10.1007/s12369-016-0336-0]
29. Arthanat S, Vroman KG, Lysack C, Grizzetti J. Multi-stakeholder perspectives on information communication technology training for older adults: implications for teaching and learning. Disabil Rehabil Assist Technol 2019 Jul;14(5):453-461. [doi: 10.1080/17483107.2018.1493752] [Medline: 30044659]
30. Thilo FJ, Hahn S, Halfens RJ, Heckemann B, Schols JM. Facilitating the use of personal safety alerting device with older adults: the views, experiences and roles of relatives and health care professionals. Geriatr Nurs 2021;42(4):935-942. [doi: 10.1016/j.gerinurse.2021.05.005] [Medline: 34130125]
31. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. Oncol Nurs Forum 2014 Sep;41(5):545-547. [doi: 10.1188/14.ONF.545-547] [Medline: 25158659]
32. Krueger RA, Casey MA. Focus Groups: A Practical Guide for Applied Research, 5th edition: Sage; 2014.
33. Rabiee F. Focus-group interview and data analysis. Proc Nutr Soc 2004 Nov;63(4):655-660. [doi: 10.1079/pns2004399] [Medline: 15831139]
34. Clarke V, Braun V. Successful Qualitative Research: A Practical Guide for Beginners: Sage; 2013.
35. Glaser BG. The constant comparative method of qualitative analysis. Soc Problems 1965 Apr;12(4):436-445. [doi: 10.2307/798843]
36. Merriam SB, Tisdell EJ. Qualitative Research: A Guide to Design and Implementation, 4th edition: John Wiley; 2015.
37. Morgan DL. Focus group interviewing. In: Gubrium JF, Holstein JA, editors. Handbook of Interview Research: Context and Method: Sage; 2002:159.
38. Kidd PS, Parshall MB. Getting the focus and the group: enhancing analytical rigor in focus group research. Qual Health Res 2000 May;10(3):293-308. [doi: 10.1177/104973200129118453] [Medline: 10947477]
39. Takashima R, Onishi R, Saeki K, Hirano M. Perception of COVID-19 restrictions on daily life among Japanese older adults: a qualitative focus group study. Healthcare 2020 Nov 1;8(4):450. [doi: 10.3390/healthcare8040450] [Medline: 33139662]
40. World report on ageing and health. World Health Organization. 2015. URL: https://apps.who.int/iris/handle/10665/186463 [accessed 2024-05-10]
41. Hou WK, Lai FTT, Hougen C, Hall BJ, Hobfoll SE. Measuring everyday processes and mechanisms of stress resilience: development and initial validation of the Sustainability of Living Inventory (SOLI). Psychol Assess 2019 Jun;31(6):715-729. [doi: 10.1037/pas0000692] [Medline: 30628819]
42. Hou WK, Lai FT, Ben-Ezra M, Goodwin R. Regularizing daily routines for mental health during and after the COVID-19 pandemic. J Glob Health 2020 Dec;10(2):020315. [doi: 10.7189/jogh.10.020315] [Medline: 33110518]

43. Palmer VJ, Gray CM, Fitzsimons CF, et al. What do older people do when sitting and why? Implications for decreasing sedentary behavior. Gerontologist 2019 Jul 16;59(4):686-697. [doi: 10.1093/geront/gny020] [Medline: 29771308]
44. Altın Z, Buran F. Attitudes of health professionals toward elderly patients during the COVID-19 pandemic. Aging Clin Exp Res 2022 Oct;34(10):2567-2576. [doi: 10.1007/s40520-022-02209-6] [Medline: 35986878]
45. Chambon C, Alescio-Lautier B. Improved executive functioning in healthy older adults after multifactorial cognitive training targeting controlled processes. J Syst Integr Neurosci 2019 Dec 2;6(1). [doi: 10.15761/JSIN.1000218]
46. Ferguson HJ, Brunsdon VEA, Bradford EEF. The developmental trajectories of executive function from adolescence to old age. Sci Rep 2021 Jan 14;11(1):1382. [doi: 10.1038/s41598-020-80866-1] [Medline: 33446798]
47. Diamond A. Executive functions. Annu Rev Psychol 2013;64:135-168. [doi: 10.1146/annurev-psych-113011-143750] [Medline: 23020641]
48. Thielke S, Harniss M, Thompson H, Patel S, Demiris G, Johnson K. Maslow's hierarchy of human needs and the adoption of health-related technologies for older adults. Ageing Int 2011 Jun 23;37(4):470-488. [doi: 10.1007/s12126-011-9121-4]

Abbreviations

ESSENCE: Empathic Platform to Personally Monitor, Stimulate, Enrich, and Assist Elders and Children in Their Environment
IADL: instrumental activities of daily living

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Technology Use Among Older Adults and Their Caregivers: Cross-Sectional Survey Study

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Abstract

Background: Informal caregivers are called upon to provide substantial care, but more needs to be known about technology use among older adult and caregiver dyads.

Objective: This study described technology use among older adults and their caregivers, explored potential correlates of technology use, and highlighted implications for practice.

Methods: A cross-sectional survey was conducted among unpaid caregivers of older adults (n=486). Primary outcomes were self-reported technology (devices and functions) use among caregivers and their oldest care recipient. The concordance of technology use among caregivers and care recipients was also examined. Multivariable regression models were conducted separately for caregivers and care recipients.

Results: Greater proportions of caregivers used all examined technologies, except for the medication alerts or tracking function, than care recipients. Caregivers used an average of 3.4 devices and 4.2 functions, compared to 1.8 devices and 1.6 functions used by their care recipients. Among caregivers, younger age, higher income, and higher education were associated with more technology use (*P*<.05). Among care recipients, younger age, not having cognitive dysfunction, and caregiver's technology use were associated with more technology use (*P*<.05).

Conclusions: Understanding technology use patterns and device adoption across diverse caregiver and care recipient populations is increasingly important for enhancing geriatric care. Findings can guide recommendations about appropriate technology interventions and help providers communicate and share information more effectively with patients and their caregivers.

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KEYWORDS

technology; caregiving; social determinants of health; health disparities; disparity; disparities; caregiver; caregivers; carers; technology use; usage; gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; cross-sectional; survey; surveys; computer use; device; devices; adoption; dyad; dyads

Introduction

Aging is occurring in most parts of the world [1]. Driven by the large baby boomer generation, the American population is aging rapidly [2], with 1 in 4 Americans estimated to be 65 years or older by 2060 [3]. Although healthy aging may be the "new normal" for some [4], normative age-related decline in physical and cognitive functions exists and often results in the need for assistance with daily household and self-care activities. Among 53 million American adult informal caregivers, nearly 42 million cared for adults aged 50 years or older [4,5]. Despite the many hours devoted to informal caregiving [4,5], many older adults face adverse consequences of unmet needs for assistance with daily activities [6,7]. In addition to inadequate caregiving resources for older Americans, the negative impacts of caregiving on caregivers' health and quality of life have raised significant programmatic and policy concerns [8-10].

An array of innovative technology solutions exists to support older adults' health, independence, and quality of life, enabling them to age in place [11-14]. These technologies also support caregivers and enhance caregiving for older adults in areas such as fall alert notifications, social supports, communication, and medication scheduling [15,16]. However, older age is frequently considered a prominent factor associated with diminished interest in, and adoption of, technology [17-19]. This can be attributed to unique barriers associated with older age, including the lack of experiences or familiarity and declining physical, cognitive, and sensory functions [20,21]. Although recent data suggest a narrowing of the age-based gap in the digital divide [5,22,23], data also show that older adults may not use technology to its full potential [5].

The latest national surveillance data showed that about 24% of baby boomers provided informal care [24], with older caregivers tending to provide care for care recipients at similar or older ages [25]. The existence of any age-related difficulty in accessing or using technology is relevant for understanding health technology use among older adults in need of care, as well as their older caregivers who can use technology for caregiving. Although abundant literature discusses technology use among older adults or caregivers [5,25-27], few studies have examined technology use among both older adults and their caregivers [28,29] and the potential relationship between older adults and their caregivers' technology use [16].

The relationship between older adults and their caregivers is interdependent, extending to their use of technology. Knowing the pattern of technology use in older adults and their caregivers can inform the development of technology-based interventions that are accessible and usable to the aging community. For example, a qualitative study involving patients with type 1 diabetes and their spouses revealed that continuous glucose monitoring technology can enhance spousal engagement in diabetes care, yet it may also introduce sources of tension within the relationship [30]. The qualitative study provided preliminary data to guide the development of a technology-based intervention, called SHARE plus [31]. In another recent study, Shih et al [32] focused on the different types of digital devices and categories of smartphone functions used by caregivers and care recipients compared to those with no caring roles. Shih et al [32] developed a health-related smartphone app for older adults and their caregivers, and their recent work was conducted to improve the design of their smartphone app.

Our study sought to further our understanding of how the use of technology by caregiver and care recipient dyads can guide intervention outlets (eg, digital platforms) and support efficient deployment of the technology interventions, including expanded access and use of technology functions. Therefore, technology use was broadly defined in this study to enable research into the use of diverse types of devices and functions. Devices and functions represent different aspects of technology use. Devices encompass the equipment or hardware of technology, whereas functions pertain to the specific tasks one can perform using technology. For instance, an individual may possess a smartphone, tablet, and computer but only use them for internet browsing. In contrast, another person with access solely to a smartphone may use it for various functions such as email and texting, internet browsing, web-based banking, and more. Analyzing devices and functions independently can offer more precise insights to inform future technology-based interventions for the aging community.

Our key aims were (1) to describe the use of various technologies (ie, both devices and functions) for caregivers and older adult care recipients; (2) to compare technology use among caregivers and older adult care recipients; and (3) to examine potential correlates of caregivers' and older adult care recipients' technology use. A study by Lindeman et al [33] offers a conceptual framework for identifying and addressing the challenges in technology-enabled solutions for family caregivers. While not yet a theoretical basis to study and analyze caregivers' and care recipients' use of technology, the conceptual framework by Lindeman et al [33] pointed to several factors that influence the caregivers' technology adoption. The individual-level moderators involved user capacity and family, and socioeconomic moderators encompassed race and ethnicity, income, and geographic location [33]. Rather than directly assessing user capacity, we explored factors potentially linked to user capacity, such as age and education for caregivers, and cognitive dysfunction for care recipients.

Methods

Data Source and Study Population

This study collected cross-sectional data from a web-based survey about technology use among paid and unpaid caregivers of older adults who were recruited through a Qualtrics panel. To be eligible to participate in the web-based survey, the respondents must have provided 8 or more hours of weekly care for at least 1 adult care recipient aged 50 years or older (N=626). Recognizing that caregivers may be caring for multiple individuals, the caregiver was asked to respond to the survey questions in the context of the oldest person to whom they provided at least 8 hours of care. Quota sampling was used to ensure data were collected from a diverse sample reflecting the general characteristics of the US caregiving population.

Predetermined targets were set: 75% of the recruited sample were to be female, 50% at least 50 years old, and no more than 60% White. Geographic targets were also set to represent the regional population proportion (ie, 17.2% in the Northwest, 20.9% in the Midwest, 23.8% in the West, and 38.1% in the South [34]). This study focused on unpaid caregivers (n=486). The web-based survey commenced with a set of screening questions to identify eligible individuals. Those who were not screened out were provided with study information necessary for informed consent. Only those who agreed to participate were invited to complete the web-based survey.

This study differentiated between technology devices and technology functions. The respondents were asked whether they used each of the 7 devices (ie, cell phone, smartphone, tablet, computer, e-reader, voice-activated assistant, and wearable or smartwatch for activity tracking) and 8 functions (ie, communication, ride-sharing, online shopping, online banking, navigation, online entertainment, medication alerts or tracking, and physical activity tracking). The types of devices and functions were determined based on the 2020 AARP *Tech and the 50+ Survey* report [25]. We dropped some of the minimally used devices (eg, virtual reality device, 1%) and combined functions (eg, instead of individually assessing games, music, and video or movie streaming, they were consolidated into the "online entertainment" category) [25]. The respondents were also asked about their oldest care recipients' use of the same devices and functions. The total numbers of devices (ranging from 0 to 7) and functions (ranging from 0 to 8) used were calculated separately for caregivers and care recipients.

Socioeconomic and demographic characteristics of the respondents were collected using the web-based survey: age (years), sex (male or female), race and ethnicity (Non-Hispanic White or others), household income (less than US $50,000 or US $50,000 or more), and education (high school graduate and lower educational attainment or higher). The web-based survey also asked about the respondents' place of residence (zip code), and rural-urban commuting area codes were used to classify the place of residence into rural or urban areas. The respondents were also asked about their oldest care recipient's age and place of residence (rural or urban areas classified based on the care recipient's zip code). Respondents who reported being aware of their care recipient's chronic conditions were also asked about their care recipients' cognitive dysfunction (eg, dementia) and sensory impairment (eg, severe vision or hearing problems).

Statistical Analysis

Frequencies and percentages or means and SDs were used to describe the caregivers' and their care recipients' background information and use of technology devices and functions. Cohen κ statistics were estimated to examine the concordance of technology use among caregivers and care recipients. The magnitude of matching was classified into poor ($\kappa<0.20$), fair ($\kappa=0.21$-0.40), moderate ($\kappa=0.41$-0.60), good ($\kappa=0.61$-0.80), and very good ($\kappa=0.81$-1.00) matching categories. Along with Cohen κ coefficient estimation, the McNemar test was performed to compare the marginal proportions of caregivers and care recipients using or not using each technology. Next, separate multivariable Poisson regression analyses were performed to predict the total number of devices and functions used among caregivers based on caregivers' age, sex, race and ethnicity, household income, education, and place of residence. Separate multivariable Poisson regression analyses were performed to predict the total number of devices and functions used among care recipients based on the care recipients' age, place of residence, cognitive dysfunction, and sensory impairment and the total number of devices and functions used among caregivers. Only 438 (90.1%) out of 486 respondents were aware of their care recipients' chronic conditions; therefore, the regression models for predicting care recipients' technology use included a smaller sample size than the regression models for predicting caregivers' technology use. All statistical analyses were performed using SAS 9.4 (SAS Institute Inc), and a significance level of .05 was used.

Ethical Considerations

The informed consent document was integrated at the outset of the web-based survey, and only those who agreed to participate proceeded to the subsequent sections of the survey. Given the web-based nature of the study, a waiver of documentation of informed consent was requested. Upon the completion of the study, any personally identifiable information (zip code) was deleted and age was truncated to 90 years old. Within Qualtrics, participant stipends were integrated into the survey, and each participant received a stipend upon the completion of the study. Based on the estimate provided Qualtrics, each participant was paid between US $7 and US $8. The study has been reviewed and approved by the Texas A&M University Institutional Review Board (IRB2019-1128M).

Results

Study Participants

The average age was 60.8 (SD 12.11) years for caregivers and 74.9 (SD 11.61) years for their oldest care recipient (Table 1). The majority of caregivers were female (363/485, 74.8%) and non-Hispanic White (331/483, 68.5%). Nearly 50% (241/486) had a household income less than US $50,000, and 20.6% (100/486) had high school or lower educational attainment. In all, 9.1% (44/483) of caregivers and 9.5% (46/482) of care recipients resided in rural areas. Of the 438 care recipients with available information, 43.2% (n=189) had cognitive dysfunction and 32.9% (n=144) had sensory impairment. On average, the caregivers used 3.4 devices and 4.2 functions, and their oldest care recipients used 1.8 devices and 1.6 functions.

Table . Characteristics of caregivers and care recipients and their technology use (n=486).

Characteristics	Caregivers	Care recipients
Age (y), mean (SD)	60.8 (12.11)	74.9 (11.61)
Female, n/N (%)	363/485 (74.8)	N/A[a]
Non-Hispanic White, n/N (%)	331/483 (68.5)	N/A
Household income less than US $50,000, n/N (%)	241/486 (49.6)	N/A
High school or lower educational attainment, n/N (%)	100/485 (20.6)	N/A
Rural residence, n/N (%)	44/483 (9.1)	46/482 (9.5)
Having cognitive dysfunction, n/N (%)[b]	N/A	189/438 (43.2)
Having sensory impairment, n/N (%)[b]	N/A	144/438 (32.9)
Number of devices used, mean (SD)[c]	3.4 (1.35)	1.8 (1.49)
Number of functions used, mean (SD)[d]	4.2 (1.73)	1.6 (1.92)

[a] N/A: not available.

[b] Cognitive function and sensory impairment information was only available for care recipients and reported by 556 (88.8%) out of 626 total eligible caregivers.

[c] Number of devices used ranged from 0 to 7.

[d] Number of functions used ranged from 0 to 8.

Comparing Technology Use Among Caregivers and Care Recipients

McNemar tests showed that significantly greater proportions of caregivers used all examined technologies than their care recipients (all $P<.05$), with the exception of the medication alerts or tracking function ($P=.45$; Table 2). κ coefficients ranged from 0.09 to 0.42 (Table 3), indicating a poor to moderate degree of matching (ie, concurrent use or no use) of technology among caregivers and care recipients. For example, there were 84% (404/481) of dyads in which the caregiver used a computer, yet there were only 31.2% (150/481) of dyads in which both the caregiver and care recipient used a computer.

Table . Use of different devices and functions among caregivers and care recipients (n=486).

Variables		Caregivers, n/N (%)	Care recipients, n/N (%)	*P* value[a]
Devices				
	Cell phone	268/481 (55.7)	231/481 (48)	.002
	Smartphone	396/480 (82.5)	209/480 (43.5)	<.001
	Tablet	263/481 (54.7)	112/481 (23.3)	<.001
	Computer	404/481 (84)	160/481 (33.3)	<.001
	E-reader	98/480 (20.4)	44/480 (9.2)	<.001
	Voice-activated assistant	143/481 (29.7)	74/481 (15.4)	<.001
	Wearables for activity tracking	73/481 (15.2)	34/481 (7.1)	<.001
Functions				
	Communication	407/481 (84.6)	178/481 (37)	<.001
	Ride-sharing	95/480 (19.8)	29/480 (6)	<.001
	Online shopping	393/481 (81.7)	133/481 (27.7)	<.001
	Online banking	358/480 (74.6)	119/480 (24.8)	<.001
	Navigation	333/479 (69.5)	89/479 (18.6)	<.001
	Online entertainment	271/480 (56.5)	128/480 (26.7)	<.001
	Medication alerts or tracking	56/481 (11.6)	50/481 (10.4)	.45
	Physical activity tracking	92/481 (19.1)	39/481 (8.1)	<.001

[a] *P* value from the McNemar test examining whether there is a statistically significant difference in the proportions of caregivers and care recipients using or not using each technology.

Table . Use and nonuse of different devices and functions in both caregivers and care recipients (n=486).

Variables		Use by both caregivers and care recipients, n/N (%)	Nonuse by both caregivers and care recipients, n/N (%)	Cohen κ coefficient[a]
Devices				
	Cell phone	180/481 (37.4)	162/481 (33.7)	0.42
	Smartphone	194/480 (40.4)	69/480 (14.4)	0.17
	Tablet	87/481 (18.1)	193/481 (40.1)	0.20
	Computer	150/481 (31.2)	67/481 (13.9)	0.11
	E-reader	26/480 (5.4)	364/480 (75.8)	0.27
	Voice-activated assistant	58/481 (12.1)	322/481 (66.9)	0.42
	Wearables for activity tracking	16/481 (3.3)	390/481 (81.1)	0.22
Functions				
	Communication	168/481 (34.9)	64/481 (13.3)	0.12
	Ride-sharing	20/480 (4.2)	376/480 (78.3)	0.25
	Online shopping	127/481 (26.4)	82/481 (17)	0.12
	Online banking	105/480 (21.9)	108/480 (22.5)	0.11
	Navigation	75/479 (15.7)	132/479 (27.6)	0.09
	Online entertainment	122/480 (25.4)	203/480 (42.3)	0.39
	Medication alerts or tracking	22/481 (4.6)	397/481 (82.5)	0.34
	Physical activity tracking	20/481 (4.2)	370/481 (76.9)	0.22

[a] Poor (κ>0.20), fair (κ=0.21-0.40), moderate (κ=0.41-0.60), good (κ=0.61-0.80), and very good (κ=0.81-1.00) matching.

Correlates of Technology Use Among Caregivers

The multivariable Poisson regression analyses suggested that the expected number of devices used among caregivers with household incomes less than US $50,000 was 0.88 times the number of devices used among those with household incomes of US $50,000 or more (*P*=.02; Table 4). Using a separate regression analysis, the results indicated that the adjusted mean number of functions used among caregivers decreased by 0.8% for every 1-year increase in the caregivers' age (*P*<.001). Additionally, the adjusted mean number of functions used among caregivers was negatively associated with household income (b=−0.097; *P*=.04) and educational attainment (b=−0.188; *P*=.002). The estimated number of functions used among caregivers in the lower household income and lower educational attainment categories was significantly lower than that of caregivers with higher socioeconomic status.

Table . Multivariable Poisson regression analysis for predicting the total number of devices and functions used among caregivers (n=486).

Outcome and variables		b[a] (SE)	IRR[b] (95% CI)	*P* value
Number of devices				
	Age	0.001 (0.002)	1.001 (0.997-1.005)	.67
	Female	0.035 (0.059)	1.036 (0.923-1.162)	.55
	Non-Hispanic White	−0.026 (0.054)	0.975 (0.877-1.083)	.63
	Household income less than US $50,000	−0.130 (0.053)	0.878 (0.791-0.975)	.02
	High school or lower educational attainment	−0.086 (0.066)	0.918 (0.806-1.045)	.20
	Rural residence	−0.079 (0.094)	0.924 (0.769-1.110)	.40
Number of functions				
	Age	−0.008 (0.002)	0.992 (0.989-0.996)	<.001
	Female	−0.017 (0.053)	0.983 (0.886-1.090)	.74
	Non-Hispanic White	−0.046 (0.048)	0.955 (0.869-1.049)	.34
	Household income less than US $50,000	−0.097 (0.048)	0.908 (0.826-0.998)	.04
	High school or lower educational attainment	−0.188 (0.061)	0.829 (0.735-0.934)	.002
	Rural residence	−0.068 (0.085)	0.934 (0.792-1.103)	.42

[a] b: regression coefficient.

[b] IRR: incidence rate ratio.

Correlates of Technology Use Among Care Recipients

For care recipients, age and cognitive dysfunction were negatively associated with number of devices (b=−0.024; *P*<.001 and b=−0.394; *P*<.001, respectively) and functions (b=−0.032; *P*<.001 and b=−0.370; *P*=.002, respectively; Table 5). In contrast, caregivers' technology use was positively associated with care recipients' technology use (b=0.184; *P*<.001 for devices and b=0.238; *P*<.001 for functions; Table 5).

Table . Multivariable Poisson regression analysis for predicting the total number of devices and functions used among care recipients (n=438).

Outcome and variables		b[a] (SE)	IRR[b] (95% CI)	*P* value
Number of devices				
	Age	−0.024 (0.003)	0.976 (0.970-0.983)	<.001
	Rural residence	−0.102 (0.125)	0.903 (0.707-1.154)	.41
	Cognitive dysfunction	−0.394 (0.080)	0.675 (0.577-0.789)	<.001
	Sensory impairment	0.002 (0.082)	1.002 (0.854-1.176)	.98
	Number of devices used by caregiver	0.184 (0.027)	1.202 (1.142-1.267)	<.001
Number of functions				
	Age	−0.032 (0.005)	0.969 (0.960-0.979)	<.001
	Rural residence	−0.069 (0.186)	0.934 (0.648-1.344)	.71
	Cognitive dysfunction	−0.370 (0.121)	0.691 (0.545-0.876)	.002
	Sensory impairment	−0.038 (0.123)	0.963 (0.756-1.225)	.76
	Number of devices used by caregiver	0.238 (0.033)	1.269 (1.189-1.354)	<.001

[a] b: regression coefficient.

[b] IRR: incidence rate ratio.

Discussion

Principal Findings

Based on the data analysis and results analyzed in the above section, some key findings provide a fuller and more specific understanding of older adults' and their caregivers' use of digital technologies and highlight the contextual factors that may either affect resistance or enhance accessibility and receptivity of technology-based interventions in a broader caregiver population.

Key findings and reflections on current and parallel research are presented below.

Use of Technology and Comparison

This study examined unpaid caregivers' use of various technology and their reports of their older adult care recipient's use. It was observed that a greater proportion of caregivers reported using technologies themselves than being used by their care recipients. In our study, although 82.5% (396/480) and 84% (404/481) of caregivers reported using smartphones and computers, only 43.5% (209/480) and 33.3% (160/481) of older adults used smartphones and computers, respectively. This implies greater access to technology by caregivers than their older adult care recipients. Furthermore, although caregivers reported a higher number of functions used than the number of device types used (eg, 3.4 devices and 4.2 functions), their older care recipients reported a fewer number of functions than the number of device types used (eg, 1.8 devices and 1.6 functions). These findings imply that caregivers are more likely to maximize the potential of a technology than their care recipients, who are typically older and in poorer health [20,21]. Our findings support the 2020 AARP tech trend report [5], which pointed out that despite older adults' high engagement with their devices, "many are not using the technology to its full potential." For example, fewer than half of smart home assistant or smart speaker owners used the device daily according to the 2019 national survey [5]. Although the proportion increased to about 57% in 2023 [35], the rate has still remained relatively low. The value of technology in enabling aging in place and reducing caregiver burden will only become further enhanced when these devices can be used to their fullest potential by older adults.

The age-related discrepancy in technology adoption is likely to be associated with skills in using technology but also with attitudes related to technology. For example, "perceived needs" is an important attitudinal factor in behavior adoption [36]. In this study, there was the lack of statistically significant differences between caregivers and their care recipients in medication management technology. These findings are consistent with research by both Abrashkin et al [28] and Portz et al [37], who also found that older adults in an advanced illness management program had significantly less access to and confidence in using technology (eg, computer, internet, tablet, and cell phone) than the program enrollees' caregivers, except for medical alert devices such as medication management systems [28,37]. While the reasons underlying these findings have not been fully examined yet, this could be related to a similar level of perceived needs by both parties.

Correlates of Technology Use in Caregivers

Among caregivers, older age and lower socioeconomic factors (household income and education) were negatively associated with the number of technological devices or functions used. This finding is consistent with extant literature [38-41]. Our study further explores this relationship by revealing a difference between devices and functions. Although the number of technological devices used by caregivers was only significantly associated with household income, the number of technological functions in use was associated with multiple factors (ie, age, household income, and education).

Regarding ownership or access to technological devices, the age and socioeconomic aspects of the digital divide seem to be narrowing [5]. However, the age and socioeconomic aspects of the digital divide appear to remain in technology use [42]. Among the more critical issues facing many older adults in using digital devices such as smartphones and tablets, they lack the basic digital literacy required to use multimedia interactive devices with touchscreen technology [43,44], and their digital literacy level is likely to diminish with age [35]. Assumptions in the past were that if access to devices and basic training were provided, the "grey span" of the digital divide could be eliminated. For older adults, each new operating system revision or interface for existing devices can be a traumatic event, as what worked before no longer does. Cao et al [45] described the information overload and system feature overload of new digital applications that resulted in increased fatigue and technostress of the older adult users, further increasing their resistance to technology adoption. These findings align with the AARP national survey findings indicating a limited set of tasks performed by older adults on technology [5,35]. This continuing of the digital divide can disproportionately impact caregiving for older care recipients, especially those whose primary caregivers are often older adults.

Correlates of Technology Use in Care Recipients

Our study found that, for care recipients, age and cognitive dysfunction were negatively associated with the number of devices and functions. In contrast, care recipients' use of a device or function was positively associated with the use of the technology among their caregivers. Along with the previous findings about the correlates of technology use in caregivers, these findings align with Baishya and Samalia's [46] assertion that technology adoption is contextual. This study's findings emphasize the need for additional research to identify and understand the contextual factors to enhance the accessibility and receptivity of technology-based interventions in a broader aging community.

Limitations

This study is not without limitations. Efforts were made to diversify the convenience Qualtrics panel sample by specifying the proportion of sample characteristics of respondents to ensure heterogeneity in key factors such as age, gender, race and ethnicity, and geographic region. However, this study did not use probability sampling and is subject to a potential nonprobability sampling bias. For example, given the nature of web-based recruitment, the study population already has access to the internet. Although the majority of caregivers have access to the internet (eg, 78% in 2018 [47]), the study findings may not be generalizable to a group of caregivers without access to the internet. Additionally, this study used proxy responses for care recipients' technology use (ie, as reported by their caregivers). Further, some key sociodemographic characteristics of care recipients were not collected.

Our restriction to unpaid caregivers who provided at least 8 weekly hours of care was intended to ensure that caregivers were familiar with their care recipients. However, it is important to note that previous literature indicates that caregivers tend to underestimate care recipients' physical and cognitive functions and certain activities [48,49] and may also be imprecise in reporting technology use. In this study, many care recipients had cognitive impairments or sensory impairments, which might have adversely affected caregivers' perception of care recipients' user capacity and actual use of technology. However, we also note that many older persons do experience these functional limitations and impairments and their inclusion is important for reflecting health conditions and technology use in this population, albeit recognizing reporting limitations. This study was not able to differentiate the cross-use or whether the technology was used explicitly for caregiving functions. Future studies can benefit from the specification of the purpose of different technologies related to caregiving tasks and more precise measurement of care recipients' technology use, such as daily diary use of technology devices and functional use over a specified period of time or digital tracking of technology use.

This study was conducted prior to the onset of the COVID-19 pandemic; hence, it does not reflect what might have changed in attitude toward or use of technologies, as well as the evolution of technologies. However, it differentiates between technology use and function among both caregivers and care recipients and provides important insights related to disparities in access to technology, which was a critical factor in access to health care and other social services during the COVID-19 pandemic. Furthermore, despite the increase in technology use in older adults since the COVID-19 pandemic, this study's findings align with the more recent report on older adults' technology use pattern regarding the use of functions and socioeconomic correlates (eg, income) [35].

Conclusions

With the increasing use of technology solutions for caregiving that are becoming available on the market, it is important to be aware of factors associated with the current digital divide in technology use—both in terms of the number and diversity of devices and their functional use. It is critical to look forward to what the future might hold regarding the technology being used to reduce caregiver burden and enhance care recipients' health, independence, and quality of life. A digital divide among older adults can exacerbate greater health disparity since technology is a powerful source for obtaining information and communicating with health care and social service providers [50].

A major finding from this study was the existence of significant disparities in the use of technological devices and functions among caregivers and their older adult care recipients. Among caregivers, significant differences were observed in technology use based on age and socioeconomic factors. In addition, this study suggested that caregivers' technology use is an enabling factor for older care recipients' technology use, independent of advanced age and cognitive impairment, which depressed use, indicating pathways for clinical intervention.

This study was conducted before the onset of the COVID-19 pandemic, which demonstrated the growing importance of connecting on the web for basic health care. The extent to which observed relationships between individual and socioeconomic moderators and technology use have changed since COVID-19 is a question for further study. The importance of technology use has become more salient during the recommended "physically distant stay at home" orders for older adults to stay socially connected with loved ones or professional social connectors, whether living at home, in assisted living facilities, or even nursing homes [51]. Additionally, familiarity with or access to technology can facilitate or act as a barrier to obtaining COVID-19 vaccinations. For example, the reach of a digital platform to track vaccinations and make follow-up interactions among older adult populations, who would benefit greatly from such technology, will depend largely upon the extent telecommunication or telehealth is used or accepted by older adults or their caregivers.

In summary, this study adds to the rapidly expanding field of technology in the health and aging realm by describing potential contextual factors in technology use, which may contribute to the disparities in technology use among older adults and their care recipients [52,53]. Further efforts are needed to expand the understanding of how these contextual factors contribute to technology adoption among caregivers and their care recipients and the benefits and costs of such technological innovations [54]. Especially relevant is how social workers, health professionals, educators, and the community can facilitate and maintain appropriate use of new and emerging technology for critical interactions normally and enable access to the needed caregiver and social resources during the COVID-19 pandemic or after it subsides. Furthermore, future research could gain additional benefits by concentrating on broader categories of functions. This approach would enable a more targeted investigation into particular functions related to specific outcomes, such as economic functions and financial health.

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Authors' Contributions

MGO lead the study conceptualization and manuscript development. SL conducted all statistical analyses. All authors contributed to the study conceptualization, data collection, and development and revision of the manuscript.

Conflicts of Interest

None declared.

References

1. United Nations, Department of Economic and Social Affairs, Population Division. World population ageing 2019: highlights. : United Nations; 2019 URL: https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Highlights.pdf [accessed 2024-03-08]
2. Mather M, Jacobsen LA, Pollard KM. Aging in the United States. Population Bulletin 70, no. 2: Population Reference Bureau; 2015 Dec URL: https://www.prb.org/wp-content/uploads/2016/01/aging-us-population-bulletin-1.pdf [accessed 2024-03-08]
3. Vespa J, Armstrong DM, Medina L. Demographic turning points for the United States: population projections for 2020 to 2060. United States Census Bureau. 2018 Feb. URL: https://www.census.gov/library/publications/2020/demo/p25-1144.html [accessed 2024-04-18]
4. Ory MG, Smith ML. What if healthy aging is the 'new normal'? Int J Environ Res Public Health 2017 Nov 15;14(11):1389. [doi: 10.3390/ijerph14111389] [Medline: 29140264]
5. National Alliance for Caregiving, AARP. Caregiving in the U.S. : AARP; 2020 May URL: https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf [accessed 2024-03-08]
6. Abdi S, Spann A, Borilovic J, de Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF). BMC Geriatr 2019 Jul 22;19(1):195. [doi: 10.1186/s12877-019-1189-9] [Medline: 31331279]
7. Freedman VA, Spillman BC. Disability and care needs among older Americans. Milbank Q 2014 Sep;92(3):509-541. [doi: 10.1111/1468-0009.12076] [Medline: 25199898]
8. Hopps M, Iadeluca L, McDonald M, Makinson GT. The burden of family caregiving in the United States: work productivity, health care resource utilization, and mental health among employed adults. J Multidiscip Healthc 2017 Dec 6;10:437-444. [doi: 10.2147/JMDH.S135372] [Medline: 29255364]
9. Swartz K, Collins LG. Caregiver care. Am Fam Physician 2019 Jun 1;99(11):699-706. [Medline: 31150177]
10. Cohen SA, Sabik NJ, Cook SK, Azzoli AB, Mendez-Luck CA. Differences within differences: gender inequalities in caregiving intensity vary by race and ethnicity in informal caregivers. J Cross Cult Gerontol 2019 Sep;34(3):245-263. [doi: 10.1007/s10823-019-09381-9] [Medline: 31407137]

11. Abrahms S. New technology could allow you or your parents to age at home. AARP Bulletin. 2014 Mar 19. URL: https://www.aarp.org/home-family/personal-technology/info-2014/is-this-the-end-of-the-nursing-home.html [accessed 2024-03-08]
12. Maresova P, Javanmardi E, Barakovic S, et al. Consequences of chronic diseases and other limitations associated with old age - a scoping review. BMC Public Health 2019 Nov 1;19(1):1431. [doi: 10.1186/s12889-019-7762-5] [Medline: 31675997]
13. Wang S, Bolling K, Mao W, et al. Technology to support aging in place: older adults' perspectives. Healthcare (Basel) 2019 Apr 10;7(2):60. [doi: 10.3390/healthcare7020060] [Medline: 30974780]
14. Dogra S, Dunstan DW, Sugiyama T, Stathi A, Gardiner PA, Owen N. Active aging and public health: evidence, implications, and opportunities. Annu Rev Public Health 2022 Apr 5;43:439-459. [doi: 10.1146/annurev-publhealth-052620-091107] [Medline: 34910580]
15. Madara Marasinghe K. Assistive technologies in reducing caregiver burden among informal caregivers of older adults: a systematic review. Disabil Rehabil Assist Technol 2016;11(5):353-360. [doi: 10.3109/17483107.2015.1087061] [Medline: 26371519]
16. Vollmer Dahlke D, Lee S, Smith ML, Shubert T, Popovich S, Ory MG. Attitudes toward technology and use of fall alert wearables in caregiving: survey study. JMIR Aging 2021 Jan 27;4(1):e23381. [doi: 10.2196/23381] [Medline: 33502320]
17. Francis J, Ball C, Kadylak T, Cotten SR. Aging in the digital age: conceptualizing technology adoption and digital inequalities. In: Neves BB, Vetere F, editors. Ageing and Digital Technology: Springer; 2019:35-49. [doi: 10.1007/978-981-13-3693-5_3]
18. Vaportzis E, Clausen MG, Gow AJ. Older adults perceptions of technology and barriers to interacting with tablet computers: a focus group study. Front Psychol 2017 Oct 4;8:1687. [doi: 10.3389/fpsyg.2017.01687] [Medline: 29071004]
19. McGrath C, Corrado AM. The environmental factors that influence technology adoption for older adults with age-related vision loss. Br J Occup Ther 2019 Aug;82(8):493-501. [doi: 10.1177/0308022618813247]
20. Lee C, Coughlin JF. Perspective: older adults' adoption of technology: an integrated approach to identifying determinants and barriers. J Prod Innov Manage 2015 Sep;32(5):747-759. [doi: 10.1111/jpim.12176]
21. Mitzner TL, Savla J, Boot WR, et al. Technology adoption by older adults: findings from the PRISM trial. Gerontologist 2019 Jan 9;59(1):34-44. [doi: 10.1093/geront/gny113] [Medline: 30265294]
22. Levine DM, Lipsitz SR, Linder JA. Trends in seniors' use of digital health technology in the United States, 2011-2014. JAMA 2016 Aug 2;316(5):538-540. [doi: 10.1001/jama.2016.9124] [Medline: 27483069]
23. Vogels EA. Millennials stand out for their technology use, but older generations also embrace digital life. Pew Research Center. 2019 Sep 9. URL: https://www.pewresearch.org/fact-tank/2019/09/09/us-generations-technology-use/ [accessed 2024-03-08]
24. Miyawaki CE, Bouldin ED, Taylor CA, McGuire LC. Baby boomers as caregivers: results from the Behavioral Risk Factor Surveillance System in 44 states, the District of Columbia, and Puerto Rico, 2015-2017. Prev Chronic Dis 2020 Aug 13;17:E80. [doi: 10.5888/pcd17.200010] [Medline: 32790608]
25. 2020 Tech and the 50+ Survey. : AARP; 2019 Dec URL: https://www.aarp.org/content/dam/aarp/research/surveys_statistics/technology/2019/2020-tech-trends-survey.doi.10.26419-2Fres.00329.001.pdf [accessed 2024-03-08]
26. Project Catalyst. Caregivers & technology: what they want and need. : AARP; 2016 Apr. [doi: 10.26419/res.00191.002]
27. Gell NM, Rosenberg DE, Demiris G, LaCroix AZ, Patel KV. Patterns of technology use among older adults with and without disabilities. Gerontologist 2015 Jun;55(3):412-421. [doi: 10.1093/geront/gnt166] [Medline: 24379019]
28. Abrashkin KA, Patel V, Kozikowski A, Zhang M, Poku A, Pekmezaris R. Access to and confidence in using technology among homebound older adults and caregivers. J Am Med Dir Assoc 2018 Nov;19(11):1023-1024. [doi: 10.1016/j.jamda.2018.05.023] [Medline: 30006014]
29. van Boekel LC, Wouters EJM, Grimberg BM, van der Meer NJM, Luijkx KG. Perspectives of stakeholders on technology use in the care of community-living older adults with dementia: a systematic literature review. Healthcare (Basel) 2019 May 28;7(2):73. [doi: 10.3390/healthcare7020073] [Medline: 31141999]
30. Allen NA, Litchman ML, Neller S, et al. Couples managing type 1 diabetes using diabetes technology. Diabetes Spectr 2021 Nov;34(4):378-387. [doi: 10.2337/ds20-0045] [Medline: 34866871]
31. Allen NA, Grigorian EG, Mansfield K, Berg CA, Litchman ML. Continuous glucose monitoring with data sharing in older adults: a qualitative study. J Clin Nurs 2023 Oct;32(19-20):7483-7494. [doi: 10.1111/jocn.16808] [Medline: 37345621]
32. Shih M, Lee WCM, Tzeng HM, Serag H, Raji M. Comparing use patterns and acceptability of mobile digital devices between care recipients and caregivers. Cureus 2023 Jul 13;15(7):e41832. [doi: 10.7759/cureus.41832] [Medline: 37575767]
33. Lindeman DA, Kim KK, Gladstone C, Apesoa-Varano EC. Technology and caregiving: emerging interventions and directions for research. Gerontologist 2020 Feb 14;60(Suppl 1):S41-S49. [doi: 10.1093/geront/gnz178] [Medline: 32057082]
34. 2018 National and state population estimates. United States Census Bureau. 2018 Dec 19. URL: https://www.census.gov/newsroom/press-kits/2018/pop-estimates-national-state.html [accessed 2024-03-08]
35. 2024 Tech trends and adults 50+. : AARP; 2024 URL: https://www.aarp.org/content/dam/aarp/research/topics/technology/internet-media-devices/2024-tech-trends-adults-50-plus.doi.10.26419-2Fres.00772.001.pdf [accessed 2024-04-08]
36. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Quarterly 1989 Sep;13(3):319-340. [doi: 10.2307/249008]

37. Portz JD, Bayliss EA, Bull S, et al. Using the Technology Acceptance Model to explore user experience, intent to use, and use behavior of a patient portal among older adults with multiple chronic conditions: descriptive qualitative study. J Med Internet Res 2019 Apr 8;21(4):e11604. [doi: 10.2196/11604] [Medline: 30958272]
38. Gordon NP, Crouch E. Digital information technology use and patient preferences for internet-based health education modalities: cross-sectional survey study of middle-aged and older adults with chronic health conditions. JMIR Aging 2019 Apr 4;2(1):e12243. [doi: 10.2196/12243] [Medline: 31518291]
39. Gordon NP, Hornbrook MC. Older adults' readiness to engage with eHealth patient education and self-care resources: a cross-sectional survey. BMC Health Serv Res 2018 Mar 27;18(1):220. [doi: 10.1186/s12913-018-2986-0] [Medline: 29587721]
40. Onyeaka HK, Romero P, Healy BC, Celano CM. Age differences in the use of health information technology among adults in the United States: an analysis of the Health Information National Trends Survey. J Aging Health 2021 Jan;33(1-2):147-154. [doi: 10.1177/0898264320966266] [Medline: 33031007]
41. Remaley E. NTIA data reveal shifts in technology use, persistent digital divide. National Telecommunications and Information Administration Blog. 2020 Jun 10. URL: https://www.ntia.doc.gov/blog/2020/ntia-data-reveal-shifts-technology-use-persistent-digital-divide [accessed 2024-03-08]
42. Friemel TN. The digital divide has grown old: determinants of a digital divide among seniors. New Media & Society 2016 Feb;18(2):313-331. [doi: 10.1177/1461444814538648]
43. Blažič BJ, Blažič AJ. Overcoming the digital divide with a modern approach to learning digital skills for the elderly adults. Educ Inf Technol 2020 Jan;25(1):259-279. [doi: 10.1007/s10639-019-09961-9]
44. Mubarak F, Suomi R. Elderly forgotten? digital exclusion in the information age and the rising grey digital divide. Inquiry 2022;59:469580221096272. [doi: 10.1177/00469580221096272] [Medline: 35471138]
45. Cao Y, Li J, Qin X, Hu B. Examining the effect of overload on the mHealth application resistance behavior of elderly users: an SOR perspective. Int J Environ Res Public Health 2020 Sep 12;17(18):6658. [doi: 10.3390/ijerph17186658] [Medline: 32932679]
46. Baishya K, Samalia HV. Extending unified theory of acceptance and use of technology with perceived monetary value for smartphone adoption at the bottom of the pyramid. Int J Inf Manag 2020 Apr;51:102036. [doi: 10.1016/j.ijinfomgt.2019.11.004]
47. Shaffer KM, Chow PI, Cohn WF, Ingersoll KS, Ritterband LM. Informal caregivers' use of internet-based health resources: an analysis of the Health Information National Trends Survey. JMIR Aging 2018 Dec 18;1(2):e11051. [doi: 10.2196/11051] [Medline: 31518244]
48. Moss SJ, Czyz SH. Level of agreement between physical activity levels measured by ActiHeart and the International Physical Activity Questionnaire in persons with intellectual disability. Disabil Rehabil 2018 Feb;40(3):360-366. [doi: 10.1080/09638288.2016.1258092] [Medline: 27967248]
49. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. J Am Geriatr Soc 2000 Dec;48(12):1646-1654. [doi: 10.1111/j.1532-5415.2000.tb03877.x] [Medline: 11129756]
50. Jiang S, Hong YA, Liu PL. Trends of online patient-provider communication among cancer survivors from 2008 to 2017: a digital divide perspective. J Cancer Surviv 2019 Apr;13(2):197-204. [doi: 10.1007/s11764-019-00742-4] [Medline: 30756225]
51. Smith ML, Steinman LE, Casey EA. Combatting social isolation among older adults in a time of physical distancing: the COVID-19 social connectivity paradox. Front Public Health 2020 Jul 21;8:403. [doi: 10.3389/fpubh.2020.00403] [Medline: 32850605]
52. Vollmer Dahlke D, Ory MG. mHealth applications use and potential for older adults, overview of. In: Pachana NA, editor. Encyclopedia of Geropsychology: Springer; 2016:1-9. [doi: 10.1007/978-981-287-080-3_289-1]
53. Vollmer Dahlke D, Ory MG. Emerging issues of intelligent assistive technology use among people with dementia and their caregivers: a U.S. perspective. Front Public Health 2020 May 21;8:191. [doi: 10.3389/fpubh.2020.00191] [Medline: 32528920]
54. Vollmer Dahlke D, Ory MG. Emerging opportunities and challenges in optimal aging with virtual personal assistants. Public Policy & Aging Report 2017;27(2):68-73. [doi: 10.1093/ppar/prx004]

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Assessing the Impact of Internet Skills on Depressive Symptoms Among Chinese Middle-Aged and Older Adults: Cross-Sectional Instrumental Variables Analysis

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Abstract

Background: The potential benefits of IT for the well-being of older adults have been widely anticipated. However, findings regarding the impact of internet use on depressive symptoms are inconsistent. As a result of IT's exponential growth, internet skills have supplanted internet access as the source of the digital divide.

Objective: This study evaluates the effect of internet skills on depressive symptoms through an instrumental variables (IV) approach.

Methods: Data from the China Health and Retirement Longitudinal Study's wave 4 (2018) were used. This included 16,949 community residents aged 45 years and older. To overcome the endogeneity issue, we used an IV approach.

Results: Our results reveal the emergence of a second-level digital divide, the disparity in internet skills, among Chinese middle-aged and older adults. Liner regression suggests that a 1% increase in internet skills is associated with a 0.037% decrease in depressive symptoms (β=−.037, SE 0.009), which underestimates the causal effect. As expected, internet skills are an endogenous variable (*F* test *P* value <.001). IV regressions indicate that a 1% increase in internet skills reduces 1.135% (SE 0.471) to 1.741% (SE 0.297) of depressive symptoms. These 2 IV are neither weak (F_{-1}=16.7 and 28.5; both >10) nor endogenous (Wu-Hausman test *P* value of .10; >.05 or >.01).

Conclusions: Better mental health is predicted through improved and higher internet skills. Consequently, residents and policy makers in China should focus on bridging the digital divide in internet skills among middle-aged and older adults.

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KEYWORDS

internet skills; depression; second-level digital divide; instrumental variables

Introduction

Background

By 2050, there will be 2.1 billion individuals aged 60 years or older, with 80% of them living in low- and middle-income countries [1]. Late-life depression is a major public health challenge for this population because of its high prevalence and poor outcomes [2,3]. China, one of the low- and middle-income countries, is predicted to reach nearly 400 million older adults by 2050 [4]. Approximately 20%-31% of individuals aged 45 years or older in China had depression in 2015, with the highest risk among all age groups [5,6]. In 2013, the annual cost for individuals with mental disorders in China was US $3665, with depression and depressive symptoms accounting for 54% of the total [7,8]. With a rapidly aging population, late-life depression may damage the well-being of older adults; it also brings more burden to the family as well as the community. China accounts for nearly 17% of the global mental health burden [9]. In contrast, China's mental health system has only 8.75 mental health workers per 100,000 residents [10], which calls for novel approaches with low cost and wide access to reduce depressive symptoms among middle-aged and older adults.

Given that the internet can improve one's mental health by reducing social isolation and loneliness, it has attracted marked attention among researchers [11]. Prior work has investigated the correlation between depression symptoms and the frequency, type, and purpose of internet use, and identified potential mechanisms from the perspective of social connectedness [12-16]. Overall, these studies suggest that internet use among older adults offers new opportunities to prevent, support, and treat late-life depression in family and community contexts.

We aim to complement this research topic in 2 ways. First, previous studies have mainly measured internet use from the perspective of the first-level digital divide, that is, whether respondents have access to the internet [12,16,17]. With the rapid penetration of IT, internet skills (the capability of internet use) have replaced internet access as the most essential variable in characterizing IT use [18-20]. We believe that we have now entered the second level of the digital divide and thus chose internet skills to measure internet use. Second, the existing literature has derived results mainly from correlation analysis and yielded mixed evidence [13,16,21,22]. However, the findings of correlation analysis cannot provide interventional insights; only causal findings can do so [23]. Several modern economic approaches have been used in empirical studies to estimate the causal relation, such as the instrumental variables (IV) approach. Joshua D Angrist, who shares the 2021 Nobel Prize for methodological contributions to the analysis of causal relationships, adopted and developed the IV approach to quantify the impact of educational attainment on wage growth [24]. In the face of rising public health challenges in an aging society, policy makers and the public need robust insights. Therefore, our goal is to uncover the causal effects of internet skills on depressive symptoms in middle-aged and older adults and provide practical implications for promoting mental health through daily IT use.

Overall, IT-based mental health promotion programs could be an essential means to address the high prevalence of depression in older adults when they lack specialized medical resources [25]. As the internet spreads to older adults, we should pay more attention to their differences in internet skills rather than in internet access [20,26]. We should also focus on causal effects to provide more valuable evidence for public health practices [23]. Therefore, this study examines the causal effect of internet skills on depressive symptoms among middle-aged and older Chinese adults by using data from the 2018 China Health and Retirement Longitudinal Study (CHARLS). We used the IV approach to address the endogeneity issue and guide daily internet use practices among middle-aged and older adults to improve their mental health.

Literature Review

Internet Use and Depressive Symptoms Among Middle-Aged and Older Adults

Numerous studies have examined the relationship between internet use and depressive symptoms in older adults using national representative data sets. Table S1 in Multimedia Appendix 1 summarizes the key findings from these studies. Several insights are worth noting. First, analyses of the correlation between internet use and depressive symptoms yielded inconsistent conclusions. Jun and Kim [27] reported in 2015 that internet use was associated with lower levels of depressive symptoms among Korean older adults. Lee et al [28] showed that older adult cancer survivors in the United States used the internet to complete personal tasks or handle health-related matters, but internet use was unrelated to their depressive symptoms. Lifshitz et al [17] found that the use frequencies of 4 web-based functions (interpersonal communication, information seeking, task performance, and leisure) were not associated with depressive symptoms among Israeli older adults.

Second, some studies have focused on the potential mechanism underlying the association between internet use and depressive symptoms. Internet use is related to a decrease in depressive symptoms among socially inactive older adults [15], and this association is mediated by social isolation [12] and loneliness [22]. Internet use also reduces the negative effect of disadvantageous socioeconomic status (SES) on depressive symptoms [16,29]. However, most studies have used correlation analyses, and only a few studies have revealed a causal effect of internet use on depressive symptoms.

Cotten et al [30] used the propensity score matching method and the cross-sectional Health and Retirement Survey and found that internet use reduced the probability of a depressed state by about 20%-28% among retired older adults in the United States. Subsequently, Cotten et al [12] used a longitudinal design and lagged variables to handle the causal effect, and found that internet use reduced the probability of a depressed state by about 33% among retired older adults in the United States. Nie et al [31] used the IV approach and 2010 cross-sectional China Family Panel Studies (CFPS) data and found that internet use was associated with higher levels of depressive symptoms among Chinese individuals aged 16-60 years. Xie et al [32] also used the CHARLS and propensity score matching method and reported that internet use increased depressive symptoms in Chinese older adults.

This study also uses a nationally representative data set, CHARLS, to examine the effect of internet use on depressive symptoms. We extend the concept of IT use by focusing on the second-level digital divide, which emphasizes the critical role of internet skills. We also attempt to identify causal effects by applying an IV approach to quantify the impact of internet skills on depressive symptoms. In the next section, we elaborate on the second-level digital divide in internet use among older adults and ways to address the endogeneity of internet skills.

Internet Skills

The digital divide refers to certain groups having better opportunities than others to benefit from IT. Prior studies have suggested three stages of the digital divide [18,20,26]: (1) economic divide, which implies that some people cannot afford access to IT; (2) usability divide, which emphasizes that IT remains so complicated that some people cannot use it even if they can afford it; and (3) empowerment divide, which refers to inequality of outcomes after IT use. As internet use becomes prevalent among older adults, it is increasingly important to look at who uses the internet and distinguish their internet skills [18,33]. For depression among middle-aged and older adults, the existing literature has primarily discussed the first-level digital divide, which refers to the impact of internet use on depressive symptoms. We further examine the second-level digital divide, namely how internet skills influence depressive symptoms among middle-aged and older adults.

IV of Internet Skills

On examining how internet skills affect depressive symptoms, endogenous issues may be raised for two main reasons: (1) internet skills and depressive symptoms are simultaneously affected by unobserved factors such as personality traits, and (2) mentally healthier individuals are more prone to use the internet and have better internet skills. We have used the IV approach to handle potential endogeneity and obtain reliable causal effects.

A few studies have applied the IV approach to capture the effect of internet use. Hong and Chang [34] used the geographical distance to the nearest telecommunication station for each household as an instrumental variable to estimate the impact of internet use on household income at forestry farms in Fujian Province in China. Gao et al [35] applied provincial internet penetration rates as an instrumental variable to capture the effect of computer penetration on Chinese rural farmers' income. Nie et al [31] used the number of provincial internet broadband access terminals as an instrumental variable to examine the relationship between internet use and depressive symptoms among 16- to 60-year-old Chinese individuals.

This study adopts the above-described "resources accessibility" approach by using the following 2 IV: mobile phone penetration and the performance of government websites. Specifically, higher mobile phone penetration in a city implies that residents have easier access to IT resources, which implies a higher level of IT acceptance and internet skills [31,35]. Similarly, better performance of government website operations indicates higher informatization of the city, which implies higher internet skills of residents in that city [34]. Furthermore, there is no evidence that city-level mobile phone penetration or government website performance is directly associated with individual depressive symptoms. Overall, mobile phone penetration and government website performance correlate with each resident's internet acceptance and skills, while not being directly correlated with individual depressive symptoms. Therefore, these variables satisfy the principle of IV selection logically [24,36]. Furthermore, when considering the population of older adults in each city, both variables are multiplied by the proportion of the city's population aged 60 years and older.

Methods

Sample and Data Collection

We analyzed data from CHARLS, a nationwide survey designed to provide comprehensive and high-quality data on the demographics, household characteristics, health status and functioning, work, and retirement information of Chinese residents aged 45 years and older [37]. CHARLS is a longitudinal study that used a 4-stage, stratified, cluster sampling design to enroll community-dwelling residents from 450 villages and 150 counties in 28 provinces in China. The national baseline study (wave 1) was conducted in 2011. The last public survey (wave 4) was conducted in 2018, with information obtained from 19,816 respondents.

Since IV regression can investigate the causal effects of independent variables on dependent variables in cross-sectional data, we selected 16,949 participants from CHARLS wave 4. The sampling process is as follows: (1) respondents aged 45 years and older (excluded 178 samples); (2) provided information on internet skills and depression (excluded 2689 samples).

The 2018 Yearbook of China Communication and the 2017 China Government Website Performance Evaluation database provide information on IV. The Yearbook of China Communication provides annual updates on the development of the Chinese telecommunication industry by city. The China Government Website Performance Evaluation contains performance evaluations of government websites for all cities in China, with the latest version being publicly available in 2017.

Variables

Depression

The 10-item Center for Epidemiologic Studies Depression Scale (CES-D-10) is used to examine depressive symptoms. The respondents were asked about their positive feelings, negative emotions, and somatic symptoms during the past week. Scores for each question ranged from 0 to 30, with high scores indicating severe depressive symptoms. Our study considers 12 as a cutoff point to describe the prevalence of depression [38], using the CES-D-10 score in IV regression.

Internet Skills

New questions about internet skills have been added in wave 4 of CHARLS. Respondents were asked whether they would use the following web-based functions on their mobile phones: (1) chat on social media (such as WeChat); (2) post on social media (such as WeChat moments); and (3) mobile payments (such as Alipay or WeChat). Respondents provided binary responses, denoting "yes" or "no." Subsequently, based on the perceived complexity associated with these distinct functions, this study assigned numerical scores to gauge respondents' internet skills. Respondents capable of using mobile payment systems were assigned a score of 9, those adept at posting on social media received a score of 5, individuals proficient in social media chat were assigned a score of 1, while those abstaining from all the aforementioned functionalities received a score of 0. The cumulative internet skills score was derived by evaluating respondents' competencies across various functions, within a scale spanning from 0 to 15 points. Higher scores herein signify enhanced internet aptitude.

To reinforce the dependability of our findings, we incorporated an additional measurement strategy, using both a Likert scale with scores ranging from 1 to 5 and a cumulative scoring method as alternative approaches for assessing internet skills. An IV analysis was conducted using these supplementary metrics of internet skills. The inferences drawn from this analysis are in concordance with the foundational model's findings. Detailed information on the measurements and the corresponding results can be found in Tables S1-S4 in Multimedia Appendix 1.

Mobile Phone Penetration and Performance of Government Websites

The first instrumental variable is mobile phone penetration: the number of mobile phone subscribers at the end of the year in a city multiplied by the proportion of individuals aged 60 years and older in each city. Another instrumental variable is the performance of government websites: the score is the sum of the operational scores of each city's government website, ranging from 50 to 100.

Potential Confounding Variables

Potential confounding variables are shown in Table 1.

Table . Definition/codes of the potential confounding variables.

Variable	Codes/definition
Age	Continuous variable
Gender	0=male; 1=female
Marital status	0=single (divorced, widowed, or single); 1=partnered (married or partnered)
Retirement	0=no; 1=yes
Education	0=less than lower secondary (no formal education, did not finish primary school but can read, private tutoring, elementary school, or middle school); 1=upper secondary (high school or vocational school); 2=tertiary (2- or 3-year college, college graduate, or postgraduate degree)
Total household per capita consumption	Total household consumption or number of people living in the household (skewed distribution, logarithmically transformed)
Residency	0=urban; 1=rural
Ever had a memory problem	Ever had doctor-diagnosed memory-related diseases, including dementia, brain atrophy, and Parkinson disease (0=no; 1=yes)
Ever had a psychological problem	Ever had doctor-diagnosed psychiatric problems, such as emotional, nervous, or psychiatric problems (0=no; 1=yes)
Mobility	A 9-item summary of any difficulty with mobility activities. The mobility activities are walking 100 m, climbing several flights of stairs, getting up from a chair, stooping or kneeling or crouching, extending arms up, lifting 5 kg, and picking up a small coin. Continuous variable: 0-27 (skewed distribution, logarithmically transformed)

Ethical Considerations

This investigation constitutes a secondary analysis of publicly available data sets; hence, prior registration was not deemed necessary. The foundational data used herein are obtainable via the official portal of the CFPS [39]. Ethical approval for the CFPS was granted from the Biomedical Ethics Committee at Peking University (IRB00001052-14010).

Statistical Analysis

To examine the effect of internet skills on depressive symptoms, we performed an IV regression to control for possible endogeneity issues. Given that both the dependent and independent variables have skewed distributions, it is meaningful to understand the impact of internet skills on depressive symptoms in terms of percentage change. Thus, we estimate a log-log specification presented in the two-stage least squares model as follows:

(1)

(2)

where refers to CES-D-10 scores for individual , denotes internet skill scores for individual , indicates potential confounding variables, is the mobile phone penetration in city , and are error terms.

We carried out regression analysis to evaluate the association of individual depressive symptoms with individuals' internet skills and the mobile phone penetration in the city. For another instrumental variable, the first stage of the two-stage least squares model also can be written as follows:

(3)

where is the government website performance of city .

Diagnostic tests including correlation, overidentification, and weak IV tests supported the validity of the aforementioned IV. The data were analyzed using R package AER (version 1.2; R Foundation for Statistical Computing).

Results

Descriptive Statistics

The demographic characteristics of the sample are shown in Table 2. There are 16,949 participants, and the mean age in wave 4 (2018) was 62.3 (SD 9.9) years. Most participants are female (n=8735, 51.5%), have a partner (n=14,672, 86.6%), have less than a lower secondary level of education (n=14,619, 86.2%), are currently employed (n=11,086, 66.5%), and are rural residents (n=10,095, 60.7%). In addition, internet skills have significant differences across demographics, including age, gender, and education levels.

Table . Characteristics of the selected respondents. The total percentage may not equal to 100 due to rounding.

Characteristics	Full sample (n=16,949)	Scores for IT skills					*P* value
		0 (n=14,601, 86.1%)	1 (n=312, 1.8%)	6 (n=558, 3.3%)	10 (n=272, 1.6%)	15 (n=1206, 7.1%)	
Age (years), mean (SD)	62.3 (9.9)	63.3 (9.8)	57.4 (7.7)	59.1 (8.2)	55.1 (7.1)	54.7 (6.4)	<.001[a]
Gender, n (%)							.001[b]
Male	8214 (48.5)	6944 (47.6)	138 (44.2)	294 (52.7)	169 (62.1)	669 (55.5)	
Female	8735 (51.5)	7657 (52.4)	174 (55.8)	264 (47.3)	103 (37.9)	537 (44.5)	
Marital status, n (%)							<.001[b]
Single	2277 (13.4)	2114 (14.5)	23 (7.4)	42 (7.5)	21 (7.7)	77 (6.4)	
Partnered	14,672 (86.6)	12,487 (85.5)	289 (92.6)	516 (92.5)	251 (92.3)	1129 (93.6)	
Education, n (%)							<.001[b]
Less than lower secondary	14,619 (86.2)	13,204 (90.4)	241 (77.2)	383 (68.6)	154 (56.6)	637 (52.8)	
Upper secondary	1939 (11.4)	1242 (8.5)	59 (18.9)	155 (27.8)	81 (29.8)	402 (33.3)	
Tertiary	391 (2.3)	155 (1.1)	12 (3.8)	20 (3.6)	37 (13.6)	167 (13.9)	
Total household per capita consumption[c], median	6240.8	5657	7400.2	10,547.5	11,580	13,780	<.001[a]
Retirement status [d] **, n (%)**							<.001[b]
Not retired	11,086 (66.5)	9527 (66.1)	208 (68.2)	327 (60.4)	184 (70.5)	840 (73.0)	
Retired	5575 (33.5)	4877 (33.9)	97 (31.8)	214 (39.6)	77 (29.5)	310 (27.0)	
Residential area [e] **, n (%)**							<.001[b]
Urban	6530 (39.3)	5149 (35.8)	146 (48.2)	299 (55.3)	175 (67.6)	761 (66.6)	
Rural	10,095 (60.7)	9231 (64.2)	157 (51.8)	242 (44.7)	84 (32.4)	381 (33.4)	
Ever had memory problems [f]							.001[b]
No	16,283 (97.9)	13,977 (97.8)	305 (99.0)	542 (97.7)	270 (99.6)	1189 (99.2)	
Yes	346 (2.1)	320 (2.2)	3 (1.0)	13 (2.3)	1 (0.4)	9 (0.8)	
Ever had psychological problems [g]							.25[b]
No	16,512 (98.9)	14,197 (98.9)	309 (99.7)	548 (99.1)	268 (99.3)	1190 (99.4)	
Yes	179 (1.1)	164 (1.1)	1 (0.3)	5 (0.9)	2 (0.7)	7 (0.6)	
Mobility[h], mean (SD)	4.1 (5.1)	4.4 (5.3)	2.7 (3.7)	2.2 (3.0)	1.5 (2.6)	1.1 (2.0)	<.001[a]
CES-D-10[i] score, mean (SD)	8.4 (6.5)	8.8 (6.6)	7.2 (6.0)	6.7 (5.5)	6.1 (5.3)	6.1 (5.3)	<.001[a]
Mobile phone user rate, mean (SD)	127.7 (127)	125.6 (125)	131 (133.6)	139.5 (148.7)	143 (132.8)	142.3 (136)	<.001[a]
Government website performance, mean (SD)	63.8 (15.1)	63.5 (14.9)	64.2 (15.4)	64.4 (15.9)	66.4 (15.7)	66.8 (15.9)	<.001[a]

[a] Outcome of the Kruskal-Wallis test.

[b] Outcomes of the chi-square test.

[c] Missing data: n=2459.

[d] Missing data: n=288.

[e] Missing data: n=324.

[f] Missing data: n=320.

[g] Missing data: n=258.

[h] Missing data: n=44.

[i] CES-D-10: 10-item Center for Epidemiologic Studies Depression Scale.

Table 1 reveals a distinct profile among individuals with elevated internet skill scores. These individuals are predominantly younger, hail from higher-income households (higher total household per capita consumption), are more likely to be male, have partners, are nonretired, and are predominantly urban residents. Additionally, this cohort is characterized by superior health outcomes, evident from lower incidences of memory-related issues, psychological problems, and reduced mobility challenges.

Further analysis of internet skill scores underscores a stark digital divide. A significant 86.1% of participants do not engage with the internet, thereby receiving a score of 0. Conversely, within the subset of internet users, those with advanced internet skills form the majority, representing 7.1% of the overall sample and 51.4% of internet users (1206 out of 2348 individuals). This disparity highlights not only a first-level digital divide but also a pronounced second-level digital divide within the middle-aged and older demographic, marked by a dual extremity of complete absence or high proficiency in internet skills.

Prevalence of Depression in Residents

The prevalence of depression varied among participants with different levels of internet skills. Respondents with lower-level internet skills are at higher risk of depression than those with higher-level internet skills (30.23% vs 20.51% vs 17.38% vs 13.24% vs 15.17%).

The Effect of Internet Skills on Depressive Symptoms in Residents

The association between internet skills and depressive symptoms was estimated using ordinary least squares (OLS) regression, and the effect of internet skills on depressive symptoms was subsequently estimated using IV regression (see Table 3). OLS regression suggests that a 1% increase in internet skills is associated with a 0.037% decrease in depressive symptoms (β=–.037, SE 0.009), which underestimates the causal effect. As expected, internet skills are an endogenous variable (*F* test *P* value <.001). IV regressions indicate that a 1% increase in internet skills leads to a 1.135% (SE 0.471) to 1.741% (SE 0.297) reduction in depressive symptoms. The 2 IV were neither weak (F_{-1}=16.7 and 28.5 both being >10) nor endogenous (Wu-Hausman test *P* value of .10; being >.05 or .01). Detailed results of the controls can be found in Table S5 in Multimedia Appendix 1.

Table . The results of ordinary least squares (OLS) and instrumental variables (IV) regression analyses. The potential confounding variables are controlled in all models.

	OLS	IV	
		Mobile phone penetration	Performance of government websites
Log (internet skills), β (SE)	–0.037 (0.009)[a]	–1.741 (0.471)[a]	–1.135 (0.297)[a]
Demographic variables	✓[b]	✓	✓
Health status	✓	✓	✓
Constant, β (SE)	2.236 (0.068)[a]	4.015 (0.503)[a]	3.383 (0.322)[a]
Observations, n	16,949	16,949	16,949
Correlation with internet skills (first stage regression)			
α (SE)	—[c]	0.032 (0.008)[a]	0.136 (0.026)[a]
Weak IV (*F* test)	—	Not supported	Not supported
F test (*df*)	—	16.7 (–1)[a]	28.5 (–1)[a]
Exogenous to depression (Wu-Hausman test)	—	IV is exogenous	IV is exogenous
P value	—	.10	.10
Endogenous to depression (*F* test)	—	Internet skills is endogenous	Internet skills is endogenous
P value	—	<.001	<.001

[a] *P*<.001.

[b] Demographic variables and health status have been controlled for in the model. To maintain the conciseness of the model's results, the coefficient estimates for demographic and health status variables are shown in Table S6 in Multimedia Appendix 1 rather than in the main text.

[c] Not available.

Sensitivity Analysis

We applied multiple imputation techniques to missing values, assuming that missing variables are missing at random. To examine the robustness of the results, we conducted OLS and IV regressions with missing values and compared the results. Our findings yielded no difference between complete cases and the prior sample. Detailed results can be found in Table S6 in Multimedia Appendix 1.

Discussion

This study explored the impact of internet skills on depressive symptoms. Our findings revealed that (1) internet skills are relatively low among Chinese middle-aged and older adults and (2) improvement of internet skills can reduce depressive symptoms.

Impact of Internet Skills on Depressive Symptoms

Our results suggest that for middle-aged and older Chinese adults, a 1% increase in their internet skills leads to a 1.1% to 1.7% reduction in depressive symptoms. Our main finding is consistent with those of Cotten et al [12,30], who reported a positive outcome of internet use reducing risk of depression by 20% to 33% among retired older adults in the United States. We used internet skills (0~15 points) to measure IT use rather than using dummy variables. In addition, since the CES-D-10 scores are a continuous variable, we could estimate the effect of internet skills on depressive symptoms.

Some studies have reported that internet use increases depressive symptoms in the context of China [31,32]. Nie et al [31] used the IV approach and 2010 CFPS data and found that internet use was associated with higher levels of depressive symptoms among Chinese individuals aged 16-60 years. Notably, in 2010, internet access among middle-aged and older Chinese individuals was limited [40], and some residents were even prejudiced and resistant to the internet [31]. These reasons may lead to a negative impact of internet use on depression. The existing literature predominantly addresses the first-level digital divide, examining the effect of internet use on depressive symptoms [31,32]. Our study expands on this by delving into the second-level digital divide, revealing that enhanced internet skills significantly mitigate depressive symptoms. This observation, divergent from prior studies, suggests a possible shift in the perception of the internet among the middle-aged and older Chinese individuals as it becomes more ingrained in various facets of society [31]. Proficiency in internet use potentially enables more effective usage [13,16,19], leading to positive psychosocial outcomes. For instance, improved internet skills facilitate web-based social interactions and content sharing, thus increasing social support and reducing isolation and loneliness [11,15,22,27]. Further skill enhancement allows these individuals to more efficiently perform daily activities such as shopping and bill payments on the web, fostering a greater sense of inclusion and autonomy in the digital era [14,16,19]. Such psychosocial benefits potentially alleviate depressive symptoms and bolster mental health.

Our study additionally revealed that populations with a higher SES and superior health tend to exhibit more advanced internet skills. While it has been acknowledged that SES can create disparities in resource access and health outcomes [29,33], our research indicates that the improvement of internet skills might mitigate depressive symptoms, even in scenarios where SES and health factors are consistent. This finding suggests that diminishing the second-level digital divide could play a role in lessening health disparities. Consequently, future research should delve into the potential mechanisms by which internet skills influence depressive symptoms and examine the interplay between this subject and health equity concerns.

Improving Internet Skills Among Middle-Aged and Older Residents

This study delves into the usage of the internet among middle-aged and older adults in China, analyzing it through the digital divide framework. As of 2018, around 86% of respondents either demonstrated limited internet skills or lacked access altogether. This figure represents an improvement from the 98% and 97% non–internet use rate observed between 2011 and 2015 [38], indicating a gradual increase in both internet usage and skill acquisition among this demographic. Such a trend suggests an ongoing closure of the first-level digital divide, marked by a shift from nonuse to initial internet engagement. Despite this progress, a second-level digital divide is apparent among those who have embraced the internet and acquired specific skills, with a substantial segment showing advanced internet skills, underscoring an uneven skill distribution. The variability in internet skills may be attributed to individual IT preferences and the consistent support from family and peers in IT usage and learning [20,31,41]. Considering the beneficial impact of internet skills on the mental health of middle-aged and older individuals, and in light of increasing internet penetration rates, it becomes crucial for society and policy makers alike to focus on bridging this second-level digital divide.

IT training programs can reduce anxiety in older adults, increase their interest and efficacy in IT, and improve their IT capability [42]. A community or senior university that provides courses on internet use can follow three guidelines: (1) provide regular long-term training: older adults prefer long-term guidance on IT use and a stable context for experience exchange [42]; (2) leverage the influence of those with good internet skills [43]: interacting with more qualified peers and obtaining guidance from them will reduce the attrition rate of courses; more skilled older adults are important role models and mentors for older adults to improve their skills [43]; and (3) develop web-based participation projects to encourage older adults to establish, maintain, and participate in their own web-based communities [44].

Technical support from the younger generation is vital: young people are “impatient” with older IT learners and lack an understanding of older adults’ special needs [41]. We need to educate younger generations about the benefits of internet use among older adults to inspire families and communities to bridge the digital divide for older adults. Improving internet skills also requires gerontological software design improvements. The Chinese government is actively promoting the gerontological design of internet-based applications [45]. The initial stages of the project mainly focus on interface design and function simplification. Follow-up studies should develop tools and applications that specifically support older adults' current activities and goals. Finally, older adults may have negative attitudes toward the internet [31]. It is necessary to reduce the negative connotations surrounding internet use and emphasize that web-based activity can be meaningful and manageable rather than just a form of entertainment.

Limitations

This study has several limitations. First, our findings are based on self-reported data, which implies potential self-reported bias. Second, we assume that the data are missing at random and used multiple imputations to resolve this issue. However, the excluded individuals are more likely to be older, less educated, have a severe disability, and more likely to have higher levels of depressive symptoms. Thus, we cannot exclude this bias. Third, while CHARLS provides a substantial sample size for investigating the relationship between internet skills and depressive symptoms, it is imperative to acknowledge certain shortcomings inherent in the measurement items within the secondary data. This study delineates and quantifies internet skills, differentiated by the level of difficulty associated with various functionalities. Future research should aim to explore more robust measurement methodologies to enhance the reliability of these findings. Lastly, in 2018, a significant majority (98.6%) of Chinese internet users accessed the internet via their mobile phones [46]. Consequently, this study used the rate of mobile phone penetration at the city level as an instrumental variable. This approach was further nuanced by incorporating the percentage of residents aged 60 years and older in each city. Future research should aim to enhance the precision of this instrumental variable by integrating data on city-level internet usage. Additionally, examining the segment of the population aged 45 years and older may offer more relevance, closely mirroring the age range of our study's sample. Future research can address these issues and explore the formative mechanisms of the second-level digital divide among older adults.

Conclusion

Understanding the role of IT in fulfilling the well-being of older adults has been limited. This study evaluates the effect of internet skills on depressive symptoms through the IV approach. The results reveal the emergence of a second-level digital divide—the disparity in internet skills among middle-aged and older Chinese adults. A 1% improvement in internet skills reduces depressive symptoms by 1.1%-1.7%. This study contributes to the literature on the societal impacts of the internet.

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Authors' Contributions

AM drafted the main manuscript and ZL reviewed the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Key findings from the literature review, results from the analysis of alternative approaches for assessing internet skills, detailed results of the controls, and detailed results of the ordinary least squares and instrumental variables regressions.

[DOCX File, 41 KB - aging_v7i1e50880_app1.docx]

References

1. Ageing and health. World Health Organization. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2021-11-13]
2. Alexopoulos GS. Depression in the elderly. Lancet 2005;365(9475):1961-1970. [doi: 10.1016/S0140-6736(05)66665-2] [Medline: 15936426]
3. Blazer DG. Depression in late life: review and commentary. J Gerontol A Biol Sci Med Sci 2003 Mar;58(3):249-265. [doi: 10.1093/gerona/58.3.m249] [Medline: 12634292]
4. Fang EF, Scheibye-Knudsen M, Jahn HJ, et al. A research agenda for aging in China in the 21st century. Ageing Res Rev 2015 Nov;24(Pt B):197-205. [doi: 10.1016/j.arr.2015.08.003] [Medline: 26304837]
5. Huang Y, Wang Y, Wang H, et al. Prevalence of mental disorders in China: a cross-sectional epidemiological study. Lancet Psychiatry 2019 Mar;6(3):211-224. [doi: 10.1016/S2215-0366(18)30511-X] [Medline: 30792114]
6. Wu Y, Lei P, Ye R, Sunil TS, Zhou H. Prevalence and risk factors of depression in middle-aged and older adults in urban and rural areas in China: a cross-sectional study. Lancet 2019 Oct;394:S53. [doi: 10.1016/S0140-6736(19)32389-X]
7. Hsieh CR, Qin X. Depression hurts, depression costs: the medical spending attributable to depression and depressive symptoms in China. Health Econ 2018 Mar;27(3):525-544. [doi: 10.1002/hec.3604] [Medline: 28990318]

8. Xu J, Wang J, Wimo A, Qiu C. The economic burden of mental disorders in China, 2005–2013: implications for health policy. BMC Psychiatry 2016 May 11;16:137. [doi: 10.1186/s12888-016-0839-0] [Medline: 27169936]
9. Liu S, Page A. Reforming mental health in China and India. Lancet 2016 Jul 23;388(10042):314-316. [doi: 10.1016/S0140-6736(16)30373-7] [Medline: 27209145]
10. World Health Organization. Mental Health Atlas 2017 member state profile. Mental Health Atlas 2017 country profile: China. 2017 Jan 1. URL: https://cdn.who.int/media/docs/default-source/mental-health/mental-health-atlas-2017-country-profiles/chn.pdf?sfvrsn=93ae998_1&download=true [accessed 2024-03-11]
11. Waycott J, Vetere F, Ozanne E. Building social connections: a framework for enriching older adults' social connectedness through information and communication technologies. In: Neves BB, Vetere F, editors. Ageing and Digital Technology: Springer Singapore; 2019:65-82. [doi: 10.1007/978-981-13-3693-5]
12. Cotten SR, Ford G, Ford S, Hale TM. Internet use and depression among retired older adults in the United States: a longitudinal analysis. J Gerontol B Psychol Sci Soc Sci 2014 Sep;69(5):763-771. [doi: 10.1093/geronb/gbu018] [Medline: 24671896]
13. Elliot AJ, Mooney CJ, Douthit KZ, Lynch MF. Predictors of older adults' technology use and its relationship to depressive symptoms and well-being. J Gerontol B Psychol Sci Soc Sci 2014 Sep;69(5):667-677. [doi: 10.1093/geronb/gbt109] [Medline: 24304556]
14. Hunsaker A, Hargittai E. A review of internet use among older adults. New Media Soc 2018 Oct;20(10):3937-3954. [doi: 10.1177/1461444818787348]
15. Lee MA, Ferraro KF, Kim G. Digital technology use and depressive symptoms among older adults in Korea: beneficial for those who have fewer social interactions. Aging Ment Health 2021 Oct;25(10):1839-1847. [doi: 10.1080/13607863.2020.1839863] [Medline: 33131296]
16. Yuan H. Internet use and mental health problems among older people in Shanghai, China: the moderating roles of chronic diseases and household income. Aging Mental Health 2021 Apr;25(4):657-663. [doi: 10.1080/13607863.2020.1711858] [Medline: 31928208]
17. Lifshitz R, Nimrod G, Bachner YG. Internet use and well-being in later life: a functional approach. Aging Ment Health 2018 Jan;22(1):85-91. [doi: 10.1080/13607863.2016.1232370] [Medline: 27657190]
18. Hargittai E. Second-level digital divide: differences in people's online skills. First Monday 2002;7(4). [doi: 10.5210/fm.v7i4.942]
19. Szabo A, Allen J, Stephens C, Alpass F. Longitudinal analysis of the relationship between purposes of internet use and well-being among older adults. Gerontologist 2019 Jan 9;59(1):58-68. [doi: 10.1093/geront/gny036] [Medline: 29688332]
20. Wei KK, Teo HH, Chan HC, Tan BCY. Conceptualizing and testing a social cognitive model of the digital divide. Inf Sys Res 2011 Mar;22(1):170-187. [doi: 10.1287/isre.1090.0273]
21. Kim J, Lee HY, Won CR, Barr T, Merighi JR. Older adults' technology use and its association with health and depressive symptoms: findings from the 2011 National Health and Aging Trends Study. Nurs Outlook 2020;68(5):560-572. [doi: 10.1016/j.outlook.2020.05.001] [Medline: 32527596]
22. Chopik WJ. The benefits of social technology use among older adults are mediated by reduced loneliness. Cyberpsychol Behav Soc Netw 2016 Sep;19(9):551-556. [doi: 10.1089/cyber.2016.0151] [Medline: 27541746]
23. Glass TA, Goodman SN, Hernán MA, Samet JM. Causal inference in public health. Annu Rev Public Health 2013;34:61-75. [doi: 10.1146/annurev-publhealth-031811-124606] [Medline: 23297653]
24. Angrist JD, Imbens GW, Rubin DB. Identification of causal effects using instrumental variables. J Am Statis Assoc 1996 Jun;91(434):468-472. [doi: 10.2307/2291634]
25. Naslund JA, Aschbrenner KA, Araya R, et al. Digital technology for treating and preventing mental disorders in low-income and middle-income countries: a narrative review of the literature. Lancet Psychiatry 2017 Jun;4(6):486-500. [doi: 10.1016/S2215-0366(17)30096-2] [Medline: 28433615]
26. Riggins FJ, Dewan S. The digital divide: current and future research directions. J Assoc Inf Syst 2005;6(12):298-337. [doi: 10.17705/1jais.00074]
27. Jun HJ, Kim MY. What accounts for the relationship between internet use and suicidal ideation of Korean older adults? A mediation analysis. J Gerontol B Psychol Sci Soc Sci 2017 Sep 1;72(5):846-855. [doi: 10.1093/geronb/gbw163] [Medline: 28025280]
28. Lee HY, Kim J, Sharratt M. Technology use and its association with health and depressive symptoms in older cancer survivors. Qual Life Res 2018 Feb;27(2):467-477. [doi: 10.1007/s11136-017-1734-y] [Medline: 29128998]
29. Mu A, Deng Z, Wu X, Zhou L. Does digital technology reduce health disparity? Investigating difference of depression stemming from socioeconomic status among Chinese older adults. BMC Geriatr 2021 Apr 21;21(1):264. [doi: 10.1186/s12877-021-02175-0] [Medline: 33882865]
30. Cotten SR, Ford G, Ford S, Hale TM. Internet use and depression among older adults. Comp Human Behav 2012 Mar;28(2):496-499. [doi: 10.1016/j.chb.2011.10.021]
31. Nie P, Sousa-Poza A, Nimrod G. Internet use and subjective well-being in China. Soc Indic Res 2017 May;132(1):489-516. [doi: 10.1007/s11205-015-1227-8]

32. Xie L, Yang HL, Lin XY, et al. Does the internet use improve the mental health of Chinese older adults? Front Public Health 2021;9:673368. [doi: 10.3389/fpubh.2021.673368] [Medline: 34336769]
33. Hargittai E, Piper AM, Morris MR. From internet access to internet skills: digital inequality among older adults. Univ Access Inf Soc 2019 Nov;18(4):881-890. [doi: 10.1007/s10209-018-0617-5]
34. Hong YZ, Chang HH. Does digitalization affect the objective and subjective wellbeing of forestry farm households? Empirical evidence in Fujian province of China. Forest Policy and Economics 2020 Sep;118:102236. [doi: 10.1016/j.forpol.2020.102236]
35. Gao Y, Zang L, Sun J. Does computer penetration increase farmers' income? An empirical study from China. Telecommun Policy 2018 Jun;42(5):345-360. [doi: 10.1016/j.telpol.2018.03.002]
36. Wooldridge JM. Econometric Analysis of Cross Section and Panel Data: The MIT Press; 2010.
37. Zhao Y, Hu Y, Smith JP, Strauss J, Yang G. Cohort profile: the China Health and Retirement Longitudinal Study (CHARLS). Int J Epidemiol 2014 Feb;43(1):61-68. [doi: 10.1093/ije/dys203] [Medline: 23243115]
38. Wang R, Chen Z, Zhou Y, Shen L, Zhang Z, Wu X. Melancholy or mahjong? Diversity, frequency, type, and rural-urban divide of social participation and depression in middle- and old-aged Chinese: a fixed-effects analysis. Soc Sci Med 2019 Oct;238:112518. [doi: 10.1016/j.socscimed.2019.112518] [Medline: 31473574]
39. CFPS. China Family Panel Studies. URL: https://www.isss.pku.edu.cn/cfps/en/index.htm [accessed 2024-03-01]
40. Statistical report on internet development in China. China Internet Network Information Center. 2011 Jan. URL: https://www.cnnic.com.cn/IDR/ReportDownloads/201209/P020120904420388544497.pdf [accessed 2024-03-11]
41. Mori K, Harada ET. Is learning a family matter?: experimental study of the influence of social environment on learning by older adults in the use of mobile phones. Jpn Psychol Res 2010 Sep 1;52(3):244-255. [doi: 10.1111/j.1468-5884.2010.00434.x]
42. Xie B, Bugg JM. Public library computer training for older adults to access high-quality internet health information. Libr Inf Sci Res 2009 Sep 1;31(3):155. [doi: 10.1016/j.lisr.2009.03.004] [Medline: 20161649]
43. Xie B. Information technology education for older adults as a continuing peer-learning process: a Chinese case study. Educ Gerontol 2007 Apr 16;33(5):429-450. [doi: 10.1080/03601270701252872]
44. Quan-Haase A, Williams C, Kicevski M, Elueze I, Wellman B. Dividing the grey divide: deconstructing myths about older adults' online activities, skills, and attitudes. Am Behav Sci 2018 Aug;62(9):1207-1228. [doi: 10.1177/0002764218777572]
45. Special action plan for internet applications gerontological design and barrier-free transformation [Article in Chinese]. Ministry of Industry and Information Technology of the People's Republic of China. URL: https://www.miit.gov.cn/jgsj/xgj/wjfb/art/2020/art_18a8b1029f724afc8b31264fcd0f4106.html [accessed 2021-10-22]
46. Statistical report on internet development in China. China Internet Network Information Center. 2019 Feb. URL: https://www.cnnic.com.cn/IDR/ReportDownloads/201911/P020191112538996067898.pdf [accessed 2023-12-04]

Abbreviations

CES-D-10: 10-item Center for Epidemiologic Studies Depression Scale
CFPS: China Family Panel Studies
CHARLS: China Health and Retirement Longitudinal Study
IV: instrumental variables
OLS: ordinary least squares
SES: socioeconomic status

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Original Paper

Adoption and Use of Telemedicine and Digital Health Services Among Older Adults in Light of the COVID-19 Pandemic: Repeated Cross-Sectional Analysis

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Abstract

Background: As the population ages and the prevalence of long-term diseases rises, the use of telecare is becoming increasingly frequent to aid older people.

Objective: This study aims to explore the use and adoption of 3 types of telehealth services among the older population in Israel before, during, and after the COVID-19 pandemic.

Methods: We explored the use characteristics of older adults (aged ≥65 years) belonging to Clalit Health Services in several aspects in the use of 3 types of telehealth services: the use of digital services for administrative tasks; the use of synchronous working-hours telehealth visits with the patient's personal physician during clinic business hours; and the use of after-hours consultations during evenings, nights, and weekends when the clinics are closed. The data were collected and analyzed throughout 3 distinct periods in Israel: before the COVID-19 pandemic, during the onset of the COVID-19 pandemic, and following the COVID-19 peak.

Results: Data of 618,850 patients who met the inclusion criteria were extracted. Telehealth services used for administrative purposes were the most popular. The most intriguing finding was that the older population significantly increased their use of all types of telehealth services during the COVID-19 pandemic, and in most types, this use decreased after the COVID-19 peak, but to a level that was higher than the baseline level before the COVID-19 pandemic. Before the COVID-19 pandemic, 23.1% (142,936/618,850) of the study population used working-hours telehealth visits, and 2.2% (13,837/618,850) used after-hours consultations at least once. The percentage of use for these services increased during the COVID-19 pandemic to 59.2% (366,566/618,850) and 5% (30,777/618,850) and then decreased during the third period to 39.5% (244,572/618,850) and 2.4% (14,584/618,850), respectively ($P<.001$). Multiple patient variables have been found to be associated with the use of the different telehealth services in each period.

Conclusions: Despite the limitations and obstacles, the older population uses telehealth services and can increase their use when they are needed. These people can learn how to use digital health services effectively, and they should be given the opportunity to do so by creating suitable and straightforward telehealth solutions tailored to this population and enhancing their usability.

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KEYWORDS

telemedicine; digital health; older adults; COVID-19; use; digital divide; usability; pandemic; telehealth; Israel; working-hours telehealth visits; after-hours consultation; teleconsultation; eHealth; mobile health; mHealth; wearables; mobile phone

Introduction

Background

Telehealth is the practice of providing patients with long-distance clinical health care through various communication technologies (television, email, telephone, videoconferencing, internet, and radio) when a patient and physician cannot be present simultaneously [1,2]. Telehealth, a more general term, encompasses health-related education programs such as diabetes management and nutrition seminars. It is distinct from telemedicine, which is more particularly concerned with the delivery of clinical care via the internet [3]. Telemedicine, which uses current information and communication technology, blends patient requirements with technological progress, going beyond the boundaries of traditional health care systems [4].

Telecare combines professional remote health care services with technological tools and assistive technologies. It offers a range of services, including training, monitoring, consultation, communication, and consultation to preserve users' autonomy and improve their quality of life. It is particularly valuable for those who live in remote areas, groups considered vulnerable, and aging populations [1,5].

The world's population is aging quickly, especially in Europe, according to demographic statistics. Aged populations are now more prevalent than ever in many countries, particularly in the more high-income areas. The percentage of people aged >60 years in the world will double between 2000 and 2050, from approximately 11% to 22%. It is predicted that between 2000 and 2050, the number of persons aged >80 years will double [6]. The aging of the population has resulted in many older people living alone in our communities. Because of instances such as the death of a spouse, older people are increasingly being compelled to singularize or live in a single home [4].

Telecare is used more frequently to assist older people in maintaining their independence and carrying on with their current way of life as the population ages and the prevalence of long-term conditions rises. It appears to be one of the most effective strategies for promoting independent living in a community-dwelling setting because it gives an older person a sense of security and comfort [1,7].

Older people have emerged as one of the primary target demographics for telecare technology in recent years, with a variety of gadgets available for those with long-term medical illnesses as well as for those who have limited mobility or memory issues associated with aging [4,8]. Living at home is associated with a superior quality of life, dignity, and independence, and there is a growing trend among older people to do so rather than age in a health care facility [9,10].

A sizeable portion of the population of older adults have at least 1 chronic illness that necessitates routine monitoring and some level of self-management [11]. However, older patients are less likely to notice signs of an exacerbation before being admitted to the hospital, have less awareness of their disease, and engage in fewer self-management activities [12]. The issue may be resolved by evolving technologies that can notify patients to monitor health status information that can help with at-home self-management [7,13,14]. Although there has been general success for many of the telehealth systems already in use, these technologies are sometimes created without considering how easy they will be for patients and caregivers to use. Although telemedicine offers a way to deliver equitable health care, many people with disabilities find it difficult and challenging to access and use telehealth services [15].

Patients participating in video visits must have the technical knowledge and aptitude to connect to the internet, use and troubleshoot audio-visual equipment, and converse without in-person cues. Due to their limitations or lack of technological skills, many older people might be unable to perform this. In addition, older individuals frequently resist using new technology, especially when it comes to gaining knowledge and learning the skills required to operate computers and other electronic devices [4,16]. Older people may also have changes in their eyesight, hearing, and dexterity in addition to the symptoms of chronic illnesses, which could make it difficult for them to use different telehealth devices [17,18].

Although phone consultations are not ideal for care that necessitates visual assessment, they may increase access for the estimated 6.3 million older people who are unfamiliar with technology or have vision impairment [19]. To safeguard both patients and medical staff during the COVID-19 pandemic, there has been a substantial shift to telemedicine, with video visits being encouraged to see patients at home [3,11].

Telehealth, which allows patients to consult with medical professionals in real time and receive advice on their health issues, has become a basic requirement for the public, especially for those who are in quarantine. Telehealth was the most often used method of service delivery during the pandemic, according to a recent report from the World Health Organization [20]. The study also revealed a trend of rise in telehealth uses as income levels rise; even low-income nations, where 42% of people experienced service interruptions during the COVID-19 pandemic, reported using this technology.

The prevalence of telemedicine unreadiness among Medicare beneficiaries aged ≥65 years in the United States during the COVID-19 pandemic was studied in cross-sectional research in community-dwelling individuals and reported by Lam et al [16]. Patients who met the criteria for unreadiness included those who were older, male, single, Black, or Hispanic; lived in a nonmetropolitan area; and had less education, less income, and worse self-reported health. In total, 72%) of adults aged> 85 years met those criteria.

Despite the difficulties with using technology mentioned earlier, there is a misperception about older adults that they either lack interest in using technology or are unable to use technological platforms. Contrary to that belief, most older persons (70%) own and regularly use a computer, smartphone, or tablet with an internet connection at home [21]. However, just a small percentage of older people are comfortable using telehealth (11%) [21].

Objectives

Considering the growing phenomena of our aging society and the need to implement telecare for this age group, specifically, this study aimed to explore the use and adoption of 3 types of telehealth services among the older population in Israel before, during, and after the COVID-19 pandemic. Using a quantitative approach, the data have been extracted before the COVID-19 pandemic, throughout the pandemic, and during the months after the peak of the epidemic in Israel.

In addition, we wanted to determine whether the COVID-19 pandemic had an impact on how older adults used telehealth services and, if so, whether those changes would last once the pandemic concluded. The results of this study will enable us to emphasize to health care decision makers the necessity for tailored telemedicine-based care that considers the needs, abilities, and preferences of the older population and adapts over time as those needs change.

Methods

Study Population

Clalit Health Services, the largest integrated health care service provider and payer system in Israel, has >4 million active members. Clalit Health Services has a comprehensive health care data warehouse, which integrates hospital and community medical records, laboratory and imaging information, pharmaceutical records, health care expenses, and Ministry of the Interior vital statistics of all the members. Clalit Health Services experiences membership turnover of <1% annually, making it easier to track population trends over time. The inclusion and exclusion criteria are presented in Textbox 1.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria

- Membership in Clalit Health Services for at least a year
- Aged ≥65 years at each period

Exclusion criteria

- No Clalit Health Services membership
- Aged <65 years at each period

Ethics Approval

The study was ethically approved by the boards of the Clalit Health Services on January 18, 2021 (reference numbers 826 and COM-0113-21).

Study Design

This study is a repeated cross-sectional analysis. This type of study looks at data collected at a single point in time, rather than over a period, which is useful for comparing and analyzing the effect of different factors on one another or describing a sample.

Data Extraction

We explored the telehealth use characteristics of older adults (aged ≥65 years) belonging to Clalit Health Services in several aspects:

1. The use of digital services for administrative tasks such as web-based medical appointment scheduling and physician request submission. This category of eHealth services was named *administrative*.
2. The use of synchronous web-based, telephone, or digital visits with the patient's personal physician during clinic business hours (through video or telephone), initiated by the patients themselves. This type of consultation was named *working hours telehealth consultations*.
3. The use of web-based or telephone consultations (not with the personal physician) during the evenings, nights, and weekends when the clinics are closed, including the use of a phone, video camera, or "tytocare" equipment [22]. The term *after-hours consultations* was used to describe this form of consultation.

Data Extraction Periods

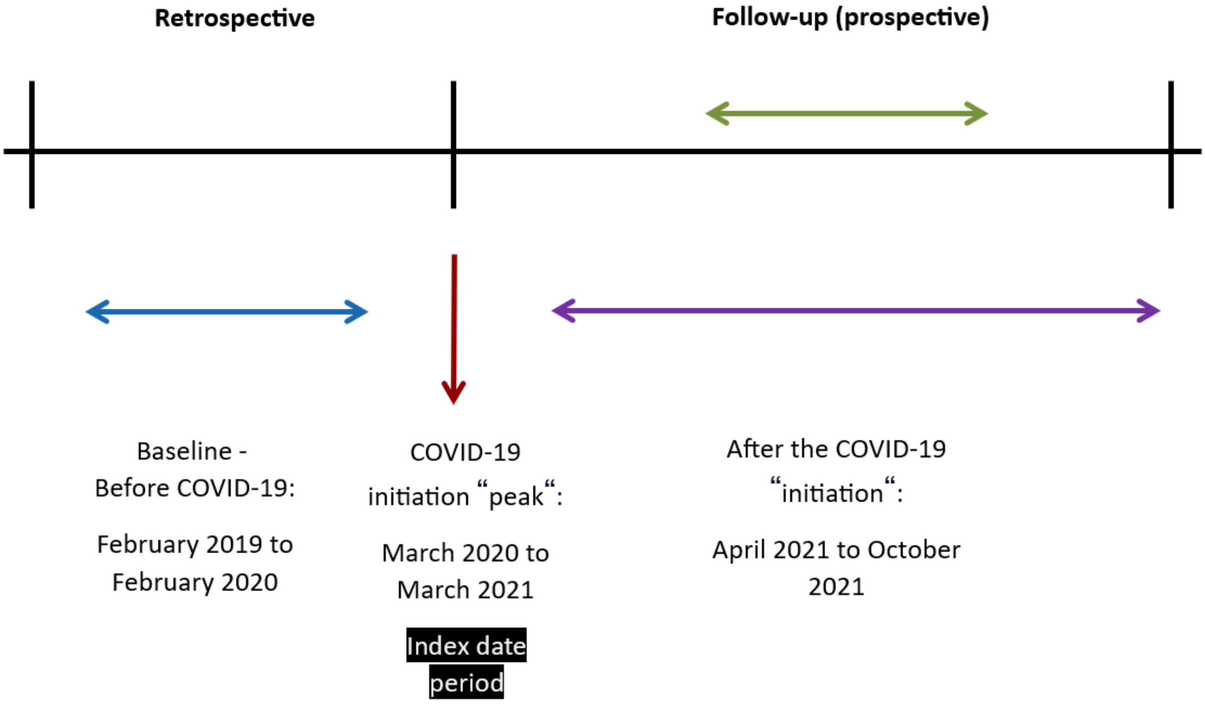
Three separate periods were used to collect and analyze the data:

1. Baseline—from February 1, 2019, to the end of February 2020, the period before the COVID-19 pandemic in Israel, which was labeled period 1 (*before*).
2. Initiation—from March 1, 2020, to March 31, 2021, when lockdowns were implemented during the COVID-19 pandemic in Israel. Period 2 (*during*) was used to designate this time frame.
3. Follow-up—from April 1, 2021, to the end of October 2021, following the COVID-19 pandemic peak in Israel. Period 3 (*after*) was used to designate this time frame.

Study Timeline

Figure 1 describes the timing scheme. The "index date period" refers to the time from March 1, 2020, to March 31, 2021, which is considered the peak of COVID-19 pandemic in Israel. The study was designed and planned during this period.

Figure 1. Study design timeline.



We planned to gather certain data retrospectively from February 1, 2019, to the index date period and the rest of the data prospectively from the index date period to the end of the follow-up period date, which was October 31, 2021. As intended, and previously indicated, the participant files were recruited from February 1, 2019, to October 31, 2021.

Finally, after gaining approval from all committees of Clalit Health Services, the raw data were accessed for research purposes between February 20, 2022, and May 16, 2022.

Study Outcomes

As previously indicated, the main outcomes (dependent variables) measured were as follows: (1) The use of digital services for *administrative* tasks, such as web-based medical appointment scheduling and physician request submission, named *administrative services* (2) The use of video or telephone calls with a personal physician conducted during clinic business hours at the patients' request, named *working-hours telehealth consultations* (3) The use of web-based consultations (not with the personal physician) during the evenings, nights, and weekends when the clinics are closed, including the use of the telephone, video camera, or Tytocare device, named *after-hours consultations*

Covariables (Covariates)

The inpatient and outpatient data warehouses of Clalit Health Services have provided the data. The information covered the use of telemedicine and digital health services during the aforementioned 3 periods. The variables can be described as dichotomous (use of telemedicine and digital health; yes or no) and as categorical in the aspect of which digital services were used: (1) administrative only use; (2) consultations with the personal physician—*working-hours telehealth consultations*; (3) consultations during the after hours of the clinic—*after-hours consultations*.

Multiple patient variables, such as sociodemographic information (age, sex, place of birth, place of residence, socioeconomic status [SES], ethnicity, country of birth, etc), clinical information (chronic diseases, habits, etc), and use of chronic medications have been examined for each period.

The different features were extracted and categorized as follows: (1) sociodemographic parameters, including sex, age, SES, country of birth (coalesced into regions when necessary), ethnicity by country of individual's or parents' birth, sector (clinic level data—predominantly Arab or Jewish), marital status and number of children, Clalit Health Services affiliation by district, subdistrict, and clinic; (2) clinical markers or comorbidities, such as smoking status, alcohol use (and related diagnoses), BMI, height, weight, Charlson comorbidity index (the most widely used comorbidity index used to determine survival rate [1 year and 10 year] in patients with multiple comorbidities), presence of chronic diseases such as active malignancy, cardiovascular diseases (ischemic heart disease, cerebrovascular disease, hypertension), asthma, diabetes, neurological diseases (Alzheimer disease and Parkinson disease), psychiatric disease, diagnosis of COVID-19 since the index period; (3) use of chronic medications, especially antianxiety, antidepression, and sleep-aid medications.

Statistical Analysis

We analyzed the data according to the type of telehealth use (working hours telehealth consultations, after-hours consultations, and administrative), the time frame in which it was used (before, during, or after the COVID-19 pandemic in Israel), and the amount of use (how often it was used) according to 2 categories (0 or ≥1 time).

We used appropriate descriptive statistics to characterize the study population. The association between telemedicine use and each available socioeconomic factor was studied using univariable analyses while comparing participants who used telemedicine at least once during the specific period with patients with zero use (Pearson χ^2 test). We have used nonparametric related samples Cochran *Q* test to compare telemedicine use during the 3 periods.

Post hoc analysis with the Dunn and McNemar post hoc tests was conducted (with a Bonferroni correction applied) to access both between-subjects and within-subjects effects, analyzing each pair of periods. In addition, we performed a set of multivariable binary logistic regression models to estimate the association between telemedicine use and socioeconomic factors during each period. These models were used to calculate odd ratios (ORs) and 95% CIs. A *P* value <.05 was considered statistically significant. SPSS IBM Statistics for Windows, predictive analytics software (version 28.0 [28.0.1]), was used for data analysis.

Privacy

Data extraction was conducted by the research room team at Clalit Health Services. The deidentified, raw extracted data were stored on the virtualization desktop infrastructure (VDI), a secure setting. Data were analyzed on the VDI, and only aggregated nonidentifiable results were moved out of the VDI for publication.

As discussed earlier, we did not have any access to identified information. We had limited and restricted access only to unidentified data. A confirmation from the special committee for data mining from Clalit Health Services authorities was received on August 25, 2021.

Results

General Characteristics

There were 669,349 patients in total who met the inclusion criteria at the start of period 1 (2019). In 2020, a total of 642,223 patients met the criterion for inclusion, whereas in 2021, only 618,850 patients met the requirements. Various analyses were carried out on this population. The general characteristics are presented in Table 1.

The mean Charlson score was 5.59 (SD 2.57), with a median of 5.00 (range 2-22). The mean age in 2019 was 75.16 (SD 7.64) years, with a median of 73.00 (range 65-110) years.

Table 1. General characteristics (N=618,850).

Characteristics	Patients, n (%)
Sex	
Female	349,069 (56.4)
Male	269,781 (46.6)
Age group in 2019 (years)	
65-74	349,477 (56.5)
75-84	188,110 (30.4)
≥85	81,263 (13.1)
Country of birth	
Israel	231,207 (37.4)
Other	387,643 (62.6)
Socioeconomic status	
Low	146,469 (23.7)
Medium	235,231 (38)
High	237,150 (38.3)
Demographic sector	
General Jewish	527,349 (85.2)
Cherkess	355 (0.1)
Religious Jewish	12,134 (2)
Arab	56,692 (9.2)
Unknown	22,320 (3.6)
District	
South	64,985 (10.5)
Center	291,145 (47)
North	168,783 (27.3)
Center east	93,937 (15.2)
Smoking status	
Never smoked	391,918 (63.3)
Past smoker	126,853 (20.5)
Current smoker	61,275 (9.9)
Status unknown	38,804 (6.3)
Any chronic disease	
Yes	520,771 (84.2)
No	98,079 (15.8)
Active malignancy	
Yes	57,452 (9.3)
No	561,398 (90.7)
Cardiovascular disease	
Yes	479,758 (77.5)
No	139,092 (22.5)
Asthma	
Yes	109,553 (17.7)
No	509,297 (82.3)

Characteristics	Patients, n (%)
Diabetes	
Yes	237,968 (38.5)
No	380,882 (61.5)
Neurological disease	
Yes	37,814 (6.1)
No	581,036 (93.9)

Telehealth Use Characteristics

Overview

Table 2 lists the visit counts (per person) according to the telehealth use type (administrative, working hours, or after hours) and time frame. For telehealth administrative purposes, we can observe that the mean count (per person) was 4.39 (SD 5.56) before the COVID-19 pandemic (period 1), increased to 5.55 (SD 6.71) during the COVID-19 pandemic (period 2), and decreased to 3.07 (SD 4.11) after the peak of the COVID-19 pandemic in Israel (period 3).

Regarding working-hours telehealth consultations with the personal physician, the mean number (per person) was 0.49 (SD 1.43) before the COVID-19 pandemic (period 1), it increased dramatically to a mean of 2.23 (3.54) during the COVID-19 pandemic (period 2), and then it decreased to a mean of 1.00 (1.95) after the peak of the COVID-19 pandemic in Israel (period 3), but still higher than that in period 1.

The mean after-hours telehealth use (per person) was 0.03 (SD 0.02) before the COVID-19 pandemic, increased to 0.07 (0.46) during the COVID-19 pandemic, and decreased again after the peak of the COVID-19 pandemic to 0.03 (SD 0.33).

The visit counts were also analyzed in a dichotomic manner into 2 categories: “no” or “yes,” that is, 0 visits versus ≥1 visit, respectively.

The comparison of telemedicine use (at least once) during 3 periods and the results of Cochran Q test are presented in Figure 2 and Table 3, respectively. The pairwise comparisons of telemedicine use (at least once) during the 3 periods, results of the Dunn and McNemar post hoc tests (with Bonferroni correction), between and within subjects, respectively, are presented in Tables 4 and 5.

Table 2. Telehealth use (visit counts) according to types and periods.

Telehealth use	Visits, mean (SD)	Visits, median (IQR)
Period 1 (before)		
Administrative	4.39 (5.56)	3.00 (0-191)
Working hours	0.49 (1.43)	0.00 (0-66)
After hours	0.03 (0.02)	0.00 (0-83)
Period 2 (during)		
Administrative	5.55 (6.71)	4.00 (0-208)
Working hours	2.23 (3.54)	1.00 (0-104)
After hours	0.07 (0.46)	0.00 (0-96)
Period 3 (after)		
Administrative	3.07 (4.11)	2.00 (0-107)
Working hours	1.00 (1.95)	0.00 (0-50)
After hours	0.03 (0.33)	0.00 (0-96)

Figure 2. Percentage of Telehealth Services Usage During 3 Periods.

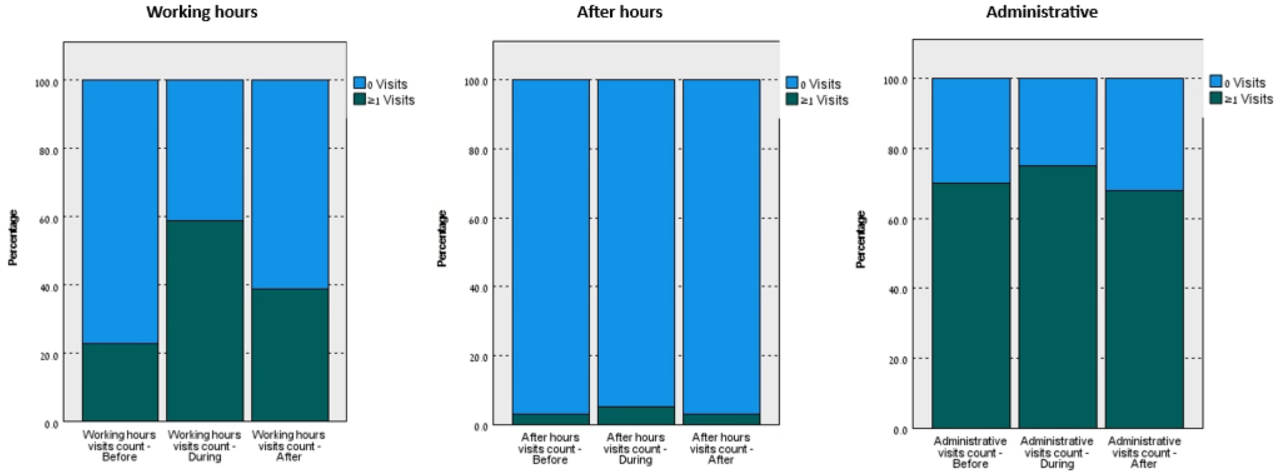


Table 3. Comparison of telemedicine use (at least once) during 3 periods, results of the Cochran Q test (N=618,850).

Period	Working-hours telehealth visits, n (%)[a]	After-hours visits, n (%)[a]	Administrative, n (%)[a]
Before	142,936 (23.1)	13,837 (2.2)	427,295 (69)
During	366,566 (59.2)	30,777 (5)	459,622 (74.3)
After	244,572 (39.5)	14,584 (2.4)	420,209 (67.9)

[a] $P<.001$.

Table 4. Pairwise comparison of telemedicine use (at least once) during 3 periods and results of the Dunn post hoc test (between-subjects analysis with Bonferroni correction).

Sample 1/sample 2	Working-hours telehealth visits		After-hours visits		Administrative	
	Test statistic	Adjusted *P* value	Test statistic	Adjusted *P* value	Test statistic	Adjusted *P* value
Before/after	−0.164	<.001	0.001	1.000	−0.011	.975
Before/during	−0.361	<.001	0.027	<.001	0.052	<.001
After/during	0.197	<.001	−0.026	<.001	−0.064	<.001

Table 5. Pairwise comparison of telemedicine use (at least once) during the 3 periods and results of the McNemar post hoc test (within-subjects analysis with Bonferroni correction).

Sample 1/sample 2	Working-hours telehealth visits		After-hours visits		Administrative	
	Chi-square[a] (*df*)	*P* value	Chi-square (*df*)	*P* value	Chi-square (*df*)	*P* value
Before/after	49,365 (1)	<.001	22 (1)	<.001	462 (1)	<.001
Before/during	184,875 (1)	<.001	7407 (1)	<.001	11,593 (1)	<.001
After/during	72,425 (1)	<.001	6702 (1)	<.001	16,358 (1)	<.001

[a] Continuity corrected.

Working-Hours Telehealth Visits (During the Regular Work Hours, With the Personal Physician)

During the first period, 23.1% (142,936/618,850) of the study population used working-hours telehealth services at least once. The percentage of use increased to 59.2% (366,566/618,850) during the second period and then decreased to 39.5% (244,572/618,850) during the third period (still higher than that in period 1).

Pairwise comparisons were performed using the Dunn [23] procedure (between-subjects analysis) with a Bonferroni correction for multiple comparisons. Adjusted *P* values are presented in Table 4. Compared to the percentage of working-hours telehealth services use during the first period, there was a statistically significant increase in the percentage of use during the second period (*P*<.001) and during the third period (*P*<.001). There was also a statistically significant decrease in the percentage of the study population that used working-hours telehealth services at least once during the third period compared to the second period (*P*<.001).

Similar results were demonstrated using the McNemar post hoc test (within-subjects analysis with Bonferroni correction), as demonstrated in Table 5.

After-Hours Telemedicine

During the first period, 2.2% (13,837/618,850) of the study population used after-hours telemedicine services at least once. The percentage of use increased to 5.0% (30,777/618,850) during the second period and then decreased to 2.4% (14,584/618,850) during the third period (still higher than that in period 1).

Pairwise comparisons were performed using the Dunn [23] procedure (between-subjects analysis) with a Bonferroni correction for multiple comparisons. Adjusted *P* values are presented in Table 4. Compared to the percentage of after-hours services use during the first period, there was a statistically significant increase in the percentage of use during the second period (*P*<.001), while there was no statistically significant difference compared to the third period. There was also a statistically significant decrease in the percentage of the study population that used after-hours telemedicine services at least once during the third period compared to the second period (*P*<.001).

When using the McNemar post hoc test (within-subjects analysis with Bonferroni correction), significant differences were demonstrated between all 3 pairs of periods, as demonstrated in Table 5.

Administrative Telemedicine

During the first period, 69% (427,295/618,850) of the study population used administrative telemedicine services at least once. The percentage of use increased to 74.3% (459,622/618,850) during the second period and then decreased to 67.9% (420,209/618,850) during the third period. Pairwise comparisons were performed using the Dunn [23] procedure (between-subjects analysis) with a Bonferroni correction for multiple comparisons. Adjusted *P* values are presented in Table 4. Compared to the percentage of administrative services use during the first period, there was a statistically significant increase in the percentage of use during the second period (*P*<.001), while there was no statistically significant difference compared to the third period. There was also a statistically significant decrease in the percentage of the study population that used administrative telemedicine services at least once during the third period compared to the second period (*P*<.001).

When using the McNemar post hoc test (within-subjects analysis with Bonferroni correction), significant differences were demonstrated between all 3 pairs of periods, as demonstrated in Table 5.

Univariate Analysis of Working-Hours Telehealth Visits

According to the dichotomous classification into 2 categories (0 uses versus ≥1 uses), a univariate analysis was conducted using Pearson χ^2 tests on the various types of telehealth use, and the results are shown in Multimedia Appendices 1-3. Multimedia Appendix 1 demonstrates the significant factors associated with the working-hours telehealth visits (telehealth services with the personal physician), with the 2 categories classification (0 visits vs ≥1 visits).

Gender

A higher percentage of female individuals than male individuals used the web-based visits at all periods. In addition, both male individuals and female individuals increased their working-hours telecare use during the COVID-19 pandemic period, which was followed by a decline, though at a higher level than before (period 1).

Age Group

The age group of 75 to 84 years had used the web-based services to a greater extent, compared to the other age groups (65-74 years and >85 years), at all the 3 periods. In addition, during the COVID-19 pandemic, all age groups significantly boosted their use of working-hours telehealth services; following the COVID-19 pandemic, the use reduced but remained significantly greater than it was before the COVID-19 pandemic (period 1).

Country of Birth

Before the COVID-19 pandemic, persons who were born in Israel used working-hours telehealth services more frequently than those who were born elsewhere. However, this tendency shifted during and after the COVID-19 pandemic, when those born outside of Israel had a larger use. Both groups had increased their use of working-hours telehealth services during the COVID-19 pandemic, and it had declined after that time to a greater level than it had been before the COVID-19 pandemic.

SES Level

Persons belonging to a higher SES level had a higher level of working-hours telehealth services use, compared to persons with lower SES, at all periods. Here also, we see that during the COVID-19 pandemic, persons in all SES levels greatly expanded their use of working-hours telehealth services; this use eventually declined, but it remained higher than it had been before the COVID-19 pandemic.

Demographic Sector

If we ignore the "unknown" portion (which accounts for only 3.6% of the populations included), we see that the religious Jewish population (followed by the general Jewish population) had higher use of working hours telehealth services, as compared to other sectors, at all periods. Here again, persons in all demographic sectors greatly expanded their use of working hours telehealth services during the COVID-19 pandemic period; this use eventually declined, but it remained higher than it had been before the COVID-19 pandemic.

District

People from the northern region of Israel had more working hours telehealth visits than people from other districts before the COVID-19 pandemic (period 1). Those from the center districts, however, made many more working-hours telehealth visits to their physician both during and after the COVID-19 pandemic. As stated in the factors described earlier, all subgroups had increased their use of working-hours telehealth services during the COVID-19 pandemic period, and it had declined after that time to a greater level than it had been before the COVID-19 pandemic.

Smoking Status

Those who were past smokers used the working hours telehealth visits more frequently than people who are currently smokers or even people who had never smoked. This held true throughout all periods. All subgroups had increased their use of working-hours telehealth services during the COVID-19 pandemic, and it had decreased after that time to a greater degree than it had been before the COVID-19 pandemic, as reflected in the factors mentioned earlier.

The Presence of a Chronic Disease

Across all periods, those with chronic diseases significantly used working-hours telehealth visits to a greater extent (more than twice as often as people without chronic diseases). Both groups had expanded their use of working hours telehealth services during the COVID-19 pandemic, and use declined after that period to a larger extent than it had before (period 1).

Univariate Analysis of Administrative Telehealth Use

Multimedia Appendix 2 shows a univariate analysis, outlining the important variables that were significantly linked to administrative telehealth use in accordance with the 2 categories used (0 visits vs ≥1 visits).

Sex

At all 3 periods, a greater proportion of female individuals than male individuals used the administrative web-based services. In contrast to the situation outlined for web-based visits, the administrative telehealth use (for this parameter and all other parameters described here) did increase throughout the COVID-19 pandemic before declining to a level below that of the before period (period 1).

Age Group

The age group of 75 to 84 years had used the administrative web-based services in a greater extent, compared to the other age groups (65-74 years and >85 years), at all the 3 periods. In addition, as reported earlier, during the COVID-19 pandemic, all age groups significantly boosted their use of web-based services, but the use reduced following the COVID-19 pandemic, to a lower level than it was before the COVID-19 pandemic.

Country of Birth

Throughout all periods, those born outside of Israel used administrative web-based services more than those who were born there. Both groups had increased their use of web-based services during the COVID-19 pandemic, and it had declined after that time to a lower level than it had been before the COVID-19 pandemic.

SES Level

Persons belonging to a higher SES level had a higher level of administrative web-based services use, compared to persons with lower SES, at all periods. Here also, we see that during the COVID-19 pandemic, persons in all SES levels greatly expanded their use of web-based services; this use eventually declined to a lower level than it had been before the COVID-19 pandemic.

Demographic Sector

Throughout all periods, the Cherkess (Circassians) had the higher use of administrative web-based services, as compared to other sectors. In this instance, as well, people in all demographic groups significantly increased their use of administrative web-based services during the COVID-19 pandemic; nevertheless, this use gradually decreased to a level that was lower than it had been before the COVID-19 pandemic.

District

People from Israel’s southern region used administrative internet services to a greater extent than residents from other districts at all times. All subgroups had increased their use of administrative web-based services during the COVID-19 pandemic, and it had decreased after that time to a lower level than it had been before the COVID-19 pandemic, as was shown in other factors mentioned earlier.

Smoking Status

People who had previously smoked used the administrative web-based services more than those who smoke now or even those who have never smoked. This was accurate at all times. All subgroups had grown their use of administrative web-based services during the COVID-19 pandemic and had declined after that period to a lesser extent than it had been before the COVID-19 pandemic.

The Presence of a Chronic Disease

Throughout all periods, persons with chronic conditions significantly used the administrative web-based services more frequently (more than twice as often as people without chronic diseases). Both groups had expanded their use of web-based services during the COVID-19 pandemic, and use decreased after that period to a lower extent than it had before (period 1).

As demonstrated in Table 2, the overall use of after-hours telemedicine services (during the evenings, nights, and weekend days) was considerably lower than that of administrative telehealth and working-hours telemedicine services (with the personal physician during opening hours).

Univariate Analysis of After-Hours Telemedicine Use

In accordance with the 2 categories used (0 visits vs ≥1 visits), Multimedia Appendix 3 presents a univariate analysis summarizing the relevant variables that were significantly associated to after-hours telemedicine use:

Sex

At all 3 periods, a greater proportion of females than males used the after-hours telemedicine services. During the COVID-19 pandemic, both men and women increased their use of after-hours telemedicine services, which was followed by a fall, but at a greater level than previously (period 1), in a manner similar to the trend outlined for the working-hours telehealth services.

Age Group

Only on the COVID-19 pandemic, the age groups of 65 to 74 years and 75 to 84 years had significantly greater use of after-hours telemedicine services, compared to the third age group (>85 years). In addition, as previously mentioned, during the COVID-19 pandemic, all age groups increased their use of after-hours services; however, after the COVID-19 pandemic, use decreased, though it remained at a higher level than it had been before the COVID-19 pandemic.

Country of Birth

During the COVID-19 pandemic and the period after the COVID-19 pandemic, those born outside of Israel significantly used after-hours telemedicine services more than those who were born there. Both groups had increased their use of after-hours telemedicine services during the COVID-19 pandemic, and it had declined after that time (for people born outside Israel, it declined to a higher level than it was before the COVID-19 pandemic).

SES Level

Similar to how it was with the other telehealth services, those with higher SES levels used after-hours telemedicine services more frequently than people with lower SES levels did always. In this area as well, the use of after-hours services by people of all SES levels significantly increased during the COVID-19 pandemic. Eventually, this use decreased but it did so at a greater level than it had been before the COVID-19 pandemic.

Demographic Sector

As described for the use of working-hours telehealth visits, here also, the religious Jewish population and the general Jewish population had the higher use of after-hours services, as compared to other sectors, at all periods (the religious Jews had a higher use during the COVID-19 pandemic). Here again, people in all demographic sectors greatly expanded their use of after-hours services during the COVID-19 pandemic, which declined after that period.

District

Contrary to the previously mentioned telehealth services, persons from Israel's central area were much more likely to use after-hours telemedicine services than those from other regions during all periods. The use of after-hours internet services had surged across all subgroups during the COVID-19 pandemic and had fallen thereafter to a greater level than it had been before the COVID-19 pandemic (except for the south region in which it declined to the same level as before).

Smoking Status

As was the case with the other telehealth services, people who had previously smoked used more the after-hours services than those who do so now or even those who have never smoked. This was accurate at all periods. All groupings had increased their use of after-hours internet services during the COVID-19 pandemic and had decreased after that typically to a greater extent than it had been before the COVID-19 pandemic.

The Presence of a Chronic Disease

Similar to other telehealth services mentioned earlier, those with chronic conditions significantly used the after-hours web-based services more often across all periods (more than twice as often as people without chronic diseases). During the COVID-19 pandemic, both groups (with and without chronic diseases) increased their use of web-based services, and after that time, use decreased but to a higher level than it had previously (period 1).

Multivariate Analysis

In the multivariate analysis, using a set of multivariable binary logistic regression models, several parameters were found to be significantly associated with the different types of telehealth use during each period: male sex (decreased use of all types of telehealth services, during all periods); country of birth–Israel (increased use of working-hours telehealth visits and after-hours visits during all periods but decreased administrative use at all periods); presence of any chronic disease (highly increased use of all types of telehealth services during all periods); Charlson comorbidity score (increased use of all types of telehealth services during all periods); medium and high SES (increased use of all types of telehealth services during all periods); Jewish religion (highly increased use of all types of telehealth services during all periods); southern district—place of residence (people living in this district used fewer working-hours telehealth services and fewer after-hours services during all periods but used more administrative services before and after the COVID-19 pandemic); northern district (people living here used more working-hours telehealth services before the COVID-19 pandemic but used less working-hours telehealth services during periods 2 and 3 and used fewer administrative services and fewer after-hours services at all periods); central east district (people living here used fewer of all types of telehealth services during all periods); current or past smokers (these people used more working-hours telehealth services, more after-hours services, and more administrative services during all periods); older age groups of those aged ≥75 years (used fewer working-hours telehealth services, fewer after-hours services, and fewer administrative services during all periods).

The multivariate analysis is demonstrated in Table 6 (for working-hours telehealth visits), Table 7 (for after-hours visits), and Table 8 (for administrative uses). The Nagelkerke R^2 values for each type of telehealth service and each period are also provided in the tables.

Table 6. Multivariate analysis—working-hours telehealth visits. Variables entered on step 1: sex (male), country of birth, any chronic disease, Charlson score, SES (medium), SES (high), Jewish nationality, district (south), district (north), district (central east), current or past smoker, age group (75-84 years), age group (≥85 years).

Working-hours visits	Variables in the equation								
	Before (period 1)[a]			During (period 2)[b]			After (period 3)[c]		
	P value	Exp (B)	95% CI	*P* value	Exp (B)	95% CI	*P* value	Exp (B)	95% CI
Sex (male)	<.001	0.717	0.708-0.726	<.001	0.741	0.733-0.749	<.001	0.701	0.694-0.709
Country of birth (Israel)	<.001	1.079	1.064-1.094	<.001	1.108	1.094-1.121	<.001	1.068	1.055-1.081
Any chronic disease	<.001	1.978	1.934-2.022	<.001	2.612	2.571-2.654	<.001	2.197	2.159-2.237
Charlson score	<.001	1.144	1.141-1.147	<.001	1.201	1.198-1.204	<.001	1.156	1.154-1.159
SES[d] (medium)	<.001	1.332	1.308-1.355	<.001	1.375	1.355-1.395	<.001	1.288	1.269-1.307
SES (high)	<.001	1.374	1.349-1.400	<.001	1.587	1.562-1.612	<.001	1.438	1.416-1.461
Jewish religion	<.001	1.065	1.042-1.088	<.001	1.318	1.294-1.343	<.001	1.277	1.253-1.301
District (south)	<.001	0.653	0.638-0.668	<.001	0.876	0.860-0.892	<.001	0.806	0.791-0.821
District (north)	<.001	1.109	1.092-1.125	<.001	0.816	0.805-0.827	<.001	0.924	0.913-0.937
District (central east)	.01	0.977	0.960-0.995	<.001	0.868	0.854-0.882	<.001	0.816	0.803-0.829
Current or past smoker	<.001	1.152	1.136-1.168	<.001	1.191	1.176-1.205	<.001	1.095	1.082-1.108
Age group (75-84 years)	<.001	0.818	0.806-0.830	<.001	0.922	0.910-0.934	<.001	0.811	0.801-0.821
Age group (≥85 years)	<.001	0.743	0.728-0.758	<.001	0.809	0.794-0.824	<.001	0.647	0.635-0.658
Constant	<.001	0.068	N/A[e]	<.001	0.169	N/A	<.001	0.124	N/A

[a] Nagelkerke R^2=0.065.

[b] Nagelkerke R^2=0.139.

[c] Nagelkerke R^2=0.090.

[d] SES: socioeconomic status.

[e] N/A: not applicable.

Table 7. Multivariate analysis—after-hours telehealth visits. Variables entered on step 1: sex (male), country of birth, any chronic disease, Charlson score, SES (medium), SES (high), Jewish nationality, district (south), district (north), district (central east), current or past smoker, age group (75-84 years), age group (≥85 years).

After-hours visits	Variables in the equation								
	Before (period 1)[a]			During (period 2)[b]			After (period 3)[c]		
	P value	Exp (B)	95% CI	*P* value	Exp (B)	95% CI	*P* value	Exp (B)	95% CI
Sex (male)	<.001	0.748	0.722-0.775	<.001	0.850	0.829-0.870	<.001	0.799	0.772-0.827
Country of birth (Israel)	<.001	1.086	1.046-1.128	.01	1.034	1.007-1.061	.12	1.030	0.992-1.069
Any chronic disease	<.001	2.063	1.925-2.210	<.001	1.813	1.736-1.893	<.001	1.701	1.598-1.810
Charlson score	<.001	1.111	1.103-1.118	<.001	1.091	1.086-1.096	<.001	1.103	1.096-1.111
SES[d] (medium)	<.001	1.264	1.199-1.333	<.001	1.213	1.171-1.257	<.001	1.208	1.148-1.271
SES (high)	<.001	1.404	1.330-1.482	<.001	1.330	1.282-1.379	<.001	1.339	1.271-1.411
Jewish religion	<.001	1.981	1.837-2.136	<.001	1.679	1.600-1.762	<.001	1.821	1.694-1.956
District (south)	<.001	0.792	0.745-0.842	<.001	0.741	0.711-0.773	<.001	0.793	0.747-0.842
District (north)	<.001	0.767	0.734-0.801	<.001	0.646	0.627-0.666	<.001	0.718	0.687-0.749
District (central east)	<.001	0.850	0.809-0.893	<.001	0.838	0.811-0.867	.001	0.923	0.880-0.967
Current or past smoker	.001	1.067	1.028-1.108	.01	1.034	1.007-1.061	.02	1.045	1.008-1.085
Age group (75-84 years)	<.001	0.780	0.749-0.812	<.001	0.807	0.785-0.830	<.001	0.818	0.786-0.851
Age group (≥85 years)	<.001	0.730	0.691-0.772	<.001	0.666	0.640-0.693	<.001	0.736	0.697-0.777
Constant	.000	0.004	N/A[e]	<.001	0.013	N/A	<.001	0.005	N/A

[a] Nagelkerke R^2=0.027.

[b] Nagelkerke R^2=0.027.

[c] Nagelkerke R^2=0.022.

[d] SES: socioeconomic status.

[e] N/A: not applicable.

Table 8. Multivariate analysis—administrative telehealth visits. Variables entered on step 1: sex (male), country of birth, any chronic disease, Charlson score, SES (medium), SES (high), Jewish nationality, district (south), district (north), district (central east), current or past smoker, age group (75-84 years), age group (≥85 years).

Administrative telehealth visits	Variables in the equation								
	Before (period 1)[a]			During (period 2)[b]			After (period 3)[c]		
	P value	Exp (B)	95% CI	*P* value	Exp (B)	95% CI	*P* value	Exp (B)	95% CI
Sex (male)	<.001	0.788	0.778-0.798	<.001	0.790	0.780-0.800	<.001	0.818	0.808-0.827
Country of birth (Israel)	<.001	0.938	0.926-0.951	.34	0.993	0.979-1.007	<.001	0.974	0.962-0.987
Any chronic disease	<.001	3.690	3.631-3.750	<.001	3.947	3.883-4.013	<.001	3.742	3.682-3.803
Charlson score	<.001	1.213	1.209-1.216	<.001	1.237	1.233-1.241	<.001	1.200	1.196-1.203
SES[d] (medium)	<.001	1.355	1.333-1.377	<.001	1.436	1.412-1.460	<.001	1.352	1.331-1.373
SES (high)	<.001	1.386	1.362-1.410	<.001	1.558	1.531-1.587	<.001	1.498	1.473-1.523
Jewish religion	<.001	2.291	2.247-2.335	<.001	1.943	1.904-1.982	<.001	2.206	2.164-2.248
District (south)	<.001	1.044	1.023-1.067	.43	0.991	0.969-1.014	.002	1.033	1.012-1.054
District (north)	<.001	0.655	0.646-0.665	<.001	0.647	0.638-0.657	<.001	0.661	0.651-0.670
District (central east)	<.001	0.702	0.690-0.714	<.001	0.724	0.711-0.738	<.001	0.760	0.747-0.773
Current or past smoker	<.001	1.311	1.293-1.329	<.001	1.354	1.334-1.374	<.001	1.289	1.272-1.306
Age group (75-84 years)	<.001	0.753	0.743-0.764	<.001	0.698	0.687-0.708	<.001	0.745	0.734-0.755
Age group (≥85 years)	<.001	0.452	0.444-0.461	<.001	0.364	0.356-0.371	<.001	0.434	0.425-0.442
Constant	<.001	0.162	N/A[e]	<.001	0.209	N/A	<.001	0.155	N/A

[a] Nagelkerke R^2=0.198.

[b] Nagelkerke R^2=0.209.

[c] Nagelkerke R^2=0.193.

[d] SES: socioeconomic status.

[e] N/A: not applicable.

Discussion

Principal Findings

In this study, we examined the use and uptake of 3 distinct telehealth services among the older population who were members of Clalit Health Services before, during, and after the COVID-19 pandemic in Israel. Data of 618,850 patients who met the inclusion criteria were extracted. Telehealth services used for administrative purposes were the most popular. The older population significantly increased their use of all types of telehealth services during the COVID-19 pandemic, and in most types of services, this use decreased after the COVID-19 peak but to a level that was higher than the baseline level before the COVID-19 pandemic. The three telehealth service types that were investigated in the study were as follows: (1) "working-hours telehealth visits" refers to video or telephone consultations with a personal physician during clinic business hours; (2) "administrative" refers to the use of digital services for administrative tasks (such as scheduling appointments or submitting requests to the physicians on the web); and (3) "after-hours visits" refers to the use of web-based consultations in the evenings, weekend days, and other nonbusiness hours (with other physicians)

A quantitative method was used to extract the data at three different time points: (1) "before" was before the COVID-19 pandemic; (2) "during" was during the COVID-19 pandemic's emergence; and (3) "after" was during the months after the peak of the pandemic in Israel.

Our main objectives were to assess how the older adults in Israel used various telehealth services, considering the challenges and difficulties they encountered; to determine what factors were associated with increased or decreased uptake; and to determine whether the COVID-19 period had any impact on use patterns and whether those patterns persisted after the period had ended.

Tables 2 and 3 show that, throughout the study periods, the telehealth services used for administrative purposes were the most popular among the older population. This was followed by "working-hours telehealth visits"—telemedicine consultations with the personal physician—during the regular business hours of clinics. Among the other services mentioned earlier, "after-hours" telemedicine visits came in last.

Another intriguing finding was that during the COVID-19 pandemic, the older population significantly increased their use of all telehealth services, and this use decreased after the peak of the COVID-19 pandemic (period 3), in all types of telehealth uses (Tables 3 and 4). However, concerning the working-hours telehealth visits, and the after-hours visits—this decrease was found to remain significantly higher than the baseline level before the COVID-19 pandemic.

These findings support our assumptions that as expected, the use of all telehealth services was increased during the COVID-19 pandemic. The working-hours telehealth visits, which are the primary telemedicine meetings (with the personal physician), prospered during the COVID-19 pandemic, but even after this period, they remained at a higher level than they had before the COVID-19 pandemic period.

These findings confirm our hypothesis that older adults are interested in and capable of using telehealth services, given the opportunity and accessibility to do so—factors that were noticeably improved during the COVID-19 pandemic—despite their hesitations and barriers and the medical system's mistaken belief that there is no point in teaching this population how to use digital health services.

In the univariate analysis, after classifying the number of telehealth services used into 2 categories (0 visits vs ≥1 visits), we found several factors that were significantly associated with increased telehealth use among the older individuals (Multimedia Appendices 1-3). Furthermore, we conducted a multivariate analysis**,** using a set of multivariable binary logistic regression models, which revealed that several parameters were significantly associated with the different types of telehealth utilization during each period (Tables 6-8).

Women were found to significantly use more working-hours telehealth visits with the personal physician, more after-hours telehealth visits, and more administrative telehealth services across all periods compared to men. This finding was supported by the multivariate analysis, showing that among men, there was decreased use of all types of telehealth services, during all periods. This finding may be explained by women's greater general health literacy, eHealth literacy, and health awareness, as previously reported [24-26].

The findings for telehealth use by age groups in the univariant analysis were somewhat unexpected because it would be reasonable to presume that younger age groups (aged 65-74 years) would use telehealth the most. The findings indicate that the older age groups used telehealth services more frequently. Specifically, those aged 75 to 84 years used more working-hours telehealth visits during opening hours, more administrative telehealth use, and more after-hours visits following the COVID-19 pandemic. However, in the multivariate analysis, older age groups (aged ≥75 years) were found to use fewer working-hours telehealth services, fewer after-hours services, and fewer administrative services, during all periods.

These findings are consistent with the general belief that "younger, more highly educated and affluent seniors use technology more readily and across broader platforms than the older old, who as a group tend to be less affluent, less educated, and often have a significantly greater burden of chronic illness and disability," as reported by Greenwald et al [21]. These authors claimed that younger seniors, who are more physically and psychologically integrated into the technological modern world, may have a more positive attitude toward the benefits of technology than older seniors. In contrast, the use of automated telephone menu systems, medical-related purchases on the internet (such as medical supplies or medications), and telemedicine videoconferencing with health care providers were all found to be more common among older adults than among younger adults in a 2011 study that looked into the type and frequency of technology use for a variety of health care activities [27].

The findings relating to SES in the univariate analysis were as expected: higher SES was significantly associated with increased telehealth use of all services investigated (working-hours telehealth visits, after hours, and administrative use) at all periods. This was also demonstrated in the multivariate analysis, in which people in medium and high SES significantly had increased use of all types of telehealth services during all periods. This could be ascribed to higher levels of education; increased knowledge and awareness of digital health services; increased income enabling the acquisition of computers, smartphones, and digital devices; and increased eHealth literacy linked to higher SES levels. These findings are in line with earlier studies, which found that people with lower median household incomes and less favorable insurance situations used web-based visits less frequently [26]. Another study also found a correlation between declining SES and declining probabilities of using telemedicine during elective surgery visits [28]. According to comparable findings among 16,000 patients with a new cancer diagnosis, those with the greatest SES were more likely to use telemedicine within 30 days of diagnosis [29].

The demographic sector findings in the univariate analysis were also a little surprising: the religious Jews, compared to other groups, had more working-hours telehealth visits with their physician, at all periods, and more after-hours visits (followed by the general Jewish population), before and during the COVID-19 pandemic. However, only in case of the administrative use, the Cherkess (Circassians) had greater use at all periods. These findings are unexpected given that using telehealth solutions in ultraorthodox communities offers several difficulties given their restricted access to virtual communication as well as their reluctance to engage in this novel modality of therapy. For many of these populations, receiving therapy through the web is strange and foreign, and it may be seen as going against their religious principles [30,31]. Nevertheless, in the multivariant analysis, those of the Jewish religion demonstrated highly increased use of all types of telehealth services during all periods.

The findings regarding the district that the older people belong to (where they reside) in the univariate analysis were inconsistent: before the COVID-19 pandemic, more working-hours telehealth visits were observed in the northern district; however, during and after the COVID-19 pandemic, more working-hours telehealth visits were made in the central areas. In addition, during all periods, more after-hours visits were made by residents of central regions. However, throughout all periods, people from the southern district used telehealth more frequently for administrative functions.

Using the multivariate analysis, we saw that people living in southern district used fewer working-hours telehealth services and fewer after-hours services during all periods but used more administrative services before and after the COVID-19 pandemic; people living in the northern district used more working-hours telehealth services before the COVID-19 pandemic but used less working-hours telehealth services during periods 2 and 3 and used fewer administrative services and fewer after-hours services in all periods; and people living in the central east district used less of all types of telehealth services during all periods. In general, we may conclude that a more peripheral place of residency was associated with reduced use of telehealth services. These findings are unexpected because one may anticipate that telehealth services would be used more frequently in remote places, where there are typically fewer health care personnel and resources.

The association of smoking status with telehealth use in the univariate analysis was interesting: for all types of telehealth services (working-hours telehealth visits with the personal physician, after-hours visits, and administrative telehealth use), people who had smoked in the past and stopped smoking (past smokers) substantially used more services compared to other groups (even more than nonusers) at all periods. This may be accounted for by such people's greater health awareness, which led to a major change in their health-related behaviors. However, the multivariate analysis demonstrated that current or past smokers used more working-hours telehealth services, more after-hours services, and more administrative services during all periods. These findings could be additionally explained by the notion that current smokers have greater health problems, necessitating more frequent appointments with health care providers.

Finally, compared to persons without chronic diseases, people with chronic diseases significantly used digital services more frequently for administrative tasks, after-hours telehealth visits, and working-hours telehealth visits during business hours. This was true throughout all periods (including those before, during, and after the COVID-19 pandemic). This group's rising use of telehealth was more than twice as high as that of people who were ordinarily healthy. These findings were also supported by the multivariate analysis demonstrating that the presence of any chronic disease was significantly associated with highly increased use of all types of telehealth services during all periods; in addition, the Charlson comorbidity score was found to be significantly associated with increased use of all types of telehealth services during all periods. This is not unexpected given that individuals with chronic illnesses or comorbid conditions may require additional help from health care professionals, and they frequently experience accessibility issues, making telehealth services particularly desirable to them.

In this study, we investigated the use of telehealth by older people who are still living at home to communicate with their clinic (administrative requests); individual physicians; or other medical professionals on evenings, weekend days, and holidays when clinics are closed. Nevertheless, there are telecare options available globally that enable the monitoring of patients with a chronic illness, such as heart failure, hypertension, diabetes, asthma, chronic obstructive pulmonary disease, or stroke [32-34]. In addition, more health care systems are using telemedicine video communication as a tool for health maintenance after discharge to lower hospital readmissions as well as expedited consult services (stroke, trauma, mental health screening, and surgical second opinions) [21]. Evaluation of telehealth programs for individuals, particularly the older adults, with chronic medical issues has yielded conflicting outcomes. Glycemic management and the use of health care services both benefited patients with diabetes [35].

The research on telemedicine-enhanced emergency care for older people has been concentrated on residents of older people living community centers and has shown that high-intensity telemedicine services for acute illnesses have been effectively carried out, believed to be acceptable by older patients, and offered definitive care without needing a referral to the emergency department or urgent care [36]. An analysis of the impact of home-based telehealth interventions on the use of secondary care and mortality in a cohort of patients with COPD (chronic obstructive pulmonary disease), diabetes, and heart failure, most of whom (70%) were aged >65 years, led to lower emergency admission rates and lower mortality. [37] However, a different analysis of the same data revealed no impact on psychological outcomes or quality of life over a 12-month period [38].

Benefits of Telemedicine

It is well agreed that telemedicine-based care offers many benefits and advantages for older people. Older adults who use eHealth services can maintain their freedom and continue to live in their own familiar homes, where they feel secure and at ease. Their sense of security and quality of life are improved by being aware that they are constantly being watched and monitored [39-41]. According to Chou et al [40], older people who frequently used their telecare program and had better social welfare and health status also embraced using technology and had a higher quality of life. Their findings also showed that older people who believed telecare could help them with their health issues and were prepared to use it had a higher opinion of their quality of life, particularly in terms of their social interactions and home environment.

When an older person has decreased mobility, easy and quick web-based communication with a health care facility or professional becomes particularly crucial. This reduces travel time, speeds up diagnosis, reduces the need for repeat diagnostic tests and clinical services, and allows for older adult triage that is appropriate [42]. By offering some medical services at the patient's home, telemonitoring and telerehabilitation help to decrease the frequency of hospitalizations and shorten their length, and the patient who is chronically ill can benefit by reducing the number of follow-up visits required at the medical facility [42-44]. In addition, due to telecare systems using eHealth services, an older person who is housebound can sign up via the web for a physician's appointment, choose to receive a reminder of a due date for a medical consultation, receive straightforward remote medical recommendations or test results (via SMS text messaging or email), and buy ongoing prescription drugs from the pharmacy of their choice [45,46].

By allowing patients to develop and select the tools they will use as well as how they will use them, telecare fosters increased involvement [47]. Patients can actively participate in their own care through the use of telecare systems rather than just receiving it as a passive benefit. They become partners on an equal footing with their physicians, capable of making choices for their health on their own while being cognizant of the repercussions [48,49].

Through telemedicine, proactive healthy behaviors are formed. During an emergency, telemonitoring can identify pathological signs and symptoms and abnormal test results earlier than during or before a typical physician's visit or examination, enabling prompt preventive action [42]. Telemonitoring also has a substantial impact on education. Patients who are conscious of their health status frequently begin to educate themselves on their disease and how to self-manage it. They have a better understanding of their body and are more motivated to modify unhealthy behaviors and live healthier lifestyles [42,50].

Telecare lessens socioeconomic and regional inequities in access to care as well as the uneven distribution of care quality. With the help of telecare technologies, older people can easily connect with a variety of functionally and geographically dispersed health care professionals at times that are convenient for both the patient and the health care provider [42].

Physicians in varied practice settings can easily access evidence-based medicine and effective clinical decision-making tools, such as knowledgeable colleagues in tertiary care facilities. In addition, patients can get the right type of care close to where they live, which is crucial for older people with chronic illnesses or disabilities because it affects their quality of life and level of care [42,51]. According to Chae et al [52], telecare was successful in lowering the frequency of clinic visits and also increased patient satisfaction in a trial of home health services for older people.

Barriers to Telecare Use

Although telecare offers undeniable advantages, it is important to understand that it also has limits, some of which are due to the older people themselves. The use of new technologies is frequently resisted by older individuals. Although computers and the internet have become important tools, older adults experience more trouble using them than younger people do.

According to a study by the Nielsen Norman Group, users aged >65 years had a success rate of just 53% when completing a series of assigned tasks (such as finding information and making a web-based purchase), compared to a group of younger users who had a success rate of 78%. In addition, the older group made an average of 3.7 errors on each task given, as opposed to the younger group's average of 0.6 errors [53]. Another issue is the decline in cognitive and motor function that comes with aging (eg, vision, hearing, short-term memory loss, and physical impairment), which makes it harder to adapt to a changing environment and assimilate new behavioral patterns [54].

The strong desire to interact directly and personally with the physician is another trait shared by older people. They typically prefer face-to-face interactions with health care providers, so telemedicine-based services delivered remotely are frequently not seen as relevant to them. In a study on older adults aged ≥60 years, Bujnowska-Fedak and Mastalerz-Migas [55] found that 61% of older adults stated a strong preference for direct contact with medical professionals as the main deterrent to contacting their family physician, specialist, or nurses via telephone or the web. Eliminating in-person care may give older persons the impression that they are engaging in less social interactions. Resistance to telemedicine in older population may be a result of their concern that the new technology will negatively impact their social and personal relationships [56].

The next barrier is money. Pensioners, typically those who are in need, worry about the high prices of buying computers or other electronics. Older persons are frequently reluctant to spend money on home health care monitoring systems, despite the health advantages and long-term cost reductions made available by telecare services [55]. In addition, for older persons, privacy and security are top personal concerns. They want more assurance that their private information is kept private from prying eyes. Better health care is not as important to them as feeling assured about the security of their medical information [56,57].

Accelerating Growth of Care Based On Telemedicine

Technology advancements have made it feasible to put into practice solutions that, up until recently, looked to be a long way off. Israel is regarded as a highly developed country with excellent infrastructure, a high degree of entrepreneurship and innovation, and widespread knowledge of telemedicine services. As part of the Digital Israel Project, the Ministry of Health declared that one of its objectives was to "bring about a leap in the health system that will enable it to become sustainable, advanced, innovative, renewed, and constantly improving, by optimally leveraging the information and communication technologies available to the entire Israeli population" [58]. Similar to other developed nations, Israel has seen a rise in telemedicine use because of the COVID-19 pandemic.

Telecare improves the quality of life of older citizens with chronic illnesses worldwide by providing them with new options for education, prevention, diagnosis, treatment, and rehabilitation. It equalizes possibilities for patients from urban and rural locations and lessens socioeconomic gaps in access to care. According to a prior study [45], 41% of older people had a favorable opinion of eHealth services and were willing to use them if and when given the chance. A considerable shift from passive monitoring to more active use of telecare technologies that enable and promote direct connection has occurred in well-developed countries in recent years. Patients now have more control over their own health and welfare because of the changing health care system [43]. They can make health-related decisions on their own and with knowledge of the repercussions, and they work as equal partners with their physicians [59,60].

Nevertheless, widespread acceptance by older persons themselves is a crucial component in the development of telecare systems for the older population [43,51]. Despite the growing popularity of computers and mobile devices among older people and improved computer literacy, many of them are still unaware of the opportunities that telemedicine presents. Training for the use of telecare appears to be quite vital, as does ongoing education of the older population in this area. The needs, abilities, and preferences of older people should now be taken into account while providing telemedicine-based care, with adjustments made over time as care requirements change. Older adults have a wide range of needs, which can alter with time. Therefore, it is essential to individualize and adapt telecare systems for a range of abilities of older people, addressing their changing care requirements in a flexible and adaptable manner, always considering their impaired motor, sensory, and cognitive function.

Before using telecare technologies, all older people must be familiar with their utilization and aware of their advantages. In addition, perceptions of older people and their caregivers about the usability of home telecare are a substantial predictor of compliance with telecare [51]. An equitable health system should understand that while many older persons are willing and able to learn how to use telemedicine, for some, such as those with dementia and social isolation, in-person visits are already challenging, and telemedicine may be impractical. Clinics and geriatric modes of treatment, such as home visits, are crucial for these individuals [59].

Telecare will soon become a crucial aspect of older people's lives, enabling them to function independently in a comfortable living environment, if technologies are developed that are familiar, usable, appealing, affordable, and fit into lives and plans of older people. Further research is required to accentuate the importance of offering the older population telehealth alternatives that are both easily accessible and easy to use.

Limitations

Despite the fact that this study included a large set of data from people belonging to Israel's largest health management organization (and one of the largest health care organizations in the world), it still represents trends in telehealth use among the older population in Israel and not necessarily in all parts of the world. Furthermore, there were several parameters that could have an additional impact on telehealth use (eg, level of education); however, we did not have access to these data.

Conclusions

It is generally acknowledged that telemedicine-based treatment for the older people has several advantages. However, telemedicine also has limitations and barriers, some of which are due to the older people themselves.

The key findings of our study demonstrate that, despite all the challenges and hurdles, the older population uses telehealth services when they need them. People use telehealth services for administrative purposes more frequently, but they also consult with their own physician via telephone and the web and sometimes even use after-hours virtual consultations. These services make it easier for individuals to get medical care without having to travel, wait, or risk infection. Older people can increase their consumption as necessary during times of pressing necessity, such as the COVID-19 pandemic, or if they are afflicted with a persistent illness.

The study also reveals that even after the COVID-19 pandemic, most uses remained higher than they were before, implying that this population can learn how to use digital health services effectively and that they should be given the opportunity to do so by creating suitable and straightforward telehealth solutions tailored for this population and enhancing their usability.

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Data Availability

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Authors' Contributions

MH was involved in the conceptualization of the study, methodology, investigation, data curation, analysis, and writing the paper. RS was involved in data curation, methodology, formal analysis, software, and supervision.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Univariate analysis (working-hours visits)—2 categories.
[DOCX File , 21 KB - aging_v7i1e52317_app1.docx]

Multimedia Appendix 2
Univariate analysis (administrative telehealth use)—2 categories.
[DOCX File , 19 KB - aging_v7i1e52317_app2.docx]

Multimedia Appendix 3
Univariate analysis (after hours visits)—2 categories.
[DOCX File , 20 KB - aging_v7i1e52317_app3.docx]

References

1. Bashshur RL, Reardon TG, Shannon GW. Telemedicine: a new health care delivery system. Annu Rev Public Health 2000 May;21(1):613-637. [doi: 10.1146/annurev.publhealth.21.1.613] [Medline: 10884967]
2. Hebda TL, Czar P. Handbook of Informatics for Nurses & Healthcare Professionals. Upper Saddle River, NJ: Pearson Prentice Hall; 2012.
3. What is telehealth? How is telehealth different from telemedicine? HealthIT.gov. URL: https://www.healthit.gov/faq/what-telehealth-how-telehealth-different-telemedicine [accessed 2023-04-21]
4. Bujnowska-Fedak MM, Grata-Borkowska U. Use of telemedicine-based care for the aging and elderly: promises and pitfalls. Smart Homecare Technol Telehealth 2015 May;3:91-105 [FREE Full text] [doi: 10.2147/shtt.s59498]
5. Telecare technology for an ageing society in Europe. Pacita Project. URL: http://wp6.pacitaproject.eu/wp-content/uploads/2014/02/Telecare-description-web.pdf [accessed 2023-04-21]
6. 10 facts on ageing and the life course. World Health Organization. URL: https://www.silverinnings.com/old/docs/Facts%20n%20Issues/10%20facts%20on%20ageing%20and%20the%20life%20course.pdf [accessed 2024-04-15]
7. Dansky KH, Vasey J, Bowles K. Use of telehealth by older adults to manage heart failure. Res Gerontol Nurs 2008 Jan;1(1):25-32. [doi: 10.3928/19404921-20080101-01] [Medline: 20078015]
8. Foster MV, Sethares KA. Facilitators and barriers to the adoption of telehealth in older adults: an integrative review. Comput Inform Nurs 2014 Nov;32(11):523-33; quiz 534. [doi: 10.1097/CIN.0000000000000105] [Medline: 25251862]
9. Dale B, Söderhamn U, Söderhamn O. Self-care ability among home-dwelling older people in rural areas in southern Norway. Scand J Caring Sci 2012 Mar 25;26(1):113-122. [doi: 10.1111/j.1471-6712.2011.00917.x] [Medline: 21883344]
10. Husebø AM, Storm M. Virtual visits in home health care for older adults. ScientificWorldJournal 2014;2014:689873 [FREE Full text] [doi: 10.1155/2014/689873] [Medline: 25506616]
11. Hollander JE, Carr BG. Virtually perfect? Telemedicine for Covid-19. N Engl J Med 2020 Apr 30;382(18):1679-1681. [doi: 10.1056/NEJMp2003539] [Medline: 32160451]
12. Stone RA, Lowe D, Potter JM, Buckingham RJ, Roberts CM, Pursey NJ. Managing patients with COPD exacerbation: does age matter? Age Ageing 2012 Jul;41(4):461-468. [doi: 10.1093/ageing/afs039] [Medline: 22454133]
13. Maric B, Kaan A, Ignaszewski A, Lear SA. A systematic review of telemonitoring technologies in heart failure. Eur J Heart Fail 2009 May;11(5):506-517 [FREE Full text] [doi: 10.1093/eurjhf/hfp036] [Medline: 19332417]
14. Radhakrishnan K, Jacelon C, Roche J. Perceptions on the use of telehealth by homecare nurses and patients with heart failure. Home Health Care Manage Pract 2012 Jan 13;24(4):175-181. [doi: 10.1177/1084822311428335]
15. Peirce SC, Hardisty AR, Preece AD, Elwyn G. Designing and implementing telemonitoring for early detection of deterioration in chronic disease: defining the requirements. Health Informatics J 2011 Sep;17(3):173-190 [FREE Full text] [doi: 10.1177/1460458211409717] [Medline: 21937461]
16. Lam K, Lu AD, Shi Y, Covinsky KE. Assessing telemedicine unreadiness among older adults in the United States during the COVID-19 pandemic. JAMA Intern Med 2020 Oct 01;180(10):1389-1391 [FREE Full text] [doi: 10.1001/jamainternmed.2020.2671] [Medline: 32744593]
17. Gill TM, Gahbauer EA, Allore HG, Han L. Transitions between frailty states among community-living older persons. Arch Intern Med 2006 Feb 27;166(4):418-423. [doi: 10.1001/archinte.166.4.418] [Medline: 16505261]
18. Berry P, Mascia J, Steinman BA. Vision and hearing loss in older adults: "double trouble". Care Manag J 2004;5(1):35-40. [doi: 10.1891/cmaj.5.1.35.61260] [Medline: 15792329]
19. Donaghy E, Atherton H, Hammersley V, McNeilly H, Bikker A, Robbins L, et al. Acceptability, benefits, and challenges of video consulting: a qualitative study in primary care. Br J Gen Pract 2019 Sep;69(686):e586-e594 [FREE Full text] [doi: 10.3399/bjgp19X704141] [Medline: 31160368]
20. The impact of the COVID-19 pandemic on noncommunicable disease resources and services: results of a rapid assessment. World Health Organization. 2020 Sep 3. URL: https://www.who.int/publications/i/item/9789240010291 [accessed 2024-04-15]
21. Greenwald P, Stern ME, Clark S, Sharma R. Older adults and technology: in telehealth, they may not be who you think they are. Int J Emerg Med 2018 Jan 03;11(1):2 [FREE Full text] [doi: 10.1186/s12245-017-0162-7] [Medline: 29299704]
22. McDaniel NL, Novicoff W, Gunnell B, Cattell Gordon D. Comparison of a novel handheld telehealth device with stand-alone examination tools in a clinic setting. Telemed J E Health 2019 Dec;25(12):1225-1230 [FREE Full text] [doi: 10.1089/tmj.2018.0214] [Medline: 30561284]
23. Dunn OJ. Multiple comparisons using rank sums. Technometrics 1964 Aug;6(3):241-252. [doi: 10.1080/00401706.1964.10490181]
24. Chakraverty D, Baumeister A, Aldin A, Seven Ü, Monsef I, Skoetz N, et al. Gender differences of health literacy in persons with a migration background: a systematic review and meta-analysis. BMJ Open 2022 Jul 19;12(7):e056090 [FREE Full text] [doi: 10.1136/bmjopen-2021-056090] [Medline: 37667874]

25. Lee HY, Lee J, Kim NK. Gender differences in health literacy among Korean adults: do women have a higher level of health literacy than men? Am J Mens Health 2015 Sep;9(5):370-379 [FREE Full text] [doi: 10.1177/1557988314545485] [Medline: 25122719]
26. Darrat I, Tam S, Boulis M, Williams AM. Socioeconomic disparities in patient use of telehealth during the coronavirus disease 2019 surge. JAMA Otolaryngol Head Neck Surg 2021 Mar 01;147(3):287-295 [FREE Full text] [doi: 10.1001/jamaoto.2020.5161] [Medline: 33443539]
27. Smith A. Older adults and technology use. Pew Research Center. 2014 Apr 3. URL: https://www.pewresearch.org/internet/2014/04/03/older-adults-and-technology-use/ [accessed 2024-04-15]
28. Zhu J, Lois AW, Gitonga B, Chen-Meekin JY, Williams EJ, Khandelwal S, et al. The impact of socioeconomic status on telemedicine utilization during the COVID-19 pandemic among surgical clinics at an academic tertiary care center. Surg Endosc 2022 Dec;36(12):9304-9312 [FREE Full text] [doi: 10.1007/s00464-022-09186-x] [Medline: 35332387]
29. Katz AJ, Haynes K, Du S, Barron J, Kubik R, Chen RC. Evaluation of telemedicine use among US patients with newly diagnosed cancer by socioeconomic status. JAMA Oncol 2022 Jan 01;8(1):161-163 [FREE Full text] [doi: 10.1001/jamaoncol.2021.5784] [Medline: 34792526]
30. Campbell H. Religion and the internet. Commun Res Trends 2006;26(1):3-24.
31. Latzer Y, Stein D, Witztum E. Treating ultra-orthodox adolescents with eating disorders in Israel: culturally-sensitive interventions, difficulties, and dilemmas. J Clin Psychol 2019 Aug;75(8):1455-1468. [doi: 10.1002/jclp.22790] [Medline: 31009552]
32. Pare G, Jaana M, Sicotte C. Systematic review of home telemonitoring for chronic diseases: the evidence base. J Am Med Inform Assoc 2007 May 01;14(3):269-277. [doi: 10.1197/jamia.m2270]
33. Clark ML, Gropen T. Advances in the stroke system of care. Curr Treat Options Cardiovasc Med 2015 Jan;17(1):355. [doi: 10.1007/s11936-014-0355-9] [Medline: 25398423]
34. Mazzanti I, Maolo A, Antonicelli R. E-health and telemedicine in the elderly: state of the art. In: Assistive Technologies: Concepts, Methodologies, Tools, and Applications. Hershey, PA: IGI Global; 2014.
35. Polisena J, Tran K, Cimon K, Hutton B, McGill S, Palmer K. Home telehealth for diabetes management: a systematic review and meta-analysis. Diabetes Obes Metab 2009 Oct;11(10):913-930. [doi: 10.1111/j.1463-1326.2009.01057.x] [Medline: 19531058]
36. Shah MN, Gillespie SM, Wood N, Wasserman EB, Nelson DL, Dozier A, et al. High-intensity telemedicine-enhanced acute care for older adults: an innovative healthcare delivery model. J Am Geriatr Soc 2013 Nov;61(11):2000-2007. [doi: 10.1111/jgs.12523] [Medline: 24164485]
37. Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Hirani S, et al. Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial. BMJ 2012 Jun 21;344:e3874 [FREE Full text] [doi: 10.1136/bmj.e3874] [Medline: 22723612]
38. Cartwright M, Hirani SP, Rixon L, Beynon M, Doll H, Bower P, et al. Effect of telehealth on quality of life and psychological outcomes over 12 months (Whole Systems Demonstrator telehealth questionnaire study): nested study of patient reported outcomes in a pragmatic, cluster randomised controlled trial. BMJ 2013 Feb 26;346:f653 [FREE Full text] [doi: 10.1136/bmj.f653] [Medline: 23444424]
39. Bujnowska-Fedak MM, Puchała E, Steciwko A. The impact of telehome care on health status and quality of life among patients with diabetes in a primary care setting in Poland. Telemed J E Health 2011 Apr;17(3):153-163. [doi: 10.1089/tmj.2010.0113] [Medline: 21375410]
40. Chou CC, Chang CP, Lee TT, Chou HF, Mills ME. Technology acceptance and quality of life of the elderly in a telecare program. Comput Inform Nurs 2013 Jul;31(7):335-342. [doi: 10.1097/NXN.0b013e318295e5ce] [Medline: 23728446]
41. Hirani SP, Beynon M, Cartwright M, Rixon L, Doll H, Henderson C, et al. The effect of telecare on the quality of life and psychological well-being of elderly recipients of social care over a 12-month period: the Whole Systems Demonstrator cluster randomised trial. Age Ageing 2014 May;43(3):334-341. [doi: 10.1093/ageing/aft185] [Medline: 24333802]
42. Bashshur RL, Shannon GW, Krupinski EA, Grigsby J, Kvedar JC, Weinstein RS, et al. National telemedicine initiatives: essential to healthcare reform. Telemed J E Health 2009;15(6):600-610 [FREE Full text] [doi: 10.1089/tmj.2009.9960] [Medline: 19534591]
43. Turner KJ, McGee-Lennon MR. Advances in telecare over the past 10 years. Smart Homecare Technol TeleHealth 2013 Nov;1:21-34. [doi: 10.2147/shtt.s42674]
44. Barlow J, Singh D, Bayer S, Curry R. A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. J Telemed Telecare 2007;13(4):172-179. [doi: 10.1258/135763307780908058] [Medline: 17565772]
45. Bujnowska-Fedak MM, Pirogowicz I. Support for e-health services among elderly primary care patients. Telemed J E Health 2014 Aug;20(8):696-704 [FREE Full text] [doi: 10.1089/tmj.2013.0318] [Medline: 24359252]
46. Duplaga M. The acceptance of e-health solutions among patients with chronic respiratory conditions. Telemed J E Health 2013 Sep;19(9):683-691 [FREE Full text] [doi: 10.1089/tmj.2012.0306] [Medline: 23734700]
47. Haleem A, Javaid M, Singh RP, Suman R. Telemedicine for healthcare: capabilities, features, barriers, and applications. Sens Int 2021;2:100117 [FREE Full text] [doi: 10.1016/j.sintl.2021.100117] [Medline: 34806053]

48. Ressi M. Today's empowered consumer: the state of digital health in 2011. Manhattan Research. 2011. URL: https://kelley.iu.edu/CBLS/files/conferences/Ressi-Indiana [accessed 2024-04-15]
49. Wentzer HS, Bygholm A. Narratives of empowerment and compliance: studies of communication in online patient support groups. Int J Med Inform 2013 Dec;82(12):e386-e394. [doi: 10.1016/j.ijmedinf.2013.01.008] [Medline: 23523082]
50. Tomita MR, Russ LS, Sridhar R, Naughton BJ. Smart home with healthcare technologies for community-dwelling older adults. In: Al-Qutayri M, editor. Smart Home Systems. London, UK: IntechOpen; 2010.
51. Hanson J, Percival J, Aldred H, Brownsell S, Hawley M. Attitudes to telecare among older people, professional care workers and informal carers: a preventative strategy or crisis management? Univ Access Inf Soc 2007 Aug 2;6(2):193-205. [doi: 10.1007/s10209-007-0075-y]
52. Chae YM, Heon Lee J, Hee Ho S, Ja Kim H, Hong Jun K, Uk Won J. Patient satisfaction with telemedicine in home health services for the elderly. Int J Med Inform 2001 May;61(2-3):167-173. [doi: 10.1016/s1386-5056(01)00139-3] [Medline: 11311671]
53. Adler R. The age wave meets the technology wave: broadband and Older Americans. SeniorNet. 2002. URL: http://www.seniornet.org/downloads/broadband.pdf [accessed 2015-03-11]
54. Understanding the brain: the birth of a learning science. Centre for Educational Research and Innovation. 2007. URL: http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/Understanding-the-brain.pdf [accessed 2015-03-11]
55. Bujnowska-Fedak MM, Mastalerz-Migas A. Usage of medical internet and e-health services by the elderly. Adv Exp Med Biol 2015;834:75-80. [doi: 10.1007/5584_2014_74] [Medline: 25315621]
56. Overcoming the psychological barriers to telemedicine: empowering older Americans to use remote health monitoring services. DocPlayer. 2007 Feb. URL: http://newmillenniumresearch.org/archive/Telemedicine_Report_022607.pdf [accessed 2024-04-15]
57. Clark J, McGee‐Lennon M. A stakeholder‐centred exploration of the current barriers to the uptake of home care technology in the UK. J Assist Technol 2011 Mar 18;5(1):12-25. [doi: 10.5042/jat.2011.0097]
58. The national program for digital health. Ministry of Health Israel. URL: https://www.gov.il/he/Departments/General/project-digital-health [accessed 2024-04-15]
59. Rowland D. A five-nation perspective on the elderly. Health Aff (Millwood) 1992;11(3):205-215. [doi: 10.1377/hlthaff.11.3.205] [Medline: 1398444]
60. Cimperman M, Brenčič MM, Trkman P, Stanonik M. Older adults' perceptions of home telehealth services. Telemed J E Health 2013 Oct;19(10):786-790 [FREE Full text] [doi: 10.1089/tmj.2012.0272] [Medline: 23931702]

Abbreviations

COPD: chronic obstructive pulmonary disease
OR: odds ratio
SES: socioeconomic status
VDI: virtualization desktop infrastructure

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Original Paper

Experiences of a Community-Based Digital Intervention Among Older People Living in a Low-Income Neighborhood: Qualitative Study

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Abstract

Background: Older adults worldwide experienced heightened risks of depression, anxiety, loneliness, and poor mental well-being during the COVID-19 pandemic. During this period, digital technology emerged as a means to mitigate social isolation and enhance social connectedness among older adults. However, older adults' behaviors and attitudes toward the adoption and use of digital technology are heterogeneous and shaped by factors such as age, income, and education. Few empirical studies have examined how older adults experiencing social and economic disadvantages perceive the learning of digital tools.

Objective: This study aims to examine the motivations, experiences, and perceptions toward a community-based digital intervention among older adults residing in public rental flats in a low-income neighborhood. Specifically, we explored how their attitudes and behaviors toward learning the use of smartphones are shaped by their experiences related to age and socioeconomic challenges.

Methods: This study adopted a qualitative methodology. Between December 2020 and March 2021, we conducted semistructured in-depth interviews with 19 participants aged ≥60 years who had completed the community-based digital intervention. We asked participants questions about the challenges encountered amid the pandemic, their perceived benefits of and difficulties with smartphone use, and their experiences with participating in the intervention. All interviews were audio recorded and analyzed using a reflexive thematic approach.

Results: Although older learners stated varying levels of motivation to learn, most expressed ambivalence about the perceived utility and relevance of the smartphone to their current needs and priorities. While participants valued the social interaction with volunteers and the personalized learning model of the digital intervention, they also articulated barriers such as age-related cognitive and physical limitations and language and illiteracy that hindered their sustained use of these digital devices. Most importantly, the internalization of ageist stereotypes of being *less worthy* learners and the perception of smartphone use as being in the realm of the privileged *other* further reduced self-efficacy and interest in learning.

Conclusions: To improve learning and sustained use of smartphones for older adults with low income, it is essential to explore avenues that render digital tools pertinent to their daily lives, such as creating opportunities for social connections and relationship building. Future studies should investigate the relationships between older adults' social, economic, and health marginality and their ability to access digital technologies. We recommend that the design and implementation of digital interventions should prioritize catering to the needs and preferences of various segments of older adults, while working to bridge rather than perpetuate the digital divide.

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KEYWORDS

digital divide; digital learning; smartphones; social gerontology; older adults; COVID-19 pandemic; technology adoption

Introduction

Globally, the COVID-19 pandemic has engendered unprecedented challenges for older adults. In addition to confronting the risks of infections and death [1], prolonged social distancing measures have worsened the physical and mental health as well as the quality of life in the older adult population. During this period, heightened loneliness, social isolation, and anxieties were attributed to reduced social engagement and support, mistreatment, and misinformation [2-4]. Loneliness is associated with higher risks of depression, functional and cognitive decline, and all-cause mortality and morbidity [5-7]. Older adults with lower socioeconomic status, preexisting comorbidities, and poorer access to health care were more likely to experience mental health–related problems [8,9]. Digital technology has surfaced as an essential way for older adults to cope with restrictions and mitigate loneliness by fostering social connections [10,11]. Studies have demonstrated the potential for technology to reduce perceived isolation via improved social support, connectedness, and engagement in activities [12,13] as well as promote a sense of autonomy and confidence [14]. Older adults who had more frequent digital contact, for example, through video calls, social media, or phone calls with friends and family, during the pandemic reported higher levels of satisfaction and well-being and a lower sense of social isolation [7,15,16]. Digital interventions have also been developed to enhance the psychosocial well-being of older adults. For example, a digital human facilitator was found to be feasible and acceptable in alleviating older adults' stress and loneliness [17], and a digitally guided group intervention increased their digital literacy and abilities to cope with distress [18].

However, a large proportion of older adults globally continue to have little or no access to digital technology [19,20]. With the accelerated digitization of basic services (eg, financial transactions, health, and communications), the growing digital divide may further worsen the inequities in health and exclude the already marginalized segments of the population. Inequalities in access to digital literacy exist not only based on age but also based on income, education, sex, disability status, and immigration status, which culminate in "distinct positionalities of privilege and disadvantage," shaping diverse attitudes and behaviors toward digital technology use [21-23]. Those with higher incomes across all age groups tend to adopt communication technologies earlier and more extensively than those with lower incomes [22]. In Singapore, older adults with poor health, with less education, and residing in low-income housing were found to experience greater difficulties with internet use [24].

The unequal access to digital technology and challenges associated with its adoption among older adults have been well established in the literature [25,26]. Studies have also reported factors, both at the individual and environmental level, that facilitate or hinder older adults' adoption of and continued engagement in digital technology [27]. While the factors influencing digital technology adoption among the older adult population have been well documented, there remains a gap in understanding the diverse attitudes, experiences, and perspectives among distinct subgroups of older adults [27]. In addition, much of the discourse and theoretical foundations regarding technology use was informed by conventional models of technology adoption (eg, Technology Acceptance Model and Unified Theory of Acceptance and Use of Technology) or behavioral health theories (eg, Theory of Planned Behavior and Social Cognitive Theory) [28]. While these models illuminate the influence of psychosocial and behavioral factors on technology adoption, they fail to account for the socioeconomic and environmental contexts that shape these attitudes and perceptions toward digital technology.

To fill this gap, this study aimed to explore the experience of and perceptions toward a community-based digital intervention among older adults living in low-income neighborhoods during the COVID-19 pandemic. Particularly, we sought to understand the motivations, perceived challenges regarding the adoption and continued use of smartphones, and benefits derived from the learning process, all in the context of social and economic vulnerabilities. The findings will inform how older adults who are considered vulnerable can most benefit from digital technology adoption and how program implementers can tailor the design of the interventions to older adults' needs to maximize their effect.

Methods

Overview

This qualitative study was part of a larger mixed methods study conducted to evaluate the impact of a community-based digital intervention, namely, Project Wire Up, on older adults' digital literacy and health-related outcomes in low-income neighborhoods in Singapore. This study used a generic qualitative methodology because the aim was to explore how older adults interpret and attribute meaning to the community-based digital intervention and smartphones [29]. Aligned with a constructivist epistemology, this methodology was selected to emphasize and foreground older adults' subjectivities and their experiences regarding the intervention.

Ethical Considerations

Ethics approval to conduct the study was obtained from the SingHealth Centralized Institutional Review Board (2020/2722). Ethical considerations were accounted for in the design and implementation of the study within the context of a marginalized older adult community. For example, as in-depth interviews with older adults regarding the challenges they face in their everyday lives may elicit sensitive or upsetting recalls, interviewers will provide options for receiving various forms of support when needed (eg, taking breaks, postponing the interview, and options for referral to mental health resources) and remind participants that responding to interview questions is voluntary. In addition, as participants are referred to the study upon completion of the digital intervention, they may feel obliged to enroll in the study. Thus, the study team will highlight that participation in the study is voluntary and will not influence their access to services or ability to participate in subsequent community interventions. Informed consent was obtained before the interviews.

Setting

Singapore is experiencing an accelerated rate of population aging [30]. By 2030, the country will have one of Asia's oldest populations, with one-fourth of the population aged >65 years. During the COVID-19 pandemic, heightened safety measures were implemented from April 2020 to June 2020 to curb widespread transmission. Nonessential services were stopped, and movement in public spaces was significantly curtailed. As most of the populace turned to digital means to maintain social connections and keep up to date with the news, a digital divide based on age became palpable [31]. Concerns that older adults would be *left behind* in the digital world became an impetus for a slew of government programs such as the Seniors Go Digital [32] to encourage smartphone adoption among this group [33,34]. Considering the heightened digital exclusion experienced by older adults with socioeconomic disadvantages, efforts were dedicated to enhancing access to digital literacy for this group of older adults [35].

Project Wire Up was established in July 2020 by TriGen, a voluntary organization, in partnership with Singapore General Hospital, Infocomm Media Development Authority, and older adult activity centers in Singapore to pilot a volunteer-led, one-on-one, home-based digital literacy program [35]. Those enrolled in Project Wire Up were eligible to purchase smartphones at subsidized rates and were matched to volunteers who provided one-to-one coaching regarding digital skills, including making video calls, connecting to Wi-Fi, performing web-based purchases, and using government services. An average of 6 sessions were conducted at participants' homes over 3 months and were personalized according to their interests and competencies. Upon the completion of the program, volunteers may connect older adults to formal and informal networks for social support [35]. The aim of the intervention was to close the digital gap and improve social connectivity among older adults with lower socioeconomic status living in public rental neighborhoods. Public rental housing units, a sensitive indicator of area-level socioeconomic status in Singapore, are heavily subsidized flats that cater to lower-income households. Individuals eligible for public rental housing have total household gross monthly incomes that do not exceed approximately US $1000 [36].

Older residents in public rental flats face higher risks of frequent hospital admission and readmission, higher use of hospital and emergency department services, and longer durations of hospital stay [37]. Living in rental flats has also been correlated with poorer physical and mental health, including poorer cognitive function and higher depression rates among older adults [38]. In addition to shouldering a higher disease burden, they are more likely to have limited social and financial support. As poorer digital literacy may negatively influence older adults' health via weaker social connections [39] and impact their ability to access health information and increasingly digitized modes of health care delivery [20], Project Wire Up's primary goal of enhancing social connectivity and digital literacy has the potential to improve older adults' well-being and mitigate health care use.

Recruitment and Data Collection

The study team worked closely with the implementation team to recruit eligible participants who met the inclusion criteria of being aged ≥60 years and successful completion of the program. Participants aged ≥60 years or who had not completed the intervention were excluded. A list of eligible participants was referred to the study team, who then contacted the participants to ask whether they were interested in participating in the study. A purposive sampling technique was used to obtain a diverse sample of participants, in terms of ethnicity, sex, and language spoken, to reflect the heterogeneous older adult population in Singapore. Between December 2020 and March 2021, the study team conducted semistructured interviews at various public rental housing estates. During the interview, participants were asked about their life histories, daily routines, challenges they faced during the lockdown, support received, meanings associated with smartphone use, and their experiences and challenges in participating in the program. Overall, 2 interviewers trained in qualitative research conducted the interviews, while observing the appropriate social distancing measures. Interviews usually lasted between 45 minutes and 1.5 hours and were conducted in English or local dialects (Mandarin, Cantonese, Hokkien, and Malay) and audio recorded.

Data Analysis

All interviews were transcribed and translated from local dialects to English. Then, the transcripts were coded using NVivo (version 12; Lumivero). Consistent with a generic qualitative methodology, a thematic analysis was conducted. An initial codebook was generated based on key sections of the interview guide. The interview guide drew on certain concepts from the existing literature, which posit that factors such as health, social network, and perceptions about technology influence how participants relate to and perceive smartphone use. These initial codes also included the challenges faced during the COVID-19 pandemic, as we anticipated that the pandemic may influence older adults' attitudes and behavior toward technology. Participants were also asked about their experiences with the program, including preprogram expectations, memorable moments, preferred mode of learning, postprogram smartphone use, and what they hoped to learn in future. These program-specific questions were intended to inform the design and implementation of future interventions.

Using this initial codebook, 2 coders coded 3 transcripts together through inductive and inductive coding methods to identify regularities in ideas and other emergent themes that may be relevant to the research problem. In this process, existing categories were expanded, and new categories were added to the codebook. Then, both coders coded the transcripts separately using the reviewed codebook. As both coders have each conducted several interviews with study participants, they had an in-depth understanding of and familiarity with the data and conducted regular discussions after coding 4 to 5 transcripts to resolve any discrepancies and discuss whether the key analytic categories that emerged were reflective of the meanings expressed by the participants. Analytic memos were also written alongside the coding process to reflect on any issues that arose during the coding process, emergent patterns, and thematic categories and subcategories [40]. Constant comparative analysis was performed throughout the process to compare the interview data to emerging categories and to determine the consistency in coding. Categories were created and refined when the data did not fit into categories. Then, the coders, together with members of the study team, discussed the key themes that were most salient in the interview data that shaped older adults' experiences with the intervention and smartphone use. This paper followed the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist to ensure comprehensive and transparent reporting of the results [41].

Results

Participant Characteristics

We conducted a total of 19 interviews over a period of 4 months. Data saturation was achieved at 15 interviews, and we conducted a few more interviews to ensure that new data did not disclose new insights. Of the 19 participants, 12 (63%) were female participants, 16 (84%) were Chinese, 13 (68%) were widowed or single, and 15 (79%) lived alone in 1-room rental flats. Most participants reported a relatively low educational attainment, where 32% (6/19) of the participants received no formal education, and 26% (5/19) received primary education. The participants' characteristics are presented in Table 1.

In this study, we identified three themes that reflect the perceived challenges and benefits related to learning the use of smartphones among older adults who live with low income: (1) age and social marginality, (2) technological design as a form of exclusion, and (3) digital learning process as a tool for mitigation of social isolation and marginality.

Table 1. Participants' characteristics (N=19).

Characteristics	Participants, n (%)
Age (years)	
60-69	5 (26)
70-79	7 (37)
≥80	7 (37)
Sex	
Male	7 (37)
Female	12 (63)
Ethnicity	
Chinese	16 (84)
Malay	1 (5)
Indian	2 (11)
Marital status	
Married	4 (21)
Widowed	6 (32)
Divorced	2 (11)
Never married or single	7 (37)
Highest level of education	
No formal education	6 (32)
Primary	5 (26)
Secondary	5 (26)
Vocational or diploma	1 (5)
University and above	1 (5)
No response	1 (5)
Housing type	
1 room	15 (79)
2 rooms	3 (16)
3 or 4 rooms	1 (5)
Living arrangement	
Staying with spouse only	3 (16)
Staying alone	15 (79)
Staying with helper	1 (5)
Employment status	
Working (full time)	2 (11)
Retired	13 (68)
Unemployed	4 (21)

Age and Social Marginality

Overview

Older adults' perceptions about smartphones and the digital intervention must be understood within the context of their experiences with aging and social precarities. Precarity refers to an existence characterized by insecurity, unpredictability, and vulnerability that could emerge at an intersection of social disadvantages that extend into later life [42]. This means that older adults' everyday experiences of aging must be understood and situated within the social structures that they are embedded in. In this study, most participants were in the middle-old category and experienced social and income-related vulnerabilities. Thus, our analysis demonstrated that the manner in which older adults relate to smartphone use and define their capacity as learners is inextricably connected to their age-related anxieties and perceived socioeconomic positioning.

Aging-Related Precarities and Internalized Ageism

The most cited barrier to learning was age-related cognitive and physical decline, including visual and hearing impairment, memory difficulties, and decreased agility in their fingers, which impeded the ability to use the smartphone and retain knowledge from each session. More than half of the participants felt embarrassed about not being able to remember what was taught. For example, some participants described the anxieties and feelings of helplessness related to a perceived "deterioration" in their minds that made it difficult to absorb and apply the information learnt—a problem they attributed to old age:

> *You are young, your minds are good, you can put many things inside but our mind is deteriorating, old already. [I] cannot see, cannot walk fast, this is natural for every person who gets old.* [Participant #3, female]

In addition to the challenges related to cognitive and physical constraints, participants also expressed negative aging self-perceptions throughout the interview. While these were not explicitly stated as barriers to smartphone learning, they reflect the attitudes toward learning or negative associations between learning and old age. For example, a participant expressed the futility and meaninglessness of learning during old age:

> *At first, I did not want to take [the phone], [but] the manager at the SAC said, "take it, learn slowly." I said I am already going to die, no point learning, so old already, no one will know what will happen tomorrow, just live one day at a time.* [Participant #6, female]

Our participants considered their unsuccessful attempts at mastering smartphone use as a sign of their inaptitude due to old age and the futility of the learning process. Participants had a strong tendency to individualize responsibility for the outcome of smartphone learning. Despite feeling uncertain about their ability to sustain smartphone use, participants chose not to seek help from volunteers after each visit due to their fear of "troubling" them and their reluctance to be seen as a "burden." For example, some participants assessed themselves as learners who were "not worthy" of the time and attention from the volunteers who have "better things to do":

> *I said as a volunteer, you need to work, if you come here it takes about 1 hour to teach us, we are wasting your time, how much can you teach us, after you leave, I cannot remember already, now we are old...I do not want to obstruct people's time...We do not want to trouble others.* [Participant #1, male]

Therefore, participants internalized ageist assumptions by viewing age-related limitations as "deficits" that prevent them from undertaking smartphone-related activities [43]. Such ageist self-judgments exacerbate their poor self-conception, low self-worth (ie, as learners with no scope for growth and whose needs should not be prioritized), and resistance toward learning.

Social Precarities and Self-Imposed Stigma

Participants' perceived lack of interest and confidence to learn smartphone use were also shaped by the awareness of their social positioning in relation to other older adults. Overall, one-third of the older adults emphasized that it was particularly difficult for them to learn to use the smartphone because of language barriers and illiteracy. For example, 1 participant was quick to distinguish himself from those who spoke English and were literate—characteristics that he felt predisposed them to increased competency and ability to acquire smartphone skills at a faster pace:

> *Those [literate] people know words, know English, know the language. It is different, teaching them is very fast. For us, we do not recognize words, you teach me 10 times but I cannot remember...Waste time, waste effort.* [Participant #1, male]

Most Chinese older adults residing in the neighborhood where the intervention was conducted are Mandarin-speaking or dialect-speaking individuals, making it challenging for them to navigate the smartphone. While volunteers helped these older adults change the default language setting to Mandarin, some participants were still not able to identify the characters due to their limited literacy. Participants viewed smartphone use as being in the realm of the privileged "other," which does not align with their identities as "low income" or "uneducated." For example, when asked how she feels about using the smartphone for purposes such as seeing the physician will change her life, 1 participant expressed that smartphones were not suitable for the "kind of people" living in her neighborhood:

> *Some of us are uneducated, if educated, they have means or help and the ability to have a higher [paying] job. They will not be living in this area, you must understand what kind of area people live and what kind of people are living inside here, it's not only when you think it's good you can see on TV it's good for old people.* [Participant #13, female]

By perceiving that smartphone use is not applicable to older adults living in a certain "kind of area," some participants "classified" themselves as failing to belong to the "in group" of digitally savvy older adults, thus reducing their self-esteem and motivation to learn.

Technological Design as a Form of Exclusion

Participants also expressed challenges related to smartphone technology, with its design primarily catering to the needs of a certain type of digitally literate individuals. Many participants described their interaction with the device as a stress-inducing process, pointing out that the sensitivity of the touch screen, small font sizes, multiple apps, and colorful esthetics made it confusing to navigate the interface. For example, 1 participant lamented that a combination of poor eyesight and stiff fingers resulted in her accidentally dialing the wrong numbers, incurring the wrath of family and friends:

> *The smartphone is very sensitive, my finger accidentally touches it, then the other person's phone will get it, so that is the trouble for [an] old lady...[my] eyesight is very poor, if our eyesight is*

> *poor and the writing is so small, how you expect us to see...This phone is sensitive. That's why I told you it's not suitable for us old people.* [Participant #13, female]

Thus, participants noted the incompatibility of smartphone's functions with the needs of older adults and suggested that smartphone use will be helpful for those in the young-old group but felt that learning at an older age may not be useful. The failure of some smartphone designs to consider older adults' age-related cognitive and physical limitations, needs, and preferences may also account for their sense of ambivalence toward smartphone use. For example, some participants expressed a disconnect between the prospects of learning a new, potentially disruptive technology and the fundamental priorities that they have at this point in their lives.

When asked what it means to be healthy, dominant themes expressed by participants included the ability to "walk," ability to eat as they desired, having a "clear" mind and good eyesight, absence of ailments and difficulties, and ability to "live day by day doing the things [they] enjoy." Therefore, the purportedly transformative potential of smartphones was incongruous with what participants valued or perceived as essential to their current life situation:

> *I want my life to be as simple as possible, do whatever I want to do...I just want to be happy, my mind has no space for other complicated things. At my age, I do not know when I am leaving this world, learn already also no point.* [Participant #8, female]
>
> *We do not use these phone applications, only the youngsters use, there is a camera, take whose picture? A lot of these games, play for what...? Young people like all these funny things, we old people only need big font, big screen, simple.* [Participant #3, female]

However, 11% (2/19) of the participants were motivated by the opportunity to learn new skills and expressed comfort and familiarity with navigating the smartphone. Their motivations were primarily shaped by active early-life work experience and the desire to keep in contact with closely connected family networks. Support from family members also facilitated their experience of uptake and sustained use. This aspect holds significance as it shows that despite cumulative disadvantages structured by lack of education, income, and employment opportunities, social support could influence their access, familiarity, and motivation to engage in digital learning.

Digital Learning Process as a Tool for Mitigation of Social Isolation and Marginality

While older adults in this study encountered challenges influenced by their experiences of aging, social precarities, and technological barriers, some participants expressed benefits related to the strengthening of relational ties with new friends or family members.

Many participants stated that their interactions with volunteers were one of the program's most memorable moments. They appreciated having "someone to talk to" and liked that the volunteers were friendly, helpful, and approachable and provided personalized attention to addressing their queries. Thus, participants enjoyed the social exchanges with the volunteers, particularly if they could "chat and get along very well":

> *I miss him [the volunteer], because when I sit here, I miss him sitting next to me, talking to me, teaching me what to do, [he] is a good person, really good, he's working, he said no problem auntie you can call me if you have any problems.* [Participant #15, female]

By learning how to make phone calls, send voice messages, and use mobile phone apps, participants mentioned improved social relationships, such as making new friends through the volunteers, and found it easier to communicate with others using the video call function:

> *It is more convenient to communicate with people, you can see them. Otherwise at that time, we did not know how to use the function, then it felt like we lost contact. You can only hear the voices but not see the people.* [Participant #12, male]

Thus, given that most older adults in this study lived alone, designing an intervention that not only emphasized acquiring smartphone skills but also concurrently nurtured social bonds and connections appeared to foster participants' initial acceptance and adoption of digital technology.

Discussion

Principal Findings

This study explored the perceptions and experience regarding a community-based digital intervention among older adults residing in a lower-income neighborhood. We sought to understand older adults' motivations for learning, challenges to uptake and sustained use, and benefits derived from the digital engagement processes in the context of age-related and social disadvantages.

We found that the meanings older adults associated with learning at old age shaped their motivation and confidence in learning. Participants cited cognitive and physical limitations such as visual or hearing impairment and memory difficulties and a perceived sense of futility and meaninglessness of learning at old age as factors that limited their capacity and interest in digital learning. Many older adults expressed embarrassment and frustration regarding not being able to retain or apply what was taught and viewed these challenges as a *natural* outcome of old age. These negative self-perceptions are emblematic of the internalization of ageist structures and stereotypes that associate "being old" with being not technologically savvy. These findings corroborate studies that have documented how older adults' identification with the negative connotations related to their age group may deter technology use [44,45]. These ageist stereotypes that depict older adults as "inflexible" or unable to "adapt to new ideas and to the use [of technology]" contribute to older adults' feelings of low self-efficacy and discomfort and beliefs that efforts to learn will be unproductive or embarrassing [46].

Our study also reveals that these age-based anxieties intersect with older adults' experiences of other forms of marginalization, including perceived stigma of being less educated and literate than other segments of the older adult population. The finding that older adults encounter language barriers aligns with those of a study in Singapore that described how the fear of information and communication technology among older adults in Singapore may be explained by their “limited command of English,” particularly among those with lower levels of education and socioeconomic status [26]. This study also found that older adults in this group expressed concerns related to the affordability of purchasing digital devices [26]. However, a novelty of our findings is that although the presence of subsidized smartphones facilitated smartphone uptake, older adults’ lingering ambivalence and aversion toward smartphone learning is also shaped by their consciousness and perception that smartphone use and technology adoption belongs to a privileged *other* from which they are excluded, and this influences their interest and motivation to learn. While the literature has recognized the importance of income and education in influencing older adults’ intention to use technology [28], our findings contribute to the existing literature by highlighting that older adults may internalize ageist attitudes and stigma resulting from their positionality within the social and economic structure. These self-perceptions hinder their desire to participate in and sustain smartphone learning. In addition, in the context of Singapore, public messages also showcase digital savviness and active social engagement as a marker of successful and healthy aging [33,47]. As studies have shown that engagement in digital practices corresponds to sociocultural conceptions of aging that is “active, engaged, independent [and] highly productive” [48], we posit that broader norms of successful aging may shape the identities, feelings of disempowerment, and negative self-perceptions of older adults with lower income and, in turn, affect their dispositions and perceptions toward smartphone learning.

In addition, our study demonstrates that older adults’ difficulties in navigating the smartphone’s user interface point to the absence of age-friendly features. These findings confirm those of earlier studies that suboptimal design features of digital devices, such as display screens that are challenging to navigate, small icons, and overall “low levels of graphic design adaptation” that fail to cater to the needs of older adults, may completely inhibit access [49]. However, our study adds to the literature by emphasizing older adults’ perceptions that the design and function of smartphones are incompatible with their existing priorities, needs, and visions of “healthy aging” and their feeling that it would be more relevant to the needs of young or middle-aged individuals or those who are digitally literate. While our study reiterates the need to examine the heterogeneity in technology use within the older adult population [50], we also emphasize that older adults’ perceived irrelevance and lack of usefulness of the smartphone in their everyday lives provoke a broader consideration of how existing digital tools and technologies often cater to the preferences and needs of a certain segment of the population, while excluding others.

Our study also highlighted that for older adults typically living alone in low-income neighborhoods, the community-based digital intervention had significant social meanings, creating new forms of social connection and relationships. In addition to improving digital literacy, most participants valued the interaction with the program volunteers. The importance of relationship building within the scope of digital learning is also underscored by the few participants who had demonstrated a strong motivation to learn. Participants in this group consistently practiced and used the smartphone to stay in contact with family and friends. This pattern is evident in studies that indicate the importance of familial and social support, particularly the efficacy of intergenerational approaches in the learning of digital skills, where older adults learn digital skills more readily from their grandchildren [50,51]. Overall, our findings reinforce how older adults’ aversion to digital technologies are shaped by factors such as age-related barriers and negative self-perceptions and a lack of user-friendly digital devices. However, our findings add to the existing literature by highlighting how individual-level factors are intertwined with and situated within the structural vulnerabilities that older adults confront such as age and income-related stigma and marginality. Thus, this study makes an important contribution to the existing theoretical models of technology use. Models such as the Senior Technology Acceptance Model have considered how technological use may differ in the context of older adults’ age-related physical, psychological, and social circumstances that predict their attitudes and behaviors toward digital technology [52]. The Senior Technology Acceptance Model explains that technology adoption is influenced by factors such as older adults’ self-reported health and cognitive ability, social relationships and life satisfaction, and levels of self-efficacy and anxiety toward gerontechnology [49,52]. However, our study’s findings supplement these frameworks by underscoring how the attitudes toward smartphone use among older adult populations that are considered vulnerable must be contextualized within intersecting age-related and income-related precarities that contribute to internalized ageist attitudes and social stigma among older learners, thereby shaping their self-perceptions, motivation, and identities. Existing models of technology use should consider the systemic ageism or exclusion that particular segments of older adults experience that may hinder technology adoption. The consideration of how older adults’ attitudes and behaviors toward digital technology are impacted by their experiences of other systemic disadvantages urges a shift from placing the onus of digital uptake on older adults toward bolstering the existing technological systems and social supports to improve digital connectedness.

Recommendations for Future Interventions

Based on our findings, 4 key strategies could be recommended to enhance the teaching methods and learning outcomes of older adults in low-income communities, as described in the following subsections.

Understanding the Compatibility of Digital Technology With Older Adults’ Lived Experiences

Implementers should consider whether the digital intervention and device are compatible with participants’ needs, preferences, and social circumstances. To comprehend the factors that influence participants’ motivations and attitudes toward learning a new technology, implementers could conduct a needs assessment to identify participants’ healthy aging goals, daily routines, support network, and interests to plan how the smartphone could be relevant to their priorities. Although the current intervention tailors the program according to participants' interests and abilities (where tier 1 involves learning "basic" phone functions such as video calls and tier 3 involves more "advanced" features such as web-based purchases or using government services), participants may not be able to derive meaning from learning these functions if they are not useful in their everyday lives. For example, if a participant wishes to increase their social interaction, the volunteer can teach them the video call function so that they can make a call to a family member or friend. Smartphone learning should not be seen as an end but as a means to fulfill objectives that are of importance to older adults.

In addition, smartphones may also not be perceived as a "resource" amidst financially precarious circumstances, where the urgent trade-offs in everyday priorities of living (eg, inability to pay for medical bills and uncertainties of welfare apps) mean that smartphone learning and its uncertain "rewards" cannot be prioritized alongside other competing demands on time and energy. Thus, volunteers and older adults should jointly examine ways in which they identify the perceived utility and relevance of the digital innovation in their current routines and life goals. Moreover, it is crucial to recognize that older adults do not necessarily share commonly held assumptions of smartphone as the indisputably "better," "more convenient," and "simpler" option; even if they do, they may also not perceive or understand these terms in the same ways. Thus, program implementers should consult older participants about what they value, the types of meanings they ascribe to the purported benefits of the smartphone, and the types of learning approaches that can best meet these needs. Expanding the discourses and meanings attributed to smartphones by different subgroups, particularly individuals considered marginalized, can promote intervention frameworks centered on equity and social justice, thus refuting "structures and systems designed by and for persons in more advantageous social positions" [21].

Strengths-Based Approach to Dismantle Ageist Stereotypes

To address older adults' negative self-perceptions about aging, digital interventions should take a directive approach to dismantle ageist stereotypes before cultivating more independent forms of learning [53]. Opportunities to contemplate age-related challenges should be built into the learning model, enabling older adults to confront their self-perceptions as being a "less worthy" or "incapable" learner. For example, techniques such as motivational interviewing can be adopted by volunteers to better understand older adults' motivations to learn or resist smartphone learning. Rather than using a deficits-based approach (eg, what older adults do not know), motivational interviewing [54] seeks to affirm participants' strengths, wisdom, and values and develops a plan toward change based on their own insights. This approach emphasizes the creation of a nonjudgmental, respectful, and compassionate space, where the older adults' choice to learn or not learn the use of smartphone is not frowned upon or stigmatized. When older adults feel more empowered to learn, they can begin to explore the possibilities of smartphone use and refute the previously held conceptions that technology use conflicts with their identities (ie, not for "someone like them"). At the same time, the encouragement of older adults to learn should not involve coercion or guilt-tripping those who choose not to participate. Efforts must be made to assure older adults that a lack of participation will not deprive them of any other community services or assistance, to reduce the likelihood of older adults participating out of fear or obligation. Moreover, the responsibility should not be completely placed on older adults to actively engage in and keep up with digital practices, where resistance to learning becomes stigmatized or viewed as a burden or sign of "backwardness;" the consequence would be a subversion of the "discourse of empowerment" that digital technology seeks to promote [48].

Strengthening Social Ties Through Technology

Our findings suggest that smartphones can be adopted to fulfill relational purposes. Incorporating the cultivation of relational ties, in the form of family members, peers, or volunteers within a digital learning model, can serve to be a "catalytic intermediary" to motivate the use of digital technology [26] and sustain older adults' interest in the program. In addition, digital technology can act as a medium through which older adults who live alone or lack a supportive social network can expand their social capital by "forming new social relationships or maintaining existing social ties" [26].

Digital technology can also serve as a medium through which older adults can acquire new skills or habits as part of a learning group. For example, a study has explored the application of gamification techniques to encourage older adults to improve digital skills through interactive games with a partner on a touch screen tablet. These games were designed to improve cognitive and motor skills and facilitate social interaction and were found to be effective in improving the acquisition of digital expertise [55]. Thus, intervention models that incorporate problem-solving activities and collaborative peer learning can create an interactive space that nurtures social connections and diminishes feelings of loneliness among isolated older adults in communities considered socially disadvantaged.

Ensuring Program Continuity

We found that the lack of opportunities for continued practice and application reduced older adults' motivation for sustained use of the smartphone following the intervention. Future interventions can provide options to participants based on their levels of interest, skills, and aptitude; this could include connecting older adults to guided learning groups to practice the skills taught or to specific interest groups (eg, playing mahjong on the web). In addition, volunteers can visit the older adults at a fixed time to resolve technical issues that they may have related to phone use.

Strengths and Limitations

While the literature has documented the challenges faced by older adults in the realm of digital learning, this is the first study that uses a qualitative approach to examine how older adults residing in low-income neighborhoods experience aging and the social and health-related challenges that facilitate or limit their self-efficacy and interest in digital devices. In a global context, there have also been other types of interventions that focus on improving older adults' digital literacy. For example, in North America, digital literacy training sessions have been conducted in public libraries and community organizations [45]; a 4-month program of weekly computer classes was organized for African American older adults with low income at an older adult community center to gain familiarity with assessing web-based information and privacy issues [56]; and a 4-week digital literacy program was conducted to equip older adults with knowledge about how to navigate their computer (eg, sending emails) during the COVID-19 pandemic [57]. However, to the best of our knowledge, it appears that no study specifically explored the impact of a home-based digital literacy intervention during the COVID-19 pandemic, particularly among older adults with lower income.

One limitation is that we were unable to analyze the data in terms of understanding how these experiences and perceptions regarding the program might have differed across different sociodemographic characteristics—sex, age profiles (young-old and old-old), and health conditions—which could have provided richer insights into the experiences of these subgroups. The distinct experiences of these subgroups and the types of responses needed to address the challenges they face also warrant further research [21]. While our study only considered the context of Singapore, we believe that these findings regarding the role of age and social and material precarities in shaping technological use and the suggested solutions to bridge the digital divide will be theoretically useful in understanding the experiences and perceptions of digital tools among marginalized populations in other contexts. Studies should be conducted to develop culturally sensitive approaches that can promote digital devices as a potential resource that is relevant to the needs of deprived communities, for example, in ways that can potentially improve the socioemotional and physical health outcomes of individuals or serve as a coping strategy in a precarious environment. Mixed methods studies using implementation science approaches [45] should also assess the maintenance of digital interventions in low-income communities, understand what is suitable for whom, and devise educational frameworks specific to the teaching of digital skills that can empower older learners.

Conclusions

The findings illuminate the need for community-based digital interventions to be designed with the particularities of the older adults' lived environment and experiences in mind and the sensitivity that these digital tools only occupy one facet of participants' lives, alongside other priorities and needs. Further studies are required to understand how these dimensions can be integrated into the intervention to enhance the smartphone's perceived relevance and utility, without being an unwelcome disruption. Measures aimed at promoting individual-level adoption of smartphones must also be addressed alongside approaches that tackle structural inequities, ageist structures, and stigma that disadvantages one group of older adults relative to others. Regarding those who choose not to participate in the "digital wave," the society must be willing to find and support alternative solutions to include these older adults in ways that promote social contact, autonomy, and socioemotional well-being—outcomes that technology purports to achieve—while not perpetuating their exclusion.

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Conflicts of Interest

None declared.

References

1. Statement – older people are at highest risk from COVID-19, but all must act to prevent community spread. World Health Organization. 2020 Apr 3. URL: https://www.who.int/europe/news/item/03-04-2020-statement-older-people-are-at-highest-risk-from-covid-19-but-all-must-act-to-prevent-community-spread [accessed 2024-04-01]
2. Banerjee D. 'Age and ageism in COVID-19': elderly mental health-care vulnerabilities and needs. Asian J Psychiatr 2020 Jun;51:102154 [FREE Full text] [doi: 10.1016/j.ajp.2020.102154] [Medline: 32403024]
3. Losada-Baltar A, Jiménez-Gonzalo L, Gallego-Alberto L, Pedroso-Chaparro MD, Fernandes-Pires J, Márquez-González M. "We are staying at home." Association of self-perceptions of aging, personal and family resources, and loneliness with psychological distress during the lock-down period of COVID-19. J Gerontol B Psychol Sci Soc Sci 2021 Jan 18;76(2):e10-e16 [FREE Full text] [doi: 10.1093/geronb/gbaa048] [Medline: 32282920]
4. van Tilburg TG, Steinmetz S, Stolte E, van der Roest H, de Vries DH. Loneliness and mental health during the COVID-19 pandemic: a study among Dutch older adults. J Gerontol B Psychol Sci Soc Sci 2021 Aug 13;76(7):e249-e255 [FREE Full text] [doi: 10.1093/geronb/gbaa111] [Medline: 32756931]
5. Roy J, Jain R, Golamari R, Vunnam R, Sahu N. COVID-19 in the geriatric population. Int J Geriatr Psychiatry 2020 Dec 26;35(12):1437-1441 [FREE Full text] [doi: 10.1002/gps.5389] [Medline: 32748545]

6. Valtorta NK, Kanaan M, Gilbody S, Ronzi S, Hanratty B. Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies. Heart 2016 Jul 01;102(13):1009-1016 [FREE Full text] [doi: 10.1136/heartjnl-2015-308790] [Medline: 27091846]
7. Kotwal AA, Holt-Lunstad J, Newmark RL, Cenzer I, Smith AK, Covinsky KE, et al. Social isolation and loneliness among San Francisco bay area older adults during the COVID-19 shelter-in-place orders. J Am Geriatr Soc 2021 Jan 09;69(1):20-29 [FREE Full text] [doi: 10.1111/jgs.16865] [Medline: 32965024]
8. Raina P, Wolfson C, Griffith L, Kirkland S, McMillan J, Basta N, et al. A longitudinal analysis of the impact of the COVID-19 pandemic on the mental health of middle-aged and older adults from the Canadian Longitudinal Study on Aging. Nat Aging 2021 Dec 25;1(12):1137-1147. [doi: 10.1038/s43587-021-00128-1] [Medline: 37117519]
9. Bergeron CD, Boolani A, Jansen EC, Smith ML. Practical solutions to address COVID-19-related mental and physical health challenges among low-income older adults. Front Public Health 2021;9:674847 [FREE Full text] [doi: 10.3389/fpubh.2021.674847] [Medline: 34322471]
10. Sen K, Prybutok G, Prybutok V. The use of digital technology for social wellbeing reduces social isolation in older adults: a systematic review. SSM Popul Health 2022 Mar;17:101020 [FREE Full text] [doi: 10.1016/j.ssmph.2021.101020] [Medline: 35024424]
11. Sayin Kasar K, Karaman E. Life in lockdown: social isolation, loneliness and quality of life in the elderly during the COVID-19 pandemic: a scoping review. Geriatr Nurs 2021 Sep;42(5):1222-1229 [FREE Full text] [doi: 10.1016/j.gerinurse.2021.03.010] [Medline: 33824008]
12. Balki E, Hayes N, Holland C. Effectiveness of technology interventions in addressing social isolation, connectedness, and loneliness in older adults: systematic umbrella review. JMIR Aging 2022 Oct 24;5(4):e40125 [FREE Full text] [doi: 10.2196/40125] [Medline: 36279155]
13. Chen YR, Schulz PJ. The effect of information communication technology interventions on reducing social isolation in the elderly: a systematic review. J Med Internet Res 2016 Jan 28;18(1):e18 [FREE Full text] [doi: 10.2196/jmir.4596] [Medline: 26822073]
14. Damant J, Knapp M, Freddolino P, Lombard D. Effects of digital engagement on the quality of life of older people. Health Soc Care Community 2017 Nov 25;25(6):1679-1703. [doi: 10.1111/hsc.12335] [Medline: 26919220]
15. Han GH. Seniors felt less socially satisfied, more isolated during Covid-19 circuit breaker period: Survey. The Straits Times. 2020 Aug 28. URL: https://www.straitstimes.com/singapore/lower-satisfaction-levels-higher-social-isolation-for-senior-citizens-during-circuit [accessed 2023-08-27]
16. Macdonald B, Hülür G. Well-being and loneliness in Swiss older adults during the COVID-19 pandemic: the role of social relationships. Gerontologist 2021 Feb 23;61(2):240-250 [FREE Full text] [doi: 10.1093/geront/gnaa194] [Medline: 33258898]
17. Loveys K, Sagar M, Pickering I, Broadbent E. A digital human for delivering a remote loneliness and stress intervention to at-risk younger and older adults during the COVID-19 pandemic: randomized pilot trial. JMIR Ment Health 2021 Nov 08;8(11):e31586 [FREE Full text] [doi: 10.2196/31586] [Medline: 34596572]
18. Shapira S, Yeshua-Katz D, Cohn-Schwartz E, Aharonson-Daniel L, Sarid O, Clarfield AM. A pilot randomized controlled trial of a group intervention via Zoom to relieve loneliness and depressive symptoms among older persons during the COVID-19 outbreak. Internet Interv 2021 Apr;24:100368 [FREE Full text] [doi: 10.1016/j.invent.2021.100368] [Medline: 33527072]
19. Martins Van Jaarsveld G. The effects of COVID-19 among the elderly population: a case for closing the digital divide. Front Psychiatry 2020 Nov 12;11:577427 [FREE Full text] [doi: 10.3389/fpsyt.2020.577427] [Medline: 33304283]
20. Litchfield I, Shukla D, Greenfield S. Impact of COVID-19 on the digital divide: a rapid review. BMJ Open 2021 Oct 12;11(10):e053440 [FREE Full text] [doi: 10.1136/bmjopen-2021-053440] [Medline: 34642200]
21. Fang ML, Canham SL, Battersby L, Sixsmith J, Wada M, Sixsmith A. Exploring privilege in the digital divide: implications for theory, policy, and practice. Gerontologist 2019 Jan 09;59(1):e1-15. [doi: 10.1093/geront/gny037] [Medline: 29750241]
22. Wang Y, Matz-Costa C, Miller J, Carr DC, Kohlbacher F. Uses and gratifications sought from mobile phones and loneliness among japanese midlife and older adults: a mediation analysis. Innov Aging 2018 Sep;2(3):igy027 [FREE Full text] [doi: 10.1093/geroni/igy027] [Medline: 30480146]
23. Klimova B, Poulova P. Older people and technology acceptance. In: Proceedings of the Human Aspects of IT for the Aged Population. Acceptance, Communication and Participation. 2018 Presented at: ITAP 2018; July 15-20, 2018; Las Vegas, NV. [doi: 10.1007/978-3-319-92034-4_7]
24. Chakraborty J, Bosman MM. Measuring the digital divide in the United States: race, income, and personal computer ownership. Prof Geogr 2005 Aug;57(3):395-410. [doi: 10.1111/j.0033-0124.2005.00486.x]
25. Haase KR, Cosco T, Kervin L, Riadi I, O'Connell ME. Older adults' experiences with using technology for socialization during the COVID-19 pandemic: cross-sectional survey study. JMIR Aging 2021 Apr 23;4(2):e28010 [FREE Full text] [doi: 10.2196/28010] [Medline: 33739929]
26. Tan KS, Chan CM. Unequal access: applying Bourdieu's practice theory to illuminate the challenges of ICT use among senior citizens in Singapore. J Aging Stud 2018 Dec;47:123-131. [doi: 10.1016/j.jaging.2018.04.002] [Medline: 30447865]
27. Kebede AS, Ozolins LL, Holst H, Galvin K. Digital engagement of older adults: scoping review. J Med Internet Res 2022 Dec 07;24(12):e40192 [FREE Full text] [doi: 10.2196/40192] [Medline: 36477006]

28. Schroeder T, Dodds L, Georgiou A, Gewald H, Siette J. Older adults and new technology: mapping review of the factors associated with older adults' intention to adopt digital technologies. JMIR Aging 2023 May 16;6:e44564 [FREE Full text] [doi: 10.2196/44564] [Medline: 37191976]
29. Kahlke RM. Generic qualitative approaches: pitfalls and benefits of methodological mixology. Int J Qual Method 2014 Feb 01;13(1):37-52. [doi: 10.1177/160940691401300119]
30. Malhotra R, Bautista MA, Müller AM, Aw S, Koh GC, Theng YL, et al. The aging of a young nation: population aging in Singapore. Gerontologist 2019 May 17;59(3):401-410. [doi: 10.1093/geront/gny160] [Medline: 30517628]
31. Ting WP. The Big Read: digitally estranged, seniors struggle with sense of displacement in pandemic-hit offline world. Today Online. 2020 May 2. URL: https://www.todayonline.com/big-read/big-read-digitally-estranged-seniors-struggle-sense-displacement-pandemic-hit-offline-world [accessed 2023-08-27]
32. More than 16000 seniors benefit from Seniors Go Digital Programme. Infocomm Media Development Authority. 2020 Aug 29. URL: http://www.imda.gov.sg/news-and-events/Media-Room/Media-Releases/2020/More-than-16000-Seniors-Benefit-From-Seniors-Go-Digital-Programme [accessed 2023-08-27]
33. Basu M. Singapore’s seniors pick up smartphones to cope with Covid-19. GovInsider. 2020 Sep 1. URL: https://govinsider.asia/digital-gov/singapore-trains-seniors-to-adapt-routines-with-smartphones/ [accessed 2023-08-27]
34. Asokan A. COVID-19: ensuring the elderly don't become isolated during the outbreak. Channel News Asia. 2020 Apr 7. URL: https://www.channelnewsasia.com/news/singapore/covid-19-loneliness-isolation-among-elderly-safe-distancing-12611158 [accessed 2023-08-27]
35. Ngiam NH, Yee WQ, Teo N, Yow KS, Soundararajan A, Lim JX, et al. Building digital literacy in older adults of low socioeconomic status in Singapore (project wire up): nonrandomized controlled trial. J Med Internet Res 2022 Dec 02;24(12):e40341 [FREE Full text] [doi: 10.2196/40341] [Medline: 36459398]
36. Eligibility. Housing & Development Board. URL: https://www.hdb.gov.sg/residential/rentiSng-a-flat/renting-from-hdb/public-rental-scheme/eligibility [accessed 2023-08-27]
37. Low LL, Liu N, Wang S, Thumboo J, Ong ME, Lee KH. Predicting frequent hospital admission risk in Singapore: a retrospective cohort study to investigate the impact of comorbidities, acute illness burden and social determinants of health. BMJ Open 2016 Oct 14;6(10):e012705 [FREE Full text] [doi: 10.1136/bmjopen-2016-012705] [Medline: 27742630]
38. Wee LE, Tsang TY, Yi H, Toh SA, Lee GL, Yee J, et al. Loneliness amongst low-socioeconomic status elderly Singaporeans and its association with perceptions of the neighbourhood environment. Int J Environ Res Public Health 2019 Mar 18;16(6):967 [FREE Full text] [doi: 10.3390/ijerph16060967] [Medline: 30889851]
39. Ang S, Lim E, Malhotra R. Health-related difficulty in internet use among older adults: correlates and mediation of its association with quality of life through social support networks. Gerontologist 2021 Jul 13;61(5):693-702. [doi: 10.1093/geront/gnaa096] [Medline: 32744310]
40. Saldana J. The Coding Manual for Qualitative Researchers. Thousand Oaks, CA: SAGE Publications; 2015.
41. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357. [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
42. Grenier A, Hatzifilalithis S, Laliberte-Rudman D, Kobayashi K, Marier P, Phillipson C. Precarity and aging: a scoping review. Gerontologist 2020 Nov 23;60(8):620-632. [doi: 10.1093/geront/gnz135] [Medline: 31675418]
43. Köttl H, Gallistl V, Rohner R, Ayalon L. "But at the age of 85? Forget it!": internalized ageism, a barrier to technology use. J Aging Stud 2021 Dec;59:100971 [FREE Full text] [doi: 10.1016/j.jaging.2021.100971] [Medline: 34794716]
44. Lagacé M, Charmarkeh H, Laplante J, Tanguay A. How ageism contributes to the second-level digital divide: the case of Canadian seniors. J Technol Hum Usab 2015;11(4):1-13. [doi: 10.18848/2381-9227/CGP/v11i04/56439]
45. Barrie H, La Rose T, Detlor B, Julien H, Serenko A. “Because I’m old”: the role of ageism in older adults’ experiences of digital literacy training in public libraries. J Technol Hum Serv 2021 Aug 18;39(4):379-404. [doi: 10.1080/15228835.2021.1962477]
46. McDonough CC. The effect of ageism on the digital divide among older adults. J Gerontol Geriatr Med 2016 Jun 16;2(1):1-7. [doi: 10.24966/ggm-8662/100008]
47. Maulod A. Who guards the bodyguard? The ethics of care for vulnerable older adults. In: Ng KH, editor. They Told Us to Move: Dakota—Cassia. Singapore, Singapore: Ethos Books; 2019.
48. Urban M. Embodying digital ageing: ageing with digital health technologies and the significance of inequalities. In: Heidkamp B, Kergel D, editors. Precarity within the Digital Age. Wiesbaden, Germany: Springer VS; 2017:163-178.
49. Shin HR, Um SR, Yoon HJ, Choi EY, Shin WC, Lee HY, et al. Comprehensive senior technology acceptance model of daily living assistive technology for older adults with frailty: cross-sectional study. J Med Internet Res 2023 Apr 10;25:e41935 [FREE Full text] [doi: 10.2196/41935] [Medline: 37036760]
50. Chan CM. Commentary: encourage seniors in digitalisation drive instead of forcing tech adoption on them. Channel News Asia. 2021. URL: https://www.channelnewsasia.com/news/commentary/digital-transformation-smart-nation-can-leave-seniors-behind-13943332 [accessed 2023-08-27]
51. Xu W, Liu X. Gamified design for the intergenerational learning: a preliminary experiment on the use of smartphones by the elderly. In: Proceedings of the Human Aspects of IT for the Aged Population. Acceptance, Communication and

Participation: 4th International Conference, ITAP 2018, Held as Part of HCI International 2018. 2018 Presented at: ITAP 2018; July 15-20, 2018; Las Vegas, NV. [doi: 10.1007/978-3-319-92034-4_43]
52. Chen K, Lou VW. Measuring senior technology acceptance: development of a brief, 14-item scale. Innov Aging 2020;4(3):igaa016 [FREE Full text] [doi: 10.1093/geroni/igaa016] [Medline: 32617418]
53. Maulod A, Lu SY. “I’m slowly ageing but I still have my value”: challenging ageism and empowering older persons through lifelong learning in Singapore. Educ Gerontol 2020 Jul 28;46(10):628-641. [doi: 10.1080/03601277.2020.1796280]
54. Resnicow K, McMaster F. Motivational interviewing: moving from why to how with autonomy support. Int J Behav Nutr Phys Act 2012 Mar 02;9(1):19 [FREE Full text] [doi: 10.1186/1479-5868-9-19] [Medline: 22385702]
55. Blažič BJ, Blažič AJ. Overcoming the digital divide with a modern approach to learning digital skills for the elderly adults. Educ Inf Technol 2019 Jul 19;25(1):259-279. [doi: 10.1007/s10639-019-09961-9]
56. Seo H, Erba J, Altschwager D, Geana M. Evidence-based digital literacy class for older, low-income African-American adults. J Appl Commun Res 2019 Mar 11;47(2):130-152. [doi: 10.1080/00909882.2019.1587176]
57. Elbaz S, Gruber J, Elberhoumi K, Bukhari SN, Rej S, Sekhon H. Evaluation of a virtual 4-week digital literacy program for older adults during COVID-19: a pilot study. Educ Gerontol 2023 Oct 13;50(4):296-303. [doi: 10.1080/03601277.2023.2268499]

Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research

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Original Paper

Digital Literacy Training for Low-Income Older Adults Through Undergraduate Community-Engaged Learning: Single-Group Pretest-Posttest Study

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Abstract

Background: Digital technology is a social determinant of health that affects older people's ability to engage in health maintenance and disease prevention activities; connect with family and friends; and, more generally, age in place. Unfortunately, disparities in technology adoption and use exist among older adults compared with other age groups and are even greater among low-income older adults.

Objective: In this study, we described the development and implementation of a digital literacy training program designed with the dual goals of training low-income older adults in the community and teaching students about aging using a community-engaged learning (CEL) approach.

Methods: The training program was embedded within a 10-week CEL course that paired undergraduates (N=27) with low-income older adults (n=18) for 8 weeks of digital literacy training. Older adults and students met weekly at the local senior center for the training. Students also met in the classroom weekly to learn about aging and how to use design thinking to train their older adult trainees. Both older adults and students completed pre- and posttraining surveys.

Results: Older adults demonstrated increased digital literacy skills and confidence in the use of digital technology. Loneliness did not change from pre to postassessment measurements; however, older adults showed improvements in their attitudes toward their own aging and expressed enthusiasm for the training program. Although students' fear of older adults did not change, their comfort in working with older adults increased. Importantly, older adults and students expressed positive feelings about the trainee-trainer relationship that they formed during the training program.

Conclusions: A CEL approach that brings together students and low-income older adults in the community has a strong potential to reduce the digital divide experienced by underserved older adults. Additional work is needed to explore the efficacy and scalability of this approach in terms of older adults' digital literacy as well as other potential benefits to both older and younger adults.

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KEYWORDS

community-engaged learning; digital divide; underserved older adults; digital literacy training; intergenerational programs

Introduction

Background

Digital technology is a social determinant of health that plays a significant role in older adults' lives, including their ability to engage in health maintenance and prevention activities; connect with family and friends; and, more generally, age in place [1-3]. Recent evidence from the COVID-19 pandemic indicates that the digital divide contributed to health inequities among older individuals who were unable to benefit from technology to support health and well-being when in-person alternatives were unavailable or unsafe [4-7]. For example, without adequate online alternatives, older adults experienced greater health challenges and increased social isolation [8,9]. Conversely, older adults who had technology support during the pandemic fared better. For example, results from a qualitative study within a continuing care community indicated that technology mitigated social isolation and loneliness during the pandemic [10].

Disparities in technology adoption and use are particularly pronounced among older adults compared with other age groups [11-13] and are even greater among low-income older adults [3,14]. Some evidence suggests that internet use among low-income older adults may be as low as 17% [11] and that health-related technology use is significantly lower among racial and ethnic minority older adults as well as among low-income older adults [15]. Barriers that contribute to low rates of technology use among older adults include broadband availability, cost of broadband and devices, lack of awareness of potential technology benefits, low self-efficacy, and lack of training [16,17]. Some estimates indicate that only 25% of older residents in low-income housing have reliable internet access [18]. However, another study on low-income housing residents showed that although the housing communities in the study had access to broadband, few of the residents used the internet [19]. Thus, providing broadband and a digital device is insufficient. Digital literacy training is particularly important within this segment of the population to overcome barriers and promote sustained engagement [20].

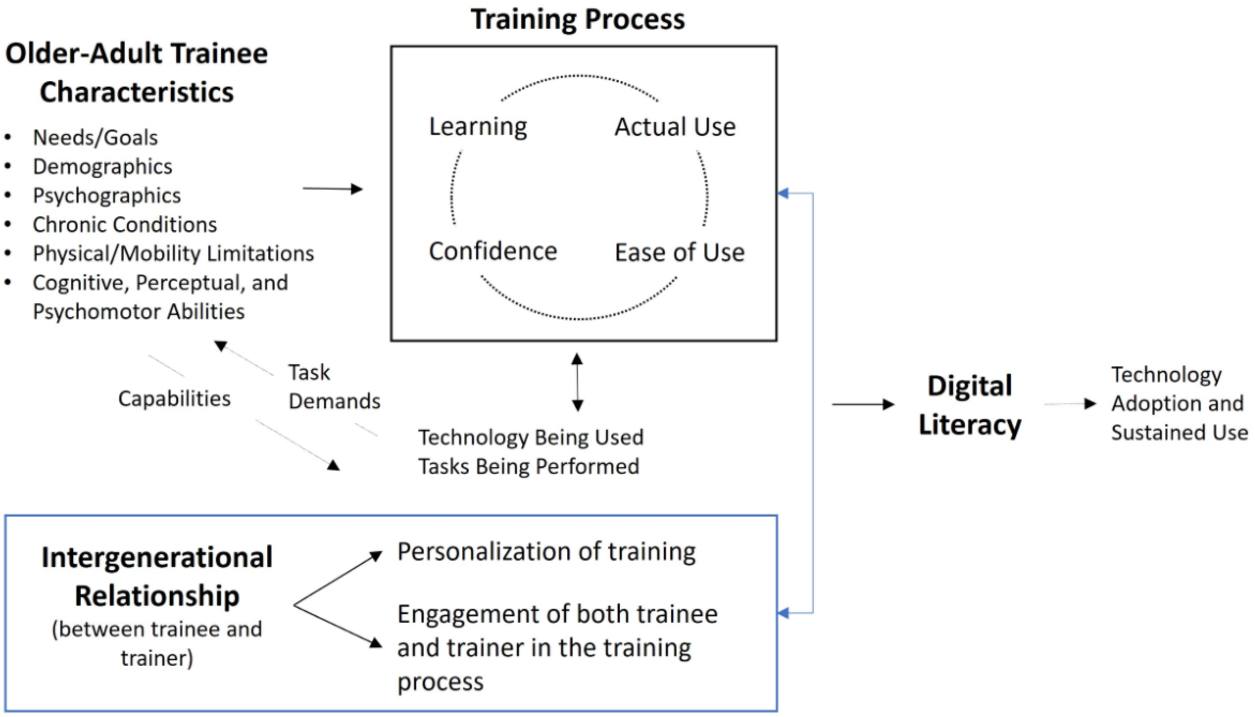
Digital Literacy Training

There have been numerous approaches used to teach older adults how to use technology [16,21-23]. Regardless of the approach, researchers tend to agree that hands-on training over multiple weeks and tailored training programs are particularly important to meet the needs of older adults [24]. Tailoring can be achieved in a variety of ways—either informally (eg, drop-in or as-needed help) or as part of an in-home or a classroom-style program in the community [25-29].

Two theoretical models of technology acceptance and use among older adults are particularly well-suited to promoting digital literacy in this population [16,24,30]. First, the Senior Technology Acceptance and Adoption Model (STAM) includes ease-of-learning and ease-of-using technology constructs and argues that these are significant drivers of actual use [31]. Second, the Center for Research and Education on Aging and Technology Enhancement (CREATE) model of technology use in later life focuses on older adults' characteristics, including demographics and psychographics (psychosocial background), cognitive, perceptual, and psychomotor abilities. The model also considers the relationship between older adults' capabilities and the demands of the technology task being performed (eg, more challenging tasks undertaken will require greater capabilities) [16,32]. Thus, the CREATE model informs training by highlighting the importance of the fit between trainee and training activities as well as the rate at which training proceeds.

Drawing on these 2 models, we developed a conceptual model of digital literacy training, which is shown below in Figure 1. First, our conceptual model incorporates the STAM's [31] close connection between ease of use on the one hand and actual use on the other. Last, the conceptual model places training at the center of adoption as being critical for low-income older adults who are far less likely to have prior experience with technology use and learning to use technology. The model provides a starting place for considering how training can be tailored to meet the needs of older adults with varying backgrounds and capabilities. Second, our model relies heavily on the CREATE model's [32] emphasis on older adults' characteristics (eg, demographics and cognitive and perceptual abilities) and the importance of the relationship between older adults' capabilities and the demands of the task being performed.

Figure 1. Conceptual model of digital literacy training.



Training programs targeting low-income older adults are far less common in the literature. Nevertheless, research suggests that factors that support older adults in general may be even more important for older adults from low-income backgrounds who may be reticent to seek training. Given the wide-ranging prior experience with technology and learning environments, a higher degree of tailoring and personalization may be critical to training those with lower-income and education backgrounds [20,24,33-35]. In addition to the insecurities surrounding the use of technology, low-income older adults may be more likely to have insecurities surrounding their ability to learn to use a computer, which in turn can impact enrollment into educational programs [33]. Low-income older adults may also lack awareness of the potential benefits of technology, which could also negatively impact motivation to learn to use technology and to persist in learning, especially when challenges arise [36,37]. For these reasons, programs that provide one-on-one training with highly individualized content and pacing may be a particularly important way to engage this population of older adults in training programs. Textbox 1 shows the training features, supported by the literature reviewed above, which may be particularly well-suited to low-income older adult populations.

Textbox 1. Evidence-based digital literacy training features proposed for low-income older adults.

Digital literacy training program features

- Hands-on (trainees use their device while being instructed)
- Tailored to the specific needs and goals of the trainee
- Personalized to optimize trainee engagement
- Delivered one-on-one (supports demonstration, practice, immediate feedback, and question and answer [Q&A] time)
- Trainee completes practices exercises in between meeting times; experience (successes and failures) is reviewed at subsequent meetings
- Same trainee-trainer pairs work together across training programs to foster trust and respect through relationship building

Intergenerational Approach to Digital Literacy Training

Another approach with the potential to engage and motivate older adults in digital literacy training, particularly older adults from underserved communities, is to provide opportunities for intergenerational relationships within the training process [38,39]. Intergenerational programs involve a younger generation (eg, college students) interacting with older adults who are typically from the same community. Opportunities in which different cohorts or age groups interact are becoming increasingly less frequent in society due to age segregation and changing family structures. In an age-segregated society, education, work, and leisure are apportioned to younger, middle, and older ages, respectively, restricting opportunities for older adults to spend time with younger individuals [40]. Intergenerational opportunities are further limited by changes in family structure, including fewer children and an increased likelihood of relocating to pursue a job or other opportunities [41]. Intergenerational programs often focus on fostering cooperation, interaction, and exchange between generations and can provide benefits, such as improved social connectedness and attitudes toward aging for both students and older adults [42-47].

Support for an intergenerational approach to digital literacy training comes from a study in which 38 pairs of high-school students and older adults met 2 or 3 times for 1.5 hours of training [21]. Although the study did not include digital literacy outcomes, results showed satisfaction for both the students and older adults. In another study, researchers explored 3 approaches to digital literacy training with students (undergraduate upperclassmen students in professional programs [eg, pharmacy]) and older adults [48]. With the first approach, students trained older adults in a 30- to 60-minute appointment at the senior center on an as-needed basis. The second approach matched students in a gerontology class with older adults from a local Osher Lifelong Learning Institute for a minimum of 6 hours of training at times and places determined by each trainer-trainee pair. The third approach consisted of as-needed, drop-in sessions held by students in 2- to 4-hour time blocks at the Osher Lifelong Learning Institute. Results showed that among older adult trainees who attended ≥3 sessions, trainees valued the intergenerational relationships developed over the training period as well as increased interest in working with technology. Moreover, younger adults showed improvement in attitudes toward aging, confidence in teaching older adults, and comfort working with older adults [48]. Similar to the matching program in Leedahl et al [48], Arthanat [49] paired undergraduate older adults in an occupational therapy degree program with older adults for 3 months of training (8 training sessions total) as part of a service learning project for an assistive technology course. Again, the training schedule was set by each pair. Before training, students attended a laboratory session on technology and aging and were encouraged to use Facebook as a forum to connect with other student trainers across the semester. Researchers reported increases in older adults' frequency of technology use for multiple purposes, including those related to health and hobbies, and self-reported independence in a range of digital activities, reflecting improved digital skills. In general, the data show that intergenerational programs can effectively engage older adults in digital literacy training.

Programs that bring together students and members of the community provide a critical opportunity for community-engaged learning (CEL). CEL incorporates activities typically associated with internships and service learning into formalized learning within courses that consider social needs and social changes in the community. It also emphasizes the significance of building relationships with individuals in the community to bring about social change [50]. Young adults are often at the forefront of social change, with a heightened interest in the broader world, where they see themselves in society and how they can make a difference [51]. Intergenerational CEL provides an opportunity for younger individuals to broaden their awareness of social needs by exposing them to issues related to digital exclusion among underserved older adults. Textbox 2 describes the intergenerational training features supported by the literature.

Textbox 2. Summary of intergenerational digital literacy training used in this study.

Intergenerational content and features

- A community-engaged learning framework was used that emphasizes providing students with the opportunities to develop academic skills, civic competencies, and ethical commitments while exploring community-based efforts to address social justice issues.
- The training program was integrated into a structured course with set weekly meeting times for (1) student classroom learning and (2) training older adults; set times remove weekly scheduling burden and uncertainty regarding the training schedule.
- Same trainer-trainee pairs worked together across the training program to enable the trainer to get to know the trainee to foster a trusting relationship that is conducive to frank and open discussion about training needs and pace.
- Weekly student classroom time used to teach students about aging (agism; technology as a structural determinant of health with cumulative disadvantage perspective; age-related changes in perceptual, cognitive, and motoric/physiological capabilities) and other factors that may impact older adults' acceptance, adoption, and sustained use of technology.
- Student classroom time was also used to teach students about design thinking and how to apply design thinking to designing personalized and tailored training for their older adult trainee.

Background Work

Before this study commenced, we explored the logistics of pairing students and older adults in the community within an existing course on aging and technology use. Students (n=30) were partnered with older adults (n=17) in small groups (typically, 3 students and 1 older adult) over 4 to 5 weeks. Students were responsible for contacting older adults by telephone (using a free app such as Google Meet) and scheduling weekly 30- to 45-minute meetings. Telephone discussions focused on older adults' current use of technology, attitudes toward technology, and what their preferences for training would be if they were to seek training. Students made notes each week to track what they learned about their partner's technology acceptance. At the end of the quarter, we asked both students and older adults to answer open-ended questions about the challenges and rewards of their student-partner interactions. Overall, we learned that both the students and older adults highly valued their time together, and their relationships grew as they got to know each other. However, scheduling weekly appointments took a substantial amount of time, due to difficulties in identifying time slots, cancelations, and rescheduling.

This Study

This study examined a digital literacy training program integrated within an intergenerational CEL course to explore a formalized pathway connecting undergraduate education and underserved older adults in the community. The digital literacy training program was embedded within a formalized course structure in which students received college credits as they learned about aging and social justice while working one-on-one with low-income older adults in the community. The training program, designed to work within a course structure rather than in parallel or as an add-on (eg, with a minimal connection between class time and training time), offered 3 additional benefits for student trainers and older adult trainees. First, a set time and place removed uncertainty in scheduling from week to week. Second, weekly contact between students and the instructor in the classroom provided time to teach students about aging, social justice, and digital literacy training. Third, weekly contact between students and older adults at the training location (ie, local senior center) allowed for meaningful relationship building. Fourth, the presence of the instructor at the training site supported the students and older adults by facilitating communication and troubleshooting should any problems arise. Overall, this provided students and older adults with formalized and consistent support and, potentially, higher-quality education for the students and training for older adults. Finally, we offered the CEL course as a first-year seminar (with no prerequisites) in an attempt to attract students early in their academic studies. Students from any majors (including “undeclared” majors) were able to review the list of first-year seminars and sign up for those they wished to take.

In pairing students with low-income older adults in the community over an 8-week period, we hypothesized that relationships would develop organically as the intergenerational pairs worked together. The CEL course included features to support the process and the course used “design thinking” to encourage students to consider the older adult holistically on how technology fits within this individual’s life. Design thinking is a human-centered approach that places the “user” at the core when solving “wicked” or ill-defined problems, such as how to design a digital literacy training program that is well-suited to the trainee [52,53]. The course also taught students about aging (eg, older adult characteristics shown in Figure 1), stereotypes and biases related to aging, and how to train older adults using a design thinking approach, which focuses on understanding the end user and defining the task at hand (ie, designing an effective training program for their trainee).

Methods

Participants

Undergraduate Students

There were no prerequisites and no restrictions on who could sign up for the course. Among the undergraduate students (N=26) in the course, 48% (n=13) were female individuals, and 77% (n=21) were underclassmen (ie, freshman or sophomore), and they represented a wide range of majors, including data science, mathematics, sociology, and animal biology.

Older Adults

Older adults (N=23) were recruited with the support of a local nonprofit organization as well as low-income housing organizations and the local senior center. Inclusion criteria consisted of older adults who were aged ≥60 years; were eligible for a federal or state safety-net program (eg, Meals on Wheels, senior low-income housing, Medi-Cal, Cal-Fresh [SNAP]); were residents in Yolo County; and had little-to-no prior experience with computers. Funds provided by the County helped pay for recruitment and enrollment support as well as new laptop computers (which the participants were allowed to keep) together with 2-year internet subscriptions for the low-income older adults in the training program. Screening resulted in 5 of 23 individuals being excluded (1 for not meeting the age criterion and 4 for not meeting the low-income criterion). The final sample of older adults (n=18) was predominantly female (n=17, 95%) and non-Hispanic White (n=10, 55%), with the remainder being Asian (n=4, 22%) and Hispanic White participants (n=4, 22%). Older adults’ age ranged from 61 to 87 (mean 72, SD 7.81) years and had a mean of 17.61 (SD 5.21) on the Lubben Social Network Scale, which assesses social networks for family and friends with possible a range of 6 to 36 and clinical cutoff of ≤12 [54].

Ethical Considerations

The study was deemed exempt by UC Davis’s institutional review board. Older adults were read an information script before the pretest, informing that they could quit anytime and that their individual-level data would be deidentified.

Measures

Undergraduate Student Pretest-Posttest Measures

Psychological Growth

The Psychological Growth scale (8 items) from the Attitudes to Aging Questionnaire [55] was used to assess students’ attitudes toward aging. The scale includes items, such as, “It is a privilege to grow old,” “As people get older they are better able to cope with life,” and “There are many pleasant things about growing older.” Responses are made on a 5-point Likert scale (1=strongly disagree; 5=strongly agree) and are summed, with higher scores reflecting more positive attitudes toward aging.

Fear of Old People

The Fear of Old People subscale of the Anxiety about Aging Scale [56] was used to assess students’ attitudes surrounding intergenerational relations. The subscale includes 5 items, such as “I enjoy being around old people” and “I like to go visit my older relatives,” with a 5-point Likert scale (1=strongly agree; 5=strongly disagree). Items were summed, with higher scores indicating more anxiety toward aging.

Working With Older Adults

We included 3 items to assess students’ attitudes toward working with older adults as they trained older adults [48]. The items were “I am comfortable working with older adults,” “I am confident in teaching older adults how to use technology,” and “I am likely to volunteer in the field of senior services,” with responses on a 5-point Likert scale (1=strongly disagree; 5=strongly agree).

Undergraduate Student Posttest-Only Measures

Rank Order

Students rank-ordered five aspects of the course from most important to least important: (1) learning about aging; (2) human-centered design and design thinking; (3) community engagement; (4) working with older adults; and (5) getting to know their trainee, specifically.

CEL Values

CEL addresses a specific community interest, problem, or public concern; includes working with and learning from a community partner; connects and integrates community-engaged experiences with educational content; and includes structured critical reflection. Students were given the following prompt: "Now that you've experienced CEL, we would like your perspective on its value. Please indicate how important the following CEL characteristics are to you," followed by 12 items, such as "It makes me a better student in the long run" and "I want to contribute to the good of our society," with responses on a scale of 1 to 3 (not very important to me, score=1; neutral, score=2; and very important to me, score=3).

Older Adult Pretest-Posttest Measures

Technology Skills

The Mobile Device Proficiency Questionnaire (MDPQ-16) was adapted to focus on "laptop" proficiency rather than mobile devices [57]. The questionnaire includes 8 scales, each assessing how easily the individual can perform digital tasks (n=18), such as navigating onscreen menus using the touchscreen, sending pictures by email, finding health information on the internet, and entering events and appointments into a calendar with responses of never tried (score=1), not at all easily (score=2), not very easily (score=3), somewhat easily (score=4), and very easily (score=5).

Loneliness

Loneliness was assessed using the 3-item Loneliness Scale [58], which asks how often individuals feel they lack companionship, are left out, and are isolated from others, on a scale ranging from hardly ever (score=1) to often (score=3). Scores are summed to create an overall assessment of loneliness. People who score 3 to 5 are considered "not lonely," whereas people who score 6 to 9 are considered "lonely."

Attitudes Toward Own Aging

Attitudes Toward Own Aging is a subscale of the Philadelphia Geriatric Center Morale Scale [59]. Respondents are asked to indicate whether they agree (score=1) or disagree (score=0), with 5 statements about aging such as "Things keep getting worse as I get older" (reverse scored) and "I have as much pep as I had last year."

Older Adults Posttest-Only Measures

Relationship Quality

On a scale of 1 to 5 (1=strongly disagree; 5=strongly agree), older adults were asked to rate the following: "To what extent do you agree with the following statements about working with the students?"; "I enjoyed working with the student(s)"; "I feel that I formed a close relationship with the student(s)"; and "I will miss interacting with the student(s) now that the project has ended."

Social Connectedness During Training

Older adults were asked how they feel about social connectedness using the following statement: "Did you feel more socially connected during the technology training program?" Responses were rated on a 3-point scale (1=no, 2=a little, and 3=a lot).

Self-Efficacy and Confidence

Three items on the extent to which participants agree with statements on computer skill improvement and confidence were as follows: "Your laptop skills have improved."; "You are more independent when using your laptop."; and "Your confidence in using laptop has improved." Responses were rated on a 5-point scale (1=strongly disagree to 5=strongly agree).

Overall Evaluation

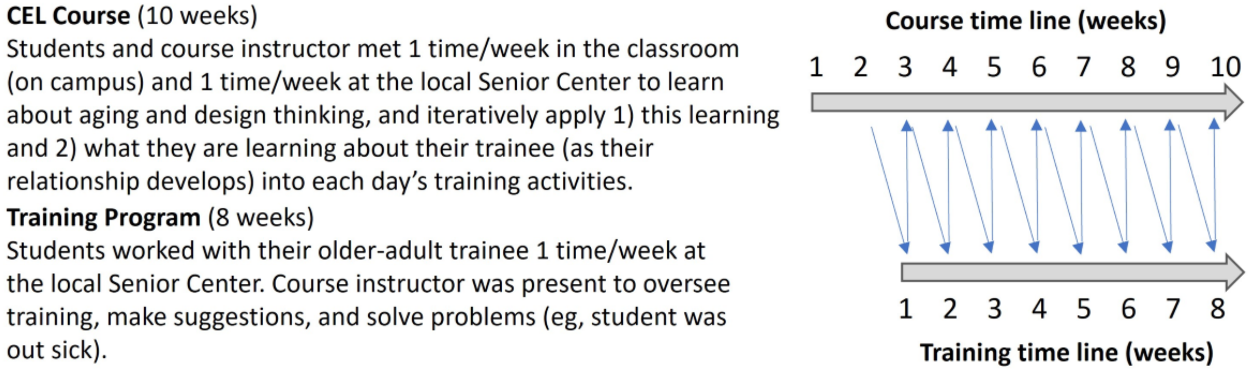
For overall evaluation, older adults were asked the following questions: "To what extent do you feel the training program was a positive experience" and "To what extent do you feel the training program was a valuable experience" with responses rated as 1=not positive or valuable to 5=very positive or valuable; "How likely would you be to recommend this technology training program to others?" with responses rated as 1=extremely unlikely to 7=extremely likely.

Procedure

Course

Undergraduate students enrolled in the CEL course in September 2022. In the first 2 weeks of the course, students (in groups of 1 or 2) were paired with an older adult so that each intergenerational group could begin to work together starting in week 3 of the course (which was week 1 of the training program) and continue to work together for the entire 8-week training program. Students met in the classroom on Tuesdays (50-min class) and in the senior center on Thursdays (50-min session), where older adults joined them for training. Figure 2 illustrates the back-and-forth nature of the education (CEL course) and training program and the overlap between the ten 50-minute classroom meetings and eight 50-minute training sessions at a nearby senior center where the training was conducted.

Figure 2. Illustration of how the digital literacy training was integrated into the community-engaged learning (CEL) course.



CEL Course (10 weeks)
Students and course instructor met 1 time/week in the classroom (on campus) and 1 time/week at the local Senior Center to learn about aging and design thinking, and iteratively apply 1) this learning and 2) what they are learning about their trainee (as their relationship develops) into each day's training activities.

Training Program (8 weeks)
Students worked with their older-adult trainee 1 time/week at the local Senior Center. Course instructor was present to oversee training, make suggestions, and solve problems (eg, student was out sick).

Each week, students submitted 2 assignments. First, they submitted their reflections on how the training process is going, observations about needs for subsequent training, and what they learned about their trainee as a person. The last part (what they learned about their trainee) formed the basis for our design thinking approach, which placed heavy emphasis on understanding older adults, including where and with whom they live, family members, motivations and needs for technology, and any other information that enabled the student to understand (get to know) the older adult trainee. Second, students submitted a training record that documented each task and their step-by-step instructions. The training records were combined to create a learner booklet for the trainee at the end of the training program.

Students completed the pretest during the second week of the quarter and the posttest during the week 9 of the quarter via Qualtrics (Qualtrics International Inc) online software. For older adults, a research assistant administered the pretest via telephone during weeks 1 and 2 of the training program and the posttest 1 to 2 weeks following the training.

Digital Literacy Training

A nonprofit community partner, Yolo Healthy Aging Alliance, provided trainees with (1) funds to purchase broadband internet for 2 years and (2) a Chromebook (a relatively inexpensive laptop costing about US $150 each, with a larger keyboard and screen than most tablets), which trainees used during training and were allowed to keep after the training. At the first session, older adults were introduced to their student trainers and were given their new laptops. Students then helped the older adults establish a user account and practice using the keyboard and touchpad to navigate to various places (note: due to an error, computer mice were not delivered until after the third week). Starting with a list of tasks that were commonly mentioned in the preliminary study and in the literature (eg, how to send and receive emails), students worked with their older adult trainees in the subsequent sessions to determine an appropriate pace and topics of importance to the trainee. See Multimedia Appendix 1 for the overview provided to students. After each session, students created step-by-step instructions for each task that they covered that day, including reminders and screenshots with arrows to direct attention. Students shared these instructions with trainees at the following session to obtain their feedback on clarity and granularity (level of detail) and adjusted the subsequent instructions as needed to maximize the older adults' learning. At the end of the training program, students presented these learner booklets to their trainees as a PDF document in hard copy and digital form (via email).

Results

Undergraduate Students

Pretest-Posttest Analyses

Table 1 shows the means for all the pretest-posttest measures. Students' scores on the Psychological Growth scale of the Attitude on Aging Questionnaire were summed to create a summary score for each time point. We found that scores did not significantly change from the beginning (mean 29.58, SD 3.11) to the end of the course (mean 29.19, SD 3.86; t_{25}<1, *P*=.46). Similarly, the sum of items on the Fear of Old People scale did not change significantly from the beginning (mean 10.19, SD 2.70) to the end of the course (mean 9.81, SD 2.95; t_{25}<1, *P*=.42). Student ratings of comfort working with older adults significantly improved from pretest (mean 4.00, SD 0.57) to posttest measurements (mean 4.27, SD 0.45; t_{25}=−3.04, *P*=.006). Neither confidence in teaching older adults how to use technology (t_{25}=1.31, *P*=.20) nor likelihood of volunteering in the field of senior services (t_{25}=1.22, *P*=.23) significantly changed.

Table 1. Pretest-posttest summary variables for students (N=26).

Pretest-posttest variables (range of possible scores)	Pretest measurements, mean (SD)	Posttest measurements, mean (SD)	*t* test (*df*=25)	*P* value
Psychological growth (8-40)	29.58 (3.11)	29.19 (3.86)	0.73	.46
Fear of old people (5-25)	10.19 (2.70)	9.81 (2.95)	0.82	.42
Comfort working with older adults (1-5)	4.00 (0.57)	4.57 (0.54)	−3.04	.006
Confidence in teaching older adults (1-5)	4.15 (0.54)	3.96 (0.72)	1.31	.20
Likelihood of volunteering in the field of senior services (1-5)	3.38 (0.98)	3.58 (0.95)	−1.22	.23

Posttest Analyses

The end-of-course rankings of course features showed that students preferred working with older adults in the community over other course features: working with their older adult trainees was ranked first by 46% (12/26) of students and ranked first or second by 70% (18/26) of students. Working with older adults in general or specifically with their trainees was ranked first by 77% (20/26) of students. Learning about aging ranked the lowest with 77% (20/26) of students placing it in the bottom 2 positions. CEL rankings dropped in the middle (12/26, 46%, in the third position), and human-centered design rankings were evenly distributed across the 5 positions. Last, endorsements of CEL statements showed that students particularly valued contributing to the good of society, with 88% (23/26) indicating that this is very important to them (highest endorsement). The following 3 statements received *very important* ratings from 84% (22/26) of the students: “It helps me build compassion for myself and other people,” “The skills and knowledge that I gain will help me in my career,” and “I build relationships with people who live and think differently than I do.” In total, 80% (21/26) rated “It makes me a better student in the long run” as being very important. The following 2 statements received the highest number of *not very important to me* endorsements: “I learn from agents of change in my community” and “I believe it’s important to live out my faith.” Table 2 shows the scores for each value.

Table 2. Student ratings of community-engaged learning (CEL) values: not very important to me (rating=1); neutral (rating=2); and very important to me (rating=3).

Statements	Scores, mean (SD); range
I want to contribute to the good of our society.	2.89 (0.31); 2-3
The skills and knowledge that I gain will help me in my career.	2.85 (0.36); 2-3
I build relationships with people who live and think differently than I do.	2.85 (0.36); 2-3
It makes me a better student in the long run.	2.81 (0.39); 2-3
It helps me build compassion for myself and other people.	2.81 (0.47); 1-3
I can learn more outside the classroom.	2.74 (0.44); 2-3
My assumptions and beliefs are challenged, and I get to challenge others.	2.67 (0.54); 1-3
It empowers me to be an agent of change.	2.63 (0.48); 2-3
I see my community in new ways.	2.56 (0.50); 2-3
It informs the way I engage with the world.	2.56 (0.57); 1-3
I learn from agents of change in my community.	2.52 (0.50); 2-3
I believe it’s important to live out my faith.	2.44 (0.63); 1-3

Older Adults

Pretest-Posttest Analyses

The means of the summary scores are presented in Table 3. Overall, digital proficiency was analyzed in 2 ways. First, the MDPQ-16 scores were summed across the 16 digital tasks to indicate changes in overall proficiency. We found that scores changed significantly from pretest (mean 33.72, SD 14.05) to posttest measurements (mean 54.89, SD 14.42; t_{17}=7.88, *P*<.001). Second, we assessed the changes in the range of activities performed by analyzing scores of 1 (never tried) on the MDPQ-16. Across all 6 activities, the number of “never tried” responses decreased from pretest (mean 9.61, SD 3.60) to posttest measurements (mean 3.83, SD 3.31), representing a significant change on a Wilcoxon signed-rank test of −3.73 (*P*<.001). Finally, we also examined the individual scales on the MDPQ-16 and found that all but basic skills (t_{17}=1.48, *P*=.16) increased from pretest to posttest measurements, with *P*<.01 for the remaining 5 scales. Figure 3 shows the scores for all 6 scales at both assessment times.

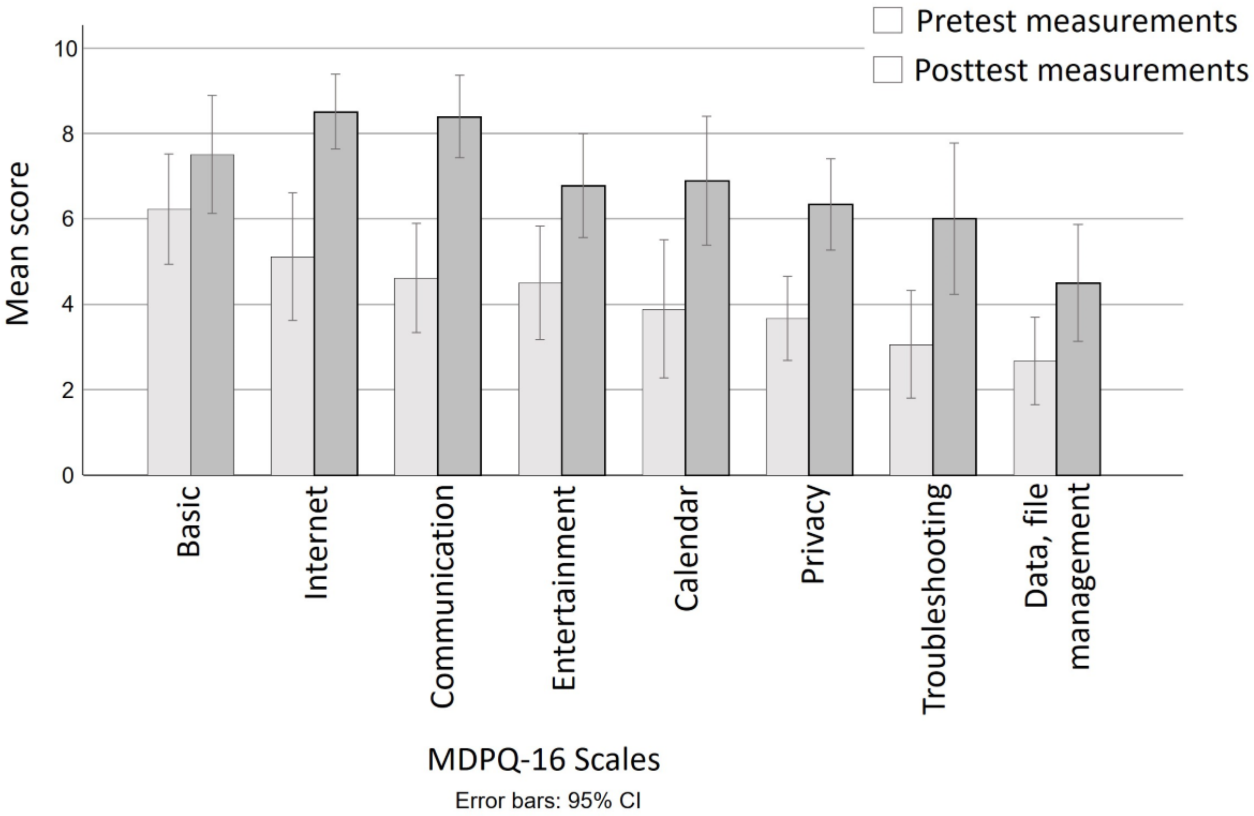
Table 3. Pretest-posttest summary variables for older adults (n=18).

Variables (range of possible scores)	Pretest measurements, mean (SD)	Posttest measurements, mean (SD)	Test statistic[a]	*P* value
MDPQ-16[b] total (16-80)	33.72 (14.05)	54.89 (14.42)	2.86	<.001
Never tried activities (0-16)	9.61 (3.60)	3.83 (3.31)	−3.73	<.001
Loneliness (3-9)	6.22 (2.58)	7.50 (2.77)	1.41	.18
Attitudes Toward Own Aging (0-5)	2.72 (1.74)	3.44 (1.50)	2.85	.01

[a] All tests are *t* test except "Never tried activities," which was tested using the Wilcoxon signed-rank test.

[b] MDPQ-16: Mobile Device Proficiency Questionnaire-16.

Figure 3. Technology proficiency at pretest and posttest by Mobile Device Proficiency Questionnaire (MDPQ-16) scale.



Loneliness scores were summed across the 3 items (possible scores of 3 to 9), with higher scores indicating greater loneliness. As shown in Table 3, loneliness scores did not change significantly from pretest (mean 6.22, SD 2.58) to posttest measurements (mean 7.50, SD 2.77; t_{17}=1.41, *P*=.18). Responses on the 5 Attitudes Toward Own Aging items were summed to create an overall score from 0 to 5, with higher scores reflecting more positive attitudes. We found significant improvements in attitudes toward aging from the pretest (mean 2.72, SD 1.74) to posttest measurements (mean 3.44, SD 1.50; t_{17}=2.85, *P*=.01).

Posttest Analyses

Relationship quality ratings were positive, with 94% (17/18) indicating that older adults strongly agreed (highest possible score) that they enjoyed working with their student trainer, 89% (16/18) strongly agreed that they formed a close relationship with their student trainer, and similarly 89% (16/18) strongly agreed that they would miss interacting with their student trainer after the project ended (Multimedia Appendix 2). More than three-quarters of older adults (16/18, 89%) responded that they felt "a lot" more socially connected during the technology training program, with the remainder (2/18, 11%) indicating that they felt "a little" more connected. Older adults' ratings of their computer abilities and confidence were also positive. Almost three-quarters of participants strongly agreed (highest endorsement) that their laptop skills had improved (13/18, 72%), that their confidence in using their laptop had improved (14/18, 78%), and that they were more independent when using their laptop (14/18, 78%). In terms of the overall evaluation of the training program, 100% (18/18) indicated their experience with the training program was very positive (highest endorsement) and 94% (17/18) indicated that the program was very valuable (highest endorsement). Finally, when asked how likely they would be to recommend the training program to others, 94% (17/18) responded extremely likely (highest endorsement) and 6% (1/18) responded very likely.

Discussion

Principal Findings

Multifactorial approaches are sorely needed to reduce the growing digital divide among low-income older adults [3,14,18]. The objective of the CEL study presented here was to address 1 component of the digital divide, digital literacy, using a potentially scalable approach. We sought to develop and implement a digital literacy training program using a CEL approach to bring together college students and low-income older adults in the community. There are several notable findings from this work.

First, we found significant improvements in digital literacy as assessed using the MDPQ-16, a measure of computer proficiency that is validated for older adults [57]. To our knowledge, proficiency has not been assessed in past work on training, regardless of whether the program used an intergenerational approach [23,48,49]. In addition to greater proficiency, we also found a significant increase in the breadth of technology use as reflected by a sharp decrease in the number of never-been-tried activities after training. This finding is consistent with intergenerational and nonintergenerational training studies, showing an increased frequency of technology use across multiple tasks [23,49]. However, another study using a similar approach (ie, the item, use of technology in many ways) showed no change following intergenerational training [48]. Overall, our findings add to a small but growing literature showing that intergenerational technology training programs can be an effective approach to improving digital literacy [25] and add to this literature by extending the findings to include digital literacy benefits for low-income older adults.

Second, we found significant improvements in older adults' confidence surrounding technology use, which is a critical component of technology acceptance and adoption [16]. This finding is consistent with past technology training studies showing improvements in older adults' confidence [23] and enjoyment of working with technology [48]. Because we included assessments of both confidence and skill, this study extends prior research by showing that both can improve when using an intergenerational approach to promoting digital inclusion.

Third, our results showed beneficial effects on how older adults think about their own aging. Although past work has shown that intergenerational contact can promote positive attitudes among younger individuals [46], we are unaware of prior studies that examined these attitudes among older adults. Past research has shown that older adults' positive attitudes toward their own aging protect against multiple diseases, including dementia [47,60]. Thus, policy makers interested in tackling the challenges of an aging population should consider investing in intergenerational programs to foster positive attitudes toward aging and enhance older adults' well-being.

Fourth, findings from this study did not show significant improvements in loneliness from pretest to posttest measurements. Although this was somewhat surprising, other training studies have also shown no effect of training on older adults' loneliness [23]. Indeed, a review of the literature on the effects of technology interventions, broadly defined, concluded that their impact on older adults' loneliness is ambiguous [61]. One reason for our findings could be that the pretest survey was administered at the start of the program when older adults had already met their trainers and worked within the same room as other trainers and trainees at the senior center. By contrast, shorter training programs (eg, 8 weeks compared with several months) tend to show null effects on loneliness [61]. Although ours was a group program (in which participants met in a setting with several other individuals), it remains unclear whether loneliness levels would have been impacted by the training program. Therefore, future research is needed to explore the effects of group training programs on loneliness in older adults.

Finally, older adults' end-of-program ratings suggest that the training program was a success. Self-reported improvements in digital literacy, program value, and program enjoyment were all high, and 94% (17/18) of older adults indicated that they were extremely likely to recommend the program to others. Enthusiasm for working with college student trainers has been reported in the past work [25,48]. High satisfaction with our digital literacy training programs may also be because the low-income older adults in our study (1) were able to keep the laptop and (2) received funds for a 2-year broadband subscription following the training (this support was for a federal low-income program called the Affordable Connectivity Program). This may also have helped to increase engagement and commitment to learning how to use the technology. Policy makers and community organizations interested in bridging the digital divide among low-income older populations should provide tangible support, such as digital devices and broadband connectivity to enhance program outcomes and promote continued digital engagement.

The significant improvements observed in older adults' digital proficiency, confidence in technology use, and attitudes toward aging underscore the potential of intergenerational approaches that bring together older adults and college students to promote digital inclusion and well-being among older adults. Programs that help to formalize opportunities for undergraduates to work with low-income older adults as part of their undergraduate education (rather than in addition to it) may be particularly impactful for both older and younger adults. In subsequent sections, we outline some of these benefits.

CEL Approach

Reduces Uncertainties Surrounding Logistics of Meeting Times and Place

The prescheduled meeting times and a meeting place at a local senior center provided structure, which reduced uncertainties for both students and older adults. Data from our preliminary study indicated that both students and older adults were frustrated and confused by scheduling constraints and last-minute changes.

Train the Trainer

Another advantage to this approach is the ability to focus on training the trainers, which in this study included students learning about design thinking and aging. The ongoing educational support to enable students to learn how to train older adults may be even more important when working with low-income older adults. Although other technology training programs have included educational support for students, they included only 1 session [48] or 1 session along with an optional social media forum for student trainers to support each other [49]. In this study, students' questions and observations about how to tailor the training to be more effective continued throughout the duration of the program.

Focus on Social Good

As with public psychology [62], CEL is concerned with social good and the welfare of others. This importance of social good is becoming increasingly acknowledged in other public and private institutions of higher education [63]. In this study, we found that the students were also concerned with social good. CEL ratings reflect students' interest in community, social welfare, and serving those in need. Developmentally, young adults tend to be concerned with the need for social change and identification of ways in which they can make a difference [51]. CEL with an intergenerational focus provides an opportunity for younger adults to express their concerns and broaden their awareness of social needs via exposure to underserved older adults. Furthermore, when CEL is embedded within the curriculum, students can more easily take advantage of opportunities to "give back" while also working toward their academic goals. This may be particularly important for underrepresented students who are often unable to do internships for a variety of reasons, including strict timelines for graduation, work obligations (sometimes several jobs), and family responsibilities.

Community and Campus Relationships

CEL relies heavily on close working ties with community members. In this study, the most important community members were the low-income older adults. Indeed, the relationship between the older adult trainees and the student trainers played a critical role in the success of the program. Community organizations also play a critical role and can help with recruiting older adults; donating space and associated services (eg, tables, chairs, parking, signage, and communication); and applying for funding to purchase laptops and broadband subscriptions. Finally, campus stakeholders also play a central role in the developing, testing, and scaling up of programs that focus on underserved older adults in the community. For example, campus leaders can express their enthusiasm for CEL courses, provide CEL experts to support instructors interested in designing courses, develop relationships with community stakeholders, and provide financial incentives (eg, to programs and departments) to incorporate these courses into existing degree requirements. The importance of campus and community partnerships cannot be underestimated [64]. Future work should therefore consider innovative ways to engage community organizations and campus leaders in efforts to build effective and sustainable intergenerational programs that improve low-income older adults' digital literacy.

Intergenerational Approach

This study used an intergenerational approach to serving low-income older adults. As suggested by the posttest scores, students valued getting to know their older adult trainees. Their experiences across the program led to greater confidence in working with older adults, as has been shown in past work [48]. In addition, consistent with past research, we did not find significant changes in fear of older adults (P=.42) [44,48]. Surprisingly, however, we did not find significant improvement in students' attitudes toward aging as has been reported in the past assessments [48]. A closer look at the prior study indicates that students in this study scored as high on the Psychological Growth scale at the pretest time point (mean 29.58, SD 3.11) as those in the study by Leedahl et al [48] at the posttest time point (mean 29.42, SD 3.19), suggesting that there was little room for improvement as a result of their interactions across the training program. In addition to whether changes in attitudes occur within an academic term, it is important to consider the possibility of longer-term effects of intergenerational programs, including CEL. In this study, the first-year seminar course had no prerequisites, potentially attracting those who would not otherwise consider working with older adults. Given an increasingly age-segregated society [40] and a severe shortage of individuals trained to work in fields related to aging [65], this approach may promote interest among students to work on solving some of the pressing issues in facing a world with an unprecedented number of older adults [66,67].

Limitations

There were several limitations of our study. First, because of our single-group design, we cannot know which components of the training program were responsible for the beneficial outcomes. For example, we cannot disentangle the effects of training from the effects of owning a new laptop or assume the intergenerational component is superior to other models of training (eg, the use of technology experts). Second, our pretest measures might have shown a stronger impact on the program had we administered them 1 or 2 weeks before the start of the training program. Because we assessed them in the first 2 weeks, it is possible that some outcomes, such as loneliness and basic technology skills, might have already improved. Third, as with some previous training studies [25,48], the sample size was small, which can limit the ability to detect smaller effects. The sample was also predominantly consisted of White and female individuals, limiting the generalizability of the findings. Our sample does not, for example, allow us to account for the potential role that sociocultural factors (eg, culture, country of origin, intersecting identities, situations, or the interplay between these factors) play in the augmentation of digital literacy in older adults. Importantly, however, participants in this study were from low-income households, which are significantly underrepresented in the literature. Finally, our study did not include a follow-up to examine the long-term impact of training on new technology adoption and sustained use of the laptops. It is also possible, for example, that greater digital literacy skills would lead to decreased loneliness over time as older adults begin to use technology for social interactions [68]. Additional work is needed to explore the longer-term impact and scalability of this approach to promoting digital literacy among low-income older adults and to examine other potential benefits to both older and younger adults.

Conclusions

Taken together, the current research contributes to a growing body of research on digital literacy training and provides a potential pathway to address the digital divide among underserved older adults [3,14,18]. Digital inclusion is central to older adults' ability to remain independent and live in their own homes as they age. Moreover, the intergenerational CEL approach used in this study promotes mutual respect across generations, breaks down harmful stereotypes, and helps to build a stronger community. Moving forward, continued research in this area is crucial for informing policy decisions that support digital inclusion for older adults and help to address broader challenges related to an aging global population, digital fairness, social justice, and the shared fate of humanity.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Digital literacy training content and process overview that students used while training older adults.
[DOCX File , 54 KB - aging_v7i1e51675_app1.docx]

Multimedia Appendix 2
Older adults' posttest-only data.
[DOCX File , 78 KB - aging_v7i1e51675_app2.docx]

References

1. Philbin MM, Parish C, Pereyra M, Feaster DJ, Cohen M, Wingood G, et al. Health disparities and the digital divide: the relationship between communication inequalities and quality of life among women in a nationwide prospective cohort study in the United States. J Health Commun 2019;24(4):405-412. [doi: 10.1080/10810730.2019.1630524] [Medline: 31198091]
2. Sieck CJ, Sheon A, Ancker JS, Castek J, Callahan B, Siefer A. Digital inclusion as a social determinant of health. NPJ Digit Med 2021 Mar 17;4(1):52. [doi: 10.1038/s41746-021-00413-8] [Medline: 33731887]
3. Singh GK, Girmay M, Allender M, Christine RT. Digital divide: marked disparities in computer and broadband internet use and associated health inequalities in the United States. Int J Transl Med Res Public Health 2020 Jun;4(1):64-79. [doi: 10.21106/ijtmrph.148]
4. Drazich BF, Lee JW, Bowles KH, Taylor JL, Shah S, Resnick B, et al. Pandemic-related changes in technology use among a sample of previously hospitalized older adult New Yorkers: observational study. JMIR Aging 2023 Mar 29;6:e41692. [doi: 10.2196/41692] [Medline: 36881528]
5. Gauthier GR, Smith JA, García C, Garcia MA, Thomas PA. Exacerbating inequalities: social networks, racial/ethnic disparities, and the COVID-19 pandemic in the United States. J Gerontol B Psychol Sci Soc Sci 2021 Feb 17;76(3):e88-e92. [doi: 10.1093/geronb/gbaa117] [Medline: 32756978]
6. Jaffe DH, Lee L, Huynh S, Haskell TP. Health inequalities in the use of telehealth in the United States in the lens of COVID-19. Popul Health Manag 2020 Oct;23(5):368-377. [doi: 10.1089/pop.2020.0186] [Medline: 32816644]
7. Seifert A, Cotten SR, Xie B. A double burden of exclusion? Digital and social exclusion of older adults in times of COVID-19. J Gerontol B Psychol Sci Soc Sci 2021 Feb 17;76(3):e99-103. [doi: 10.1093/geronb/gbaa098] [Medline: 32672332]
8. Molinsky J, Herbert C, Forsyth A. Housing and planning supporting healthy aging. In: Coll P, editor. Healthy Aging. Cham, Switzerland: Springer; Mar 30, 2019.
9. National Academies of Sciences, Engineering, and Medicine, Division of Behavioral and Social Sciences and Education, Health and Medicine Division, Board on Behavioral, Cognitive, and Sensory Sciences, Board on Health Sciences Policy. Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System. Washington, DC: National Academies Press; 2020.
10. Daly JR, Depp C, Graham SA, Jeste DV, Kim HC, Lee EE, et al. Health impacts of the stay-at-home order on community-dwelling older adults and how technologies may help: focus group study. JMIR Aging 2021 Mar 22;4(1):e25779. [doi: 10.2196/25779] [Medline: 33690146]
11. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: internet use patterns, eHealth literacy, and attitudes toward computer/internet use. J Med Internet Res 2013 May 02;15(5):e93. [doi: 10.2196/jmir.2645] [Medline: 23639979]
12. Gordon NP, Crouch E. Digital information technology use and patient preferences for internet-based health education modalities: cross-sectional survey study of middle-aged and older adults with chronic health conditions. JMIR Aging 2019 Apr 04;2(1):e12243. [doi: 10.2196/12243] [Medline: 31518291]

13. Jensen JD, King AJ, Davis LA, Guntzviller LM. Utilization of internet technology by low-income adults: the role of health literacy, health numeracy, and computer assistance. J Aging Health 2010 Sep;22(6):804-826. [doi: 10.1177/0898264310366161] [Medline: 20495159]
14. Marston HR, Shore L, White PJ. How does a (smart) age-friendly ecosystem look in a post-pandemic society? Int J Environ Res Public Health 2020 Nov 09;17(21):8276. [doi: 10.3390/ijerph17218276] [Medline: 33182413]
15. Mitchell UA, Chebli PG, Ruggiero L, Muramatsu N. The digital divide in health-related technology use: the significance of race/ethnicity. Gerontologist 2019 Jan 09;59(1):6-14. [doi: 10.1093/geront/gny138] [Medline: 30452660]
16. Czaja SJ, Charness N, Fisk AD, Hertzog C, Nair SN, Rogers WA, et al. Factors predicting the use of technology: findings from the center for research and education on aging and technology enhancement (CREATE). Psychol Aging 2006 Jun;21(2):333-352. [doi: 10.1037/0882-7974.21.2.333] [Medline: 16768579]
17. Czaja SJ, Boot WR, Charness N, Rogers WA, Sharit J. Improving social support for older adults through technology: findings from the PRISM randomized controlled trial. Gerontologist 2018 May 08;58(3):467-477. [doi: 10.1093/geront/gnw249] [Medline: 28201730]
18. Ellison-Barnes A, Moran A, Linton S, Chaubal M, Missler M, Evan Pollack C. Limited technology access among residents of affordable senior housing during the COVID-19 pandemic. J Appl Gerontol 2021 Sep;40(9):958-962. [doi: 10.1177/07334648211013634] [Medline: 33980058]
19. Golomski C, Corvini M, Kim B, Wilcox J, Valcourt S. Aspects of ICT connectivity among older adults living in rural subsidized housing: reassessing the digital divide. J Enabling Technol 2022;16(1):17-27. [doi: 10.1108/jet-12-2020-0052]
20. Kebede AS, Ozolins LL, Holst H, Galvin K. Digital engagement of older adults: scoping review. J Med Internet Res 2022 Dec 07;24(12):e40192. [doi: 10.2196/40192] [Medline: 36477006]
21. López Seguí F, de San Pedro M, Aumatell Verges E, Simó Algado S, Garcia Cuyàs F. An intergenerational information and communications technology learning project to improve digital skills: user satisfaction evaluation. JMIR Aging 2019 Aug 09;2(2):e13939. [doi: 10.2196/13939] [Medline: 31518276]
22. Wu YH, Damnée S, Kerhervé H, Ware C, Rigaud AS. Bridging the digital divide in older adults: a study from an initiative to inform older adults about new technologies. Clin Interv Aging 2015 Jan 09;10:193-200. [doi: 10.2147/CIA.S72399] [Medline: 25624752]
23. Fields J, Cemballi AG, Michalec C, Uchida D, Griffiths K, Cardes H, et al. In-home technology training among socially isolated older adults: findings from the tech allies program. J Appl Gerontol 2021 May;40(5):489-499. [doi: 10.1177/0733464820910028] [Medline: 32141373]
24. Cotten SR. Technologies and aging: understanding use, impacts, and future needs. In: Handbook of Aging and the Social Sciences (Ninth Edition). Cambridge, MA: Academic Press; 2021.
25. Arthanat S, Vroman KG, Lysack C. A home-based individualized information communication technology training program for older adults: a demonstration of effectiveness and value. Disabil Rehabil Assist Technol 2016;11(4):316-324. [doi: 10.3109/17483107.2014.974219] [Medline: 25512061]
26. Campbell RJ, Nolfi DA. Teaching elderly adults to use the internet to access health care information: before-after study. J Med Internet Res 2005 Jun 30;7(2):e19. [doi: 10.2196/jmir.7.2.e19] [Medline: 15998610]
27. Chan MY, Haber S, Drew LM, Park DC. Training older adults to use tablet computers: does it enhance cognitive function? Gerontologist 2016 Jun;56(3):475-484. [doi: 10.1093/geront/gnu057] [Medline: 24928557]
28. Quialheiro A, Miranda A, Garcia MJ, Carvalho AC, Costa P, Correia-Neves M, et al. Promoting digital proficiency and health literacy in middle-aged and older adults through mobile devices with the workshops for online technological inclusion (OITO) project: experimental study. JMIR Form Res 2023 Feb 08;7:e41873. [doi: 10.2196/41873] [Medline: 36753331]
29. Tsai HY, Rikard RV, Cotten SR, Shillair R. Senior technology exploration, learning, and acceptance (STELA) model: from exploration to use – a longitudinal randomized controlled trial. Educ Gerontol 2019 Nov 18;45(12):728-743. [doi: 10.1080/03601277.2019.1690802]
30. Charness N, Boot WR. A grand challenge for psychology: reducing the age-related digital divide. Curr Dir Psychol Sci 2022;31(2):187-193. [doi: 10.1177/09637214211068144] [Medline: 35754678]
31. Renaud K, van Biljon J. Predicting technology acceptance and adoption by the elderly: a qualitative study. In: Proceedings of the 2008 annual research conference of the South African Institute of Computer Scientists and Information Technologists on IT research in developing countries: riding the wave of technology. 2008 Presented at: SAICSIT '08; October 6-8, 2008; Wilderness, South Africa. [doi: 10.1145/1456659.1456684]
32. Czaja SJ, Boot WR, Charness N, Rogers WA. Designing for Older Adults: Principles and Creative Human Factors Approaches, Third Edition. Boca Raton, FL: CRC Press; 2019.
33. Jung Y, Peng W, Moran M, Jin SA, McLaughlin M, Cody M, et al. Low-income minority seniors' enrollment in a cybercafé: psychological barriers to crossing the digital divide. Educ Gerontol 2010 Feb 08;36(3):193-212. [doi: 10.1080/03601270903183313]
34. Klimova B. Computer-based cognitive training in aging. Front Aging Neurosci 2016 Dec 20;8:313. [doi: 10.3389/fnagi.2016.00313] [Medline: 28066236]
35. Tappen RM, Cooley ME, Luckmann R, Panday S. Digital health information disparities in older adults: a mixed methods study. J Racial Ethn Health Disparities 2022 Feb;9(1):82-92. [doi: 10.1007/s40615-020-00931-3] [Medline: 33415705]

36. Bandura A. Regulation of cognitive processes through perceived self-efficacy. Dev Psychol 1989;25(5):729-735. [doi: 10.1037//0012-1649.25.5.729]
37. Miller LM, Lachman ME. The sense of controlcognitive aging: toward a model of mediational processes. In: Social Cognition and Aging. Cambridge, MA: Academic Press; 1999.
38. Gruenewald TL, Tanner EK, Fried LP, Carlson MC, Xue QL, Parisi JM, et al. The Baltimore experience corps trial: enhancing generativity via intergenerational activity engagement in later life. J Gerontol B Psychol Sci Soc Sci 2016 Jul;71(4):661-670. [doi: 10.1093/geronb/gbv005] [Medline: 25721053]
39. Murayama Y, Ohba H, Yasunaga M, Nonaka K, Takeuchi R, Nishi M, et al. The effect of intergenerational programs on the mental health of elderly adults. Aging Ment Health 2015;19(4):306-314. [doi: 10.1080/13607863.2014.933309] [Medline: 25010219]
40. Riley MW, Riley JWJ. Age integration: conceptual and historical background. Gerontologist 2000 Jun;40(3):266-270. [doi: 10.1093/geront/40.3.266] [Medline: 10853514]
41. Wilmoth JM, Longino CFJ. Demographic trends that will shape U.S. Policy in the twenty-first century. Res Aging 2006;28(3):269-288. [doi: 10.1177/0164027505285920]
42. Martins T, Midão L, Martínez Veiga S, Dequech L, Busse G, Bertram M, et al. Intergenerational programs review: study design and characteristics of intervention, outcomes, and effectiveness. J Intergenerational Relatsh 2018 Dec 16;17(1):93-109. [doi: 10.1080/15350770.2018.1500333]
43. Canedo-García A, García-Sánchez JN, Pacheco-Sanz DI. A systematic review of the effectiveness of intergenerational programs. Front Psychol 2017 Oct 27;8:1882. [doi: 10.3389/fpsyg.2017.01882] [Medline: 29163269]
44. Andreoletti C, Howard JL. Bridging the generation gap: intergenerational service-learning benefits young and old. Gerontol Geriatr Educ 2018;39(1):46-60. [doi: 10.1080/02701960.2016.1152266] [Medline: 26905456]
45. Breck BM, Dennis CB, Leedahl SN. Implementing reverse mentoring to address social isolation among older adults. J Gerontol Soc Work 2018 Jul;61(5):513-525. [doi: 10.1080/01634372.2018.1448030] [Medline: 29528785]
46. Burnes D, Sheppard C, Henderson CRJ, Wassel M, Cope R, Barber C, et al. Interventions to reduce ageism against older adults: a systematic review and meta-analysis. Am J Public Health 2019 Aug;109(8):e1-e9. [doi: 10.2105/AJPH.2019.305123] [Medline: 31219720]
47. Levy BR, Slade MD, Chang ES, Kannoth S, Wang SY. Ageism amplifies cost and prevalence of health conditions. Gerontologist 2020 Jan 24;60(1):174-181. [doi: 10.1093/geront/gny131] [Medline: 30423119]
48. Leedahl SN, Brasher MS, Estus E, Breck BM, Dennis CB, Clark SC. Implementing an interdisciplinary intergenerational program using the Cyber Seniors reverse mentoring model within higher education. Gerontol Geriatr Educ 2018 Jan 24:1-19 (forthcoming). [doi: 10.1080/02701960.2018.1428574] [Medline: 29364782]
49. Arthanat S. Promoting information communication technology adoption and acceptance for aging-in-place: a randomized controlled trial. J Appl Gerontol 2021 May;40(5):471-480. [doi: 10.1177/0733464819891045] [Medline: 31782347]
50. Mitchell T. Traditional vs. critical service-learning: engaging the literature to differentiate two models. Mich J Community Serv Learn 2008:50-65.
51. Institute of Medicine and National Research Council. Investing in the Health and Well-Being of Young Adults. Washington, DC: The National Academies Press; 2015.
52. Adams C, Nash JB. Exploring design thinking practices in evaluation. J Multidiscip Eval 2016;12(26):12-17. [doi: 10.56645/jmde.v12i26.434]
53. Panke S. Design thinking in education: perspectives, opportunities and challenges. Open Educ Stud 2019;1(1):281-306. [doi: 10.1515/edu-2019-0022]
54. Lubben J, Blozik E, Gillmann G, Iliffe S, von Renteln Kruse W, Beck JC, et al. Performance of an abbreviated version of the Lubben social network scale among three European community-dwelling older adult populations. Gerontologist 2006 Aug;46(4):503-513 [FREE Full text] [doi: 10.1093/geront/46.4.503] [Medline: 16921004]
55. Laidlaw K, Kishita N, Shenkin SD, Power MJ. Development of a short form of the attitudes to ageing questionnaire (AAQ). Int J Geriatr Psychiatry 2018 Jan;33(1):113-121. [doi: 10.1002/gps.4687] [Medline: 28326605]
56. Lasher KP, Faulkender PJ. Measurement of aging anxiety: development of the anxiety about aging scale. Int J Aging Hum Dev 1993;37(4):247-259. [doi: 10.2190/1u69-9au2-v6lh-9y1l]
57. Roque NA, Boot WR. A new tool for assessing mobile device proficiency in older adults: the mobile device proficiency questionnaire. J Appl Gerontol 2018 Feb;37(2):131-156. [doi: 10.1177/0733464816642582] [Medline: 27255686]
58. Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A short scale for measuring loneliness in large surveys: results from two population-based studies. Res Aging 2004;26(6):655-672 [FREE Full text] [doi: 10.1177/0164027504268574] [Medline: 18504506]
59. Lawton MP. The Philadelphia geriatric center morale scale: a revision. J Gerontol 1975 Jan;30(1):85-89. [doi: 10.1093/geronj/30.1.85] [Medline: 1109399]
60. Levy BR, Slade MD, Pietrzak RH, Ferrucci L. Positive age beliefs protect against dementia even among elders with high-risk gene. PLoS One 2018 Feb 7;13(2):e0191004. [doi: 10.1371/journal.pone.0191004] [Medline: 29414991]

61. Balki E, Hayes N, Holland C. Effectiveness of technology interventions in addressing social isolation, connectedness, and loneliness in older adults: systematic umbrella review. JMIR Aging 2022 Oct 24;5(4):e40125. [doi: 10.2196/40125] [Medline: 36279155]
62. Eaton AA, Grzanka PR, Schlehofer MM, Silka L. Public psychology: introduction to the special issue. Am Psychol 2021 Nov;76(8):1209-1216. [doi: 10.1037/amp0000933] [Medline: 35113588]
63. Jacob WJ, Sutin S, Weidman JL, Yeager JC. Community Engagement in Higher Education: Policy Reforms and Practice. Rotterdam, The Netherlands: Sense Publishers; 2015.
64. Roodin P, Brown LH, Shedlock D. Intergenerational service-learning: a review of recent literature and directions for the future. Gerontol Geriatr Educ 2013;34(1):3-25. [doi: 10.1080/02701960.2012.755624] [Medline: 23362852]
65. Rowe JW. The US eldercare workforce is falling further behind. Nat Aging 2021 Apr;1(4):327-329. [doi: 10.1038/s43587-021-00057-z] [Medline: 37117593]
66. Christensen K, Doblhammer G, Rau R, Vaupel JW. Ageing populations: the challenges ahead. Lancet 2009 Oct 03;374(9696):1196-1208. [doi: 10.1016/S0140-6736(09)61460-4] [Medline: 19801098]
67. Gu D, Andreev K, Dupre ME. Major trends in population growth around the world. China CDC Wkly 2021 Jul 09;3(28):604-613. [doi: 10.46234/ccdcw2021.160] [Medline: 34594946]
68. Aarts S, Peek ST, Wouters EJ. The relation between social network site usage and loneliness and mental health in community-dwelling older adults. Int J Geriatr Psychiatry 2015 Sep;30(9):942-949. [doi: 10.1002/gps.4241] [Medline: 25503540]

Abbreviations

CEL: community-engaged learning
CREATE: Center for Research and Education on Aging and Technology Enhancement
MDPQ-16: Mobile Device Proficiency Questionnaire
STAM: Senior Technology Acceptance and Adoption Model

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Original Paper

Long-Term Adoption of Televisits in Nursing Homes During the COVID-19 Crisis and Following Up Into the Postpandemic Setting: Mixed Methods Study

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Abstract

Background: There is growing evidence that telemedicine can improve the access to and quality of health care for nursing home residents. However, it is still unclear how to best manage and guide the implementation process to ensure long-term adoption, especially in the context of a decline in telemedicine use after the COVID-19 crisis.

Objective: This study aims to identify and address major challenges for the implementation of televisits among residents in a nursing home, their caring nurses, and their treating general practitioners (GPs). It also evaluated the impact of televisits on the nurses' workload and their nursing practice.

Methods: A telemedical system with integrated medical devices was introduced in 2 nursing homes and their cooperating GP offices in rural Germany. The implementation process was closely monitored from the initial decision to introduce telemedicine in November 2019 to its long-term routine use until March 2023. Regular evaluation was based on a mixed methods approach combining rigorous qualitative approaches with quantitative measurements.

Results: In the first phase during the COVID-19 pandemic, both nursing homes achieved short-term adoption. In the postpandemic phase, an action-oriented approach made it possible to identify barriers and take control actions for long-term adoption. The implementation of asynchronous visits, strong leadership, and sustained training of the nurses were critical elements in achieving long-term implementation in 1 nursing home. The implementation led to enhanced clinical skills, higher professional recognition, and less psychological distress among the nursing staff. Televisits resulted in a modest increase in time demands for the nursing staff compared to organizing in-person home visits with the GPs.

Conclusions: Focusing on health care workflow and change management aspects depending on the individual setting is of utmost importance to achieve successful long-term implementation of telemedicine.

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KEYWORDS

telemedicine; televisits; telehealth; eHealth; electronic health; older adult care; nursing homes; change management; implementation science; technology transfer; innovation transfer; long-term adoption; COVID-19 crisis; postpandemic; coronavirus; digitalization

Introduction

Background

Population aging is an ongoing trend in industrialized countries and significantly impacts the health care sector [1-3]. Germany currently faces a steep increase in the number of older adult citizens and, concomitantly, in people needing care. Compared to the 2.63 million people needing care in 2013, this figure will increase by approximately 32% to estimated 3.48 million in 2030 [4]. As a consequence, more older adults will receive long-term care in nursing homes (NHs). To avoid future overcrowding of German hospitals and control overall health care costs, limiting hospital admissions (HAs) from NHs will be a major challenge. In fact, these HAs from NHs are frequently avoidable, with potentially avoidable HA cases from NHs accounting for €770 million (US $829 million) in avoidable health care costs in Germany each year [5].

Telemedicine is effective in reducing HAs from NHs and is an attractive modality of care, especially in the context of fewer home visits by general practitioners (GPs), a shortage of geriatricians, and difficulties in accessing health care in rural areas [6,7]. Both synchronous telemedicine, where a physician visits a patient in real time, and asynchronous telemedicine, where information on the patient is entered into a telemedical system and reviewed by a physician at a later time, can be implemented in NHs [8].

Another distinction of telemedical modalities is based on whether patients are accompanied by caregivers or not. Televisits are defined by the authors as videoconferencing among a remote physician, an NH resident, and an on-site caregiver (in this setting, a geriatric nurse) while having access to point-of-care (PoC) diagnostic devices that are integrated into the telemedical system. Televisits enable a structured physical examination and direct patient care, delegated by the remote physician and executed by the caregiver. This is not possible in video consultations, defined as simple videoconferencing between a physician and a patient. In the latter, the examination is limited without access to diagnostic devices, and direct patient care is not possible because there is no caregiver next to the patient.

Telemedicine is a safe modality of care and is noninferior in older adult patients presenting acute medical conditions in cases in which they are accompanied on-site by a nursing caregiver [9]. Several studies evaluating telemedicine for older adults have shown a reduced number of emergency department visits and HAs from NHs [10-22]. Despite these positive effects on the overall level of care and the widespread accessibility of telemedical tools, deployment in primary care and NHs is only progressing slowly.

Even though several implementation frameworks for telemedicine have been proposed in the literature [23,24], a lot of projects transferring telemedical or digital innovation into routine care fail due to poor consideration of change management (CM) aspects [25]. CM can be understood as an organized approach to drive organizational transformation from one current state to a new desired state. The concepts and various models commonly used for business transformation can be applied to health care, where new innovations are also constantly integrated [26-28]. While clinical research mainly focuses on creating evidence for better health-related outcomes, CM aims to ensure long-term adoption of change processes by promoting staff engagement and fostering a culture of continuous improvement. In fact, most of the clinical studies assessing the implementation of new technologies such as telemedicine focus on short-term adoption and technical issues but do not specifically address organizational, cultural, and educational challenges [29-31]. In contrast, the structured approach of CM involves methodically planning and monitoring the entire process to promptly identify and address challenges. This allows for the reduction in resistance to change, ensuring a smooth transition for health care providers and patients and, ultimately, enhancing the quality of care and organizational effectiveness. CM methods are action-oriented approaches focusing on managing specific change processes within one institution by directly addressing challenges. The field of implementation science (IS) must be distinguished from CM applied to health care. While IS also aims to understand implementation and the sustainability of implementation efforts, it takes a broader perspective. In fact, IS aims to create generalizable knowledge about effective implementation strategies of evidence-based health interventions by identifying facilitators and barriers across different contexts and health care settings [32].

Currently, many barriers to the implementation of telemedical tools are known, such as unstable internet connections and other technical issues, insufficient acceptance, privacy and security concerns, poor usability of the systems, a lack of patient support from health care professionals (HCPs), inadequate motivation and training, a shortage of staff, poor planning and engagement, and the fear of misdiagnosis or lack of trust in the technology [31,33-36]. However, implementation guidelines are still missing, and the best practice for implementing telemedicine for ensuring long-term adoption is still unknown. Moreover, there is a gap in research concerning the impact on nursing practice triggered by the organizational implementation of televisits.

Objectives

This study aimed to identify and address major challenges for long-term implementation of televisits as well as evaluating the impact of televisits on nurses' workload and their nursing practice.

Methods

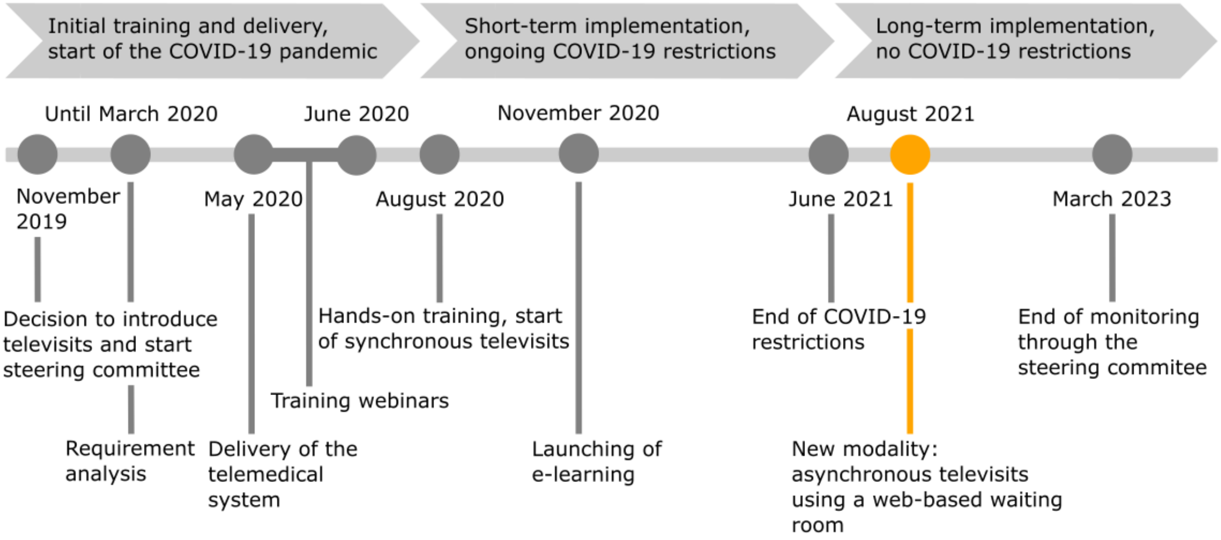
Setting

This study was conducted in 2 NHs located in 2 different rural areas of the federal state of North Rhine-Westphalia (Germany). Both NHs provide long-term stationary care for older adults, with an average resident age of >85 years. Although they are comparable in size (NH 1 provides care for 93 residents, and NH 2 provides care for 90 residents), they differed in the number of employees within the study period (NH 1 had 64 nurses and nursing assistants for a total of 39.6 full-time equivalents, and NH 2 had 37 nurses and nursing assistants for 32.5 full-time equivalents) and in the number of trainee nurses (14 in NH 1 and 69 in NH 2). There were more women (86% of the employees in NH 1 vs 70% in NH 2, trainees excluded) and older employees (mean age 47.8 years in NH 1 vs 33.3 years in NH 2, trainees excluded) in NH 1 than in NH 2. NH 1 was built in the 1970s and is administered by a foundation managing NH 1, a local ambulatory care service, and 1 facility for assisted living for older adults. NH 2 is run by a local nonprofit organization with a history of >150 years that provides stationary care in 3 NHs. The organization that runs NH 2 also offers care in all the other relevant fields of older adults' care (intensive care nursing, ambulatory care, assisted living communities, and palliative care). The regional district of NH 1 faces a steeper decline in the number of physicians than that of NH 2. This is reflected in the average travel time to the nearest GP practice, which was twice as long in the district of NH 1 as in the district of NH 2 (4.4 vs 2.0 minutes) in 2021 [37]. For the medical care of the residents, both NHs collaborate with a coordinating GP, who cares for approximately one-third to half of the total number of residents living in the NH. This is common in Germany, where the remaining residents are followed up on by other GPs located within the catchment area of the NHs. Only the corresponding GPs, and not the GPs of the other 2 NHs, participated in the implementation of televisits. However, an NH resident followed up on by a GP other than the corresponding one could still benefit from a televisit if the coordinating GP was covering for other GPs on holiday or sick leave.

Timeline

The timeline of the covered implementation process during this study is shown in Figure 1. The total follow-up period between November 2019 and the end of March 2023 can be divided into 3 phases. The first phase between November 2019 and mid-August 2020 consisted in planning the implementation process, supplying and setting up the telemedical system, and initial training of the HCPs. This was followed by 2 distinct implementation phases: a short-term implementation phase until June 2021, during which restrictions due to the COVID-19 pandemic were still in place, and a subsequent long-term implementation phase after the COVID-19 restrictions had been lifted.

Figure 1. Timeline of the implementation process.



From the very beginning, an interdisciplinary steering committee (see the *Evaluation: Steering Committee and Systematic Analysis of the First Implementation Phase* section) organized and supervised the entire change process. After a requirement analysis, the telemedical system was first delivered in May 2020. The initial training was delivered via web-based seminars as COVID-19 restrictions did not allow access to the NHs for external persons. A total of 5 webinars lasting approximately 1 hour each and held consecutively every week covered all the relevant aspects of televisits (the topics were *Introduction to telemedicine*, *Televisits*, *Televisits: the nurse's perspective*, *Televisits: the GP's perspective*, and *ECG, auscultation, and other diagnostic devices*). In parallel, the battery lifetime was enhanced, a bigger screen was installed, and the internet connection in the NHs was improved. In August 2020, hands-on training was organized for the entire staff in both NHs. After a short theoretical introduction summarizing the main learning points of the webinars, the participants were trained in televisits using simulated scenarios. Workflow organization was not part of the initial training. The nurse managers in the NHs received advanced training to become superusers, enabling them to feel comfortable in performing televisits, administering the users in the software, and guiding other nurses in their learning process. They later acted as contact persons for their colleagues regarding televisits. After the hands-on training sessions in August 2020, the NHs were asked to perform—whenever possible—weekly televisits with their coordinating GPs while still maintaining the weekly on-site home visits. No specific instructions or guidelines were provided regarding how the televisits should be incorporated into the existing workflows of the NHs. This provided the NHs with the flexibility to integrate televisits according to their specific requirements and organizational contexts.

To allow for continuous training, the webinar sessions, as well as additional step-by-step guides, were made available on an e-learning platform. The nurse managers continued weekly training of their colleagues and accompanied them in televisits when necessary. After a short familiarization period during which the nurse managers provided significant support, effective routine use was achieved between February 2021 and July 2021, covering the last COVID-19 lockdown in Germany from April 2021 to June 2021. When the COVID-19 restrictions ended, the first implementation phase was systematically analyzed within the steering committee. Challenges preventing further implementation were identified and addressed through specific control measures. This led to a new organization of televisits and marked the beginning of a second implementation phase beyond the constraints of the COVID-19 pandemic, referred to in this study as the long-term implementation phase.

The change process was monitored until the end of March 2023.

Telemedical System

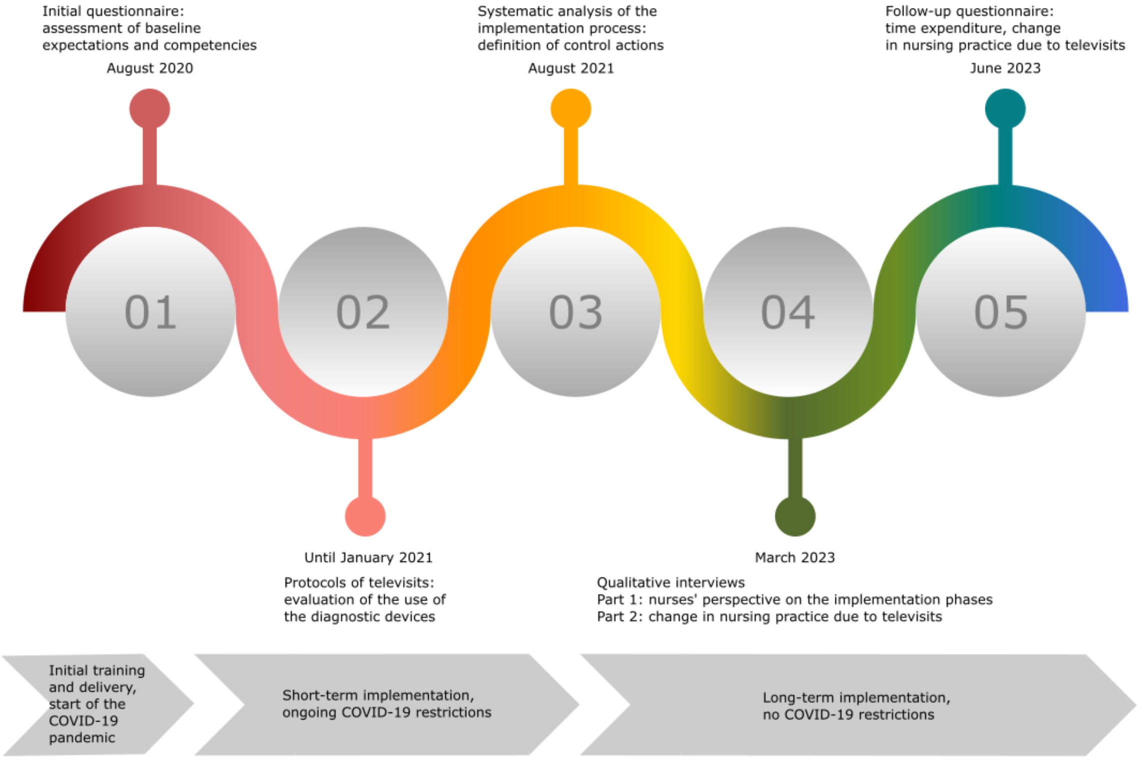
Televisits were performed using the so-called TeleDoc Mobile system (Docs in Clouds TeleCare GmbH), a market-available and mobile medical cart system for televisits with integrated medical diagnostic devices. The TeleDoc Mobile system was equipped with a blood pressure meter (BU 540 connect; medisana GmbH), a blood glucose meter (MediTouch 2; medisana GmbH), a 1-canal electrocardiogram (ECG; WIWE pocket ECG; myWIWE Diagnosztika Kft), and an electronic stethoscope (Littmann stethoscope model 3200; 3M). A conference camera offered a 10-time optical zoom in high definition (PTZ Pro 2; Logitech International S. A.). Screens on both sides of the system allowed for synchronous video communication among the GP, the nurse, and the resident. The software version of the TeleDoc Mobile system underwent multiple updates during the study period from version 1.0 in 2019 to version 3.6.2 in 2023. Feedback from HCPs was directly incorporated into these updates to meet their specific requirements. Previous work on the TeleDoc Mobile system had already demonstrated the technical feasibility of televisits and good acceptance by users [38].

Evaluation

Overview

A mixed methods approach was used for evaluation at different time points, as shown in Figure 2. A project diary in paper format containing a questionnaire and televisit documentation protocols (Multimedia Appendix 1) served to assess the nurses' baseline expectations and competencies and document the first televisits. This diary was distributed to all nurses in the NHs in May 2020, when the final telemedical system was delivered and the NHs were about to be trained and begin but had not yet done real televisits. The nursing staff were asked to fill in the questionnaire and document key elements of their first televisits, such as the date, the motive for consultation, and the number of PoC diagnostic devices used. The diaries were collected in January 2021. As already mentioned, the first implementation phase was observed and systematically analyzed within the steering committee in August 2021. At the conclusion of the study period in March 2023, qualitative interviews were conducted to retrospectively evaluate the nursing perspective regarding the implementation phases and the experienced change related to the implementation of televisits. The qualitative assessment of changes experienced in nursing practice was further quantitatively evaluated using a follow-up questionnaire in June 2023. The individual methods are described in detail in the following subsections.

Figure 2. Overview of the methods used for evaluation.



Questionnaire on Baseline Expectations and Competencies

The initial questionnaire (Multimedia Appendix 1) assessed nurses' self-reported competencies in the use of both medical devices and computer programs. A scale from 1 to 6 following the German school grading system was used (1=very good, 2=good, 3=satisfactory, 4=sufficient, 5=poor, and 6=deficient). Baseline expectations regarding the impact of implementing televisits on the residents' medical care and the nurses' time spent on televisits were assessed using preformulated multiple-choice questions. The nurses were also asked to rate, according to the German school grading system and before starting real televisits, their self-perceived level of knowledge of the medical devices as well as their level of understanding of the TeleDoc software. As the questionnaire was linked with the televisit documentation protocols, the questionnaire was not collected directly after the nurses had received training but only with the diaries in January 2021. In total, 20 diaries (n=12, 60% in NH 1 and n=8, 40% in NH 2) were handed back for analysis. After 1 diary was excluded because of missing data, 19 (n=11, 58% in NH 1 and n=8, 42% in NH 2) were used for analysis. Single missing data points were imputed with median imputation. Only the results regarding the self-reported competencies and the initial expectations are presented in the main text of this paper; however, the data for all questions can be found in Multimedia Appendix 2. Continuous variables were described as medians and IQRs and compared using the Mann-Whitney *U* test. Categorical data were described as numbers and percentages and compared using the Fisher exact test. All statistical tests were 2-sided with an α significance level of .05. They were applied in Python (version 3.9.7; Python Software Foundation) using the *scipy.stats* package.

Televisit Documentation Protocols

Televisit documentation protocols (Multimedia Appendix 1) were included in the second part of the project diaries. The nurses recorded in these protocols when a televisit took place and whether the televisit was preplanned or organized for an acute issue, such as an acute medical presentation by a resident. The nurses also documented the reason for the consultation and indicated whether they would have contacted the emergency service or the GP out-of-hours service or waited until the GP was available if they had not had access to televisits. In a second part, the nurses were asked to indicate which medical devices they used and rate how well they got along with these devices and the software. Data presentation and statistical analysis were conducted in the same manner as for the data of the initial questionnaire (continuous variables: medians, IQRs, and Mann-Whitney *U* test; categorical variables: numbers, percentages, and Fisher exact test; 2-sided statistical tests; α=.05; Python version 3.9.7). The protocols ended with questions regarding the interaction with the GPs and how the residents felt about the medical care during the televisits. They also contained some open-ended questions for providing personal detailed responses. These data are not presented in this paper but can also be found in Multimedia Appendix 2.

Steering Committee and Systematic Analysis of the First Implementation Phase

An interdisciplinary steering committee monitored the entire implementation process. It consisted of members from clinical and change research fields (n=3 physicians doing clinical research and n=2 researchers in CM), a health insurance representative (AOK Rheinland/Hamburg, Düsseldorf, Germany), NH and nurse managers of the participating NHs (n=3), and technical developers from the telemedical system manufacturer (n=2). All authors were part of the steering committee. The steering committee conducted the requirement analysis and organized and developed all forms of training and information material for the nursing staff, such as the hands-on training, the e-learning classes, standard operating procedures for specific presentations, and pocket cards for the use of the medical devices. As the nurses in the NHs reported directly to the senior nurses of their NHs, they were indirectly represented in this committee. Monthly meetings were held throughout the follow-up period to discuss the ongoing process and challenges encountered. If the challenges could not be resolved immediately, specific committee members were assigned to elaborate possible control measures and action plans, which were then presented and discussed in subsequent meetings. The challenges and the resulting actions are presented descriptively. The figures describing this process were created using Inkscape (version 1.3, Free Software Foundation, Inc) and based on free images from Freepik [39] designed by the authors Freepik, Slidesgo (Freepik Company SL), and stories.

Qualitative Interviews

The COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines were used to present the design and results of the qualitative interviews [40]. The COREQ checklist can be found in Multimedia Appendix 3 [40]. From March 2023 to June 2023, a semistructured interview study was conducted with nurses directly involved in the care of the residents (n=5 in NH 1 and n=3 in NH 2) and with senior nurses with additional administrative roles during the implementation of the televisits (n=1 in NH 1 and n=2 in NH 2). These senior nurses had all been part of the steering committee during the implementation process. The interview guide (Multimedia Appendix 4) was developed by TM, a physician and clinical researcher, and checked for consistency and missing questions by HG, a CM expert. The participants were selected through convenience sampling. The nurse managers proposed interview participation to all nurses who had performed televisits. The voluntary participants then received appointments for interviews via videoconferencing. The interviews took place in a dedicated room in the NHs where the nurses were alone and not interrupted during the interview. Before starting the interview, all interview partners were informed about the aim of the interview, which was to collect the individual perceptions and experiences related to the process of implementing televisits in their NH. All interviews were conducted by TM. While the senior nurses with additional administrative roles were known to TM before the interview, there was no previous relationship with the other interviewed nurses. The participants were also informed about TM's background and that this study on televisit implementation was part of his research for gaining his degree as Doctor of

Medicine. They were also informed about his role in the steering committee, where he provided scientific guidance and assistance. The participants received information and gave informed consent for the interviews.

Most of the interview sections were dedicated to evaluating expectations, experiences, and perspectives regarding televisits as well as assessing the impact of their implementation on the nursing practice. These inquiries were all presented as open-ended questions. Another part focused on the addressed challenges and control measures adopted throughout the implementation process. To facilitate focused and structured responses, the nurses were asked to comment freely on predefined statements regarding various aspects of the implementation process within the study period.

The interviews were conducted once without follow-up or subsequent interviews. All the interviews were held in German, visually recorded, transcribed, and analyzed using thematic analysis. No field notes were made during the interviews or when reviewing the interviews. The transcripts were not returned to the participants for comments. As most of the questions directly evoked specific aspects of the implementation process, such as the nurses' expectations for televisits (asked as follows: "What expectations did you have regarding telemedicine and televisits [note: before the implementation process]?"), the questions themselves predefined the main themes. The coding was done manually within different columns in Microsoft Excel (Microsoft Corp). The responses of the interview partners were divided into sections with different ideas, each collected in separate rows. In a second step, inductive coding was done by defining labels created based on the data. These were then regrouped into categories based on recurring patterns. The labels and the themes were translated into English. To present the data, the different categories under each main theme were condensed into key points or brief sentences.

Follow-Up Questionnaire

In June 2023, a follow-up questionnaire (Multimedia Appendix 5) was distributed via a web-based survey tool (UmfrageOnline; enuvo GmbH) to all the nursing staff in NH 1, in which long-term implementation of televisits had been achieved. For comparing pre- and postimplementation results, nurses were tasked with evaluating the time spent on televisits and the impact of implementing televisits on residents' medical care, mirroring the approach used in the initial questionnaire. In multiple-choice questions, the nurses also reported the impact on nursing practice. Several other aspects, such as the interaction with the GP, the usability of the telemedical system, and the potential of televisits with physicians from medical specialties other than family medicine, were assessed. Only the main results are presented in this paper.

Ethical Considerations

This study was approved by the ethics committee at the Faculty of Medicine of the Rheinisch-Westfälische Technische Hochschule Aachen (EK 23-178).

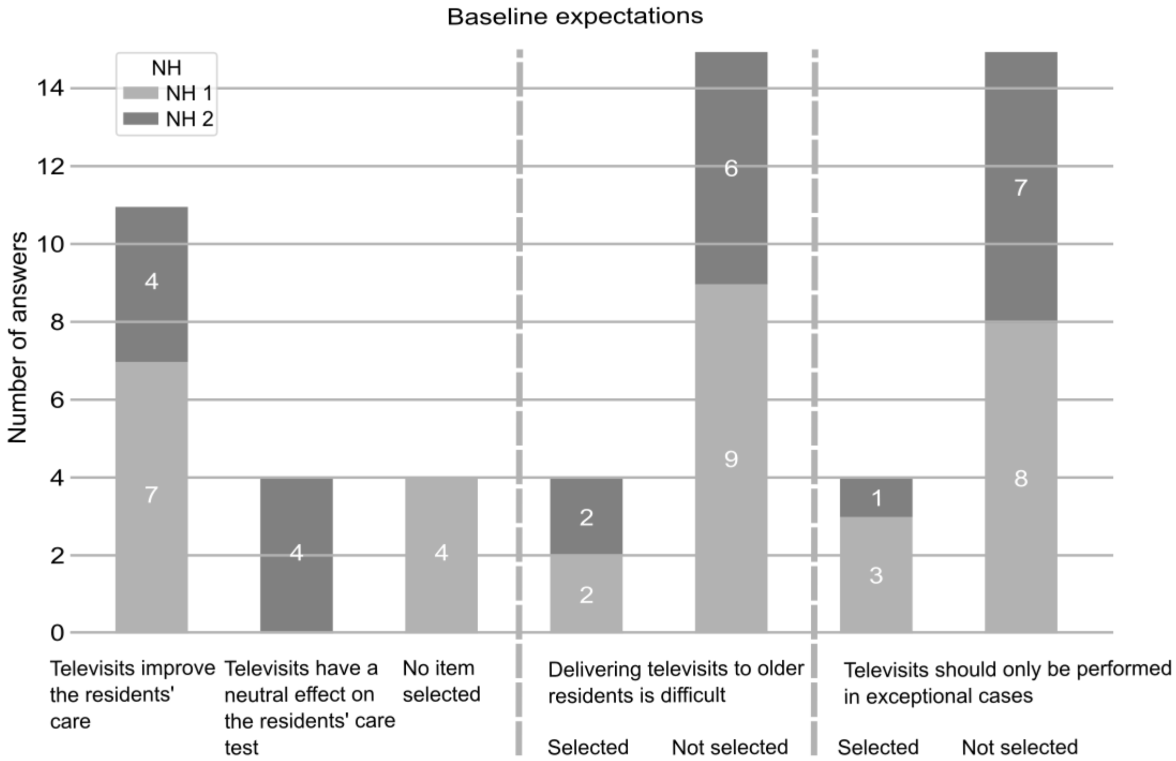
Results

Questionnaire on Baseline Expectations and Competencies

Before the implementation of televisits, nurses rated both their computer competencies and their clinical skills in taking vital parameters and examining a resident using medical diagnostic devices as good, with slightly better levels in NH 2 (computer competencies: median 2.0, IQR 2.0-3.0, and n=11 in NH 1 vs median 1.5, IQR 1.0-2.0, and n=8 in NH 2, *P*=.06; diagnostic devices: median 2.0, IQR 2.0-2.0, and n=11 in NH 1 vs median 1.5, IQR 1.0-2.0, and n=8 in NH 2, *P*=.10).

With regard to baseline expectations, slightly more than half (7/11, 64% of respondents in NH 1 and 4/8, 50% of respondents in NH 2; *P*=.66) of the nurses expected televisits to improve the residents' care, 4 nurses expected the positive and negative effects of televisits to be equal (0/11, 0% in NH 1 and 4/8, 50% in NH 2; *P*=.02), and 20% of the total nurses (4/11 in NH1 and 0/8, 0% in NH2, *P*=.1) agreed with neither of these 2 statements (Figure 3). In total, 4 nurses (3/11, 27% in NH 1 and 1/8, 13% in NH 2; *P*=.60) declared that televisits should only be performed in exceptional cases (see the raw data in Multimedia Appendix 2), 1 (25%) of whom expected that delivering televisits to older residents would be difficult and 2 (50%) of whom did not expect to see positive effects from televisits on the residents' care (Figure 3). The effect of implemented televisits on the nursing workload was estimated to be neutral by the vast majority in both NHs (9/11, 82% in NH 1 and 6/8, 75% in NH 2; *P*>.99) and to be time saving or time consuming by 3 (1/11, 9% in NH 1 and 2/8, 25% in NH 2) and 1 (1/11, 9% in NH 1 and 0/8, 0% in NH 2) respondents, respectively, with no significant differences between the NHs (*P*=.55 and *P*>.99, respectively).

Figure 3. Baseline expectations of the nurses as reported in the initial questionnaire; data presented for n=11 nurses in nursing home (NH) 1 and n=8 nurses in NH 2.



The initial training sessions on the diagnostic devices were rated as very good to good, and the software instructions were rated as good to satisfactory.

Televisit Documentation Protocols

A total of 30 televisits in NH 1 and 19 televisits in NH 2 performed between May 2020 and January 2021 were documented by 10 and 6 nurses, respectively, averaging 3.00 and 3.16 televisits per nurse, respectively. Of the total of 49 televisits, 36 (73%; 23/30, 77% in NH 1 and 13/19, 68% in NH 2; *P*=.53) were used for planned routine assessment. In 13 cases (7/30, 23% in NH 1 and 6/19, 32% in NH 2; *P*=.53), the televisits were scheduled at short notice for urgent assessments of residents who had acute medical presentations and issues. In NH 2, all the medical devices provided by the telemedical system were systematically used in every single televisit. In NH 1, the televisits included the use of 1 medical device in 50% (15/30) of cases. In 30% (9/30) of cases, the system was used for videoconferencing without further use of diagnostic devices. In total, 2 or 3 medical devices were only used in 13% (4/30) and 7% (2/30) of televisits, respectively. The blood pressure meter was the PoC device used most often for televisits (16 times), followed by the electronic stethoscope (8 times) and the 1-canal ECG (3 times; Table 1). During these first televisits, the nurses rated their competencies in handling the software and the medical devices as good (Table 2). In an open-ended question asking for possible improvements, they mentioned the need for further training in half (8/16, 50%) of the answers, followed by technological (6/16, 37%) and organizational (2/16, 13%; Multimedia Appendix 6) issues.

Table 1. Use of point-of-care (PoC) medical devices in nursing home (NH) 1 within the initial testing and familiarization period. Data presented for a subset of n=21 televisits where one or multiple PoC devices were used. In 9 additional televisits documented in NH 1, no PoC devices were used. The data for NH 2, where measurements were systematically taken using all the PoC devices in every televisit, are not presented (n=19).

Name or number of medical devices	Uses, n (%)
Medical device	
BP[a] meter	16 (53)
Blood glucose meter	2 (7)
1-canal ECG[b]	3 (10)
Electronic stethoscope	8 (27)
Number of devices	
No diagnostic devices	9 (30)
1 device	15 (50)
2 devices	4 (13)
3 devices	2 (7)

[a] BP: blood pressure.

[b] ECG: electrocardiogram.

Table 2. Self-reported competencies in handling the telemedical software and the point-of-care medical devices as assessed by the nurses themselves. *P* values are given for the Mann-Whitney U test comparing the results in nursing homes (NHs) 1 and 2. Scale from 1.0 to 6.0, with 1.0 corresponding to very good and 6.0 to deficient.

Point-of-care device and population	Number of ratings, n	Values, median (IQR)	*P* value
Camera			
NH 1	20	1.0 (1.0-2.0)	—[a]
NH 2	19	2.0 (2.0-2.0)	.02
Total	39	2.0 (1.0-2.0)	—
Blood pressure meter			
NH 1	14	1.0 (1.0-2.0)	—
NH 2	19	2.0 (1.0-2.0)	.73
Total	33	2.0 (1.0-2.0)	—
Blood glucose meter			
NH 1	1	1.0 (1.0-1.0)	—
NH 2	19	2.0 (1.0-2.0)	.31
Total	20	2.0 (1.0-2.0)	—
1-canal ECG[b]			
NH 1	3	2.0 (1.5-2.5)	—
NH 2	19	2.0 (1.0-2.0)	.47
Total	22	2.0 (1.0-2.0)	—
Electronic stethoscope			
NH 1	8	2.0 (1.75-3.0)	—
NH 2	19	2.0 (1.0-2.0)	.09
Total	27	2.0 (1.0-2.0)	—
Software			
NH 1	29	2.0 (1.0-3.0)	—
NH 2	19	2.0 (1.0-2.0)	.13
Total	48	2.0 (1.0-2.0)	—

[a] Not applicable.

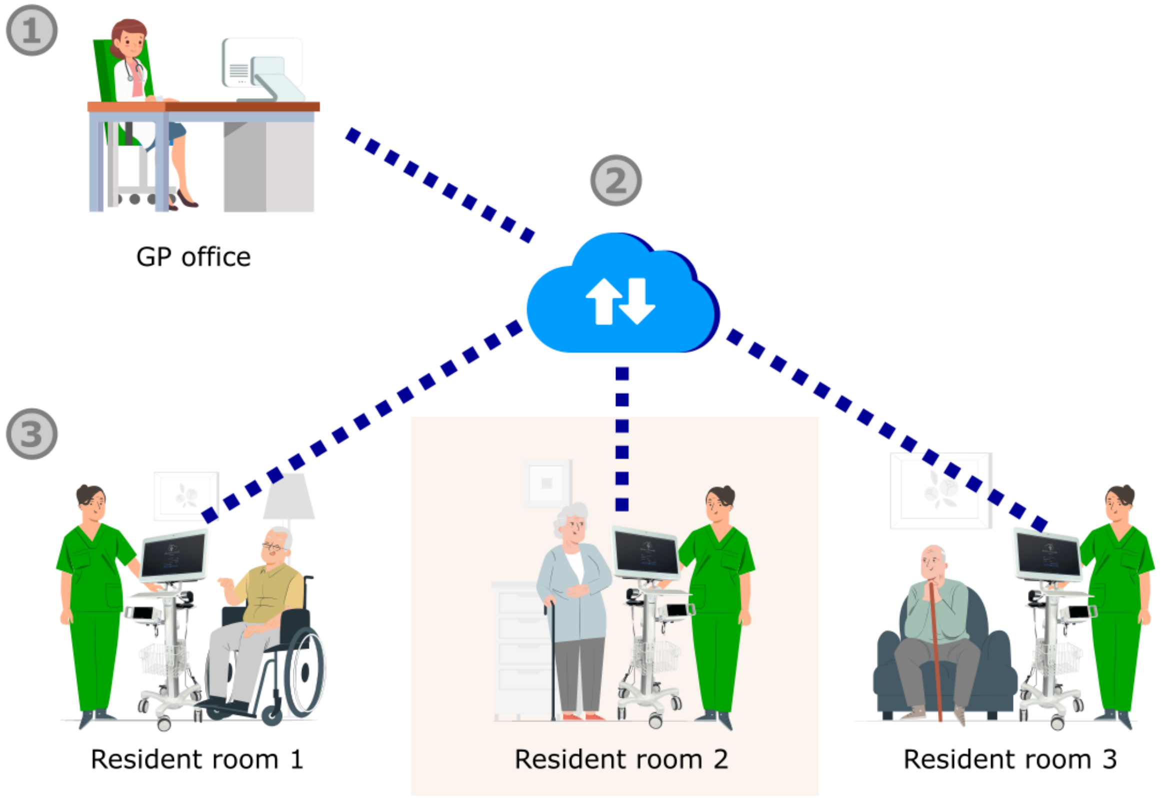
[b] ECG: electrocardiogram.

Systematic Analysis of the First Implementation Phase

Initial Organization of Televisits

In the first phase of implementation, televisits were organized in the same way as on-site home visits, where a physician sees several residents in an NH while moving between the different residents' rooms. The remote physician working in the GP office connected via the telemedical system to a nurse in the NH standing next to a resident to be consulted. The televisits had been synchronous at the beginning—thus, the GP in the office as well as the nurse and the resident in the NH both connected to the telemedical interface at the same time and no previous assessment of the resident such as taking of the vital parameters had been conducted beforehand. When the GP requested measurements, the nurses used the medical devices for taking vital signs during the ongoing televisits. Meanwhile, the physician connected to the telemedical system in the GP office via internet waited until completion before deciding which steps to take next. When one televisit had been completed, the nurse on-site moved the telemedical device (with the physician connected via internet) from one resident's room to another. During these transfer times, the GP also waited. We called this modality *synchronous televisits in the modality of web-based home visits* (Figure 4). During the first implementation period, the issues evoked by the NHs and addressed by the steering committee essentially concerned signal stability, specific software features, and the use of the medical devices. Issues on the side of the GP such as the billing of telemedical visits were also addressed. Televisits were performed regularly in both NHs until the easing of lockdown restrictions in Germany in June 2021.

Figure 4. Synchronous televisits in the modality of web-based home visits by a remote general practitioner (GP) in a GP office (1) connected via a telemedical system (2) with a nurse in the nursing home next to a resident (3).



Descriptive Presentation of Encountered Challenges and Adopted Control Measures

Health Care Context at the Time of the Systematic Analysis

When the German health care system and society were in transition between the pandemic and the postpandemic situation, the steering committee systematically analyzed in August 2021 the experiences of the first implementation phase. At that point, the last German COVID-19 restrictions were over, and normal home visits were possible again. Resistance to change was rising in the HCPs, who reported a lot of challenges and issues. Three main barriers to long-term adoption were identified: (1) conflicting workflows between the NHs and the GP offices, (2) the lack of time efficiency of the televisits, and (3) perceived uncertainty in using the technology among the nursing staff.

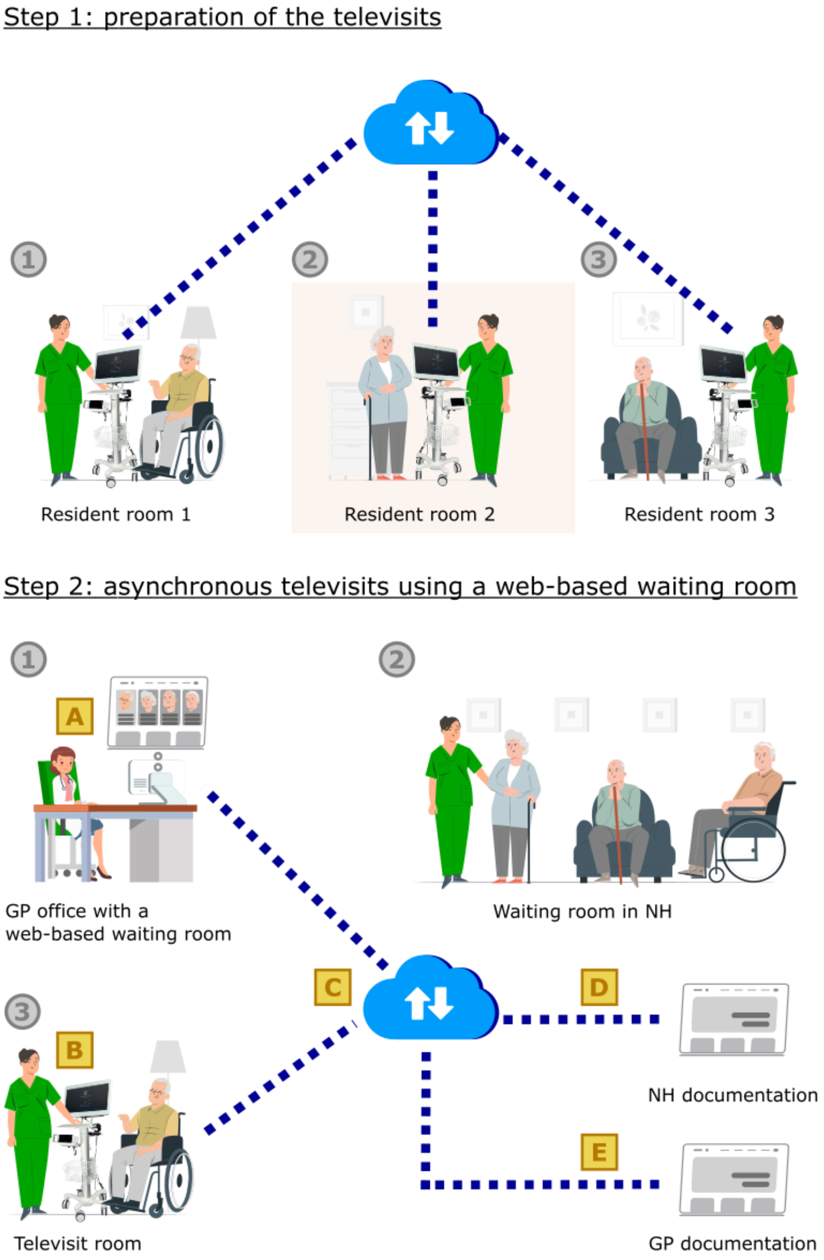
Conflicting Workflows

The daily routines and workflows were different in the NHs and in the GP offices. Finding suitable moments for televisits was difficult. For example, noon was a time when there were no consultations in the GP office, and thus, it was ideal for televisits from the GP's perspective. However, in the NHs, all the staff were busy serving and delivering lunch. Initially, televisits were scheduled at varying times every week, resulting not in the desired flexibility but in organizational stress and discomfort. This was addressed by agreeing on fixed weekly time slots for the routine televisits. With regard to unplanned televisits in the case of acute medical presentations, the workflows were also initially conflicting. The NHs did not bundle calls to the GP office. As a consequence, the workflow of the GP office was interrupted multiple times a day when 2 or more visits had to be planned. During the consultation hours in the GP office, phone calls were particularly disruptive because the GP was seeing other patients at that moment. To avoid disruption due to phone calls, the GP office and the NH grouped requests. Phone calls were completely abandoned except for extreme emergencies. The NH sent a fax containing a list with the residents proposed for consultations along with the reasons for consultation and some contextual information. On the basis of this information, the GP then responded with a fax indicating the vital parameters that should be assessed before the actual consultation (the organization of televisits was changed for an asynchronous modality with vital parameters being taken beforehand; see the following section).

Lack of Time Efficiency of the Televisits

The televisits, highly valued during the pandemic phase, were perceived as overly time consuming compared to normal home visits when the latter were regularly possible again. As mentioned previously, the workflows were interrupted during the transit times and when vital signs were taken. This was perceived by the GPs as a significant loss of time they could not spend with other patients in their offices. For the GPs, the time spent on televisits needed to be reduced so that the televisits were a real benefit to them compared to on-site home visits. As these challenges were mainly linked to the synchronous modality of televisits, the organization was completely changed for the modality of *asynchronous televisits using a web-based waiting room* (Figure 5). In this approach, the vital signs of the residents to be seen are taken beforehand by the nurses on-site. Then, with all diagnostic measures completed and documented, the televisits are performed at a scheduled time. The residents to be consulted physically wait in a waiting room in the NH. They also appear in a web-based waiting room in the GP's telemedical interface. The televisits take place in a dedicated room where the telemedical cart is used while stationary. Instead of moving the telemedical cart, the residents enter the televisit room one at a time as they would a consultation room in a GP office (Figure 5). This greatly improved the time efficiency of the televisits. To avoid losing time spent with doubled-up documentation, interfaces among the telemedical system, the GP, and the NH documentation systems were created. This made it possible to directly export the medical documentation from the TeleDoc software to the other programs.

Figure 5. Asynchronous televisits using a web-based waiting room. Step 1: taking of the vital parameters of the residents to be seen. Step 2: asynchronous televisits at a scheduled time using a web-based waiting room for the general practitioner (GP; 1), a physical waiting room in the nursing home (NH; 2), and a defined televisit room (3). The control actions were the creation of the web-based waiting room (A), training of the nursing staff (B), allowing for asynchronous documentation in the software (C), and interfaces to the existing programs (D and E).



Perceived Uncertainty in Using the Technology Among the Nursing Staff

Moreover, the nursing staff also requested more intense training. To this end, NH 1 and the cooperating GP office jointly hosted a medical student for 4 weeks, during which the student supported the training of the nursing staff. He trained nurses in the use of the PoC devices, helped prepare televisits, and accompanied them during these visits. During these 4 weeks, daily televisits were performed.

Finally, long-term implementation was reached in NH 1, with regular, most of the time weekly, televisits between the GP and

NH 1 from August 2021 until the end of follow-up in March 2023. A total of 163 televisits were performed during this period of 20 months. The televisits did not replace the preceding rhythm of on-site home visits but were performed in addition. In NH 2, further efforts to implement televisits after the COVID-19 period remained unsuccessful throughout the follow-up period.

Interview Findings

Selection and Characteristics of Interview Participants

In both NHs, it was planned that the first 5 nurses who volunteered would be included. In NH 2, many nurses considered their experience with telemedicine to be too little and too far away, so no one else wanted to participate after the first 3 nurses were recruited. As NH 2 did not achieve long-term implementation and had not regularly performed televisits since August 2021, additional interviews were unlikely to reveal new themes, insights, or perspectives. Thus, data saturation had already been reached after these 3 interviews. The interviewed nurses were predominantly male (5/8, 62%), with a median age of 26 years. The youngest and oldest participants were aged 26 and 63 years, respectively. The nurse managers were all male (3/3, 100%), with the youngest and oldest participants being aged 30 and 56 years, respectively. The interviews took, on average, 33 minutes for the nurses and 40 minutes for the nurse managers.

Interview Findings Concerning the Implementation Phases

In the follow-up interviews, the nurses and nurse managers stated that their main expectation before the implementation of televisits was to enhance residents' access to physicians, particularly beyond the regular GP consultation hours. The nurse managers further expected a decrease in psychological distress in their staff, along with enhanced legal protection through telemedical expertise during emergency situations with acute health-related deteriorations in their residents.

As regards the subsequent implementation, the interview findings are consistent with the analysis of the steering committee. Nurses in both NHs agreed that televisits were seen as useful during the COVID-19 pandemic and had offered manifest benefits for the residents. Televisits addressed the specific need for thorough medical assessment in the context of the then current contact restrictions. However, the benefits of the televisits seemed less identifiable for most of the nurses of both NHs after the end of the contact restrictions given that normal home visits were possible again and because the telemedical system did not provide the residents with better access to the health care system in terms of other medical specialties or access to physicians outside of the normal office hours. In total, 25% (2/8) of the nurses explicitly saw a benefit of televisits with the GP for residents with acute medical presentations outside the hours of the on-site home visits.

Nurses in NH 1, where long-term implementation was achieved, all agreed that "long-term benefits of televisits became apparent only after many repeated adjustments and training sessions." The nurses stated that the system became more user-friendly and easier to handle. Repeated use led to more routine use and more self-confidence in the televisits. For this, the repeated training and accompaniment in the televisits were very important for the nurses.

When asked about the factors that had contributed to the success of long-term implementation, the nurses underlined the adoption of asynchronous visits and the transformation of the workflows to a modality with a *web-based waiting room*. They also mentioned the crucial role of the nurse manager's and the GP's personal commitment in ensuring the long-term implementation of televisits. The fact that there was a clear benefit for the residents also added to the motivation.

Interview Findings Regarding the Change in Nursing Practice Due to Televisits

The 3 interviewed NH and nurse managers and 88% (7/8) of the interviewed nurses retrospectively evaluated the overall experience as positive. However, one nurse felt that the televisits were too impersonal and described difficulties in handling the telemedical system and in performing televisits for people with dementia. This nurse preferred in-person home visits.

The nurse managers stated that televisits reduced the psychological distress experienced by their nursing staff, improved the clinical skills of their employees, and led to greater employee satisfaction during the COVID-19 pandemic (in both NHs) and beyond (for NH 1 in achieving long-term implementation). The interviewed nurses mostly acknowledged the same effect on their clinical skills, but most denied psychological distress and insecurities in their work environment. While most of the nurses stated that asynchronous televisits compared to home visits translated to substantial time savings for the GP, the opinions varied regarding the effect on the nursing workload. Televisits were rather perceived as additional workload when performed for routine visits. In the case of unscheduled visits with GPs, some nurses praised the televisits as time saving, whereas other nurses considered telephone calls to be the faster solution. With regard to consultations outside GP hours, the nurses consistently declared that televisits would allow for a faster medical assessment and reduce nursing workload compared to calling the in-person out-of-hours GP service, for which a considerable waiting time is usual. On top of the organizational and technical challenges regarding the cooperation between the GP offices and the NHs, the nurses described personal challenges in adapting to change, using the technology, and developing effective skills for video communication. Some nurses saw positive effects of televisits on the nurses' self-image and with regard to legal certainty. Training in simulated televisits and support from nursing peers in a tandem approach were considered adequate to offer continuous training after the initial familiarization phase (Textbox 1).

Textbox 1. Summarized interview findings regarding relevant topics raised during the implementation process.

Psychological distress in situations with acute deterioration of a resident’s health status (need for prompt medical assessment)

- A total of 62% (5/8) of the nurses denied experiencing psychological distress in these situations.
- A total of 38% (3/8) of the nurses described psychological distress in these situations.
- Access to televisits can provide nurses with emotional security and reduce psychological stress.

Clinical skills of the nurses

- Most nurses saw improvements in their clinical skills, mainly due to more diagnostic equipment being available in the nursing home (NH), increased awareness of recognizing changes in residents’ conditions, and a more active participation in the residents’ medical care.
- Nurses reported higher confidence in the interactions with physicians since the implementation of televisits.

Nursing workload

- Asynchronous televisits saved time for the general practitioner (GP).
- Routine televisits seemed to be associated with a slight increase in workload.
- For unscheduled visits, some nurses considered the televisits to be time saving. However, for other nurses, telephone calls seemed to be faster.
- Televisits can be time saving for the nursing staff provided that a telemedical system is always available on standby (no loss of time due to booting), the nurses are experienced in televisits, and a physician is quickly available (direct medical assessment).
- A telemedical service with 24/7 access to a GP was seen as an advantage over the current out-of-hours GP service and would save time for the NHs (reduced waiting time—obsolete telephone waiting line and transfer time of the physician on duty).

Challenges in performing televisits at the beginning

- Technical challenges (software bugs, usability, and user experience aspects) and change management (for generating willingness in the nursing staff and the physicians) were seen as challenging at the beginning.
- Collaboration with the physicians, especially in scheduling televisits, and ensuring adequate staffing and support for the televisits were identified as the biggest organizational challenges.

Communication in a televisit between the nurse, the resident, and the physician

- It was completely unproblematic for one nurse and difficult and uncomfortable in all televisits for another.
- Most nurses reported challenges in this new setting at the beginning.
- Acoustic problems made televisits difficult for residents with hearing impairments, particularly those who partly relied on lipreading.
- By ensuring a calm and friendly environment and facilitating communication, televisits were possible for residents with dementia.
- Communication is likely to be easier with the next generations of residents in NHs who are already more familiar with modern communication technology.

Professional identity and self-image of the nurses

- Nurses understood televisits as a logical and upcoming innovation arriving in the nursing profession in the context of general progress in technology and digitalization.
- However, they did not think that televisits elevate the nursing profession.
- One nurse felt that his self-image in the interaction with the physician improved by experiencing close cooperation and teamwork in televisits.

Medico-legal aspects of the telemedical documentation

- Main advantage: written prescriptions and medication schedules established by the physician and serving as legal documents are available faster in the NHs.
- However, nurses did not consider the legal certainty that a televisit provides to be higher than that of telephone calls and their subsequent documentation.

Cooperation between GPs and NHs

- In both NHs, the cooperation with the physicians was perceived as already good or very good before the introduction of televisits.
- The implementation of televisits did not change the cooperation from the perspective of the nurses.

Training

- Training based on a tandem approach, where more experienced colleagues train less experienced colleagues in televisits, was considered useful. Training in simulated televisits with the opportunity to review the use of the technology hands-on meets the needs of the nurses. This also applied for training in the clinical aspects of resident care.

Follow-Up Questionnaire: Time Expenditure and Change in Nursing Practice Due to the Televisits

The follow-up questionnaire showed that most of the responding nurses performed televisits ≤5 times throughout the study period and only some nurses did so >10 times (>10 times: 4/19, 21%; 5-10 times: 4/19, 21%; 1-5 times: 11/19, 58%; median 1-5 times). Half (9/18, 50%) of the nurses agreed with the statement that televisits were associated with an additional burden related to uncertainty in using the new technology. The nurses rated the time expenditure for performing televisits significantly higher at the end of the follow-up than they did before starting the first televisits. At both timepoints, only very few nurses considered the televisits to be time saving for them (1/11, 9% before implementation, vs 3/18, 17% after implementation; *P*>.99). While the nurses did not expect the televisits to be time consuming in the initial assessment (1/11, 9%), the assessment was significantly different after the implementation process, where the vast majority of the nurses rated them as time consuming (12/18, 67%; *P*=.006). The relative percentage of nurses expecting a neutral effect on the nursing workload was accordingly lower after implementation (3/18, 16%) than before (9/11, 82%; *P*=.001). Compared to the assessment done before the intervention, the evaluation of the impact of televisits on the care of the residents remained unchanged, with half (10/19, 53%) of the nurses estimating a positive effect, one-third (6/19, 31%) estimating a neutral effect, only 1 person estimating a negative effect (1/19, 5%), and two persons with missing answers (2/19, 11%; *P*>.99 for the positive effect and *P*=.71 for the neutral effect when compared to the preimplementation assessment; see the *Evaluation of the Initial Testing and Familiarization Period Up Until January 2021* section). Most nurses fully or generally agreed that televisits were entirely suitable for assessing the residents and for initiating treatment decisions in the case of GP-related medical queries (full approval: 5/19, 26%; predominant approval: 11/19, 58%; mild disagreement: 2/19, 11%; full disagreement: n=0; 1/19, 5% missing answers). As in the interviews, the quantitative evaluation also showed further positive effects of the televisits in addition to improving the clinical and technological competencies of the nurses. These include a sense of empowered participation in the implementation process for about every fourth responding nurse (5/18, 28%), higher professional recognition from the GP and the residents for approximately every third responding nurse (each 7/18, 39%), and a decrease in psychological distress and greater legal certainty for more than half of the respondents (10/18, 56%; Multimedia Appendix 7).

Discussion

Principal Findings

Key Drivers for Successful Implementation

This study evaluated the implementation of televisits during the COVID-19 crisis in 2 NHs with a follow-up in the postpandemic setting. While both NHs achieved short-term implementation within the pandemic phase, only 1 NH attained long-term implementation. This was achieved in an action-based approach after control measures had been implemented following an analysis of the barriers to further implementation. Adapting the telemedical system and changing the workflows especially to asynchronous televisits with a web-based waiting room were key drivers for successful implementation.

There was no difference in the initial evaluation between the 2 NHs explaining why long-term implementation was only achieved in NH 1. It is noteworthy that, during the first implementation phase, NH 1 adopted a more pragmatic resident-centered approach using only the PoC devices required for the individual patients as shown in the documented televisits. In contrast, NH 2 systematically used all the devices for training purposes in their initial televisits. Moreover, there is a common perception that older nursing staff may possess lower levels of digital literacy, which in turn might render them more resistant to the adoption of new technologies. Interestingly, the staff in NH 1 was older than that in NH 2. Several factors may explain why, contrary to this perception, long-term implementation was achieved in NH 1 with the older nurses.

First, NH 2 simultaneously engaged in a second change process after the end of the COVID-19 pandemic when it changed its NH documentation software in November 2021. At this point, the nursing staff of NH 2 were extremely challenged by adapting to the new software. This competing project was more prioritized than continuing to implement televisits. Second, the interviews revealed that the nurses felt that the personal engagement of the nurse manager and the GP was very important for achieving long-term implementation. This barrier is consistent with findings in the literature indicating that gaining leadership and clarifying roles are important for driving implementation processes [32,34]. Competencies and criteria for leaders in implementing digital health care should be clearly defined in the future to enhance the implementation of telemedicine and digital health [41,42]. Third, NH 1 developed a specific training strategy with the medical student who helped train the nursing staff for 4 weeks. This also contributed greatly to the nurses' compliance and subsequent implementation.

Importance of Considering the User Perspective

The initial vision of how the televisits would be delivered differed significantly from how they were finally integrated by the HCPs to achieve long-term adoption. At the beginning of the transformation process, everybody involved (developers, GPs, nurse managers, and nurses) envisioned a modality that mirrored the workflow of a normal GP home visit (*synchronous televisits in the modality of web-based home visits*). However, another modality, that of “asynchronous televisits using a web-based waiting room,” proved to be more suitable and efficient for routine consultations. The conceptual shift from web-based home visits to the web-based waiting room led to profound organizational modifications and practice changes. Both the participating nurse managers and the developers of the telemedical system stated that they could not have anticipated the web-based waiting room modality before starting the implementation. This highlights the importance of considering the users’ perspective in all phases of development of eHealth solutions, including once a new system is made market available. This approach of broadly involving “a wide range of stakeholders in the entire development process, including especially end-users—patients and physicians” is referred to as “co-creation” [43]. In this study, the HCPs acted as cocreators for developing the asynchronous televisits using a web-based waiting room. They reported their in-use experience with the telemedical system to the steering committee, which triggered discussion on change within the committee. The telemedical system and the workflows were then adapted to allow for asynchronous televisits. This resulted in an improved telemedical system and, thus, a more valuable product. As it provides greater usability for the HCPs, their acceptance of the system and the implementation process increases. The CM approach in this study allowed for this interaction between end users and developers and additionally provided an organized platform for identifying ongoing challenges and steering the transformation process in the right direction. Imposing overly rigid application frameworks for new digital innovation in health care may be a major contributor to the failure of health innovations to be transferred into routine care.

Change in Nursing Practice Due to Televisits

In NH 1, the nurses were positive about the long-term implementation and acknowledged improvements in their clinical skills and technological competencies. In addition, the televisits improved their self-image and their recognition as nurses. These positive results were found in the interviews and confirmed in the follow-up questionnaire. When asked directly in the interviews, only a minority of the nurses reported experiencing physical distress when residents show acute medical presentations requiring prompt medical assessment. However, most agreed in the quantitative analysis that access to televisits was perceived as relieving and reducing emotional distress. The lack of consistency here is probably due to response bias, with nurses responding more honestly in an anonymous questionnaire than in a face-to-face interview.

Televisits were perceived as time saving for the GP but were associated with an additional technological burden and a slight increase in time spent by the nursing staff. The latter was not expected by the nurses when they were assessed before the implementation process. Interestingly, this observation is in line with those of other studies [44-46], which also show that televisits in NHs are associated with an increased workload for the nursing staff. Although most nurses in this study expected a neutral effect on workload rather than an increase, the staff in NH 1 adapted to televisits even though they increased their workload. This is a good indication that the other effects are seen as positive and valuable.

The taking of vital parameters using medical diagnostic devices or recording on an ECG are not among the normal tasks of a geriatric nurse in Germany. This means that there is unlikely to be an increase in the overall workload but rather a shift from GP activity to tasks performed by geriatric nurses. The GPs can use the time they save for other patients. This can be beneficial in the context of a shortage of GPs, especially in rural areas. Given the overall positive effects, health insurers and public health managers should consider providing financial support for the implementation of televisits in NHs. In particular, the initial setup and training should be financially supported to maintain high motivation for further implementation.

This work logically builds on and complements the group’s previous research, which demonstrated the technical feasibility and usefulness of integrating PoC diagnostic devices into video consultations for the assessment of older adult patients in NHs [38]. This study shows that there is no need to take all the vital parameters of the residents in every consultation. In more than three-quarters of the televisits (24/30, 80%), no or one single measurement was sufficient. Access to the right diagnostic device at the right time for the right resident with the right physician connected via telemedicine is essential for personalized care and to avoid unnecessary HAs. In line with the idea of effective workforce management, it does not make sense to ask nurses to take all the vital parameters but rather to decide in advance (ie, when planning the televisit) which vital parameters should be taken.

Limitations and Future Research

This study has certain limitations for the interpretation and generalizability of the results. The implementation of televisits in NHs was only evaluated in 2 NHs, and 1 failed to achieve long-term implementation. Therefore, generalization to other NHs may depend strongly on their individual organization and health care environment. However, this study shows that an action-based CM approach piloted by an interdisciplinary steering committee can allow for successful implementation. Future studies in the field of IS may add valuable insights to determine more objective criteria for the success of telemedical implementation efforts. Another major limitation is the relatively small number of televisits in the documentation protocols. However, this was sufficient to show that it is not useful to systematically take measurements using all diagnostic devices integrated into the system. This study was not designed to assess how the residents felt about being involved in promoting telecare. However, this is an important research question that should be evaluated in other studies. Furthermore, this study investigated the implementation of one technology—televisits—in NHs. Other digital technologies such as NH managing software, wearables, and home automation systems may also improve workforce management, enhance the quality of care, and provide a better living environment in NHs. As some authors believe that all these technologies are likely to be integrated into so-called “smart

NHs," possibly replacing conventional NHs in the decades to come [47-49], the implementation processes of these technologies should be specifically investigated as generalizability from this study is very limited.

Future research should focus on training and staffing concepts for nursing. First, performing televisits is a new approach to care and needs specific education. While the need for specific curricular training in telemedicine has already been identified for medical students [50-53], it should also be integrated into nursing education. Second, a notable finding in the follow-up questionnaire was that most televisits were conducted by a small number of nurses with some performing a significant number whereas most only conducted a few (>10 televisits: 4/19, 21%; <10 televisits: 15/19, 79%), Therefore, future research should explore whether certain nurses should specialize in televisits within a nursing facility whereas less qualified nurses or nursing assistants could focus on other nursing tasks. Maybe this would lead to workforce optimization. In theory, telemedically advanced nurses could also use telemedicine for telenursing, that is, for advising and supporting nursing assistants via telemedical solutions.

Conclusions

An action-oriented CM approach made it possible to achieve long-term implementation of televisits in NH 1. Abandoning synchronous televisits in favor of asynchronous ones improved the workflows and was a critical facilitator of long-term implementation. Strong leadership, as well as sustained training of the nurses, also contributed to this success. The implementation of televisits had positive effects on the HCPs. They experienced an improvement in their clinical skills and a higher professional recognition. According to the nurse managers, their psychological distress also decreased. Performing televisits did not save time for the nursing staff in comparison to scheduling and assisting a GP in in-person home visits. Instead, the nurses believed that televisits led to a slight increase in their time spent on organizing the assessment of the patient. CM aspects must be considered to achieve long-term implementation.

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Authors' Contributions

TM and AF conceptualized and designed the study. SV organized the initial training of the health care providers. HG and PFF provided advice on the qualitative research. AF, MC, and PFF obtained research funding. TM collected, managed, and analyzed the data. TM interpreted the findings and drafted the manuscript. All authors contributed substantially to its revision. All authors approved the published version of the manuscript. TM takes responsibility for the paper as a whole.

Conflicts of Interest

MC is the chief executive officer and cofounder of Docs in Clouds TeleCare GmbH, a company that purchases telemedical solutions including the TeleDoc system, which was used in this study. AF worked part time as chief medical officer for Docs in Clouds TeleCare GmbH until March 2023. All other authors declare that they have no other conflicts of interest.

Multimedia Appendix 1
Project diary.
[PDF File (Adobe PDF File), 1430 KB - aging_v7i1e55471_app1.pdf]

Multimedia Appendix 2
Excel (Microsoft Corp) sheet data from project diaries.
[XLSX File (Microsoft Excel File), 25 KB - aging_v7i1e55471_app2.xlsx]

Multimedia Appendix 3
COREQ (Consolidated Criteria for Reporting Qualitative Research) reporting guidelines.
[PDF File (Adobe PDF File), 186 KB - aging_v7i1e55471_app3.pdf]

Multimedia Appendix 4
Interview guide.
[PDF File (Adobe PDF File), 295 KB - aging_v7i1e55471_app4.pdf]

Multimedia Appendix 5
Follow-up questionnaire.
[PDF File (Adobe PDF File), 553 KB - aging_v7i1e55471_app5.pdf]

Multimedia Appendix 6
Comments of the nurses regarding improvement potential for further televisits. The number of times a specific topic was mentioned is indicated in brackets.
[PDF File (Adobe PDF File), 94 KB - aging_v7i1e55471_app6.pdf]

Multimedia Appendix 7
Nurses' self-assessment of the positive effects of implementing televisits in nursing home 1. Agreement with the individual aspects shown for 18 nurses; n=1 respondent in the postevaluation period did not select an answer.
[PNG File , 83 KB - aging_v7i1e55471_app7.png]

References

1. World report on ageing and health. World Health Organization. 2015 Sep 29. URL: https://www.who.int/publications/i/item/9789241565042 [accessed 2024-05-04]
2. Kontis V, Bennett JE, Mathers CD, Li G, Foreman K, Ezzati M. Future life expectancy in 35 industrialised countries: projections with a Bayesian model ensemble. Lancet 2017 Apr 01;389(10076):1323-1335 [FREE Full text] [doi: 10.1016/S0140-6736(16)32381-9] [Medline: 28236464]
3. Harris J. Geriatric trends facing nursing with the growing aging. Crit Care Nurs Clin North Am 2019 Jun;31(2):211-224. [doi: 10.1016/j.cnc.2019.02.007] [Medline: 31047094]
4. Rothgang H, Kalwitzki T, Amsbeck H. Pflege in Deutschland im Jahr 2030 – regionale Verteilung und Herausforderungen. Bertelsmann Stiftung. 2016 Aug 4. URL: https://www.bertelsmann-stiftung.de/fileadmin/files/user_upload/Policy_LebensWK_4_2016_final.pdf [accessed 2024-05-05]
5. Bohnet-Joschko S, Valk-Draad MP, Schulte T, Groene O. Nursing home-sensitive conditions: analysis of routine health insurance data and modified Delphi analysis of potentially avoidable hospitalizations. F1000Res 2021 Dec 01;10:1223 [FREE Full text] [doi: 10.12688/f1000research.73875.2] [Medline: 35464174]
6. Morley JE. Telemedicine: coming to nursing homes in the near future. J Am Med Dir Assoc 2016 Jan;17(1):1-3. [doi: 10.1016/j.jamda.2015.10.012] [Medline: 26620072]
7. May S, Jonas K, Fehler GV, Zahn T, Heinze M, Muehlensiepen F. Challenges in current nursing home care in rural Germany and how they can be reduced by telehealth - an exploratory qualitative pre-post study. BMC Health Serv Res 2021 Sep 06;21(1):925 [FREE Full text] [doi: 10.1186/s12913-021-06950-y] [Medline: 34488746]
8. Groom LL, McCarthy MM, Stimpfel AW, Brody AA. Telemedicine and telehealth in nursing homes: an integrative review. J Am Med Dir Assoc 2021 Sep;22(9):1784-1801.e7 [FREE Full text] [doi: 10.1016/j.jamda.2021.02.037] [Medline: 33819450]
9. Huang GY, Kumar M, Liu X, Irwanto D, Zhou Y, Chirapa E, et al. Telemedicine vs face-to-face for nursing home residents with acute presentations: a noninferiority study. J Am Med Dir Assoc 2023 Oct;24(10):1471-1477. [doi: 10.1016/j.jamda.2023.05.031] [Medline: 37419143]
10. Hui E, Woo J, Hjelm M, Zhang YT, Tsui HT. Telemedicine: a pilot study in nursing home residents. Gerontology 2001;47(2):82-87 [FREE Full text] [doi: 10.1159/000052778] [Medline: 11287732]
11. Hsu MH, Chu TB, Yen JC, Chiu WT, Yeh GC, Chen TJ, et al. Development and implementation of a national telehealth project for long-term care: a preliminary study. Comput Methods Programs Biomed 2010 Mar;97(3):286-292. [doi: 10.1016/j.cmpb.2009.12.008] [Medline: 20092907]
12. Grabowski DC, O'Malley AJ. Use of telemedicine can reduce hospitalizations of nursing home residents and generate savings for medicare. Health Aff (Millwood) 2014 Feb;33(2):244-250. [doi: 10.1377/hlthaff.2013.0922] [Medline: 24493767]
13. Hex N, Tuggey J, Wright D, Malin R. Telemedicine in care homes in Airedale, Wharfedale and Craven. Clin Gov Int J 2015;20(3):146-154. [doi: 10.1108/CGIJ-07-2015-0022]
14. Shah MN, Wasserman EB, Gillespie SM, Wood NE, Wang H, Noyes K, et al. High-intensity telemedicine decreases emergency department use for ambulatory care sensitive conditions by older adult senior living community residents. J Am Med Dir Assoc 2015 Dec;16(12):1077-1081. [doi: 10.1016/j.jamda.2015.07.009] [Medline: 26293419]
15. Hofmeyer J, Leider JP, Satorius J, Tanenbaum E, Basel D, Knudson A. Implementation of telemedicine consultation to assess unplanned transfers in rural long-term care facilities, 2012-2015: a pilot study. J Am Med Dir Assoc 2016 Nov 01;17(11):1006-1010. [doi: 10.1016/j.jamda.2016.06.014] [Medline: 27477614]
16. Gillespie SM, Shah MN, Wasserman EB, Wood NE, Wang H, Noyes K, et al. Reducing emergency department utilization through engagement in telemedicine by senior living communities. Telemed J E Health 2016 Jun;22(6):489-496. [doi: 10.1089/tmj.2015.0152] [Medline: 26741194]

17. Gillespie SM, Moser AL, Gokula M, Edmondson T, Rees J, Nelson D, et al. Standards for the use of telemedicine for evaluation and management of resident change of condition in the nursing home. J Am Med Dir Assoc 2019 Feb;20(2):115-122. [doi: 10.1016/j.jamda.2018.11.022] [Medline: 30691620]
18. Gayot C, Laubarie-Mouret C, Zarca K, Mimouni M, Cardinaud N, Luce S, et al. Effectiveness and cost-effectiveness of a telemedicine programme for preventing unplanned hospitalisations of older adults living in nursing homes: the GERONTACCESS cluster randomized clinical trial. BMC Geriatr 2022 Dec 22;22(1):991 [FREE Full text] [doi: 10.1186/s12877-022-03575-6] [Medline: 36550496]
19. Valk-Draad MP, Bohnet-Joschko S. Nursing home-sensitive hospitalizations and the relevance of telemedicine: a scoping review. Int J Environ Res Public Health 2022 Oct 10;19(19):12944 [FREE Full text] [doi: 10.3390/ijerph191912944] [Medline: 36232255]
20. Lyketsos CG, Roques C, Hovanec L, Jones BN3. Telemedicine use and the reduction of psychiatric admissions from a long-term care facility. J Geriatr Psychiatry Neurol 2001;14(2):76-79. [doi: 10.1177/089198870101400206] [Medline: 11419571]
21. Low JA, Hui Jin T, Tan Lean Chin L, Agarwal N, Kim Huat G, Yeow A, et al. Cost analysis of implementing a telegeriatrics ecosystem with nursing homes: panel data analysis. Health Syst (Basingstoke) 2019 Mar 21;9(4):285-292 [FREE Full text] [doi: 10.1080/20476965.2019.1589390] [Medline: 33354321]
22. Joseph JW, Kennedy M, Nathanson LA, Wardlow L, Crowley C, Stuck A. Reducing emergency department transfers from skilled nursing facilities through an emergency physician telemedicine service. West J Emerg Med 2020 Oct 08;21(6):205-209 [FREE Full text] [doi: 10.5811/westjem.2020.7.46295] [Medline: 33207167]
23. Moullin JC, Sabater-Hernández D, Fernandez-Llimos F, Benrimoj SI. A systematic review of implementation frameworks of innovations in healthcare and resulting generic implementation framework. Health Res Policy Syst 2015 Mar 14;13:16 [FREE Full text] [doi: 10.1186/s12961-015-0005-z] [Medline: 25885055]
24. Rangachari P, Mushiana SS, Herbert K. A scoping review of applications of the Consolidated Framework for Implementation Research (CFIR) to telehealth service implementation initiatives. BMC Health Serv Res 2022 Nov 30;22(1):1450 [FREE Full text] [doi: 10.1186/s12913-022-08871-w] [Medline: 36447279]
25. Hospodková P, Berežná J, Barták M, Rogalewicz V, Severová L, Svoboda R. Change management and digital innovations in hospitals of five European countries. Healthcare (Basel) 2021 Nov 05;9(11):1508 [FREE Full text] [doi: 10.3390/healthcare9111508] [Medline: 34828554]
26. Campbell RJ. Change management in health care. Health Care Manag (Frederick) 2020;39(2):50-65. [doi: 10.1097/HCM.0000000000000290] [Medline: 32345939]
27. Harrison R, Fischer S, Walpola RL, Chauhan A, Babalola T, Mears S, et al. Where do models for change management, improvement and implementation meet? A systematic review of the applications of change management models in healthcare. J Healthc Leadersh 2021 Mar 12;13:85-108 [FREE Full text] [doi: 10.2147/JHL.S289176] [Medline: 33737854]
28. Augustsson H, Churruca K, Braithwaite J. Change and improvement 50 years in the making: a scoping review of the use of soft systems methodology in healthcare. BMC Health Serv Res 2020 Nov 23;20(1):1063 [FREE Full text] [doi: 10.1186/s12913-020-05929-5] [Medline: 33228657]
29. Meskó B. COVID-19's impact on digital health adoption: the growing gap between a technological and a cultural transformation. JMIR Hum Factors 2022 Sep 19;9(3):e38926 [FREE Full text] [doi: 10.2196/38926] [Medline: 36121692]
30. Scott Kruse C, Karem P, Shifflett K, Vegi L, Ravi K, Brooks M. Evaluating barriers to adopting telemedicine worldwide: a systematic review. J Telemed Telecare 2018 Jan;24(1):4-12 [FREE Full text] [doi: 10.1177/1357633X16674087] [Medline: 29320966]
31. Kho J, Gillespie N, Martin-Khan M. A systematic scoping review of change management practices used for telemedicine service implementations. BMC Health Serv Res 2020 Sep 01;20(1):815 [FREE Full text] [doi: 10.1186/s12913-020-05657-w] [Medline: 32873295]
32. Bauer MS, Kirchner J. Implementation science: what is it and why should I care? Psychiatry Res 2020 Jan;283:112376 [FREE Full text] [doi: 10.1016/j.psychres.2019.04.025] [Medline: 31036287]
33. Khalid A, Dong Q, Chuluunbaatar E, Haldane V, Durrani H, Wei X. Implementation science perspectives on implementing telemedicine interventions for hypertension or diabetes management: scoping review. J Med Internet Res 2023 Mar 14;25:e42134 [FREE Full text] [doi: 10.2196/42134] [Medline: 36917174]
34. Ye J, He L, Beestrum M. Implications for implementation and adoption of telehealth in developing countries: a systematic review of China's practices and experiences. NPJ Digit Med 2023 Sep 18;6(1):174 [FREE Full text] [doi: 10.1038/s41746-023-00908-6] [Medline: 37723237]
35. Lopez AM, Lam K, Thota R. Barriers and facilitators to telemedicine: can you hear me now? Am Soc Clin Oncol Educ Book 2021 Mar;41:25-36 [FREE Full text] [doi: 10.1200/EDBK_320827] [Medline: 34010056]
36. Weißenfeld MM, Goetz K, Steinhäuser J. Facilitators and barriers for the implementation of telemedicine from a local government point of view - a cross-sectional survey in Germany. BMC Health Serv Res 2021 Sep 06;21(1):919 [FREE Full text] [doi: 10.1186/s12913-021-06929-9] [Medline: 34488753]

37. Erreichbarkeit von Hausärzten: 99 Prozent brauchen mit dem Pkw längstens 10 Minuten. Deuschlandatlas. 2023. URL: https://www.deutschlandatlas.bund.de/DE/Karten/Unsere-Gesundheitsversorgung/120-PKW-Hausaerzte.html [accessed 2024-05-05]
38. Ohligs M, Stocklassa S, Rossaint R, Czaplik M, Follmann A. Employment of telemedicine in nursing homes: clinical requirement analysis, system development and first test results. Clin Interv Aging 2020 Aug 18;15:1427-1437 [FREE Full text] [doi: 10.2147/CIA.S260098] [Medline: 32884251]
39. Freepik homepage. Freepik. URL: https://www.freepik.com/ [accessed 2024-05-17]
40. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357. [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
41. Alanazi AT. Digital leadership: attributes of modern healthcare leaders. Cureus 2022 Feb 07;14(2):e21969 [FREE Full text] [doi: 10.7759/cureus.21969] [Medline: 35282530]
42. Laukka E, Huhtakangas M, Heponiemi T, Kanste O. Identifying the roles of healthcare leaders in HIT implementation: a scoping review of the quantitative and qualitative evidence. Int J Environ Res Public Health 2020 Apr 21;17(8):2865 [FREE Full text] [doi: 10.3390/ijerph17082865] [Medline: 32326300]
43. Laurisz N, Ćwiklicki M, Żabiński M, Canestrino R, Magliocca P. Co-creation in health 4.0 as a new solution for a new era. Healthcare (Basel) 2023 Jan 27;11(3):363 [FREE Full text] [doi: 10.3390/healthcare11030363] [Medline: 36766938]
44. Plunger P, Eitenberger M, Kletecka-Pulker M, Wochele-Thoma T, Klager E, Ruf AK, et al. Using telemedicine in nursing homes during the COVID-19 pandemic: a multi-perspective view on the implementation process. Nurs Open 2022 Mar;9(2):1155-1163 [FREE Full text] [doi: 10.1002/nop2.1155] [Medline: 34918492]
45. Powell KR, Winkler AE, Liu J, Alexander GL. A mixed-methods analysis of telehealth implementation in nursing homes amidst the COVID-19 pandemic. J Am Geriatr Soc 2022 Dec;70(12):3493-3502 [FREE Full text] [doi: 10.1111/jgs.18020] [Medline: 36054440]
46. Cormi C, Chrusciel J, Fayol A, Van Rechem M, Abou-Amsha K, Tixier M, et al. The use of telemedicine in nursing homes: a mixed-method study to identify critical factors when connecting with a general hospital. Int J Environ Res Public Health 2021 Oct 23;18(21):11148 [FREE Full text] [doi: 10.3390/ijerph182111148] [Medline: 34769665]
47. Zhao Y, Rokhani FZ, Sazlina SG, Devaraj NK, Su J, Chew BH. Defining the concepts of a smart nursing home and its potential technology utilities that integrate medical services and are acceptable to stakeholders: a scoping review. BMC Geriatr 2022 Oct 07;22(1):787 [FREE Full text] [doi: 10.1186/s12877-022-03424-6] [Medline: 36207705]
48. Booth RG, Strudwick G, McBride S, O'Connor S, Solano López AL. How the nursing profession should adapt for a digital future. BMJ 2021 Jun 14;373:n1190. [doi: 10.1136/bmj.n1190]
49. Chen C, Ding S, Wang J. Digital health for aging populations. Nat Med 2023 Jul;29(7):1623-1630. [doi: 10.1038/s41591-023-02391-8] [Medline: 37464029]
50. Bajra R, Frazier W, Graves L, Jacobson K, Rodriguez A, Theobald M, et al. Feasibility and acceptability of a US national telemedicine curriculum for medical students and residents: multi-institutional cross-sectional study. JMIR Med Educ 2023 May 08;9:e43190 [FREE Full text] [doi: 10.2196/43190] [Medline: 37155241]
51. Khullar D, Mullangi S, Yu J, Weems K, Shipman SA, Caulfield M, et al. The state of telehealth education at U.S. medical schools. Healthc (Amst) 2021 Jun;9(2):100522. [doi: 10.1016/j.hjdsi.2021.100522] [Medline: 33548854]
52. Kumra T, Amundsen DB, Mullins A, Hindman DJ, Hughes HK, Pahwa AK. Telehealth curricula in the pediatric core clerkship: results from a survey of clerkship directors. Cureus 2023 May 18;15(5):e39200 [FREE Full text] [doi: 10.7759/cureus.39200] [Medline: 37337508]
53. Stovel RG, Gabarin N, Cavalcanti RB, Abrams H. Curricular needs for training telemedicine physicians: a scoping review. Med Teach 2020 Nov;42(11):1234-1242. [doi: 10.1080/0142159X.2020.1799959] [Medline: 32757675]

Abbreviations

CM: change management
COREQ: Consolidated Criteria for Reporting Qualitative Research
ECG: electrocardiogram
GP: general practitioner
HA: hospital admission
HCP: health care professional
IS: implementation science
NH: nursing home
PoC: point-of-care

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Original Paper

Exploring the Sociodemographic and Health-Related Determinants of Telehealth Use Among a Cohort of Older Australians During the COVID-19 Pandemic: Repeated Cross-Sectional Study

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Abstract

Background: During the COVID-19 pandemic, there was a rapid adoption of telehealth care services as a public health strategy to maintain access to essential health care. In Australia, there has been increasing optimism for the expansion of telehealth services. However, little is known about the patterns and determinants of telehealth adoption among older adults, with concerns that an expansion of telehealth services may only be of benefit to those who already have better access to health care.

Objective: Leveraging data collected by The Sax Institute's 45 and Up COVID Insights study between November 2020 and April 2022, the objective of this study was to identify and describe the sociodemographic and health-related determinants of telehealth adoption and use among a cohort of older Australians. We hypothesized that health-related factors would be key determinants of telehealth adoption for Australians aged ≥65 years during the COVID-19 pandemic.

Methods: A repeated cross-sectional design was used. The relationships between telehealth use (classified as low, moderate, or high) and selected sociodemographic and health-related characteristics were assessed using logistic regression techniques. Variable selection and findings were situated within the Technology Acceptance Model, the Unified Theory of Acceptance, and the Use of Technology theoretical frameworks.

Results: Of the 21,830 participants aged ≥65 years, the proportion who indicated adopting telehealth ranged from 50.77% (11,082/21,830) at survey 1 in 2020 to 39.4% (7401/18,782) at survey 5 in 2022. High levels of telehealth use were associated with being female, aged <85 years, living in a major city, cohabiting with others, and being from the most socioeconomically disadvantaged areas (deciles 1-3). Individuals with a disability, chronic disease, multimorbidity, and lower perceived quality of life and those experiencing missed or delayed care were significantly more likely to use telehealth across all levels ($P<.001$). A temporal association was observed, whereby participants who engaged with telehealth services before or early in the pandemic (as assessed in survey 1) were more likely to continue telehealth use when assessed in survey 5 in 2022 (*P*<.001).

Conclusions: This research contributes to the broader understanding of telehealth adoption and use among older adults. As telehealth models of care expand, there is an opportunity to tailor these services to the needs of older adults, particularly those living with chronic diseases and multimorbidity, by using targeted strategies that overcome barriers to accessing specialized health care services.

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KEYWORDS

telehealth; telemedicine; aging; older people; COVID-19; Australia; 45 and Up Study; health-related determinates; Technology Acceptance Model; mobile phone

Introduction

Overview

The COVID-19 pandemic triggered a rapid transformation in the delivery of health care. Because of adaptive necessity, in-person visits to health care providers were augmented through the widespread adoption of digital technology mediums [1]. In countries such as Australia, telehealth was incentivized as a national public health strategy to facilitate remote patient and practitioner interactions, given social distancing and lockdown measures [2-4]. Noting that telehealth and telemedicine are often used interchangeably within the literature [5], this paper uses telehealth to denote the delivery of health care services at a distance by health care professionals for remote patient engagement (synchronous or asynchronous), using information and communication technologies (ICTs), such as telephone or video mediums [6].

Before the COVID-19 pandemic, telehealth services in countries with high income, such as Australia, Canada, New Zealand, and the United States, had been established to facilitate access to health care services across vast geographic distances [2,7]. The sustained integration and adoption of telehealth services pose ongoing challenges, as evidenced by a notable decline in use after the acute pandemic phase [8,9]. Barriers to telehealth integration and adoption are well documented [10]. These include health care consumer and provider resistance and skepticism [8,10], concerns over patient safety (inability to undertake hands-on assessments) [8], confidentiality and privacy of medical information [4,6,10], a lack of digital technology infrastructure [8,10], socioeconomic disadvantage [4,6,11], varying levels of digital technology literacy [10], increasing age [4,6,8,10,12], education levels [10], and poorly designed platforms [10]. Since the start of the pandemic, there has been increasing optimism for the expansion of telehealth services to increase equity of health care access for those living outside of metropolitan areas in which poor health outcomes are increased. This is particularly relevant given the backdrop of the ever-increasing prevalence of noncommunicable chronic disease, multimorbidity, and aging populations [1,6,8,13,14]. A central concern is whether the expansion of telehealth services will genuinely improve health care access or disproportionately benefit those who already have better access to health care [4,6,15-17].

Background

"The digital divide" has become increasingly prevalent in discussions around technology use, including telehealth [4,12]. The term encompasses the socioeconomic, ICT resource-related, and other accessibility disparities and their impacts on vulnerable groups. These groups typically include people of cultural and linguistic diversity (CALD); those with chronic disease, multimorbidity (defined as having more than one chronic disease), or disability; older adults; those living in rural and remote geographic areas; and those of lower income [4,12]. A recent systematic review by Haimi and Gesser-Edelsburg [6] highlighted a gap in the literature regarding telehealth engagement among older adults (aged ≥65 years) during the COVID-19 pandemic. Of the 11 reviewed studies, it was evident that although telehealth service availability increased, telehealth adoption and participation among older adults was low [6]. This is particularly concerning given that older people were more likely to develop severe disease, with those experiencing multimorbidity at even higher risk, emphasizing the need for further studies to identify challenges with telehealth adoption among this age group [6].

In Australia, where 1 in every 6 people is aged ≥65 years and where a significant proportion reside outside of metropolitan areas, challenges with the equitable provision of health care services are exacerbated [18-21]. There is considerable demand among policy makers for upscaled telehealth service models, particularly given the distinctive characteristics of older Australians [20]. A total of 50% of people aged ≥65 years are affected by disability [18], whereas 85% have at least 1 chronic disease, with 60% reporting multimorbidity [14]. For these people, overcoming barriers to telehealth adoption becomes imperative.

Dykgraaf et al [4] suggest that the adoption of telehealth by older Australians extends beyond conventional barriers, such as personal socioeconomics, ICT ownership, and internet or network connectivity issues. They propose that barriers to the adoption of telehealth involve a more nuanced interplay of factors related to digital literacy rather than digital deprivation, as well as being influenced by practical factors related to physical and cognitive health, trust and familiarity with technology, and ease of use, particularly during the COVID-19 pandemic [4]. Broader research suggests that for older people, attitudes, perceptions, and experience of digital technologies influence their intention to adopt these mediums, with characteristics such as age, gender, education, health status, social influences, and income identified as influencing (barriers and enablers) factors [15,22,23].

In this context, the Technology Acceptance Model provides a valuable framework and lens for examining the factors that determine an individual’s potential acceptance or rejection of technologies, including telehealth [24]. Originally developed by Davis [25], the Technology Acceptance Model is an adaption of the well-established Theory of Reasoned Action [24]. Although the Theory of Reasoned Action primarily focuses on understanding the motivational factors and determinates of health-related behaviors [26], the Technology Acceptance Model was tailored to elucidate the influencing factors related to information technology use [24,27]. Grounded in the concept that people tend to engage in behaviors that have a positive effect, the Technology Acceptance Model posits that perceived usefulness and perceived ease of use are the main determining factors underlying technology adoption. These factors are influenced by antecedent personal factors (attitudes) that impact behavioral intention and actual technology use [24]. The Unified Theory of Acceptance and Use of Technology, a recent extension of the Technology Acceptance Model, explains the individual influencing factors related to technology use across four constructs: (1) performance expectancy, the degree to which an individual believes the technology with help them; (2) effort expectancy, the degree of perceived ease of use; (3) social influence, the degree to which an individual perceives how others view the importance of using the technology is for them; and (4) facilitating conditions, the degree to which the individual believes that infrastructure exists to support their use of the technology [28].

The circumstances surrounding the COVID-19 pandemic present a unique opportunity to observe the real-world dynamics in telehealth adoption at the population level. The expansion of services and forced adoption of telehealth acts as a natural experiment for exploration, whereby external circumstances dictate the implementation of an intervention [29]. Mao et al [15] analyzed data from the Irish Longitudinal Study on Aging collected during the COVID-19 pandemic (COVID-19 wave, June to November 2020). Their findings suggest health-related factors (chronic conditions, multimorbidity, and poor mental health) and, to a lesser extent, sociodemographic factors (younger age [<70 years] and socioeconomic disadvantage) are determinants of telehealth use. A study conducted by Choi et al [12] analyzing data from the United States National Health and Aging Trend Study-COVID supplement (collected in 2020) similarly observed health-related factors (chronic conditions, impairments with activities of daily living, and moderate levels of mental distress) and younger age (<80 years) as determinants of telehealth use [10].

Leveraging data collected by The Sax Institute’s 45 and Up COVID Insights substudy, the objective of this study was to identify and describe the sociodemographic and health-related determinants of telehealth adoption and use among a cohort of older Australians. Consistent with the Technology Acceptance Model and Unified Theory of Acceptance and Use of Technology, we hypothesized that health-related factors will be key determinants of telehealth adoption and use for older Australians during the COVID-19 pandemic. These findings will contribute to our understanding of factors that influence telehealth adoption beyond conventional barriers for older Australians, working toward equity of health service provision for this population [4,28].

Methods

Study Design

This study uses survey data collected by The Sax Institute’s 45 and Up COVID Insights substudy (hereon referred to as COVID Insights study). Conducted in the state of New South Wales, Australia, between November 2020 and April 2022 [30], the COVID Insights study is an extension of the larger 45 and Up prospective longitudinal cohort study. The COVID Insights study covers critical themes addressing health care use, mental health and well-being, financial aspects, COVID-19 preventive measures, and lifestyle behaviors.

Population

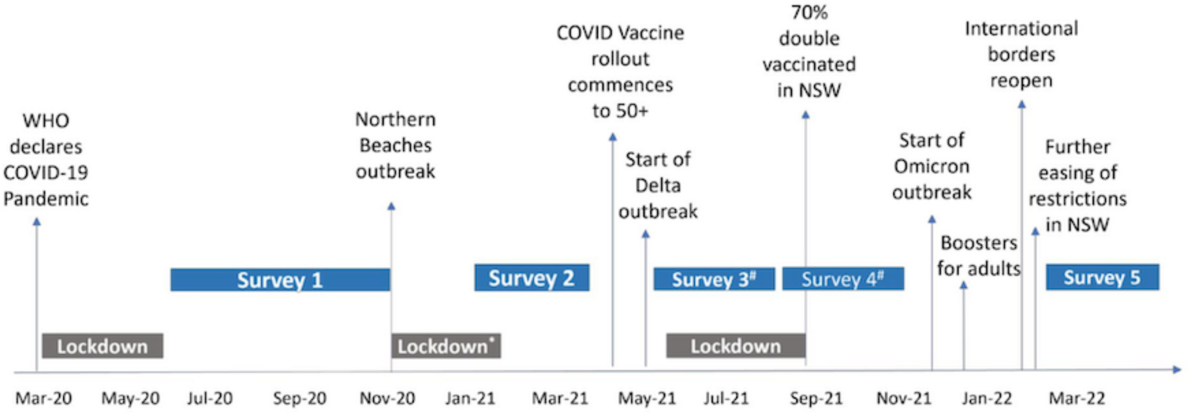
The Sax Institute’s 45 and Up Study, initiated between 2005 and 2009, has recruited a total of 267,357 participants from New South Wales [31]. Recruitment methods have been previously published [31]. Prospective participants were drawn at random from the Services Australia Medicare enrollment database, with those aged ≥80 years and residents of rural and remote areas intentionally oversampled [31]. About 19% of those invited to the study consented to participate. Consenting participants were followed up every 5 years in waves. Because of the large number of participants, surveys were also distributed in phases. For example, the wave-2 follow-up surveys were distributed in 4 phases between 2012 and 2015, with wave-3 follow-up surveys distributed across 3 phases between 2018 and 2020 [31].

The 45 and Up COVID Insights study was established in 2020 through collaborative efforts with key health industry stakeholders and policy makers and engaged 32,115 participants between November 2020 and April 2021 [30]. The cohort was formed through 2 distinct recruitment methods [30,32]. Method 1 involved reaching out to existing 45 and Up Study participants (n=85,299) who were completing their routine wave-3 (phase 3) follow-up survey. During the period between July and December 2020, these participants were asked to complete an additional COVID supplement survey, resulting in 28,840 participants expressing interest in the COVID Insights study [30,32]. From this group, 15,252 completed both the COVID supplement survey (which featured variables similar to the COVID Insights survey 1) and COVID Insights survey 2, officially joining the substudy at this time point [30,32].

Method 2 encompassed the distribution of invitations to a random sample of existing 45 and Up Study participants (n=60,000) between November and December 2020. Of these invitations, 40,000 were sent by email and 20,000 were distributed through traditional mail-in postal procedures. A total of 16,863 participants responded, completed the COVID Insights survey 1, and were successfully recruited to the substudy [30,32]. Five COVID Insights surveys were developed for rapid data collection and were strategically administered over various pandemic time points between 2020 and 2022, as displayed in

Figure 1 [33]. All follow-up surveys (COVID Insights surveys 2-5) were exclusively administered via the web.

Figure 1. COVID Insights Survey administration, pandemic outbreaks, and pandemic policy implementation in New South Wales, Australia. The number sign (#) from surveys 3 and 4 indicates that data were collected in 3 consecutive month-long tranches. NSW: New South Wales; WHO: World Health Organization. *Lockdown in place across Sydney's Northern Beaches with some restrictions for Greater Sydney.



Participants

Of the 32,115 participants available for analysis, 21,830 participants aged ≥65 years who completed telehealth adoption questions were identified. This subset was chosen for the current analysis as it aligns with the Australian Institute of Health and Welfare's age criterion for older adults [21] and is supported by the age classification used in the systematic review by Haimi and Gesser-Edelsburg [6] for ease of comparison across data sets.

Variable Selection

Using a repeated cross-sectional design and guided by previous research and the Technology Acceptance Model and Unified Theory of Acceptance and Use of Technology frameworks, a comprehensive set of sociodemographic and health-related variables was considered for analysis. Specifically, these frameworks helped us to select a set of variables aimed at understanding the individual influencing factors related to perceived usefulness, ease of use, performance expectancy, effort expectancy, social influence, and facilitating conditions [28]. Therefore, we included the following variables: age, gender, CALD, disability status, chronic disease and multimorbidity status, carer status, housing type, number of people in the household, geographic location (as per the Accessibility/Remoteness Index of Australia [34]), socioeconomic disadvantage (as per the Socioeconomic Indexes For Areas [35]), information related to cigarette smoking and alcohol consumption, vehicle driving, experiences of missed or delayed health care, Kessler–6 psychological distress scores [36], De Jong Gierveld Loneliness scores [37], and general quality of life ratings.

Sociodemographic and Health-Related Variables

With the exception of smoking, alcohol consumption, vehicle driving, missed or delayed care, Kessler–6, De Jong Gierveld scores, and quality of life ratings, all other listed sociodemographic and health-related variables were packaged as static variables for the COVID Insights study [32]. This means they were either derived from the wider 45 and Up Study or collected as part of the COVID Insights survey series and do not change over time [32]. Participants were identified as people of CALD if they were born outside of Australia, New Zealand, the United Kingdom, Ireland, Canada, the United States, or South Africa. In addition, individuals who indicated speaking a language other than English at home were classified as people of CALD [32]. Chronic conditions were assessed by asking participants whether a doctor had ever told them that they had cancer, cardiovascular disease, stroke, diabetes, asthma, arthritis, Parkinson disease, or chronic kidney disease. With count data only supplied, multimorbidity was determined by the number of chronic diseases reported, indicating the presence of >1 concurrent chronic disease. Individuals residing in outer regional, rural, and very remote geographic localities were combined into one category because of the small samples of participants within these subgroups. The socioeconomic disadvantage area deciles, in which decile 1 equates to the most disadvantaged areas, were collapsed into 3 categories for ease of interpretation.

The missed or delayed care variable was derived from participant responses to whether they had experienced missed or delayed health care from a general practitioner visit, hospital visit, specialist doctor, or prescription medication visit. The mental health of participants was assessed using mean Kessler–6 scores. Kessler–6 scores range from 0 to 24; higher scale scores indicate more serious mental distress [36,38], with a cutoff point of ≥13 suggesting probable mental illness [38]. Mean De Jong Gierveld Loneliness (short form) scores were used. The scale comprised 3 positively framed questions and 3 negatively framed questions, with responses provided as "Yes," "More or less," or "No" [37]. Only positive (Yes) and neutral responses (More or less) to the 3 negatively framed questions are counted, resulting in scores ranging from 0 to 3, whereby 0 indicates no emotional loneliness and 3 suggests intense emotional loneliness [37]. Mean general quality of life scores were derived from responses to a 5-point rating scale, whereby lower scores indicate better quality of life (eg, 1=excellent and 5=poor).

Telehealth Variables

Telehealth use was defined as the use of health care services via telephone or video call. Questions related to telehealth adoption and use were assessed in surveys 1, 4, and 5. In the initial survey (administered between July and December 2020), participants were asked whether they had used telehealth services since January 2020, which is defined as an appointment with a health care provider by video or telephone instead of an in-person visit. Participants were asked to specify whether the telehealth mode was via telephone or video call at this time point only. In survey 4 (administered between September and November 2021), participants were asked whether they had used telehealth (via telephone or video call) in the last 3 months and for which purposes (eg, a regular check-up, medical diagnosis or advice, initial consultation, follow-up consultation, receive test results, or treatment or therapy review). In survey 5 (administered between March and April 2022), participants were again asked whether they had used telehealth (via telephone or video call) in the past 3 months and which health care provider they saw (general practitioner, specialist doctor, pharmacist, nurse, mental health care [eg, psychologist or counselor], physiotherapist, occupational therapist, dietitian).

For this analysis, participants who indicated telehealth use across the 3 surveys were categorized on the basis of their individual level of telehealth use as follows: no adoption (did not use telehealth at any survey); low use (used telehealth at 1 of the 3 surveys only); moderate use (used telehealth at 2 surveys); and high use (used telehealth at all 3 surveys).

Statistical Analysis

All sociodemographic, health-related, and telehealth-related variables were summarized and reported using descriptive statistics. To investigate the determinants of telehealth use (dependent variable), a multinomial logistic regression model was developed using the selected sociodemographic and health-related characteristics as independent variables. Data were pooled across all 3 surveys (surveys 1, 4, and 5). Participants with missing data on any of the analysis variables were excluded. An additional logistic regression analysis was conducted to explore the determinants of telehealth adoption, specifically investigating whether prior telehealth adoption, assessed in survey 1, predicted telehealth use in survey 5. All variables were checked for independence and multicollinearity, satisfying these assumptions with telehealth variables organized into mutually exclusive and exhaustive categories. All analyses were conducted by a statistician (SM) using R programming language (version 4.3.0; R Development Core Team) within The Sax Institute’s Secure Unified Research Environment. The criterion for statistical significance was set at the .05 α level.

Ethical Considerations

For The 45 and Up Study, all participants provided written informed consent with approval obtained from the University of New South Wales, Human Research Ethics Committee (HC210602) [31]. The COVID Insights study was approved by the University of New South Wales, Human Research Ethics Committee (reference HC200597) [30] with approval for the current analysis also obtained by the authors institutional Human Research Ethics Committee (reference H23582).

Results

Sociodemographic, Health-Related, and Telehealth-Related Characteristics

Table 1 displays the sociodemographic and health-related characteristics of the cohort, categorized by telehealth use across surveys. Inspection of baseline sociodemographic and health-related characteristics at survey 1 (n=21,830) revealed most participants were women, were not people of CALD, lived in a house, lived with ≥1 other person, resided in a major city, and did not have carer responsibilities. Regarding health, most did not live with a disability but were impacted by chronic disease. Most had not experienced missed or delayed health care because of the COVID-19 pandemic. Mean Kessler–6 scores were <13, and mean De Jong Gierveld Loneliness scores were <2. The cohort reported relatively high levels of perceived quality of life. The cohort was assumed to have adequate levels of technology literacy as surveys 2 to 5 were administered electronically. When assessed at survey 4, most participants reported regular use of a smartphone (7166/7890, 90.82%) and computer device (6809/7890, 86.3%).

Table 1. Sociodemographic, health-related, and telehealth-related cohort characteristics[a].

Variables	Survey 1 (n=21,830)		Survey 4 (n=18,268)		Survey 5 (n=18,782)	
	Used telehealth	Did not use telehealth	Used telehealth	Did not use telehealth	Used telehealth	Did not use telehealth
Cohort, n (%)	11,082 (50.77)	10,748 (49.23)	7890 (43.19)	10,378 (56.81)	7401 (39.4)	11,381 (60.6)
Sociodemographic characteristics						
Age group (y), n (%)						
65-74	7674 (69.25)	7516 (69.93)	5271 (66.81)	6891 (66.4)	4735 (63.98)	7451 (65.47)
75-84	3040 (27.43)	2878 (26.78)	2330 (29.53)	3104 (29.91)	2395 (32.36)	3481 (30.59)
>85	368 (3.32)	354 (3.29)	289 (3.66)	383 (3.69)	271 (3.66)	449 (3.95)
Gender, n (%)						
Man	4777 (43.11)	5511 (51.27)	3423 (43.38)	5037 (48.54)	3266 (44.13)	5357 (47.07)
Woman	6305 (56.89)	5237 (48.73)	4467 (56.62)	5341 (51.46)	4135 (55.87)	6024 (52.93)
Which of the following devices do you use regularly?, n (%)[b]						
A smartphone (Android, Apple, or other)	—[c]	—	7166 (90.82)	9205 (88.7)	—	—
A computer (Windows or Apple)	—	—	6809 (86.3)	8853 (85.31)	—	—
A tablet device (Apple or other tablets)	—	—	4607 (58.39)	5682 (54.75)	—	—
A wearable device (Fitbit, Garmin, Apple Watch, or other)	—	—	1769 (22.42)	2034 (19.6)	—	—
Cultural and linguistic diverse, n (%)	833 (7.52)	984 (9.16)	622 (7.88)	830 (8)	585 (7.9)	913 (8.02)
Has carer responsibilities[d], n (%)	1405 (12.68)	997 (9.28)	1005 (12.74)	1010 (9.73)	989 (13.36)	1086 (9.54)
Drives a car, n (%)	—	—	—	—	5970 (80.66)	9277 (81.51)
Housing[e], n (%)						
House or house on a farm	8817 (79.56)	8765 (81.55)	6198 (78.56)	8473 (81.64)	5843 (78.95)	9288 (81.61)
Flat, unit, apartment, or granny flat	1644 (14.83)	1529 (14.23)	1272 (16.12)	1434 (13.82)	1175 (15.88)	1585 (13.93)
Retirement village, self-care unit, hostel for the aged, or nursing home	515 (4.65)	362 (3.37)	353 (4.47)	361 (3.48)	319 (4.31)	399 (3.51)
Mobile home, temporary housing, or boarding house	58 (0.52)	48 (0.45)	34 (0.43)	65 (0.63)	39 (0.53)	64 (0.56)
Other	47 (0.42)	44 (0.41)	33 (0.42)	44 (0.42)	25 (0.34)	45 (0.4)
Living arrangements[f], n (%)						
Lives alone	2398 (21.64)	2291 (21.32)	1720 (21.8)	2303 (22.19)	1543 (20.85)	2462 (21.63)
Lives with 1 or more other persons	8577 (77.4)	8382 (77.99)	6170 (78.2)	8075 (77.81)	5843 (78.95)	8896 (78.17)
ARIA[g,h], n (%)						
Major city	6248 (56.38)	6002 (55.84)	5016 (63.57)	5437 (52.39)	4712 (63.67)	6085 (53.47)
Inner regional areas	4006 (36.15)	3788 (35.24)	2398 (30.39)	3987 (38.42)	2212 (29.89)	4312 (37.89)
Outer regional, remote, very remote areas	817 (7.37)	936 (8.71)	467 (5.92)	935 (9.01)	462 (6.24)	968 (8.51)
Socioeconomic disadvantage[i], n (%)						
1-3	2451 (22.12)	2041 (18.99)	1505 (19.07)	2133 (20.55)	1434 (19.38)	2312 (20.31)
4-7	4026 (36.33)	4004 (37.25)	2821 (35.75)	3894 (37.52)	2656 (35.89)	4207 (36.97)
8-10	4476 (40.39)	4588 (42.69)	3474 (44.03)	4235 (40.81)	3220 (43.51)	4733 (41.59)
Health-related characteristics						

Variables	Survey 1 (n=21,830)		Survey 4 (n=18,268)		Survey 5 (n=18,782)	
	Used telehealth	Did not use telehealth	Used telehealth	Did not use telehealth	Used telehealth	Did not use telehealth
Alcohol intake[j], n (%)						
Consumers	4674 (42.18)	4447 (41.38)	—	—	5607 (75.76)	8932 (78.48)
Nonconsumers	1449 (13.08)	1226 (11.41)	—	—	1794 (24.24)	2449 (21.52)
Smoking Status n (%)						
Smokers	—	—	—	—	99 (1.34)	179 (1.57)
Nonsmokers	—	—	—	—	7302 (98.66)	11,202 (98.43)
Has a disability[k], n (%)	638 (5.76)	231 (2.15)	389 (4.93)	229 (2.21)	367 (4.96)	244 (2.14)
Has a chronic condition, n (%)	3590 (32.39)	4068 (37.85)	2563 (32.48)	3929 (37.85)	2360 (31.89)	4321 (37.97)
Has multimorbidity[l], n (%)	6186 (55.83)	4636 (4313)	4398 (55.74)	4538 (43.73)	4205 (56.82)	4954 (43.53)
Missed or delayed health care[m], n (%)						
Experienced missed or delayed care	1579 (14.25)	970 (9.02)	1079 (13.68)	951 (9.16)	841 (11.36)	768 (6.75)
Did not experience missed or delayed care	4544 (41.00)	4703 (43.76)	1109 (14.06)	1270 (12.24)	538 (7.27)	651 (5.72)
Kessler–6 (psychological distress) scale[n,o], mean (SD)	8.32 (3.03)	7.75 (2.59)	—	—	9.32 (3.46)	8.63 (3.13)
De Jong Gierveld Loneliness Scale[p,q], mean (SD)	1.96 (1.66)	1.82 (1.6)	—	—	2.02 (1.77)	1.77 (1.67)
Rate quality of life[r,s], mean (SD)	2.09 (0.79)	1.94 (0.74)	2.23 (0.87)	2.04 (0.81)	2.22 (0.83)	2.04 (0.76)

[a] All values in the table have been rounded to two decimal places nearest as such percentages may not sum up to exactly 100% because of rounding error and missing data.

[b] Missing: survey 4 (n=272).

[c] Responses to these questions were not elicited at these timepoints and reflect the change in survey questions overtime.

[d] Missing: survey 1 (n=1) and survey 5 (n=1).

[e] Missing: survey 1 (n=1) and survey 4 (n=1).

[f] Missing: survey 1 (n=182) and survey 5 (n=38).

[g] ARIA: Accessibility Remoteness Index of Australia.

[h] Missing: survey 1 (n=33), survey 4 (n=28), and survey 5 (n=31).

[i] Socioeconomic disadvantage lower rankings indicate most disadvantaged.

[j] Missing: survey 1 (n=10,034).

[k] Missing: survey 1 (n=14), survey 4 (n=9), and survey 5 (n=7).

[l] Multimorbidity refers to those who have indicated having >1 chronic disease.

[m] The missed or delayed care variable includes those indicating missed or delayed care pertaining to a visit to a general practitioner, hospital, specialist, and prescription medication (missing survey 1, n=10,034; survey 4, n=13,859; and survey 5, n=15,984).

[n] Kessler–6—scores are summarized on a scale of 0-24, with higher scores indicating greater distress; scores ≥13 indicating probable mental illness.

[o] Missing: survey 1 (n=266).

[p] De Jong Gierveld Loneliness Scale is scored on a scale of 0-3, with scores of 3 indicating intense emotional loneliness and 0 indicating no loneliness.

[q] Missing: survey 1 (n=230).

[r] Quality of life rating scores are based on a Likert scale of 1-5 (1=excellent; 2=very good; 3=good; 4=fair; 5=poor).

[s] Missing: survey 1 (n=10,034).

A decreasing trend in telehealth adoption was evident across survey time points. Adoption was highest at survey 1 in 2020, with 51.77% (11,082/21,830) of the cohort using telehealth services (telephone or video), indicative of both prepandemic and early pandemic adoption (official announcement of the pandemic in March 2020, with lockdown measures occurring up until May 2020). The proportion of users had decreased at survey 4 to 43.19% (7890/18,268), capturing use in response to the COVID-19 Delta outbreak and associated lockdowns occurring in 2021. The lowest levels of use were observed in survey 5, with only 39.4% (7401/18,782) of participants using telehealth at this time point (capturing use following the vaccination rollout in 2022). As per Table 2, when assessed in survey 4, a total of 42.72% (3371/7890) of participants indicated that they were more likely to use telehealth for a follow-up consultation or to receive test results (2901/7890, 36.81%). A smaller proportion (1608/7890, 20.38%) indicated using telehealth for initial health care consultations or to receive a medical diagnosis or advice (1693/7890, 21.46%). By survey 5, telehealth was primarily being used for general practitioner appointments (5634/7401, 76.12%) or specialist health care appointments (1421/7401, 19.2%), with most participants (4629/7401, 62.55%) preferring a hybrid health care model involving both telehealth and in-person care.

Table 2. Telehealth-related cohort characteristics[a].

Telehealth-related characteristics	Used telehealth		
	Survey 1 (n=11,082)	Survey 4 (n=7890)	Survey 5 (n=7401)
Mode of telehealth service, n (%)[b]			
Telephone	9857 (88.95)	—[c]	—
Video	350 (3.16)	—	—
Both	706 (6.37)	—	—
How likely would you be to recommend telehealth services to someone else?, n (%)[d]			
Definitely will not	371 (3.35)	—	—
Probably will not	2676 (24.15)	—	—
Probably will	5587 (50.42)	—	—
Definitely will	2320 (20.93)	—	—
How useful do you think it will be to have appointments via telehealth after the COVID-19 emergency is over?, n (%)[e]			
Not at all	1257 (11.34)	—	—
Slightly	2205 (19.9)	—	—
Moderately	3869 (34.91)	—	—
Very	2759 (24.9)	—	—
Extremely	976 (8.81)	—	—
In the last 3 months have you used telehealth for any of the following? (Participants could choose multiple options), n (%)			
Regular check-up	—	1158 (14.68)	—
Medical diagnosis or advice	—	1693 (21.46)	—
Initial consultation	—	1608 (20.38)	—
Follow-up consultation	—	3371 (42.72)	—
Receive test results	—	2904 (36.81)	—
Treatment or therapy	—	447 (5.67)	—
Treatment or therapy review	—	848 (10.75)	—
Other	—	788 (9.99)	—
Thinking about your latest telehealth appointment, which health provider did you see on this occasion?, n (%)			
General practitioner	—	—	5634 (76.12)
Specialist doctor	—	—	1421 (19.2)
Pharmacist	—	—	16 (0.22)
Nurse	—	—	57 (0.77)
Mental health care	—	—	143 (1.93)
Physiotherapist or occupational therapist	—	—	46 (0.62)
Dietician	—	—	17 (0.23)
Other	—	—	67 (0.91)
What is your preferred way of receiving this type of care?, n (%)			
I would prefer to have all of this type of care via telehealth	—	—	178 (2.41)
I would prefer to have some of this type of care via telehealth and some face-to face	—	—	4629 (62.55)
I would prefer to have all of this type of care face-to-face	—	—	2263 (30.58)
I do not have a preference	—	—	331 (4.47)

Telehealth-related characteristics	Used telehealth		
	Survey 1 (n=11,082)	Survey 4 (n=7890)	Survey 5 (n=7401)
How did your latest telehealth service compare to a traditional in-person medical visit?, n (%)			
Better than a traditional visit	—	—	207 (2.8)
Just as good as a traditional visit	—	—	4765 (64.38)
Worse than a traditional visit	—	—	1893 (25.58)
Not sure	—	—	536 (7.24)

[a] All values in the table have been rounded to the nearest whole percent, as such percentages may not sum up to exactly 100% because of rounding errors, missing data, and options in which multiple responses could be provided.

[b] Missing: survey 1 (n=169).

[c] Responses to these questions were not elicited at these timepoints and reflect the change in survey questions overtime.

[d] Missing: survey 1 (n=128).

[e] Missing: survey 1 (n=16).

Logistic Regression Models

The results of the multinomial regression model, identifying sociodemographic and health-related determinates of telehealth use, are presented in Table 3. Women were more likely to engage with telehealth services across all categories (low, moderate, and high) compared with men (*P*<.001), with odds ratios indicating an increasing likelihood of use. Individuals aged ≥85 years were significantly (*P*=.01) less likely to exhibit high telehealth use compared with the reference group (aged 65-74 years). Living alone was associated with lower odds of moderate (*P*=.002) and high (*P*<.001) telehealth use when compared with living with others. Inner regional residents and those in outer regional, rural, and very remote areas were less likely to use telehealth at moderate and high levels (*P*<.001) compared with major city dwellers. Individuals from areas of socioeconomic disadvantage (deciles 1-3) were more likely to use telehealth than those with lower levels of socioeconomic disadvantage (deciles 8-10; *P*=.02).

Table 3. Multinomial logistic regression model of sociodemographic and health-related determines of telehealth use (n=10,518)[a].

Demographic and psychosocial characteristics	Coefficient	*Z* score	*P* value	Odds ratio (95% CI)
Female (reference: male)				
Low[b]	0.26	4.69	<.001	1.30 (1.16-1.45)
Moderate	0.39	6.69	<.001	1.48 (1.32-1.66)
High	0.44	7.13	<.001	1.55 (1.38-1.75)
Age (y; reference: 65-74 y)				
75-84				
Low[b]	0.04	0.68	.50	1.04 (0.92-1.17)
Moderate	–0.09	–1.41	.16	0.91 (0.80-1.04)
High	–0.09	–1.31	.19	0.92 (0.43-0.87)
≥85 y				
Low[b]	–0.12	–0.80	.43	0.89 (0.66-1.19)
Moderate	–0.24	–1.46	.14	0.79 (0.58-1.08)
High	–0.49	–2.77	.01	0.61 (0.43-0.87)
Smokers (reference: nonsmokers)				
Low[b]	–0.34	–1.54	.12	0.71 (0.46-1.10)
Moderate	–0.57	–2.32	.02	0.57 (0.35-0.92)
High	–0.47	–1.93	.05	0.63 (0.39-1.01)
Alcohol consumers (reference: nonconsumers)				
Low[b]	0.07	–1.03	.30	0.94 (0.83-1.06)
Moderate	–0.01	–0.10	.92	0.99 (0.87-1.13)
High	–0.10	–1.41	.16	0.91 (0.79-1.04)
Has a disability (reference: no disability)				
Low[b]	0.43	2.10	0.04	1.53 (1.03-2.29)
Moderate	0.70	3.51	<.001	2.01 (1.36-2.96)
High	1.12	5.87	<.001	3.06 (2.11-4.45)
Has a chronic disease (reference: no chronic disease)				
Low[b]	0.16	2.15	.03	1.17 (1.01-1.36)
Moderate	0.31	3.72	<.001	1.36 (1.16-1.60)
High	0.54	5.65	<.001	1.72 (1.43-2.08)
Has multimorbidity (reference: no multimorbidity)				
Low[b]	0.45	5.98	<.001	1.57 (1.35-1.82)
Moderate	0.84	10.17	<.001	2.32 (1.97-2.73)
High	1.29	13.63	<.001	3.63 (3.01-4.36)
Lives alone (reference: lives ≥1 other person)				
Low[b]	–0.12	–1.88	.06	0.88 (0.78-1.01)
Moderate	–0.22	–3.08	.002	0.81 (0.70-0.92)
High	–0.33	–4.41	<.001	0.72 (0.62-0.83)
Vehicle drivers (reference: nondrivers)				
Low[b]	–0.01	–0.12	.90	0.99 (0.87-1.14)
Moderate	–0.06	–0.85	.39	0.94 (0.82-1.08)

Demographic and psychosocial characteristics	Coefficient	*Z* score	*P* value	Odds ratio (95% CI)
High	0.12	1.58	.11	1.13 (0.97-1.31)
Remoteness (reference: major city)				
Inner regional				
Low[b]	–0.03	–0.58	.56	0.97 (0.86-1.09)
Moderate	–0.37	–5.91	<.001	0.69 (0.61-0.78)
High	–0.61	–9.04	<.001	0.54 (0.48-0.62)
Outer regional, rural, or very remote				
Low[b]	–0.06	–0.61	.54	0.94 (0.77-1.15)
Moderate	–0.51	–4.49	<.001	0.60 (0.48-0.75)
High	–0.93	–7.29	<.001	0.40 (0.31-0.51)
Relative socioeconomic disadvantage (SEIFA[c] deciles) (reference deciles 1-3)				
4-7				
Low[b]	–0.10	–1.35	.18	0.91 (0.78-1.05)
Moderate	–0.12	–1.57	.12	0.88 (0.76-1.03)
High	–0.09	–1.14	.25	0.91 (0.77-1.07)
8-10				
Low[b]	–0.11	–1.41	.16	0.90 (0.77-1.04)
Moderate	–0.14	–1.69	.09	0.87 (0.74-1.02)
High	–0.19	–2.27	.02	0.82 (0.70-0.97)
Experienced missed or delayed health care (reference no missed delayed care)				
Low[b]	0.22	3.87	<.001	1.25 (1.12-1.40)
Moderate	0.32	5.38	<.001	1.38 (1.23-1.56)
High	0.53	8.51	<.001	1.70 (1.50-1.92)
Kessler 6 (psychological distress)[d]				
Low[b]	0.02	1.86	.06	1.02 (1.00-1.05)
Moderate	0.03	2.47	.01	1.03 (1.01-1.06)
High	0.07	4.96	<.001	1.07 (1.04-1.10)
De Jong (loneliness) scores[d]				
Low[b]	–0.06	–2.46	.01	0.95 (0.91-0.99)
Moderate	–0.05	–2.30	.02	0.95 (0.90-0.99)
High	–0.03	–1.19	.23	0.97 (0.93-1.02)
Quality of life scores[d]				
Low[b]	0.14	2.87	.004	1.15 (1.05-1.26)
Moderate	0.25	4.95	<.001	1.28 (1.16-1.42)
High	0.31	5.88	<.001	1.36 (1.23-1.51)

[a] *Z* scores (Wald *z* test).

[b] Reference category for telehealth use was 0=did not use telehealth at all.

[c] SEIFA: Socioeconomic Indexes For Areas.

[d] Mean scores were derived from repeated measures.

In terms of health-related determinates, the presence of a disability, chronic disease, or multimorbidity was positively associated with all levels of telehealth use, with a clear trend of increasing odds from low to high levels observed. Experiences of missed or delayed health care were linked to higher odds of using telehealth across all levels. Higher levels of psychological distress were related to an increased likelihood of moderate (*P*=.01) and high (*P*<.001) telehealth use. An inverse relationship between loneliness and moderate (*P*=.02) and low levels (*P*=.01) of telehealth use was evident, with lower loneliness scores associated with higher odds of telehealth use. A lower quality of life was significantly associated with telehealth adoption across all levels (*P*=.004 to *P*<.01), with a notable increase in odds from low to high levels observed.

As displayed in Table 4, a strong positive association was found between early telehealth adoption (measured in survey 1) and subsequent telehealth use (measured in survey 5; *P*<.001). Having a chronic condition (*P*=.006) or multimorbidity (*P*<.001) was significantly associated with ongoing telehealth use at survey 5. The interaction between early telehealth adoption and having a chronic condition or multimorbidity was not significant.

Table 4. Survey effect, telehealth adoption, and ongoing use.

Telehealth use in survey 5 is predicted by?	Coefficient	*Z* score	*P* value
Telehealth adoption at S1[a]	1.11	12.15	<.001
Has a chronic condition	0.21	2.76	.006
Has multimorbidity	0.57	7.81	<.001
Has a disability	0.63	0.72	.47
Interaction effects			
Telehealth adoption at S1[a] and chronic conditions	0.05	0.51	.61
Telehealth adoption at S1 and multimorbidity	0.01	0.08	.93

[a] S1: survey 1.

Discussion

Principal Findings

We aimed to investigate the sociodemographic and health-related determinants influencing telehealth adoption and use among a cohort of older Australians during the COVID-19 pandemic. The objective was to contribute to a comprehensive understanding of the factors influencing adoption and use, surpassing traditional barriers related to ICT ownership and access and motivated by a central concern that the expansion of telehealth services outside of pandemic conditions may exacerbate health care disparities.

Our analyses have revealed a unique set of determinants related to varying levels of telehealth use, suggesting a more nuanced interplay of factors that extend beyond sociodemographic determinants [4]. High telehealth use was significantly more prevalent among women, individuals in the younger age brackets (<85 years), city-dwelling residents, those living with others, and those from the most socioeconomically disadvantaged areas (deciles 1-3).

These results challenge traditional assumptions regarding the digital divide, specifically that low socioeconomic status and ICT ownership are barriers to telehealth adoption for older adults. Rather, our findings are consistent with arguments made by Dykgraaf et al [4], who suggest that for older people, digital literacy, trust, and familiarity are significant factors that can influence the adoption and use of telehealth. These results support our hypothesis and complement the findings by Mao et al [15] and Choi et al [12], affirming that health-related factors are critical determinants of telehealth adoption and use for older Australians. Individuals with a disability, chronic disease, multimorbidity and lower perceived quality of life and those experiencing missed or delayed care were more likely to exhibit telehealth use across all levels, highlighting the importance of telehealth as a supportive tool for managing complex health needs during the pandemic and out of pandemic conditions.

In addition, our findings have revealed that early or prior experience with telehealth is a significant predictor of its sustained use. Participants who engaged with telehealth before or early in the pandemic (as assessed in survey 1) were more likely to continue its use. This suggests that initial exposure and satisfaction with telehealth services are important predictors of adoption and long-term use for this population. The psychosocial factors of loneliness and psychological distress were linked to moderate levels of telehealth use, inferring that telehealth may have also played a role in mitigating mental health challenges by providing continued access to these health professionals.

Moreover, the study affirms the central concern that the expansion of telehealth services during the COVID-19 pandemic may have disproportionately benefited certain groups. For example, telehealth use was observed to be higher among those living in major cities, suggesting that older adults residing outside of city areas were less likely to adopt and use telehealth, potentially exacerbating health care disparities for those living in these underserviced geographic areas.

Although telehealth emerged as a supportive tool for many older people experiencing complex health conditions, it is important to acknowledge that a large proportion of the cohort did not adopt telehealth. A modest uptake of telehealth services was observed during the initial phase of the pandemic that was not sustained, declining over time even when ICT ownership was not a limiting factor. These findings are congruent with observations made by Haimi and Gesser-Edelsburg [6] and Lee et al [3], whereby increased telehealth service availability was not met by increased telehealth adoption or use. In particular, Lee et al [3] analyzed Australian Medicare data evaluating trends in telehealth and in-person health care visits (March 2020-2021). Similar to our findings, they observed an early surge in telehealth use during the introduction of initial lockdown restrictions with an associated decrease with in-person health care visits. Over time, in-person health care visits increased as telehealth visits decreased, suggesting a New South Wales population preference (personal and medical professional) for in-person health care [3].

Given our findings, further exploration of the interplay between sociodemographic and health-related factors as barriers and enablers to telehealth adoption use is warranted. Situating our results within the 4 domains of the Unified Theory of Acceptance and Use of Technology framework (ie, performance expectancy, effort expectancy, social influence, and facilitating conditions) may offer additional insights into an individual's decision-making process related to telehealth adoption and integration into routine health care management [28].

Performance Expectancy

Our findings emphasize the significant influence of health-related determinants on telehealth adoption and ongoing use. This aligns with the concept of performance expectancy, whereby a person's decision to adopt a technology is influenced by the degree to which they believe the technology will help them [28]. Our findings indicate that an individual's decision to adopt telehealth was significantly related to poorer health with those experiencing disability, chronic disease, or multimorbidity more likely to adopt and use telehealth across all levels. Moreover, experiencing missed or delayed care, experiencing psychological distress, and reporting a low perceived quality of life were also associated with moderate levels of telehealth use compared with those in the relevant reference groups. A systematic review by Wang et al [22] highlighted performance expectancy as a significant determinant of technology adoption among older adults. In this study, individuals reporting higher numbers of physical conditions and disability were found to be more willing to adopt long-distance caregiving technologies, including telehealth, to support their health and independence [22]. In addition, Mao et al [15] and Choi et al [12] similarly observed chronic conditions, multimorbidity, impairments with activities of daily living, and mental distress were determinants of telehealth use among their cohorts of older adults, further supporting the proposition that perceived health benefits drive technology adoption and use among older populations.

Effort Expectancy

Our findings did not directly access effort expectancy, defined as perceived ease of use [28]; however, they do suggest an indirect relationship. Indicators, such as early or prior adoption and patterns of telehealth use, assist in explaining this construct. The logistic regression results revealed that early or prior exposure to telehealth (as assessed in survey 1) was a predictor of its sustained use in survey 5. Furthermore, in survey 1, approximately 50% of participants indicated that they probably would recommend telehealth to others, with an additional 21% indicating a definite willingness to endorse the use of telehealth services. These findings imply that initial, positive experiences with telehealth foster adoption. In addition, the high preference for telephone modes of telehealth (88.95% in survey 1) and low preference for video modes (3.16% in survey 1) suggests that familiarity with ICT mediums influences adoption. These observations collectively support the notion that perceived ease of use is a key factor influencing telehealth adoption among older adults.

Dykgraaf et al [4] emphasize the significance of ensuring that telehealth services are user-friendly in their design, supporting the need for telehealth platforms to use familiar technology and intuitive interfaces, particularly for enhancing usability by older people. Moreover, Choi et al [12] observed that ICT ownership and having the knowledge to use technology were significant enablers of telehealth use during the COVID-19 pandemic, suggesting that both familiarity with technology and the knowledge to use it are essential requisite skills required for adoption. This may be especially pertinent for those aged ≥85 years, who, in our analysis, were found to be less likely to exhibit high levels of telehealth use when compared with their younger peers. These results are again congruent with findings by Choi et al [12], whereby those of older age (>80 years) demonstrated decreased odds for telehealth use. Bridging this aspect of the digital divide is crucial, as a lack of ICT access and digital skills is a known barrier to telehealth adoption for older people [4,12]. However, according to Kruse et al [10] technology acceptance in older age groups may be more aligned with preferences for in-person health care, declaring that public policy may not help in this area and that health care providers may need to accept this preference.

Social Influence

The role of social influence, defined as how individuals perceive the importance others place on using telehealth, also appears to play a role in an older person's decision to adopt and use telehealth. In our analysis, individuals living with ≥1 other person were significantly more likely to adopt and have high use of telehealth compared with those who live alone ($P<.001$), suggesting an enabling effect. This could be through direct encouragement or through indirect influence of observing other's positive experiences with telehealth. Wang et al [39] identified social support as a critical element in fostering telehealth adoption for older adults. A systematic review investigating factors influencing the acceptance of technology for aging in place additionally revealed the social environment as a determining factor [40]. In particular, the influence of children, health professionals, and caregivers was associated with technology adoption. The enabling effects of social influence on technology adoption are also suggested to increase as personal dependence on health care services increases, with older people being more open to influence by others, given their changing health circumstances [28].

In addition, from our analysis, approximately 50% of participants who used telehealth in survey 1 indicated that they probably would recommend telehealth to others, with an additional 21% indicating a definite willingness to endorse the use of telehealth. These findings suggest that a positive experience with telehealth may influence its social advocacy, with telehealth services being recommended to others. Similarly, poor experiences with telehealth may negatively affect the social advocacy of telehealth. For example, a mixed methods social media survey ascertained the experiences of telehealth use among a general population of Australians (>18 years, n=369) during the COVID-19 pandemic [9]. Findings from this study revealed that for many users, their telehealth experience was poor, as the service did not meet their health care needs and expectations. Contributing factors included a lack of visual cues, eye contact, and body language; an inability to be physically assessed; poor audio quality; poor connectivity; being seen by unknown health care providers; and feeling rushed when using telehealth services [9]. Experiences such as these will influence social advocacy for the use of telehealth services and are particularly relevant given that our findings indicate that approximately 24% of our sample that used telehealth probably will not and 3% definitely will not recommend telehealth services to someone else.

Facilitating Conditions

Facilitating conditions, reflecting the degree to which a person believes that infrastructure exists to support their use of the technology, also influenced telehealth adoption [28]. Although the infrastructure required to support telehealth was in place and incentivized, it was less likely to be adopted or used by those living in inner regional, outer regional, rural, and very remote areas. It is well known that the IT infrastructure required to support telehealth varies in Australia especially for those living outside of city areas, thus limiting access [20]. Given that both moderate and high telehealth use were more likely to occur for participants living in a major city, it may be that underdeveloped digital technology infrastructure also led to disproportionate telehealth service access during this time [20].

Implications of Findings

When considered alongside the principal findings, the expansion of telehealth services necessitates a nuanced understanding of the diverse factors that influence telehealth adoption and use behaviors, particularly for older Australians. This study revealed that high telehealth use was prevalent among women, those younger than 85 years, those residing within major cities, those who live with others, and those of socioeconomic disadvantage. The observed higher frequency of telehealth use among women compared with men suggests potential gender-related barriers to telehealth adoption. Gender differences in telehealth use have been noted in various studies. Choi et al [12] found that gender was not a significant predictor of telehealth use. In contrast, Mao et al [15] reported that women, especially those with chronic conditions and poorer mental health, were more likely to use telehealth compared with men. A more recent study by Haimi and Sergienko [41] also observed that women significantly increased their use of telehealth services during the COVID-19 pandemic across different types of telehealth services.

A recent rapid review by Turcotte et al [42] found age and gender to be moderating factors (barriers and enablers) for telehealth use, highlighting that older men, in particular, might face barriers related to mental health care that could affect their telehealth adoption. They noted that further research is required to understand gender differences in telehealth service use. To increase the frequency of telehealth adoption and use among older men, targeted strategies could include addressing specific concerns related to technology use, providing gender-sensitive training and support, and highlighting the benefits of telehealth for managing health conditions that are more prevalent among men. Encouraging health care providers to actively engage older male patients in discussions about telehealth options may also help increase adoption rates.

The provision of telehealth services for chronic disease and disability management shows promise as being associated with high telehealth use. Early or prior telehealth experiences that are perceived as positive and that use familiar technology require thoughtful consideration, potentially facilitating sustained use among this cohort. Telehealth technology is well positioned to overcome geographic barriers, particularly as specialist health care professionals in Australia, required to treat and manage chronic disease and disability, are concentrated within metropolitan areas [20]. However, significant investments are required to support information technology infrastructure for those living outside of city areas. As IT infrastructure improves, piloting specialist chronic disease telehealth models of care that link city specialists to those outside of these areas, using hybrid telehealth modes (combining in-person and telehealth), is one area for future research. To increase older adults' willingness to adopt and use telehealth, subjective improvements, such as increasing awareness about the benefits of telehealth, providing user-friendly interfaces, and ensuring positive initial experiences with telehealth services, are essential. In addition, offering personalized assistance and training to build confidence in using telehealth technology may enhance the willingness to adopt telehealth into their nonpandemic health care routines.

Limitations

The insights derived from this large-scale study on telehealth adoption and use during the COVID-19 pandemic by people aged ≥65 years are instrumental in understanding behavioral trends. However, the study's cross-sectional nature limits our ability to infer causality despite identifying a temporal association between early telehealth use and sustained adoption. Self-reporting can introduce bias, potentially skewing the motivations behind telehealth use, especially given the variation in wording of questions across surveys. This is particularly relevant as, although we observed a higher reliance on telephone-based telehealth compared with video-based telehealth in the survey 1 time point, the question was not asked uniformly across surveys, and we could not provide trends of telephone and video telehealth use over time. Although the size of the cohort lends credibility to the generalizability of our findings, it does not fully capture individual longitudinal experiences or control for all potential confounding variables. In addition, the high level of technology literacy within our cohort might not reflect the broader older Australian population, who may encounter different challenges, as indicated by the underrepresentation of culturally and linguistically diverse participants. There is a clear need for longitudinal studies to trace the telehealth adoption journey over time and to consider a more diverse population to enhance the applicability of the findings.

Conclusions

This study investigated the sociodemographic and health-related determinants influencing telehealth adoption and use among a cohort of older Australians during the COVID-19 pandemic. Our findings revealed that health-related characteristics, including those living with a disability, having a chronic disease, and multimorbidity, were significant predictors of telehealth adoption and ongoing use. Early or prior telehealth adoption was also found to be associated with its sustained use, independent of health-related factors, highlighting the importance of initial positive user experiences, familiarity with technology, and ease of use of the telehealth platforms required for this population. This research contributes to the broader understanding of telehealth adoption and use among older adults and highlights the necessity for targeted strategies to support its integration into routine health care delivery for older adults. As the world continues to navigate the pandemic and witnesses the increasing prevalence of noncommunicable chronic disease, our findings provide a foundation for policymakers and health care providers to optimize telehealth services, thereby promoting equitable health care access and supporting the well-being of older populations.

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Data Availability

The data sets analyzed for this study are not publicly available as they are privately owned and accessed through The Sax Institute. All data analyzed during this study are included in this published article.

Conflicts of Interest

None declared.

References

1. Jones D, Galvez R, Evans D, Hazelton M, Rossiter R, Irwin P, et al. The integration and application of Extended Reality (XR) technologies within the general practice primary medical care setting: a systematic review. Virtual Worlds 2023 Nov 02;2(4):359-373. [doi: 10.3390/virtualworlds2040021]
2. Taylor A, Caffery LJ, Gesesew HA, King A, Bassal AR, Ford K, et al. How Australian health care services adapted to telehealth during the COVID-19 pandemic: a survey of telehealth professionals. Front Public Health 2021 Feb 26;9:648009 [FREE Full text] [doi: 10.3389/fpubh.2021.648009] [Medline: 33718325]
3. Lee J, Park JS, Wang KN, Feng B, Tennant M, Kruger E. The use of telehealth in Australia during the coronavirus (COVID-19) pandemic for medical practitioners: a retrospective epidemiological analysis. Asia Pac J Health Manag 2022;17(3). [doi: 10.24083/apjhm.v17i3.1433]
4. Hall Dykgraaf S, Desborough J, Sturgiss E, Parkinson A, Dut GM, Kidd M. Older people, the digital divide and use of telehealth during the COVID-19 pandemic. Aust J Gen Pract 2022 Sep;51(9):721-724 [FREE Full text] [doi: 10.31128/AJGP-03-22-6358] [Medline: 36045630]
5. Implementing telemedicine services during COVID-19 : guiding principles and considerations for a stepwise approach. World Health Organization. 2020 Nov 13. URL: https://www.who.int/publications/i/item/WPR-DSE-2020-032 [accessed 2024-05-18]
6. Haimi M, Gesser-Edelsburg A. Application and implementation of telehealth services designed for the elderly population during the COVID-19 pandemic: a systematic review. Health Informatics J 2022;28(1):14604582221075561 [FREE Full text] [doi: 10.1177/14604582221075561] [Medline: 35175881]
7. Fisk M, Livingstone A, Pit SW. Telehealth in the context of COVID-19: changing perspectives in Australia, the United Kingdom, and the United States. J Med Internet Res 2020 Jun 09;22(6):e19264 [FREE Full text] [doi: 10.2196/19264] [Medline: 32463377]

8. Doraiswamy S, Jithesh A, Mamtani R, Abraham A, Cheema S. Telehealth use in geriatrics care during the COVID-19 pandemic-a scoping review and evidence synthesis. Int J Environ Res Public Health 2021 Feb 11;18(4):1755 [FREE Full text] [doi: 10.3390/ijerph18041755] [Medline: 33670270]
9. Isautier JM, Copp T, Ayre J, Cvejic E, Meyerowitz-Katz G, Batcup C, et al. People's experiences and satisfaction with telehealth during the COVID-19 pandemic in Australia: cross-sectional survey study. J Med Internet Res 2020 Dec 10;22(12):e24531 [FREE Full text] [doi: 10.2196/24531] [Medline: 33156806]
10. Scott Kruse C, Karem P, Shifflett K, Vegi L, Ravi K, Brooks M. Evaluating barriers to adopting telemedicine worldwide: a systematic review. J Telemed Telecare 2018 Jan;24(1):4-12 [FREE Full text] [doi: 10.1177/1357633X16674087] [Medline: 29320966]
11. Miyawaki A, Tabuchi T, Ong MK, Tsugawa Y. Age and social disparities in the use of telemedicine during the COVID-19 pandemic in Japan: cross-sectional study. J Med Internet Res 2021 Jul 23;23(7):e27982 [FREE Full text] [doi: 10.2196/27982] [Medline: 34259641]
12. Choi NG, DiNitto DM, Marti CN, Choi BY. Telehealth use among older adults during COVID-19: associations with sociodemographic and health characteristics, technology device ownership, and technology learning. J Appl Gerontol 2022 Mar;41(3):600-609 [FREE Full text] [doi: 10.1177/07334648211047347] [Medline: 34608821]
13. Esber A, Teufel M, Jahre L, In der Schmitten J, Skoda EM, Bäuerle A. Predictors of patients' acceptance of video consultation in general practice during the coronavirus disease 2019 pandemic applying the unified theory of acceptance and use of technology model. Digit Health 2023 Jan 18;9:20552076221149317 [FREE Full text] [doi: 10.1177/20552076221149317] [Medline: 36815005]
14. National strategic framework for chronic conditions. Department of Health and Aged Care, Australian Government. 2019. URL: https://www.health.gov.au/resources/publications/national-strategic-framework-for-chronic-conditions?language=en [accessed 2024-05-18]
15. Mao L, Mohan G, Normand C. Use of information communication technologies by older people and telemedicine adoption during COVID-19: a longitudinal study. J Am Med Inform Assoc 2023 Nov 17;30(12):2012-2020 [FREE Full text] [doi: 10.1093/jamia/ocad165] [Medline: 37572310]
16. Ivancic L, Bond DM, Nassar N. Impact of the COVID-19 pandemic on access and use of health services by middle-aged and older Australians. Aust Health Rev 2023 Feb;47(1):100-109 [FREE Full text] [doi: 10.1071/AH22183] [Medline: 36395815]
17. Sachs JW, Graven P, Gold JA, Kassakian SZ. Disparities in telephone and video telehealth engagement during the COVID-19 pandemic. JAMIA Open 2021 Aug 02;4(3):ooab056 [FREE Full text] [doi: 10.1093/jamiaopen/ooab056] [Medline: 34632322]
18. Disability, ageing and carers, Australia: summary of findings. Australian Bureau of Statistics. URL: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings [accessed 2024-05-18]
19. Regional population by age and sex. Australian Bureau of Statistics. URL: https://www.abs.gov.au/statistics/people/population/regional-population-age-and-sex [accessed 2024-05-18]
20. Evidence base for additional investment in rural health in Australia. National Rural Health Alliance. 2023 Jun 23. URL: https://www.ruralhealth.org.au/document/evidence-base-additional-investment-rural-health-australia [accessed 2024-05-18]
21. Older Australians. Australian Institute of Health and Welfare. 2023. URL: https://www.aihw.gov.au/reports/older-people/older-australians/contents/health/health-status-and-functioning [accessed 2024-05-18]
22. Wang J, Fu Y, Lou V, Tan SY, Chui E. A systematic review of factors influencing attitudes towards and intention to use the long-distance caregiving technologies for older adults. Int J Med Inform 2021 Sep;153:104536. [doi: 10.1016/j.ijmedinf.2021.104536] [Medline: 34325206]
23. Schroeder T, Dodds L, Georgiou A, Gewald H, Siette J. Older adults and new technology: mapping review of the factors associated with older adults' intention to adopt digital technologies. JMIR Aging 2023 May 16;6:e44564 [FREE Full text] [doi: 10.2196/44564] [Medline: 37191976]
24. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Manag Sci 1989 Aug 1;35(8):982-1003. [doi: 10.1287/mnsc.35.8.982]
25. Davis FD. A technology acceptance model for empirically testing new end-user information systems : theory and results. Massachusetts Institute of Technology. 1986. URL: https://dspace.mit.edu/handle/1721.1/15192 [accessed 2024-05-18]
26. Glanz K, Rimer BK, Viswanath K. Health Behavior: Theory, Research, and Practice. Hoboken, NJ: John Wiley & Sons; 2015.
27. Tao D, Wang T, Wang T, Zhang T, Zhang X, Qu X. A systematic review and meta-analysis of user acceptance of consumer-oriented health information technologies. Comput Hum Behav 2020 Mar;104:106147 [FREE Full text] [doi: 10.1016/j.chb.2019.09.023]
28. de Veer AJ, Peeters JM, Brabers AE, Schellevis FG, Rademakers JJ, Francke AL. Determinants of the intention to use e-Health by community dwelling older people. BMC Health Serv Res 2015 Mar 15;15:103 [FREE Full text] [doi: 10.1186/s12913-015-0765-8] [Medline: 25889884]
29. Leatherdale ST. Natural experiment methodology for research: a review of how different methods can support real-world research. Int J Soc Res Methodol 2018 Jul 02;22(1):19-35. [doi: 10.1080/13645579.2018.1488449]

30. Dawson G, Bleicher K, Baynes S, D'Este C, Steinberg J, Weber MF, et al. 45 and Up COVID Insights: a dynamic and collaborative approach to evidence-making during the COVID-19 pandemic. Public Health Res Pract 2022 Dec 13;32(4):32232214 [FREE Full text] [doi: 10.17061/phrp32232214] [Medline: 36065021]
31. Bleicher K, Summerhayes R, Baynes S, Swarbrick M, Navin Cristina T, Luc H, et al. Cohort profile update: the 45 and up study. Int J Epidemiol 2023 Feb 08;52(1):e92-101 [FREE Full text] [doi: 10.1093/ije/dyac104] [Medline: 35604374]
32. Technical note: The 45 and up study COVID data hub. Sax Institute. 2022 Nov. URL: https://www.saxinstitute.org.au/wp-content/uploads/Technical-Note-The-45-and-Up-Study-COVID-Data-Hub.pdf [accessed 2024-05-18]
33. COVID Data Hub: overview for researchers and policymakers. Sax Institute 45 and Up Study. 2022. URL: https://www.saxinstitute.org.au/wp-content/uploads/Factsheet-45-and-Up-Study-COVID-Data-Hub_August-2022.pdf [accessed 2024-05-18]
34. Remoteness areas. Australian Bureau of Statistics. 2023 Mar 21. URL: https://www.abs.gov.au/statistics/standards/australian-statistical-geography-standard-asgs-edition-3/jul2021-jun2026/remoteness-structure/remoteness-areas [accessed 2024-05-18]
35. Socio-Economic Indexes For Areas. Australian Bureau of Statistics. 2023 Apr 27. URL: https://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa [accessed 2024-05-18]
36. Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SL, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. Psychol Med 2002 Aug;32(6):959-976. [doi: 10.1017/s0033291702006074] [Medline: 12214795]
37. De Jong Gierveld J, van Tilburg T. The De Jong Gierveld short scales for emotional and social loneliness: tested on data from 7 countries in the UN generations and gender surveys. Eur J Ageing 2010 Jun;7(2):121-130 [FREE Full text] [doi: 10.1007/s10433-010-0144-6] [Medline: 20730083]
38. Information paper: use of the Kessler psychological distress scale in ABS health surveys, Australia, 2007-08. Australian Bureau of Statistics. 2012. URL: https://www.abs.gov.au/ausstats/abs@.nsf/mf/4817.0.55.001 [accessed 2024-05-18]
39. Wang KH, Chen G, Chen HG. A model of technology adoption by older adults. Soc Behav Pers Int J 2017;45(4):563-572. [doi: 10.2224/sbp.5778]
40. Peek ST, Wouters EJ, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJ. Factors influencing acceptance of technology for aging in place: a systematic review. Int J Med Inform 2014 Apr;83(4):235-248. [doi: 10.1016/j.ijmedinf.2014.01.004]
41. Haimi M, Sergienko R. Adoption and use of telemedicine and digital health services among older adults in light of the COVID-19 pandemic: repeated cross-sectional analysis. JMIR Aging 2024 Apr 24;7:e52317 [FREE Full text] [doi: 10.2196/52317] [Medline: 38656768]
42. Turcotte S, Bouchard C, Rousseau J, DeBroux Leduc R, Bier N, Kairy D, et al. Factors influencing older adults' participation in telehealth interventions for primary prevention and health promotion: a rapid review. Australas J Ageing 2024 Mar;43(1):11-30. [doi: 10.1111/ajag.13244] [Medline: 38014903]
43. Sax Institute homepage. Sax Institute. URL: https://www.saxinstitute.org.au/ [accessed 2024-07-29]

Abbreviations

CALD: cultural and linguistic diversity
ICT: information and communication technology

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Original Paper

Requirement Analysis of Different Variants of a Measurement and Training Station for Older Adults at Risk of Malnutrition and Reduced Mobility: Focus Group Study

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Abstract

Background: Demographic change is leading to an increasing proportion of older people in the German population and requires new approaches for prevention and rehabilitation to promote the independence and health of older people. Technical assistance systems can offer a promising solution for the early detection of nutritional and physical deficits and the initiation of appropriate interventions. Such a system should combine different components, such as devices for assessing physical and nutritional status, educational elements on these topics, and training and feedback options. The concept is that the whole system can be used independently by older adults (aged ≥70 years) for monitoring and early detection of problems in nutrition or physical function, as well as providing opportunities for intervention.

Objective: This study aims to develop technical and digital elements for a measurement and training station (MuTs) with an associated app. Through focus group discussions, target group requirements, barriers, and favorable components for such a system were identified.

Methods: Older adults (aged ≥70 years) were recruited from a community-based setting as well as from a geriatric rehabilitation center. Focus group interviews were conducted between August and November 2022. Following a semistructured interview guideline, attitudes, requirements, preferences, and barriers for the MuTs were discussed. Discussions were stimulated by videos, demonstrations of measuring devices, and participants’ ratings of the content presented using rankings. After conducting 1 focus group in the rehabilitation center and 2 in the community, the interview guide was refined, making a more detailed discussion of identified elements and aspects possible. The interviews were recorded, transcribed verbatim, and analyzed using content analysis.

Results: A total of 21 older adults (female participants: n=11, 52%; mean age 78.5, SD 4.6 years) participated in 5 focus group discussions. There was a strong interest in the independent measurement of health parameters, such as pulse and hand grip strength, especially among people with health problems who would welcome feedback on their health development. Participants emphasized the importance of personal guidance and interaction before using the device, as well as the need for feedback mechanisms and personalized training for everyday use. Balance and coordination were mentioned as preferred training areas in a MuTs. New training options that motivate and invite people to participate could increase willingness to use the MuTs.

Conclusions: The target group is generally open and interested in tracking and optimizing diet and physical activity. A general willingness to use a MuTs independently was identified, as well as a compelling need for guidance and feedback on measurement and training to be part of the station.

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KEYWORDS

gerontechnology; physical activity; diet; technical assistance system; health data; qualitative research

Introduction

Background

As a result of demographic change, the proportion of older people (aged ≥67 years) in the total population in Germany is steadily increasing. It is predicted that, by 2040, a quarter of the total population will be older than 67 years. This demographic change is leading to a decline in the working population, including in the health and care sectors. In this context, new approaches to prevention and rehabilitation are needed to enable older people to live longer, more independent, and healthier lives [1,2]. This pursuit of longer independence and well-being is known as healthy aging and aims to maintain mental, physical, and social health for as long as possible. The 2 important elements of healthy aging are a balanced diet and regular physical activity. These 2 elements not only influence each other, but are also linked to other determinants, such as cognitive health [3]. Individuals aged >80 years, women, those with multiple comorbid conditions, and older adults living alone are at higher risk for malnutrition [4,5]. Among older people living in the community, the prevalence of being at risk of malnutrition, as measured by the Mini Nutritional Assessment or Mini Nutritional Assessment Short Form, is 19% and is significantly associated with reduced physical functioning, reduced independence in activities of daily living, and the presence of physical frailty and sarcopenia [6,7]. Low physical activity is generally associated with an increased risk of death; in particular, people who spend >10 hours a day sitting have a significantly increased risk of death [8]. For people with sarcopenia, that is a significant loss of muscle mass, function, or strength, or any combination, exercise training and nutritional interventions are among the most effective interventions to improve strength, walking speed, and balance [9]. In addition to structural and health system conditions, the health literacy of older people plays a crucial role in healthy aging. Although health literacy in Germany is somewhat higher than in other European countries, 54% of people aged >76 years have limited health literacy and may have limited knowledge about the importance of a balanced diet and sufficient physical activity in older age [10]. Older adults with low health literacy have been found to have lower levels of physical activity [11,12]. In the area of dietary adherence, current evidence from systematic reviews suggests that improving self-efficacy expectations is a key factor in the long-term implementation of healthy eating habits [12,13]. Accordingly, strategies such as psychological models should be used to increase participants' self-efficacy expectations. To be able to respond to problems in these areas at an early stage, it would make sense to regularly check the nutritional and physical status of older people. In practice, however, such screening and advice are often not carried out due to a lack of resources and information about available interventions [14].

A technical assistance system could be an approach for the early detection of nutritional and physical activity deficits and the initiation of appropriate measures. Several approaches already exist to enable older adults to self-report nutrition and physical activity parameters. Parts of the geriatric assessment can already be automated [15-17]. In addition, there are programs that support older people to independently implement interventions to improve dietary and physical activity behavior [18-21]. However, most of these programs are interventions without automated assessment and are targeted at people with high functionality or specific medical conditions. A technical assistance system that can objectively measure the nutritional and physical activity status of community-dwelling older adults, as well as provide individualized feedback and training, could help to identify deficits at an early stage for secondary prevention, prevent negative health outcomes, and reduce the burden on the health care system.

However, before developing such a system, it is important to analyze in detail the general acceptance of older people for it, as well as their needs and their specific requirements for implementation and design.

Aim

The aim of the study was to identify technical and digital elements that could be integrated into the technical assistance system to develop a system that is as effective and usable as possible. In addition, the target group's requirements for the system and the general conditions for its use were determined.

Methods

Ethical Considerations

The study was approved by the ethical review board of the Carl von Ossietzky Universität Oldenburg (registration 2022-089). We conducted the study in accordance with the Declaration of Helsinki [22], as amended, and the underlying data protection regulation. Reporting followed the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist for interviews and focus groups [23]. All participants included in the study provided written informed consent.

Participants

We recruited the participants from a geriatric rehabilitation center and in the community in the northwest of Germany.

Flyers were placed on the wards of the geriatric rehabilitation center and the electronic patient database was checked by a member of the study team for patients aged >70 years without known cognitive impairment. These patients were contacted and informed about the study.

Recruitment of the older adults in the community was done by placing flyers and organizing information sessions in various community-based organizations and settings, for example, sports groups for older adults, community or church-run public meeting places, and classes for older adults.

Interested people were approached in a face-to-face meeting to answer questions about the project and, if consent was given, to check the inclusion criteria. Inclusion criteria were (1) aged

≥70 years; (2) the presence of malnutrition according to the Mini Nutritional Assessment Short Form (0-7 points) or the presence of 1 or more risk factors for malnutrition: weight loss in the last 3 months, reduced food intake in the last 3 months, or a reduced BMI (<23 kg/m²) [24]; and (3) presence of 1 or more signs of reduced mobility (walking speed <0.8 m/s and Short Physical Performance Battery <8 points). Exclusion criteria were (1) lack of ability to give consent and (2) insufficient ability to understand the study content and procedure or the German language. Eligible persons were interviewed for sociodemographic data (sex and age), and technology commitment was assessed using a questionnaire by Neyer et al [25] with a 5-point Likert scale with 12 items about personal contact, interest, and general use of technology. A higher score indicates a higher technology commitment [25].

Once 6 suitable participants agreed and their eligibility was checked, a date for the focus group was arranged. All focus groups were held in person. To minimize the burden on the participants, the focus groups were held in the rehabilitation center, in the rooms of the respective sports club or senior citizens' program, or the facilities of the study team, depending on the participants' preference. There were no repeated discussions, and each participant was only allowed to take part in 1 focus group.

Interview Guide

On the basis of the project objective, which was the development of a measurement and training station (MuTs) and corresponding app that could be used independently, key issues were identified for discussion in the focus groups. This was done through discussions within the project team involving people from different professions, such as nutritionists, physiotherapists, physicians, and computer scientists. For the selection of the health data and sensors to be presented, it was checked which possibilities for autonomous recording already exist and which parameters have already been identified in other work in other contexts as relevant for older adults, such as activity sensors, which can have a motivational effect to increase activity. In terms of training equipment, the aim was to represent different training areas and types of training. The areas chosen were endurance (bicycle ergometer), balance (oscillatory platform), coordination and cognition (exergaming system), strength training using body weight (3D depth image–based training correction), and everyday training (exercise stairs). The devices presented were also selected to ensure that independent training was possible. In the first phase of the focus groups (focus groups 1-3), these 5 training options were presented to the participants. In focus groups 4 and 5, only the 3 variants that had received the highest approval in the previous groups were shown. These were the oscillating platform, the exergaming system, and the 3D depth image–based training correction.

The guide was pretested with a pilot focus group of community-dwelling older adults and minor adjustments were made. The selection of devices was also discussed in the pilot focus group, and it was emphasized that the opportunity for participants to contribute their own experiences and wishes regarding measurement and training devices could and should be included in the discussions. The participants of the pilot focus group were not involved in the focus groups 1 to 5). The final interview guide covered 4 main topics in the first focus groups (focus groups 1-3) presented in Textbox 1.

Following the first 3 focus groups, the semistructured guide was adapted to obtain more detailed information on the previously identified relevant aspects. The revised interview guide used in focus groups 4 and 5 included 4 main themes presented in Textbox 2.

Textbox 1. Main topics covered in focus groups 1 to 3.

Relevant health data and measurement tools for independent use

- Presentation of different health data and measurement devices
- Participants were asked to mark on paper with photos of the devices what they were interested in and what they could imagine using
- Open discussion on the participants' choice

Exercise or training options that are of interest for use in the measurement and training station (MuTs)

- Presentation of different training devices through videos
- Each participant should enter numbers from 1 (most likely to be used in the MuTs) to 5 (least likely to be used) in an overview of training devices
- Open discussion about the participant's choice

Frequency and amount of time the participants were willing to spend in the MuTs

- Brainstorming: Participants were asked to express their thoughts on the frequency of measurement and training, and statements were written on posters

Using the MuTs and receiving instructions

- Participants were asked to express their thoughts and needs, and statements were written on a large poster

Textbox 2. Main themes included in focus groups 4 and 5.

Usability of an electronic device for measuring handgrip strength (KForce Grip, Kinvent Biomecanique) and requirements for a corresponding evaluation screen

- Demonstration of the handgrip strength measuring device and testing by participants
- Open discussion on thoughts and experiences during measurement
- Presentation of 3 different mock-ups of the grip strength feedback screen; each participant was given 3 printouts and asked to mark what they liked and disliked
- Open discussion on the comprehensibility of the mock-ups and ideas for improvement

Abilities and requirements for self-administered questionnaires

- Demonstration of how to complete the questionnaire on the tablet, with participants trying it out and watching a video of how to complete it on the screen

Exercise or training options that are of interest for use in the measurement and training station

- Presentation of different training devices through videos
- Brainstorming on the pros and cons of the training options

Frequency and amount of time for additional training at home with a corresponding tablet

- Demonstration of the exercise diary on the tablet for participants to try out
- Brainstorming: Participants were asked to express their thoughts on the frequency of measurement and training, and statements were written on posters

Procedure

All focus groups were structured in a standardized way. First, the participants were welcomed and made comfortable with drinks and snacks. Then, a short input was given on the importance of a healthy diet and sufficient physical activity for older adults. The links between diet and physical activity were also discussed. This was followed by a presentation of the project idea of developing a MuTs, accessible to the public, where older people can independently measure their nutritional and physical activity status and have the opportunity to complete a training program and continue training at home using an app. A 3D model of a prototype of the MuTs was shown to give the first spatial impression of such a MuTs. Then, the interviewers introduced themselves and explained their role in the project. The participants were then asked to introduce themselves to the group.

The discussion started following the semistructured interview guide. For each topic, a short prompt was used, for example, showing videos of the use of the different training devices, and field notes were taken. To facilitate discussion, participants were also asked to mark their favorite aspects of health data, measurement devices, and training options with stickers or rank them in order of importance. After the semistructured guide was completed, participants were asked whether they wanted to add anything. Finally, the focus groups were closed by thanking the older adults for their thoughts and discussions. The transcripts of the focus groups were not returned to the participants for organizational reasons.

All interviews, except focus group 2, were conducted by the same 2 female interviewers together (LH and MS). The interviewers are a physiotherapist and a nutritionist working as scientific researchers in the field of technical assistance systems for nutrition and mobility in older adults. Focus group 2 was conducted by MS and VQ, who are a male physician and a computer scientist. At the beginning of each focus group, the aim of the project and the researchers involved with their expertise and credentials were introduced.

The focus group discussions were audio recorded. The length of the focus groups varied from an average of 76 (SD 6.2) minutes in the first 3 focus groups to an average of 96 (SD 11.5) minutes in focus groups 4 and 5.

Analysis

The audio recordings were transcribed by 1 person using f4 software (f4, audiotranskription) in the form of an extended semantic transcription. When identifiable aspects were mentioned, this text was deleted and replaced by neutral words, for example, city. Pseudonyms were used to distinguish between the speakers. All transcripts were checked against the audio recordings by a study team member. A structured qualitative content analysis was conducted according to the concept of Kuckartz [26]. Computer-assisted coding was performed using MAXQDA 2022 software (MAXQDA Analytics Pro 2022; VERBI Software). Two members of the study team (LH and MS) derived main categories a priori from the interview guide. Subcategories were generated inductively during the coding process. LH and MS performed the coding process independently and then discussed the categories and coding critically until consensus was reached. Code saturation was checked by analyzing how many new categories could be found using additional focus groups [27]. The project's participatory research council, consisting of older adults (aged ≥70 years), reviewed and critically discussed the material and categories for discrepancies in interpretation or understanding.

Results

Overview

A total of 21 older adults (female participants: n=11, 52%; mean age 78.5, SD 4.6 years) participated in the focus group discussions. In round 1, only 2 (33%) of the originally recruited 6 people participated in the first community-based focus group. It was, therefore, decided to conduct a second community-based focus group in this round with n=5 participants (42% of the total from the second round). Of the 9 older adults in the second round, 5 (55%) older adults participated in the community-based focus group and 4 (45%) in the rehabilitation focus group. The characteristics of the participants of the 5 focus groups are shown in Table 1.

The content analysis of the focus groups 1 to 3 revealed 6 main categories with 19 subcategories (Multimedia Appendix 1). After focus group 1, there were 17 (89%) subcategories out of 19 subcategories. The 2 new subcategories were both created after the analysis of focus group 2. Focus group 3 did not produce any new subcategories. In the focus groups with the revised interview guide, 5 main categories with 15 subcategories were found (Multimedia Appendix 2). In focus group 4, a total of 14 (93%) subcategories of the 15 subcategories were found in the focus group that took place in the rehabilitation center. Moreover, 1 additional subcategory was found in the community focus group (focus group 5).

Table 1. Overview of participants characteristics (N=21).

	Round 1			Round 2	
	Rehabilitation (n=5)	Community 1 (n=2)	Community 2 (n=5)	Rehabilitation (n=4)	Community (n=5)
Sex (female), n (%)	3 (60)	1 (50)	2 (40)	1 (25)	4 (80)
Age (y), mean (SD)	82.8 (3.1)	78.5 (0.5)	76.6 (3.6)	78.3 (4.0)	77.8 (5.1)
SPPB[a] (score),mean (SD)	4.8 (1.3)	8.5 (0.5)	9.6 (1.7)	7.5 (1.8)	7.8 (2.2)
MNA-SF[b] (score), mean (SD)	7.8 (2.8)	9.4 (1.9)	9.5 (0.5)	8.5 (3.5)	7.8 (1.0)
TC[c] (score), mean (SD)	30.8 (8.8)	36.0 (1.0)	37.2 (5.1)	45.0 (6.0)	42.8 (8.6)

[a] SPPB: Short Physical Performance Battery.

[b] MNA-SF: Mini Nutritional Assessment Short Form.

[c] TC: technology commitment.

Round 1

Health Data and Measurements

Participants expressed a general interest in different types of health data. Most of them were also very interested in self-measurement in the MuTs. Some health data were already regularly measured at home by older adults, such as blood pressure and the number of steps. They also mentioned that measuring health data is of special interest if they have a disease or health limitation related to these health data, especially in the discussion about cardiovascular diseases. The participants discussed that health data should be assessed every time they visit the MuTs, with some people also expressing concerns about measuring too much data because of the psychological stress that can be caused by a huge amount of different data and not listening to themselves and how they feel:

> *What's the point of all these measurements and, um, these people wearing these watches and all that.... I want to live and not control myself all the time.* [Female, 79 years]

As different types of health data were shown and discussed, we found that handgrip strength measurement was largely unknown to our participants. After explanation, most participants expressed interest in this parameter. Different opinions were expressed regarding the assessment of oxygen saturation. Some participants were very interested and explained that this health data would be useful in combination with a fitness tracker to assess physical activity. However, some participants also had concerns about the interpretability of this data.

Measuring activity was relevant for almost all participants but more as an assessment in everyday life and not as part of every visit to the MuTs. Measuring activity during the visit to the MuTs was discussed, and it was expressed that it would be biased if activity was only measured during the visit. Some participants expressed that it should be combined with the collection of other health data, such as pulse or oxygen saturation.

The evaluation of cardiological health data in the MuTs was discussed intensively. Participants were especially interested in pulse and blood pressure data and mentioned that these are the data that most of them measure at home. In particular, people with cardiovascular disease expressed a general interest in this type of health data. Other cardiological data, such as electrocardiography (ECG) and heart sounds, were described as data that should be assessed and evaluated by physicians and not as part of MuTs:

> *Um, and ECG less, because that's a story that I think is a bit more difficult in terms of effort and too many mistakes can be made. Um, I think it's very difficult when there are methods that are easy, ok, but yes.* [Male, 77 years]

Using Measuring Devices

The handling of the different devices (blood pressure monitor [wrist and upper arm], fitness tracker [wrist and clip], and hand dynamometer) was described as relatively easy by all participants, with the exception of the upper arm blood pressure monitor, where participants reported difficulties with the readability of the display. Some devices were already used regularly by participants, most commonly blood pressure monitors (wrist) and fitness trackers. People who already used devices also reported varying degrees of difficulty or compliance with regularly monitoring their blood pressure, and some mentioned that they did not rely on the results. The use of a home emergency call system was raised as an issue by the participants, and including some kind of emergency call system in the MuTs was seen as highly relevant. In general, participants expressed a preference for devices that can measure multiple health outcomes and include some form of direct data transfer to the MuTs:

> *But if I could go to the station and wear this watch and it would immediately measure my steps, pulse and oxygen. That would be very good. So, for me, the difference is that if I go there specifically, I can use more complex things, they give me more.* [Female, 78 years]

Physical Training Variants

To ensure a good training environment, several aspects should be met. These include the relevance of the exercises to everyday life (eg, steps should have real heights, and the training should aim to make everyday life easier and should be individually tailored to the problems of the participants). Another important aspect that was frequently mentioned was safety during the training. For example, the risk of falling should be reduced using handrails.

Although familiar devices would be easier to use, they would be less attractive if they were already available at home. Sports clubs are visited by some participants; further training should only take place if training is not available at the sports club. Instructions from the physician about which sports to avoid are taken very seriously. An advantage of the MuTs over training at home is that there is space for all the training equipment and the availability of new, additional training equipment that participants may not have at home.

Training should challenge different areas and be adapted to the ability of the user. In general, training balance to prevent falls, training reaction time, cognition, and muscle strength for improve everyday activities were described as important. Training should also be fun, enjoyable, and motivating. An insight into one’s own past results would encourage ambition; comparison with the training results of others was rejected. An overly technical look of a training device could be a deterrent.

An overview of the participants’ comments on the different training devices is given in Multimedia Appendix 3. Overall, devices for training coordination and balance were rated higher than those for training endurance. In addition, devices offering training options that are less available in everyday life were preferred.

Range of Use

Almost all participants emphasized that the use of the MuTs should not restrict other areas of life. In many cases, other activities would already compete with the use of the MuTs and take up more time in the lives of older people. In addition, the participants emphasized that self-motivation, the distance to the MuTs, and the travel possibilities had a great influence on the extent to which the station would be used:

> *And I would, um... once a week, because I also want to do other things than for my body, I also want to do something for my mind and for my social life. And I also need time for that. And of course, I need more time for everything than I used to. You have to go slower to get there...yes, everything takes more time.* [Female, 78 years]

One participant expressed that the MuTs should not replace medical examinations but only support or relieve the physician at times when there are no serious health problems.

Many participants stated that they would be guided by official recommendations for use, such as information on the frequency at which training begins to have a positive effect, or how often to measure which health parameter. It was generally stated that the MuTs would not be used spontaneously but would have to be planned in advance by the participants. Participants indicated that they would like to stay between 15 and 90 minutes. Participants most often indicated that 30 to 45 minutes would be appropriate, that a shorter duration would not be worth the journey, and that a longer duration would reduce strength and concentration.

Expectations and Requirements for Using the MuTs

All participants considered human involvement to be an important prerequisite for the use of the MuTs. The initial introduction should always be given by a person, and there should also be the possibility to contact this person in the course of the use of the station if there are any uncertainties or problems. Aspects mentioned regarding the use of the MuTs instructions for measurement or training were asking questions, repeating instructions, or skipping instructions if they were already known. Disadvantages mentioned in the course of use due to the lack of a real trainer were that the station does not provide social interaction to alleviate loneliness and that interaction with a real trainer would lead to more fun, better results, and higher motivation:

> *I have problems with voices talking to me and telling me what to do. That it’s not a person at all. So, for example, with this instruction of what to do, um, it wasn’t clear to me when I was watching, when she said it, should I do it right away or should I listen to it all together and then do it?... And that’s when a certain aggression starts to develop against this machine voice.* [Female, 78 years]

If the health parameters measured in the MuTs deteriorated significantly, a physician should definitely be involved, or the person should be advised to have the change checked out by a physician. Particularly in the case of cardiological measurements, such as an ECG, there was little confidence in a measurement taken on the station, and the importance of involving a physician was highlighted.

The general usability of a touch system to control the MuTs is considered to be good and is already known from other situations (supermarket checkout). Short and simple sentences would be important for the usability of the MuTs, as well as sufficient volume for the audio output to enable people with hearing impairments to use them. For structuring purposes, information should be broken down into small action steps, as it is feared that comprehension may be impaired in the MuTs due to anxiety, excitement, fatigue, or pain.

Round 2

Measuring Handgrip Strength via an Electronic Measurement Device

Although there was no prior knowledge or expectation of handgrip strength measurement, the participants showed great interest and understanding of the relationship between overall muscle status and the measured value. After an explanation of the handgrip strength parameter and its significance, many participants emphasized that they would find regular monitoring useful. The fact that the measurement required little equipment and was quick and not very strenuous was rated positively. Several participants described the process of measuring handgrip strength as logical or not difficult. Opinions differed as to whether instructions should be given once before the first measurement or before each measurement. Options for this were written or audio instructions:

> *And I think it's really good when you're guided through it. So, I start and then it says "next" and then the next picture comes up and then there's the hint again. Something like I have to press again or I have to press now. So, I think that explains it quite well at the beginning because you can see it.* [Female, 74 years]

Many participants emphasized that it should be easy to log in for measurement. A familiar system such as ID cards should be used for registration, or access data should be entered manually.

Presenting and Interpreting Results of Handgrip Strength Measurement

The focus groups generally showed a good understanding of the various examples of graphs showing the results of the grip strength measurements used to stimulate discussion. In general, the diagrams should be short and clear, have strong contrasts, and not be overloaded with too much information (especially text). All participants were in favor of including a cut-off value in the figures so that they could interpret whether their own handgrip strength corresponded to the corresponding standard values and, if necessary, estimate the amount of deviation. An overview of previous measurements would be important to be able to assess one's own development over time.

A graph showing a comparison with other study participants was discussed intensively. Most participants were against a comparison. The comparison was not relevant to them, not interesting, and not very meaningful:

> *That's the thing, I have too much information, I don't need it. I want to know my results.* [Male, 73 years]

Answering Questionnaires on a Touch Screen

To stimulate discussion, participants were shown how to complete a questionnaire on a tablet in the session and a video of the questionnaire being completed on a 139.7 cm touch screen. A general comment was that it would depend on the prior technical knowledge of the participants as to whether problems would arise in completing digital questionnaires. If there was little prior knowledge, an introduction to the technology would be helpful. Further support should be provided depending on the technical skills of the participants:

> *I would have to learn how to deal with it. It's a foreign object to me.... But I would learn, probably.... I would want to learn it, yes.* [Female, 74 years]

The font size of the questions on the tablet was found to be easy to read. However, the legibility on the screen at the station was even better. The advantages of completing the questionnaire at the station were the better clarity and larger font size. Filling in the questionnaire was said to be quicker because everything was immediately visible and there was no need to scroll. Other participants suggested that it was quicker to complete the questionnaire on the tablet. It was also noted that the time window for completing the questionnaire on the tablet was flexible.

Contextual factors were particularly criticized when the questionnaire was completed at the station. The main concern was that the time spent at the station to complete the questionnaire would be significantly longer and that the user would be under time pressure from waiting participants. The perceived time pressure would lead to a lack of concentration and influence response behavior. Another concern expressed by 1 participant was that the data entered could be seen by other participants and that privacy could no longer be guaranteed. It was also criticized that completing the questionnaire in the MuTs was less convenient than at home and that it did not make sense to go to the MuTs just to complete the questionnaire there:

> *You can sit down, you can sit down quietly and concentrate.* [Male, 73 years]

Physical Training Variants

In general, all 3 training options (oscillatory platform, exergaming system, and 3D depth image–based training correction) were well received, as shown in Multimedia Appendix 3. The exergaming system received the most positive feedback and generated the most interest. The various advantages and disadvantages of the 3 training options presented and discussed are summarized in Multimedia Appendix 3. In this focus group phase, the participants also discussed which form of presentation of the 3D depth images they would prefer when using the camera system. The color image was the preferred form of presentation, as the sequence of steps in the exercise is easier to recognize and the exercise is shown more clearly due to the higher contrast.

In general, the adaptability of the training to different performance levels would be important. Regardless of the type of training, many participants considered balance training to be very important and some also considered coordination training to be very important. Participants described how older people were more likely to use familiar equipment. New equipment that requires extensive instruction was more likely to be rejected. Complicated equipment could also be overwhelming for older people. Equipment with multiple components, a lot of technology, or a high susceptibility to faults was rated as complicated. Experiences were reported that frustration quickly sets in, and successes become less visible:

> *Especially the potential for failure. The more you build in, isn't it, the more you run the risk of failing again in the whole story. The simpler it is, the less you can have a mistake somewhere in there.... That also frustrates you. You also want to see some success, or it's not like that.* [Male, 83 years]

Continuing Exercises at Home

As part of this discussion, a digital training plan for the autonomous performance of simple physical exercises at home was shown and found useful by the participants. The training plan itself and the symbols used (exercise duration and number of repetitions) were understood by all participants. The font size and readability were also rated positively. One person with little experience of using tablets was initially very reluctant to use the device and expressed concern about breaking something.

The desired frequency of use per week varied considerably. Most participants favored a training frequency of 2 to 3 times per week, assuming a training duration of 20 to 30 minutes per session.

One of the most frequently mentioned factors influencing the implementation of home exercise was how it could be integrated into the participants' daily lives and how flexible it would be. Both the physical condition of the participants and their own sporting activities or social life were seen as competing with a home exercise program. Adequate space or exercises that do not take up much space would also be a prerequisite for exercising at home. Motivation to exercise also depends on whether success is visible, whether the exercises are variable, and whether exercising has already become an integral part of the participant's everyday life:

> *You might have to move a carpet or two to avoid falling. But that's, that's quite feasible. So, if you...seriously want to do it, you'll find a way.* [Male, 79 years]

Discussion

Principal Findings

The aim of the study was to identify technical and digital elements that could be integrated into the technical assistance system to develop a system that is as effective and usable as possible. In addition, the target group's requirements for the system and the general conditions for its use were determined.

We were able to conduct 3 focus group discussions with older people living in the community and 2 focus group discussions in a geriatric rehabilitation center. Our focus group discussions revealed general interest and openness among the target group to track and optimize nutrition and mobility independently.

When discussing relevant health data and the competence of older people to record it independently in the MuTs, we observed that the willingness and interest to perform measurements seemed to be greater, especially if there was already a health limitation. Similar observations were made in the study by Bian et al [28], which investigated the use of a home sensor system for frailty diagnosis. People who described themselves as healthy and physically active saw less sense in using certain sensors. In the study by Seinsche et al [29], willingness to use an exergame-based telerehabilitation device was evaluated by focus groups. They found that the willingness to use technical devices with a meaningful purpose was even more pronounced than the general willingness to use technology. This demand for a perceived benefit from the use of an assistive technology system had already been observed in an earlier focus group study with older people [30].

Participants in our focus groups were mostly positive about the use of technical measurement devices to collect health data. They were confident enough to use almost all the devices presented independently after receiving instruction. The fact that it often seems to be a prejudice that older people tend to have problems with technology has also been shown in other qualitative studies conducted with older people on the development of MuTs [28,29,31]. The studies by Bian et al [28] and Seinsche et al [29] describe that older people have few problems using technology and are interested in modern technologies. They note that it is particularly important to build confidence and self-efficacy in using technology and that general knowledge of how to use it is usually less of a problem.

Possibly, another factor contributing to the acceptance of automated health records is the age of the study participants. The average age of the participants in our study was 78.5 years. This makes them slightly older than participants in other publications (average age 71.3-76.6 years) on older people's willingness to use and perception of autonomous technical assistance systems in the area of nutrition and activity [28,29,32]. Our study and the other aforementioned studies showed a general willingness to use such systems. On the other hand, a study of people aged >85 years in a nursing home showed that these people were less interested in monitoring their health status [33].

People using the MuTs should also be able to get direct feedback on their measurements and training. For our target group, issues such as simple visualization, reporting of cut-offs and trends, and step-by-step instructions are important. A study of people with multimorbid chronic conditions also described how a simple digital representation of health data could help, as the graphs and tables they receive from their physicians are often not easy to understand [31]. A point also raised by our participants was the synchronization of measurements in a system and their interpretable presentation; this point was also discussed as very important by older people in a study of requirements for sensor-based frailty assessment at home [32].

Despite the general willingness and openness to the possibility of early detection of changes in nutritional and physical activity outcomes and targeted training, it was clear that human involvement was desired. The presumed desired level of involvement varied between the opinion that it would be sufficient if a qualified person introduced the user to the use of the MuTs and the opinion that independent use would not be possible without the constant presence of qualified staff. Therefore, the MuTs should be set up in a public place that is connected to the research facility or, for example, to a physiotherapy practice or a medical facility. Our findings reflect the findings of a scoping review of web-based interventions to promote healthy lifestyles in older adults. The review identified 5 papers that addressed the issue of support. Results of the review showed that although the need for human involvement was emphasized, the desired level of support varied from purely web-based support to a personal introduction to the system to face-to-face sessions with a trainer [34]. Similar results were found in a focus group study with older people on the use of an exergame telerehabilitation program. Participants also felt that human involvement and the possibility of human contact would be important to them [29]. Participants in our focus groups also discussed the desire for a means of contact and the interest in integrating an emergency system. The importance of human involvement in the use of automated measurement systems is also apparent in a qualitative study of the development of a home-based frailty assessment. Participants described concerns about the loss of personal contact with health care professionals when measurements were taken by sensors [32]. In our focus groups, participants also expressed that they would generally welcome a reduction in the burden on physicians and other health care professionals but that the station should rather be used for monitoring over time and that professional advice should be sought if there are signs of health problems, for example, by making an appointment with a physician. During the discussion on the collection of cardiological health data, it also became clear that measurements that are perceived as more complicated or demanding (such as ECG) should be carried out by a physician.

The results of our focus groups indicated that participants were less concerned about data protection and their privacy. Although it was discussed that it would be important for other participants not to be in the same room when completing questionnaires on the MuTs screen, there were no comments about the concerns about general data security or worries about unauthorized access to data collected in the station. In general, there seem to be different perceptions and needs of older people in terms of privacy and data security. While some studies using sensor-based systems in the home environment to collect health data seem to be more associated with concerns about these parameters, and there are also increased concerns in the context of using apps to support the recording of various disease-related symptoms [28,31,32], a study of exergame-based telerehabilitation also reported fewer concerns among participants about data security [29]. Interestingly, the study by Bian et al [28] also explicitly opposed the use of cameras. In our focus groups, participants were shown the analysis of exercise performance using 3D depth cameras, and different types of recording were also discussed, with the color image being the most popular. It is likely that a key difference between our study and the study by Bian et al [28] is that in the study by Bian et al [28], the cameras were installed in the participants' home environment, and in our study, they were installed in the MuTs. This may suggest that, in this context, a more comprehensive collection of health data could be carried out with sensor technology that may be less accepted in the home environment for people who still have sufficient mobility to visit a MuTs.

The results of this study must be considered in the context of a number of limitations. No systematic sampling strategy was used, and the study was not stratified by age or sex. In particular, the second focus group in the rehabilitation center had fewer female participants than the actual proportion of women in this age group in the German population [35]. Recruitment in the rehabilitation center was particularly challenging: As inpatient geriatric rehabilitation in Germany usually lasts about 3 weeks, the focus group appointment had to be arranged quickly after the participants had given their consent and also had to be coordinated with the patients' other therapy measures and appointments. In addition, 1 ward was closed during recruitment due to a COVID-19 outbreak, and patients from this ward could not be recruited. In addition, the main diagnosis of people in geriatric rehabilitation was not recorded. It is, therefore, possible that rehabilitants responded differently depending on their main diagnosis. This cannot be verified with the available data. In general, it cannot be ruled out that more homogeneous focus groups would have allowed for different responses and opinions. Moreover, it is also possible that the focus groups were composed of people who were generally more interested in nutrition, exercise, and technology.

Conclusions

For older people with initial health limitations in particular, the regular use of a MuTs could be a promising approach to enable independent monitoring of nutrition and physical activity status. Important requirements and prerequisites for the development of a MuTs were collected, which will be developed and evaluated with the involvement of the target group. In particular, aspects such as the necessary level of supervision by a real person on site and the independent usability of several measuring and training devices in the context of using the MuTs should be given special consideration in further development.

Acknowledgments

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Data Availability

The data generated during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

LH and RD contributed to the study concept and design. LH, MS, and VQ contributed to the acquisition of data. LH, MS, MF, and VQ contributed to the analysis of data. LH contributed to drafting the manuscript. MS, VQ, MF, and RD revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Coding system for focus groups 1 to 3.
[DOCX File , 13 KB - aging_v7i1e58714_app1.docx]

Multimedia Appendix 2
Coding system for focus groups 4 and 5.
[DOCX File , 13 KB - aging_v7i1e58714_app2.docx]

Multimedia Appendix 3
Presented training options and list of discussed advantages and disadvantages of each training option.
[DOCX File , 16 KB - aging_v7i1e58714_app3.docx]

References

1. Bevölkerung im Wandel: Ergebnisse der 14. koordinierten Bevölkerungsvorausberechnung. Statistisches Bundesamt (Destatis). 2019. URL: https://www.destatis.de/DE/Presse/Pressekonferenzen/2019/Bevoelkerung/bevoelkerung-uebersicht.html [accessed 2024-04-29]
2. Tiemann M, Mohokum M. Demografischer Wandel, Krankheitspanorama, Multimorbidität und Mortalität in Deutschland. In: Tiemann M, Mohokum M, editors. Prävention und Gesundheitsförderung. Berlin, Germany: Springer; 2021:3-11.
3. Abud T, Kounidas G, Martin KR, Werth M, Cooper K, Myint PK. Determinants of healthy ageing: a systematic review of contemporary literature. Aging Clin Exp Res 2022 Jun;34(6):1215-1223 [FREE Full text] [doi: 10.1007/s40520-021-02049-w] [Medline: 35132578]
4. Leij-Halfwerk S, Verwijs MH, van Houdt S, Borkent JW, Guaitoli PR, Pelgrim T, MaNuEL Consortium. Prevalence of protein-energy malnutrition risk in European older adults in community, residential and hospital settings, according to 22 malnutrition screening tools validated for use in adults ≥65 years: a systematic review and meta-analysis. Maturitas 2019 Aug;126:80-89. [doi: 10.1016/j.maturitas.2019.05.006] [Medline: 31239123]
5. Walker-Clarke A, Walasek L, Meyer C. Psychosocial factors influencing the eating behaviours of older adults: a systematic review. Ageing Res Rev 2022 May;77:101597 [FREE Full text] [doi: 10.1016/j.arr.2022.101597] [Medline: 35219902]
6. Verlaan S, Ligthart-Melis GC, Wijers SL, Cederholm T, Maier AB, de van der Schueren MA. High prevalence of physical frailty among community-dwelling malnourished older adults-a systematic review and meta-analysis. J Am Med Dir Assoc 2017 May 01;18(5):374-382 [FREE Full text] [doi: 10.1016/j.jamda.2016.12.074] [Medline: 28238676]
7. Sieber CC. Malnutrition and sarcopenia. Aging Clin Exp Res 2019 Jun;31(6):793-798. [doi: 10.1007/s40520-019-01170-1] [Medline: 31148100]
8. Ekelund U, Tarp J, Steene-Johannessen J, Hansen BH, Jefferis B, Fagerland MW, et al. Dose-response associations between accelerometry measured physical activity and sedentary time and all cause mortality: systematic review and harmonised meta-analysis. BMJ 2019 Aug 21;366:l4570 [FREE Full text] [doi: 10.1136/bmj.l4570] [Medline: 31434697]
9. Wu PY, Huang KS, Chen KM, Chou CP, Tu YK. Exercise, nutrition, and combined exercise and nutrition in older adults with sarcopenia: a systematic review and network meta-analysis. Maturitas 2021 Mar;145:38-48. [doi: 10.1016/j.maturitas.2020.12.009] [Medline: 33541561]
10. Sørensen K, Pelikan JM, Röthlin F, Ganahl K, Slonska Z, Doyle G, et al. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). Eur J Public Health 2015 Dec;25(6):1053-1058 [FREE Full text] [doi: 10.1093/eurpub/ckv043] [Medline: 25843827]
11. Wolf MS, Feinglass J, Thompson J, Baker DW. In search of 'low health literacy': threshold vs. gradient effect of literacy on health status and mortality. Soc Sci Med 2010 May;70(9):1335-1341. [doi: 10.1016/j.socscimed.2009.12.013] [Medline: 20167411]

12. Geboers B, de WA, Luten KA, Jansen CJ, Reijneveld SA. The association of health literacy with physical activity and nutritional behavior in older adults, and its social cognitive mediators. J Health Commun 2014;19 Suppl 2:61-76. [doi: 10.1080/10810730.2014.934933] [Medline: 25315584]
13. Carrara A, Schulz PJ. The role of health literacy in predicting adherence to nutritional recommendations: a systematic review. Patient Educ Couns 2018 Jan;101(1):16-24. [doi: 10.1016/j.pec.2017.07.005] [Medline: 28739178]
14. Wangler J, Jansky M. Potenziale der Bewegungsförderung älterer Menschen im hausärztlichen Setting – eine explorative Interviewstudie mit Allgemeinmedizinern. Präv Gesundheitsf 2021 Apr 06;17(1):44-50. [doi: 10.1007/s11553-021-00844-x]
15. Fudickar S, Hellmers S, Lau S, Diekmann R, Bauer JM, Hein A. Measurement system for unsupervised standardized assessment of timed "up and go" and five times sit to stand test in the community-a validity study. Sensors (Basel) 2020 May 15;20(10):2824 [FREE Full text] [doi: 10.3390/s20102824] [Medline: 32429306]
16. Bergquist R, Vereijken B, Mellone S, Corzani M, Helbostad JL, Taraldsen K. App-based self-administrable clinical tests of physical function: development and usability study. JMIR Mhealth Uhealth 2020 Apr 27;8(4):e16507 [FREE Full text] [doi: 10.2196/16507] [Medline: 32338616]
17. Hsieh KL, Frechette ML, Fanning J, Chen L, Griffin A, Sosnoff JJ. The developments and iterations of a mobile technology-based fall risk health application. Front Digit Health 2022;4:828686 [FREE Full text] [doi: 10.3389/fdgth.2022.828686] [Medline: 35574255]
18. Happe L, Sgraja M, Hein A, Quinten V, Diekmann R. Usability and feasibility of a tablet-based e-coach for older adults in rehabilitation units to improve nutrition and physical activity: a prospective pilot study. BMC Geriatr 2023 Sep 19;23(1):578 [FREE Full text] [doi: 10.1186/s12877-023-04204-6] [Medline: 37726662]
19. Van Dyck D, Herman K, Poppe L, Crombez G, De Bourdeaudhuij I, Gheysen F. Results of MyPlan 2.0 on physical activity in older Belgian adults: randomized controlled trial. J Med Internet Res 2019 Oct 07;21(10):e13219 [FREE Full text] [doi: 10.2196/13219] [Medline: 31593541]
20. Robert C, Erdt M, Lee J, Cao Y, Naharudin NB, Theng Y. Effectiveness of eHealth nutritional interventions for middle-aged and older adults: systematic review and meta-analysis. J Med Internet Res 2021 May 17;23(5):e15649 [FREE Full text] [doi: 10.2196/15649] [Medline: 33999005]
21. van den Helder J, Mehra S, van Dronkelaar C, Ter Riet G, Tieland M, Visser B, et al. Blended home-based exercise and dietary protein in community-dwelling older adults: a cluster randomized controlled trial. J Cachexia Sarcopenia Muscle 2020 Dec;11(6):1590-1602 [FREE Full text] [doi: 10.1002/jcsm.12634] [Medline: 33103379]
22. World Medical Association. World medical association declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA 2013 Nov 27;310(20):2191-2194. [doi: 10.1001/jama.2013.281053] [Medline: 24141714]
23. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007 Dec;19(6):349-357 [FREE Full text] [doi: 10.1093/intqhc/mzm042] [Medline: 17872937]
24. Kaiser MJ, Bauer JM, Ramsch C, Uter W, Guigoz Y, Cederholm T, MNA-International Group. Validation of the Mini Nutritional Assessment short-form (MNA-SF): a practical tool for identification of nutritional status. J Nutr Health Aging 2009 Nov;13(9):782-788. [Medline: 19812868]
25. Neyer FJ, Felber J, Gebhardt C. Entwicklung und Validierung einer Kurzskala zur Erfassung von Technikbereitschaft. Diagnostica 2012 Apr;58(2):87-99. [doi: 10.1026/0012-1924/a000067]
26. Kuckartz U. Qualitative Inhaltsanalyse. Methoden, Praxis, Computerunterstützung. In: Beltz Verlagsgruppe. Weinheim, Germany: Beltz Verlagsgruppe; 2018.
27. Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. Qual Health Res 2019 Aug;29(10):1483-1496 [FREE Full text] [doi: 10.1177/1049732318821692] [Medline: 30628545]
28. Bian C, Ye B, Hoonakker A, Mihailidis A. Attitudes and perspectives of older adults on technologies for assessing frailty in home settings: a focus group study. BMC Geriatr 2021 May 08;21(1):298 [FREE Full text] [doi: 10.1186/s12877-021-02252-4] [Medline: 33964887]
29. Seinsche J, de Bruin ED, Carpinella I, Ferrarin M, Moza S, Rizzo F, et al. Older adults' needs and requirements for a comprehensive exergame-based telerehabilitation system: a focus group study. Front Public Health 2022 Jan 11;10:1076149 [FREE Full text] [doi: 10.3389/fpubh.2022.1076149] [Medline: 36711352]
30. Happe L, Hein A, Diekmann R. What do geriatric rehabilitation patients and experts consider relevant? Requirements for a digitalised e-coach for sustainable improvement of nutrition and physical activity in older adults - a qualitative focus group study. BMC Geriatr 2021 Dec 18;21(1):712 [FREE Full text] [doi: 10.1186/s12877-021-02692-y] [Medline: 34922492]
31. Nambisan P, Stange KC, Lyytinen K, Kahana E, Duthie E, Potnek M. A comprehensive digital self-care support system for older adults with multiple chronic conditions: development, feasibility, and usability testing of myHESTIA. J Appl Gerontol 2023 Feb;42(2):170-184. [doi: 10.1177/07334648221129859] [Medline: 36226748]
32. Blinka MD, Buta B, Bader KD, Hanley C, Schoenborn NL, McNabney M, et al. Developing a sensor-based mobile application for in-home frailty assessment: a qualitative study. BMC Geriatr 2021 Feb 04;21(1):101 [FREE Full text] [doi: 10.1186/s12877-021-02041-z] [Medline: 33541276]
33. Wang J, Carroll D, Peck M, Myneni S, Gong Y. Mobile and wearable technology needs for aging in place: perspectives from older adults and their caregivers and providers. Stud Health Technol Inform 2016;225:486-490. [Medline: 27332248]

34. Lavoie A, Dubé V. Web-based interventions to promote healthy lifestyles for older adults: scoping review. Interact J Med Res 2022 Aug 23;11(2):e37315 [FREE Full text] [doi: 10.2196/37315] [Medline: 35998024]
35. Anzahl der Einwohner in Deutschland nach Generationen am 31. Statista. 2022. URL: https://de.statista.com/statistik/daten/studie/1130193/umfrage/bevoelkerung-in-deutschland-nach-generationen/ [accessed 2024-04-29]

Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
ECG: electrocardiography
MuTs: measurement and training station

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Original Paper

Internet Use and Higher-Level Functional Capacity Decline Suppression in Japanese Older Adults With Low Education: JAGES 2016-2019 Longitudinal Study

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Abstract

Background: Higher-level functional capacity (HLFC) is crucial for the independent living of older adults. While internet use positively impacts the health of older adults, its effect on HLFC and how this effect varies with educational attainment remains uncertain.

Objective: This longitudinal study aimed to investigate whether internet use could mitigate the risk of HLFC decline and if this benefit extends to older adults with lower levels of education.

Methods: The data were sourced from the Japan Gerontological Evaluation Study (JAGES), encompassing 8050 community-dwelling adults aged 65 years and older from 2016 to 2019. The study focused on those who remained self-sufficient from 2016 to 2019, identifying participants with independent HLFC in 2016. The Tokyo Metropolitan Institute of Gerontology Index of Competence defined HLFC operationally, consisting of 3 subscales, namely instrumental activities of daily living, intellectual activity, and social role. The primary variable was the frequency of internet use in 2016; participants who reported using the internet were classified as internet users, while those who answered “No” were identified as nonusers. The study compared the effects of internet use on HLFC decline across educational levels of ≤9 years, 10-12 years, and ≥13 years using Poisson regression analysis adjusted for robust SE to calculate the risk ratio (RR) and 95% CI for HLFC decline in 2019.

Results: After adjusting for demographic and health condition risk factors, internet use was significantly linked to a decreased risk of HLFC decline in older adults over 3 years, including those with lower educational levels. Internet users with ≤9 years of educational attainment experienced a suppressed decline in the total score (RR 0.57, 95% CI 0.43-0.76; *P*<.001); instrumental activities of daily living (RR 0.58, 95% CI 0.38-0.91; *P*=.02), intellectual activity (RR 0.60, 95% CI 0.41-0.89; *P*=.01), and social role (RR 0.74, 95% CI 0.56-0.97; *P*=.03) compared with nonusers. Participants with 10-12 years of education showed suppression rates of 0.78 (95% CI 0.63-0.98; *P*=.03), 0.59 (95% CI 0.39-0.90; *P*=.01), 0.91 (95% CI 0.63-1.31; *P*=.61), and 0.82 (95% CI 0.68-1.00; *P*=.05), respectively, and those with ≥13 years displayed suppression rates of 0.65 (95% CI 0.51-0.85; *P*=.001), 0.55 (95% CI 0.36-0.83; *P*=.01), 0.64 (95% CI 0.37-1.10; *P*=.11), and 0.83 (95% CI 0.64-1.08; *P*=.17), respectively.

Conclusions: These findings indicate that internet use supports the maintenance of HLFC independence in older adults with higher education and those with lower educational levels. Encouraging internet use among older adults with lower levels of education through future policies could help narrow functional health disparities associated with educational attainment.

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KEYWORDS

functional capacity; instrumental activities of daily living; older adults' cognitive engagement; older adults' social role; internet impact on seniors; educational attainment; low education; independent living; older adults; health disparities

Introduction

Maintaining Higher-Level Functional Capacity Is Essential for the Independent Living of Older Adults

The World Health Organization Scientific Group on the Epidemiology of Aging suggests using autonomy or independence in life functioning as a health index for the older adult demographic [1]. In Japan, over 70% of older adults express a desire to continue residing in familiar surroundings and at home; they prefer to receive nursing care services at their residence, even if such care becomes necessary [2]. The Ministry of Health, Labour, and Welfare is advocating for the development of a comprehensive community support and service system known as the community-based integrated care system. This initiative aims to uphold the dignity of older adults and support their independent living within their local communities throughout their lives [3]. Nonetheless, even with this system, the gap between average and healthy life expectancy, referred to as the restriction period for daily life, stands at 8.7 years for men and 12.1 years for women [4].

Lawton [5] defined and systematized 7 hierarchical competencies for older adults: life maintenance, functional health, perception and cognition, physical self-maintenance (corresponding to basic activities of daily living), instrumental self-maintenance, effectance, and social role in the order of increasing complexity. "Instrumental self-maintenance" corresponds to instrumental activities of daily living (IADL) as the capability to maintain one's life independently at home. "Effectance" is associated with engagement in intellectual activities, such as leisure and creativity, and "social role" corresponds to the ability to engage in intimate societal interactions. A study analyzing a nationally representative sample in Japan revealed that most community-dwelling older adults exhibit proficient functional capacity (eg, IADL, intellectual activity, and social role), although this capacity tends to diminish with age [6] and often deteriorates before declines in basic activities of daily living are observed [7]. Further research indicates that, after retirement, older adults aged ≥65 years' experience a gradual decline in their higher-level functional capacity (HLFC; IADL, intellectual activity, and social role) [8] and that HLFC is linked to mortality as well as medical and long-term care expenses [9,10]. Consequently, HLFC emerges as a modifiable health factor vital for sustaining independent living among older adults, highlighting the importance of preventing HLFC loss.

Addressing the Impact of Educational Disparities on HLFC Maintenance Is Imperative for All Older Adults

The capacities of older adults are likely influenced by the cumulative effect of health inequalities, which are exacerbated by factors, such as gender and education level, over the lifespan [11]. Longitudinal research in Japan has shown a significant correlation between HLFC and educational achievement [6], with additional studies indicating notably poor IADL among older adults with lower levels of education [12-15]. To facilitate independent living across this demographic, it is crucial to propose intervention strategies aimed at mitigating the decline in HLFC, including measures to enhance IADL capabilities, irrespective of educational background. Despite this need, established strategies for enabling older adults to decelerate the HLFC decline, especially among those with minimal educational attainment, remain scarce.

The Internet May Have a Positive Effect on the HLFC of Older Adults

In Japan, the number of older adults using the internet in the past year has risen by 10.5% among those aged 60-69 years, 12.7% among those aged 70-79 years, and 7.5% among those aged 80 years and older, compared with 4 years earlier [16]. The spread of information and communication technology (ICT) among older adults is not limited to Japan but is also observed globally [17]. ICT has been demonstrated to yield numerous health benefits [18-39]. However, the relationship between internet use and HLFC has been the subject of limited research. Digital illiteracy, often attributed to a lack of education, emerges as a principal factor behind the digital divide, particularly among older populations [40]. Consequently, the effectiveness of the Internet in enhancing HLFC may be diminished for older adults with lower educational levels. Nevertheless, from the perspective of addressing health disparities, it is crucial to ascertain whether the internet can play a role in preventing HLFC loss among older adults with minimal education.

Aims of This Study

To ensure that all older adults, irrespective of educational background, can maintain independent living, this study seeks to examine whether internet use can mitigate the risk of HLFC decline. In addition, it investigates whether such benefits extend to older adults with limited education. Until now, no research has explored the relationship between internet use and HLFC across different levels of educational attainment. This study aims to determine whether internet use can reduce the risk of HLFC decline among older adults with lower educational backgrounds, focusing on 3 subscales, which are "IADL," "intellectual activity," and "social role," by categorizing individuals aged ≥65 years based on their educational levels.

Methods

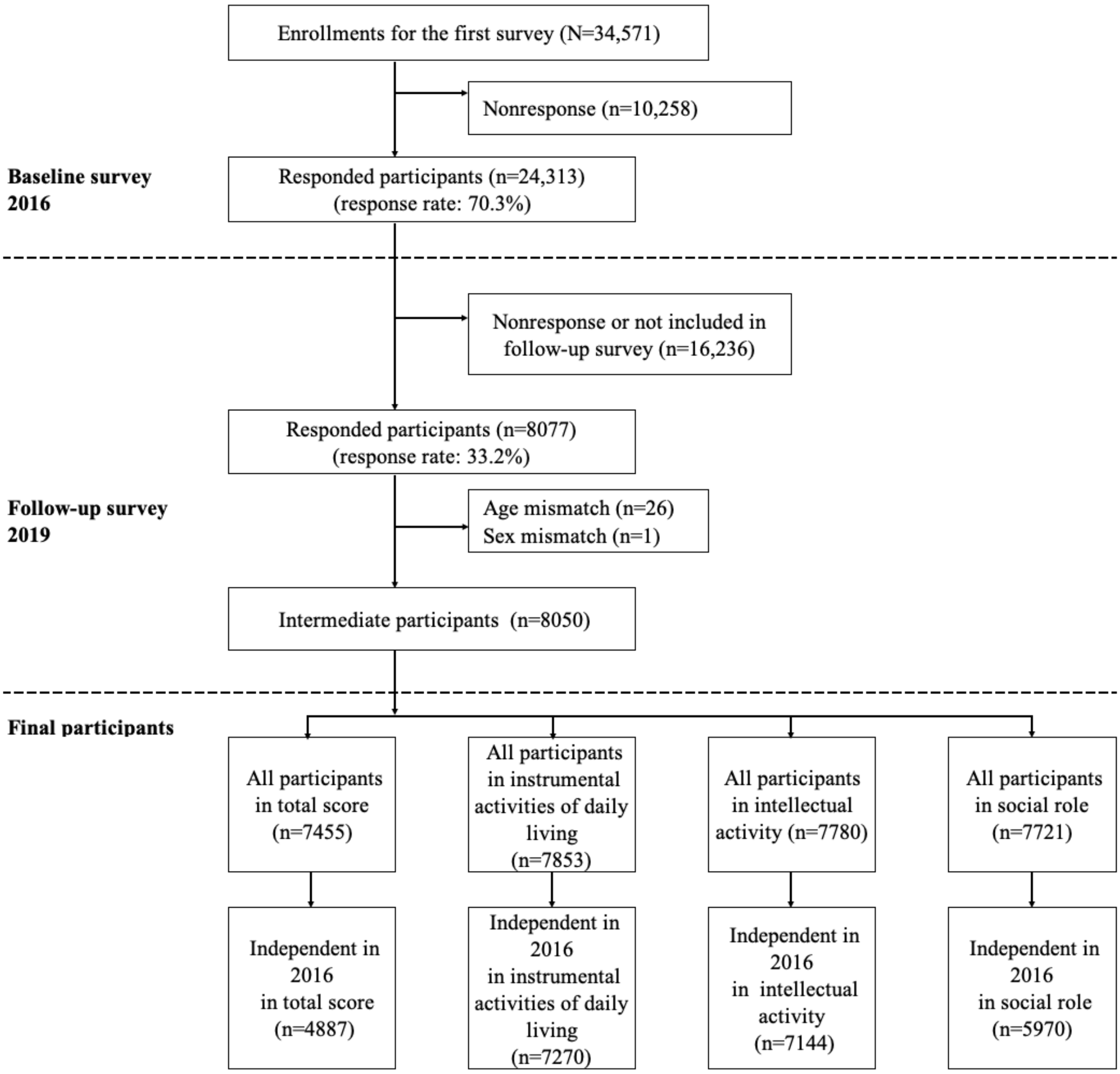
Design, Setting, and Study Participants

Data were collected from the Japan Gerontological Evaluation Study (JAGES), a triennial community-based survey tracking older adults in Japan [41]. Longitudinal panel data from surveys conducted in 2016 and 2019 were used. The baseline survey took place between September 2016 and January 2017, with self-reported questionnaires dispatched to 34,571 independent community-dwelling individuals aged ≥65 years. Of these, 24,313 responded (response rate 70.3%).

The follow-up survey was carried out between November 2019 and January 2020. From the 24,313 baseline respondents, 8077 participated in the follow-up survey (response rate 33.2%). We excluded 27 responses due to discrepancies in reported age (n=26) and sex (n=1) between the baseline and follow-up surveys, leaving 8050 participants for analysis. In Japan, 81.6% of older adults in the community live independently [4]. Given the Japanese long-term care prevention project's goal to avert HLFC decline among community-dwelling older adults, this demographic was deemed the most appropriate for the study.

Thus, the study focused on individuals who maintained their independence in 2016. Participants were selected based on their independent HLFC (total score of 3 subscales, namely, IADL, intellectual activity, and social role) in 2016. Those who did not meet the criteria for independent HLFC in 2016 were excluded, resulting in a final analytical sample of 4887 individuals in total score, 7270 in IADL, 7144 in intellectual activity, and 5970 in social role. A flowchart detailing the participant selection process is provided in Figure 1.

Figure 1. Participant recruitment process for the study.



Ethical Considerations

This study was approved by the Ethics Committee of the National Center for Geriatrics and Gerontology (No. 992, 1274-2), the Ethics Committee of Chiba University (No. 2493, 3442), and Hamamatsu University School of Medicine (approval number: 91-123). Informed consent was obtained by requiring all respondents to select an acceptance checkbox on the questionnaire before returning it. The study used anonymized data. The participants were not compensated.

Outcome Variable: HLFC

HLFC was assessed using the Tokyo Metropolitan Institute of Gerontology Index of Competence (TMIG-IC) [7], which is grounded in the Lawton Instrumental Activities of Daily Living Scale. This 13-item index comprises three subscales of competence, each requiring a yes or no response, which are (1) IADL (5 items: the capability to travel by train or bus, shop for daily necessities, cook, pay bills, and manage a bank and postal savings account); (2) intellectual activity (4 items: the capacity to complete paperwork, read newspapers, read books or magazines, and interest in health-related articles or television programs); and (3) social role (4 items: the capability to visit friends' homes, offer advice to family members or friends, visit ill individuals, and initiate conversations with young people; Table S1 in Multimedia Appendix 1). The TMIG-IC is extensively used as an HLFC evaluation tool. Scores for each subscale were calculated by summing the responses (yes=1 and no=0), with a higher score indicating greater competence. The maximum scores for the total score, IADL, intellectual activity, and social role are 13, 5, 4, and 4 points, respectively. Based on previous research [42,43], we defined a decline in HLFC subscales as (1) a reduction of ≥2 points in the total score, (2) a reduction of ≥1 point in IADL, (3) a reduction of ≥2 points in intellectual activity, and (4) a reduction of ≥2 points in social role. Participants with a high total score (12 or 13 points), IADL (5 points), intellectual activity (3 or 4 points), and social role (3 or 4 points) were considered to have maintained integrity in HLFC subscales, respectively. In this study, intactness in subscales was classified as "independent," and decline in subscales was classified as "dependent," respectively.

Explanatory Variables

Internet Use

The 2016 frequency of internet use served as the variable for internet use. The pertinent question was "Have you used the Internet or emails in the past year? If yes, please specify the frequency." The response options were "1. no," "2. yes (less than a few times a month)," "3. yes (two to three times a week)," and "4. yes (almost every day)." Those who reported yes (2, 3, and 4) were categorized as internet users, and the response "1. no" identified internet nonusers.

Educational Attainment

Educational attainment was gauged by the completed years of schooling (≤9, 10-12, and ≥13 years).

Covariates

Covariates included sex, age (65-69, 70-74, 75-79, 80-84, and ≥85 years), annual household equivalized income (3 quantiles: low, middle, and high), employment status (never employed, retired or not employed, and employed), marital status (married, widowed, divorced, never-married, and other), living arrangement (living with someone or living alone), self-rated health (good or poor), BMI (<18.5, 18.5-25, 25-30, and >30 kg/m^2), diseases under treatment (hypertension, diabetes mellitus, stroke, cardiac diseases, cancer, and respiratory diseases; no or yes) [9,44], depression (no or yes), and population density (metropolitan, urban, semiurban, and rural). The 15-item Geriatric Depression Scale was used, defining mild depression as >5 points and severe depression as >10 points [45,46]. For depression data, responses with up to 2 missing items were included, with missing values replaced by the mean of the answers of respondents to the items. Population density was calculated for each municipality by dividing the population by the habitable land area, resulting in the number of residents per km² per unit area. Municipalities were then categorized based on the population density of the habitable area into 4 groups, that are metropolitan (≥4000/km²), urban (1500-3999/km²), semiurban (1000-1499/km²), and rural (<1000/km²). Missing data for each variable were assigned to missing groups, except for sex, age, and population density.

Statistical Analysis

A descriptive analysis delineated the baseline characteristics of the study participants, differentiating between internet users and nonusers, and assessed the correlations between internet use and HLFC, as well as educational attainment and HLFC in 2016. Items missing from the 2019 HLFC variable, along with missing and other items from the educational attainment variable, were excluded from the analysis. HLFC changes in 2019 were set as binary outcomes, some showing a common prevalence (>10%). Therefore, we used Poisson regression analysis, adjusted for robust SE, and computed the risk ratio (RR) and 95% CI for the decline in HLFC in 2019 while avoiding overestimation [47]. To examine the impact of educational attainment on the association between internet use and HLFC decline, we conducted stratified analyses by educational level using a single model with all covariates included simultaneously. Significance tests were performed for each main effect and interaction, with statistical significance set at *P*<.05. Statistical analyses were carried out using Stata SE/15.0 (Stata Corp).

Results

Characteristics of Participants

The baseline characteristics of internet users and nonusers in 2016 are presented in Table 1. While no significant gender disparity in internet use was observed (*P*=.01), a strong correlation between educational attainment and income with internet use was noted (both *P*<.001). In addition, an inverse relationship between age and internet use was identified. The internet use rate was significantly higher among those who were currently working or had worked in the past compared with those who had never been employed (*P*<.001). Similarly, individuals residing in metropolitan and urban areas demonstrated a significantly higher internet use rate than those in rural areas (*P*<.001). Cross-tables that compare internet use or educational attainment with HLFC are depicted in Tables 2 and 3 and Table S2 in Multimedia Appendix 1. Older adults who used the internet showed higher independence across all subscales, including the total score, IADL, intellectual activity, and social role, compared with those who did not use the internet (Table 2). The lower the educational attainment, the fewer the number of older adults who exhibited independence in the total score and all subscales (Table 3).

Table 1. Characteristics of study participants by internet use in 2016 (n=8050). Those with missing values for internet use in 2016 were omitted (n=524).

Variables	Internet use (2016)		*P* value
	Yes (n=4336)	No (n=3190)	
Sex, n (%)			.01
Male	2116 (55.9)	1452 (38.4)	
Female	2220 (52)	1738 (40.7)	
Age (years), n (%)			<.001
65-69	1824 (69.9)	672 (25.8)	
70-74	1357 (58.1)	834 (35.7)	
75-79	771 (41.7)	928 (50.2)	
80-84	318 (33.9)	541 (57.7)	
≥85	66 (21)	215 (67.2)	
Income (3 quantiles), n (%)			<.001
Q1 (low)	990 (42.4)	1189 (50.9)	
Q2 (middle)	1353 (61.9)	726 (33.2)	
Q3 (high)	1441 (69.2)	552 (26.5)	
Missing	552 (38.2)	723 (50)	
Educational attainment (years), n (%)			<.001
≤9	631 (29.8)	1288 (60.7)	
10-12	1956 (56.6)	1298 (37.6)	
≥13	1721 (72.3)	559 (23.5)	
Other	11 (37)	16 (53)	
Missing	17 (27)	29 (47)	
Employment status, n (%)			<.001
Never employed	171 (38.4)	244 (54.8)	
Retired or not employed	2430 (56.6)	1643 (38.3)	
Employed	1270 (60.7)	705 (33.7)	
Missing	465 (38.1)	598 (49)	
Marital status, n (%)			<.001
Married	3409 (57.1)	2227 (37.3)	
Widowed	596 (43.6)	651 (47.7)	
Divorced	177 (55)	126 (39.1)	
Never married	116 (45.7)	119 (46.9)	
Other	22 (37)	26 (44)	
Missing	16 (22)	41 (55)	
Living arrangement, n (%)			<.001
Living with someone	3610 (55.5)	2500 (38.5)	
Living alone	580 (49.1)	515 (43.6)	
Missing	146 (39.9)	175 (47.8)	
Self-rated health, n (%)			<.001
Good	3902 (55.7)	2661 (38)	
Poor	353 (41.3)	439 (51.4)	
Missing	81 (42)	90 (46)	
BMI (kg/m^2), n (%)			<.001

Variables	Internet use (2016)		*P* value
	Yes (n=4336)	No (n=3190)	
<18.5	255 (50)	220 (43.1)	
18.5-25	3161 (55.6)	2174 (38.3)	
25-30	803 (51.6)	639 (41)	
>30	80 (49)	73 (45)	
Missing	37 (27)	84 (60)	
Diseases under treatment, n (%)			.003
No	1826 (56.2)	1232 (37.9)	
Yes	2319 (52.6)	1801 (40.8)	
Missing	191 (49.6)	157 (40.5)	
Depression, n (%)			<.001
No	3541 (57)	2311 (37.2)	
Yes	631 (42.9)	732 (49.7)	
Missing	164 (45.1)	147 (40.4)	
Population density, n (%)			<.001
Metropolitan	2184 (61.6)	1196 (33.7)	
Urban	1286 (54.7)	910 (38.7)	
Semiurban	503 (48.6)	457 (44.1)	
Rural	363 (32.4)	627 (56)	

Table 2. Higher-level functional capacity of independent and dependent individuals by internet use in 2016. Higher-level functional capacity comprises 3 subscales: IADL[a], intellectual activity, and social role. The total scores on the 3 subscales were also calculated.

	2016 Internet use			*P* value
	Yes, n (%)	No, n (%)	Missing, n (%)	
Total score[b] (n=7455)				<.001
Independent[c] (n=4887)	2953 (68.1)	1644 (51.5)	290 (55.3)	
Dependent[d] (n=2568)	1172 (27)	1235 (38.7)	161 (30.7)	
IADL (n=7853)				<.001
Independent (n=7270)	4063 (93.7)	2749 (86.2)	458 (87.4)	
Dependent (n=583)	201 (4.6)	340 (10.7)	42 (8)	
Intellectual activity (n =7780)				<.001
Independent (n=7144)	4019 (92.7)	2683 (84.1)	442 (84.4)	
Dependent (n=636)	225 (5.2)	367 (11.5)	44 (8)	
Social role (n =7721)				<.001
Independent (n=5970)	3459 (79.8)	2147 (67.3)	364 (69.5)	
Dependent (n=1751)	752 (17.3)	884 (27.7)	115 (21.9)	

[a] IADL: instrumental activities of daily living.

[b] Missing values were omitted for the total score and 3 subscales.

[c] Cutoff values for "independent" in the Tokyo Metropolitan Institute of Gerontology Index of Competence (TMIG-IC): "total score 12-13/13 points," "IADL 5/5 points," "intellectual activity 3-4/4 points," and "social role 3-4/4 points" [42,43].

[d] Cutoff values for "dependent" in the TMIG-IC: "total score 1-11/13 points," "IADL 1-4/5 points," "intellectual activity 1-2/4 points," and "social role 1-2/4 points."

Table 3. Higher-level functional capacity of independent and dependent individuals by educational attainment in 2016. Higher-level functional capacity comprises 3 subscales: IADL[a], intellectual activity, and social role. The total scores on the 3 subscales were also calculated.

	2016 Educational attainment (years)					*P* value
	≤9, n (%)	10-12, n (%)	≥13, n (%)	Other, n (%)	Missing, n (%)	
Total score[b] (n=7455)						<.001
Independent[c] (n=4887)	1081 (51)	2206 (63.8)	1559 (65.5)	14 (47)	27 (44)	
Dependent[d] (n=2568)	818 (38.6)	1005 (29.1)	714 (30)	12 (40)	19 (31)	
IADL (n =7853)						<.001
Independent (n=7270)	1838 (86.7)	3172 (91.8)	2188 (91.9)	25 (83)	47 (76)	
Dependent (n=583)	210 (9.9)	207 (6)	154 (6.5)	4 (13)	8 (13)	
Intellectual activity (n =7780)						<.001
Independent (n=7144)	1734 (81.8)	3129 (90.5)	2215 (93)	23 (77)	43 (69)	
Dependent (n=636)	282 (13.3)	218 (6.3)	124 (5.2)	4 (13)	8 (13)	
Social role (n =7721)						<.001
Independent (n=5970)	1481(69.8)	2620 (75.8)	1812 (76.1)	20 (67)	37 (60)	
Dependent (n=1751)	530 (25)	700 (20.3)	500 (21)	7 (23)	14 (23)	

[a] IADL: instrumental activities of daily living.

[b] Missing values were omitted for the total score and 3 subscales.

[c] Cutoff values for "independent" in Tokyo Metropolitan Institute of Gerontology Index of Competence (TMIG-IC): "total score 12-13/13 points," "IADL 5/5 points," "intellectual activity 3-4/4 points," and "social role 3-4/4 points" [42,43].

[d] Cutoff values for "dependent" in TMIG-IC: "total score 1-11/13 points," "IADL 1-4/5 points," "intellectual activity 1-2/4 points," and "social role 1-2/4 points."

Moreover, among all subscales, the proportion of older adults independent in social roles was the lowest. In addition, the relationships exhibited similar trends across responses to the TMIG-IC's 13 questions (Table S3 in Multimedia Appendix 1). The baseline characteristics of the participants by educational attainment in 2016 indicated an inverse relationship between age and educational attainment (Table S4 in Multimedia Appendix 1).

Results of the Poisson Regression Analysis

Upon categorizing the independent individuals of each subgroup by 3 levels of educational attainment in 2016, we analyzed their internet use. The results revealed that internet users exhibited a suppressed decline in independence across the total score, IADL, intellectual activity, and social role subscales in 2019. Notably, among older adults with lower levels of education, significant suppression effects were observed in the total score and all subscales (Table 4).

Table 4. Associations between internet use in 2016 and suppression of higher-level functional capacity (HLFC) decline in 2019, segmented by educational attainment. In 2016, study participants were older adults with "independent" total score, IADL[a], intellectual activity, and social role. Items missing in the 2019 HLFC variable were excluded from the verification targets.

Educational attainment (years) and internet use	HLFC							
	Total score		IADL		Intellectual activity		Social role	
	RR[b,c] (95% CI)	*P* value	RR (95% CI)	*P* value	RR (95% CI)	*P* value	RR (95% CI)	*P* value
≤9[d] (total score: n=928; IADL: n=1757; intellectual activity: n=1619; social role: n=1353)								
No	Reference	—[e]	Reference	—	Reference	—	Reference	—
Yes	0.57 (0.43-0.76)	<.001	0.58 (0.38-0.91)	.02	0.60 (0.41-0.89)	.01	0.74 (0.56-0.97)	.03
Missing	0.95 (0.68-1.32)	.75	0.87 (0.52-1.46)	.60	0.76 (0.47-1.22)	.25	0.68 (0.47-0.98)	.04
10-12 (total score: n=2077; IADL: n=3095; intellectual activity: n=3018; social role: n=2531)								
No	Reference	—	Reference	—	Reference	—	Reference	—
Yes	0.78 (0.63-0.98)	.03	0.59 (0.39-0.90)	.01	0.91 (0.63-1.31)	.61	0.82 (0.68-1.00)	.05
Missing	0.83 (0.59-1.17)	.28	0.71 (0.34-1.52)	.38	0.29 (0.07-1.24)	.10	0.71 (0.48-1.05)	.09
≥13 (total score: n=1486; IADL: n=2141; intellectual activity: n=2163; social role: n=1755)								
No	Reference	—	Reference	—	Reference	—	Reference	—
Yes	0.65 (0.51-0.85)	.001	0.55 (0.36-0.83)	.01	0.64 (0.37-1.10)	.11	0.83 (0.64-1.08)	.17
Missing	0.89 (0.50-1.58)	.69	0.62 (0.28-1.37)	.24	0.95 (0.34-2.65)	.93	1.15 (0.59-2.21)	.68

[a] IADL: instrumental activities of daily living.

[b] RR: risk ratio.

[c] Risk ratio with adjustment for sex, age, annual household equivalized income, employment status, marital status, living arrangement, self-rated health, BMI, diseases under treatment, depression, and population density.

[d] Both missing and other items from the educational attainment variable were excluded from the verification targets.

[e] Not applicable.

Compared with nonusers, internet users with ≤9 years of educational attainment experienced a reduced decline in the total score in 2019 (RR 0.57, 95% CI 0.43-0.76; *P*<.001) and in the subscales of IADL (RR 0.58, 95% CI 0.38-0.91; *P*=.02), intellectual activity (RR 0.60, 95% CI 0.41-0.89; *P*=.01), and social role (RR 0.74, 95% CI 0.56-0.97; *P*=.03). Similarly, those in the 10-12 years of educational attainment group showed a mitigated decline in the total score (RR 0.78, 95% CI 0.63-0.98; *P*=.03), IADL (RR 0.59, 95% CI 0.39-0.90; *P*=.01), intellectual activity (RR 0.91, 95% CI 0.63-1.31; *P*=.61), and social role (RR 0.82, 95% CI 0.68-1.00; *P*=.05). The group with ≥13 years of educational attainment demonstrated a lesser decline in the total score (RR 0.65, 95% CI 0.51-0.85; *P*=.001), IADL (RR 0.55, 95% CI 0.36-0.83; *P*=.01), intellectual activity (RR 0.64, 95% CI 0.37-1.10; *P*=.11), and social role (RR 0.83, 95% CI 0.64-1.08; *P*=.17; Table 4). No interaction was identified between internet use and educational attainment (Table S5 in Multimedia Appendix 1).

Discussion

Principal Findings

This study explored the relationship between internet use and the maintenance of independence in HLFC among older adults, including the varying impacts based on educational attainment, through analysis of panel data from longitudinal surveys in 2016 and 2019. In this extensive population-based analysis, internet use among older adults was significantly linked to the suppression of HLFC decline, irrespective of educational level. Specifically, significant effects in mitigating decline were notable in all HLFC subscales, including IADL, intellectual activity, social role, and the total score, particularly in older adults with low education (≤9 years). These findings indicate that older adults with lower levels of education could benefit from internet use in suppressing HLFC decline. To our knowledge, this is the inaugural study to assess the relationship between internet use and the mitigation of HLFC decline among older adults with low education, by segmenting based on their educational attainment, an aspect challenging to enhance retrospectively.

HLFC Can Contribute to the Independent Living of Older Adults

Many older adults prefer to remain in their familiar residences [2]. Hence, maintaining a relatively independent HLFC, which encompasses capabilities, such as using public transportation, shopping, cooking, accessing information from various sources, and socializing with family, friends, and acquaintances, is crucial for fostering independent living. However, functional capacity tends to diminish with age [6], posing a risk of encountering numerous health challenges [9,10]. Consequently, preserving and enhancing HLFC plays a pivotal role in promoting the health of older adults and potentially extending their capability to live independently within their communities.

HLFC Could Benefit from Improved IADL Through Internet Use

A digital divide among older adults has been linked to educational disparities [40]. Moreover, a survey in Japan highlighted a digital divide wherein internet use among older adults is increasing, while the proportion of lower-income individuals using the internet remains low [16]. This study corroborated that older adults with lower education or income levels were less likely to be internet users compared with those with higher education or income levels. However, numerous studies have documented the health improvement effects of ICT use, including the internet, irrespective of educational attainment or income. Our findings align with previous research, indicating that internet and email use can likely mitigate and improve the risk of IADL decline [34,35]. IADL impairment may signal early reductions in physical and cognitive functions, potentially leading to adverse health outcomes, increased incidents of heart failure, and mortality among older adults [48]. Factors associated with IADL include social isolation [49], depression [50,51], subjective health [50,52], cognitive function [52], intellectual activity [53-55], social role [54,55], community-level social capital [56], and social participation [57,58]. The health improvement effects gained through internet use, such as mitigating social isolation and loneliness [24,27,29,33,35-39], preventing and reducing depression [21-23,32,33], maintaining good subjective health [23,33,35], reducing dementia risk [19], enhancing cognitive function [18,20,31], and fostering social participation [28,39], overlap with factors related to IADL. Our results suggest that internet use may aid in suppressing HLFC decline by enhancing factors associated with IADL, a key component of HLFC.

The benefits of internet use are interrelated. For instance, internet users exhibit lower levels of social isolation compared with nonusers [37], and ICT use has been shown to reduce social isolation among older adults through 4 mechanisms: connecting with the external world, acquiring social support, pursuing activities of interest, and enhancing self-confidence [27]. In addition, while nonusers demonstrated a decline in social contact, internet users maintained stable social connections and alleviated loneliness [36], consistent with findings that social contact and perceived social support mediate the relationship between social media communication and reduced loneliness levels [38]. Internet use alleviates loneliness [24,29,33,35,36,38,39] and contributes to improved self-rated health, reduced chronic illnesses, increased subjective well-being, and fewer depressive symptoms through the mediated effect of decreased loneliness [33]. Beyond preventing and ameliorating depression [21-23,32,33] and enhancing self-rated health [23,33,35], positive effects on cognitive function [18,20,31] have also been reported. Moreover, beneficial impacts on well-being [25,26,33,35,39], quality of life [22], and health literacy [30] have been confirmed. Thus, the influence of internet use on the daily lives of older adults may be substantial.

Many older adults in Japan use the internet to connect with family, friends, and acquaintances and to discover interesting information [16]. Given that internet use constitutes an "intellectual activity" in itself, using it for instrumental, informational, and social purposes [39] may further mitigate the decline in "intellectual activity" activities, such as "completing paperwork," "reading newspapers," "reading books or magazines," and "showing interest in health-related articles or television programs."

Increased social participation [28] and diverse volunteer activities [39] through internet use could establish a foundation for exchange relationships that encourage actions, such as "visiting friends' homes," "offering advice to family members or friends," "visiting ill individuals," and "initiating conversations with young people," thereby preventing the decline in social roles. Strong associations between good intellectual activity and social role with remaining independent in IADL [53,54], along with reports that impairments in social role and intellectual activity not only often precede IADL disability but also significantly forecast the onset of IADL disability [55], suggest that enhancements in "intellectual activity" and "social role" through internet use could lead to improved IADL and, subsequently, help suppress the overall decline in HLFC.

Internet Use May Mitigate Educational Inequality in HLFC

Socioeconomic disparities were evident across all subscales of HLFC, underscoring educational inequalities [6] (Table 3 and Table S2 in Multimedia Appendix 1). Consequently, to address health disparities among older adults in the community, it is imperative to implement strategies to preserve the HLFC of older adults, especially those with lower levels of education, although enhancing educational attainment retrospectively poses a significant challenge.

This study found that even at baseline, older adults who used the internet tended to maintain higher levels of independence in terms of the total score, IADL, intellectual activity, and social role compared with nonusers. Furthermore, longitudinal analysis revealed that internet use significantly curbed the decline in HLFC among older adults, irrespective of their educational background.

Recognized for fostering social participation among older adults [28], internet use may counteract the trend where wealthier or more educated older adults are more engaged in social activities [59]. Social participation can diminish the risk of loneliness across socioeconomic statuses, potentially serving as a countermeasure to health disparities [60]. Moreover, community activity participation has been identified as a key mediator in the relationship between educational level and incident functional disability among older adults aged 65-74 years [61], suggesting that enhanced social participation through internet use [28] may mediate the link between educational inequality and HLFC in this study. In addition, internet use may serve as a proxy for continuous educational attainment, with its protective effects independent of "past" education levels; instead, these effects may rely on middle- and late-life cognitive activity [19]. Late-life cognitive activity has been shown to impact subsequent cognitive health [62], suggesting that this study may illustrate how internet use later in life, as a form of continuous educational attainment, could improve educational inequality in HLFC.

Limitations

This study has several limitations. First, since internet use was assessed in 2016, changes in use by 2019 were not captured. However, even previous internet use experiences may have contributed to suppressing HLFC decline in older adults, warranting further investigation into the impact of internet use duration. Second, the study did not account for the purpose of internet use. The analysis encompassed a broad range of internet activities, including communication, health and medical information search, navigation, online shopping, banking, and stock trading. These activities represent the majority of internet use by older adults, suggesting the study's findings broadly reflect the positive impact of diverse internet use on maintaining HLFC independence. Third, the validity and reliability of the TMIG-IC as an evaluative tool for HLFC were not addressed. With the changing lifestyles of older adults, there is a call for developing scales that can measure higher levels of HLFC reflective of these changes. In addition, considering the psychological aspects of IADL, future studies might benefit from using scales with psychometric properties. Fourth, our data included only 2 waves. We acknowledge that interpreting results from only 2 time points requires caution because longitudinal data with 3 or more time points would provide a stronger basis for capturing dynamic links between exposures and outcomes [63]. Finally, using data from the JAGES study, comprising healthy participants, might have led to overestimating the association between internet use and HLFC independence.

Conclusion

In conclusion, this study indicates that internet use can support the maintenance of HLFC independence among older adults with higher education and those with lower education levels. Internet use can mitigate declines in key components of HLFC, such as IADL, intellectual activity, and social role, which are essential for independent living in familiar communities, even for older adults with low educational attainment. These findings underscore the importance of promoting internet use among older adults to support their independence. Moreover, engaging with more devices and applications is linked to fewer functional limitations, higher life satisfaction, and greater goal attainment [35]. Thus, expanding internet access and use among older adults, particularly those with lower education, is vital for reducing functional health disparities attributed to educational attainment.

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Authors' Contributions

AT conceptualized the study and prepared the draft of the manuscript. AN, YM, KK, and TO planned and arranged the data acquisition. AN, YM, and CK prepared the data for the analyses. AT, AN, and YM performed the statistical analysis. All authors were involved in the study concept and design and acquisition, analysis, or interpretation of the data. All authors gave final approval and agreed to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The Tokyo Metropolitan Institute of Gerontology Index of Competence (TMIG-IC); characteristics of the study participants, by higher-level functional capacity (HLFC) and each independence; answer results of TMIG-IC by educational attainment; characteristics of study participants by educational attainment in 2016; and interaction.

[DOCX File , 74 KB - aging_v7i1e53384_app1.docx]

References

1. The uses of epidemiology in the study of the elderly. report of a WHO scientific group on the epidemiology of aging. World Health Organization. 1984. URL: https://apps.who.int/iris/bitstream/handle/10665/39136/WHO_TRS_706.pdf?sequence=1&isAllowed=y [accessed 2024-03-23]

2. White paper on health, labour and welfare. The Ministry of Health, Labour and Welfare, Government of Japan. 2016. URL: https://www.mhlw.go.jp/wp/hakusyo/kousei/16/dl/1-02.pdf [accessed 2024-03-23]
3. The community-based integrated care system. The Ministry of Health, Labour and Welfare, Government of Japan. URL: https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi_kaigo/kaigo_koureisha/chiiki-houkatsu/ [accessed 2024-03-23]
4. White paper on aging society. The Cabinet Office, Government of Japan. 2022. URL: https://www8.cao.go.jp/kourei/whitepaper/w-2022/html/zenbun/s1_2_2.html [accessed 2024-03-23]
5. Lawton MP. Assessing the competence of older people. In: Kent DP, Kastenbaum R, Sherwood S, editors. Research, Planning, and Action for the Elderly: the Power and Potential of Social Science. New York, NY: Behavioral Publications; 1972.
6. Koyano W, Hashimoto M, Fukawa T, Shibata H, Gunji A. Functional capacity of the elderly: measurement by the TMIG index of competence. Nihon Koshu Eisei Zasshi 1993;40(6):468-474. [Medline: 8347862]
7. Koyano W, Shibata H, Nakazato K, Haga H, Suyama Y. Measurement of competence: reliability and validity of the TMIG index of competence. Arch Gerontol Geriatr 1991;13(2):103-116. [doi: 10.1016/0167-4943(91)90053-s] [Medline: 15374421]
8. Minami U, Nishi M, Fukaya T, Hasebe M, Nonaka K, Koike T, et al. Effects of the change in working status on the health of older people in Japan. PLoS One 2015;10(12):e0144069 [FREE Full text] [doi: 10.1371/journal.pone.0144069] [Medline: 26633033]
9. Nagata H, Miura K, Tanaka S, Kadota A, Hayakawa T, Kondo K, et al. Relationship of higher-level functional capacity with long-term mortality in Japanese older people: NIPPON DATA90. J Epidemiol 2023;33(3):136-141 [FREE Full text] [doi: 10.2188/jea.JE20210077] [Medline: 34248110]
10. Taniguchi Y, Kitamura A, Nofuji Y, Ishizaki T, Seino S, Yokoyama Y, et al. Association of trajectories of higher-level functional capacity with mortality and medical and long-term care costs among community-dwelling older Japanese. J Gerontol A Biol Sci Med Sci 2019;74(2):211-218. [doi: 10.1093/gerona/gly024] [Medline: 29596617]
11. World report on ageing and health. World Health Organization. 2015. URL: https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1&isAllowed=y [accessed 2024-03-23]
12. Yang L, Konttinen H, Martikainen P, Silventoinen K. Socioeconomic status and physical functioning: a longitudinal study of older chinese people. J Gerontol B Psychol Sci Soc Sci 2018;73(7):1315-1329. [doi: 10.1093/geronb/gbx010] [Medline: 28329825]
13. Carmona-Torres JM, Rodríguez-Borrego MA, Laredo-Aguilera JA, López-Soto PJ, Santacruz-Salas E, Cobo-Cuenca AI. Disability for basic and instrumental activities of daily living in older individuals. PLoS One 2019;14(7):e0220157 [FREE Full text] [doi: 10.1371/journal.pone.0220157] [Medline: 31348797]
14. Rodríguez López S, Colantonio SE, Celton DE. Socioeconomic inequalities in self-reported health and physical functioning in Argentina: findings from the national survey on quality of life of older adults 2012 (ENCaViAM). J Biosoc Sci 2017;49(5):597-610. [doi: 10.1017/S0021932016000651] [Medline: 27825400]
15. Ferreira Agreli B, Aparecida Dias F, Dos Santos Ferreira PC, Cândida Gomes N, Dos Santos Tavares DM. Functional disability and morbidities among the elderly people, according to socio-demographic conditions and indicative of depression. Invest Educ Enferm 2017;35(1):48-58 [FREE Full text] [doi: 10.17533/udea.iee.v35n1a06] [Medline: 29767923]
16. The communications usage trend survey 2021. The Ministry of Internal Affairs and Communications, Government of Japan. 2022. URL: https://www.soumu.go.jp/johotsusintokei/statistics/data/220527_1.pdf [accessed 2024-03-23]
17. König R, Seifert A, Doh M. Internet use among older Europeans: an analysis based on SHARE data. Univ Access Inf Soc 2018;17(3):621-633. [doi: 10.1007/s10209-018-0609-5]
18. Kamin S, Lang FR. Internet use and cognitive functioning in late adulthood: longitudinal findings from the survey of health, ageing and retirement in Europe (SHARE). J Gerontol B Psychol Sci Soc Sci 2020;75(3):534-539. [doi: 10.1093/geronb/gby123] [Medline: 30346591]
19. d'Orsi E, Xavier AJ, Rafnsson SB, Steptoe A, Hogervorst E, Orrell M. Is use of the internet in midlife associated with lower dementia incidence? Results from the English Longitudinal Study of Ageing. Aging Ment Health 2018;22(11):1525-1533 [FREE Full text] [doi: 10.1080/13607863.2017.1360840] [Medline: 28795579]
20. Xavier AJ, d'Orsi E, de Oliveira CM, Orrell M, Demakakos P, Biddulph JP, et al. English Longitudinal Study of Aging: can internet/e-mail use reduce cognitive decline? J Gerontol A Biol Sci Med Sci 2014;69(9):1117-1121 [FREE Full text] [doi: 10.1093/gerona/glu105] [Medline: 25116923]
21. Cotten SR, Ford G, Ford S, Hale TM. Internet use and depression among retired older adults in the United States: a longitudinal analysis. J Gerontol B Psychol Sci Soc Sci 2014;69(5):763-771. [doi: 10.1093/geronb/gbu018] [Medline: 24671896]
22. Wallinheimo A, Evans SL. More frequent internet use during the COVID-19 pandemic associates with enhanced quality of life and lower depression scores in middle-aged and older adults. Healthcare (Basel) 2021;9(4):393 [FREE Full text] [doi: 10.3390/healthcare9040393] [Medline: 33916054]
23. Kim J, Lee HY, Won CR, Barr T, Merighi JR. Older adults' technology use and its association with health and depressive symptoms: findings from the 2011 National Health and Aging Trends study. Nurs Outlook 2020;68(5):560-572 [FREE Full text] [doi: 10.1016/j.outlook.2020.05.001] [Medline: 32527596]

24. Casanova G, Zaccaria D, Rolandi E, Guaita A. The Effect of information and communication technology and social networking site use on older people's well-being in relation to loneliness: review of experimental studies. J Med Internet Res 2021;23(3):e23588 [FREE Full text] [doi: 10.2196/23588] [Medline: 33439127]
25. Fang Y, Chau AKC, Wong A, Fung HH, Woo J. Information and communicative technology use enhances psychological well-being of older adults: the roles of age, social connectedness, and frailty status. Aging Ment Health 2018;22(11):1516-1524. [doi: 10.1080/13607863.2017.1358354] [Medline: 28777010]
26. Quintana D, Cervantes A, Sáez Y, Isasi P. Internet use and psychological well-being at advanced age: evidence from the English Longitudinal Study of Aging. Int J Environ Res Public Health 2018;15(3):480 [FREE Full text] [doi: 10.3390/ijerph15030480] [Medline: 29522486]
27. Chen YRR, Schulz PJ. The effect of information communication technology interventions on reducing social isolation in the elderly: a systematic review. J Med Internet Res 2016;18(1):e18 [FREE Full text] [doi: 10.2196/jmir.4596] [Medline: 26822073]
28. Kim J, Lee HY, Christensen MC, Merighi JR. Technology access and use, and their associations with social engagement among older adults: do women and men differ? J Gerontol B Psychol Sci Soc Sci 2017;72(5):836-845. [doi: 10.1093/geronb/gbw123] [Medline: 28073816]
29. Cotten SR, Anderson WA, McCullough BM. Impact of internet use on loneliness and contact with others among older adults: cross-sectional analysis. J Med Internet Res 2013;15(2):e39 [FREE Full text] [doi: 10.2196/jmir.2306] [Medline: 23448864]
30. Kobayashi LC, Wardle J, von Wagner C. Internet use, social engagement and health literacy decline during ageing in a longitudinal cohort of older English adults. J Epidemiol Community Health 2015;69(3):278-283 [FREE Full text] [doi: 10.1136/jech-2014-204733] [Medline: 25428933]
31. Tun PA, Lachman ME. The association between computer use and cognition across adulthood: use it so you won't lose it? Psychol Aging 2010;25(3):560-568 [FREE Full text] [doi: 10.1037/a0019543] [Medline: 20677884]
32. Nakagomi A, Shiba K, Kondo K, Kawachi I. Can online communication prevent depression among older people? A longitudinal analysis. J Appl Gerontol 2022;41(1):167-175. [doi: 10.1177/0733464820982147] [Medline: 33356760]
33. Chopik WJ. The benefits of social technology use among older adults are mediated by reduced loneliness. Cyberpsychol Behav Soc Netw 2016;19(9):551-556 [FREE Full text] [doi: 10.1089/cyber.2016.0151] [Medline: 27541746]
34. d'Orsi E, Xavier AJ, Steptoe A, de Oliveira C, Ramos LR, Orrell M, et al. Socioeconomic and lifestyle factors related to instrumental activity of daily living dynamics: results from the English Longitudinal Study of Ageing. J Am Geriatr Soc 2014;62(9):1630-1639. [doi: 10.1111/jgs.12990] [Medline: 25243677]
35. Sims T, Reed AE, Carr DC. Information and communication technology use is related to higher well-being among the oldest-old. J Gerontol B Psychol Sci Soc Sci 2017;72(5):761-770. [doi: 10.1093/geronb/gbw130] [Medline: 27702839]
36. Yu K, Wu S, Chi I. Internet use and loneliness of older adults over time: the mediating effect of social contact. J Gerontol B Psychol Sci Soc Sci 2021;76(3):541-550. [doi: 10.1093/geronb/gbaa004] [Medline: 31942629]
37. Silva P, Matos AD, Martinez-Pecino R. The contribution of the Internet to reducing social isolation in individuals aged 50 years and older: quantitative study of data from the survey of health, ageing and retirement in Europe. J Med Internet Res 2022;24(1):e20466 [FREE Full text] [doi: 10.2196/20466] [Medline: 34982040]
38. Zhang K, Kim K, Silverstein NM, Song Q, Burr JA. Social media communication and loneliness among older adults: the mediating roles of social support and social contact. Gerontologist 2021;61(6):888-896. [doi: 10.1093/geront/gnaa197] [Medline: 33284972]
39. Szabo A, Allen J, Stephens C, Alpass F. Longitudinal analysis of the relationship between purposes of Internet use and well-being among older adults. Gerontologist 2019;59(1):58-68. [doi: 10.1093/geront/gny036] [Medline: 29688332]
40. Nishijima M, Ivanauskas TM, Sarti FM. Evolution and determinants of digital divide in Brazil (2005–2013). Telecommunications Policy 2017;41(1):12-24. [doi: 10.1016/j.telpol.2016.10.004]
41. Kondo K, Rosenberg M. Advancing universal health coverage through knowledge translation for healthy ageing: lessons learnt from the Japan gerontological evaluation study. World Health Organization. 2018. URL: https://apps.who.int/iris/bitstream/handle/10665/279010/9789241514569-eng.pdf [accessed 2024-03-23]
42. Fujiwara Y, Shinkai S, Amano H, Watanabe S, Kumagai S, Takabayashi K, et al. Test-retest variation in the Tokyo metropolitan institute of gerontology index of competence in community-dwelling older people independent in daily living toward individual assessment of functional capacity. Nihon Koshu Eisei Zasshi 2003;50(4):360-367. [Medline: 12772615]
43. Otsuka R, Nishita Y, Tange C, Tomida M, Kato Y, Nakamoto M, et al. The effect of modifiable healthy practices on higher-level functional capacity decline among Japanese community dwellers. Prev Med Rep 2017;5:205-209 [FREE Full text] [doi: 10.1016/j.pmedr.2016.12.022] [Medline: 28070478]
44. Amemiya A, Kondo N, Saito J, Saito M, Takagi D, Haseda M, et al. Socioeconomic status and improvement in functional ability among older adults in Japan: a longitudinal study. BMC Public Health 2019;19(1):209 [FREE Full text] [doi: 10.1186/s12889-019-6531-9] [Medline: 30782149]
45. Shin C, Park MH, Lee SH, Ko Y, Kim Y, Han K, et al. Usefulness of the 15-item geriatric depression scale (GDS-15) for classifying minor and major depressive disorders among community-dwelling elders. J Affect Disord 2019;259:370-375. [doi: 10.1016/j.jad.2019.08.053] [Medline: 31470180]

46. Nyunt MSZ, Fones C, Niti M, Ng T. Criterion-based validity and reliability of the geriatric depression screening scale (GDS-15) in a large validation sample of community-living Asian older adults. Aging Ment Health 2009;13(3):376-382. [doi: 10.1080/13607860902861027] [Medline: 19484601]
47. Knol MJ, Le Cessie S, Algra A, Vandenbroucke JP, Groenwold RH. Overestimation of risk ratios by odds ratios in trials and cohort studies: alternatives to logistic regression. CMAJ 2012;184(8):895-899 [FREE Full text] [doi: 10.1503/cmaj.101715] [Medline: 22158397]
48. Bowling CB, Fonarow GC, Patel K, Zhang Y, Feller MA, Sui X, et al. Impairment of activities of daily living and incident heart failure in community-dwelling older adults. Eur J Heart Fail 2012;14(6):581-587 [FREE Full text] [doi: 10.1093/eurjhf/hfs034] [Medline: 22492539]
49. Guo L, An L, Luo F, Yu B. Social isolation, loneliness and functional disability in Chinese older women and men: a longitudinal study. Age Ageing 2021;50(4):1222-1228. [doi: 10.1093/ageing/afaa271] [Medline: 33352582]
50. Vaughan L, Leng X, La Monte MJ, Tindle HA, Cochrane BB, Shumaker SA. Functional independence in late-life: maintaining physical functioning in older adulthood predicts daily life function after age 80. J Gerontol A Biol Sci Med Sci 2016;71 Suppl 1(Suppl 1):S79-S86 [FREE Full text] [doi: 10.1093/gerona/glv061] [Medline: 26858328]
51. Kondo N, Kazama M, Suzuki K, Yamagata Z. Impact of mental health on daily living activities of Japanese elderly. Prev Med 2008;46(5):457-462. [doi: 10.1016/j.ypmed.2007.12.007] [Medline: 18258290]
52. Fujiwara Y, Yoshida H, Amano H, Fukaya T, Liang J, Uchida H, et al. Predictors of improvement or decline in instrumental activities of daily living among community-dwelling older Japanese. Gerontology 2008;54(6):373-380. [doi: 10.1159/000151221] [Medline: 18679020]
53. Fujiwara Y, Chaves PHM, Yoshida H, Amano H, Fukaya T, Watanabe N, et al. Intellectual activity and likelihood of subsequently improving or maintaining instrumental activities of daily living functioning in community-dwelling older Japanese: a longitudinal study. Int J Geriatr Psychiatry 2009;24(6):547-555. [doi: 10.1002/gps.2148] [Medline: 19132642]
54. Ishizaki T, Watanabe S, Suzuki T, Shibata H, Haga H. Predictors for functional decline among nondisabled older Japanese living in a community during a 3-year follow-up. J Am Geriatr Soc 2000;48(11):1424-1429. [doi: 10.1111/j.1532-5415.2000.tb02632.x] [Medline: 11083318]
55. Fujiwara Y, Shinkai S, Kumagai S, Amano H, Yoshida Y, Yoshida H, et al. Longitudinal changes in higher-level functional capacity of an older population living in a Japanese urban community. Arch Gerontol Geriatr 2003;36(2):141-153. [doi: 10.1016/s0167-4943(02)00081-x] [Medline: 12849088]
56. Fujihara S, Tsuji T, Miyaguni Y, Aida J, Saito M, Koyama S, et al. Does community-level social capital predict decline in instrumental activities of daily living? A JAGES prospective cohort study. Int J Environ Res Public Health 2019;16(5):828 [FREE Full text] [doi: 10.3390/ijerph16050828] [Medline: 30866468]
57. Tomioka K, Kurumatani N, Saeki K. The differential effects of type and frequency of social participation on IADL declines of older people. PLoS One 2018;13(11):e0207426 [FREE Full text] [doi: 10.1371/journal.pone.0207426] [Medline: 30462711]
58. Tomioka K, Kurumatani N, Hosoi H. Association between social participation and 3-year change in instrumental activities of daily living in community-dwelling elderly adults. J Am Geriatr Soc 2017;65(1):107-113. [doi: 10.1111/jgs.14447] [Medline: 27673582]
59. Feng ZY, Cramm JM, Jin C, Twisk J, Nieboer AP. The longitudinal relationship between income and social participation among Chinese older people. SSM Popul Health 2020;11:100636 [FREE Full text] [doi: 10.1016/j.ssmph.2020.100636] [Medline: 32802932]
60. Niedzwiedz CL, Richardson EA, Tunstall H, Shortt NK, Mitchell RJ, Pearce JR. The relationship between wealth and loneliness among older people across Europe: is social participation protective? Prev Med 2016;91:24-31 [FREE Full text] [doi: 10.1016/j.ypmed.2016.07.016] [Medline: 27471027]
61. Nurrika D, Zhang S, Tomata Y, Sugawara Y, Tanji F, Tsuji I. Education level and incident functional disability in elderly Japanese: the Ohsaki Cohort 2006 study. PLoS One 2019;14(3):e0213386 [FREE Full text] [doi: 10.1371/journal.pone.0213386] [Medline: 30861035]
62. Wilson RS, Segawa E, Boyle PA, Bennett DA. Influence of late-life cognitive activity on cognitive health. Neurology 2012;78(15):1123-1129 [FREE Full text] [doi: 10.1212/WNL.0b013e31824f8c03] [Medline: 22491864]
63. Parsons S, McCormick EM. Limitations of two time point data for understanding individual differences in longitudinal modeling - what can difference reveal about change? Dev Cogn Neurosci 2024;66:101353 [FREE Full text] [doi: 10.1016/j.dcn.2024.101353] [Medline: 38335910]

Abbreviations

HLFC: higher-level functional capacity
IADL: instrumental activities of daily living
ICT: information and communication technology
JAGES: Japan Gerontological Evaluation Study
RR: risk ratio

TMIG-IC: Tokyo Metropolitan Institute of Gerontology Index of Competence

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Original Paper

Examining Whether Patient Portal and Video Visit Use Differs by Race and Ethnicity Among Older Adults in a US Integrated Health Care Delivery System: Cross-Sectional Electronic Health Record and Survey-Based Study

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Abstract

Background: Health care systems are increasingly encouraging patients to use patient portals and participate in video visits. However, there is limited information about how portal use differs among older adults.

Objective: This study aimed to understand how patient portal and video visit use differed by age, race, and ethnicity among older adult patients with access to the same digital health resources.

Methods: This cross-sectional study used electronic health record and survey data for adults aged 65 to 85 years who were members of a large Northern California health care delivery system throughout 2019 and 2020. The electronic health record cohort (N=471,152) included 320,686 White, 35,892 Black, 44,922 Latino, 20,786 Chinese, 28,732 Filipino, 8473 South Asian, 6716 Japanese, 2930 Vietnamese, and 2015 Korean adults. Racial and ethnic group and age group (65 to 75 years vs 76 to 85 years) differences in having a patient portal account by December 2020, the performance of 2 portal activities (sending ≥1 message to a clinician in 2019 or 2020 and viewing ≥1 laboratory test result in 2020), and having ≥1 video visit during 2020 were examined. Modified log-Poisson regression was used to examine prevalence ratios for portal and video visit use, comparing racial and ethnic groups to White adults and Asian ethnic groups to Chinese adults after adjusting for sex and age. Data from a 2020 member survey were used to compare internet use factors among 2867 White, 306 Black, 343 Latino, 225 Chinese, and 242 Filipino adults.

Results: Black, Latino, and Filipino adults were less likely to have a patient portal account than White adults, and Filipino adults were less likely to have a patient portal account than Chinese adults. Black, Latino, Filipino, Korean, Vietnamese, and South Asian adults were less likely to have sent messages and viewed test results than White adults, while Chinese and Japanese adults' use of these features was similar to that of White adults. Filipino, Vietnamese, and Korean adults were less likely to have performed the aforementioned activities than Chinese adults. Video visit use was lower among Black and Latino adults and higher among Chinese and South Asian adults compared with White adults (aged 76 to 85 years) and lower among Filipino, Korean, and Vietnamese adults compared to Chinese adults. Survey data suggested that underlying differences in internet use may partially explain the lower use of messaging by Black, Latino, and Filipino adults compared with White and Chinese adults.

Conclusions: Patient portal and video visit use differed by race, ethnicity, and age group among older adult patients with access to the same patient portal. Internet use factors may contribute to these differences. Differences in patient portal and video visit use across Asian subgroups underscore the importance of disaggregating use data by Asian ethnicity.

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KEYWORDS

patient portal use; video visit use; older adults; racial and ethnic differences; telehealth; mobile phone

Introduction

Background

Clinicians and patients are increasingly communicating and accessing health information electronically using patient portals [1,2]. Patient portals enable patients and their health care proxies to access selected health information in the patient's electronic health record (EHR), exchange messages with health care providers, view laboratory test results, order prescription refills, and schedule appointments, among other health care–related activities [3]**.** These patient portal activities, grouped under the umbrella of asynchronous telehealth, can be conveniently undertaken by both patients and clinicians at any time and from any location with internet service. Video visits, a form of synchronous telehealth, enable patients and health care providers to interact face to face from different locations. Video visits improve access and convenience for patients and can reduce clinic visit–related costs (eg, transportation and copays) [4-8]. Video visits also help address outpatient health care worker shortages and reduce physician burnout [9,10], although evidence is mixed for these outcomes and whether they ultimately reduce health care delivery costs [11]. Video visit use greatly increased in 2020 during the COVID-19 public health emergency as delivery of health care shifted from in-person clinic visits to video and phone visits when in-person care was not necessary [12-15]. During this time, Medicare reimbursed clinicians for virtual visits at the same rate as in-clinic visits, and many health insurers temporarily waived copays for video visits for commercially insured members [16,17].

Patient portals have the potential to enhance the patient-clinician relationship; improve health status; and increase self-management behaviors, including adherence to therapy [18]. Older adults stand to benefit a great deal from the ability to use patient portals and video visits. As a demographic group, they have a high burden of chronic health problems [19], with concomitant higher use of prescription medications, laboratory tests, medical visits, and the need to communicate with their health care providers outside of scheduled visits. Portals provide a convenient way to send and receive detailed communications rather than leaving brief phone messages with support staff during regular business hours. Portals also give patients and their proxies 24/7 access to viewing laboratory test results, appointment scheduling, ordering prescription refills, and viewing medical and visit history. Video visits can make it easier for older adults to access health care when in-clinic examinations or tests are not needed, especially for those who are frail, have mobility limitations, or have transportation-related difficulties. Video visits can also enable spouses and other caregivers to participate in scheduled visits in a way that is not always possible in clinic-based visits.

While the use of patient portals and video visits has been increasing among older adults, it remains substantially lower among middle-aged and younger adults. Philpot et al [20] used the term "digital determinants of health" to describe barriers to the use of patient portals and video visits, including lack of access to an internet-enabled device and webcam (for video visits); lack of high speed or broadband internet at home; lack of digital health literacy, skill, or confidence in the ability to use digital health technologies; concerns about privacy and security; cognitive or physical impairment that limits the use of a computer or touchscreen devices, internet, or complex websites; and lack of technical assistance from others [3,21-24]. In several studies, successful use of digital health tools by older adults depended on older adults' motivation and the support that they received [25].

While several studies have documented racial and ethnic group differences in patient portal and video visit use among general and disease-specific populations of US adults [26-31], there is a lack of contemporary data regarding racial and ethnic group differences in use of patient portal functions and video visits among US adults aged ≥65 years in health care systems that provide access to patient portals and video visits for all patients. Using 2013 to 2014 EHR and survey data to examine patient portal use and factors associated with use among Kaiser Permanente Northern California (KPNC) health plan members aged 65 to 79 years, our team previously observed that Black, Latino, and Filipino adults were less likely than White and Chinese adults to have to a patient portal account; to have signed into the patient portal at least once; and to have used the patient portal to send a secure message, view laboratory test results, or order prescription refills at least once by the end of 2013 [31]. In the same study, a mailed survey conducted in a random subset of health plan members in winter 2013-2014 found that Black, Latino, and Filipino, but not Chinese, adults were less likely than White adults to have access to digital tools, to have experience performing a variety of web-based tasks, to feel they were capable of going on the internet to obtain health information, and to be interested in using web-based health information modalities [31]. However, this early study was limited to those from 5 racial and ethnic groups aged 65 to 79 years and did not examine racial and ethnic differences in patient portal use among younger or older subsets. In addition, video visit use was not examined because video visits were not widely offered until 2020.

Since the start of the COVID-19 pandemic, health care providers have increasingly transitioned to the use of patient portals as a primary platform for sharing laboratory test results and other health care–related information with patients, for bidirectional messaging with patients to address health concerns rather than having phone calls, and for patients to self-schedule nonurgent appointments and order prescription medication refills on the web rather than through a call center. This transition could potentially exacerbate existing disparities in health information access and disparities in access to and use of digital health tools [32], the latter recently termed as gaps in digital health equity

[33] or health "techquity" [34]. Given well-documented evidence of racial and ethnic disparities in access to and use of the internet [27,35-38], it is important to understand the extent to which racial and ethnic differences in the use of patient portal functions and video visits occur among older adults. Furthermore, as ethnic diversity increases within the older adult population, especially within the Asian population, it is important to learn how the use of patient portals and video visits may vary across Asian ethnic groups, a currently understudied segment of the US population.

This Study

Our study addresses the aforementioned knowledge gaps by analyzing contemporaneous EHR and survey data for older members of a large Northern California health care delivery system. We first documented racial and ethnic differences in health plan patient portal and video visit use among adults aged 65 to 85 years whose preferred language for written materials in the EHR was English, including comparisons among Asian ethnic groups. We then used data from a health plan member survey for a subset of adults in the EHR cohort to examine educational attainment and internet use factors that might contribute to the differences in patient portal use across racial and ethnic subgroups.

Methods

Ethical Considerations

This work was conducted in accordance with procedures approved by the Kaiser Permanente Northern California (KPNC) Institutional Review Board. For the EHR cohort study (IRBnet #1279536-6), the KPNC Institutional Review Board waived the requirements to obtain informed consent and privacy rule authorization for use and disclosure of protected health information. The secondary analysis of the 2020 Member Health Survey data and linkage of survey respondent data to EHR data for the survey cohort study fell within the scope of the original 2020 Member Health Survey research protocol approved by the KPNC Institutional Review Board (IRBnet #1539606-3) which waived the requirement to document informed consent and privacy rule authorization for use and disclosure of protected health information.

Setting

KPNC is an integrated health care delivery system that provides primary and specialty health care, laboratory testing, and pharmacy services to a racially, ethnically, and sociodemographically diverse membership that includes >3.2 million adults who mostly reside in the Greater San Francisco Bay Area, Sacramento area, Silicon Valley, and the Central Valley. The KPNC adult membership has been shown to be very similar to the insured population of Northern California adults with regard to sociodemographic and health characteristics [39,40]. Since 2007, KPNC has maintained a patient portal as part of its website that enables members to communicate with their health care team and member services using secure messages; view laboratory test results, immunizations, past office visits, prescriptions, and health conditions; order prescription refills; and schedule or cancel nonurgent appointments [41]. To use the patient portal, members must register for and activate a patient portal account and sign onto the portal with their user ID and password to perform portal activities. During the study period (2019-2020), members were able to set up and activate their patient portal account or reset their password through the health plan's website or a Kaiser Permanente app for immediate use. Some patient portal content was available in Spanish but not in other non-English languages.

Study Population

EHR Cohort

The EHR study cohort was a subset of a 2019 EHR-based research cohort created to study demographic differences in health status and health care use in a very large (>2.4 million) cohort of adults aged 25 to 89 years who were KPNC members throughout 2019. More detail on how the demographic cohort was created can be found in an earlier publication [42]. The cohort for this study (N=471,152) comprised 320,686 (68.06%) non-Hispanic White (White); 35,892 (7.62%) African American or Black (Black); 44,922 (9.53%) Hispanic or Latino (Latino); 28,732 (6.1%) Filipino; 20,786 (4.41%) Chinese; 8473 (1.8%) South Asian; 6716 (1.43%) Japanese; 2930 (0.62%) Vietnamese; and 2015 (0.43%) Korean men and women who were aged 65 to 85 years on December 1, 2020. All adults had English as their preferred written language in the EHR and were KPNC members for all 24 months from 2019 to 2020.

Survey Cohort

The KPNC Member Health Survey is an English-only self-administered (mail or on the web) research survey that collects information about sociodemographic and health characteristics and the use of digital information technology. Survey details are published elsewhere [43,44]. Because the 2020 Member Health Survey sample was drawn from the same source cohort used to create the EHR cohort for this study, the survey cohort is a subset of the larger EHR cohort. The survey sample included 2867 White, 306 Black, 343 Latino, 225 Chinese, and 242 Filipino adults aged 65 to 85 years who answered survey questions pertaining to internet use factors. Only the 2 largest Asian ethnic groups are represented as the other 4 Asian ethnic groups had too few respondents to examine as a subgroup. Of the 52.9% (4269/8065) of adults aged 65 to 85 years in these 5 racial and ethnic groups who responded to the survey, a total of 93.9% (3983/4269) answered internet use questions.

Study Variables

EHR Cohort

A description of the methods used to assign race and ethnicity, including the use of language preference in the EHR, member survey sources, and surname assignment can be found in an earlier 2019 publication appendix [42]. Age on December 1, 2020 (integer variable), was determined from the date of birth. Sex was restricted to male or female as indicated in the EHR. Chronic cardiovascular conditions (diabetes, hypertension, ischemic heart disease, and heart failure) were assigned using International Classification of Disease Tenth Revision outpatient visit and problem list diagnoses from 2018 to 2019.

We used data abstracted from KPNC EHRs to create the following 4 variables: (1) indication of an activated patient portal account by December 1, 2020; (2) history of having sent ≥1 secure message to a clinician during 2019 or 2020; (3) history of viewing laboratory test results during 2020 if ≥1 laboratory test result was released during 2020; and (4) history of having ≥1 video visit during 2020 if the person had ≥1 ambulatory visit in a department that offered video visits during 2020. Because sending a secure message was not restricted to a subset of the population that experienced a particular event (ie, having a laboratory test released during the year), we ascertained this outcome over a larger 2-year window to allow more time for patients to have sent a secure message. Video visit use was only examined for 2020 due to its infrequent use before the onset of the COVID-19 pandemic emergency in March 2020. Because an activated patient portal account was necessary for sending secure messages and viewing laboratory test results, we examined differences in the use of these patient portal functions by all patients and by patients who had an activated portal account by the end of 2020. An activated patient portal account was not required for a video visit. Starting in March 2020, most outpatient visits were conducted by video or phone due to the COVID-19 pandemic.

Survey Cohort

We examined 6 variables from survey data and 3 variables from EHR data. Educational attainment was examined as a 3-level variable: high school graduate or less, some college or associate degree, or bachelor's degree or higher. Use of the internet was based on the question, "Do you use the internet (go online) to get information, watch videos, fill out forms, pay for things, etc.?" Response options included "Yes, I use it by myself;" "Yes, but someone else helps or uses it for me;" or "No, I don't use the internet." Access to a desktop, laptop, or tablet computer was based on a "yes" to the question, "Do you have access to a desktop, laptop, or tablet computer that you can (or could) use to go online (use the internet)?" and access to an internet-capable device was assigned based on having a computer, tablet, or smartphone. Internet users were asked, "Can you easily print information/forms you get from the internet?" Respondent data were linked to EHR patient portal use data: having an activated patient portal account by June 2020, sending ≥1 message using the patient portal between January 2019 and June 2020, and having a video visit in 2020.

Statistical Analyses

EHR Cohort Analyses

All analyses were performed using SAS (version 9.4; SAS Institute). For each patient portal use variable and video visit use, we examined portal use statistics for the 9 racial and ethnic groups, overall, and for those aged 65 to 75 and 76 to 85 years within the racial and ethnic groups. Chi-square tests were used to compare demographic groups, with the largest group (White adults) serving as the reference. Chinese adults were used as the reference group for comparisons among the 6 disaggregated Asian ethnic groups. Previous KPNC research on the use of digital information technologies and patient portal functions found that Chinese adults were more likely to use the internet, obtain health information from websites, and use the patient portal than Filipino adults [31,35].

Because the racial and ethnic groups being compared were very large, very small differences in percentages that were statistically significant were not always meaningful. We thus made an a priori decision to use a between-group absolute difference of ≥5 percentage points as the threshold for meaningful difference. Hence, for descriptive analyses pertaining to the EHR cohort, all demographic differences described in the Results section met the criterion of an absolute difference of ≥5 percentage points and a chi-square P value of <.05 for differences in proportions. Modified log-Poisson regression models were used to estimate adjusted prevalence ratios (aPRs) with 95% CIs for each portal use outcome using White or Chinese groups as reference and controlling for sex and age as a continuous variable. As the portal use outcomes being modeled were not rare events and we were comparing group-level prevalence rather than individual likelihood of portal outcome use, the aPR is a more appropriate measure of association than an adjusted odds ratio derived from a logistic regression model, which can inflate the strength of association [45].

Survey Cohort Analyses

Survey respondents were assigned poststratification population weighting factors so that the analytic weighted sample would more closely approximate the age, sex, and racial composition of adults aged 65 to 85 years with English written language preference in the 2019 KPNC membership (ie, the same population that was used for the EHR cohort). To prevent variance inflation, population weights were normalized (rescaled) so that the number in the analytically weighted sample would be equivalent to the number of survey respondents while maintaining the same age-sex-racial-ethnic composition of the population-weighted sample. Normalized weighting factors were created by multiplying the population weighting factors by the reciprocal of the sum of the survey population weights divided by the total number of survey respondents.

All analyses were performed using weighted survey data with SAS (version 9.4). Cross-tabular analyses were used to produce estimates of internet use, device access, and portal use for each racial and ethnic group. To test for racial and ethnic group differences, we used modified log-Poisson regression models that adjusted for age (5-year age group) and sex (female vs male) and for age, sex, and education (≤ high school graduate and some college or associate degree vs ≥ bachelor's degree). Modified log-Poisson regression models were also used to examine the association of internet use status with patient portal use after controlling for demographic characteristics, reporting aPRs with 95% CIs.

Results

EHR Cohort

Demographic and Health Characteristics of the EHR Study Cohort

As presented in Table 1, all 9 racial and ethnic groups had approximately the same mean age, but Chinese and South Asian groups had higher proportions of adults aged 65 to 75 years compared to White adults. The South Asian group had a higher proportion of men. Black, Latino, Filipino, and South Asian groups had higher proportions of adults with a chronic cardiovascular condition (diabetes, hypertension, ischemic heart disease, or heart failure). Among the Asian ethnic groups, compared to the Chinese group, the Japanese and Korean groups had higher proportions of adults aged 65 to 75 years, whereas the Filipino and South Asian groups had higher proportions of adults with chronic cardiovascular conditions.

Table 1. Characteristics of racial and ethnic groups in the electronic health record study cohort of adults aged 65 to 85 years (N=471,152).

Characteristic	White (n=320,686)	Black (n=35,892)	Latino (n=44,922)	Chinese (n=20,786)	Filipino (n=28,732)	Japanese (n=6716)	Korean (n=2015)	Vietnamese (n=2930)	South Asian (n=8473)
Sex (%)									
Male	45.1	40.7	44.2	47.7	41	41.4	40.9	51.4[a]	57.2[a]
Female	44.9	59.3	55.8	52.3	59.0	58.16	59.1	48.6	42.8
Age, Mean (SD)	73.5 (5.2)	73.1 (5.3)	73.1 (5.3)	72.8 (5.2)	73.0 (5.2)	73.8 (5.4)	73.7 (5.1)	72.1 (4.8)	72.5 (5.0)
65 to 75 (%)	66.3	68.7	68.4	72.8[a]	70	63.4[b]	65.4[b]	76	73.2[a]
76 to-85 (%)	33.7	31.3	31.6	27.2	30	36.6	34.6	24	26.8
≥1 chronic cardiovascular condition[c] (%)	63.8	83.7[a]	73.1[a]	63.4	84.9[a,b]	67.4	64.4	66.5	77.9[a,b]

[a] Racial-ethnic group differed from White adults by ≥5 percentage points and the difference was statistically significant at *P*<.001.

[b] Asian ethnic group differed from Chinese adults by ≥5 percentage points and the difference was statistically significant at *P*<.001.

[c] Chronic cardiovascular conditions included diabetes, hypertension, ischemic heart disease, or heart failure diagnosis.

Patient Portal Account Status by the End of the Year 2020

As presented in Table 2, ≥80% (range 81%-94%) of adults aged 65 to 85 years in each of the 9 racial and ethnic groups had an activated patient portal account by the end of 2020. The lowest percentage was seen for Black adults aged 76 to 85 years (73%), and the highest percentage (95%) was seen for White, Chinese, and Japanese adults aged 65 to 75 years. In all age groups, Black, Latino, and Filipino adults were less likely to have an activated portal account than White adults, and Filipino adults were less likely to have an activated portal account than Chinese adults. After adjusting for age and sex, Black, Latino, Filipino, and Vietnamese adults, respectively, were 14%, 10%, 7%, and 5% less likely than White adults to have a patient portal account, and Filipino adults were 7% less likely than Chinese adults to have a patient portal account (Figure S1 in Multimedia Appendix 1). More than 90% of adults (range 92%-99%) with an activated portal account by December 2020 also had an activated account in 2019 (data not shown).

Table 2. Racial and ethnic group differences in patient portal and video visit use from 2019 to 2020 by adults aged 65 to 85 years, overall and by age group.

	White	Black	Latino	Chinese	Filipino	Japanese	Korean	Vietnamese	South Asian
Had a patient portal account by the end of 2020[a]									
All aged 65 to 85 years, n (%)	320,686 (94.1)	35,892 (80.8)[b,c]	44,922 (85.4)[b,c]	20,786 (93.9)	28,732 (87.3)[b,c,d]	6716 (93.1)[c]	2015 (89.4)	2930 (91.7)	8473 (93.6)
Those aged 65 to 75 years, n (%)	212,545 (95.6)	24,647 (84.5)[b]	30,705 (87.7)[b]	15,126 (95.1)	20,120 (89.1)[b,d]	4257 (95.4)	1318 (90.1)[b,d]	2227 (92.4)	6204 (93.8)
Those aged 76 to 85 years, n (%)	108,141 (91.2)	11,245 (72.6)[b]	14,217 (80.3)[b]	5660 (90.6)	8612 (83.2)[b,d]	2459 (89.3)	697 (88.1)	703 (89.5)	2269 (93.1)
Sent ≥1 secure message in 2019 or 2020[a]									
All aged 65 to 85 years, n (%)	320,686 (80.2)[c]	35,892 (54.2)[b,d]	44,922 (60.8)[b,d]	20,786 (76.3) [c]	28,732 (59.9)[b,c,d]	6716 (75.8)[c]	2015 (61.1)[b,d]	2930 (66.7)[b,c,d]	8473 (74.5)[b]
Those aged 65 to 75 years, n (%)	212,545 (82.9)	24,647 (58.7)[b]	30,705 (64.2)[b]	15,126 (78)	20,120 (62.9)[b,d]	4257 (79.5)	1318 (62.3)[b,d]	2227 (68.3)[b,d]	6204 (74.5)[b]
Those aged 76 to 85 years, n (%)	108,141 (74.8)	11,245 (44.4)[b]	14,217 (53.5)[b]	5660 (71.8)	8612 (53.1)[b,d]	2459 (69.3)[b]	697 (59)[b,d]	703 (61.6)[b,d]	2269 (74.7)
Viewed laboratory results ≥1 time in 2020 (adults with ≥1 laboratory result released in 2020)[a]									
All aged 65 to 85 years, n (%)	277,726 (84.4)[c]	31,145 (59.2)[b,d]	39,582 (66.8)[b,d]	17,743 (83.7)[c]	25,087 (68.9)[b,c,d]	5738 (83)[c]	1742 (71.4)[b,c,d]	2536 (76.4)[b,d]	7517 (80.9)
Those aged 65 to 75 years, n (%)	186,871 (87.1)	21,781 (63.8)[b]	27,471 (70.6)[b]	13,195 (85.3)	18,057 (71.8)[b,d]	3744 (86.4)	1163 (73.5)[b,d]	1958 (77.9)[b,d]	5619 (81.1)[b]
Those aged 76 to 85 years, n (%)	90,855 (78.8)	9364 (48.6)[b]	12,111 (58.2)[b]	4548 (78.9)	7030 (61.2)[b,d]	1994 (76.4)	579 (67)[b,d]	578 (71.5)[b,d]	1898 (80.2)
Had ≥1 video visit in 2020 (adults with ≥1 ambulatory visit in 2020)[a]									
All aged 65 to 85 years, n (%)	286,687 (48)[b]	32,374 (43.6)[b]	40,815 (43.4)[b]	17,902 (52.8)[b]	25,678 (47.1)[c]	5778 (49.6)[b]	1791 (44.4)[b,c]	2569 (46.9)[c]	7688 (54.4)[a]
Those age 65 to 75 years, n (%)	187,475 (50.6)	22,132 (46.2)	27,593 (46.1)	12,848 (54.4)	17,905 (47.9)[c]	3562 (53)	1150 (46.3)[c]	1930 (47.5)[c]	5615 (54.3)
Those aged 76 to 85 years, n (%)	99,212 (42.9)	10,242 (37.9)[a]	13,222 (37.8)[a]	5054 (48.8)[a]	7773 (45.3)[c]	2216 (44)	641 (41)[c]	639 (45.2)	2073 (54.7)[a,c]

[a] n: total number of adults in this age subgroup used as the denominator to calculate the percentage.

[b] Meaningful difference between this racial-ethnic group and White adults based on ≥5 percentage point difference that was statistically significant at *P*<.05. Differences remained statistically significant after controlling for age and sex.

[c] Meaningful difference between those aged 65 to 75 years and 76 to 85 years within this racial or ethnic group based on ≥5 percentage point difference that was statistically significant at *P*<.05. Differences remained statistically significant after controlling for age and sex.

[d] Meaningful difference between this Asian ethnic group and Chinese adults based on ≥5 percentage point difference that was statistically significant at *P*<.05. Differences remained statistically significant at *P*<.05 after controlling for age and sex.

Use of Secure Messaging Through the Patient Portal During 2019 and 2020

There was substantial racial and ethnic variation in the use of secure messaging, ranging from a low value of 54% for Black adults to a high value of 80% for White adults. The lowest percentage was seen for Black adults aged 76 to 85 years (44%) and the highest percentage was seen for White adults aged 65 to 75 years (83%). Significant racial and ethnic differences in the percentage of adults who sent ≥1 secure message in 2019 or 2020 were seen in the overall 65- to 85-year age group and both age subgroups (Table 2). Black, Latino, Filipino, Korean, and Vietnamese adults in all 3 age groups and South Asian adults aged 65 to 85 years and 65 to 75 years were less likely than White adults to have sent a secure message during that time, and in all but the South Asian group, adults aged 76 to 85 years were less likely to have sent a secure message than adults in the 65 to 75 years age group. Among Asian ethnic groups, Filipino, Korean, and Vietnamese adults in all 3 age groups were less likely than Chinese adults to have used secure messaging. After adjusting for age and sex, Black, Latino, Chinese, Filipino, Korean, Vietnamese, and South Asian adults, respectively, were 33%, 25%, 6%, 26%, 24%, 18%, and 8% less likely than White adults to have sent a secure message (Figure S2 in Multimedia Appendix 1). Filipino, Korean, and Vietnamese adults, respectively, were 21%, 19%, and 13% less likely than Chinese adults to have sent ≥1 secure message. The same racial and ethnic differences were seen in the subset of adults who had an activated portal account by the end of 2020, but some of the meaningfully significant age-specific differences within racial and ethnic groups in the full population were nonsignificant among those with activated accounts (Table 3).

Table 3. Racial and ethnic differences in patient portal use during 2019 and 2020 among adults aged 65 to 85 years, overall and by age group, restricted to adults who had an activated patient portal account by the end of 2020.

	White	Black	Latino	Chinese	Filipino	Japanese	Korean	Vietnamese	South Asian
Sent ≥1 secure message in 2019 or 2020[a]									
Overall cohort, aged 65 to 85 years, n (%)	301,855 (85.2)	28,991 (67.1)[b,c]	38,346 (71.2)[b,c]	19,511 (81.2)	25,090 (68.6)[b,c,d]	6255 (81.3)[c]	1801 (68.4)[b,d]	2687 (72.7)[b,d]	7931 (79.6)[b]
Aged 65 to 75 years, n (%)	203,219 (86.7)	20,832 (69.5)[b]	26,928 (73.2)[b]	14,385 (82)	17,922 (70.6)[b,d]	4060 (83.4)	1187 (69.1)[b,d]	2058 (74)[b,d]	5818 (79.4)[b]
Aged 76 to 85 years, n (%)	98,636 (81.9)	8159 (61.1)[b]	11,418 (66.4)[b]	5126 (79.1)	7168 (63.6)[b,d]	2195 (77.4)	614 (66.9)[b,d]	629 (68.7)[b,d]	2113 (80.2)
Viewed laboratory results ≥1 time in 2020 (adults with ≥1 laboratory result released in 2020)[a]									
Overall cohort, aged 65 to 85 years, n (%)	263,937 (88.8)	25,652 (71.9)[b,c]	34,263 (77)[b,c]	16,818 (88.2)	22,242 (77.6)[b,c,d]	5425 (87.7)[c]	1577 (78.7)[b,d]	2355 (82.3)[b,d]	7072 (85.9)
Aged 65 to 75 years, n (%)	180,024 (90.4)	18,691 (74.3)[b]	24,410 (79.4)[b]	12,655 (88.9)	16,260 (79.6)[b,d]	3610 (89.6)	1066 (80.1)[b,d]	1832 (83.2)[b,d]	5292 (86.1)
Aged 76 to 85 years, n (%)	83,913 (85.3)	6,961 (65.3)[b]	6961 (65.3)[b]	4163 (86)	5952 (72.1)[b,d]	1815 (83.7)	511 (75.7)[b,d]	9853 (71.3)[b]	1780 (85.5)

[a] n: total number of adults in this age subgroup used as the denominator to calculate the percentage.

[b] Meaningful difference between this racial-ethnic group and White adults based on ≥5 percentage point difference that was statistically significant. Differences remained statistically significant at *P*<.05 after controlling for age and sex.

[c] Meaningful difference between those aged 65 to 75 years and 76 to 85 years within this racial or ethnic group based on ≥5 percentage point difference that was statistically significant at *P*<.05. Differences remained statistically significant after controlling for age and sex.

[d] Meaningful difference between this Asian ethnic group and Chinese adults based on ≥5 percentage point difference that was statistically significant at *P*<.05. Differences remained statistically significant after controlling for age and sex.

Viewed Laboratory Test Results Using the Portal During 2020

Among adults aged 65 to 85 years with ≥1 laboratory test result released in 2020, the percentage of those who viewed laboratory results using the portal ranged from 67% for Latino adults to 84% for White adults. The lowest percentage was seen for Black adults aged 76 to 85 years (49%) and the highest was seen for White adults aged 65 to 75 (87%). Black, Latino, Filipino, Korean, and Vietnamese adults in all age groups and South Asian adults aged 65 to 75 years were less likely to have viewed laboratory test results using the portal than White adults (Table 2). In all age groups, Filipino, Korean, and Vietnamese adults were less likely to have viewed laboratory results on the web than Chinese adults. In all racial and ethnic groups except Vietnamese and South Asian groups, adults aged 76 to 85 years were less likely to have viewed laboratory results using the portal than adults aged 65 to 75 years. Adjusting for age and sex, Black, Latino, Filipino, Korean, Vietnamese, and South Asian adults aged 65 to 85 years were 30%, 21%, 19%, 15%, 11%, and 5%, respectively, less likely than White adults to have viewed a laboratory test result using the portal during that year, and Filipino, Korean, and Vietnamese adults were 17%, 14%, and 9% less likely than Chinese adults to have done so (Figure S3 in Multimedia Appendix 1). The same racial and ethnic differences were seen among adults who had a portal account in 2020, except for the South Asian group (Table 3).

Video Visit During 2020

Among adults who had ≥1 ambulatory visit with a department that offered video visits during 2020, the percentages of those who used this modality ranged from a low value of 43% for Black and Latino adults to a high value of 54% for South Asian adults in the 65 to 85 years age group (Table 2). The lowest use was seen for Black and Latino adults aged 76 to 85 years (38%) and the highest (54%) for South Asian adults in all age groups and Chinese adults aged 65 to 75 years. Overall, South Asian adults were more likely than White adults to have had a video visit. Otherwise, differences between White adults and the other racial and ethnic groups were observed only in the 76- to 85-year age group (Black and Latino adults were less likely and Chinese and South Asian adults were more likely to have had a video visit during 2020). Filipino and Korean adults in all age groups and Vietnamese adults aged 65 to 85 years and 65 to 75 years were less likely to have had a video visit than Chinese adults, and South Asian adults aged 76 to 85 years were more likely to have had a video visit than Chinese adults. Adjusting for age and sex, Black, Latino, and Korean adults, respectively, were 10%, 10%, and 7% less likely, and Chinese and South Asian adults were 9% and 12% more likely than White adults to have had a video visit in 2020. After adjusting for age and sex, Filipino, Japanese, Korean, and Vietnamese adults, respectively, were 11%, 5%, 15%, and 12% less likely to have had a video visit than Chinese adults (Figure S4 in Multimedia Appendix 1).

Survey Cohort

Racial and Ethnic Group Differences in Educational Attainment

Black and Latino adults were less likely than White and Chinese adults to have a bachelor’s degree or higher and more likely to have low educational attainment (≤ high school graduate), while educational attainment for Filipino adults was not significantly different from White or Chinese adults (Table 4). Chinese adults were more likely to have a higher educational attainment (at least a bachelor’s degree) than White adults. Among White, Black, and Filipino adults, older adults aged 76 to 85 years (vs those aged 65 to 75 years) were more likely to have low educational attainment.

Table 4. Comparison of educational attainment, digital information technology use, and patient portal use across White, Black, Latino, Chinese, and Filipino health plan members aged 65 to 85 with English language preference[a].

	White (%)	Black (%)	Latino (%)	Chinese (%)	Filipino (%)
Educational attainment					
High school diploma or less	17.2[b,c]	22.7[b,c,d]	40.4[b,d]	10.7[d]	16.8[c]
Some college or associate degree	33.9	44.2	35.8	26.7	26.4
Bachelor's degree or higher	48.9[b]	33.1[b,d]	23.8[b,d]	62.6[d]	56.7[e]
Uses the internet (alone or with help) to get information or watch videos (all adults)	93[e]	83.7[b,d,e]	84.9[b,d,e]	94.3[e]	87.9[b,d,e]
Uses the internet without help					
All adults	86.2[e]	71.3[b,d,e]	71.9 [b,d,e]	90.5[e]	67.2[b,d,e]
Internet users only	93[e]	85.9[b,d,e]	85[b,d,e]	96.2[e]	78.2[b,d,e]
Uses the internet with someone's help					
All adults	6.7[c]	12.4[b,c,d]	13[b,c,d]	3.8[c]	20.7[b,c,d]
Internet users only	7.2[e]	14.8[b,c,d]	15.4[b,c,d]	4.1[c]	23.5[b,c,d]
Has an internet-capable device[f]					
All adults	94.6[e]	88.6[d,e]	88.5[d]	94.1	91.6[e]
Internet users only	99	98.3	97.3	97.6	97.5
Has a desktop, laptop, or tablet computer					
All adults	93.9[e]	86.5[b,d,e]	86.3[b,d]	93[e]	85.9[b,d]
Internet users only	98.4	96.2	95.7	96.4	92.5[d]
Has access to a printer that can be used to print information from the internet or email (internet users only)	90.4	84	86.9	88	86.9
Had a patient portal account by June 2020[g]					
All adults	95.7[e]	86.1[b,d,e]	90.1[b,c,d]	97.2	92.7
Internet users only	98.4	94.6[b,d]	96.9	98.8	95.9
Sent ≥1 message through the patient portal between January 2019 and June 2020[g]					
All adults	67.9[f]	44.1[b,d,e]	54.6[b,d]	68.3	49.1[b,d]
Internet users only	72[f]	52.8[b,d,e]	63.2[c]	71.3	52.3[b,d]
Had ≥1 video visit during 2020 (whether the user had ≥1 outpatient visit in 2020)[g]					
All adults	50.7[f]	46	51.3[f]	56.7	51.5
Internet users only	53[f]	51.3	56[f]	57.3	53.6

[a] Estimates are based on 2020 Member Health Survey data weighted to the age, sex, and racial and ethnic composition of the health plan's adult membership in 2019. Unweighted Ns for racial-ethnic groups are as follows: n=2867 White adults, n=225 Chinese adults, n=306 Black adults, n=343 Latino adults, and n=242 Filipino adults and internet users: n=2655 White adults, n=213 Chinese adults, n=255 Black adults, n=286 Latino adults, and n=206 Filipino adults. Survey respondents are a subset of the adults in the electronic health record study cohort.

[b] Prevalence significantly (*P*<.05) differs from that of Chinese adults after adjusting for age and sex.

[c] Within racial and ethnic groups, the percentage is significantly (*P*<.05) higher among those aged 76 to 85 years versus those aged 65 to 75 years after adjusting for sex (data not shown).

[d] Percentage significantly (*P*<.05) differs from that of White adults after adjusting for age and sex.

[e] Within racial and ethnic groups, the percentage is significantly (*P*<.05) lower among those aged 76 to 85 years versus those aged 65 to 75 years after adjusting for sex (data not shown).

[f] Computer, tablet, or smartphone.

[g] Patient portal use data for survey respondents were abstracted from their electronic health records.

Factors Associated With Digital Information Technology Use

Black, Latino, and Filipino adults aged 65 to 85 years were less likely than both White and Chinese adults to use the internet (with or without help; Table 4). Among internet users, Black, Latino, and Filipino adults were significantly less likely to use the internet without help than both White and Chinese adults.

Black and Latino adults were also less likely to have an internet-capable device than White adults, but this difference was not seen among internet users. Furthermore, Black, Latino, and Filipino adults were less likely than both White and Chinese adults to have access to an internet-enabled computer, and Filipino internet users were less likely than White internet users to have computer access. Among adults who used the internet, 10% to 16% did not have a printer they could use to print information from the internet or emails. Among all 5 racial and ethnic groups, adults aged 76 to 85 years were less likely to be internet users and to be able to use the internet without help than those aged 65 to 75 years. Among White, Black, and Chinese adults, those aged 76 to 85 years were also less likely to have an internet-capable device than those aged 65 to 75 years.

Demographic and Internet Use Factors Associated With Differences in Patient Portal Use

Similar to the full EHR cohort, Black and Latino adults in the survey population were less likely to have a patient portal account than both White and Chinese adults. However, in contrast to the EHR cohort, Filipino adults did not significantly differ from either White or Chinese adults in the survey cohort (Table 4 and model 1 in Table 5). Moreover, similar to the EHR cohort, Black, Latino, and Filipino adults were less likely to have sent a message to their physician through the patient portal than both White and Chinese adults (from January 2019 to June 2020).

Table 5. Prevalence ratios showing racial and ethnic group differences in percentages of adults aged 65 to 85 years in the survey population who sent ≥1 secure message, after adjusting for demographic and internet use characteristics.[a]

Model	Reference group	
	White adults, aPR[b] (95% CI)	Chinese adults, aPR (95% CI)
Model 1: adjusted for age[c] and sex		
White adults	Reference	1.02 (0.92-1.13)
Black adults	0.66 (0.58-0.75)	0.67 (0.58-0.79)
Latino adults	0.81 (0.73-0.90)	0.83 (0.72-0.95)
Chinese adults	0.98 (0.89-1.09)	Reference
Filipino adults	0.72 (0.62-0.83)	0.73 (0.62-0.86)
Model 2: adjusted for age[c], sex, and education[d]		
White adults	Reference	1.05 (0.94-1.16)
Black adults	0.69 (0.60-0.78)	0.72 (0.61-0.84)
Latino adults	0.87 (0.78-0.97)	0.91 (0.79-1.05)
Chinese adults	0.95 (0.86-1.06)	Reference
Filipino adults	0.71 (0.62-0.82)	0.75 (0.63-0.89)
Model 3: adjusted for age[c], sex, education[d], and internet use		
White adults	Reference	1.04 (0.94-1.14)
Black adults	0.73 (0.64-0.82)	0.75 (0.65-0.88)
Latino adults	0.89 (0.81-0.99)	0.93 (0.81-1.06)
Chinese adults	0.97 (0.88-1.07)	Reference group
Filipino adults	0.75 (0.65-0.86)	0.78 (0.65-0.92)

[a] For these analyses, demographic and internet use data were collected from the 2020 Kaiser Permanente Northern California Member Health Survey and were linked with electronic health record data regarding secure message use from January 2019 through June 2020. Respondent data have been weighted to reflect the age, sex, and racial and ethnic composition of the adult health plan membership in 2019. The aPR estimates the percentage of adults in a racial or ethnic group who sent ≥1 secure message during the study period compared to the percentages of White or Chinese adults who did so, after adjusting for covariates using log-Poisson regression models.

[b] aPR: adjusted prevalence ratio.

[c] Age in 5-year intervals (65-69, 70-74, 75-79, and 80-85 years).

[d] Education is a 3-level variable, with ≤ a high school graduate and some college or associate degree compared to ≥ a bachelor's degree.

Among all adults, after adjusting for age, sex, education, and racial and ethnic groups, internet users were nearly 70% more likely to have a patient portal account than nonusers (aPR 1.66, 95% CI 1.51-1.83) and >4 times more likely to have sent a message through the patient portal (aPR 4.18; 95% CI 3.19-5.48) than nonusers. Within individual racial and ethnic groups, after adjusting for age, sex, and education, internet users were 40% to 60% more likely to have a patient portal account than nonusers (White users: aPR 1.62, 95% CI 1.45-1.82; Black users: aPR 2.09, 95% CI 1.47-2.97; Latino users: aPR 1.78, 95% CI 1.35-2.35; Filipino users: aPR 1.41, 95% CI 1.11-1.79; and Chinese users: aPR 1.42, 95% CI 0.91-2.21; *P*=.12) and >3 times more likely to have sent a message through the patient portal (White users: aPR 4.33, 95% CI 3.12-6.02; Black users: aPR 5.70, 95% CI 2.35-13.84; Latino users: aPR 5.12, 95% CI 2.11-12.40; Chinese users: aPR 3.78, 95% CI 1.06-13.46; and Filipino users: aPR 1.76, 95% CI 0.87-3.55; *P*=.11). Educational attainment was not associated with having a portal account or with sending a message through the portal after controlling for internet user status.

As presented in Table 5 (models 2 and 3), adjusting for internet user status, in addition to age, sex, and education, did not reduce racial and ethnic group differences in the use of the patient portal to send a message to a health care provider. Black, Latino, and Filipino adults were less likely to have sent a portal message than White adults, and Black and Filipino adults were less likely to have sent a portal message than Chinese adults.

Demographic and Internet Factors Associated With Video Visit Use in 2020

Approximately half (46% to 57%) of the older adults in the survey population who had at least 1 outpatient visit from a department that offered video visits had ≥1 video visit during 2020, and similar to the full EHR cohort, no significant racial and ethnic group differences were observed. After adjusting for age, sex, and education, being an internet user was associated with approximately 2-fold greater use of video visits in the overall study population (aPR 2.28, 95% CI 1.79-2.90), but analyses by racial and ethnic groups found that this difference was only among White (aPR 2.71, 95% CI 1.91-3.85), Black (aPR 3.21, 95% CI 1.45-7.11), and Latino (aPR 1.85, 95% CI 1.09-3.15) adults. After adjusting for age, sex, and internet use, educational attainment was neither significantly associated with video visit use in the overall study population nor any of the racial or ethnic groups.

Discussion

Principal Findings

In this study, we examined how the use of a health plan patient portal and video visit use differed across racial and ethnic groups in a population of insured older adults whose preferred spoken language was English and who had access to the same health plan patient portal during 2019 and 2020. Using EHR-derived data, we documented lower use of patient portal functions (sending messages and viewing laboratory test results) among Black, Latino, Filipino, Korean, and Vietnamese older adults compared to similarly aged White and Chinese adults; similar use of these patient portal functions among Chinese, Japanese, and South Asian older adults compared to White adults; and lower use of these patient portal functions among older adults (those aged 76 to 85 years) compared to younger (those aged 65 to 75 years) groups. We then used survey information for a subset of White, Black, Latino, Chinese, and Filipino respondents in the EHR cohort to explore potential factors that might contribute to lower engagement in patient portal activities observed in EHR cohort analyses for Black, Latino, and Filipino adults compared to White and Chinese adults.

Overall and for both age groups, Black, Latino, and Filipino adults were less likely to have an activated patient portal account and less likely to have sent messages and viewed laboratory results using their portal account than White adults. Korean, Vietnamese, and South Asian adults did not differ from White adults in having a portal account but were less likely to have used the portal for sending messages and viewing laboratory results. Chinese and Japanese adults did not generally differ from White adults on any of the portal use outcomes, but older Japanese adults (aged 76 to 85 years) were less likely to send secure messages than White adults.

Furthermore, our analyses of racial and ethnic differences in secure messaging and viewing of laboratory results by patients with an activated patient portal account showed that these differences were not simply associated with the lack of an activated patient portal account, although age group differences were attenuated in some cases. Racial and ethnic variations in the video visit use were mainly evident in the 76 to 85 age group, where Black and Latino adults were less likely and Chinese and South Asian adults were more likely to have had a video visit than White adults.

The survey data elucidated factors that might account for the lower patient portal use among Black, Latino, and Filipino adults compared to White and Chinese adults. Black and Latino adults had lower educational attainment than White, Filipino, and Chinese adults, which has been identified as a barrier to the use of the internet and patient portals among older adults in previous research [31,35,46]. Black, Latino, and Filipino adults were less likely to be internet users and to have an internet-enabled computer or tablet, and Black and Latino adults were less likely than White and Chinese adults to have any internet-capable device. While Black, Latino, and Filipino adults who were internet users were more likely than nonusers to have a patient portal account and to have sent a message using the portal, their use of patient portal messaging remained lower than that among White and Chinese adults after controlling for internet user status. Finally, we found that not being an internet user was associated with a lower prevalence of video visit use for older Black and Latino adults, but not for White, Chinese, and Filipino adults.

Our study results are consistent with previous research that found lower rates of patient portal use among US Black, Latino, and Asian older adults compared to White adults [26-30] and among older versus younger Medicare-age adults. Importantly, our study provides novel and contemporary information about racial and ethnic and age group differences in patient portal and video visit use among US Medicare-age adults whose primary language is English. A major contribution is the provision of disaggregated data for Asian ethnic groups, demonstrating variation in the patient portal and video visit use among Asian ethnic groups and identification of factors that may contribute to a lower portal use among the selected ethnic groups.

The survey data for a subset of adults in the EHR cohort suggest that the lower percentages of Black, Latino, and Filipino older adults using patient portal functions compared to White and Chinese adults may in part be due to their lower overall internet use. Internet user status is a barrier to patient portal use that could potentially be removed by providing free or subsidized laptop or tablet computers and printers along with Wi-Fi or data plans for those who do not use the patient portal due to financial barriers. In addition, training on how to use the internet and patient portal for those who lack these skills can be offered. However, the survey data also suggest that factors beyond access to and skills in using the internet may contribute to the observed demographic disparities in patient portal use, especially among adults aged >75 years who do not have as much experience as adults aged 65 to 75 years in using digital information technologies. These factors could include how comfortable and articulate the patient is with composing written digital communications, how important it is to the patient to be able to ask follow-up questions during clinical interactions, and the extent to which patients feel that solely exchanging written messages decreases their sense of interpersonal connection with health care providers [35,47,48].

The disparities we identified in patient portal use and internet use capabilities have implications for a US health care system that is increasingly shifting to using patient portals to share health-related information with patients and to enable bidirectional communication between patients and their health care team. Specifically, to increase patient portal use by Medicare-age adults and to reduce racial, ethnic, and age-related disparities, health plans and community-based institutions, such as libraries and older person centers, should offer skill training, technical support and written instructions, and ongoing encouragement specific to performing patient portal activities for adults who do not use the patient portal on their own but want to learn [20,31,49,50]. This recommendation is supported by a 2023 national survey that found that 24% of older adults whose health plan had a patient portal thought it would be helpful to receive training or a tutorial on patient portal use [48]. Health plans may need to consider loaning or subsidizing the purchase of a low-end internet-enabled computer or tablet with accessories for older adults who do not own one. Research has shown that many older adults find it easier to complete online tasks that involve entering information using a computer with a keyboard and mouse, rather than a touch screen tablet or smartphone [51].

In the first full year of the COVID-19 pandemic, only half of the adults aged 65 to 85 years who had an outpatient visit opted to have a video visit, with lower percentages in the 76 to 85 years age group and among Black and Latino adults compared to White adults in that older age group. While we cannot determine whether the lack of video visits is due to patient preference or digital health access barriers, Medicare and other health insurers should consider parity for phone and video visit reimbursement so that health care systems and clinicians are not financially incentivized to schedule video or in-clinic visits rather than phone visits if doing so is not aligned with patient preferences.

Finally, we want to clearly state that lower use of patient portal functions and video visits by some racial and ethnic groups and by adults aged >75 years should not be construed as lower access to care. Patients are able to get messages to health care providers by contacting the health plan's regional appointment and advice call center and are able to obtain laboratory test results by a system-generated mailed letter or by requesting a call from their health care team. In addition, patients who had an outpatient visit but not a video visit would have had that visit by phone or in person.

Limitations and Strengths

Our study has several limitations. First, our EHR cohort was restricted to KPNC members whose preferred language for written materials was English. This restriction was by design because an adult unable to read English and without a proxy user who can read English would have had difficulty interacting with the existing patient portal, which had only basic Spanish text as a second web page language, no functionality in other non-English languages, and limited ability to send secure messages in languages other than English. However, the exclusion of those whose preferred written language is not English limits the generalizability of the study results to adults who can read and understand written English well. Previous studies found large disparities in the use of patient portals and video visits between adults with limited English proficiency and adults with English as their preferred language [52-57]. Our analyses also did not account for health status or recent interactions with the health care system, which have both been shown to influence patient portal access and use [30]. Another limitation is that we had survey data for relatively small samples of Black, Latino, Chinese, and Filipino adults, limiting the statistical power to examine differences between racial and ethnic groups, and no survey data for other Asian ethnic groups. Furthermore, we lacked survey data to examine factors beyond educational attainment and access to digital devices and the internet that have been shown to influence and contribute to patient portal use, including competency and comfort in accessing information on the internet, eHealth literacy, privacy and security concerns, patient communication preferences, physical and cognitive limitations, and availability of high-speed broadband internet in the home [3]. Finally, the study population was restricted to members of 1 Northern California health plan with an older adult membership that is better educated than the general older adult population and that serves a geographic area of the United States that has relatively good high-speed broadband access [35].

However, our study also has several strengths, including a sociodemographically diverse EHR cohort with very large numbers of adults in each of the 9 racial and ethnic subgroups examined. These large subgroup sizes enabled us to document the prevalence of patient portal engagement and video visit use across racial and ethnic groups and by age group within racial and ethnic groups. We believe that this is the first study to document and compare patient portal and video visit use data for such large groups of older adults among 6 different Asian ethnicities and to be able to additionally compare findings across 2 age strata within each ethnic group. In doing so, we found that reporting engagement with patient portal functions and video visit use in just the aggregate 65 to 85 years age group in many instances masked substantially lower engagement with these portal functions in the 76- to 85-year versus 65- to 75-year age group (for all racial and ethnic groups except South Asian group). Another study strength is the examination of patient portal and video visit use based on EHR data rather than self-report and the examination of demographic differences for 3 patient portal outcomes. Finally, we used contemporaneous survey data from the same study population to explore associations of educational attainment and internet access factors with sending messages using the patient portal and having video visits.

Conclusions

Racial and ethnic group and age group differences in patient portal and video visit use persisted in 2020 in a community-dwelling Medicare-age population that had access to the same patient portal and received care from the same health care delivery system. Contemporary survey data suggested that internet use factors may contribute to lower use among older Black, Latino, and Filipino adults compared to White and Chinese adults. Patient portal use also varied across Asian ethnic groups, underscoring the importance of disaggregating data by Asian ethnicity. Our research highlights the importance of health care providers assessing older adults’ capabilities for engaging with patient portals and video visits, providing training and ongoing technical support to those who are not currently using the patient portal or those who want to improve their navigation skills, making digital equipment accessible when needed, and maintaining nondigital health modalities for health-related communications, including letters, hard copy information (eg, visit summaries, results, instructions, and benefit information), and phone visits. Future research is needed to identify cost-effective ways to reduce racial and ethnic disparities and age-related disparities in the use of patient portals and video visits among older adults and to serve older adults with limited English proficiency.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Forest plots showing prevalence ratios comparing patient portal outcomes (non-White racial and ethnic groups to White adults and non-Chinese Asian ethnic groups to Chinese adults) after adjusting for age and sex.

[PDF File (Adobe PDF File), 548 KB - aging_v7i1e63814_app1.pdf]

References

1. Heisey-Grove DM, Carretta HJ. Disparities in secure messaging uptake between patients and physicians: longitudinal analysis of two national cross-sectional surveys. J Med Internet Res 2020 May 01;22(5):e12611 [FREE Full text] [doi: 10.2196/12611] [Medline: 32356775]
2. Richwine C. Progress and persistent disparities in patient access to electronic health information. JAMA Health Forum 2023 Nov 03;4(11):e233883 [FREE Full text] [doi: 10.1001/jamahealthforum.2023.3883] [Medline: 37948063]
3. Sakaguchi-Tang DK, Bosold AL, Choi YK, Turner AM. Patient portal use and experience among older adults: systematic review. JMIR Med Inform 2017 Oct 16;5(4):e38 [FREE Full text] [doi: 10.2196/medinform.8092] [Medline: 29038093]
4. Powell RE, Henstenburg JM, Cooper G, Hollander JE, Rising KL. Patient perceptions of telehealth primary care video visits. Ann Fam Med 2017 May;15(3):225-229 [FREE Full text] [doi: 10.1370/afm.2095] [Medline: 28483887]
5. Reed ME, Huang J, Parikh R, Millman A, Ballard DW, Barr I, et al. Patient-provider video telemedicine integrated with clinical care: patient experiences. Ann Intern Med 2019 Aug 06;171(3):222-224. [doi: 10.7326/M18-3081] [Medline: 31035294]
6. Mohanty A, Srinivasan VM, Burkhardt JK, Johnson J, Patel AJ, Sheth SA, et al. Ambulatory neurosurgery in the COVID-19 era: patient and provider satisfaction with telemedicine. Neurosurg Focus 2020 Dec;49(6):E13. [doi: 10.3171/2020.9.FOCUS20596] [Medline: 33260126]
7. Picardo E, Baù MG, Anatrone C, Mondino A, Surace A, Gallo F, et al. Oncophone20 study: patients' perception of telemedicine in the COVID-19 pandemic during follow-up visits for gynecological and breast cancers. Int J Gynaecol Obstet 2021 Dec;155(3):398-403 [FREE Full text] [doi: 10.1002/ijgo.13825] [Medline: 34258764]
8. Patel KB, Turner K, Alishahi Tabriz A, Gonzalez BD, Oswald LB, Nguyen OT, et al. Estimated indirect cost savings of using telehealth among nonelderly patients with cancer. JAMA Netw Open 2023 Jan 03;6(1):e2250211 [FREE Full text] [doi: 10.1001/jamanetworkopen.2022.50211] [Medline: 36626174]

9. Siwicki B. Is telemedicine an answer to physician burnout and staffing shortages? Healthcare IT News. 2022 May 24. URL: https://www.healthcareitnews.com/news/telemedicine-answer-physician-burnout-and-staffing-shortages [accessed 2024-04-28]
10. Malouff TD, TerKonda SP, Knight D, Abu Dabrh AM, Perlman AI, Munipalli B, et al. Physician satisfaction with telemedicine during the COVID-19 pandemic: the Mayo Clinic Florida experience. Mayo Clin Proc Innov Qual Outcomes 2021 Aug;5(4):771-782 [FREE Full text] [doi: 10.1016/j.mayocpiqo.2021.06.006] [Medline: 34226884]
11. Snoswell CL, Taylor ML, Comans TA, Smith AC, Gray LC, Caffery LJ. Determining if telehealth can reduce health system costs: scoping review. J Med Internet Res 2020 Oct 19;22(10):e17298 [FREE Full text] [doi: 10.2196/17298] [Medline: 33074157]
12. Koonin LM, Hoots B, Tsang CA, Leroy Z, Farris K, Jolly T, et al. Trends in the use of telehealth during the emergence of the COVID-19 pandemic - United States, January-March 2020. MMWR Morb Mortal Wkly Rep 2020 Oct 30;69(43):1595-1599 [FREE Full text] [doi: 10.15585/mmwr.mm6943a3] [Medline: 33119561]
13. Baum A, Kaboli PJ, Schwartz MD. Reduced in-person and increased telehealth outpatient visits during the COVID-19 pandemic. Ann Intern Med 2021 Jan;174(1):129-131 [FREE Full text] [doi: 10.7326/M20-3026] [Medline: 32776780]
14. Patel SY, Mehrotra A, Huskamp HA, Uscher-Pines L, Ganguli I, Barnett ML. Trends in outpatient care delivery and telemedicine during the COVID-19 pandemic in the US. JAMA Intern Med 2021 Mar 01;181(3):388-391 [FREE Full text] [doi: 10.1001/jamainternmed.2020.5928] [Medline: 33196765]
15. Xu S, Glenn S, Sy L, Qian L, Hong V, Ryan DS, et al. Impact of the COVID-19 pandemic on health care utilization in a large integrated health care system: retrospective cohort study. J Med Internet Res 2021 Apr 29;23(4):e26558 [FREE Full text] [doi: 10.2196/26558] [Medline: 33882020]
16. COVID-19 emergency declaration blanket waivers for health care providers. Centers for Medicare & Medicaid Services. 2020 Mar 30. URL: https://www.cms.gov/files/document/covid19-emergency-declaration-health-care-providers-fact-sheet.pdf [accessed 2024-04-28]
17. Hudman J, McDermott D, Shanosky N, Cox C. How private insurers are using telehealth to respond to the pandemic. Peterson-KFF Health System Tracker. 2020 Aug 07. URL: https://www.healthsystemtracker.org/brief/how-private-insurers-are-using-telehealth-to-respond-to-the-pandemic/ [accessed 2024-04-28]
18. Carini E, Villani L, Pezzullo AM, Gentili A, Barbara A, Ricciardi W, et al. The impact of digital patient portals on health outcomes, system efficiency, and patient attitudes: updated systematic literature review. J Med Internet Res 2021 Sep 08;23(9):e26189 [FREE Full text] [doi: 10.2196/26189] [Medline: 34494966]
19. Silberman S. The inequities in the cost of chronic disease: why it matters for older adults. National Council on Aging. 2022 Apr 21. URL: https://www.ncoa.org/article/the-inequities-in-the-cost-of-chronic-disease-why-it-matters-for-older-adults/ [accessed 2024-04-29]
20. Philpot LM, Ramar P, Roellinger DL, Njeru JW, Ebbert JO. Individual-level digital determinants of health and technology acceptance of patient portals: cross-sectional assessment. JMIR Form Res 2024 Jun 10;8:e56493 [FREE Full text] [doi: 10.2196/56493] [Medline: 38695754]
21. Perrin A. Mobile technology and home broadband 2021. Pew Research Center. 2021 Jun 03. URL: https://tinyurl.com/2xjt8vp2 [accessed 2024-04-29]
22. Aging connected: exposing the hidden connectivity crisis for older adults. Older Adults Technology Services. 2021. URL: https://tinyurl.com/4hra8nna [accessed 2024-10-18]
23. Choi NG, DiNitto DM, Marti CN, Choi BY. Telehealth use among older adults during COVID-19: associations with sociodemographic and health characteristics, technology device ownership, and technology learning. J Appl Gerontol 2022 Mar;41(3):600-609 [FREE Full text] [doi: 10.1177/07334648211047347] [Medline: 34608821]
24. Powell KR. Patient-perceived facilitators of and barriers to electronic portal use: a systematic review. Comput Inform Nurs 2017 Nov;35(11):565-573. [doi: 10.1097/CIN.0000000000000377] [Medline: 28723832]
25. Kampmeijer R, Pavlova M, Tambor M, Golinowska S, Groot W. The use of e-health and m-health tools in health promotion and primary prevention among older adults: a systematic literature review. BMC Health Serv Res 2016 Sep 05;16 Suppl 5:290 [FREE Full text] [doi: 10.1186/s12913-016-1522-3] [Medline: 27608677]
26. Chang E, Blondon K, Lyles CR, Jordan L, Ralston JD. Racial/ethnic variation in devices used to access patient portals. Am J Manag Care 2018 Jan 01;24(1):e1-e8 [FREE Full text] [Medline: 29350513]
27. Turner K, Hong YR, Yadav S, Huo J, Mainous AG. Patient portal utilization: before and after stage 2 electronic health record meaningful use. J Am Med Inform Assoc 2019 Oct 01;26(10):960-967 [FREE Full text] [doi: 10.1093/jamia/ocz030] [Medline: 30947331]
28. Conroy M, Kamaraju S, Powell M, Harris A, Beckius A, Nagavally S, et al. Racial and ethnic differences in the use of electronic medical record messaging among patients with breast cancer: a quality improvement study. Clin Breast Cancer 2023 Oct;23(7):e434-e440. [doi: 10.1016/j.clbc.2023.07.001] [Medline: 37482498]
29. Wedd J, Basu M, Curtis LM, Smith K, Lo DJ, Serper M, et al. Racial, ethnic, and socioeconomic disparities in web-based patient portal usage among kidney and liver transplant recipients: cross-sectional study. J Med Internet Res 2019 Apr 22;21(4):e11864 [FREE Full text] [doi: 10.2196/11864] [Medline: 31008707]
30. Richwine C, Johnson C, Patel V. Disparities in patient portal access and the role of providers in encouraging access and use. J Am Med Inform Assoc 2023 Jan 18;30(2):308-317 [FREE Full text] [doi: 10.1093/jamia/ocac227] [Medline: 36451262]

31. Gordon NP, Hornbrook MC. Differences in access to and preferences for using patient portals and other ehealth technologies based on race, ethnicity, and age: a database and survey study of seniors in a large health plan. J Med Internet Res 2016 Mar 04;18(3):e50 [FREE Full text] [doi: 10.2196/jmir.5105] [Medline: 26944212]
32. Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. J Am Med Inform Assoc 2018 Aug 01;25(8):1080-1088. [doi: 10.1093/jamia/ocy052] [Medline: 29788380]
33. Lyles CR, Wachter RM, Sarkar U. Focusing on digital health equity. JAMA 2021 Nov 09;326(18):1795-1796. [doi: 10.1001/jama.2021.18459] [Medline: 34677577]
34. Johnson KB, Ibrahim SA, Rosenbloom ST. Ensuring equitable access to patient portals-closing the "Techquity" gap. JAMA Health Forum 2023 Nov 03;4(11):e233406 [FREE Full text] [doi: 10.1001/jamahealthforum.2023.3406] [Medline: 37948065]
35. Crouch E, Gordon NP. Prevalence and factors influencing use of internet and electronic health resources by middle-aged and older adults in a US health plan population: cross-sectional survey study. JMIR Aging 2019 Mar 26;2(1):e11451 [FREE Full text] [doi: 10.2196/11451] [Medline: 31518256]
36. Levine DM, Lipsitz SR, Linder JA. Trends in seniors' use of digital health technology in the United States, 2011-2014. JAMA 2016 Aug 2;316(5):538-540. [doi: 10.1001/jama.2016.9124] [Medline: 27483069]
37. Mitchell UA, Chebli PG, Ruggiero L, Muramatsu N. The digital divide in health-related technology use: the significance of race/ethnicity. Gerontologist 2019 Jan 09;59(1):6-14. [doi: 10.1093/geront/gny138] [Medline: 30452660]
38. Gandrakota N, Ali MK, Shah MK. Trends in health information technology use among the US population with and without cardiovascular risk factors, 2012-2018: evidence from the National Health Interview Survey. JMIR Public Health Surveill 2021 Sep 30;7(9):e29990 [FREE Full text] [doi: 10.2196/29990] [Medline: 34591026]
39. Gordon NP. Similarity of adult Kaiser Permanente members to the adult population in Kaiser Permanente’s Northern California service area: comparisons based on 2017/2018 cycle of the California Health Interview Survey. ResearchGate.net. 2020 Nov. URL: https://tinyurl.com/bdz7wh7p [accessed 2024-10-18]
40. Davis AC, Voelkel JL, Remmers CL, Adams JL, McGlynn EA. Comparing Kaiser Permanente members to the general population: implications for generalizability of research. Perm J 2023 Jun 15;27(2):87-98 [FREE Full text] [doi: 10.7812/TPP/22.172] [Medline: 37170584]
41. Silvestre A, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. Health Aff (Millwood) 2009;28(2):334-344 [FREE Full text] [doi: 10.1377/hlthaff.28.2.334] [Medline: 19275988]
42. Gordon NP, Lin TY, Rau JL, Lo JC. Aggregation of Asian-American subgroups masks meaningful differences in health and health risks among Asian ethnicities: an electronic health record based cohort study. BMC Public Health 2019 Nov 25;19(1):1551 [FREE Full text] [doi: 10.1186/s12889-019-7683-3] [Medline: 31760942]
43. Gordon NP, Lin TY. The Kaiser Permanente Northern California adult Member Health Survey. Perm J 2016 Dec 01;20(4):34-42 [FREE Full text] [doi: 10.7812/TPP/15-225] [Medline: 27548806]
44. Gordon NP, Zhang S, Lo JC, Li CF. The digital transition: are adults aged 65 years or older willing to complete online forms and questionnaires in patient portals? Perm J 2024 Mar 15;28(1):68-75 [FREE Full text] [doi: 10.7812/TPP/23.112] [Medline: 38317596]
45. Gnardellis C, Notara V, Papadakaki M, Gialamas V, Chliaoutakis J. Overestimation of relative risk and prevalence ratio: misuse of logistic modeling. Diagnostics (Basel) 2022 Nov 17;12(11):2851 [FREE Full text] [doi: 10.3390/diagnostics12112851] [Medline: 36428910]
46. Smith SG, O'Conor R, Aitken W, Curtis LM, Wolf MS, Goel MS. Disparities in registration and use of an online patient portal among older adults: findings from the LitCog cohort. J Am Med Inform Assoc 2015 Jul;22(4):888-895 [FREE Full text] [doi: 10.1093/jamia/ocv025] [Medline: 25914099]
47. Kumar D, Gordon N, Zamani C, Sheehan T, Martin E, Egorova O, et al. Cancer patients' preferences and perceptions of advantages and disadvantages of telehealth visits during the COVID-19 pandemic. JCO Clin Cancer Inform 2023 Sep;7:e2300040 [FREE Full text] [doi: 10.1200/CCI.23.00040] [Medline: 37656925]
48. Kullgren J, Solway E, Roberts S, Anthony D, Singer D, Kirch M, et al. National Poll on Healthy Aging: use and experiences with patient portals among older adults. University of Michigan National Poll on Healthy Aging. 2023 May 24. URL: https://tinyurl.com/5ekemdxz [accessed 2024-04-29]
49. Portz JD, Bayliss EA, Bull S, Boxer RS, Bekelman DB, Gleason K, et al. Using the technology acceptance model to explore user experience, intent to use, and use behavior of a patient portal among older adults with multiple chronic conditions: descriptive qualitative study. J Med Internet Res 2019 Apr 08;21(4):e11604 [FREE Full text] [doi: 10.2196/11604] [Medline: 30958272]
50. Gordon NP, Hornbrook MC. Older adults' readiness to engage with eHealth patient education and self-care resources: a cross-sectional survey. BMC Health Serv Res 2018 Mar 27;18(1):220 [FREE Full text] [doi: 10.1186/s12913-018-2986-0] [Medline: 29587721]
51. Awan M, Ali S, Ali M, Abrar MF, Ullah H, Khan D. Usability barriers for elderly users in smartphone app usage: an analytical hierarchical process-based prioritization. Sci Program 2021 Dec 26;2021:1-14 [FREE Full text] [doi: 10.1155/2021/2780257]

52. Allard CT, Krasowski MD. Data on the activation and utilization of an electronic health record patient portal in an adult inpatient population at an academic medical center. Data Brief 2021 Apr;35:106806 [FREE Full text] [doi: 10.1016/j.dib.2021.106806] [Medline: 33604427]
53. Thomason J, Bays A, Mantilla B, Huang I, Najjar R, Singh N, et al. Non-English language preference associated with decreased rheumatology telehealth use during the COVID-19 pandemic. ACR Open Rheumatol 2022 May;4(5):385-394 [FREE Full text] [doi: 10.1002/acr2.11407] [Medline: 35084116]
54. Wood KE, Greene HR, Krasowski MD. Patient portal activation and use in hospitalized children at an academic medical center. Hosp Pediatr 2021 Jun 01;11(6):587-594 [FREE Full text] [doi: 10.1542/hpeds.2020-003707] [Medline: 34006533]
55. Casillas A, Moreno G, Grotts J, Tseng CH, Morales LS. A digital language divide? The relationship between internet medication refills and medication adherence among limited English proficient (LEP) patients. J Racial Ethn Health Disparities 2018 Dec;5(6):1373-1380 [FREE Full text] [doi: 10.1007/s40615-018-0487-9] [Medline: 29600351]
56. Rosenthal JL, O'Neal C, Sanders A, Fernandez Y Garcia E. Differential use of pediatric video visits by a diverse population during the COVID-19 pandemic: a mixed-methods study. Front Pediatr 2021;9:645236 [FREE Full text] [doi: 10.3389/fped.2021.645236] [Medline: 34322458]
57. Rodriguez JA, Betancourt JR, Sequist TD, Ganguli I. Differences in the use of telephone and video telemedicine visits during the COVID-19 pandemic. Am J Manag Care 2021 Jan;27(1):21-26 [FREE Full text] [doi: 10.37765/ajmc.2021.88573] [Medline: 33471458]

Abbreviations

aPR: adjusted prevalence ratio
EHR: electronic health record
KPNC: Kaiser Permanente Northern California

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Original Paper

Nurses' and Nursing Assistants' Experiences With Teleconsultation in Small Rural Long-Term Care Facilities: Semistructured Interview Pilot Study

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Abstract

Background: In Quebec, the shortage of nurses during night shifts compromises the safety and quality of resident care, particularly in small residential and long-term care centers ("Centres d'hébergement et de soins de longue durée"; CHSLDs) located in rural areas. The need to ensure the continuous presence of nurses 24 hours a day in CHSLDs has become more pressing, forcing some facilities to implement exceptional measures such as on-call telephone services to ensure access to a nurse. In light of these challenging circumstances, the Direction nationale des soins et des services infirmiers of Quebec's Ministère de la Santé et des Services sociaux has rolled out a teleconsultation pilot project.

Objective: This study aims to explore nurses' and nursing assistants' experience of integrating teleconsultation during night shifts in rural CHSLDs with ≤50 residents.

Methods: The 6-month pilot project was rolled out sequentially in 3 rural CHSLDs located in 2 administrative regions of Quebec between July 2022 and March 2023. A total of 18 semistructured interviews were conducted with 9 nurses and nursing assistants between February and July 2023.

Results: Participants' experiences revealed that teleconsultation provided significant added value by improving clinical, administrative, and organizational practices. Some practices remained unchanged, indicating stable workflows. Workflow optimization through an expanded scope of practice ensured efficient and safe continuity of care. Enhanced collaboration between nurses and nursing assistants led to improved care coordination and communication. The leadership played a significant role in clarifying professionals' roles and in supporting effective adaptation to teleconsultation.

Conclusions: This pilot project represents a significant step forward in improving care for CHSLD residents in Quebec. Teleconsultation not only makes it possible to overcome recruitment challenges and ensure the continuous presence of nurses during night shifts but also optimizes professional practices while ensuring the safety and quality of care provided to residents.

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KEYWORDS

teleconsultation; long-term care facilities; nursing; nursing practices; workflow optimization; residents; rural; telehealth; Quebec

Introduction

The Health Care Situation for Older Adults in Quebec

The health care landscape in Quebec, particularly for older adults, presents numerous challenges and opportunities for improvement. Health and social services professionals work in an environment that is both demanding and constantly evolving. Thanks to scientific progress and medical advances, Western populations, including those in Quebec, are enjoying increased life expectancy. According to the latest demographic data, Quebec is facing a significant aging of its population, and approximately 25% will be considered older within the next decade [1]. This demographic shift creates specific health care needs, particularly in settings, such as residential and long-term care centers (Centres d'hébergement et de soins de longue durée; CHSLDs), where vulnerable populations often require extensive care and support. However, increased longevity often comes with multiple comorbidities and chronic conditions that necessitate holistic care approaches addressing physical, psychological, social, and functional needs [2].

For the past several years, the Quebec government has implemented programs enabling older adults to remain at home for as long as possible [3]. Maintaining older adults' autonomy in their own living environment reduces pressure on health care facilities while providing personalized, high-quality care [4]. However, older adults living in CHSLDs often experience chronic illnesses that lead to significant disabilities and severe functional limitations [5]. It is estimated that 3% to 4% of Quebecers aged ≥65 years reside in CHSLD [6]. The main reasons why older adults move to long-term care facilities include neurocognitive disorders, chronic pathologies, severe degenerative diseases, and mental health problems [6,7]. These particularly susceptible residents require rigorous attention from multidisciplinary care teams.

The Role of the Nurse and Nursing Assistant in CHSLDs

Nurses play a central and essential role in Quebec's CHSLDs [8]. To become a nurse, candidates must complete college- or university-level education and successfully pass a professional examination regulated by the Order of Quebec Nurses (Ordre des infirmières et infirmiers du Québec; OIIQ). Nurses ensure a continuous presence for residents, assess their physical and mental condition, develop therapeutic nursing plans (TNPs) to coordinate interventions, and prescribe treatments with the approval of their professional regulatory body, under defined conditions. The OIIQ stresses the importance of nurses' contribution to CHSLDs, across all shifts, given the residents' fragility and the growing complexity of clinical situations [9].

In addition to nurses, nursing assistants also play a fundamental role in CHSLDs. They complete a 2-year vocational training program and must pass a professional examination regulated by the Order of Quebec Nursing Assistants (Ordre des infirmières et infirmiers auxiliaires du Québec [OIIAQ]). Working closely with the nurses, they take part in the entire care process within their professional scope of practice [10]. Their interventions are based on verbal or written medical orders, the TNP, organizational protocols, and the rules governing care. The renewed position of the OIIAQ highlights the nursing assistants' skills and the significance of their contribution to the quality of care and services provided in CHSLDs.

In Quebec, CHSLDs are integrated within regional health and social service structures. The management of these facilities is overseen by local administrators and supported by a range of clinical managers. Multidisciplinary teams work in CHSLDs, but the residents' primary needs are largely met by professional nursing teams and personal support workers.

A key aspect of nursing roles in CHSLD is the dynamic collaboration between the nurses and the nursing assistants. The work environment in CHSLDs often features a strict hierarchy, where decisions are shared using a top-down approach [11]. This hierarchical structure is reflected in the collaboration between the nurse and the nursing assistant, which is generally characterized by a supervisory relationship [12]. This type of hierarchy can generate tensions, undermining collaboration [13] and professional identity [14]. Because of their heavy workloads, nurses and nursing assistants rarely have time to exchange ideas, collaborate, and organize the division of tasks [11]. Nevertheless, when they are able to work collaboratively, the partnership between the nurse and the nursing assistant in CHSLDs is particularly beneficial [15,16]. Such collaboration fosters better professional communication [17] and high-quality care for residents [18].

Workforce Challenges in CHSLDs and Implications for Resident Safety

In Québec, the shortage of nursing staff is particularly acute in rural areas, where attracting and retaining personnel is a persistent challenge. Long-term care is often perceived as an unattractive and difficult sector [7]. Consequently, CHSLDs have experienced staff shortages for several years, a situation that was exacerbated further by the COVID-19 pandemic. To address this, various initiatives have aimed to improve the perception of working in CHSLDs [6]. In the meantime, administrative solutions, such as employing independent workers, overtime, or on-call telephone services, have been used to meet staffing needs. Despite the financial incentives for nurses to take night shifts, this work schedule remains unattractive due to its impact on social [19] and personal health [20]. This is particularly problematic in rural areas, where the availability of nursing expertise is even more limited during night shifts.

The literature indicates that a considerable number of adverse events occur during the night in CHSLDs [21]. Without an on-site nurse, staff are forced to transfer residents to hospital emergency rooms to obtain the care they need [22]. Yet, if there are not any unexpected incidents, the skills of night nurses are often underused. They end up performing support tasks that could be carried out by other professionals, such as nursing assistants or orderlies [23]. Although it is frequently considered as a way of overcoming the challenges of recruiting care staff, replacing a nurse with a nursing assistant in an older adult's residence amounts to a halfway solution [17]. Researchers agree on the relevance of reviewing the management of time dedicated to care [24], adopting mechanisms to optimize professional expertise [6], and improving care by exploring innovative approaches that are tailored to the CHSLD environment [11].

The Potential of Teleconsultation in CHSLDs

Faced with challenges that potentially compromise the quality and safety of resident care in CHSLDs, the Quebec government introduced a teleconsultation pilot project for small, rural CHSLDs. This initiative, the first of its kind in the province, aimed to provide web-based access to nurses' expertise during night shifts when nursing assistants were present at residents' bedside.

Inspired by on-call telephone service practices, this initiative enabled nursing assistants to consult a nurse by regular phone calls when a resident experienced a health issue. The teleconsultation pilot project formalized improved nursing practice by integrating organizational and technological innovations.

The deployment of the pilot project was carried out in accordance with strict criteria established by Quebec's Ministère de la Santé et des Services sociaux (MSSS). The project sought to enhance the quality of care provided to residents while ensuring that nursing expertise was readily accessible, even in the most challenging circumstances. Teleconsultation is based on a new organization of care, requiring that institutional documents governing the practices of nurses and nursing assistants be updated, while respecting their separate scopes of practice. The addition of technological tools enables the nursing assistant, who is on-site at the CHSLD, to benefit from the expertise of a remote nurse in real time when a resident's health situation requires it. To develop this practice effectively, the innovations must work together to meet the needs of all stakeholders [25]. The teleconsultation project uses the Microsoft Teams platform, with nursing assistants using tablets and nurses using laptops, making real-time communication possible.

Although telehealth practices are already well established in long-term care facilities internationally [26], they are yet to be adopted in Quebec CHSLDs. The literature shows that teleconsultation improves access to health care and services when they are needed while optimizing coverage by health care professionals beyond business hours [27-29]. In addition, residents benefit from quick and easy access to an in-depth assessment by a competent health care professional [30].

One of the critical reasons for focusing on small CHSLDs is the chronic shortage of health care staff, particularly during night shifts when nursing expertise is limited. By leveraging teleconsultation and IT tools, this pilot project helps address these workforce issues, allowing small CHSLDs to provide timely and appropriate care even with reduced on-site staff. Teleconsultation offers a solution to help mitigate the ongoing challenges related to recruitment and retention, particularly in rural settings where staffing is a persistent issue. The integration of teleconsultation enhances health care accessibility and helps ensure continuity of care for residents, thus reducing the burden on overworked personnel.

Successful implementation of teleconsultation services relies on close collaboration between the players involved, healthy relationships [31], and intuitive IT systems that support access to all data relevant to the remote care management of residents [32,33]. Thus, it is important that we study the rollout of the nursing teleconsultation pilot project in small CHSLDs and its impact on the professional practice of nurses and nursing assistants.

Objective

The aim of this study is to explore nurses' and nursing assistants' experience of the integration of teleconsultation during night shifts in rural Quebec CHSLDs with ≤50 beds.

Methods

Study Design and Setting

The 6-month pilot project was rolled out in 3 rural CHSLDs located in 2 administrative regions of Quebec. The regions were selected by the MSSS for the alignment with the project's outlined criteria, which include facilities situated in semiremote and remote areas, those already experiencing nursing shortages during the night shift, and those reporting issues and risks related to the shortages. In addition, at least 30% of all CHSLD facilities in the territory have a capacity of ≤50 beds. The rollout was conducted sequentially from July 2022 to March 2023 at different sites. During the project, participants documented 19 clinical situations using teleconsultation and 14 clinical situations without teleconsultation. According to the organization's previous year's statistics regarding on-call telephone services, the number of clinical situations remains similar year over year. This attests to the stability of the environment, providing an appropriate context to study the implementation of teleconsultation. Given the innovative nature of the pilot project, an exploratory qualitative study was conducted to understand the impact of implementing teleconsultation in nighttime nursing care.

Data Collection

In total, 2 interview guides were designed, tested, and validated by the research team. The first guide, comprising 12 open-ended questions, aimed to identify the barriers and facilitators to the implementation of teleconsultation. This guide provided a better understanding of the context and experiences surrounding the pilot project's deployment. The study was guided by key factors influencing the implementation of health innovations, as outlined in the framework proposed by Chaudoir et al [34], along with the Consolidated Framework for Implementation Research [35]. The second guide, including 12 open-ended questions, focused on assessing the impact of newly introduced workflows on nurses and nursing assistants in the context of teleconsultation. This guide was based on a comprehensive literature review associated with nursing roles [36], the use of nursing resources [37], and the scope of professional practice [38]. According to the findings, 3 distinct levels of nursing practice were identified—clinical, administrative, and organizational—allowing a thorough assessment of the contributions made by both nurses and nursing assistants. By using both interview guides, the research provides a more holistic and nuanced understanding of the phenomenon under study. The interview guides are included in Multimedia Appendix 1.

In addition, a web-based sociodemographic data collection form, created on the Google Forms platform, was also shared with and completed by participants, enabling the collection of information about their current employment, work experience, and academic background. Participants were contacted by email, which included the research consent form, interview guides, and the project poster. The consent form explained the context, project objective, procedure and duration, anticipated benefits, and anonymity and confidentiality.

Participants

Participant recruitment was done using nonprobability sampling [39], through which participants were identified by pilot project managers. To be eligible, participants had to be nurses or nursing assistants, have a formal employment relationship with the organization, and have used teleconsultation during the 6 months that it was deployed in the CHSLDs. A total of 8 nurses and 7 nursing assistants were contacted by the research team between March and July 2023. In total, 62% (5/8) nurses and 57% (4/7) nursing assistants consented to participate. The remaining individuals did not respond to the email invitation.

Pursuant to an agreement with the Direction nationale des soins et services en soins infirmiers of the MSSS, the semistructured interviews were conducted during the participants' working hours or, if this was not possible, participants were compensated for the time devoted to the interview according to the conditions of their work agreement. Regarding this directive, only 22% (2/9) of the participants conducted the interviews during off-hours.

A total of 2 semistructured interviews, each with a duration of 60 minutes, were conducted in French. Of the 9 participants, 3 (33%) were interviewed via videoconference (Zoom; Zoom Video Communications, Inc), and 6 (67%) were interviewed by phone, according to each participant's preference. The main researcher (VN) conducted the interviews associated with the first guide, drawing on her previous experience in this specific field. In contrast, the coresearcher (MCL) conducted the interviews associated with the second guide due to her nursing qualifications and knowledge of the profession. All interviews were audio recorded with participants' permission, and then transcribed in compliance with ethical and confidentiality standards. The deidentified recordings were transcribed verbatim by a third-party transcription service bound by a confidentiality agreement. Participants were given the option to review the transcripts of each interview, but none of the participants chose to receive the transcripts.

No additional recruitment process was necessary, as information redundancy indicated data saturation [40]. Each participant completed 2 semistructured interviews, resulting in a total of 18 interviews conducted with 5 nurses and 4 nursing assistants between March and July 2023. The participants had no personal or professional relationship with any members of the research team.

Data Analysis

Interview data were processed using NVivo software (version 14; Lumivero). Each interview was transcribed verbatim immediately after it had been conducted and analyzed by the research team. Validation and reflexivity steps were integrated throughout the analysis process to ensure compliance and authenticity of the approach.

Before beginning the analysis, we planned to structure the data using a 3-level framework (clinical, administrative, and organizational), as it aligned with our understanding of nursing and nursing assistant practices. This framework was supported by relevant literature [36-38]. The clinical level relates to the care provided directly to residents, the administrative level concerns the organization of interventions, and the organizational level focuses on innovative initiatives.

Initially, the research team familiarized themselves with the data by reading and rereading the transcripts to gain an in-depth understanding of the content. This immersive experience confirmed the suitability of the 3 levels of the framework and revealed interactions between the levels, such as how the organizational level influences the administrative level, which in turn impacts the clinical level.

Following familiarization, the team engaged in a systematic coding process, identifying key themes and categories that emerged from the data. The coded data were then regrouped into categories that reflected the interactions among the 3 levels of practice. In addition, participants' lived experiences and perspectives regarding the deployment of the pilot project were categorized as either hindering or facilitating factors. The directed approach to qualitative data analysis, as used here, aligns with previous research aimed at better understanding nursing practice and its impact [41].

Workflows, inspired by lean methodology, played a central role in understanding the practices of nurses and nursing assistants. These workflows ensured the smooth flow of operations to improve performance and create value [42]. The clinical approach to nursing encompasses tasks such as data collection, analysis, planning, intervention, and outcome assessment related to the care and services provided directly to residents. The administrative and organizational levels of nursing practice have an overarching influence on these workflows, serving as the foundation for clinical activities.

The integration of teleconsultation impacted nurses' and nursing assistants' practices in various ways. The research team categorized key findings at each level of practice based on their impact on workflows. Enhanced practices added value to workflows by improving the quality of interventions, while unchanged practices demonstrated an inherent stability in CHSLDs despite the integration of this new technology.

To finalize the analysis process, data organization and interpretation allowed the research team to identify 3 major underlying themes: leadership, collaboration, and impact on residents.

Ethical Considerations

Ethics approval was obtained from the research ethics committee of the Outaouais Integrated Health and Social Services Centre before the beginning of the study (reference number 2022-353_195), in Quebec, Canada. All participants gave their consent electronically before beginning the survey. Participation was anonymous and voluntary. The privacy rights of the study participants were observed. The study participants did not receive monetary compensation. The study's findings will be disseminated through presentations at conferences and publications in peer-reviewed journals using anonymized data. Findings will also be shared through presentations to various MSSS stakeholders and the nursing community.

Results

Characteristics of Participants

The sociodemographic data collection form provided a brief portrait of the study participants. All 9 participating interviewees completed the form. In total, 5 (56%) of the participants were nurses and 4 (44%) were nursing assistants. Of these participants, 7 (78%) worked full time, while 2 (22%) worked part time. In terms of educational background, 3 (33%) participants had a vocational diploma, 2 (22%) had a college diploma, and 4 (44%) had a university degree. It is important to note that, in Quebec, it is possible to become a member of the OIIQ and enter the nursing profession with a college or university degree.

The participants' experience of working in CHSLDs varied: 33% (3/9) of the participants had been working there for <5 years, 33% (3/9) had between 5 and 10 years of experience, 22% (2/9) had between 11 and 20 years of experience, and 11% (1/9) participant had >21 years of experience. According to the literature, a nurse with ≥5 years of experience in a specific field can be considered an expert [43].

The integration of teleconsultation into their professional practice led to a variety of responses and experiences for participants. Their diverse reactions highlighted the benefits and challenges associated with implementing new technology in long-term care. The subsequent sections present nurses' and nursing assistants' perceptions of the impact of teleconsultation on the 3 levels of their practice examining areas where it created unchanged practices, demonstrating stability, and where it introduced enhanced practices, enabling the illustration of optimized workflows when using teleconsultation.

Unchanged Practices

Unchanged practices reflect an inherent stability within CHSLDs, even with the integration of teleconsultation. This stability indicates that certain fundamental aspects of care delivery and professional interactions have remained consistent, despite the introduction of this new technology.

Organizational Level

Participants were asked to share their views on their level of involvement in planning the pilot project. Most (8/9, 89%) of the participants agreed that they had been presented with well-defined, predeveloped content at the teleconsultation information meetings. This approach came as no surprise to participants, who said they were satisfied with this aspect:

> *Everything was already in place. Basically, they worked together, the manager, the project manager, and our administrative officer. When we first heard about the project, everything was already in motion, it was already set up. The binders were already made. The step-by-step instructions were already inside. All our protocols too. I'd say we didn't really participate. We just kind of stepped into the project, then set it in motion, that's all. We weren't consulted beforehand.* [Participant 6]

However, the nurses and nursing assistants did say that they wished they had been involved in the initial reflection and decision-making on the pilot project:

> *Well, I could have shared my opinion, and some ideas too.* [Participant 3]
>
> *I'd say that everything was really well structured and complete. That's why I didn't have anything to add. But of course, if they had asked my opinion, I would have wanted to participate, of course, to share my point of view.* [Participant 6]

In this regard, participants shared some of the issues associated with the planning. They expressed dissatisfaction with the time frames determined by the managers:

> *We had time, but it kind of dragged on at some point. You know, you tell yourself: Well, are we going to do it or not? When are we starting? We've all been trained. It's been three months, but nothing is happening yet. That's why, you know, I thought it took a long time to get started.* [Participant 2]
>
> *It was pretty drastic. It was like "OK, you're getting teleconsultation training..." Uh, what's that? We were kind of thrown into it, and we were a bit taken aback.* [Participant 7]

Finally, participants wished they had had ongoing support throughout the pilot project, not just at the start:

> *The project was launched and we just went on from there. Then, there was no real support from the manager.* [Participant 6]

Participants highlighted a relevant point related to professional maturity, experience, and ease. Having significant work experience contributes to the enrichment of professional practice every day, not just within the context of the pilot project. Professional maturity, in the nursing field, refers to the ability to apply clinical judgment with confidence, adapt to complex situations, demonstrate autonomy in decision-making, and help improve the interventions carried out with residents:

> *Maturity, yes, that...well, there's training and all that, but there's not just that, there's life experience. If I'd been a new nurse, I'd have been very uncomfortable. After all, I have over twenty years' service.* [Participant 1]
>
> *Prior to the teleconsultation program, even a few years ago, nursing assistants were already covering*

> *the nighttime shifts. Then, at some point, they abolished that, and decided that they needed a nurse on duty 24-7. So, you know, the rest of us were already used to it, because I've always worked nights, so I was used to the process. So for me, it wasn't anything new.* [Participant 4]

Administrative Level

Participants discussed the various aspects of working collaboratively, including documentation in the resident's medical record. The experiences suggest that the rules of documentation were not implemented in a standardized way. Some participants documented too much, others just enough, while some opted to enter information later. However, according to 1 participant, this phenomenon had already been observed before the implementation of teleconsultation:

> *In the morning, the nursing assistant would tell me: "I gave her a Tylenol, she had pain in such and such a place. It was already in the TNP, so I didn't need to consult on this." Indeed, it was fine, but I would, let's say, write my note, then enter the nighttime call for such-and-such a case, confirm with the TNP, and everything, so it was fine.* [Participant 1]
>
> *There's a lack of information being shared, but that, as I say, is not just because of teleconsultation, not at all. It's a generalized issue.* [Participant 8]

Another unchanged element, at the administrative level, is the importance afforded to residents' families and loved ones. The nurses and nursing assistants maintained a special focus on this relationship, upholding the same values and principles:

> *It hasn't changed the practice. That's why this aspect hasn't been integrated as such. We'll talk about it with the family, but really, you know, the "We're now using video teleconsultation" aspect, well, there were people who weren't even aware of the fact that there wasn't a nurse on site during the night.* [Participant 6]
>
> *Well, Mom fell last night. I was the one on duty, and then I took care of her. They won't ask me if I used teleconsultation or not. They just need to ask me if there are any after-effects, if there's anything wrong.* [Participant 2]

Clinical Level

Participants highlighted a number of limitations associated with a virtual assessment of residents' physical and mental condition. As with on-call telephone services, certain practices, such as palpating residents and managing certain clinical situations, are incompatible with teleconsultation:

> *I'm actually someone who likes to move around, who likes to see things in real life to validate certain information, to palpate, you know, to conduct a fuller assessment.* [Participant 6]
>
> *Many, many of our residents suffer from cognitive decline and unfortunately they don't understand. They didn't understand the instructions; they don't understand when we speak to them. They can't see us in the camera. You know, because it's nighttime, they're often sleepy as well. It's not always easy.* [Participant 1]

Despite the integration of teleconsultation, the sense of responsibility, clinical judgment, and desire to provide safe, high-quality care and services to residents remains unshaken. Teleconsultation has not changed the values and principles of nursing assistants:

> *My decision-making would probably have been the same, with or without teleconsultation, once I came here. It didn't change my decision-making.* [Participant 2]
>
> *I'm still part of the same order, I still have the same scope of practice to uphold. So, from my standpoint, my responsibilities remain the same. Just because you have a tablet doesn't mean you're protected. No, it gives us an additional tool, but we still have to use our judgment.* [Participant 8]

Enhanced Practices

Enhanced practices refer to the added value brought to workflows by improving the quality of interventions. These advancements not only streamline processes but also elevate the standard of care provided, resulting in more effective and responsive support for residents.

Organizational Level

Participants praised the rigorous planning of the pilot project and the quality of training. Presentations were clear and the content was well documented:

> *I think the training was well done; we were well trained.* [Participant 2]

In addition, the sessions dealt with updating and creating clinical tools tailored to teleconsultation:

> *For example, we didn't used to have algorithms. That was something new with teleconsultation.* [Participant 4]
>
> *We updated all our protocols, you know, to raise awareness. We updated "Are the collective prescriptions correct?" So, you know, we did a good job of updating, which should be ongoing, but which, well, isn't necessarily done as part of day-to-day activities.* [Participant 5]

In addition, the training sessions prompted group discussions on professional roles, professional order guidelines, understanding the scope of practice, and recognition of the expertise of other disciplines:

> *It's when we did the training with the project officer. Well, with the eligibility criteria, you know, exclusions and so on. We realized that, oops, sometimes our nursing assistants were being very autonomous. We've now rectified that. I think we adjusted well after that.* [Participant 6]
>
> *Inevitably, with everything being more up to date like this, I don't need to communicate with my nurse as much. I'm more independent.* [Participant 7]

In addition, participants appreciated the attention paid to their concerns and the opportunity to provide immediate feedback during the training sessions:

> *We were asked if there were things we thought should be added, things that were missing.* [Participant 9]

> *But more so in connection to, say, the material we put in the case, the forms, the step-by-step instructions. Yes, we were consulted. We were asked if there were things they thought we should add, things that were missing. They were also available if we wanted to add anything along the way.* [Participant 8]

Administrative Level

Teleconsultation enabled the remote nurse to contribute to the coordination of interventions in real time and adjust the resident's medical record. For example, the remote assessment of a resident's physical and mental condition was immediately documented in the TNP, enabling the nursing assistant to intervene according to her scope of practice when the health situation changed unexpectedly:

> *Well, with teleconsultation, I changed an TNP remotely...with this tool, we're able to directly change things remotely.* [Participant 5]

> *The fact of sending prescriptions, the fact of sending notes, of sending everything directly to the home, I find that it...How can I say this? It decreases the risk of errors in the end.* [Participant 8]

Another element mentioned by participants was predictability. Because the pilot project was formalized, supported, and recognized by the organization, nurses and nursing assistants knew in advance when teleconsultation was taking place and who would be involved. This enabled better care planning, made it easier to anticipate potential needs, and gave nurses and nursing assistants a greater sense of security:

> *If I see that the patient...I know that in two hours his third dose will be due, then I'm going to get organized.* [Participant 1]

Some participants noted a marked improvement in the design and writing of the TNP, believed to be attributable to a growing awareness of the need to optimize the nursing assistants' scope of practice. In the context of nursing teleconsultation, the TNP is written jointly by the nurse and the nursing assistant to target residents' health problems efficiently. The nursing assistant exercises full autonomy when updating the TNP, adapting it to the resident's health-related condition and needs, and proposing relevant interventions:

> *I think this process, with the night nurses, forces us to have nice TNPs. So, you know, it may have been...That was during our first calls. But shortly after, we got back on track.* [Participant 5]

> *We also established plans, well, our TNPs. We really updated them to enable [nursing assistants] to be autonomous.* [Participant 6]

Clinical Level

Participants noticed that the pilot project helped improve the professional bond between the nurse and the nursing assistant. During the calls, a knowledge-sharing and coaching process was established between them. The nurse ensured a real-time virtual presence for the nursing assistant, guiding them, suggesting interventions, and supporting their practice:

> *You know, we were able to work a bit as a team there. In the sense that, you know, she could suggest things that I could pay more attention to.* [Participant 3]

> *It means I can talk to my nursing assistant. Then, it's like we're really comfortable; it's like we're together. I think that makes it easier to conduct the interventions.* [Participant 8]

The rollout and updating of the pilot project–related clinical tools clarified professional roles and fostered the achievement of full autonomy with confidence. For example, the addition of decision-making algorithms, improved TNP writing, and adjustments to nursing protocols built nursing assistants' confidence and contributed to their empowerment. This process facilitates decision-making, promotes the development of clinical judgment, and improves professional ease:

> *For example, we didn't used to have algorithms. That was something new with teleconsultation. Yes. When there's a situation that's a little ambiguous, you feel like you're sitting on the fence. Then you're not sure which side to choose. Well, you follow your algorithm and it leads you straight to the correct way of doing things.* [Participant 4]

> *I'd say it's generally going well. I haven't experienced any ambiguous situations. The thing is that teleconsultation can only make it even better. I think the fact of talking to and also seeing your nursing assistant...I think it can only bring positive elements in that regard...being able to exchange with them as such.* [Participant 6]

Finally, participants stated that teleconsultation enhances remote nursing by enabling visual inspection. Assessing the physical and mental condition of a symptomatic resident is the responsibility of the nurse, requiring professionalism, diligence, and conscientiousness. Teleconsultation provides valuable visual support to nurses, enabling them to observe clinical situations directly, make more accurate assessments, and monitor the evolution of the resident's health condition. Furthermore, the addition of this tool also benefits the nursing assistant, fostering more enriching discussions with the nurse and enabling a better understanding of the situation, thus refining the chosen intervention:

> *For me, teleconsultation using a tablet was a practical way of getting a visual. It helps justify a problem. Then, afterwards, once you have visualized the problem, you can find more solutions to solve it. So I found that it was like an additional tool to support and reinforce my role and responsibilities.* [Participant 4]

> *We have a lot of patients who are agitated and aggressive. This video aspect is good, because I can see in real time what the patient is doing, without having to go there myself. It's a situation. Otherwise, in the case of a wound, you know. You can see it.* [Participant 6]

Table 1 summarizes the unchanged and enhanced practices for each level of practice.

Table 1. Enhanced and unchanged practices by level.

Level of practice	Enhanced practices	Unchanged practices
Clinical level	• Collaborative team dynamics during teleconsultation, where knowledge is shared between remote nurses and nursing assistants, reinforcing their respective professional roles • Remote nurses' clinical decisions are reflected in the TNP[a] in real time • Addition of visual support to improve data collection, situation analysis, and intervention implementation	• Palpation remains impossible when using teleconsultation • Certain clinical situations make teleconsultation-based assessment difficult • Professionalism is ensured in the interest of providing exemplary care
Administrative level	• Improved clinical communication enabling the remote nurse to make additions to the medical record • Proactive drafting of the TNP to reinforce collaboration between remote nurses and nursing assistants for optimal professional practice	• Resident medical record documentation rules are not implemented in a standardized way • Communication is maintained between nursing professionals and residents' families and loved ones
Organizational level	• Openness and availability of project managers to provide information at the start of the project • Complete and tailored training program • Updated protocols, rules governing care, collective prescriptions, and additional clinical tools • Enhanced scope of practice-related knowledge	• Professional nursing team members not solicited enough during the planning phase of the pilot project—change management • Professional experience and maturity are essential to rolling out teleconsultation

[a] TNP: therapeutic nursing plan.

Discussion

Principal Findings

Overview

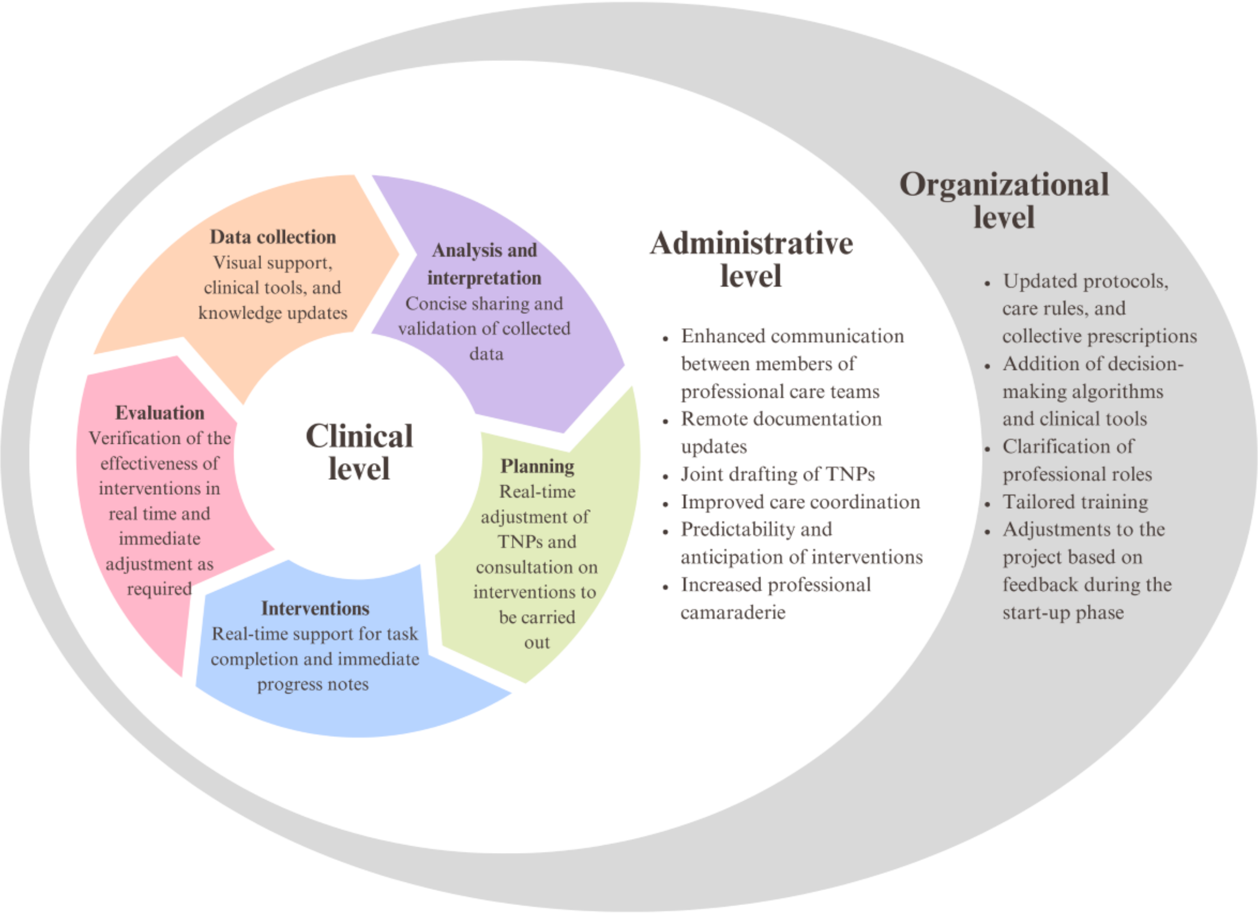
The implementation of teleconsultation elicited a diverse range of responses from participants, revealing both unchanged and enhanced experiences. These findings underline the benefits of adopting new health care technologies. The nurses' and nursing assistants' perceptions highlighted several positive aspects where teleconsultation introduced beneficial changes. Figure 1 illustrates the workflows optimized by teleconsultation in nursing and shows the interactions between different levels of practice and their associated benefits. The organizational and administrative levels supported clinical practice, which is represented by the clinical approach in nursing. From planning to assessment, each step benefited from the integration of technology and increased collaboration within the care team. Real-time documentation, visual support, role clarity, and proactive communication ensured seamless continuity of care, with an emphasis on efficient and safe interventions.

However, the experience also raised concerns about administrative management, change management, and compliance with documentation rules. Nevertheless, most (8/9, 89%) participants enjoyed the structure and quality of the training courses as well as the clarification of professional roles and the opportunity to update and implement clinical tools tailored to teleconsultation. Participants did not report any scope creep during the pilot project.

Although teleconsultation enhanced certain aspects of nursing practice, namely by facilitating care coordination and boosting professional confidence, it also required adjustments to optimize integration. These findings underline the importance of appropriate support and careful planning to maximize the benefits of such technological innovations in long-term care settings.

The qualitative findings will be discussed around 3 cross-cutting topics. It is important to note that they emerged from the data analyses: leadership, collaboration, and impact on residents.

Figure 1. Workflows optimized by teleconsultation in nursing. TNP: therapeutic nursing plan.



Leadership

Overview

Nurses' and nursing assistants' workflows were improved through an extended scope of practice, which can be attributed to the leadership exercised during the teleconsultation project. Interventions and discussions initiated by project managers clarified scopes of practice, eliminating ambiguities, and building the confidence of nurses and nursing assistants [44]. This led to an increased commitment from participants and extended the scope of practice. The literature has highlighted that clinical leadership can be exercised in a caring way to improve the quality of interventions with residents [45]. The OIIAQ's recent work to strengthen the role of nursing assistants [46] is embodied by this teleconsultation pilot project, demonstrating how a supportive environment can promote optimal practice [47].

Nurses' leadership is also linked to their experience and professional maturity. The leadership exercised by an expert nurse leads to positive results for residents and care teams alike [45,48]. Indeed, most (8/9, 89%) interviewees had >5 years of experience working with older adults, and the literature supports the view that expertise contributes to the success of teleconsultation projects [49,50].

Shared Governance

Shared governance is an important concept for the development of high-level leadership among nurses and nursing assistants. Researchers have pointed to a gap between managers' and nurses' vision, sometimes making it difficult for these 2 groups to communicate [51]. During the pilot project, participants were not always asked about their perspectives, leading to dissatisfaction with the planning and the intensity of follow-up.

Shared governance, involving nurses and nursing assistants from the outset of the pilot project, could have improved the planning of health care projects, refined the prioritization of initiatives, and promoted ongoing improvement [52]. Moreover, it would enable project managers to better meet the technology-related needs and expectations of end users: the nursing staff [53].

Collaboration

Overview

Nurses' and nursing assistants' workflows were improved by strengthening their collaborative relationships. Teleconsultation consolidated these relationships, leading to optimized care planning, intervention coordination, and access to clinical documentation.

First, teleconsultation enabled nurses to share information with the nursing assistant and complete clinical documentation in real time, thereby reducing the number of interpretation errors.

This synchronous and asynchronous communication ensured better continuity and coordination of care [54]. The care team was able to access progress notes, prescriptions, and the TNP as required [55,56]. However, despite these benefits, there were issues related to the implementation of documentation. Although documenting interventions is a professional obligation [57], studies have shown that nursing notes are sometimes superficial, affecting the quality and continuity of care [58]. This highlights the importance of integrating users, processes, and technology [59,60].

Second, the collaborative dynamic between nurses and nursing assistants was strengthened by a clear definition of their roles. Project managers played a decisive role in optimizing the use of people's skills [44]. However, professional development remains a contextual phenomenon, influenced by local and organizational factors [61,62]. By harmonizing nurses' and nursing assistants' contributions, they fostered collaborative practice and improved communication within teams [63].

Finally, team stability is crucial to strengthening collaborative relationships. It helps establish a climate of trust between colleagues, which is essential to ensure optimal professional practice [64]. The pilot project demonstrated that collaboration, underpinned by effective consultation, enables the achievement of targeted objectives and the provision of care tailored to residents' needs [65].

Predictability

Teleconsultation improves schedule predictability, an important consideration for nursing staff [66]. Clearly identifying the schedule or timetable of night shifts, during which telecommunication would be used, facilitated collaboration between nurses and nursing assistants, enabling them to anticipate and respond proactively to residents' needs. For example, a jointly drafted TNP improves care management for residents with recurring health problems [57]. The nursing assistant can then rapidly carry out the necessary interventions safely and with confidence.

In addition, teleconsultation reduces the need for mandatory overtime, preserving nurses' physical and psychological health [67,68]. Teleconsultation makes it possible to organize required interventions in advance to ensure the continuity and safety of care [69].

Impact on Residents and Their Loved Ones

Overview

Interviews with nurses and nursing assistants revealed that the well-being of residents, as well as that of their families and loved ones is a constant and central concern. Every intervention, whether or not it includes the use of teleconsultation, must be of impeccable quality, ensuring the well-being of residents at all times. Therefore, it is obvious that when using teleconsultation, nurses' and nursing assistants' workflows must establish the resident as the top priority.

Clinical Aspect of Practice

Participants demonstrated unwavering professionalism and respect for professional values when using teleconsultation. They recognized both the benefits and limitations of the technology. During complex clinical situations, they intervened with greater confidence and ease. Because it involves the use of a camera, teleconsultation facilitates the physical assessment of a resident's condition. However, participants were also aware of situations where teleconsultation was less suitable and recognized the imperative need to comply with the professional and ethical standards in remote practice.

The amount of literature on integrating technology into health care is growing rapidly [70]. Recent initiatives on remote clinical monitoring [71] have led to the publication of nursing practice standards that also consider technological practices [50]. Participants agreed that teleconsultation is a useful additional tool but that it can never replace a full physical examination or direct interaction with the resident. A similar case study on teleconsultation also concluded that this modality of care does not replace the presence of a nurse with the resident but can effectively support clinical practice when the situation allows [72]. In short, pilot project participants demonstrated a strong commitment to and rigorous professional integrity in providing safe, high-quality care to residents.

Involvement of Family and Loved Ones

The active presence of residents' families and loved ones in the organization of care and services in CHSLDs is not only desirable but also essential. The teams who took part in the pilot project set up a communication plan to inform residents' families and loved ones of this initiative, encouraging them to ask questions as needed. Nurses and nursing assistants then discussed the specifics of the pilot project when obtaining consent for the residents to participate, providing an opportunity to clarify certain aspects, to chat with their families and loved ones, and to reinforce existing bonds of trust.

The literature on this subject supports the participants' observations. Introducing the technology-based project to residents' families and loved ones and obtaining their formal consent is essential [71]. Strengthening the relationships between care staff and the residents' families and loved ones is highly beneficial. The integration of technology in long-term care facilities is now widely accepted [73] and promotes the involvement of residents' loved ones in clinical decisions [74].

Finally, this integrated approach to leadership, collaboration, and resident-centered health care in a teleconsultation context illustrates how these elements depend on each other to optimize practices and improve clinical and organizational outcomes.

Limitations and Future Research

Despite the rigorous methods used as part of the study, certain limitations must be considered to improve the interpretation of the results and more accurately target the prospects for teleconsultation in long-term nursing care during night shifts. First, the pilot project was conducted in 2 Quebec regions, it involved 3 rural CHSLDs, and the sample size was limited to 9 participants. However, it is important to note that these participants used teleconsultation for 6 months, logging 19 clinical situations, a number similar to data collected by the CHSLDs over the same period in the previous year. This exploratory study was conducted in small care settings, where care teams are limited by the number of residents, justifying the scope of the study. Nevertheless, caution is paramount when generalizing the results to other regions or similar contexts.

To broaden our understanding and increase the effectiveness of teleconsultation in long-term nursing care during night shifts in small, rural CHSLDs, several avenues of research may be considered. Expanding this research to a larger number of small CHSLDs in different regions would improve the representativeness and generalizability of the results. A larger sample would more accurately capture the context-specific and organizational variability.

In addition, a comparative analysis of different geographical and organizational settings would be relevant to identify the factors that influence the success of teleconsultation. This type of analysis would shine a light on best practices and the conditions required for successful implementation.

It would also be worthwhile to assess the long-term impact of teleconsultation on quality of care, resident and caregiver satisfaction, and associated costs. Longitudinal studies could provide valuable data on the benefits and challenges of this approach over an extended period.

Finally, exploring the impact of teleconsultation from the residents' and families' point of view would enable us to understand their perceptions, the elements with which they were satisfied, and their concerns. This perspective could provide crucial insights, helping to adjust practices and improve the care experience.

In addition to this study, developing continuing education programs on the use of teleconsultation technology for health care professionals in rural settings could facilitate the adoption of teleconsultation and optimize the use of these tools. Establishing standardized protocols for the integration of teleconsultation into daily care routines could also foster greater efficiency and broader adoption of this technology.

Conclusions

The implementation of nursing teleconsultation in rural CHSLDs with ≤50 beds has shown promising results in terms of improved workflow, interprofessional collaboration, and the quality of resident care. Nurses' and nursing assistants' perceptions revealed tangible benefits such as real-time documentation, increased visual support, and proactive communication. These elements promoted the efficient and safe continuity of care while highlighting the need for adequate support and careful planning to maximize the benefits of this technology.

Their experiences also highlighted challenges such as administrative management, change management, and compliance with documentation rules. Nevertheless, the structured training and clarification of professional roles were widely appreciated, contributing to the successful implementation of teleconsultation without any reported scope creep.

In total, 3 main themes emerged from the data analysis: leadership, collaboration, and impact on residents. Leadership played an important role in clarifying scopes of practice and building nurses' and nursing assistants' confidence. Collaboration was enhanced through synchronous and asynchronous communication, enabling better care coordination. Finally, the predictability of schedules and the involvement of residents' families and loved ones ensured more proactive care management tailored to the residents' needs.

Although teleconsultation cannot entirely replace the physical presence of nurses, it has been shown to be a valuable tool to support clinical practice and improve the quality of care in CHSLDs. To optimize the integration of teleconsultation, ongoing development of appropriate support and training strategies is essential while also promoting shared governance and the active involvement of residents' families and loved ones. These measures will help maximize the benefits of this technological innovation and guarantee high-quality resident-centered care.

In short, this study demonstrates that nursing teleconsultation represents a promising technological advance to optimize professional practice and strengthen team collaboration. In light of these findings, it is essential that we carry out in-depth discussions on the future of virtual nursing to better understand and efficiently integrate this practice in long-term care settings.

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Authors' Contributions

VN and MCL conceptualized and designed the study, collected the data, conducted the interviews, performed analysis, and wrote the first draft of the manuscript. All the authors (VN, MCL, and VP) have read, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guides.

[DOCX File , 18 KB - aging_v7i1e65111_app1.docx]

References

1. Kergoat MJ, Légaré J, Violo P. Les aspects démographiques et épidémiologiques du vieillissement de la population du Québec. In: Arcand M, Hebert R, editors. Précis Pratique de Gériatrie, Third Edition. Montréal, QC: EDISEM; 1999.
2. Lacombe G. L'évaluation clinique. In: Arcand M, Hebert R, editors. Précis Pratique de Gériatrie, Third Edition. Montréal, QC: EDISEM; 1999.
3. Chez soi : le premier choix: la politique de soutien à domicile. Ministère de la Santé et des Services Sociaux. 2002. URL: https://publications.msss.gouv.qc.ca/msss/fichiers/2002/02-704-01.pdf [accessed 2024-08-03]
4. Plan stratégique 2023-2027. Ministère de la Santé et des Services Sociaux. 2023. URL: https://cdn-contenu.quebec.ca/cdn-contenu/adm/min/sante-services-sociaux/publications-adm/plan-strategique/PL_23-717-01W_MSSS.pdf [accessed 2024-08-03]
5. Institut National d'excellence en Santé et en Services Sociaux. Conciliation du milieu de soins et du milieu de vie en centre d'hébergement et de soins de longue durée. État des pratiques rédigé par Isabelle David et Marie-Hélène Raymond. 2020 Sep. URL: https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/ServicesSociaux/INESSS_Conciliation_CHSLD_Etat_pratiques_2020.pdf [accessed 2024-08-03]
6. Lanteigne G, Duchesneau A. L'hébergement et les soins de longue durée. In: Arcand M, Hebert R, editors. Précis Pratique de Gériatrie, Third Edition. Montréal, QC: EDISEM; 1999.
7. Champoux N, Lebel S. Hébergement et soins de longue durée. In: Dans Précis Pratique de Gériatrie. Acton Vale, QC: Edisem; 2007:1177-1191.
8. McGregor MJ, Abu-Laban RB, Ronald LA, McGrail KM, Andrusiek D, Baumbusch J, et al. Nursing home characteristics associated with resident transfers to emergency departments. Can J Aging 2014 Jan 03;33(1):38-48. [doi: 10.1017/s0714980813000615]
9. Exercice infirmier auprès des personnes hébergées en centre d'hébergement et de soins de longue durée. Ordre des Infirmières et Infirmiers du Québec. 2018. URL: https://fsi.umontreal.ca/nouvelles/nouvelle/news/detail/News/exercice-infirmier-aupres-des-personnes-hebergees-en-centre-dhebergement-et-de-soins-de-longue-duree-chsld-cadre-de-reference/ [accessed 2023-08-03]
10. Les activités professionnelles de l'infirmière auxiliaire. Ordre des Infirmières et Infirmiers Auxiliaires du Québec. 2020. URL: https://www.oiiaq.org/files/common/OIIAQ-2020-ACTIVITES-PROFESSIONNELLES-PEDIATRIE-v13.pdf [accessed 2024-08-03]
11. Etheridge F. Chapitre 2 Pour une meilleure gestion des organisations et une utilisation optimale des ressources actuelles. In: Les Organisations de Soins de Longue Durée. Montreal, QC: Les Presses de l'Université de Montréal; 2020:33-49.
12. Aubry F, Couturier Y, Gilbert F. L'application de l'approche milieu de vie en établissement d'hébergement de longue durée par les préposés aux bénéficiaires point de vue des préposés, des infirmiéres auxiliaires et des infirmiéres. L'infirmiére Clinicienne 2013;10(1):52-61 [FREE Full text]
13. Kvarnström S. Difficulties in collaboration: a critical incident study of interprofessional healthcare teamwork. J Interprof Care 2008 Mar 06;22(2):191-203. [doi: 10.1080/13561820701760600] [Medline: 18320453]
14. Zahreddine J. Exploration de la perception de l'interdisciplinarité de la part des infirmières en milieu gériatrique. Université de Montréal. 2010 Mar. URL: https://hdl.handle.net/1866/4104 [accessed 2024-08-03]
15. Bostick JE, Rantz MJ, Flesner MK, Riggs CJ. Systematic review of studies of staffing and quality in nursing homes. J Am Med Dir Assoc 2006 Jul;7(6):366-376. [doi: 10.1016/j.jamda.2006.01.024] [Medline: 16843237]
16. Kim H, Harrington C, Greene WH. Registered nurse staffing mix and quality of care in nursing homes: a longitudinal analysis. Gerontologist 2009 Feb 18;49(1):81-90. [doi: 10.1093/geront/gnp014] [Medline: 19363006]
17. Corazzini KN, Anderson RA, Mueller C, Hunt-McKinney S, Day L, Porter K. Understanding RN and LPN patterns of practice in nursing homes. J Nurs Regul 2013 Apr;4(1):14-18. [doi: 10.1016/s2155-8256(15)30173-3]
18. Paquette A. La collaboration dans l'équipe de soins quant à la gestion de la douleur chronique chez la personne âgée atteinte de troubles cognitifs en centre d'hébergement. Université de Montréal. 2018 Aug. URL: https://hdl.handle.net/1866/21880 [accessed 2024-08-03]
19. Vitale SA, Varrone-Ganesh J, Vu M. Nurses working the night shift: impact on home, family and social life. J Nurs Educ Pract 2015 Jul 27;5(10). [doi: 10.5430/jnep.v5n10p70]
20. Boivin DB, Boudreau P, Kosmadopoulos A. Disturbance of the circadian system in shift work and its health impact. J Biol Rhythms 2022 Feb;37(1):3-28 [FREE Full text] [doi: 10.1177/07487304211064218] [Medline: 34969316]
21. Dwyer R, Gabbe B, Stoelwinder JU, Lowthian J. A systematic review of outcomes following emergency transfer to hospital for residents of aged care facilities. Age Ageing 2014 Nov;43(6):759-766. [doi: 10.1093/ageing/afu117] [Medline: 25315230]
22. Peguero-Rodriguez G, Polomeno V, Lalonde M. Le transfert des aînés des résidences pour personnes âgées vers l'urgence : l'état actuel des connaissances. Soins d'urgence 2023 Jul 20;2(1):11-20. [doi: 10.7202/1101991ar]
23. Voyer P. L'infirmière en CHSLD: d'hier à aujourd'hui. Ordre des Infirmières et Infirmiers du Québec. 2008. URL: https://www.oiiq.org/documents/20147/1456160/PVoyer.pdf/04985afeeaf-303e-a59f-218ee31e6cf1 [accessed 2024-08-04]

24. Voyer P, Cyr N, Abran MC, Bérubé L, Côté S, Coulombe A, et al. Les ratios infirmière/résidents en CHSLD. Pénurie de soins ou pénurie d'infirmières? Perspect Infirm 2016;13(3):45-50. [Medline: 27400604]
25. Habib J, Yatim F, Sebai J. Analyse des facteurs influençant l'émergence des pratiques de télémédecine : le cas des Maisons de Santé en France. Systèmes D'information Management 2019;24:47-85. [doi: 10.3917/sim.191.0047]
26. Alexander GL, Powell KR, Deroche CB. An evaluation of telehealth expansion in U.S. nursing homes. J Am Med Inform Assoc 2021 Feb 15;28(2):342-348 [FREE Full text] [doi: 10.1093/jamia/ocaa253] [Medline: 33164054]
27. Chess D, Whitman JJ, Croll D, Stefanacci R. Impact of after-hours telemedicine on hospitalizations in a skilled nursing facility. Am J Manag Care 2018 Aug;24(8):385-388 [FREE Full text] [Medline: 30130033]
28. Driessen J, Castle NG, Handler SM. Perceived benefits, barriers, and drivers of telemedicine from the perspective of skilled nursing facility administrative staff stakeholders. J Appl Gerontol 2018 Jan;37(1):110-120. [doi: 10.1177/0733464816651884] [Medline: 27269289]
29. Grabowski DC, O'Malley AJ. Use of telemedicine can reduce hospitalizations of nursing home residents and generate savings for medicare. Health Aff (Millwood) 2014 Feb;33(2):244-250. [doi: 10.1377/hlthaff.2013.0922] [Medline: 24493767]
30. Ohligs M, Stocklassa S, Rossaint R, Czaplik M, Follmann A. Employment of telemedicine in nursing homes: clinical requirement analysis, system development and first test results. Clin Interv Aging 2020;15:1427-1437 [FREE Full text] [doi: 10.2147/CIA.S260098] [Medline: 32884251]
31. Esterle L, Mathieu-Fritz A. Teleconsultation in geriatrics: impact on professional practice. Int J Med Inform 2013 Aug;82(8):684-695. [doi: 10.1016/j.ijmedinf.2013.04.006] [Medline: 23746716]
32. Olenik K, Lehr B. Counteracting brain drain of health professionals from rural areas via teleconsultation: analysis of the barriers and success factors of teleconsultation. J Public Health 2013 Apr 27;21(4):357-364. [doi: 10.1007/s10389-013-0565-8]
33. Mills CA, Tran Y, Yeager VA, Unroe KT, Holmes A, Blackburn J. Perceptions of nurses delivering nursing home virtual care support: a qualitative pilot study. Gerontol Geriatr Med 2023;9:23337214231163438 [FREE Full text] [doi: 10.1177/23337214231163438] [Medline: 36968120]
34. Chaudoir SR, Dugan AG, Barr CH. Measuring factors affecting implementation of health innovations: a systematic review of structural, organizational, provider, patient, and innovation level measures. Implement Sci 2013 Feb 17;8:22 [FREE Full text] [doi: 10.1186/1748-5908-8-22] [Medline: 23414420]
35. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009 Aug 07;4:50 [FREE Full text] [doi: 10.1186/1748-5908-4-50] [Medline: 19664226]
36. Besner J, Doran D, Hall LM, Giovannetti P, Girard F, Hill W, et al. A systematic approach to maximizing nursing scopes of practice. Alta RN 2006 Jan;62(1):14-15. [Medline: 16602342]
37. Dubois CA, D'Amour D, Tchouaket E, Rivard M, Clarke S, Blais R. A taxonomy of nursing care organization models in hospitals. BMC Health Serv Res 2012 Aug 28;12(1):286 [FREE Full text] [doi: 10.1186/1472-6963-12-286] [Medline: 22929127]
38. D'Amour D, Dubois CA, Déry J, Clarke S, Tchouaket E, Blais R, et al. Measuring actual scope of nursing practice: a new tool for nurse leaders. J Nurs Adm 2012 May;42(5):248-255. [doi: 10.1097/NNA.0b013e31824337f4] [Medline: 22525288]
39. Fortin MF, Gagnon J. Foundations and Stages of the Research Process: Quantitative and Qualitative Methods Third Edition. Montréal, QC: Chenelière éducation; 2016.
40. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 2018;52(4):1893-1907 [FREE Full text] [doi: 10.1007/s11135-017-0574-8] [Medline: 29937585]
41. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005 Nov;15(9):1277-1288. [doi: 10.1177/1049732305276687] [Medline: 16204405]
42. Landry S, Beaulieu M. Lean, Kata et Système de Gestion: Réflexions, Observations et Récits D'organisations. Montréal, QC: Éditions JFD; 2022.
43. Benner P, Tanner C, Chesla C. From beginner to expert: gaining a differentiated clinical world in critical care nursing. ANS Adv Nurs Sci 1992 Mar;14(3):13-28. [doi: 10.1097/00012272-199203000-00005] [Medline: 1550330]
44. Kim R. Les interventions prometteuses pour des infirmières gestionnaires au regard du déploiement optimal de l'étendue de pratique infirmière : un rapid review. Université de Montréal. 2021 Dec. URL: https://hdl.handle.net/1866/27231 [accessed 2024-08-04]
45. Chávez EC, Yoder LH. Staff nurse clinical leadership: a concept analysis. Nurs Forum 2015;50(2):90-100. [doi: 10.1111/nuf.12100] [Medline: 24935803]
46. Énoncé de position sur les soins et services aux personnes hébergées en CHSLD. Ordre des infirmières et infirmiers auxiliaires du Québec. 2016 Sep. URL: https://www.oiiaq.org/publications/enonce-de-position-sur-les-soins-et-les-services-aux-personnes-hebergees-en-chsld-1 [accessed 2024-08-04]
47. Rosa MC. La pratique de l'infirmière auxiliaire en CHSLD. Ordre des infirmières et infirmiers auxiliaires du Québec. URL: https://www.oiiaq.org/actualites/la-pratique-de-linfirmiere-auxiliaire-en-chsld [accessed 2024-08-04]
48. Mannix J, Wilkes L, Daly J. Attributes of clinical leadership in contemporary nursing: an integrative review. Contemp Nurse 2013 Aug 17;45(1):10-21. [doi: 10.5172/conu.2013.45.1.10] [Medline: 24099222]

49. Groff C. Centralized virtual nurses enable team-based care, address staff shortages. Epic. 2023 Aug 7. URL: https://www.epic.com/epic/post/centralized-virtual-nurses-enable-team-based-care-address-staff-shortages/ [accessed 2024-08-04]
50. Roberson AE, Carlson M, Kohler CM, Harris PA, Volkmann CL. Initiating virtual nursing in general inpatient care. Am J Nurs 2023 Jun 01;123(6):48-54. [doi: 10.1097/01.NAJ.0000938736.42266.5e] [Medline: 37233140]
51. Glouberman S, Mintzberg H. Gérer les soins de santé et le traitement de la maladie. Gestion 2002;27(3):12-22. [doi: 10.3917/riges.273.0012]
52. Dallaire C. L'action politique: une stratégie pour l'engagement professionnel. In: Le Savoir Infirmier Au Coeur de la Discipline et de la Profession. Montréal, QC: Gaétan Morin; 2008.
53. Dobbins M, DeCorby K, Twiddy T. A knowledge transfer strategy for public health decision makers. Worldviews Evid Based Nurs 2004 May 21;1(2):120-128. [doi: 10.1111/j.1741-6787.2004.t01-1-04009.x] [Medline: 17129325]
54. Naik AD, Singh H. Electronic health records to coordinate decision making for complex patients: what can we learn from wiki? Med Decis Making 2010;30(6):722-731. [doi: 10.1177/0272989X10385846] [Medline: 21183759]
55. Parker J, Coiera E. Improving clinical communication: a view from psychology. J Am Med Inform Assoc 2000;7(5):453-461 [FREE Full text] [doi: 10.1136/jamia.2000.0070453] [Medline: 10984464]
56. Weiner SJ, Barnet B, Cheng TL, Daaleman TP. Processes for effective communication in primary care. Ann Intern Med 2005 Apr 19;142(8):709-714. [doi: 10.7326/0003-4819-142-8-200504190-00039] [Medline: 15838090]
57. Norme d'exercice : documentation des soins infirmiers. Ordre des infirmières et infirmiers du Québec. URL: https://www.oiiq.org/documents/20147/237836/4544-norme-documentation-web.pdf/e36399e8-db1c-8329-288a-4a258bde5901 [accessed 2024-08-04]
58. Steis MR, Fick DM. Are nurses recognizing delirium? A systematic review. J Gerontol Nurs 2008 Sep;34(9):40-48. [doi: 10.3928/00989134-20080901-12] [Medline: 18795564]
59. Brault I, Therriault PY, St-Denis L, Lebel P. Implementation of interprofessional learning activities in a professional practicum: the emerging role of technology. J Interprof Care 2015;29(6):530-535. [doi: 10.3109/13561820.2015.1021308] [Medline: 25955721]
60. Arcand M, Hebert R. Précis Pratique de Gériatrie, Third Edition. Montréal, QC: EDISEM; 1999.
61. Forrest CB. A typology of specialists' clinical roles. Arch Intern Med 2009 Jun 08;169(11):1062-1068. [doi: 10.1001/archinternmed.2009.114] [Medline: 19506176]
62. Morin M, Lessard L. [The actual scope of nursing practice in community health services in remote areas]. Rech Soins Infirm 2019 Sep;138(3):75-93. [doi: 10.3917/rsi.138.0075] [Medline: 31959245]
63. Roy C. Stratégies à privilégier pour permettre aux infirmières et infirmiers de déployer pleinement leur étendue de pratique. Université de Montréal. 2015 Jun. URL: https://hdl.handle.net/1866/13141 [accessed 2024-08-04]
64. Gauthier J, Haggerty J, Lamarche P, Lévesque JF, Morin D, Pineault R, et al. Entre adaptabilité et fragilité : les conditions d’accès aux services de santé des communautés rurales et éloignées. Institut National De Santé Publique Du Québec. 2009 Oct. URL: https://www.inspq.qc.ca/sites/default/files/publications/1014_conditionsaccesservsantecommunrurales.pdf [accessed 2023-08-03]
65. Careau E, Brière N, Houle N, Dumont S, Maziade J, Paré L, et al. Continuum des pratiques de collaboration interprofessionnelle en santé et services sociaux - guide explicatif. Réseau de Collaboration Surles Pratiques Interprofessionnelles en Santé et Services Sociaux. 2014. URL: https://www.ciusss-capitalenationale.gouv.qc.ca/sites/d8/files/docs/ProfSante/RCPI/Guide-continuum-pratique-CIP.pdf [accessed 2024-08-04]
66. Buffington A, Zwink J, Fink R, Devine D, Sanders C. Factors affecting nurse retention at an academic Magnet® hospital. J Nurs Adm 2012 May;42(5):273-281. [doi: 10.1097/NNA.0b013e3182433812] [Medline: 22525291]
67. Bougie M. La signification du temps supplémentaire obligatoire tel que vécu par des infirmières en centre hospitalier. Université de Montréal. 2007. URL: https://hdl.handle.net/1866/17944 [accessed 2024-08-04]
68. Pinard R. La pénurie de main-d’oeuvre, réalité ou prétexte? Érudit. 2019 Sep 16. URL: https://www.erudit.org/fr/revues/rel/2019-n804-rel04861/91738ac/ [accessed 2024-08-04]
69. Code de déontologie des infirmières et infirmiers. Éditeur officiel du Québec. 2004. URL: https://www.legisquebec.gouv.qc.ca/fr/pdf/rc/I-8,%20R.%209.pdf [accessed 2024-08-04]
70. Afzal A, Gauthier JB. Project management and practitioners in the health sector: from the Quebec healthcare system perspective to pm literature review. HAL Open Science. 2017. URL: https://hal.science/hal-01579996v1/document [accessed 2024-08-04]
71. Boston-Fleischhauer C. The explosion of virtual nursing care. J Nurs Adm 2017 Feb;47(2):85-87. [doi: 10.1097/NNA.0000000000000444] [Medline: 28106680]
72. Cloyd B, Thompson J. Virtual care nursing: the wave of the future. Nurse Lead 2020 Apr;18(2):147-150 [FREE Full text] [doi: 10.1016/j.mnl.2019.12.006]
73. Hardy MS, Fanaki C, Savoie C, Dallaire C, Wilchesky M, Gallani MC, et al. Acceptability of videoconferencing to preserve the contact between cognitively impaired long-term care residents and their family caregivers: a mixed-methods study. Geriatr Nurs 2022;48:65-73 [FREE Full text] [doi: 10.1016/j.gerinurse.2022.09.006] [Medline: 36155311]

74. Garnett A, Connelly D, Yous ML, Hung L, Snobelen N, Hay M, et al. Nurse-led virtual delivery of PIECES in Canadian long-term care homes to support the care of older adults experiencing responsive behaviors during COVID-19: qualitative descriptive study. JMIR Nurs 2022 Dec 13;5(1):e42731 [FREE Full text] [doi: 10.2196/42731] [Medline: 36446050]

Abbreviations

CHSLD: Centre d'hébergement et de soins de longue durée (French for "residential and long-term care center")
MSSS: Ministère de la Santé et des Services sociaux
OIIAQ: Ordre des infirmières et infirmiers auxiliaires du Québec
OIIQ: Ordre des infirmières et infirmiers du Québec
TNP: therapeutic nursing plan

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Original Paper

Tailored Self-Management App to Support Older Adults With Cancer and Multimorbidity: Development and Usability Testing

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Abstract

Background: Globally, cancer predominates in adults aged older than 60 years, and 70% of older adults have ≥1 chronic condition. Cancer self-management interventions can improve symptom management and confidence, but few interventions target the complex needs of older adults with cancer and multimorbidity. Despite growing evidence of digital health tools in cancer care, there is a paucity of theoretically grounded digital self-management supports for older adults. Many apps for older adults have not been co-designed with older adults to ensure that they are tailored to their specific needs, which would increase usability and uptake.

Objective: We aim to report on the user evaluations of a self- and symptom-management app to support older adults living with cancer and multimorbidity.

Methods: This study used Grey’s self-management framework, a design thinking approach, and involved older adults with lived experiences of cancer to design a medium-fidelity app prototype. Older adults with cancer or caregivers were recruited through community organizations or support groups to participate in co-designing or evaluations of the app. Data from interviews were iteratively integrated into the design process and analyzed using descriptive statistics and thematic analyses.

Results: In total, 15 older adults and 3 caregivers (n=18) participated in this study: 10 participated (8 older adults and 2 caregivers) in the design of the low-fidelity prototype, and 10 evaluated (9 older adults and 1 caregiver) the medium-fidelity prototype (2 older adults participated in both phases). Participants emphasized the importance of tracking functions to make sense of information across physical symptoms and psychosocial aspects; a clear display; and the organization of notes and reminders to communicate with care providers. Participants also emphasized the importance of medication initiation or cessation reminders to mitigate concerns related to polypharmacy.

Conclusions: This app has the potential to support the complex health care needs of older adults with cancer, creating a “home base” for symptom management and support. The findings from this study will position the researchers to conduct feasibility testing and real-world implementation.

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KEYWORDS

cancer; aging; self-management; usability testing; design thinking; design; oncology; develop; development; usability; gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; mHealth; mobile health; app; apps; application; applications; symptom; symptoms; comorbidity; comorbidities; comorbid; multimorbidity; multimorbidities; co-design

Introduction

Cancer morbidity and mortality increase with age for most cancers [1,2]. With the rapidly aging population, the number of older adults (≥65 years) with cancer is estimated to double globally by 2035 [1] and triple in those aged ≥80 years in the next decades [3]. In Canada, 2 in every 5 older adults aged ≥70 years are diagnosed with cancer, accounting for 28.2% of all deaths [4]. Approximately 70% of older adults with cancer have pre-existing illnesses that occur with aging [5]. Having multiple conditions alongside cancer can lower one’s functional and cognitive status, increase the likelihood of treatment complications, and negatively impact health outcomes [1,3,5].

Given the possible deleterious side effects of cancer-related treatments, older adults and their families require self-management support during the cancer care trajectory [6,7]. Self-management refers to the ability to manage treatment effects and psychosocial changes arising as a result of illness [7]. Within the context of cancer, self-management refers to one’s ability to manage the effects of diagnosis and treatment [7]. Self-management encompasses the capacity to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with cancer [6]. Self-management support programs are often tailored to the needs and abilities of patients and their relatives [6] and comprise several core skills and responsibilities, including problem-solving, resource use, partnering with health care providers, decision-making, self-tailoring, and action planning [7]. These core skills help people with cancer and their caregivers to actively manage the illness and treatment effects, thereby reducing the effects on daily functioning and improving health [7]. For those with multimorbidity, there is more to manage, and engaging in self-management may be more challenging. Interventions that support this complexity are needed.

Digital health tools present opportunities for self-management support for older adults and caregivers [8]. A recent study by Leigh and colleagues [9] found that 68% of older adults aged ≥60 years owned and used smartphones and were interested in using mobile health apps to self-manage heart failure conditions. Mobile health apps have features that can address older adults’ needs and expectations, contributing to enhanced cancer self-management [10-12]. Cancer apps designed for older adults have been reported to enable better communication [13], the potential for patient-reported outcome collection [14], and the feasibility of electronic rapid frailty screening [15-17]. If self- and symptom-management support for older adults with cancer is tailored to the usability and capability preferences of older adults, they can optimize the management of cancer symptoms [7,8]. However, a limited number of mobile health interventions target older adults with cancer and other conditions to support self- and symptom management [10].

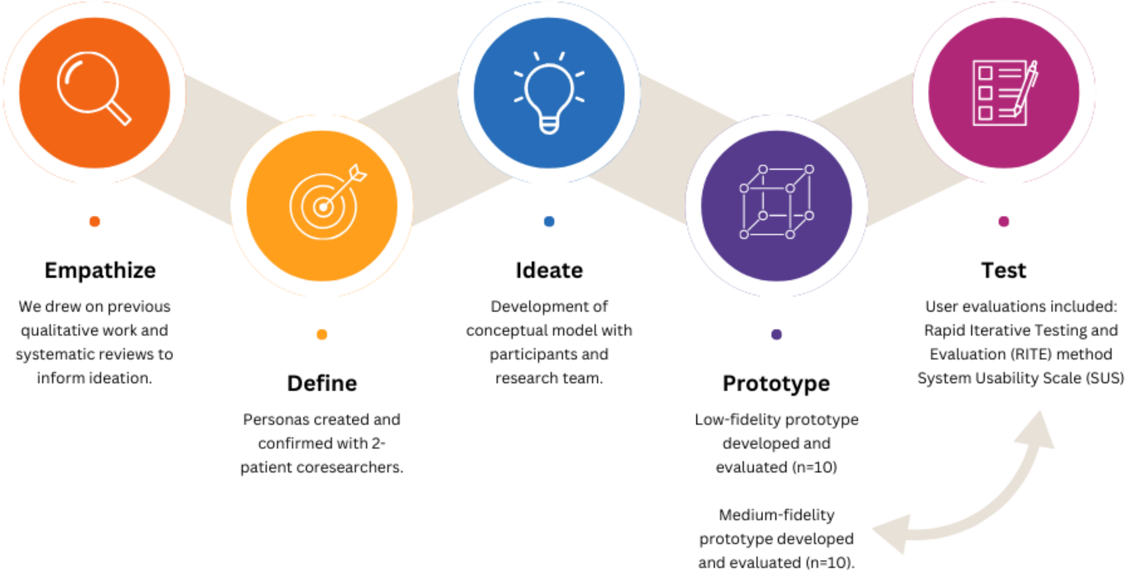
In our prior work with older adults, they described both the complex work of cancer self-management and a dearth of supports to manage the complex interplay of their cancer diagnosis with other illnesses [18,19]. Therefore, the purpose of this study was to address this critical gap, by reporting on the user evaluations of the design of a self-management app to support older adults living with cancer and multimorbidity. In this paper, we report on the process and outcomes of this iterative co-design process.

Methods

Study Design

We used the Design Thinking model [20,21], involving a user-centered approach, with engagement from patient partners as coresearchers. A Design Thinking model involves iterative rounds of developing empathy for users, defining functional and usability requirement priorities, and ideating collective perspectives to produce a final prototype [20]. We gathered participant feedback in multiple waves to ensure that the design was user-validated at every step. Figure 1 shows an overview of our methods.

Figure 1. Overview of methods. Note: empathize, define, ideate, prototype, and test are the 5 stages of design thinking. RITE: Rapid Iterative Testing and Evaluation; SUS: System Usability Scale.



Ethical Considerations

This study underwent ethical review by the harmonized research ethics review board at the University of British Columbia (BREB H21-03052). All participants completed an informed consent process and participated voluntarily. All personal data has been anonymized. All participants were provided an honorarium in the form of a gift card of their choice of $40 per design session.

Recruitment and Participants

Data collection for this study took place between 2021 and 2023 in British Columbia, Canada. We used purposive sampling to recruit older adults with cancer and caregivers. The inclusion criteria for the older adults were aged ≥ 65 years; experiencing or had previously experienced cancer; had received cancer treatment within the previous year; and had at least 1 chronic illness in addition to the cancer diagnosis that required the use of medication or treatment. They also needed to have access and be able to use an internet-connected device, such as a tablet, phone, or laptop. Participants were recruited from community centers, community meetings, support groups, and a registry of patients who had participated in prior research. Caregivers were people who identified as individuals who cared for or supported an older adult during their cancer diagnosis or treatment.

We collected demographic and medical information, health literacy (using the eHealth literacy scale [eHEALS] [22]), and fitness or frailty (using the Vulnerable Elders Survey [23]) scores on all participants, over the telephone, or in person.

We recruited a total of 18 participants comprising 15 older adults and 3 caregivers. In total, 2 older adults participated in evaluating both the low-fidelity and medium-fidelity prototypes to determine whether they perceived any improvements in the design. Thus, a total of 10 participants (8 older adults and 2 caregivers) contributed to the design of the low-fidelity prototype and 10 participants (9 older adults and 1 caregiver) evaluated the medium-fidelity prototype.

Of the 18 participants, 12 (67%) of them were women and 6 (33%) were men. The ages ranged from 40 to 88 years (only age ranges were collected; half [n=9, 50%] of the participants were between 70 and 75 years old). Most were currently married or partnered (n=7, 39%) and college or university educated (n=18, 100%), and they experienced diverse cancers. When asked, they all reported feeling comfortable using the internet.

Defining and Ideating

Using findings from previous work [18] that encapsulated the empathizing stage, we proceeded to define and ideate concepts that could help ground the prototyping phase. We broadly defined this study’s problem statement as supporting older adults’ self-management of their health to improve their quality of life. Using this definition as a prompt, as well as personas to promote empathy with the end users, the research team conducted a brainwriting exercise [24] with the target group to obtain a preliminary understanding of the key tasks that the app should support. A brainwriting exercise is an idea-generation method in human-computer interaction designed to brainstorm and generate what might be a good idea for systems design [24]. From this exercise, we shortlisted tasks that could promote users’ self-management skills according to Grey’s revised self-management theory [25] (Textbox 1). Grey’s revised self-management theory proposes that self-management for both the individual and family should be characterized as interacting with and upon a variety of proximal and distal outcomes [25]. We also highlighted tasks that promoted a more holistic and subjective understanding of users’ health, as those types of tasks could help users think about their quality of life more explicitly.

Textbox 1. Brainwriting outcomes mapped to Grey's self-management theory domains: tasks and subtasks with descriptions.

Make daily health reports

- Report symptoms: a daily report of the user's symptoms, compared to the day before.
- Report events: a daily report of events that can impact the user's symptoms, whether they are physical (taking a walk), emotional (visiting friends), or miscellaneous (weather).
- Report the day: a daily report of the day that can contextualize symptoms and events.
- Report questions and notes: a daily report of any questions or notes they may have for their health care provider.
- Report emoji: a daily report of an emoji that best represents the user's day. Emojis are effective in comprehension and utility when understanding health reports [26].

Learn weekly health trends

- Read brief weekly summaries: a textual summary of the trends of a previous week.
- View visualizations of weekly data: a graphical summary that is equivalent to the textual summary. Informatics have been shown to support holistic wellness by helping older adults with decision-making and identifying trends [27].

Schedule reminders

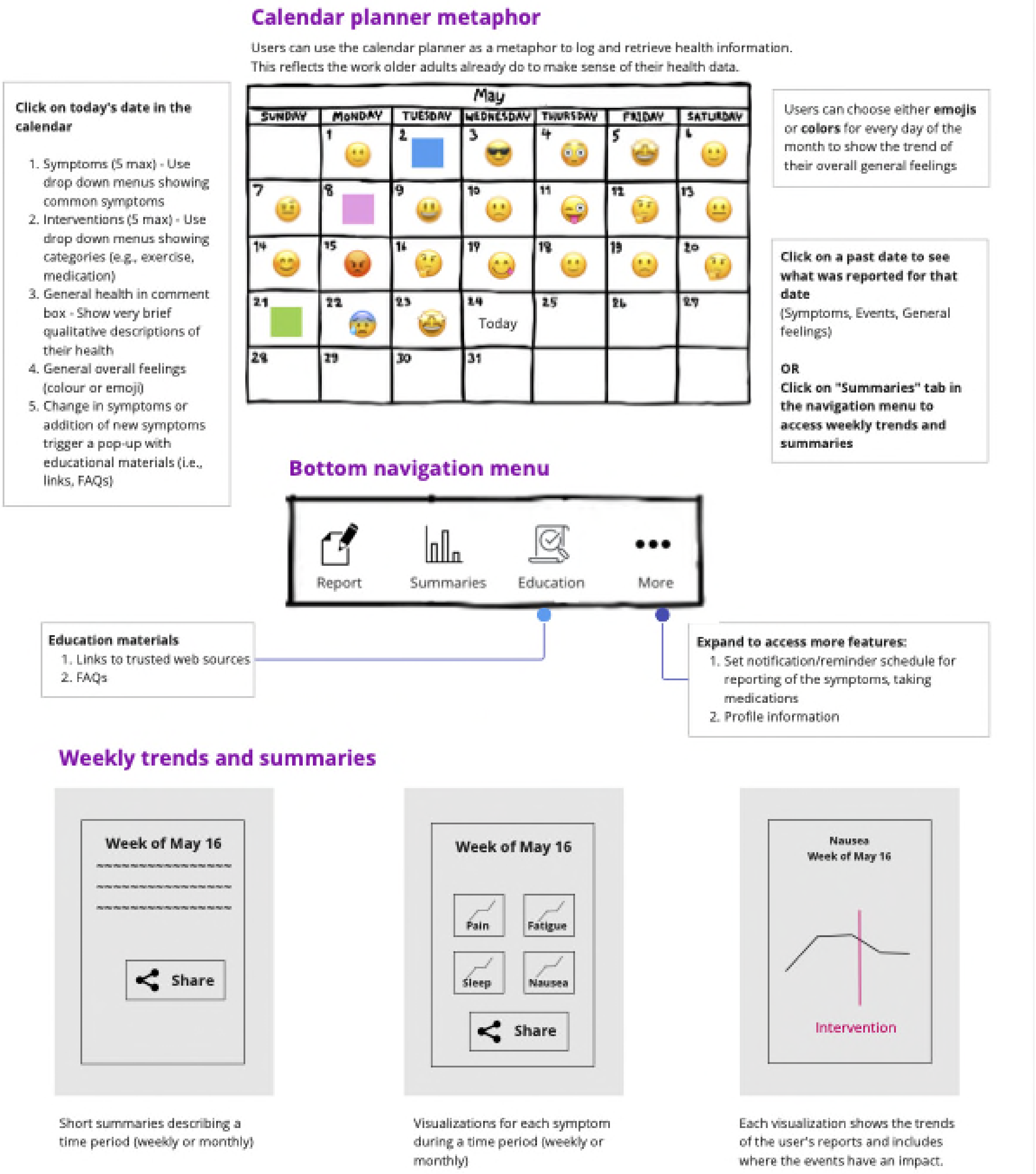
- Schedule reminders to be notified of important times (medications, health care visits, and other events) [28].

Share information

- Email trends and daily reports to health care providers and caregivers, or download them for printing.

Following the brainwriting exercises, we developed a conceptual model [24] to hypothesize, at a high level, how all the tasks should fit together (Figure 2). We leveraged the metaphor of a calendar planner that older adults frequently use to record and keep a journal of their health as a starting point for our model. To validate the usefulness of the model, and to ensure we were on the right track before prototyping, we evaluated the model with 2 participants (P1 and P2) through informal interviews held on Zoom (Zoom Video Communications, Qumu Corporation). As the model was still highly conceptual, their feedback was generally well received, but with the caveat that their positive responses may change once they saw a working prototype.

Figure 2. Conceptual model.



Users can use the calendar planner as a metaphor to log and retrieve health information. This reflects the work older adults already do to make sense of their health data.

Click on today's date in the calendar

1. Symptoms (5 max) - Use drop down menus showing common symptoms
2. Interventions (5 max) - Use drop down menus showing categories (e.g., exercise, medication)
3. General health in comment box - Show very brief qualitative descriptions of their health
4. General overall feelings (colour or emoji)
5. Change in symptoms or addition of new symptoms trigger a pop-up with educational materials (i.e., links, FAQs)

Users can choose either **emojis** or **colors** for every day of the month to show the trend of their overall general feelings

Click on a past date to see what was reported for that date
(Symptoms, Events, General feelings)

OR
Click on "Summaries" tab in the navigation menu to access weekly trends and summaries

Education materials
1. Links to trusted web sources
2. FAQs

Expand to access more features:
1. Set notification/reminder schedule for reporting of the symptoms, taking medications
2. Profile information

Short summaries describing a time period (weekly or monthly)

Visualizations for each symptom during a time period (weekly or monthly)

Each visualization shows the trends of the user's reports and includes where the events have an impact.

Development of Prototypes

We first acquainted ourselves with the basic human-computer interaction recommendations for older adults in interface design: minimal new concepts, plain language, unambiguous icons, accessible user interface, larger font and buttons, and consistent visual cues [29]. We also considered how to split information into smaller and more logical steps for more actionable tasks with less cognitive load [30]. This is especially important, as older adults often require more time to learn new computer skills, make more errors, and (generally) need more assistance than younger people [31,32].

We developed a low-fidelity prototype of a minimum viable product using Axure (Axure Software Solutions) and Sketch (Bohemian Coding Company) as our prototyping tools [33,34].

To rapidly assess where the app could be improved (and because we started this work in 2021 at a time when there were still limitations around social gatherings), we remotely evaluated the prototype on Zoom with 8 different participants. Participants showed how they would complete tasks on a browser and verbalized their thoughts, primarily to validate the usefulness of features and assess their high-level usability. We used the Rapid Iterative Testing and Evaluation (RITE) method, which is effective and efficient in identifying and fixing problems [35]. The main problem we identified was that the low-fidelity prototype needed to give more instructions and use plainer language. We also validated whether the visualizations would be easy to interpret, by having participants evaluate several versions of them to assess understandability: those who described having prior training to read graphs (6/8, 75%) highly preferred the visualizations, whereas the others preferred the textual summaries. This suggested that it would benefit users to implement both versions (text and graphs) in the app. Overall, the prototype was well received by all 8 participants.

Next, we proceeded with the development of the medium-fidelity prototype using Figma (Figma, Inc) as our prototyping tool [36] (Figure S1 in Multimedia Appendix 1). We also adopted the name *Mantra*, which draws on the terms “Managing Cancer” and “Comorbidity in Older Adults.” For the medium-fidelity prototype, we focused on the higher fidelity of both aesthetics and interaction compared to the low-fidelity version. The information architecture was determined by the high-level tasks, with more important task flows (ie, daily reports and weekly summaries) explicitly shown in the bottom navigation. Embedded in these 2 task flows was the ability to support information sharing. Scheduling of reminders was placed in the “More” menu (Figure S2 in Multimedia Appendix 1). The “More” menu shows the extent of design capabilities and contains unimplemented tasks to be considered for future iterations.

The task for making daily reports was designed to flow like a web-based questionnaire, with the subtasks taking up steps 1-5 (Figure S2 in Multimedia Appendix 1, shows a symptom report). To alleviate the burden of making daily reports, each step could be skipped and the system autosaved progress so that the user could continue where they had left off. The task for learning weekly health trends was designed so that the textual summary and the visualization for the same week were on the same page but in different tabs to show that they were equivalent (Figure S2 in Multimedia Appendix 1).

Evaluations

We designed the evaluation study to be conducted both remotely and in person, as in-person evaluation may have been too physically demanding for some participants. However, we do acknowledge that the validity of the evaluation may be compromised, as the remote participants were interacting with the prototype through a browser and not on a smartphone, which has different usability concerns. We recruited 6 older adults for remote evaluations and 4 older adults for in-person evaluations of the medium-fidelity prototype.

We had three goals for the evaluation: (1) to understand whether the participants could complete the tasks (assessed through task completion rates); (2) to understand the usability of the prototype (assessed through the System Usability Scale [SUS] [37]); and (3) to understand how the app could be integrated into participants’ existing health management practices (assessed through qualitative interviews after the evaluation of the prototype; see Multimedia Appendix 2 for sample interview questions). The data collected were both qualitative and quantitative. We audio recorded and transcribed all evaluation interviews, which on average lasted 45 (SD 3.0) minutes. Thematic analysis was completed by one of the lead authors with support from the first and final authors [38,39]. We followed the 6-stage approach, which included familiarization, generating initial codes, and searching for themes. The remaining steps related to the naming and thematic structure were refined through an iterative process with weekly meetings between the 2 first authors and the senior author.

Results

Demographic Characteristics of Participants

In total, 15 older adults and 3 caregivers (n=18) participated in this study: 10 participated (8 older adults and 2 caregivers) in the design of the low-fidelity prototype, and 10 evaluated (9 older adults and 1 caregiver) the medium-fidelity prototype (2 older adults participated in both phases). Participants emphasized the importance of tracking functions to make sense of information across physical symptoms and psychosocial aspects symptoms; a clear display; and the organization of notes and reminders to communicate with care providers. The majority of participants were women (8/10, 80%), lived alone (6/10, 60%), and lived at home (10/10, 100%; see Table 1). Only 1 participant was considered frail according to the Vulnerable Elders Survey–13. Most (8/10, 80%) had adequate eHealth literacy according to the eHEALS (mean scores 30.6, SD 9.0), with scores ranging from 8 to 40.

Table 1. Sociodemographic information for all participants: older adults (n=15) and caregivers (n=3).

Characteristics	Participants (N=18), n (%)
Age group (y)	
<70	4 (22)
70-75	9 (50)
76-80	4 (22)
81-85	0 (0)
>86	1 (6)
Gender	
Men	6 (33)
Women	12 (67)
First language	
English	18 (100)
Housing situation	
At home (house, condo, or apartment)	18 (100)
Living situation	
Alone	9 (50)
Spouse	8 (44)
Other	1 (6)
Marital status	
Married or living common law	7 (39)
Widow or widower	3 (17)
Separated or divorced	5 (28)
Single (never married)	2 (11)
Other	1 (5)
Education level	
In total, 13 years and more (some or completed college or university)	18 (100)
Type of cancer treatment (could select more than 1 type; n=15)[a,b]	
Surgery	13 (87)
Radiation	6 (40)
Chemotherapy, targeted therapy, or immunotherapy	10 (67)
Hormone therapy	5 (33)
Other	1 (7)
Treatment intent as reported by patient	
Curative	14 (93)
Palliative	2 (13)
Current comorbidities	
Asthma, emphysema, chronic bronchitis, or COPD[c]	4 (22)
Arthritis or rheumatism	12 (67)
Diabetes	1 (6)
Digestive problems (ulcer, colitis, and gallbladder disease)	5 (28)
Heart trouble (angina, congestive heart failure, or coronary artery disease)	1 (6)
Depression or anxiety	2 (11)

Characteristics	Participants (N=18), n (%)
Other	13 (72)

[a] Data collected only for older adults, not for caretakers; thus, 15 participants were included.

[b] Participants could select more than 1 option.

[c] COPD: chronic obstructive pulmonary disease.

Task Completion and Usability

In terms of task completion, we found that 90% (9/10) of participants who evaluated the medium-fidelity prototype were able to complete all of the tasks as scored and presented in Multimedia Appendix 3. However, 1 participant (P18) experienced initial difficulty reading the text on the screen and would not have been able to complete the "Report Symptom" feature if not for the hints we provided. Nevertheless, this high completion rate indicates that the app was sufficiently designed for older adults in our target population to accomplish the key tasks.

We also assessed the general usability of the app, by administering the SUS, and found that participants evaluated the system as very usable, with an average of 87 which is described as the "best imaginable" according to Bangor and colleagues [37]. Table 2 shows the individual scores for each participant, broken down by question. Furthermore, according to Sauro and Lewis [40], the scale can be defined by 2 dimensions, that is, learnability (questions 4 and 10) and usability (all other questions). As seen in Table 2, only P18 struggled with learnability while all others perceived the app to be easy to learn. In sum, the high SUS score from the user evaluations, reflecting high user satisfaction and usability, shows that this app has great potential to assist older adults in their self-management activities.

Table 2. System Usability Scale responses[a].

Participant	Q1[b]	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
P3	5	1	4	1	4	2	5	1	5	1	92.5
P9	5	1	5	1	5	1	5	1	5	1	100
P11	4	2	4	2	4	2	4	1	5	2	80
P12	5	1	5	2	5	1	5	1	4	1	95
P13	4	1	5	1	5	1	4	1	4	2	90
P14	5	1	5	1	4	1	5	1	5	1	97.5
P15	5	1	5	1	4	1	5	1	5	1	97.5
P16	3	2	4	2	4	3	4	2	4	2	70
P17	4	1	3	1	5	1	5	1	5	1	92.5
P18	3	3	4	5	3	2	5	2	4	5	55

[a] Table explanation: there are 10 questions in total, ranging from strongly disagree (1 point) to strongly agree (5 points). The tone of the questions (see Multimedia Appendix 3) switches from positive (odd questions) to negative (even questions). The score for each person is calculated as follows: X = sum of the points for all odd-numbered questions – 5; Y = 25 – sum of the points for all even-numbered questions; individual SUS score = (X + Y) × 2.5. An average score of 85-100 is the best imaginable, while 52-85 is still considered excellent [37]. All participants evaluated the system as having high usability, except P18 who strongly agreed with the need for support from a technical person or additional knowledge to comfortably use the app.

[b] Q: question.

Qualitative Findings

Overview

Based on our thematic analysis, we constructed 3 global themes from the data, related to both the nature of the app and its value in supporting self-management. These themes were organized and labeled as follows: (1) app conceptual model matches users' mental model, (2) value and usefulness for self-management, and (3) confusing icons and buttons. These themes are discussed further below.

App Conceptual Model Matches Users' Mental Model

Overview

In our user testing, participants found the app interfaces easy to navigate with straightforward steps to complete tasks. They also found the text summaries and data visualizations to be visually engaging with clear health-related feedback, which contributed to the ease of use of the app. In light of these user experiences, the following subthemes were constructed from the data, related to the app structure, its usability, and its ease of use: (1) transferability; (2) intuitiveness and ease of navigation; (3) clear data visualization; and (4) simplified and comprehensive summary reports.

Transferability

In our user testing, participants found the app to have a familiar interface, with similar features to other popular health apps that they had used or were using, which reinforced a sense of transferability. For example, 1 participant stated: "I would say that the labels were very clear to me which are similar to some of the apps I've used" (P15). Participants also described the app prompts as predictable with simple steps to complete tasks and found the app's phrases and concepts to be familiar and understandable. Overall, the words and concepts used in the app followed real-world conventions which made the information appear in a logical order for participants. One of the participants said: "It was very predictable and understandable using it the first time" (P12).

Intuitiveness and Ease of Navigation

The app user interface offered a sharp, constant, and uncluttered background, which enhanced readability. Participants felt that the steps and buttons needed to complete the tasks were easy to navigate, which motivated them to use the app. They appreciated the simplicity of the app features which contributed to its intuitiveness. One participant commented: "I think even an elementary student could probably use this app quite easily" (P12). Furthermore, the simple interface and the easy task flow from the home page to completion, shaped user experiences as reflected here: "It was easy to use...the app is simple...but these other apps have a lot and it's always difficult" (P14).

For some participants, the app features felt orderly and streamlined, increasing accessibility even for users with color sensitivity. The legibility and high-contrast colors of the interface alongside the large font size were perceived as being visually engaging and readable. Some participants suggested an adjustable font size should be embedded in the app to allow customization: "Everything looks clear except that the fonts needed to be adjusted big enough. I was straining to see some things" (P9).

Overall, participants found the app easy to use regardless of their level of experience with technology and cancer type. Although older adults reported feeling comfortable using the app; some users required guidance to navigate certain icons on the app. Specifically, the remote participants had more difficulty navigating the prototype if they used a phone remotely than in-person participants. One participant stated: "I had to ask for help to identify icons on the phone" (P11). Another said: "You know, I could go through it [the app] but I needed some help" (P9).

Clear Data Visualization

Participants' most desired accurate unambiguous feedback with simple and clear data visualizations. Participants perceived the clarity and accuracy of the data visualizations as visually appealing, engaging, and readable.

While acknowledging color contrast in the charts and graphs, participants described how texts and labels highlighted important information. Participants reported that they could easily understand the visual elements, facilitating the effective abstraction of actionable insights from the data visuals. For instance, 1 participant stated: "The texts are fine with me...I can understand the data from the graphs" (P11). However, 1 participant highlighted their difficulty understanding the meanings of the different colors included in the charts. As a remedy, they suggested 1 color stream to ensure consistency. They also suggested that emojis should be used in place of graphs since emojis are considered a universal language for most users. Additionally, the text or data presented in the graphs might be difficult to understand and interpret by some non-English users of the app. As presented to participants, the app allowed for only 1 representative emoji per day. However, users suggested combining many emojis that best represent their emotions and feelings for the day. For example, users could combine 2 or more emojis to illustrate their emotions since they could have different experiences within a day—positive, neutral, and negative emotions: "I prefer more emojis, in fact a combination of them...because they tell more story about my emotions" (P9). Participants noted clear data visualization and accuracy of information displayed and affirmed the relevance of having readable and understandable trends of their health data tracked and presented to them in graphs covering either a month or week period.

Simplified and Comprehensive Summary Reports

Participants observed that the clear and comprehensive nature of the health data summaries helped to make connections between day-to-day emotions and changes over time. Some users noted the easy, actionable steps of reporting symptoms and feelings that were directly linked to the feedback. Participants found that displaying multiple types of data on 1 page was more intuitive and comprehensive and helped them make sense of their overall health:

> *Usually, what I see when I look at my blood reports [in leukaemia] is, I click on a report and I see a single trend line [in another app]. Now, with this app, I can see all different types of reports on one page. That's good. It keeps it together. Because I can see that it's helping me make connections of all the data.* [P15]

In comparing this app with other apps, participants noted that this app tends to present an integrated analysis of their health, emotions, and present health state, which made it more interesting to track and review. For example, 1 older adult stated:

> *The Apple Health app was the only one that I have used. And that tends to be reflecting sort of like a simplified quantitative analysis, not qualitative, not including emotions and things. And I think that would be an interesting thing to record and then to review. The correlation between my actual situation of cancer and how I felt about it at the time.* [P15]

Participants appreciated summary reports, although some older adults expressed a preference for monthly summary reports rather than weekly reports. They argued that cancer is a long-term condition that requires a summary of the symptoms over a longer period. Further, 1 participant said: "I would like a monthly report summary...the other apps I do it monthly...I will go over and look at the trend lines over the months. This would fit into that whole world that I'm a part of and have been now since 2015" (P3).

Value and Usefulness for Self-Management

Overview

Participants described how the app was valuable and useful in supporting them to manage their health, in the presence of a cancer diagnosis. Participants felt that the various dimensions of the app could support self-management as captured and explained in the following subthemes: (1) integration into existing self-management routines; (2) app design linked to user personal health needs; (3) recording and sharing of health information; and (4) digital health calendar.

Integration Into Existing Self-Management Routines

Our user testing demonstrated that users were ready and willing to use the app for self-management and felt the app could help them meet their health needs. App features such as the daily symptom report—which required users to report symptoms daily at a time convenient to them—were perceived as a normal daily activity that could easily be done without hassle. Participants found the app's notifications feature a useful way to engage them and remind them to report their feelings, adhere to treatments, and honor appointments with their clinicians. For example, a participant observed that the notifications could easily be synchronized with other daily tasks:

> *I could see myself spending probably half an hour a day inputting information and then reviewing the results. [With another app], every morning, I wake up and check what my sleep score was and what my resting heart rate was. And when my resting heart rate goes up, it tells me that I'm not behaving myself, or stressed. So, it's just kind of a check-in with myself almost to make sure that I'm, you know, kind of following the health path that I want to be on. Again, the reminder notification is great for reporting my emotions.* [P15]

To encourage consistent and continuous engagement of the app in daily self-management, the app was designed to prompt users to input their health report daily.

Participants expressed that reporting their symptoms and interventions daily in the app would not impact other life activities or routines and they never found tracking in the app troubling or burdensome. Further, 1 participant said:

> *For me it would be because I don't have many other obligations. I'm retired. And my wife and I live at home. We don't travel much. Not at all really. So, I mean to us, you know, this is the sort of thing that I do every day. I'm on the computer doing stuff like this* [P11]

However, some participants felt there might be user resistance during the initial stage of the app implementation particularly for those who are not technologically savvy and may also not have a family member to guide them to navigate the app. Further, 1 participant speculated about possible resistance: "I think there's going to be some resistance to adapt for those who are not good at the computer. It's doable, but it's going to be difficult for them" (P3). Overall, participants expressed high intentions of integrating the app into their daily routines for self-management.

Design Linked to User Personal Health Needs

Participants reported that the app design supported their individual health needs—symptom-monitoring, tracking, and self-managing. While the app was perceived to keep users motivated, they also felt it was designed with user needs at the forefront. Further, 1 participant, who had an adult son with autism who needed to track his diet, felt the app could be useful not only in monitoring their own treatment-related symptoms, but also for noncancer patients: "Excellent, this app could align well to my health needs and also probably work well with my son too" (P3). Older adult users could in real time monitor their unique cancer symptoms, track medication adherence, and receive reminders for appointments and other relevant health updates. Further, 1 participant stated:

> *Well, I mean I wanted to set some goals in terms of, you know, trying to fit exercise in, and it was a way for me to challenge myself, I guess, the features that I do use are here [on this app] to receive notifications and track my health.* [P9]

Recording and Sharing of Health Information

Participants reported the value of the app's capability to record and track information for later sharing with their clinicians. This act of keeping track of information in the form of note-taking was perceived as a better alternative to electronically record, share, and communicate users' health issues with their health care providers than other analogue strategies. Further, 1 older adult said:

> *It's a better way to organize notes and trends and see about trends. Just as a communication tool...maybe a better communication tool to use to talk to the different healthcare providers that we communicate with...rather than recording in so many places.* [P13]

Some participants observed that the app features mimic what older adults usually do in keeping track of events by documenting on a piece of paper their daily feelings, thoughts, and other related health issues. Some participants felt that better symptom tracking helped to gain control over symptoms and improve general well-being. Further, 1 participant stated:

> *So what this does is that you know. So, this feature imitates older adults, what they do with their own, like say journal or calendar or anything that they write things on. They keep track of their questions or note what they're feeling.* [P12]

Older adults repeatedly voiced their willingness to use the app because it offered them the ability to share their health information with their clinicians during appointment visits. Most participants felt that clinicians could deliver more tailored care when provided with additional information during consultations.

Digital Health Calendar

All necessary details regarding patients' symptom-tracking reports, treatments, and cancer education, including schedules and reminders or alerts are diarized for future reference.

Participants reported how app features particularly the “reporting” and “summaries” features provide a safe place to store more secure information in the app for reference. Further, 1 participant said:

> *It’s like an electronic diary...a good calendar to write and keep track of notes about their feelings...So you have that instant data that you can look at where you've been and where you're going.* [P14]

In addition to storing information related to a person’s cancer, the app also makes it easier for the user to edit and update information with new tasks and reschedule appointments. According to participants, the app guides users to know their current state of health and to predict their future health by simply referring to the calendar. For instance, 1 older adult stated: “I mean, one of the things you can do is to keep information here [in app]...you can schedule new appointments with your doctor. It's like I could see it having lots of benefits” (P11).

Other participants emphasized the value and usefulness of the app for older adults in keeping their health records. Participants argued that most older adults are forgetful as a consequence of aging, and this app could be a great tool to help them remember their changing health. Further, 1 participant stated:

> *I mean, one of the things is as we age, if your memory is having trouble with remembering things, that probably helps...it would help that because then you could go back and when was I really feeling so bad and you know? That’s great to know.* [P9]

For some participants, this app could also help in tracking different types of treatment and associated side effects, especially for users starting new treatments. Participants also emphasized the value of this tool early in the treatment process, given the capability to track changes over time and remind users of appointments to and schedules. A participant stated:

> *Well, what I do is I have to go through and scroll every appointment. But where this is useful for me is when, especially when I'm starting a new treatment that I've never done before. I want to track the side effects and I want to know what the trigger points are on it...the notification reminders, it’s like a reminder of things that you have to experience. Those kinds of elements that I want to be able to look at and see how that changed over six months.* [P12]

Confusing Icons and Buttons

The last theme relates to opportunities to improve the app based on evaluations. Despite the intuitiveness and ease of navigation of the prototype, some participants found the icons and buttons confusing while others could not understand some features and information displayed. These attributes impeded usability. Further, 1 participant noted:

> *Consider seeking medical care. Is this with my GP? Is this with the oncologist? Do I call for medical care for fatigue? Community health news, what does this button mean? I also wonder what that recommendation is?* [P3]

Another participant expressed their dissatisfaction with not being able to find suitable emojis to express their emotions and asked: “I don't even see happy on the list here. Where can I find happy emoji? It's rather lots of other things here” (P9). While this participant could not find suitable emojis to express their emotions, others too found the buttons too hard to tap causing frustration as they engaged with the app prototype. A participant stated:

> *...because I’m not fluent with how the technology always is depicted. I tend to tap, tap, and click, click, click fast. It’s hard...It draws, but has been crazy and often I freeze something because I’ve tried to make it all go too quickly right and I’ve not given the computer time to catch what I’m doing.* [P13]

Participants also found some icons not matching their current state. For example, participants who are used to seeing a little pencil icon indicating “write something more” were confused when it was rather meant for “edit.” A participant stated:

> *I'm accustomed to seeing...the little pencil with respect to writing something more. So I think I would have assumed I should write something about nausea as opposed to edit my answer...And it’s possible that people don’t realize [it].* [P3]

Discussion

Principal Findings

In this paper, we present the findings of an iterative co-design and evaluation study of a cancer self-management app prototype designed specifically for the needs of older adults living with cancer and multimorbidity. Our key finding was that creating a space for this population to track and interpret data related to their health, in a way that made sense to them, would support their self-management needs. The app we designed built on the concept of the calendar, a routine activity that many older adults already participate in. By drawing on this common routine we developed an app that is both useful and acceptable and was not considered burdensome. This work is novel as it acknowledges the complex health states that this population experiences and aims to address their challenges through an app that was co-designed with them, for them. Our approach was user-centered, with a research team co-led by older adults with cancer experiences and comorbidities.

Limitations

The main limitations of this study relate to the sampling. First, most of the participants were not on active treatment at the time of study participation. Future studies of the app should study usability for those with a new diagnosis using the app for the first time. Second, most participants spoke English, making usability generally easier. Third, all participants were college or university educated. Future studies should include participants with secondary education or lower to gather more broader and diverse perspectives across all levels of education and experience for the design. Finally, many of the participants regularly used technology and smartphones—however, 2 scored low on the eHEALS measure of health literacy. Nevertheless, we observe growing rates of smartphone use among older adults

[41,42] and note that views that older adults do not use technology are ageist and dated. We also acknowledge that the validity of the evaluation may be compromised, as the remote participants were interacting with the prototype through a browser and not on a smartphone, which has different usability concerns. Finally, we only included participants who had their own devices, meaning that they (may) have better technical skills than those who do not own devices, and that may overestimate the usability.

Comparison With Prior Work

This study underscores older adults' interest in proactively managing their own cancer diagnosis and other existing conditions. While older adults' interest in self-management has been reported in other studies [5,43], our study highlights the functionalities that support this work. Given that many older adults are managing distressing symptoms as a result of cancer and its treatments, alongside existing chronic illnesses, the impetus to mobilize self-management supports is critical [44]. Our app in its current state is designed for all older adults with cancer and other illnesses to self-manage their conditions, but it is most useful and valuable for older adults who have just been diagnosed with cancer.

Through our iterative co-design process, several noteworthy features were emphasized by older adults involved in this study. One of the features most valued by participants was the ability to facilitate meaningful connections across all aspects of health. A recent scoping review by Wilson and colleagues [45] found that apps that do not support older adults to make connections across functions were a key barrier to meaningful engagement with apps. The app developed in this study provides direction and guidance on how to report symptoms, events, and daily emotional states and provides an easy display to integrate these various inputs and share insights with health care providers. Unlike existing mobile apps with several views on multiple interfaces [46-48], this app provides a single view of all symptoms, events, and emotions consolidated on 1 page which aims to improve usability, efficiency, and satisfaction among users. The design also allows an effective presentation of daily reports in a comprehensive and easy-to-understand manner. Additionally, the app's design exhibits flexibility, allowing older adults—in collaboration with their health clinicians and caregivers—to prioritize specific symptoms (or variables) of focus. These features are in sharp contrast to existing apps and websites used by older adults to track health information, which often have a narrow scope, concentrating solely on particular cancers or symptoms [27,49-52]. Health apps with narrow scopes may hamper a comprehensive understanding of health and quality of life from a multidimensional perspective [27].

While other studies detail older adults reporting difficulties with limited functionalities and comprehension of visual health data [45,53], participants in this study emphasized a preference for both text and visual summaries to help them make sense of patterns in the data. Older adults also appreciated and valued different modes to view data trends. For example, notes and textual summaries served as an alternative means of conveying information for those who struggled with graphical representations. This has been reported in other studies both within cancer [54] and elsewhere [55]. For example, in a recent pilot randomized controlled trial by Lally and colleagues [54], older adults expressed a preference for information leaflets and text notes to describe the trends of their health. Our study reiterates those findings and also highlights the possibility of text summaries becoming "a voice" for older adults during consultations with their clinicians. Text summaries allow for better and more streamlined conversations with clinicians, thereby promoting shared decision-making [56,57]. It is important to note that the preferences and recommendations of our participants informed revisions of the app features and functionalities in the prototype iterations, and the current state of the app reflects the needs of its potential users. Overall, the app developed in this study represents an acceptable and usable app that is adaptable to the unique needs of older adults with cancer in monitoring changes in their health.

Conclusions

Our self-management app prototype has both content and face validity among older adults with cancer and comorbidities. At this stage, the app requires further refinements and testing to understand its efficacy and to gauge its acceptability and implementation potential within the cancer care system in Canada and beyond.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Medium-fidelity prototype.
[DOCX File , 1682 KB - aging_v7i1e53163_app1.docx]

Multimedia Appendix 2
Interview sample questions.
[DOCX File , 15 KB - aging_v7i1e53163_app2.docx]

Multimedia Appendix 3
System Usability Scale questions (rated between strongly agree to strongly disagree).
[DOCX File , 14 KB - aging_v7i1e53163_app3.docx]

References

1. Mikkelsen M, Lund CM, Vinther A, Tolver A, Johansen JS, Chen I, et al. Effects of a 12-week multimodal exercise intervention among older patients with advanced cancer: results from a randomized controlled trial. Oncologist 2022;27(1):67-78 [FREE Full text] [doi: 10.1002/onco.13970] [Medline: 34498352]
2. Shaw JF, Budiansky D, Sharif F, McIsaac DI. The association of frailty with outcomes after cancer surgery: a systematic review and metaanalysis. Ann Surg Oncol 2022;29(8):4690-4704. [doi: 10.1245/s10434-021-11321-2] [Medline: 35072860]
3. Pilleron S, Alqurini N, Ferlay J, Haase KR, Hannan M, Janssen-Heijnen M, et al. International trends in cancer incidence in middle-aged and older adults in 44 countries. J Geriatr Oncol 2022;13(3):346-355. [doi: 10.1016/j.jgo.2021.11.011] [Medline: 34866023]
4. Canadian cancer statistics: a 2022 special report on cancer prevalence. Canadian Cancer Society. Toronto, ON; 2022. URL: https://tinyurl.com/bdurukhb [accessed 2024-01-31]
5. Corbett T, Lee K, Cummings A, Calman L, Farrington N, Lewis L, et al. Self-management by older people living with cancer and multi-morbidity: a qualitative study. Support Care Cancer 2022;30(6):4823-4833 [FREE Full text] [doi: 10.1007/s00520-022-06892-z] [Medline: 35147757]
6. van Dongen SI, de Nooijer K, Cramm JM, Francke AL, Oldenmenger WH, Korfage IJ, et al. Self-management of patients with advanced cancer: a systematic review of experiences and attitudes. Palliat Med 2020;34(2):160-178 [FREE Full text] [doi: 10.1177/0269216319883976] [Medline: 32009565]
7. Haase KR, Sattar S, Hall S, McLean B, Wills A, Gray M, et al. Systematic review of self-management interventions for older adults with cancer. Psychooncology 2021;30(7):989-1008. [doi: 10.1002/pon.5649] [Medline: 33724608]
8. Lattie EG, Bass M, Garcia SF, Phillips SM, Moreno PI, Flores AM, et al. Optimizing health information technologies for symptom management in cancer patients and survivors: usability evaluation. JMIR Form Res 2020;4(9):e18412 [FREE Full text] [doi: 10.2196/18412] [Medline: 32955450]
9. Leigh JW, Gerber BS, Gans CP, Kansal MM, Kitsiou S. Smartphone ownership and interest in mobile health technologies for self-care among patients with chronic heart failure: cross-sectional survey study. JMIR Cardio 2022;6(1):e31982 [FREE Full text] [doi: 10.2196/31982] [Medline: 35029533]
10. Li C, Neugroschl J, Zhu CW, Aloysi A, Schimming CA, Cai D, et al. Design considerations for mobile health applications targeting older adults. J Alzheimers Dis 2021;79(1):1-8 [FREE Full text] [doi: 10.3233/JAD-200485] [Medline: 33216024]
11. Wildenbos GA, Peute L, Jaspers M. Aging barriers influencing mobile health usability for older adults: a literature based framework (MOLD-US). Int J Med Inform 2018;114:66-75. [doi: 10.1016/j.ijmedinf.2018.03.012] [Medline: 29673606]
12. Gomez-Hernandez M, Ferre X, Moral C, Villalba-Mora E. Design guidelines of mobile apps for older adults: systematic review and thematic analysis. JMIR mHealth uHealth 2023;11:e43186 [FREE Full text] [doi: 10.2196/43186] [Medline: 37733401]
13. Noordman J, Driesenaar JA, van Bruinessen IR, van Dulmen S. ListeningTime; participatory development of a web-based preparatory communication tool for elderly cancer patients and their healthcare providers. Internet Interv 2017;9:51-56 [FREE Full text] [doi: 10.1016/j.invent.2017.05.002] [Medline: 30135837]
14. Riedl D, Lehmann J, Rothmund M, Dejaco D, Grote V, Fischer MJ, et al. Usability of electronic patient-reported outcome measures for older patients with cancer: secondary analysis of data from an observational single center study. J Med Internet Res 2023;25:e49476 [FREE Full text] [doi: 10.2196/49476] [Medline: 37733409]
15. Shahrokni A, Tin A, Downey RJ, Strong V, Mahmoudzadeh S, Boparai MK, et al. Electronic rapid fitness assessment: a novel tool for preoperative evaluation of the geriatric oncology patient. J Natl Compr Canc Netw 2017;15(2):172-179 [FREE Full text] [doi: 10.6004/jnccn.2017.0018] [Medline: 28188187]
16. Shahrokni A, Vickers AJ, Mahmoudzadeh S, Korc-Grodzicki B. Assessing the clinical feasibility of electronic Rapid Fitness Assessment (eRFA): a novel geriatric assessment tool for the oncology setting. J Clin Oncol 2016;34(15_suppl):10011. [doi: 10.1200/jco.2016.34.15_suppl.10011]
17. Cook S, Munteanu C, Papadopoulos E, Abrams H, Stinson JN, Pitters E, et al. The development of an electronic geriatric assessment tool: Comprehensive Health Assessment for My Plan (CHAMP). J Geriatr Oncol 2023;14(1):101384. [doi: 10.1016/j.jgo.2022.09.013] [Medline: 36216760]
18. Haase KR, Hall S, Sattar S, Ahmed S. Living with cancer and multimorbidity: a qualitative study of self-management experiences of older adults with cancer. Eur J Oncol Nurs 2021;53:101982. [doi: 10.1016/j.ejon.2021.101982] [Medline: 34265510]

19. Haase KR, Tompson MA, Hall S, Sattar S, Ahmed S. Engaging older adults with cancer and their caregivers to set research priorities through cancer and aging research discussion sessions. Oncol Nurs Forum 2021;48(6):613-622. [doi: 10.1188/21.ONF.613-622] [Medline: 34673758]
20. Meinel C, Leifer L. Design thinking research. In: Plattner H, Meinel C, Leifer L, editors. Design Thinking Research: Studying Co-Creation in Practice. Berlin, Heidelberg: Springer; 2012:1-11.
21. Oliveira M, Zancul E, Fleury AL. Design thinking as an approach for innovation in healthcare: systematic review and research avenues. BMJ Innov 2021;7(2):491-498 [FREE Full text] [doi: 10.1136/bmjinnov-2020-000428]
22. Norman CD, Skinner HA. eHEALS: the eHealth literacy scale. J Med Internet Res 2006;8(4):e27 [FREE Full text] [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
23. Saliba D, Elliott M, Rubenstein LZ, Solomon DH, Young RT, Kamberg CJ, et al. The Vulnerable Elders Survey: a tool for identifying vulnerable older people in the community. J Am Geriatr Soc 2001;49(12):1691-1699. [doi: 10.1046/j.1532-5415.2001.49281.x] [Medline: 11844005]
24. Cirucci AM, Pruchniewska UM. Brain writing and darkside writing. In: UX Research Methods for Media and Communication Studies: An Introduction to Contemporary Qualitative Methods. New York: Routledge; 2022:129-135.
25. Grey M, Schulman-Green D, Knafl K, Reynolds NR. A revised self- and family management framework. Nurs Outlook 2015;63(2):162-170. [doi: 10.1016/j.outlook.2014.10.003] [Medline: 25771190]
26. Snyder LE, Phan DF, Williams KC, Piqueiras E, Connor SE, George S, et al. Comprehension, utility, and preferences of prostate cancer survivors for visual timelines of patient-reported outcomes co-designed for limited graph literacy: meters and emojis over comics. J Am Med Inform Assoc 2022;29(11):1838-1846 [FREE Full text] [doi: 10.1093/jamia/ocac148] [Medline: 36040190]
27. Demiris G, Thompson HJ, Reeder B, Wilamowska K, Zaslavsky O. Using informatics to capture older adults' wellness. Int J Med Inform 2013;82(11):e232-e241 [FREE Full text] [doi: 10.1016/j.ijmedinf.2011.03.004] [Medline: 21482182]
28. Campbell CL, Campbell LC. A systematic review of cognitive behavioral interventions in advanced cancer. Patient Educ Couns 2012;89(1):15-24 [FREE Full text] [doi: 10.1016/j.pec.2012.06.019] [Medline: 22796302]
29. Dai Y, Karalis G, Kawas S, Olsen C. Tipper: contextual tooltips that provide seniors with clear, reliable help for web tasks. New York, NY, US: Association for Computing Machinery; 2015 Presented at: Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing; April 18-23, 2015; Seoul, Republic of Korea p. 1773-1778. [doi: 10.1145/2702613.2732796]
30. Chiu CJ, Tasi WC, Yang WL, Guo JL. How to help older adults learn new technology? results from a multiple case research interviewing the internet technology instructors at the senior learning center. Comput Educ 2019;129:61-70. [doi: 10.1016/j.compedu.2018.10.020]
31. Czaja SJ, Boot WR, Charness N, Rogers WA, Sharit J. Improving social support for older adults through technology: findings from the PRISM randomized controlled trial. Gerontologist 2018;58(3):467-477 [FREE Full text] [doi: 10.1093/geront/gnw249] [Medline: 28201730]
32. Czaja SJ, Sharit J, Nair SN, Lee CC. Older adults and internet health information seeking. Proc Hum Factors Ergon Soc Annu Meet 2016;53(2):126-130. [doi: 10.1177/154193120905300204]
33. Li J, Tigwell GW, Shinohara K. Accessibility of high-fidelity prototyping tools. New York, NY, US: Association for Computing Machinery; 2021 Presented at: Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems; May 8-13, 2021; Yokohama, Japan p. 1-17. [doi: 10.1145/3411764.3445520]
34. Silva TR, Hak JL, Winckler M, Nicolas O. A comparative study of milestones for featuring GUI prototyping tools. J Softw Eng Appl 2017;10(6):564-589 [FREE Full text] [doi: 10.4236/jsea.2017.106031]
35. Medlock MC, Wixon D, McGee M, Welsh D. The rapid iterative test and evaluation method: better products in less time. In: Bias RG, Mayhew DJ, editors. Cost-Justifying Usability: An Update for the Internet Age. San Francisco, CA: Elsevier; 2005:489-517.
36. Kim MJ, Schroeder S, Chan S, Hickerson K, Lee YC. Reviewing the user-centered design process for a comprehensive Gastroesophageal Reflux Disease (GERD) app. Int J Environ Res Public Health 2022;19(3):1128 [FREE Full text] [doi: 10.3390/ijerph19031128] [Medline: 35162160]
37. Bangor A, Kortum PT, Miller JT. An empirical evaluation of the system usability scale. Int J Hum-Comput Interact 2008;24(6):574-594. [doi: 10.1080/10447310802205776]
38. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
39. Braun V, Clarke V. Thematic Analysis: A Practical Guide. London: SAGE; 2022.
40. Sauro J, Lewis JR. When designing usability questionnaires, does it hurt to be positive? New York, NY, US: Association for Computing Machinery; 2011 Presented at: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; May 7-12, 2011; Vancouver, BC, Canada. [doi: 10.1145/1978942.1979266]
41. Busch PA, Hausvik GI, Ropstad OK, Pettersen D. Smartphone usage among older adults. Comput Hum Behav 2021;121:106783 [FREE Full text] [doi: 10.1016/j.chb.2021.106783]

42. Yang CC, Li CL, Yeh TF, Chang YC. Assessing older adults' intentions to use a smartphone: using the meta-unified theory of the acceptance and use of technology. Int J Environ Res Public Health 2022;19(9):5403 [FREE Full text] [doi: 10.3390/ijerph19095403] [Medline: 35564798]
43. Kadambi S, Soto-Perez-de-Celis E, Garg T, Loh KP, Krok-Schoen JL, Battisti NML, et al. Social support for older adults with cancer: Young International Society of Geriatric Oncology review paper. J Geriatr Oncol 2020;11(2):217-224 [FREE Full text] [doi: 10.1016/j.jgo.2019.09.005] [Medline: 31628066]
44. Parthipan M, Feng G, Toledano N, Donison V, Breunis H, Sudharshan A, et al. Symptom experiences of older adults during treatment for metastatic prostate cancer: a qualitative investigation. J Geriatr Oncol 2023;14(1):101397. [doi: 10.1016/j.jgo.2022.10.012] [Medline: 36988104]
45. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021;21(1):1556 [FREE Full text] [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]
46. Eisenstadt A, Liverpool S, Metaxa AM, Ciuvat RM, Carlsson C. Acceptability, engagement, and exploratory outcomes of an emotional well-being app: mixed methods preliminary evaluation and descriptive analysis. JMIR Form Res 2021;5(11):e31064 [FREE Full text] [doi: 10.2196/31064] [Medline: 34569466]
47. Rashid NSA, Chen XW, Mohamad Marzuki MF, Takshe AA, Okasha A, Maarof F, et al. Development and usability assessment of a mobile app (Demensia KITA) to support dementia caregivers in Malaysia: a study protocol. Int J Environ Res Public Health 2022;19(19):11880 [FREE Full text] [doi: 10.3390/ijerph191911880] [Medline: 36231181]
48. Kim JC, Saguna S, Åhlund C. Acceptability of a health care app with 3 user interfaces for older adults and their caregivers: design and evaluation study. JMIR Hum Factors 2023;10:e42145 [FREE Full text] [doi: 10.2196/42145] [Medline: 36884275]
49. Monteiro-Guerra F, Rivera-Romero O, Mylonopoulou V, Signorelli GR, Zambrana F, Fernandez-Luque L. The design of a mobile app for promotion of physical activity and self-management in prostate cancer survivors: personas, feature ideation and low-fidelity prototyping. : IEEE; 2017 Presented at: 2017 IEEE 30th International Symposium on Computer-Based Medical Systems (CBMS); June 22-24, 2017; Thessaloniki, Greece p. 761-766. [doi: 10.1109/cbms.2017.75]
50. Brown-Johnson CG, Berrean B, Cataldo JK. Development and usability evaluation of the mHealth tool for lung cancer (mHealth TLC): a virtual world health game for lung cancer patients. Patient Educ Couns 2015;98(4):506-511 [FREE Full text] [doi: 10.1016/j.pec.2014.12.006] [Medline: 25620075]
51. Børøsund E, Mirkovic J, Clark MM, Ehlers SL, Andrykowski MA, Bergland A, et al. A stress management app intervention for cancer survivors: design, development, and usability testing. JMIR Form Res 2018;2(2):e19 [FREE Full text] [doi: 10.2196/formative.9954] [Medline: 30684438]
52. Griffin L, Lee D, Jaisle A, Carek P, George T, Laber E, et al. Creating an mHealth app for colorectal cancer screening: user-centered design approach. JMIR Hum Factors 2019;6(2):e12700 [FREE Full text] [doi: 10.2196/12700] [Medline: 31066688]
53. van Acker J, Maenhout L, Compernolle S. Older adults' user engagement with mobile health: a systematic review of qualitative and mixed-methods studies. Innov Aging 2023;7(2):igad007 [FREE Full text] [doi: 10.1093/geroni/igad007] [Medline: 37007638]
54. Lally P, Miller N, Roberts A, Beeken RJ, Greenfield DM, Potts HWW, et al. An app with brief behavioural support to promote physical activity after a cancer diagnosis (APPROACH): study protocol for a pilot randomised controlled trial. Pilot Feasibility Stud 2022;8(1):74 [FREE Full text] [doi: 10.1186/s40814-022-01028-w] [Medline: 35351187]
55. Mansson L, Wiklund M, Öhberg F, Danielsson K, Sandlund M. Co-creation with older adults to improve user-experience of a smartphone self-test application to assess balance function. Int J Environ Res Public Health 2020;17(11):3768 [FREE Full text] [doi: 10.3390/ijerph17113768] [Medline: 32466484]
56. Bennett R, DeGuzman PB, LeBaron V, Wilson D, Jones RA. Exploration of shared decision making in oncology within the United States: a scoping review. Support Care Cancer 2022;31(1):94 [FREE Full text] [doi: 10.1007/s00520-022-07556-8] [Medline: 36585510]
57. Xu L, Sanders L, Li K, Chow JCL. Chatbot for health care and oncology applications using artificial intelligence and machine learning: systematic review. JMIR Cancer 2021;7(4):e27850 [FREE Full text] [doi: 10.2196/27850] [Medline: 34847056]

Abbreviations

eHEALS: eHealth literacy scale
RITE: Rapid Iterative Testing and Evaluation
SUS: System Usability Scale

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Original Paper

Remote Evidence-Based Programs for Health Promotion to Support Older Adults During the COVID-19 Pandemic and Beyond: Mixed Methods Outcome Evaluation

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Abstract

Background: Evidence-based programs (EBPs) for health promotion were developed to reach older adults where they live, work, pray, and play. When the COVID-19 pandemic placed a disproportionate burden on older adults living with chronic conditions and the community-based organizations that support them, these in-person programs shifted to remote delivery. While EBPs have demonstrated effectiveness when delivered in person, less is known about outcomes when delivered remotely.

Objective: This study evaluated changes in remote EBP participants' health and well-being in a national mixed methods outcome evaluation in January 1, 2021, to March 31, 2022.

Methods: We used the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) for equity framework to guide the evaluation. We purposively sampled for diverse remote EBP delivery modes and delivery organizations, staff, and traditionally underserved older adults, including people of color and rural dwellers. We included 5 EBPs for self-management, falls prevention, and physical activity: videoconferencing (Chronic Disease Self-Management Program, Diabetes Self-Management Program, and EnhanceFitness), telephone plus mailed materials (Chronic Pain Self-Management Program), and enhanced self-directed mailed materials (Walk With Ease). Participant and provider data included validated surveys, in-depth interviews, and open-ended survey questions. We used descriptive statistics to characterize the sample and the magnitude of change and paired *t* tests (2-tailed) and the Fisher exact test to test for change in outcomes between enrollment and 6-month follow-up. Thematic analysis was used to identify similarities and differences in outcomes within and across programs. Joint display tables facilitated the integration of quantitative and qualitative findings.

Results: A total of 586 older adults, 198 providers, and 37 organizations providing EBPs participated in the evaluation. Of the 586 older adults, 289 (49.3%) provided follow-up outcome data. The mean age of the EBP participants was 65.4 (SD 12.0) years. Of the 289 EBP participants, 241 (83.4%) were female, 108 (37.3%) were people of color, 113 (39.1%) lived alone, and 99 (34.3%) were experiencing financial hardship. In addition, the participants reported a mean of 2.5 (SD 1.7) chronic conditions. Overall, the remote EBP participants showed statistically significant improvements in health, energy, sleep quality, loneliness, depressive symptoms, and technology anxiety. Qualitatively, participants shared improvements in knowledge, attitudes, and skills for healthier living; reduced their social isolation and loneliness; and gained better access to programs. Three-fourths of the providers (149/198, 75.2%) felt that effectiveness was maintained when switching from in-person to remote delivery.

Conclusions: The findings suggest that participating in remote EBPs can improve health, social, and technological outcomes of interest for older adults and providers, with benefits extending to policy makers. Future policy and practice can better support remote EBP delivery as one model for health promotion, improving access for all older adults.

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KEYWORDS

older adults; health equity; rural; chronic disease; outcome evaluation; behavior change; technology; community based; evidence based; health promotion; mobile phone

Introduction

Background

One in 6 adults living in the United States is an older adult (aged ≥60 y). This number is expected to double in the next 40 years [1]. While older adults possess the wisdom of experience and are often actively involved in taking care of themselves, their family members, and their communities, they also face a wide range of unique health challenges that come with aging [2]. A disproportionate number of older adults live with chronic health conditions: 85% have 1 chronic health condition, and 60% report managing at least two [3]. One in 4 older adults reports at least 1 fall every year, and falls remain a leading cause of death and injury among this age group [4]. These health issues—combined with social determinants of health such as older adults' built environment, social context, and access to medical care—put older adults at risk for premature death and poorer quality of life [5]. While only accounting for 17% of the population, older adults make up 35% of health care costs, according to 2019 Medical Expenditure Panel data [6]. Furthermore, 86 cents of every dollar of health care spending goes toward chronic conditions [7,8], and the burden of chronic disease is unevenly borne by women; older adults; people of color; and people living in poverty who experience disparities in access to, and quality of, care [9].

To address these challenges, many health promotion programs have been created based on the Chronic Care Model [10], to improve access and quality of care through community-based programs that teach knowledge, skills, and self-efficacy to enhance older adults' health and well-being in their daily lives. Among these are evidence-based programs (EBPs) that have been researched and recognized by national and federal agencies, such as the Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) Arthritis Management and Well-Being Program, as being effective in promoting health outcomes through standardized interventions [11,12].

Investigating the Effectiveness of Remote EBPs

Before the COVID-19 pandemic, many of these EBPs were primarily offered in person. This was not possible during the pandemic due to safety guidelines regarding physical distancing. At the same time, there was an increased need for programs because older adults became more isolated and less physically active, and they had less access to an overtaxed medical system [13,14]. Seeing this need, EBPs quickly pivoted to remote delivery by mail, telephone, videoconferencing, or a combination of these modes. While researchers suggest that EBPs will work as intended using different forms as long as core functions are not modified [15,16], it is unknown whether program effectiveness is maintained when switching from in-person to remote delivery. To date, there have been limited studies investigating the effectiveness of remote EBPs that were originally designed to be offered in person [17-21]. As such, we conducted a longitudinal national outcome evaluation of several EBPs to assess changes in older participants' health.

Methods

Framework and Design

We used the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) for equity framework [22] to evaluate the potential impact of remote EBPs on older adults' health and well-being. The equity lens means that in addition to evaluating impact, we looked at outcomes across programs, sampled organizations that reach older adults who are underserved, reported EBP reach, and assessed whether there were any unintended consequences. As such, we used mixed methods to "give voice to participants as well as report statistical trends" [23]. We conducted a multisite single-group pre-post evaluation. Multiple sites were selected to facilitate the generalizability of the findings, and a single-group design was chosen to make it feasible to conduct the evaluation during the COVID-19 pandemic and due to the descriptive nature of this study.

Ethical Considerations

This study was considered exempt from University of Washington Institutional Review Board review because the activities fell under category 2 with regard to quality improvement and program evaluation (STUDY00011549). Participants who completed the preprogram survey were given a US $10 gift card, and participants who completed the follow-up survey were given a US $20 gift card (we provided electronic gift cards unless participants requested a physical card). Providers who completed the survey received a US $10 electronic gift card.

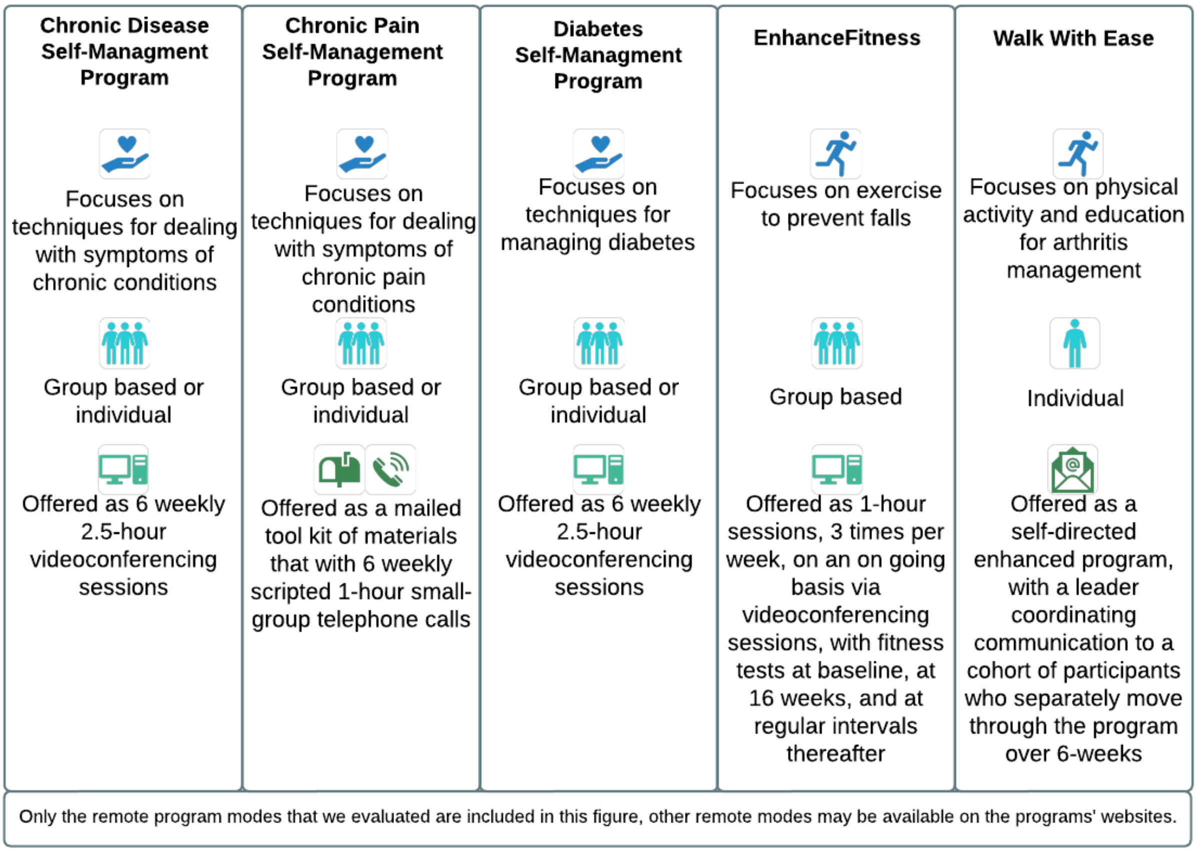
Selected EBPs

EBPs are health promotion programs that have been evaluated and proven to be effective. We included 5 EBPs in our evaluation: Chronic Disease Self-Management Program (CDSMP), Diabetes Self-Management Program (DSMP), EnhanceFitness (EF), Chronic Pain Self-Management (CPSMP), and Walk With Ease (WWE). These EBPs are all currently recognized by the national social services agency for older adults (ACL) and public health agencies (CDC) [11,12]. Before the

COVID-19 pandemic, these programs were offered in person in group formats; they were adapted as follows for remote delivery in response to the COVID-19 pandemic: videoconferencing (CDSMP, DSMP, and EF), telephone plus mailed materials (CPSMP), and self-directed mailed materials plus enhanced support (WWE).

These 5 EBPs were selected because they had sufficient program reach and represented different remote modes (telephone, videoconferencing, mail, or a combination of these modes) and health topics (chronic disease self-management, falls prevention, and physical activity). The adaptation process largely involved planned changes to modify delivery context (eg, smaller class size; adding a cofacilitator to support engagement with, and the usability of, technology; and providing telephone options for people without access to reliable internet or videoconferencing technology) as well as some unplanned changes that occurred organically during field experience in consultation with the program leads (rather than changes to program content) [24]. It should be noted that WWE had created an enhanced self-directed program before the pandemic; we included this program in the evaluation to assess different modes of remote EBP delivery, given partners', policy makers', and older adults' interest in diverse ways to engage in remote health promotion. The enhanced self-directed WWE is delivered via a cohort, with a trained leader providing web-based motivation and support to individual participants during the program period. More information about the included programs is provided below (Figure 1) and on each program's website, including guidance for remote delivery.

Figure 1. Participating remote evidence-based programs.



Chronic Disease Self-Managment Program	Chronic Pain Self-Management Program	Diabetes Self-Managment Program	EnhanceFitness	Walk With Ease
Focuses on techniques for dealing with symptoms of chronic conditions	Focuses on techniques for dealing with symptoms of chronic pain conditions	Focuses on techniques for managing diabetes	Focuses on exercise to prevent falls	Focuses on physical activity and education for arthritis management
Group based or individual	Group based or individual	Group based or individual	Group based	Individual
Offered as 6 weekly 2.5-hour videoconferencing sessions	Offered as a mailed tool kit of materials that with 6 weekly scripted 1-hour small-group telephone calls	Offered as 6 weekly 2.5-hour videoconferencing sessions	Offered as 1-hour sessions, 3 times per week, on an on going basis via videoconferencing sessions, with fitness tests at baseline, at 16 weeks, and at regular intervals thereafter	Offered as a self-directed enhanced program, with a leader coordinating communication to a cohort of participants who separately move through the program over 6-weeks

Only the remote program modes that we evaluated are included in this figure, other remote modes may be available on the programs' websites.

Recruitment

In early 2021, we recruited organizations delivering remote EBPs with a brief web-based interest survey and webinars through several networks: EBP training listserves, the CDC Arthritis Program and ACL grantees, the Evidence-Based Leadership Collaborative, and regional EBP networks. The organizations included social services, public health, and health care agencies that were largely community based, although some were located in clinical settings. We used maximum variation purposive sampling [25] to identify organizations of diverse sizes and types, varied provider characteristics, and from different geographic areas to aid the generalizability of the evaluation findings. This sampling prioritized organizations engaging older populations with low-income status with multiple chronic conditions who are vulnerable to both COVID-19 infection and poor health outcomes and care (eg, people of color, those with disabilities, and those living in rural areas). The eligibility criteria for organizations was the delivery of at least 1 of the 5 remote EBPs from January 2021 through March 2022.

We then used convenience sampling to invite all remote EBP participants to take part in the evaluation. Participant surveys were primarily conducted on the web using REDCap (Research Electronic Data Capture; Vanderbilt University) [26], with options to complete surveys by telephone or by mail.

Participants were surveyed when they enrolled in the program and again 6 months after program enrollment (regardless of when they finished the program). At both time points, a link to the survey was emailed to participants, and they received up to 3 additional reminder emails and 3 reminder calls during the month of survey eligibility. In addition, community-based organizations encouraged baseline survey completion as part of program intake and orientation.

Furthermore, all EBP providers at participating organizations were invited to take part in a 1-time survey eliciting their perspectives regarding the impact of remote EBPs on participants as well as providers. The EBP providers included leaders (people who delivered remote programs directly) and managers (people who coordinated and oversaw program delivery).

Data Collection

Quantitative

The participant outcome survey (Multimedia Appendix 1) combined several brief self-rated health measures that have been validated with older adults: single-item self-rated health [27,28], pain [29], fatigue or energy [30], loneliness (University of California Los Angeles 3-item Loneliness Scale [31]), social isolation (4-item Social Network Index [32]), depression (Patient Health Questionnaire [PHQ]-8 [33]), anxiety (Generalized Anxiety Disorder-2 [34]), physical activity (Exercise Vital Sign [35]), and social needs [36]. These cross-cutting outcomes were selected in partnership with organizations, developers or administrators, and policy makers to identify key outcomes of interest across the health promotion programs.

We also collected several program-specific outcomes [37] related to their health focus: self-efficacy for CDSMP, hypoglycemia for DSMP, and pain and the use of opioid medications for CPSMP. In addition, the preprogram survey included questions about remote EBP participant demographics: age, gender, race, ethnicity, living alone, caregiving, and chronic conditions. Rurality was defined using the participant's zip code and several federal criteria for rural funding [38]. The 6-month follow-up survey included 3 additional quantitative items: two examining the usability of and anxiety about technology using the Senior Technology Acceptance Measure [39] and the other calculating a single-item net promoter score [40,41] to assess acceptability [42].

Provider survey data included multiple-choice questions about demographics, experience delivering EBPs, and the impact of remote EBPs on both participants and providers. Response choices were created from open-ended responses to an earlier Evidence-Based Leadership Collaborative remote EBP web-based survey in 2020 (L, Steinman, personal communication, December 2020).

Qualitative

The 6-month follow-up participant survey included open-ended items about program acceptability and unintended consequences or impacts. Participants who completed the follow-up survey over the telephone were also asked 2 additional qualitative questions about participating in the evaluation. Providers were also asked an open-ended question about any additional benefits for both remote EBP participants and providers.

Data Analysis

Quantitative

Data were managed in REDCap [26] and analyzed using R software (R Foundation for Statistical Computing) [43]. Our primary aim was to evaluate changes in remote EBP participants' health and well-being (self-rated health, fatigue or energy, exercise, pain, sleep, depression, anxiety, loneliness, social isolation, and program-specific outcomes) between program enrollment and 6-month follow-up. Only participants who included both baseline and 6-month follow-up data were included in these analyses. We assessed the magnitude of the changes using descriptive statistics, percentage change, and Cohen *d* effect sizes and tested for statistical significance of the changes using paired *t* tests (2-tailed). Percentage change was reported for both people who improved—or maintained—outcomes between remote EBP enrollment and 6-month follow-up, given the importance of maintaining health in an aging population [44]. Effect sizes were calculated as mean (SD) [45]. We also used descriptive statistics to characterize the sociodemographic characteristics of remote EBP participants and providers. We chose not to use the Bonferroni correction to adjust the *P* values because we carried out tests on multiple outcomes of interest across programs without a priori hypotheses (rather than 1 primary outcome of interest) [46].

Qualitative

Audio-recorded data were transcribed into Microsoft Word documents. These text data from transcripts and open-ended survey questions were analyzed using Dedoose software (SocioCultural Research Consultants, LLC) [47]. For qualitative data, we used thematic analysis [48,49] to understand similarities and differences across and within remote EBP acceptability and benefits or unintended consequences. Two researchers (KC and LS) created a codebook to organize important text for comparison, using deductive codes from the interview guide and inductive codes from an initial read of the transcripts [50]. We conducted 2 rounds of reliability coding, adjusted the codebook codes and definitions as needed, then completed coding using 1 coder. Coded exports were then organized in interpretation memos to summarize possible explanations for what was happening, including a summary of findings, key distinctions and counterexamples, and further points for consideration [51].

Integration

We used joint display tables [52] and compared quantitative and qualitative results to see where the findings converged, diverged, or expanded [23].

Results

Participants

A total of 586 older adults participated in the evaluation over the study period, of whom 289 (49.3%) completed the 6-month follow-up survey (n=25, 8.7% completed the survey over the telephone). The primary reason for noncompletion was our inability to contact the older adults by telephone or email; only 10 (1.7%) of the 586 older adults declined to participate in the follow-up survey after being contacted.

Table 1 shows remote EBP evaluation participant demographics for those who completed both baseline and 6-month follow-up surveys. The mean age of the participants was 65.4 (SD 12.0) years. The majority were female (241/289, 83.4%) and White (184/289, 63.7%). A little more than one-third (108/289, 37.3%) identified as people of color: American Indian or Alaska Native (2/289, 0.7%), Asian (12/289, 4.2%), Black or African American (77/289, 26.6%), and Latinx (17/289, 5.9%). One in 7 (41/289, 14.2%) lived in a rural area, and 1 in 3 (99/289, 34.3%) found it “somewhat hard” or “very hard” to pay for basics such as food and housing. Of the 289 participants, 113 (39.1%) lived alone, and 58 (20.1%) were providing caregiving. The participants reported a mean of 2.5 (SD 1.7) chronic conditions, with the most common being hypertension (145/289, 50.2%), arthritis (131/289, 45.3%), diabetes (130/289, 45%), and mental health conditions (80/289, 27.7%). The prevalence of all chronic conditions is provided in Table 1, including more rare but still impactful conditions such as Crohn disease and ulcerative colitis.

Table 1. Demographics of remote evidence-based program evaluation participants.

Demographics	Total (n=289)	CDSMP[a] (n=69)	CPSMP[b] (n=47)	DSMP[c] (n=118)	EF[d] (n=12)	WWE[e] (n=40)
Age (y), mean (SD)	65.4 (12.0)	60.2 (13.5)	67.5 (12.4)	64.9 (11.1)	72.2 (6.13)	71.2 (8.5)
Gender, n (%)						
Female	241 (83.4)	58 (84.1)	39 (83)	93 (78.8)	12 (100)	36 (90)
Male	48 (16.6)	11 (15.9)	8 (17)	25 (21.2)	0 (0)	4 (10)
Nonbinary	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Race, n (%)						
American Indian or Alaska Native	2 (0.7)	1 (1.4)	0 (0)	1 (0.8)	0 (0)	0 (0)
Asian	12 (4.2)	2 (2.9)	2 (4.3)	6 (5.1)	2 (16.7)	0 (0)
Black or African American	77 (26.6)	15 (21.7)	23 (48.9)	25 (21.2)	1 (8.3)	13 (32.5)
Native Hawaiian or Pacific Islander	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
White	184 (63.7)	47 (68.1)	19 (40.4)	81 (68.6)	8 (66.7)	26 (65)
Ethnicity (Latinx), n (%)	17 (5.9)	9 (13)	2 (4.3)	5 (4.2)	1 (8.3)	0 (0)
Living in a rural area, n (%)	41 (14.2)	12 (17.4)	7 (14.9)	12 (10.2)	3 (25)	6 (15)
Somewhat hard or very hard to pay for basics, n (%)	99 (34.3)	28 (40.6)	12 (25.6)	45 (38.1)	2 (16.7)	12 (30)
Living alone, n (%)	113 (39.1)	25 (36.2)	24 (51.1)	40 (33.9)	5 (41.7)	18 (45)
Caregiver, n (%)	58 (20.1)	14 (20.3)	8 (17)	26 (22)	2 (16.7)	7 (17.5)
Chronic conditions, mean (SD)	2.5 (1.7)	2.5 (1.5)	2.6 (2.0)	2.7 (1.7)	1.7 (2.0)	1.8 (1.3)
Chronic conditions[f], n (%)						
Asthma, emphysema, chronic obstructive pulmonary disease, or chronic bronchitis	46 (15.9)	12 (17.4)	11 (23.4)	18 (15.3)	2 (16.7)	3 (7.5)
Arthritis (rheumatoid arthritis)	18 (6.2)	3 (4.3)	2 (4.3)	8 (6.8)	1 (8.3)	4 (10)
Arthritis (osteoarthritis)	72 (24.9)	18 (26.1)	6 (12.8)	28 (23.7)	3 (25)	17 (42.5)
Arthritis (other diagnosis)	41 (14.2)	11 (15.9)	16 (34)	8 (6.8)	0 (0)	6 (15)
Cancer	15 (5.2)	1 (1.4)	3 (6.4)	9 (7.6)	2 (16.7)	0 (0)
Diabetes	130 (45)	24 (34.8)	13 (27.7)	84 (71.2)	3 (25)	6 (15)
Heart trouble (eg, angina, congestive heart failure, and coronary artery disease)	49 (17)	12 (17.4)	7 (14.9)	25 (21.2)	2 (16.7)	3 (7.5)
Hypertension or high blood pressure	145 (50.2)	29 (42)	27 (57.4)	65 (55.1)	5 (41.7)	19 (47.5)
Irritable bowel syndrome	18 (6.2)	7 (10.1)	2 (5.9)	7 (5.9)	0 (0)	2 (5)
Kidney problems	22 (7.6)	6 (8.7)	5 (10.6)	9 (7.6)	1 (8.3)	1 (2.5)
Liver problems (eg, cirrhosis)	3 (1)	1 (1.4)	0 (0)	2 (1.7)	0 (0)	0 (0)
Mental health conditions (eg, depression, anxiety, posttraumatic stress disorder, and bipolar disorder)	80 (27.7)	28 (40.6)	15 (31.9)	31 (26.3)	0 (0)	6 (15)
Other digestive problems (besides irritable bowel syndrome, ulcerative colitis, and Crohn disease)	34 (11.8)	10 (14.5)	3 (6.4)	15 (12.7)	1 (8.3)	5 (12.5)
Stroke and other cerebrovascular disease	13 (4.5)	13 (4.3)	4 (8.5)	6 (5.1)	0 (0)	0 (0)

[a] CDSMP: Chronic Disease Self-Management Program.

[b] CPSMP: Chronic Pain Self-Management Program.

[c] DSMP: Diabetes Self-Management Program.

[d] EF: EnhanceFitness.

[e] WWE: Walk With Ease.

[f] Less than 1% of the participants reported these chronic conditions: HIV or AIDS, Crohn disease, and ulcerative colitis.

Participants who completed the 6-month follow-up survey had similar demographic characteristics and baseline health status as those who completed only the baseline survey, with a few exceptions. A larger proportion of the CDSMP and CPSMP survey completers identified as Black compared to non–survey completers (15/69, 22% vs 13/98, 13%, and 23/47, 49% vs 31/75, 41%, respectively). WWE survey completers were less likely to be living alone (18/40, 45% vs 24/41, 59%). EF survey completers were more likely to be caregivers than not (2/12, 16% vs 0/10, 0%). Finally, across all programs except EF, survey completers were less likely to be living in a rural area than non–survey completers (37/274, 13.5% vs 109/284, 38.4%).

A total of 198 remote EBP providers (n=123, 62.1% leaders; n=75, 37.9% managers) from 107 EBP organizations in 33 states participated in the evaluation. The majority of the leaders identified as female (113/120, 94.2%). Furthermore, 4.3% (5/117) identified as Asian, 12.8% (15/117) as Black or African American, 11.7% (14/120) as Latinx, and 0.9% (1/117) as biracial. One-quarter of the leaders (31/113, 27.4%) lived in rural settings, one-third (36/120, 30%) were caregivers, and one-third (37/123, 30.1%) had ≥2 chronic conditions. One-fourth (30/121, 24.7%) identified as certified health professionals and 43.3% (52/120) as community health workers, promotoras, or other lay health providers. The leaders had a range of experience in EBP delivery: a little more than half (65/123, 52.8%) had delivered both in-person and remote programs before the survey, while 36.6% (45/123) were conducting remote EBPs for the first time. In addition to completing the survey, 26 EBP administrators, managers, and leaders took part in qualitative interviews. Most of the interview participants (22/26, 85%) identified as female and worked at community or government organizations.

Outcomes (Quantitative)

Overview

Outcomes are reported by specific program and across the 5 programs included in our evaluation (Tables 2 and 3; Figure 2; Multimedia Appendix 2).

Table 2. Participant health outcomes at enrollment and 6-month follow-up by remote evidence-based program.

Outcome	Total (n=289), mean (SD)		CDSMP[a] (n=69), mean (SD)		CPSMP[b] (n=47), mean (SD)		DSMP[c] (n=118), mean (SD)		EF[d] (n=12), mean (SD)		WWE[e] (n=40), mean (SD)	
	Pre[f]	Follow-up	Pre	Follow-up	Pre	Follow-up	Pre	Follow-up	Pre	Follow-up	Pre	Follow-up
Health (range 1-5) ↓[g]	3.23 (0.9)	2.80[h] (0.9)	3.36 (0.9)	2.91[h] (1)	3.38 (0.8)	3.21 (1.0)	3.19 (0.8)	2.71[h] (0.8)	2.86 (1.0)	2.27 (1.0)	2.98 (0.8)	2.59[h] (0.8)
Fatigue (range 1-10) ↓	5.49 (2.3)	4.98[h] (2.3)	6.05 (2.1)	5.61[h] (2.4)	5.92 (2.3)	4.88[h] (2.1)	5.28 (2.4)	4.91 (2.5)	4.05 (1.7)	3.91 (2.2)	4.86 (2.1)	4.42 (2.1)
Pain (range 1-10) ↓	4.86 (2.6)	4.44 (2.7)	5.02 (2.4)	4.78 (2.6)	6.41 (2.3)	5.67[h] (2.3)	4.14 (2.6)	4.16 (2.9)	4.14 (2.4)	3.64 (2.7)	4.13 (2.3)	3.68 (2.3)
Sleep quality (range 1-10) ↓	4.95 (2.5)	4.49[h] (2.6)	5.32 (2.4)	5.07[h] (2.8)	5.64 (2.6)	5.19 (2.5)	4.73[h] (2.5)	4.15 (2.5)	3.91 (2.4)	3.91 (3.1)	4.14 (2.5)	3.79 (2.3)
Loneliness (range 3-9) ↓	4.67 (1.8)	4.45[h] (1.8)	5.04 (1.9)	4.74 (2.0)	4.57 (1.7)	4.67 (2.0)	4.54 (1.8)	4.33 (1.8)	3.65 (1.0)	3.91 (1.0)	4.64 (1.7)	4.11 (1.3)
Social isolation (range 5-25) ↑[i]	15.7 (3.7)	16.2 (3.8)	15.2 (3.4)	16.3 (3.5)	15.9 (4.1)	16.7 (4.5)	15.6 (3.7)	15.6 (3.8)	18.1 (2.8)	18.6 (1.8)	16.5 (3.6)	16.8 (4.0)
Physical activity (day; range 0-7) ↑	2.3 (2.3)	2.6 (2.3)	2.0 (2.1)	2.2 (2.2)	2.5 (2.7)	2.6 (2.5)	2.2 (2.3)	2.4 (2.4)	3.3 (1.9)	3.8 (1.7)	2.7 (2.4)	3.3[g] (2.1)
Physical activity (min; range 0-679) ↑	82.5 (113)	98.5[h] (124)	54.7 (74)	74.7[h] (106)	86.4 (117)	99.4 (149)	90.1 (128)	94.7 (126)	140.8 (95)	179.5[h] (94)	107.5 (118)	130.1[h] (118)
Depression (range 0-24) ↓	6.20 (5.3)	5.05[h] (5.2)	7.47 (5.8)	6.07 (5.2)	7.63 (5.6)	6.50 (5.7)	5.43 (4.6)	4.83 (5.2)	4.17 (5.6)	2.10 (2.7)	3.77 (3.6)	2.77 (4.0)
Anxiety (range 0-6) ↓	1.48 (1.6)	1.30 (1.6)	1.95 (1.7)	1.65 (1.6)	1.67 (1.7)	1.54 (1.6)	1.27 (1.5)	1.26 (1.7)	0.74 (0.9)	0.60 (0.8)	1.11 (1.3)	0.67 (1.2)
Technology anxiety (range 1-10) ↓	2.74 (2.4)	2.53[h] (2.4)	3.24 (2.7)	2.81 (2.6)	3.30 (3.1)	2.87 (2.5)	2.28 (2.1)	2.52 (2.4)	2.38 (2.7)	2.13 (2.1)	2.30 (1.8)	1.97 (1.6)
Technology usability (range 1-10) ↑	7.94 (2.6)	8.22 (2.6)	7.66 (2.5)	8.48 (2.4)	7.15 (3.3)	7.82 (2.9)	8.54 (2.3)	8.17 (2.6)	7.56 (3.0)	8.61 (2.0)	8.16 (2.4)	8.22 (2.7)
Self-efficacy (range 1-10) ↑	N/A[j]	N/A	6.16 (2.3)	6.89[h] (2.2)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Pain interference (range 6-30) ↓	N/A	N/A	N/A	N/A	16.6 (7.3)	16.7 (7.5)	N/A	N/A	N/A	N/A	N/A	N/A
Diabetes (hypoglycemia; range 1-7) ↓	N/A	N/A	N/A	N/A	N/A	N/A	1.92 (2.0)	1.84 (2.2)	N/A	N/A	N/A	N/A

[a] CDSMP: Chronic Disease Self-Management Program.

[b] CPSMP: Chronic Pain Self-Management Program.

[c] DSMP: Diabetes Self-Management Program.

[d] EF: EnhanceFitness.

[e] WWE: Walk With Ease.

[f] Pre: health outcomes at program enrollment; follow-up: health outcomes at 6-month follow-up from program enrollment.

[g] Lower scores indicate better health.

[h] P<.05 (paired 2-tailed t tests, except for EF, which used the Fisher exact test).

[i] Higher scores indicate better health.

[j] N/A: not applicable.

Table 3. Six-month effect sizes for remote evidence-based program participant health outcomes.

Outcome	Range direction	Effect size					
		Total (n=289)	CDSMP[a] (n=69)	CPSMP[b] (n=47)	DSMP[c] (n=118)	EF[d] (n=12)	WWE[e] (n=40)
Health	1-5↓[f]	−0.37[g]	−0.37[g]	−0.23[h]	−0.44[g]	−0.58[i]	−0.35[g]
Fatigue	1-10↓	−0.23[h]	−0.20[h]	−0.42[g]	−0.13[h]	−0.25[h]	−0.33[g]
Pain	1-10↓	−0.13[h]	−0.11[h]	−0.49[g]	0.05[j]	−0.17[h]	−0.21[h]
Sleep quality	1-10↓	−0.18[h]	−0.19[h]	−0.08[j]	−0.21[h]	−0.66[i]	−0.22[h]
Loneliness	3-9↓	−0.13[h]	−0.24[h]	0.06[j]	−0.13[h]	0.58[j]	−0.30[g]
Social isolation	5-25↑[k]	0.08[j]	0.03[j]	0.07[j]	0.00[j]	0.23[h]	0.23[h]
Physical activity (days)	0-7↑	0.13[h]	0.17[h]	0.07[j]	0.10[j]	0.35[g]	0.18[h]
Physical activity (min)	3-679↑	0.15[h]	0.22[h]	0.18[h]	0.08[j]	0.36[g]	0.18[h]
Depression	0-24↓	−0.23[h]	−0.24[h]	−0.27[h]	−0.23[h]	−0.34[g]	0.06[j]
Anxiety	0-6↓	−0.08[j]	−0.12[h]	−0.36[g]	0.03[j]	0.00[j]	−0.06[j]
Technology anxiety	1-10↓	−0.13[h]	−0.17[h]	−0.23[h]	−0.08[j]	−0.03[j]	−0.24[h]
Technology usability	1-10↑	−0.05[j]	−0.06[j]	0.23[h]	−0.13[h]	0.59[i]	−0.07[j]
Self-efficacy	1-10↑	N/A[l]	0.38[g]	N/A	N/A	N/A	N/A
Pain interference	6-30↓	N/A	N/A	−0.37[g]	N/A	N/A	N/A
Diabetes (hypoglycemia)	1-7↓	N/A	N/A	N/A	−0.06[j]	N/A	N/A

[a] CDSMP: Chronic Disease Self-Management Program.

[b] CPSMP: Chronic Pain Self-Management Program.

[c] DSMP: Diabetes Self-Management Program.

[d] EF: EnhanceFitness.

[e] WWE: Walk With Ease.

[f] Lower scores indicate better health.

[g] Cohen *d* effect sizes 0.3 to 0.5=moderate.

[h] Cohen *d* effect sizes 0.1 to 0.3=small.

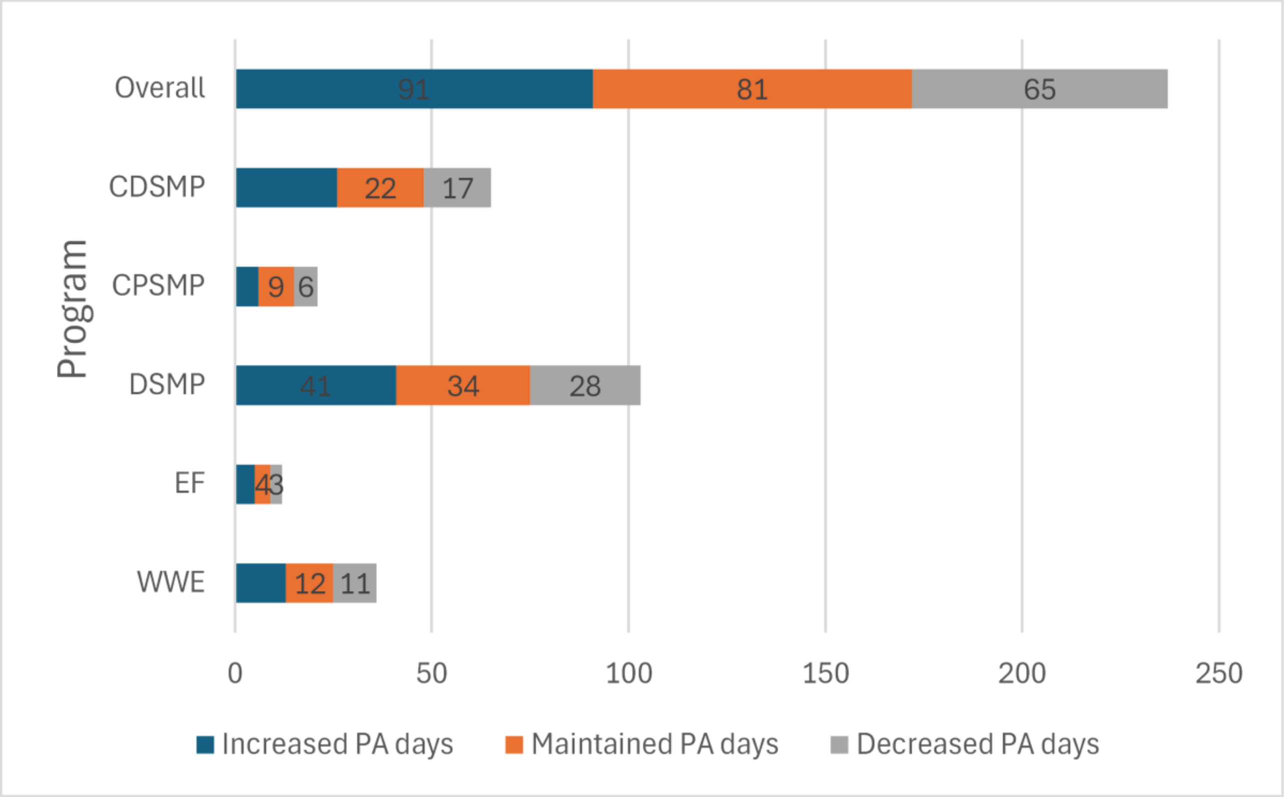
[i] Cohen *d* effect sizes >0.5=large.

[j] Cohen *d* effect sizes <0.1=trivial.

[k] Higher scores indicate better health.

[l] N/A: not applicable.

Figure 2. Change in the number of physical activity (PA) days between enrollment and 6-month follow-up for remote evidence-based program outcome evaluation participants. The participants were asked about the number of days on which they were physically active per week at both program enrollment and 6-month follow-up. The completion rates for this question, by program and overall, are as follows: Walk With Ease (WWE)=90% (36/40), EnhanceFitness (EF)=100% (12/12), Diabetes Self-Management Program (DSMP)=87.3% (103/118), Chronic Pain Self-Management Program (CPSMP)=45% (21/47), Chronic Disease Self-Management Program (CDSMP)=94% (65/69), and overall=82% (237/289).



CDSMP Participants

When testing for whether these changes over time were not due to chance, CDSMP participants showed statistically significant improvements in health (mean change 0.32, 95% CI 0.117-0.530; *P*=.003; t_{67}=3.12), energy (fatigue; mean change 0.73, 95% CI 0.061-1.408; *P*=.03; t_{63}=2.18), sleep quality (mean change 0.89, 95% CI 0.216-1.561; *P*=.01; t_{62}=2.64), and self-efficacy (mean change −0.53, 95% CI −0.970 to −0.091; *P*=.02; t_{43}=-2.49). Participants with depression at baseline (19/69, 28%; PHQ-8 score <10) also significantly reduced their depression symptom severity from mean 14.7 (SD 4.2) to mean 11.5 (SD 5.1) on the PHQ-8 (*P*=.03). Overall, 58% (40/69) of the participants improved their self-efficacy over time, with a moderate effect size of 0.38. From program enrollment to 6-month follow-up, 40% (26/65) of the participants showed improvement, and 34% (22/65) of the participants maintained the number of days on which they were physically active.

CPSMP Participants

CPSMP participants significantly improved their energy (fatigue; mean change 1.11, 95% CI 0.248-1.968; *P*=.01; t_{36}=2.61) and pain (mean change 0.97, 95% CI 0.186-1.763; *P*=.02; t_{38}=2.50). Moderate effect sizes were seen for fatigue (−0.42), pain (−0.49), anxiety (−0.36), and pain interference (−0.38). The participants with pain interference at baseline (30/289, 10.4%; PROMIS [Patient-Reported Outcomes Measurement Information System] score >6) also reduced their pain interference from mean 16.9 (SD 6.6) to mean 15.5 (SD 7.3). Only 1 (2.1%) of the 47 participants was taking opioid medications at enrollment. From program enrollment to 6-month follow-up, 29% (6/21) of the participants showed improvement, and 43% (9/21) of the participants maintained the number of days on which they were physically active.

DSMP Participants

DSMP participants demonstrated better health (mean change 0.41, 95% CI 0.259-0.552; *P*<.001; t_{110}=5.48). People with at least 1 hypoglycemia symptom at baseline (70/289, 24.2%) reduced their symptoms from mean 2.4 (SD 1.3) to mean 2.1 (SD 1.7); the effect size was low (−0.06). DSMP participants had a moderate effect size for overall improvement in health (−0.44). Participants with depression at baseline (19/118, 16.1%) also significantly reduced their depression symptom severity from mean 13.9 (SD 3.0) to mean 11.1 (SD 6.5) on the PHQ-8. From program enrollment to 6-month follow-up, 39.8% (41/103) of the participants showed improvement, and 33% (34/103) of the participants maintained the number of days on which they were physically active.

EF Participants

EF participants demonstrated better sleep quality (Fisher exact test: *P*=.001), with a large effect size of −0.66. Participants also showed strong improvements in health (effect size: −0.58) and technology usability (effect size: 0.60). From program enrollment to 6-month follow-up, 42% (5/12) of the participants showed improvement, and 33% (4/12) of the participants maintained the number of days on which they were physically active.

WWE Participants

WWE participants demonstrated better health (mean change 0.25, 95% CI 0.046-0.454; *P*=.02; t_{35}=2.49), with a moderate effect size of −0.35. Participants also had moderate effect sizes for improvements in fatigue (−0.33) and loneliness (−0.30). From program enrollment to 6-month follow-up, 36% (13/36) of the participants showed improvement, and 33% (12/36) of the participants maintained the number of days on which they were physically active.

Across Remote EBPs

Across programs, remote EBP participants showed statistically significant improvements in their health (mean change 0.33, 95% CI 0.235-0.422; *P*<.001; t_{267}=6.92), energy (mean change 0.56, 95% CI 0.264-0.853; *P*<.001; t_{264}=3.73), sleep quality (mean change 0.53, 95% CI 0.245-0.812; *P*<.001; t_{262}=3.67) loneliness (mean change 0.25, 95% CI 0.057-0.437; *P*=.01; t_{242}=2.55), depressive symptoms (mean change 0.60, 95% CI 0.111-1.091; *P*=.02; t_{212}=2.42), and technology anxiety (mean change 0.34, 95% CI 0.010-0.665; *P*=.04; t_{233}=2.03). For people living with clinically significant depressive symptoms (PHQ-8 score ≥10; 24/114, 21.1% of the sample), the overall mean change in the PHQ-8 score from enrollment to 6-month follow-up was 3.025 (95% CI 1.379-4.671; *P*<.001; t_{39}=3.717). People with clinically significant depression at baseline (52/289, 18%) also significantly reduced their depression symptom severity from mean 14.7 (SD 4.2) to mean 11.5 (SD 5.1).

The percentage change is reported in Multimedia Appendix 2. Across programs, 26.7% (66/247) to 49.8% (136/273) of the participants improved health outcomes over time, and 17.4% (41/235) to 53.8% (133/247) of the participants maintained their health. Most effect sizes (Table 3) were small (<0.3), except for change in health over time, which had an effect size of −0.37.

Outcomes (Qualitative)

Participants

Overall, participants shared that they liked and enjoyed participating in the remote EBPs and identified several ways in which the program impacted their lives. First, they reported changes in their knowledge, attitudes, and practices in promoting their health and well-being. Participating in remote EBPs helped older adults manage their chronic conditions, become more active, and feel more confident and better equipped to take care of themselves:

> *I feel as if this program literally changed the trajectory of my life. Prior to it, I was diagnosed as prediabetic and was put on medication, which made me very sick. My next option was a very expensive diabetes drug. But, through following this program, I learned about insulin resistance and what I could do to combat my descent into diabetes. I was encouraged and coached in inspiring ways. I am now barely considered even prediabetic.* [Female DSMP participant #1454; aged 66 years; living with ulcerative colitis]

> *The program helped me understand how exercise can improve my mobility, and it encouraged me to remain active.* [Male WWE participant #1346; aged 63 years; living with arthritis and asthma]

Likewise, the remote EBP participants stated that they learned a lot from the program, including from the materials, leaders, and other participants. This was true across programs: WWE participants learned about new walking spots in their communities from other walkers in their cohort, while self-management program participants learned new ways and tips for managing their condition (expanded their sense of their own options) and broadened their understanding of what life was like at different severity levels of their condition. The group-based formats of the remote EBPs helped provide accountability and motivation and also provided a variety of perspectives and ideas. For some participants, the remote program helped them accept the reality and seriousness of their condition and the changes needed to manage it. In addition, participants believed that others could benefit from the program as well.

The participants also reported social benefits from being part of the programs. Many participants felt less alone, gained a sense of comfort from talking with others struggling with the same conditions, and made friends over the course of the program. A sense of camaraderie was reported often:

> *I liked the interaction with other people, it's helpful to find out how others are going through. To know that there's other people out there with a lot of pain and they're struggling with it, made me feel not alone. Some are worse and some are better. It feels isolating a lot with pain, so that was really nice to experience, seeing others.* [Female CPSMP participant #1344; aged 74 years; living alone and managing multiple chronic conditions]

Furthermore, remote EBP participants from various programs who were grappling with new or existing chronic conditions, changes in mobility and function due to aging, and the challenges of physical distancing during the pandemic, emphasized the value of learning together and feeling less alone. Even participants in the remote WWE program (self-directed tool kit enhanced with a leader virtually supporting a cohort of participants) found social benefits:

> *I did appreciate the opportunity to meet with the group assigned to me and get the encouragement to get out and walking.* [Female WWE participant #1249; aged 65 years; living with arthritis and a mental health condition]

In addition, older adults shared how remote EBPs improved their access to the programs. The remote format made accessing these programs during the pandemic both safe and very convenient, in particular for people living with chronic pain or disabilities. Some participants would not have been able to participate if the programs had only been offered in person. That said, a few participants did not like the remote format and found it more difficult to access. For these participants, the downsides of not being able to meet and connect in person or the challenges with participating via telephone, mail, or videoconferencing outweighed the benefits of participating in class. Examples include issues with the technology itself (eg, poor internet connections that made the videoconferencing software freeze up) and discomfort with using technology (eg, unfamiliarity with navigating Zoom functions or unease using a mobile phone where they cannot see other participants). It should be noted that technology encompasses using a telephone (landline, smartphone, or other mobile phone) in addition to laptop computers, tablet devices, and PCs; dial-up or broadband internet; and videoconferencing platforms such as Zoom and Webex.

Finally, many participants shared that they wanted to take part in the remote EBP again, and some participants shared that they desired more follow-ups after the program ended. For these participants, there was a sense of having missed or forgotten some of what had been taught and wanting to refresh their knowledge. Others felt that they needed the motivation of continued check-ins to keep using what they had learned. In addition, some were not sure how to get their questions answered after the program ended, how to sign up for other programs offered by the organization, or whether they were allowed to take part in the program again. This points to opportunities for future supports and services after remote EBP engagement, such as monthly check-ins via telephone, videoconferencing, or social media to "keep the feelings of motivation and community after the program ends...[to] meet or discuss what folks are doing and what works and encourage each other to keep going" (female DSMP participant #1190; aged 61 years; living with multiple chronic conditions [arthritis, hypertension, diabetes, heart troubles, and a mental health condition]). Post-EBP supports and services could also provide a way to reinforce and deepen knowledge and skills that are learned and practiced during a relatively brief program and offer ways for family, friends, and caregivers to support the maintenance of program gains as well as widen program benefits to other people in the participants' communities.

Providers

Table 4 summarizes provider's perspectives on the impact of remote EBPs. Some of these impacts were expected; for example, 3 in 4 providers (149/198, 75.2%) reported improved health outcomes for older remote EBP participants, and reducing social isolation and loneliness emerged as the most common benefit for both participants and EBP providers (leaders and managers). In addition, half of the providers (102/198, 51.5%) noted that connections to other supports and services were a participant benefit; while this typically occurs during in-person EBP delivery, remote EBP delivery allowed for sharing timely and ever-changing information about testing for COVID-19 infection and recommended safety protocols, as well as referrals to services that may have paused or been shifted due to pandemic-related closures or physical distancing requirements.

Table 4. Perceived benefits of remote evidence-based program (EBP) delivery for participants (from providers' perspectives) and for providers (n=198).

Benefits	Survey data, n (%)		Interview data
	Leaders (n=123)	Managers (n=75)	
Benefits for participants (from providers' perspectives)			
Improved health outcomes	93 (75.6)	56 (74.7)	• Kept participants safe while also allowing them to access the benefits of these programs. • The program was still effective, and the benefit it had on participants could be seen.
Reduced social isolation and loneliness	116 (94.3)	66 (88)	• Enhanced socialization and helped with isolation, which is really needed right now. The bonds formed within the groups are really important. • Clients appreciated getting checked on; many were feeling isolated during the COVID-19 pandemic.
Improved access to technology	52 (42.3)	30 (40)	• By participating in the remote EBP, participants gained access to new or loaner technology.
Improved comfort with using technology	91 (74)	52 (69.3)	• Increased technology literacy and comfort of participants, which encourages them to explore other web-based resources. • Clients felt accomplished to have completed a class that required new technology, such as video-conferencing platforms, without help.
Enhanced access to other supports and services	67 (54.5)	35 (46.6)	• Able to educate older adults in their program about COVID-19 vaccines. • Remote program improved cross-referrals, which is good for holistically addressing health.
Improved access to EBPs	N/A[a]	N/A	• Participants can repeat the program because it is easier to access. • No concerns about driving in bad weather . • Some participants liked the virtual class and want remote options in the future.
Benefits for providers			
Improved health outcomes	58 (47.2)	27 (36)	N/A
Reduced social isolation and loneliness	61 (49.6)	39 (52)	• Able to keep working and connecting with colleagues and participants.
Improved access to technology	34 (27.6)	22 (29.3)	• Gained access to technology via work or family, friends, and neighbors. • For leaders without access, some stopped delivering the program.

[a] N/A: not applicable (either the benefit was not one of the multiple-choice answer choices in the provider survey or did not emerge during the interview data analysis).

Some of the impacts were positive but unintended; for example, providers reported improved comfort using technology as a benefit for remote EBP participants. Increasing the usability of technology and reducing anxiety about technology are not original outcomes that in-person EBPs strived to impact, but in remote EBP delivery, opportunities arose for some participants to become more comfortable using technology (telephone, videoconferencing, or tool kits) for engaging in, and receiving, other supports and services. Comfort using technology was a more prevalent impact than access to technology, which aligns with other findings that access was a challenge even when organizations provided software or hardware [53]. Other unexpected positive impacts from the providers' perspectives include that delivering EBPs remotely allowed them to continue providing the program to older adults throughout the COVID-19 pandemic, reach participants they had not reached before, connect participants to each other, learn how to use technology, and be able to continue working or volunteering during the pandemic.

We also gathered data via surveys and interviews on the unintended negative consequences of delivering EBPs remotely, an important aspect when evaluating the public health impact of these programs with an equity lens. For some leaders, teaching remotely was too difficult or disconnecting due to not being able to see people's nonverbal cues and having to work harder to teach technology, engage people, or address emotional issues such that they felt that "something was lost." Strategies for mitigating this reduced impact included reducing class sizes or duration (for both telephone and videoconferencing sessions) and requiring people attending videoconferencing sessions to have their camera on and having 2 leaders taking part so that one could focus on engagement while one managed technology.

Discussion

Principal Findings

Our evaluation found that remote EBP participants showed improvements on various outcomes from program enrollment to 6-month follow-up, including their self-rated health, energy, sleep quality, loneliness, depressive symptoms, and technology anxiety, within and across programs. Some program participants also reduced their anxiety, pain, pain interference, physical activity and self-efficacy, and enhanced their technology usability. The quantitative findings yielded mainly small effect sizes. This may be due to the heterogeneity of the participants; in particular, participants who did not enter the program as lonely or inactive would have no room to improve over time. The qualitative findings suggest that remote EBP participants improved knowledge, attitudes, and skills on how to live healthier lives; reduced social isolation and loneliness; and gained better access to programs. In addition, providers shared that they too benefited from delivering programs remotely by staying connected, having access to technology, and improving their own health and well-being.

In some cases, the findings support previous research on the effectiveness of the remote EBPs that were part of our evaluation; for example, 1 study of 213 videoconferencing CDSMP participants in rural and remote Ontario, Canada, found similar improvements in self-rated health, energy, and psychological well-being (a measure related to depressive symptoms) 4 months after their last class [54]. Another study of 97 telephone plus tool kit CPSMP participants in Cleveland, Ohio, United States, also reported better pain outcomes immediately after program completion [17]. Furthermore, a study of self-directed WWE participants (n=270) in rural and urban North Carolina, United States, who were living with arthritis found that participants also reduced fatigue at follow-up 1 year after program enrollment [21]. Our findings are also comparable to those of similar health promotion programs, such as increased physical activity and reduced depression for a remote DSMP [55].

In other cases, our findings contrast with those of previous research; for instance, 1 study of remote-delivered EF [20] found that the participants (n=15) decreased their knee pain as measured by the Knee Injury and Osteoarthritis Outcome Score; however, all study participants had symptomatic knee osteoarthritis, and the postprogram outcome was measured directly after active intervention at 12 weeks. It may be that our evaluation participants did not significantly improve pain outcomes due to their less severe baseline pain. In addition, the study of CPSMP participants mentioned previously [17] found statistically significant improvements in sleep and depression; our evaluation participants too improved their sleep quality and reduced their depressive symptom severity, but this change was not statistically significant. Our differing findings may be due to our smaller sample size (47 vs 97), which lowered our power to detect significant change, or a longer follow-up period (6 months vs 6 weeks), during which improvements may have been attenuated.

Furthermore, it should be noted that our outcome evaluation was not designed to compare in-person EBP delivery with remote EBP delivery. We used a common set of outcome measures of interest to older adults, EBP delivery organizations, and policy makers; as such, some of these measures look at similar constructs as the in-person EBP effectiveness studies but use different instruments, and some of these measures that are newly being evaluated (eg, loneliness and depression) were not evaluated in the in-person EBP research studies. In addition, we used a different time period compared to studies that evaluated the effectiveness of in-person EBP delivery: we looked at changes between program enrollment and 6-month follow-up, regardless of program duration, whereas prior effectiveness research looked at pre-post change over time based on program duration [21,56-59]. Our sample sizes were also smaller than those of previous in-person EBP research studies; therefore, the lack of statistical significance may be due to a lack of power to detect change. That said, it may be helpful to contextualize our remote EBP outcome evaluation findings with those from in-person EBP outcome evaluations. Remote CDSMP evaluation participants reported improvements in self-efficacy, health, energy (fatigue), sleep quality, physical activity, and depression, all outcomes that were also reported in previous studies of in-person CDSMP [37,60-62]. Furthermore, remote CDSMP evaluation participants did not show the significant improvements in pain outcomes that were seen in research with in-person program participants. Remote CPSMP evaluation participants reported outcome improvements similar to those of in-person CPSMP participants regarding pain and pain interference [56,63], while our evaluation added evidence for remote CPSMP participant improvements in energy (fatigue), anxiety, and physical activity; these 3 outcomes were not assessed in in-person CPSMP studies. However, remote CPSMP participants did not report significant improvements in self-efficacy, as was reported in previous in-person CPSMP studies. Looking at the DSMP, both remote and in-person delivery participants showed reduced hypoglycemia symptoms, health, and depression [57]. Earlier research with in-person program participants found improved self-efficacy as well, and remote program participants showed improvement in terms of their physical activity days. For EF, both remote and in-person program participants reported improvements in self-rated health as well as physical activity [64,65]. This evaluation adds novel findings on improved sleep quality and the usability of technology for remote program participants. In addition, in-person EF participants have reported reduced depression in other studies [64]. Looking at WWE, both in-person and remote program participants have demonstrated improvements in health, fatigue, and physical activity [21]. Remote WWE participants reduced their loneliness, which was not assessed in previous studies of in-person WWE [21]. Previous research of in-person WWE also found participant improvement in pain and self-efficacy [21].

Although EBPs shifting to remote delivery was necessitated by the pandemic-related lockdown and other restrictions [24], the findings suggest that remote delivery can improve access to quality health promotion programs outside the COVID-19 pandemic context; for example, a caregiver for a person living with dementia can join a physical activity program from home to support their own health while not having to find respite care for their loved one, an older adult living with chronic pain can join a class even if they are experiencing elevated pain levels that would make it hard to leave even their bedroom, and a program leader can deliver the program across a region in Spanish to participants who may not have access to language-specific health promotion. This is similar to other studies of remote EBPs (eg, the value for people living with cancer to be able to participate from a distance despite living with weakened immune systems [66]).

Adapting the format and channels through which an EBP is delivered [67] is considered an appropriate modifiable intervention characteristic to better align with the needs and preferences of participants, as well as organizational and geographic contexts in which a remote option improves program feasibility and sustainability [68]. Implementation science increasingly recognizes the need for adaptations [69] to improve the intervention-context fit (eg, increasing both practical and value fit [70]; increasing EBP feasibility to a given context [71]; and making sure that the EBPs can be delivered for different systems, organizations, providers, and participants than was originally studied [72]), support people living with multiple chronic conditions because comorbidity is the rule rather than the exception [73], and ensure EBP effectiveness by evaluating the intervention in different settings with varying provider and participant attributes [74]. Our complementary process evaluation found that delivering in-person EBPs remotely did not require modifications to core program components [53], suggesting that fidelity to the active ingredients of the program models was maintained. That said, some of the observed lack of improvement in health outcomes by remote EBP participants may be due to failures in implementation (eg, inadequate intervention dose due to technology issues) that negatively impacted program effectiveness [42].

Strengths and Limitations

Our evaluation comes with several strengths. First, we conducted a pragmatic evaluation across the country in partnership with policy makers and delivery organizations so that the findings would have direct implications for improving older adults' health equity. Specifically, we built upon trusting relationships and took time to foster new relationships to engage people most impacted by implementing remote EBPs; we also gathered qualitative data to put quantitative outcomes in context for future quality improvement [75]. Second, we included multiple brief, validated health outcomes across various EBPs and diverse participants and providers, centering outcomes that are important and meaningful to participants, providers, organizations, and policy makers that were not measured in previous studies [76]. These include social factors such as social isolation and loneliness and mental health factors such as depression and anxiety, which lead to premature mortality for older adults [77,78]. While measuring multiple outcomes across heterogeneous populations and programs made it harder to see large effect sizes, it better reflects how organizations work (delivering multiple programs) and how participants view health more holistically rather than as just 1 primary outcome. It may also be that small effect sizes suggest that these programs provided primary or secondary prevention to delay the onset of more impairing symptoms and conditions that was not picked up from our measures or relatively study time frame [79]. Third, collecting qualitative as well as quantitative data from the perspectives of both participants and providers provides consistent measures to compare across studies as well as stories and unanticipated outcomes to explore more broadly in future research.

Looking at limitations, first, using a single-group design with the lack of a comparison group or randomization means that we cannot attribute change in health outcomes over time to participating in the remote EBP. Second, we recognize that the lack of statistical significance when assessing for whether change was due to chance or program participation may be due to small sample sizes that lack power. This is partly why we collected qualitative data from both providers and participants: we wanted to understand the magnitude of change from their perspectives. Third, our response rate was lower than is typical in controlled research studies, with only half of the remote EBP participants (289/586, 49.3%) providing follow-up data. This was due to pandemic-related logistical and methodological challenges faced by our evaluation team, program providers, and older adult participants; conducting an evaluation during the COVID-19 pandemic has been deemed more challenging than conducting evaluations in conflict areas [80]. This suggests limitations to both internal validity through biases such as selection bias (eg, persons who liked the program or had access to a mobile phone or the internet to complete the evaluation were overrepresented) and external validity, with the COVID-19 pandemic being a unique context, because of which our findings may not be generalizable (eg, were improvements in social connection due to the high level of disconnectedness faced by everyone during the pandemic-related lockdown?). Finally, our convenience sample only included group-based programs and as such may not be applicable to one-on-one EBPs. We also did not have access to data on the entire remote EBP delivery population; therefore, we cannot comment on the representativeness of our outcome evaluation sample. Our process evaluation [24] suggests that persons who have been historically underserved by EBPs (eg, people of color, those with disabilities, and those living in rural areas) can be reached through remote delivery; however, care must be taken to ensure that remote delivery does not widen the health inequities caused by the digital divide.

Conclusions

In closing, the findings from this outcome evaluation suggest that participating in remote EBPs can improve health, social, and technology outcomes of interest for older adults, providers, and policy makers (Textbox 1). Future policy and practice can better support remote EBPs, improving access for all older adults (regardless of income, geography, and ability) and strengthening delivery organizations.

Textbox 1. Lessons learned for evidence-based program (EBP) administrators, developers, and implementers.

Key takeaways

- Delivering EBPs remotely (by telephone, videoconferencing, mail, or a combination of these modes) offers a new format for engaging older adults in quality health promotion programming.
- Outcome evaluation findings suggest that remote EBPs are effective at improving health, social, and technology outcomes for older adult participants and providers who deliver the programs, although impacts are not experienced universally across programs or outcomes.
- Interviews and surveys with remote EBP participants and providers suggest that these outcomes can be achieved because remote EBPs are acceptable; increase knowledge, skills, motivation, support, and accountability; connect people to peers and leaders; and support tech access and comfort.
- Include brief, validated pre- and postprogram surveys in your routine program delivery to understand changes in outcomes that matter to your community, organization, and funders. (The surveys may include traditional health outcomes you assessed with in-person EBPs as well as new outcomes, such as social isolation, loneliness, technology anxiety, and technology usability. Our survey measures are cited in this paper and available on request.)
- Gather data on remote EBP participant demographics to understand who is being reached and who is not being reached by remote programs to strategize engagement via other outreach strategies or in-person EBP modes.
- Remote EBP delivery may improve access to health promotion programming for people facing inequitable access to in-person programming; however, caution is needed to ensure that remote delivery does not widen the digital divide; for example, while remote delivery can support rural-dwelling older adults from areas without nearby programs or dependable transportation, the lack of reliable internet in some rural areas may necessitate a telephone or mail remote EBP delivery mode.
- Supports for remote EBPs include orienting participants to using program technology before and during the program and providing ways for program participants to connect after the program ends.

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Conflicts of Interest

PD and KL work for organizations that administer remote evidence-based programs. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Participant outcomes survey.
[PDF File (Adobe PDF File), 142 KB - aging_v7i1e52069_app1.pdf]

Multimedia Appendix 2
The percentages of improvement and maintenance in participant health outcomes at enrollment and 6-month follow-up in remote evidence-based programs for health promotion.
[DOCX File , 45 KB - aging_v7i1e52069_app2.docx]

References

1. 2020 profile of older Americans. Administration for Community Living, U.S. Department of Health and Human Services. 2021 May. URL: https://acl.gov/sites/default/files/aging%20and%20Disability%20In%20America/2020Profileolderamericans.final_.pdf [accessed 2022-12-18]

2. The Longevity Economy® Outlook: how people age 50 and older are fueling economic growth, stimulating jobs, and creating opportunities for all. AARP. 2019. URL: https://www.aarp.org/content/dam/aarp/research/surveys_statistics/econ/2019/longevity-economy-outlook.doi.10.26419-2Fint.00042.001.pdf [accessed 2022-12-18]
3. Fong JH. Disability incidence and functional decline among older adults with major chronic diseases. BMC Geriatr 2019 Nov 21;19(1):323. [doi: 10.1186/s12877-019-1348-z] [Medline: 31752701]
4. Bergen G, Stevens MR, Burns ER. Falls and fall injuries among adults aged ≥65 years - United States, 2014. MMWR Morb Mortal Wkly Rep 2016 Sep 23;65(37):993-998. [doi: 10.15585/mmwr.mm6537a2] [Medline: 27656914]
5. Healthy Aging Through The Social Determinants of Health. Washington, DC: American Public Health Association; 2021.
6. McGough M, Claxton G, Amin K, Cox C. How do health expenditures vary across the population? Peterson-KFF Health System Tracker. 2024 Jan 4. URL: https://www.healthsystemtracker.org/chart-collection/health-expenditures-vary-across-population/#Proportion%20of%20individuals%20by%20health%20status,%202019 [accessed 2023-08-12]
7. Gerteis J, Izrael D, Deitz D, LeRoy L, Ricciardi R, Miller T, et al. Multiple chronic conditions chartbook. Agency for Healthcare Research and Quality. 2014. URL: https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/prevention-chronic-care/decision/mcc/mccchartbook.pdf [accessed 2023-08-12]
8. Health, United States, 2015: with special feature on racial and ethnic health disparities. National Center for Health Statistics (US). 2016. URL: https://pubmed.ncbi.nlm.nih.gov/27308685/ [accessed 2024-04-20]
9. CDC health disparities and inequalities report — United States, 2011. Centers for Disease Control and Prevention. 2011. URL: https://www.cdc.gov/mmwr/preview/ind2011_su.html#HealthDisparities2011 [accessed 2024-04-20]
10. Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? Eff Clin Pract 1998;1(1):2-4. [Medline: 10345255]
11. Health promotion. Administration for Community Living. URL: https://acl.gov/programs/health-wellness/disease-prevention [accessed 2024-04-20]
12. Arthritis-Appropriate, Evidence-Based Interventions (AAEBI). Osteoarthritis Action Alliance. URL: https://oaaction.unc.edu/aaebi/#:~:text=Arthritis%2DAppropriate%2C%20Evidence%2DBased%20Interventions%20(AAEBIs)%20are,pain%20or%20limitations%20in%20function [accessed 2024-04-20]
13. Tyrrell CJ, Williams KN. The paradox of social distancing: implications for older adults in the context of COVID-19. Psychol Trauma 2020 Aug;12(S1):S214-S216. [doi: 10.1037/tra0000845] [Medline: 32525379]
14. Smith ML, Steinman LE, Casey EA. Combatting social isolation among older adults in a time of physical distancing: the COVID-19 social connectivity paradox. Front Public Health 2020 Jul 21;8:403. [doi: 10.3389/fpubh.2020.00403] [Medline: 32850605]
15. Aarons GA, Sklar M, Mustanski B, Benbow N, Brown CH. "Scaling-out" evidence-based interventions to new populations or new health care delivery systems. Implement Sci 2017 Sep 06;12(1):111. [doi: 10.1186/s13012-017-0640-6] [Medline: 28877746]
16. Perez Jolles M, Lengnick-Hall R, Mittman BS. Core functions and forms of complex health interventions: a patient-centered medical home illustration. J Gen Intern Med 2019 Jun;34(6):1032-1038. [doi: 10.1007/s11606-018-4818-7] [Medline: 30623387]
17. Sheth K, Ritter PL, Lorig K, Steinman L, FallCreek S. Remote delivery of the chronic pain self-management program using self-directed materials and small-group telephone support: a pilot study. J Appl Gerontol 2022 May;41(5):1329-1335. [doi: 10.1177/07334648211062805] [Medline: 34965766]
18. Jernigan VB, Lorig K. The internet diabetes self-management workshop for American Indians and Alaska Natives. Health Promot Pract 2011 Mar;12(2):261-270. [doi: 10.1177/1524839909335178] [Medline: 20534807]
19. Lorig K, Ritter PL, Plant K, Laurent DD, Kelly P, Rowe S. The South Australia health chronic disease self-management internet trial. Health Educ Behav 2013 Feb;40(1):67-77. [doi: 10.1177/1090198112436969] [Medline: 22491008]
20. Patel KV, Hoffman EV, Phelan EA, Gell NM. Remotely delivered exercise to rural older adults with knee osteoarthritis: a pilot study. ACR Open Rheumatol 2022 Aug;4(8):735-744. [doi: 10.1002/acr2.11452] [Medline: 35687577]
21. Callahan LF, Shreffler JH, Altpeter M, Schoster B, Hootman J, Houenou LO, et al. Evaluation of group and self-directed formats of the Arthritis Foundation's Walk With Ease Program. Arthritis Care Res (Hoboken) 2011 Aug 01;63(8):1098-1107. [doi: 10.1002/acr.20490] [Medline: 21560255]
22. Shelton RC, Chambers DA, Glasgow RE. An extension of RE-AIM to enhance sustainability: addressing dynamic context and promoting health equity over time. Front Public Health 2020;8:134. [doi: 10.3389/fpubh.2020.00134] [Medline: 32478025]
23. Creswell JW, Plano Clark VL. Designing and Conducting Mixed Methods Research Third Edition. Thousand Oaks, CA: SAGE Publications; 2017.
24. Onyeaka H, Anumudu CK, Al-Sharify ZT, Egele-Godswill E, Mbaegbu P. COVID-19 pandemic: a review of the global lockdown and its far-reaching effects. Sci Prog 2021 Jun 01;104(2):368504211019854. [doi: 10.1177/00368504211019854] [Medline: 34061685]

25. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health 2015 Sep 6;42(5):533-544. [doi: 10.1007/s10488-013-0528-y] [Medline: 24193818]
26. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381. [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
27. Schoenfeld DE, Malmrose LC, Blazer DG, Gold DT, Seeman TE. Self-rated health and mortality in the high-functioning elderly--a closer look at healthy individuals: MacArthur field study of successful aging. J Gerontol 1994 May 01;49(3):M109-M115. [doi: 10.1093/geronj/49.3.m109] [Medline: 8169332]
28. Ware JE, Sherbourne CD. The MOS 36-ltem Short-Form Health Survey (SF-36). Med Care 1992;30(6):473-483. [doi: 10.1097/00005650-199206000-00002]
29. Ritter PL, González VM, Laurent DD, Lorig KR. Measurement of pain using the visual numeric scale. J Rheumatol 2006 Mar;33(3):574-580. [Medline: 16511926]
30. Lorig KR, Ritter PL, Jacquez A. Outcomes of border health Spanish/English chronic disease self-management programs. Diabetes Educ 2005 Dec 07;31(3):401-409. [doi: 10.1177/0145721705276574] [Medline: 15919640]
31. Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A short scale for measuring loneliness in large surveys: results from two population-based studies. Res Aging 2004 Aug 19;26(6):655-672. [doi: 10.1177/0164027504268574] [Medline: 18504506]
32. Berkman LF, Syme SL. Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. Am J Epidemiol 1979 Feb;109(2):186-204. [doi: 10.1093/oxfordjournals.aje.a112674] [Medline: 425958]
33. Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. J Affect Disord 2009 Apr;114(1-3):163-173. [doi: 10.1016/j.jad.2008.06.026] [Medline: 18752852]
34. Kroenke K, Spitzer RL, Williams JB, Monahan PO, Löwe B. Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. Ann Intern Med 2007 Mar 06;146(5):317-325. [doi: 10.7326/0003-4819-146-5-200703060-00004] [Medline: 17339617]
35. Coleman KJ, Ngor E, Reynolds K, Quinn VP, Koebnick C, Young DR, et al. Initial validation of an exercise "vital sign" in electronic medical records. Med Sci Sports Exerc 2012 Nov;44(11):2071-2076. [doi: 10.1249/MSS.0b013e3182630ec1] [Medline: 22688832]
36. Protocol for responding to and assessing patient assets, risks, and experiences (PRAPARE). Association of Asian Pacific Community Health Organizations (AAPCHO). URL: https://aapcho.org/focusareas/prapare/ [accessed 2024-04-20]
37. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract 2001;4(6):256-262. [Medline: 11769298]
38. Am I rural? – tool. Rural Health Information Hub. URL: https://www.ruralhealthinfo.org/am-i-rural [accessed 2023-08-13]
39. Chen K, Lou VW. Measuring senior technology acceptance: development of a brief, 14-item scale. Innov Aging 2020 Jun 27;4(3):igaa016. [doi: 10.1093/geroni/igaa016] [Medline: 32617418]
40. Reichheld FF. The one number you need to grow. Harvard Business Review. 2003 Dec. URL: https://hbr.org/2003/12/the-one-number-you-need-to-grow [accessed 2024-04-21]
41. Hamilton DF, Lane JV, Gaston P, Patton JT, MacDonald DJ, Simpson AH, et al. Assessing treatment outcomes using a single question. Bone Joint J 2014 May 01;96-B(5):622-628. [doi: 10.1302/0301-620x.96b5.32434]
42. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health 2011 Mar;38(2):65-76. [doi: 10.1007/s10488-010-0319-7] [Medline: 20957426]
43. R Core Team. R: a language and environment for statistical computing. R Foundation for Statistical Computing. 2019. URL: https://www.R-project.org/ [accessed 2024-04-21]
44. Ageing and health. World Health Organization. 2022 Oct 01. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2023-08-13]
45. Dankel SJ, Loenneke JP. Effect sizes for paired data should use the change score variability rather than the pre-test variability. J Strength Cond Res 2021 Jun 01;35(6):1773-1778. [doi: 10.1519/JSC.0000000000002946] [Medline: 30358698]
46. Armstrong RA. When to use the Bonferroni correction. Ophthalmic Physiol Opt 2014 Sep;34(5):502-508. [doi: 10.1111/opo.12131] [Medline: 24697967]
47. Dedoose version: web application for managing, analyzing, and presenting qualitative and mixed method research data. SocioCultural Research Consultants. 2019. URL: https://www.dedoose.com/ [accessed 2024-04-21]
48. Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. Int J Qual Methods 2017;16(1):1-13. [doi: 10.1177/1609406917733847]
49. Gale RC, Wu J, Erhardt T, Bounthavong M, Reardon CM, Damschroder LJ, et al. Comparison of rapid vs in-depth qualitative analytic methods from a process evaluation of academic detailing in the Veterans Health Administration. Implement Sci 2019 Feb 01;14(1):11. [doi: 10.1186/s13012-019-0853-y] [Medline: 30709368]
50. Saldaña J. The Coding Manual for Qualitative Researchers. Thousand Oaks, CA: SAGE Publications; 2015.

51. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013 Sep 18;13:117. [doi: 10.1186/1471-2288-13-117] [Medline: 24047204]
52. Guetterman TC, Fetters MD, Creswell JW. Integrating Quantitative and Qualitative Results in Health Science Mixed Methods Research Through Joint Displays. Ann Fam Med 2015 Nov;13(6):554-561 [FREE Full text] [doi: 10.1370/afm.1865] [Medline: 26553895]
53. Steinman L, Chavez Santos E, Chadwick K, Mayotte C, Johnson SS, Kohn M, et al. Remote evidence-based health promotion programs during COVID: a national evaluation of reach and implementation for older adult health equity. Health Promot Pract 2023 Jun 06:15248399231175843. [doi: 10.1177/15248399231175843] [Medline: 37282506]
54. Jaglal SB, Haroun VA, Salbach NM, Hawker G, Voth J, Lou W, et al. Increasing access to chronic disease self-management programs in rural and remote communities using telehealth. Telemed J E Health 2013 Jun;19(6):467-473. [doi: 10.1089/tmj.2012.0197] [Medline: 23570277]
55. Rosal MC, Heyden R, Mejilla R, Capelson R, Chalmers KA, Rizzo DePaoli M, et al. A virtual world versus face-to-face intervention format to promote diabetes self-management among African American women: a pilot randomized clinical trial. JMIR Res Protoc 2014 Oct 24;3(4):e54. [doi: 10.2196/resprot.3412] [Medline: 25344620]
56. LeFort SM, Gray-Donald K, Rowat KM, Jeans ME. Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain. Pain 1998 Feb;74(2-3):297-306. [doi: 10.1016/s0304-3959(97)00190-5] [Medline: 9520244]
57. Lorig K, Ritter PL, Villa FJ, Armas J. Community-based peer-led diabetes self-management: a randomized trial. Diabetes Educ 2009 Apr 30;35(4):641-651. [doi: 10.1177/0145721709335006] [Medline: 19407333]
58. Leveille SG, Wagner EH, Davis C, Grothaus L, Wallace J, LoGerfo M, et al. Preventing disability and managing chronic illness in frail older adults: a randomized trial of a community-based partnership with primary care. J Am Geriatr Soc 1998 Oct;46(10):1191-1198. [doi: 10.1111/j.1532-5415.1998.tb04533.x] [Medline: 9777899]
59. Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999 Jan;37(1):5-14. [doi: 10.1097/00005650-199901000-00003] [Medline: 10413387]
60. Ritter PL, Ory MG, Laurent DD, Lorig K. Effects of chronic disease self-management programs for participants with higher depression scores: secondary analyses of an on-line and a small-group program. Transl Behav Med 2014 Dec;4(4):398-406. [doi: 10.1007/s13142-014-0277-9] [Medline: 25584089]
61. Ory MG, Ahn S, Jiang L, Smith ML, Ritter PL, Whitelaw N, et al. Successes of a national study of the chronic disease self-management program: meeting the triple aim of health care reform. Med Care 2013 Nov;51(11):992-998 [FREE Full text] [doi: 10.1097/MLR.0b013e3182a95dd1] [Medline: 24113813]
62. Ahn S, Jiang L, Smith ML, Ory MG. Improvements in sleep problems among the chronic disease self-management program participants. Fam Community Health 2014;37(4):327-335 [FREE Full text] [doi: 10.1097/FCH.0000000000000045] [Medline: 25167073]
63. Pullyblank K, Brunner W, Scribani M, Krupa N, Wyckoff L, Strogatz D. Evaluation of a peer led chronic pain self-management program in a rural population. J Prim Care Community Health 2022 Sep 12;13:21501319221121464. [doi: 10.1177/21501319221121464] [Medline: 36112865]
64. Wallace JI, Buchner DM, Grothaus L, Leveille S, Tyll L, LaCroix AZ, et al. Implementation and effectiveness of a community-based health promotion program for older adults. J Gerontol A Biol Sci Med Sci 1998 Jul 01;53(4):M301-M306. [doi: 10.1093/gerona/53a.4.m301] [Medline: 18314570]
65. Belza B, Shumway-Cook A, Phelan EA, Williams B, Snyder SJ, LoGerfo JP. The effects of a community-based exercise program on function and health in older adults: the EnhanceFitness program. J Appl Gerontol 2016 Jun 29;25(4):291-306. [doi: 10.1177/0733464806290934]
66. Gell NM, Dittus K, Caefer J, Martin A, Bae M, Patel KV. Remotely delivered exercise to older rural cancer survivors: a randomized controlled pilot trial. J Cancer Surviv 2024 Apr 14;18(2):596-605. [doi: 10.1007/s11764-022-01292-y] [Medline: 36374436]
67. Stirman SW, Miller CJ, Toder K, Calloway A. Development of a framework and coding system for modifications and adaptations of evidence-based interventions. Implement Sci 2013 Jun 10;8(1):65. [doi: 10.1186/1748-5908-8-65] [Medline: 23758995]
68. Aarons GA, Ehrhart MG, Farahnak LR, Sklar M. Aligning leadership across systems and organizations to develop a strategic climate for evidence-based practice implementation. Annu Rev Public Health 2014;35:255-274. [doi: 10.1146/annurev-publhealth-032013-182447] [Medline: 24641560]
69. von Thiele Schwarz U, Aarons GA, Hasson H. The value equation: three complementary propositions for reconciling fidelity and adaptation in evidence-based practice implementation. BMC Health Serv Res 2019 Nov 21;19(1):868. [doi: 10.1186/s12913-019-4668-y] [Medline: 31752846]
70. Moore JE, Bumbarger BK, Cooper BR. Examining adaptations of evidence-based programs in natural contexts. J Prim Prev 2013 Jun 19;34(3):147-161. [doi: 10.1007/s10935-013-0303-6] [Medline: 23605294]

71. Rabin BA, McCreight M, Battaglia C, Ayele R, Burke RE, Hess PL, et al. Systematic, multimethod assessment of adaptations across four diverse health systems interventions. Front Public Health 2018;6:102. [doi: 10.3389/fpubh.2018.00102] [Medline: 29686983]
72. Green LW, Glasgow RE. Evaluating the relevance, generalization, and applicability of research: issues in external validation and translation methodology. Eval Health Prof 2006 Mar 23;29(1):126-153. [doi: 10.1177/0163278705284445] [Medline: 16510882]
73. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition--multimorbidity. JAMA 2012 Jun 20;307(23):2493-2494. [doi: 10.1001/jama.2012.5265] [Medline: 22797447]
74. Wiltsey Stirman S, Gamarra JM, Bartlett BA, Calloway A, Gutner CA. Empirical examinations of modifications and adaptations to evidence ‐ based psychotherapies: methodologies, impact, and future directions. Clin Psychol Sci Pract 2017 Dec;24(4):396-420. [doi: 10.1037/h0101747]
75. Metz A, Woo B, Loper A. Equitable implementation at work. Stanford Social Innovation Review. 2021. URL: https://ssir.org/articles/entry/equitable_implementation_at_work# [accessed 2024-04-20]
76. Kerkhoff AD, Farrand E, Marquez C, Cattamanchi A, Handley MA. Addressing health disparities through implementation science-a need to integrate an equity lens from the outset. Implement Sci 2022 Jan 31;17(1):13. [doi: 10.1186/s13012-022-01189-5] [Medline: 35101088]
77. Holt-Lunstad J. The potential public health relevance of social isolation and loneliness: prevalence, epidemiology, and risk factors. Public Policy Aging Report 2017;27(4):127-130. [doi: 10.1093/ppar/prx030]
78. Hawkley LC, Cacioppo JT. Aging and loneliness: downhill quickly? Curr Dir Psychol Sci 2016 Jun 24;16(4):187-191. [doi: 10.1111/j.1467-8721.2007.00501.x]
79. Picture of America. Centers for Disease Control and Prevention. URL: https://stacks.cdc.gov/view/cdc/142637 [accessed 2023-08-13]
80. Srivastava A. Challenges for evaluation practices and innovative approaches: lessons during COVID-19 pandemic. Eval Program Plann 2022 Jun;92:102095. [doi: 10.1016/j.evalprogplan.2022.102095] [Medline: 35500477]

Abbreviations

ACL: Administration for Community Living
CDC: Centers for Disease Control and Prevention
CDSMP: Chronic Disease Self-Management Program
CPSMP: Chronic Pain Self-Management Program
DSMP: Diabetes Self-Management Program
EBP: evidence-based program
EF: EnhanceFitness
PHQ: Patient Health Questionnaire
PROMIS: Patient-Reported Outcomes Measurement Information System
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance
REDCap: Research Electronic Data Capture
WWE: Walk With Ease

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Original Paper

Self-Explainable Graph Neural Network for Alzheimer Disease and Related Dementias Risk Prediction: Algorithm Development and Validation Study

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Abstract

Background: Alzheimer disease and related dementias (ADRD) rank as the sixth leading cause of death in the United States, underlining the importance of accurate ADRD risk prediction. While recent advancements in ADRD risk prediction have primarily relied on imaging analysis, not all patients undergo medical imaging before an ADRD diagnosis. Merging machine learning with claims data can reveal additional risk factors and uncover interconnections among diverse medical codes.

Objective: The study aims to use graph neural networks (GNNs) with claim data for ADRD risk prediction. Addressing the lack of human-interpretable reasons behind these predictions, we introduce an innovative, self-explainable method to evaluate relationship importance and its influence on ADRD risk prediction.

Methods: We used a variationally regularized encoder-decoder GNN (variational GNN [VGNN]) integrated with our proposed relation importance method for estimating ADRD likelihood. This self-explainable method can provide a feature-important explanation in the context of ADRD risk prediction, leveraging relational information within a graph. Three scenarios with 1-year, 2-year, and 3-year prediction windows were created to assess the model's efficiency, respectively. Random forest (RF) and light gradient boost machine (LGBM) were used as baselines. By using this method, we further clarify the key relationships for ADRD risk prediction.

Results: In scenario 1, the VGNN model showed area under the receiver operating characteristic (AUROC) scores of 0.7272 and 0.7480 for the small subset and the matched cohort data set. It outperforms RF and LGBM by 10.6% and 9.1%, respectively, on average. In scenario 2, it achieved AUROC scores of 0.7125 and 0.7281, surpassing the other models by 10.5% and 8.9%, respectively. Similarly, in scenario 3, AUROC scores of 0.7001 and 0.7187 were obtained, exceeding 10.1% and 8.5% than the baseline models, respectively. These results clearly demonstrate the significant superiority of the graph-based approach over the tree-based models (RF and LGBM) in predicting ADRD. Furthermore, the integration of the VGNN model and our relation importance interpretation could provide valuable insight into paired factors that may contribute to or delay ADRD progression.

Conclusions: Using our innovative self-explainable method with claims data enhances ADRD risk prediction and provides insights into the impact of interconnected medical code relationships. This methodology not only enables ADRD risk modeling but also shows potential for other image analysis predictions using claims data.

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KEYWORDS

Alzheimer disease and related dementias; risk prediction; graph neural network; relation importance; machine learning

Introduction

Background

Alzheimer disease and related dementias (ADRD) currently rank as the sixth leading cause of death in the United States [1]. Currently, 47 million people live with ADRD globally [2]. By the year 2050, the prevalence of dementia is expected to triple worldwide [3]. These alarming statistics emphasize the pressing need for accurately predicting ADRD risk, which holds immense significance for several reasons. First, it enables early detection and diagnosis, which can facilitate timely interventions and treatment plans that have the potential to slow down disease progression, improve patient outcomes, and enhance the quality of life for individuals affected by ADRD. Second, it also plays a crucial role in advancing research and drug development. It provides valuable insights into disease progression, risk factors, and potential therapeutic targets. By identifying individuals at high risk of developing ADRD, researchers can conduct targeted studies and clinical trials and explore preventive measures to mitigate the impact of this debilitating disease. Third, early prediction and intervention may help reduce health care costs associated with ADRD. By identifying individuals at risk and providing appropriate care, the burden on the health care system can be lessened. Nevertheless, predicting ADRD risks is an intricate task due to its nature as a long-term chronic disease with multifaceted underlying causes.

In the context of ADRD risk prediction, the conventional approach predominantly involves using machine learning (ML) models with medical imaging data as primary resources to achieve commendable success [4-6]. However, it is important to acknowledge that not all patients undergo routine clinical imaging tests during their regular visits, rendering medical imaging data less accessible for certain individuals. In contrast, claims data provide a more readily available data source for the ML predictors. Hence, the development of a valuable and easily trainable risk prediction tool necessitates the use of existing claims data as the primary input for prediction. This approach not only enhances the model's generalizability but also facilitates its adaptation to other diverse data sources.

In recent years, the emergence of graph-structured data has received significant interest within the realm of deep learning [7-11]. Graphs are composed of nodes and relationships, resulting in the representation and analysis of intricate connections and patterns within the data they encapsulate. They also offer a unique combination of topological structure and individual features, which enables a rich source of information [12,13]. To analyze and model the complex relations of interconnected graph data, graph neural networks (GNNs) have emerged as a powerful tool [14]. Unlike traditional ML models that operate on fixed-dimensional inputs, GNNs operate directly on the graph structure, which allows them to learn the representation of individuals, attributes, and relationships. In the biomedical domain, GNNs have been used for tasks such as protein function prediction, drug discovery, disease classification, and personalized medicine [15-20]. Li et al [21] proposed a multi-channel GNN for predicting drug-target interactions that combines a multi-channel graph convolutional network and graph attention network (GAT). This framework uses a topology graph for contextual representation, a feature graph for semantic representation, and a common representation of drug and protein pairs. It has demonstrated remarkable accuracy in identifying drug-target interactions, achieving an impressive area under the receiver operating characteristic (AUROC) score of 0.9665. Wang et al [22] introduced a deep learning framework, Deep Learning for Drug-Drug Synergy prediction (DeepDDS), for predicting drug-drug interactions for anticancer treatments. DeepDDS uses gene expression data from the cancer cell line and the molecular graph of the drugs as input. It leverages GAT and graph convolution transformers (GCTs) to accurately predict the synergistic effect between drug combinations. DeepDDS has achieved an AUROC score of 0.67 on an independent test set. In the task of ADRD prediction, GCT obtained an area under the precision-recall curve of 0.34 on the inpatient and outpatient electronic health record (EHR) data from NYU Langone Health (briefly called AD-EHR) [23]. Klepl et al [24] integrated functional connectivity methods with GNNs to evaluate ADRD prediction performance using electroencephalography brain data. They showed that the GNN-based approach outperformed convolutional neural network and support vector machine models and obtained an AUROC of 0.984 [24]. Zhu and Razavian [23] presented variational GNN (VGNN), a variationally regularized encoder-decoder GNN, designed specifically for EHRs. This framework showed robustness in learning graph structures by applying regularization techniques to node representations. VGNN was used for ADRD risk prediction, and it attained an area under the precision-recall curve of 0.46 when using AD-EHR.

The abovementioned GNN models [23,24] have demonstrated the potential to uncover hidden patterns, reveal biological insights, and facilitate advancements in ADRD prediction. However, because the GNN architecture is a black-box model, the absence of interpretability is harmful to both users and society [25], especially in critical applications where decisions need to be explained or understood. Even though some advanced models such as GAT, GCT, and VGNN have the ability to explain the importance of individual nodes by using attention mechanisms, they still face a limitation in their interpretability concerning the significance of underlying relationships in the prediction process. As a consequence, there is a pressing demand for research and development efforts to enhance GNNs and elucidate the influence of relationship importance in achieving more precise ADRD predictions. By addressing this interpretability issue, GNNs can become more valuable tools in advancing our understanding of ADRD and contributing to improved patient care and treatment strategies.

Objective

The first focus of this study lies in the domain of risk prediction for ADRD. In this particular context, our investigation aims to use claims data as the sole input for our GNN-based predictive model for accurate ADRD risk prediction. We enhance the predictive power of our model by incorporating advanced GNN models into a framework that enables us to effectively capture the intricate relationships and dependencies inherent in the claims data.

Second, we introduced a novel method to assess the importance of relationships within the patients' individual medical record graphs and their influence on ADRD risk prediction. Generally, an additional graph explanation technique, such as GNNExplainer [26], is used as a post hoc method to interpret the predictions made by the GNNs. However, our proposed relation importance method enables an "in-process" explanation approach that leverages the relation weights from each patient's individual graph. This method facilitates the interpretation of the GNN's predictions during the graph generation process itself. Besides that, our method aims to adequately calibrate the importance of each relationship within the graph, reflecting their true impact on prediction. Since, typically, when a relation connects to nodes that are highly prevalent in the graph, there is a risk of misdefining its significance. The frequent occurrence of these nodes can distort the perception of the relationship's importance, potentially leading to erroneous interpretations or biased conclusions. This bias can result in a skewed importance assigned to relationships, and hence potentially affecting the accuracy of ADRD risk prediction. By considering the patient groups with and without ADRD, our approach helps to mitigate the potential bias resulting from node frequency, enabling a more comprehensive and reliable interpretability of relation importance for ADRD risk prediction.

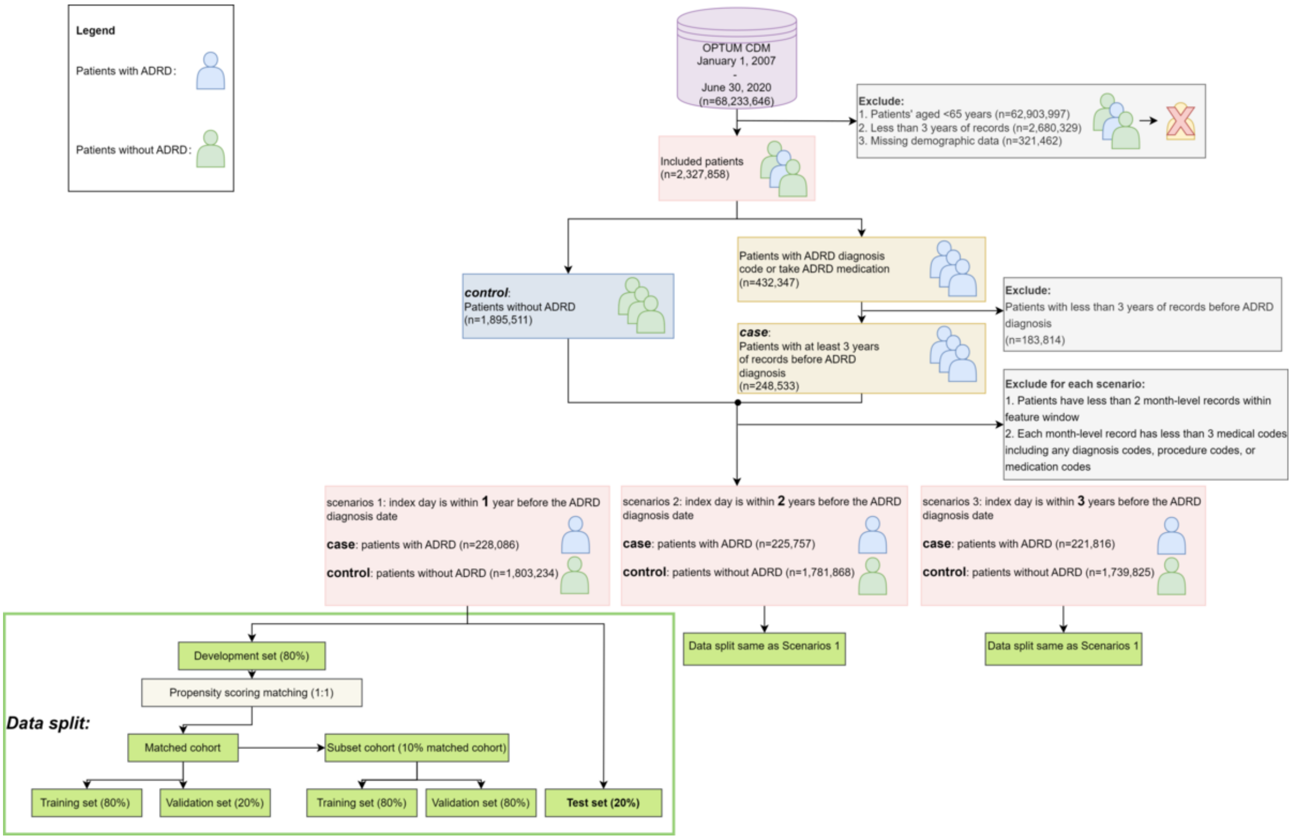
Methods

Cohort Description

We used deidentified administrative health claims data from Optum's Clinformatics Data Mart, spanning from 2007 to 2020. This data set comprises over 68 million patient-level enrollment records submitted by various health care providers, pharmacies, and other health care service organizations for reimbursement purposes. It is accessible for researchers through a subscription provided by the University of Texas Health Science Center (UTHealth) [27].

Several criteria were applied to construct the study cohort, as illustrated in Figure 1. Considering that ADRD primarily affects older individuals and is a chronic condition, we initially filtered out patients (n=62,903,997) who were younger than 65 years. To ensure a sufficient data history for tracking their medical conditions, patients (n=2,680,329) with a time span of less than 3 years between their initial and final medical records were excluded. Patients (n=321,462) who lacked demographic information were also excluded from the study. To further establish the ADRD cohort, we used the definition outlined by Kim et al [28]. Patients were classified as having ADRD if they presented specific diagnosis codes or were prescribed relevant medications. The specified diagnosis codes are Alzheimer dementia (331.0*/G30.*), vascular dementia (290.4*/F01.*), frontotemporal dementia (331.1*/G31.0*), lewy body dementia (331.82*/G31.83), senile dementia (290.0*), presenile dementia (290.1*), other specified senile psychotic (290.8*), and unspecified senile psychotic condition (290.9*), and the medication includes aricept, donepezil, razadyne, reminyl, galantamine, exelon, rivastigmine, namenda, memantine, acetylcholine, and memantine. Based on the criteria mentioned above, the resulting cohort included 432,374 patients with ADRD and 1,895,511 patients without ADRD.

Figure 1. Overview of cohort selection for 3 scenarios. ADRD: Alzheimer disease and related dementias.



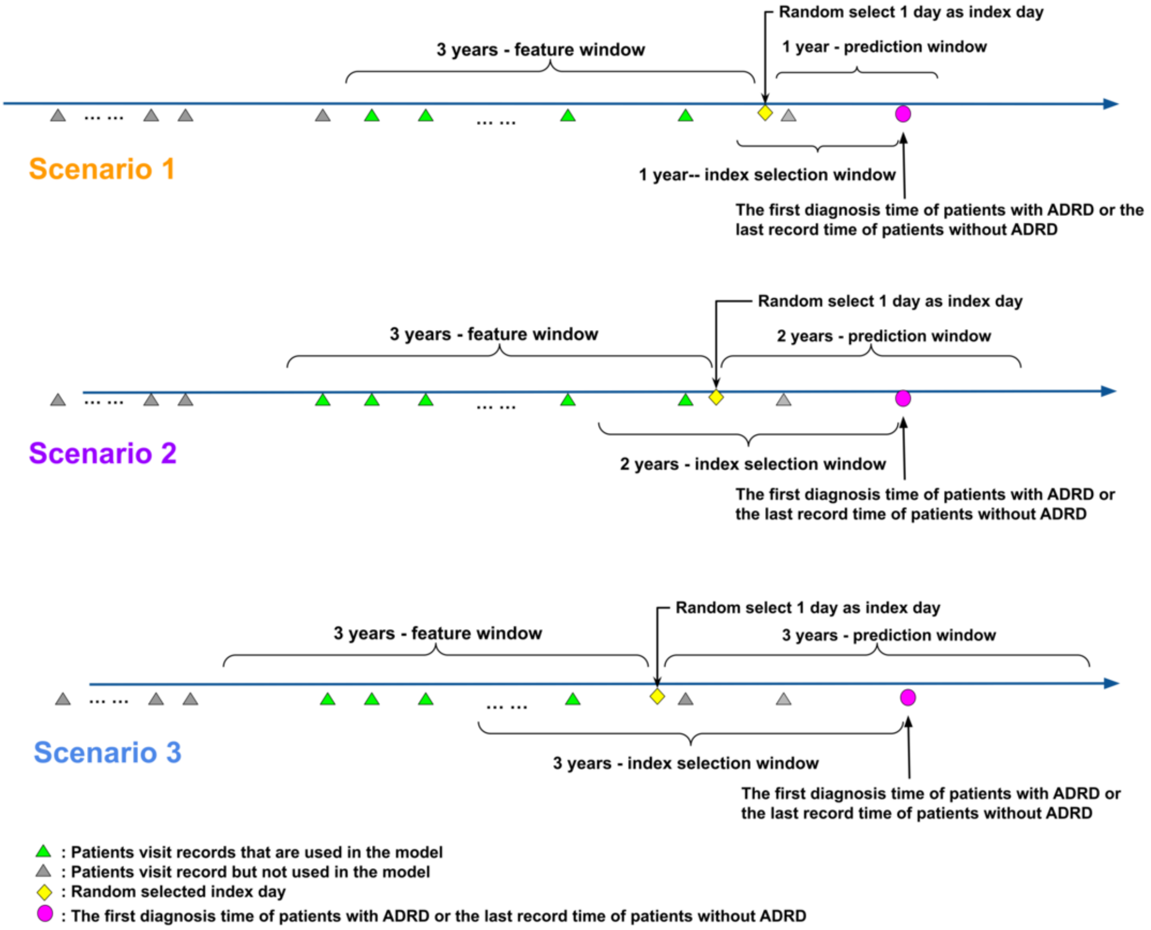
Data Preprocessing

In this study, we used a partitioning approach to categorize each patient's records into 3 time windows, such as an index selection window, a feature window, and a prediction window (shown in Figure 2). First, we designated a specific period before the initial diagnosis of patients with ADRD or the last record for patients without ADRD as the index selection window. In the real world, patients may seek consultations for their health conditions at any time. To simulate this visiting setting, we randomly select the index day within each patient's index selection window instead of using a fixed day. The 3-year period before the index day serves as the feature window for model training purposes, while a certain period after the index day is defined as the "prediction window" for ADRD risk prediction. Additionally, we designed 3 scenarios with index selection windows and prediction windows of 1, 2, and 3 years in length, respectively. By using this partitioning approach, we can comprehensively evaluate our model's predictive accuracy in dynamically predicting ADRD diagnoses. It should be noted that researchers can easily adjust the lengths of these windows to align with their specific requirements and objectives.

There are also other inclusion criteria that were applied to ensure the quality of the data and the fairness of the cohort. Specifically, within the feature window, it was required that each patient have a minimum of 2 month-level records. Furthermore, within the records in the same month, a minimum of 3 medical codes (eg, diagnosis codes, procedure codes, and medication codes) needed to be present. After applying these criteria, the resulting cohort for each scenario is presented in Figure 1. In scenario 1, the cohort consisted of a total of 2,031,320 patients, comprising 228,086 patients with ADRD and 1,803,234 patients without ADRD. For scenario 2, the cohort comprised 2,007,625 patients, including 225,757 patients with ADRD and 1,781,868 patients without ADRD. Finally, in scenario 3, the cohort encompassed 1,961,641 patients, with 221,816 patients with ADRD and 1,739,825 patients without ADRD. These cohorts provide a robust foundation for further analysis and investigation in this study.

The data used in all cohorts included claims data consisting of diagnoses encoded with both International Classification of Diseases, 9th revision (ICD-9) codes and 10th version (ICD-10) codes, the National Drug Code for pharmacy claims, current procedural terminology, and Healthcare Common Procedure Coding System codes for procedures. The inclusion of both ICD-10 and ICD-9 codes was necessary as the study period spanned the transition from ICD-9 to ICD-10 coding systems. All these different types of medical codes have been converted to a higher-level categorization scheme to achieve feature reduction, uniformity, and compatibility within the study analysis. The ICD-9 and ICD-10 codes and the current procedural terminology and Healthcare Common Procedure Coding System codes are converted to clinical classification software, which is a tool for clustering patient diagnoses and procedures into a manageable number of clinically meaningful categories developed at the Agency for Healthcare Research and Quality (formerly known as the Agency for Health Care Policy) [29]. Similarly, we are using the Pharmacologic-Therapeutic Classification System from the American Hospital Formulary Service to represent and group the drug National Drug Code in the data set [30]. It is a method of grouping drugs with similar pharmacologic, therapeutic, and chemical characteristics in a 4-tier hierarchy associated with a numeric code consisting of 2 to 8 digits. By following the conversion of these codes, the number of features was reduced from tens of thousands to hundreds. This reduction not only helps address the issue of sparsity in the model input but also improves its overall efficiency.

Figure 2. The definition of 3 scenarios. We established a time frame that includes an index selection window, a feature window, and a prediction window. The index selection window spanned a specific period before the initial diagnosis of patients with Alzheimer disease and related dementias (ADRD) or the last record for patients without ADRD. We randomly selected a day within the index selection window as the index day to simulate real-world visiting settings. The period up to 3 years before this index day was considered the feature window for training the model, while the period after the index day was used as the prediction window. We used 1 year, 2 years, and 3 years as the lengths of the index selection window and corresponding prediction window, respectively, to predict ADRD diagnosis dynamically.

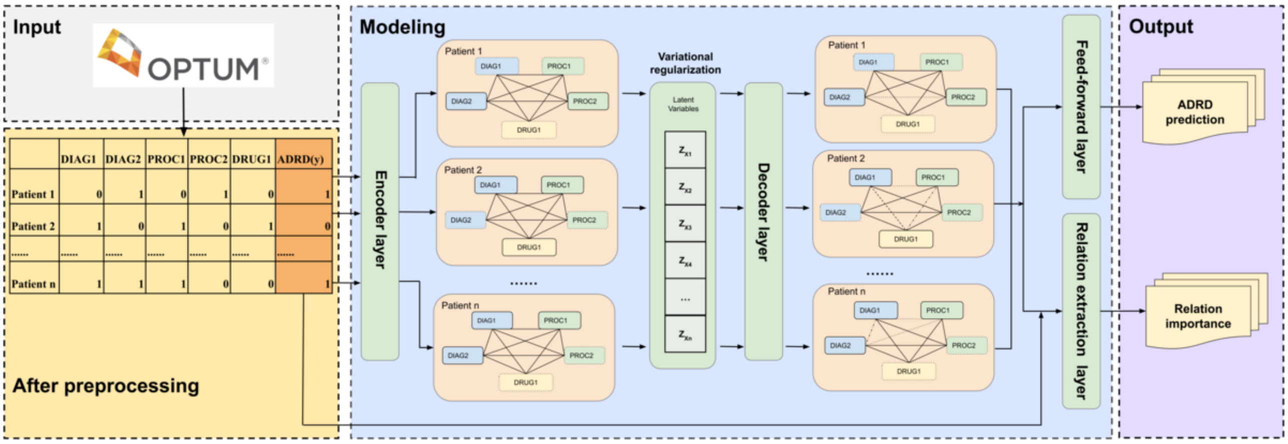


Modeling

We used the VGNN in combination with patients' diagnosis, procedure, and medication codes to estimate the likelihood of patients having ADRD within a designated prediction window. VGNN consists of 4 modules, such as the encoder graph, variational regularization, decoder graph, and fully connected layer. In the encoder graph module, VGNN takes 3 types of patients' medical codes from the feature window as input and constructs a fully connected graph comprising medical codes for each patient. The representation of each node is iteratively updated through multiple graph attention layers. To address the challenges of generating node embeddings within clusters and achieving balanced attention weights, VGNN incorporates a variational regularization layer. This layer helps prevent model collapse and maintains the model's expressive capacity. The decoder graph module uses the node representations generated by the encoder graph and the variational regularization layer to compute the weighted relations between each node. These weighted relationships effectively capture the relationships among different medical codes. Finally, a linear feed-forward layer is used to calculate the probability and produce the binary classification for identifying an individual with ADRD.

We initiated the modeling process by reserving 20% of patients from the entire data set for testing purposes. Given that ADRD is more prevalent in the older population [1] and our data set exhibits a high imbalance, we used the propensity score matching method based on age and gender to mitigate potential biases associated with these factors. This matching process ensured that our model's input cohort consisted of individuals with similar age and gender distributions, reducing the potential confounding effects associated with these variables. As a result, we created a balanced cohort with a one-to-one ratio of control and case groups from the remaining 80% of the entire data set. This downsampling approach is a popular method in clinical research to create a balanced covariate distribution between treated and untreated groups, which could help significantly improve the model's ability to handle imbalanced data [31]. We named it the matched cohort and used it for the purposes of model development and validation. Additionally, we generated a smaller subset named the subset cohort, which is 10% of the matched cohort. This action allows us to evaluate the model's performance on a smaller-scale data set effectively. In order to assess the efficacy of our approach, we built models for 3 different scenarios. Moreover, we used random forest (RF) and light gradient boost machine (LGBM) as baseline models and compared their performance with that of VGNN. The overall workflow of our model pipeline is shown in Figure 3.

Figure 3. The workflow of sour study pipeline, including data preprocessing, graph modeling, and final output. The DIAG, PROC, and DRUG represent 3 types of medical codes: diagnosis, procedure, and medication, respectively. We used the variationally regularized encoder-decoder graph neural network (VGNN) to predict the likelihood of Alzheimer disease and related dementias (ADRD) using patients' medical records sourced from Optum Clinformatics. The data were input into the encoder layer of VGNN, generating a fully connected graph specific to each patient. The variational regularization layer was then applied to prevent issues like mode collapse and maintain the model's capacity to represent information effectively. Additionally, the decoder graph module used node representations to compute weighted relations between nodes, which effectively captured relationships among different medical codes. Finally, a linear feed-forward layer was used to calculate probabilities and perform binary classification.



	DIAG1	DIAG2	PROC1	PROC2	DRUG1	ADRD(y)
Patient 1	0	1	0	1	0	1
Patient 2	1	0	1	0	1	0
......	......	......	......	......	......	......
Patient n	1	1	1	0	0	1

Relation Importance

After the completion of model training, we then used the trained model to build the interconnected medical record graph for each individual patient. In order to evaluate the significance of various relationships in ADRD prediction, we extracted adjacency matrices . from the medical graphs of N patients in the training set of the matched cohort. The values within these adjacency matrices serve as indicators of the relational importance associated with predicting ADRD. Given that the generated graphs are directional, the adjacency matrices *A* are not symmetric. Therefore, we took an additional step to mitigate the influence of directionality by computing the average of the original adjacency matrix and its transposed matrix. Then, the updated adjacency matrix is:

This adjacency matrix enables us to gain insights into the intricate relationships between medical codes and their predictive power for ADRD.

However, it is crucial to consider that medical codes with higher frequencies may have received relatively larger weights compared to others, potentially introducing bias in the analysis. Given that A^+ are the adjacency matrices of patients with ADRD case group and $A^-$are the adjacency matrices of ADRD patient control group, we calculated the mean adjacency matrix of these 2 patient groups as:

By subtracting the negative mean adjacency matrix from the positive mean adjacency matrix, we eventually obtained a mean weight-difference matrix:

This mean weight-difference matrix *W* captured the relative significance of the medical code weights. A higher positive value inside *W* indicates a greater importance in predicting ADRD, while a lower negative value suggests a reduced likelihood of ADRD occurrence. A value of 0 in *W* means that the relationship does not affect a patient with ADRD.

Ethical Considerations

The approval for the use of data in this study was obtained from the UTHealth Committee for the Protection of Human Subjects, under protocol HSC-SBMI-21-0965, with a waiver of consent granted.

Results

Hyperparameter Setting

We trained the VGNN model with the following hyperparameters: a learning rate of 0.0001, a batch size of 128, and a dropout rate of 0.1. We used the Adam optimizer for gradient descent and trained the model for 200 epochs. The model consisted of 2 graph layers and 1 attention head. To balance the binary cross-entropy and Kullback-Leibler divergence losses, a parameter value of 0.002 was used. Additionally, edge information was extracted after the attention layer to facilitate future calculations of relational importance. Additionally, we used the grid search method to tune the RF and LGBM baseline models. The hyperparameters for RF and

LGBM are n_estimators=100, min_samples_split=2, and min_samples_leaf=1, and n_estimators=300, boosting_type="gbdt," num_leaves=31, and learning_rate=0.1, respectively.

Performance Evaluation

We used AUROC as a measurement to evaluate the performance of each model. As shown in Table 1, the VGNN model achieved AUROC scores of 0.7272 and 0.7480 for the subset cohort and the matched cohort, respectively, in scenario 1. It outperformed the RF and LGBM models by an average of 10.6% and 9.1% across the 2 data sets. For scenario 2, the VGNN model obtained AUROC scores of 0.7125 and 0.7281 for the subset cohort and matched cohort, respectively. It exhibited superior performance compared to the other 2 models by an average of 10.5% and 8.9% across the 2 data sets. Finally, in scenario 3, the VGNN model achieved AUROC scores of 0.7001 and 0.7187, which were surpassed by an average of 10.1% and 8.5% across the 2 data sets. The results clearly demonstrate that the GNN approach (VGNN) outperforms the tree-based models (RF and LGBM) significantly in predicting ADRD. The bar chart for the performance comparison can be found in Multimedia Appendix 1.

Furthermore, we identified the 5 most important relationships for both positive and negative predictions of ADRD in Table 2. Among the top 5 negative highest-weighted relationships, "neoplasms of unspecified nature or uncertain behavior" exhibits its influence across all relations within scenario 1, "consultation, evaluation, and preventative care" makes a total of 4 appearances within scenario 2, while "quinolone antibiotics" spans all relations in scenario 3. Within the set of the top 5 positive highest-weighted relationships, both "routine chest x-ray" and "electrocardiogram" appear 3 times each in scenario 1, "substance-related disorders" contributes to 4 relationships in scenario 2, and "substance-related disorders" emerges as the most frequently occurring medical code in scenario 3.

Table 1. The model performance (area under the receiver operating characteristic curve scores) for Alzheimer disease and related dementias risk prediction.

Scores	Random forest	Light gradient boost machine	Variational graph neural network
Matched cohort			
Scenario 1	0.6710	0.6809	0.7480
Scenario 2	0.6565	0.6658	0.7281
Scenario 3	0.6468	0.6589	0.7187
Subset cohort			
Scenario 1	0.6629	0.6720	0.7272
Scenario 2	0.6474	0.6570	0.7125
Scenario 3	0.6425	0.6490	0.7001

Table 2. Top 5 positive highest-weighted relations and top 5 negative highest-weighted relations.

Scenarios and relations	Scenario 1		Scenario 2		Scenario 3	
Top 5 negative highest-weighted relations						
1	Neoplasms of unspecified nature or uncertain behavior	Consultation, evaluation, and preventative care	Consultation, evaluation, and preventative care	Dihydropyridines	Quinolone antibiotics	Suture of skin and subcutaneous tissue
2	Neoplasms of unspecified nature or uncertain behavior	Lens and cataract procedures	Consultation, evaluation, and preventative care	Diseases of white blood cells	Quinolone antibiotics	Lens and cataract procedures
3	Neoplasms of unspecified nature or uncertain behavior	Hyperlipidemia	Consultation, evaluation, and preventative care	Upper gastrointestinal endoscopy, biopsy	Quinolone antibiotics	Essential hypertension
4	Neoplasms of unspecified nature or uncertain behavior	Diabetes mellitus with complications	Consultation, evaluation, and preventative care	Other CT scan	Quinolone antibiotics	Diagnostic ultrasound of head and neck
5	Neoplasms of unspecified nature or uncertain behavior	Diagnostic ultrasound of head and neck	Diseases of white blood cells	Dihydropyridines	Quinolone antibiotics	Psychological and psychiatric evaluation and therapy
Top 5 positive highest-weighted relations						
1	Routine chest x-ray	Electrocardiogram	Substance-related disorders	Electrocardiogram	Schizophrenia and other psychotic disorder	Substance-related disorders
2	Routine chest x-ray	Other laboratory	Substance-related disorders	Other laboratory	Schizophrenia and other psychotic disorder	Diagnostic procedures on nose, mouth, and pharynx
3	Routine chest x-ray	Heart valve disorders	Substance-related disorders	Routine chest x-ray	Diagnostic ultrasound of head and neck	Arthrocentesis
4	Electrocardiogram	Other laboratory	Electrocardiogram	Inguinal and femoral hernia repair	Diagnostic ultrasound of head and neck	Substance-related disorders
5	Electrocardiogram	Heart valve disorders	Substance-related disorders	Coronary atherosclerosis and other heart disease	Substance-related disorders	Other diagnostic radiology and related techniques

Discussion

Principal Findings

Based on this study's results, we found that some potential candidates might be relevant to ADRD risk prediction and treatment. Our self-explainable GNN prediction method reveals the underneath connections between medical codes for ADRD risk prediction. Some code pairs have been shown to accelerate ADRD progression, while others exhibit potential to slow down its development. When implementing our relation importance interpretation method, the GNN results are explainable, setting it apart from other deep learning models. Moreover, several code pairs extracted from the GNN align with findings from previous research. Those code pairs that are not proven could offer valuable insights beyond the scope of current studies, opening up avenues for further investigation and enhancing our understanding of ADRD risk prediction. Table 2 shows the top 5 positive highest-weighted relations and the top 5 negative highest-weighted relations. In the following sections, we will present examples of code pairs derived from the GNN model results and highlight their significance based on validated evidence from previous studies.

This study found that certain pairs of medical codes can be associated with a decreased likelihood of an ADRD diagnosis. For instance, the treatment of more acute conditions, such as cancer or neoplasms, may delay the diagnosis of ADRD. We hypothesize that "neoplasms of unspecified nature or uncertain behavior" may be correlated with higher health care use or more frequent physician visits, similar to the code "consultation, evaluation, and preventative care." The cooccurrence of these 2 types of coding could potentially lower the risk of ADRD. Regular health care visits could potentially reduce the risk of ADRD by improving modifiable risk factors and mitigating social isolation in older patients. Lee et al [32] revealed that cataract extraction is linked to a reduced risk of developing dementia among older adults. Cataract extraction has been associated with enhanced engagement in intellectually stimulating activities, such as reading and video consumption, as well as increased physical activity. These changes in lifestyle and cognitive engagement following cataract surgery may contribute to a delay in the onset of ADRD. Consequently, the second node pair involving “neoplasms of unspecified nature or uncertain behavior” and “lens and cataract procedures” also holds relevance and supports the observed association. In scenario 2, Peters et al [33] have indicated that the use of calcium channel blockers, specifically dihydropyridines, is associated with a lower decline in cognitive function compared to other hypertensive treatments. Thus, the presence of the “consultation, evaluation, and preventative care” and “dihydropyridines” nodes pair ranking first in importance is consistent with the reported associations. The most frequently appearing node in scenario 3 is “quinolone antibiotics.” According to the study by Pham et al [34], it is a class of medication commonly prescribed to treat various bacterial infections and is primarily used for its antimicrobial properties [34]. Additionally from a study by Gao et al [35], their review study indicates that the brain inflammation caused by microbial infections may be one of the etiologies of ADRD, and antibiotics as novel treatments may be beneficial for delaying the development of ADRD. Quinolones exhibit a distinct pharmacokinetic profile characterized by a higher cerebrospinal fluid to serum concentration ratio compared to other commonly prescribed antibiotics [36]. This unique attribute may underlie the observed robust negative correlation between quinolone administration and the development of ADRD, distinguishing its potential protective effect from that of other antibiotics. The use of quinolones likely correlates with younger age, as its use in older adults is less frequent due to the increased risk of tendon rupture. However, this is less likely to explain its negative correlation with the onset of ADRD in our age-matched cohorts. So, in other words, it can be hypothesized that “quinolone antibiotics” may potentially exhibit a slowing effect on the progression of ADRD. Combined with the aforementioned node “lens and cataract procedures,” the observed association of this node pair holds validity and is worth further investigation.

This study also found certain medical codes to be positively associated with a higher likelihood of an ADRD diagnosis. This can be explained by the fact that Alzheimer disease, to a certain degree, is a “diagnosis of exclusion.” Procedures like “routine chest x-ray” and “electrocardiogram” are commonly used as initial steps in diagnosing altered mental status, which is often the first sign of ADRD. A chest x-ray is often used to rule out any underlying pneumonia, while an electrocardiogram may be used to rule out arrhythmia [37]. Similarly, “diagnostic ultrasound of head and neck” is commonly done to rule out conditions like carotid artery clot, stenosis, or plaque in the setting of stroke workups. Once patients begin to verify these initial diagnoses of altered mental status, they are more likely to undergo comprehensive and relevant testing to exclude other potential causes of the symptoms, which may potentially lead to a timely determination of ADRD. Several studies have also found that alcohol and drug use could affect mental state and cognitive function [38]. People who abuse intoxicating substances for a considerable period may develop dementia or accelerate the neurological damage associated with Alzheimer [39].

From the modeling aspect, to the best of our knowledge, our approach offers distinct advantages in comparison to previous studies on the early diagnosis of ADRD with or without GNN methods. For instance, Li et al [40] used a gradient boost tree and logistic regression to assess ADRD risk using EHR data from the OneFlorida+ Clinical Research Consortium. They identified significant clinical and social factors through SHAP values; however, these factors were commonly known risk factors. In contrast, our findings unveil potential risk factors and explain the interaction among these factors in ADRD prediction. While VGNN demonstrates good interpretability by showcasing attention weights among features, it fails to explain how these features positively or negatively impact ADRD prediction [23]. On the other hand, our model offers interpretations of potential risk factors and illustrates their influence on outcomes. Furthermore, our proposed self-explainable framework mitigates the potential bias resulting from the prevalence of medical codes. Klepl et al [24] conducted electroencephalography-based ADRD prediction using GNN methods. As medical image data are unavailable for every patient during routine examinations, limitations arise due to the restricted user cases. Furthermore, they only assessed model performance against baseline models without providing any feature interpretation. Conversely, our method enhances interpretability by leveraging more accessible data, thereby promoting broader applicability and understanding in ADRD prediction. Overall, this is the first work that proposes a self-explainable framework, providing a feature-important explanation in the context of ADRD risk prediction leveraging relational information within a graph. Compared with other studies on ADRD risk predictions, our method can directly interpret the relationship’s importance within the training process. It does not require any additional post hoc explanation methods, such as GNNExplainer [26]. In other words, within our framework, it takes no additional time to get an explanation.

In summary, we showed that using the GNN approach for ADRD prediction has better performance compared to baseline models. Moreover, with the incorporation of our relation importance method, the model’s results become explainable, providing valuable insights into the underlying factors contributing to ADRD risk prediction.

Limitations

Our prediction does not incorporate time information into the modeling process. In this study, we aggregated 3 years of records into a single representation and treated them equally without considering their temporal sequence. In the real-world clinical setting, medical events, procedures, or medications obtained at different times should carry different levels of significance. In other words, events occurring closer in time to the prediction window are expected to have a greater impact on the disease prediction. In our future study, we could use a time series model and positional encoding method to establish connections between patients’ multiple visit records for more accurate predictions and provide more valuable insights into ADRD prediction.

On the other hand, it is important to note that certain predicted correlations may not causally assist clinicians in diagnosing ADRD. For instance, initiating tests for early detection of altered mental status might lead patients to identify ADRD through various related tests. Nonetheless, from the clinician's perspective, ordering these test results may not be helpful for early ADRD prediction. In our future work, we could try to exclude these "subjective patient-related factors" and instead focus on investigating more objective risk factors that could potentially influence the prediction of ADRD.

Conclusion

In this study, we used an advanced self-explainable GNN approach and developed a relation importance interpretation method for the ADRD risk prediction task based on claims data sources. The VGNN model's effectiveness was evaluated across 3 distinct scenarios, with comparisons made against RF and LGBM ML models. The model's performance achieved satisfactory results. In addition, we provided the interpretation for the node pairs extracted from the KG, which was generated from the VGNN model. Furthermore, we demonstrated the results' future applicability and explained the important node pairs that align with previous research findings. This work contributes to the advancement of ADRD prediction models and reinforces the importance of interpretable results for informed clinical decision-making and early detection, etc.

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Authors' Contributions

CT conceived the research project, supervised the research, and critically revised the manuscript. XH, ZS, and YN designed the pipeline and method and implemented the deep learning model of the study and the explanation method. XH, ZS, and YW prepared the manuscript. XH and YD provided the cohort selection, scenario definitions, model workflow, and model performance figures. XH and JF prepared the data. FL and EY provided suggestions on data filtering, index day selection, and model design. YW composed a clinical discussion on the principal findings. All authors proofread the paper, provided valuable suggestions, and have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The model performance (area under the receiver operating characteristic scores) for Alzheimer disease and related dementia risk prediction. Matched cohort: employ 1:1 propensity score match for case and control in the original training data (i.e., 80% of full data), to achieve a balanced dataset and train the models, and test the models in the hold-out 20% of full data. Subset cohort: use around 10% of the Matched cohort (i.e., 20,000 for both case and control) to train the models, and test the models in the hold-out 20% of full data.

[PNG File , 832 KB - aging_v7i1e54748_app1.png]

References

1. Alzheimer's Association. 2019 Alzheimer's disease facts and figures. Alzheimer's Dementia 2019 Mar;15(3):321-387. [doi: 10.1016/j.jalz.2019.01.010]
2. Tiwari S, Atluri V, Kaushik A, Yndart A, Nair M. Alzheimer's disease: pathogenesis, diagnostics, and therapeutics. Int J Nanomedicine 2019;14:5541-5554 [FREE Full text] [doi: 10.2147/IJN.S200490] [Medline: 31410002]
3. Scheltens P, De Strooper B, Kivipelto M, Holstege H, Chételat G, Teunissen CE, et al. Alzheimer's disease. Lancet 2021;397(10284):1577-1590 [FREE Full text] [doi: 10.1016/S0140-6736(20)32205-4] [Medline: 33667416]
4. James C, Ranson JM, Everson R, Llewellyn DJ. Performance of machine learning algorithms for predicting progression to dementia in memory clinic patients. JAMA Netw Open 2021;4(12):e2136553 [FREE Full text] [doi: 10.1001/jamanetworkopen.2021.36553] [Medline: 34913981]
5. Ota K, Oishi N, Ito K, Fukuyama H, SEAD-J Study Group, Alzheimer's Disease Neuroimaging Initiative. Effects of imaging modalities, brain atlases and feature selection on prediction of Alzheimer's disease. J Neurosci Methods 2015;256:168-183 [FREE Full text] [doi: 10.1016/j.jneumeth.2015.08.020] [Medline: 26318777]
6. Palmqvist S, Tideman P, Cullen N, Zetterberg H, Blennow K, Alzheimer's Disease Neuroimaging Initiative, et al. Prediction of future Alzheimer's disease dementia using plasma phospho-tau combined with other accessible measures. Nat Med 2021;27(6):1034-1042. [doi: 10.1038/s41591-021-01348-z] [Medline: 34031605]
7. Mohamed SK, Nounu A, Nováček V. Biological applications of knowledge graph embedding models. Brief Bioinform 2021;22(2):1679-1693. [doi: 10.1093/bib/bbaa012] [Medline: 32065227]
8. Yue X, Wang Z, Huang J, Parthasarathy S, Moosavinasab S, Huang Y, et al. Graph embedding on biomedical networks: methods, applications and evaluations. Bioinformatics 2020;36(4):1241-1251 [FREE Full text] [doi: 10.1093/bioinformatics/btz718] [Medline: 31584634]

9. Zhang X, Liang L, Liu L, Tang M. Graph neural networks and their current applications in bioinformatics. Front Genet 2021;12:690049 [FREE Full text] [doi: 10.3389/fgene.2021.690049] [Medline: 34394185]
10. Zhu L, Lan Q, Velasquez A, Song H, Kamal A, Tian Q, et al. TMHOI: Translational Model for Human-Object Interaction detection. arXiv Preprint posted online on March 7, 2023 [FREE Full text] [doi: 10.48550/arXiv.2303.04253]
11. Li F, Nian Y, Sun Z, Tao C. Advancing biomedicine with graph representation learning: recent progress, challenges, and future directions. arXiv Preprint posted online on June 18, 2023 [FREE Full text] [doi: 10.1055/s-0043-1768735]
12. Li MM, Huang K, Zitnik M. Graph representation learning in biomedicine and healthcare. Nat Biomed Eng 2022 Dec;6(12):1353-1369 [FREE Full text] [doi: 10.1038/s41551-022-00942-x] [Medline: 36316368]
13. Sun Z, Su J, Jeon D, Velasquez A, Song H, Niu S. Reinforced Contrastive Graph Neural Networks (RCGNN) for Anomaly Detection. : IEEE; 2022 Presented at: 2022 IEEE International Performance, Computing, and Communications Conference; 11-13 November 2022; Austin, TX, USA p. 65-72 URL: https://doi.org/10.1109/IPCCC55026.2022.9894334 [doi: 10.1109/IPCCC55026.2022.9894334]
14. Zhou J, Cui G, Hu S, Zhang Z, Yang C, Liu Z, et al. Graph neural networks: a review of methods and applications. AI Open 2020;1:57-81. [doi: 10.1016/j.aiopen.2021.01.001]
15. Nian Y, Hu X, Zhang R, Feng J, Du J, Li F, et al. Mining on Alzheimer's diseases related knowledge graph to identity potential AD-related semantic triples for drug repurposing. BMC Bioinformatics 2022 Sep 30;23(Suppl 6):407 [FREE Full text] [doi: 10.1186/s12859-022-04934-1] [Medline: 36180861]
16. Gaudelet T, Day B, Jamasb A, Soman J, Regep C, Liu G, et al. Utilizing graph machine learning within drug discovery and development. Brief Bioinform 2021 Nov 05;22(6):bbab159 [FREE Full text] [doi: 10.1093/bib/bbab159] [Medline: 34013350]
17. Gligorijević V, Renfrew PD, Kosciolek T, Leman JK, Berenberg D, Vatanen T, et al. Structure-based protein function prediction using graph convolutional networks. Nat Commun 2021 May 26;12(1):3168. [doi: 10.1038/s41467-021-23303-9] [Medline: 34039967]
18. Lu H, Uddin S. A weighted patient network-based framework for predicting chronic diseases using graph neural networks. Sci Rep 2021 Nov 19;11(1):22607. [doi: 10.1038/s41598-021-01964-2] [Medline: 34799627]
19. Wu C, Wu F, Lyu L, Qi T, Huang Y, Xie X. A federated graph neural network framework for privacy-preserving personalization. Nat Commun 2022 Jun 02;13(1):3091. [doi: 10.1038/s41467-022-30714-9] [Medline: 35654792]
20. Li Y, Zhang G, Wang P, Yu Z, Huang G. Graph neural networks in biomedical data: a review. Curr Bioinformatics 2022 Jul;17(6):483-492. [doi: 10.2174/1574893617666220513114917]
21. Li Y, Qiao G, Wang K, Wang G. Drug-target interaction predication via multi-channel graph neural networks. Brief Bioinform 2022 Jan 17;23(1):bbab346. [doi: 10.1093/bib/bbab346] [Medline: 34661237]
22. Wang J, Liu X, Shen S, Deng L, Liu H. DeepDDS: deep graph neural network with attention mechanism to predict synergistic drug combinations. Brief Bioinform 2022 Jan 17;23(1):bbab390. [doi: 10.1093/bib/bbab390] [Medline: 34571537]
23. Zhu W, Razavian N. Variationally regularized graph-based representation learning for electronic health records. In: Proceedings of the Conference on Health, Inference, and Learning. 2021 Apr Presented at: CHIL '21; April 8-10, 2021; Virtual Event p. 1-13. [doi: 10.1145/3450439.3451855]
24. Klepl D, He F, Wu M, Blackburn DJ, Sarrigiannis P. EEG-based graph neural network classification of Alzheimer's disease: an empirical evaluation of functional connectivity methods. IEEE Trans Neural Syst Rehabil Eng 2022;30:2651-2660 [FREE Full text] [doi: 10.1109/TNSRE.2022.3204913] [Medline: 36067099]
25. Dai E, Zhao T, Zhu H, Xu J, Guo Z, Liu H, et al. A comprehensive survey on trustworthy graph neural networks: privacy, robustness, fairness, and explainability. arXiv Preprint posted online on April 18, 2022 [FREE Full text] [doi: 10.48550/ARXIV.2204.08570]
26. Ying R, Bourgeois D, You J, Zitnik M, Leskovec J. GNNExplainer: generating explanations for graph neural networks. Adv Neural Inf Process Syst 2019 Dec;32:9240-9251 [FREE Full text] [Medline: 32265580]
27. Optum's Clinformatics Data Mart. The University of Texas Health Science Center at Housto. URL: https://sbmi.uth.edu/sbmi-data-service/data-set/optum/ [accessed 2024-06-06]
28. Kim Y, Zhang K, Savitz SI, Chen L, Schulz PE, Jiang X. Counterfactual analysis of differential comorbidity risk factors in Alzheimer's disease and related dementias. PLOS Digit Health 2022 Mar;1(3):e0000018 [FREE Full text] [doi: 10.1371/journal.pdig.0000018] [Medline: 36812506]
29. Clinical Classifications Software (CCS) for ICD-9-CM. Healthcare Cost and Utilization Project. URL: https://hcup-us.ahrq.gov/toolssoftware/ccs/ccs.jsp [accessed 2024-06-07]
30. Overview of the American Hospital Formulary Service (AHFS) Pharmacologic-Therapeutic Classification© System. Ontario College of Pharmacists. URL: https://www.ocpinfo.com/wp-content/uploads/2022/12/AHFS-american-hospital-formulary-service-rise-online-training.pdf [accessed 2024-06-19]
31. Zhang Z, Kim HJ, Lonjon G, Zhu Y, written on behalf of AME Big-Data Clinical Trial Collaborative Group. Balance diagnostics after propensity score matching. Ann Transl Med 2019 Jan;7(1):16 [FREE Full text] [doi: 10.21037/atm.2018.12.10] [Medline: 30788363]

32. Lee CS, Gibbons LE, Lee AY, Yanagihara RT, Blazes MS, Lee ML, et al. Association between cataract extraction and development of dementia. JAMA Intern Med 2022 Feb 01;182(2):134-141 [FREE Full text] [doi: 10.1001/jamainternmed.2021.6990] [Medline: 34870676]
33. Peters J, Booth A, Peters R. Potential for specific dihydropyridine calcium channel blockers to have a positive impact on cognitive function in humans: a systematic review. Ther Adv Chronic Dis 2015 Jul;6(4):160-169 [FREE Full text] [doi: 10.1177/2040622315582353] [Medline: 26137206]
34. Pham TDM, Ziora ZM, Blaskovich MAT. Quinolone antibiotics. Medchemcomm 2019 Oct 01;10(10):1719-1739 [FREE Full text] [doi: 10.1039/c9md00120d] [Medline: 31803393]
35. Gao L, Shuai Y, Wen L, Zhang H, Zhang Y, Zhang X. Benefit and safety of antibiotics for Alzheimer's disease: protocol for a systematic review and meta-analysis. Medicine (Baltimore) 2022 Nov 25;101(47):e31637 [FREE Full text] [doi: 10.1097/MD.0000000000031637] [Medline: 36451430]
36. Nau R, Sörgel F, Eiffert H. Penetration of drugs through the blood-cerebrospinal fluid/blood-brain barrier for treatment of central nervous system infections. Clin Microbiol Rev 2010 Oct;23(4):858-883 [FREE Full text] [doi: 10.1128/CMR.00007-10] [Medline: 20930076]
37. Kanich W, Brady WJ, Huff J, Perron AD, Holstege C, Lindbeck G, et al. Altered mental status: evaluation and etiology in the ED. Am J Emerg Med 2002 Nov;20(7):613-617. [doi: 10.1053/ajem.2002.35464] [Medline: 12442240]
38. Hulse GK, Lautenschlager NT, Tait RJ, Almeida OP. Dementia associated with alcohol and other drug use. Int Psychogeriatr 2005;17 Suppl 1:S109-S127. [doi: 10.1017/s1041610205001985] [Medline: 16240487]
39. Durnham A. Alzheimer's disease and addiction. Best Alzheimer's Products. URL: https://best-alzheimers-products.com/alzheimers-disease-addiction.html [accessed 2024-06-07]
40. Li Q, Yang X, Xu J, Guo Y, He X, Hu H, et al. Early prediction of Alzheimer's disease and related dementias using real-world electronic health records. Alzheimers Dement 2023 Aug;19(8):3506-3518. [doi: 10.1002/alz.12967] [Medline: 36815661]

Abbreviations

ADRD: Alzheimer disease and related dementias
AUROC: area under the receiver operating characteristic curve
DeepDDS: Deep Learning for Drug-Drug Synergy prediction
EHR: electronic health record
GAT: graph attention network
GCT: graph convolution transformer
GNN: graph neural network
ICD-9: International Classification of Diseases, 9th revision
ICD-10: International Classification of Diseases, 10th revision
LGBM: light gradient boost machine
ML: machine learning
RF: random forest
VGNN: Variationally regularized encoder-Decoder Graph Neural Network

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Original Paper

Exploring Older Adults' Perceptions of Using Digital Health Platforms for Self-Managing Musculoskeletal Health Conditions: Focus Group Study

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Abstract

Background: Digital technologies can assist and optimize health care processes. This is increasingly the case in the musculoskeletal health domain, where digital platforms can be used to support the self-management of musculoskeletal conditions, as well as access to services. However, given a large proportion of the population with musculoskeletal conditions are older adults (aged ≥60 years), it is important to consider the acceptability of such platforms within this demographic.

Objective: This study aims to explore participants' opinions and perceptions on the use of digital platforms for supporting the self-management of musculoskeletal conditions within older adult (aged ≥60 years) populations and to gather their opinions on real examples.

Methods: A total of 2 focus groups (focus group 1: 6/15, 40%; focus group 2: 9/15, 60%) were conducted, in which participants answered questions about their thoughts on using digital health platforms to prevent or manage musculoskeletal conditions. Participants were further presented with 2 example scenarios, which were then discussed. Interviews were audio recorded, transcribed, and analyzed thematically. Participants were aged ≥60 years and with or without current musculoskeletal conditions. Prior experience of using smartphone apps or other digital health platforms for musculoskeletal conditions was not required. Focus groups took place virtually using the Teams (Microsoft Corp) platform.

Results: A total of 6 themes were identified across both focus groups: "experiences of digital health platforms," "preference for human contact," "barriers to accessing clinical services," "individual differences and digital literacy," "trust in technology," and "features and benefits of digital health technologies." Each theme is discussed in detail based on the interview responses. The findings revealed that most participants had some existing experience with digital health platforms for preventing or managing musculoskeletal conditions. Overall, there was a lack of trust in and low expectations of quality for digital platforms for musculoskeletal health within this age group. While there was some concern about the use of digital platforms in place of in-person health consultations, several benefits were also identified.

Conclusions: Results highlighted the need for better communication on the benefits of using digital platforms to support the self-management of musculoskeletal conditions, without the platforms replacing the role of the health care professionals. The concerns about which apps are of suitable quality and trustworthiness lead us to recommend raising public awareness around the role of organizations that verify and assess the quality of digital health platforms.

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KEYWORDS

musculoskeletal; digital health platform; physiotherapy self-management; digital triaging; phone app; qualitative; focus group; mobile phone

Introduction

Background

Musculoskeletal health conditions are highly prevalent, with chronic conditions such as osteoarthritis affecting an estimated 8.5 million people in the United Kingdom. Moreover, more than half of the adults aged ≥75 have sought treatment for osteoarthritis [1]. Similarly, back pain affects 10 million adults in the United Kingdom and is the top cause of years lived with disability [2]. Physiotherapy services primarily deal with most referrals for musculoskeletal conditions. In the United Kingdom, there is an increasing burden of musculoskeletal conditions [3] and as such increasing pressure on general practitioner (GP) and physiotherapy services. This increasing burden on services has created the opportunity to develop digital health platforms (eg, a computer or remote device that can help patients manage their health remotely, such as a mobile phone app) to support patients with their physiotherapy needs. Since the COVID-19 pandemic, many digital platforms are being used in conjunction with in-person physiotherapy appointments [4]. Such digital platforms have been developed for a range of purposes, including the triaging of patients with musculoskeletal conditions (ie, assessment of patients' severity of symptoms and signposting to appropriate services) as well as the self-management of musculoskeletal conditions (eg, physiotherapy exercises [5]). Digital health platforms for musculoskeletal conditions have also been shown to improve patient outcomes (eg, in terms of reduced pain [6]) and, further, in terms of physiotherapy interventions, allow a more interactive and engaging approach to the traditional instruction leaflet, subsequently leading to better intervention adherence [7].

This Study

A large proportion of patients requiring physiotherapy who are awaiting an appointment are older adults, with age greatly increasing the likelihood of musculoskeletal conditions [8,9]. However, older adults are traditionally considered less confident with technology [10]. A recent focus group study investigated the experiences of older adults using a wide range of diabetes apps. One of the key outcomes from this study highlighted that usability was a major barrier, with participants giving an average System Usability Score [11] across all apps of just 48, equating to the lowest grade category based on the percentile classifications from a wide range of studies [12]. Similarly, an investigation into the use of digital tools in clinical research suggested that older adults are less likely to use digital technology [13]. Therefore, given the increased availability and use of digital platforms for accessing physiotherapy services and supporting the self-management of musculoskeletal conditions, it is important to consider the accessibility and acceptance of such platforms for older adults. This study uses a qualitative approach to gather older adult participants' opinions and perspectives on using technology for managing musculoskeletal conditions. The aims of the study were to (1) identify any prior experience or knowledge of digital tools to support self-management strategies for musculoskeletal problems, (2) gather opinions on the transition from seeing a health professional in person to using more technology-based support, and (3) gather and present opinions on real-world scenarios where digital platforms support access to and provide guidance on physiotherapy. The results give insights into current perceptions on the use of these technologies for managing musculoskeletal conditions in the older adult population, and we provide recommendations on how to ensure such technologies are accepted by and trustworthy to this patient group.

Methods

Participants

Participants were aged ≥60 years. We recruited participants regardless of whether they did or did not have any current musculoskeletal conditions. Similarly, we did not require participants to have any prior experience of using smartphone apps or other digital health platforms for managing musculoskeletal conditions or accessing services. This allowed us to gain a more generalized, unbiased view of using digital health technology for supporting musculoskeletal health. Participants were, however, encouraged to share their prior experiences of using technology (if appropriate).

Recruitment

The focus groups formed part of a wider study that included a trial investigating the feasibility of using smartphone sensors to objectively measure physiotherapy-related functional tests [14]. Some participants took part in both this focus group study and the trial.

The research team used a strategy to recruit from a wide range of community organizations and venues. These included community centers; local charity groups; libraries; supported living accommodations; and religious centers, such as churches and mosques. A total of 21 local organizations were contacted using the research team's professional networks along with the networks of the West Midlands Clinical Research Network [15]. Paper and digital format flyers were distributed in these locations through relevant contacts at each organization or via an in-person visit by a member of the research team.

Participants were able to register their interest by providing their name and contact details (email address or postal address) via (1) a web-based form, (2) email, or (3) a telephone voice message, details of which were provided on the flyer. The participant information leaflet and consent form were then sent to those who registered their interest (via either email or post).

Following their registration of interest, a research team member contacted each individual, offering 1 of 2 potential dates on which the focus groups were to be held. Participants registering interest in the later stages, when participation in the first focus group was not practical, were offered only the second date. Consent to participate was acknowledged via email before the focus group date (see *Procedure* section).

Ethical Considerations

This study involved human participants and was approved by the University of Warwick’s Biomedical and Scientific Research Ethics Committee (147/20-21). All participants gave informed consent, by signing a consent form after reading information about the study prior. Participants were able to withdraw from the study along with their data at any point up to 5 days after participation. The focus groups were recorded and transcribed using Microsoft Teams built-in tools. Data were pseudonymized such that any identifiable details were removed and participant quotes were identified by their first initial and focus group session. No patients or public were involved in the design, conduct, reporting, or dissemination plans of this research. All participants who attended the focus group received a £20 (US $26) gift voucher for their participation.

Procedure

A total of 2 focus groups were conducted virtually using Microsoft Teams (Microsoft Corp; on August 9 and 29, 2023). This method was chosen to remove the need for the participants, recruited across a relatively wide geographical region, to travel to a specific location for the focus group.

Before the focus group, participants were sent an invite with a clickable Microsoft Teams meeting link. Participants were also sent instructions on how to join the Microsoft Teams meeting, a study information sheet, and a consent form. Participants were instructed to read the information sheet and complete the consent form ahead of the focus group (if participants could not complete the consent form electronically, consent was accepted via email). Participants were also asked to complete a web-based demographic form. The form gathered demographic information, namely age, gender, ethnicity, and self-disclosed musculoskeletal conditions (optional), and consent to receive a £20 (US $26) voucher for participation and provided a summary of the study findings.

Each focus group lasted a total of 1 hour 15 minutes. Both focus groups were recorded and transcribed using the built-in functionality in Microsoft Teams.

Before asking any questions, the facilitator (SC) gave a brief presentation that contained a broad definition of (1) digital health platforms and (2) musculoskeletal conditions (Multimedia Appendix 1). Participants were then initially asked 3 questions covering their experiences of self-managing musculoskeletal conditions, the use of technology to manage musculoskeletal conditions, and their feelings on switching to using more technology in place of a health professional (Multimedia Appendix 1).

The initial questions were followed by participants being presented with 2 different representative scenarios based on the use of digital health apps to support musculoskeletal conditions. These scenarios were used to provide examples of real apps that were currently used in practice. This provided context to participants who were less familiar with the types of digital health apps currently in use. Scenario 1 related to physiotherapy self-referral using a clinician-developed mobile phone app (Figure 1 [16]). Scenario 2 related to support for the self-management of physiotherapy exercises through the use of a mobile phone app (Figure 2). For each scenario, participants were shown a flowchart describing the app scenario and, on a separate slide, a screenshot of each digital health platform. Alongside the flowchart and image, the facilitator described how each digital health platform worked. Participants were then asked 4 questions about each scenario (Multimedia Appendix 1). The scenarios were kept general; however, they were inspired by apps already developed and used by a UK health technology company (EQL Ltd), which was a partner in the wider project. The images used were from EQL’s apps.

Figure 1. Flowchart describing scenario 1: self-referral using a clinician-developed mobile phone app. GP: general practitioner; NHS: National Health Service.

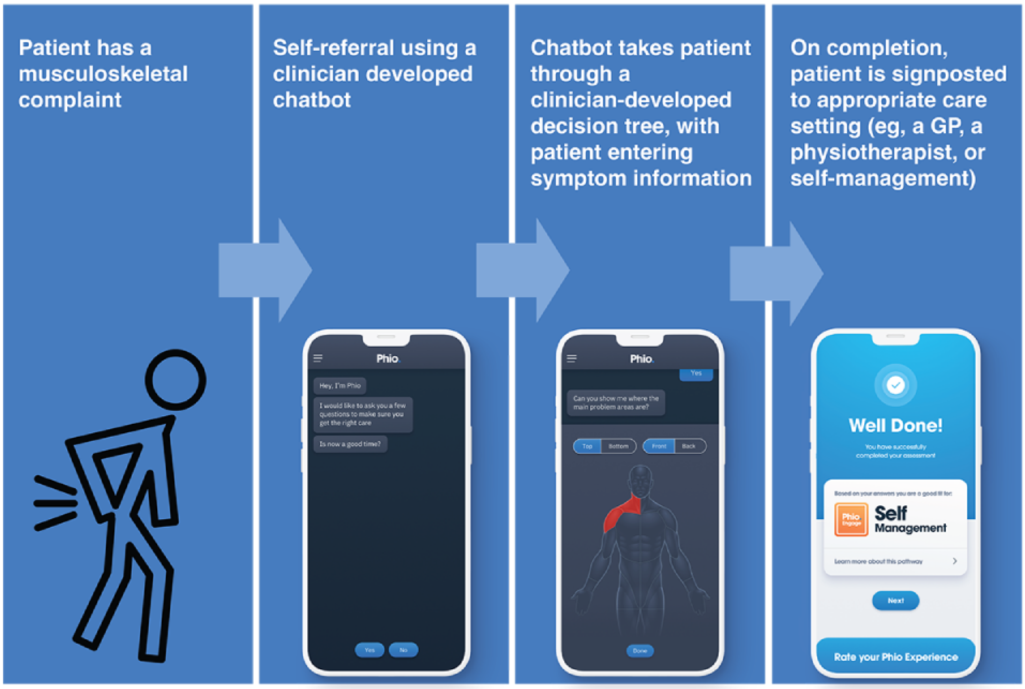
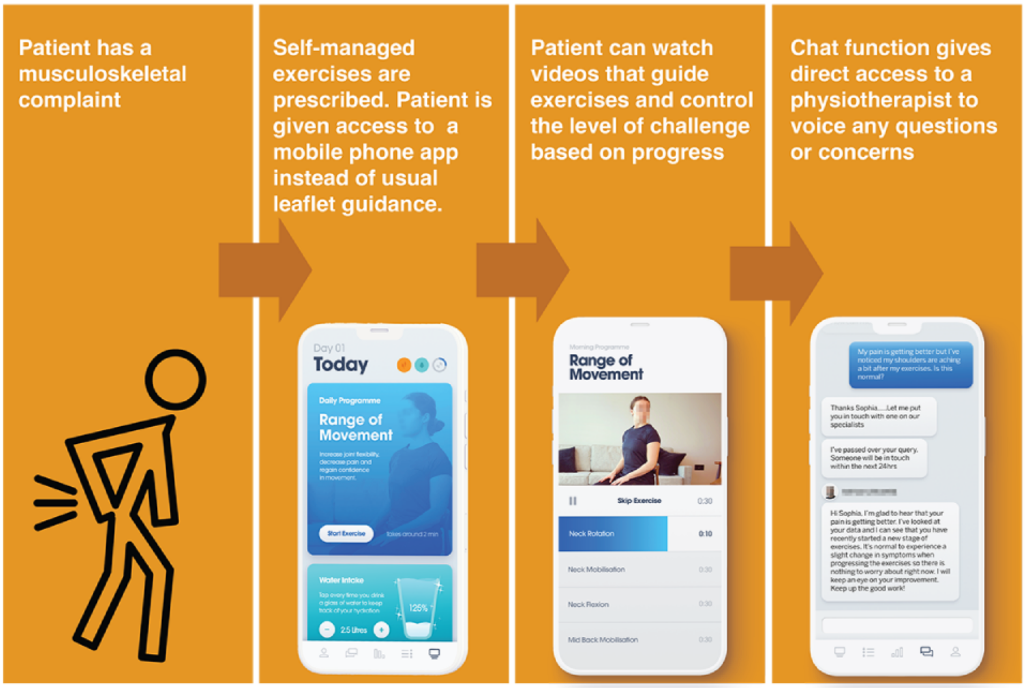


Figure 2. Flowchart describing scenario 2: self-management of physiotherapy exercises using a mobile phone app.



Data Analysis

Transcripts were anonymized and cross-checked for accuracy by the first author (SC) against the recordings. After each interview, the interviewer, SC, summarized key themes to inform the coding framework. Interview transcripts were then uploaded into the NVivo qualitative analysis software (version 12; QSR International). A thematic analysis was performed using an inductive approach, meaning that codes were derived from the data, and in accordance with the 6-stage model developed by Braun and Clarke [17]. To enhance validity, SC and MTE discussed the resulting coding framework, and themes were identified, reviewed, and defined iteratively. Themes and subthemes are presented and demonstrated by representative quotes.

Results

Overview

A total of 15 participants took part in 2 separate focus groups (focus group 1: n=6, 40%; focus group 2: n=9, 60%). During the second focus group, in addition to the 9 participants, a carer acted as a translator for 1 participant. A summary of participant characteristics can be found in Table 1. Of the 15 participants, 12 (80%) reported having current musculoskeletal health conditions; these are listed in Table 2, along with associated *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* codes. A total of 2 (13%) participants had no or did not specifically mention experience of using digital technologies. The remaining participants (n=13, 87%) mentioned they had some experience of using digital technologies relating to musculoskeletal health. In this study, we defined digital technologies relatively broadly and included smartphone apps, smart watches, YouTube (Google LLC), and relevant website content.

Table 1. Participant characteristics (N=15).

Participant characteristic	Values
Age (y), mean (SD; range)	71 (8.4; 61-87)
Gender, n (%)	
Woman	10 (67)
Man	5 (33)
Nonbinary	0 (0)
Ethnic group, n (%)	
Asian or Asian British	2 (13)
Black, African, Caribbean, or Black British	3 (20)
White	10 (67)
Are there any current musculoskeletal conditions? n (%)	
No	3 (20)
Yes	12 (80)

Table 2. Health conditions recorded by participants on the demographic form (N=15). Participants could list multiple conditions, so total entries add up to greater than the number of participants.

Reported musculoskeletal conditions	*ICD-10*[a] mappings	Participants, n (%)
Osteoarthritis	M15.0	4 (27)
Joint pain (hip and knee)	M25.55 and M25.56	2 (13)
Back pain	M54.5 and M54.9	2 (13)
Hypothyroid	E03.9	1 (7)
Peripheral arterial disease	I73.9	1 (7)
Peripheral neuropathy	G62.9	1 (7)
Condition not stated	—[b]	2 (13)
No reported health conditions	—	3 (20)

[a] *ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th Revision*.

[b] Not applicable.

A total of 6 themes were identified across the transcripts:

- Theme 1: experiences of digital health platforms
- Theme 2: preference for human contact
- Theme 3: barriers to accessing clinical services
- Theme 4: individual differences and digital literacy
- Theme 5: trust in technology
- Theme 6: features and benefits of digital health technologies.

These themes are discussed in detail in the following sections, supported by representative quotes.

Theme 1: Experiences of Digital Health Platforms

Most participants referenced previous or current use of digital technology to help prevent or manage musculoskeletal conditions. Examples provided included smartwatches, completing physiotherapy exercises or exercise classes via YouTube or Zoom (Zoom Video Communications, Inc). They further referenced walking as an activity they engage in to either prevent or manage musculoskeletal conditions. Some participants referenced the use of digital health platforms (eg, smartwatch) while walking to count their number of steps. It appears specific features on smartwatches encouraged users to engage in more movement (eg, step count and prompt to move when sitting for a certain length of time):

> *I try to walk 7000 steps a day, I measure on my wrist. I don't always do it. I used to do 5000, but then I decided that wasn't enough. So I try to do 7000 if I can.* [M, focus group 1]
>
> *I use my smart watch a hell of a lot. Cause' it's an apple one and it has the exercise mode it has the pedometer, it has all that kind of stuff...my watch will tell me when I'm sitting down for too long, so I go and get up and just walk around. So I do utilize the fitness and the health stuff that come with my watch.* [L, focus group 2]

Apps were highlighted as beneficial when participants encountered barriers (eg, bad weather conditions) that prevented them from walking outdoors:

> *I like to go for a walk and I've got rheumatoid arthritis. So I'm sometimes a bit limited, but I have used apps and to do exercise which were appropriate for me and just, well, keep moving or keep moving anyway. But just to keep moving and you know, just to do my best cause sometimes if the weather's not good, you don't feel like going out, do you? So you can do these sort of things indoors, so I found the apps very good.* [N, focus group 1]

Theme 2: Preference for Human Contact

Participants expressed concerns when using a digital health platform for an initial musculoskeletal diagnosis or referral. There were concerns that digital health platforms (scenario 1) might fail to identify the full spectrum of a musculoskeletal condition compared to seeing a health professional in person. One of the participants expressed concerns that a more serious diagnosis might be missed if self-diagnosing via information on the internet. There was a sense that an in-person appointment would also cover the wider well-being of a person (eg, identify signals that someone is experiencing domestic abuse):

> *I mean, if you go online and you start diagnosing yourself...it always ends up to be something else less serious. I couldn't do that not unless the law changed, but not for me.* [S, focus group 2]
>
> *What you can never get from an app is the face to face, because quite often when people go to the doctor with one thing, the doctor looking at them see's something else that they hadn't sometimes realised themselves. In domestic abuse situations, someone can go in regarding something, but the doctor looking at that person can see there's more to this situation than just what she's telling me. So you just can't get that from an app. So this is why I think face to face with always remain a crucial part of the you know, welfare of human being.* [J, focus group 2]
>
> *If I was going to go down the route of asking an app about my symptoms with a chance that it might be self-management, I would have figured out where the self-management things myself first before I would start. If I've got to the stage where I'm asking for help, I want help from a person, not from an app.* [M, focus group 1]

Participants further cited concerns toward carrying out physiotherapy exercises without physical observation or input from an in-person physiotherapist. One of the participants explained how following a hospital appointment, they had been given physiotherapy exercises to complete (the exercises were described on a sheet of paper). They described how they realized they were carrying out the exercises incorrectly only after a family member had observed them:

> *I was given some exercises to do pelvic floor exercises which I must have been doing for about a month or so and thought I was getting on well. And then my midwife daughter said you're not doing those right at all. I'd been given a sheet at the hospital to follow, and I thought I was doing exactly what the sheet said. And she said, mum, what you're doing is useless now. I've been doing that for four or five weeks. There are things that you can benefit, but I didn't know I wasn't doing the exercises correctly, so I presume thousands of other people in the country who have walked away from hospital with a sheet of paper, get home and think they're doing them properly and they're not. But I don't know how to overcome that because it was only my daughter visiting me that I found out about that.* [M, focus group 2]

Participants reported further experiences of completing physiotherapy exercises incorrectly without direct observation or supervision. Consequently, some participants appeared to be wary of carrying out physiotherapy exercises alone (scenario 2):

> *My dad had online physio through his iPad and he was doing this exercise to try and strengthen his glutes. He was doing it and he was turning his whole body and a physio in person would have seen that and known that he wasn't actually doing the right exercise. So I'm not a fan of online or apps for the consultation and monitoring.* [My, focus group 2]
>
> *I think there is one issue with that, which is how the patient knows that he or she actually does the exercise in a correct way without monitoring by the presence of the physio. I think they need to look at it and then to find some ways in order to ensure that the messages delivered and the exercises are the way the GP wanted or the way their physiotherapist wants.* [H, focus group 2]

Given these concerns around the lack of person input, a hybrid approach appeared to be favored by participants in which they used digital health platforms alongside some form of face-to-face meetings with a health professional (eg, a general practitioner or physiotherapist). Participants explained a hybrid approach was preferred to ensure they are completing physiotherapy exercises correctly. It was suggested that patients could record themselves completing exercises. These recordings could be sent via the internet to physiotherapists who could track their progress ahead of a face-to-face meeting, rather than as a substitute for a meeting entirely:

> *I feel I would use it, but I would want a health professional to tell me what to do and then I would go on to technology and then be able to report back to the health professional.* [M, focus group 1]
>
> *And as long as you've had the proper consultant consultation with the physio, I don't see this taking the place of a physio appointment at all in anyway, but in terms of monitoring and feeding back your progress to your physio in advance of the next meeting, because one of the things that I would look for in that like this is to be accountable and to get to the end of the week and say yes I did do that. Yeah, I did that three times a day all. But for the whole week and to have that recorded and for the physio to have access to that.* [M, focus group 2]

Another participant suggested patients could complete exercises in a group (even virtually, using a platform such as Microsoft Teams), which could help increase their confidence:

> *So, if you do it with support possibly even with for example a group. Some get together where you like you are now. And you can see us all individually doing the therapies. You can then say oh excuse me you're doing that incorrectly or something like that. So we get that input in a better way.* [L, focus group 2]

It was observed that using technology would depend on a patient's circumstances:

> *So last time I saw a physiotherapist when I had a blood test from the doctor beforehand to check it wasn't some biological problem. It was mechanical and then the physiotherapist was a mixture of exercises and also ultrasound treatment. I obviously can't do that at home and don't have the skill to apply the ultrasonic probe in the correct manner, so I think it depends on the injury and what the best treatment is, whether you can go a hybrid mode or whether its technology or just physio.* [M, focus group 1]

Theme 3: Barriers to Accessing Clinical Services

While expressing a preference for human contact, participants recognized the role of technology when there are barriers to accessing services. Participants referenced seeking help from medical professionals (eg, occupational health practitioners, general practitioners, and physiotherapists) for musculoskeletal conditions and explained how they decided to use technology while waiting to hear back from a health professional. One of the participants described how they had been assigned self-management exercises by their physician but did not receive the exercises. As a result, they sourced their own self-management exercises on the United Kingdom's National Health Service (NHS) website. A second participant felt it was not always clear which health professional they needed to see (ie, a physiotherapist or a chiropractor) and had experienced a long wait to get a physiotherapy appointment. Due to this long wait, they had engaged in self-management by trying to move their body regularly and using apps:

> *I had just sciatica not so long ago and it got diagnosed by the doctor. And he said he'd give me some exercises to do, but he never actually did. So when I went on the web and went on the NHS website and found some site, sciatica specific exercises, which I then started doing on a regular basis.* [J, focus group 2]
>
> *I've had to wait six months on the NHS to get a physio appointment. I wasn't sure whether to go to a chiropractor or a physio. And so just thought I'll just follow the doctor's advice and wait. And it was a long wait we didn't go privately and I'm not being seen. I like to go for a walk and I've got rheumatoid arthritis so I'm sometimes a bit limited, but I have used apps to do exercises which were appropriate for me and just, well, keep moving.* [N, focus group 1]

The availability and accessibility of resources were raised by participants. It appears some participants may have access to health professionals more readily. According to one of the participants, patients can access health professionals with greater ease if they pay for their appointments privately. Despite this perceived benefit, another participant noted it was very difficult to obtain a private physiotherapist's appointment due to long waiting times:

> *If you're privileged enough to be able to pay privately, then there will be a few, a lot fewer barriers.* [My, focus group 1]
>
> *I will say at the moment it's very difficult to see people privately at, whereas at one time you rang and you saw them the next day. I've had to wait two months for appointments, even privately.* [B, focus group 1]

Considering scenario 1 and in light of current waiting lists, a participant saw the benefits of a referral app:

> *I was just going to say if you've sprained knee or have a hand sprain, for example you go to the GP. You're not going to see the same GP that you've seen last time. And if you get referred for Physio, you'll be lucky to see a physiotherapist for six months. So an app would be more useful because you would have some advice if you like online immediately.* [S, focus group 2]

In terms of accessing support for self-management via digital means, participants mentioned accessing useful resources on YouTube. One of the participants described how they had found trained physiotherapists on YouTube to follow a program of physiotherapy exercises and stretches:

> *I found Bob and Brad on YouTube and that really good, really entertaining.* [J, focus group 2]

A participant described how they already had an experience of scenario 1. However, they noted It was only certain physicians or healthcare organizations that offered the digital services, suggesting not all members of the public can access this service:

> *It's already out there. So as far as I'm concerned, I've done it. It's ok, it's only experimental in certain surgeries and things, but it's out there.* [L, focus group 2]

Theme 4: Individual Differences and Digital Literacy

The topic of inclusivity arose from the focus groups (ie, can individuals aged >60 years successfully access and use digital technology to manage their health?). Participants acknowledged there may be a range of individual differences when it comes to using digital health platforms. There was acknowledgment that users may differ on a variety of characteristics; for example, age and several elements of apps were highlighted as challenging for users. One of the participants expressed concerns toward people in an older age group (aged ≥75 years) using a referral app (scenario 1). They believed this group of people may prefer to speak with a health professional in person. They explained that chatbots can be difficult to use (eg, a chatbot might not recognize certain phrases or words):

> *I think the older people, older generation, probably people 75-80 don't feel ready for it. Even just the telephone conversations with doctors. I like to go in person to see my doctor. Whereas when I talk to my children, they think telephone triage is brilliant, so I think it and that's not to say I mean there's a lot of very technical people in the older group, but the vast majority, like people have said either or, not, or are distrusting of it. I just think they much on the whole, much prefer seeing someone, even the telephone, does mean you are talking to your doctor, even if you're not seeing them face to face. Even though you can do video calls with your doctor, I just think that while it's good I don't get on with chat bot, I never put the right words in. You've got to know what words to use to make the thing effective.* [F, focus group 2]

Another participant also raised the issue of accessing digital health platforms. It was implied some people may find it more challenging:

> *I went into hospital and I had to have physio afterwards and that was given as a YouTube thing with the nurse. My only problem with it, I did most of the exercises and things that were required and requested. The only thing I found was I kept losing the YouTube and trying to find the link to it because they sent it as a link. Because you're not feeling 100%, I didn't secure it, so I forgot where I put it and so I stopped doing it so probably didn't complete the course... because at that point I wasn't feeling physically fit and I wasn't very well and probably wasn't thinking the way I would normally think. Apps need to be absolutely simple and as somebody else said, idiot proof.* [F, focus group 2]

Theme 5: Trust in Technology

Issues around the legitimacy of some health apps were highlighted. Participants expressed concerns about not knowing whether apps are real or fake:

> *It's not beyond the bounds of possibility that you get on to the wrong sort of website and you get the wrong sort of information. You would need to know that what you've accessed is in fact a genuine one.* [B, focus group 1]

Several suggestions were made to help to instill confidence in users. One of the participants suggested that they would feel more comfortable if information or link for a digital health platform came straight from health care professionals rather than an unknown source:

> *Nowadays we are bombarded with a lot of information. So if there is a direct communication between the people who supply this app and the clinic itself or the hospital, which means that I received the information from the clinic or from the hospital that gives me confidence and that's giving me trust that I can trust the source of this information. Rather than it is, it is independent from the hospital or from the clinic, which makes me think is this genuine? Is it the same people?* [H, focus group 1]

There was also the proposal that app developers might wish to include some form of legitimacy mark (eg, kite mark) to help users know that the app has been verified and delivers accurate health care advice:

> *It needs a sort of kite mark, if you remember what they are, but I don't know how you do that.* [B, focus group 1]

Training was also suggested as a method to encourage greater uptake and use of such apps:

> *I think the issue is not with using them. I think the main issue is we need more training on how to implement, how to use these apps and how to become familiar with them. This is very important if the training is not available then I think it will create some frustration and with the users and users may refuse or may not like to use them.* [H, focus group 2]
>
> *I think until people can be trained to use it a lot better than. You know, it's people gonna still find it difficult to use. If you feel you've pulled a muscle and you're in pain, you don't wanna be fiddling about with technology at that time.* [L, focus group 1]

In the context of scenario 1, a participant suggested that case studies of worked examples would be useful to instill trust in the referral app:

> *I guess what we really want is case examples, so a worked example where a patient that goes through what the questions are ends up with self-management. Then a different patient, different symptoms ends up with consult your GP. So examples of how it actually works in practise. But what would what they would be looking for to validate it.* [M, focus group 1]

One of the participants described how they had recently trialed new technology after being invited by their local hospital. They stated that technology needs to become the norm, which will encourage people to try it:

> *So you know the technology is out there. It's just you've gotta have people who are prepared to try it. And to make it become the norm. Once it's the norm, then the fear disappears and so on. But at present a lot of this stuff is new, and it's scary for a lot of people. You take the fear out and then it's fine.* [L, focus group 2]

Theme 6: Features and Benefits of Digital Health Technologies

In the context of scenario 2, participants stated a number of positive views toward the use of videos demonstrating physiotherapy exercises. Using an app to perform physiotherapy exercises was compared to using a piece of paper with static poses on it. One of the main perceived benefits of videos was the ability to stop and start the video according to the individual's own pace. Participants also compared watching videos to meeting with a medical professional, who may not always have time to demonstrate exercises, or alternatively, appointments are rushed, and patients are unable to clarify what is correct:

> *Having the videos online...you can see how your body should be positioned, you can see from one position to the next where your body should be. Where sometimes we just get the instructions or guidance on the flat sheet of paper, you're unsure how to move next or how your body should be positioned so having the video of the graphics or whatever it is online I think would definitely be beneficial for someone who's going down that route. Also online you can do exercises at your own pace. Whereas sometimes medical professionals are on a clock, so ok do this, do this and then they're off. Whereas if you're online, you've got time to go how did that one go again? And you can see it again, slow it down, pause it, look again.* [J, focus group 2]

> *If you watch an app, it's easier to understand what you meant to be doing than looking at a sheet cause I find that if you have followed the exercises from you're trying to, even if you're lying down, you're trying to hold the sheet of the air to check that you're doing the exercise correctly. I found an app quite good really for showing you how to do them.* [N, focus group 2]

Other benefits of using apps included reducing the need to travel to a physical location for an appointment, saving patients' time:

> *I think it is a good idea because it saves time for a patient to travel from his or her home to the clinic or to the hospital.* [H, focus group 2]

> *Well, going to the doctor or physician or therapist, it takes more time... the technology is much better for me at my own pace, at my own time.* [S, focus group 1]

Participants considered a number of benefits of using the chatbot referral app (scenario 1) compared to going directly to a health professional. These benefits included reducing wait times for patients as well as freeing up time for health professionals:

> *It's the way forward, 'cos it means you're freeing up GP time, you're freeing up hospital time. So the people who are more needy can actually get that support. You are getting your support is a slightly easier and slightly less cumbersome way I suppose.* [L, focus group 2]

> *I was just going to say if you've sprained your knee or have a hand sprain, for example you go to the GP. You're not going to see the same GP that you've seen last time. And if you get referred for Physio, you'll be lucky to see a physiotherapist for six months. So an app would be more useful because you would have some advice if you like online immediately.* [S, focus group 2]

Participants spoke of adapting digital health platforms to suit their needs. For example, one of the participants described adapting app exercises to suit their own abilities and pain level:

> *It started off quite gently and that used every part of your body and something that I had to adapt because I've also had an operation on my thought and I am a replacement hips, so I'll just adapt whatever, but yeah. I just think. That's what you know most of the things you try to do your best, don't you try to do them and but just adapt them...Yeah, some exercises are found too fast for me and some too slow. I think the pace of exercise is sometimes very helpful. And also whether you can follow it or not.* [N, focus group 1]

Suggestions were made for future adaptations to apps. There was a desire for information on the timings of each exercise to be specific. Participants expressed a concern that sometimes it is not clear how long they need to hold a certain position for; as a result, they suggested embedding a countdown or timer into the app:

> *Sometimes it doesn't say how long you're to hold a position for.* [N, focus group 1]

> *Like how many times should you do an exercise within a minute or like a time scale so that you're not doing it too quickly or too slowly? You can then try to keep some sort of balance.* [N, focus group 1]

Another participant described adapting a phone app from its original use of sending medication reminders. The participant described how they instead used the function on the app to remind them to do specific physiotherapy exercises at specific points in the day. This insight suggests that reminders for physiotherapy exercises could be inbuilt into existing physiotherapy apps (scenario 2):

> *One thing I've found quite useful when I was doing my post-surgery exercises was there's an app...it tells you when to take pills so it reminds you when it's time to take your medication, but rather than entering medication, I entered each of the exercise and then I've got a record of when I done the exercises and it reminded me to do, it reminded me to take the pink tablet, but I've actually got that it was leg raises or whatever and I haven't been able to find something like that, that is for exercise, rather than just adapting*

> *the medication one but that was good cause you have records and you could sort of see progress.* [My, focus group 1]

Discussion

Principal Findings

This study aimed to explore older adults' opinions and perceptions on the use of digital platforms for supporting the self-management of musculoskeletal conditions. Using a focus group approach, we found that most participants had some knowledge or experience of using digital tools for supporting musculoskeletal problems, although this could be something as simple as YouTube guidance videos. As health care organizations are increasingly focusing on the delivery of digital services (eg, the NHS Long Term Plan in the United Kingdom [18]), we further wanted to gather opinions from participants around potentially using technology-based support as an alternative or a complement to traditional face-to-face services. In the initial stages of discussions, participants were skeptical of this and highlighted a lack of trust in the quality and scope of digital services. However, we further included real-world examples of physiotherapy-related digital health technologies into our focus group discussions. By moving away from theoretical perceptions to specific examples, we found participants subsequently recognized the potential advantages of such platforms and how they could provide relevant support to self-managing musculoskeletal health conditions. In the following sections, we discuss the main findings in more detail.

Experiences of Using Digital Tools for Self-Managing Musculoskeletal Conditions

In this study, we purposefully aimed to recruit participants for the focus group without explicitly requiring them to either have current musculoskeletal conditions or experience of using technology for managing musculoskeletal health. Despite these broad inclusion criteria and recruitment across a diverse set of community groups, we found that most participants (12/15, 80%) had some type of current musculoskeletal condition. Furthermore, most participants had used a form of technology to help self-manage their condition. Around 60% of adults aged >65 years live with a musculoskeletal condition in the United Kingdom [3]. Therefore, it was expected that a significant proportion of our participants would have current musculoskeletal conditions, as observed. It was less expected to find that most of our participants had some experience of using technology to support the management of their musculoskeletal conditions. However, this included the use of exercise and guidance videos on YouTube, a medium that is accessed by 52% of older adults (aged >65 years) in the United Kingdom [19]. A study investigating the quality of physiotherapy videos for older adults on YouTube [20] found that the content was rated as poor or lower when assessed according to DISCERN [21] and Journal of American Medical Association scoring methods. This highlights the need for high-quality digital tools and resources that are easily accessible for older adults to avoid the default option of using nonregulated or low-quality resources.

Quality and Expectation

There was some dismissiveness around the ability of a digital health platform to diagnose conditions fully or correctly, highlighting a low expectation for the accuracy or quality of a digital service. However, these comments emphasize the disparities between the perspectives of what the technology is trying to do and the scope of what it is actually doing. For example, in scenario 1, the scope of the chatbot tool covers triaging and signposting the most appropriate service. To achieve this, it does not need to diagnose the condition per se (as inferred by a participant) but rather assess the risk and urgency based on the patient's symptoms and direct to the most relevant service. One of the participants notably raised the need for education on such technologies. Understanding the aim and scope of a platform, along with its limitations, is important. This sets expectations and ensures there is clarity on what functions the platform will and will not perform, particularly in the context of any traditional (eg, human interaction) functions it will replace [22].

A previous study of diabetes apps with older adults highlighted that usability is the main concern [12]. Here, the use of a chatbot raised usability issues, with participants highlighting that chatbots often fail to function correctly unless exactly the correct wording or phrasing is used to describe their condition. This highlights issues with earlier technologies and limitations in health-based chatbots [23]. The recent advent of large language models has created a step change in the interaction with chatbots, creating significantly increased flexibility in the conversational style in terms of inputs and responses [24]. This is likely to make chatbots more practical and, importantly, accessible in the future. For example, chatbots are likely to be able to quickly switch between different languages for conversations [25], without requiring complex remapping of decision trees or separate database content. However, this broader scope of chat ability comes with challenges around maintaining boundaries within which conversations must remain (ie, forcing the chatbot to discuss content outside the scope of the health conditions it is designed for) [24].

Trust

Participants raised several issues around trusting the use of technology for self-managing their health. Notably, this was in response to the initial questions before specific scenarios were introduced and highlights a general distrust around health technologies and digital tools for health, with a concern that this is reducing the quality of the health care patients receive. Once the specific scenarios were presented (which contained details about the functionality of digital health tools), then positives were identified. An example of this was when scenario 2 demonstrated the use of videos to provide guidance on exercises, rather than the leaflets with photographs or diagrams that participants would normally receive. Participants immediately recognized the advantages of being able to watch and pause the video to gain more detailed guidance. It has further been shown that people can accurately follow the movements of an avatar [26] or video-based movements for physiotherapy [27], confirming the advantages of animated or video-based guidance. However, additional annotation of videos maybe required, with guidance on the timing of an exercise requested for specific details on how long a position should be held, for example. The advantages of using video-based guidance through an app also included being able to do exercises at one's own pace and being able to repeat and retry exercises without the pressure of a physiotherapist observing. The patient-therapist relationship can be complex, with the physiotherapist often seen as an educator [28]. These comments from participants demonstrate a flip side to in-person consultations, where a health professional can create anxiety rather than reassurance in some cases, possibly due to an expectation that the patient must perform the exercises correctly while under observation.

Issues in trust also arose around how to determine whether a digital health platform is genuine. One of the participants referred to using a scheme similar to a "kitemark," referring to the British Standard Institution Kitemark symbol used on products to show it is approved by the British Standard Institution [29]. In fact, in the United Kingdom, the Organisation for the Review of Care and Health Apps (ORCHA [30]) assesses and provides quality assurance to digital health and care platforms. At a more regulatory level, the evidence standards framework for digital health technologies [31] has been developed by the UK National Institute for Health and Care Excellence to provide standardized guidance on the levels of evidence needed for the clinical and economic evaluation of digital health technologies. However, these are aimed more toward delivering guidance to developers and commissioners. It could be argued that a more consumer (ie, patient)-focused communication campaign could raise the awareness of ORCHA and hence allow potential users of the apps to quickly check whether they have been reviewed and rated.

Balancing Face-to-Face Consultations With Technology

It was clear that during the initial questions, participants were highly reluctant to reduce or replace face-to-face time with a health professional for a digital health platform. Participants highlighted that one of the advantages of in-person consultations was around the more comprehensive and wide-ranging assessments, with participants mentioning that clinicians are more likely to diagnose more complex issues or other unrelated health conditions during a consultation for a musculoskeletal health issue. This further extended to a patient safety aspect, with the opportunity for health care professionals to spot cases of domestic abuse during face-to-face consultations. While in-person consultations were clearly important to participants, it was acknowledged that waiting times to see a physiotherapist and other health professionals are continuing to increase [32], and it was highlighted by one of the participants that this is also increasingly the case with accessing private practitioners as well as NHS in the United Kingdom.

Given this, the advantages of a hybrid approach were recognized, keeping in-person consultations but using digital platforms in-between appointments. In reality, this is the most likely use case in the future, but more evidence is required on how this can be optimized [4]. Digital platforms can deliver a way to provide continuous guidance and support during the long periods between in-person consultations [33] and potentially increase adherence to the physiotherapy program [7]. In some cases, apps have built-in communication functions to allow chat or video call with a physiotherapist, further bridging the gap between in-person sessions (eg, [34]). This approach can help reduce the demand for in-person consultations and thus offer the opportunity for optimally timed regular face-to-face sessions complementing self-management using digital platforms [33].

Strengths and Limitations of This Study

This study has gathered opinions from a diverse sample of older adults. Although ethnicity was not formally recorded, we recruited participants through a mixture of supported living complexes. We purposely aimed for broad inclusion criteria, where participants were not required to have a current musculoskeletal condition or an experience of using technologies to manage musculoskeletal conditions to participate. While this aimed to get a broad range of opinions, we found most participants did have current musculoskeletal conditions and experience of using technologies. Therefore, a more targeted recruitment approach may have helped balance the sample. A limitation of this study is that it may have attracted participants who already used digital health platforms or had an interest in digital health technology. In particular, our requirement to access the focus group via a web-based platform could have excluded certain individuals with less technical literacy. In contrast, however, a web-based platform can make access easier for some groups (eg, those with mobility problems) [13].

Future research could further explore opinions of health professionals toward these digital platforms, thus providing perspectives from both the patient and health professional sides.

Conclusions

In conclusion, it is promising that digital health platforms for musculoskeletal conditions appear to be used and normalized within this age group. However, to enhance trust in these technologies, there needs to be clear communication around how digital platforms can support and assist with the self-management of musculoskeletal conditions and that their role is to complement rather than reduce or replace the role of the health care professional. In addition, we recommend raising public awareness around the role of organizations (such as ORCHA) that verify and assess the quality of digital health platforms to further enhance trust in the use of these technologies.

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Authors' Contributions

MTE and SC drafted initial qualitative interview questions. SC, MTE, PG, and KR reviewed the draft survey and qualitative questions. SC, MTE, and CK were directly involved in activities relating to participant recruitment. SC tidied the qualitative interview transcripts and analyzed qualitative data. SC and MTE conducted data analysis and drafted the manuscript. All authors reviewed the final manuscript.

Conflicts of Interest

KR and PG are employed by EQL Ltd. This study is part of a wider project that KR and PG helped conceptualize with MTE. MTE is in receipt of Medical Research Council funding covering his time on secondment with EQL Ltd for 1 day per week. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Focus group materials.
[DOCX File , 24 KB - aging_v7i1e55693_app1.docx]

References

1. Osteoarthritis: how common is it? National Institute for Clinical Excellence. 2023. URL: https://cks.nice.org.uk/topics/osteoarthritis/background-information/prevalence/ [accessed 2024-03-20]
2. The state of musculoskeletal health 2021. Versus Arthritis. URL: https://www.versusarthritis.org/media/24238/state-of-msk-health-2021.pdf [accessed 2024-03-20]
3. The state of musculoskeletal health. Versus Arthritis. 2023. URL: https://versusarthritis.org/about-arthritis/data-and-statistics/the-state-of-musculoskeletal-health/ [accessed 2024-07-11]
4. Bearne LM, Gregory WJ, Hurley MV. Remotely delivered physiotherapy: can we capture the benefits beyond COVID-19? Rheumatology (Oxford) 2021 Apr 06;60(4):1582-1584 [FREE Full text] [doi: 10.1093/rheumatology/keab104] [Medline: 33547773]
5. Webb J, Horlock R, Ahlquist A, Hall A, Brisby K, Hills S, et al. The reach and benefits of a digital intervention to improve physical activity in people with a musculoskeletal condition delivered during the COVID-19 pandemic in the UK. Perspect Public Health 2023 Mar 03;143(2):97-104 [FREE Full text] [doi: 10.1177/17579139221085098] [Medline: 35369806]
6. Hewitt S, Sephton R, Yeowell G. The effectiveness of digital health interventions in the management of musculoskeletal conditions: systematic literature review. J Med Internet Res 2020 Jun 05;22(6):e15617 [FREE Full text] [doi: 10.2196/15617] [Medline: 32501277]
7. Lang S, McLelland C, MacDonald D, Hamilton DF. Do digital interventions increase adherence to home exercise rehabilitation? a systematic review of randomised controlled trials. Arch Physiother 2022 Oct 03;12(1):24 [FREE Full text] [doi: 10.1186/s40945-022-00148-z] [Medline: 36184611]
8. Cross M, Smith E, Hoy D, Nolte S, Ackerman I, Fransen M, et al. The global burden of hip and knee osteoarthritis: estimates from the global burden of disease 2010 study. Ann Rheum Dis 2014 Jul;73(7):1323-1330. [doi: 10.1136/annrheumdis-2013-204763] [Medline: 24553908]
9. Smith E, Hoy DG, Cross M, Vos T, Naghavi M, Buchbinder R, et al. The global burden of other musculoskeletal disorders: estimates from the Global Burden of Disease 2010 study. Ann Rheum Dis 2014 Aug;73(8):1462-1469. [doi: 10.1136/annrheumdis-2013-204680] [Medline: 24590181]
10. Hill R, Betts LR, Gardner SE. Older adults’ experiences and perceptions of digital technology: (dis)empowerment, wellbeing, and inclusion. Comput Hum Behav 2015 Jul;48:415-423. [doi: 10.1016/j.chb.2015.01.062]
11. Lewis JR. The system usability scale: past, present, and future. Int J Hum Comput Interact 2018 Mar 30;34(7):577-590. [doi: 10.1080/10447318.2018.1455307]
12. Ye Q, Boren SA, Khan U, Simoes EJ, Kim MS. Experience of diabetes self-management with mobile applications: a focus group study among older people with diabetes. Eur J Person Centered Healthcare 2018 Jun 01;6(2). [doi: 10.5750/ejpch.v6i2.1451]
13. Clohessy S, Arvanitis TN, Rashid U, Craddock C, Evans M, Toro CT, et al. Using digital tools in clinical, health and social care research: a mixed-methods study of UK stakeholders. BMJ Open 2024 Apr 03;14(4):e076613 [FREE Full text] [doi: 10.1136/bmjopen-2023-076613] [Medline: 38569710]
14. Dobson F, Hinman RS, Roos EM, Abbott JH, Stratford P, Davis AM, et al. OARSI recommended performance-based tests to assess physical function in people diagnosed with hip or knee osteoarthritis. Osteoarthritis Cartilage 2013 Aug;21(8):1042-1052 [FREE Full text] [doi: 10.1016/j.joca.2013.05.002] [Medline: 23680877]
15. CRN west midlands. National Institute for Health and Care Excellence. URL: https://local.nihr.ac.uk/lcrn/west-midlands/ [accessed 2023-12-20]
16. Gymer M, Guard M, Grinbergs P. A case report: digital musculoskeletal triage and rehabilitation tools improve outcomes and offer a positive experience for lower back pain. JMIR Preprints. Preprint posted online on October 20, 2022 [FREE Full text] [doi: 10.2196/preprints.43686]

17. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
18. The NHS long term plan. NHS England. 2019 Jan 7. URL: https://www.england.nhs.uk/publication/the-nhs-long-term-plan/ [accessed 2024-06-13]
19. YouTube in the United Kingdom - statistics and facts. Statista. 2024. URL: https://www.statista.com/topics/11253/youtube-in-the-uk/ [accessed 2024-07-08]
20. Özerdoğan Ö, Kuru T. Assessment of ‘physical therapy for elderly people’ videos on YouTube. Nobel Med 2020;16(2):62-70.
21. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. J Epidemiol Community Health 1999 Feb;53(2):105-111 [FREE Full text] [doi: 10.1136/jech.53.2.105] [Medline: 10396471]
22. O'Connor S, Hanlon P, O'Donnell CA, Garcia S, Glanville J, Mair FS. Understanding factors affecting patient and public engagement and recruitment to digital health interventions: a systematic review of qualitative studies. BMC Med Inform Decis Mak 2016 Sep 15;16(1):120 [FREE Full text] [doi: 10.1186/s12911-016-0359-3] [Medline: 27630020]
23. You Y, Gui X. Self-diagnosis through AI-enabled chatbot-based symptom checkers: user experiences and design considerations. AMIA Annu Symp Proc 2020 Jan 25;2020:1354-1363 [FREE Full text] [Medline: 33936512]
24. Thirunavukarasu AJ, Ting DS, Elangovan K, Gutierrez L, Tan TF, Ting DS. Large language models in medicine. Nat Med 2023 Aug 17;29(8):1930-1940. [doi: 10.1038/s41591-023-02448-8] [Medline: 37460753]
25. Radford A, Wu J, Child R, Luan D, Amodei D, Sutskever I. Language models are unsupervised multitask learners. GitHub. URL: https://d4mucfpksywv.cloudfront.net/better-language-models/language_models_are_unsupervised_multitask_learners.pdf [accessed 2023-10-31]
26. Khan O, Ahmed I, Cottingham J, Rahhal M, Arvanitis TN, Elliott MT. Timing and correction of stepping movements with a virtual reality avatar. PLoS One 2020 Feb 28;15(2):e0229641 [FREE Full text] [doi: 10.1371/journal.pone.0229641] [Medline: 32109252]
27. Tang R, Yang XD, Bateman S, Jorge J, Tang A. Physio@Home: exploring visual guidance and feedback techniques for physiotherapy exercises. In: Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. 2015 Presented at: CHI '15; April 18-23, 2015; Seoul, Republic of Korea. [doi: 10.1145/2702123.2702401]
28. Besley J, Kayes NM, McPherson KM. Assessing therapeutic relationships in physiotherapy: literature review. N Z J Physiother 2011;39(2):81.
29. Accelerating progress towards a sustainable world. British Standards Institute. URL: https://www.bsigroup.com/en-GB/ [accessed 2023-12-20]
30. The Organisation for the Review of Care and Health Apps homepage. The Organisation for the Review of Care and Health Apps. URL: https://orchahealth.com/ [accessed 2023-12-20]
31. Unsworth H, Dillon B, Collinson L, Powell H, Salmon M, Oladapo T, et al. The NICE Evidence Standards Framework for digital health and care technologies - developing and maintaining an innovative evidence framework with global impact. Digit Health 2021 Jun 24;7:20552076211018617 [FREE Full text] [doi: 10.1177/20552076211018617] [Medline: 34249371]
32. More than 2 million people waiting longer than statutory 18 weeks for NHS treatment. Royal College of Surgeons of England. 2022 Jan 13. URL: https://www.rcseng.ac.uk/news-and-events/media-centre/press-releases/waiting-times-press-notice-november-2021/ [accessed 2023-08-17]
33. Kelly M, Fullen B, Martin D, McMahon S, McVeigh JG. eHealth interventions to support self-management in people with musculoskeletal disorders, "eHealth: it's TIME"-a scoping review. Phys Ther 2022 Apr 01;102(4):pzab307 [FREE Full text] [doi: 10.1093/ptj/pzab307] [Medline: 35079826]
34. Phio engage - digital marketplace. United Kingdom Government. URL: https://www.applytosupply.digitalmarketplace.service.gov.uk/g-cloud/services/44394770495820 [accessed 2023-10-30]

Abbreviations

GP: general practitioner
NHS: National Health Service
ORCHA: Organisation for the Review of Care and Health Apps

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Original Paper

Perspectives and Experiences on eHealth Solutions for Coping With Chronic Pain: Qualitative Study Among Older People Living With Chronic Pain

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Abstract

Background: Chronic noncancer pain (CNCP) is a major health issue among the older population, affecting multiple aspects of individual functioning. Recently, the use of eHealth solutions has been proposed in supporting chronic pain self-management even among older adults, although some barriers have emerged. Few qualitative studies, with none conducted in Mediterranean countries, have explored older people's experiences and perceptions regarding the types of strategies used to cope with chronic pain and eHealth tools for chronic pain management.

Objective: This study's objectives were to explore the perspectives and experiences of older adults regarding the coping strategies used to manage chronic pain, the use of digital technologies in everyday life, and the potentiality and barriers in using those technologies for health and pain management.

Methods: A multimethod approach (ie, self-report questionnaires and a semistructured interview) has been adopted targeting older adults (ie, those who are aged 65 to 80 years and presenting different types of CNCP) who are attending a pain therapy center in Italy. Qualitative answers were analyzed using thematic analysis.

Results: Overall, participants reported using a variety of pain coping strategies; however, they showed an attitude of resignation to their CNCP condition. Nearly 70% (12/18) of the interviewees referred to using digital technologies for purposes related to health and pain management, mostly involving very basic management activities. The participants' opinions on the useful functions that need to be incorporated in eHealth tools for chronic pain management have been categorized into four themes: (1) *specific pain self-management skills*, (2) *support in organizing various health-related aspects*, (3) *sharing experiences with other*s, and (4) *increasing pain-related personal knowledge*. Conversely, the following potential barriers to adopting eHealth tools emerged: (1) *computer illiteracy*, (2) *negative effects or risks*, (3) *impersonal interaction*, and (4) *physical limitations*.

Conclusions: The use of eHealth solutions still seems low, often being accompanied by a perceived lack of digital skills or attitude among a sample of older adults from Italy with CNCP. Before introducing innovative eHealth solutions, it would be of primary importance to take action to enhance, on the one hand, self-efficacy in pain management and, on the other, the digital literacy level among older people.

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KEYWORDS

older adults; qualitative method; pain; coping strategies; eHealth; pain management; mobile phone

Introduction

Background

Chronic pain (ie, pain lasting for >3 months) [1] is a major global health issue, affecting approximately 20% of people worldwide [2]. The prevalence of chronic pain generally increases with age, and it is estimated to be higher in adults aged ≥65 years, with a substantial negative impact on their physical, psychological, and social functioning [3-5]. Because of the several physiological age-related changes and frequent pathological comorbidities, effective treatment of chronic pain can be challenging in the older population [6]. Furthermore, in addition to the reluctance of older people to seek or accept medical help, the common belief among older adults and health care providers that pain is a normal part of aging may partially explain why chronic pain is often underestimated and underreported [7]. In this regard, a few studies showed that older adults tend to adopt a stoic attitude while experiencing pain, most often preferring to use self-reliance–based coping strategies, although they are not always effective [7,8]. Several studies have explored the life experiences and needs of older adults with chronic pain as well as the strategies they use to cope with it [9-11]. These studies also aim to promote more effective and tailored pain self-management interventions [8,11,12].

In recent years, particularly in the wake of the COVID-19 pandemic, there has been a massive increase in the adoption of eHealth solutions to ensure the continuity and accessibility of care [13]. Preliminary evidence supports the potential of these solutions in pain assessment, diagnosis, and treatment [14]. However, older adults, especially subgroups aged 75 to 84 years and ≥85 years, still seem to be underrepresented in this field of research [15]. There is, indeed, evidence that older people are more likely to experience digital exclusion, even in research settings, due to age-related negative stereotypes that depict them as a homogeneous group of technologically illiterate users [16-18]. This often results in a lack of consideration of their needs and preferences from the earliest stages of the eHealth solutions design process, with the risk that the proposed tools do not fully match the real needs of end users and are thereby weak in terms of feasibility and acceptability for older people [19-22].

Although it represents a growing area of interest, to date, to the best of our knowledge, only a few qualitative studies have explored the specific experiences and perspectives of older adults on the use of eHealth solutions in the context of coping with chronic pain. Among the recent studies, Bhattarai et al [23] carried out a qualitative study aimed at evaluating older people's views and experiences of using a smartphone app, with the sole focus on chronic arthritic pain management. In addition, O'Reilly et al [20] identified barriers and specific needs of both middle-aged and older adults (mean age of 61.3, SD 7.7 y) regarding the use of eHealth solutions for chronic pain self-management. Further qualitative approaches have been introduced with the specific aim of developing eHealth tools and often targeting a specific population of patients with chronic pain (those with osteoarthritis [24], older adults with obesity and experiencing chronic pain [25], those with chronic back pain [26], those with chronic pain in comorbidity with cognitive decline [27], and those with chronic musculoskeletal pain [28]).

To the best of our knowledge, none of the aforementioned studies were carried out in a Mediterranean country, such as Italy.

It should be indeed considered that values; norms; and, in general, the cultural framework can significantly affect people's life experiences and health-related issues, including the ways in which pain is perceived and managed [11,29]. For example, older adults living in Mediterranean countries seem to value and rely more strongly on close family support in managing well-being, compared with those living in Nordic countries, for whom values such as autonomy and a tendency to rely on formal caregivers outside the immediate family entourage prevail [30]. Concurrently, the use of technology may vary according to the sociocultural context [31]. Interestingly, as shown in recent qualitative research about internet use among people aged ≥65 years during the COVID-19 pandemic [32], many Italian older people tended to seek technological help from close family members such as children or grandchildren. This propensity to ask for help or to totally delegate the execution of activities using technological devices, for example, may at least partly impact the degree to which older people are motivated and willing to enhance their digital skills for independent use of such devices.

Objectives

This study aims to integrate previous research by exploring perspectives and experiences regarding eHealth solutions for coping with chronic pain among older adults with different types of chronic noncancer pain (CNCP) in the context of an Italian center for pain management. Specifically, this paper aims to explore the perspectives of this population regarding (1) the types of strategies used by older adults to cope with chronic pain and the related perceived effectiveness, (2) the types of digital technologies adopted in everyday life and the purposes of their use, (3) the use of digital solutions for health and pain management and older adults' experience with those solutions, and (4) the potential useful functions to be included in eHealth solutions for chronic pain self-management and the barriers to use such tools.

Methods

Ethical Considerations

The study was approved by the local clinical research committee of the Verona University Hospital (Registro del Dolore protocol, ID 1751CESC) and was conducted in accordance with the principles of the Declaration of Helsinki. Written informed consent was obtained from all participants. The participants did not receive any form of compensation. The collected data have been anonymized to safeguard participants information.

Study Design

This study used a multimethod approach: self-report questionnaires and semistructured interviews.

Participants and Setting

A purposive sample of community-dwelling older adults living with chronic pain was recruited from the pain therapy unit of the Verona University Hospital, Italy. This highly specialized center offers clinical activities for the diagnosis and pharmacological and nonpharmacological treatment of all forms of pain (eg, low back and osteomuscular pain, fibromyalgia syndrome, maxillofacial complex pain forms, headaches, neuropathic pain, complex regional pain syndromes, and district pain). It is mainly attended by people whose pain is difficult to manage in primary care settings and who often undergo several types of treatments unsuccessfully.

Self-report questionnaires and a semistructured interview were administered to all patients evaluated at the outpatient center who met the following inclusion criteria: age range between 65 and 80 years; having a clinical diagnosis of CNCP (lasting for at least 3 months), as defined by the referring physicians according to the clinical records; being an Italian speaker; and being able to answer interviews and questionnaires as established by the referring physicians.

Available patients were approached from the end of September to the beginning of December 2023 at the pain therapy unit, and recruitment continued until data saturation in the interviews was reached [33].

Measures

Sociodemographic (ie, sex, age, educational level, and civil status) and clinical data (ie, type of CNCP diagnosis, pain intensity, and duration) were collected immediately before starting the administration of the questionnaires and interviews. The specific diagnosis of CNCP was made by the referring physicians based on the widely accepted temporal criterion by which persistent pain is any pain lasting >3 months [34]. Pain intensity on average over the last week was measured by verbally asking participants to rate their pain on a scale from 0 (ie, no pain) to 10 (ie, the worst pain imaginable).

Participants were asked to fill out the following self-reported questionnaires: the Psychological Well-Being Questionnaire (Ben-SSC [35]) and the Chronic Pain Coping Inventory-Italian version (CPCI-I [36]).

The Ben-SSC [35] is a validated 37-item questionnaire specifically constructed to assess psychological well-being in both the adult and older Italian populations. It is inspired by the eudaimonic perspective of well-being [37], covering 3 different dimensions: personal life satisfaction, sense of autonomy and self-efficacy, and emotion-regulating skills. The participants are asked to indicate their degree of agreement with each item on a 4-point Likert scale, ranging between 1 (not at all) and 4 (always). The Ben-SSC provides a total well-being score, obtained by summing the score for each of the 37 items, where higher scores indicate higher levels of psychological well-being. The 3 subscale scores are calculated by dividing the sum of the items' scores by the number of items in that subscale. The Ben-SSC demonstrated good reliability (Cronbach α=0.91) [35].

The Italian version of the 42-item CPCI-I [36] is a self-report questionnaire that focuses on asking the users to rate the frequency of use of cognitive and behavioral pain coping strategies during the previous week. The strategies are categorized into the following 8 subscales: guarding (avoiding or restricting the use of a body part or movement or specific activities), resting (eg, sitting and laying), asking for assistance (asking someone for help with a task), relaxation (engaging in specific relaxation exercises to reduce muscle tension, eg, slow, deep breathing), task persistence (eg, ignoring pain and carrying out an activity despite the pain), exercise or stretch (doing specific muscle-strengthening or stretching exercises), seeking social support (talking with a significant person to receive support when one experiences pain), and coping self-statements (encouraging oneself through positive thoughts about the painful condition). Each item is scored on a 0 to 8 points scale, where higher scores indicate a greater use of coping strategies. Subscale scores are obtained by dividing the sum of the items' scores by the number of items in that subscale. The CPCI-I proved to have a good factorial structure and psychometric properties similar to the original and adapted versions [36].

The face-to-face semistructured interviews were conducted by ADL at the pain therapy unit. Interviews were based on an interview guide developed by the multidisciplinary research team (Multimedia Appendix 1). The included questions mainly explored the following aspects: the pain coping strategies perceived as most effective among those indicated in the CPCI-I and potential additional helpful coping strategies (ie, not included in the CPCI-I coping categories), the type of digital technologies used and their purposes of use, the experiences regarding health-related purposes of use for digital technologies, and the potential useful functions and barriers to use eHealth solutions for chronic pain management.

Data Analysis

Descriptive statistics were used to summarize the sociodemographic and clinical characteristics of the sample and questionnaire scores.

For data collected qualitatively (ie, semistructured interview), for each theme, we reported examples (the participant ID code to which the quote corresponds is provided in brackets) and the number of quotes related to that theme. All interviews were transcribed "verbatim" in real time and anonymized by alphanumeric codes. A reflexive thematic analysis was used to identify and analyze patterns within the collected qualitative data following the 6 steps proposed by Braun and Clarke [38-40]. More specifically, an inductive and epistemologically constructionist approach to understanding the data was adopted to better capture the meaning and meaningfulness attributed by the participants. Consequently, apart from the recurrence of certain themes within the data set, major importance in the coding process was placed on the significance or relevance of potential themes to the research questions. After familiarizing ourselves with the data by reading the transcripts several times and noting down initial ideas (step 1), the data were initially coded (step 2) and then sorted into potential themes and subthemes (step 3). Next, these preliminary themes were compared and refined repeatedly (step 4) until coherent and meaningful patterns were obtained both at the level of individual themes and of the data set as a whole (step 5). Finally, a concise, coherent, and nonrepetitive story of the data was provided, and representative quotes were provided to exemplify the themes selected (step 6). Data analysis was performed by 2 researchers (ADL and IP) independently, and a third researcher was involved in the discussion when disagreement emerged (VD).

Diverse steps have been used to guarantee the rigor of qualitative methods [41]. More specifically, credibility was ensured by investing an adequate period in the research setting and interacting with the participants (ie, prolonged engagement) and using investigator triangulation. The triangulation, along with the involvement of a researcher not directly engaged in the data analysis and collection (LDP), allowed us to ensure consistency, repeatability, and confirmability of the methods.

Results

Sociodemographic and Clinical Characteristics of the Sample

A total of 23 participants were considered eligible according to the inclusion criteria and approached during the recruitment period. Of these 23 participants, 3 (13%) refused to participate in the study, 1 (4%) discontinued completing the questionnaires due to time constraints, and 1 (4%) was excluded because of substantial hearing impairment that prevented an accurate understanding of the interview questions. However, data saturation (ie, recurrence of themes when no new information emerged) was achieved after interviews with 18 participants, thus not proceeding with the recruitment. The numerosity results are in line with the sample sizes reported in previously published qualitative exploratory research [10,11,42].

On average, the completion of the questionnaires and interviews took about 40 minutes, ranging from 30 to 50 minutes. All questions included in the questionnaires and the interviews were answered by the participants.

Table 1 describes the participants' sociodemographic and clinical characteristics. The average age of the participants was 72.7 (SD 5.2; range 65-79) years. Most of them were female (14/18, 78%) and married (12/18, 67%), with a primary or middle school level of education (14/18, 78%).

Table 1. Participants' sociodemographic and clinical characteristics.

ID	Sex	Age (years)	Educational level	Civil status	Chronic pain condition	Pain intensity (0-10)	Pain duration
1	Female	79	Primary school	Married	L5 radiculopathy (persistent canalar stenosis) on the right side	10	7 to 8 years
2	Female	75	Primary school	Married	Fibromyalgia	8	Lifelong
3	Female	75	Middle school	Married	Low back pain on the right side	5.5	4 to 5 years
4	Male	78	Primary school	Married	Postherpetic neuralgia	10	3 years and 7 months
5	Female	66	Middle school	Married	Low back pain	7	About 8 months
6	Male	74	Middle school	Married	Low back pain	5	Pain for several years that has worsened for about 20 days
7	Female	73	Middle school	Married	Radiculopathy and rheumatoid arthritis	8	18 years
8	Female	79	Primary school	Widower	Neck pain	8	A few years
9	Male	75	Middle school	Married	Postherpetic neuralgia	3	1 year
10	Female	65	University	Married	Fibromyalgia and Sjögren syndrome	4.5	10-year diagnosis but lifelong pain
11	Female	65	High school	Married	Postherpetic neuralgia	10	4 years
12	Female	75	Middle school	Married	Low back pain	10	36 years
13	Male	75	Primary school	Celibate	Neuropathic pain	10	33 years
14	Female	74	Primary school	Divorced	Low back pain	10	20 years
15	Female	79	Primary school	Widower	Fibromyalgia	9	Lifelong
16	Female	70	University	Widower	Fibromyalgia	8	Diagnosed in 2018 but pain for almost 20 years
17	Female	66	High school	Divorced	Chronic migraine	7	46 years
18	Female	65	Middle school	Married	Lumbosciatalgia and neck pain	7	8.5 years

Participants reported a wide range of CNCP conditions, among which the most frequent were low back pain, fibromyalgia, and postherpetic neuralgia, with an average pain intensity level of 8.1 (0 to 10 scale). The duration of pain ranged between 8 months and "lifelong," with 50% (9/18) of participants experiencing pain for >20 years.

Psychological Well-Being

The total mean score of the Ben-SSC was 109.2 (SD 17.2), indicating a medium level of perceived psychological well-being. The mean scores obtained in each subscale of the Ben-SCC also reflect a medium level regarding the specific constructs of personal satisfaction (mean 32.3, SD 8.1; possible range 11-44), perceived self-efficacy and sense of autonomy (mean 25.7, SD 5.2; possible range 9-36), and emotion regulation skills (mean 30.8, SD 3.6; possible range 10-40).

Coping Strategies to Manage Chronic Pain

The most adopted strategies to cope with pain, as assessed by the CPCI-I, were coping self-statements (mean 4.3, SD 1.6), resting (mean 4, SD 1.9), task persistence (mean 3.9, SD 1.6), and guarding (mean 3.7, SD 1.9). The least used strategies were relaxation (mean 2, SD 1.4) and exercise or stretch (mean 2.3, SD 1.7; Table 2).

Table 2. Total sample mean scores for each of the Chronic Pain Coping Inventory-Italian version subscales (score range for each subscale: 0-8).

Coping strategies	Score, mean (SD)
Coping self-statements	4.3 (1.6)
Resting	4 (1.9)
Task persistence	3.9 (1.6)
Guarding	3.7 (1.9)
Seeking social support	3.3 (2)
Asking for assistance	3.2 (1.7)
Exercise or stretch	2.3 (1.7)
Relaxation	2 (1.4)

On the basis of the participants' responses to the interview questions, among the strategies indicated in the CPCI-I, those perceived to be most effective were resting (6/18, 33%), followed by exercise or stretch (3/18, 17%), task persistence (2/18, 11%), guarding (2/18, 11%), relaxation (1/18, 6%), and seeking social support (1/18, 6%). Of the 18 participants, 1 (6%) participant indicated >1 strategy as the most effective, and 4 (22%) participants reported that none of these strategies were effective. The average perceived efficacy level in terms of pain reduction of the referred strategies was 5.9 (SD 3.4; 0 to 10 scale). As for the scores assigned to each CPCI-I strategy, the values ranged from 7 to 10 for exercise or stretch, 1 to 10 for resting, while the remaining strategies—mentioned less frequently as being effective—were assigned the following scores: 3 and 5.5. for task persistence, 4 and 7 for guarding, 3 for relaxation and 6 for seeking social support.

Additional coping strategies (ie, not evaluated through the CPCI-I) have been reported by participants during the interview. Quotes regarding the additional coping strategies were grouped into the following categories:

1. Body treatments with home remedies: some participants (n=6 quotes) reported resorting to home-based informal strategies to relieve pain, including massages, warm or cold modalities, and salt and water baths, such as in the following case:

> *I take a bath with water and salt. Also, I warm my leg with my phono, and I have to warm it slowly or it hurts even more.* [ID 13]

2. Medications: for 4 participants (n=4 quotes), taking medications, for example, anti-inflammatory drugs, have been described as an effective, and sometimes as the only possible, strategy:

> *Besides resting, there is no other strategy, only anti-inflammatories.* [ID 2]

3. Spirituality, such as prayer: 2 respondents (n=2 quotes) declared that they seek hope and comfort in faith:

> *I pray a lot; prayer calms me down... in addition to reciting the formulas, I speak within myself freely, from the heart.* [ID 7]

4. Adjusting daily rhythms to pain: this strategy reflects the tendency to perceive pain as unavoidable and the consequent need to change certain lifestyle habits to continue one's daily activities to the best of one's capabilities. Specifically, to best pursue his professional activity, a participant said the following:

> *I adopted a system, I sleep from 8 p.m. to midnight, the pain is not so intense... afterward I take the pills and sleep maybe half an hour until morning... I totally changed my routine, but I had to do it.* [ID 6]

5. Resignation: an attitude of distrust of health services emerged from 1 participant, indicating a reduction in expectations regarding the actual help provided by the health care system for the treatment of pain:

> *I feel little help from institutions, doctors, professionals, there is no listening. We are numbers, when I come to a new institution my motto is don't expect anything.* [ID 10]

Type of Digital Technologies Used by the Participants and Purposes of Use

All the interviewees (18/18, 100%) reported owning a mobile phone and using it independently, while only 3 (17%) of them referred to using other technological devices, such as computers, tablets, and smartwatches.

As for the general purposes of use in daily life, all participants indicated that they use digital technology tools *to keep up connections with others* (n=18 quotes), and more than half of them also use these tools *for leisure activities* (n=14 quotes):

> *The mobile phone for me is essential for communicating with my daughters and grandchildren who don't live very close to my home... either with calls or messages or even video calls.* [ID 14]
>
> *I usually use my mobile phone to play cards to while away the time....* [ID 4]
>
> *I like visiting websites of catechesis and prayer, listening, watching videos...* [ID 11]

Of the 18 participants, 6 (33%) declared *other daily life uses* of digital solutions, such as web banking and shopping. (n=7 quotes):

> *Other things that I do are for example accessing my bank account, making payments and bank transfers....* [ID 14]

Only 1 (6%) of the 18 participant spontaneously reported engaging in health-related activities, specifically searching the internet for information related to one's medical condition or any new pharmacological therapies being undertaken (ID 12).

Experiences of Using Technological Solutions for Health-Related and Pain-Related Purposes

When participants were explicitly asked whether they use such devices for purposes related to health management (including pain conditions), nearly 70% (12/18) of the interviewees answered affirmative, while the other participants declared that they do not directly use eHealth solutions (even if in some of these cases, they delegate the use of these tools to informal caregivers).

The quotes reported by affirmative responders have been categorized into the following themes:

1. *Booking medical visits or tests* (n=11 quotes):

> *I often book medical examinations on the internet or call the medical service directly.* [ID 18]

2. *Searching health information* (n=8 quotes):

> *When I am prescribed new drugs, I go and look online to find out what it is.* [ID 12]

3. *Managing pharmaceutical prescriptions* (n=6 quotes):

> *Sometimes I use this app of the National Health System, that allows you to receive and manage medical prescriptions.* [ID 11]

4. *Accessing the personal electronic health record* (n=4 quotes):

> *I always use the Electronic Health Record, for example, I check if the doctors have uploaded the reports, I keep track of all the medical examinations...* [ID 16]

5. *Purchasing medicines on the web*: Of 18 participants, 2 (11%) stated ordering and purchasing medications on the web (n=2 quotes):

> *I find it good to order medication on the internet, it is a fast method, the medicines arrive directly at home in no time.* [ID 18]

As for the participants' current use experiences of digital devices for health-related purposes, the reported quotes have been categorized into 3 themes, with 1 concerning the quantity and 2 regarding the quality (respectively, positive or negative) of such experiences.

1. *Limited to few activities*: for 5 (28%) of the 18 participants, the use of digital technologies (mainly mobile phones) is limited to a few activities related to their health management (eg, booking medical visits and tests and downloading clinical reports) or is not very frequent (n=5 quotes):

> *I don't know many things, but I am able to do the things that are essential to me [for healthcare].* [ID 8]

2. *Positive and helpful experience* refers to fulfilling experiences related to the use of digital technologies in health care, as reported by 4 (22%) of the 18 participants, with the following example being 1 of the 4 quotes:

> *Technology is a great help and support in managing several aspects of my health and my painful condition.* [ID 10]

3. *Negative experience*, which was reported by 3 (17%) of the 18 participants, included answers related to "external support/delegating to others" (n=2 quotes) and "unsatisfactory" in relation to malfunctions (n=1 quote):

> *There are some things that I can't do, for example checking emails, and therefore I ask my neighbor, a very nice lady, to do these things for me.* [ID 15]
>
> *Some systems, such as the Electronic Health Record, are potentially useful, but they must work properly! But it rarely happens, there is always a problem.* [ID 16]

Specifically, for the first subtheme, despite the independent use of digital devices for some basic health-related activities (eg, making a phone call to book a medical visit), a few of the interviewees (3/12, 25%) highlighted the need for assistance or to delegate the execution of more complex operations to others.

Potential Useful Functions of eHealth Tools for Chronic Pain Self-Management

According to 10 (56%) of the 18 interviewees, adopting eHealth tools specifically designed for pain management might be useful.

Regarding the potential useful functions of possible new eHealth tools for pain management, we identified the following four themes: (1) *specific pain self-management skills* (n=7 quotes), (2) *support in organizing various health-related aspects* (n=2 quotes), (3) *sharing experiences with others* (n=2 quotes), and (4) *increasing pain-related personal knowledge* (n=2 quotes). Of the 18 participants, 3 (17%) reported having no specific ideas about possible functions to be included in such tools, although they expressed themselves favorably about the usefulness of possible eHealth solutions.

The first theme includes several strategies that participants find helpful for achieving better self-management of pain to be delivered, for example, through text, audio, or video files explaining good practices, physical exercises or stretching, and relaxation or meditation practices. Indeed, just over half of the interviewees (6/10, 60%) expressed the need to strengthen their pain self-management skills through targeted content relating to both the physical or biological and psychological or educational fields. For example, a participant said the following:

> *Looking for an alternative to medication... for example, when I wake up in the morning, I feel the need to stretch my muscles... so an alternative might be videos showing specific exercises or relaxing therapies.* [ID 12]

In addition, some participants argued for the usefulness of providing professionals with different backgrounds and the possibility to select the proposed activities according to one's interests. This is to emphasize the necessity of interacting with a range of experts and choosing content that is not "standard" and applicable to all but rather unique depending on the specific requirements of everyone:

> *It would be helpful to include the names of experts with different backgrounds, not only health care, but also theologians or meditation teachers to have moments of reflection.* [ID 11]
>
> *I would include both "random" and "user-selected" activities, because I would be interested, for example, in videos of professionals with a spiritual background but others might prefer a more medical approach.* [ID 15]

The second theme focused on the support provided by digital tools in organizing various health-related aspects. Some participants stated it could be helpful to receive automatic notifications on their smartphones to prevent forgetfulness regarding scheduled appointments, as explained in the following case:

> *First of all, a reminder if I have to do something, for example, appointment reminders... for example, the day before the visit it comes up on my cell phone screen that tomorrow I have to undergo that medical examination.* [ID 1]

Furthermore, the need for digital systems that allow medical appointments to be booked quickly and easily was highlighted:

> *A program that allows me to quickly book visits.* [ID 5]

The third theme addresses the need for social support and the desire to share experiences with others facing similar circumstances, as explained by the following participant:

> *It would be important to share my experience with other people who may be experiencing the same issues, this would be helpful and allow to exercise one's skills of listening to the other.* [ID 11]

The fourth theme highlights the need to increase one's knowledge about their medical condition, obtain reliable information about chronic pain and treatment options, and directly consult experts in the field. The following are 2 exemplary quotes on this theme:

> *Since these are unknown diseases, there are no effective drugs, only supplements, it would be helpful to have a source of up-to-date information.* [ID 7]
>
> *An app where you can contact experts to ask for information, to receive support.* [ID 10]

Potential Barriers to the Use of eHealth Tools

Finally, with regard to the potential barriers to using eHealth tools, the following four themes were identified: (1) *computer illiteracy* (n=7 quotes), (2) *negative effects or risks* (n=3 quotes), (3) *impersonal interaction* (n=2 quotes), and (4) *physical limitations* (n=2 quotes).

In general, the first theme concerns the perceived lack of technological skills or attitude and the reduced interest in learning how to use new technologies, sometimes citing advanced age or the belief that such digital devices are substantially useless in the treatment of pain as reasons. The following are some examples of quotes to support this theme:

> *I find technology difficult, I'm not capable, I never did bother to learn it.* [ID 7]
>
> *I'm not really into technology, it has never been my strong suit.* [ID 14]
>
> *Honestly, I'm not interested in learning to use technology... And then at my age...* [ID 4]
>
> *I'm not someone who believes in these fancy things. If you feel pain and it doesn't go away, you keep it and that's it.* [ID 6]

The second theme addresses concerns of older adults regarding potential risks or negative effects arising from the use of eHealth tools. On the one hand, these concerns pertain to the risk of developing technology addiction, as pointed out by the following interviewee:

> *Then you get used to it, you always look for more... you get addicted to that too.* [ID 8]

On the other hand, these risks might involve potential adverse effects. For example, 1 participant stated the following:

> *When you search for information on the internet, for example, sometimes it seems like you have more pain, you start to fantasize about having a serious pathology...* [ID 3]

The third theme explains the idea that interaction with a device cannot be considered as satisfactory as that with a real person (eg, health care professional), which is, instead, considered essential. In this regard, 1 participant stated the following:

> *I need to hear from someone, not technology... not for human issues like health care.* [ID 9]

In this sense, several participants considered the eHealth tools to be inadequate substitutes for in-person interaction, also expressing a clear preference for the latter:

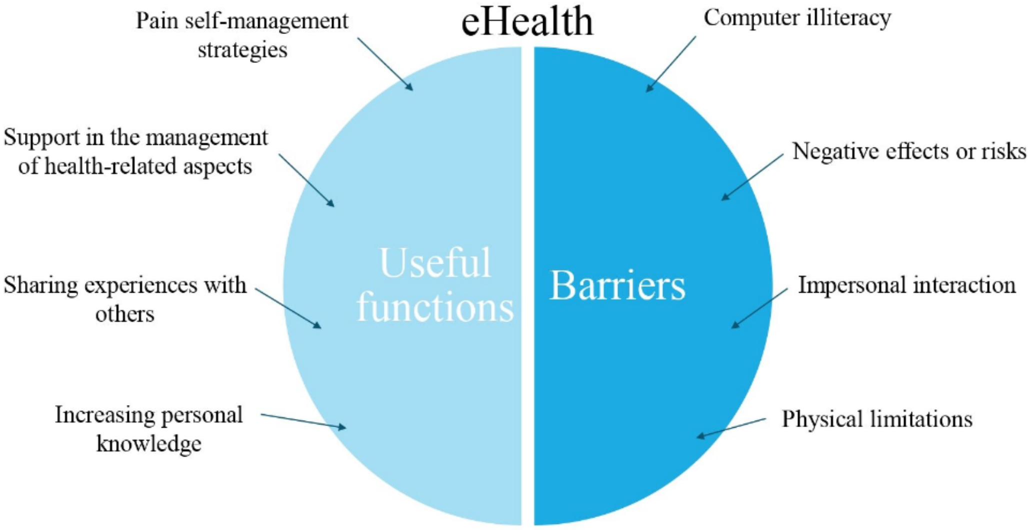
> *I think talking to a person, to a doctor, is more helpful than looking at your cell phone. I prefer it...* [ID 3]

The fourth theme concerns physical limitations that could prevent the use of the technology, such as visual and hearing impairments, as reported by a participant:

> *I don't even watch television, my hearing is bad, I understand little of what I hear, I get about 40% of what I listen to.* [ID 13]

Figure 1 shows an overview of the themes related to the potential useful functions and the barriers to the use of eHealth solutions in the context of CNCP management.

Figure 1. Potential useful functions and barriers to the use of eHealth solutions in the context of chronic noncancer pain management.



Discussion

Principal Findings

This study aimed to explore perspectives and experiences of older adults (aged 65 to 80 years) with any type of CNCP regarding the strategies used to cope with chronic pain and the related perceived effectiveness; the types of digital technologies adopted in everyday life and the purposes of their use, including those related to health and pain management; the potential useful functions to be included in any eHealth solutions; and the potential barriers to use such tools in the context of chronic pain self-management. To the best of our knowledge, this is the first qualitative study to investigate the abovementioned aspects in a population of older adults with CNCP without focusing on a specific pain-related diagnosis but in the general context of a pain therapy outpatient center. Moreover, looking at the previous literature, the main research in this field has not been conducted in a Mediterranean country, such as Italy. This study thus enables insight into the specific features and needs of the Italian older population with chronic pain. This is of particular relevance considering that, as reported in the *Background* section, sociocultural factors may significantly affect how people perceive and manage well-being and health-related aspects, including the experience of chronic pain [11,29,43], along with the degree to which technology is accepted and used [31].

Regarding the first aim, the most frequently declared strategies to cope with chronic pain were coping self-statements, resting, task persistence, and guarding, while the least used strategies were relaxation and exercise or stretch. These findings are consistent with those found in 2 previous research carried out in the United States, targeting older adults with chronic pain, in facilities homes and community-based settings [44,45]. Interestingly, compared to those studies, we found greater use of resting as a strategy for managing pain, which was also qualitatively described as the most effective in terms of perceived pain reduction by the study sample. It must be noted that although a certain strategy was designated as the most effective, some participants were assigned a minimal score in terms of effectiveness in reducing pain. Similarly, although some strategies (eg, task persistence) were among the most widely used, they have been reported as effective by only a few participants. Overall, the results seem to show that in this study sample, the use of a specific strategy is not aimed at achieving a significant pain reduction but rather at obtaining some relief to be able to maintain their daily activities, often under the belief that pain will always be a part of their lives. As for this emerging attitude, the findings are consistent with the passive acceptance attitude that was found in older people with long-term pain conditions [8]. In this regard, it should be noted that this disposition may also have been influenced by the very long duration of chronic pain in our sample and by having experienced numerous medical treatments that were nevertheless unresolved. When faced with this sort of scenario, which often underlies a belief of total ineffectiveness and uselessness of any interventions, it is, therefore, of primary relevance to foster a more proactive attitude and simultaneously an increased self-efficacy to promote better chronic pain management, including the use of eHealth solutions.

Regarding the type of digital technologies used, all participants reported owning a mobile phone and using it independently, while only a few other digital tools were considered. This result is in line with international statistics indicating that the number of people aged >65 years who smartphones is increasing considerably, while for other modern technological devices (eg, tablets, computers, and smartwatches), there seems to still be a larger gap with younger age groups [46]. Especially following the acceleration induced by the COVID-19 pandemic, there has been an increasingly widespread use of technology, which also involved the older population. Indeed, some evidence showed higher levels of digital device adoption in daily life (eg, for entertainment, socialization, and health needs) by older adults already in the first stages of the COVID-19 pandemic [42,47,48]. Even in the Italian context, the frequency of use of digital technologies by the older population appears to have risen between 2019 and 2022 [49]. For example, the percentage of individuals who reported using a smartphone “often” or “always” increased by 16.3% (ie, from 37.7% in 2019 to 54% in 2022). This tendency is also supported by statistics from the European Commission, indicating that the percentage of Italian older people aged 65 to 74 years who have used the internet in the past 12 months increased from 44.6% in 2019 to 62.3% in 2023 [50]. Our results concerning the purposes of use in everyday life (eg, keeping in touch with others and leisure activities) also seem to point out in this direction. Despite this increase, it has to be considered that to date, a digital divide still remains with some northern European countries, where this percentage is significantly higher (eg, 97% in the Netherlands, 96.6% in Denmark and Luxembourg, and 94% in Sweden) [50].

Notably, none of the participants spontaneously indicated activities related in any way to health management, except for one who referred to using the internet to seek information about one's medical condition or newly prescribed medications. Concerning the use of digital devices for health-related purposes, it is interesting to note that in our sample, these mostly involved very basic organizational activities (eg, booking medical visits and managing pharmaceutical prescriptions), and none of the participants reported the use of digital technologies for treatment purposes (eg, telemedicine) with respect to either their general health or CNCP condition. Although telemedicine interventions have also been implemented in Italy in the wake of the COVID-19 pandemic–induced acceleration [51], significant disparities remain in the country, with the telemedicine approaches (eg, televisiting, teleconsulting, and telemonitoring) offered to patients across the different Italian regions, varying in number from 1 (ie, telereferencing and televisiting in Basilicata Region and Autonomous Province of Bolzano, respectively) to 66 typologies (Lombardia Region) [52]. Moreover, according to the results of recent studies, a large proportion of Italian citizens are unaware of the availability of such digital health solutions [53], and especially among older adults living in remote areas of Italy, a digital health gap exists due to both infrastructural deficiencies and a lack of digital skills [54]. In light of the potential benefits offered by the digitization of the health care field, it would, therefore, be important to implement more large-scale initiatives aimed at raising awareness of the potentialities of digital technologies on a broad scale, involving both health care professionals as well as patients and their caregivers.

Consistent with the framework outlined here, several participants in our study described the experience of using eHealth tools as limited in terms of the number of activities performed or frequency. In addition, some older adults reported needing external assistance from informal caregivers in using digital devices or completely delegating to them the execution of health-related management activities, citing as the main explanation the lack of familiarity with the technology in general. This attitude may, to some extent, disincentive them from experiencing the use of eHealth tools on their own.

Nevertheless, in other cases, the experience of using such tools was defined as positive or helpful with respect to one's purposes. Indeed, more than half of the respondents (10/18, 56%) were favorable about the potential usefulness of any eHealth tools specifically designed for chronic pain self-management, suggesting several potential useful functions to be included in such digital health solutions. More specifically, consistent with the findings of previous research [20,23], participants in this study highlighted the need to obtain updated and reliable information regarding their medical condition and available treatment options, including the option of contacting experts directly for questions or advice. In addition, there was a desire to improve pain self-management skills by learning new physical and psychological strategies. This highlights the need for targeted and diverse content to accommodate individual preferences. As observed in other studies [20,55], the inclusion in any eHealth solutions of features that allow remote interaction and sharing of experiences with others experimenting with a similar condition has been described as potentially helpful by several participants. This may also be beneficial in countering social isolation as a risk factor for poor well-being in older adults [56], which, especially in Mediterranean countries, seems to be one of the main factors affecting the psychological well-being older people aged 80 years and above [30].

Among the possible barriers to the use of eHealth solutions, just under half of the study participants (7/18, 40%) reported a lack of digital skills or technological attitude, resulting in a reduced sense of familiarity and trust in the potential of these tools for CNCP self-management. This is coherent with the evidence that older adults are less digitally literate than younger cohorts [57,58]. Even in previous research, this represents one of the main obstacles to the adoption of digital devices for health-related purposes [20,42]. Looking at the specific Italian sociocultural context, according to the Digital Economy and Society Index report of 2022 [59], Italy ranks 18th out of 27 European Union member states, and, to date, more than half of the Italian population does not have at least basic digital skills. If the analysis is extended to different age groups, the disparities widen even further: the percentage of Italian people who have at least basic digital skills stands at 42.2% in those aged 55 to 59 years and drops to 19.3% among those aged 65 to 74 years compared to 61.7% among young people aged 20 to 24 years [60]. Interestingly, according to a recent study that explored the digital divide of older adults living in peripherical areas of Italy, those with higher levels of education are more likely to use new digital technologies [54], and this could partly support our results because almost 80% (14/18) of our sample has a primary or middle school education level.

Among the potential barriers to the use of digital health tools, concerns about possible risks and negative effects were highlighted, such as the risk of developing a technological addiction or worsening one's chronic pain condition. As previously mentioned, because these concerns may arise at least in part from misinformation, it might be useful to propose educational initiatives also aimed at promoting more accurate knowledge and thus greater awareness regarding the potential and the correct use of these tools in the health care context [61]. Regarding the physical limitations (eg, visual and hearing impairments) that could prevent the adoption of digital health devices, as pointed out in previous studies [20,23], it is crucial to attentively address design aspects to tailor the features of these tools to the age-related psychophysical needs of the older population (eg, provide adequate font size and screen brightness and the ability to select visual and auditory aids).

Finally, the lack of human interaction and the preference for an in-person relationship (ie, with health care providers) emerged in this study as possible deterrents to the adoption of eHealth solutions. This seems to be in line with previous evidence both internationally [62] and pertaining to the Italian population [53], which suggested a favorability for traditional visits over remote visiting modalities. In this regard, as pointed out by Bhattarai et al [23], it might be useful to support older people in the use of such tools by providing for the direct involvement of physicians and health care professionals and thus promoting such innovative modalities to be better integrated into the care process.

Strengths and Limitations

This study has several strengths and limitations. The first strength is that it involved a diversified sample of Italian older adults, that is, including older people in the age range of 65 to 80 years experiencing a wide range of CNCP conditions, mainly of high-medium intensity and long-term duration, and referring to a clinical center for pain management. Although the upper age limit of the participants has been set to 80 years due to clinical and practical reasons (ie, physical and mental discomfort due to the time-consuming medical examination that preceded the evaluation), we have broadened the target population generally involved in these typologies of studies by including not only those aged 65 to 74 years but also a subgroup of people aged 75 to 80 years. This is noteworthy considering that people aged 75 to 80 years have traditionally been underrepresented in clinical research, despite the high comorbidity and presence of chronic pain [63].

In addition, a high percentage (18/23, 78%) of older individuals who visited the center during the recruitment period participated in the study, which helped reduce selection bias. As an additional strength, this is the only study conducted in Italy to have considered the older population with chronic pain. Considering the differences in the digital skills and pain perception across the culture and context, this represents a strength. The findings could inform the future development of eHealth solutions tailored to the specific needs and characteristics of the older Italian population with CNCP.

However, other limitations should be considered. First, we recruited a small sample size, although this was in line with other qualitative studies, and data saturation was achieved. This also precludes further considerations regarding the attitudes that emerged toward eHealth in relation to gender, age subgroups, or type of chronic pain. Therefore, future studies could focus on these aspects. Second, we enrolled participants among those already accessing health care services for pain management while not reaching out to individuals who might benefit and need eHealth solutions even more due to residing in geographically distant, poorly connected, or isolated areas.

Conclusions

To conclude, this study contributed to integrating and extending the current literature on the potentiality and barriers of eHealth for chronic pain management among older adults with different types of CNCP. Being aware of the differences in pain perception and management and the level of digital skills according to the sociocultural contexts, the results of this study allowed us to explore perspectives and experiences about the eHealth solutions for coping with chronic pain in a sample of older adults in the context of an Italian pain therapy center.

Results have been discussed considering how health care services can be directed to promote the use of these solutions and improve the management of chronic pain in older people.

Overall, participants showed an attitude of resignation to their chronic pain condition. Moreover, the use of digital solutions for health and pain management purposes is still scarce, even considering the perception of a lack of digital skills or technological attitude, resulting in a reduced sense of familiarity and trust in the potential of these tools for CNCP self-management. However, older adults are able to identify potential in the adoption of such tools.

The findings of this study may inform the development of new digital health tools specifically targeted at the characteristics of the Italian older population with CNCP. They also provide insights into how these tools should be proposed for them to be useful and feasible, emphasizing, in this regard, the importance of enhancing self-efficacy in pain management and digital literacy among older adults.

To summarize, the need to foster educational initiatives on the actual potential and purposes of eHealth solutions emerged, addressing the specific needs and challenges encountered by older adults and eventually involving their formal and informal caregivers. At the same time, it is of paramount importance to increase public welfare policies aimed at enhancing the older population's digital skills and consequently reducing the existing digital divide before introducing innovative eHealth solutions.

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Authors' Contributions

VD and CP were involved in the conceptualization of the study. ADL, VD, and CP were involved in the data curation and writing of the original draft. EP, LDP, SV, and IP were involved in reviewing and editing of the paper. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Semistructured interview guide.
[PDF File (Adobe PDF File), 31 KB - aging_v7i1e57196_app1.pdf]

References

1. Treede RD, Rief W, Barke A, Aziz Q, Bennett MI, Benoliel R, et al. Chronic pain as a symptom or a disease: the IASP Classification of Chronic Pain for the International Classification of Diseases (ICD-11). Pain 2019 Jan;160(1):19-27. [doi: 10.1097/j.pain.0000000000001384] [Medline: 30586067]
2. Sá KN, Moreira L, Baptista AF, Yeng LT, Teixeira MJ, Galhardoni R, et al. Prevalence of chronic pain in developing countries: systematic review and meta-analysis. Pain Rep 2019 Dec 6;4(6):e779 [FREE Full text] [doi: 10.1097/PR9.0000000000000779] [Medline: 31984290]
3. Cravello L, Di Santo S, Varrassi G, Benincasa D, Marchettini P, de Tommaso M, et al. Chronic pain in the elderly with cognitive decline: a narrative review. Pain Ther 2019 Jun;8(1):53-65 [FREE Full text] [doi: 10.1007/s40122-019-0111-7] [Medline: 30666612]
4. Stompór M, Grodzicki T, Stompór T, Wordliczek J, Dubiel M, Kurowska I. Prevalence of chronic pain, particularly with neuropathic component, and its effect on overall functioning of elderly patients. Med Sci Monit 2019 Apr 12;25:2695-2701 [FREE Full text] [doi: 10.12659/MSM.911260] [Medline: 31018630]
5. GBD 2021 Low Back Pain Collaborators. Global, regional, and national burden of low back pain, 1990-2020, its attributable risk factors, and projections to 2050: a systematic analysis of the Global Burden of Disease Study 2021. Lancet Rheumatol 2023 May 22;5(6):e316-e329 [FREE Full text] [doi: 10.1016/S2665-9913(23)00098-X] [Medline: 37273833]
6. Chen CY, Verdoorn B. Can pain management be safely optimized in older adults? Mayo Clin Proc 2020 Mar;95(3):445-448. [doi: 10.1016/j.mayocp.2019.10.033] [Medline: 32138877]
7. Gillsjö C, Nässén K, Berglund M. Suffering in silence: a qualitative study of older adults' experiences of living with long-term musculoskeletal pain at home. Eur J Ageing 2020 Apr 16;18(1):55-63 [FREE Full text] [doi: 10.1007/s10433-020-00566-7] [Medline: 33746681]
8. Crowe M, Gillon D, Jordan J, McCall C. Older peoples' strategies for coping with chronic non-malignant pain: a qualitative meta-synthesis. Int J Nurs Stud 2017 Mar;68:40-50. [doi: 10.1016/j.ijnurstu.2016.12.009] [Medline: 28073051]
9. Brunkert T, Simon M, Haslbeck J, Zúñiga F. Who to talk to about my pain? A brief qualitative study on perception of pain and its management in Swiss nursing home residents. Pain Manag Nurs 2020 Apr;21(2):151-156. [doi: 10.1016/j.pmn.2019.06.003] [Medline: 31324393]
10. Schoeb V, Misteli M, Kwan C, Wong CW, Kan MM, Opsommer E, et al. Experiences of community-dwelling older adults with chronic low back pain in Hong Kong and Switzerland - a qualitative study. Front Rehabil Sci 2022 Aug 17;3:920387 [FREE Full text] [doi: 10.3389/fresc.2022.920387] [Medline: 36188964]
11. Wong TH, Lee KS, Lo SM, Kan MM, Kwan C, Opsommer E, et al. Challenges, concerns, and experiences of community-dwelling older women with chronic low back pain-a qualitative study in Hong Kong, China. Healthcare (Basel) 2023 Mar 24;11(7):945 [FREE Full text] [doi: 10.3390/healthcare11070945] [Medline: 37046873]
12. Ho LY. A concept analysis of coping with chronic pain in older adults. Pain Manag Nurs 2019 Dec;20(6):563-571. [doi: 10.1016/j.pmn.2019.03.002] [Medline: 31103511]
13. Yagiz JI, Goderis G. The impact of the COVID-19 pandemic on eHealth use in the daily practice and life of Dutch-speaking general practitioners in Belgium: qualitative study with semistructured interviews. JMIR Form Res 2022 Nov 28;6(11):e41847 [FREE Full text] [doi: 10.2196/41847] [Medline: 36399650]
14. Hadjiat Y, Arendt-Nielsen L. Digital health in pain assessment, diagnosis, and management: overview and perspectives. Front Pain Res (Lausanne) 2023 Apr 17;4:1097379 [FREE Full text] [doi: 10.3389/fpain.2023.1097379] [Medline: 37139342]
15. De Lucia A, Perlini C, Chiarotto A, Pachera S, Pasini I, Del Piccolo L, et al. eHealth-integrated psychosocial and physical interventions for chronic pain in older adults: scoping review. J Med Internet Res 2024 Jul 29;26:e55366 [FREE Full text] [doi: 10.2196/55366] [Medline: 39073865]
16. Mannheim I, Schwartz E, Xi W, Buttigieg SC, McDonnell-Naughton M, Wouters EJ, et al. Inclusion of older adults in the research and design of digital technology. Int J Environ Res Public Health 2019 Oct 02;16(19):3718 [FREE Full text] [doi: 10.3390/ijerph16193718] [Medline: 31581632]

17. Fischer B, Peine A, Östlund B. The importance of user involvement: a systematic review of involving older users in technology design. Gerontologist 2020 Sep 15;60(7):e513-e523 [FREE Full text] [doi: 10.1093/geront/gnz163] [Medline: 31773145]
18. Stypinska J. AI ageism: a critical roadmap for studying age discrimination and exclusion in digitalized societies. AI Soc 2023;38(2):665-677 [FREE Full text] [doi: 10.1007/s00146-022-01553-5] [Medline: 36212226]
19. Gilbert RM. Reimagining digital healthcare with a patient-centric approach: the role of user experience (UX) research. Front Digit Health 2022 Aug 09;4:899976 [FREE Full text] [doi: 10.3389/fdgth.2022.899976] [Medline: 36016600]
20. O'Reilly PM, Harney OM, Hogan MJ, Mitchell C, McGuire BE, Slattery B. Chronic pain self-management in middle-aged and older adults: a collective intelligence approach to identifying barriers and user needs in eHealth interventions. Digit Health 2022 Jun 07;8:20552076221105484 [FREE Full text] [doi: 10.1177/20552076221105484] [Medline: 35694121]
21. Donisi V, Poli S, Mazzi MA, Gobbin F, Schena F, Del Piccolo L, et al. Promoting participatory research in chronicity: the ESPRIMO biopsychosocial intervention for young adults with multiple sclerosis. Front Psychol 2022 Nov 03;13:1042234 [FREE Full text] [doi: 10.3389/fpsyg.2022.1042234] [Medline: 36405126]
22. Morote R, Las Hayas C, Izco-Basurko I, Anyan F, Fullaondo A, Donisi V, et al. Co-creation and regional adaptation of a resilience-based universal whole-school program in five European regions. Eur Educ Res J 2020 Sep 03;21(1):138-164. [doi: 10.1177/1474904120947890]
23. Bhattarai P, Newton-John TR, Phillips JL. Apps for pain self-management of older people's arthritic pain, one size doesn't fit all: a qualitative study. Arch Gerontol Geriatr 2020;89:104062. [doi: 10.1016/j.archger.2020.104062] [Medline: 32428787]
24. Pearson J, Walsh N, Carter D, Koskela S, Hurley M. Developing a web-based version of an exercise-based rehabilitation program for people with chronic knee and hip pain: a mixed methods study. JMIR Res Protoc 2016 May 19;5(2):e67 [FREE Full text] [doi: 10.2196/resprot.5446] [Medline: 27197702]
25. Fanning J, Brooks AK, Ip E, Nicklas BJ, Rejeski WJ. A mobile health intervention to reduce pain and improve health (MORPH) in older adults with obesity: protocol for the MORPH trial. JMIR Res Protoc 2018 May 14;7(5):e128 [FREE Full text] [doi: 10.2196/resprot.9712] [Medline: 29759957]
26. Stamm O, Dahms R, Müller-Werdan U. Virtual reality in pain therapy: a requirements analysis for older adults with chronic back pain. J Neuroeng Rehabil 2020 Sep 29;17(1):129 [FREE Full text] [doi: 10.1186/s12984-020-00753-8] [Medline: 32993678]
27. Mace RA, Gates MV, Bullard B, Lester EG, Silverman IH, Quiroz YT, et al. Development of a novel mind-body activity and pain management program for older adults with cognitive decline. Gerontologist 2021 Apr 03;61(3):449-459 [FREE Full text] [doi: 10.1093/geront/gnaa084] [Medline: 32601670]
28. Janevic M, Robinson-Lane SG, Courser R, Brines E, Hassett AL. A community health worker-led positive psychology intervention for African American older adults with chronic pain. Gerontologist 2022 Oct 19;62(9):1369-1380 [FREE Full text] [doi: 10.1093/geront/gnac010] [Medline: 35394525]
29. Rogger R, Bello C, Romero CS, Urman RD, Luedi MM, Filipovic MG. Cultural framing and the impact on acute pain and pain services. Curr Pain Headache Rep 2023 Sep;27(9):429-436 [FREE Full text] [doi: 10.1007/s11916-023-01125-2] [Medline: 37405553]
30. Castelletti C, Martín-María N, Cresswell-Smith J, Forsman AK, Nordmyr J, Ådnanes M, et al. Comprehending socio-relational factors of mental wellbeing in the oldest old within Nordic and Mediterranean countries. Ageing Soc 2021 Oct 19;43(9):2001-2021. [doi: 10.1017/s0144686x21001458]
31. Cai Z, Fan X, Du J. Gender and attitudes toward technology use: a meta-analysis. Comput Educ 2017 Feb;105:1-13. [doi: 10.1016/j.compedu.2016.11.003]
32. Rinaldi EE, Strizzolo N. Competenze digitali e finanziarie nel primo lockdown: l'impatto sul benessere finanziario degli anziani. Salute e Societa 2022 Jun(2022/3):47-63. [doi: 10.3280/SES2022-003004]
33. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? Qual Health Res 2017 Mar;27(4):591-608 [FREE Full text] [doi: 10.1177/1049732316665344] [Medline: 27670770]
34. Nicholas M, Vlaeyen JW, Rief W, Barke A, Aziz Q, Benoliel R, et al. The IASP classification of chronic pain for ICD-11: chronic primary pain. Pain 2019 Jan;160(1):28-37. [doi: 10.1097/j.pain.0000000000001390] [Medline: 30586068]
35. De Beni R, Borella E, Carretti B, Marigo C, Nava L. BAC. Benessere e Abilita` Cognitive nell'eta` adulta e avanzata. Giunti O.S. Organizzazioni Speciali. 2008. URL: https://galileodiscovery.unipd.it/discovery/fulldisplay?docid=alma9939029460706046&context=L&vid=39UPD_INST:VU1&lang=it&search_scope=MyInst_and_CI&adaptor=Local%20Search%20Engine&tab=Everything&query=sub,exact,%20Life%20span%20,AND&mode=advanced [accessed 2024-08-23]
36. Monticone M, Ferrante S, Giorgi I, Galandra C, Rocca B, Foti C. Development of the Italian version of the 42-item chronic pain coping inventory, CPCI-I: cross-cultural adaptation, factor analysis, reliability and validity. Qual Life Res 2013 Aug;22(6):1459-1465. [doi: 10.1007/s11136-012-0271-y] [Medline: 23011492]
37. Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. J Personal Soc Psychol 1989;57(6):1069-1081. [doi: 10.1037/0022-3514.57.6.1069]
38. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101. [doi: 10.1191/1478088706qp063oa]

39. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019 Jun 13;11(4):589-597. [doi: 10.1080/2159676x.2019.1628806]
40. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qual Res Psychol 2020 Aug 12;18(3):328-352. [doi: 10.1080/14780887.2020.1769238]
41. Lincoln YS, Guba EG. Naturalistic Inquiry. Thousand Oaks, CA: SAGE Publications; 1985.
42. Garcia Reyes EP, Kelly R, Buchanan G, Waycott J. Understanding older adults' experiences with technologies for health self-management: interview study. JMIR Aging 2023 Mar 21;6:e43197 [FREE Full text] [doi: 10.2196/43197] [Medline: 36943333]
43. Rodrigues-de-Souza DP, Palacios-Ceña D, Moro-Gutiérrez L, Camargo PR, Salvini TF, Alburquerque-Sendín F. Socio-cultural factors and experience of chronic low back pain: a Spanish and Brazilian patients' perspective. A qualitative study. PLoS One 2016 Jul 19;11(7):e0159554 [FREE Full text] [doi: 10.1371/journal.pone.0159554] [Medline: 27434594]
44. Ersek M, Turner JA, Kemp CA. Use of the chronic pain coping inventory to assess older adults' pain coping strategies. J Pain 2006 Nov;7(11):833-842 [FREE Full text] [doi: 10.1016/j.jpain.2006.04.002] [Medline: 17074625]
45. Molton I, Jensen MP, Ehde DM, Carter GT, Kraft G, Cardemas DD. Coping with chronic pain among younger, middle-aged, and older adults living with neurological injury and disease. J Aging Health 2008;20(8):972-996 [FREE Full text] [doi: 10.1177/0898264308324680] [Medline: 18791184]
46. Faverio M. Share of those 65 and older who are tech users has grown in the past decade. Pew Research Center. 2022 Jan 13. URL: https://www.pewresearch.org/fact-tank/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/ [accessed 2024-01-22]
47. Sixsmith A, Horst BR, Simeonov D, Mihailidis A. Older people's use of digital technology during the COVID-19 pandemic. Bull Sci Technol Soc 2022 Jun;42(1-2):19-24 [FREE Full text] [doi: 10.1177/02704676221094731] [Medline: 38603230]
48. Elimelech OC, Ferrante S, Josman N, Meyer S, Lunardini F, Gómez-Raja J, et al. Technology use characteristics among older adults during the COVID-19 pandemic: a cross-cultural survey. Technol Soc 2022 Nov;71:102080 [FREE Full text] [doi: 10.1016/j.techsoc.2022.102080] [Medline: 35991080]
49. Melchior C. Gli anziani e lo scarso utilizzo (e desiderio) di tecnologia digitale. Salute e Società 2022(2022/3):106-120. [doi: 10.3280/ses2022-003008]
50. Statistics. Eurostat. URL: https://ec.europa.eu/eurostat/databrowser/product/page/ISOC_CI_IFP_IU [accessed 2024-08-28]
51. Maria Cati M. Innovation in the Italian national health system and the cost-reducing impact of e-health and telemedicine: the special case of the telemedicine project of the Casa Sollievo della Sofferenza Hospital (Apulia region)—when information and communication technology comes to the aid of the territory. Int J Appl Biol Pharm Technol 2022 Dec 28;13(04):51-63. [doi: 10.26502/ijabpt.202119]
52. eHealth - Sanità digitale. Ministero della Salute. URL: https://www.salute.gov.it/imgs/C_17_pagineAree_2515_4_file.pdf [accessed 2024-08-28]
53. Gallè F, Oliva S, Covelli E, Del Casale A, Da Molin G, Liguori G, et al. Introducing telemedicine in Italy: citizens' awareness of a new healthcare resource. Healthcare (Basel) 2023 Jul 28;11(15):2157 [FREE Full text] [doi: 10.3390/healthcare11152157] [Medline: 37570397]
54. Vainieri M, Vandelli A, Benvenuti SC, Bertarelli G. Tracking the digital health gap in elderly: a study in Italian remote areas. Health Policy 2023 Jul;133:104842 [FREE Full text] [doi: 10.1016/j.healthpol.2023.104842] [Medline: 37247605]
55. Richardson JE, Lee JI, Nirenberg A, Reid MC. The potential role for smartphones among older adults with chronic noncancer pain: a qualitative study. Pain Med 2018 Jun 01;19(6):1132-1139 [FREE Full text] [doi: 10.1093/pm/pnw284] [Medline: 28108642]
56. Nakagomi A, Tsuji T, Saito M, Ide K, Kondo K, Shiba K. Social isolation and subsequent health and well-being in older adults: a longitudinal outcome-wide analysis. Soc Sci Med 2023 Jun;327:115937. [doi: 10.1016/j.socscimed.2023.115937] [Medline: 37167920]
57. van Deursen AJ. Digital inequality during a pandemic: quantitative study of differences in COVID-19-related internet uses and outcomes among the general population. J Med Internet Res 2020 Aug 20;22(8):e20073 [FREE Full text] [doi: 10.2196/20073] [Medline: 32750005]
58. Vercruyssen A, Schirmer W, Geerts N, Mortelmans D. How “basic” is basic digital literacy for older adults? Insights from digital skills instructors. Front Educ 2023 Sep 13;8:1231701. [doi: 10.3389/feduc.2023.1231701]
59. Italy in the digital economy and society index. European Commission. URL: https://digital-strategy.ec.europa.eu/it/policies/desi-italy [accessed 2024-05-10]
60. Competenze digitali e caratteristiche socio-culturali della popolazione: forti divari. ISTAT. 2023. URL: https://www.istat.it/it/files/2023/12/Cittadini-e-ICT-2023.pdf [accessed 2024-05-10]
61. Global strategy on digital health 2020-2025. World Health Organization. URL: https://www.who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf [accessed 2024-01-26]
62. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021 Aug 17;21(1):1556 [FREE Full text] [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]

63. Ridda I, MacIntyre CR, Lindley RI, Tan TC. Difficulties in recruiting older people in clinical trials: an examination of barriers and solutions. Vaccine 2010 Jan 22;28(4):901-906. [doi: 10.1016/j.vaccine.2009.10.081] [Medline: 19944149]

Abbreviations

Ben-SSC: Psychological Well-Being Questionnaire
CNCP: chronic noncancer pain
CPCI-I: Chronic Pain Coping Inventory−Italian version

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Original Paper

Exploring the Linkages Among Chronic Illness, Substance Use, and COVID-19 Infection in Adults Aged 50 Years and Older: Retrospective Cross-Sectional Analysis of National Representative Data

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Abstract

Background: The co-occurrence of chronic illnesses and substance use presents complex challenges for health care systems. Understanding the interplay between these factors, compounded by the context of the COVID-19 pandemic, is essential for effective intervention strategies.

Objective: This study aims to investigate the relationships among chronic illness, substance use, and COVID-19 infection in adults aged 50 years and older.

Methods: Participants were 1196 adults aged 50 years and older. Descriptive statistics were used to describe demographic information. Logistic regressions and multiple regression analyses were used to determine associations between chronic illnesses, substance use, and COVID-19 infection. Mediation analysis was used to determine the effect of chronic illness mediators in the association between COVID-19 concerns and substance use.

Results: The mean age was 68 (SD 10.3) years, with 58.6% (701/1196) being women. Adjusted analysis revealed that age and sex (women) significantly predicted a lower level of substance use ($P<.05$). However, marital status (separated or widowed) and chronic illness significantly predicted a higher level of substance use ($P<.05$). Furthermore, having dementia, arthritis, and high cholesterol significantly predicted a higher level of concern about the COVID-19 pandemic ($P<.05$). Logistic regression analysis indicated that individuals with hypertension (odds ratio [OR] 1.91, 95% CI 1.37-2.66; $P<.001$), lung disease (OR 2.42, 95% CI 1.23-4.75; $P=.01$), heart condition (OR 1.99, 95% CI 1.28-3.10; $P=.002$), stroke (OR 2.35, 95% CI 1.07-5.16; $P=.03$), and arthritis (OR 1.72, 95% CI 1.25-2.37; $P=.001$) were more likely to have their work affected by the COVID-19 pandemic. The mediation analysis showed a significant effect of COVID-19 concern on substance use through the mediation of chronic illness, with a 95% CI of –0.02 to –0.01 and an indirect effect of –0.01.

Conclusions: Our study reveals complex associations among chronic illnesses, substance use, and COVID-19 infection among adults aged 50 years and older. It underscores the impact of demographics and specific chronic conditions on substance use behaviors and COVID-19 concerns. In addition, certain chronic illnesses were linked to heightened vulnerability in employment status during the pandemic. These findings emphasize the need for targeted interventions addressing physical health and substance use in this population during the COVID-19 pandemic.

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KEYWORDS

multiple chronic conditions; medical complexity; co-occurring conditions; substance use; COVID-19; SARS-CoV-2; older adults; gerontology; geriatrics

Introduction

Background

Chronic illnesses are persistent health conditions requiring long-term management [1]. Common examples include diabetes [2], cardiovascular diseases [3], and respiratory infections [4], which contribute significantly to the increasing burden of chronic conditions among adults aged 50 years and older [5,6]. The high prevalence of these conditions highlights the importance of examining the factors that influence health trajectories in this age group [7]. While managing chronic illnesses is critical, it is also important to consider other health issues that can compound the challenges faced by this demographic. Among these, substance use problems stand out as a significant concern. Substance use, which includes excessive alcohol and drug consumption, not only jeopardizes mental and physical health but also complicates the management of chronic illnesses [8,9]. The relationship between chronic illnesses and substance use is intricate, with substance use potentially exacerbating chronic conditions and vice versa. A study using electronic health records from the United States found that 48.3% (102,324/211,880) of individuals were diagnosed with at least 1 chronic disease [10]. Furthermore, those with at least 1 substance use disorder had higher odds of having a chronic disease [10]. Another retrospective study explored the association between chronic disease and substance use among older adults and found that marijuana use and smoking were significantly associated with chronic disease, while alcohol use was not [11]. This interplay highlights the need for a comprehensive approach that addresses both chronic conditions and substance use, ensuring that health care strategies are well-rounded and effective in managing the multifaceted health needs of older adults.

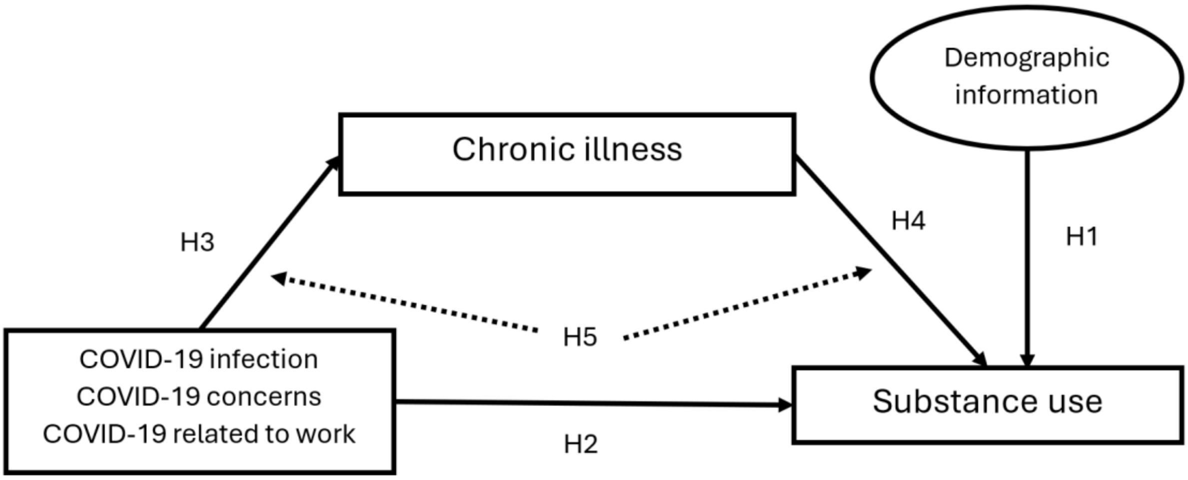
As the COVID-19 pandemic continues to reshape the health care landscape, the interplay between chronic illnesses and substance use has grown increasingly complex. Beyond the direct impact of the virus, the pandemic has introduced additional stressors and challenges, influenced health behaviors, and exacerbated preexisting health conditions [12-14]. In particular, the pandemic has intensified the prevalence and severity of chronic illnesses, while also disrupting health care access and support systems. A study shows that the COVID-19 pandemic has worsened chronic illnesses by increasing their severity and risk. Patients with conditions such as cardiovascular diseases and diabetes experience more severe outcomes due to factors such as elevated angiotensin-converting enzyme 2 levels and cytokine storms. In addition, the COVID-19 pandemic can also induce new chronic conditions, highlighting the need for targeted management strategies [15]. The pandemic's impact on substance use patterns is of particular interest. Factors such as isolation, economic uncertainties, and disruptions in health care access may contribute to shifts in how individuals cope with stress, potentially affecting substance use trends [16,17]. Amid this complex backdrop, the relationship between substance use and chronic illnesses takes on heightened significance [10]. While research has explored these factors individually, a comprehensive understanding of their interconnection—particularly within the unique context of COVID-19 pandemic—is lacking. It is plausible that both the effects of COVID-19 pandemic and chronic illness are related to substance use. Therefore, chronic illnesses could serve as a mediating variable in the relationship between COVID-19 infection and substance use. This study addresses this gap by conducting secondary data analysis on the HRS (Health and Retirement Study) 2020, a retrospective cohort study. The HRS 2020 represents American adults aged 50 years and older, investigating characteristics, health behaviors, and the unique context of the COVID-19 pandemic.

This research holds practical implications that extend beyond theoretical contributions. By identifying and elucidating the pathways through which chronic illness impacts substance use, our mediation analysis can inform public health strategies. This investigation aims to contribute to a comprehensive understanding of the multifaceted challenges faced by adults aged 50 years and older, ultimately enhancing the effectiveness of health care interventions and care for these vulnerable groups.

Study Aims

This study aims to investigate the relationships among chronic illness, substance use, and COVID-19 infection in adults aged 50 years and older. We hypothesized that the undesirable demographic factors of adults aged 50 years and older (ie, lower number of years in school, being separated or divorced or widowed) would be positively associated with substance use (hypothesis 1). Furthermore, we anticipated that higher odds of COVID-19 components, including COVID-19 infection, COVID-19–related concerns, and its relationship to work (hereinafter "COVID-19 related to work"), would increase the likelihood of substance use (hypothesis 2). In addition, we hypothesized that the odds of all COVID-19 components would be associated with a number of chronic illnesses (hypothesis 3) and a higher number of chronic illnesses would be positively linked with the likelihood of substance use (hypothesis 4). Finally, we expected that the direct effect of all COVID-19 components would be mitigated and the indirect effect through chronic illness would be significant among adults aged 50 years and older, thus revealing a mediating role of chronic illness (hypothesis 5; Figure 1).

Figure 1. Hypothesis model. H: hypothesis.



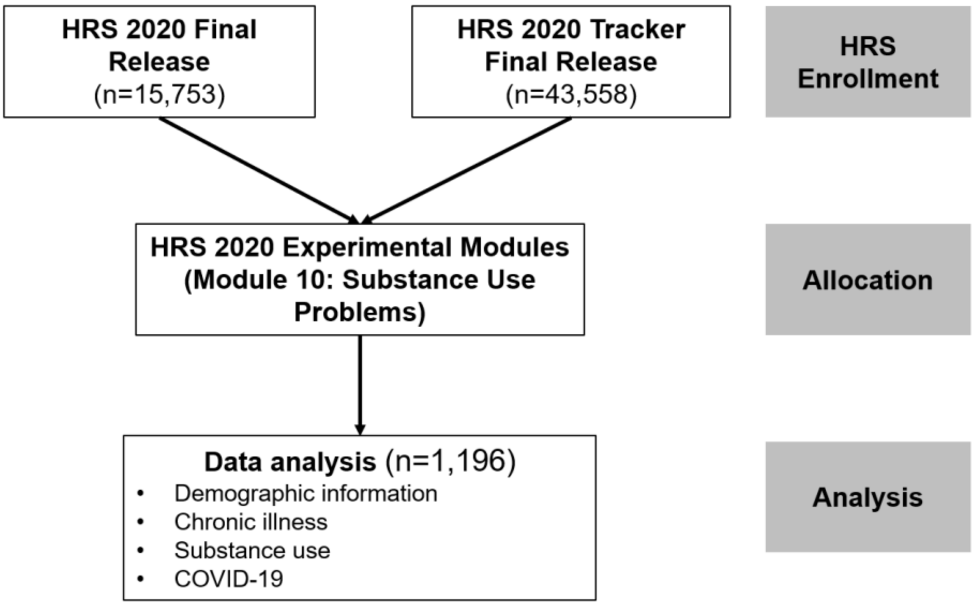
Methods

Study Design and Data Collection

The research was carried out following the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for cross-sectional studies (Multimedia Appendix 1). In this retrospective cross-sectional study, we used public data from the HRS, an ongoing longitudinal panel survey [18]. The HRS sample follows a multistage, stratified study design conducted every 2 years since 1992, interviewing approximately 20,000 Americans aged 50 years and older [19]. This study used the HRS 2020 Final Release, HRS 2020 Tracker Final Release, and HRS 2020 Experimental Modules (specifically, Module 10: Substance Use Problems). In every wave, HRS incorporates numerous experimental modules (eg, Module 10: Substance Use Problems), which are conducted following the core interview. These modules, typically lasting 2-3 minutes, are deliberately crafted to address various topics, including both new subjects and those that augment the core information. While sample sizes may vary, they generally constitute approximately 10% of a random sample drawn from the core. Importantly, each respondent is assigned only 1 experimental module per wave.

For this study, 15,753 participants were recruited from the HRS 2020 final release, and 43,558 people were included from the HRS 2020 Tracker final release. After including only those who participated in Module 10: Substance Use in Experimental Modules, 1196 participants were eligible and will be included in the final analysis (Figure 2).

Figure 2. Study flowchart. HRS: Health and Retirement Study.



Measures

Demographic Information

In this study, demographic information included age (in years), sex (“men” or “women”), race or ethnicity (“White/Caucasian,” “Black/African American,” or “Other”), number of school years (“no formal education” [0 years], “grades” [1-11 years], “high school” [12 years], “some college” [13-15 years], “college graduate” [16 years], or “post college” [17 years or more]), and marital status (“married,” “separated or divorced,” “widowed,” or “never married”). Demographic data were extracted from the HRS 2020 Final Release and HRS 2020 Tracker Final Release to facilitate consistent use of HRS data across waves.

Chronic Illness

Chronic illnesses, as defined by the Centers for Disease Control and Prevention (CDC), are conditions that persist for 1 year or more and require ongoing medical attention or limit daily activities [1]. In this study, we examined 9 chronic conditions: hypertension, diabetes mellitus, lung disease, heart conditions, stroke, depression, dementia, arthritis, and high cholesterol. Participants were asked whether they had ever been diagnosed with each condition, with responses coded as binary: “No” was coded as 0, and “Yes” as 1. The total number of chronic conditions was summed to create a “Chronic Illness” variable, ranging from 0 to 9, where a higher score indicates a greater number of chronic illnesses. Data were extracted from the HRS 2020 Final Release, and recoding was performed as necessary to facilitate analysis.

COVID-19

COVID-19 variables consisted of 6 measures, which can be categorized into three categories: (1) COVID-19 Concern (assessed on a scale from 1 to 10, where 1 indicated the least concern and 10 the most); (2) COVID-19 Infection: Self-report (Had you had or did you then have COVID-19, the disease caused by the novel coronavirus?) and Test-based (Did any tests indicate that you had the virus?); and (3) COVID-19 Related to Work: Working Affected by COVID-19 (Was your work affected because of the coronavirus pandemic?) and Stop Working (Did you have to stop work entirely because of COVID-19?). The responses to the questions COVID-19 Self-report, COVID-19 Test-based, Working Affected by COVID-19, and Stop Working were “No = 0” and “Yes = 1.” All variables were extracted from the HRS 2020 Final Release. Original response categories for each variable were combined and recoded as necessary to facilitate data analysis.

Substance Use

Module 10 in HRS 2020 Experimental Modules [20] focused on issues related to substances, encompassing medications, other substances, tobacco, and alcohol that HRS participants might have encountered. Developed by the National Institutes of Health, these questions, now commonly posed in various medical settings such as doctors’ offices and hospitals, aimed to address concerns regarding substance use among Americans. The module prompted respondents to indicate how frequently they had used various substances over the past few months to a year.

In this study, we analyzed variables associated with the use of alcohol, tobacco, cannabis, prescription medications for nonmedical purposes, illegal substances, cocaine, stimulants, methamphetamines, inhalants, sleeping pills, hallucinogens, street opioids, and prescription opioids. Responses to these questions were coded as “Never = 1” and “At least 1 time (including once or twice, monthly, weekly, daily, or almost daily) = 0.” Substance use was then coded such that a higher total score indicated less frequent use, with scores ranging from 0 to 13, where 0 represented the most frequent use.

Statistical Analysis

In this study, we combined the HRS 2020 Final Release, the HRS 2020 Tracker Final Release, and the HRS 2020 Experimental Modules’ respondent-level analytic weights and used the combined weight in the analyses. Listwise deletion, which means deleting cases with missing data, was used to deal with the missing data [21]. Analyses were conducted using SPSS Statistics (version 20.0; IBM Corp). In our study, demographic information of participants was assessed using descriptive statistics such as percentages or means as appropriate. Logistic regressions and multiple linear regression analysis were used for associations where the outcome variable was categorical (binary) and continuous, respectively. For logistic regression, odds ratio (OR), 95% CI, and *P* value (significance level<.05) were reported as appropriate. For multiple linear regression, R^2, adjusted R^2, unstandardized and standardized b, SE, and *P* value were reported. The mediation analysis, the “PROCESS” Procedure for the SPSS (version 3.3), written by Hayes [22], was used. A total of 5000 bootstraps were applied to estimate 95% CI and evaluate the significance of indirect effects. Strategies proposed by Preacher and Hayes [23] were adapted to evaluate the pathway, and 4 necessary steps were followed to assess mediation. Step 1: association between the predictor and outcome (path $c = X \rightarrow Y$; total effect or the sum of the direct and indirect effects); step 2: association between the predictor and mediators (path $a = X \rightarrow M$); step 3: association between mediators and outcome (path $b = M \rightarrow Y$); and step 4: association between the predictor and outcome after controlling for mediators (path c’ = direct effect). The indirect effect was the coefficient of the “a” path multiplied by the coefficient of the “b” path, representing the effect of X on Y through M.

Ethical Considerations

The University of Michigan’s institutional review board (IRB) approved the HRS survey. The HRS provides financial payments as tokens of appreciation to respondents for their participation in various aspects of the study, rather than as compensation. For all regular study components involving enrolled participants, these payments are typically issued via check, included in advance letters informing them of upcoming participation requests. The primary exception is for baseline interviews with new participants, for whom there is no prior information available to issue checks in advance. In these cases, compensation is provided in cash at the time of the interview. Since 2016, the payment schedule for research activities has been structured as follows: US $100 for the baseline core interview, US $80 for the core panel interview, US $20 for the leave-behind after the core, US $25 for mail surveys, and US $50 for in-home venous phlebotomy. Moreover, informed consent is not required in this study as the original consent was obtained in the original HRS study. The data used in this study have been publicly released and deidentified, and are available from the HRS website. Therefore, it did not require ethical approval (project no. MU-MOU-IRB-NS 2024/13.2901 exemption approved by the IRB, Faculty of Nursing, Mahidol University).

Results

Sample Characteristics

Table 1 shows the characteristics of adult and older adult participants. Overall, 1196 participants were included. The mean age was 68 (SD 10.3) years, and most of them were women (701/1196, 58.6%), White individuals (765/1196, 64%), had completed high school (363/1196, 30.4%), and were married (631/1196, 52.8%). In terms of chronic illnesses, the mean number of chronic illnesses was 2.54 (SD 1.6). Also, 64.2% (768/1196) of participants had hypertension, 27.6% (330/1196) had diabetes mellitus, 11.1% (133/1196) had lung disease, 24.2% (289/1196) had a heart condition, 8.2% (98/1196) had a stroke, 26.7% (319/1196) had depression, 1.7% (20/1196) had dementia, 38.7% (463/1196) had arthritis, and 29.2% (349/1196) had high cholesterol. Regarding COVID-19 infection, the average concern score about the virus was 7.89 (SD 2.7). Only 3.3% (39/1196) of respondents reported contracting COVID-19 infection, while 2.2% (26/1196) tested positive for the virus. Concerning employment, 20.5% (245/1196) of participants indicated that COVID-19 infection had an impact on their work, with 9.4% (113/1196) of individuals halting work entirely due to the pandemic. As for substance use, the mean score was 11.37 (SD 0.85), ranging from 0 to 13; a higher score reflects lower levels of substance use.

Table 1. Characteristics of participants (adults aged 50 years and older).

Characteristics of participants[a]	Values
Age (years), mean (SD; range)	68 (10.3; 50-99)
Gender, n (%)	
Men	495 (41.4)
Women	701 (58.6)
Race and ethnicity, n (%)	
White	765 (64.0)
Black or African American	279 (23.3)
Other	152 (12.7)
Number of years in school, n (%)	
No formal education (0)	18 (1.5)
Grades (1-11)	195 (16.3)
High school (12)	363 (30.4)
Some colleges (13-15)	312 (26.1)
College graduate (16)	171 (14.3)
Postcollege (≥17)	137 (11.5)
Marital status, n (%)	
Married	631 (52.8)
Separated or divorced	270 (22.6)
Widowed	191 (16)
Never married	104 (8.7)
Chronic illness	
Number of chronic illness[b], mean (SD; range)	2.54 (1.6; 0-9)
Hypertension, n (%)	768 (64.2)
Diabetes mellitus, n (%)	330 (27.6)
Lung's disease[c], n (%)	133 (11.1)
Heart condition[d], n (%)	289 (24.2)
Stroke, n (%)	98 (8.2)
Depression, n (%)	319 (26.7)
Dementia, n (%)	20 (1.7)
Arthritis, n (%)	463 (38.7)
High cholesterol, n (%)	349 (29.2)
COVID-19	
COVID-19 concern, mean (SD)	7.89 (2.7)
COVID-19 infection	
Self-report, n (%)	39 (3.3)
Test-based, n (%)	26 (2.2)
COVID-19 related to work	
Working affected by COVID-19, n (%)	245 (20.5)
Stop working, n (%)	113 (9.4)
Substance use	
Substance use[e], mean (SD; range)	11.37 (0.85; 0-13)

[a] Listwise deletion, which entails deleting cases with missing data, was used to handle missing data.

[b] The sum of chronic illnesses includes hypertension, diabetes mellitus, lung disease, heart condition, stroke, depression, dementia, arthritis, and high cholesterol (score range between 0 and 9; a higher score indicates a higher number of chronic illnesses).

[c] This encompasses chronic bronchitis or emphysema.

[d] This encompasses heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems.

[e] Substance use (score range between 0 and 13; a higher score indicates a lower level of substance use, including drinking alcohol, tobacco use, cannabis use, prescription drugs for nonmedical reasons, illegal drugs, cocaine, stimulants, methamphetamines, inhalants, sleeping pills, hallucinogens, street opioids, and prescription opioids).

Association Between the Characteristics of Adults Aged 50 Years and Older and Substance Use

The association between the characteristics of adults aged 50 years and older and substance use is shown in Table 2. In model 1, where characteristics of participants including age, sex, race or ethnicity, number of years in school, marital status, and chronic illnesses are independent variables, and substance use is the dependent variable, a significant equation was found ($F_{6,589}$=13.55; P<.001), with an R^2 of 0.12 and adjusted R^2=0.11. The results show that age (B=0.03; P<.001) and being women (B=0.18; P=.007) significantly predict a lower level of substance use. However, marital status (separate or widow; B=–0.11; P=.001) and chronic illnesses (B=–0.11; P<.001) significantly predict a higher level of substance use. After excluding race or ethnicity and number of years in school in model 1 as they are insignificant, age, sex, marital status, and chronic illnesses remain significant predictors of substance use (model 2).

Table 2. The association between the characteristics of adults aged 50 years and older and substance use[a].

Characteristics	Unstandardized coefficients		Standardized coefficients	*t* test (*df*)	*P* value[c]
	B [b]	SE	*b*		
Model 1 (n=596)					
Constant	9.84	0.329	—[d]	29.87 (6,589)	<.001
Age (years)	0.03	0.004	.29	7.07 (6,589)	*<.001*
Sex (reference group: women)	0.18	0.066	.11	2.69 (6,589)	*.007*
Race/ethnicity (reference group: White)	0.06	0.052	.05	1.21 (6,589)	.23
Number of years in school	–0.01	0.010	–.02	–0.51 (6,589)	.61
Marital status (reference group: married)	–0.11	0.034	–.13	–3.20 (6,589)	*.001*
Number of chronic illness[e]	–0.11	0.021	–.21	–5.24 (6,589)	*<.001*
Model 2 (n=596)					
Constant	9.94	0.27		37.15 (4,591)	<.001
Age (years)	0.03	0.01	.27	6.93 (4,591)	*<.001*
Sex	0.17	0.07	.10	2.58 (4,591)	*.01*
Marital status	–0.10	0.03	–.12	–3.02 (4,591)	*.003*
Number of chronic illnesses[e]	–0.11	0.02	–.20	–5.18 (4,591)	*<.001*

[a] Dependent variable: substance use (score range between 0 and 13; a higher score indicates a lower level of substance use, including drinking alcohol, tobacco use, cannabis use, prescription drugs for nonmedical reasons, illegal drugs, cocaine, stimulants, methamphetamines, inhalants, sleeping pills, hallucinogens, street opioids, and prescription opioids).

[b] *B*: unstandardized *b*.

[c] Italicized values are significant at *P*<.05.

[d] Not applicable.

[e] The sum of chronic illnesses includes hypertension, diabetes mellitus, lung disease, heart condition, stroke, depression, dementia, arthritis, and high cholesterol (score range between 0 and 9; a higher score indicates a higher number of chronic illnesses).

The Association Between Chronic Illness in Adults Aged 50 Years and Older and COVID-19 Concern

Table 3 shows the association between chronic illnesses in adults aged 50 years and older and concern about the COVID-19 pandemic. After adjusting for age, sex, race or ethnicity, number of years in school, and marital status in model 1, a significant equation was found ($F_{14,861}$=5.81; P<.001), with an R^2 of 0.09 and adjusted R^2=0.07. The results indicate that having dementia (B=1.60; P=.02), arthritis (B=0.69; P=.001), and high cholesterol (B=0.49; P=.02) significantly predict a higher level of concern about the COVID-19 pandemic. In model 2, adjusting for sex and race or ethnicity, dementia, arthritis, and high cholesterol remain significant predictors of COVID-19 concern with slightly changed significance values.

Table 3. The association between chronic illness of adults aged 50 years and older and concern about COVID-19 pandemic[a].

Characteristics	Unstandardized coefficients		Standardized coefficients	*t* test (*df*)	*P* value[c]
	B[b]	SE	*b*		
Model 1 (n=876)					
Constant	5.08	0.85	—[d]	5.97 (14,861)	<.001
Hypertension	0.28	0.20	.05	1.41 (14,861)	.16
Diabetes mellitus	0.21	0.21	.03	0.99 (14,861)	.32
Lung’s disease	–0.20	0.30	–.02	–0.66 (14,861)	.51
Heart condition	0.32	0.22	.05	1.44 (14,861)	.15
Stroke	–0.56	0.34	–.06	–1.65 (14,861)	.10
Depression	–0.14	0.21	–.02	–0.68 (14,861)	.50
Dementia	1.60	0.66	.08	2.44 (14,861)	*.02*
Arthritis	0.69	0.20	.12	3.49 (14,861)	*.001*
High cholesterol	0.49	0.20	.08	2.39 (14,861)	*.02*
Model 2 (n=876)					
Constant	5.10	0.39		13.15 (11,864)	<.001
Hypertension	0.28	0.19	.05	1.42 (11,864)	.15
Diabetes mellitus	0.21	0.21	.03	0.99 (11,864)	.32
Lung’s disease	–0.18	0.30	–.02	–0.62 (11,864)	.54
Heart condition	0.30	0.22	.05	1.40 (11,864)	.16
Stroke	–0.54	0.34	–.05	–1.62 (11,864)	.11
Depression	–0.12	0.21	–.02	–0.58 (11,864)	.56
Dementia	1.62	0.66	.08	2.47 (11,864)	*.01*
Arthritis	0.68	0.19	.12	3.58 (11,864)	*<.001*
High cholesterol	0.48	0.20	.08	2.39 (11,864)	*.02*

[a] Dependent variable: COVID-19 concern (overall, on a scale from 1 to 10, where 1 is the least concerned and 10 is the most concerned, how concerned are you about the coronavirus pandemic?). Model 1: adjust for age, sex, race or ethnicity, number of years in school, and marital status. Model 2: adjust for sex and race or ethnicity.

[b] *B*: unstandardized *b*.

[c] Italicized values are significant at *P*<.05.

[d] Not applicable.

The Adjusted OR of COVID-19 Infection and COVID-19 Related to Work in Adults Aged 50 Years and Older With Chronic Illness

The adjusted (sex and race or ethnicity) association between chronic illnesses and various COVID-19 components, including COVID-19 infection and COVID-19 related to work, was determined (Table 4). In model 1, the independent variables are chronic illnesses, and the outcome variable is work affected by COVID-19 pandemic (Was your work affected because of the coronavirus pandemic?). The results indicate that for individuals with hypertension (OR 1.91, 95% CI 1.37-2.66; *P*<.001), lung disease (OR 2.42, 95% CI 1.23-4.75; *P*=.01), heart condition (OR 1.99, 95% CI 1.28-3.10; *P*=.002), stroke (OR 2.35, 95% CI 1.07-5.16; *P*=.03), and arthritis (OR 1.72, 95% CI 1.25-2.37; *P*=.001), their work is more likely to be affected because of the COVID-19 pandemic. Moreover, model 2 shows the association between chronic illnesses and stopping work as an outcome (Did you have to stop working entirely because of COVID-19?). The results reveal that individuals with diabetes mellitus are 49% as likely to stop working entirely because of the COVID-19 pandemic compared with those with no diabetes mellitus (OR 0.49, 95% CI 0.25-0.95; *P*=.04). No significance was found in the model in which COVID-19 infections (both self-report and test-based) are dependent outcome variables, so they are not shown in Table 4 but can be found in Multimedia Appendix 2.

Table 4. The association between chronic illness of adults aged 50 years and older and COVID-19 infection and COVID-19 related to work[a].

Chronic illness	COVID-19–related factors					
	Model 1[b]: working affected by COVID-19[c] (n=876)			Model 2[b]: stop working[d] (n=245)		
	P value	OR[e]	95% CI	*P* value	OR	95% CI
Hypertension	*<.001*	*1.91*	*1.37-2.66*	.48	0.82	0.47-1.44
Diabetes mellitus	.20	1.29	0.87-1.89	*.04*	*0.49*	*0.25-0.95*
Lung disease	*.01*	*2.42*	*1.23-4.75*	.23	0.43	0.11-1.68
Heart condition	*.002*	*1.99*	*1.28-3.10*	.67	1.21	0.52-2.81
Stroke	*.03*	*2.35*	*1.07-5.16*	.36	2.29	0.40-13.26
Depression	.50	0.88	0.60-1.20	.51	1.24	0.66-2.37
Dementia	.73	1.26	0.33-4.86	.45	0.33	0.02-5.77
Arthritis	*.001*	*1.72*	*1.25-2.37*	.95	0.98	0.57-1.71
High cholesterol	.93	0.99	0.68-1.42	.66	1.15	0.62-2.14

[a] No significance was found in the model in which COVID-19 self-report and COVID-19 test-based are dependent outcome variables; therefore, it was not shown in Table 4. The reference group consists of the respondents who did not report having any chronic illnesses. *P* values in italics indicate statistically significant results (*P*<.05).

[b] Adjusted for sex and race or ethnicity.

[c] Working affected by COVID-19: Was your work affected because of the coronavirus pandemic?

[d] Stop working: Did you have to stop working entirely because of COVID-19?

[e] OR: odds ratio.

Examining the Role of Chronic Illness as a Mediator in the Relationship Between COVID-19 Concern and Substance Use

The effect of COVID-19 concern (X) on substance use (Y) through the mediator of chronic illness (M) was examined. The path from COVID-19 concern to chronic illness exhibited a significant positive relationship (*b*=0.12, SE=0.03; *P*<.001).

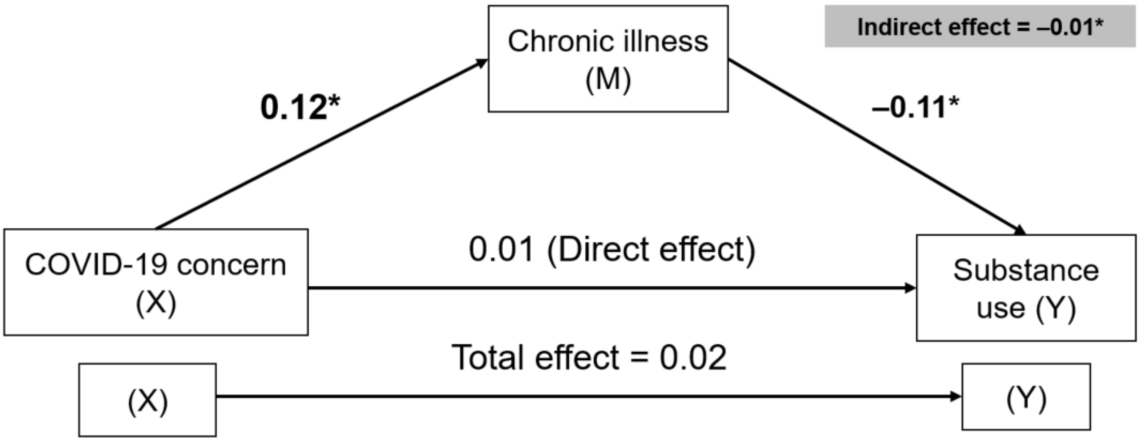
The path from the chronic illness mediator to substance use exhibited a significant negative relationship (*b*=–0.11, SE=0.02; *P*<.001), suggesting that individuals with higher numbers of chronic illnesses were more likely to demonstrate a higher level of substance use. The direct effect of COVID-19 concern on substance use was positive and insignificant (*b*=0.01, SE=0.02; *P*=.57). The indirect effect was assessed using nonparametric 5000 bootstrapping. The 95% CI for the indirect effect (–0.01) was –0.02 to –0.01, indicating a significant effect of COVID-19 concern on substance use through the mediation of chronic illness (Table 5 and Figure 3).

Table 5. The effect of chronic illness mediators (M) in the association between COVID-19 concern (X) and substance use (Y).[a]

	COVID-19 concern (X) (n=460)										
Chronic illness (M)	X→M (a)			M→Y (b)			X→Y (c’)			Indirect effect (a×b)	
	a	SE	*P* value	*b*	SE	*P* value	c’	SE	*P* value	a×b	95% CI
	0.12	0.03	<.001	–0.11	0.02	<.001	0.01	0.02	.57	–0.01	–0.02 to –0.01

[a] Dependent variable: substance use (score range between 0 and 13; a higher score indicates a lower level of substance use, including drinking alcohol, tobacco use, cannabis use, prescription drugs for nonmedical reasons, illegal drugs, cocaine, stimulants, methamphetamines, inhalants, sleeping pills, hallucinogens, street opioids, and prescription opioids). Total effect (X→Y): effect 0.02 (95% CI –0.03 to 0.03).

Figure 3. The mediation analysis model of the effect of chronic illness mediators (M) in the association between COVID-19 concern (X) and substance use (Y). *Statistically significant at *P*<.05.



Discussion

Characteristics of Adults Aged 50 Years and Older and Substance Use

Focusing upon adults aged 50 years and older, prior studies revealed that substance use is increasing in comparison with younger adults, and this trend has been well documented [24,25]. In our research, when considering characteristics of substance use in this demographic, we found that age, sex, race or ethnicity, number of years in school, marital status, and chronic illnesses explained 12.0% of substance use behaviors. However, only age, sex, marital status (being widowed or separated), and chronic illnesses added statistically significantly to the prediction of substance use. Our findings showed that women aged 50 years and older used fewer substances than men in the same age group. However, widowed or separated individuals and those dealing with chronic illnesses were more likely to engage in substance use. These findings align with prior studies, which showed that more than half of older adults (ranging from 54.5% to 57.8%) engaged in substance use, with higher rates observed among those aged 65 years and older [26,27]. However, substance usage among older women and men varies based on the particular types of substances. Older women are more likely to use sedatives, weight loss medications, and pain relievers, while older men are more likely to consume alcohol [24,28,29]. In terms of chronic illnesses, Ahuja et al [11] found similar results to our findings, indicating a correlation between chronic illnesses and various substance use among the older adults. Specifically, this earlier work highlighted that reporting 2 or more chronic illnesses is linked to a higher probability of substance use, such as marijuana [11]. Regarding marital status, our results correspond with those of Johar et al [30]. Their research suggests that the experience of being widowed or separated is frequently tied to emotions of loneliness, social isolation, or lifestyle changes, which could impact substance use behavior [30]. Based on our findings, it is unclear whether the specific substances used among older women present an opportunity to delve into why substance use is relatively low in this group. Moreover, taking into account specific conditions such as dementia, arthritis, and high cholesterol may influence substance use to alleviate chronic illnesses; therefore, screening and assessment are important to identify the factors affecting substance use.

Chronic Illness, COVID-19 Concerns, and Adults Aged 50 Years and Older

Individuals with dementia experience a loss of cognitive functioning, including rationality, memory, and logical thinking. This condition is recognized as one of the significant causes of dependency among adults aged 50 years and older [31]. The COVID-19 pandemic has raised concerns for individuals with dementia, who are at high risk of severe COVID-19 infection [32]. Those with dementia may face challenges in following safeguarding procedures, such as maintaining social distancing, wearing masks, and practicing hand hygiene, which all leave them more vulnerable to COVID-19 infection [33] and encounter difficulty communicating their health concerns and face barriers to accessing health care services during the COVID-19 pandemic [31]. The impact of the COVID-19 pandemic on adults aged 50 years and older with dementia has been reported, including worsening mental health while receiving live-in home health care [34] and poor health outcomes from COVID-19 hospitalization [35,36]. Individuals with arthritis may have significant concerns as they are at risk of COVID-19 infection. A recent study found that individuals with arthritis have a significantly higher risk of contracting COVID-19 infection [37]. This increased risk may be attributed to factors such as receiving treatment involving immunosuppressant medications, which can predispose them to COVID-19 infection and severe illness, potentially leading to hospitalization or death when compared with those with no arthritis [37,38]. In addition, the literature indicates that individuals with arthritis face an elevated risk of experiencing severe COVID-19 symptoms, particularly those associated with interstitial lung disease [39]. These findings may heighten concerns among individuals with arthritis about navigating the COVID-19 pandemic. Social isolation stemming from the COVID-19 pandemic poses a significant concern for individuals' lifestyles, particularly those with high cholesterol. Managing high cholesterol necessitates lifestyle modifications such as adopting a healthy diet, engaging in regular physical activity, and reducing stress to mitigate cholesterol levels and delay-associated mortality [40]. However, adhering to these recommendations has been challenging during the pandemic, with individuals facing limited access to healthy food options, disrupted eating patterns, reduced physical activity, heightened stress levels, and compromised sleep quality [41]. These factors can impede efforts to control cholesterol levels and elevate the risk of progression to comorbidities such as metabolic syndrome and cardiovascular disease [42]. Furthermore, research indicates a correlation between cholesterol levels, higher body mass index, and susceptibility to COVID-19 infection, as well as the severity of COVID-19 illness [43-45]. These findings underscore the heightened concerns surrounding COVID-19 infection for individuals managing high cholesterol.

The Impact of COVID-19 Pandemic on Employment in Adults Aged 50 Years and Older With Chronic Illness

Our findings indicate the effect of the COVID-19 pandemic on work among individuals with hypertension, lung disease, heart condition, stroke, or arthritis. According to the CDC, individuals with chronic illnesses are at higher risk for poor health outcomes and developing more serious complications from COVID-19 infection [46]. The Occupational Safety and Health Administration launched general guidance for employees and employers based on the CDC's statement on recognizing personal health risk factors and helping facilitate their work [47]. For example, people with chronic illnesses are allowed to work from home every day to reduce contact with other coworkers. Moreover, employees with chronic illnesses reported higher levels of COVID-19 fear than employees with no chronic illnesses, which may affect how they work [48]. However, our findings indicate that the effect of the COVID-19 pandemic on work is not correlated with individuals with diabetes, depression, dementia, or high cholesterol, despite being listed in the CDC's statement. These findings remain inconclusive in previous studies. Regarding the association between the effect of the COVID-19 pandemic and leaving the workforce entirely, our findings reported the significance of diabetes mellitus, while other chronic illnesses are not significant. Individuals with diabetes mellitus may have to maintain their financial stability in managing their diabetes treatment, especially oral medications and insulin regimens. On the other hand, other chronic illnesses may have a lower cost of health care than diabetes mellitus. A study conducted in Tanzania reported that the financial burden relative to household income in individuals with diabetes mellitus increased by 32.1% [49]. As a result, individuals with diabetes mellitus may have to continue working during the COVID-19 pandemic.

Chronic Illness as a Mediator in the Relationship Between COVID-19 Concerns and Substance Use

Based on our analysis, chronic illnesses act as a mediator in the relationship between COVID-19 concerns and substance use. There are 2 main postulations drawn from the results. First, individuals with chronic illnesses face a higher risk of COVID-19 infection, leading to increased stress and anxiety, which may prompt them to use substances as a coping strategy. This could be due to concerns about visiting hospitals amid the pandemic, driving them toward substance use to manage their heightened emotions, fears, and health conditions. Second, individuals may turn to substances as a means of self-medication to alleviate the psychological distress caused by both their chronic illnesses and the added anxiety from the pandemic. However, it is important to note that the cross-sectional nature of the study limits our ability to establish the temporal relationship conclusively. Nevertheless, evidence suggests an uptick in substance use among adults aged 50 years and older with chronic conditions during the COVID-19 period. Studies, such as one conducted in Chicago, observed a surge in alcohol consumption among adults aged 50 years and older with chronic conditions at the onset of the pandemic, which then declined by late summer 2021 with the expiration of stay-at-home orders [50]. This indicates a possible impact of lockdown measures on substance use [50]. This effect could be especially pronounced among adults aged 50 years and older with chronic illnesses who were significantly affected by lockdown policies and harbored heightened concerns about the pandemic, potentially leading them toward substance use. Moreover, a network analysis involving 3075 adults from the United States and Canada found strong links among COVID-19 stress syndrome, COVID-19 disregard syndrome, and substance use [51]. Symptoms of traumatic stress and disregard for social distancing were particularly associated with alcohol and drug abuse [51]. Interestingly, concerns about the severity of the COVID-19 pandemic emerged as a central factor in the network, suggesting that targeting this concern could help reduce substance abuse [51]. Another study also proposed a pathway linking COVID-19 concerns to substance use among underserved populations such as patients with chronic illness [52]. It suggested that COVID-19 concerns and social isolation could impact health care access and worsen economic statuses, potentially driving individuals toward self-medication with substances such as opiates [52]. The relationship among COVID-19 concerns, chronic illnesses, and substance use is undoubtedly complex. However, it provides valuable insights and a framework for future efforts to mitigate substance use.

Moving forward, proactive measures are crucial to support adults with chronic conditions during pandemics. By addressing pandemic-related stress and improving health care access, we can help prevent reliance on substance use as a coping mechanism. This proactive approach is vital not only for individual well-being but also for the broader public health landscape. In addition, this call for health care providers to play a pivotal role in intensifying screening efforts for stress and substance use concerns, particularly among the older adults, may require enhanced training to address mental health issues effectively.

Limitations

Several limitations are noteworthy. First, the exclusion of psychological illness, which is prevalent among older adults, might fail to fully grasp the correlation between psychological illness and substance use. Hence, future studies should incorporate psychological illness to foster a more comprehensive understanding of the subject. Second, self-reported substance use may underestimate actual prevalence due to social desirability bias. Therefore, future studies should integrate self-reported data with objective measures such as prescription records or biological markers to enhance accuracy in estimating substance use among older adults. Third, using a cross-sectional study design might fail to establish the relationship between COVID-19 concern and substance use. Therefore, future studies should consider a longitudinal approach to track substance use patterns among older adults over time, facilitating a clearer understanding of the temporal relationship between pandemic-related concerns and substance use. Finally, there is a modest R^2 change between model 1 (adjusted for age, sex, race or ethnicity, number of years in school, and marital status) and model 2 (adjusted for sex and race or ethnicity) of 2 associations: (1) the association between characteristics of adults aged 50 years and older on substance use and (2) the association of chronic illness in adults aged 50 years and older and COVID-19 concern. Therefore, the findings should be interpreted with caution and future studies should include a larger sample to strengthen statistical analysis and result findings.

Conclusions

Our study highlights the intricate relationship between chronic illnesses, COVID-19 infection, and substance use among adults aged 50 years and older. We found that age, sex, marital status, and chronic illnesses significantly influence substance use behaviors in this demographic. Older adults with certain chronic conditions exhibited heightened COVID-19 concerns, which, in turn, mediated their substance use. These findings underscore the importance of proactive support for older adults with chronic conditions during pandemics and the need for further research to elucidate these complex dynamics.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement—checklist of items that should be included in reports of observational studies.

[DOCX File , 36 KB - aging_v7i1e63024_app1.docx]

Multimedia Appendix 2

Association between chronic illness and COVID-19 Self-report and COVID-19 Test-based.

[DOCX File , 19 KB - aging_v7i1e63024_app2.docx]

References

1. CDC. About chronic diseases. National Center for Chronic Disease Prevention and Health Promotion. 2022. URL: https://www.cdc.gov/chronic-disease/about/index.html [accessed 2024-09-14]
2. Laiteerapong N, Huang ES, Cowie CC, Casagrande SS. Diabetes in older adults. In: Diabetes in America. Bethesda, MD: National Institute of Diabetes and Digestive and Kidney Diseases; 2021.
3. Roth GA, Mensah GA, Fuster V. The Global Burden of Cardiovascular Diseases and Risks: A Compass for Global Action. Washington, DC: American College of Cardiology Foundation; 2020:2980-2981.
4. Häder A, Köse-Vogel N, Schulz L, Mlynska L, Hornung F, Hagel S, et al. Respiratory infections in the aging lung: implications for diagnosis, therapy, and prevention. Aging Dis 2023;14(4):1091-1104 [FREE Full text] [doi: 10.14336/AD.2023.0329] [Medline: 37163442]
5. Sun X, Li X. Editorial: aging and chronic disease: public health challenge and education reform. Front Public Health 2023;11:1175898 [FREE Full text] [doi: 10.3389/fpubh.2023.1175898] [Medline: 37228734]
6. Wang S, Liu Y, Lam J, Gao Z. Chronic illness, subjective wellbeing, and health services availability: a study of older adults in Australia. Int J Environ Res Public Health 2021;18(15):7718 [FREE Full text] [doi: 10.3390/ijerph18157718] [Medline: 34360012]
7. Oduro JK, Okyere J, Nyador JKMT. Risky health behaviours and chronic conditions among aged persons: analysis of SAGE selected countries. BMC Geriatr 2023;23(1):145 [FREE Full text] [doi: 10.1186/s12877-023-03836-y] [Medline: 36932319]
8. National Institutes on Drug Abuse. Common Comorbidities With Substance Use Disorders Research Report. Bethesda, MD: National Institutes on Drug Abuse; 2020:1-46.
9. Lo TW, Yeung JWK, Tam CHL. Substance abuse and public health: a multilevel perspective and multiple responses. Int J Environ Res Public Health 2020;17(7):2610 [FREE Full text] [doi: 10.3390/ijerph17072610] [Medline: 32290248]

10. Wu LT, Zhu H, Ghitza UE. Multicomorbidity of chronic diseases and substance use disorders and their association with hospitalization: results from electronic health records data. Drug Alcohol Depend 2018;192:316-323 [FREE Full text] [doi: 10.1016/j.drugalcdep.2018.08.013] [Medline: 30312893]
11. Ahuja M, Stamey J, Cimilluca J, Al Skir K, Herndon MK, Baggett K, et al. Association between chronic disease and substance use among older adults in Tennessee. J Public Health Res 2023;12(3):22799036231193070 [FREE Full text] [doi: 10.1177/22799036231193070] [Medline: 37636292]
12. Bambra C, Riordan R, Ford J, Matthews F. The COVID-19 pandemic and health inequalities. J Epidemiol Community Health 2020;74(11):964-968 [FREE Full text] [doi: 10.1136/jech-2020-214401] [Medline: 32535550]
13. Manchia M, Gathier AW, Yapici-Eser H, Schmidt MV, de Quervain D, van Amelsvoort T, et al. The impact of the prolonged COVID-19 pandemic on stress resilience and mental health: a critical review across waves. Eur Neuropsychopharmacol 2022;55:22-83 [FREE Full text] [doi: 10.1016/j.euroneuro.2021.10.864] [Medline: 34818601]
14. Neelam K, Duddu V, Anyim N, Neelam J, Lewis S. Pandemics and pre-existing mental illness: a systematic review and meta-analysis. Brain Behav Immun Health 2021;10:100177 [FREE Full text] [doi: 10.1016/j.bbih.2020.100177] [Medline: 33251527]
15. Alyammahi SK, Abdin SM, Alhamad DW, Elgendy SM, Altell AT, Omar HA. The dynamic association between COVID-19 and chronic disorders: an updated insight into prevalence, mechanisms and therapeutic modalities. Infect Genet Evol 2021;87:104647 [FREE Full text] [doi: 10.1016/j.meegid.2020.104647] [Medline: 33264669]
16. Yahaya AZB, Yee A, Sulaiman AH. The pattern of substance use among people who use drugs (PWUD) receiving treatment at University Malaya Medical Centre (UMMC) during the COVID-19 pandemic and the associated factors. Healthcare (Basel) 2022;10(8):1366 [FREE Full text] [doi: 10.3390/healthcare10081366] [Medline: 35893189]
17. McCann V, Allen R, Purkey E. Exploring the impact of COVID-19 on substance use patterns and service access of street involved individuals in Kingston, Ontario: a qualitative study. BMC Public Health 2022;22(1):571 [FREE Full text] [doi: 10.1186/s12889-022-12976-6] [Medline: 35317773]
18. University of Michigan. The Health and Retirement Study. URL: https://hrs.isr.umich.edu/ [accessed 2024-09-14]
19. Grinshteyn EG, Sugar JA. Active aging through volunteerism: a longitudinal assessment of perceived neighborhood safety as a predictor among older adults, 2008-2018. Biomed Res Int 2021;2021:5185264 [FREE Full text] [doi: 10.1155/2021/5185264] [Medline: 34778451]
20. Health and Retirement Study. University of Michigan. Experimental modules. URL: https://hrs.isr.umich.edu/documentation/modules#2020 [accessed 2024-09-14]
21. Kang H. The prevention and handling of the missing data. Korean J Anesthesiol 2013;64(5):402-406 [FREE Full text] [doi: 10.4097/kjae.2013.64.5.402] [Medline: 23741561]
22. Hayes AF. Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach. New York, NY: Guilford Press; 2017.
23. Preacher KJ, Hayes AF. Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. Behav Res Methods 2008;40(3):879-891. [doi: 10.3758/brm.40.3.879] [Medline: 18697684]
24. Kuerbis A. Substance use among older adults: an update on prevalence, etiology, assessment, and intervention. Gerontology 2020;66(3):249-258. [doi: 10.1159/000504363] [Medline: 31812954]
25. Sutherland R, Gisev N, Larney S. Trends in substance use and related harms among older adults in high-income countries. Addiction 2024. [doi: 10.1111/add.16469] [Medline: 38494921]
26. Han BH, Palamar JJ. Marijuana use by middle-aged and older adults in the United States, 2015-2016. Drug Alcohol Depend 2018;191:374-381 [FREE Full text] [doi: 10.1016/j.drugalcdep.2018.07.006] [Medline: 30197051]
27. Han BH, Sherman S, Mauro PM, Martins SS, Rotenberg J, Palamar JJ. Demographic trends among older cannabis users in the United States, 2006-13. Addiction 2017;112(3):516-525 [FREE Full text] [doi: 10.1111/add.13670] [Medline: 27767235]
28. Chhatre S, Cook R, Mallik E, Jayadevappa R. Trends in substance use admissions among older adults. BMC Health Serv Res 2017;17(1):584 [FREE Full text] [doi: 10.1186/s12913-017-2538-z] [Medline: 28830504]
29. Fonseca F, Robles-Martínez M, Tirado-Muñoz J, Alías-Ferri M, Mestre-Pintó JI, Coratu AM, et al. A gender perspective of addictive disorders. Curr Addict Rep 2021;8(1):89-99 [FREE Full text] [doi: 10.1007/s40429-021-00357-9] [Medline: 33614395]
30. Johar H, Atasoy S, Beutel M, Braehler E, Schomerus G, Binder H, et al. Gender-differential association between loneliness and alcohol consumption: a pooled analysis of 17,808 individuals in the multi-cohort GESA consortium. Int J Ment Health Addiction 2023. [doi: 10.1007/s11469-023-01121-y]
31. Cations M, Day S, Laver K, Withall A, Draper B. People with young-onset dementia and their families experience distinctive impacts of the COVID-19 pandemic and associated restrictions. Int Psychogeriatr 2021;33(8):839-841. [doi: 10.1017/S1041610221000879] [Medline: 34275499]
32. Numbers K, Brodaty H. The effects of the COVID-19 pandemic on people with dementia. Nat Rev Neurol 2021;17(2):69-70 [FREE Full text] [doi: 10.1038/s41582-020-00450-z] [Medline: 33408384]

33. Sadigh-Eteghad S, Sahebari SS, Naseri A. Dementia and COVID-19: complications of managing a pandemic during another pandemic. Dement Neuropsychol 2020;14(4):438-439 [FREE Full text] [doi: 10.1590/1980-57642020dn14-040017] [Medline: 33354300]
34. Caroppo E, Mazza M, Sannella A, Marano G, Avallone C, Claro AE, et al. Will nothing be the same again?: Changes in lifestyle during COVID-19 pandemic and consequences on mental health. Int J Environ Res Public Health 2021;18(16):8433 [FREE Full text] [doi: 10.3390/ijerph18168433] [Medline: 34444180]
35. Axenhus M, Frederiksen KS, Zhou RZ, Waldemar G, Winblad B. The impact of the COVID-19 pandemic on mortality in people with dementia without COVID-19: a systematic review and meta-analysis. BMC Geriatr 2022;22(1):878 [FREE Full text] [doi: 10.1186/s12877-022-03602-6] [Medline: 36402953]
36. Ghaffari M, Ansari H, Beladimoghadam N, Aghamiri SH, Haghighi M, Nabavi M, et al. Neurological features and outcome in COVID-19: dementia can predict severe disease. J Neurovirol 2021;27(1):86-93 [FREE Full text] [doi: 10.1007/s13365-020-00918-0] [Medline: 33417193]
37. England BR, Roul P, Yang Y, Kalil AC, Michaud K, Thiele GM, et al. Risk of COVID-19 in rheumatoid arthritis: a national Veterans Affairs matched cohort study in at-risk individuals. Arthritis Rheumatol 2021;73(12):2179-2188 [FREE Full text] [doi: 10.1002/art.41800] [Medline: 33955209]
38. Williamson EJ, Walker AJ, Bhaskaran K, Bacon S, Bates C, Morton CE, et al. Factors associated with COVID-19-related death using OpenSAFELY. Nature 2020;584(7821):430-436 [FREE Full text] [doi: 10.1038/s41586-020-2521-4] [Medline: 32640463]
39. Figueroa-Parra G, Gilbert EL, Valenzuela-Almada MO, Vallejo S, Neville MR, Patel NJ, et al. Risk of severe COVID-19 outcomes associated with rheumatoid arthritis and phenotypic subgroups: a retrospective, comparative, multicentre cohort study. Lancet Rheumatol 2022;4(11):e765-e774 [FREE Full text] [doi: 10.1016/S2665-9913(22)00227-2] [Medline: 36118532]
40. Grundy SM, Stone NJ, Bailey AL, Beam C, Birtcher KK, Blumenthal RS, et al. 2018 AHA/ACC/AACVPR/AAPA/ABC/ACPM/ADA/AGS/APhA/ASPC/NLA/PCNA guideline on the management of blood cholesterol: executive summary: a report of the American College of Cardiology/American Heart Association Task Force on clinical practice guidelines. J Am Coll Cardiol 2019;73(24):3168-3209. [doi: 10.1016/j.jacc.2018.11.002] [Medline: 30423391]
41. Laddu DR, Biggs E, Kaar J, Khadanga S, Alman R, Arena R. The impact of the COVID-19 pandemic on cardiovascular health behaviors and risk factors: a new troubling normal that may be here to stay. Prog Cardiovasc Dis 2023;76:38-43 [FREE Full text] [doi: 10.1016/j.pcad.2022.11.017] [Medline: 36481209]
42. Nour TY, Altintaş KH. Effect of the COVID-19 pandemic on obesity and it is risk factors: a systematic review. BMC Public Health 2023;23(1):1018 [FREE Full text] [doi: 10.1186/s12889-023-15833-2] [Medline: 37254139]
43. Dai J, Wang H, Liao Y, Tan L, Sun Y, Song C, et al. Coronavirus infection and cholesterol metabolism. Front Immunol 2022;13:791267 [FREE Full text] [doi: 10.3389/fimmu.2022.791267] [Medline: 35529872]
44. Mohammadshahi J, Ghobadi H, Matinfar G, Boskabady MH, Aslani MR. Role of lipid profile and its relative ratios (Cholesterol/HDL-C, Triglyceride/HDL-C, LDL-C/HDL-C, WBC/HDL-C, and FBG/HDL-C) on admission predicts in-hospital mortality COVID-19. J Lipids 2023;2023:6329873 [FREE Full text] [doi: 10.1155/2023/6329873] [Medline: 36923284]
45. Zhang K, Dong SS, Guo Y, Tang SH, Wu H, Yao S, et al. Causal associations between blood lipids and COVID-19 risk: a two-sample mendelian randomization study. Arterioscler Thromb Vasc Biol 2021;41(11):2802-2810 [FREE Full text] [doi: 10.1161/ATVBAHA.121.316324] [Medline: 34496635]
46. Centers for Disease Control and Prevention. People with certain medical conditions. URL: https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#print [accessed 2024-09-14]
47. Occupational Safety and Health Administration. Control and prevention. 2024. URL: https://www.osha.gov/coronavirus/control-prevention [accessed 2024-09-14]
48. Tengilimoğlu D, Gönüllü U, Işık O, Tosun N, Zekioğlu A, Tengilimoğlu O, et al. The problems experienced by employees with chronic disease during the COVID-19 pandemic. Int J Environ Res Public Health 2022;19(1):578 [FREE Full text] [doi: 10.3390/ijerph19010578] [Medline: 35010836]
49. Binyaruka P, Mtenga S. Catastrophic health care spending in managing type 2 diabetes before and during the COVID-19 pandemic in Tanzania. PLOS Glob Public Health 2023;3(8):e0002180 [FREE Full text] [doi: 10.1371/journal.pgph.0002180] [Medline: 37607181]
50. Phillips AZ, Carnethon MR, Bonham M, Lovett RM, Wolf MS. Hazardous drinking by older adults with chronic conditions during the COVID-19 pandemic: evidence from a chicago-based cohort. J Am Geriatr Soc 2023;71(11):3508-3519. [doi: 10.1111/jgs.18497] [Medline: 37403969]
51. Taylor S, Paluszek MM, Rachor GS, McKay D, Asmundson GJG. Substance use and abuse, COVID-19-related distress, and disregard for social distancing: a network analysis. Addict Behav 2021;114:106754 [FREE Full text] [doi: 10.1016/j.addbeh.2020.106754] [Medline: 33310690]

52. Chacon NC, Walia N, Allen A, Sciancalepore A, Tiong J, Quick R, et al. Substance use during COVID-19 pandemic: impact on the underserved communities. Discoveries (Craiova) 2021;9(4):e141 [FREE Full text] [doi: 10.15190/d.2021.20] [Medline: 35261922]

Abbreviations

CDC: Centers for Disease Control and Prevention
HRS: Health and Retirement Study
IRB: institutional review board
OR: odds ratio
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Original Paper

An eHealth Intervention to Improve Quality of Life, Socioemotional, and Health-Related Measures Among Older Adults With Multiple Chronic Conditions: Randomized Controlled Trial

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Abstract

Background: In the United States, over 60% of adults aged 65 years or older have multiple chronic health conditions, with consequences that include reduced quality of life, increasingly complex but less person-centered treatment, and higher health care costs. A previous trial of ElderTree, an eHealth intervention for older adults, found socioemotional benefits for those with high rates of primary care use.

Objective: This study tested the effectiveness of an ElderTree intervention designed specifically for older patients with multiple chronic conditions to determine whether combining it with primary care improved socioemotional and physical outcomes.

Methods: In a nonblinded randomized controlled trial, 346 participants recruited from primary care clinics were assigned 1:1 to the ElderTree intervention or an attention control and were followed for 12 months. All participants were aged 65 years or older and had electronic health record diagnoses of at least three of 11 chronic conditions. Primary outcomes were mental and physical quality of life, psychological well-being (feelings of competence, connectedness, meaningfulness, and optimism), and loneliness. Tested mediators of the effects of the study arm (ElderTree vs active control) on changes in primary outcomes over time were 6-month changes in health coping, motivation, feelings of relatedness, depression, and anxiety. Tested moderators were sex, scheduled health care use, and number of chronic conditions. Data sources were surveys at baseline and 6 and 12 months comprising validated scales, and continuously collected ElderTree usage.

Results: At 12 months, 76.1% (134/176) of ElderTree participants were still using the intervention. There was a significant effect of ElderTree (vs control) on improvements over 12 months in mental quality of life (arm × timepoint interaction: b=0.76, 95% CI 0.14-1.37; *P*=.02; 12-month Δd=0.15) but no such effect on the other primary outcomes of physical quality of life, psychological well-being, or loneliness. Sex moderated the effects of the study arm over time on mental quality of life (b=1.33, 95% CI 0.09-2.58; *P*=.04) and psychological well-being (b=1.13, 95% CI 0.13-2.12; *P*=.03), with stronger effects for women than men. The effect of the study arm on mental quality of life was mediated by 6-month improvements in relatedness (α=1.25, *P*=.04; *b*=0.31, *P*<.001). Analyses of secondary and exploratory outcomes showed minimal effects of ElderTree.

Conclusions: Consistent with the previous iteration of ElderTree, the current iteration designed for older patients with multiple chronic conditions showed signs of improving socioemotional outcomes but no impact on physical outcomes. This may reflect the choice of chronic conditions for inclusion, which need not have impinged on patients' physical quality of life. Two ongoing trials are testing more specific versions of ElderTree targeting older patients coping with (1) chronic pain and (2) greater debilitation owing to at least 5 chronic conditions.

Trial Registration: ClinicalTrials.gov NCT03387735; https://clinicaltrials.gov/study/NCT03387735

International Registered Report Identifier (IRRID): RR2-10.2196/25175

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KEYWORDS

eHealth; telemedicine; aged; geriatrics; multiple chronic conditions; social support; quality of life; primary care; mobile phone; smartphone

Introduction

Background

Global data indicate that among adults with a chronic disease, more than half have multiple diagnosable conditions [1]. Although the consequences of multimorbidity vary by the particular array of conditions, research often indicates a compounding effect on the complexity of medical treatment [2-4], a reduction in patient-centered care as clinicians respond to the most pressing medical needs [5], and markedly increased medical costs [6-8]. For patients, multiple chronic conditions (MCCs) heighten the treatment burden [9] and the risk of adverse outcomes such as prolonged hospitalization and mortality [10]. Research also suggests that patients with MCCs tend to experience reduced quality of life (QOL) [11,12] as well as greater depression [13,14] and loneliness [15].

The prevalence of multimorbidity increases with age and low-income status. Assessments of United States data from 2018 found diagnoses of MCCs among more than 60% of those aged 65 years or older (vs 27.2% of the total adult population) and among 76.9% of older adults who qualified for low-income medical care (ie, “dual eligible” for Medicare and Medicaid) [16]. As such, the burden of MCCs often falls on those patients who may have fewer resources to navigate the complexities of their conditions.

One of the core challenges of MCCs is that the specific combination of conditions experienced by a given patient can vary widely. Clinical practice guidelines and recommendations for self-management tend to be based on specific diseases or conditions, and adjusting those guidelines and recommendations becomes more difficult as the number of comorbid conditions rises [17,18]. As various authors have noted, the risk of polypharmacy and the difficulty of self-management escalate with the number of comorbid conditions [19,20]. Given these challenges, the National Institutes of Health called for researchers to develop and test behavioral interventions that could be implemented in primary care and that would offer one broadly applicable and effective tool to help manage a wide array of combinations of chronic conditions [21]. This project was funded by the National Institutes of Health and responds to that call.

A recent review and meta-analysis of 16 randomized controlled trials (RCTs) of interventions to address multimorbidity in primary care and community settings was not encouraging [22]. Interventions were broadly grouped into those focused on medication management, self-management support, or care coordination plus self-management support. Most were designed to enhance patients’ interactions with their primary care team by coaching or informational sessions and materials. Across the 4753 participants, with most of them being older adults with 3 or more chronic conditions, there was “little or no evidence” of effects (relative to usual care [UC]) on health-related QOL or mental health, or on an array of secondary outcomes, including health care use, medication adherence, and self-efficacy. Notably, only 2 of the 16 interventions (both relatively brief, at 6 weeks in length) offered peer support in the form of weekly meetings [23,24], and none provided online resources for communicating with clinicians or peers.

A second meta-analysis, focusing on “digital telemedicine interventions” for patients with at least 2 comorbid chronic conditions [25], found somewhat more encouraging results, though the authors noted the prevalence of low-quality study designs, small sample sizes, and short durations (2-6 months with limited follow-up). The interventions were typically multifaceted, offering services such as telemonitoring (eg, online tracking of blood glucose, blood pressure, or weight, to be reviewed by the medical team), telecare (eg, online feedback or appointments with clinicians based on health-tracking scores and online yoga classes), or automated reminders (eg, for exercise or medications). The results across 2 or 3 studies for each outcome indicated moderate decreases in systolic blood pressure and cholesterol and small to moderate decreases in hemoglobin A_{1c}. In contrast, the effects on patient-centered outcomes, such as QOL, perceived health status, and depression, were largely nonsignificant. Again, it was notable that no interventions involved peer support, and most focused on tracking specific health indicators rather than patient well-being.

The current RCT was designed to build on this prior work but to avoid key limitations, including small sample size, short intervention duration, and limited or no opportunity for communicating with clinicians or peers. It presents a relatively novel and rigorous approach to multimorbidity, testing a 12-month eHealth intervention designed to improve QOL, socioemotional outcomes, and health-related outcomes among older adults with 3 or more chronic conditions. The intervention, ElderTree (ET), is an information and support platform developed by our Center of Excellence in Active Aging, which was funded by the Agency for Healthcare Research and Quality, and is one of a collection of eHealth systems known as CHESS (Comprehensive Health Enhancement Support System) [26,27].

All CHESS systems, including ET, are built on the principles of continuing care and self-management, including long duration

[28]; assertive outreach [29]; tracking [30]; prompts [31]; problem solving [32]; and peer, family, or clinical support [33]. In addition, CHESS systems are consistent with Self-Determination Theory, which asserts that satisfying the fundamental psychological needs of competence (feeling effective), relatedness (feeling connected to others), and autonomy (feeling internally motivated rather than coerced) contributes to adaptive functioning [34]. In randomized trials, our interventions significantly improved asthma control [35]; QOL and cost of care in HIV patients [36]; QOL and self-efficacy in breast cancer patients [37-39]; risky drinking [40]; and caregiver burden, symptom distress, and median length of survival in lung cancer patients [41].

ET was previously tested in an RCT involving 390 adults aged 65 years or older with at least one health risk factor (eg, recent fall, depression, or emergency room visit) in 3 Wisconsin communities (urban, suburban, and rural), who were followed for an intervention period of 12 months [27]. There were no significant effects in the sample as a whole, but subgroup analyses indicated that among participants who had 3 or more primary care visits in the 6 months prior to baseline, those in the ET group performed significantly better than those in the control group on measures of mental QOL, social support, and depression.

The results suggested that (1) ET may be more effective for patients who are dealing with multiple chronic conditions (MCCs), given that primary care use is relatively high among such patients, and (2) a system such as ET may be most effective if integrated into primary care. Building on those findings, this study examined the effects of an enhanced version of ET specifically for patients with MCCs rather than a general older population, focusing on not only QOL and socioemotional outcomes but also health measures and health care use.

Study Objectives

The overall goal of the study was to assess the effects of ET versus attention control in older patients with MCCs. Our primary objective was to determine whether, and to what extent, supplementing patients' UC with ET would lead to improvements in 4 primary outcomes. Like other interventions for chronic conditions (eg, those reviewed above), we assessed physical and mental QOL. Additionally, given the focus of our intervention on the core constructs of Self-Determination Theory (ie, motivation, competence, and autonomy), we assessed psychological well-being, using a measure that focused on feelings of competence, connectedness, meaningfulness, and optimism [42]. Finally, given the evidence about the bidirectional causal impact of loneliness on the progression of chronic conditions in older adults [43,44], we assessed participants' loneliness. We also tested whether the effects of the study arm on these primary outcomes were mediated by 6-month changes in health-related coping strategies and motivation, social relatedness, anxiety, and depressive symptoms and whether effects were moderated by sex, scheduled health care use, and the number of chronic conditions.

As prespecified in the trial protocol [26], we tested the effects of the study arm (ET vs active control) on changes over time in a number of health-related secondary and exploratory outcomes: pain, number and severity of falls, symptom distress, medication adherence, use of crisis health care and long-term care, diet, alcohol use, cigarette use, and pain medication issues. To restrict the paper length, we only briefly summarize the results for these nonprimary outcomes. Complete descriptions and analyses of these variables are reported in Multimedia Appendix 1.

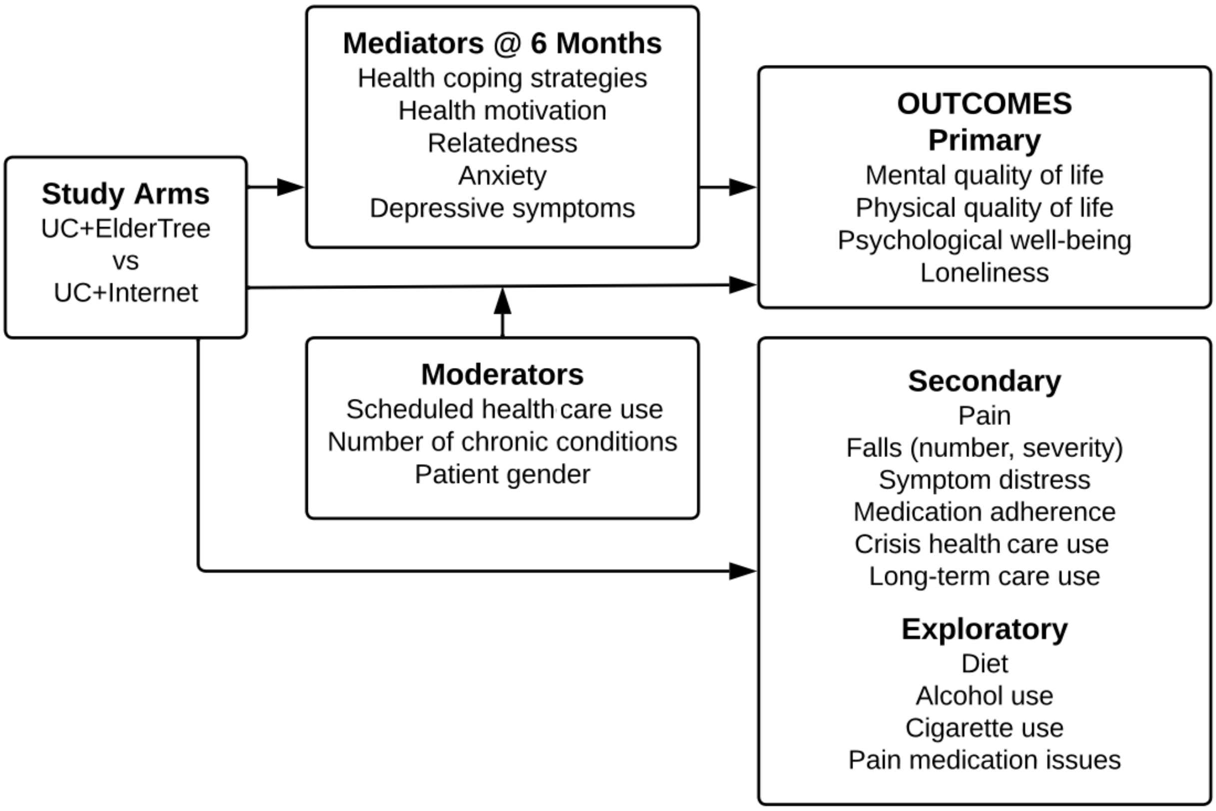
Lastly, the COVID-19 pandemic, which began mid-way through the study, overlapped with some portion of the 12-month intervention period for nearly half of the participants. As a result, we conducted post-hoc analyses, examining the months of overlap with the pandemic as a possible unanticipated moderator of the effects of the study arm.

Methods

Trial Design

The trial was a nonblinded, randomized controlled design with 1:1 allocation to the intervention arm or an attention control for a period of 12 months. Assessments were conducted at baseline, 6 months, and 12 months. We originally planned an 18-month follow-up assessment (ie, 6 months after the end of the intervention). However, with the start of the pandemic and lock-down, as we considered the role that ET played in connecting participants to each other and to their primary care team, we (the study investigators) made an ethical decision to offer continued access to ET to those participants who were approaching months 13-18. This did not change the study design for the 12 months of the intervention, but it meant that the 18-month follow-up comparison between study arms was compromised: Participants in the ET arm varied in their access to the intervention during their final 6 months of the study, depending on whether that period coincided with the pandemic. We continued to gather the 18-month data to offer participants closure, but we no longer planned to analyze and did not reach out to participants in cases of incomplete or ambiguous data. As such, we did not analyze and do not report the 18-month results. Figure 1 shows the study design.

Figure 1. Study design. UC: usual care.



Participants

Older adult patients with at least three chronic conditions were recruited from primary care clinics within the UW Health Department of Family Medicine and General Internal Medicine at the University of Wisconsin–Madison (UW Health). Eligible patients (1) were aged 65 years or older; (2) had been treated in the clinic for the previous 18 months or longer with no plans to leave during the study period; and (3) had diagnoses of 3 or more of the following 11 chronic conditions: hypertension, hyperlipidemia, diabetes, arthritis, BMI ≥30, chronic kidney disease, chronic pain, chronic obstructive pulmonary disease (COPD), congestive heart failure, arrhythmia/atrial fibrillation, and pulmonary heart disease. We originally planned to recruit participants based on self-reports of the first 5 conditions (4 of them related to metabolic syndrome). Before recruitment began, we changed our criterion to 3 or more of any of the 11 conditions listed above. We did so both to increase the pool of eligible patients and to provide a more expansive test of the effectiveness of ET in addressing a wide array of comorbid conditions prevalent among older adults.

Prior to recruitment, we also decided to use documented diagnoses from electronic health records (EHRs) as inclusion criteria, rather than relying on participant self-report (including possible self-diagnosis). This not only provided a more standardized assessment of chronic conditions but also allowed clinics to identify eligible participants and send them a recruitment letter describing the study.

Further eligibility criteria were as follows: (4) no current psychotic disorder that would prevent participation; (5) no acute medical problem requiring immediate hospitalization; (6) no visual or motor impairment preventing the use of a computer; (7) ability to read and sign the consent form in English; (8) agreement to share health-related study data (eg, lab scores and health care utilization); (9) permission to share information with the patient's primary care physician; and (10) no moderate or advanced dementia.

Interventions

Patients in both conditions continued with their UC provided by primary care and internal medicine clinics in the University of Wisconsin–Madison system and received their assigned intervention.

Control Condition

In addition to their UC, patients in the control condition received internet service and a laptop computer for 12 months. Shortcuts to 4 general health information websites, vetted for quality by our research team, were placed on the computer desktop for easy access: the Cleveland Clinic [45], National Institute on Aging [46], the American Academy of Family Physicians [47], and Mayo Clinic [48]. We expected this UC+internet intervention to be relatively ineffective because information alone is unlikely to have much impact on health behaviors [39,49-51]. Instead, access to the device, the internet, and the sites functioned as a form of attention control versus pure control comparison and as a way to isolate the specific effects of access to ET. In an attention control group, participants receive the same amount of interaction and "attention" from the research team as the intervention group, but that interaction does not contain the hypothesized therapeutic content [52]. In our case, control participants could go online and interact with others but did not do so in the context of ET.

Experimental Condition

Patients in the experimental condition received UC plus ET access and a laptop computer, along with internet for 12 months. This UC+ET group did not receive the health information websites placed on computers for control patients, although they could have sought them out independently.

ET System Overview

As described previously [26], ET provides tools, motivation, and social support to help patients manage their chronic conditions, communicate with peers and research staff, and improve communication with clinicians. The system was developed specifically for older adults with extensive input from advisory and focus groups of older adults. It featured large fonts, few options, and uncluttered screens for easy comprehension, navigation, and usability. Areas of the site were Community (with chatroom-like discussion groups, email-like private messaging, and a bulletin board of local events); Well-Being (offering relaxation and meditation videos and journaling with positive psychology prompts); and My Health (a collection of health information resources). The content was continuously refreshed. While the design and navigation were based on the original ET and principles established in our earlier testing [27,53], we enhanced the system for this study as described below. A sample of the home screen is shown in Figure S1 in Multimedia Appendix 2.

ET Enhancements

We made 3 major enhancements to the original ET. First, we expanded a basic health-tracking feature in the original ET to create a weekly survey with feedback. Patients were prompted to complete weekly check-ins regarding 10 general health indicators: sleep, nutrition, physical activity, cognition, balance, falls, mood, pain management, medication adherence, and quality of social interactions. As soon as the survey was completed, ET feedback commended any improvements. If survey results showed mild reductions in any of the health indicators, ET feedback directed the patient to relevant articles in the ET My Health library. If the algorithm detected a sudden or steep negative change in any of the indicators or a problem that was not improving over several weeks, ET recommended that the patient contact their clinic. ET also generated a graph charting the patient's responses for each indicator over the last 3 months to facilitate self-monitoring (Figure S2 in Multimedia Appendix 2).

Second, we used the survey-generated graph as the basis for a clinician report that was shared with the patient's primary care clinic. We used a similar report in a lung cancer trial comparing a CHESS system alone to a CHESS system combined with a clinician report [54] and found that the addition improved symptom distress by more than 100% (26.2% improvement with CHESS alone vs 53% with CHESS+clinician report; n=71 vs 68, respectively; *P*<.001). The clinician report was designed to offer specific benefits in health care delivery for patients with MCCs. While MCCs can lead to rapid declines in health [55], care for such patients usually consists of periodic onsite contact with primary care clinicians, who may be unaware of such changes or cannot respond as promptly as may be warranted. The report, sent the week before a patient's scheduled visit, shared timely information on health indicators and helped both patients and clinicians make the most of these visits. As a single-page graphic summary of health-tracking data, the report could be viewed and understood at a glance, avoiding a time burden for clinicians while allowing them to provide responsive and appropriate treatment. A hard copy of the report was also mailed directly to the participant to take to the appointment.

When the COVID-19 lockdown began and clinics transitioned to telehealth and fewer in-person visits, we altered our strategy for the clinician report. Every 2 months, the study project manager prepared a clinician report summary providing an overview for all participants at each clinic. The goal was to help clinicians identify patients who were reporting issues such as missed medications or mood changes between appointments, particularly as patients continued to isolate due to COVID-19. This summary was emailed to clinic managers to share with individual clinicians (Figure S3 in Multimedia Appendix 2).

Third, because our original trial of ET identified the greatest improvements in mental QOL, social support, and depression, we tried to strengthen these effects still further by adding an interactive Fun & Games area (light-hearted polls, quizzes, videos, and games) and a weekly Lifestyle article (topics included travel, mind and body, etc). Both features were designed to increase participants' enjoyment of the site and engagement with others via asynchronous comment threads.

Measures

Participants were assessed for all study variables at baseline, 6 months, and 12 months, as described below. To assess system use, time-stamped usage data from ET participants were continuously captured in our database, including specific services used; date and time the system was accessed; and text entered into discussions, comment threads, and message features.

Primary Outcomes

Mental and physical QOL were assessed using the 8-item PROMIS (Patient-Reported Outcomes Measurement Information System) Global Health measure [56,57], with 4 items for mental QOL (eg, "How would you rate your mental health, including your mood and your ability to think?") and 4 for physical QOL (eg, "To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?"). Scoring of individual items varies and is calculated by the scale's developers; the total possible ranges are 21.2-67.6 for mental QOL and 16.2-67.7 for physical QOL, with higher values indicating better QOL [58]. For consistency with other primary outcome measures, the timeframe was modified to the past 2 weeks.

Psychological well-being was assessed with the 8-item Psychological Flourishing Scale (eg, "My social relationships are supportive" and "I lead a meaningful life") [42]. Each item is scored on a 5-point scale, for a total possible range of 8-40, with higher scores indicating greater flourishing.

Loneliness was measured with 8 items from the UCLA Loneliness Scale that showed the highest factor loadings among elderly adults in prior work (eg, “How often do you feel part of a group of friends?”) [59]. Each item is scored on a 5-point scale, for a total possible range of 8-40, with higher scores indicating increasing loneliness.

Mediators

We measured 5 possible mediators. Health coping strategies were assessed with 10 items from the Ways of Coping Scale (eg, “Made a plan of action and followed it” and “Accepted the situation”) [60]. Each item is assessed on a 5-point scale, for a possible range of 10-50, with higher scores indicating better coping.

Motivations were assessed with four 5-point items from the Treatment Self-Regulation Questionnaire [61]; 2 items assessed autonomous motivation (eg, “I try to manage my health conditions because I want to take responsibility for my own health”) and 2 assessed external regulation (eg, “I try to manage my health conditions because I feel pressure from others to do so”). The total possible range for each motivation subscale is 2-10, with higher scores indicating greater autonomous and external motivation.

Relatedness was assessed with the 6-item McTavish Bonding Scale [62] plus 3 items from the short form of the PROMIS emotional support scale [63]. For all items, patients indicated on a 5-point scale the frequency of the type of support (eg, “Someone you can count on to listen when you need to talk” and “Someone to love and make you feel wanted”). The total possible range is 9-45, with higher scores reflecting more support.

Anxiety and depressive symptoms were assessed with the 7-item Generalized Anxiety Disorder scale [64] and the 8-item version of the Patient Health Questionnaire Depression scale [65], respectively. The response option in both 4-point scales was the frequency of a symptom (eg, “Trouble relaxing” and “Poor appetite or overeating”) in the past 2 weeks. Higher scores indicate more anxiety or depression symptoms.

Moderators

We investigated whether the effects of the study arm on change from baseline to endpoint in primary outcomes were moderated by sex, health care use, and number of chronic conditions. Participants indicated their sex (male or female) at baseline. On all assessments, they reported scheduled visits in the preceding 3 months to primary care, specialists, physical and occupational therapists, chiropractors, and counseling. For the number of chronic conditions, we used EHR data obtained during enrollment for each participant, and the range was 3-11.

Potential Covariates

Potential covariates included comfort or familiarity with technology, physical challenges using technology, and life stressors. Patients rated on a 6-point scale their comfort with 6 communication technologies: computer, smartphone, tablet, smart speaker, email, and Facebook. The total possible range is 0-30, with higher scores indicating greater comfort. For physical challenges, participants reported vision, hearing, hand pain or tremors, memory, “other,” or no limitations for both a computer/tablet and a smartphone, checking all that applied. To gauge life stressors, they reported on 14 possible stressors from the Social Readjustment Rating Scale (eg, “Death of a very close friend or family member” and “Change in financial status”) [66], checking all that applied (possible range is 0-14). Participants also reported sociodemographic variables of race and ethnicity, education, income, health insurance, whether they had a significant other, housing type, and whether they lived alone or with others. We planned to control for these if they varied by study arm.

Sample Size Determination and Power

We focused on the effect of Cohen d=0.50 on the primary outcome of patients’ perceptions of their QOL, given recommendations that this is the minimally important difference for QOL measures in clinical trials [67]. For our other primary outcomes (psychological well-being and loneliness), effect sizes tend to be smaller. For example, a prior web-based intervention for rural women with chronic diseases showed an effect of Cohen d=0.29 on loneliness among those who scored above the median on baseline levels of loneliness, depression, and stress [68]. Given that our intervention was substantially longer (12 months vs 22 weeks) and had more components specifically designed to address social connectedness, we expected somewhat larger effects but did not expect to reach Cohen d=0.50. Balancing the need to be adequately powered with the need to focus on meaningful impacts, the study was powered to detect a main effect of Cohen d=0.35 for our primary outcomes. Adequate power to detect a between-subjects effect of Cohen d=0.35 ($1-\beta=0.80$; $\alpha=.05$) with repeated measures on the outcome required a final sample of 262 patients (130 per arm). On the basis of our prior trial of ET, we assumed 20.5% attrition and thus arrived at a recruitment goal of 330 patients (165 per arm).

Recruitment

The UW–Madison Clinical Research Data Service examined UW Health Clinic EHRs to identify patients who met the eligibility criteria, including chronic conditions. Potential participants then received an opt-in letter from the university’s Office of Clinical Trials. The letter described the study and included a postage-paid return invitation for further contact from the study team.

After a patient returned the invitation, study staff called and provided a detailed trial overview, including benefits and potential risks of participation. If interested, patients were screened on all eligibility criteria. Those who verbally confirmed they wanted to participate and met the criteria were mailed the baseline survey and received a home visit from a member of the research team, at which time written consent was obtained, baseline data were collected, and randomization was determined.

Randomization

The project manager used a computer-generated allocation sequence to randomize patients in a 1:1 ratio to the experimental (UC+ET) or control (UC+internet) group, stratified by sex, clinic site, and number of chronic conditions (3-5 vs. ≥6). The block size was 10. When baseline assessment and consent were complete, the research staff person opened the numbered, sealed, opaque envelope revealing group assignment, and then conducted equipment setup and training for either the intervention (including all the services and how to use them) or control device. Once the assignment was made, participants could not be blind to their condition, given that those in the experimental arm were asked to use ET, while those in the control arm were not. The training researcher also could not be blind to the condition after the assignment was revealed.

Statistical Methods

From the list of our prespecified potential covariates, we selected covariates to include in analyses by examining whether they were moderately correlated (0.30 or higher) with at least one of the primary outcomes [69]. Only life stressors met the correlation benchmark (mental QOL: r=–0.35; physical QOL: r=–0.34).

In addition, given that participants varied in the extent of overlap between the COVID-19 pandemic and the 12-month intervention period (range=0.02 to 6.33 months), we included this variable (defined as participant's number of months during the pandemic prior to each survey timepoint) in our analyses at each timepoint as a covariate. Of note, pandemic months significantly influenced mental QOL (*P*=.03) but none of the other primary outcomes (all *P*>.31). Ultimately, life stressors and pandemic months were the only covariates included in the models.

Normality, linearity, and homoscedasticity/homogeneity of variance for outcome data were assessed using descriptive statistics and graphical representations. Outcomes were analyzed with mixed-effects models, using (g)lmer() from the lme4 package, implemented in the R statistical software environment. These models account for correlated measurements within participants, use all available data (allowing for intention-to-treat rather than only complete-case analysis), and provide unbiased estimates when data are missing at random [70]. Each model included a random effect for participant, as well as fixed effects for survey timepoint, study arm, and arm-by-timepoint interaction. The survey timepoint was entered as a continuous variable with 3 timepoints (baseline, 6 months, and 12 months).

Ethical Considerations

This study received ethical approval from the University of Wisconsin Health Sciences Institutional Review Board (reference number: 2017-0849) and has been registered at ClinicalTrials.gov (NCT03387735).

Results

Participants

A total of 346 participants were randomized, and 344 received either the assigned intervention or control device and were included in the analyses (Figure 2). Of the 344 receiving an intervention, 321 (93.3%) completed the 6-month survey and 309 (89.8%) completed the 12-month survey. As data were analyzed with mixed-effects models, which use all available data rather than only complete cases, 318 (92.4%) were included in the analyses. Recruitment began in February 2018 and ended in December 2019. The intervention period concluded in December 2020 (Figure 2). The CONSORT (Consolidated Standards of Reporting Trials) checklist is presented in Multimedia Appendix 3.

Participant characteristics at baseline are presented in Table 1. Most participants identified as white (317/344, 92.2%) and female (209/344, 60.8%), and the average age was 74 years 9 months. The average number of chronic conditions was 5.28. For a detailed breakdown of chronic conditions by group, see Multimedia Appendix 4.

Figure 2. CONSORT (Consolidated Standards of Reporting Trials) flow diagram of participants through the study. Data were analyzed with mixed-effects models, which use all available data rather than only complete cases.

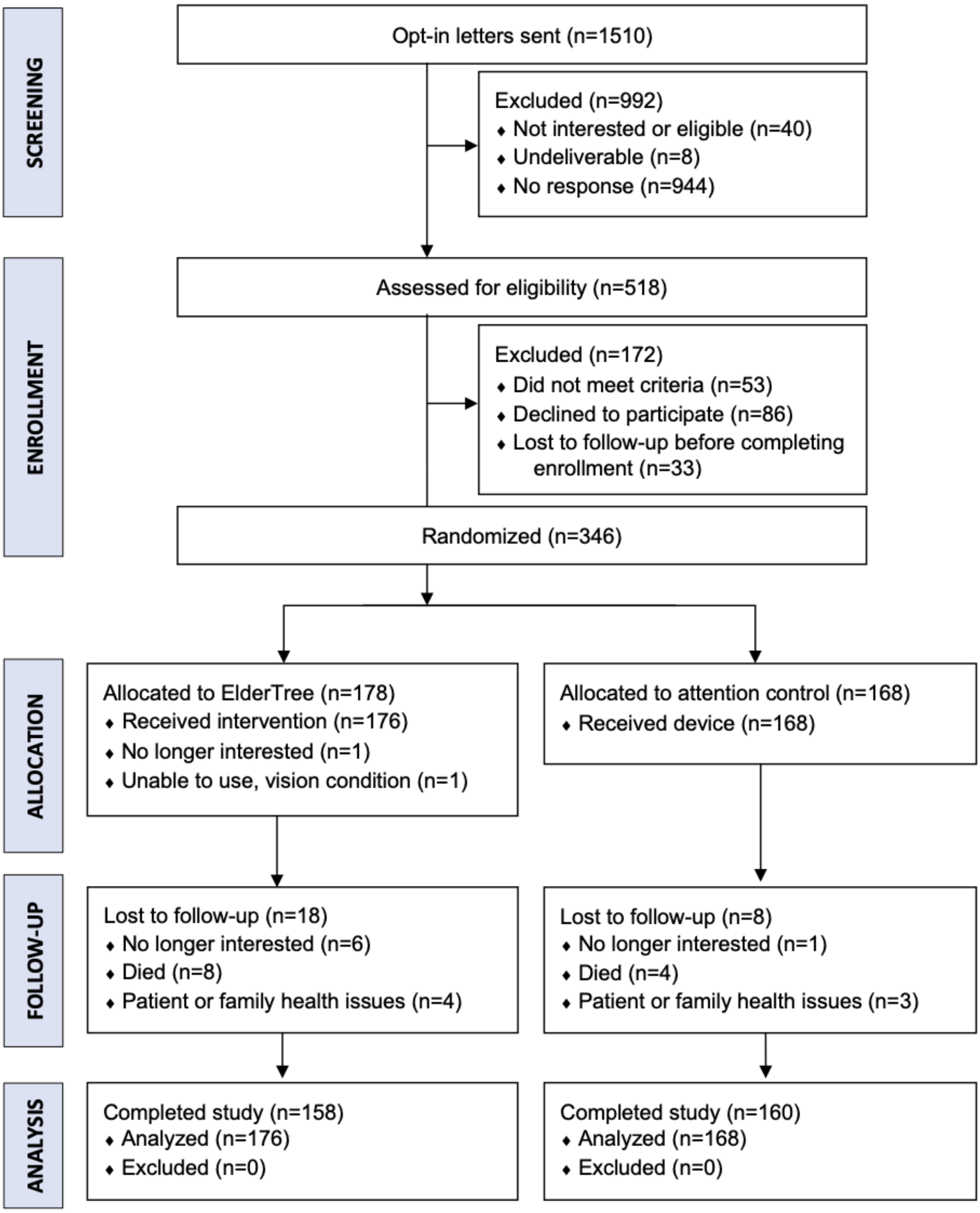


Table 1. Participant characteristics by study arm at baseline.

Characteristic	UC[a]+internet (N=168)	UC+ElderTree (N=176)
Female, n (%)	103 (61.3)	106 (60.2)
Number of chronic conditions at enrollment (from EHRs[b]), n (%)		
3-5 chronic conditions	104 (61.9)	108 (61.4)
6-11 chronic conditions	64 (38.1)	68 (38.6)
Race, n (%)		
American Indian, White	1 (0.6)	2 (1.1)
Black	14 (8.3)	8 (4.6)
Jewish	0 (0.0)	1 (0.6)
Unspecified mixed race	0 (0.0)	1 (0.6)
White	153 (91.1)	164 (93.2)
Ethnicity Hispanic or Latino, n (%)	1 (0.6)	0 (0.0)
Highest level of completed education, n (%)		
Middle school	2 (1.2)	1 (0.6)
High school	40 (23.8)	30 (17.1)
Vocational or technical school	19 (11.3)	26 (14.8)
Some college	38 (22.6)	49 (27.8)
College graduate	30 (17.9)	35 (19.9)
Postgraduate or professional	39 (23.2)	35 (19.9)
Annual income, n (%)		
Less than US $12,000	5 (3.0)	7 (4.0)
US $12,000-24,999	34 (20.2)	32 (18.2)
US $25,000-49,999	44 (26.2)	41 (23.3)
US $50,000-74,999	30 (17.9)	34 (19.3)
US $75,000 or above	41 (24.4)	43 (24.4)
Did not report	14 (8.3)	19 (10.8)
Had significant other, n (%)	105 (62.5)	110 (62.5)
Housing, n (%)		
Nursing home	1 (0.6)	0 (0.0)
Own	114 (67.9)	134 (76.1)
Rent	33 (19.6)	27 (15.3)
Assisted living facility	3 (1.8)	1 (0.6)
With family or friends	11 (6.6)	11 (6.3)
Live alone, n (%)	118 (70.2)	124 (70.5)
Age (years), mean (SD)	74.54 (6.45)	74.88 (6.11)
Comfort using technology (range 0-5)[c], mean (SD)	2.81 (1.30)	2.79 (1.34)
Physical issues with technology (range 0-10)[d], mean (SD)	0.46 (1.19)	0.38 (0.87)
Life stressors (range 0-14)[e], mean (SD)	1.11 (1.46)	1.01 (1.36)

[a] UC: usual care.

[b] EHRs: electronic health records.

[c] Higher values indicate greater comfort.

[d] Higher values indicate more physical issues.

[e] Higher values indicate more stressors.

ET Use

We defined “use” as accessing any service or feature beyond the home screen at least once during a given time period. Of the 176 participants randomized to UC+ET, 166 (94.3%) had used ET in their first month, 164 (93.2%) used it in months 2-6, 137 (77.8%) used it in months 7-11, and 134 (76.1%) used it in the final month of the study.

Number of days of use (ie, accessing any ET service in a 24-hour period) also indicated sustained use. In the first 6 months (180 days), participants accessed ET for a mean of 48.95 days (SD 35.16 days; 27.2% of days; range 0-179 days). During months 7-12, participants used the intervention for a mean of 31.40 days (SD 32.07 days; 17.44% of days; range 0-167 days). These means include participants with no days of use (scored 0).

Participants made the most use of ET services that facilitated social interaction. Of the 6 main areas on the site, Community was the most active. During their year on the intervention, 172 of the 176 UC+ET participants used this area a mean of 42.78 days (SD 59.66 days; range 1-305 days). Discussion Groups, an activity within the Community area, was the most heavily used single service on the system. During their intervention year, a total of 162 participants used it for a mean of 34.82 days (SD 57.48 days; range 1-295 days). Of the other main areas, Fun & Games was the second most visited (n=163 participants; mean 32.74 days, SD 57.50 days; range 1-311 days), followed by Lifestyle (n=163; mean 15.34 days, SD 23.81 days; range 1-214 days), both of which allowed for asynchronous interaction via comments. The nonsocial areas were used somewhat less often: My Health informational resources were used by 169 participants for a mean of 24.89 days (SD 21.66 days; range 1-135 days), and Well-Being was used by 158 participants for a mean of 15.32 days (SD 35.14 days; range 1-290 days).

Regarding the weekly health-tracking feature, 162 of the 176 UC+ET participants (92.0%) used the tracker during their first 6 months in the study, and 134 (76.1%) were still using it in the 12th month. Prior to the 6-month survey, participants used the tracker for a mean of 20.16 weeks (SD 7.11 weeks; range 0-30 weeks). Between the 6- and 12-month surveys, participants used it for a mean of 16.99 weeks (SD 8.21 weeks; range 0-26 weeks). These means include participants with no weekly tracker use (scored 0).

Use of the Clinician Report and Summaries

We had planned to conduct study-end quantitative assessments and qualitative interviews with clinicians about their uses and perceptions of the clinician report. Because of the pandemic, clinicians were unavailable to provide feedback on either the prepandemic individual reports or the clinic summaries we pivoted to once the pandemic started. We had anecdotal feedback from staff members that the clinic summaries were helpful in highlighting patients who might need outreach, but we had no way of assessing the extent to which clinicians used the reports or summaries and which aspects they found helpful or cumbersome. We did not measure patients’ uses and perceptions of the clinician reports, but some participants volunteered instances in which the clinician report sparked a conversation with their doctor (eg, about sleep).

Effects of the Study Arm on Changes Over Time in Primary Outcomes

Primary outcomes were physical and mental QOL, psychological well-being, and loneliness. We conceptualized these as distinct though related variables. In fact, the 3 socioemotional outcomes (mental QOL, psychological well-being, and loneliness) were more strongly correlated than we had anticipated (Table 2).

Table 2. Correlations between primary outcomes.

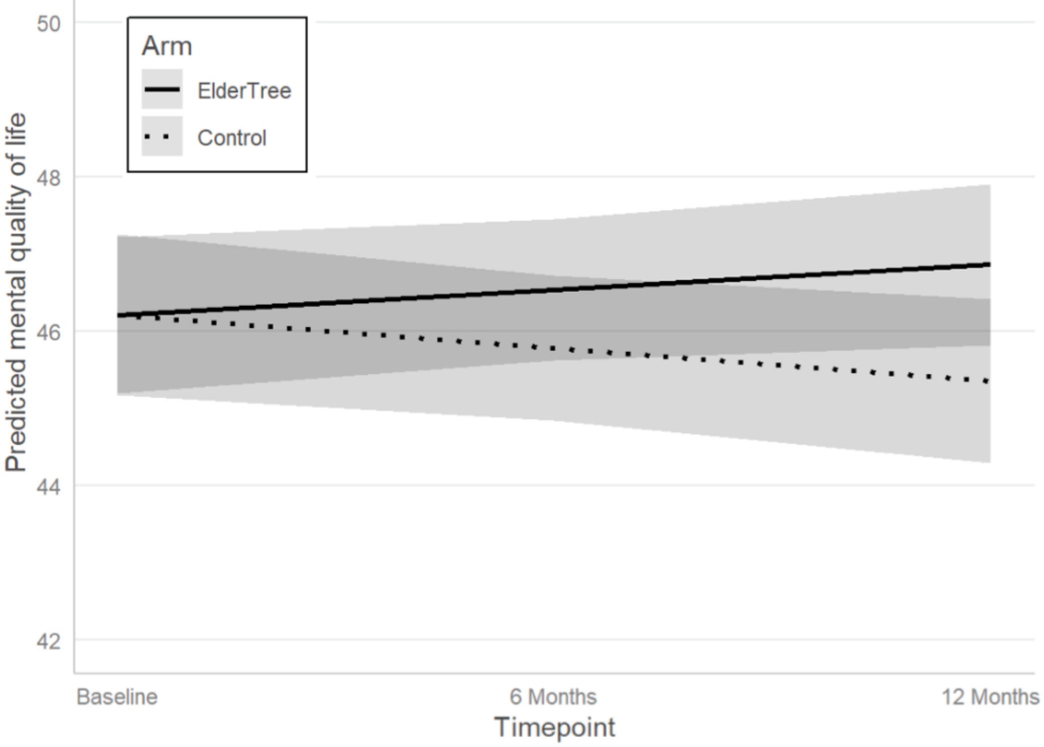
Variable	Data		Correlation			
	Number	Mean (SD)	Mental quality of life	Physical quality of life	Psychological well-being	Loneliness
Mental quality of life	344	46.25 (7.28)	—[a]	0.50[b]	0.61[b]	–0.56[b]
Physical quality of life	344	42.39 (6.23)	0.50[b]	—	0.37[b]	–0.17[b]
Psychological well-being	344	31.33 (5.23)	0.61[b]	0.37[b]	—	–0.68[b]
Loneliness	344	16.59 (5.93)	–0.56[b]	–0.17[b]	–0.68[b]	—

[a] Not applicable.

[b] *P*<.05.

Controlling for life stressors and pandemic months, we found a significant difference between the ET and control arms in the extent of change in mental QOL over time from baseline to 12 months (arm × timepoint interaction: b=0.76, 95% CI 0.14-1.37; *P*=.02). Specifically, as shown in Figure 3, the ET arm showed an increase in mental QOL and the control arm showed a decrease, for a total difference of 1.5 T-score points (PROMIS measures are standardized so that scores have a mean of 50 and SD of 10. Thus, the T-score difference can be interpreted as Cohen d divided by 10, that is, 1.5 points can be read as Cohen d=0.15). Although this difference in means between the 2 groups at 12 months was statistically significant (*P*=.04), PROMIS scoring guidelines [71,72] state that a difference is considered meaningful at 3 or more T-score points when comparing groups.

Figure 3. Predicted mean values of mental quality of life over time. Possible range is 21.2-67.6, with higher values indicating better mental quality of life. Shaded areas represent 95% CIs.



We did not find significant differences between groups in changes over time for physical QOL (b=0.10, 95% CI –0.44 to 0.64; *P*=.71), psychological well-being (b=0.23, 95% CI –0.26 to 0.72; *P*=.36), or loneliness (b=–0.25, 95% CI –0.73 to 0.22; *P*=.29).

ET System Use as a Predictor of Primary Outcomes

As the overall goal of the study was to assess the effects of ET, we examined whether the amount of use of the ET system would predict changes in our primary outcomes, as specified in our protocol [26]. For these analyses, the amount of ET use was measured as days of any use. If a participant in the intervention arm did not use the system after training, they were assigned a value of 0 days. Both arms (control and intervention) were included in these analyses, with all control participants assigned values of 0 days.

With regard to mental QOL, controlling for baseline scores, days of ET use significantly predicted improvement over the 12 months of the intervention (b=0.02, 95% CI 0.00-0.03; *P*=.046), and the magnitude of this effect did not change over time (b=0.00, 95% CI –0.02 to 0.02; *P*=.72). The model predicted that those using ET every day within a 6-month time span (180 days) would show a 3.23-point increase in mental QOL compared to those not using the system. A clinically meaningful difference of 3 points would thus be seen at 167 days within a 180-day span or 92.7% of days.

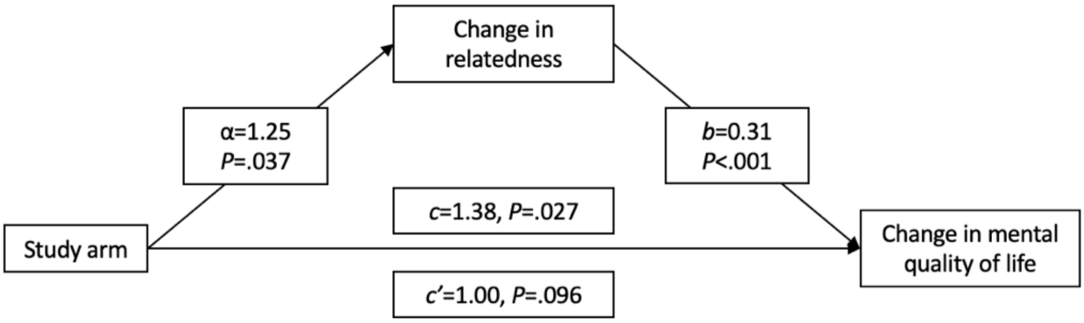
Days of ET use did not statistically predict a difference in the other primary outcomes: physical QOL (b=–0.00, 95% CI –0.02 to 0.01; *P*=.90), psychological well-being (b=0.01, 95% CI –0.01 to 0.02; *P*=.26), or loneliness (b=–0.01, 95% CI –0.02 to 0.00; *P*=.20).

Mediation of the Effects of the Study Arm

As proposed, we investigated whether the effects of the study arm on changes in primary outcomes over time would be mediated by 6-month changes in health coping strategies, health-related motivation, feelings of relatedness, depression symptoms, and anxiety symptoms. Controlling for baseline, the study arm did not significantly predict coping (b=–0.69, 95% CI –2.14 to 0.75; *P*=.34), motivation (b=0.04, 95% CI –0.56 to 0.64; *P*=.88), depression (b=0.05, 95% CI –0.53 to 0.64; *P*=.86), or anxiety (b=0.12, 95% CI –0.48 to 0.71; *P*=.70) at 6 months (simple test of path α). However, the study arm did significantly predict feelings of relatedness (b=1.35, 95% CI 0.13-2.57; *P*=.03) at 6 months. Given this, we tested a simple mediation model of the effect of the study arm on the change from baseline to 12 months in our primary outcome mental QOL, mediated by the change from baseline to 6 months in relatedness. We did not test mediation for our other 3 primary outcomes because the arm-by-time analyses were nonsignificant.

The mediation analysis showed that the study arm was significantly associated with changes in mental QOL from baseline to 12 months (path *c*=1.38; *P*=.03), as was demonstrated by our main primary outcome analyses. The inclusion of relatedness in the model resulted in significant associations between the study arm and relatedness (path α=1.25; *P*=.04) and between relatedness and mental QOL (path *b*=0.31; *P*<.001). The association between the study arm and changes in mental QOL (direct effect) was not significant (path *c′*=1.00; *P*=.10), indicating complete mediation. See Figure 4 for a diagram of this mediation model.

Figure 4. Diagram of the study arm mediational model.

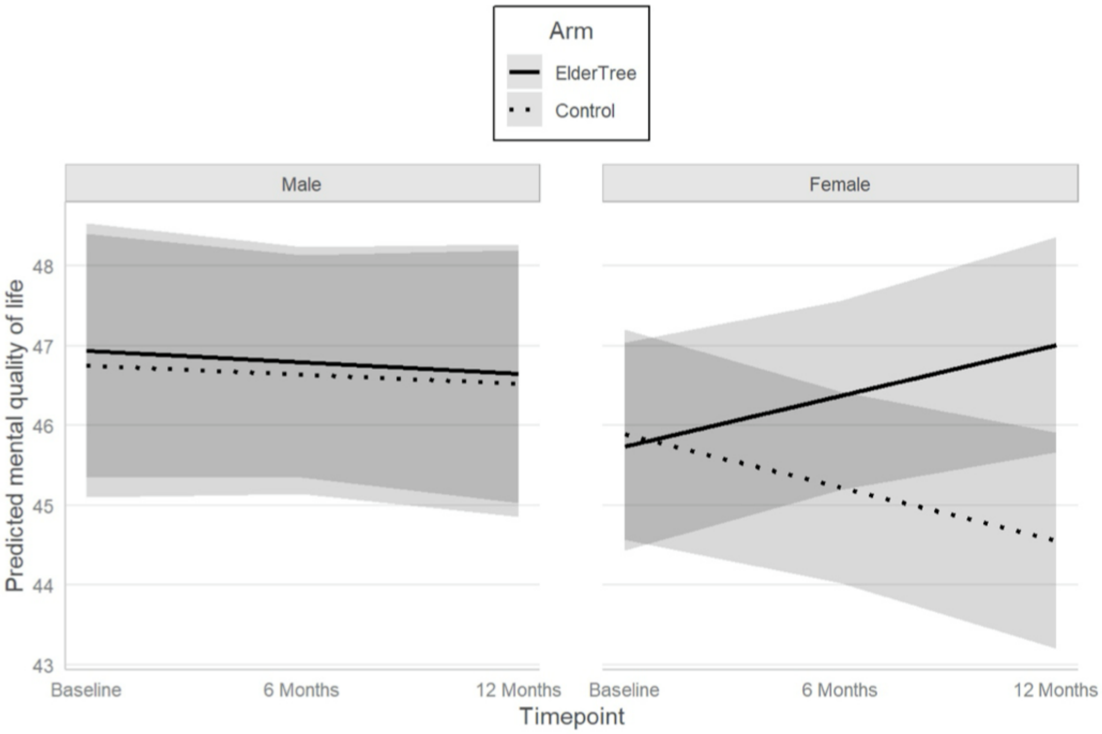


Moderation of the Effects of the Study Arm

We examined whether the effects of the study arm on changes over time in the primary outcomes were moderated by sex, amount of scheduled health care use, and number of chronic conditions.

Sex moderated the effect of the study arm over time on mental QOL (sex × arm × time interaction: b=1.33, 95% CI 0.09-2.58; *P*=.04). To understand this 3-way interaction, we looked at the simple effects of time for the 4 combinations of sex and arm. For female participants, the ET arm showed an increase in mental QOL over time, while the control arm showed a decrease. By 12 months, the difference in means was statistically significant (mean difference=2.60; *P*=.002) for females, although it did not exceed the benchmark of 3.0 considered meaningful. For male participants, no difference in means was seen between groups over time (12-month mean difference=–0.06; *P*=.95). Data are presented in Figure 5.

Figure 5. Predicted mean values of mental quality of life by sex over time. Possible range is 21.2-67.6, with higher values indicating better mental quality of life. Shaded areas represent 95% CIs.



Sex also moderated the effect of the study arm over time for psychological well-being (sex × arm × time interaction: b=1.13, 95% CI 0.13-2.12; *P*=.03). To understand this 3-way interaction, we looked at the simple effects of time for the 4 combinations of sex and arm. For female participants, the ET arm showed an increase in well-being over time and the control arm showed a decrease. By 12 months, the difference in means was statistically significant (mean difference=1.38; *P*=.04; Cohen d=0.28). For male participants, the ET arm remained steady while the control group showed an increase in psychological well-being over time. However, at 12 months, the difference in means was not statistically significant (12-month mean difference=0.88; *P*=.28; Cohen d=0.18). Data are presented in Figure 6.

No other moderation of the effect of the study arm over time was found. Inferential statistics for all moderation analyses are presented in Table 3.

Figure 6. Predicted mean values of psychological well-being by sex over time. The possible range is 8-40, with higher values indicating greater psychological well-being. Shaded areas represent 95% CIs.

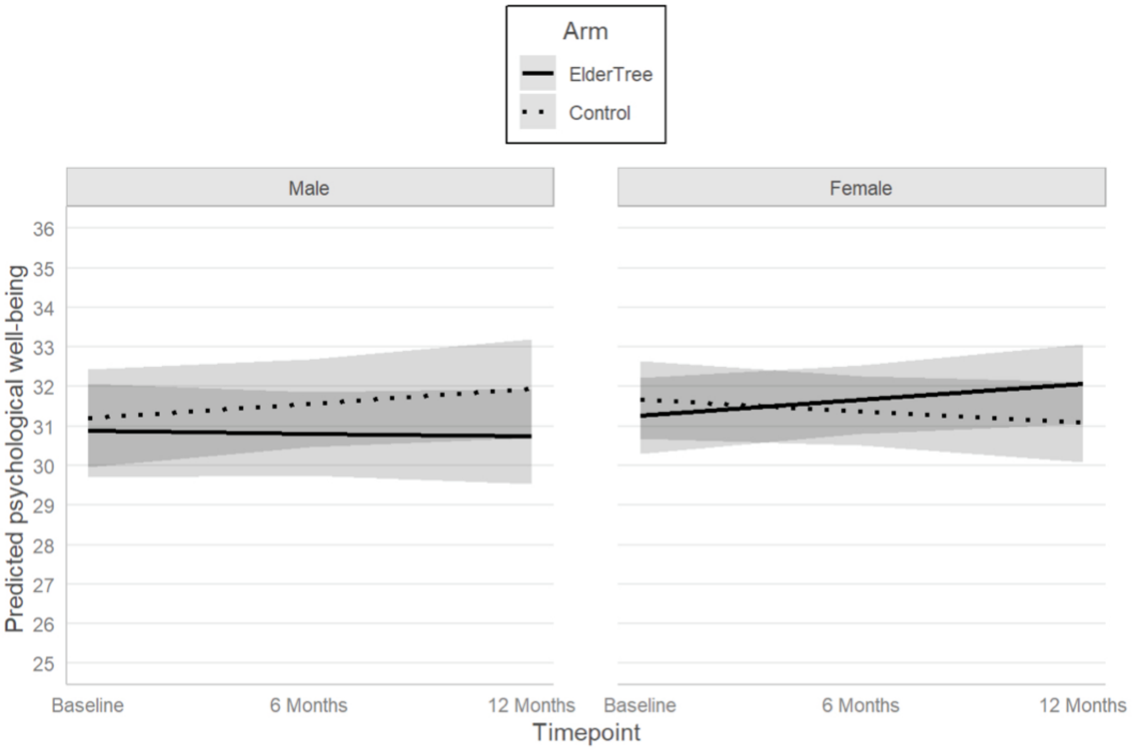


Table 3. Inferential statistics for the moderators of the study arm regarding primary outcomes.

Moderator and outcome	Inferential statistics for moderator × arm × timepoint		
	b	95% CI	*P* value
Sex			
Mental quality of life	1.33	0.09 to 2.58	.04
Physical quality of life	0.08	–1.02 to 1.18	.88
Psychological well-being	1.13	0.13 to 2.12	.03
Loneliness	0.51	–0.45 to 1.48	.30
Number of scheduled health care visits			
Mental quality of life	–0.06	–0.17 to 0.04	.26
Physical quality of life	0.00	–0.09 to 0.10	.92
Psychological well-being	–0.05	–0.13 to 0.04	.28
Loneliness	–0.00	–0.09 to 0.08	.91
Number of chronic conditions from EHRs[a]			
Mental quality of life	–0.02	–0.49 to 0.45	.94
Physical quality of life	–0.01	–0.42 to 0.41	.97
Psychological well-being	–0.02	–0.40 to 0.35	.91
Loneliness	–0.01	–0.38 to 0.35	.94

[a] EHRs: electronic health records.

Post Hoc Probing of Sex Moderation

To probe the finding that the effects of the study arm on mental QOL and psychological well-being were stronger for women than for men, we began by examining whether there were sex differences in variables that might explain this pattern: other demographic or background variables that we had considered as covariates, baseline levels of relatedness and primary outcomes, days of ET use, and (more specifically) days of ET discussion group use. There were only 2 significant differences. For education (4=some college, 5=college graduate, 6=postgraduate or professional degree), men (mean 5.37, SD

1.36) had higher levels than women (mean 4.85, SD 1.46; *P*<.001). For the likelihood of having a partner, men (n=112, 83%) had a higher likelihood than women (n=103, 49%; *P*<.001). However, adding education and the presence of a partner as covariates to the moderation analyses for mental QOL and psychological well-being did not alter the significance of the study arm × time × sex interactions or the magnitude or direction of the coefficients for the study arm (b=1.35, 95% CI 0.10-2.60; *P*=.03 for mental QOL; b=1.14, 95% CI 0.15-2.14; *P*=.025 for psychological well-being). See Table 3 for values without education and partner. Further exploratory analyses examining possible moderated mediation are reported in Multimedia Appendix 1.

Post Hoc Moderation Analysis: Effect of COVID-19 on the Study Arm for Primary Outcomes

Because our outcomes seemed likely to be impacted by the extended isolation of lockdowns, which began in March 2020, and because our older health-compromised population was among the most vulnerable to the illness [73,74], we conducted post hoc analyses. Specifically, to understand how the pandemic may have affected primary outcomes, we tested pandemic months as a moderator.

The pandemic overlapped with some portion of the 12-month intervention period for 158 (45.9%) of the 344 participants who received an intervention. A total of 77 (43.8%) ET and 81 (48.2%) control participants completed the 12-month survey during the pandemic, and of these, 3 (1.7%) ET and 6 (3.6%) control participants also completed the 6-month survey during this period. The 81 control participants experienced a mean overlap of 3.11 months (SD 2.03 months; range 0.02-6.33 months), while the mean overlap for the 77 ET participants was 3.02 months (SD 1.94 months; range 0.20-6.10 months). Given this, we examined months of overlap with the pandemic as a possible unanticipated moderator (rather than covariate) of the effects of the study arm.

The pandemic did not appear to impact the effects of the study arm on the primary outcomes. Controlling for baseline, we found that months during COVID-19 did not moderate the effect of the study arm for mental QOL (b=–0.98, 95% CI –4.03 to 2.08; *P*=.53), physical QOL (b=–0.13, 95% CI –2.91 to 2.64; *P*=.93), psychological well-being (b=–1.73, 95% CI –4.16 to 0.71; *P*=.16), or loneliness (b=1.15, 95% CI –1.27 to 3.57; *P*=.35).

Secondary and Exploratory Outcomes

Results for secondary and exploratory outcomes are presented and discussed in Multimedia Appendix 1. To summarize, we found a significant effect of the study arm on changes over time in the level of pain, such that the ET arm showed a slight increase in pain over time, while the control arm showed a slight decrease, resulting in a significant difference between study arms at 12 months. We did not find significant effects of ET versus control on changes over time in falls, symptom distress, medication adherence, use of crisis health care, pain medication issues, alcohol use problems, or diet. We were unable to test cigarette use due to a lack of participants who smoked at any point during the study.

Discussion

Summary and Interpretation

Given the need for broadly applicable behavioral interventions that could be implemented in primary care to help manage patients' varied combinations of chronic conditions [20,21], this study was designed to test the effectiveness of an online intervention, ET. Given that prior interventions for multimorbidity have been critiqued for low-quality assessments [25], this study was designed to be a high-quality clinical trial featuring a large sample of older adults with 3 or more of 11 chronic conditions randomized to the ET intervention or an attention control group for a full year. The goals of the intervention were to help older adults manage their chronic conditions (in part by providing their primary care team with insights about their ongoing health status) and to connect them with peers for social support. A previous iteration of ET yielded positive effects on socioemotional outcomes of mental QOL, social support, and depression among those with high levels of primary care use [27]. The current iteration leaned into this finding, with system enhancements designed to connect participants with their primary care team and to strengthen peer interactions and pleasurable aspects of the site.

Consistent with the findings for the earlier version of ET, the current ET version showed signs of improving socioemotional outcomes. There was a significant effect of ET (vs control) on improvements over the 12-month intervention period regarding the primary outcome of mental QOL, as well as a significant study arm × sex interaction, indicating stronger effects for women than men. There was a significant moderated effect of ET on improvements over the 12-month intervention period in the primary outcome of psychological well-being, again indicating stronger effects for women than men. There was a significant effect on improvements over 6 months in relatedness, which was our hypothesized mediator variable that assessed feelings of social support, love, and connectedness.

As such, even though we did not find the predicted effects on the primary outcome of loneliness, ET relative to an attention control group showed socioemotional benefits for older adults with MCCs. We acknowledge that the 3 socioemotional primary outcome variables (mental QOL, psychological well-being, and loneliness) were more strongly correlated than we initially anticipated. Given that we had preregistered the analyses in our protocol paper and given that we continue to believe these are important and conceptually distinct variables, we have treated them as separate variables. However, it is important to note that doing so inflates the risk of type 1 errors across the set of outcomes, and therefore, the identified effects should be considered preliminary until replicated.

It is also important to acknowledge that the difference between study arms for mental QOL at 12 months was smaller than the benchmark for a clinically meaningful effect (benchmark = T-score difference of 3.0), both in the overall sample (difference=1.5) and for women (difference=2.6). Our analyses examining days of ET use predicted that the benchmark difference between study arms would occur with at least 167 days of app use over 6 months (or at least 93% of days), suggesting that while clinically meaningful effects for mental QOL may be possible, substantial engagement with ET would be needed. Possible strategies to foster sustained high levels of engagement are being examined in our subsequent ongoing RCT of ET. Our current iteration of ET is now being tested on smart displays as well as laptops, the content library is much larger, and we now have weekly video-chat "meet-ups." These meet-ups not only allow participants to interact with each other and build social connections but also provide opportunities for a trained moderator to highlight key aspects of ET and their uses.

Although participants' engagement with ET was markedly lower than our analyses suggest would be needed for clinically meaningful effects on mental QOL, it is noteworthy that the percentage of participants who were still using ET at the end of the year-long intervention (76.14%) was far higher than is typical for mental health apps. A 2019 review of 93 apps targeting emotional well-being, anxiety, or depression found median 30-day retention rates of 3.3%, with somewhat higher rates for 2 apps offering peer support (8.9%) [75]. A 2022 review of 56 mental health apps found that retention 7 days after download varied from 5.5% to 19% [76]. Although ET use was undoubtedly higher because participants were aware of being in a study, they were not required to use the app. The fact that they showed the most use of the tools for social engagement suggests that these forms of contact continued to have meaning and value for them across the year of the study.

In contrast to the effects on a subset of socioemotional outcomes, we found no significant effects of ET on any of our physical health outcomes. Due to insufficient EHR data, as described in Multimedia Appendix 1, we were unable to conduct planned analyses for participants' lab scores. However, there were no significant effects of ET on participants' physical QOL or the secondary outcome of "symptom distress" (eg, shortness of breath, bowel problems, cough, and weakness) or scheduled health care use. This lack of effects on physical outcomes is consistent with the weak mostly null effects yielded in a meta-analysis of 16 RCTs of in-person primary care interventions for multimorbidity [22] and is in contrast to the moderate effects on lab scores observed in a meta-analysis of digital telemedicine interventions [25], perhaps reflecting the fact that the latter interventions tended to engage medical care more directly and specifically (eg, via online tracking of blood pressure). On the other hand, those interventions found scant effects on patients' QOL.

Our expanded inclusion criteria meant that participants could have varied combinations of 11 chronic conditions. This was arguably a strength of the study, in that such diverse arrays are a key challenge of treating patients with multimorbid conditions. On the other hand, this design decision may also have contributed to the lack of effects on physical outcomes and the relatively weak effects on mental QOL, in that some patients' chronic conditions need not have been particularly onerous. A patient could have high blood pressure, high cholesterol, and a BMI over 30 without feeling much incentive to engage with the health-related aspects of the intervention and without much impact on their ability to engage in social activities. Although, as shown in Multimedia Appendix 1, the majority of participants in both study arms had EHR diagnoses of chronic pain or arthritis, there were signs that patients did not see themselves as incapacitated and that many had active social lives. In exit interviews, participants made comments such as, "If I had more medical problems, this could be more helpful. But I am pretty healthy" and "I don't have any chronic aches or pains, nothing constant that bothers me. I think this doesn't apply to me." Others made comments about their high levels of social engagement as a reason for not needing the interactions offered by ET (eg, "I'm not a shut-in. We're very active, do lots of things with family, don't need interaction with other people that much"). In our current RCT of a subsequent iteration of ET, we are focused on older adults with at least 5 (rather than 3) chronic conditions to probe whether there are indeed stronger effects for patients with more complex sets of conditions.

It is also possible that the effects of ET were reduced by the overlap of the study with the pandemic. A key component of ET was the health tracking survey and the ensuing clinician report. The goals of the clinician report were to not only flag potential issues for health care providers (eg, recent falls could signal important health risks) but also open conversations during appointments about issues, such as sleep, diet, or mood, that may not be primary concerns for clinicians in the context of more urgent medical indicators but that may affect patients' physical and socioemotional QOL. As clinic visits ceased and clinical staff were triaging the crises of the pandemic, the potential for such expansive conversations decreased, even though we adapted to send clinics a summary of their patients' health tracker responses. However, despite the intuitive appeal of the pandemic as a potential limiting factor, we found no indication that days of overlap with the pandemic moderated the effects of the study arm for either physical or socioemotional outcomes. Approximately half of the sample who completed the 12-month intervention period prior to the pandemic did not appear to respond differently than those who overlapped with the pandemic.

It is also worth noting that these analyses leave the pattern of stronger effects for women (vs men) unexplained. One possibility is that there were sex differences in the types of messages posted and received on ET and that this had implications for participants' socioemotional outcomes. A 2020 meta-analysis found that women were more likely than men to give social support in online communities (eg, social networking sites) and were also slightly more likely than men to receive social support [77]. This pattern of sex differences was also observed in a CHESS intervention for alcohol use disorder [78]. Moreover, giving and receiving social support via the discussion groups in CHESS interventions was previously found to predict more positive outcomes: improved mental well-being in a CHESS intervention for women with breast cancer [79] and reduced drinking in a CHESS intervention for alcohol use disorder [80]. Further work is needed with the current data set to code the types of online interactions that took place on ET and to assess how they may have contributed to socioemotional outcomes.

Limitations

We have already alluded to several limitations, including the issues of multiple primary outcomes potentially inflating type 1 error and the lack of EHR lab data. The latter issue means that this is a study of the effects of ET on older adults' perceptions of their physical status, rather than a study of whether the intervention could induce sufficient behavioral changes to be reflected in participants' physical health indicators. While our focus was more on participants' QOL than lab scores, as evidenced by our choice of primary versus secondary outcomes, this nonetheless leaves an important question about physical effects to be answered by further work.

As noted in the Methods section, we lost the 18-month follow-up timepoint, given our ethics-based decision to allow participants during the pandemic to continue their use of ET beyond the 12-month study period. The goal of the follow-up period is, of course, to assess whether any effects observed during the intervention period endure even after the intervention ends. While we acknowledge the loss of these insights, we also note that they may be less critical than for other types of interventions. Unlike interventions that are highly burdensome for clinicians or that involve biomedical procedures, the online accessibility of ET resources could potentially be an ongoing open-ended opportunity for patients, rather than coming to an end once a "dose" is completed.

Perhaps a more substantive limitation was the lack of data about the clinician report. We originally intended to gather both quantitative and qualitative data from primary care clinicians to gain insights into the ways they did (or did not) engage with patients' health tracking data. Given the effort involved in making sure that clinicians received the relevant report in a timely manner before a patient's appointment, it would have been useful to understand the results of those efforts. This was intended to be an intervention implemented within primary care. It is possible that the benefits could be observed even in the absence of engaging directly with clinics, simply by encouraging participants to reflect on their health tracking data and to use their EHRs or clinic visits to flag changes over time that mattered to them. The relatively high sustained rates of engagement with the tracker suggested that participants found some utility, but we did not obtain their ratings of the helpfulness of the tracker or the associated clinician report. Measures of patient perceptions of the intervention or the 6- and 12-month participant surveys would have helped us assess the value of the feature and determine possible improvements for future interventions.

Finally, it is important to highlight that participants were all located in Wisconsin and were mainly white (92.2%), with at least some education beyond high school (78.8%), limiting the generalizability of the results. This limitation reflected our focus on implementing ET into primary care and our goal of using EHR data to assess physical outcomes. The complexity of engaging with clinics and accessing EHR data limited the number of clinics that participated and restricted us to 1 health care organization. A possible solution is to prioritize the accessibility of ET over the as-yet-unknown benefits of trying to implement ET within specific primary care clinics. In our ongoing RCT, we have made that trade-off by recruiting participants via television and social media rather than through specific clinics, allowing us to recruit a more diverse sample.

Conclusions

This study extends our prior findings by focusing exclusively on the growing complex population of older adults coping with MCCs. The current findings continue to support the value of ET for patients' socioemotional outcomes, with less impact on physical outcomes. Subsequent RCTs of ET are underway with (1) older adults experiencing chronic pain and (2) older adults with 5 or more chronic conditions for whom there may indeed be greater decrements to physical and mental QOL, with content more explicitly focused on addressing their serious health-related needs.

Acknowledgments

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Conflicts of Interest

DHG Sr has a small shareholder interest in CHESS Health, a corporation that develops health care technology for patients and family members struggling with addiction; this relationship is managed by DHG and the UW–Madison's Conflict of Interest Committee. The authors have no other disclosures to report.

Multimedia Appendix 1
Additional prespecified analyses: secondary and exploratory outcomes.
[DOCX File , 261 KB - aging_v7i1e59588_app1.docx]

Multimedia Appendix 2

ElderTree system samples.
[DOCX File , 754 KB - aging_v7i1e59588_app2.docx]

Multimedia Appendix 3
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 983 KB - aging_v7i1e59588_app3.pdf]

Multimedia Appendix 4
Breakdown of chronic conditions by group.
[DOCX File , 42 KB - aging_v7i1e59588_app4.docx]

References

1. GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet 2020 Oct 17;396(10258):1204-1222 [FREE Full text] [doi: 10.1016/S0140-6736(20)30925-9] [Medline: 33069326]
2. Gomis-Pastor M, Roig Mingell E, Mirabet Perez S, Brossa Loidi V, Lopez Lopez L, Diaz Bassons A, et al. Multimorbidity and medication complexity: New challenges in heart transplantation. Clin Transplant 2019 Oct;33(10):e13682. [doi: 10.1111/ctr.13682] [Medline: 31368585]
3. Juul-Larsen HG, Christensen LD, Bandholm T, Andersen O, Kallemose T, Jørgensen L, et al. Patterns of multimorbidity and differences in healthcare utilization and complexity among acutely hospitalized medical patients (≥65 years) - A latent class approach. Clin Epidemiol 2020;12:245-259 [FREE Full text] [doi: 10.2147/CLEP.S226586] [Medline: 32184671]
4. Sturmberg JP, Getz LO, Stange KC, Upshur REG, Mercer SW. Beyond multimorbidity: What can we learn from complexity science? J Eval Clin Pract 2021 Oct;27(5):1187-1193. [doi: 10.1111/jep.13521] [Medline: 33588522]
5. Kuipers SJ, Nieboer AP, Cramm JM. Easier said than done: healthcare professionals' barriers to the provision of patient-centered primary care to patients with multimorbidity. Int J Environ Res Public Health 2021 Jun 04;18(11):6057 [FREE Full text] [doi: 10.3390/ijerph18116057] [Medline: 34199866]
6. Soley-Bori M, Ashworth M, Bisquera A, Dodhia H, Lynch R, Wang Y, et al. Impact of multimorbidity on healthcare costs and utilisation: a systematic review of the UK literature. Br J Gen Pract 2021 Jan;71(702):e39-e46 [FREE Full text] [doi: 10.3399/bjgp20X713897] [Medline: 33257463]
7. Sum G, Hone T, Atun R, Millett C, Suhrcke M, Mahal A, et al. Multimorbidity and out-of-pocket expenditure on medicines: a systematic review. BMJ Glob Health 2018;3(1):e000505 [FREE Full text] [doi: 10.1136/bmjgh-2017-000505] [Medline: 29564155]
8. Bähler C, Huber CA, Brüngger B, Reich O. Multimorbidity, health care utilization and costs in an elderly community-dwelling population: a claims data based observational study. BMC Health Serv Res 2015 Jan 22;15:23 [FREE Full text] [doi: 10.1186/s12913-015-0698-2] [Medline: 25609174]
9. Sheehan OC, Leff B, Ritchie CS, Garrigues SK, Li L, Saliba D, et al. A systematic literature review of the assessment of treatment burden experienced by patients and their caregivers. BMC Geriatr 2019 Oct 11;19(1):262 [FREE Full text] [doi: 10.1186/s12877-019-1222-z] [Medline: 31604424]
10. Buja A, Rivera M, De Battisti E, Corti MC, Avossa F, Schievano E, et al. Multimorbidity and hospital admissions in high-need, high-cost elderly patients. J Aging Health 2020;32(5-6):259-268. [doi: 10.1177/0898264318817091] [Medline: 30522388]
11. Makovski TT, Schmitz S, Zeegers MP, Stranges S, van den Akker M. Multimorbidity and quality of life: Systematic literature review and meta-analysis. Ageing Res Rev 2019 Aug;53:100903. [doi: 10.1016/j.arr.2019.04.005] [Medline: 31048032]
12. She R, Yan Z, Jiang H, Vetrano DL, Lau JTF, Qiu C. Multimorbidity and health-related quality of life in old age: role of functional dependence and depressive symptoms. J Am Med Dir Assoc 2019 Sep;20(9):1143-1149. [doi: 10.1016/j.jamda.2019.02.024] [Medline: 30979676]
13. Triolo F, Harber-Aschan L, Belvederi Murri M, Calderón-Larrañaga A, Vetrano DL, Sjöberg L, et al. The complex interplay between depression and multimorbidity in late life: risks and pathways. Mech Ageing Dev 2020 Dec;192:111383 [FREE Full text] [doi: 10.1016/j.mad.2020.111383] [Medline: 33045250]
14. Qiao Y, Liu S, Zhang Y, Wu Y, Shen Y, Ke C. Bidirectional association between depression and multimorbidity in middle-aged and elderly Chinese adults: a longitudinal cohort study. Aging Ment Health 2022 Apr;26(4):784-790. [doi: 10.1080/13607863.2021.1877609] [Medline: 33512250]
15. Hajek A, Kretzler B, König H. Multimorbidity, loneliness, and social isolation. a systematic review. Int J Environ Res Public Health 2020 Nov 23;17(22):8688 [FREE Full text] [doi: 10.3390/ijerph17228688] [Medline: 33238506]
16. Boersma P, Black LI, Ward BW. Prevalence of multiple chronic conditions among US adults, 2018. Prev Chronic Dis 2020 Sep 17;17:E106 [FREE Full text] [doi: 10.5888/pcd17.200130] [Medline: 32945769]

17. Boyd CM, Fortin M. Future of multimorbidity research: how should understanding of multimorbidity inform health system design? Public Health Rev 2010 Dec 10;32(2):451-474. [doi: 10.1007/BF03391611]
18. Roland M, Paddison C. Better management of patients with multimorbidity. BMJ 2013 May 02;346:f2510. [doi: 10.1136/bmj.f2510] [Medline: 23641032]
19. Boyd CM, Darer J, Boult C, Fried LP, Boult L, Wu AW. Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance. JAMA 2005 Aug 10;294(6):716-724. [doi: 10.1001/jama.294.6.716] [Medline: 16091574]
20. Guthrie B, Payne K, Alderson P, McMurdo MET, Mercer SW. Adapting clinical guidelines to take account of multimorbidity. BMJ 2012 Oct 04;345:e6341 [FREE Full text] [doi: 10.1136/bmj.e6341] [Medline: 23036829]
21. Behavioral interventions to address multiple chronic health conditions in primary care (Funding Opportunity Announcement [FOA] No. PA-14-114). US Department of Health and Human Services. URL: https://grants.nih.gov/grants/guide/pa-files/PA-14-114.html [accessed 2024-11-11]
22. Smith SM, Wallace E, Clyne B, Boland F, Fortin M. Interventions for improving outcomes in patients with multimorbidity in primary care and community setting: a systematic review. Syst Rev 2021 Oct 20;10(1):271 [FREE Full text] [doi: 10.1186/s13643-021-01817-z] [Medline: 34666828]
23. Garvey J, Connolly D, Boland F, Smith SM. OPTIMAL, an occupational therapy led self-management support programme for people with multimorbidity in primary care: a randomized controlled trial. BMC Fam Pract 2015 May 12;16:59 [FREE Full text] [doi: 10.1186/s12875-015-0267-0] [Medline: 25962515]
24. O'Toole L, Connolly D, Boland F, Smith SM. Effect of the OPTIMAL programme on self-management of multimorbidity in primary care: a randomised controlled trial. Br J Gen Pract 2021 Apr;71(705):e303-e311 [FREE Full text] [doi: 10.3399/bjgp20X714185] [Medline: 33685920]
25. Kraef C, van der Meirschen M, Free C. Digital telemedicine interventions for patients with multimorbidity: a systematic review and meta-analysis. BMJ Open 2020 Oct 13;10(10):e036904 [FREE Full text] [doi: 10.1136/bmjopen-2020-036904] [Medline: 33051232]
26. Gustafson DH, Mares M, Johnston DC, Mahoney JE, Brown RT, Landucci G, et al. A web-based eHealth intervention to improve the quality of life of older adults with multiple chronic conditions: protocol for a randomized controlled trial. JMIR Res Protoc 2021 Feb 19;10(2):e25175 [FREE Full text] [doi: 10.2196/25175] [Medline: 33605887]
27. Gustafson DH, Kornfield R, Mares M, Johnston DC, Cody OJ, Yang EF, et al. Effect of an eHealth intervention on older adults' quality of life and health-related outcomes: a randomized clinical trial. J Gen Intern Med 2022 Feb;37(3):521-530 [FREE Full text] [doi: 10.1007/s11606-021-06888-1] [Medline: 34100234]
28. Maisto SA, Zywiak WH, Connors GJ. Course of functioning 1 year following admission for treatment of alcohol use disorders. Addict Behav 2006 Jan;31(1):69-79. [doi: 10.1016/j.addbeh.2005.04.008] [Medline: 15919159]
29. Godley MD, Godley SH, Dennis ML, Funk R, Passetti LL. Preliminary outcomes from the assertive continuing care experiment for adolescents discharged from residential treatment. J Subst Abuse Treat 2002 Jul;23(1):21-32. [doi: 10.1016/s0740-5472(02)00230-1] [Medline: 12127465]
30. Scherr D, Kastner P, Kollmann A, Hallas A, Auer J, Krappinger H, MOBITEL Investigators. Effect of home-based telemonitoring using mobile phone technology on the outcome of heart failure patients after an episode of acute decompensation: randomized controlled trial. J Med Internet Res 2009 Aug 17;11(3):e34 [FREE Full text] [doi: 10.2196/jmir.1252] [Medline: 19687005]
31. Davis JR, Glaros AG. Relapse prevention and smoking cessation. Addict Behav 1986;11(2):105-114. [doi: 10.1016/0306-4603(86)90034-1] [Medline: 3739795]
32. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003 Aug;26(1):1-7. [doi: 10.1207/S15324796ABM2601_01] [Medline: 12867348]
33. Shaw BR, Jeong Yeob H, Hawkins RP, McTavish FM, Gustafson DH. Communicating about self and others within an online support group for women with breast cancer and subsequent outcomes. J Health Psychol 2008 Oct;13(7):930-939 [FREE Full text] [doi: 10.1177/1359105308095067] [Medline: 18809644]
34. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol 2000 Jan;55(1):68-78. [doi: 10.1037//0003-066x.55.1.68] [Medline: 11392867]
35. Gustafson D, Wise M, Bhattacharya A, Pulvermacher A, Shanovich K, Phillips B, et al. The effects of combining Web-based eHealth with telephone nurse case management for pediatric asthma control: a randomized controlled trial. J Med Internet Res 2012 Jul 26;14(4):e101 [FREE Full text] [doi: 10.2196/jmir.1964] [Medline: 22835804]
36. Gustafson DH, Hawkins R, Boberg E, Pingree S, Serlin RE, Graziano F, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med 1999 Jan;16(1):1-9. [doi: 10.1016/s0749-3797(98)00108-1] [Medline: 9894548]
37. Gustafson DH, McTavish F, Hawkins R, Pingree S, Arora N, Mendenhall J, et al. Computer support for elderly women with breast cancer. JAMA 1998 Oct 21;280(15):1305. [doi: 10.1001/jama.280.15.1305] [Medline: 9794300]
38. Gustafson DH, Hawkins R, Pingree S, McTavish F, Arora NK, Mendenhall J, et al. Effect of computer support on younger women with breast cancer. J Gen Intern Med 2001 Jul;16(7):435-445 [FREE Full text] [doi: 10.1046/j.1525-1497.2001.016007435.x] [Medline: 11520380]

39. Gustafson DH, Hawkins R, McTavish F, Pingree S, Chen WC, Volrathongchai K, et al. Internet-based interactive support for cancer patients: Are integrated systems better? J Commun 2008 Jun;58(2):238-257 [FREE Full text] [doi: 10.1111/j.1460-2466.2008.00383.x] [Medline: 21804645]
40. Gustafson DH, McTavish FM, Chih M, Atwood AK, Johnson RA, Boyle MG, et al. A smartphone application to support recovery from alcoholism: a randomized clinical trial. JAMA Psychiatry 2014 May;71(5):566-572 [FREE Full text] [doi: 10.1001/jamapsychiatry.2013.4642] [Medline: 24671165]
41. Gustafson DH, DuBenske LL, Namkoong K, Hawkins R, Chih M, Atwood AK, et al. An eHealth system supporting palliative care for patients with non-small cell lung cancer: a randomized trial. Cancer 2013 May 01;119(9):1744-1751 [FREE Full text] [doi: 10.1002/cncr.27939] [Medline: 23355273]
42. Diener E, Wirtz D, Tov W, Kim-Prieto C, Choi D, Oishi S, et al. New well-being measures: Short scales to assess flourishing and positive and negative feelings. Soc Indic Res 2009 May 28;97(2):143-156. [doi: 10.1007/s11205-009-9493-y]
43. Phillips DM, Finkel D, Petkus AJ, Muñoz E, Pahlen S, Johnson W, et al. Longitudinal analyses indicate bidirectional associations between loneliness and health. Aging Ment Health 2023 Jun;27(6):1217-1225 [FREE Full text] [doi: 10.1080/13607863.2022.2087210] [Medline: 35699236]
44. Corno D, Burns RJ. Loneliness and functional limitations among older adults with diabetes: Comparing directional models. J Psychosom Res 2022 Mar;154:110740. [doi: 10.1016/j.jpsychores.2022.110740] [Medline: 35114603]
45. Cleveland Clinic. URL: https://health.clevelandclinic.org/ [accessed 2024-11-11]
46. National Institute on Aging. URL: https://www.nia.nih.gov/ [accessed 2024-11-11]
47. Family Doctor (American Academy of Family Physicians). URL: https://familydoctor.org/ [accessed 2024-11-11]
48. Mayo Clinic. URL: https://www.mayoclinic.org/patient-care-and-health-information [accessed 2024-11-09]
49. Kruglanski A, Higgins E. Social Psychology: Handbook of Basic Principles (2nd edition). New York, NY: Guilford Press; 2007.
50. Edelman C, Kudzma E, Mandle C. Health Promotion Throughout the Life Span. Maryland Heights, Missouri: Mosby; 2013.
51. Ryan P. Integrated Theory of Health Behavior Change: background and intervention development. Clin Nurse Spec 2009;23(3):161-70; quiz 171 [FREE Full text] [doi: 10.1097/NUR.0b013e3181a42373] [Medline: 19395894]
52. Aycock DM, Hayat MJ, Helvig A, Dunbar SB, Clark PC. Essential considerations in developing attention control groups in behavioral research. Res Nurs Health 2018 Jun;41(3):320-328. [doi: 10.1002/nur.21870] [Medline: 29906317]
53. Gustafson DH, Maus A, Judkins J, Dinauer S, Isham A, Johnson R, et al. Using the NIATx model to implement user-centered design of technology for older adults. JMIR Hum Factors 2016 Jan 14;3(1):e2 [FREE Full text] [doi: 10.2196/humanfactors.4853] [Medline: 27025985]
54. Gustafson DH, DuBenske LL, Atwood AK, Chih M, Johnson RA, McTavish F, et al. Reducing symptom distress in patients with advanced cancer using an e-alert system for caregivers: pooled analysis of two randomized clinical trials. J Med Internet Res 2017 Nov 14;19(11):e354 [FREE Full text] [doi: 10.2196/jmir.7466] [Medline: 29138131]
55. Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Arch Intern Med 2002 Nov 11;162(20):2269-2276. [doi: 10.1001/archinte.162.20.2269] [Medline: 12418941]
56. Hays RD, Bjorner JB, Revicki DA, Spritzer KL, Cella D. Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. Qual Life Res 2009 Sep;18(7):873-880 [FREE Full text] [doi: 10.1007/s11136-009-9496-9] [Medline: 19543809]
57. Barile JP, Reeve BB, Smith AW, Zack MM, Mitchell SA, Kobau R, et al. Monitoring population health for Healthy People 2020: evaluation of the NIH PROMIS® Global Health, CDC Healthy Days, and satisfaction with life instruments. Qual Life Res 2013 Aug;22(6):1201-1211 [FREE Full text] [doi: 10.1007/s11136-012-0246-z] [Medline: 23404737]
58. Global Health scoring manual: A brief guide to scoring the PROMIS Global Health instruments. HealthMeasures. URL: https://www.healthmeasures.net/images/PROMIS/manuals/Scoring_Manuals_/PROMIS_Global_Health_Scoring_Manual.pdf [accessed 2024-11-11]
59. Russell DW. UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure. J Pers Assess 1996 Feb;66(1):20-40. [doi: 10.1207/s15327752jpa6601_2] [Medline: 8576833]
60. Folkman S, Lazarus RS, Gruen RJ, DeLongis A. Appraisal, coping, health status, and psychological symptoms. J Pers Soc Psychol 1986 Mar;50(3):571-579. [doi: 10.1037//0022-3514.50.3.571] [Medline: 3701593]
61. Levesque CS, Williams GC, Elliot D, Pickering MA, Bodenhamer B, Finley PJ. Validating the theoretical structure of the Treatment Self-Regulation Questionnaire (TSRQ) across three different health behaviors. Health Educ Res 2007 Oct;22(5):691-702. [doi: 10.1093/her/cyl148] [Medline: 17138613]
62. Namkoong K, DuBenske LL, Shaw BR, Gustafson DH, Hawkins RP, Shah DV, et al. Creating a bond between caregivers online: effect on caregivers' coping strategies. J Health Commun 2012;17(2):125-140 [FREE Full text] [doi: 10.1080/10810730.2011.585687] [Medline: 22004055]
63. Patient-Reported Outcomes Measurement Information System (PROMIS): Emotional Support Scoring Manual. HealthMeasures. URL: https://www.healthmeasures.net/images/promis/manuals/PROMIS_Emotional_Support_Scoring_Manual.pdf [accessed 2024-11-11]

64. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med 2006 May 22;166(10):1092-1097. [doi: 10.1001/archinte.166.10.1092] [Medline: 16717171]
65. Kroenke K, Strine TW, Spitzer RL, Williams JBW, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. J Affect Disord 2009 Apr;114(1-3):163-173. [doi: 10.1016/j.jad.2008.06.026] [Medline: 18752852]
66. Holmes TH, Rahe RH. The social readjustment rating scale. J Psychosom Res 1967 Aug;11(2):213-218. [doi: 10.1016/0022-3999(67)90010-4] [Medline: 6059863]
67. Sloan J, Symonds T, Vargas-Chanes D, Fridley B. Practical guidelines for assessing the clinical significance of health-related quality of life changes within clinical trials. Drug Information J 2003 Dec 30;37(1):23-31. [doi: 10.1177/009286150303700105]
68. Weinert C, Cudney S, Hill WG. Rural women, technology, and self-management of chronic illness. Can J Nurs Res 2008 Sep;40(3):114-134 [FREE Full text] [Medline: 18947095]
69. Cohen J. Statistical Power Analysis for the Behavioral Sciences (Second Edition). Hillsdale, NJ: Lawrence Erlbaum Associates; 1988.
70. Bates D, Mächler M, Bolker B, Walker S. Fitting linear mixed-effects models using lme4. J Stat Soft 2015;67(1):1-48. [doi: 10.18637/jss.v067.i01]
71. Meaningful Change for PROMIS. HealthMeasures. URL: https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/meaningful-change [accessed 2024-11-11]
72. Terwee CB, Peipert JD, Chapman R, Lai J, Terluin B, Cella D, et al. Minimal important change (MIC): a conceptual clarification and systematic review of MIC estimates of PROMIS measures. Qual Life Res 2021 Oct;30(10):2729-2754 [FREE Full text] [doi: 10.1007/s11136-021-02925-y] [Medline: 34247326]
73. Marengoni A, Zucchelli A, Vetrano DL, Armellini A, Botteri E, Nicosia F, et al. Beyond chronological age: frailty and multimorbidity predict in-hospital mortality in patients with Coronavirus Disease 2019. J Gerontol A Biol Sci Med Sci 2021 Feb 25;76(3):e38-e45 [FREE Full text] [doi: 10.1093/gerona/glaa291] [Medline: 33216846]
74. Agrawal U, Azcoaga-Lorenzo A, Fagbamigbe AF, Vasileiou E, Henery P, Simpson CR, et al. Association between multimorbidity and mortality in a cohort of patients admitted to hospital with COVID-19 in Scotland. J R Soc Med 2022 Jan;115(1):22-30 [FREE Full text] [doi: 10.1177/01410768211051715] [Medline: 34672832]
75. Baumel A, Muench F, Edan S, Kane JM. Objective user engagement with mental health apps: systematic search and panel-based usage analysis. J Med Internet Res 2019 Sep 25;21(9):e14567 [FREE Full text] [doi: 10.2196/14567] [Medline: 31573916]
76. Kaveladze BT, Wasil AR, Bunyi JB, Ramirez V, Schueller SM. User experience, engagement, and popularity in mental health apps: secondary analysis of app analytics and expert app reviews. JMIR Hum Factors 2022 Jan 31;9(1):e30766 [FREE Full text] [doi: 10.2196/30766] [Medline: 35099398]
77. Tifferet S. Gender differences in social support on social network sites: A meta-analysis. Cyberpsychol Behav Soc Netw 2020 Apr;23(4):199-209. [doi: 10.1089/cyber.2019.0516] [Medline: 32096662]
78. Yoo W, Shah DV, Chih M, Gustafson DH. Predicting changes in giving and receiving emotional support within a smartphone-based alcoholism support group. Computers in Human Behavior 2018 Jan;78:261-272. [doi: 10.1016/j.chb.2017.10.006]
79. Yoo W, Namkoong K, Choi M, Shah DV, Tsang S, Hong Y, et al. Giving and receiving emotional support online: communication competence as a moderator of psychosocial benefits for women with breast cancer. Comput Human Behav 2014 Jan;30:13-22 [FREE Full text] [doi: 10.1016/j.chb.2013.07.024] [Medline: 24058261]
80. Liu Y, Kornfield R, Shaw BR, Shah DV, McTavish F, Gustafson DH. Giving and receiving social support in online substance use disorder forums: How self-efficacy moderates effects on relapse. Patient Educ Couns 2020 Jun;103(6):1125-1133 [FREE Full text] [doi: 10.1016/j.pec.2019.12.015] [Medline: 31901364]

Abbreviations

CHESS: Comprehensive Health Enhancement Support System
EHR: electronic health record
ET: ElderTree
MCCs: multiple chronic conditions
QOL: quality of life
RCT: randomized controlled trial
UC: usual care
UC+ET: usual care+ElderTree access (experimental condition)
UC+internet: usual care+internet access but no ElderTree (attention control condition)

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Age Variation Among US Adults' Social Media Experiences and Beliefs About Who Is Responsible for Reducing Health-Related Falsehoods: Secondary Analysis of a National Survey

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Abstract

Background: We live in a digital age where social media has become an essential part of people's lives. It is also one of the leading platforms responsible for spreading health-related falsehoods. This study explores who adults of different age groups perceive as responsible for reducing health-related falsehoods on social media.

Objective: Despite growing concern over older adults' exposure to false health information on social media, little research examines their beliefs on how to address the problem. This study examines how the age of US adults is associated with their reported experiences with health-related falsehoods on social media and their beliefs about who should be tasked with reducing such falsehoods.

Methods: This study is a secondary analysis of data from the 2022 Health Information National Trends Survey, a nationally representative survey of US adults (18 years and older). Multivariable logistic regressions estimated how a respondent's age was associated with their self-reported social media use, their difficulty to detect health-related falsehoods on social media, their discussion of health information found on social media with medical providers, and their beliefs regarding who should be responsible for reducing health-related falsehoods on social media. Regression estimates were adjusted for respondents' sociodemographic and health characteristics.

Results: Daily social media use decreased with respondents' age. Respondents aged 50 - 64 years (*b*=0.515, *P*=.01) and 65 - 74 years (*b*=0.697, *P*=.002) were more likely than respondents aged 18 - 34 years to report they strongly agree that it is difficult for them to detect health-related falsehoods on social media. Compared to younger adults, older adults (65 - 74 years: *b*=0.818, *P*=.002; 75 years and older: *b*=1.058, *P*<.001) were more likely to believe medical providers should be responsible for reducing online falsehoods.

Conclusions: In addition to ongoing efforts by social media platforms to detect and remove falsehoods, the findings suggest medical providers should be tasked with discrediting health-related falsehoods on social media for older adults. However, time during the clinical visit is limited. Future research is needed to discover new approaches and tools tailored to older adults to assist with filtering and discrediting health-related falsehoods on social media.

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KEYWORDS

social media; health misinformation; gray digital divide; United States; older adults; aging; health information; false information; falsehoods

Introduction

The COVID-19 pandemic heightened attention to concerns about the prevalence of false health-related information circulating on social media [1,2]. Of particular concern is exposure to falsehoods among older adults (≥65 years old), who generally have less experience with social media than younger adults [3]. Older adults are more inclined to interact with false information [4,5], perhaps due to their longer experience managing truths from both digital and nondigital news sources [6]. Compared to younger adults, older adults exhibit less confidence in discerning false information [7]. Altogether, this suggests older adults are more susceptible to harms stemming from health-related falsehoods on social media.

To reduce online falsehoods, various entities have adopted several measures, including the use of algorithms by social media companies to automatically detect falsehoods, but these are neither built nor deployed with older adults in mind [8,9]. Few studies examine the perspectives of older adults regarding their beliefs about the best ways to address falsehoods online. An exception is a Pew Research Center survey from 2021, in which older adults were the least likely to prefer social media platforms address online falsehoods [10]. However, it is unknown what older adults would prefer, especially given the COVID-19 pandemic potentially altering their adoption and use of information and communication technologies. To address this gap, we analyzed data collected in 2022 from a national sample of US adults to understand how respondents' age is associated with their social media experiences and their beliefs about the best way to address health-related falsehoods online. We discuss how the findings could be used to shape the policy-making process and to design interventions to assist older adults in filtering out falsehoods.

Methods

Sample

We derived data from the 2022 Health Information National Trends Survey (HINTS), a cross-sectional survey by the National Cancer Institute to document how noninstitutionalized US adults (≥18 years old) access and process health information. Complete survey design details are available elsewhere [11]. Briefly, the survey was fielded from March to November 2022 and included 6242 respondents, with a final weighted response rate of 28.1%.

The outcomes of interest, which broadly assessed experiences with and beliefs about falsehoods on social media, were asked only of respondents who reported social media use (n=4415). Among these respondents, most missing values were for the item asking respondents their race and ethnicity (n=439), which we accounted for by including an indicator for those with a missing response. Respondents with missing values on other measures were dropped from the analysis. The final analytic sample comprised 3941 respondents.

Measures

We analyzed three survey items to characterize respondents' experiences with social media and falsehoods. Daily social media users were identified as those who reported they visited a social media site "Almost every day." Self-reported difficulty to detect health-related falsehoods was measured using their level of agreement with the item, "I find it hard to tell whether health information on social media is true or false." Discussion of social media with medical providers was determined based on their level of agreement with the item, "I use information from social media in discussions with my health care provider." The latter two items were ordinal variables with four response options each. Because the proportional odds assumption was violated, to simplify the table summaries, we present results in the main text that compare those selecting the modal response option (assessment: strongly agree; discussion: strongly disagree) to all others (assessment: somewhat agree, somewhat disagree, strongly disagree; discussion: somewhat disagree, somewhat agree, strongly agree). Multimedia Appendix 1 includes full results using partial proportional odds models to analyze the outcomes in their original ordinal form. Conclusions about older adults from the simplified models shown in the text are the same as those drawn from analyses that address the violation via estimating partial proportional odds models.

A fourth item determined respondents' beliefs regarding who should reduce health-related falsehoods on social media. The question posed was, "Who do you think has the main responsibility for reducing the amount of false or misleading health information on social media?" The five response options included news media, social media platforms, government, individual users, and medical providers. The respondents were limited to select only one option.

Respondents' age was measured using categories (18 - 34, 35 - 49, 50 - 64, 65 - 74, and ≥75 years). We adjusted estimates based on respondents' sociodemographic and health background. These were measures of respondents' sex (male, female), race and ethnicity (Black, Latino, White, other, missing), education (high school or less, some college, college graduate, and postgraduate), relationship status (single, divorced/widowed/separated, and married/cohabitating), and self-rated health (excellent, very good, good, fair, poor).

Statistical Analyses

After characterizing the sample by examining frequencies and proportions, we estimated eight binary logit regressions to understand how respondents' age was associated with the outcomes of interest. The first three logit regressions estimated responses to items assessing participants' experiences with social media and health-related falsehoods. Because self-reported difficulty to detect falsehoods and discussion of social media information with providers may be less likely among more frequent social media users, we included being a daily social media user as a covariate for these regressions. The next five regressions estimated responses to the item assessing participants' beliefs about who should be responsible for reducing health-related falsehoods on social media. The item had five possible options, and thus each regression estimated the likelihood of selecting a given option. Because one possible option was social media companies, we included being a daily social media user as a covariate for these regressions. All regressions adjusted estimates based on covariates. All analyses were weighted (except for the calculation of frequencies) with survey weights provided by the HINTS methodologists to approximate the US adult population, which accounted for the sampling design and nonresponses. Analyses were performed with Stata 18. Statistical significance is defined as $P<.05$, determined by a 2-tailed t test.

Ethical Considerations

Ethics review for this study was waived because it is a secondary analysis of deidentified survey data.

Results

Sample Characteristics

Table 1 summarizes sample characteristics. Approximately 14.7% of the sample comprised older adults (≥65 years old). The majority of the sample (73.1%) reported daily usage of social media. Around 58.3% of the respondents reported they strongly disagree that they discuss social media with their health care provider, and around 28.8% of the respondents reported they strongly agree that it is difficult for them to detect health-related falsehoods on social media. When considering responsibility for addressing health-related falsehoods on social media, approximately 13.1% of the sample believed the news media should take responsibility, 34% felt social media platforms were responsible, around 15.5% assigned the responsibility to the government, 22.5% believed individual users of social media should take action, and 14.8% believed it should be medical providers.

Table . Sample characteristics.

Characteristic	Frequency, n (weighted %)[a]
Respondents reported they strongly agree that it is difficult for them to detect health-related falsehoods on social media	1338 (28.8)
Respondents reported they use social media daily	2771 (73.1)
Respondents reported they strongly disagree that they discuss social media information with health care practitioners	2312 (58.3)
Who should reduce falsehoods	
News media	473 (13.1)
Social media platforms	1452 (34)
Government	578 (15.5)
Individual users	843 (22.5)
Medical providers	595 (14.8)
Sex	
Female	2474 (53.2)
Male	2176 (46.8)
Age (years)	
18 - 34	747 (29)
35 - 49	966 (29)
50 - 64	1181 (27.3)
65 - 74	728 (10)
≥75	319 (4.7)
Education	
High school or less	782 (25.1)
Some college	1157 (39.6)
College graduate	1175 (20.3)
Postgraduate	827 (15)
Race and ethnicity	
White	2183 (59.3)
Black	603 (11.1)
Latino	704 (17.3)
Other	348 (10.5)
Missing	103 (1.8)
Self-rated health is excellent, very good, or good	3295 (84.4)
Relationship status	
Single	821 (32.4)
Divorced, widowed, or separated	951 (10.1)
Married or cohabitating	2169 (57.5)

[a] Weighted frequencies were calculated using the weighted averages provided by the Health Information National Trends Survey.

Logit Regressions

The binary logit regressions estimating how respondents’ age was associated with their experiences with social media and health-related falsehoods are shown in Table 2. Older adults were significantly less likely to use social media daily than 18-34 year olds (65-74 year olds: b=−1.603, P<.001; ≥75 year olds: b=−1.427, P<.001). Adults aged 35-49 years were significantly more likely than those aged 50 to ≥75 years to strongly disagree they discuss social media with their health care provider (b=0.309, P=.04). Adults aged 50-74 years old were significantly more likely than 18-34 year olds to strongly agree that it is difficult for them to detect health-related falsehoods on social media (50-64 years olds: b=0.515, P=.01; 65-74 years olds: b=0.697, P=.002).

Table . Binary logit regression predicting experiences with social media and falsehoods online.

	Respondents who reported they use social media daily			Respondents who reported they strongly disagree that they discuss social media information with health care practitioners			Respondents who reported they strongly agree that it is difficult for them to detect health-related falsehoods on social media		
Variable	*b*[a]	SE	*P* value	*b*	SE	*P* value	*b*	SE	*P* value
Female (vs male)	0.283	0.128	.03	−0.070	0.116	.55	0.198	0.154	.20
Age (years; vs 18-34 years)									
35-49	−0.953	0.223	<.001	0.309	0.149	.04	0.140	0.148	.35
50-64	−1.106	0.213	<.001	−0.100	0.150	.51	0.515	0.194	.01
65-74	−1.603	0.274	<.001	0.118	0.138	.40	0.697	0.211	.002
≥75	−1.427	0.262	<.001	−0.011	0.205	.96	0.422	0.235	.08
Race and ethnicity (vs White)									
Black	−0.342	0.192	.08	0.042	0.174	.81	−0.264	0.186	.16
Latino	0.170	0.198	.40	−0.287	0.152	.06	−0.289	0.147	.054
Other	−0.194	0.189	.31	−0.257	0.187	.18	−0.308	0.196	.12
Missing	−0.636	0.321	.053	0.438	0.291	.14	0.633	0.375	.10
Education (vs high school or less)									
Some college	0.299	0.166	.08	−0.038	0.157	.81	0.358	0.161	.03
College graduate	0.189	0.177	.29	−0.189	0.157	.23	0.383	0.166	.82
Postgraduate	−0.074	0.181	.68	−0.243	0.176	.17	−0.418	0.195	.04
Relationship status (vs single)									
Divorced, widowed, or separated	−0.037	0.165	.82	0.269	0.170	.12	0.203	0.221	.36
Married or cohabitating	0.083	0.154	.56	0.129	0.155	.41	0.028	0.175	.87
Daily social media use	—[b]	—	—	−0.331	0.124	.01	−0.243	0.138	.86
Self-rated health is excellent, very good, and good	0.088	0.149	.56	−0.024	0.181	.90	0.234	0.160	.15

[a] *b*: sample regression coefficient.

[b] As being a daily social media user was a covariate and the regression was between daily social media users against daily social media users, this did not generate any values.

Table 2 also shows that, compared to respondents with high school or less education, postgraduates were less likely to strongly agree that it is difficult to detect health-related falsehoods on social media (b=−0.418, P=.04), while those with some college education were more likely to agree (b=0.358, P=.03). This pattern does not hold in the supplemental analyses in Multimedia Appendix 1.

Table 3 summarizes binary logit regressions estimating how respondents’ age was associated with their beliefs about who should be responsible for reducing health-related falsehoods on social media. Respondents aged 75 years and older were significantly less likely than 18‐34 year olds to believe individual users are responsible for reducing online falsehoods (*b*=−0.888, *P*<.001). Compared to 18‐34 year olds, older adults were significantly more likely to believe medical providers were responsible (65‐74 year olds: *b*=0.818, *P*=.002; ≥75 year olds: *b*=1.058, *P*<.001). Respondents' ages were unrelated to the likelihood of selecting any of the other three entities (news media, social media platforms, government) as responsible.

Table . Binary logit regressions predicting beliefs about who should reduce falsehoods online.

	News media			Social media platforms			Government			Individual users			Medical providers		
Variable	*b*[a]	SE	*P* value	*b*	SE	*P* value	*b*	SE	*P* value	*b*	SE	*P* value	*b*	SE	*P* value
Female (vs male)	0.079	–0.19	.68	0.083	–0.117	.48	–0.109	–0.183	.55	–0.254	–0.139	.07	0.253	–0.173	.15
Age (years; vs 18 - 34)															
35 - 49	–0.188	–0.29	.52	0.079	–0.178	.66	–0.102	–0.204	.62	0.1	–0.183	.59	–0.044	–0.259	.87
50 - 64	–0.061	–0.263	.82	–0.012	–0.187	.95	0.078	–0.216	.72	–0.251	–0.185	.18	0.355	–0.198	.08
65 - 74	–0.405	–0.273	.14	0.25	–0.195	.21	–0.492	–0.266	.07	–0.464	–0.235	.054	0.818	–0.254	.002
≥75	0.084	–0.307	.79	–0.138	–0.208	.51	–0.008	–0.341	.98	–0.888	–0.888	<.001	1.058	–0.223	<.001
Race and ethnicity (vs White)															
Black	–0.004	–0.252	.99	–0.229	–0.153	.14	0.52	–0.267	.06	–0.213	–0.208	.31	0.12	–0.24	.62
Latino	0.08	–0.222	.72	–0.134	–0.165	.42	0.607	–0.243	.02	–0.161	–0.196	.42	–0.332	–0.253	.20
Other	–0.196	–0.24	.42	–0.332	–0.214	.13	0.5	–0.254	.054	–0.007	–0.27	.98	0.224	–0.524	.67
Missing	–0.926	–0.475	.06	–0.136	–0.338	.69	0.845	–0.413	.046	0.255	–0.576	.66	–0.363	–0.43	.40
Education (versus high school or less)															
Some college	–0.315	–0.256	.22	–0.32	–0.136	.02	0.072	–0.2	.72	0.575	–0.2	.006	0.107	–0.225	.64
College graduate	–0.67	–0.232	.006	–0.035	–0.152	.82	–0.045	–0.204	.83	0.65	–0.222	.005	–0.103	–0.233	.66
Post graduate	–0.766	–0.27	.007	0.675	–0.186	.72	–0.081	–0.223	.72	0.687	–0.186	.001	–0.275	–0.204	.18
Relationship status (versus single)															
Divorced, widowed, or separated	–0.113	–0.269	.68	0.205	–0.166	.22	–0.037	–0.21	.09	0.164	–0.207	.43	–0.457	–0.247	.07
Married or cohabitating	–0.087	–0.241	.72	0.497	–0.14	.72	–0.083	–0.195	.67	0.264	–0.171	.13	–0.292	–0.172	.10
Daily social media user	–0.254	–0.185	.18	0.145	–0.129	.27	0.131	–0.17	.44	–0.09	–0.147	.54	–0.025	–0.185	.90
Self-rated health is excellent, very good, and good	0.144	–0.202	.48	0.114	–0.16	.48	–0.383	–0.224	.09	0.184	–0.204	.37	–0.108	–0.19	.57

[a]b: sample regression coefficient.

Table 3 shows additional demographic patterns that were unrelated to our focus on age, but warrant detailing. Among these include educational differences. Specifically, college graduates (b=−0.670, P=.006) and postgraduates (b=−0.766, P=.007) were less likely than those with high school degree or less to feel that news media should be held responsible. Individuals reporting some college (b=0.575, P=.006), college graduate (b=0.650, P=.005), and postgraduate (b=0.687, P=.001), were more likely than people with high school or less education to believe that individual users should be held responsible for reducing health-related falsehoods online.

Discussion

From the results, we see that adults aged 50 years or older reported that they strongly agree that it is difficult for them to detect health-related falsehoods on social media. Compared to younger adults (18-34 years old), older adults (≥65 years old) were more likely to believe medical providers should be responsible for reducing online falsehoods. Despite heightened scrutiny of the veracity of health information on social media during the COVID-19 pandemic, little research has examined the public's perspective on who should be held responsible for reducing the prevalence of falsehoods. In particular, such information would be useful from older adults because, compared to younger adults, they are both more likely to engage with falsehoods on social media and are less confident in deciphering its veracity [1,4-7,9]. We discuss implications stemming from our findings regarding the development of interventions to assist older adults with interpreting the health-related information they find on social media.

Consistent with other research [8,12], we found an age divide for who is likely to use social media. We found older adults were less likely to report using social media daily than younger adults. While the COVID-19 pandemic may have encouraged older adults to turn to social media for pandemic-related information [13-15], the age divide remains among US adults in 2022. This may be due to continued barriers faced among older adults to learn new information and communication technologies [15].

Despite the age divide in social media use, we found that some experiences with health-related information on social media were comparable between older and younger adults. We found older adults were just as likely as younger adults (18 - 34 years old) to discuss information they found on social media with health care providers. Overall, only 58% of the respondents reported they strongly disagree that they discuss health information found on social media with medical providers, likely due to concerns about feeling embarrassed or receiving disapproval from the provider [16]. Where we found differences was in the reported difficulty in detecting falsehoods. Specifically, older adults were more likely than younger adults to report they strongly agree that it is difficult for them to detect health-related falsehoods on social media. This is concerning, especially given other research showing older adults are the most likely to be exposed to falsehoods online [5]. Thus, although older adults are less frequent users of social media than younger adults, they tend to be exposed to more falsehoods and are also less confident in their ability to detect them. Such a concentration of falsehood exposure and difficulty detecting falsehoods warrants seeking interventions tailored to this population.

To begin to identify how to tailor interventions, we turn to our final set of findings. Regarding beliefs in who should be responsible for reducing health-related falsehoods on social media, we found older adults were more likely than younger adults to choose medical providers. The differences may be due to older adults exhibiting higher levels of trust in medical providers [17]. Older adults are also more likely to turn to medical providers for health information than their younger counterparts [18]. We also found adults who were aged 75 years and older were less likely than younger adults to believe individual users should be responsible for reducing online falsehoods. This may be due to age differences in confidence in detecting falsehoods, as well as the differences in digital and health literacy skills necessary to curate one's own social media experience [19]. We found no other associations between the respondents' age and the selection of any of the other three entities (news media, government, social media platforms). Altogether, these patterns suggest that, while the emphasis within the United States has been for social media platforms to reduce health-related falsehoods, medical providers may be key for designing interventions to assist older adults in identifying and debunking falsehoods.

Besides age, we found additional demographic variables were related to the outcomes studied. Results show that respondents with postgraduate, college graduate, and some college education are more likely than respondents with high school or less education to feel that individual users should be held responsible for reducing health-related falsehoods on social media. This could be in part because individuals who pursue higher education are more likely to exhibit prosocial behavior, which can be understood as an individual's responsibility to contribute to the social good [20]. We also see that college graduates and individuals with postgraduate education are less likely to feel that news media should be held responsible for removing health-related falsehoods online than respondents with a high school education or less. This could be due to people with a higher level of educational reporting they support freedom of the press, even if that means falsehoods can be published [21].

This study has a few limitations. Because this is a secondary analysis of survey data, and we are limited in the questions available, we cannot evaluate the mechanisms underlying why older adults prefer medical providers as being responsible for reducing falsehoods online. The questions of interest were only asked of those who are current social media users, and thus we cannot tell what the preferences are among those who do not currently use social media but may use it in the future. The analysis also relies on self-reported data, which may be subject to biases. Because the data are cross-sectional, we cannot distinguish age effects from cohort effects. Age effects refer to how a person's age can biologically influence their physical, cognitive, emotional, and social experiences, while cohort effects refer to how the era in which a group of individuals is born can influence their experiences, behaviors, and attitudes. From the results, we see that adults aged 50‐64 years and 65‐74 years were more likely than younger adults to report they strongly agree that it is difficult for them to detect health-related falsehoods on social media. This finding could be explained by an age effect, perhaps due to age-related cognitive and physical challenges, or a cohort effect because older adults are from a generation that grew up with no internet and no social media [22]. Lastly, the survey was only available in English and Spanish, thereby missing the preferences of those who speak other languages.

Despite these limitations, this study's findings shed light on targeted interventions for assisting older adults in filtering falsehoods from the health-related information they encounter on social media. Social media platforms have sought to combat falsehoods by implementing algorithms, moderation teams, and options for users to report posts, but falsehoods persist. Only 58% of respondents reported discussing what they found on social media with their medical providers, suggesting an opportunity to spend more time with the small percentage of older adults on social media to discuss the health-related information they encounter. However, time during the clinic visit is limited. Other research has explored how medical providers can present themselves on social media to appear credible and combat falsehoods by sharing their own advice [23], but this still requires time on behalf of the provider. New technological tools may be needed [24], such as a mobile app endorsed by medical providers for older adults to confirm the accuracy of the health information they encounter online. Future research is needed to identify how best to build on our findings to develop and test targeted interventions for older adults that identify and discredit online falsehoods.

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Data Availability

The Health Information National Trends data are publicly available from the National Cancer Institute [25].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Partial proportional odds model results.
[DOCX File, 28 KB - aging_v7i1e56761_app1.docx]

References

1. Wang Y, McKee M, Torbica A, Stuckler D. Systematic literature review on the spread of health-related misinformation on social media. Soc Sci Med 2019 Nov;240:112552. [doi: 10.1016/j.socscimed.2019.112552] [Medline: 31561111]
2. Cinelli M, Quattrociocchi W, Galeazzi A, et al. The COVID-19 social media infodemic. Sci Rep 2020 Oct 6;10(1):16598. [doi: 10.1038/s41598-020-73510-5] [Medline: 33024152]
3. Charness N, Boot WR. A grand challenge for psychology: reducing the age-related digital divide. Curr Dir Psychol Sci 2022;31(2):187-193. [doi: 10.1177/09637214211068144] [Medline: 35754678]
4. Brashier NM, Schacter DL. Aging in an era of fake news. Curr Dir Psychol Sci 2020 Jun;29(3):316-323. [doi: 10.1177/0963721420915872] [Medline: 32968336]
5. Grinberg N, Joseph K, Friedland L, Swire-Thompson B, Lazer D. Fake news on Twitter during the 2016 U.S. presidential election. Science 2019 Jan 25;363(6425):374-378. [doi: 10.1126/science.aau2706] [Medline: 30679368]
6. Munyaka INS, Hargittai E, Redmiles EM. Misinformation paradox: older adults are cynical about news media, but engage with it anyway. J Online Trust Saf 2022;1(4). [doi: 10.54501/jots.v1i4.62]
7. Scherer LD, Pennycook G. Who is susceptible to online health misinformation? Am J Public Health 2020 Oct;110(S3):S276-S277. [doi: 10.2105/AJPH.2020.305908] [Medline: 33001736]
8. Choudrie J, Banerjee S, Kotecha K, Walambe R, Karende H, Ameta J. Machine learning techniques and older adults processing of online information and misinformation: a covid 19 study. Comput Hum Behav 2021 Jun;119:106716. [doi: 10.1016/j.chb.2021.106716] [Medline: 34866770]
9. Seo H, Blomberg M, Altschwager D, Vu HT. Vulnerable populations and misinformation: a mixed-methods approach to underserved older adults' online information assessment. New Media Soc 2021 Jul;23(7):2012-2033. [doi: 10.1177/1461444820925041]
10. Mitchell A, Walker M. More Americans now say government should take steps to restrict false information online than in 2018. Pew Research Center. 2021. URL: https://www.pewresearch.org/short-reads/2021/08/18/more-americans-now-say-government-should-take-steps-to-restrict-false-information-online-than-in-2018 [accessed 2024-11-04]

11. Methodology reports | HINTS. National Institutes of Health. 2022. URL: https://hints.cancer.gov/data/methodology-reports.aspx [accessed 2024-11-04]
12. Anderson M, Perrin A. Tech adoption climbs among older adults. Pew Research Center. 2020. URL: https://www.pewresearch.org/internet/2017/05/17/tech-adoption-climbs-among-older-adults/ [accessed 2024-11-04]
13. Campos-Castillo C. Gender divides in engagement with COVID-19 information on the internet among U.S. older adults. J Gerontol B Psychol Sci Soc Sci 2021 Feb 17;76(3):e104-e110. [doi: 10.1093/geronb/gbaa133] [Medline: 32845009]
14. Lee S. Internet use and well-being of older adults before and during the COVID-19 pandemic: findings from European Social Survey. J Gerontol Soc Work 2024 Jan;67(1):96-113. [doi: 10.1080/01634372.2023.2217682] [Medline: 37246398]
15. Li W, Ornstein KA, Li Y, Liu B. Barriers to learning a new technology to go online among older adults during the COVID-19 pandemic. J Am Geriatr Soc 2021 Nov;69(11):3051-3057. [doi: 10.1111/jgs.17433] [Medline: 34409589]
16. Tan SSL, Goonawardene N. Internet health information seeking and the patient-physician relationship: a systematic review. J Med Internet Res 2017 Jan 19;19(1):e9. [doi: 10.2196/jmir.5729] [Medline: 28104579]
17. Murray B, McCrone S. An integrative review of promoting trust in the patient-primary care provider relationship. J Adv Nurs 2015 Jan;71(1):3-23. [doi: 10.1111/jan.12502] [Medline: 25113235]
18. Swoboda CM, Van Hulle JM, McAlearney AS, Huerta TR. Odds of talking to healthcare providers as the initial source of healthcare information: updated cross-sectional results from the Health Information National Trends Survey (HINTS). BMC Fam Pract 2018 Aug 29;19(1):146. [doi: 10.1186/s12875-018-0805-7] [Medline: 30157770]
19. Choukou MA, Sanchez-Ramirez DC, Pol M, Uddin M, Monnin C, Syed-Abdul S. COVID-19 infodemic and digital health literacy in vulnerable populations: a scoping review. Dig Health 2022;8:20552076221076927. [doi: 10.1177/20552076221076927] [Medline: 35223076]
20. Tendhar T, Mesquita P. Compassion education for prosocial behavior and well-being among college students. J Ment Health Soc Behav 2020;2(2):115. [doi: 10.33790/jmhsb1100115]
21. Eddy K. Most americans say a free press is highly important to society. Pew Research Center. 2024. URL: https://www.pewresearch.org/short-reads/2024/04/23/most-americans-say-a-free-press-is-highly-important-to-society/ [accessed 2024-11-04]
22. Vercruyssen A, Schirmer W, Geerts N, Mortelmans D. How “basic” is basic digital literacy for older adults? Insights from digital skills instructors. Front Educ 2023;8. [doi: 10.3389/feduc.2023.1231701]
23. Ferrell D, Campos-Castillo C. Factors affecting physicians’ credibility on Twitter when sharing health information: online experimental study. JMIR Infodemiol 2022;2(1):e34525. [doi: 10.2196/34525] [Medline: 37113807]
24. Swire-Thompson B, Lazer D. Public health and online misinformation: challenges and recommendations. Annu Rev Public Health 2020 Apr 2;41:433-451. [doi: 10.1146/annurev-publhealth-040119-094127] [Medline: 31874069]
25. Health Information National Trends Survey. National Cancer Institute. URL: https://hints.cancer.gov/ [accessed 2024-11-06]

Abbreviations

HINTS: Health Information National Trends Survey

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Advocating for Older Adults in the Age of Social Media: Strategies to Achieve Peak Engagement on Twitter

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Abstract

Background: Over the last decade, many organizations dedicated to serving the needs and interests of older adults have turned to social media platforms, such as Twitter, subsequently rebranded X, to improve the visibility of age-related issues. However, notwithstanding their growing digital presence and participation, minimal attention has been paid to the use of social media among these advocacy groups. To achieve policy change, advocacy organizations must first be able to engage and mobilize audiences.

Objective: Our study aims to elucidate how different tweet features affect the time it takes for posts uploaded by age advocacy organizations to reach peak engagement.

Methods: We collated 204,905 tweets from 53 age advocacy organizations posted over a 12-year period. The engagement score of each tweet was calculated by combining well-established metrics, namely likes, retweets, quote tweets, and replies. We ran Cox models with tweet features as predictors and time-to-peak engagement as the outcome. “Peak engagement” (event) refers to engagement scores above the 75th percentile, and “time” refers to months taken to reach peak engagement per tweet.

Results: Approximately 1 in 2 tweets (n=103,068, 50.3%) had either no hashtags or just 1 hashtag. Around two-thirds (n=131,220, 64%) of the tweets included a URL. Visual information was highly underused, with most tweets not including GIFs (n=204,202, 99.7%), videos (n=199,800, 97.5%), or photos (n=143,844, 70.2%). Roughly half (n=101,470, 49.5%) of the tweets contained mentions and 9.3% (n=19,009) of tweets were replies. Only 4.5% (n=9285) of tweets were quote tweets. Most tweets were uploaded in the afternoon (n=86,004, 42%) and on a weekday (n=180,499, 88.1%). As hypothesized, features associated with peak engagement were the inclusion of visual elements like photos, which increased peak engagement by 3 times ($P<.001$), and the use of 3 or more hashtags ($P<.001$). Quote tweets increased engagement by 3 times ($P<.001$), as compared to regular tweets, controlling for account-level covariates. Tweets from organizations with a higher tweet volume were 40% less likely to reach peak engagement ($P<.001$).

Conclusions: Social media as a networked platform has the potential to reach users on a global scale and at an exponential speed. Having uncovered the features that are more likely to reach peak engagement on Twitter, our study serves as an invaluable resource for age advocacy organizations in their movement to create a more age-inclusive world.

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KEYWORDS

age advocacy; social media engagement; older adults; ageism; data science

Introduction

Over the last decade, many organizations dedicated to serving the needs and interests of older adults have turned to social media platforms, such as Twitter, consequently rebranded as X, to improve the visibility of age-related issues. However, notwithstanding their growing digital presence and participation, minimal attention has been paid to the use of social media among these advocacy groups. To achieve policy change, advocacy organizations must first be able to engage and mobilize audiences. Our study elucidates how different tweet features affect the time it takes for posts uploaded by age advocacy organizations to reach peak engagement. We define “age advocacy” as the act of supporting or championing initiatives that address the needs of older adults.

The advent of social media has been profitable to advocacy groups for multiple reasons. First, although the visibility of a social movement was formerly determined by its ability to make headlines [1], social media has democratized the process of activism, allowing social actors to bypass the lack of attention received by a particular issue [2]. Second, the exchange of information via social media channels is not constrained by geographical barriers, thus enabling the rapid diffusion of information worldwide [1]. Third, social media platforms are a cost-effective means through which information can be transmitted and awareness of social issues heightened. Fourth, social media facilitates interaction between organizations and the public, thereby fostering sociopolitical discussion and participation [3].

When using social media, organizations typically set out to engage followers by uploading content that resonates with audiences [4] especially in view of the constant influx of information on the internet [5,6]. A well-engaged audience is essentially proof that a particular account has content which audiences find valuable and meaningful. Over the years, this concept of engagement has gained popularity across myriad disciplines, including marketing, psychology, communication, public relations, and organizational studies [3].

Twitter is a microblogging service home to over 300 million active users monthly [7]. Although originally viewed as an avenue for personal communication, the social media platform has since been used by academics, policy makers, and advocacy groups to access, share, and disseminate information [8]. Given the growing presence of age advocacy organizations on Twitter, this study looks at how different tweet features affect the time taken to reach peak engagement for posts uploaded by these organizations.

Both marketing experts and academics have conducted research on the features that promote user engagement on Twitter [9-15]. Although it is clear that adding photos and videos improves engagement [10,14], it remains a scholarly crux when the best time to post is [9,10,14,15], what the ideal number of hashtags to include is [11,12,14], and whether quote tweets drive engagement. There is, therefore, a need to ascertain which tweet features are linked to greater user engagement for content uploaded by age advocacy organizations specifically.

To date, only 1 study has explored the concept of engagement in relation to tweets uploaded by age advocacy organizations [16]. However, this study did not consider the time taken to reach peak engagement, which is important for several reasons. First, the time taken to hit peak engagement may be viewed by potential funders as a key performance indicator, which is a signal of the ability of an organization to retain the interest of its user base and consequently be eligible for further funding. Second, being able to reach peak engagement within a short period of time is vital if age advocacy organizations happen to be posting about time-sensitive issues.

From a conceptual angle, this study is significant in that it is one of the first to develop a framework that age advocacy organizations can use to optimize their social media posts for increased engagement. Existing studies have traced the origins of age advocacy in the United States [17] and have covered the need to advocate for older persons [18-24]. Research on web-based age advocacy, however, remains conspicuously absent, with most social media analyses in the gerontological field analyzing attitudes toward older persons [25-32]. From a practical angle, this study provides organizations with a road map to raise consciousness of age-related matters, which is especially pressing given the increasing proportion of older adults in populations worldwide [33]. By successfully engaging audiences, age advocacy organizations will be able to spur collective action and create policy change.

The tweet features examined in this study include the number of hashtags, URLs, and mentions present in the tweet; whether the tweet contains a GIF, photo, or video; whether the tweet is a “quote tweet”—a retweet with a comment added by the account—or a “reply”; the time of day the tweet was uploaded; and whether the tweet was uploaded on a weekday or the weekend.

We sought to test 4 hypotheses. First, in light of past findings that the inclusion of hashtags predicts the likelihood of a post to get retweeted [9,10,12], we hypothesized that tweets with more hashtags would be quicker to reach peak engagement (hypothesis 1). Second, in line with evidence that visual information is usually more stimulating than textual information [34,35], we hypothesized that tweets with GIFs, photos, or videos would be quicker to reach peak engagement than those without (hypothesis 2). Third, since followers of age advocacy organizations are likely to include scholars and policy makers who may value dialogue, input, or commentary [9,12,36,37], we hypothesized that quote tweets would be quicker to reach peak engagement (hypothesis 3). Finally, consistent with prior research, which finds higher tweet counts to be associated with negative engagement [9], we hypothesized that tweets uploaded by accounts with a higher tweet count would be slower to reach peak engagement (hypothesis 4).

Methods

Data Set

As few studies have looked at age advocacy organizations on Twitter, we first consolidated a list of organizations by referring to various sources [38-40]. Next, we checked whether these accounts had a presence on Twitter. To build a more comprehensive list of accounts, we looked through the list of followers of these accounts and identified other organizational accounts with large followings using a snowball sampling method. The organizations were eventually chosen based on the following inclusion criteria: (1) the organization was based in North America; (2) the organization was dedicated to serving the needs and interests of older persons specifically; and (3) the organization had at least 1000 followers. In total, there were 53 accounts (Multimedia Appendix 1).

We retrieved the data using the Twitter application programming interface (API) v2, which was accessed through Twitter’s Academic Research Product Track [41]. The v2 full-archive search allows for the programmatic access of public tweets from the complete archive dating back to the first tweet in March 2006, when the application was created. Relative to what was achievable with the standard v1.1 API, the v2 API grants users a higher monthly tweet cap and access to more precise filters [42].

Tweets collected (n=403,426) covered a period of 12 years, from July 17, 2009, to October 8, 2021, with the start date as the earliest date a particular tweet from any of the sampled accounts was uploaded and the end date a week after October 1, 2021, which was designated by the United Nations as the

International Day of Older Persons [43]. “Retweets” (n=118,454) were excluded since they are not original content. Similarly, tweets with zero engagement (n=80,065) were excluded, as our focus was to observe the time taken to reach peak engagement. Finally, due to glitches with the API during the period of data collection—there were inaccuracies in the number of “likes” received by certain tweets—a few posts (n=2) were excluded. The final data set comprised 204,905 tweets.

Tweet Features (Predictors and Covariates)

Similar to earlier work [9], we divided the tweet features into 2 categories: tweet-level (predictors) and account-level (covariates) features. The tweet-level features include the number of hashtags, URLs, and mentions present in the tweet; whether the tweet contains a GIF, photo or video; whether the tweet is a “quote tweet” or a “reply”; the time of day the tweet was uploaded; and the day—weekday or weekend—the tweet was uploaded. Following past literature [14], we divided the time of day based on CST into the following periods: morning (6 AM to 11:59 PM), afternoon (noon to 16:59 PM), evening (5 PM to 8:59 PM), and night (9 PM to 5:59 AM).

Account-level features, which served as covariates in our modeling, were consistent across all tweets belonging to a given account. These covariates included the number of followers, the number of accounts followed, the total number of tweets, and whether the account was “verified.” Except for the last variable, all skewed account-level variables were log transformed. Multimedia Appendix 2 contains a list of definitions of terms used on Twitter.

Time-to-Peak Engagement (Outcome)

Following Twitter’s data dictionary [44], we used “likes” (ie, the number of times a particular tweet has been liked by other Twitter users), “retweets” (ie, the number of times a particular tweet has been retweeted), “quote tweets” (ie, the number of times a particular tweet has been quoted by other Twitter users) and “replies” (ie, the number of times a particular tweet has been replied to) as a proxy for user engagement. Our measurement of engagement aligns with that of previous studies [9,10,12-14]. To model the temporal aspects of engagement, we applied methods from survival analysis [45,46], which involved operationalizing engagement as a time-to-event variable. “Peak engagement” (event) refers to engagement scores above the 75th percentile, and “time” refers to months taken to reach peak engagement per tweet.

Analytic Strategy

First, we performed Kaplan-Meier analyses to assess differences in engagement between categorical features—type of tweet and presence or absence of visual elements, such as photos, GIFs, videos, hashtags, URLs, and mentions. Respective curves were compared using the log-rank statistic. Second, we ran Cox regression models to identify the tweet features significantly associated with time-to-peak engagement, controlling for account-level variables. Since tweets from the same account contained identical account-level information, the independent assumption did not hold. To achieve a more robust variance, we set different user IDs as clusters [47]. Model 1 consisted of tweet-level features. Model 2 contained tweet-level features, controlling for account-level variables as covariates.

Ethical Considerations

Ethical approval was not deemed necessary, as all the data used were publicly available and anonymized.

Results

Descriptive Statistics

Approximately 1 in 2 tweets (n=103,068, 50.3%) had either no hashtags or just 1 hashtag. Around two-thirds (n=131,220, 64%) of the tweets included a URL. Visual information was highly underused, with most tweets not including GIFs (n=204,202, 99.7%), videos (n=199,800, 97.5%), or photos (n=143,844, 70.2%). Roughly half (n=101,470, 49.5%) of the tweets contained mentions, and 9.3% (n=19,009) of the tweets were replies. Only 4.5% (n=9285) of the tweets were quote tweets. Most tweets were uploaded in the afternoon (n=86,004, 42%) and on a weekday (n=180,499, 88.1%). Table 1 summarizes the descriptive statistics. With regard to engagement, the lowest score was 1, and the highest score was 18,558. The engagement score at the 75th percentile was 8. Of the 204,905 tweets, 48,103 received an engagement score above 8.

Table . Description of tweets (n=204,905) from 53 age advocacy organizations posted over 12 years.

Tweet-level variables		Values, n (%)[a]	F [b]	P value[c]
Number of hashtags			859.3	<.001
	0 or 1	103,068 (50.3)		
	2	53,336 (26.0)		
	≥3	48,501 (23.7)		
Number of URLs			137.5	<.001
	0	61,346 (29.9)		
	1	131,220 (64.0)		
	≥2	12,339 (6.0)		
Number of mentions			1252	<.001
	0	103,435 (50.5)		
	1	65,869 (32.2)		
	≥2	35,601 (17.4)		
GIF			701.2	<.001
	No	204,202 (99.7)		
	Yes	703 (0.3)		
Photo			11,540	<.001
	No	143,844 (70.2)		
	Yes	61,061 (29.8)		
Video			894.2	<.001
	No	199,800 (97.5)		
	Yes	5105 (2.5)		
Type of tweet			4800	<.001
	Original tweet	176,611 (86.2)		
	Quote tweet	9285 (4.5)		
	Reply	19,009 (9.3)		
Time of upload			498.2	<.001
	Afternoon	86,004 (42)		
	Evening	28,606 (14.0)		
	Morning	81,041 (39.6)		
	Night	9254 (4.5)		
Day of upload			132.1	<.001
	Weekday	180,499 (88.1)		
	Weekend	24,406 (11.9)		

[a] Percentages may not add up to 100 due to rounding.

[b] F refers to the F-statistic for the ANOVA test.

[c] P values are for the ANOVA test.

Kaplan-Meier Analysis: Differences in Engagement Across Tweet Features

We performed Kaplan-Meier analyses to examine differences in engagement across tweet features for 204,905 tweets posted over 146 months. Quote tweets achieved median engagement twice (log-rank test: χ^2=3820; P<.0001) as fast as regular tweets (Figure 1). Specifically, there was an engagement advantage of 65 months, meaning that on average, quote tweets achieved peak engagement 65 months faster than regular tweets. Regarding visual elements, tweets with photos reached 75th percentile engagement 2.5 times faster than tweets without photos (log-rank test: χ^2=1070; P<.0001), having an engagement advantage of 80 months (Figure 2). Similar results were observed for tweets containing GIFs (log-rank test: χ^2=1070; *P*<.0001) and videos (log-rank test: χ^2=8069; *P*<.0001) as compared to tweets without the respective features. Tweets with 3 or more hashtags had an engagement advantage of 14 months as compared to those with 2 hashtags (log-rank test: χ^2=2700; *P*<.0001). Similar patterns emerged for URLs and mentions. Tweets with 2 or more URLs achieved an engagement advantage of 14 months compared to tweets with 1 URL (log-rank test: χ^2=514; *P*<.0001). Conversely, tweets without mentions had greater engagement advantage than tweets with at least 1 mention (log-rank test: χ^2=850; *P*<.0001).

Figure 1. Engagement trajectories for 204,905 quote tweets, regular tweets, and replies posted over 12 years.

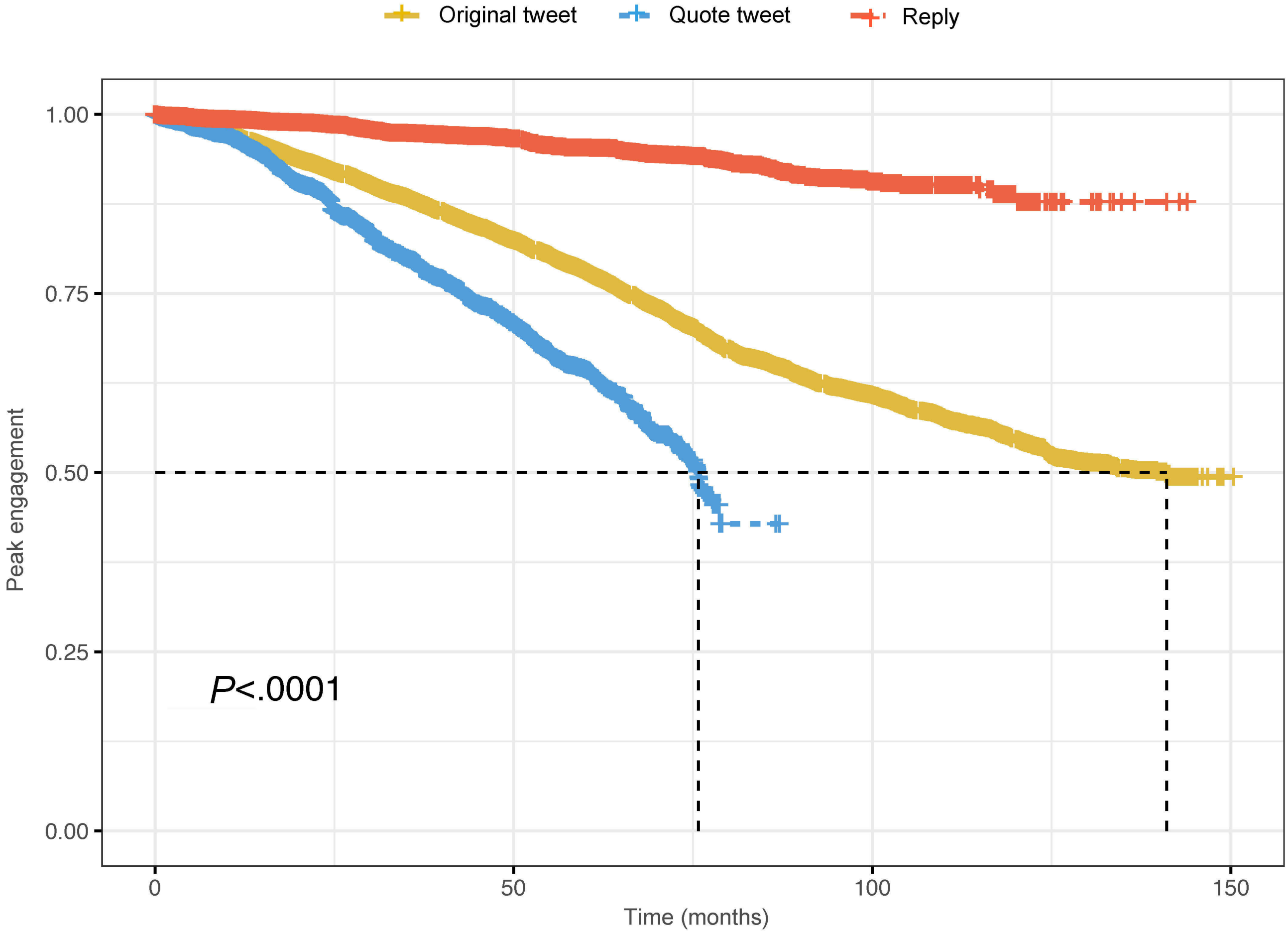
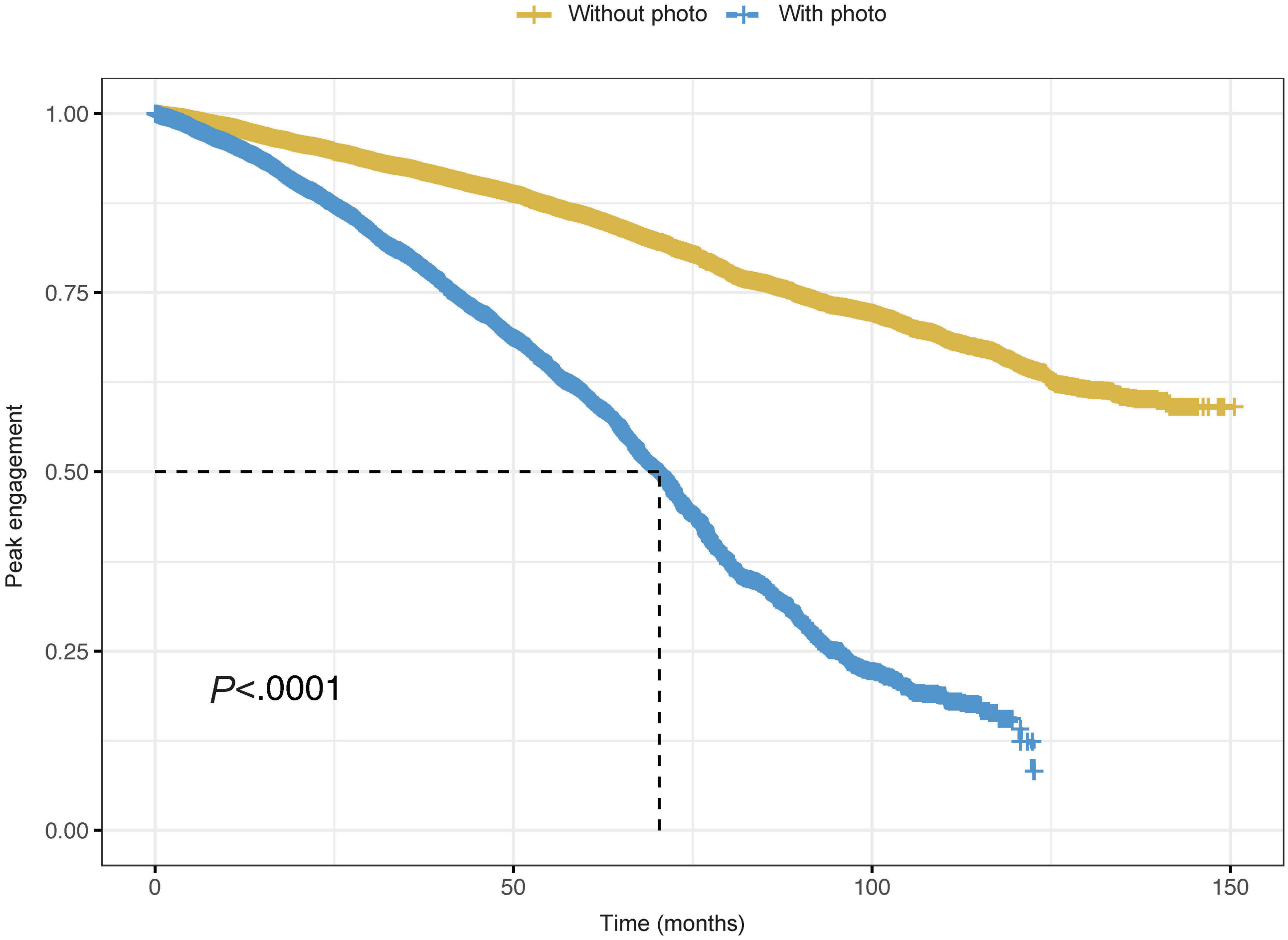


Figure 2. Engagement trajectories for 204,905 tweets with and without photos posted over 12 years.



Multivariable Cox Regression: Tweet Features Associated With Time-to-Peak-Engagement

Tweets with 3 or more hashtags were 75% more likely to reach peak engagement than those with 1 or no hashtags (hazard ratio 1.75; *P*<.001), supporting hypothesis 1. Visual elements were particularly effective in nudging tweets toward peak engagement, being 4.25 times more effective for tweets with photos (*P*<.001), 6.38 times more effective for tweets with GIFs (*P*<.001), and 9.97 times more effective for tweets with videos (*P*<.001). This provided support for hypothesis 2. Consistent with hypothesis 3, quote tweets were 3.15 times more likely to achieve peak engagement (*P*<.001), as compared to regular tweets, controlling for account-level variables, such as the number of followers, the number of people followed, the number of tweets, and verified status. Meanwhile, at the account level, tweets posted by organizations with a higher tweet count were 40% less likely to reach peak engagement (hazard ratio 0.60; *P*<.001) as compared to those with a lower tweet count, providing support for hypothesis 4. The regression results are presented in Table 2. Coefficients reached significance at *P*<.05 after correcting for multiple comparisons using the Bonferroni method [48].

Table . Multivariable Cox models of tweet-level and account-level predictors of time-to-peak engagement for tweets (n=204,905) posted by age advocacy organizations over 12 years. Variables were log transformed.

Tweet-level variables		Model 1[a]		Model 2[a]	
		Hazard ratio (95% CI)	*P* value[b]	Hazard ratio (95% CI)	*P* value[b]
Number of hashtags					
	0 or 1	Reference	Reference	Reference	Reference
	2	1.19 (0.95-1.50)	>.99	1.19 (1.00-1.42)	.90
	≥3	1.50 (1.12-2.02)	.11	1.75 (1.37-2.22)	<.001
Number of URLs					
	0	Reference	Reference	Reference	Reference
	1	1.18 (0.94-1.48)	>.99	1.25 (1.07-1.45)	.07
	≥2	1.43 (1.01-2.01)	.62	1.44 (1.05-1.98)	.42
Number of mentions					
	0	Reference	Reference	Reference	Reference
	1	0.80 (0.67-0.97)	.32	0.84 (0.71-0.99)	.74
	≥2	0.95 (0.71-1.26)	>.99	1.03 (0.82-1.29)	>.99
GIF		8.63 (6.33-11.77)	<.001	6.38 (3.62-11.24)	<.001
Photo		4.06 (2.76-5.96)	<.001	4.25 (3.19-5.68)	<.001
Video		13.39 (6.06-29.58)	<.001	9.97 (3.36-29.65)	<.001
Type of tweet					
	Original	Reference	Reference	Reference	Reference
	Quote tweet	3.03 (1.96-4.68)	<.001	3.15 (2.02-4.90)	<.001
	Replies	0.41 (0.14-1.21)	>.99	0.28 (0.07-1.17)	>.99
Time of upload					
	Afternoon	Reference	Reference	Reference	Reference
	Evening	1.21 (1.01-1.45)	.63	1.09 (0.92-1.29)	>.99
	Morning	1.02 (0.90-1.15)	>.99	0.98 (0.86-1.12)	>.99
	Night	1.10 (0.81-1.48)	>.99	1.07 (0.73-1.57)	>.99
Day of upload					
	Weekday	Reference	Reference	Reference	Reference
	Weekend	1.00 (0.89-1.12)	>.99	0.98 (0.88-1.08)	>.99
Account-level variables					
	Follower count	—[c]	—	1.42 (1.17-1.73)	.009
	Friend count	—	—	1.60 (1.16-2.21)	.08
	Tweet count	—	—	0.60 (0.49-0.73)	<.001
	Verified status	—	—	1.20 (0.78-1.86)	>.99

[a] Constant not shown.

[b] *P* values have been adjusted using Bonferroni correction.

[c] Not applicable.

Discussion

Principal Findings

Although the technological era has ushered in numerous opportunities for advocacy organizations, scant attention has been devoted to examining the use of social media as a tool for age advocacy. As social media can be instrumental in fostering policy change, we sought to fill this gap by examining how different tweet features influence engagement for tweets uploaded by age advocacy organizations. Findings indicate that tweets that are more likely to reach peak engagement are those that include 3 or more hashtags, contain visual elements, or are quote tweets. In contrast, tweets posted by organizations with a higher tweet count are less likely to reach peak engagement as compared to those with a lower tweet count.

Unsurprisingly, tweets with hashtags are more likely to achieve peak engagement. Arguably the most iconic feature of Twitter, the hashtag is an organizational device that connects users to a broader community of individuals who use the same hashtag [1]. Although movements concerning race- or gender-related matters are notably associated with hashtags, such as #BlackLivesMatter and #MeToo, hashtags related to age have not garnered the same level of success. Nevertheless, several age advocacy groups have rolled out their own hashtag campaigns in recent years. For example, the American Association of Retired Persons started the hashtag #DisruptAging as a way to spark conversations on what it means to grow older [49]. Age Platform Europe, a network lobbying for the rights of older adults, began the #AgeingEqual campaign in 2018 to raise awareness of ageism [50]. More recently, the World Health Organization started the hashtag #AWorld4AllAges in a bid to encourage individuals to build a more age-inclusive world [51]. Moving forward, age advocacy organizations could consider embedding their tweets with more hashtags to improve the visibility of their content.

Peak engagement is also achieved when visual elements, such as GIFs, photos, or videos, are included in a tweet. That the brain absorbs and synthesizes visual information faster than textual information is an insight from past research [34,35]. Our results reveal that GIFs, photos, and videos are all piteously underused in content uploaded by age advocacy organizations. These organizations should therefore strive to include visual elements in their tweets to bolster their chances of capturing the attention of followers. Importantly, these elements should be carefully selected to avoid perpetuating visual ageism [52]. Organizations could consider selecting images from the newly launched Age-Positive Image Library, which houses images that portray old age more realistically [53].

Quote tweets reach peak engagement faster than original tweets. Whereas the retweet function enables users to repost a tweet verbatim, quote tweets give users the option of adding their own comments to the tweet being reposted and is often used by individuals who wish to express their opinions in the context of the original tweet [54]. Given how a large subset of those following age advocacy organizations likely comprises academics and policy makers—people who may rely on Twitter for sharing knowledge or participating in intellectual discussions [9,12]—it makes sense that quote tweets take less time to reach peak engagement. With less than 5% of the tweets collected being quote tweets, age advocacy organizations should consider using the quote tweet function more regularly to establish a dialogic relationship with the public.

As expected, having a high follower count lessens the time needed to reach peak engagement. Both older and newer accounts should therefore make concerted efforts to amass as many followers as possible. In particular, age advocacy organizations with little or no digital presence should prioritize crafting strategies to increase their follower count before attempting to bolster engagement.

Not spamming audiences with content is considered by marketing experts to be a basic rule of Twitter etiquette [55]. By posting too often, organizations risk losing public interest or frustrating followers [9]. In seeking to forge a connection with the public, organizations must exercise prudence with regard to how frequently they post to prevent inundating followers' feeds. There are no hard and fast rules about how often to tweet, but social media managers of age advocacy organizations could monitor levels of engagement using the platform's "Tweet Activity Dashboard" [55]. By tracking the level of engagement of each tweet, organizations will be able to gain insight into the optimal frequency for tweeting.

As age advocacy organizations curate their content with the goal of maximizing engagement, it is imperative that these organizations extend their outreach beyond researchers and policy makers to the larger society. This is especially critical since age-related issues have yet to gain widespread awareness among the public. Moreover, age advocacy organizations could involve older adults in the cocreation of initiatives, such as by collaborating with older influencers [56,57]. In addition, amid the prevalence of intergenerational tension in the digital sphere [29,30], there is a need to create opportunities for older and younger generations to interact. Hashtag campaigns could be used to encourage both generations to engage in meaningful dialogues.

Limitations

This study has a number of limitations. First, the period that the tweets were posted is likely to have been a confounder in our analysis. It was only in 2014 that GIFs could be shared on Twitter. Likewise, the quote tweet feature was introduced only in 2015. However, tweets uploaded from 2009 onwards were included in our data set. The fact that there are now many more users on Twitter also means that posts that were uploaded before the platform was popular were less likely to be well engaged with. Second, considering that our objective was to look specifically at organizations, we could not offer insight into the level of engagement of tweets belonging to influential activists who champion the rights of older persons. Third, age advocacy organizations that are newer to Twitter were not included in the study since they did not fulfill the inclusion criterion of having at least 1000 followers at the time of analysis. Fourth, it is important to highlight that some tweets may have been uploaded solely for the purpose of informing or educating the public, rather than with the goal of engagement [9]. Finally, whether or not digital engagement actually inspires real-world action remains a moot point. Future analyses could adopt survey-based techniques [58,59] to understand activists' perceptions of digital activism and how it compares to traditional offline activism.

Despite these limitations, our study contributes to the field of gerontology by developing some practical guidelines for improving age advocacy efforts on Twitter. With research on this topic still at the outset, directions for future research are plentiful. Foremost among them is the need to construct a theoretical framework outlining the concept of age advocacy. Subsequent research could also explore how levels of engagement vary across organizations specializing in areas like retirement, housing, or health care. Additionally, it would be worthwhile to dissect the profile of followers of age advocacy organizations. This could include an analysis of the distribution of followers based on characteristics such as age, gender, and occupation.

Conclusions

Social media as a networked platform has the potential to reach users on a global scale and at an exponential speed. Having uncovered the features that are more likely to reach peak engagement on Twitter, our study serves as an invaluable resource for age advocacy organizations in their movement to create a more age-inclusive world.

Conflicts of Interest

None declared.

Multimedia Appendix 1
List of age advocacy organizations.
[DOCX File, 22 KB - aging_v7i1e49608_app1.docx]

Multimedia Appendix 2
Definitions of terms used on Twitter.
[DOCX File, 20 KB - aging_v7i1e49608_app2.docx]

References

1. Wang R, Liu W, Gao S. Hashtags and information virality in networked social movement: examining hashtag co-occurrence patterns. Online Inf Rev 2016 Nov 4;40(7):850-866. [doi: 10.1108/OIR-12-2015-0378]
2. Ofori-Parku SS, Moscato D. Hashtag activism as a form of political action: a qualitative analysis of the #BringBackOurGirls campaign in Nigerian, UK, and U.S. press. Int J Commun 2018 Jun;12 [FREE Full text]
3. Avidar R. Engagement, interactivity, and diffusion of innovations. In: Johnston KA, Taylor M, editors. The Handbook of Communication Engagement: Wiley-Blackwell; 2018:505-514. [doi: 10.1002/9781119167600]
4. Kim SM, Kageura K, McHugh J, et al. Twitter content eliciting user engagement: a case study on Australian organisations. In: WWW '17 Companion: Proceedings of the 26th International Conference on World Wide Web Companion: International World Wide Web Conferences Steering Committee; 2017:807-808. [doi: 10.1145/3041021.3054237]
5. Ng R, Tan YW. Diversity of COVID-19 news media coverage across 17 countries: the influence of cultural values, government stringency and pandemic severity. Int J Environ Res Public Health 2021 Nov 9;18(22):11768. [doi: 10.3390/ijerph182211768] [Medline: 34831524]
6. Giest S, Ng R. Big data applications in governance and policy. Politics and Governance 2018 Nov 21;6(4). [doi: 10.17645/pag.v6i4.1810]
7. Iqbal M. Twitter revenue and usage statistics. Bussiness of Apps. 2021. URL: https://www.businessofapps.com/data/twitter-statistics/ [accessed 2021-10-14]
8. Dadas C. Hashtag activism: the promise and risk of "attention". In: Walls DM, Vie S, editors. Social Writing/Social Media: Publics, Presentations, and Pedagogies: The WAC Clearinghouse; University Press of Colorado; 2017:17-36 URL: https://wac.colostate.edu/docs/books/social/writing.pdf [accessed 2024-04-15] [doi: 10.37514/PER-B.2017.0063]
9. Bhattacharya S, Srinivasan P, Polgreen P. Engagement with health agencies on Twitter. PLoS One 2014 Nov 7;9(11):e112235. [doi: 10.1371/journal.pone.0112235] [Medline: 25379727]
10. Saxton GD, Niyirora JN, Guo C, Waters RD. #AdvocatingForChange: the strategic use of hashtags in social media advocacy. ASW 2015;16(1):154-169 [FREE Full text] [doi: 10.18060/17952]
11. Siyam N, Alqaryouti O, Abdallah S. Mining government tweets to identify and predict citizens engagement. Technology in Society 2020 Feb;60:101211. [doi: 10.1016/j.techsoc.2019.101211]
12. Suh B, Hong L, Pirolli P, Chi EH. Want to be retweeted? Large scale analytics on factors impacting retweet in Twitter network. Presented at: 2010 IEEE Second International Conference on Social Computing; Aug 20 to 22, 2010; Minneapolis, MN.
13. Tomblinson CM, Wadhwa V, Latimer E, Gauss CH, McCarty JL. Publicly available metrics underestimate AJNR Twitter impact and follower engagement. AJNR Am J Neuroradiol 2019 Dec;40(12):1994-1997. [doi: 10.3174/ajnr.A6299] [Medline: 31727751]
14. Wadhwa V, Latimer E, Chatterjee K, McCarty J, Fitzgerald RT. Maximizing the tweet engagement rate in academia: analysis of the AJNR Twitter feed. AJNR Am J Neuroradiol 2017 Oct;38(10):1866-1868. [doi: 10.3174/ajnr.A5283] [Medline: 28663265]

15. Xiong Y, Cho M, Boatwright B. Hashtag activism and message frames among social movement organizations: semantic network analysis and thematic analysis of Twitter during the #MeToo movement. Public Relat Rev 2019 Mar;45(1):10-23. [doi: 10.1016/j.pubrev.2018.10.014]
16. Ng R, Indran N, Liu L. A playbook for effective age advocacy on Twitter. J Am Geriatr Soc 2022 Aug;70(8):2363-2370. [doi: 10.1111/jgs.17909] [Medline: 35748402]
17. Hudson RB. Advocacy and policy success in aging. Gener J Am Soc Aging Am Soc Aging 2004;28(1):17-24 [FREE Full text]
18. Myers JE, Shannonhouse LR. Combating ageism: advocacy for older persons. In: Multicultural Issues in Counseling: New Approaches to Diversity, 4th edition: American Counseling Association; 2013:151-170.
19. Ng R, Indran N. Age advocacy on Twitter over 12 years. Gerontologist 2024 Jan 1;64(1):gnac183. [doi: 10.1093/geront/gnac183] [Medline: 36516463]
20. Ng R, Chow TYJ, Yang W. The impact of aging policy on societal age stereotypes and ageism. Gerontologist 2022 Apr 20;62(4):598-606. [doi: 10.1093/geront/gnab151] [Medline: 34636402]
21. Ng R, Indran N. Role-based framing of older adults linked to decreased ageism over 210 years: evidence from a 600-million-word historical corpus. Gerontologist 2022 Apr 20;62(4):589-597. [doi: 10.1093/geront/gnab108] [Medline: 34323967]
22. Ng R, Lim SQ, Saw SY, Tan KB. 40-year projections of disability and social isolation of older adults for long-range policy planning in Singapore. Int J Environ Res Public Health 2020 Jul 9;17(14):4950. [doi: 10.3390/ijerph17144950] [Medline: 32659983]
23. Ng R, Indran N. Youth is prized in medicine, old age is valued in law: analysis of media narratives over 200 years. J Med Internet Res 2024 Mar 26;26:e45855. [doi: 10.2196/45855] [Medline: 38530338]
24. Ng R, Indran N. #ProtectOurElders: analysis of tweets about older Asian Americans and anti-Asian sentiments during the COVID-19 pandemic. J Med Internet Res 2024 Mar 29;26:e45864. [doi: 10.2196/45864] [Medline: 38551624]
25. Jimenez-Sotomayor MR, Gomez-Moreno C, Soto-Perez-de-Celis E. Coronavirus, ageism, and Twitter: an evaluation of tweets about older adults and COVID-19. J Am Geriatr Soc 2020 Aug;68(8):1661-1665. [doi: 10.1111/jgs.16508] [Medline: 32338787]
26. Levy BR, Chung PH, Bedford T, Navrazhina K. Facebook as a site for negative age stereotypes. Gerontologist 2014 Apr;54(2):172-176. [doi: 10.1093/geront/gns194] [Medline: 23392643]
27. Skipper AD, Rose DJ. #Boomerremover: COVID-19, ageism, and the intergenerational Twitter response. J Aging Stud 2021 Jun;57:100929. [doi: 10.1016/j.jaging.2021.100929] [Medline: 34082999]
28. Xiang X, Lu X, Halavanau A, et al. Modern senicide in the face of a pandemic: an examination of public discourse and sentiment about older adults and COVID-19 using machine learning. J Gerontol B Psychol Sci Soc Sci 2021 Mar 14;76(4):e190-e200. [doi: 10.1093/geronb/gbaa128] [Medline: 32785620]
29. Ng R, Indran N. Hostility toward baby boomers on TikTok. Gerontologist 2022 Sep 7;62(8):1196-1206. [doi: 10.1093/geront/gnac020] [Medline: 35106587]
30. Ng R, Indran N. Videos about older adults on TikTok. PLoS One 2023 Aug 2;18(8):e0285987. [doi: 10.1371/journal.pone.0285987] [Medline: 37531317]
31. Ng R, Indran N, Liu L. Ageism on Twitter during the COVID-19 pandemic. J Soc Issues 2022 Jul 20. [doi: 10.1111/josi.12535] [Medline: 35942488]
32. Ng R, Indran N. Does age matter? Tweets about gerontocracy in the United States. J Gerontol B Psychol Sci Soc Sci 2023 Nov 14;78(11):1870-1878. [doi: 10.1093/geronb/gbad113] [Medline: 37584274]
33. Ageing and health. World Health Organanization. 2021. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2021-03-26]
34. Chaiken S, Eagly AH. Communication modality as a determinant of message persuasiveness and message comprehensibility. J Pers Soc Psychol 1976;34(4):605-614. [doi: 10.1037//0022-3514.34.4.605]
35. Powell TE, Boomgaarden HG, De Swert K, de Vreese CH. A clearer picture: the contribution of visuals and text to framing effects: visual framing effects. J Commun 2015 Nov;65(6):997-1017. [doi: 10.1111/jcom.12184]
36. Fuller MY, Allen TC. Let's have a tweetup: the case for using Twitter professionally. Arch Pathol Lab Med 2016 Sep;140(9):956-957. [doi: 10.5858/arpa.2016-0172-SA] [Medline: 27195434]
37. Letierce J, Passant A, Decker S, Breslin J. Understanding how Twitter is used to spread scientific messages. Presented at: Web Science Conference; Apr 26 to 27, 2010; Raleigh, NC.
38. Hanscom Federal Credit Union. 23 organizations dedicated to the needs of seniors. MoneyWisdom. 2019. URL: https://go.hfcu.org/blog/23-organizations-dedicated-to-the-needs-of-seniors [accessed 2021-11-19]
39. Rodriguez J. Senior organizations: list of groups for older adults. Griswold Home Care. 2020 Jun 11. URL: https://www.griswoldhomecare.com/blog/2020/june/senior-organizations-list-of-groups-for-older-ad/ [accessed 2021-11-19]
40. National and international private and public organizations. West Virginia Bureau of Senior Services. URL: http://www.wvseniorservices.gov/GettingAnswers/LinkstoHelpfulSites/NationalInternationalPrivatePublicOrgs/tabid/102/Default.aspx [accessed 2021-11-19]

41. Tornes A. Enabling the future of academic research with the Twitter API. Developer Platform. 2021 Jan 26. URL: https://tinyurl.com/bdtbnscb [accessed 2021-10-13]
42. Barrie C, Ho J. AcademictwitteR: an R package to access the Twitter academic research product track v2 API endpoint. JOSS 2021 Jun 7;6(62):3272. [doi: 10.21105/joss.03272]
43. International Day of Older Persons. United Nations. 2021. URL: https://www.un.org/en/observances/older-persons-day [accessed 2021-10-14]
44. Twitter API v2 data dictionary. Twitter Developer Platform. 2021. URL: https://developer.twitter.com/en/docs/twitter-api/data-dictionary/object-model/tweet [accessed 2021-11-20]
45. Elandt-Johnson RC, Johnson NL. Survival Models and Data Analysis: John Wiley & Sons; 1980.
46. Kalbfleisch JD, Prentice RL. The Statistical Analysis of Failure Time Data: John Wiley & Sons; 2011.
47. Therneau TM, Grambsch PM. Multiple events per subject. In: Therneau TM, Grambsch PM, editors. Modeling Survival Data: Extending the Cox Model: Springer; 2000:169-229. [doi: 10.1007/978-1-4757-3294-8]
48. Mundfrom D, Perrett J, Schaffer J, Piccone A, Roozeboom M. Bonferroni adjustments in tests for regression coefficients. Mult Linear Regres Viewp 2006 Jan;32 [FREE Full text]
49. AARP wants to disrupt the image of aging. AARP. 2021. URL: https://www.aarp.org/about-aarp/info-2019/disrupt-aging-collection.html [accessed 2024-04-19]
50. #AgeingEqual: why this campaign? Ageing Equal. 2019. URL: https://ageing-equal.org/about/ [accessed 2021-10-20]
51. Combatting ageism. World Health Organization. 2021. URL: https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combatting-ageism [accessed 2021-10-20]
52. Loos E, Ivan L. Visual ageism in the media. In: Ayalon L, Tesch-Römer C, editors. Contemporary Perspectives on Ageism: Springer International Publishing; 2018:163-176. [doi: 10.1007/978-3-319-73820-8]
53. Age-positive image library. Centre for Ageing Better. 2023. URL: https://ageing-better.org.uk/news/age-positive-image-library-launched [accessed 2023-11-09]
54. Garimella K, Weber I, De Choudhury M. Quote RTs on Twitter: usage of the new feature for political discourse. In: WebSci ’16: Proceedings of the 8th ACM Conference on Web Science: Association for Computing Machinery; 2016:200-204. [doi: 10.1145/2908131.2908170]
55. Lee K. Social media frequency: how often to post on social media channels. Buffer. 2014. URL: https://buffer.com/library/social-media-frequency-guide/ [accessed 2022-01-27]
56. Ng R, Indran N. Not too old for TikTok: how older adults are reframing aging. Gerontologist 2022 Sep 7;62(8):1207-1216. [doi: 10.1093/geront/gnac055] [Medline: 35512401]
57. Ng R, Indran N. Granfluencers on TikTok: factors linked to positive self-portrayals of older adults on social media. PLoS One 2023 Feb 7;18(2):e0280281. [doi: 10.1371/journal.pone.0280281] [Medline: 36749797]
58. Ng R, Levy B. Pettiness: conceptualization, measurement and cross-cultural differences. PLoS One 2018;13(1):e0191252. [doi: 10.1371/journal.pone.0191252] [Medline: 29385157]
59. Sima LC, Ng R, Elimelech M. Modeling risk categories to predict the longitudinal prevalence of childhood diarrhea in Indonesia. Am J Trop Med Hyg 2013 Nov;89(5):884-891. [doi: 10.4269/ajtmh.12-0540] [Medline: 24019442]

Abbreviations

API: application programming interface

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Perceptions and Utilization of Online Peer Support Among Informal Dementia Caregivers: Survey Study

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Abstract

Background: Informal dementia caregivers are those who care for a person living with dementia and do not receive payment (eg, family members, friends, or other unpaid caregivers). These informal caregivers are subject to substantial mental, physical, and financial burdens. Online communities enable these caregivers to exchange caregiving strategies and communicate experiences with other caregivers whom they generally do not know in real life. Research has demonstrated the benefits of peer support in online communities, but this research is limited, focusing merely on caregivers who are already online community users.

Objective: We aimed to investigate the perceptions and utilization of online peer support through a survey.

Methods: Following the Andersen and Newman Framework of Health Services Utilization and using REDCap (Research Electronic Data Capture), we designed and administered a survey to investigate the perceptions and utilization of online peer support among informal dementia caregivers. Specifically, we collected types of information that influence whether an informal dementia caregiver accesses online peer support: predisposing factors, which refer to the sociocultural characteristics of caregivers, relationships between caregivers and people living with dementia, and belief in the value of online peer support; enabling factors, which refer to the logistic aspects of accessing online peer support (eg, eHealth literacy and access to high-speed internet); and need factors, which are the most immediate causes of seeking online peer support. We also collected data on caregivers’ experiences with accessing online communities. We distributed the survey link on November 14, 2022, within two online locations: the Alzheimer’s Association website (as an advertisement) and ALZConnected (an online community organized by the Alzheimer’s Association). We collected all responses on February 23, 2023, and conducted a regression analysis to identifyn factors that were associated with accessing online peer support.

Results: We collected responses from 172 dementia caregivers. Of these participants, 140 (81.4%) completed the entire survey. These caregivers were aged 19 to 87 (mean 54, SD 13.5) years, and a majority were female (123/140, 87.9%) and White (126/140, 90%). Our findings show that the behavior of accessing any online community was significantly associated with participants’ belief in the value of online peer support (P=.006). Moreover, of the 40 non–online community caregivers, 33 (83%) had a belief score above 24—the score that was assigned when a neutral option was selected for each belief question. The most common reasons for not accessing any online community were having no time to do so (14/140, 10%) and having insufficient online information–searching skills (9/140, 6.4%).

Conclusions: Our findings suggest that online peer support is valuable, but practical strategies are needed to assist informal dementia caregivers who have limited time or online information–searching skills.

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KEYWORDS

informal dementia caregiver; online health community; social support; survey; online peer support; caregiving challenges

Introduction

Alzheimer disease—the most common cause of dementia—is a brain disorder that affects the thinking, comprehension, and learning capacity of more than 6 million Americans and is the seventh leading cause of death in the United States [1]. An estimated 80% of people living with Alzheimer disease or related dementia are cared for by unpaid informal caregivers (eg, family members, friends, or other unpaid caregivers) [2]. In 2021, over 11 million informal dementia caregivers provided 16 billion hours of care to people living with dementia [1]. Although this care was valued at nearly US $271.6 billion, it imposed substantial physical, financial, and mental burdens on these informal caregivers [3]. Additionally, 30% of informal dementia caregivers are aged ≥65 years [1]. They are likely to experience reduced social engagement due to caring for people living with dementia, which increases their risk of developing Alzheimer disease or some other dementia [4-6] and their risk of early death [7,8]. To ensure sufficient support for both informal caregivers and care recipients, it is essential for society to develop effective support mechanisms for the needs of informal dementia caregivers [9].

Research on how to best support informal dementia caregivers has focused primarily on assistance from credentialed professionals [10-12]. This type of assistance can improve a caregiver’s emotional well-being and caring skills, but maintaining this assistance over time can be difficult to achieve on a large scale. This is due, in part, to an insufficiently sized workforce, limited financial support [13,14], the stigma of asking for help, and difficulties encountered when leaving individuals with dementia [15,16]. In addition, if they lack a shared experience, it may be difficult for health care professionals or other family members to respond to the specific needs of informal caregivers. The perception that “they simply do not understand” [17] can contribute to feelings of loneliness [18], which were found to be negatively associated with the health and well-being of these caregivers [19].

The integration of the internet into daily life has enabled many people, including informal caregivers, to discuss health-related topics on online social media platforms [20,21]. For example, ALZConnected [22], which is organized by the Alzheimer’s Association, is the largest online community for people living with Alzheimer disease or related dementia and their caregivers in North America. ALZConnected has accumulated tens of thousands of online community users to discuss a broad range of topics regarding dementia caregiving and disease management [23]. Through online communities, informal dementia caregivers seek support and are willing to share experiences and practical information that they believe will assist other caregivers [24]. A study that analyzed an Alzheimer caregiver group on Facebook found that online peer social support had decreased the caregivers’ burdens while increasing their emotional and informational well-being [3]. Similarly, a survey found that increased online activity among caregivers was associated with lower levels of depression and loneliness [25]. In addition, many online communities provide added benefits, such as anonymity, asynchronous participation, and connection to numerous caregivers without physical location and time constraints [26], which provide cost-effective and convenient ways for informal dementia caregivers to gain support and access resources.

Based on internet utilization, informal dementia caregivers can be categorized as (1) *non-internet caregivers*, who never use the internet; (2) *non–online community caregivers*, who use the internet but do not participate in online communities; and (3) *online community caregivers*, who both use the internet and participate in online communities. Current social media–based dementia caregiving research primarily focuses on online community caregivers [25-27]. Although improving the online experiences of these caregivers is important [28], understanding how non–online community caregivers perceive the value of online peer support is significant as well. This would inform the development of interventions for non–online community caregivers to use and benefit from online peer support, thereby helping to mitigate the potential digital divide and decreasing existing health disparities in accessing online peer support [29].

The primary objective of this research was to gain insight into the perceptions and utilization of online community support among informal dementia caregivers, specifically non–online community caregivers and online community caregivers. To do so, we designed and administered a survey based on the Andersen and Newman Framework of Health Services Utilization (ANFHSU) [30]. The ANFHSU is a classical model for identifying and describing the factors that may affect a person’s access to and utilization of health services. Within this framework, we can analyze the various factors gathered through a survey questionnaire to determine an informal dementia caregiver’s access to or utilization of online peer support. Our findings suggest that online peer support is valuable, but practical strategies are needed to assist caregivers with limited time or online information–searching skills. This investigation marks the initial step toward addressing a long-term research objective, aiming to comprehensively elucidate the intricate mechanisms underlying online social support in dementia caregiving.

Methods

Online Peer Support

We begin this section with the definition of *online peer support*. Although peer support groups can be organized in an online format (eg, via Zoom meetings), the online peer support in this paper refers to the communications among informal dementia caregivers who may not know each other in real life but connect in online communities, forums, or websites (eg, Twitter, Facebook, Reddit, or ALZConnected). More broadly, since reading online caregiving discussions from other caregivers can serve as a way to obtain information and resources or learn caregiving skills, we also treated reading online posts as an online peer support–seeking behavior.

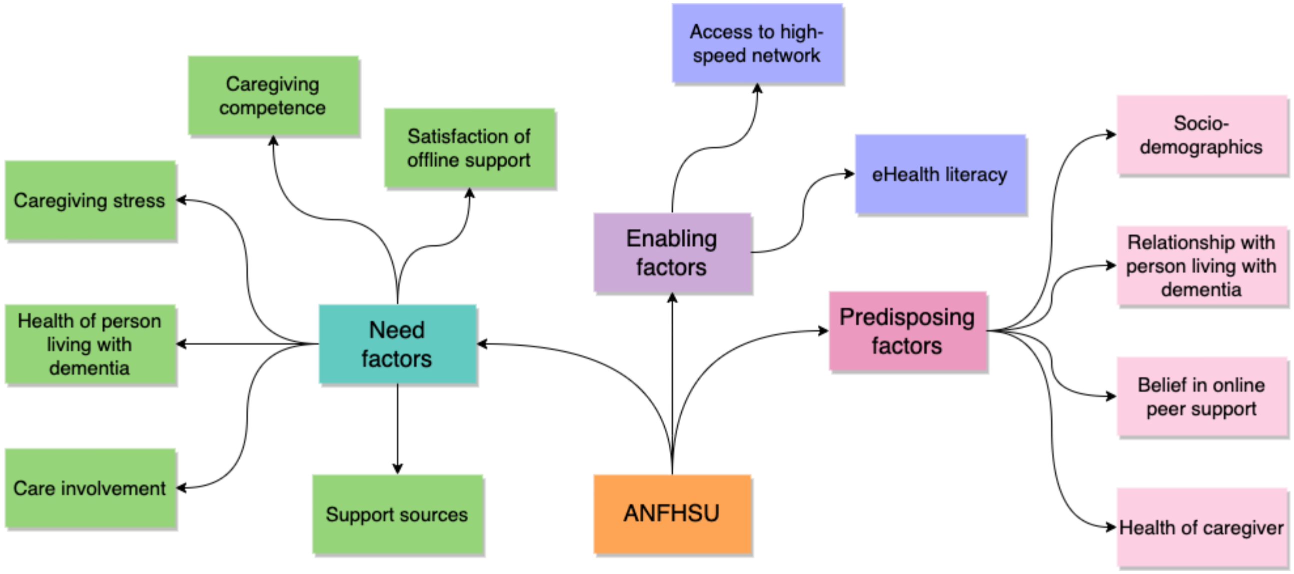
Ethical Considerations

This study was reviewed and deemed as non-human subjects research by the Vanderbilt University Medical Center Institutional Review Board (IRB 221732). Each survey participant was asked to confirm that they were unpaid informal dementia caregivers and that they were voluntarily participating in this survey in an information sheet. The sheet also included the definitions of *informal Alzheimer disease and related dementia caregivers* and *online communities*; the research purpose; a notice that the data would be collected, processed, and used; the methods applied to protect participant privacy; and a contact number for the Institutional Review Board.

Questionnaire Design

Social support is valuable in improving personal health [31]. In this study, we designed the survey based on the ANFHSU, whereby an informal dementia caregiver's access to or utilization of online peer support was considered to be a function of 3 characteristics (Figure 1).

Figure 1. The predisposing, enabling, and need factors in the ANFHSU. ANFHSU: Andersen and Newman Framework of Health Services Utilization.



Predisposing factors were the sociocultural characteristics of individuals or other factors that existed before these individuals became dementia caregivers. Specifically, we included the following predisposing factors:

- Sociodemographics: these included age, biological sex, education level, race, ethnicity, occupational status, and income; we also inquired about the number of children being cared for (if applicable), acknowledging the significant challenges in life balance experienced by caregivers in the "sandwich generation" [23].
- Relationship between the caregiver and a person living with dementia: this was included because caregivers who have different relationships with a person living with dementia face different caregiving challenges and burdens.
- Belief in the value of online peer support: we asked the following seven 7-point Likert scale (ranging from "Strongly disagree" to "Strongly agree") questions: "Do you believe that reading online discussions from, or directly writing posts to discuss with, other caregivers whom you do not know in the real world will help a) find caregiving resources that you need, b) increase caregiving knowledge, c) increase understanding of the disease and patient, d) improve caregiving skills, e) increase confidence in caregiving, f) reduce caregiving stress or g) reduce the feeling of loneliness as a caregiver?"
- Health of the caregiver: we collected data on this factor through the following 7-point Likert scale (ranging from "Extremely disagree" to "Extremely agree") item: "I feel healthy and do not have any major diseases that affect my daily life."

Enabling factors referred to the logistic aspects of accessing online peer support. The following enabling factors were included:

- Access to a high-speed network, which is an important contributor to the digital divide [32].
- eHealth literacy: this was measured through the eHealth Literacy Scale (eHEALS) [33] to evaluate if a caregiver could process online health-related information.

Need factors referred to the most immediate causes of seeking online peer support. The following need factors were included:

- Health of the person living with dementia: for simplicity, caregivers reported the dementia stage for people living with dementia as "early," "middle," or "late."
- Care involvement: this was measured through two questions ("How long have you been taking care of the PLWD (caregiving duration)?" and "How frequently do you care for the PLWD per week (caregiving workload)?"), and this design was based on the facts that dementia caregiving is a long-term dynamic process and that the weekly caregiving workload would affect the need for online peer support.
- Caregiving challenges: data on these were obtained via an open-ended question that requested caregivers to indicate the most challenging issues that they have faced when caring for a person living with dementia.
- Offline support sources: we also asked caregivers to describe (in a textbox) where to obtain support in the real world to handle the aforementioned challenges.
- Satisfaction with any support received in offline environments (7-point Likert scale).
- Caregiving stress: improving psychological well-being is a key focus of many interventions. The intuition is that

higher levels of stress in caregivers often drive them to seek support. We measured this factor by using the Zarit Burden Interview (12-item) scale [34].

- Caregiver competence: this factor referred to one's self-evaluation of their capacity to care for a person living with dementia and was measured by using the CARERS (Coaching, Advocacy, Respite, Education, Relationship, and Simulation) Interview (4-item) scale [35].

The rationale of the design of the survey was that if an informal dementia caregiver finds offline support to be insufficient in solving their caregiving challenges, they may turn to online environments for peer support. In addition to the ANFHSU factors, we surveyed each participant's experiences with using online peer support in the past 3 months (ie, their behavior). For the survey participants who were already online community users, we asked the following questions: (1) "Which online platforms have you visited in the past three months?" (2) "How frequently did you visit those online communities?" (3) "Will you intend to revisit these online communities in the next three months (intention)?" (4) "If the answer to question 3) is yes, what are your motivations for revisiting these online communities?" For participants who were not online community users, we asked them an open-ended question regarding why they did not seek online peer support in the past 3 months.

Implementation and Dissemination

We implemented the survey questionnaire in REDCap (Research Electronic Data Capture; Vanderbilt University) [36]—a secure web application for building and managing online surveys. We distributed the survey link within 2 online locations. The first was ALZConnected, where we posted the survey link at the top of the thread board in the community's two major caregiver forums: (1) *Caregivers Forum* and (2) *Spouse or Partner Caregiver Forum*. The second was the Alzheimer's Association website [37], where an advertisement for this survey was created to allow any person who visited the website to have a chance to access the survey link. Given that this website is a popular source of information for patients with dementia and dementia caregivers, we expected to obtain survey responses from caregivers who were not part of online communities.

Analysis

We performed three types of analyses. First, we summarized the answers to the multiple-choice questions by illustrating the respondent distribution for each choice. This was done to paint a broad picture of who the responding caregivers were and their perceptions and utilization of online peer support.

Second, we summarized the answers to the open-ended questions through manual annotation. This was not a trivial task because the responses were written as free text, and there were no predefined categories before the annotation. To address these issues, two authors (CN and QS) read the responses and annotated the categories for each open-ended question independently. Next, both annotators compared and discussed their summarized categories to create the final categories, including category names and definitions. Both annotators then independently modified their annotations with the agreed upon categories. For each response, we adopted a conservative approach and only reported the interactions of the categories summarized by the two annotators.

Finally, we fitted a logistic regression model (R v4.2.2; R Foundation for Statistical Computing) to analyze how the proposed ANFHSU factors were associated with using online peer support. Due to the small sample size, we converted some categorical variables into binary ones. Specifically, we encoded *gender* as "female/non-female," *race* as "white/non-white," *education level* as "4-year college degree or above/below 4-year college degree," *access to high-speed network* as "yes/no," *relationship* as "spouse/non-spouse," and all the other categorical variables (eg, *annual income*, *dementia stage*, *caregiving duration*, and *caregiving workload*) as ordinal variables (eg, numerical values with equal distance). A 2-sided P value of <.05 was considered to be statistically significant.

Results

Survey Overview

We distributed the survey link on November 14, 2022, leaving it open for over 3 months until February 23, 2023. During this time period, we collected responses from 172 dementia caregivers. Of these participants, 140 (81.4%) completed the entire survey.

Characteristics of Caregivers and People Living With Dementia

Table 1 summarizes the sociodemographic and caregiving characteristics of the 140 caregivers who completed the survey. These caregivers were aged 19 to 87 (mean 54, SD 13.5) years, and a majority were female (123/140, 87.9%) and White (126/140, 90%). Over 60% (89/140, 63.6%) of these caregivers had a 4-year college degree or higher, whereas 36.4% (51/140) had a below–4-year college education level. A majority of the caregivers were the adult children of the people living with dementia (71/140, 50.7%), followed by spouses or partners (41/140, 29.3%) and other relatives (19/140, 13.6%). Only 40.7% (57/140) of these caregivers were employed full-time, and 28.6% (40/140) took care of the person living with dementia and at least one child simultaneously. Further, 17.9% (25/140) and 32.1% (45/140) of the respondents reported taking care of the person living with dementia for <1 year and >4 years, respectively, and 66.4% (93/140) provided daily care. The caregivers' annual income was approximately uniformly distributed across incomes of less than US $25,000 to incomes ranging between US $100,000 and US $149,999. Only 7.9% (11/140) of these caregivers earned more than US $149,999.

Table 2 presents the characteristics of the people living with dementia reported by 140 survey participants. The ages of the people living with dementia ranged from 46 to 97 (mean 76, SD 9.5) years, and 65% (91/140) were female. Over 60% (86/140, 61.4%) of the people living with dementia were at the middle stage of dementia, 21.4% (30/140) were at the late stage, and 17.1% (24/140) were at the early stage.

Table . Summary of the sociodemographics and caregiving characteristics of the 140 survey caregiver participants.

Characteristic		Caregivers (N=140)
Age (y), mean (SD; range)		54 (13.5; 19-87)
Gender, n (%)		
	Female	123 (87.9)
	Male	16 (11.4)
	Undifferentiated	1 (0.7)
Race, n (%)		
	White	126 (90)
	Asian	8 (5.7)
	Black or African American	5 (3.6)
	Unknown	1 (0.7)
Ethnicity, n (%)		
	Not Hispanic or Latino	130 (92.9)
	Hispanic or Latino	10 (7.1)
Education level, n (%)		
	Above a 4-y college degree	57 (40.7)
	4-y college graduate	32 (22.9)
	Some college or 2-y degree	40 (28.6)
	High school or General Educational Development	11 (7.9)
Employment status, n (%)		
	Full time	57 (40.7)
	Retired	40 (28.6)
	Part time	22 (15.7)
	Unemployed	21 (15)
Relationship, n (%)		
	Adult child	71 (50.7)
	Spouse or partner	41 (29.3)
	Other relative	19 (13.6)
	Grandchild	6 (4.3)
	Neighbor	1 (0.7)
	Friend	1 (0.7)
	Other	1 (0.7)
Number of children cared for, n (%)		
	1	15 (10.7)
	2	20 (14.3)
	3	2 (1.4)
	>3	3 (2.1)
	Does not apply	100 (71.4)
Caregiving duration, n (%)		
	<6 mo	12 (8.6)
	6-12 mo	13 (9.3)
	1-2 y	35 (25)

Characteristic		Caregivers (N=140)
	2-4 y	35 (25)
	>4 y	45 (32.1)
Caregiving workload, n (%)		
	<1 time per week	6 (4.3)
	1-2 times per week	21 (15)
	3-6 times per week	20 (14.3)
	Daily	93 (66.4)
Annual income (US $), n (%)		
	<25,000	24 (17.1)
	25,000-49,999	30 (21.4)
	50,000-74,999	26 (18.6)
	75,000-99,999	21 (15)
	100,000-149,999	28 (20)
	≥150,000 or more	11 (7.9)

Table . Characteristics of the people living with dementia reported by survey participants.

Characteristic		People living with dementia (N=140)
Age (y), mean (SD; range)		76 (9.5; 46-97)
Gender, n (%)		
	Female	91 (65)
	Male	49 (35)
Dementia stage, n (%)		
	Early stage	24 (17.1)
	Middle stage	86 (61.4)
	Late stage	30 (21.4)

Caregiving Challenges and Support Sources

Table 3 summarizes reported caregiving challenges and the sources where caregivers sought support. The main caregiving challenges included dealing with the memory issues of a person living with dementia (40/140, 28.6%), supporting a person living with dementia in their daily life (such as showering and transportation; 30/140, 21.4%), and maintaining a balanced life (24/140, 17.1%). It should be noted that life balancing included the ability to (1) balance taking care of one’s children and a person living with dementia, (2) balance work and caregiving, and (3) balance one’s social life and caregiving. Dealing with the emotional fluctuations of the person living with dementia (21/140, 15%) and dealing with financial issues (14/140, 10%) were also major caregiving challenges. Some caregivers expressed concerns about the dementia treatment (11/140, 7.9%) for people living with dementia and their own mental health issues (10/140, 7.1%).

Table . Summary of caregiving challenges and specific support sources.[a]

		Caregivers (N=140), n (%)
Challenge		
	Legal issue	1 (0.7)
	Physical health	1 (0.7)
	Other health issue	2 (1.4)
	Mental health (caregiver)	10 (7.1)
	Treatment concern	11 (7.9)
	Family conflict	13 (9.3)
	Financial issue	14 (10)
	Emotion change	21 (15)
	Life balancing	24 (17.1)
	Daily caregiving	30 (21.4)
	Memory issue	40 (28.6)
Support source		
	Self-learning (book)	4 (2.9)
	Dementia caregivers (offline)	7 (5)
	Self-learning (online search)	8 (5.7)
	Local support group	23 (16.4)
	Friend	35 (25)
	Dementia caregivers (online community)	35 (25)
	Health care provider	38 (27.1)
	Family member	66 (47.1)

[a] Caregivers could report multiple challenges and support sources, which is why the total of the percentages for each section exceed 100%.

Satisfaction With Support and Network Access

Table 4 depicts the distribution of caregivers by satisfaction with the support they sought and by their access to a high-speed network. Of the 140 caregivers, 69 (49.3%) reported an "agree" or above response (which included "Slightly agree," "Quite agree," and "Extremely agree") for their satisfaction with the sought support. Among the 56 (40%) caregivers who reported negative experiences, 12 (8.6%) reported "Extremely disagree," indicating the challenging situations faced by these caregivers. Only 6 caregivers reported that they could not access a high-speed network.

Table . Distribution of caregivers by satisfaction with support that was sought and by access to a high-speed network.

Items and responses		Caregivers, n
Satisfaction with the sought support		
	Extremely disagree	12
	Quite disagree	29
	Slightly disagree	15
	Neither	15
	Slightly agree	37
	Quite agree	31
	Extremely agree	1
Access to a high-speed network		
	Extremely disagree	1
	Quite disagree	2
	Slightly disagree	3
	Slightly agree	11
	Quite agree	38
	Extremely agree	85

Measures of Caregiving Stress and Competence, eHEALS, and Belief

Figure 2 illustrates the distribution of the scores associated with caregiving stress, caregiving competence, eHealth literacy, and a caregiver's belief in the value of peer support from an online environment. The Cronbach α—a measure of the internal consistency of a questionnaire or survey (the higher, the better)—of these measures was 0.86 (95% CI 0.82-0.89), 0.83 (95% CI 0.78-0.87), 0.87 (95% CI 0.84-0.90), and 0.87 (95% CI 0.83-0.89), respectively. These indicated very good internal consistency. Specifically, of the 140 caregivers, 121 (86.4%) had a stress score above 30 (the score when "neutral" was selected for all the questions; the same cutoffs were used for each measure), 67 (47.9%) had a competence score above 12, 138 (98.6%) had an eHealth literacy score above 20, and 125 (89.3%) had a belief score above 24. These results suggested that most of the caregivers were in stressful caregiving experiences, had high eHealth literacy, and believed in the value of online peer support. However, over half (73/140, 52.1%) of these caregivers were not confident in their caregiving skills.

Figure 3 provides a detailed illustration (in the form of heat maps) of the responses for each belief category and the correlations in the responses. It shows that obtaining the needed resources, increasing one's understanding of the patient and the disease, and improving caregiving skills and confidence were the top "believed" values of online peer support. In contrast, reducing caregiving stress and the loneliness of being a caregiver was slightly more challenging. However, both categories received more "likely" responses than "unlikely" responses, with 57.1% (80/140) and 65% (91/140) of caregivers selecting "likely" responses, respectively. There were also several interesting observations made. First, reducing loneliness as a caregiver was highly correlated with reducing stress. Second, improving caregiving skills was highly correlated with increasing caregiving confidence. Third, reducing stress was correlated with improving caregiving skills and increasing caregiving confidence. Although correlation does not necessarily imply causation, these results suggested that improving caregiving skills and reducing loneliness may help to reduce caregiving stress.

Figure 2. Distribution of scores for the four measures. The red vertical lines in the "Caregiving stress," "eHealth literacy," and "Belief" in online peer support graphs correspond to the scores when "neutral" or "undecided" was selected for all the questions in each measure. The red vertical line in the "Caregiving competence" graph corresponds to the score when the "fairly" option was selected for all the questions.

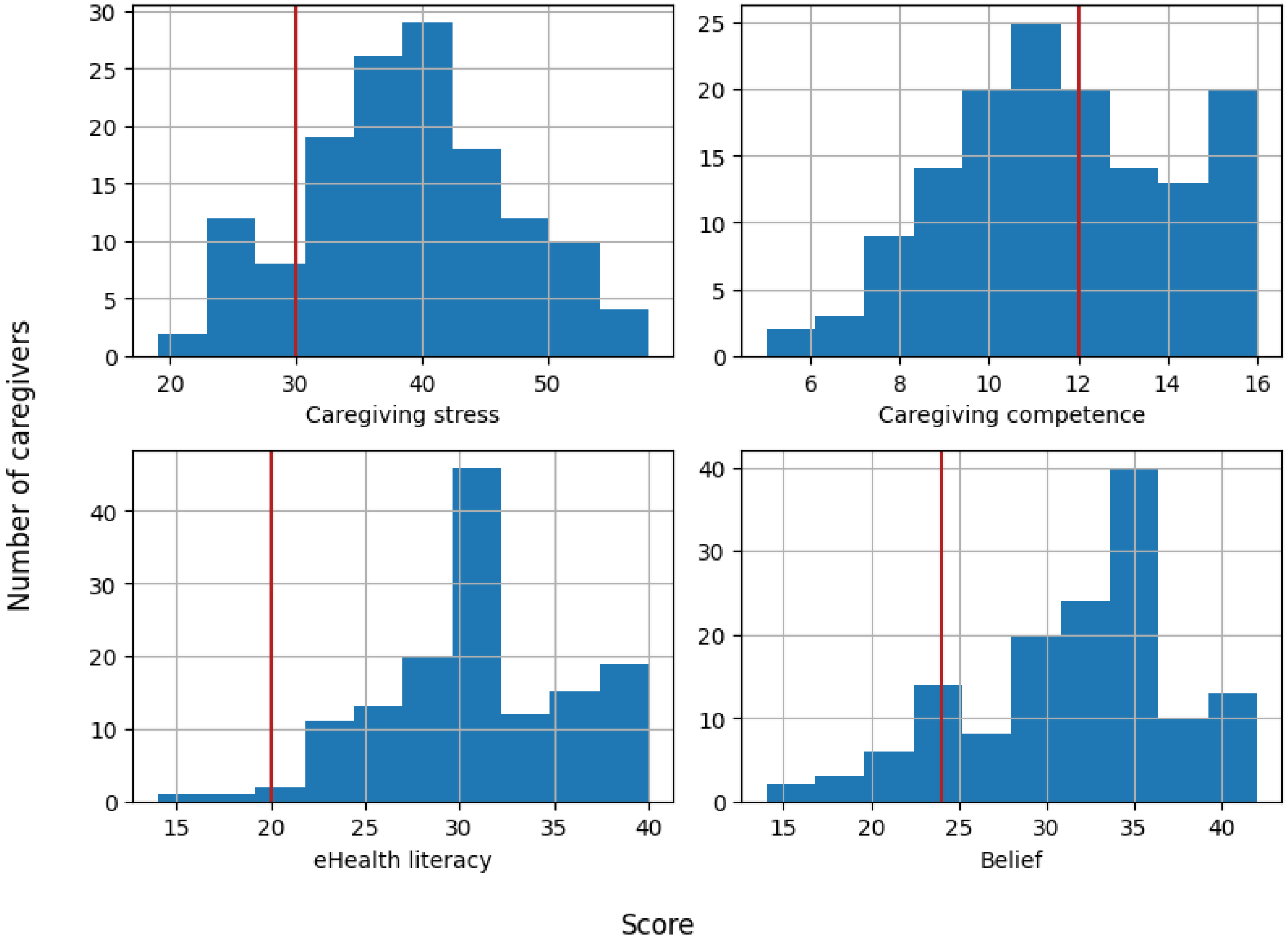
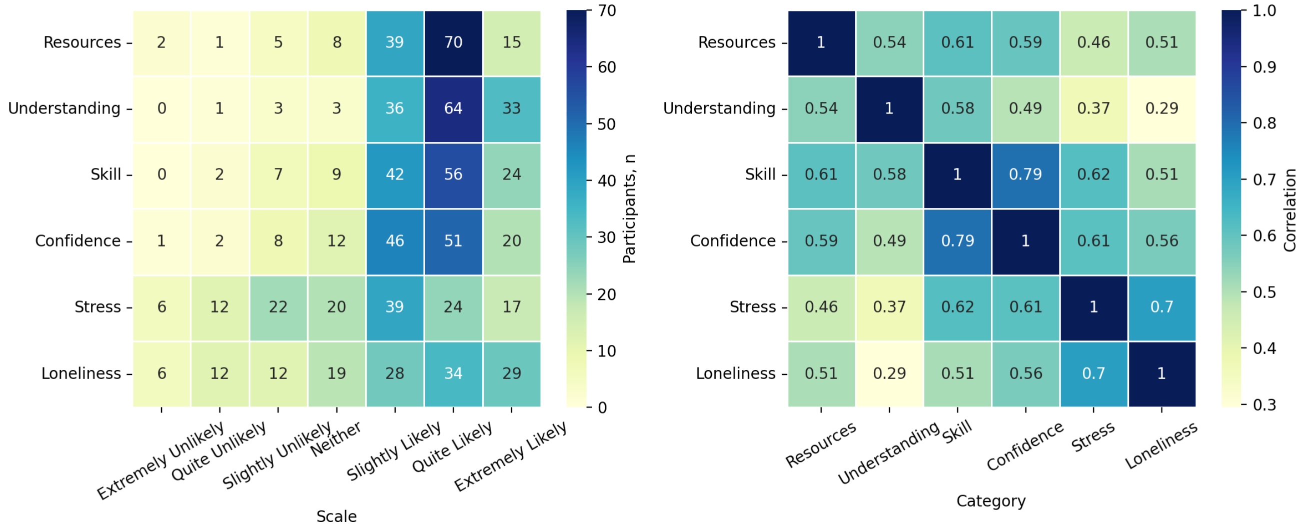


Figure 3. Heat maps of the number of survey participants in each belief category and scale pair (left) and the correlations in the responses (right). *Resources*: obtain the needed resources; *Understanding*: understanding patients or the disease; *Skill*: improve caregiving skills; *Confidence*: increase caregiving confidence or competence; *Stress*: reduce caregiving stress; *Loneliness*: reduce the feeling of loneliness as a caregiver.



	Extremely Unlikely	Quite Unlikely	Slightly Unlikely	Neither	Slightly Likely	Quite Likely	Extremely Likely
Resources	2	1	5	8	39	70	15
Understanding	0	1	3	3	36	64	33
Skill	0	2	7	9	42	56	24
Confidence	1	2	8	12	46	51	20
Stress	6	12	22	20	39	24	17
Loneliness	6	12	12	19	28	34	29

	Resources	Understanding	Skill	Confidence	Stress	Loneliness
Resources	1	0.54	0.61	0.59	0.46	0.51
Understanding	0.54	1	0.58	0.49	0.37	0.29
Skill	0.61	0.58	1	0.79	0.62	0.51
Confidence	0.59	0.49	0.79	1	0.61	0.56
Stress	0.46	0.37	0.62	0.61	1	0.7
Loneliness	0.51	0.29	0.51	0.56	0.7	1

Utilization of Online Peer Support

Of the 140 survey participants, 40 (28.6%) reported never using any online community to either read online caregiving discussions or discuss caregiving issues with other online peers in the past 3 months. The regression analysis showed that only the belief score was statistically significantly associated with the utilization of online peer support (β: 0.11, SD 0.041; *P*=.006). All the other factors, including sociodemographics, care duration and workload, dementia stage, access to a high-speed network, eHealth literacy, stress score, and competence score, did not have statistically significant effects (all *P* values were >.10). Additionally, of the 40 non–online community caregivers, 33 (83%) had a belief score above 24—the score when “neutral” was selected for all the questions. The reasons for not using any online community to access online peer support included having no time for online activities due to the intensive caregiving workload (14/140, 10%), having a lack of searching skills (9/140, 6.4%), having belief in unreliable online information (6/140, 4.3%), and having security and privacy concerns (2/140, 1.4%). Further, 4 (2.9%) caregivers reported not wanting to spend time online after working on a computer during the daytime. Interestingly, 99 of the 100 online community caregivers reported an intention to revisit online communities in the following 3 months. The only caregiver who did not do so said that too many sad stories in online communities made her worry about her father’s future.

Discussion

Principal Results

When comparing with *2022 Alzheimer’s Disease Facts and Figures* (AFF) [1], we observed that our survey recruited a similar proportion of caregivers who were Hispanic caregivers (our survey: 10/140, 7.1%; AFF: 8%) and Asian caregivers (our survey: 8/140, 5.7%; AFF: 5%). However, the proportion of Black or African American caregivers we recruited was far below that reported in AFF (our survey: 5/140, 3.6%; AFF: 10%), which suggests that Asian and Hispanic caregivers are more likely to participate in research studies when compared to Black caregivers [38]. To gain greater insight into the situation, we reviewed the responses of the five caregivers who reported their race as Black. We found that two of the caregivers accessed online communities in the past 3 months, with one (age: 49 y; education level: college degree; stress score: 51) reporting this at least once per week and the other (age: 50 y; education level: more than a 4-y college degree; stress score: 19) reporting doing this when she had a caregiving question that needed an answer. Among the three remaining caregivers who reported their race as Black and did not access any online community in the past 3 months, one (age: 60 y; education level: 4-y college degree; stress score: 55) said, “I have used books and I think some information on the internet can be misinterpreted”; another one (age: 29 y; education level: some college or 2-y degree; stress score: 55) said, “In [*sic*] recently started looking for online communities”; and the third (age: 30 y; education level: some college or 2-y degree; stress score: 52) said that they were “unaware.” However, all their belief scores were above 24 and ranged from 25 to 42, which suggests that these three caregivers believed in the value of online peer support, but they may not have known how to search online communities for peer support. Notably, the caregiver who relied on books for information seeking exhibited the lowest belief score (ie, a score of 25), indicating the survey results’ reliability.

Our study shows that the most prevalent challenges faced by these informal caregivers were (1) handling the memory issues of a person living with dementia, (2) daily caregiving, (3) life balance, and (4) emotional fluctuations. Caregivers facing such challenges can, at times, receive guidance from their peers who have shared the same firsthand experiences. This suggests that online communities, such as ALZConnected, that provide an online platform for caregivers to discuss their challenges and experiences can be a valuable resource for those seeking informational or emotional peer support. This implication is further supported by our observation that a large proportion of the surveyed caregivers indicated a belief in the value of online peer support. Still, given that some caregivers did not access online environments for peer support, it is evident that online environments alone are not a comprehensive solution and that caregivers need other types of support. Moreover, there are various caregiving challenges that are more likely to be addressed by professionals rather than peers, such as clinical questions about treatment, legal issues, and financial concerns. Given that 50.7% (71/140) of the survey participants were not satisfied with their received support, it is essential to diversify the support source portfolio to assist a broad range of caregivers. As such, the use of online environments can serve as one of a collection of strategies that, in concert with one another, provide a support structure for informal caregivers.

Another main result of this study is that whether an informal dementia caregiver accessed online health communities in the past 3 months depended upon their belief in the value of peer support obtained from online health communities but not upon their sociodemographics or any other ANFHSU factors. For example, one caregiver said, “I don’t find comfort from strangers on the internet. I would love to, and I am willing to go to an in-person meeting of a support group, but I don’t have anyone to watch my mother so that I could attend,” and they exhibited a belief score of 14, which is logical based on their reason for not accessing any online communities. This further highlights the dilemma that there is limited time to attend local support groups because of intensive caregiving [15]. Another caregiver, who had a belief score of 14, indicated that their health insurance could only cover 40 days of at-home nursing support in 1 year, which made their family feel so “helpless and alone.” Despite various reasons for not using online health communities in the past 3 months, 89.3% (125/140) of respondents exhibited a belief score above 24. This suggests that online peer support was valuable to them, but an effective strategy for bridging their needs and the desired online peer support is needed. Finally, the correlation of the survey responses to the six value aspects implied that an intervention designed around peer learning can effectively enhance a caregiver’s caregiving competence and reduce feelings of loneliness.

Limitations

There are, however, several limitations to this study that can serve as a basis for future research. First, since we distributed our survey link in the ALZConnected online community and the Alzheimer’s Association’s website, our results may be biased toward online community users. A less biased approach may be designed to collect data that reflect the perceptions and utilization of online peer support in the dementia caregiver population. Making online peer support beneficial to noninternet caregivers is equally essential, but determining how to address the internet access issue is a priority and is beyond the scope of this study. Second, only a small percentage of the participants were caregivers who reported their race as Black. Increasing participation in this group would increase the understanding of their perceptions and utilization of online peer support. Third, the analysis relied on 140 completed responses, indicating limited statistical power. Although statistically significant findings emerged, larger sample sizes are necessary for a more precise examination of this research. Fourth, in an open-ended question, we inquired about the types of offline support caregivers received to address their caregiving challenges. Some caregivers mentioned online peer support in their responses, leading to misalignment between their answers and the original research design, particularly regarding satisfaction with offline support. Future investigations should clarify this question or convert this question to a multiple-choice version. Finally, it is essential to study how to help caregivers without time or sufficient online information–searching skills screen the online caregiving discussions they need.

Conclusions

This study reported on an online survey about the perceptions and utilization of online peer support among informal dementia caregivers. Belief in the value of online peer support was statistically significantly associated with accessing online communities (*P*=.006). Moreover, there were a number of caregivers who were not using online peer support but held belief in the value of such support. As such, there is clearly an opportunity to build tools that help caregivers who are existing online community users and caregivers who intend to seek online information find reliable, matched online peer support.

Acknowledgments

ZY and L Stratton designed the survey questionnaire. L Song provided the theoretical support for the survey design. L Song and PC revised the survey questionnaire. QS implemented the questionnaire with REDCap (Research Electronic Data Capture). L Stratton disseminated the questionnaires. CN conducted the regression analysis. QS collected and cleaned the survey responses. ZY drafted the first version of the manuscript. All the other authors edited and approved the manuscript.

Conflicts of Interest

None declared.

References

1. 2022 Alzheimer's disease facts and figures. Alzheimers Dement 2022 Apr;18(4):700-789. [doi: 10.1002/alz.12638] [Medline: 35289055]
2. Corbett A, Stevens J, Aarsland D, et al. Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. Int J Geriatr Psychiatry 2012 Jun;27(6):628-636. [doi: 10.1002/gps.2762] [Medline: 22038644]
3. Oh S, Syn SY. Motivations for sharing information and social support in social media: a comparative analysis of Facebook, Twitter, Delicious, YouTube, and Flickr. . 2015 Apr 21(10) p. 2045-2060. [doi: 10.1002/asi.23320]
4. Barnes LL, de Leon CFM, Wilson RS, Bienias JL, Evans DA. Social resources and cognitive decline in a population of older African Americans and Whites. Neurology 2004 Dec 28;63(12):2322-2326. [doi: 10.1212/01.wnl.0000147473.04043.b3] [Medline: 15623694]
5. Boss L, Kang DH, Branson S. Loneliness and cognitive function in the older adult: a systematic review. Int Psychogeriatr 2015 Apr;27(4):541-553. [doi: 10.1017/S1041610214002749] [Medline: 25554219]
6. Fratiglioni L, Wang HX, Ericsson K, Maytan M, Winblad B. Influence of social network on occurrence of dementia: a community-based longitudinal study. Lancet 2000 Apr 15;355(9212):1315-1319. [doi: 10.1016/S0140-6736(00)02113-9] [Medline: 10776744]
7. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. PLoS Med 2010 Jul 27;7(7):e1000316. [doi: 10.1371/journal.pmed.1000316] [Medline: 20668659]
8. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci 2015 Mar;10(2):227-237. [doi: 10.1177/1745691614568352] [Medline: 25910392]
9. Wennberg A, Dye C, Streetman-Loy B, Pham H. Alzheimer’s patient familial caregivers: a review of burden and interventions. Health Soc Work 2015 Nov;40(4):e162-e169. [doi: 10.1093/hsw/hlv062]
10. Devor M, Renvall M. An educational intervention to support caregivers of elders with dementia. Am J Alzheimers Dis Other Demen 2008;23(3):233-241. [doi: 10.1177/1533317508315336] [Medline: 18364457]
11. Kwok T, Au A, Wong B, Ip I, Mak V, Ho F. Effectiveness of online cognitive behavioral therapy on family caregivers of people with dementia. Clin Interv Aging 2014 Apr 11;9:631-636. [doi: 10.2147/CIA.S56337] [Medline: 24748781]
12. Cheng ST, Mak EPM, Kwok T, Fung H, Lam LCW. Benefit-finding intervention delivered individually to Alzheimer family caregivers: longer-term outcomes of a randomized double-blind controlled trial. J Gerontol B Psychol Sci Soc Sci 2020 Oct 16;75(9):1884-1893. [doi: 10.1093/geronb/gbz118] [Medline: 31556447]
13. Sanders S, Ott CH, Kelber ST, Noonan P. The experience of high levels of grief in caregivers of persons with Alzheimer’s disease and related dementia. Death Stud 2008;32(6):495-523. [doi: 10.1080/07481180802138845] [Medline: 18958942]

14. Woods RT, Orrell M, Bruce E, et al. REMCARE: pragmatic multi-centre randomised trial of reminiscence groups for people with dementia and their family carers: effectiveness and economic analysis. PLoS One 2016 Apr 19;11(4):e0152843. [doi: 10.1371/journal.pone.0152843] [Medline: 27093052]
15. Brodaty H, Thomson C, Thompson C, Fine M. Why caregivers of people with dementia and memory loss don’t use services. Int J Geriatr Psychiatry 2005 Jun;20(6):537-546. [doi: 10.1002/gps.1322] [Medline: 15920707]
16. Park VMT, Ly Q, von Oppenfeld J, et al. A scoping review of dementia caregiving for Korean Americans and recommendations for future research. Clin Gerontol 2023;46(2):223-239. [doi: 10.1080/07317115.2022.2133907] [Medline: 36268979]
17. Bruinsma J, Peetoom K, Bakker C, Boots L, Verhey F, de Vugt M. 'They simply do not understand': a focus group study exploring the lived experiences of family caregivers of people with frontotemporal dementia. Aging Ment Health 2022 Feb;26(2):277-285. [doi: 10.1080/13607863.2020.1857697] [Medline: 33325262]
18. Beeson RA. Loneliness and depression in spousal caregivers of those with Alzheimer’s disease versus non-caregiving spouses. Arch Psychiatr Nurs 2003 Jun;17(3):135-143. [doi: 10.1016/s0883-9417(03)00057-8] [Medline: 12840806]
19. Kovaleva M, Spangler S, Clevenger C, Hepburn K. Chronic stress, social isolation, and perceived loneliness in dementia caregivers. J Psychosoc Nurs Ment Health Serv 2018 Oct 1;56(10):36-43. [doi: 10.3928/02793695-20180329-04] [Medline: 29667698]
20. Yin Z, Xie W, Malin BA. Talking about my care: detecting mentions of hormonal therapy adherence behavior in an online breast cancer community. AMIA Annu Symp Proc 2018 Apr 16;2017:1868-1877. [Medline: 29854258]
21. Yin Z, Malin B, Warner J, Hsueh PY, Chen CH. The power of the patient voice: learning indicators of treatment adherence from an online breast cancer forum. In: Proceedings of the Eleventh International AAAI Conference on Web and Social Media: AAAI Press; 2017, Vol. 11:337-346. [doi: 10.1609/icwsm.v11i1.14892]
22. Home - ALZConnected. ALZConnected. URL: https://alzconnected.org/ [accessed 2024-05-06]
23. Cheng K, Yin Z. "Please Advise": understanding the needs of informal caregivers of people with Alzheimer’s disease and related dementia from online communities through a structured topic modeling approach. AMIA Jt Summits Transl Sci Proc 2022 May 23;2022:149-158. [Medline: 35854737]
24. Erdelez S, Tanacković SF, Balog KP. Online behavior of the Alzheimer’s disease patient caregivers on Croatian online discussion forum. Proc Assoc Inf Sci Technol 2019 Oct 18;56(1):78-88. [doi: 10.1002/pra2.8]
25. Leszko M. The role of online communication among spousal caregivers of individuals with Alzheimer’s disease. J Women Aging 2020;32(4):462-480. [doi: 10.1080/08952841.2020.1754119] [Medline: 32302267]
26. Hodgkin P, Horsley L, Metz B. The emerging world of online health communities. Stanf Soc Innov Rev 2018 Apr 10. [doi: 10.48558/9JGH-H283]
27. Ni C, Malin B, Song L, Jefferson A, Commiskey P, Yin Z. “Rough Day … Need a Hug”: learning challenges and experiences of the Alzheimer’s disease and related dementia caregivers on Reddit. In: Proceedings of the Sixteenth International AAAI Conference on Web and Social Media: AAAI Press; 2022, Vol. 16:711-722. [doi: 10.1609/icwsm.v16i1.19328]
28. Vaughan C, Trail TE, Mahmud A, Dellva S, Tanielian T, Friedman E. Informal caregivers’ experiences and perceptions of a web-based peer support network: mixed-methods study. J Med Internet Res 2018 Aug 28;20(8):e257. [doi: 10.2196/jmir.9895] [Medline: 30154074]
29. Olagoke A, Kaur H, Hughes AM. Digital divide among caregivers of chronic disease patients. Proc Int Symp Hum Factors Ergon Health Care 2019 Sep 15;8(1):43-46. [doi: 10.1177/2327857919081010]
30. Andersen RM, Newman JF. Andersen and Newman Framework of Health Services Utilization. J Health Soc Behav 1995 Mar;36:1-10.
31. Song L, Zhang Z. Social support. In: McLevey J, Scott J, Carrington PJ, editors. The Sage Handbook of Social Network Analysis: Sage Publications; 2023:322-335.
32. Sanders CK, Scanlon E. The digital divide is a human rights issue: advancing social inclusion through social work advocacy. J Hum Rights Soc Work 2021;6(2):130-143. [doi: 10.1007/s41134-020-00147-9] [Medline: 33758780]
33. Norman CD, Skinner HA. eHEALS: the eHealth Literacy Scale. J Med Internet Res 2006 Nov 14;8(4):e27. [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
34. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O’Donnell M. The Zarit Burden Interview: a new short version and screening version. Gerontologist 2001 Oct;41(5):652-657. [doi: 10.1093/geront/41.5.652] [Medline: 11574710]
35. Chiu M, Wesson V, Sadavoy J. Improving caregiving competence, stress coping, and mental well-being in informal dementia carers. World J Psychiatry 2013 Sep 22;3(3):65-73. [doi: 10.5498/wjp.v3.i3.65] [Medline: 24255878]
36. REDCap. Research Electronic Data Capture. URL: https://www.project-redcap.org/ [accessed 2024-05-06]
37. Alzheimer's disease & dementia help. Alzheimer’s Association. URL: https://www.alz.org/ [accessed 2024-05-06]
38. Barrett NJ, Ingraham KL, Vann Hawkins T, Moorman PG. Engaging African Americans in research: the recruiter’s perspective. Ethn Dis 2017 Dec 7;27(4):453-462. [doi: 10.18865/ed.27.4.453] [Medline: 29225447]

Abbreviations

AFF: *2022 Alzheimer’s Disease Facts and Figures*

ANFHSU: Andersen and Newman Framework of Health Services Utilization
CARERS: Coaching, Advocacy, Respite, Education, Relationship, and Simulation
eHEALS: eHealth Literacy Scale
REDCap: Research Electronic Data Capture

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Original Paper

The #SeePainMoreClearly Phase II Pain in Dementia Social Media Campaign: Implementation and Evaluation Study

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Abstract

Background: Social media platforms have been effective in raising awareness of the underassessment and undertreatment of pain in dementia.

Objective: After a successful pilot campaign, we aimed to scale our pain-in-dementia knowledge mobilization pilot initiative (ie, #SeePainMoreClearly) to several social media platforms with the aid of a digital media partner. The goal of the initiative was to increase awareness of the challenges in the assessment and management of pain among people with dementia. A variety of metrics were implemented to evaluate the effort. Through this work, we endeavored to highlight key differences between our pilot initiative (which was a grassroots initiative), focusing largely on Twitter and YouTube, and the current science-media partnership. We also aimed to generate recommendations suitable for other social media campaigns related to health or aging.

Methods: Evidence-based information about pain in dementia was summarized into engaging content (eg, videos) tailored to the needs of various knowledge users (eg, health professionals, families, and policy makers). We disseminated information using Facebook (Meta Platforms), Twitter (X Corp), YouTube (Alphabet Inc), Instagram (Meta Platforms), and LinkedIn (LinkedIn Corp) and measured the success of the initiative over a 12-month period (2020 to 2021). The evaluation methods focused on web analytics and questionnaires related to social media content. Knowledge users' web responses about the initiative and semistructured interviews were analyzed using thematic analysis.

Results: During the course of the campaign, >700 posts were shared across all platforms. Web analytics showed that we drew >60,000 users from 82 countries to our resource website. Of the social media platforms used, Facebook was the most effective in reaching knowledge users (ie, over 1,300,000 users). Questionnaire responses from users were favorable; interview responses indicated that the information shared throughout the initiative increased awareness of the problem of pain in dementia and influenced respondent behavior.

Conclusions: In this investigation, we demonstrated success in directing knowledge users to a resource website with practical information that health professionals could use in patient care along with pain assessment and management information for caregivers and people living with dementia. The evaluation metrics suggested no considerable differences between our pilot campaign and broader initiative when accounting for the length of time of each initiative. The limitations of large-scale health campaigns were noted, and recommendations were outlined for other researchers aiming to leverage social media as a knowledge mobilization tool.

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KEYWORDS

knowledge translation; Twitter; older adults; Facebook; knowledge mobilization

Introduction

Background

Social media platforms play an important role in academic dissemination and have untapped potential as knowledge mobilization (KM) tools that can allow researchers to interact directly with the public worldwide [1]. KM encompasses activities involved in the synthesis and dissemination of research information; this process includes knowledge synthesis, dissemination, transfer, exchange, and cocreation by researchers and knowledge users [2]. Knowledge users, such as older adults and their families, are increasingly turning to web-based platforms (eg, Twitter [subsequently rebranded as X] and Facebook) to share and obtain information [3,4]. Health-related initiatives on social media networks have successfully raised awareness about a host of topics (eg, mental health, breastfeeding, and cancer) [5]. For example, a nationwide HIV prevention campaign (#PrEP4Love) garnered >40 million views across various social media platforms [6].

Researchers have supplemented social media KM initiatives with other web-based KM methods (eg, web-based repositories, educational videos, and community groups) [7,8]. Despite the innovation of this approach, the sustainability of social media health campaigns is contingent upon different factors (eg, continued content generation and ongoing funding) [9]. As such, there is a growing need for partnerships with digital media experts to aid in health KM. A notable example of this is the work by Chambers [10], who mobilized knowledge about pediatric pain within the context of a science-media partnership through her #ItDoesntHavetoHurt campaign. The initiative demonstrated worldwide impact and great success in producing and disseminating digital evidence–based content tailored to the needs of parents and health professionals, obtaining 1.3 million Twitter impressions, 5.5 million hashtag mentions, and >250,000 views of her YouTube video [10]. Impact was also demonstrated through indices of adoption and changed practices [10].

Although researchers have attempted to track the reach and impact of social media for KM through web metrics and the use of social listening software [11,12], very little research has been conducted using social media for KM in older adults with dementia. To address limitations in the reach of traditional KM campaigns and a gap in the literature, we launched and evaluated the pilot #SeePainMoreClearly (phase I) social media KM campaign with messages that reached >2,376,853 unique individuals on Twitter [9]. The goal of the pilot initiative was to increase awareness of the challenges in the assessment and management of pain among people with moderate to severe dementia with limited ability to communicate [13,14]. Moreover, we aimed to disseminate information on evidence-based approaches to effectively assess and manage pain in this population (eg, [15-18]). To maximize uptake, we created a web-based repository of pain assessment and management information [19]. We also prepared an engaging 2-minute YouTube video with evidence-based information about pain in dementia [20].

The script for the video was created and modified with input from health professionals, caregiver partners, researchers, and knowledge user organizations. The pilot campaign was evaluated by tracking social media and web metrics and by conducting qualitative analyses of social media posts in response to the #SeePainMoreClearly campaign over a 5-month period. #SeePainMoreClearly demonstrated substantial reach with >5,000,000 hashtag impressions on Twitter. The short video was viewed >50,000 times, and our web-based repository was visited by people in >55 countries. Moreover, the content analysis of social media posts (ie, tweets) from users who used the hashtag or responded to our messaging and content posted on Twitter were favorable. Many users expressed support for the initiative and increased advocacy for improved pain care for people living with dementia.

Our findings showed the effectiveness of web-based KM methods in reaching very broad international audiences quickly. Perhaps most importantly, without counting the posts that were produced by members of our team, the initiative doubled the number of posts made on the topic of pain dementia on Twitter during the campaign period as compared with a control period of the previous year [9]. It is important to note that the #SeePainMoreClearly pilot campaign took place in 2019, before the COVID-19 pandemic. The pilot #SeePainMoreClearly was a grassroots initiative in which a small number of researchers prepared engaging materials and disseminated them on their own with support from several knowledge user organizations that agreed to help disseminate the message. A lesson from the pilot #SeePainMoreClearly experience was that although KM grassroots campaigns can be very successful, lengthier social media campaigns (run solely by researchers) would not be sustainable, as involvement can be very time-consuming for researchers who generally must attend to multiple other obligations. A partner with digital media expertise and time to dedicate resources is necessary for a sustainable large-scale KM campaign. Hence, we sought and obtained funding to support such a partnership.

Objectives

The primary purpose of this study was to launch and evaluate a longer (12 months instead of 5 months) #SeePainMoreClearly campaign with expanded social media platform coverage (eg, Twitter, Instagram, Facebook, and LinkedIn as opposed to just Twitter) with the following additional objectives:

1. Track the reach of a larger social media KM campaign over a 12-month period on various platforms (eg, Facebook, Twitter, Instagram, and LinkedIn)
2. Evaluate the impact of the campaign on knowledge users' (eg, patient, caregiver, health professional, and policy maker) knowledge
3. Evaluate the impact of a science-media partnership on our pilot campaign in meeting knowledge users' needs
4. Outline recommendations to develop and scale social media KM initiatives.

We expected the results to demonstrate a large scope and breadth of our campaign, resulting in a large number of visits to our resource website [19]. Moreover, we predicted that our results would demonstrate the value of a science-media partnership as a strategy for improving KM in the area of pain in dementia. We contrast the experiences of the digital media partnership campaign with the pilot #SeePainMoreClearly campaign. The findings from this project can inform subsequent evaluations of social media as a KM tool.

Methods

Ethical Considerations

The evaluation process involving contact with human participants (eg, questionnaires and semistructured interviews) was approved by the University of Regina Research Ethics Board (#REB 2020-036).

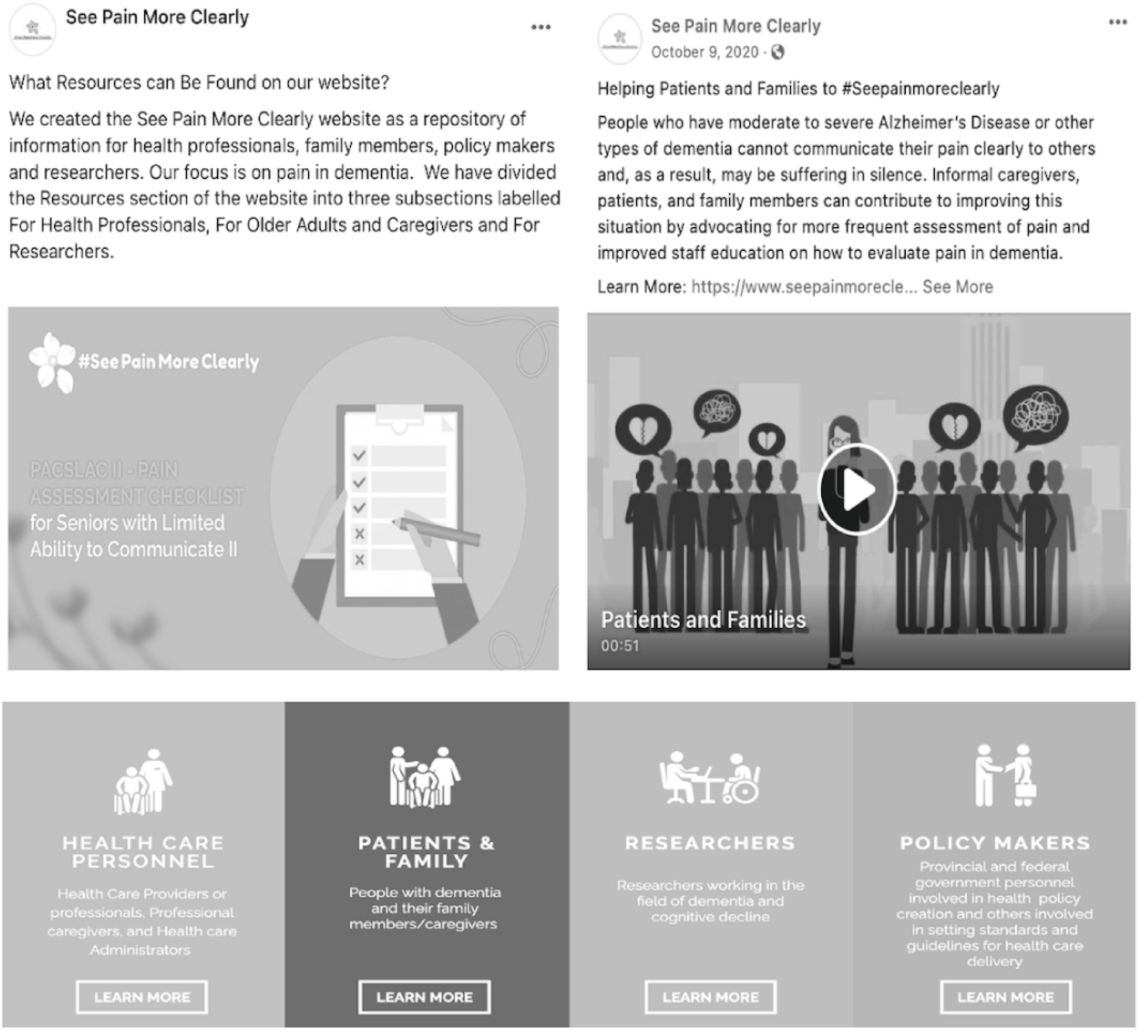
Identification and Engagement of Digital Media Partner

Given the nature of our funding, we were restricted to identify a digital media partner within our home province. As such, a web search was conducted to identify potential locally based digital media partners that listed social media promotion as part of their services. We then communicated with 2 of the firms that, based on their websites, seemed highly experienced with social media marketing and described the nature of our work to confirm that they understood the needs of our project and that they were interested in partnering with us for the campaign. Our institution required us to subject the project to an open competitive bidding process before awarding the contract. This process allows qualified bidders to submit proposals and budgets. The 2 firms with which we had communicated were invited to submit their proposals. On the basis of this process, the best qualified bidder who offered competitive pricing was selected from a total of 3 bidders.

Development of Content and the Campaign

We worked with the selected digital media partner to develop the campaign content and KM strategy as well as to collect social media analytics in response to our campaign. An iterative process was implemented with team collaborators (eg, caregiver partners, researchers with knowledge of the content area, media experts, and health care professionals) with the aim of developing lay summaries of evidence-based information about pain in dementia. Specifically, a series of web-based meetings with members of the team were coordinated to identify pertinent information about pain assessment and management among older adults with dementia, which served as the basis of the campaign's content. Accordingly, the general topics agreed upon by the team were as follows: (1) the feasibility of regular pain assessments, (2) available guidelines for pain assessment, (3) resources for informal caregivers, (4) effects of psychotropic medication in long-term care (LTC), (5) validated pain assessment tools, (6) implementing regular pain care in LTC, (7) gaps in education for health professionals and ways to address this challenge, (8) effects of untreated pain in dementia, (9) pain care during the COVID-19 pandemic, (10) cost of untreated pain for the health care system, (11) benefits of regular pain assessments, and (12) effective ways to assess pain in dementia. Once the general topics were identified, information was gathered that corresponded to established guidelines (eg, [17,18,21,22]) or was supported by published research in leading peer-reviewed journals. Specific evidence-based information was selected by our team, which included content experts and caregivers with lived experience. Next, the team developed lay summaries (eg, 200-300 words) of the evidence present in the literature covering each aforementioned topic (eg, [17,18,21,22]). Several rounds of refinement were conducted by team members. Following this, the team developed 8 cross-cutting messages and key points (Multimedia Appendix 1) divided by the target group (eg, health professionals, policy makers, and public or families). These messages were then relayed to the digital media team as the basis for the messaging developed for the campaign. The digital marketing team developed a series of images and posts for each target group. Moreover, a short animated (ie, 2-minute long) video was created for each target group (eg, family, health care professionals, researchers, and policy makers). The animated videos were posted on the web page and on social media platforms. Examples of the content and posts are shown in Figure 1. Blog posts written by team members and people with lived experiences related to the topics outlined in this section were shared throughout the initiative. A total of 42 blog posts [23] were created and posted on the web page of this project.

Figure 1. Digital content samples shared throughout the initiative.



See Pain More Clearly

What Resources can Be Found on our website?

We created the See Pain More Clearly website as a repository of information for health professionals, family members, policy makers and researchers. Our focus is on pain in dementia. We have divided the Resources section of the website into three subsections labelled For Health Professionals, For Older Adults and Caregivers and For Researchers.

See Pain More Clearly
October 9, 2020 ·

Helping Patients and Families to #Seepainmoreclearly

People who have moderate to severe Alzheimer's Disease or other types of dementia cannot communicate their pain clearly to others and, as a result, may be suffering in silence. Informal caregivers, patients, and family members can contribute to improving this situation by advocating for more frequent assessment of pain and improved staff education on how to evaluate pain in dementia.

Learn More: https://www.seepainmorecle... See More

Dissemination Strategy

Unlike the pilot campaign [9], which focused on Twitter and YouTube, information was disseminated on 5 social media platforms used for the campaign: Facebook (Meta Platforms), Twitter (X Corp), YouTube (Alphabet Inc), Instagram (Meta Platforms), and LinkedIn (LinkedIn Corp).

A total of 756 posts were shared across Facebook, Twitter, Instagram, and LinkedIn, and 5 videos were posted on YouTube over a 12-month period (ie, October 1, 2020, to September 30, 2021). A key goal of the dissemination strategy was to direct knowledge users to the web-based repository to share further information and resources about pain in dementia [19]. We designed the content (eg, social media posts, images, and short animated videos) to be of interest to our target groups. Moreover, we developed social media posts to gain the attention of specific target groups (eg, by including an image with the statement *Resources for researchers* prominently displayed). As with the pilot initiative, the #SeePainMoreClearly hashtag was used to maximize the reach of the content and information. We leveraged events (eg, the International Day of Older Persons in October, World Alzheimer Awareness Month in September, and Alzheimer Awareness Month in January) to develop tailored content. The total amount of money spent on post promotion and advertisements was CAD $29,793.86 (US $22,133.06); the vast majority of this amount was spent on Facebook and Instagram, CAD $26,384 (US $19,599.96), Twitter, CAD $3045 (US $2262.05), and LinkedIn, CAD $364.86 (US $271.04).

Evaluation of the Campaign

Engagement and Reach of the Initiative

Web Analytics

A longitudinal data collection strategy was used to obtain web and social media metrics over a 12-month campaign period (ie, October 1, 2020, to September 30, 2021). For the website, the number of content viewers and pages views were tracked using Google Analytics [24]. For our analysis, we reported a descriptive count (eg, count of total engagement, reach, and impressions) of all web and social media analytics. Google Analytics was used to collect data from the website. To clarify how Google Analytics works, each time a user visits a web page, a tracking code by Google Analytics collects information on how that user interacted with the page [25]. Google Analytics then aggregates and organizes this information in the Google Analytics portal as a report detailing different metrics (eg, the count of web page visits and the number of pages viewed). Similarly, the social media metrics were aggregated by each social media platform. This information was accessed through the social media platform’s website (eg, Facebook Analytics). Web and social media analytics were exported and reported.

Social Media Analytics

The reach, scope, and engagement of the initiative and web-based repository were monitored through social media metrics (eg, web analytics, hashtag analytics, and social media analytics). Similar metrics have been used in previous research to quantify the impact of social media initiatives [10,12]. The number of impressions (ie, the number of times users have seen the web-based content), reach (ie, the number of unique users who have seen the web-based content), and engagement (ie, the number of comments, retweets, “likes,” and shares) were extracted using the analytics provided by each platform. Not all analytics were available for each social media platform (eg, reach was not available for LinkedIn). Analytics were summarized based on three sources of information: (1) analytics of only paid posts provided by the social media platform, (2) analytics of the total number of posts (ie, paid and unpaid) provided by the social media platform, and (3) third-party social media analytics manager (eg, CloudCampaign) provided by the digital marketing team. Moreover, our digital media partner could only obtain data for specific periods (eg, year-long data could not always be obtained) for some platforms owing to limitations in the sources of information. Nevertheless, attempts were made to encompass the entire evaluation period. Depending on the data source, data were provided from (1) October 1, 2020, to September 3, 2021; (2) October 1, 2020, to November 2, 2020; or (3) November 3, 2020, to September 30, 2021. Thus, the reported numbers varied as a function of the period. The Keyhole social media monitoring (also known as social listening) software [26] was used to collect the metrics and analytics for the #SeePainMoreClearly hashtag on Twitter.

Knowledge Users’ Responses to the Initiative

Semistructured Interviews With Knowledge Users

Individuals who viewed and engaged with the content (eg, responded to social media posts or added their own commentary when reposting content shared throughout the initiative) on social media were invited to participate (ie, research personnel commented back to users who responded to social media posts and invited them to participate in interview) in semistructured interviews with a researcher to gain an understanding of their perceptions about the initiative. Moreover, invitations (ie, through social media posts or recruitment posters) to participate in the interview were circulated across social media platforms. All participants recruited through social media posts were asked to contact the research team to indicate their interest. The interviews were conducted over Zoom (Zoom Video Communications Inc) audio-only and covered the following topics: perceptions about the initiative, quality of information and messages disseminated, and impact of the initiative on knowledge and behavior (Multimedia Appendix 2). Zoom’s automated transcription feature was used to facilitate the transcription of the interviews. The transcription was then reviewed with the interview audio recording to ensure accuracy. NVivo (version 12; Lumivero) software [27] was used to facilitate the coding reliability thematic analysis [28]. Two independent researchers initially organized a subset of data into clusters based on commonalities and recurring ideas to develop a coding book [28]. Consistent with a coding reliability thematic analysis approach, themes were developed inductively and aligned with the data collection questions of the study [28]. Themes that emerge from this analysis can be viewed as a summary of the participant responses. Codes were developed after data familiarization, while keeping the data collection questions in mind. Two coders individually coded a subset (3/13, 20%) of the data to develop a coding book. They grouped each line of text into clusters and then into higher-level codes (ie, themes). The coders then met to discuss and finalize the coding book. Discrepancies between the coding researchers and decisions to merge or split categories were discussed throughout the process until a consensus was reached. The developed coding book was applied to the remaining data to identify the prevalent categories and obtain a frequency count of the identified themes. To ensure rigor in our analysis, we conducted consistency checks on the coded themes and categories (eg, discussing discrepancies between coders) and maintained ongoing communication among coders throughout the process to establish consensus. Moreover, a randomly selected subset of data was coded to assess intercoder agreement. Triangulation was considered through the different perspectives (eg, health professionals, caregivers, and people with dementia) obtained in this study and the use of a mixed methods approach (ie, use of interview and numeric questionnaire data). A primary coder coded the entire data set, and a secondary coder coded a subset of the data to establish intercoder agreement. The second coder coded a randomly selected 20% (3/13) of the participant data. NVivo calculates a κ coefficient to evaluate agreement as follows: total units of agreement between the 2 coders minus the expected frequency of the agreement occurring by chance, divided by the total units within the source minus the expected frequency of the agreement occurring by chance [29].

Social Media Comments About the Campaign

Social media analytics do not provide information about the content of the comments in response to our initiative (ie, whether users liked or disliked the content). As such, we analyzed the responses to the initiative to better understand users’ perception of our campaign. To assess the perception of a wider sample of knowledge users, comments by web users in response to the posts made during the campaign across Facebook, Twitter, Instagram, and LinkedIn were collected manually and subjected to a coding reliability thematic analysis, consistent with the method outlined in the *Semistructured Interviews With Knowledge Users* section. The aim was to understand the type of comment (ie, opinion, personal experiences, and information) in response to the content shared to determine prevalent themes.

Overview of Evaluation Questionnaires

A brief survey was circulated across the campaign’s social media platforms to receive feedback about users’ perception of the content and information shared during the initiative. The participants were recruited via invitations on social media platforms. For example, social media posts were created to encourage participants to provide their input on the initiative by clicking on the link that directed users to the questionnaires. The link to the questionnaire was also available on the website for this project. Individuals who accessed the surveys were asked to indicate the group they belonged to (1) caregiver, family member, or friend of a person with dementia, (2) person living with dementia, (3) public, (4) health professional, or (5) policy maker. Demographic information questions about participant age, gender, country, relationship with the person living with dementia, and type of health care provider (ie, for individuals who identified as a health care professional) were collected and outlined using descriptive and frequency statistics.

Pain in Dementia Evaluation Questionnaire

A short questionnaire, used in the pilot campaign evaluation [9], was used to solicit anonymous responses from various knowledge users. The survey included both general and specific questions for the general public, health professionals, and caregivers and family of people with dementia. Most responses were provided along 7-point Likert scales (eg, 1=not very likely to 7=very likely) and focused on viewers' opinions about the initiative, content, and likelihood of using the information provided. Descriptive statistics were calculated for the Likert scale items in the evaluation questionnaire.

Information Assessment Method for All

Users' perception of the content and potential benefit of the information were assessed using the IAM4all (Information Assessment Method for All) [30]. The IAM4all consists of 6 general questions assessing information relevance and use, with nested follow-up questions depending on participant responses. Accordingly, the IAM4all is a 28-item self-report questionnaire designed to measure 4 levels of outcomes associated with receiving or seeking web-based information: situational relevance, cognitive impact, information use, and health benefits. Each item is rated based on agreement to a question (ie, yes, no, or possibly). Content validity of the IAM4all has been substantiated through a review of the theories of information science and feedback from knowledge users (eg, laypersons, health professionals, and experts) [30]. Descriptive and frequency statistics were used to calculate the means and SDs for the items in the questionnaire.

Web-Based Discussions About Pain in Dementia

The level of web-based discussions about pain in dementia was determined by examining the number of posts on Twitter and Facebook. Three periods of comparison were established: (1) a precampaign period (ie, a 7-month period following the end of the pilot campaign and before the start of #SeePainMoreClearly phase II, March 1, 2020, to September 30, 2020); (2) a campaign period (October 1, 2020, to September 30, 2021); and (3) a postcampaign period (ie, a corresponding 7-month period following the end of #SeePainMoreClearly phase II, October 1, 2021, to April 30, 2022). Searches for unique (ie, not retweets or reposts) tweets on Twitter containing the hashtags "#pain #dementia" AND/OR key words "pain dementia" were conducted for all 3 periods using the Keyhole software. A catalog of all the tweets during the specified periods was collated on a spreadsheet by Keyhole. A similar method could not be used to obtain Facebook posts on Keyhole (ie, this feature was not available on Keyhole for Facebook posts); hence, a manual search using the aforementioned keywords was conducted for all 3 periods. That is, the specific keywords were typed in the search bar on Facebook, and the period (eg, precampaign period, campaign period, and postcampaign period) was specified in the search filter. Posts for each platform across the 3 periods were cataloged. The following types of posts were excluded: (1) pertaining to pain as a metaphor (ie, using "pain" as a metaphor for psychological distress, such as in the context of grief "I feel your pain"), (2) unrelated to the problem of pain in dementia, (3) shared by our own research group, and (4) not in the English language.

Results

Engagement and Reach of the Initiative

Web Analytics

Over 60,000 users from 82 countries viewed the web-based repository website, which resulted in 83,247 page views over the 12-month period (ie, October 1, 2020, to September 30, 2021). In examining the manner (ie, how people found the website) in which users were directed to the website, a majority of users (ie, 51,693 users) were directed to the website through links (ie, posts including a link to the website) from social media platforms. Other users directly typed the website link (ie, 6927 users) or searched the website link (ie, 2152). A small number of website users (ie, 116 users) were referred by other sites (ie, partnering organizations linking the web-based repository website on their web page). The blog web pages were viewed 59,919 times. Of the blogs posted during the project, the article written (on the request of our team) by an acclaimed author, Louise Penny, in which she relayed her experiences caring for her husband who lived with dementia [31], garnered most of the views (ie, received 33,226 views).

Social Media Analytics

The analytics are summarized in Table 1 based on the 3 sources of information and data periods described in the *Methods* section. The advertisements that were initiated on Facebook could also be posted on Instagram based on advertisement specifications. To maximize reach, the digital media team specified advertisements on Facebook and Instagram to be displayed on all available placements and to the specified targeted audiences. This includes Facebook and Instagram feeds (ie, advertisements displayed on the user's feed), in-stream advertisements for videos, search results, and external apps and sites (ie, advertisements displayed to audiences on additional websites and mobile apps, such as newspaper websites). That is, advertisements initiated on Facebook could be displayed on Facebook, Instagram, or to external websites or apps connected to Facebook, resulting in increased impression and reach than organically derived engagement. The advertisements analytics (eg, impression and reach) on Facebook and Instagram differs from Twitter and LinkedIn as a function of the data source (ie, paid impression or reach on Facebook and Instagram are higher because they capture not just impression or reach derived on Facebook and Instagram but also on third-party websites such as newspaper websites; Table 1).

Table 1. Summary of the social media analytics for the #SeePainMoreClearly campaign.

Period, metric, and source of information[a]	Facebook, n	Twitter, n	Instagram, n	LinkedIn, n
Period 1[b]				
Impressions				
Facebook overall analytics[c]	4,100,000	—[d]	—	—
Twitter only analytics[e]	—	724,200	—	—
Instagram only analytics[e]	—	—	4883[f]	—
LinkedIn advertisement analytics[g]	—	—	—	8538
Twitter advertisement analytics[g]	—	365,935	—	—
Reach				
Instagram advertisement analytics[h]	—	—	138,833	—
Instagram only analytics[e]	—	—	4420	—
Facebook only analytics[i]	1,313,485	—	—	—
Engagement				
Facebook only analytics[i]	282,704	—	—	—
Cloud Campaign[j]	—	—	977	—
Period 2[k]				
Impressions				
Facebook only analytics[i]	519,929	—	—	—
Reach	—	—	—	—
Engagement				
Twitter only analytics[e]	—	630	—	—
Period 3 [l]				
Impressions				
Cloud Campaign[i]	871,800	—	—	1267
Reach	—	—	—	—
Engagement				
Cloud Campaign[j]	—	2125	—	193

[a] Some analytics could not be obtained for specific platforms because they were not available. Moreover, the digital marketing team could only obtain data for specific periods (eg, year-long data could not be obtained) for some platforms owing to limitations in the sources of information. Nonetheless, efforts were made to capture the entire period.

[b] Period 1=October 1, 2020, to September 30, 2021.

[c] "Facebook overall analytics"=generated from paid and unpaid impressions on Facebook and third-party websites such as newspaper websites that are part of the Facebook advertising display network across Canada.

[d] Data for this period or metric were not applicable or not available.

[e] "Twitter/Instagram/LinkedIn only analytics"=analytics based on unpaid posts circulated only on Twitter, Instagram, or LinkedIn.

[f] On Instagram, the period 1 impressions only include impressions for unpaid posts posted on Instagram. It does not include paid posts that were posted on Facebook but reached Instagram audiences.

[g] "Twitter/LinkedIn advertisement analytics"=analytics based on paid posts circulated on Twitter and LinkedIn.

[h] "Instagram advertisement analytics"=the analytics are based on paid posts that were posted on Facebook but reached Instagram audiences based on specified target audiences.

[i] "Facebook only analytics"=based on paid and unpaid posts that were circulated only on Facebook.

[j] CloudCampaign (ie, third-party social media monitoring software): these analytics are based on unpaid posts circulated individually on Twitter, LinkedIn, and Instagram. The Cloud Campaign analytics from Facebook includes analytics of paid and unpaid posts circulated only within Facebook.

[k] Period 2=October 1,2020, to November 2, 2020.

[l]Period 3=November 3,2020, to September 30, 2021.

For a graphical illustration of the analytics, refer to Multimedia Appendix 3. Social media analytics indicated that 1,313,485 people were reached by the content shared on the Facebook page created for this project (Table 1). The #SeePainMoreClearly hashtag on Twitter (eg, obtained by Keyhole) was used by 540 users, resulting in 2835 posts. Moreover, the hashtag reached 1,691,440 users and gained 8,592,929 impressions and 8696 engagements. The 4 animated videos developed during the initiative were viewed over 257,000 times across the web page and social media platforms. The views for each video were as follows: 106,055 (family), 102,407 (health care professionals), 42,731 (policy makers), and 5911 (researchers). The pilot campaign video was also disseminated during phase II of the campaign across social media platforms and received 45,637 views (ie, 43,870 views on Facebook, 1043 on Twitter, 709 views on YouTube, and 15 views on Instagram).

Knowledge Users' Responses to the Initiative

Semistructured Interviews

Overview

A total of 13 knowledge users who interacted with the initiative's posts participated in semistructured interviews. All participants provided informed consent. Participants had varied perspectives: 1 participant had lived experience of dementia, 4 participants had family members living with dementia and were health professionals, 4 participants were caregivers, and 4 were clinicians. A thematic analysis was conducted by 2 separate coders to establish an intercoder agreement. A randomly selected 20% (3/13) subset was coded by a second coder to assess for agreement. Overall agreement was excellent (k=0.81). Five themes emerged from the data: (1) increased awareness about the problem of pain in dementia, (2) perceived barriers to pain management, (3) increased knowledge and changes in behavior, (4) value of social media as a method of scientific dissemination, and (5) suggestions for improvement.

Increased Awareness About the Problem of Pain in Dementia

A majority of participants expressed positive views about the initiative, particularly about the manner in which the content was shared throughout the initiative and the resulting increased awareness about the problem of pain in dementia. One participant noted the importance of the information shared during the initiative:

> *Overall as a whole, I really liked it. I like the messaging that comes out of it, and I think it's something really important to continue doing...I don't think there's a real understanding about pain and older adults. I like the messaging and I think it's something that's really important for us, as well as a society to promote.*

Participants also expressed that the information shared during the initiative highlighted the experiences of older adults with dementia and pain. A person indicated that they thought the initiative was "great" because "the more information that can get out to caregivers, the better it will be for the residents [and] the people that have loved ones at home." Furthermore, the initiative brought awareness to an underdiscussed problem of pain in dementia. For example, one participant stated:

> *Oh it's good thing to put out here, something that people haven't really thought about even the health care system and [pain in dementia] is a huge problem...so to bring it to the forefront is good, it needs to be brought to the forefront.*

Overall, participant responses described a lack of prior understanding related to the experience of pain in dementia and the need for increased awareness about this topic.

Some individuals commented on the significance of the specific messages shared throughout the campaign in raising awareness about pain in dementia. For example, a participant noted the following:

> *I love what you're doing. It's a concern that everybody has, and why I call you a niche [because] it is a subject that people haven't traditionally thought of.*

Similarly, one participant expressed that the messaging on the videos were informational. This participant noted the following:

> *I guess one thing that stood out to me so much was the video of the man who seemed very angry. And so, I think back of all the people who've been labeled as the "angry person" could be the person in pain. And I think that message really hit me the most on pain.*

Several participants expressed that the messaging shared during the initiative changed their perception about the problem of pain in people with dementia. A person commented on the videos:

> *You know one thing I did really like is the video with the gentleman that they thought was being kind of aggressive...I thought that video was really good but then on the other side [you] have the gentleman communicating how he is feeling. That was really good because that was really eye-opening.*

Perceived Barriers to Pain Management

Knowledge users described various barriers that they have experienced in managing pain in their clinical practice or as a family member caring for a person living with dementia. The barriers encountered by knowledge users centered on inadequate pain assessments conducted in their practice or of their family member and relative living with dementia. For example, a health care professional reported the inadequate frequency of pain assessment in their facility:

> *You know, often in Ontario anyway, where I live, assessments in long-term care are done quarterly on clients and that's, you know, that'll be an all-encompassing assessment but certainly pain is part of that evaluation and, I mean, four times a year is not even close to being adequate to properly address and intervene if someone is living with pain.*

In light of inadequate pain assessment practices, caregivers are often left to advocate for their family member or relative living with dementia. A caregiver in the study expressed the importance of families in advocating for assessment for their loved one:

> *I realized I don't know if [my mother] might have tooth decay in her teeth [or if it] would be hurting her, and I don't know how to figure that out. And I don't think anyone else is checking. Yeah, because I think the lesson of my story here is that I am more likely to assess pain in my mom than her* [care providers]

Participants described lack of continuing education and awareness as significant barriers to improving practices in LTC settings. For instance, a participant indicated the following:

> *I think there's certainly a lack of understanding and education by many health care professionals who are working with older adults who live with dementia, so I think a barrier is getting that education, well, I mean, it's an opportunity for people to have more education but a barrier is kind of reaching the people.*

Participants also indicated that the lack of education of the public at large was a significant barrier to improving current practices:

> *I think the barrier is the lack of education, the lack of knowledge that people with dementia can have pain and express it in a different way. So, I think that the lack of education of health care workers, but the public in general.*

Insufficient education about the topic means that health professionals or caregivers of persons with dementia may not be aware of the signs and symptoms that can indicate pain. A caregiver in the study reflected on this notion and shared their lack of knowledge about the signs of pain in her mother living with dementia:

> *I mean I can think back to my mother who had two strokes. And after the second one, she used to scream all the time. She used to scream. And she never spoke to anyone, but she screamed. And when I questioned the doctor, if could she be in pain, he was so sure that she was not. It doesn't manifest that way. And so, I think back like, "was she in pain all the time?" When she screamed louder when we came, was it a plea for help. I think lot about that.*

Increased Knowledge and Changes in Behavior

Participants described the positive impact of the information on their knowledge and behavior. Some participants noted that the information shared during the initiative influenced their awareness and advocacy in their personal life or in clinical practice. Health professionals indicated that they found gaps in their own practice as a result of viewing the content shared in this initiative. A participant said the following:

> *It made me more aware of the gap in pain assessment with people like my mom. And then it also made me more aware that the onus then is on me as a caregiver to be doing it, and I feel woefully inadequate, that fact that I encountered the research has made me realize that it's me doing the diagnostic [work] and I have no medical skill at all.*

Greater insight into their own behavior was also reported by the participants. A clinician noted the following:

> *It also made me more aware for myself in my own practice...so that's changed my practice in that way. To be more cognizant that behaviors the patient is displaying could be manifested due to pain. So, I need to ask the caregivers and ask the family, "Has he or she changed in behaviors in any way recently?" "Have you noticed, you know, a consistent type of behavior? Is it a specific time of day, is it related to something?" So that I could look more into pain and assessing it in a roundabout way, rather than asking them straight, "Do you think that your husband or wife is in pain?"*

Other participants indicated that the initiative largely impacted their perspective on this issue (eg, "I would say it's definitely changed the viewpoint"). Finally, participants indicated that they shared the knowledge they obtained with others:

> *I share things that you guys put out there, if you look back at my timeline, you'll see periodically I make reference to you guys.*

Similarly, one participant noted the following:

> *I forward all this information off to my colleagues that work in this [area] that are even more focused in the nursing aspect that would have a more direct impact on client care needs.*

Value of Social Media as a Tool for Scientific Dissemination

Participants underscored the importance of leveraging social media to share research information in the age of the internet. Participants expressed that sharing evidence-based information fosters trust and credibility among users seeking information on social media platforms. For example, one participant noted the following:

> *I think it has a lot of positive benefits. Where to start? After this past year right, social media and technology were probably utilized more than they ever have been. So, I actually think it's a really great way to disseminate that information. And then further to that too, because I've been following all your accounts for a while, just there again, yeah, the quality of the content is also really good. So, with that being said, it creates that credibility and that trust. And then that also really feeds into where social media sometimes isn't the most trusted source. So, I do think that it's been a really great way to get that information out there.*

Participants also acknowledged the salience of social media platforms that needs to be further leveraged for scientific dissemination (eg, "social media certainly in light of COVID, like it is the way that information gets disseminated right now so I think it's very appropriate and it is a strength that you're on various platforms sharing resources"). Other participants expressed the importance of health initiatives in combating misinformation over the web:

> *I think a lot of times there's a lot of misinformation for people and families and health care practitioners and [they] want to have some valid research-based information for best practices and when you do things like this and have it more accessible then it's easier for people to gain the right information and make the best decisions for their family members or their clients that they can.*

Other participants commented on the reach that social media platforms hold in raising awareness of issues in a short amount of time and connecting knowledge users across the world. One participant indicated the following:

> *It's brilliant, social media has always been very, very good at distributing information. Creating awareness. Highlighting anything in social media catches the eye of the person. Because people are looking for answers.*

In particular, one participant commented on the utility of Facebook targeting specific demographic groups:

> *I think, using social media is great, you know, the thing about Facebook, is that it is now an older person's social media and people often think that that young people are caregivers of people with dementia. But it's not always so–it's old people who are caring for people with dementia. Facebook is good because most of us use Facebook.*

Suggestions for Improvement

Finally, participants made suggestions about scaling and improving the initiative. One participant said the following:

> *I think it would be effective for you to reach out to the Alzheimer's Society...I would love to see you partner with them in an active way on their media.*

One participant suggested focusing on reaching individuals who may not be directly reached by the initiative. For example, one participant noted individuals who may not be using or cannot access social media platforms:

> *I think smaller communities don't have the access or don't know about it. I mean now we do have the Internet and that sort of thing which is fabulous but lots of time we don't even know it's out there.*

As another example, one participant stated the following:

> *It's the reachability...say like you know, even for me, it was from [someone else] that I found out about this, I have never seen it while using any of the social media account before. And like that largely depends on my browsing habits too right? But it's the reachability that you guys have to concentrate on.*

Other participants suggested incorporating information to traditionally delivered pain education:

> *And so, if there was a way, we could get this added into a pain curriculum, I think that would be excellent, because I never had it in my course, and I've learned from this.*

In clinical practice, one participant expressed the following:

> *Well, I think, for so many people with dementia, their care is being provided by people with minimal education or I should say varying levels. If [people could get] a little certificate put into their little portfolios that would show, they have completed a course in pain assessment for people with dementia and that would somehow be an incentive for them as workers.*

Social Media Comments

Overview

A total of 895 comments were included in the analysis. Most of the comments were retrieved from Facebook (eg, 822/895, 91.8%), followed by Twitter (eg, 68/895, 7.6%), and a small subset was comments by users on Instagram (eg, 5/895, 0.6%). A randomly selected 20% (179/895) subset was coded by a second coder to assess for agreement. The overall intercoder agreement was excellent (ie, k=0.80). Six themes emerged from the analysis: (1) positive comments in response to the initiative, (2) sharing their personal experiences in response to the content, (3) criticisms about and suggestions to improve pain management practices, (4) responses related to the COVID-19 pandemic, (5) negative comments in response to the content, and (6) advertisements.

Positive Comments in Response to the Initiative

Many users provided positive comments in response to the content. Facebook users expressed empathy in response to the content shared in the form of comments (eg, "I am praying for you" and "Amen") and with the use of "emojis" (eg, praying emoji and red hearts). Other respondents commented on the importance of the initiative. For instance, a user on Facebook provided a comment noting the following:

> *The work you are doing is so important to all.*

As another example, other users commended the initiative (eg, "such an important campaign #seepainmoreclearly"). Blog posts written by care partners in which they relayed their experiences as caregivers stimulated various positive discussions about the initiative. For example, a user commented "thanks for bravely sharing your experience with having a spouse with dementia, what a difficult journey, I enjoy [your books] so much!" in response to Louise Penny's blog post shared on social media. As another example, a user expressed the following:

> *Thank you for this information which is truly important. Your story is important to open our minds to an area of Alzheimer's that many did not think of.*

Sharing Their Personal Experiences in Response to the Content

Other users responded to the initiative by sharing their personal experiences with the posted content. For example, one user stated the following:

> *My family went through this when my dad was only in his early 50s...no one had heard of*

> *Alzheimer's...this disease is so sad and robs the family of so much. I'm glad there's more support for families now, and wish we'd had more support when we needed it.*

Another user expressed their experience of caring for their mother:

> *I wonder this all the time. My mom is nearly 101 and has dementia. She rarely expressed having pain. But how can she not when she is quite hunched over and has arthritis.*

Other individuals provided additional commentary on the shared information. A user emphasized the importance of pain assessment:

> *People with dementia, people unable to clearly explain [their] pain, we need to look for clues daily that would help us determine if something out of the norm is going on.*

Criticisms About and Suggestions to Improve Pain Management Practices

Critical comments about current practices or advocating for improved practices were also present. For instance, a user expressed the following in response to a post:

> *There is a problem with doctors overlooking any kind of pain.*

Another user pointed out the issue of resource limitations in LTC facilities (eg, "staffing is a huge issue which needs a timely resolution"). Moreover, a user indicated that "seniors deserve much more than the less of minimum care they get." Other users provided suggestions to improve practices:

> *There are so many kinds of dementia, each with their own stages. We need more access to good education and support for home care to help families cope.*

Another user stated the following:

> *Pain assessment only on admission and then every 3 months? Pain must be assessed whenever there is the slightest indication of pain. A formal assessment every 3 months should reflect how effective the measures were.*

Responses Related to the COVID-19 Pandemic

As the campaign occurred during the COVID-19 pandemic and disseminated vaccination information related to residents in LTC, a subset of the comments was related to the pandemic. Some users noted the negative ramifications of isolation in LTC (eg, "I am sick of the lockdowns in care homes. Not being able to take them out for a day for visits...is absolutely insane. They are suffering terribly over this, and it has to stop.") Other comments denounced the significance of vaccines (eg, "the fake pandemic was created for the COVID vaccines").

Negative Comments in Response to the Content

A subset of the comments expressed negative responses to the information shared. A few of these comments perpetuated stereotypes about older adults (eg, "people with dementia still feel pain?") or dementia (eg, "reading this is enough to get dementia"). A user expressed disagreement with one of the information shared:

> *We assess residents for pain every time we see them. We are not stupid; we can tell when someone is in pain.*
>
> *Do any of you work in LTC facility? Staff in dementia units are trained to look for any behavioral issues that may arise from pain.*

Advertisements

Finally, a small subset of comments was from users advertising a product or information (eg, "Dementia and Alzheimer's affects so many. Please don't forget to check out my podcast, if you haven't already" and "Can we help your loved one/care home/hospital/nursing home in UK with our free mp3s preloaded with the music of their own choice?? Contact me asap please click on the link.").

Responses to the Evaluation Questionnaires

The demographic characteristics of the knowledge users who responded to the questionnaires are presented in Multimedia Appendix 4. The majority of the survey respondents were caregivers of people living with dementia. Moreover, most respondents indicated that they had found the #SeePainMoreClearly campaign on Facebook and were living in Canada. Not all participants who responded to the survey completed all the questionnaires; therefore, the number of respondents is indicated in Tables 2 and 3. Table 2 outlines the respondents' impression of the campaign. Across respondent groups, respondents endorsed a favorable impression of the campaign, a great likelihood of sharing information with others, and the use of social media for KM. Of note, the question regarding the new information provided by the content was rated lowest in each respondent group. Table 3 outlines the descriptive statistics based on the responses to the 6 general questions assessed by the IAM4all questionnaire. As noted in Table 3, responses indicated that most individuals (eg, 138/178, 77.5%) indicated the likelihood of using the information for themselves or someone else. Moreover, 77.1% (131/170) of the individuals expressed benefitting from the information shared during the initiative.

Table 2. Respondents' impression of the campaign.

	Caregivers	Public	Health professional	Person living with dementia	Researcher	Policy maker
Overall impression of the campaign[a]						
Value, mean (SD)	4.67 (1.63)	4.33 (1.49)	5.16 (1.72)	4.18 (1.72)	__[b]	—
Value, n[c]	78	24	25	11	—	—
Level of new information provided[d]						
Value, mean (SD)	3.91 (1.83)	4.21 (1.74)	4.04 (2.09)	3.50 (2.07)	—	—
Value, n[c]	79	24	25	10	—	—
Impact on information-seeking behavior[e]						
Value, mean (SD)	4.90 (1.89)	4.33 (1.76)	4.84 (1.82)	5.10 (2.33)	—	—
Value, n[c]	79	24	25	10	—	—
Using social media for scientific dissemination[f]						
Value, mean (SD)	5.48 (1.74)	5.00 (1.67)	5.44 (1.53)	5.00 (1.83)	—	—
Value, n[c]	87	25	25	10	—	—

[a] Ratings are based on a 7-point scale, ranging from 1 (not at all) to 7 (very much): "Overall, how much did you like the image/clip/video?"

[b] Cell sizes <5 were not reported to protect the confidentiality of the participants.

[c] n=not all participants who responded to the survey completed all the questionnaires in the study; this number represents the number of participants who answered this question.

[d] "Did the video/image/clip provide you with new information?"

[e] "Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video/viewing this content?"

[f] "It takes an average of 17 years until professionals start to use important research results into their practice Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia?"

Table 3. Survey responses to the IAM4all[a] questionnaire (N=190).

Question	Respondents, n (%)
"Why did you look for this information?"[b]	
To answer a question about the health of someone else (total number of respondents=190)	116 (61.1)
To satisfy my curiosity about a health matter (total number of respondents=172)	108 (62.8)
To find choices different from those given by a health professional (total number of respondents=172)	61 (35.5)
To follow-up on the information given by a health professional (total number of respondents=168)	52 (31)
To prepare myself before talking to a health professional (total number of respondents=168)	50 (29.8)
To help me decide if I should see a health professional (total number of respondents=169)	40 (23.7)
To answer a question about my health (total number of respondents=177)	30 (17)
"Did you find the information you were looking for?" (total number of respondents=181)	
Yes	73 (40.3)
Yes, but I did not understand it	15 (8.3)
No, I did not find it	72 (39.8)
No, but I found something else	21 (11.6)
"What did you think about this information?"[b]	
Now I want to learn more about this health matter (total number of respondents=161)	112 (69.6)
Now I know something new (total number of respondents=163)	79 (48.5)
I am reminded of something I already knew (total number of respondents=157)	76 (48.4)
This information says I did, or I am doing the right thing (total number of respondents=158)	66 (41.8)
Now I am reassured (total number of respondents=158)	66 (41.8)
I am not satisfied with this information (total number of respondents=153)	33 (21.6)
I think there is a problem with this information (total number of respondents=151)	14 (9.3)
I think this information could be harmful (total number of respondents=148)	2 (1.4)
"Did you or will you use the information for yourself" (total number of respondents=178)	
Yes	55 (30.9)
No, not for myself, but I used it for someone else	83 (46.6)
No, I did not use this information for myself or for someone else	40 (22.5)
"Did you (do you expect to) benefit from this information?" (total number of respondents=170)	
Yes	131 (77.1)
No	39 (22.9)
Did something negative come out from using this information? (total number of respondents=148)	
Yes	4 (2.7)
No	144 (97.3)

[a] IAM4all: Information Assessment Method for all.

[b] Refers to participants who answered "Yes" with possible choices of yes, no, or possibly.

Comparison of Web-Based Discussions About Pain in Dementia

The extent of discussions about pain in dementia was assessed by examining the total number of posts on Twitter and Facebook. After excluding posts pertaining to pain as a metaphor, unrelated to the problem of pain in dementia, shared by our own research group, and not in the English language, the number of tweets that were retained doubled from the precampaign period compared with during the campaign period (see Multimedia Appendix 5). A similar increase was also observed on Facebook. The number of discussions about pain in dementia decreased in the postcampaign period compared with during the campaign period (see Multimedia Appendix 5). The number of excluded posts in each period is summarized in Multimedia Appendix 6.

Discussion

Principal Findings

Social media allows the immediate dissemination of information to a large number of knowledge users. Although our relatively short pilot KM campaign (phase I) was successful, its longer-term continuation by researchers alone was not feasible owing to competing demands. As such, we partnered with a digital media company to launch phase II of the #SeePainMoreClearly campaign with expanded social media platform coverage. The goal of the initiative was to increase awareness of the challenges in the assessment and management of pain among people with dementia. We codeveloped key messages with partners (eg, health professionals, caregivers, and researchers) that served as the basis of our messaging.

Our findings demonstrated the effectiveness of social media KM methods in reaching very broad audiences over a 12-month period. Evidence of positive impact on knowledge users' knowledge was demonstrated. The participants described positive perceptions in response to the information shared throughout the initiative. Survey respondents (eg, caregivers, health professionals, researchers, the public, and people with dementia) endorsed a favorable impression of the campaign. Overall, our initiative highlighted the advantages of using a science-media partnership (eg, collaboration with digital media experts, resources to develop tailored content and resources, and consistent dissemination of information). However, broad social campaigns require extensive resources and time commitments. We outline the recommendations to address these areas.

The current (phase II) initiative involving a science-media partnership was different in several regards from our pilot campaign that focused only on Twitter and a YouTube video. In comparison with the pilot campaign [9], visits to our web-based repository substantially increased in phase II, even when considering the difference in the lengths of the 2 campaigns. Phase II used extended evaluation metrics through the inclusion of interviews, in addition to social media analytics, questionnaires, and the analysis of social media responses over a 12-month period. Hashtag analytics on Twitter across the 2 phases were comparable, despite differences in the length of evaluation (eg, 5 months vs 12 months). We observed lower outside organization engagement during phase II of our initiative, which could have contributed to lower phase II engagement when accounting for the length of evaluation. Moreover, our social media presence was greater in phase II compared with our pilot campaign.

Overall, our findings demonstrated the effectiveness of social media KM methods in reaching very broad audiences quickly. In this study, we demonstrated success in directing knowledge users to a resource website with practical information for health professionals, caregivers, and people living with dementia. For instance, over 60,000 users from 82 countries viewed the web-based repository website over the 12-month period. In particular, the blog posts shared during the project attracted many readers. The blog web pages were viewed 59,919 times, providing evidence for their reach. This is comparable with other KM efforts showing the use of blogs as an engaging way of connecting to targeted users [32].

The reach and engagement of users on social media platforms also provided evidence for the success of the initiative in raising awareness about the problem of pain in dementia. Information shared on Facebook was successful at reaching a wide range of audience, with 1,313,485 people reached by the content shared on the Facebook page. However, it should be noted that some analytics (eg, reach and engagement) could not be obtained from social media sites (eg, LinkedIn) because these analytics were not provided by the platform. This limits our ability to deduce the full extent of engagement on these platforms. Nonetheless, the number of impressions on Facebook was the highest (eg, 4,100,000) compared with Twitter, Instagram, and LinkedIn. This is consistent with previous research showing extensive reach and engagement on Facebook compared with other platforms [6,33]. In contrast, Neil-Sztramko et al [34] conducted an awareness campaign targeted toward working caregivers and found that although Facebook posts generated the most reach, the quality of the engagement was low. The topic area, targeted audience, and length of evaluation could explain the differences between our findings and those of previous research. We observed the lowest reach and engagement on Instagram and LinkedIn. This is not surprising given that our primary audience comprised caregivers of people with dementia who tend to be older [35,36]. Older adults have shown a preference for Facebook in comparison with other social platforms [37]. Taken together, our findings suggest that Facebook may be the most suitable platform for disseminating information related to pain in dementia.

Our findings extend our pilot evaluation by including in-depth interviews with knowledge users who interacted with the campaign in addition to the analysis of social media analytics and evaluation questionnaires. Many interview participants indicated positive perceptions in response to the information shared throughout the initiative. Moreover, the participants expressed that the significance of the initiative was in bringing awareness to an underdiscussed problem. The interview participants acknowledged the utility of social media as a tool for scientific dissemination. Many participants noted the importance of leveraging social media to share research information. Other participants expressed the importance of health initiatives in combating misinformation over the web. Quantitative responses to the surveys also supported this view. Survey respondents endorsed the use of social media as a way of spreading important health information to caregivers of people with dementia and to people with dementia. We found evidence of the information and resources impacting users' knowledge and behavior. For example, interview participants noted increased awareness and advocacy in their personal life and awareness of assessing for pain in their clinical practice. More importantly, participants frequently expressed intent to share the knowledge they obtained with others. This is consistent with the survey responses, indicating that a majority of respondents intended to use the information for themselves or others. Moreover, the respondents expressed benefitting from the information shared during the initiative.

The initiative stimulated web-based discussions about pain in dementia. Consistent with themes that emerged from social media responses on Twitter during the pilot campaign [9], many web users expressed positive comments in response to the initiative. In particular, expressions of support were prevalent in both the pilot and phase II of our campaign. Many web users who responded to the content disseminated during the campaign shared their personal experiences or added commentary to the posted content. In addition to sentiments of advocacy for better care, which was observed in our pilot campaign, social media comments in response to phase II of our campaign also highlighted criticism and suggestions to improve practices related to pain management in dementia. Users highlighted the need for access to continuing education and support for staff and families to increase the frequency of pain assessment in LTC. This demonstrated meaningful engagement by users in response to posts. Increased discussions also highlighted negative responses about the information shared (eg, perpetuating stereotypes about older adults and dementia), which was not observed in the pilot campaign. Differences in themes that emerged between the pilot and phase II could be due to the broader reach of phase II (eg, inclusion of Facebook), as the pilot campaign only examined responses using the #SeePainMoreClearly hashtag on Twitter. We also found increased discussion about pain in dementia during the initiative on Twitter and Facebook in comparison with before and after the initiative. However, this discussion was not sustained months following the end of the campaign. This highlights the importance of continuous and meaningful engagement to maintain gains made by an initiative. Given our methodology, we collected a substantially lower number of posts on Facebook in comparison with Twitter. This discrepancy is likely owing to the manual search that was conducted to obtain Facebook posts in comparison with the data that were easily pulled by Keyhole for Twitter posts. Depending on a user's privacy settings, posts shared on personal or private accounts are excluded when conducting a general search on Facebook.

Limitations and Directions for Future Research

A particular strength of this study is that the content shared during the initiative was developed collaboratively with family caregiver partners, researchers, media experts, and health care professionals. Various measures were also used to assess not only the web-based reach of the initiative but also the perceptions of knowledge users. Nonetheless, we acknowledge that the use of social media for KM research represents a new area that does not lend itself to strict scientific control in the evaluation of its effectiveness. We adapted a more nuanced approach in developing partnerships and using multimodal approaches to show the impact in different ways. Although we aimed to assess the impact on users' knowledge and behavior, we did not directly evaluate behavior change. Future research should examine the associated behavior outcomes (eg, increased pain assessment) in addition to the spread of information (eg, analytics). It is also difficult to measure the impact of the initiative at an organizational or policy level. This could be an important avenue for future research. Individuals in our interview and surveys expressed their intention to use the information; however, the adoption and use of information was not obtained. Perhaps, a follow-up assessment of how or whether knowledge users applied learned information could be investigated. Moreover, the effectiveness of social and web modalities in creating meaningful changes in knowledge and behavior is subject to further examination. Notably, the landscape of social media is constantly changing, and researchers will need to adapt to these changes if they want to leverage this modality. For example, social media can be used to spread health misinformation [38]. Using social media for KM health efforts can also be used to combat false and unscientific web-based information. As such, ensuring the quality of scientific evidence disseminated on the web should be considered in the development of social media–based dissemination efforts. Although these findings may not be generalizable to other KM initiatives, our investigation adds to the growing body of knowledge leveraging social media as a KM tool.

Recommendations

Our study highlighted the successes and challenges of social media KM initiatives. When comparing the pilot with the scaled initiative (phase II), there appears to be no considerable difference with regard to views, impressions, or reach when accounting for the length of time of each initiative (5 months vs 12 months). Although this scaled initiative demonstrated success in garnering a large reach across social media platforms, broad initiatives such as phase II of our campaign require extensive resources and time commitment, which may not be feasible for researchers in the long term. The following recommendations are proposed to assist researchers and partners who may be interested in developing and maintaining a web-based KM initiative:

1. Researchers could collaborate with established communication and marketing departments at their institution or other digital media partners to aid in digital and social media outreach of research information and internal and external advertising. Granting agencies may be able to allocate funds for such purposes.
2. Facebook and Twitter appear to be the most relevant platforms for KM for the topic of pain and dementia. However, researchers from other disciplines may find other platforms more helpful in reaching their target audience. For example, if a researcher's area of research is adolescent mental health, Instagram or TikTok and the use of stories may increase engagement among knowledge users. Although we found success in using multiple social media platforms, it may be more sustainable to pool resources on 1 or 2 of the most used platforms based on the target audience.
3. Investments in targeted and paid advertisements can be an effective mechanism to increase the exposure and engagement of campaign posts at a low cost per engagement [39,40].
4. Our initiative highlighted the importance of codeveloping the initiative with partners of our intended target groups. Many of our partners developed blog posts about their lived experience, which generated the most engagement. As such, personalized blog posts and opportunities for knowledge users to share their experiences (ie, turning comments on)

can be an easy and cost-effective way to stimulate discussions.

5. The success of our pilot initiative was largely influenced by partnering with professional organizations that helped disseminate information and resources to their audiences. Engagement from external organizations was lower during phase II of our initiative, potentially contributing to the overall decrease in engagement. We observed that external organizations were more inclined to retweet our content when it originated from our individual researcher accounts rather than from a generic SeePainMoreClearly social media account. Researchers should collaborate with organizations within their specific area of interest who can support in meaningfully engaging with their targeted audiences. Connecting with trusted messengers (eg, influencers, people with lived experience, and large followings) could help to penetrate targeted groups.

Conclusions

We partnered with a digital media partner to launch phase II of the #SeePainMoreClearly campaign with expanded social media platform coverage. The goal of the initiative was to increase awareness of and provide resources related to the challenges in the assessment and management of pain among people with dementia. Although this scaled initiative demonstrated success in garnering large reach across social media platforms, broad initiatives such as phase II of our campaign (reported in this manuscript) require extensive resources and time commitments, which may not be feasible for researchers in the long term. Researchers should leverage collaborations with their institutions to aid in the digital media outreach of research information. Furthermore, granting agencies should consider allocating more funds for such KM purposes. Our initiative highlighted the importance of codeveloping KM efforts with the partners of our intended target groups and working with professional organizations to disseminate information to our target audience. Collaborations with people with lived experiences and professional organizations will be key to the success of any future KM effort. Our study adds to the growing body of knowledge that leverages social media as a KM tool.

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Authors' Contributions

TH wrote the grant application that supported this research; played a key role in project conceptualization, knowledge mobilization (KM) messaging, analytic direction, and manuscript writing; and oversaw all aspects of this study. LIRC prepared the first draft of this manuscript and played a key role in project conceptualization, data collection, data analysis, and KM messaging. MB, a partner with lived experience as a caregiver, played a key role in KM messaging; provided input in the manuscript; and contributed to team discussions. VT contributed to data analysis. CTC was a consultant on research design and development, provided detailed feedback on the manuscript, and participated in team discussions about project progress and development. SW, a digital media partner, oversaw the collection of web analytics and digital dissemination. All authors participated in team discussions that directed this work, provided input on multiple aspects of the project (eg, social media dissemination strategy) and messaging content, and reviewed and approved the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Key points (cross-cutting messages).
[DOCX File , 21 KB - aging_v7i1e53025_app1.docx]

Multimedia Appendix 2
Interview moderator guide.
[DOCX File , 15 KB - aging_v7i1e53025_app2.docx]

Multimedia Appendix 3
Summary of the social media analytics for the #SeePainMoreClearly campaign.
[DOCX File , 28 KB - aging_v7i1e53025_app3.docx]

Multimedia Appendix 4
Demographic characteristics of the survey respondents.
[DOCX File , 15 KB - aging_v7i1e53025_app4.docx]

Multimedia Appendix 5
Number of posts on Twitter and Facebook about pain in dementia.
[DOCX File , 19 KB - aging_v7i1e53025_app5.docx]

Multimedia Appendix 6
Number of excluded posts for each criterion.
[DOCX File , 21 KB - aging_v7i1e53025_app6.docx]

References

1. Brownson RC, Eyler AA, Harris JK, Moore JB, Tabak RG. Getting the word out: new approaches for disseminating public health science. J Public Health Manag Pract 2018;24(2):102-111 [FREE Full text] [doi: 10.1097/PHH.0000000000000673] [Medline: 28885319]
2. Guidelines for effective knowledge mobilization. Social Sciences and Humanities Research Council, Canada. 2023. URL: https://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge_mobilisation-mobilisation_des_connaissances-eng.aspx [accessed 2023-12-04]
3. Castillo LIR, Hadjistavropoulos T, Beahm J. Social media discussions about long-term care and the COVID-19 pandemic. J Aging Stud 2022 Dec;63:101076 [FREE Full text] [doi: 10.1016/j.jaging.2022.101076] [Medline: 36462920]
4. Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak. PLoS One 2010 Nov 29;5(11):e14118 [FREE Full text] [doi: 10.1371/journal.pone.0014118] [Medline: 21124761]
5. Faus M, Alonso F, Javadinejad A, Useche SA. Are social networks effective in promoting healthy behaviors? A systematic review of evaluations of public health campaigns broadcast on Twitter. Front Public Health 2022;10:1045645 [FREE Full text] [doi: 10.3389/fpubh.2022.1045645] [Medline: 36483260]
6. Dehlin JM, Stillwagon R, Pickett J, Keene L, Schneider JA. #PrEP4Love: an evaluation of a sex-positive HIV prevention campaign. JMIR Public Health Surveill 2019 Jun 17;5(2):e12822 [FREE Full text] [doi: 10.2196/12822] [Medline: 31210141]
7. Coughlan H, Quin D, O'Brien K, Healy C, Deacon J, Kavanagh N, et al. Online mental health animations for young people: qualitative empirical thematic analysis and knowledge transfer. J Med Internet Res 2021 Feb 09;23(2):e21338 [FREE Full text] [doi: 10.2196/21338] [Medline: 33560231]
8. Andrade EL, Evans WD, Barrett N, Edberg MC, Cleary SD. Strategies to increase Latino immigrant youth engagement in health promotion using social media: mixed-methods study. JMIR Public Health Surveill 2018 Dec 19;4(4):e71 [FREE Full text] [doi: 10.2196/publichealth.9332] [Medline: 30567689]
9. Castillo LIR, Hadjistavropoulos T, Brachaniec M. The effectiveness of social media in the dissemination of knowledge about pain in dementia. Pain Med 2021 Nov 26;22(11):2584-2596 [FREE Full text] [doi: 10.1093/pm/pnab157] [Medline: 34009395]
10. Chambers CT. From evidence to influence: dissemination and implementation of scientific knowledge for improved pain research and management. Pain 2018 Sep;159 Suppl 1(1):S56-S64. [doi: 10.1097/j.pain.0000000000001327] [Medline: 30113948]
11. Hand RK, Kenne D, Wolfram TM, Abram JK, Fleming M. Assessing the viability of social media for disseminating evidence-based nutrition practice guideline through content analysis of Twitter messages and health professional interviews: an observational study. J Med Internet Res 2016 Nov 15;18(11):e295 [FREE Full text] [doi: 10.2196/jmir.5811] [Medline: 27847349]
12. Featherstone RM, Leggett C, Knisley L, Jabbour M, Klassen TP, Scott SD, et al. Creation of an integrated knowledge translation process to improve pediatric emergency care in Canada. Health Commun 2018 Aug;33(8):980-987. [doi: 10.1080/10410236.2017.1323538] [Medline: 28537762]
13. Malara A, De Biase GA, Bettarini F, Ceravolo F, Di Cello S, Garo M, et al. Pain assessment in elderly with behavioral and psychological symptoms of dementia. J Alzheimers Dis 2016;50(4):1217-1225 [FREE Full text] [doi: 10.3233/JAD-150808] [Medline: 26757042]
14. Williams CS, Zimmerman S, Sloane PD, Reed PS. Characteristics associated with pain in long-term care residents with dementia. Gerontologist 2005 Oct;45 Spec No 1(1):68-73. [doi: 10.1093/geront/45.suppl_1.68] [Medline: 16230752]
15. Chan S, Hadjistavropoulos T, Williams J, Lints-Martindale A. Evidence-based development and initial validation of the pain assessment checklist for seniors with limited ability to communicate-II (PACSLAC-II). Clin J Pain 2014 Sep;30(9):816-824. [doi: 10.1097/AJP.0000000000000039] [Medline: 24281294]
16. Fuchs-Lacelle S, Hadjistavropoulos T, Lix L. Pain assessment as intervention: a study of older adults with severe dementia. Clin J Pain 2008 Oct;24(8):697-707. [doi: 10.1097/AJP.0b013e318172625a] [Medline: 18806535]
17. Hadjistavropoulos T, Herr K, Turk DC, Fine PG, Dworkin RH, Helme R, et al. An interdisciplinary expert consensus statement on assessment of pain in older persons. Clin J Pain 2007 Jan;23(1 Suppl):S1-43. [doi: 10.1097/AJP.0b013e31802be869] [Medline: 17179836]

18. Herr K, Bursch H, Ersek M, Miller LL, Swafford K. Use of pain-behavioral assessment tools in the nursing home: expert consensus recommendations for practice. J Gerontol Nurs 2010 Mar;36(3):18-31 [FREE Full text] [doi: 10.3928/00989134-20100108-04] [Medline: 20128526]
19. Dementia research. #SeePainMoreClearly. URL: https://www.seepainmoreclearly.org [accessed 2023-07-24]
20. Pain in dementia (see pain more clearly). YouTube. 2019. URL: https://www.youtube.com/watch?v=9ONjQ7_ZvZA [accessed 2023-07-24]
21. Hadjistavropoulos T, Marchildon GP, Fine PG, Herr K, Palley HA, Kaasalainen S, et al. Transforming long-term care pain management in North America: the policy-clinical interface. Pain Med 2009 Apr;10(3):506-520. [doi: 10.1111/j.1526-4637.2009.00566.x] [Medline: 19254336]
22. Reynolds KS, Hanson LC, DeVellis RF, Henderson M, Steinhauser KE. Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. J Pain Symptom Manage 2008 Apr;35(4):388-396 [FREE Full text] [doi: 10.1016/j.jpainsymman.2008.01.001] [Medline: 18280101]
23. Home page. #SeePainMoreClearly. URL: https://www.seepainmoreclearly.org/ [accessed 2023-07-24]
24. Google Analytics. Google. URL: https://analytics.google.com/analytics/web/provision/#/provision [accessed 2023-07-24]
25. How Google Analytics works - analytics help. Google. URL: https://support.google.com/analytics/answer/12159447?hl=en [accessed 2023-12-06]
26. Hashtag analytics for Twitter, Instagram and Facebook. Keyhole. URL: https://keyhole.co/hashtag-analytics-2/free-hashtag-analytics/ [accessed 2023-07-24]
27. NVivo (Version 12). Lumivero. URL: https://www.lumivero.com [accessed 2024-01-18]
28. Braun V, Clarke V. Conceptual and design thinking for thematic analysis. Qual Psychol 2022 Feb 13;9(1):3-26 [FREE Full text] [doi: 10.1037/qup0000196]
29. NVivo 11 for Windows help - run a coding comparison query. NVivo. URL: https://help-nv11.qsrinternational.com/desktop/procedures/run_a_coding_comparison_query.htm#MiniTOCBookMark5 [accessed 2023-12-04]
30. Pluye P, Granikov V, Bartlett G, Grad RM, Tang DL, Johnson-Lafleur J, et al. Development and content validation of the information assessment method for patients and consumers. JMIR Res Protoc 2014 Feb 18;3(1):e7 [FREE Full text] [doi: 10.2196/resprot.2908] [Medline: 24550180]
31. Caregiver's story #4: Louise Penny. #SeePainMoreClearly. URL: https://www.seepainmoreclearly.org/post/caregiver-s-story-4-louise-penny [accessed 2023-07-24]
32. Valdez Soto M, Balls-Berry JE, Bishop SG, Aase LA, Timimi FK, Montori VM, et al. Use of web 2.0 social media platforms to promote community-engaged research dialogs: a preliminary program evaluation. JMIR Res Protoc 2016 Sep 09;5(3):e183 [FREE Full text] [doi: 10.2196/resprot.4808] [Medline: 27613231]
33. Grantham JL, Verishagen CL, Whiting SJ, Henry CJ, Lieffers JR. Evaluation of a social media campaign in Saskatchewan to promote healthy eating during the COVID-19 pandemic: social media analysis and qualitative interview study. J Med Internet Res 2021 Jul 21;23(7):e27448 [FREE Full text] [doi: 10.2196/27448] [Medline: 34133314]
34. Neil-Sztramko SE, Dobbins M, Williams A. Evaluation of a knowledge mobilization campaign to promote support for working caregivers in Canada: quantitative evaluation. JMIR Form Res 2023 Jun 22;7:e44226 [FREE Full text] [doi: 10.2196/44226] [Medline: 37347525]
35. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. Int Nurs Rev 2015 Sep 08;62(3):340-350. [doi: 10.1111/inr.12194] [Medline: 26058542]
36. Tsai CF, Hwang WS, Lee JJ, Wang WF, Huang LC, Huang LK, et al. Predictors of caregiver burden in aged caregivers of demented older patients. BMC Geriatr 2021 Jan 14;21(1):59 [FREE Full text] [doi: 10.1186/s12877-021-02007-1] [Medline: 33446114]
37. Yu RP, Ellison NB, Lampe C. Facebook use and its role in shaping access to social benefits among older adults. J Broadcast Electron Media 2018 Jan 30;62(1):71-90 [FREE Full text] [doi: 10.1080/08838151.2017.1402905]
38. Wang Y, McKee M, Torbica A, Stuckler D. Systematic literature review on the spread of health-related misinformation on social media. Soc Sci Med 2019 Nov;240:112552 [FREE Full text] [doi: 10.1016/j.socscimed.2019.112552] [Medline: 31561111]
39. Batra N, Colson CD, Alberto EC, Burd RS. Using social media for the prevention of pediatric burn injuries: pilot design and usability study. JMIR Form Res 2021 Jul 15;5(7):e23242 [FREE Full text] [doi: 10.2196/23242] [Medline: 34264194]
40. Harding K, Pérez-Escamilla R, Carroll G, Aryeetey R, Lasisi O. Four dissemination pathways for a social media-based breastfeeding campaign: evaluation of the impact on key performance indicators. JMIR Nurs 2019 Sep 26;2(1):e14589 [FREE Full text] [doi: 10.2196/14589] [Medline: 34345773]

Abbreviations

IAM4all: Information Assessment Method for all
KM: knowledge mobilization
LTC: long-term care

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Original Paper

Social Media Discourse Related to Caregiving for Older Adults Living With Alzheimer Disease and Related Dementias: Computational and Qualitative Study

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Abstract

Background: In the United States, caregivers of people living with Alzheimer disease and Alzheimer disease–related dementias (AD/ADRD) provide >16 billion hours of unpaid care annually. These caregivers experience high levels of stress and burden related to the challenges associated with providing care. Social media is an emerging space for individuals to seek various forms of support.

Objective: We aimed to explore the primary topics of conversation on the social media site Reddit related to AD/ADRD. We then aimed to explore these topics in depth, specifically examining elements of social support and behavioral symptomology discussed by users.

Methods: We first generated an unsupervised topic model from 6563 posts made to 2 dementia-specific subreddit forums (r/Alzheimers and r/dementia). Then, we conducted a manual qualitative content analysis of a random subset of these data to further explore salient themes in the corpus.

Results: The topic model with the highest overall coherence score (0.38) included 10 topics, including caregiver burden, anxiety, support-seeking, and AD/ADRD behavioral symptomology. Qualitative analyses provided added context, wherein users sought emotional and informational support for many aspects of the care experience, including assistance in making key care-related decisions. Users expressed challenging and complex emotions on Reddit, which may be taboo to express in person.

Conclusions: Reddit users seek many different forms of support, including emotional and specific informational support, from others on the internet. Users expressed a variety of concerns, challenges, and behavioral symptoms to manage as part of the care experience. The unique (ie, anonymous and moderated) nature of the forum allowed for a safe space to express emotions free from documented caregiver stigma. Additional support structures are needed to assist caregivers of people living with AD/ADRD.

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KEYWORDS

caregiving; dementia; social support; social media; Reddit

Introduction

Background

There are an estimated 11 million people in the United States currently living with Alzheimer disease and Alzheimer disease–related dementias (AD/ADRD)—a number that is expected to more than double by 2050 [1]. Most people living with AD/ADRD receive informal (ie, unpaid) care support from family members or other personal connections due to the high costs of professional care, the limited capacity of assisted living and memory care facilities, and a strong desire to age in place [2-5]. Recent estimates suggest informal AD/ADRD caregivers in the United States provide >16 billion hours of care labor annually. This has led to calls from national health organizations to prioritize the expansion of support systems for informal caregivers of people living with AD/ADRD. Caregiving for people living with AD/ADRD is a complex and challenging role that is associated with a broad set of suboptimal economic, physical, and psychological outcomes. For example, caregiver burden is associated with negative mental health outcomes, including high levels of stress and depressive symptomology. However, social support may offer a means for reducing caregiver burden and improving health outcomes for both caregiver and care recipient. This study aimed to understand the ways AD/ADRD caregivers seek and experience social support on the web, specifically through the social media platform Reddit (Reddit, Inc).

Caregiving for Individuals Living With AD/ADRD

Recent studies have estimated that approximately 15 million Americans currently provide care for individuals living with AD/ADRD [6]. Most are classified as informal caregivers, meaning they are not paid for labor and time associated with care responsibilities and are typically family members or friends of the person with AD/ADRD. The average life expectancy for individuals diagnosed with dementia can vary widely, from 3 to 10 years, depending on the specific diagnosis, age at the time of diagnosis, and other health factors [7]. Not surprisingly, the caregiving experience can also vary widely. A recent study found that near the time of diagnosis, people with AD/ADRD received an average of 151 hours (approximately 6.5 days) of caregiving monthly, typically provided by 1 caregiver. However, over time, their needs progress, requiring nearly twice the hours of care and support of additional caregivers [8].

Caregiver burden describes the multifaceted strain faced by individuals in providing care, which may include financial, emotional, and physical stressors [9,10]. The challenges of AD/ADRD care are associated with significant health impacts for caregivers [11,12]. Providing care is often associated with higher levels of reported stress [13]. Furthermore, caregivers report high levels of psychiatric symptoms, most commonly depressive symptoms—particularly as the care recipient's AD/ADRD symptomology progresses [14,15]. Caregivers also report high levels of financial strain related to high costs of care and lost earning potential due to time commitments of care responsibilities [9,16].

Regardless of the dementia subtype, a broad range of neuropsychiatric symptoms, including both behavioral and cognitive changes, can present [17]. Behavioral symptoms of AD/ADRD, for example, can include confusion, aggression, and increased hospital or emergency department visits. Dementia is also associated with neuropsychiatric symptoms, including agitation, depression, hallucinations, anxiety, and apathy [18-20]. Furthermore, dementia is often associated with reduced function of other organs, resulting in symptoms such as voice or speaking challenges, skin injuries, urinary incontinence, constipation, urinary tract infections, dental and vision problems, and hearing loss, among others [18-20]. Some symptoms, such as anxiety and depression, are fairly common across patients with AD/ADRD and with disease progression [20]. Others, such as psychosis, aggression, and agitation, are often exacerbated as cognitive decline increases and are thus associated with steep increases in caregiver burden due to the impact these symptoms have on the completion of basic activities of daily living [18].

As AD/ADRD progresses, more severe symptoms reduce individuals' capacity to independently complete activities of daily living, thereby necessitating increased assistance and caregiver supervision [21]. Therefore, the time spent on caregiving activities and the number of individuals providing care generally increase across the disease progression [2,3]. Naturally, increased time spent on care, combined with increasingly severe symptoms to manage, is associated with increased feelings of burden. As such, caregivers often spend less time and energy on their own self-care, particularly as the care recipient's neuropsychiatric symptoms worsen [22]. The emotional, financial, and physical strain of caregiving may contribute to reduced overall health of caregivers [5]. AD/ADRD caregivers often report high levels of stress and depression themselves, may get poor sleep, and neglect their own well-being (eg, diet and physical activity) [11,14,15]. As such, recent epidemiological research has found spousal caregivers are at increased risk of dementia themselves and has found caregiving to be an independent risk factor for mortality [23,24]. Notably, strategies and interventions are needed to reduce burden and improve outcomes for both the caregiver and care recipient.

Social Media and Caregiver Social Support

Over the past 3 decades, people have increasingly sought health information and support on the web. In high-resource countries, more than half of the adults use the internet for health reasons, often searching for information related to symptomology, diagnoses, and treatment options for health conditions. Online health information seeking is particularly common when users themselves or a close family member have a chronic health condition. While there are numerous websites from which users may access health information, they are increasingly likely to do so specifically via social media platforms.

Defining and delineating what constitutes a "social media platform" has proved challenging; however, most definitions broadly include a limitation to digital technologies, content generation by users, and the capacity for users to interact or share directly with others [25-27]. Over time, the use of social media has exploded, with a vast majority of adults in the United States reporting regular engagement with at least 1 platform and an average daily use of >2 hours [28,29]. Important to the current research, social media is widely used as a tool for people to connect with mutual friends, interests, circumstances, and hobbies [30-32].

To date, research related to caregivers' use of social media has spanned many chronic conditions (eg, cancer, diabetes, and physical and mental disability); ages (ie, older adults and children); and platforms (eg, Twitter, X, Facebook, Instagram, and Reddit). Much of this exploratory work has examined use patterns and user needs [33,34], broadly suggesting caregivers most often use social media to exchange information related to care recipient health, psychosocial issues, and daily care activities [33-35]. Among the latter, caregivers may use social media to discuss activities of living, sleep, diet, finance, showering or bathing, transportation, medical care, and formal disease diagnoses [35]. Some research suggests online support is associated with a positive impact on the emotional well-being of medical caregivers, especially for those who used online support for a long term [36]. However, to date, limited literature exists examining the use of social media for support-seeking among AD/ADRD caregivers, specifically [35,36].

AD/ADRD caregivers may be particularly likely to seek support on the web due to myriad factors that limit social support in their offline lives and community settings. For example, AD/ADRD caregivers face documented stigmatization and progressive social isolation as care recipient symptomology worsens and it becomes more challenging to engage in public social settings [6,34,37]. As such, early social interventions for AD/ADRD caregivers have often focused on creating shared spaces with others in similar situations [5,38]. However, rural residents and others who are not located near needed resources (eg, respite or adult day care and support groups) may face challenges in finding others who have similar experiences or a shared understanding of care responsibilities [39]. Furthermore, AD/ADRD caregiving requires substantial time and financial commitments, which create logistical limitations on opportunities for social engagement outside of one's care responsibilities [23,34,40]. Finally, even in shared spaces with similar others, it may be challenging to express complex or difficult emotions that are common among caregivers [15,22]. Notably, AD/ADRD caregivers may be particularly likely to pursue support on the web via social media, rather than through in-person or community-based programs.

Therefore, this study aimed to explore how caregivers use the social media platform Reddit, with particular emphasis on social support and AD/ADRD information seeking. To this end, we first collected and applied computational natural language processing (NLP) tools to a large corpus of Reddit posts to identify salient themes across the site. We then conducted a manual qualitative content analysis of a random subset (ie, 657/6563, 10.05%) of the corpus to gain a more nuanced understanding of support and information-seeking behaviors of AD/ADRD caregivers through the site.

Methods

Ethical Considerations

For this project, we analyzed only existing data (ie, publicly available information), posted directly to Reddit. All study procedures were approved by the Indiana University Institutional Review Board (#23662).

Data Collection

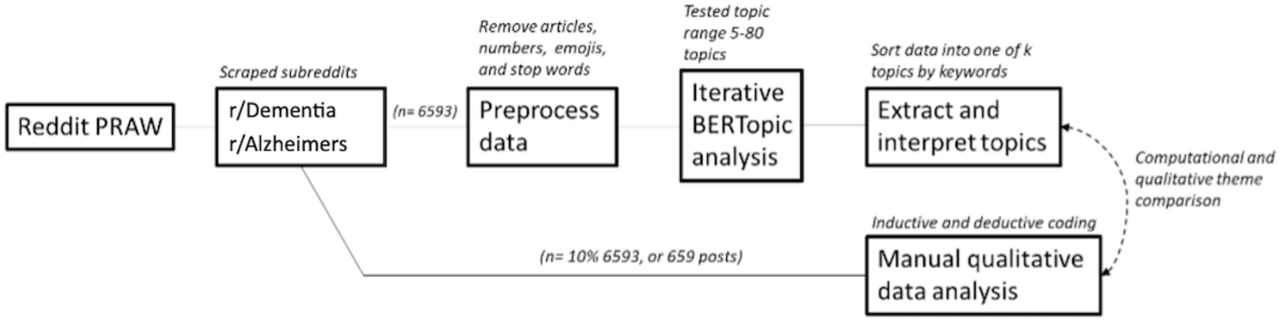
We collected data for this study from Reddit, a social news aggregation, content rating, and discussion social media platform. Unlike other social media platforms, including Instagram, TikTok, and X (formerly Twitter), Reddit represents a forum of communities where people can "opt in" to subreddits, which are moderated subspaces within the wider platform, dedicated to a certain topic. This allows users to seek community and interaction based on specific interests or needs [41]. Subreddit content varies extensively. However, in recent years, subreddits specific to health and well-being–related topics have become increasingly used by people in need of social support, connection, or solidarity [42,43]. Reddit data are also unique in that posts are unincumbered by length limitations. Therefore, data collected from Reddit tend to be more comprehensive and nuanced compared with data from other social media platforms.

Using the Python Reddit API Wrapper [44], a third-party Reddit data scraper, we identified 2 subreddits specific to our research purpose (r/Alzheimers and r/dementia). We then programmed the Python Reddit API Wrapper to collect new, popular, and trending posts, along with relevant metadata, in both subreddits between May and June 2022. These data were saved as a single CSV file for further computational and qualitative data analysis. Upon completion of data collection and excluding duplicates, blank entries, and those deemed irrelevant to discussions about AD/ADRD, we retained 6593 posts.

Analysis

Given our exploratory research purpose, we undertook a two-step process to analyze our data: (1) computational analyses and (2) manual qualitative coding and review. This 2-step approach afforded the ability to identify topics embedded across the entirety of our data using NLP methods and to understand the meaning of each topic at a deeper and more nuanced level through traditional qualitative analyses (Figure 1). We offer a brief explanation of each method applied to the data in subsequent sections.

Figure 1. Workflow depicting computational and qualitative data analyses pipeline. PRAW: Python Reddit API Wrapper.



Natural Language Processing

BERTopic

Topic models refer to any series of NLP tasks that consolidate large language data sets into representative topics or themes. While there are a variety of topic modeling tools, including the highly established latent Dirichlet allocation (LDA) approach, our study used a neural network pipeline leveraging Bidirectional Encoder Representations from Transformers (BERT) vectors using the BERTopic topic modeling tool [45,46]. Indeed, BERTopic is unique among established LDA approaches in that this pipeline specifically uses neural networks and BERT embeddings to approximate latent topics. Topics derived using the BERTopic tool tend to be clearer and more nuanced due to the encoding process, where raw text data are compared against a large language data set. At this stage, raw text data are converted into numerical form, which creates dense vector representations for each document in a given data set. These representations capture contextual nuances of each word across documents, which is not attainable using LDA or other probabilistic topic modeling approaches. Vectors are calculated for each document. As these vectors are difficult to model and interpret, we then perform a dimensionality reduction technique, principal components analysis. Following dimensionality reduction, we extract a series of topics that represent a synopsis of the entire corpus.

Coherence Score Check

BERTopic, and most other topic modeling tools, can generate any number of latent topics specified by a predetermined parameter *k*. However, this fixed topic number may not always reflect the optimal number of topics for a given corpus. Therefore, multiple models may be run and compared, retaining the best overall topic solution for the research. Coherence scores, which are a statistical value predicting the overall interpretability of topics, are a common metric for assessing model fit and choosing the optimal solution. Coherence scores are calculated using pointwise mutual information, which is a measure of the strength of association between 2 words in each document and a collection of documents. In brief, this calculation tells us the degree to which 2 words are more likely to appear together than what would be expected by chance. Therefore, higher coherence scores generally indicate a more interpretable topic solution, as words that co-occur in the corpus more often than they would by random chance are sorted together as topics.

Qualitative Content Analysis

To support findings derived from computational analyses and to better understand nuance related to social support and AD/ADRD information seeking within our data, we conducted a manual qualitative content analysis of a subset of posts previously analyzed. For this analysis, we adopted an approach that was both inductive and deductive in nature. Given our specific research interests related to the ways users sought support on the web, we deductively mapped data codes onto existing conceptual frameworks related to social support and known AD/ADRD behavioral symptomology. However, we inductively allowed for additional codes to emerge from the data.

Procedure

Natural Language Processing

Once we completed data collection, we began preprocessing our data, a common procedure in computational analyses that seeks to standardize and add cohesive structure to messy text data. Part of this standardization includes removing parts of speech that may detract from the clarity of the models, including first-person names, numbers, special characters, emojis, articles, and a series of stop words. Once our data were preprocessed, we proceeded to analyze the data with the BERTopic tool. To identify the optimal number of topics, we performed an iterative topic model analysis that tests a range of topics by iterations of 5 (eg, 5, 10, 15,......*k)*. For each iteration, we calculated coherence scores. We selected the optimal number of topics based on the highest coherence score among topics, ranging from 5 to 80. Once we identified the optimal topic number, we performed a sorting function, which triaged all tokenized sentences into one of *k* latent topics. This sorting feature allowed us to examine topic numbers, keywords associated with each topic, and the number of parsed sentences sorted in each topic. Once computational analyses were complete, we performed a manual review of a random 10.05% (657/6563) of posts within our larger sample. These posts were manually coded and independently compared to the BERTopic output to ascertain overlap.

Qualitative Content Analysis

Initial coding was undertaken by 3 individuals on the research team. First, coders trained together on sample data that were not included in later analyses. This initial coding was subsequently reviewed by 2 established researchers who were not initial coders. After review, the research team met 3 times to review the coding of the training data, which helped crystallize code definitions and identify early emergent themes. Any disagreements in the coding of these training data were discussed until a consensus was reached.

After training, a similar coding process was adopted for the larger data set. Initial coding was completed by the same 3 individuals who provided initial open codes in the training data. This initial coding was then reviewed independently by 2 established researchers from the team for consistency and accuracy. We began to draw connections between initial open codes via axial and selective coding processes to arrive at the final structure, as outlined in the Results section. The coding team met twice to discuss the overall coding structure, again resolving disagreements via discussion until a consensus was reached.

Results

Unsupervised Topic Modeling

Our first set of analyses used NLP to identify the broad themes discussed by users in subreddits related to AD/ADRD. The optimal solution, as determined by the coherence score, included 10 topics, with a coherence score of 0.38. Table 1 provides a summary of each topic, including each topic name, keywords associated with each topic, and its proportional representation within the larger corpus. Importantly, our analysis tokenized data at the sentence level. We chose to analyze at the sentence level, rather than the post level, to identify more granular topics within the corpus. Had we analyzed at the post level, the algorithm would have sought to identify the primary overarching theme across the entire post. Because Reddit posts have no limitations on length, users may include multiple topics in a single entry; such intrapost thematic variability would be poorly reflected with a postlevel analysis, likely resulting in very general and hard-to-interpret topics. Therefore, to avoid such a loss of nuance, we chose the more granular sentence-level approach.

Proportionally, the topic with the greatest representation in our corpus was topic 0, “Reddit inquiries, narratives, and advice,” comprising 17.45% (16,152/ 92,562) of sentences in the total corpus. Other prominent topics include topic 1, “venting/expressing feelings and emotions” (12,652/ 92,562, 13.67%); topic 2, “moving- and housing-related adjustments” (12,090/ 92,562, 13.06%); and topic 3, “ADRD diagnosis and other acute illnesses” (10,695/ 92,562, 11.55%). The remaining topics were marginally consistent in terms of distribution, with topic 9, “hospital, assisted living, and memory care,” having the lowest representation of 5.4% (4994/92,562).

Topics derived using any topic modeling tool are potentially overly generalized or difficult to parse if topics share similar keywords. As such, additional review of the topic solution by researchers with topical knowledge is needed to ascribe meaning to each latent topic. To do so, we applied a sorting function based on keywords to sort tokenized sentences into 1 of 10 possible topics. We then reviewed individual posts to understand and contextualize each topic. Table 2 provides excerpts of posts sorted into each topic to assist the reader in understanding the latent topics identified in the corpus. We observed some generalized themes, as well as more specific AD/ADRD caregiving and contextual topics.

The first 2 identified topics are more general in nature. For example, topic 0, “Reddit inquiries, narratives, and advice,” is quite general and reflects the common language of Redditors asking questions to the community. What follows in any given sentence varies (eg, diagnoses, caregiving advice, or difficulties associated with AD/ADRD symptoms), but there was a common theme of seeking, whether related to information or emotional support. Similarly, topic 1, the second most common in the corpus, encapsulated users’ many and varied expressions of emotion. These more generalized themes are often found in the first few sentences of a Reddit post, wherein the user expresses a wider sentiment before providing more specific and varied details.

Another grouping of topics related to the varied contexts of AD/ADRD caregiving and related decision-making. Topic 2, for example, focused on housing- and moving-related concerns, where users often sought information and advice related to the appropriate time to limit a loved one’s capacity to live alone or strategies for ensuring the safety of community-dwelling individuals living with AD/ADRD. Topics 7 and 9, respectively, centered on more professional care settings. Topic 9 focused on hospitals, assisted living, memory care, or other such facilities; many of these posts were regarding providing or seeking information about proper care, identifying a quality facility, financing options, or the appropriate timing for seeking professional care support. Finally, topic 7 included posts related to hospice (ie, end-of-life) care. Notably, users often sought guidance on the appropriate time to move their loved ones to this type of care and emotional support at this challenging stage.

The remaining topics related to different aspects of the caregiving experience, including the impact of diagnosis (and comorbidities) and care on the family, caregiver burden, and 2 general caregiving topics. In topic 3, for example, we observed many posts that related to physical symptoms related to both dementia and related health challenges (eg, injuries from falls). For many who may not have opportunities to connect with similar others, platforms such as Reddit may be the only source of support available (eg, “I really just don’t know where else to turn”). Others either sought or provided specific advice related to managing certain symptoms (eg, aggression and anxiety) and strategies for managing the burdens of care.

Notably, topics 6 and 4 were highly interrelated and discussed a broad set of caregiving-related topics. While the content in these 2 topics was highly related and posts were often similar, topic 4 focused more specifically on women, while topic 6 was less-based on gender overall. Because of the unsupervised nature of NLP, wherein latent topics are generated based on word co-occurrence but are not constrained to be perfectly orthogonal, it is possible to generate highly correlated topics, as in our data. To further contextualize this overlap (and other bivariate relationships between topics), we generated a correlation matrix using the BERTopic Python module (Figure 2). This figure offers a visual representation of relative topic overlap, with darker colors indicating higher levels of overlap. Not surprisingly, we can see high levels of overlap between topics 6 and 4. The presence of overlapping or highly correlated topics may imply the existence of more generalized themes or a hierarchical structure, which is beyond the scope of this analysis.

Table 1. BERTopic 10-topic solution, including topic name, top associated words, and overall corpus representation (N=92,562).

Topic ID	Topic name	Short name	Top associated words	Sentences, n (%)
0	Reddit inquiries, narratives, and advice	Inquiries	ago, today, night, say, asked, ask, day, asking, guess, idea	16,152 (17.45)
1	Venting or expressing feelings and emotions	Expressing emotion	situation, feel, say, talk, feeling, felt, saying, talking, thinking, think	12,652 (13.67)
2	Moving- and housing-related adjustments	Housing or moving	moved, house, moving, apartment, bedroom, phone, home, stay, job, contact	12,090 (13.06)
3	AD/ADRD[a] diagnosis and other acute illnesses	AD/ADRD diagnosis	treatment, patient, med, dr, doctor, hospital, diagnosis, medical, appointment, medicine	10,695 (11.55)
4	Women and caregiving	Women and caregiving	mom, mother, mum, parent, shes, upset, daughter, aunt, angry, grandma	9065 (9.79)
5	AD/ADRD caregiving burden	Caregiver burden	depression, depressed, cope, stress, stressed, caring, grief, feel, burden, family	7637 (8.25)
6	Family caregiving	Family caregiving	grandparent, grandchild, sibling, parent, caregiving, grandmother, grandpa, grandma, family, aunt	7624 (8.24)
7	Hospice care and decision-making	Hospice	caregiving, caregiver, hospice, wheelchair, hospital, aide, health care, rehab, nursing, home	6280 (6.78)
8	AD/ADRD impact	AD/ADRD impact	dementia, alzheimer, alzheimers, elderly, diagnosed, grandma, grandmother, diagnosis, grandpa, impairment	5373 (5.80)
9	Hospital, assisted living, and memory care	Professional care settings	Hospital, hospice, grandmother, nurse, nursing, grandma, illness, diagnosis, caregiver, medical	4994 (5.40)

[a] AD/ADRD: Alzheimer disease and Alzheimer disease–related dementias.

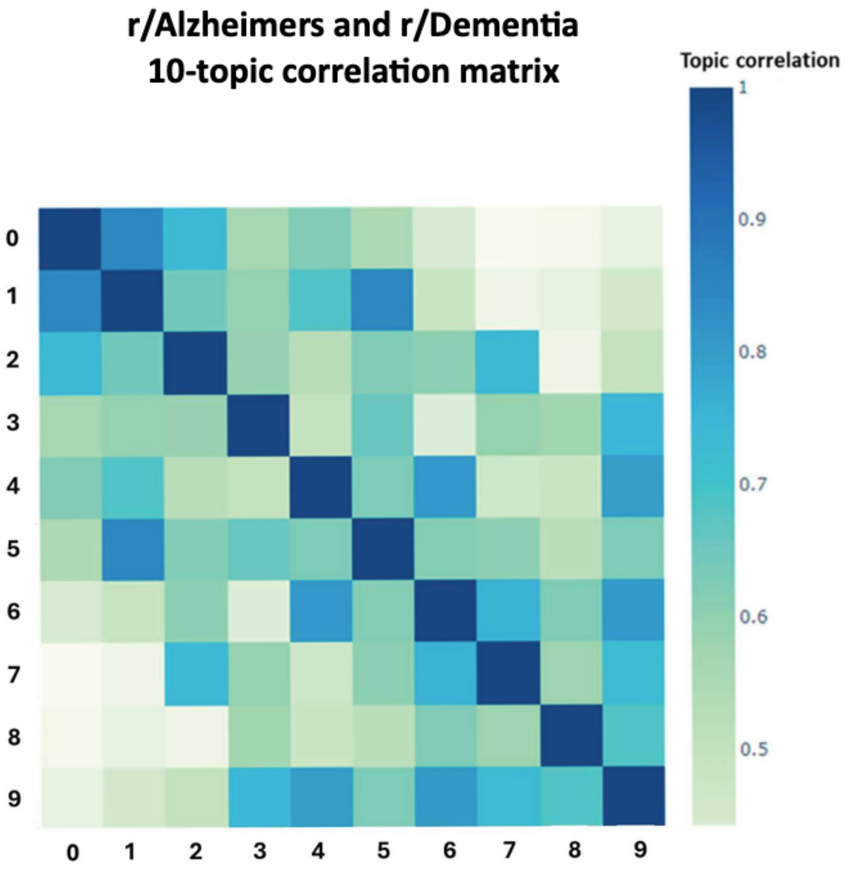
Table 2. Representative post excerpts per topic, derived from our sorting function.

Topic ID	Topic name	Representative quotation
0	Reddit inquiries, narratives, and advice	• “Just curious if anyone has more information.” • “I'll probably poke around this subreddit every once in a while.” • “Hey Lovelies - just bouncing in to share a little tip that has made a HUGE difference in our household.
1	Venting or expressing feelings and emotions	• “I made the mistake of lashing out when he asked why I didn't do his stretches Monday morning, saying ‘do you really think I have time in the mornings to do that?’...I feel like he only wants me around to do everything for him” • “Like, I have no one to talk to. No one will understand. I just want to run away and be left alone. I did not ask for this to be my life” • “Even before the pandemic I felt like my soul was being pulled from me. I just wish I could be around ‘normal’ people”
2	Moving- and housing-related adjustments	• “We recently bought some cameras and a door sensor and suddenly we know that he’ll go outside at 3 AM for whatever reason. Are there locks that can be connected to a C02 or smoke alarm?” • “He also shows no interest in leaving his home; he spends his days in his recliner reading or watching TV.” • “I want her to go to AL, which in our area averages about $5k a month [for care]. She has enough money in the bank to live in AL for 4-5 years. She doesn't want to go to AL because ‘It’s too expensive.’”
3	AD/ADRD[a] diagnosis and other acute illnesses	• “They told us they could force-feed her via intravenously or put a tube down her throat or stomach. The doctor’s other suggestion was to ‘make her comfortable.’” • “And then one morning...she fell and broke her hip because she didn't use her walker while heading to the bathroom.” • “Symptoms started last November. By January she was hospitalized. After the diagnosis of LBD, medical practitioners started treating her differently.”
4	Women and caregiving	• “I picked out a room yesterday and while the guilt is getting to me too, my sibling is having a harder time dealing with it. My heart is breaking over this cat and the bond my mom has with him.” • “We gave our youngest kids OUR house and animal because I had made a promise to my mother she wouldn't go into a home years before this s**t got real. My mother was still in total denial, and we were basically ignorant in a not stupid way.” • “My grandma is 75 years old and has been acting kinda not herself most of the time since February. But by this time I’ve noticed that she’s often confused, asks the same stuff a lot sometimes, has spontaneous bad mood, crying thinking of something bad.”
5	AD/ADRD caregiving burden	• “My thoughts run to upping my anxiety meds, cry in my mothers arms, post vague rants on Facebook, depress friends with the tearful story about my situation or pop a Xanax and sleep.” • “I always talk about the little adjustments you have to make as your loved one gets worse. I’ve cried for about 50 mins and done the stupid rocking myself back and forth in efforts to comfort myself.” • “I feel so powerless and I just want to make you healthy again. Every day I am so happy and put a smile on my face, trying to ignore the gnawing thoughts of your illness and how it is slowly destroying you from the inside.”
6	Family caregiving	• “My only experience with this sort of thing is with my spouses family situation. With their family, they do not let the grandma go to her old house any more. I was told by my wife not to bring my mom back to her old home, as it would cause trouble or upset her like how her grandma got upset.” • “My father-in-law was hiding from us just how bad it was (Not sure why as we where/are very active in their lives) and until FiL death she put on more of a front for us (didn’t always manage it, but managed enough to hide just how bad it was).” • “My dad started answering the phone as my mom became more confused and often asked for her mom (died 50 years ago). Constant desire to go home and find her mom. Not recognizing my dad has been her caregiver through it all.”
7	Hospice care and decision-making	• “She was released from the hospital into the care of one of her brothers, but as of today she has returned back home on her own. Basically, Family Care is not an option.” • “He’s at the stage where he can opt for hospice care, but he’s choosing to prolong life treatment (or at least try.) I told him if he wants to do whatever he wants then hospice care is an option but he will live a lot less longer.” • “After days of back-to-back seizures, she is in the hospital completely unresponsive and I got the news they don’t expect she will recover. I have an appointment tomorrow to go over our hospice care options. I thought we had more time. I wont ever hear her voice again. I used to get annoyed at all of the voicemails she would leave because I always called her back as soon as I could.”

Topic ID	Topic name	Representative quotation
8	AD/ADRD impact	• "The husband has dementia and his wife was taking care of him. I could feel the heart break behind her words as her husband had clearly deteriorated over the years to resemble less and less of the person she described." • "She passed last night, a decade since it first became clear that the disease that had taken her sister had come for her as well. For most deaths 'I'm sorry' suffices, but we all know that with dementia that's not exactly true." • "Over the past four years, my family has come to suspect that my mother has dementia, which doesn't make a whole lot of sense, given that she's 52. The further irony is that my grandmother has just now started displaying symptoms of dementia, at almost 90 years old."
9	Hospital, assisted living, or memory care	• "With my dad in the hospital, my mom has been a complete wreck! The doctor said she'd have to go into a home and she flipped out begging me to bring her to my house." • "My mother is in a memory care facility - she's been there since last July. My father cant face the fact that this is a behavior situation, not a 'see yet another doctor for a magic cream that will stop this.'" • "I have been slowly priming my sister regarding getting mom ready for a home, as she is now truly requiring intense supervision for just about everything and i think my sister is realizing this as her decline has been incredibly apparent over the last few months since dad is gone."

[a] AD/ADRD: Alzheimer disease and Alzheimer disease–related dementias.

Figure 2. A 10-topic solution correlation matrix denoting topic similarity.



Qualitative Content Analysis

Overview

Through this analysis, we sought to situate prior NLP findings in the context of existing research on caregiving for people living with AD/ADRD. Specifically, we qualitatively analyzed a subset of our existing corpus, deductively mapping onto existing conceptual models of social support and AD/ADRD behavioral symptomology. We allowed for additional inductive themes to emerge.

Social Support

A total of 2 primary forms of social support were observed among Reddit users: informational and emotional. Of note, companionship behaviors and relatedness (other theoretical forms of social support) were not commonly observed in our data. Among the subcategories of informational forms of social support identified by Yao et al [47], 2 subcategories were observed frequently among our data: advice and teaching. Users sought advice from others related to a broad variety of topics, including help with decision-making (eg, seeking professional care support, admission to a care facility, and beginning hospice care); managing challenging symptomology (eg, aggression and wandering); coordinating care networks; and strategies to prevent burnout. For example, one user posted as follows:

> *I need help. With anger. With boundaries. Active things I already do: meditation, avoiding most substances, gardening, painting, journaling... tried therapy a few times they always offer meds which I dont [sic] want due to chronic illness I dont [sic] want to flare up... thank you.*

Beyond this more generalized advice seeking, users sometimes sought or provided specific forms of teaching informational support. Often, these threads surrounded discussions of new medications or clinical trials for people living with dementia. Others offered practical tips and supports. For example, one user described the placement of an "orientation board" in a conspicuous place to provide useful information for their care recipient, including the day or date, expected appointments, weather, and other basics that helped reduce confusion.

In addition, we observed users both seeking and providing emotional social support. We observed a broad array of emotional support, including words of affirmation, expressions of care or concern, encouragement, sympathy, and understanding. Frequently, users expressed a vague or nonspecific need for support—that they had come to the forum seeking others with similar experiences who understood the challenges associated with caregiving. However, many users noted the sense of community and the value of the group's shared experience in helping them individually. For example, a user thanked the group, saying the following:

> *I appreciate everyone so much. I know that what were [sic] experiencing with loved ones and or friends is painful, tiring, and other things. Your questions and experiences have given me a heads up on situations.*

In a different case, users specifically coalesced and supported a member who was going through a particularly challenging period, including providing donations and financial support. The user thanked the group, saying the following:

> *Feeling a little better today and am very overwhelmed by the support. You all really did make me feel less alone and I appreciate your support and offers to talk when you could have easily scrolled past. I also appreciate the awards but next time, take that money and please donate it to the Alz [sic] association. I do love the hug and silver award though, that is very very very kind.*

AD/ADRD Behavioral Symptomology

Overview

We coded AD/ADRD behavioral symptoms using the standard Neuropsychiatric Inventory [48]. We found users regularly discussed symptomology to approximate or assess disease progression, particularly in the context of major decision-making (eg, care levels and power of attorney). A total of 3 categories of neuropsychiatric behavioral symptoms were commonly observed in Reddit posts.

Agitation or Aggression

One primary behavioral concern that appeared consistently in the discussion was increasing levels of aggression or agitation. Users noted that as part of the disease progression, care recipients increasingly struggled with emotional regulation; this often led to outbursts and physical aggression. Users recalled incidents where care recipients had yelled at caregivers, thrown objects, and attempted physical violence—sometimes without explanation. For example, one user described attempts to keep a loved one from wandering by securing doors and fences on the property; during the resulting "tirade," the care recipient "grabbed my brother by the front of his shirt and began screaming in his face" and they also noted the following:

> *He has threatened to slash the tires on the car. The other day I caught him just before he swung a metal pipe at the windshield of my rental car.*

Among Reddit users, we found these discussions were often related to larger caregiving decisions. For some, the emergence of violence was an inflection point in seeking full-time or professional care. However, others sought help, as the aggressive behaviors of care recipients caused them to be removed from care facilities.

Delusions and Hallucinations

Another prominent theme in the data was increasing delusions among care recipients. These delusions often manifested as care recipients' mistrust of those around them due to unfounded beliefs that these individuals would harm them in some way (eg, physical violence and theft) or as a conspiracy against them. Episodes of delusion covered a broad range of experiences, from a more benign suspicion that others were lying to more elaborate, reoccurring fantasies. For example, one user posted regarding regular hallucinations their parent had about a fantasy world:

> *[A] fantasy world he created involving red-robed people who came into the room uninvited and stayed overnight.*

Regarding aggressive behaviors, many discussions around delusions and hallucinations were part of larger threads seeking support and understanding about dementia progression. Delusions were regularly discussed as a motivation for seeking external care support.

Nighttime Behaviors

The final commonly discussed behavioral symptom category related to nighttime issues. In the context of dementia, this category relates to a broad set of behaviors, including rising too early in the morning, awakening during the night, and excessive daytime napping—all generally related to sleep disturbance of some kind. Users regularly discussed the progression of sundowning—wherein individuals may experience restlessness, confusion, or irritability in the evening as daylight fades and progresses into the night. Users noted that sundowning symptoms continued into nighttime and often caused an inability to sleep or that patients would experience nightmares or terrors and stay awake throughout the night. In some cases, this inability to sleep resulted in the individual becoming fearful, seeking to escape, or taking additional medication. For example, one user noted the following about their mother:

> *[K]eeps getting up in the middle of the night, walking unassisted, digging around in her med suitcase taking God knows how many extra meds in the middle of the night.* [sic]

Commonly, these nighttime behaviors also had negative health repercussions for caregivers and family members who could not sleep themselves, either due to disturbances caused by the care recipient or by the need to provide supervision and care while the individual was awake.

Emergent Codes

Caregiver Anxiety or Guilt

The most frequently observed code across the entire data set related to caregiver guilt or anxiety, with users expressing distress related to their caring role and responsibilities, as well as their own emotions and personal challenges. For example, some users expressed fear of failing in their caregiving role, such as a user who expressed, “My biggest fear is that I’m not doing enough,” or another who said the following:

> *I’m struggling hard tonight. I want to want to fix this for my dad so badly but I can’t and I hate it. I hate that he has no idea what’s going on or why its happening and I hate that I can’t just make it all better for him.* [sic]

Another primary form of guilt and anxiety that emerged related to the users’ emotions and feelings. Some felt anger toward their care recipient. For example, some users noted they experienced emotional exhaustion related to caregiving and challenges coping with the loss of a loved one. One user, for example, lamented the loss of their mother’s cognitive function and was struggling with the decision to place her in an assisted living facility. The user experienced guilt around their feelings, noting the following:

> *[T]o me, my mother has been gone a long time. Am I an asshole for not wanting to see her...?* [sic]

Furthermore, multiple users expressed guilt associated with feelings of relief (both realized and expected) upon the passing of the person in their care, such as the user who stated the following:

> *I feel sad but also I feel free...I think sometimes “now I can start my life” and then I feel selfish and sad.*

Decisions-Making About Care Facilities

Another commonly observed theme in the data involved decision-making about care facilities and other forms of assisted living. Prospectively, users sought advice and validation related to deciding when in the disease progression it was appropriate to place their loved ones in an assisted living facility. In addition, users sought practical advice on finding and selecting the right place and evaluating quality of care. However, many posts discussed challenges related to patients already in an assisted living facility. For some, there were unexpected or short-notice care expectations, even after the individual was placed in an assisted living facility. One user noted as follows:

> *The facility staff are telling me we either need to coordinate a sitter to literally sit outside his door 24/7 and physically keep him from leaving, or to send him to a mental institution until they get his meds right. This change needs to happen within 24 hours.*

Other users were disappointed with the quality of care their loved ones were receiving. For example, one user said the following:

> *She was able to get out via an alarmed door, which apparently didn’t sound, get past reception, out the front door and walked up a super busy street to a grocery store 1/2 mile away! The street is almost a highway with. 3 lanes of traffic on each side. I don’t know all of the details yet but clearly this is not acceptable...I’m so angry that this could happen. My family is paying a ton of money to keep them safe and this happens.*

Therefore, the myriad challenges associated with care facilities were common themes in the discussion on dementia-related subreddits.

Legal and Financial Planning

Users also commonly discussed the challenges associated with legal and financial planning for their loved ones living with AD/ADRD. These posts largely centered on the high financial costs of professional care and assisted living facilities and the steps caregivers and families could take to afford this support and protect family assets. Many users noted that their loved ones did not have sufficient resources (eg, retirement savings, long-term care insurance, and state support) to cover the costs of needed full-time care. In some cases, users reported subsidizing their loved ones’ care with their own funds:

> *I used to be what I would consider reasonably well off, now I have nothing left and struggle daily to make ends meet.*

Others described an impossible tension, wherein they could neither afford to pay for needed care nor quit their own jobs to provide full-time care, such as the user who said the following:

> *My only word of advice is, unless you’re a millionaire and can afford home care, which we were most certainly not, there is no solution and no easy road to this disease.*

One common concern in the discussion of care was the protection or leveraged use of assets, specifically houses owned by the care recipient. For example, one user described a situation in which their parent could not live in his home because he needed rental income to pay for his care, effectively forcing him to move in with relatives. Others noted that owning a home precluded access to social support programs as it counted as a substantial asset that had to be depleted before receiving assistance. Several threads related to strategies for protecting such assets (eg, placing the home in a trust) or challenges in liquidating them (eg, relatives living in the house or unwillingness to sell). Furthermore, these conversations commonly discussed the need to get legal affairs in order, such as establishing power of attorney and writing a living will early in the disease progression.

Thematic Comparison

Across both forms of data analysis, we observed similar overall topical structures within Reddit posts related to AD/ADRD caregiving. The most salient NLP-identified topics were very general and focused on making inquiries or sharing emotions with the forum. In our qualitative analysis, the most common coding was quite similar, related to users' expressions of emotion. However, through qualitative coding, we identified added nuance to these emotions of guilt, anxiety, and the struggles of AD/ADRD caregiving. Furthermore, we noted users sometimes expressed feelings that may be socially unacceptable outside an anonymous online space. For example, some users expressed relief upon the death of their care recipient. While likely not an uncommon emotional response given the myriad challenges associated with care, this relief may be uncomfortable to express to others for fear of judgment.

Similarly, the corpus-wide NLP analysis identified information seeking as a primary use of Reddit forums for AD/ADRD caregivers. However, in our qualitative coding, we identified specific informational needs of caregivers (eg, legal and financial planning advice) that were not apparent in the wider analysis. Moreover, we found through the qualitative analysis that users often sought normative standards for decision-making at common key time points in the disease progression, such as the "right" time to move a care recipient to professional or end-of-life care. While we observed themes related to assisted living and hospice care in the NLP, the qualitative coding provided a deeper understanding, finding that users were most often seeking external standards from others, which they could then apply to their unique situations and reduce doubt in their own decision-making. Therefore, our broad NLP analyses gave a high-level, atheoretical overview of themes in a large corpus beyond what is generally feasible for manual, human-driven analysis. Our qualitative coding fleshed out these findings, incorporating existing conceptual frameworks to contextualize and provide a more detailed understanding of the social support and information-seeking behaviors of AD/ADRD caregivers on Reddit.

Discussion

Principal Findings

Users sought community and informational support in dealing with the challenges associated with caregiving for people living with AD/ADRD. Consistent with prior literature, users reported a variety of emotional challenges related to providing care [34-36]; caregiver guilt and anxiety was a highly salient theme across the forum. The sources and manifestations of these emotions were highly variable across the forum. For example, users noted feelings of inadequacy in their capacity to care for loved ones, guilt associated with a lack of patience for their care recipient, loneliness and social isolation, burnout, and anxiety related to the varied stressors associated with care. While caregiver burden is well-established in the literature [15], it was particularly salient in the online space, wherein this seemed to be a primary point of conversation between users. Given the documented social stigmatization of dementia caregivers [37], users may seek to express these feelings and find support online as they do not feel comfortable expressing their challenges in day-to-day life. Furthermore, and unique to the anonymous online space, users felt empowered to discuss potentially taboo topics, including relief upon the passing of their care recipient. It is important to note the subreddits analyzed in this study are moderated to avoid bullying and spam and to establish a respectful dialogue in the forum. Notably, users may feel particularly safe to express these otherwise stigmatized beliefs and challenges. Creating this trust and safe space to discuss the complex emotions associated with dementia care may be similarly useful in face-to-face caregiver support interventions.

Consistent with other studies, Reddit users discussed myriad behavioral symptoms of AD/ADRD and strategies for providing effective care related to each symptom [19,20]. Manual coding identified instances of 14 different behavioral symptoms of dementia. The most identified among these were agitation or aggression, delusions, and bathroom or toileting issues. These are, perhaps, not surprising, given that these are symptoms with higher associated costs or challenges of care. Therefore, these may be the symptoms most discussed when seeking support. Often, users reported multiple symptoms together in the same post, consistent with the nonlinear nature of disease progression. Many users sought to map symptomology onto a disease progression timeline to better understand their own situation. However, as was noted by multiple users, this is challenging as dementia can present and progress differently across individuals. As such, the presentation of behavioral symptomology was often highly variable across the sample.

Finally, discussions with the forum also often related to difficult decisions facing caregivers of people living with dementia [4,49]. Many posts focused, for example, on the legal and financial planning challenges of care; users provided resources to others to help create power of attorney documentation and to navigate health care systems. The complicated legal and financial challenges associated with dementia and end-of-life care have been documented elsewhere. In our sample, users sought to crowdsource resources to navigate these complex systems, potentially without the high costs associated with hiring specialist attorneys and personal financial planners. Furthermore, users sought feedback associated with care decisions, particularly the proper timing for moving their loved ones into a full-time care facility. User discussions often compared symptomology and family circumstances, seeking validation or support in making the choice to seek professional care help. Again, these discussions often centered on stigma, fears associated with care quality, and the financial costs of professional care. As users faced difficult but common decisions related to transitions in care—times associated with higher perceived caregiver burden—they sought online emotional and informational support.

Implications for Practice

Our study findings suggest the need for increased social support structures for AD/ADRD caregivers, a special population who may experience challenges associated with seeking information and other forms of support on the web. This is consistent with the wider literature surrounding caregiver burden, suggesting high rates of burnout and needs for additional support beyond localized networks [34,35]. However, our study findings introduce important additional considerations. Recent literature has begun to document mental health risks associated with extensive social media use, particularly linked to unfavorable social comparison (ie, to others with fewer perceived challenges) [50]. There are further risks associated with seeking health-related information on the internet, given the high rates of misinformation found on social media [51]. Therefore, despite the somewhat closed and moderated nature of dementia-related subreddit forums, the overall absolute value for AD/ADRD caregivers of seeking support and information therein is unknown. Online resources and spaces for social connection, such as Reddit, which also feature expert fact-checking and seek to reduce harmful social comparisons, may be needed to support caregivers. Furthermore, there are opportunities for the development of mobile apps specific to AD/ADRD caregiving; however, additional research on the relative benefit of new mobile apps versus commonly used social media platforms is needed [40].

In addition, users noted specific informational needs with which they struggled to find high-quality support, including legal or financial planning and strategies for coping with feelings of inadequacy or guilt. These gaps in readily available information offer opportunities for intervention. For example, programs designed to teach caregivers about complex legal and financial planning documents (eg, power of attorney, living wills, and advance directives) may reduce burden. Given the well-documented financial strain associated with providing care, a centralized, online information hub for legal and financial planning may increase the capacity to proactively manage the complex tasks associated with estate planning and long-term care financing. Furthermore, specialized support groups for caregivers may use acceptance and commitment therapy techniques, which emphasize self-compassion around perceived personal shortcomings [52]. Acceptance and commitment therapy techniques are increasingly used in family caregiving settings (including for dementia), with promising early acceptance or feasibility and results related to psychological flexibility, which is the capacity to stay in contact with the present, irrespective of negative thoughts or feelings [52-54]. Unfortunately, access to such interventions and therapies remains limited, leading caregivers to seek information and social support in free and open online spaces. Future intervention work may leverage such opportunities to create readily accessible supports to assist caregivers in managing both specific care tasks (eg, financial management) and emotional challenges associated with caring for a loved one living with AD/ADRD.

Limitations and Future Directions

As with all research, this study has certain limitations that should be considered. First, the sample was drawn from a single, moderated, online space, which may limit some of the most extreme responses from being published. Reddit users are, on average younger, highly educated, and more likely to be male than the general population. Furthermore, because data were published anonymously and are self-reported, we have no mechanism by which to directly assess truthfulness. However, this anonymity was a key feature to our findings and has been reported as a strength in other social media studies. Future research may explore AD/ADRD caregivers' use of different social media platforms, as social media use varies across demographic groups. Similarly, future research may examine differences between social media platforms, due to the differing nature of the content (ie, images, text, and video) found on each platform. In addition, while we analyzed a large sample using computational methods, the qualitative process for deeper analysis was limited to a smaller subsample. Therefore, our findings are not necessarily representative of all dementia caregivers and should be considered with these limitations in mind.

Conclusions

In this study, we used both computational and traditional qualitative analyses to explore the experiences of caregivers of people living with AD/ADRD who posted to the social media channel Reddit. Using an unsupervised topic modeling approach, we generated a 10-topic solution (coherence score=0.38) from a corpus of more than 6500 posts. These topics broadly centered on emotional and logistical challenges associated with care, as well as a cluster of topics associated with various symptomology. To gain a deeper understanding of these topics, we conducted a qualitative review of a subset of posts. Users noted high levels of burden, guilt, and anxiety associated with caregiving. Users sought emotional and informational support to manage the behavioral symptomology of their care recipients and to make key legal, financial, and other care-related decisions. Interestingly, the anonymous and moderated nature of the Reddit platform seemed to reduce the perceived risk of stigmatization, allowing users to express difficult and complex emotions related to the care experience, including resentment and relief upon the passing of a loved one. These findings suggest the need for additional caregiver support interventions to reduce burden and improve overall well-being for both the caregiver and care recipient.

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Authors' Contributions

ACP, DV, and NEW conceptualized the study and contributed to data collection. ACP, DV, KLS, WJK, and BF conducted formal data analysis. ACP, DV, and KLS drafted the original manuscript, which was reviewed and edited by all authors.

Conflicts of Interest

None declared.

References

1. 2024 Alzheimer's disease facts and figures. Alzheimer's Association. URL: https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf [accessed 2024-06-05]
2. Jutkowitz E, Mitchell LL, Bardenheier BH, Gaugler JE. Profiles of caregiving arrangements of community-dwelling people living with probable dementia. J Aging Soc Policy 2022 Nov 02;34(6):860-875 [FREE Full text] [doi: 10.1080/08959420.2021.1927613] [Medline: 34003081]
3. Jutkowitz E, Gaugler JE, Trivedi AN, Mitchell LL, Gozalo P. Family caregiving in the community up to 8-years after onset of dementia. BMC Geriatr 2020 Jun 19;20(1):216 [FREE Full text] [doi: 10.1186/s12877-020-01613-9] [Medline: 32560701]
4. Waligora KJ, Bahouth MN, Han HR. The self-care needs and behaviors of dementia informal caregivers: a systematic review. Gerontologist 2019 Sep 17;59(5):e565-e583. [doi: 10.1093/geront/gny076] [Medline: 29931147]
5. Wennberg A, Dye C, Streetman-Loy B, Pham H. Alzheimer's patient familial caregivers: a review of burden and interventions. Health Soc Work 2015;40(4):e162-e169. [doi: 10.1093/hsw/hlv062]
6. Shin JY, Habermann B. Caregivers of adults living with Alzheimer's disease or dementia in 2020: a secondary analysis. J Gerontol Nurs 2022 Sep;48(9):15-25. [doi: 10.3928/00989134-20220805-02] [Medline: 36007215]
7. Zanetti O, Solerte SB, Cantoni F. Life expectancy in Alzheimer's disease (AD). Arch Gerontol Geriatr 2009 Jan;49 Suppl 1:237-243. [doi: 10.1016/j.archger.2009.09.035] [Medline: 19836639]
8. Ajrouch KJ, Webster NJ, Zahodne LB, Antonucci TC. Introduction to ADRD care in context. J Gerontol B Psychol Sci Soc Sci 2023 Mar 13;78(Suppl 1):S1-S3 [FREE Full text] [doi: 10.1093/geronb/gbac181] [Medline: 36477194]
9. Liu Z, Heffernan C, Tan J. Caregiver burden: a concept analysis. Int J Nurs Sci 2020 Oct 10;7(4):438-445 [FREE Full text] [doi: 10.1016/j.ijnss.2020.07.012] [Medline: 33195757]
10. Werner NE, Stanislawski B, Marx KA, Watkins DC, Kobayashi M, Kales H, et al. Getting what they need when they need it. Appl Clin Inform 2017 Dec 20;26(01):191-205. [doi: 10.4338/aci-2016-07-ra-0122]
11. Iriarte ES, Jimenez DE. A caregiver must be healthy to be able to care. Am J Geriatr Psychiatry 2021 May;29(5):473-475 [FREE Full text] [doi: 10.1016/j.jagp.2020.10.003] [Medline: 33168389]
12. Linden A, Jolliff A, Gonzalez D, Loganathar P, Elliott C, Zuraw M, et al. "It made me feel like I wasn't alone in the darkness": exploring dementia care network communication and coordination through a digital health platform. J Am Med Inform Assoc 2022 Nov 14;29(12):2003-2013 [FREE Full text] [doi: 10.1093/jamia/ocac172] [Medline: 36166717]
13. Llanque S, Savage L, Rosenburg N, Caserta M. Concept analysis: Alzheimer's caregiver stress. Nurs Forum 2016 May 01;51(1):21-31 [FREE Full text] [doi: 10.1111/nuf.12090] [Medline: 24787468]
14. Harris ML, Titler MG, Hoffman GJ. Associations between Alzheimer's disease and related dementias and depressive symptoms of partner caregivers. J Appl Gerontol 2021 Jul 29;40(7):772-780 [FREE Full text] [doi: 10.1177/0733464820952252] [Medline: 32865109]
15. Clyburn LD, Stones MJ, Hadjistavropoulos T, Tuokko H. Predicting caregiver burden and depression in Alzheimer's disease. J Gerontol B Psychol Sci Soc Sci 2000 Jan 01;55(1):S2-13. [doi: 10.1093/geronb/55.1.s2] [Medline: 10728125]
16. Bauer JM, Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. Popul Ageing 2015 Feb 14;8(3):113-145. [doi: 10.1007/s12062-015-9116-0]
17. Sloane PD, Schifeling CH, Beeber AS, Ward KT, Reed D, Gwyther LP, et al. New or worsening symptoms and signs in community-dwelling persons with dementia: incidence and relation to use of acute medical services. J Am Geriatr Soc 2017 Apr 02;65(4):808-814 [FREE Full text] [doi: 10.1111/jgs.14672] [Medline: 28152160]
18. Devanand DP, Lee S, Huey ED, Goldberg TE. Associations between neuropsychiatric symptoms and neuropathological diagnoses of Alzheimer disease and related dementias. JAMA Psychiatry 2022 Apr 01;79(4):359-367 [FREE Full text] [doi: 10.1001/jamapsychiatry.2021.4363] [Medline: 35171235]
19. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. Front Neurol 2012;3:73 [FREE Full text] [doi: 10.3389/fneur.2012.00073] [Medline: 22586419]
20. Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioral and psychological symptoms of dementia. BMJ 2015 Mar 02;350(mar02 7):h369 [FREE Full text] [doi: 10.1136/bmj.h369] [Medline: 25731881]
21. Allegri RF, Sarasola D, Serrano CM, Taragano FE, Arizaga RL, Butman J, et al. Neuropsychiatric symptoms as a predictor of caregiver burden in Alzheimer's disease. Neuropsychiatr Dis Treat 2006 Mar;2(1):105-110 [FREE Full text] [Medline: 19412452]

22. Mangone CA, Sanguinetti RM, Baumann PD, Gonzalez RC, Pereyra S, Bozzola FG, et al. Influence of feelings of burden on the caregiver's perception of the patient's functional status. Dementia 1993 May 26;4(5):287-293. [doi: 10.1159/000107335] [Medline: 8261026]
23. Tremont G. Family caregiving in dementia. Med Health R I 2011 Feb;94(2):36-38 [FREE Full text] [Medline: 21456372]
24. Norton MC, Smith KR, Østbye T, Tschanz JT, Corcoran C, Schwartz S, et al. Greater risk of dementia when spouse has dementia? The Cache County study. J Am Geriatr Soc 2010 May 07;58(5):895-900 [FREE Full text] [doi: 10.1111/j.1532-5415.2010.02806.x] [Medline: 20722820]
25. Dyer HT. Defining social media…It's complicated. In: Designing the Social: Unpacking Social Media Design and Identity. Singapore: Springer; 2020.
26. Obar JA, Wildman S. Social media definition and the governance challenge: an introduction to the special issue. Telecommun Policy 2015 Oct;39(9):745-750. [doi: 10.1016/j.telpol.2015.07.014]
27. Rhee L, Bayer JB, Lee DS, Kuru O. Social by definition: how users define social platforms and why it matters. Telemat Inform 2021 Jun;59:101538. [doi: 10.1016/j.tele.2020.101538]
28. Daily time spent on social networking by internet users worldwide from 2012 to 2024. Statista. URL: https://www.statista.com/statistics/433871/daily-social-media-usage-worldwide/ [accessed 2024-05-19]
29. Gottfried J. Americans' social media use. Pew Research Center. 2024 Jan 31. URL: https://www.pewresearch.org/internet/2024/01/31/americans-social-media-use/ [accessed 2024-05-19]
30. Twenge JM. Does online social media lead to social connection or social disconnection? J Coll Character 2013 Feb 08;14(1):11-20. [doi: 10.1515/jcc-2013-0003]
31. Roberts JA, David ME. On the outside looking in: social media intensity, social connection, and user well-being: the moderating role of passive social media use. Can J Behav Sci 2023 Jul;55(3):240-252. [doi: 10.1037/cbs0000323]
32. Clark JL, Algoe SB, Green MC. Social network sites and well-being: the role of social connection. Curr Dir Psychol Sci 2017 Dec 19;27(1):32-37. [doi: 10.1177/0963721417730833]
33. Hamm MP, Chisholm A, Shulhan J, Milne A, Scott SD, Given LM, et al. Social media use among patients and caregivers: a scoping review. BMJ Open 2013 May 09;3(5):e002819 [FREE Full text] [doi: 10.1136/bmjopen-2013-002819] [Medline: 23667163]
34. Bachmann P. Caregivers' experience of caring for a family member with Alzheimer's disease: a content analysis of longitudinal social media communication. Int J Environ Res Public Health 2020 Jun 19;17(12):4412 [FREE Full text] [doi: 10.3390/ijerph17124412] [Medline: 32575455]
35. Anderson JG, Hundt E, Dean M, Rose KM. "A fine line that we walk every day": self-care approaches used by family caregivers of persons with dementia. Issues Ment Health Nurs 2019 Mar 13;40(3):252-259. [doi: 10.1080/01612840.2018.1499156] [Medline: 30422041]
36. Ni C, Malin B, Song L, Jefferson A, Commiskey P, Yin Z. "Rough day … need a hug": learning challenges and experiences of the Alzheimer's disease and related dementia caregivers on Reddit. In: Proceedings of the International AAAI Conference on Web and Social Media. 2022 Presented at: ICWSM 2022; June 6-9, 2022; Atlanta, GA. [doi: 10.1609/icwsm.v16i1.19328]
37. Mak WW, Cheung RY. Affiliate stigma among caregivers of people with intellectual disability or mental illness. J Appl Res Intellect Disabil 2008 Oct 13;21(6):532-545. [doi: 10.1111/j.1468-3148.2008.00426.x]
38. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. Gerontologist 2015 Apr;55(2):210-226 [FREE Full text] [doi: 10.1093/geront/gnu123] [Medline: 26035597]
39. Williamson HJ, McCarthy MJ, Garcia YE, Bacon R, Dunn DJ, Baldwin JA. Addressing the needs of rural caregivers of individuals with Alzheimer's disease and related dementias during and beyond coronavirus disease 2019 (COVID-19). Public Policy Aging Rep 2020 Sep 04;30(4):178-180 [FREE Full text] [doi: 10.1093/ppar/praa024] [Medline: 33185627]
40. Jolliff A, Dudek A, Parks R, Linden A, Elliott C, Zuraw M, et al. Design requirements for financial and legal planning platforms to support care partners of people living with Alzheimer's disease and related dementias. Alzheimer's Dement 2022 Dec 20;18(S8):e069225. [doi: 10.1002/alz.069225]
41. Wang HM, Bulat B, Fujimoto S, Frey S. Governing for free: rule process effects on Reddit moderator motivations. In: Proceedings of the 24th International Conference on Human-Computer Interaction. 2022 Presented at: HCII 2022; June 26-July 1, 2022; Virtual Event. [doi: 10.1007/978-3-031-19682-9_14]
42. Valdez D, Patterson MS. Computational analyses identify addiction help-seeking behaviors on the social networking website Reddit: insights into online social interactions and addiction support communities. PLOS Digit Health 2022 Nov 9;1(11):e0000143 [FREE Full text] [doi: 10.1371/journal.pdig.0000143] [Medline: 36812569]
43. Valdez D, Mena-Meléndez L, Crawford BL, Jozkowski KN. Analyzing Reddit forums specific to abortion that yield diverse dialogues pertaining to medical information seeking and personal worldviews: data mining and natural language processing comparative study. J Med Internet Res 2024 Feb 14;26:e47408 [FREE Full text] [doi: 10.2196/47408] [Medline: 38354044]
44. Madan P. Web scraping Reddit with python: a complete guide with code. GoLogin. 2023 Mar 23. URL: https://gologin.com/blog/web-scraping-reddit [accessed 2024-03-29]
45. Grootendorst M. BERTopic: neural topic modeling with a class-based TF-IDF procedure. arXiv Preprint posted online March 11, 2022 [FREE Full text]

46. Egger R, Yu J. A topic modeling comparison between LDA, NMF, Top2Vec, and BERTopic to demystify Twitter posts. Front Sociol 2022 May 6;7:886498 [FREE Full text] [doi: 10.3389/fsoc.2022.886498] [Medline: 35602001]
47. Yao T, Zheng Q, Fan X. The impact of online social support on patients' quality of life and the moderating role of social exclusion. J Serv Res 2015 May 08;18(3):369-383. [doi: 10.1177/1094670515583271]
48. Cummings J. The neuropsychiatric inventory: development and applications. J Geriatr Psychiatry Neurol 2020 Mar 04;33(2):73-84 [FREE Full text] [doi: 10.1177/0891988719882102] [Medline: 32013737]
49. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. J Am Geriatr Soc 2013 Dec 25;61(12):2087-2095 [FREE Full text] [doi: 10.1111/jgs.12549] [Medline: 24479141]
50. Braghieri L, Levy R, Makarin A. Social media and mental health. Am Econ Rev 2022 Nov 01;112(11):3660-3693. [doi: 10.1257/aer.20211218]
51. Suarez-Lledo V, Alvarez-Galvez J. Prevalence of health misinformation on social media: systematic review. J Med Internet Res 2021 Jan 20;23(1):e17187 [FREE Full text] [doi: 10.2196/17187] [Medline: 33470931]
52. Larmar S, Wiatrowski S, Lewis-Driver S. Acceptance and commitment therapy: an overview of techniques and applications. J Serv Sci Manag 2014;07(03):216-221. [doi: 10.4236/jssm.2014.73019]
53. Han A, Yuen HK, Lee HY, Zhou X. Effects of acceptance and commitment therapy on process measures of family caregivers: a systematic review and meta-analysis. J Context Behav Sci 2020 Oct;18:201-213. [doi: 10.1016/j.jcbs.2020.10.004]
54. Atefi GL, de Vugt ME, van Knippenberg RJ, Levin ME, Verhey FR, Bartels SL. The use of Acceptance and Commitment Therapy (ACT) in informal caregivers of people with dementia and other long-term or chronic conditions: a systematic review and conceptual integration. Clin Psychol Rev 2023 Nov;105:102341 [FREE Full text] [doi: 10.1016/j.cpr.2023.102341] [Medline: 37776577]

Abbreviations

AD/ADRD: Alzheimer disease and Alzheimer disease–related dementias
BERT: Bidirectional Encoder Representations from Transformers
LDA: latent Dirichlet allocation
NLP: natural language processing

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Original Paper

Internet Use as a Moderator of the Relationship Between Personal Resources and Stress in Older Adults: Cross-Sectional Study

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Abstract

Background: Internet use has dramatically increased worldwide, with over two-thirds of the world's population using it, including the older adult population. Technical resources such as internet use have been shown to influence psychological processes such as stress positively. Following the Conservation of Resources theory by Hobfoll, stress experience largely depends on individuals' personal resources and the changes in these resources. While personal resource loss has been shown to lead to stress, we know little regarding the role that technical resources may play on the relationship between personal resources and stress.

Objective: This study aims to investigate the moderating effect of technical resources (internet use) on the relationship between personal resources and stress in younger and older adults.

Methods: A total of 275 younger adults (aged 18 to 30 years) and 224 older adults (aged ≥65 years) indicated their levels of stress; change in personal resources (ie, cognitive, social, and self-efficacy resource loss and gain); and internet use. Variance analyses, multiple regression, and moderation analyses were performed to investigate the correlates of stress.

Results: Results showed that older adults, despite experiencing higher levels of resource loss (questionnaire scores: 1.82 vs 1.54; $P<.001$) and less resource gain (questionnaire scores: 1.82 vs 2.31; $P<.001$), were less stressed than younger adults (questionnaire scores: 1.99 vs 2.47; $P<.001$). We observed that the relationship among resource loss, resource gain, and stress in older adults was moderated by their level of internet use ($\beta=.09$; $P=.05$). Specifically, older adults who used the internet more frequently were less stressed when they experienced high levels of both loss and gain compared to their counterparts who used internet the less in the same conditions. Furthermore, older adults with low resource gain and high resource loss expressed less stress when they used the internet more often compared to those with low internet use.

Conclusions: These findings highlight the importance of internet use in mitigating stress among older adults experiencing resource loss and gain, emphasizing the potential of digital interventions to promote mental health in this population.

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KEYWORDS

internet use; aging; stress; personal resources; technical resources; Hobfoll's Conservation of Resources theory; COR theory

Introduction

Background

Internet use has increased drastically in the last decade, with two-thirds of the world's population now being familiar with it [1]. For example, in Switzerland, 90% of people aged >15 years use the internet daily, and even 70.3% of people aged >65 years use it regularly [2]. However, few studies have explored the role of internet use on psychological processes such as stress in the context of personal resource loss and its age-related specificities.

Older adults are often confronted with a variety of challenges that can result in social, health, and cognitive losses. Specifically, older adults may experience reduced social support networks, decreased physical functioning, and a decline in cognitive abilities such as memory and executive functioning [3,4]. These losses can have a negative impact on overall well-being, including increased levels of stress, depression, and anxiety [5,6]. Moreover, individuals tend to place greater value on avoiding losses than on acquiring gains and, as a result, are often more motivated to take action to avoid potential losses than to pursue potential gains. Technical resources can serve as an additional resource that helps older adults maintain or improve their level of mental health in various ways [7,8], such as through web-based social interaction, web-based counseling, health services, or cognitive stimulation. In other words, technical resources can help older adults reach their maintenance and loss managements goals.

In this study, we investigated the effect of technical resources, specifically internet use, and the extent to which they can buffer the relationship between personal resources and stress in both younger and older adults.

Age-Related Differences in Personal Resources and Their Impact on Stress Levels

Personal resources are typically considered attributes that individuals value and that enhance their ability to function effectively in terms of controlling and impacting their environment [9,10]. Moreover, individuals' personal resources, including their health, social support, and financial means, along with their mental strengths such as self-efficacy, change over the course of life due to a combination of factors, including biological aging, life experiences, and environmental factors. According to the life span theory, personal resources tend to decrease as individuals age, putting older individuals at risk of decline in overall well-being [11]. For instance, age-related changes such as declining social networks, poor mobility, retirement, and development of chronic illness can contribute to social isolation and feelings of loneliness in older adults [12-14], which have been associated with increased stress and poor well-being [15-17].

Various theories suggest that older adults may develop compensatory strategies to manage the decline in personal resources and maintain well-being [5,18-22]. According to the Conservation of Resources (COR) theory by Hobfoll [20], individuals seek to gain new resources to maintain or enhance their well-being, particularly in the face of stress and adversity [6]. More specifically, when individuals experience a loss of resources, such as a decline in health or social support, they may be more vulnerable to stress and negative well-being outcomes. However, if they can gain new resources, this can help offset the negative impact of the loss and buffer against the effects of stress. Thus, while resource losses can have a significant negative impact on individuals' well-being, resource gains can help replenish those losses and promote resilience.

For older adults, resource gains may involve engaging in activities such as taking classes, volunteering, participating in social activities, or learning new skills. Specifically, technical resources provide a support to access new activities [23]. However, the extent to which internet use influences the relationship between personal resources and stress in aging is not yet fully understood. This study aimed to better understand how the internet can be used as a resource to support the well-being of older adults, particularly in the context of stress and aging.

Internet Use Role as a Resource Gain in the Context of Older Adults' Stress

Internet use can facilitate the gain of resources, providing older adults with additional means to cope with stress and improve their mental health outcomes [24-29]. For instance, the internet can serve as a platform for social support, information seeking, and engaging in meaningful activities, all of which can contribute to better mental health outcomes in later life [23]. More specifically, higher levels of internet use predict higher levels of social support, reduced loneliness, and better life satisfaction and psychological well-being among older adults [26].

For example, by using the internet for social interactions, older adults can increase their social networks, receive emotional support, and build relationships with others [28-30] to reduce social isolation and stress. For example, Li et al [31] examined the relationship among social isolation, cognitive functioning, depression, and internet use among older adults. The results showed that social isolation was significantly associated with poorer cognitive functioning and higher levels of depression among older adults. Moreover, internet use moderated the relationship between social isolation and cognitive functioning, suggesting that internet use may have a protective effect on cognitive functioning among socially isolated older adults. Finally, the results showed that internet use was associated with lower levels of depression among older adults regardless of their level of social isolation. This suggests that internet use could serve as a protective factor for cognitive functioning and that it represents an important factor for improving mental health outcomes among older adults.

Moreover, through information research using the internet, older adults can gain knowledge and skills to manage stressors that arise in later life. Being confronted with or anticipating age-related loss of physiological functioning, older adults are interested in acquiring health knowledge [32-34]. Higher web-based health literacy is associated with more positive health behaviors and better health knowledge and attitudes in older adults [35]. In addition, engaging in other meaningful activities such as web-based learning, gaming, shopping, and hobbies can also have positive effects on the psychological outcomes of older adults [36-41]. For example, Gallistl and Nimrod [36] examined the relationship between internet use for leisure activities and well-being among older adults. The results showed that older adults who used the internet for leisure activities reported higher levels of subjective well-being, social connectedness, and life satisfaction than those who did not use the internet for these activities. Moreover, several studies have reported that web-based gaming improves older adults' physical and cognitive functioning [42,43], social interaction, and enjoyment and decreases social isolation [44-46]. These studies commonly suggest that, by participating in web-based activities, older adults can gain new skills, challenge themselves, increase their social networks, and find enjoyment in their free time.

Little research has been conducted on the relationship among personal resources, internet use, and stress at different ages. However, determining the potential benefits of internet use in managing stress in later life may highlight the importance of promoting access to and use of technology among older adults.

This Study

The main objective of this study was to better understand the underlying mechanisms contributing to age-related differences in stress as a function of changes in personal resources and internet use. More specifically, we investigated (1) age-related differences in stress and its associated predictors; (2) whether the level of resource gains buffered the relationship between resource losses and stress in younger and older adults, replicating the findings by Hobfoll [20]; and (3) whether the profile of internet use in younger and older adults moderated the relationship between resource gains and losses and stress levels.

First, we tested the hypothesis that stress levels differed by age group. We expected that older adults would report lower levels of stress compared to younger adults. This hypothesis was based on previous research that has consistently demonstrated that older adults are exposed to fewer stressors than younger adults [46,47], leading to better well-being outcomes such as less stress [48-50].

The second set of hypotheses concerned the replication of the COR theory [20], describing that resource losses would have a considerably stronger impact than resource gains on individuals' stress perception [6]. Moreover, COR theory explains that resource gains buffer the effect of resource losses on stress [20]. Accordingly, we expected that (1) more resource losses would be associated with a higher level of stress; (2) resources losses would have a stronger impact on stress than resource gains; and (3) the relationship between resource losses and stress would be moderated by the level of resource gains, with higher levels of gains helping buffer the negative impact of losses on stress levels.

Finally, we hypothesized that the moderating effect of resource gains on the relationship between resource losses and stress would vary based on levels of internet use, presenting distinct profiles for the younger and older adults. First, given previous findings showing that internet use may have a positive impact on older adults' well-being and stress levels [51-53], we expected that internet use would moderate the relationship between resource gains and losses and stress—individuals who reported higher levels of internet use would experience a greater protective effect of resource gains (ie, stronger effect of gains) than those who reported lower levels of internet use. This hypothesis was based on previous studies demonstrating that higher use of the internet was associated with higher levels of stress, depression, loneliness, and anxiety in young adults [54,55].

Methods

Procedures and Participants

We conducted a cross-sectional study in the French-speaking part of Switzerland. The participants were native or fluent French speakers. We recruited 510 individuals, of whom 280 (54.9%) were aged <30 years (mean age 25.00, SD 2.09 y) and 230 (45.1%) were aged >65 years (mean age 73.55, SD 7.16 y; see Table 1 for detailed participant characteristics). Younger participants were mainly undergraduates from the University of Lausanne, whereas the rest of the participants were recruited using the snowball sampling technique [56]. Recruited individuals volunteered to participate in the study and were not remunerated. For being included, participants had to be able to speak and understand French and had to be aged between 18 and 30 years or >65 years. Participants filled out a web-based open questionnaire containing questions on stress and potential predictors or moderators such as personal resources and internet use (ie, questions presented in a specific order).

The sample size used in this experiment was based on an a priori power analysis conducted in G*Power (version 3.1) [57]. We assumed an effect size of Cohen f=0.06, which was derived from previous relevant studies on the buffer effect of resource gains on the association between resource losses and stress [58,59], and an α of .05. Specifically, a total sample size of 404 participants (n=202 per group) provided 90% power to detect effects. To exceed this criterion and achieve >80% power, we recruited 510 participants (ie, n=280, 54.9% younger adults and n=230, 45.1% older adults).

Table 1. Participant characteristics (N=510).

Variable	Younger adults (n=280)	Older adults (n=230)	Chi-square test for group comparison	
			Chi-square (*df*)	*P* value
Age (y), mean (SD; range)	25.00 (2.09; 18-29)	73.55 (7.16; 65-98)	—[a]	—
Gender, n (%)				
Women	190 (67.9)	130 (56.5)	6.9 (1, 510)	.01
Men	90 (32.1)	96 (41.7)	5.0 (1, 510)	.03
Educational level[b], n (%)				
Obligatory school not finished	1 (0.4)	16 (7)	17.1 (1, 510)	<.001
Obligatory school	4 (1.4)	51 (22.2)	56.5 (1, 510)	<.001
Professional formation	18 (6.4)	79 (34.3)	63.9 (1, 510)	<.001
General education	4 (1.4)	5 (2.2)	0.4 (1, 510)	.56
Professional maturity	15 (5.4)	10 (4.3)	0.3 (1, 510)	.60
Gymnasium maturity	49 (17.5)	9 (3.9)	24.0 (1, 510)	<.001
Specialized university	15 (5.4)	20 (8.7)	2.2 (1, 510)	.14
University	173 (61.8)	37 (16.1)	108.9 (1, 510)	<.001
Doctoral degree	0 (0)	3 (1.3)	3.7 (1, 510)	.06
Financial adequacy, n (%)				
More money than needed	54 (19.3)	59 (25.7)	3.2 (1, 510)	.08
Enough money	177 (63.2)	158 (68.7)	1.3 (1, 510)	.25
Less money than needed	48 (17.1)	13 (5.7)	15.6 (1, 510)	<.001

[a] Chi-square analyses were not conducted on participants' mean ages.

[b] The term *obligatory school not finished* corresponds to <11 years of education; *obligatory school* corresponds to 11 years of education; *professional formation, general education, professional maturity, and gymnasium maturity* correspond to 4 additional years of education; *university and specialized university* correspond to 3 to 5 additional years of education; and *doctoral degree* corresponds to 3 to 5 additional years of education.

Ethical Considerations

This study was approved by the Social and Political Sciences Ethics Committee of the University of Lausanne (C-SSP-092022-00002). Written informed consent was obtained from participants before the questionnaire was made available, and they were informed that they could decide to quit the study at any point. This ensured that participants were well informed of the study's objectives and the potential impact of their contribution. Furthermore, participants were made aware of the duration of their involvement, which entailed completing a web-based questionnaire lasting approximately 30 minutes (ie, the questionnaire comprised 27 pages with 15 items per page and the possibility to go back).

Before deployment, the questionnaire was tested to ensure its feasibility, enhancing its clarity and ease of completion. For nonapplicable items or when participants chose not to respond, options such as "not applicable" or "prefer not to say" were provided, respecting participant autonomy while preserving data integrity. In addition, to ensure valid responses, at least one answer selection per question was mandated, minimizing incomplete or inconsistent submissions and maintaining data reliability.

The informed consent process outlined the data management protocols, including the types of data collected, the methodologies used for data treatment using SPSS (IBM Corp), and the storage solutions provided by Switch Drive (Switch). A commitment was made to the participants that their data would be anonymized and held confidentially, with plans for eventual sharing in an open-access data repository (eg, SWISSUbase for 5 years) after the removal of any personally identifiable information. This study was developed using SurveyMonkey (for the Checklist for Reporting Results of Internet E-Surveys, see Multimedia Appendix 1), a web-based survey platform known for its ease of use and robust data analysis tools. It allows for the creation, distribution, and analysis of surveys, making it an ideal choice for collecting detailed feedback and insights. In addition, SurveyMonkey's strong emphasis on data security and privacy ensures the integrity and confidentiality of the data collected in the study. Multiple submissions were controlled by monitoring IP addresses and the anonymous codes assigned to each participant in addition to checking for consistency in the responses. Moreover, analyses were performed on questionnaires that were fully completed. No monetary compensation was provided to participants upon the completion of the questionnaire.

Measures

Predictors

Sociodemographic Variables

Demographic variables included age (in years), gender (0=*men*; 1=*women*), educational level (1=*obligatory school not finished*, 2=*obligatory school*, 3=*professional formation*, 4=*general education*, 5=*professional maturity*, 6=*gymnasium maturity*, 7=*specialized university*, 8=*university*, and 9=*doctoral degree*), and financial adequacy (1=*more money than needed*, 2=*enough money*, and 3=*less money than needed*).

Personal Resources

Personal resources were assessed using the 13-item Personal Resource Questionnaire–Short Form [60]. The short version of the questionnaire includes items concerning cognition, self-efficacy, and social relations. For this study, we used 2 parts of the questionnaire: losses ("To what extent did the listed resources decrease in the last year?") and gains ("To what extent did the listed resources increase in the last year?"; a total of 13 items × 2 = 26 items; for details, see Table 2). Each item was evaluated on a 5-point Likert scale ranging from 1=*none* to 5=*great amount*. Mean composite scores were calculated for losses and gains. Specifically, we created 2 types of indicators (ie, domain-general resources=resource gains and losses) and 3 types of resources in each condition (ie, domain-specific resources=self-efficacy, cognition, and social resources). Lower scores indicate lower levels of each personal resource condition.

Table 2. Details of the Personal Resource Questionnaire used in this study.

Resource	Number of items	Items	Cronbach α	
			Gains	Losses
Cognition	5	"Sound cognitive functioning" "Intelligence" "Good memory ability" "Ability to concentrate" "Ability to think and understand quickly"	0.96	0.93
Self-efficacy	4	"Sense of control over my life" "Ability to control my future" "Ability to achieve my goals" "Ability to put my plans into action"	0.95	0.92
Social relations	4	"Companionship of other people" "Close relationship to at least one friend" "Positive relationship partner" "Close relationship to one or more family members"	0.79	0.64

Internet Use

Internet use was assessed using the 8-item Mobile Device Proficiency Questionnaire [61] measuring participants' ability to perform on the internet using a mobile device (example item: "Using a mobile device I can read the news on the Internet?"). Each item was scored on a 5-point Likert scale ranging from 1=*never tried* to 5=*very easily*. A mean composite score was calculated, with lower scores indicating low levels of internet use. The Cronbach α for this study was 0.96.

Outcome Variable: Stress

Participants' stress level was assessed using the 5-item Perceived Stress Scale by Cohen et al [62] (eg, "In the last month, how often have you felt anxious and stressed?"). Each item was scored on a 4-point Likert scale ranging from 0=*never* to 4=*very often*. We calculated a mean composite score in which lower values indicated a less frequent experience of stress in the last month. The Cronbach α was 0.80.

Analytical Strategy

Differences between younger and older adults were first tested on stress and its predictors or moderators (eg, personal resources) using between-group ANOVAs. We then conducted correlation analyses to gain a better understanding of relationships among age, gender, educational level, financial adequacy, personal resources, internet use, and stress and prepare a more complex moderation analysis.

Second, to replicate the findings by Hobfoll and Lilly [6] and Hobfoll [21] regarding the stronger effect of resource losses than resource gains on stress, we conducted simple regression using participants' characteristics and personal resource variables as predictors. Moreover, to explore the moderating effect of resource gains on the relationship between resource losses and stress levels, we conducted moderation analyses using PROCESS (version 3.5) by Hayes [63], model 1. These analyses allowed for the examination of how the relationship between resource losses and stress levels varied depending on the level of resource gains reported by participants (ie, effect of the 2-way interaction gains × losses on stress).

Finally, to determine whether internet use influenced the moderation effect of resource gains on the association between resource losses and stress, a moderation analysis was performed using model 3 on PROCESS (ie, version 3.5 for SPSS by Hayes [63]). This method allowed for the testing of the effect of the triple interaction, internet use × gains × losses, on stress. In all moderation analyses, we controlled for age, gender, educational level, and financial adequacy.

In each regression and moderation analysis, we divided the analysis into 2 sets: the first set included the domain-general resources as general gains and losses, and the second set included the gains and losses of domain-specific resources such as social, cognition, and self-efficacy.

Unstandardized coefficients and 95% CIs were reported. The level of statistical significance was set at $P<.05$. All analyses were performed using SPSS (version 26; IBM Corp).

Results

Mean-Level Comparisons

Mean-level tests were conducted to determine the age-related differences in stress and personal resources (Table 3).

The results showed that older adults were less stressed than younger adults (1.99 vs 2.47; $P<.001$; ie, questionnaire scores). Older adults had more losses compared to younger adults (1.82 vs 1.54; $P<.001$; ie, questionnaire scores), whereas they presented less resource gains (1.82 vs 2.31; $P<.001$; ie, questionnaire scores). More specifically, the analyses conducted on domain-specific resources (ie, social, self-efficacy, and cognition) revealed that the resource losses in the social, self-efficacy, and cognitive domains tended to increase with age, whereas the social, self-efficacy, and cognitive resource gains tended to decrease with age. Finally, older adults reported less internet use than younger adults (3.35 vs 4.91; $P<.001$; ie, questionnaire scores).

Table 3. Younger and older adults' mean stress and personal resource variables (ie, questionnaire scores).

	Younger adults (n=275), mean (SD)	Older adults (n=224), mean (SD)	Test for mean-level differences (N=499)	
			F test (*df*)	*P* value
Stress	2.47 (0.70)	1.99 (0.69)	58.45 (1, 497)	<.001
Resources				
Losses	1.54 (0.63)	1.82 (0.76)	14.97 (1, 497)	<.001
Social	1.54 (0.63)	1.60 (0.72)	1.07 (1, 497)	.30
Self-efficacy	1.74 (0.92)	1.90 (0.93)	3.62 (1, 497)	<.06
Cognition	1.47 (0.73)	1.92 (0.88)	39.27 (1, 497)	<.001
Gains	2.31 (0.97)	1.82 (0.95)	32.72 (1, 497)	<.001
Social	2.57 (1.04)	2.00 (1.02)	37.37 (1, 497)	<.001
Self-efficacy	2.41 (1.14)	1.82 (1.06)	34.79 (1, 497)	<.001
Cognition	2.03 (1.08)	1.67 (0.99)	15.57 (1, 497)	<.001
Internet use	4.91 (0.23)	3.35 (1.38)	342.74 (1, 497)	<.001

Correlation Analysis

We performed correlational analyses to highlight relationships among sociodemographics, independent variables (domain-general and domain-specific resources and internet use), and stress (Table 4; for a complete table of correlations, see Multimedia Appendix 2).

In the total sample group, age, gender, and financial adequacy were correlated with stress; being female, having less money than needed, and being younger were associated with higher stress. Moreover, resource losses were related to higher stress. Specifically, higher stress was associated with more social, cognition, and self-efficacy losses. Participants who used the internet more often reported higher levels of stress.

In the separate age group analyses, we found that higher levels of stress were associated with higher levels of resources losses and, more specifically, social, cognitive, and self-efficacy losses in both younger and older adults. Moreover, correlations in the younger adult group revealed that being female and having less money than needed were associated with higher stress. Furthermore, higher levels of domain-general resource gains in younger adults were associated with stress, and domain-specific resource gains such as cognitive and self-efficacy were related to being less stressed. Concerning the older adult group, analyses revealed that having a higher level of education was associated with lower stress. Finally, while the use of the internet was not associated with stress scores among the younger participants, it was negatively associated with stress among the older participants, indicating that more internet use was linked to lower stress levels.

Table 4. Significant Pearson correlations (r) between participant characteristics and personal resources and stress levels for the total sample (younger and older adults; N=510).

	Younger adults (n=280)		Older adults (n=230)		Total sample	
	r	*P* value	*r*	*P* value	*r*	*P* value
Age	–0.01	.81	0.02	.81	–0.32	<.001
Gender	0.21	<.001	0.11	.08	0.20	<.001
Educational level	–0.03	.59	–0.25	<.001	0.08	.08
Financial adequacy	0.28	<.001	0.12	.08	0.25	<.001
Losses	0.42	<.001	0.36	<.001	0.30	<.001
Social	0.21	<.001	0.21	.002	0.18	<.001
Self-efficacy	0.49	<.001	0.40	<.001	0.40	<.001
Cognition	0.30	<.001	0.33	<.001	0.20	<.001
Gains	–0.21	<.001	–0.01	.87	–0.03	.49
Social	–0.08	.18	–0.01	.81	0.04	.41
Self-efficacy	–0.28	<.001	–0.01	.85	–0.07	.12
Cognition	–0.18	.003	–0.00	.97	–0.04	.35
Internet use	–0.05	.39	–0.17	.01	0.12	.005

Moderation Analyses

Overview

Regarding the profiles of internet use between younger and older adults, we found notable differences. Specifically, younger adults exhibited uniformly high use rates (median 5.00, range 3.38-5.00), whereas older adults demonstrated a considerable range in their internet use behavior, from very low to very high (median 3.56, range 1.00-5.00). To evaluate the moderating effect of age on the link between resource loss, resource gain, and internet use on stress, we initially tested a model including the age group variable in a quadruple interaction term (loss × gain × internet use × age groups; not presented). However, no significant interaction was found (β=–.02; P=.95), possibly due to the complexity of the interaction term and the unequal variances in internet use across age groups. Indeed, the assumption of homogeneity of variances for internet use was not respected (Levene test: $F_{1,502}$=536.63; P<.001), showing a difference in variances across groups. On the basis of these findings but also on previous research in the field suggesting that internet use may influence the level of stress, we decided to present the following analysis separately for younger and older individuals (although the results should be interpreted with caution). This methodological approach was crucial for understanding how internet use influenced the relationship between resource loss and gain and stress, allowing for an exploration of use trajectories characteristic of younger and older adults without the confounding influence of the homogeneous high internet use found in the younger cohort.

Domain-General Resources

First, simple regression (model 1; Multimedia Appendix 3) revealed that resource indicators accounted for 32% and 20% of the individual differences in stress levels in younger and older adults, respectively. Similarly, for younger and older adults, the strongest predictor was resource losses (younger adults: β=.45 and P<.001; older adults: β=.37 and P<.001) followed by resource gains (younger adults: β=–.20 and P<.001; older adults: β=–.13 and P=.01), suggesting that individuals who experienced higher resource losses and lower gains tended to feel more stressed as compared to those with lower levels of losses and higher levels of gains.

Second, we found a significant 2-way interaction (model 2; Multimedia Appendix 3 and Figure 1) between resource gains and resource losses on levels of stress as the dependent variable in both younger and older adults, confirming our second hypothesis (β=.26 and β=.16 for younger and older adults, respectively). Specifically, individuals with high levels of resource gains who also reported high levels of losses felt less stressed compared to individuals with lower levels of resource gains and higher levels of resource losses.

Finally, internet use influenced the moderation effect of resource gains on the relationship between resource losses and stress, as seen in a significant 3-way interaction among internet use, gains, and losses in older adults (model 3; Multimedia Appendix 3; β=.09). More specifically, compared to the second model, the third model presented an increase in the index of adjustment (ie, a change in explained variance) of 0.05 (ΔR^2=0.05; P=.002). The 3-way interaction was not significant in younger adults (β=.22).

To further the understanding of the 3-way interaction in older adults, we examined the conditional effects of resource losses at 1 SD above (+1 SD) and 1 SD below (–1 SD) the mean scores of resource gains (first moderator) and internet use (second moderator; Table 5 and Figure 2). As the 3-way interaction (losses × gains × internet use) was not significant in younger adults, we reported only the conditional effects of older adults. The results showed significant moderation effects of resource gains and internet use on the relationship between domain-general losses and stress. Specifically, significant moderation effects were observed only in cases in which individuals reported high levels of gains and high levels of internet use (β=.37), as well as in cases in which individuals reported low levels of gains and high levels of internet use (β=.55) and low levels of both gains and internet use (β=.66). These results suggest that the use of the internet reinforces the buffering effect of gains on the relationship between resource losses and stress.

According to the third hypothesis, we conducted an additional analysis to examine the differences between individuals with high internet use and those with low internet use in relation to their gains and losses (Table 6). As the 3-way interaction (losses × gains × internet use) was not significant in younger adults, we reported only the conditional effects of older adults. The results showed that internet use effects (ie, differences between participants with a higher internet use and participants with a lower internet use) were marginally significant only in cases in which individuals reported high levels of gains and low levels of losses (β=–.21).

Figure 1. Mean stress depending on the level of gains (high vs low) and losses (high vs low) in younger and older adults. The slopes’ values represent the coefficients and 95% CIs.

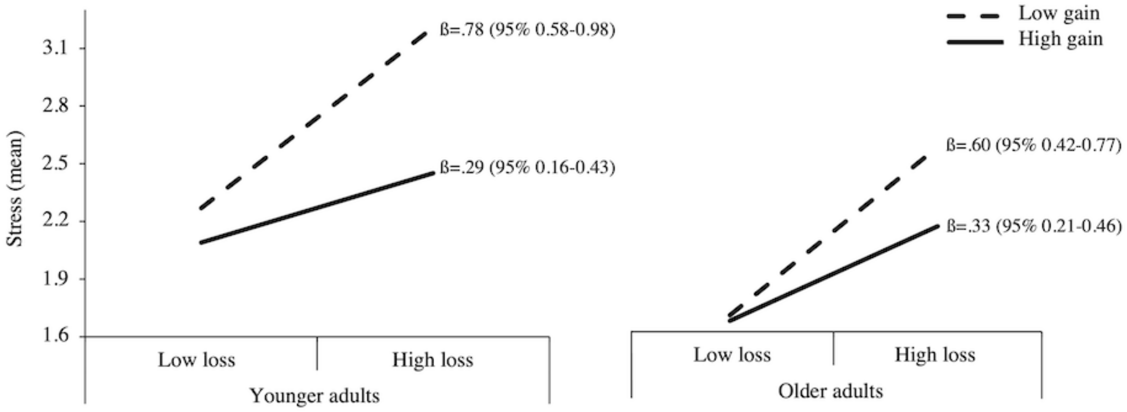

Table 5. Conditional effects of domain-general resource losses (ie, independent variable) at +1 SD and –1 SD of the mean scores of gains and internet use (ie, moderators) in older adults.

	β coefficient (SE; 95% CI)	*P* value
Losses at –1 SD of gains and –1 SD of internet use	0.66 (0.12; 0.34 to 0.89)	.001
Losses at –1 SD of gains and +1 SD of internet use	0.55 (0.14; 0.28 to 0.83)	.001
Losses at +1 SD of gains and –1 SD of internet use	0.04 (0.17; –0.30 to 0.37)	.84
Losses at +1 SD of gains and +1 SD of internet use	0.37 (0.08; 0.20 to 0.53)	.001

Figure 2. Mean stress depending on the level of gains (high vs low), internet use (high vs low), and losses (high vs low) in older adults.

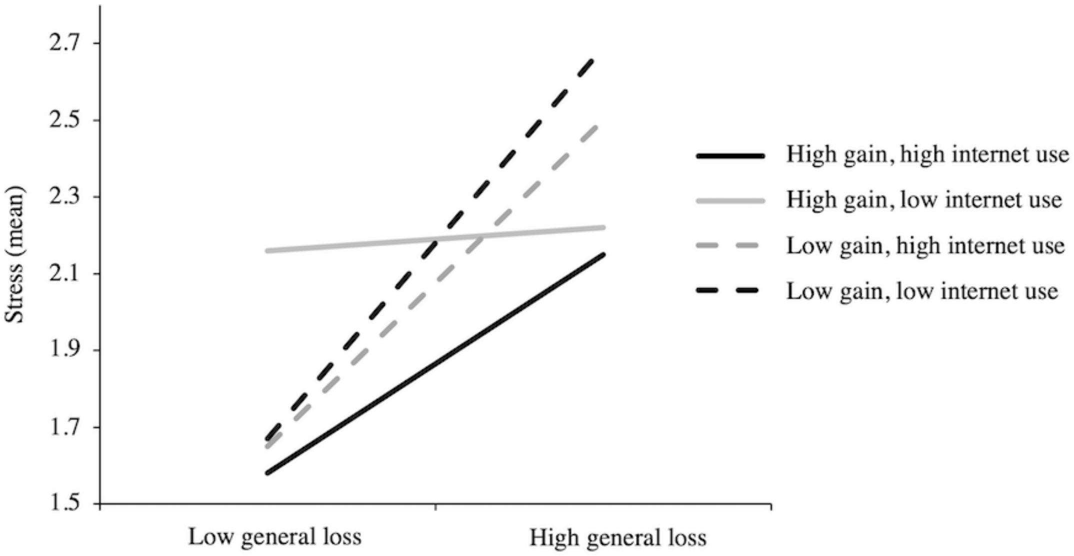

Table 6. Conditional effects of internet use (ie, independent variable) on stress at +1 SD and –1 SD of the mean scores of resource losses and gains (ie, moderators) in older adults.

	β coefficient (SE; 95% CI)	*P* value
Internet use at –1 SD of gains and –1 SD of losses	–0.01 (0.06; –0.12 to 0.10)	.89
Internet use at –1 SD of gains and +1 SD of losses	–0.07 (0.08; –0.23 to 0.09)	.40
Internet use at +1 SD of gains and –1 SD of losses	–0.21 (0.12; –0.44 to 0.02)	.08
Internet use at +1 SD of gains and +1 SD of losses	–0.03 (0.06; –0.14 to 0.09)	.67

Domain-Specific Resources

Similarly to the domain-general resources, we conducted 3 regression models for the domain-specific resources in both younger and older adults (self-efficacy, cognition, and social resources; Multimedia Appendix 4). The first model showed that resource losses were the strongest predictor of stress levels across different age groups regardless of the specific type of resource considered. The coefficient of losses for self-efficacy was found to be the highest in both younger and older adults, with more losses being related to higher levels of stress in both groups. Moreover, higher gains in self-efficacy, cognition, and social resources significantly predicted lower stress levels in younger adults. However, in older adults, the only significant predictor was self-efficacy gains, with more gains being associated with less stress. These findings suggest that different types of resource gains may play varying roles in shaping stress experiences across different age groups.

Moreover, the impact of resource losses on stress in younger and older adults was significantly influenced by their levels of gains, which varied depending on the type of resource. Those with high levels of self-efficacy and cognition gains tended to experience less stress when they also presented high levels of self-efficacy and cognition losses (younger adults: unstandardized coefficient $\beta_{\text{Cognition}}$=.21, 95% CI 008-0.34 and $\beta_{\text{Self-efficacy}}$=.20, 95% CI 0.08-0.32; older adults: $\beta_{\text{Cognition}}$=.23, 95% CI 0.11-0.34 and $\beta_{\text{Self-efficacy}}$=.23, 95% CI 0.13-0.34) compared to individuals with lower levels of resource gains who tended to experience higher levels of stress under similar circumstances (ie, younger adults: $\beta_{\text{Cognition}}$=.40, 95% CI 0.21-0.60 and $\beta_{\text{Self-efficacy}}$=.40, 95% CI 0.30-0.50; older adults: $\beta_{\text{Cognition}}$=.37, 95% CI 0.23-0.50 and $\beta_{\text{Self-efficacy}}$=.43, 95% CI 0.30-0.55). While there were no significant results regarding social resources for younger adults, older adults with high levels of social gains experienced less stress when they also presented high levels of social losses (β_{Social}=.18, 95% CI 0.04-0.32) compared to older adults with lower levels of resource gains who experienced higher levels of stress under similar circumstances (β_{Social}=.45, 95% CI 0.23-0.67).

This study also revealed a significant influence of internet use on the relationship between resource losses and stress levels in both younger and older adults, as indicated by the 2-way interaction effect (internet use × losses). Specifically, the interaction effect was found to be significant for different types of resources in younger and older adults. Among younger adults, a significant interaction effect was observed for self-efficacy and social resources ($\beta_{\text{Self–efficacy}}$=.30, 95% CI –0.02 to 0.31; β_{Social}=.67, 95% CI 0.09-1.25). Specifically, younger individuals who reported high losses in social and self-efficacy resources and had higher internet use experienced more stress compared to their counterparts with lower internet use. At the same time, younger adults with low levels of social and self-efficacy losses and higher internet use exhibited lower stress levels than those with lower internet use.

In the case of older adults, a significant interaction effect was observed specifically for cognition resources ($\beta_{\text{Cognition}}$=.08, 95% CI 0.00-0.16). Older individuals who experienced fewer losses in cognition and had higher levels of internet use reported lower levels of stress than individuals with lower internet use. In addition, a significant 2-way interaction effect between internet use and gain was marginally significant ($\beta_{\text{Cognition}}$=–.09, 95% CI –0.21 to .02). Older adults who had high gains in cognition resources and high levels of internet use exhibited lower levels of stress than older adults with lower internet use.

Finally, in older adults, internet use influenced the moderating effect of self-efficacy gains on the relationship between self-efficacy losses and stress and the moderating effect of social gains on the relationship between social losses and stress. This was evidenced by the significant 3-way interactions between internet use, self-efficacy gains, and self-efficacy losses ($\beta_{\text{Self-efficacy}}$=.07, 95% CI 0.01-0.14) but also between internet use, social gains, and social losses (β_{Social}=.11, 95% CI 0.03-0.19). Specifically, compared to the second model, the third model presented an increase in the index of adjustment (ie, a change in explained variance) of 0.02 (ΔR^2=0.02; *P*=.03) for the self-efficacy model and .03 (ΔR^2=0.03; *P*=.006) for the social model.

It is important to note that in younger adults, regardless of the type of resources, triple interactions between internet use, self-efficacy, cognition or social gains, and self-efficacy, cognition or social losses were not significant, in line with the findings on the triple interaction of the domain-general resources (Multimedia Appendix 4). As the 3-way interaction (losses × gains × internet use) was not significant in younger adults, we reported only the conditional effects of older adults. In older adults, conditional effects analyses (Table 7 and Figure 3) revealed significant moderation effects of self-efficacy gains and internet use on the relationship between self-efficacy losses and stress. Specifically, the moderation effects were observed only when individuals reported high levels of self-efficacy gains and high levels of internet use (β=.29), as well as when individuals reported low levels of self-efficacy gains and high levels of internet use (β=.38) and low levels of both self-efficacy gains and internet use (β=.45). Moreover, significant moderation effects of social gains and internet use on the relationship between social losses and stress were observed only when individuals reported high levels of social gains and high levels of internet use (β=.19) and low levels of both social gains and internet use (β=.64). Regarding domain-general resources, these results suggest that the use of the internet increases the buffering effect of self-efficacy and social gains on the relationship between self-efficacy and social losses and stress.

Regarding the domain-general resources, we conducted an additional analysis to examine the differences between older adults with high internet use and those with low internet use in relation to their gains and losses (Table 8). As the 3-way interaction (losses × gains × internet use) was not significant in younger adults, we reported only the conditional effects of older adults. The results showed that the internet use effects (ie, differences between participants with greater internet use and participants with lower internet use) were observed in older individuals who reported high levels of self-efficacy gains and low levels of self-efficacy losses (β=–.21). Moreover, significant internet use effects were observed in cases in which older adults experienced low levels of social gains and high levels of social losses (β=–.18), as well as in older individuals with low levels of social gains and high levels of social losses (β=–.17).

Table 7. Conditional effects of domain-specific resource losses (ie, independent variable) at +1 SD and –1 SD of the mean scores of gains and internet use (ie, moderators) in older adults.

	β coefficient (SE; 95% CI)	*P* value
Self-efficacy		
Losses at –1 SD of gains and –1 SD of internet use	0.45 (0.07; 0.31 to 0.59)	.001
Losses at –1 SD of gains and +1 SD of internet use	0.38 (0.10; 0.18 to 0.58)	.001
Losses at +1 SD of gains and –1 SD of internet use	–0.02 (0.12; –0.26 to 0.23)	.88
Losses at +1 SD of gains and +1 SD of internet use	0.29 (0.07; 0.15 to 0.43)	.001
Social relations		
Losses at –1 SD of gains and –1 SD of internet use	0.64 (0.15; 0.35 to 0.93)	.001
Losses at –1 SD of gains and +1 SD of internet use	0.23 (0.16; –0.09 to 0.54)	.16
Losses at +1 SD of gains and –1 SD of internet use	–0.02 (0.14; –0.29 to 0.25)	.88
Losses at +1 SD of gains and +1 SD of internet use	0.19 (0.08; 0.02 to 0.36)	.02

Figure 3. Plots of 3-way interaction effects for the self-efficacy model (self-efficacy losses × self-efficacy gains × internet use) and the social model (social losses × social gains × internet use) in older adults.

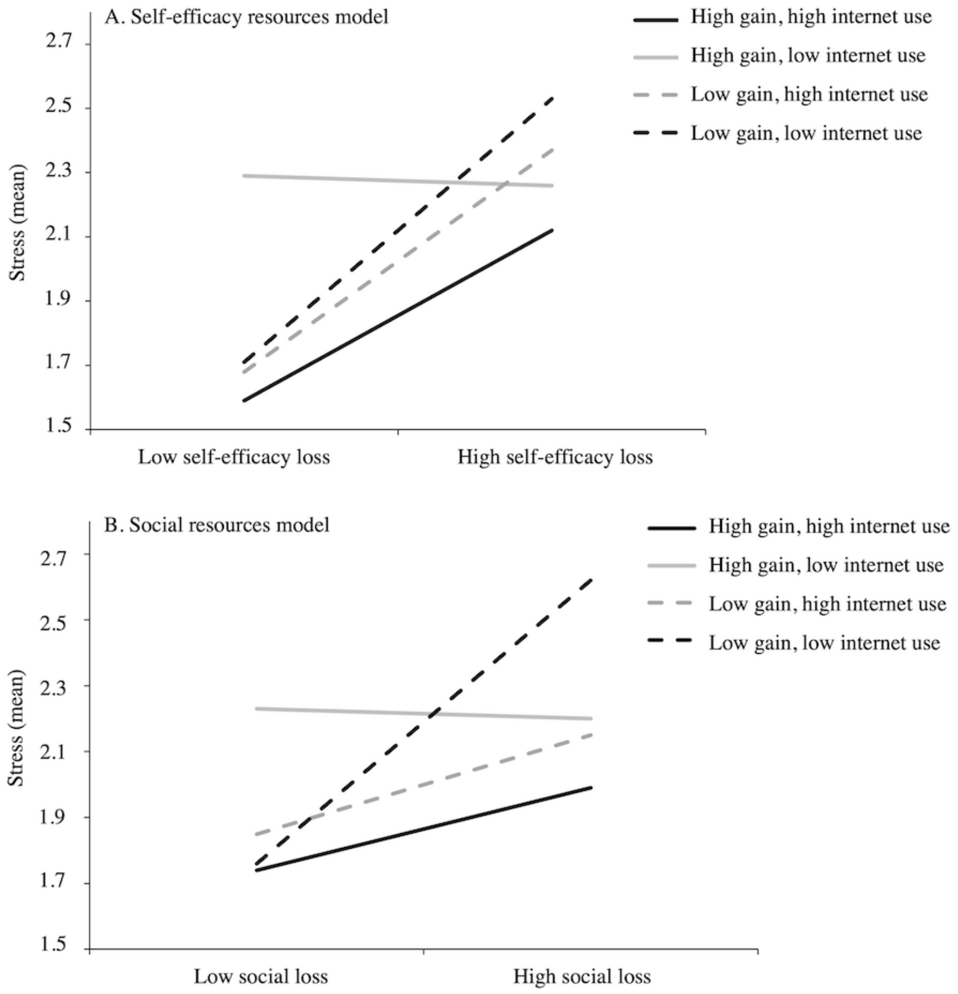

Table 8. Conditional effects of internet use (ie, independent variable) at +1 SD and –1 SD of the mean scores of domain-specific resource gains and losses (ie, moderators) in older adults.

	β coefficient (SE; 95% CI)	*P* value
Self-efficacy		
Internet use at –1 SD of gains and –1 SD of losses	–0.01 (0.05; –0.11 to 0.09)	.82
Internet use at –1 SD of gains and +1 SD of losses	–0.06 (0.07; –0.19 to 0.07)	.39
Internet use at +1 SD of gains and –1 SD of losses	–0.25 (0.11; –0.46 to –0.04)	.02
Internet use at +1 SD of gains and +1 SD of losses	–0.05 (0.06; –0.16 to 0.06)	.39
Social relations		
Internet use at –1 SD of gains and –1 SD of losses	0.03 (0.06; –0.08 to 0.15)	.57
Internet use at –1 SD of gains and +1 SD of losses	–0.17 (0.09; –0.35 to 0.01)	.07
Internet use at +1 SD of gains and –1 SD of losses	–0.18 (0.08; –0.34 to –0.01)	.03
Internet use at +1 SD of gains and +1 SD of losses	–0.08 (0.06; –0.19 to 0.04)	.20

Discussion

Principal Findings

This study investigated the influence of internet use on the relationship between personal resources and stress in both younger and older adults. The findings indicated that older adults were less stressed than younger adults. Moreover, resource gains moderated the relationship between resource losses and stress, and this effect was similar in both younger and older individuals. Finally, internet use seems to act as a buffer on the dynamics between social and self-efficacy resource losses and stress, amplifying the positive influence of resource gains in reducing the adverse effects of these losses. In older adults, internet use was beneficial as a means of dealing with losses in social and self-efficacy resources.

Age-Associated Differences in Stress Levels

In support of our first hypothesis, we found that older individuals reported less stress than younger adults. This finding is consistent with those of extant research that has also documented the stress-buffering effect of age among older adults. This phenomenon has been attributed to several personal factors, including cognitive and emotional processing differences between age groups [64,65], greater use of emotion regulation strategies [66,67], and greater life experience and wisdom that allow for more effective coping with stressors [68,69]. Moreover, older adults may be more skilled at regulating their emotions, which may reduce the impact of stressful events on their psychological well-being.

Specifically, stress-inducing situations are related to an increase in negative emotions, and several studies have shown that older adults tend to experience more positive and less negative emotions [70-74]. Therefore, it can be inferred that older adults may possess a greater capacity to regulate and inhibit negative emotions, leading to a reduced impact of stressful events on their psychological well-being. Older adults may further be more resilient than younger adults due to their accumulated life experience and developed coping mechanisms, including proactive problem-solving strategies, effective emotion regulation, and strong sense of personal control and self-efficacy [75-78]. For example, several studies have reported a coping shift during aging to match the constraints experienced and preserve well-being [79-82]. Older adults, who often face a range of losses associated with aging such as declining health, social network changes (eg, death of partner), and retirement, tend to exhibit a greater preference for accommodation, including emotion- and cognition-focused coping. In contrast, younger adults, who typically have fewer losses, displayed a higher preference for assimilation, including problem-focused coping, and actively sought solutions to alleviate stress, reflecting their developmental stage characterized by a stronger drive for achievement, personal growth, and the ability to confront different types of challenges. The observed shift from assimilation to accommodation [19] across the life span suggests a developmental trajectory in coping strategies, with older adults adapting their coping approaches to address the unique challenges and losses they experience. Overall, older adults may be more resilient to stress than younger adults, and their adaptive coping strategies, social support, and emotion regulation strategies may contribute to their ability to maintain psychological well-being in the face of adversity.

Resource Gains Moderated the Relationship Between Resource Losses and Stress Levels

We found that resource gains moderated the relationship between resource losses and stress levels, confirming our second hypothesis. In line with the COR theory [20], we found that resource gains buffered the negative impact of resource losses on stress levels. More specifically, COR theory emphasizes the significance of resource gains, which have the potential to assist individuals in restoring their resources and avoiding further depletion. The gain paradox posits that individuals who have experienced losses are more likely to recognize and appreciate resource gains. This phenomenon can be attributed to the increased awareness among individuals of the value and importance of resources as a result of experiencing losses, which in turn serves as a motivation for them to actively seek and increase those resources. Consequently, resource gains are crucial in moderating the negative relationship between resource losses and stress levels as individuals with greater resource gains possess better coping abilities and are more likely to recover from losses [21].

Replicating the COR theory by Hobfoll [20], we also found that resource gains buffered the impact of resource losses in both age groups on stress. That the same buffering effect was found in both age groups could be attributed to some universality of the losses-gains dynamic across life phases. The COR theory posits that individuals across the life span share a fundamental drive to accumulate and protect resources as a means of maintaining well-being and minimizing stress [20]. Therefore, the importance of resource gains in mitigating the negative impact of resource losses on stress levels may hold regardless of age.

Effect of the Relationship Between Internet Use and Domain-Specific Resources on Stress in Younger and Older Adults

In addition, this study revealed distinct patterns of interaction between effect of internet use as an external technical resource and domain-specific personal resources on stress levels among younger and older adults. Our findings suggest that the relationship between social or self-efficacy losses and stress levels in younger individuals is significantly influenced by their use of the internet. Specifically, younger individuals who reported fewer social or self-efficacy losses experienced lower levels of stress when they used the internet, indicating a buffering effect. On the other hand, those who reported higher social or self-efficacy losses exhibited increased levels of stress when they used the internet, suggesting an exacerbating effect. These results highlight the complex interplay among social or self-efficacy losses, internet use, and stress levels in younger individuals. It appears that the internet may serve as a supportive resource for individuals with fewer social losses, providing them with a means for social connection and support [83]. Furthermore, the internet may serve as a resource for providing access to information, support, and opportunities for skill development, which can bolster self-efficacy beliefs and resilience and promote adaptive coping strategies [84-88]. However, for those experiencing higher social or self-efficacy losses, the internet may exacerbate stress. Indeed, the losses in social resources, such as social contacts, are associated with higher feelings of loneliness [89], which contribute to the development of excessive internet use, commonly referred to as internet addiction [90,91]. This pattern of excessive internet use, driven by the absence of social support and challenges in communication and in emotion identification and regulation, is linked to higher levels of stress [92,93]. This suggests that individuals experiencing significant social losses may increase their use of the internet as a compensatory mechanism to mitigate the impact of these losses, resulting in increased stress levels. Moreover, previous research has documented a generational-situated use of the internet, with younger adults using it for leisure activities whereas older individuals' preferred use of the internet is to facilitate the realization of daily activities such as medical consultations [94,95].

In addition, this study highlights an interesting pattern regarding the relationship among internet use, cognitive losses, and stress levels in older adults. Specifically, older adults with lower levels of cognitive losses who engaged in internet use experienced lower levels of stress compared to those who did not use the internet, suggesting that internet use may serve as a protective means against stress for older adults with fewer cognitive losses. One possible explanation can be that internet use provides opportunities to be engaged in web-based activities for cognitive stimulation, accessing information, or social interaction [8,96], which may help mitigate the negative effects of cognitive losses on stress levels. Considering that higher frequency of digital device use has been associated with fewer subjective cognitive concerns [97-99] and that cognitive losses have been associated with higher levels of stress in older adults [23,100,101], we found that older adults with less cognitive losses who used the internet more were less stressed compared to older adults who did not use the internet, suggesting a buffer effect of internet use on the relationship between cognitive losses and stress.

However, older adults with high levels of cognitive losses experienced similar levels of stress regardless of their internet use. This suggests that the influence of high cognitive losses on stress may remove any potential benefits derived from internet use. It is possible that older adults with high cognitive losses may have difficulties using the internet effectively due to their subjective cognitive losses, which could be explained by the digital distraction hypothesis [102-104]. According to this hypothesis, increased engagement with technology may have detrimental consequences for cognitive processes, manifesting as executive dysfunction characterized by heightened distractibility, superficial cognitive processing, and difficulties in task organization and completion. In addition, technology reliance may contribute to increased forgetfulness by undermining the natural memory systems used for tasks such as navigation or recalling personal information such as phone numbers [102,104]. The detrimental effects of excessive digital engagement on cognitive functioning may override any potential benefits of internet use for stress reduction in older adults with higher cognitive losses.

Internet Use Moderated the Relationship Between Resource Losses and Gains and Stress Levels in Older Adults

The final hypothesis of our study, which examined the influence of internet use on the relationship between resources and stress, was confirmed for older adults. More specifically, older adults with fewer losses in self-efficacy and social resources and greater gains in these domains experienced lower levels of stress when they engaged in more internet use. This suggests that the internet can be considered as an "amplifier" of the positive effects of resource gains, particularly in terms of self-efficacy and social resources.

Previous studies have reported that internet use by older adults has been associated with decreased loneliness and depression; better social connectedness, self-esteem, and cognitive functioning [105,106]; and improved self-efficacy, self-control, self-determination, and skill development [107-111]. For example, the study by Karavidas et al [110] examined the association between internet use, self-efficacy resources, and life satisfaction among older adults. The results revealed a positive correlation between internet use and life satisfaction. This relationship was mediated by self-efficacy resources, indicating that increased internet use among older individuals was associated with the development of higher self-efficacy skills, which in turn contributed to an improved overall quality of life. The findings suggest that frequent internet use may serve as a platform for older adults to develop and enhance their self-efficacy, leading to greater life satisfaction. Similarly, Chaumon et al [107] found that older adults with functional loss living in long-term care institutions showed a positive impact of internet use on self-sufficiency, self-efficiency, and psychological empowerment [112].

Moreover, the internet facilitates stronger social connections and easier access to social networks, such as through engaging in web-based conversations with new contacts or actively participating in web-based social events [76,105,107,113]. For example, White et al [105] presented a randomized controlled trial to investigate the psychosocial impact of providing internet training and access to older adults. The study involved a sample of older individuals who were randomly assigned to either an intervention group, which received internet training, or a control group that did not receive any intervention. The results showed significant improvements in several psychosocial factors among the intervention group compared to the control group. Specifically, older adults who received internet training reported increased social support, higher levels of social engagement, reduced feelings of loneliness, and enhanced subjective well-being. These findings suggest that providing older adults with internet training and access can have positive effects on their psychosocial well-being.

In line with previous findings, we found that internet use can support the buffer effects from gains in self-efficacy and social resources when individuals have low levels of losses in each type of resource. Moreover, internet use can also substitute the effects of gains in older adults with low gains and high losses. More specifically, our findings demonstrated that individuals who reported high losses and low gains in social resources experienced lower levels of stress when they engaged in more internet use. This can be attributed to the compensatory role of the internet in filling the gaps caused by the limited gains in social resources. Several studies have provided evidence supporting the notion that the internet can compensate for losses in social resources among individuals [114-118]. Older adults who experience a decline in face-to-face social interactions due to factors such as retirement or physical limitations can benefit from web-based social networking platforms. For example, Khoo and Yang [116] conducted a study that examined the impact of social media use on the perception of social support among middle-aged and older adults. The researchers found that using social media platforms for interactions with broader social networks such as friends was as beneficial as using them to connect with family members in terms of enhancing social support.

Limitations

This study entails certain limitations that warrant consideration. These pertain both to the representativeness of the recruited sample and to the measures used therein [119]. On the one hand, the results should be interpreted cautiously due to potential sampling error. Indeed, stemming from a nonprobabilistic sampling approach, the characteristics of the participants who voluntarily engaged in the study may also influence the variables of interest [119,120]. For instance, participants' income could influence their willingness to participate in surveys [121], their resource losses and gains, and their internet use [122]. Consequently, the sampling strategy used (ie, snowball volunteer sampling) likely did not capture older individuals marked by resource losses and sociodemographic characteristics (eg, isolation and low socioeconomic status) that are particularly stressful.

On the other hand, the nature of the measures used may introduce limitations. The results should be interpreted with caution when examining age-related differences in the role of internet use. Reflecting on the issue of causality, it is important to consider how the cross-sectional nature of our study limits our ability to ascertain changes in internet use and its effects over time, especially across different age groups [52]. While we identified associations among changes in personal resources, stress levels, and internet use, these findings are not sufficient to establish a causal link or to delineate the temporal evolution of internet use's impact on stress and personal resources. This caution extends to interpreting the dynamics of internet use across the life span, where cross-sequential research is essential for distinguishing between the effects of aging and those attributable to cohort-specific experiences or generational differences [94].

Moreover, the decision not to include age group as a factor in an interaction analysis was based on significant differences in internet use between younger and older adults. Preliminary findings indicated uniform high use among younger participants, which could confound nuanced age-related interactions with internet use and stress outcomes. Therefore, analyses were conducted separately for each age group to accurately capture distinct use patterns, especially among the older adults who demonstrated a broader range of internet behaviors. This approach helped avoid the confounding effects of uniform use in younger adults. However, it limited the exploration of broader age-related dynamics, potentially affecting a comprehensive understanding of how age influences the relationship between internet use and stress.

In addition, it is essential to recognize that this study's focus primarily lay on the frequency of internet use, measured equivalently for both younger and older adults. However, this approach disregards the plausible generational disparities in internet use patterns, as noted in previous research [94,123], which might inadvertently introduce errors in measurement [119]. Notably, the lack of statistical significance concerning the impact of internet use on stress in younger adults, a group extensively engaged with the internet, might potentially be attributed to the distinct "youthful" internet use styles, as proposed by Boullier [94]. Indeed, the presence of measurement errors, such as those arising from questionnaire elaboration, can introduce challenges such as ceiling and floor effects [119,124], impeding the identification of statistically significant differences between groups [125]. Moreover, future studies should develop measures to better capture interindividual differences in internet use in younger individuals to further investigate the multifaceted relationship between internet use and different age groups.

Moreover, the consideration of a singular internet use style in measurement limits the possibility of identifying the styles that may be most beneficial for each age group during resource losses. Indeed, the beneficial role of internet use derives from the meanings attributed to its use and the opportunities it offers to address needs [126-128]. Consequently, it would be of great interest for future studies to focus on identifying favorable internet use styles for stress reduction in a context of personal resource loss across different age groups.

Conclusions

This study examined the effect of internet use on the relationship between personal resources and stress. The findings revealed a nuanced understanding of how digital engagement can serve as a buffer against stress, particularly among older adults who experienced resource losses and gains. Specifically, older adults who frequently used the internet reported less stress when exposed to high levels of both resource losses and gains compared to their counterparts with lower levels of internet engagement. This underscores the importance of internet use in mitigating stress among older adults, highlighting the potential of digital tools in promoting well-being in older populations.

This study's novel contribution lies in its empirical support for the beneficial role of internet use among older adults within the framework of the COR theory by Hobfoll [20]. By demonstrating that internet use can moderate the effects of resource losses and gains on stress, this research provides valuable insights for developing targeted interventions aimed at leveraging technology to support well-being. Understanding these dynamics will help researchers, practitioners, and policy makers recognize the role of the internet as a facilitator of resource gains and a compensatory mechanism for social deficits in older adults. Encouraging and supporting older adults in using the internet can promote access to valuable resources and enhance their self-efficacy and social connections, ultimately contributing to improved stress management and, more generally, well-being.

Acknowledgments

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Authors' Contributions

AR was responsible for the study design; data collection, analysis, and interpretation; and writing of the original draft. PM contributed to data analysis and interpretation and the writing, review, and editing of the draft. CL contributed to study design and review. DSJ contributed to review and editing of the draft. All authors agreed to the submission of the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Checklist for Reporting Results of Internet E-Surveys.
[DOCX File , 21 KB - aging_v7i1e52555_app1.docx]

Multimedia Appendix 2
Pearson correlations (r) between the main variables.
[DOCX File , 28 KB - aging_v7i1e52555_app2.docx]

Multimedia Appendix 3
Unstandardized regression coefficients for domain-general resources in younger and older adults.
[DOCX File , 20 KB - aging_v7i1e52555_app3.docx]

Multimedia Appendix 4
Unstandardized regression coefficients for domain-specific resources (self-efficacy, cognition, and social relations) in younger and older adults.
[DOCX File , 27 KB - aging_v7i1e52555_app4.docx]

References

1. Two-thirds of the world's population uses the Internet, but 2.7 billion people remain offline. International Telecommunication Union. URL: https://www.itu.int/itu-d/reports/statistics/2022/11/24/ff22-internet-use/ [accessed 2022-07-09]
2. Utilisation d'internet. Office Fédéral de la Statistique. URL: https://www.bfs.admin.ch/bfs/fr/home/statistiques/culture-medias-societe-information-sport/societe-information/indicateurs-generaux/menages-population/utilisation-internet.html [accessed 2022-07-09]
3. Hofer M. Older adults' media use and well-being: media as a resource in the process of successful aging. In: Reinecke L, Oliver MB, editors. The Routledge Handbook of Media Use and Well-Being. New York, NY: Taylor & Francis Group; 2016.
4. Hofer M, Hargittai E, Büchi M, Seifert A. Older adults' online information seeking and subjective well-being: the moderating role of internet skills. Int J Commun 2019;13(2019):4426-4443 [FREE Full text]
5. Hobfoll SE, Freedy J. Conservation of resources: a general stress theory applied to burnout. In: Schaufeli WB, Maslach C, Marek T, editors. Professional Burnout: Recent Developments in Theory and Research. Oxfordshire, UK: Routledge; 1993:115-133.
6. Hobfoll SE, Lilly RS. Resource conservation as a strategy for community psychology. J Community Psychol 1993 Apr;21(2):128-148. [doi: 10.1002/1520-6629(199304)21:2<128::aid-jcop2290210206>3.0.co;2-5]
7. Nakagomi A, Shiba K, Kawachi I, Ide K, Nagamine Y, Kondo N, et al. Internet use and subsequent health and well-being in older adults: an outcome-wide analysis. Comput Human Behav 2022 May;130:107156. [doi: 10.1016/j.chb.2021.107156]
8. Szabo A, Allen J, Stephens C, Alpass F. Longitudinal analysis of the relationship between purposes of internet use and well-being among older adults. Gerontologist 2019 Jan 09;59(1):58-68. [doi: 10.1093/geront/gny036] [Medline: 29688332]
9. Floyd SW, Lane PJ. Strategizing throughout the organization: managing role conflict in strategic renewal. Acad Manage Rev 2000 Jan;25(1):154-177. [doi: 10.5465/amr.2000.2791608]
10. Hobfoll SE, Johnson RJ, Ennis N, Jackson AP. Resource loss, resource gain, and emotional outcomes among inner city women. J Pers Soc Psychol 2003;84(3):632-643. [doi: 10.1037/0022-3514.84.3.632]
11. Baltes PB, Lindenberger U, Staudinger UM. Life span theory in developmental psychology. In: Damon W, Lerner RM, editors. Handbook of Child Psychology. Hoboken, NJ: John Wiley & Sons; 1998:1029-1143.

12. Hawkins-Elder H, Milfont TL, Hammond MD, Sibley CG. Who are the lonely? A typology of loneliness in New Zealand. Aust N Z J Psychiatry 2018 Apr 14;52(4):357-364. [doi: 10.1177/0004867417718944] [Medline: 28707520]
13. Hawkley LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. Ann Behav Med 2010 Oct;40(2):218-227 [FREE Full text] [doi: 10.1007/s12160-010-9210-8] [Medline: 20652462]
14. Perissinotto CM, Stijacic Cenzer I, Covinsky KE. Loneliness in older persons: a predictor of functional decline and death. Arch Intern Med 2012 Jul 23;172(14):1078-1083 [FREE Full text] [doi: 10.1001/archinternmed.2012.1993] [Medline: 22710744]
15. Andersson L. Intervention against loneliness in a group of elderly women: an impact evaluation. Soc Sci Med 1985 Jan;20(4):355-364. [doi: 10.1016/0277-9536(85)90010-3] [Medline: 3992279]
16. Domènech-Abella J, Mundó J, Haro JM, Rubio-Valera M. Anxiety, depression, loneliness and social network in the elderly: longitudinal associations from the Irish Longitudinal Study on Ageing (TILDA). J Affect Disord 2019 Mar 01;246:82-88. [doi: 10.1016/j.jad.2018.12.043] [Medline: 30578950]
17. Huang B, Liu Y, Feng Z, Pearce JR, Wang R, Zhang Y, et al. Residential exposure to natural outdoor environments and general health among older adults in Shanghai, China. Int J Equity Health 2019 Nov 21;18(1):178 [FREE Full text] [doi: 10.1186/s12939-019-1081-4] [Medline: 31752984]
18. Baltes PB, Baltes MM. Psychological perspectives on successful aging: the model of selective optimization with compensation. In: Baltes PB, Baltes MM, editors. Successful Aging: Perspectives from the Behavioral Sciences. Cambridge, MA: Cambridge University Press; 1990:1-34.
19. Brandtstädter J. Goal pursuit and goal adjustment: self-regulation and intentional self-development in changing developmental contexts. Adv Life Course Res 2009 Mar;14(1-2):52-62. [doi: 10.1016/j.alcr.2009.03.002]
20. Hobfoll SE. Conservation of resources: a new attempt at conceptualizing stress. Am Psychol 1989;44(3):513-524. [doi: 10.1037/0003-066x.44.3.513]
21. Hobfoll SE. The influence of culture, community, and the nested‐self in the stress process: advancing conservation of resources theory. Appl Psychol 2001 Dec 21;50(3):337-421. [doi: 10.1111/1464-0597.00062]
22. Hobfoll SE. Conservation of resources theory: its implication for stress, health, and resilience. In: Folkman S, editor. The Oxford Handbook of Stress, Health, and Coping. Oxford, UK: Oxford University Press; 2011:127-147.
23. Aggarwal B, Xiong Q, Schroeder-Butterfill E. Impact of the use of the internet on quality of life in older adults: review of literature. Prim Health Care Res Dev 2020 Dec 02;21:1-6. [doi: 10.1017/s1463423620000584]
24. Chen Y, Persson A. Internet use among young and older adults: relation to psychological well-being. Educ Gerontol 2002 Oct;28(9):731-744. [doi: 10.1080/03601270290099921]
25. Erickson J, Johnson GM. Internet use and psychological wellness during late adulthood. Can J Aging 2011 Jun 23;30(2):197-209. [doi: 10.1017/S0714980811000109] [Medline: 24650669]
26. Heo J, Chun S, Lee S, Lee KH, Kim J. Internet use and well-being in older adults. Cyberpsychol Behav Soc Netw 2015 May;18(5):268-272. [doi: 10.1089/cyber.2014.0549] [Medline: 25919967]
27. Shapira N, Barak A, Gal I. Promoting older adults' well-being through internet training and use. Aging Ment Health 2007 Sep;11(5):477-484. [doi: 10.1080/13607860601086546] [Medline: 17882585]
28. Sum S, Mathews RM, Hughes I, Campbell A. Internet use and loneliness in older adults. Cyberpsychol Behav 2008 Apr;11(2):208-211. [doi: 10.1089/cpb.2007.0010] [Medline: 18422415]
29. White H, McConnell E, Clipp E, Bynum L, Teague C, Navas L, et al. Surfing the net in later life: a review of the literature and pilot study of computer use and quality of life. J Appl Gerontol 2016 Jun 29;18(3):358-378. [doi: 10.1177/073346489901800306]
30. Cotten SR, Anderson WA, McCullough BM. Impact of internet use on loneliness and contact with others among older adults: cross-sectional analysis. J Med Internet Res 2013 Feb 28;15(2):e39 [FREE Full text] [doi: 10.2196/jmir.2306] [Medline: 23448864]
31. Li Y, Bai X, Chen H. Social isolation, cognitive function, and depression among Chinese older adults: examining internet use as a predictor and a moderator. Front Public Health 2022 Mar 14;10:809713 [FREE Full text] [doi: 10.3389/fpubh.2022.809713] [Medline: 35359786]
32. Duplaga M. The association between internet use and health-related outcomes in older adults and the elderly: a cross-sectional study. BMC Med Inform Decis Mak 2021 May 06;21(1):150 [FREE Full text] [doi: 10.1186/s12911-021-01500-2] [Medline: 33957909]
33. Gordon NP, Hornbrook MC. Older adults' readiness to engage with eHealth patient education and self-care resources: a cross-sectional survey. BMC Health Serv Res 2018 Mar 27;18(1):220 [FREE Full text] [doi: 10.1186/s12913-018-2986-0] [Medline: 29587721]
34. Sun N, Wei L, Shi S, Jiao D, Song R, Ma L, et al. A qualitative study on the psychological experience of caregivers of COVID-19 patients. Am J Infect Control 2020 Jun;48(6):592-598 [FREE Full text] [doi: 10.1016/j.ajic.2020.03.018] [Medline: 32334904]
35. Manafo E, Wong S. Health literacy programs for older adults: a systematic literature review. Health Educ Res 2012 Dec;27(6):947-960. [doi: 10.1093/her/cys067] [Medline: 22752153]

36. Gallistl V, Nimrod G. Media-based leisure and wellbeing: a study of older internet users. Leis Stud 2019 Nov 25;39(2):251-265. [doi: 10.1080/02614367.2019.1694568]
37. Heo J, Lee Y. Serious leisure, health perception, dispositional optimism, and life satisfaction among senior games participants. Educ Gerontol 2010 Jan 05;36(2):112-126. [doi: 10.1080/03601270903058523]
38. Chen YR, Schulz PJ. The effect of information communication technology interventions on reducing social isolation in the elderly: a systematic review. J Med Internet Res 2016 Jan 28;18(1):e18 [FREE Full text] [doi: 10.2196/jmir.4596] [Medline: 26822073]
39. Choi I, Zou J, Titov N, Dear BF, Li S, Johnston L, et al. Culturally attuned Internet treatment for depression amongst Chinese Australians: a randomised controlled trial. J Affect Disord 2012 Feb;136(3):459-468. [doi: 10.1016/j.jad.2011.11.003] [Medline: 22177742]
40. Damant J, Knapp M, Freddolino P, Lombard D. Effects of digital engagement on the quality of life of older people. Health Soc Care Community 2017 Nov 25;25(6):1679-1703. [doi: 10.1111/hsc.12335] [Medline: 26919220]
41. Forsman AK, Nordmyr J. Psychosocial links between internet use and mental health in later life: a systematic review of quantitative and qualitative evidence. J Appl Gerontol 2017 Dec;36(12):1471-1518. [doi: 10.1177/0733464815595509] [Medline: 26245208]
42. Bleakley CM, Charles D, Porter-Armstrong A, McNeill MD, McDonough SM, McCormack B. Gaming for health: a systematic review of the physical and cognitive effects of interactive computer games in older adults. J Appl Gerontol 2015 Apr 17;34(3):NP166-NP189. [doi: 10.1177/0733464812470747] [Medline: 24652863]
43. Toril P, Reales JM, Ballesteros S. Video game training enhances cognition of older adults: a meta-analytic study. Psychol Aging 2014 Sep;29(3):706-716. [doi: 10.1037/a0037507] [Medline: 25244488]
44. Kaufman D, Sauvé L, Renaud L, Sixsmith A, Mortenson B. Older adults' digital gameplay: patterns, benefits, and challenges. Simul Gaming 2016 Apr 21;47(4):465-489. [doi: 10.1177/1046878116645736]
45. Khosravi P, Rezvani A, Wiewiora A. The impact of technology on older adults' social isolation. Comput Human Behav 2016 Oct;63:594-603. [doi: 10.1016/j.chb.2016.05.092]
46. Almeida DM, Horn MC. Is daily life more stressful during middle adulthood? In: Brim OG, Ryff CD, Kessler RC, editors. How Healthy are We?: A National Study of Well-Being at Midlife. Chicago, IL: The University of Chicago Press; 2004:425-451.
47. Stawski RS, Sliwinski MJ, Almeida DM, Smyth JM. Reported exposure and emotional reactivity to daily stressors: the roles of adult age and global perceived stress. Psychol Aging 2008 Mar;23(1):52-61 [FREE Full text] [doi: 10.1037/0882-7974.23.1.52] [Medline: 18361654]
48. Carstensen LL, Turan B, Scheibe S, Ram N, Ersner-Hershfield H, Samanez-Larkin GR, et al. Emotional experience improves with age: evidence based on over 10 years of experience sampling. Psychol Aging 2011 Mar;26(1):21-33 [FREE Full text] [doi: 10.1037/a0021285] [Medline: 20973600]
49. Grzywacz JG, Almeida DM, Neupert SD, Ettner SL. Socioeconomic status and health: a micro-level analysis of exposure and vulnerability to daily stressors. J Health Soc Behav 2004 Mar 23;45(1):1-16. [doi: 10.1177/002214650404500101] [Medline: 15179904]
50. Pinquart M, Sörensen S. Risk factors for loneliness in adulthood and old age--a meta-analysis. In: Shohov SP, editor. Advances in Psychology Research. Hauppauge, NY: Nova Science Publishers; 2004:113-143.
51. Boucher E, Honomichl R, Ward H, Powell T, Stoeckl SE, Parks A. The effects of a digital well-being intervention on older adults: retrospective analysis of real-world user data. JMIR Aging 2022 Sep 02;5(3):e39851 [FREE Full text] [doi: 10.2196/39851] [Medline: 36053569]
52. Wang S, Bolling K, Mao W, Reichstadt J, Jeste D, Kim H, et al. Technology to support aging in place: older adults' perspectives. Healthcare (Basel) 2019 Apr 10;7(2):60 [FREE Full text] [doi: 10.3390/healthcare7020060] [Medline: 30974780]
53. Yang HL, Zhang S, Zhang SQ, Xie L, Wu YY, Yao YD, et al. Internet use and depressive symptoms among older adults in China. Front Psychiatry 2021 Dec 7;12:739085 [FREE Full text] [doi: 10.3389/fpsyt.2021.739085] [Medline: 34950065]
54. Morahan-Martin J, Schumacher P. Incidence and correlates of pathological Internet use among college students. Comput Human Behav 2000 Jan;16(1):13-29. [doi: 10.1016/s0747-5632(99)00049-7]
55. Mozafar Saadati H, Mirzaei H, Okhovat B, Khodamoradi F. Association between internet addiction and loneliness across the world: a meta-analysis and systematic review. SSM Popul Health 2021 Dec;16:100948 [FREE Full text] [doi: 10.1016/j.ssmph.2021.100948] [Medline: 34754896]
56. Etikan I, Rukayya A, Sulaiman A. Comparision of snowball sampling and sequential sampling technique. Biom Biostat Int J 2016 Jan 2;3(1):55. [doi: 10.15406/bbij.2016.03.00055]
57. Faul F, Erdfelder E, Lang A, Buchner A. G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behav Res Methods 2007 May;39(2):175-191. [doi: 10.3758/BF03193146]
58. Wells JD, Hobfoll SE, Lavin J. Resource loss, resource gain, and communal coping during pregnancy among women with multiple roles. Psychol Women Q 2016 Jun 23;21(4):645-662. [doi: 10.1111/j.1471-6402.1997.tb00136.x]
59. Wells JD, Hobfoll SE, Lavin J. When it rains, it pours: the greater impact of resource loss compared to gain on psychological distress. Pers Soc Psychol Bull 2016 Jul 02;25(9):1172-1182. [doi: 10.1177/01461672992512010]

60. Jopp D, Leipold B. [Perception of resources and their meaning for well-being: age-associated similarities and differences among young and old adults]. Z Gerontol Geriatr 2004 Oct;37(5):354-356. [doi: 10.1007/s00391-004-0258-6] [Medline: 15503071]
61. Roque NA, Boot WR. A new tool for assessing mobile device proficiency in older adults: the mobile device proficiency questionnaire. J Appl Gerontol 2018 Feb 11;37(2):131-156 [FREE Full text] [doi: 10.1177/0733464816642582] [Medline: 27255686]
62. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav 1983 Dec;24(4):385. [doi: 10.2307/2136404]
63. Hayes AF. Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach. New York, NY: The Guilford Press; 2013.
64. Charles ST, Reynolds CA, Gatz M. Age-related differences and change in positive and negative affect over 23 years. J Health Soc Behav 2001;80(1):136-151. [doi: 10.1037/0022-3514.80.1.136]
65. Mroczek DK, Almeida DM. The effect of daily stress, personality, and age on daily negative affect. J Pers 2004 Apr;72(2):355-378. [doi: 10.1111/j.0022-3506.2004.00265.x] [Medline: 15016068]
66. Mather M. The emotion paradox in the aging brain. Ann N Y Acad Sci 2012 Mar 12;1251(1):33-49 [FREE Full text] [doi: 10.1111/j.1749-6632.2012.06471.x] [Medline: 22409159]
67. Reed AE, Carstensen LL. The theory behind the age-related positivity effect. Front Psychol 2012;3:339 [FREE Full text] [doi: 10.3389/fpsyg.2012.00339] [Medline: 23060825]
68. Blanchard-Fields F. Everyday problem solving and emotion: an adult developmental perspective. Curr Dir Psychol Sci 2016 Jun 24;16(1):26-31. [doi: 10.1111/j.1467-8721.2007.00469.x]
69. Kunzmann U, Little TD, Smith J. Is age-related stability of subjective well-being a paradox? Cross-sectional and longitudinal evidence from the Berlin Aging Study. Psychol Aging 2000;15(3):511-526. [doi: 10.1037/0882-7974.15.3.511]
70. Charles ST, Mather M, Carstensen LL. Aging and emotional memory: the forgettable nature of negative images for older adults. J Exp Psychol Gen 2003 Jun;132(2):310-324. [doi: 10.1037/0096-3445.132.2.310] [Medline: 12825643]
71. Isaacowitz DM, Wadlinger HA, Goren D, Wilson HR. "Selective preference in visual fixation away from negative images in old age? An eye-tracking study": correction. Psychol Aging 2006 Jun;21(2):221. [doi: 10.1037/0882-7974.21.2.221]
72. Isaacowitz DM, Wadlinger HA, Goren D, Wilson HR. Is there an age-related positivity effect in visual attention? A comparison of two methodologies. Emotion 2006 Aug;6(3):511-516. [doi: 10.1037/1528-3542.6.3.511] [Medline: 16938091]
73. Kennedy A, Kunwar PS, Li L, Stagkourakis S, Wagenaar DA, Anderson DJ. Stimulus-specific hypothalamic encoding of a persistent defensive state. Nature 2020 Oct 16;586(7831):730-734 [FREE Full text] [doi: 10.1038/s41586-020-2728-4] [Medline: 32939094]
74. Roquet A, Lallement C, Lemaire P. Sequential modulations of emotional effects on cognitive performance in young and older adults. Motiv Emot 2022 Mar 15;46(3):366-381. [doi: 10.1007/S11031-022-09932-7]
75. Hildon Z, Montgomery SM, Blane D, Wiggins RD, Netuveli G. Examining resilience of quality of life in the face of health-related and psychosocial adversity at older ages: what is "right" about the way we age? Gerontologist 2010 Feb 23;50(1):36-47. [doi: 10.1093/geront/gnp067] [Medline: 19549715]
76. Kim SH. Older people's expectations regarding ageing, health-promoting behaviour and health status. J Adv Nurs 2009 Jan 17;65(1):84-91. [doi: 10.1111/j.1365-2648.2008.04841.x] [Medline: 19032514]
77. Tugade MM, Fredrickson BL. Resilient individuals use positive emotions to bounce back from negative emotional experiences. J Pers Soc Psychol 2004 Feb;86(2):320-333 [FREE Full text] [doi: 10.1037/0022-3514.86.2.320] [Medline: 14769087]
78. Brandtstädter J, Rothermund K. The life-course dynamics of goal pursuit and goal adjustment: a two-process framework. Developmental Review 2002 Mar;22(1):117-150. [doi: 10.1006/drev.2001.0539]
79. Hajek A, König HH. Social isolation and loneliness of older adults in times of the COVID-19 pandemic: can use of online social media sites and video chats assist in mitigating social isolation and loneliness? Gerontology 2021;67(1):121-124 [FREE Full text] [doi: 10.1159/000512793] [Medline: 33264778]
80. Martin P, Rott C, Poon LW, Courtenay B, Lehr U. A molecular view of coping behavior in older adults. J Aging Health 2001 Feb 30;13(1):72-91. [doi: 10.1177/089826430101300104] [Medline: 11503848]
81. Rothermund K, Brandtstädter J. Depression in later life: cross-sequential patterns and possible determinants. Psychol Aging 2003 Mar;18(1):80-90. [doi: 10.1037/0882-7974.18.1.80] [Medline: 12641314]
82. Uittenhove K, Jopp DS, Lampraki C, Boerner K. Coping patterns in advanced old age: findings from the Fordham centenarian study. Gerontology 2023 Feb 25;69(7):888-898 [FREE Full text] [doi: 10.1159/000529896] [Medline: 36843110]
83. Cole J, Watkins C, Kleine D. Health advice from internet discussion forums: how bad is dangerous? J Med Internet Res 2016 Jan 06;18(1):e4 [FREE Full text] [doi: 10.2196/jmir.5051] [Medline: 26740148]
84. Baños RM, Etchemendy E, Mira A, Riva G, Gaggioli A, Botella C. Online positive interventions to promote well-being and resilience in the adolescent population: a narrative review. Front Psychiatry 2017;8:10 [FREE Full text] [doi: 10.3389/fpsyt.2017.00010] [Medline: 28194117]

85. Heber E, Ebert DD, Lehr D, Cuijpers P, Berking M, Nobis S, et al. The benefit of web- and computer-based interventions for stress: a systematic review and meta-analysis. J Med Internet Res 2017 Feb 17;19(2):e32 [FREE Full text] [doi: 10.2196/jmir.5774] [Medline: 28213341]
86. Kazdin AE, Rabbitt SM. Novel models for delivering mental health services and reducing the burdens of mental illness. Clin Psychol Sci 2013 Jan 23;1(2):170-191. [doi: 10.1177/2167702612463566]
87. Reid Chassiakos YL, Radesky J, Christakis D, Moreno MA, Cross C, Council on Communications and Media. Children and adolescents and digital media. Pediatrics 2016 Nov;138(5):1-18. [doi: 10.1542/peds.2016-2593] [Medline: 27940795]
88. Sander L, Rausch L, Baumeister H. Effectiveness of internet-based interventions for the prevention of mental disorders: a systematic review and meta-analysis. JMIR Ment Health 2016 Aug 17;3(3):e38 [FREE Full text] [doi: 10.2196/mental.6061] [Medline: 27535468]
89. Hemingway A, Jack E. Reducing social isolation and promoting well being in older people. Qual Ageing Older Adults 2013;14(1):25-35. [doi: 10.1108/14717791311311085]
90. Niu GF, Sun XJ, Subrahmanyam K, Kong F, Tian Y, Zhou ZK. Cue-induced craving for internet among internet addicts. Addict Behav 2016 Nov;62:1-5. [doi: 10.1016/j.addbeh.2016.06.012] [Medline: 27305097]
91. Zhang S, Tian Y, Sui Y, Zhang D, Shi J, Wang P, et al. Relationships between social support, loneliness, and internet addiction in Chinese postsecondary students: a longitudinal cross-lagged analysis. Front Psychol 2018 Sep 11;9:1707 [FREE Full text] [doi: 10.3389/fpsyg.2018.01707] [Medline: 30258387]
92. Karaer Y, Akdemir D. Parenting styles, perceived social support and emotion regulation in adolescents with internet addiction. Compr Psychiatry 2019 Jul;92:22-27 [FREE Full text] [doi: 10.1016/j.comppsych.2019.03.003] [Medline: 31003724]
93. Odacı H, Çikrıkci Ö. Differences in problematic internet use based on depression, anxiety, and stress levels. Addicta 2017 Mar 30;4(1):41-61. [doi: 10.15805/addicta.2017.4.1.0020]
94. Boullier D. Sociologie des usages. In: Boullier D, editor. Sociologie du Numérique. Paris, France: Armand Colin Editeur; Aug 24, 2022:99-129.
95. Dagnaud M. Génération Y: Les Jeunes et Les Réseaux Sociaux, de la Dérision à la Subversion. Paris, France: Les Presses de Sciences Po; 2011.
96. Aggarwal NT, Wilson RS, Beck TL, Rajan KB, Mendes de Leon CF, Evans DA, et al. Perceived stress and change in cognitive function among adults 65 years and older. Psychosom Med 2014 Jan;76(1):80-85 [FREE Full text] [doi: 10.1097/PSY.0000000000000016] [Medline: 24367123]
97. Benge JF, Kiselica AM, Aguirre A, Hilsabeck RC, Douglas M, Paydarfar D, et al. Technology use and subjective cognitive concerns in older adults. Arch Gerontol Geriatr 2023 Mar;106:104877 [FREE Full text] [doi: 10.1016/j.archger.2022.104877] [Medline: 36459914]
98. Dequanter S, Fobelets M, Steenhout I, Gagnon M, Bourbonnais A, Rahimi S, et al. Determinants of technology adoption and continued use among cognitively impaired older adults: a qualitative study. BMC Geriatr 2022 Apr 28;22(1):376 [FREE Full text] [doi: 10.1186/s12877-022-03048-w] [Medline: 35484488]
99. LaMonica HM, English A, Hickie IB, Ip J, Ireland C, West S, et al. Examining internet and eHealth practices and preferences: survey study of Australian older adults with subjective memory complaints, mild cognitive impairment, or dementia. J Med Internet Res 2017 Oct 25;19(10):e358 [FREE Full text] [doi: 10.2196/jmir.7981] [Medline: 29070481]
100. Crosswell AD, Whitehurst L, Mendes WB. Effects of acute stress on cognition in older versus younger adults. Psychol Aging 2021 Mar;36(2):241-251 [FREE Full text] [doi: 10.1037/pag0000589] [Medline: 33539149]
101. Ihle A, Bavelier D, Maurer J, Oris M, Kliegel M. Internet use in old age predicts smaller cognitive decline only in men. Sci Rep 2020 Jun 02;10(1):8969 [FREE Full text] [doi: 10.1038/s41598-020-65846-9] [Medline: 32488153]
102. Ng TP, Lim ML, Niti M, Collinson S. Long-term digital mobile phone use and cognitive decline in the elderly. Bioelectromagnetics 2012 Feb 31;33(2):176-185. [doi: 10.1002/bem.20698] [Medline: 25929484]
103. Schacter DL. Memory sins in applied settings: what kind of progress? J Appl Res Mem Cogn 2022 Dec;11(4):445-460 [FREE Full text] [doi: 10.1037/mac0000078] [Medline: 37035272]
104. Small GW, Lee J, Kaufman A, Jalil J, Siddarth P, Gaddipati H, et al. Brain health consequences of digital technology use . Dialogues Clin Neurosci 2020 Jun;22(2):179-187 [FREE Full text] [doi: 10.31887/DCNS.2020.22.2/gsmall] [Medline: 32699518]
105. White H, McConnell E, Clipp E, Branch LG, Sloane R, Pieper C, et al. A randomized controlled trial of the psychosocial impact of providing internet training and access to older adults. Aging Ment Health 2002 Aug;6(3):213-221. [doi: 10.1080/13607860220142422] [Medline: 12217089]
106. Czaja SJ, Lee CC. The impact of aging on access to technology. Univ Access Inf Soc 2006 Dec 8;5(4):341-349. [doi: 10.1007/s10209-006-0060-x]
107. Chaumon MB, Michel C, Bernard FT, Croisile B. Can ICT improve the quality of life of elderly adults living in residential home care units? From actual impacts to hidden artefacts. Behav Inf Technol 2013 Oct 29;33(6):574-590. [doi: 10.1080/0144929x.2013.832382]
108. Hendrix CC. Computer use among elderly people. Comput Nurs 2000;18(2):62-69. [Medline: 10740912]

109. Jokisch MR, Schmidt LI, Doh M. Acceptance of digital health services among older adults: findings on perceived usefulness, self-efficacy, privacy concerns, ICT knowledge, and support seeking. Front Public Health 2022 Dec 13;10:1073756 [FREE Full text] [doi: 10.3389/fpubh.2022.1073756] [Medline: 36582385]
110. Karavidas M, Lim NK, Katsikas SL. The effects of computers on older adult users. Comput Human Behav 2005 Sep;21(5):697-711. [doi: 10.1016/j.chb.2004.03.012]
111. Xie B. Information technology education for older adults as a continuing peer-learning process: a Chinese case study. Educ Gerontol 2007 Apr 16;33(5):429-450. [doi: 10.1080/03601270701252872]
112. Osman Z, Poulson D, Nicolle CA. Introducing computers and the Internet to older users: findings from the Care OnLine project. Univ Access Inf Soc 2005 May 24;4(1):16-23. [doi: 10.1007/s10209-005-0111-8]
113. Nimrod G. Seniors' online communities: a quantitative content analysis. Gerontologist 2010 Jun;50(3):382-392. [doi: 10.1093/geront/gnp141] [Medline: 19917645]
114. Aarts S. Social media and loneliness among community-dwelling older adults. Int J Geriatr Psychiatry 2018 Mar 09;33(3):554-555. [doi: 10.1002/gps.4769] [Medline: 29424110]
115. Beacker R, Sellen K, Crosskey S, Boscart V, Neves BB. Technology to reduce social isolation and loneliness. In: Proceedings of the 16th International ACM SIGACCESS Conference on Computers & accessibility. 2014 Presented at: ASSETS'14; October 20-22, 2014; Rochester, NY p. 27-34 URL: https://dl.acm.org/doi/10.1145/2661334.2661375 [doi: 10.1145/2661334.2661375]
116. Khoo SS, Yang H. Social media use improves executive functions in middle-aged and older adults: A structural equation modeling analysis. Comput Human Behav 2020 Oct;111:106388. [doi: 10.1016/j.chb.2020.106388]
117. Groves A. Inference and error in surveys. In: Groves RM, Couper MP, Lepkowski JM, Singer E, Tourangeau R, editors. Survey Methodology. Hoboken, NJ: John Wiley & Sons; 2004:36-39.
118. Sheldon P, Antony MG, Ware LJ. Baby Boomers' use of Facebook and Instagram: uses and gratifications theory and contextual age indicators. Heliyon 2021 Apr;7(4):e06670 [FREE Full text] [doi: 10.1016/j.heliyon.2021.e06670] [Medline: 33889780]
119. Sinclair TJ, Grieve R. Facebook as a source of social connectedness in older adults. Comput Human Behav 2017 Jan;66(5):363-369. [doi: 10.1016/j.chb.2016.10.003]
120. Groves RM. Nonresponse rates and nonresponse bias in household surveys. Public Opin Q 2006;70(5):646-675 [FREE Full text] [doi: 10.1093/poq/nfl033]
121. Dunn KM, Jordan K, Lacey RJ, Shapley M, Jinks C. Patterns of consent in epidemiologic research: evidence from over 25,000 responders. Am J Epidemiol 2004 Jun 01;159(11):1087-1094. [doi: 10.1093/aje/kwh141] [Medline: 15155293]
122. Facchini C. Personnes âgées et technologies numériques: différences sociales, différences de genre. In: Pitaud P, editor. Vieillir Dans une Société Connectée?. Toulouse, France: Érès; 2021:83-110.
123. Brotocrone P, Damhuis L, Laurent V, Valenduc G, Vendramin P. Diversité et vulnérabilité dans les usages des TIC. La fracture numérique au second degré. Gent, Belgium: Academia Press; 2010.
124. Haynes SN, Richard DC, Kubany ES. Content validity in psychological assessment: a functional approach to concepts and methods. Psychol Assess 1995 Sep;7(3):238-247. [doi: 10.1037/1040-3590.7.3.238]
125. Šimkovic M, Träuble B. Robustness of statistical methods when measure is affected by ceiling and/or floor effect. PLoS One 2019 Aug 19;14(8):e0220889. [doi: 10.1371/journal.pone.0220889] [Medline: 31425561]
126. Mallein P, Tarozzi S. Des signaux d'usage pertinents pour la conception des objets communicants. Les Cahiers numérique 2002;3:61-70 [FREE Full text] [doi: 10.3845/ree.2002.093]
127. Martinelli P. Internet et bien-être au troisième âge. PsyArXiv [FREE Full text] [doi: 10.31234/osf.io/k42mr]
128. Pirhonen J, Lolich L, Tuominen K, Jolanki O, Timonen V. “These devices have not been made for older people's needs” – older adults' perceptions of digital technologies in Finland and Ireland. Technol Soc 2020 Aug;62:101287. [doi: 10.1016/j.techsoc.2020.101287]

Abbreviations

COR: Conservation of Resources

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Determinants of Telemedicine Service Use Among Middle-Aged and Older Adults in Germany During the COVID-19 Pandemic: Cross-Sectional Survey Study

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Abstract

Background: The occurrence of the COVID-19 pandemic demanded fast changes in the delivery of health care. As a result, significant growth in the use of telemedicine services occurred. Research, especially from nationally representative German samples, is needed to better understand determinants of telemedicine use.

Objective: The purpose of this study was to identify determinants of telemedicine service use among middle-aged and older adults during the COVID-19 pandemic in Germany.

Methods: Cross-sectional, nationally representative data were taken from the German sample of the Survey of Health, Ageing and Retirement in Europe (SHARE). The German Corona Survey 2 (n=2039), which was conducted between June and August 2021, was used for this study. Reporting experience with remote medical consultations during the COVID-19 pandemic served as the outcome measure. Associations with socioeconomic, psychological, social, health-related, and COVID-19–related determinants were examined using multiple Firth logistic regressions.

Results: Psychological factors including feeling nervous, anxious, or on edge (odds ratio [OR] 1.61, 95% CI 1.04-2.50; *P*=.03), feeling sad or depressed (OR 1.62, 95% CI 1.05-2.51; *P*=.03) and feelings of loneliness (OR 1.66, 95% CI 1.07-2.58; *P*=.02) were positively associated with telemedicine use. Moreover, forgoing medical treatment because of being afraid of being infected by SARS-CoV-2 (OR 1.81, 95% CI 1.10-2.97; *P*=.02) and describing limitations because of a health problem as severe were positively associated with the outcome (OR 2.11, 95% CI 1.12-4.00; *P*=.02). Socioeconomic and social factors were not significantly associated with telemedicine use in our sample.

Conclusions: Middle-aged and older individuals in Germany seem to use telemedicine services according to psychological needs and health limitations. Especially when psychological symptoms are experienced, telemedicine seems to be a promising service option in this age group. Future research is needed to confirm these initial findings in postpandemic circumstances.

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KEYWORDS

telemedicine; telehealth; digital health; service use; COVID-19

Introduction

Telemedicine has been a big part of the digital transformation of the health care sector. Multiple definitions of telemedicine have been introduced in the past [1]. The World Health Organization (WHO) Global Observatory for eHealth [2] identified the four key characteristics of telemedicine: (1) its purpose is to provide clinical support, (2) it is intended to overcome geographical barriers, connecting users who are not in the same physical location, (3) it involves the use of various types of information and communication technology, and (4) its goal is to improve health outcomes. Therefore, telemedicine includes synchronous (eg, videoconferencing, telephone) as well as asynchronous (eg, mobile apps) health services, which are delivered via electronic devices.

Telemedicine is a presumably promising method to provide health care in the future, as it can improve access to care, save costs, and close treatment gaps [3,4]. For example, it could be a potentially valuable tool when dealing with future shortages of physicians as well as the increased demand for health care services caused by population aging; underserved rural areas can also easily be reached through telemedicine [3,5]. In past research, telemedicine was found to be an effective and cost-effective service delivery model that can be equal to in-patient visits in a variety of specialties [3,6-9]. Additionally, practitioners (eg, physicians and psychotherapists), as well as patients with conditions covered by various specialties, were found to be greatly satisfied with this form of service [8-10]. Despite the clear advantages of telemedicine, it has not yet been widely implemented. Implementations have often been decelerated by limitations regarding reimbursement, as well as clinical, legal, cost, and social issues [11,12]. Telemedicine rates of use were gradually increasing over the previous years but remained at a low level [13].

The occurrence of the COVID-19 pandemic demanded fast changes in the delivery of health care. COVID-19 caused a major public health burden globally and it was essential to reduce in-person contacts to decrease further spreading of the virus [14]. Therefore, many nonessential appointments with physicians were canceled or postponed [15]. In a German population-based sample, this was the case for about one-third of respondents after containment measures were implemented in March 2020 [16]. Moreover, overall use of health care decreased in the first months of the pandemic, a phenomenon that was also observed in Germany [17].

Telemedicine appeared to be a key solution to major pandemic challenges. To facilitate the transformation to telemedicine, changes in infrastructure, reimbursement, and legal conditions were made worldwide. In Germany, legal efforts for the digital transformation of the health care system had already been made in November 2019 with the Digital Healthcare Act (Digitale-Versorgung-Gesetz) [18]. Consequently, it was easier for physicians to prescribe, deliver, and bill for telemedicine, and also for patients to use the services. In response to the pandemic, additional teleconsultation services were developed and regulations concerning video consultations were adapted [19,20]. Thus, telemedicine rates of use increased tremendously [21]. For example, the trend report of the Central Research Institute of Ambulatory Care in Germany reported that the number of video consultations increased from 743 conducted in December 2019 to 302,180 conducted in December 2020 [21]. Especially when there was limited access to in-person medical appointments during the pandemic in Germany, telemedicine services seemed to be a frequently used alternative, and satisfaction with the services was found to be moderately high [22,23]. Even though telephone services were used most frequently in Germany during the pandemic, a sharp increase was observed in the use of video consultations [24,25].

Besides technological, financial, organizational, and legal aspects, patient acceptance seems to be a crucial factor for the successful implementation of telemedicine services [26]. Patient characteristics that have been found to be associated with telemedicine use in past systematic reviews include, for example, age, gender, education, marital status, health status, and prior experience with computers and health technology [27,28]. A preliminary selective review of large-scale studies that were conducted during the pandemic in the United States found that telemedicine rates of use were higher among patients from urban areas, areas with greater broadband availability, and areas with higher prepandemic levels of telehealth use [29]. Moreover, being White; speaking English as first language; having health insurance, higher income, and greater disease burden; and being middle-aged were associated with greater use [29]. Nevertheless, more studies examining the use of telemedicine services and associated patient characteristics during pandemic times are needed.

Studies with samples from Germany, where telemedicine played a major role and was frequently used during the pandemic, are especially scarce. Few studies have looked at different German samples during the pandemic. While some of these studies examined large, nationally representative or quota-based samples [22,23,30], other studies only included convenience or smaller selective samples [31-33]. These studies identified potential socioeconomic (male sex, younger age, higher or lower education, living with a partner in the same household, having children younger than 18 years), psychosocial (increased loneliness, increased life satisfaction, severe psychological distress, frequent social isolation, lack of company), health-related (poor self-rated health), experience-related (higher electronic literacy, past use of telemedicine) and COVID-19–related (higher perceived severity of COVID-19 infection, having had COVID-19 infection, subjective COVID-19–related challenges, COVID-19–related cognitive preoccupation, anxiety, and worries) determinants that were positively associated with actual telemedicine use during the pandemic [22,23,30-33]. However, more studies including large nationally representative samples from Germany are needed to secure these initial findings. Moreover, the different categories of determinants, which were only partly included in single studies (eg, psychosocial or COVID-19–related determinants), should be explored further.

Middle-aged and older individuals represent the largest age group in the German population [34]. Considering population aging, the proportion of middle-aged and older adults will grow even further in the near future in Germany. Due to their increased need for health care (due to, eg, chronic conditions, frailty, and cognitive or functional decline) and potentially limited mobility, these age groups represent a major target group for future telemedicine services. Nevertheless, they seem to use telemedicine less often than other age groups [28]. Although past systematic reviews found that telemedicine is an effective and feasible service delivery model in older adults, it was also stated that further research was required to determine how services could be adapted to the individual needs of older patients [35-37]. Better understanding the telemedicine use behavior of middle-aged and older individuals could significantly contribute to increased use, as well as widespread acceptance and satisfaction with future telemedicine services. Therefore, this study aimed to explore determinants of patient use of telemedicine services in a nationally representative sample of middle-aged and older individuals during the COVID-19 pandemic in Germany.

Methods

Sample

Cross-sectional data for this study were taken from the Corona Survey 2 [38] of the Survey of Health, Ageing and Retirement in Europe (SHARE) study [39]. SHARE is a multidisciplinary and cross-national panel study that explores health, social, economic, and environmental policies in individuals aged 50 years or older and their partners (regardless of age) from 26

European countries, Switzerland, and Israel. Starting in 2004, SHARE has so far conducted 8 waves. In each wave, new respondents are added to the sample to compensate for attrition. In response to the global COVID-19 pandemic, a special Corona Survey, to examine the health-related and socioeconomic impact of COVID-19, was introduced in June 2020. In the course of this survey, the usual computer-assisted personal interviews were replaced by telephone-administered interviews.

Participation rates for waves 1 to 8 and the Corona Survey 1 have been provided by SHARE [40,41]. According to Bergmann et al [40], these rates increased over time and reflect high overall panel stability. The final rates for the Corona Survey 2 are not available yet; however, an average retention rate of 86% (excluding recovery of respondents) was confirmed by SHARE user support. Due to the fact that SHARE assessed telemedicine service use for the first time in the Corona Survey 2, only data from this survey, which was conducted from June until August 2021, were included in our analyses. Moreover, only the German subsample (n=2039) was considered, which was done to promote comparability among participants due to existing heterogeneity regarding characteristics of health care systems, telemedicine regulations, and telemedicine use across the different countries [20,42,43]. For example, whereas countries such as Denmark, Italy, and Germany are described as advanced in telemedicine use trends, countries like Poland, Portugal, or Slovakia are still developing in the telemedicine field since the pandemic [42].

Ethical Considerations

Verbal informed consent was collected from all individuals that participated in the telephone-administered interviews for the Corona Survey 2. The SHARE project has been repeatedly reviewed and approved by the ethics committee of the University of Mannheim (waves 1-3) and the Ethics Council of the Max Planck Society (waves 4-9; most recently in June 2021 with the ethics approval number 2021_24).

Dependent Variable

In the SHARE Corona Survey 2, telemedicine service use by middle-aged and older adults during the pandemic was assessed with a metric variable: “Since the outbreak of Corona, how many remote medical consultations over the phone, computer, or any other electronic means, did you have, if any, with or without video?” Therefore, this study did not focus on one specific form of telemedicine or patient group and included consultations on online platforms (eg, video calls), as well as telephone appointments. The response format in the original questionnaire was numerical (ie, the number of experienced telemedicine consultations). For the sake of this analysis, this item was dichotomized (1=one or more remote medical consultations since the outbreak of the COVID-19 pandemic; 0=no use) because of small case numbers.

Independent Variables

Independent variables were chosen in line with former research and based on theoretical considerations. Previous systematic reviews identified mostly socioeconomic (eg, sex, age, education, relationship status, area lived in) and health (eg, disease burden, psychological symptoms) determinants of telemedicine use [27-29]. Moreover, we considered the pandemic context, including the pandemic and social consequences, when choosing independent variables. Therefore, socioeconomic, psychological, social, health-related, and COVID-19–related factors were taken into account to explore their potential relationships with telemedicine service use. Socioeconomic factors that were included were sex, age, area lived in (big city, suburbs or outskirts of a big city, large town, small town, rural area or village), living with a partner in the same household (yes or no), employment status (retired, employed or self-employed, unemployed, or other) and the household’s ability to make ends meet regarding their total monthly income (with great difficulty or some difficulty, fairly easily, easily). Included psychological factors were feeling nervous, anxious, or on edge in the last month (yes or no), feeling sad or depressed in the last month (yes or no), and feeling lonely in the last month (yes or no). Furthermore, social factors included social and electronic contact frequency with people other than relatives (never, less than once a week, about once a week, several times a week, daily). Concerning health-related factors, having trouble sleeping recently (yes or no), the number of physical illnesses (including hip fracture; diabetes or high blood sugar; high blood pressure or hypertension; a heart attack, including myocardial infarction or coronary thrombosis; any other heart problem, including congestive heart failure; chronic lung diseases, such as chronic bronchitis or emphysema; and cancer or malignant tumor, including leukemia or lymphoma, but excluding minor skin cancers), limitations because of a health problem in usual activities (not limited; limited, but not severely; severely limited) and self-rated health (excellent, very good, good, fair, poor) were inspected. COVID-19–related factors that were included in the analyses were having received the COVID-19 vaccination (yes or no), oneself or anyone close having tested positive for COVID-19 (yes or no), forgoing medical treatment because of being afraid to become infected by SARS-CoV-2 (yes or no), and taking drugs or medicine as prevention against COVID-19 (yes or no).

Statistical Analysis

First, sample characteristics were computed. Second, Firth logistic regressions were conducted to identify determinants of telemedicine service use during the pandemic. The Firth method was used to reduce small-sample bias, considering the small case numbers for some of the variables [44]. Due to high correlations, the variables regarding psychological symptoms (including feeling nervous, anxious, or on edge; feeling sad or depressed; and feeling lonely in the last month) were entered separately into the model. For sensitivity analyses, conventional multiple logistic regressions were also performed. Moreover, we computed additional analyses with age as a categorical variable (40-64 years, 65-74 years, ≥75 years) to test for a nonlinear relationship with the outcome. Odds ratios (ORs) are presented with the 95% CI. *P* values were considered statistically significant at an α level of <.05. Since the number of missing values for the independent variables was very small (below 1%), we did not use imputation techniques. Small levels of missing values are usually less likely to significantly bias results [45,46]. Therefore, listwise deletion was applied. Stata (version 16.1; StataCorp) was used for all statistical analyses.

Results

Sample Characteristics

The total sample consisted of 2039 individuals. The sample characteristics for all included variables are presented in Table 1. Overall, 54.2% (1105/2039) of the sample were women. The mean age of the participants was 70.6 (SD 8.7) years. Considering telemedicine service use during the pandemic, 5.7% (115/2031) of the sample reported that they had had remote medical consultations at least once.

Table . Sample characteristics (N=2039).

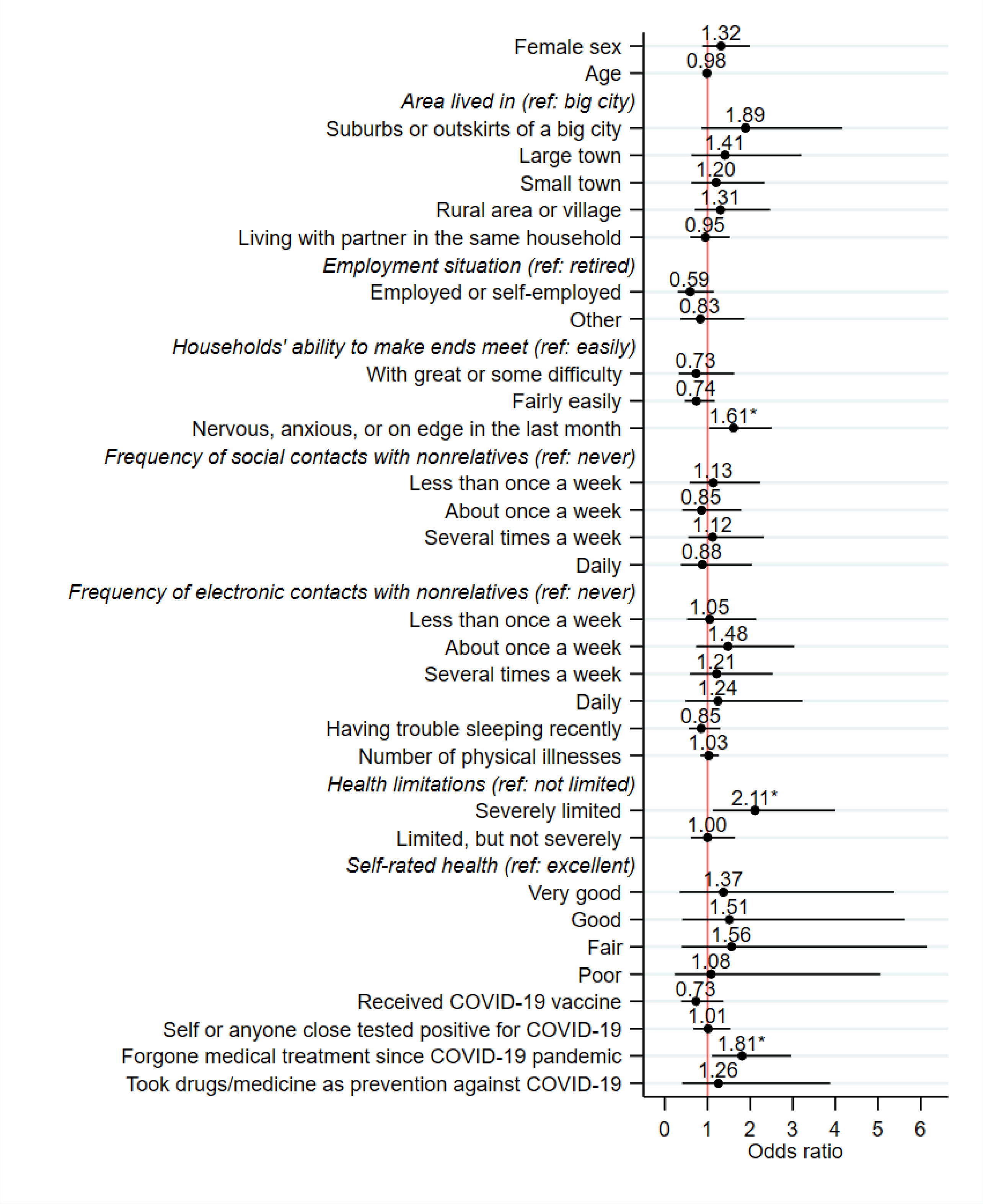
Characteristics		Values
Telemedicine service use, n (%)		
	Never	1916 (94.3)
	At least once	115 (5.7)
Sex, n (%)		
	Male	934 (45.8)
	Female	1105 (54.2)
Age (years), mean (SD)		70.6 (8.7)
Age (years), n (%)		
	40-64	573 (28.1)
	65-74	1083 (53.1)
	≥75	383 (18.78)
Area lived in, n (%)		
	Big city	289 (14.3)
	Suburbs or outskirts of a big city	177 (8.8)
	Large town	198 (9.8)
	Small town	549 (27.2)
	Rural area or village	807 (40)
Living with partner in the same household, n (%)		
	Yes	1521 (74.6)
	No	518 (25.4)
Employment situation, n (%)		
	Retired	1445 (70.9)
	Employed or self-employed	457 (22.4)
	Other	135 (6.6)
Households’ ability to make ends meet, n (%)		
	With great or some difficulty	151 (7.4)
	Fairly easily	599 (29.6)
	Easily	1277 (63)
Nervous, anxious, or on edge in the last month, n (%)		
	Yes	524 (25.8)
	No	1507 (74.2)
Sad or depressed in the last month, n (%)		
	Yes	609 (30)
	No	1419 (70)
Feelings of loneliness in the last month, n (%)		
	Yes	442 (21.8)
	No	1583 (78.2)
Frequency of social contacts with nonrelatives, n (%)		
	Never	229 (11.3)
	Less than once a week	583 (28.7)
	About once a week	452 (22.3)
	Several times a week	452 (22.3)

Characteristics		Values
	Daily	312 (15.4)
Frequency of electronic contacts with nonrelatives, n (%)		
	Never	253 (12.5)
	Less than once a week	617 (30.4)
	About once a week	505 (24.9)
	Several times a week	504 (24.8)
	Daily	150 (7.4)
Having trouble sleeping recently, n (%)		
	Yes	686 (33.8)
	No	1344 (66.2)
Number of physical illnesses (range 0-6), mean (SD)		1.1 (1)
Health limitations, n (%)		
	Severely limited	310 (15.2)
	Limited, but not severely	744 (36.6)
	Not limited	981 (48.2)
Self-rated health, n (%)		
	Excellent	82 (4)
	Very good	320 (15.7)
	Good	839 (41.2)
	Fair	629 (30.9)
	Poor	166 (8.2)
Received COVID-19 vaccine, n (%)		
	Yes	189 (9.3)
	No	1847 (90.7)
Self or anyone close tested positive for COVID-19, n (%)		
	Yes	592 (29.1)
	No	1441 (70.9)
Forgone medical treatment since COVID-19 pandemic, n (%)		
	Yes	225 (11.1)
	No	1810 (88.9)
Took drugs/medicine as prevention against COVID-19, n (%)		
	Yes	45 (2.2)
	No	1990 (97.8)

Regression Analysis

The analytic sample for the Firth logistic regressions included 1976 individuals. Results for the model, including anxiety symptoms, are presented in Figure 1 (see Multimedia Appendix 1 for detailed results for all models). Most of the included independent variables were not significantly associated with the outcome (*P*>.05). However, some associations were observed. Psychological factors, including feeling nervous, anxious, or on edge (OR 1.61, 95% CI 1.04-2.50; *P*=.03), feeling sad or depressed (OR 1.62, 95% CI 1.05-2.51; *P*=.03) and feeling lonely (OR 1.66, 95% CI 1.07-2.58; *P*=.02) in the last month were positively associated with the likelihood of telemedicine service use during the pandemic. Moreover, forgoing medical treatment because of being afraid to become infected by SARS-CoV-2 was positively associated with the outcome (OR 1.81, 95% CI 1.10-2.97; *P*=.02). Describing limitations because of health problems in the last 6 months as severe was also positively associated with the likelihood of telemedicine use during the pandemic (OR 2.11, 95% CI 1.12-4.00; *P*=.02).

Figure 1. Results from Firth logistic regression for determinants of telemedicine service use during the COVID-19 pandemic. The model includes anxiety symptoms. Numbers represent odds ratios, with the 95% CIs shown as bars. More detailed results are provided in Table S1 in Multimedia Appendix 1. ref: reference category. *P<.05.



In a sensitivity analysis in which Firth logistic regressions were replaced by conventional logistic regressions, similar associations were observed (see Tables S1-S3 in Multimedia Appendix 1 for detailed results). When age was included as a categorical variable in the models (see Table S4 in Multimedia Appendix 1 for detailed results), the youngest age group (40-64 years) was significantly more likely to use telemedicine services compared to the older age groups in our sample (65-74 and ≥75 years). Moreover, in these models, being employed or self-employed versus retired achieved statistical significance and was negatively associated with telemedicine use.

Discussion

Key Findings

This study aimed to identify determinants of telemedicine service use in a nationally representative sample of middle-aged and older adults during the COVID-19 pandemic in Germany. Based on data from the German sample of the SHARE Corona Survey 2, some associations of patient characteristics with telemedicine use were identified. This partly included health, psychological, and COVID-19–related factors. Socioeconomic and social determinants were not significantly associated with the outcome in this sample. So far, there has been limited research on determinants of telemedicine use in German samples. Our study findings thus extend our current knowledge regarding socioeconomic, social, health, psychological, and COVID-19–related determinants.

Relation to Previous Research

Whereas none of the included socioeconomic determinants were associated with telemedicine service use in our sample, some recent studies identified significant relationships. Findings regarding associations of sex and age with telemedicine use were mixed in recent studies conducted during the pandemic in Germany, with some studies observing higher rates of use in male and younger individuals [22,23,30-32]. When observing age groups in our sample, older age groups (65-74 and ≥75 years) were less likely to use telemedicine. While our study did not indicate a significant association, Hajek and König [30] observed that middle-aged and older individuals who reported living with a partner in the same household were more likely to have participated in online consultations with physicians or therapists during the pandemic. These mixed findings could potentially be explained by variations in outcomes (eg, web-based consultations vs mobile app use), samples (eg, all age groups vs only those middle-aged and older), and time frames (2020 vs 2021 vs 2022) of the different studies. This clearly highlights the need for further studies on sociodemographic determinants in German samples. Similar to our results, employment status, financial situation, and area lived in were not significantly associated with telemedicine use in other German samples during the pandemic [23,30]. However, this is in contrast to research from the United States regarding telemedicine use during the pandemic [29,47]. This contrast may be explained by a larger variation in state-specific telehealth policies before and during the pandemic [48], as well as access factors, such as possession of digital devices or availability of high speed internet [49] in the United States compared to the German samples. In contrast to Germany, health care insurance is not obligatory in the United States and additional costs arise for uninsured individuals [50], which could have contributed to telemedicine use disparities caused by socioeconomic factors in the United States [49,51-53]. Further attention should be given to the impact of socioeconomic factors on telemedicine use in future research, especially with respect to postpandemic changes and the increasing availability of in-person visits.

Our study is one of very few that has examined the association of social determinants (ie, electronic and social contact frequency) and telemedicine service use. These determinants were not significantly associated with telemedicine use in our sample. This could mean that middle-aged and older adults used telemedicine services during the pandemic based more on health factors than on reduced social contact. Nevertheless, Rauschenberg et al [33] observed that telemedicine use was higher among young individuals who reported higher perceived social isolation and lack of company during the pandemic in Germany. These contrasting findings may imply that younger individuals have used telemedicine more frequently to deal with reduced social contact during the pandemic.

Furthermore, we found that perceiving one’s limitations because of a health problem as severe was associated with telemedicine service use. This suggests that individuals with severe health limitations preferentially used telemedicine services during the pandemic. Likewise, Hajek and König [30] found a significant association of poor self-rated health and telemedicine use during the pandemic in Germany. Additionally, a positive association of disease burden and telemedicine use was observed by Harju and Neufeld [29] in large-scale US samples during the pandemic. Potential reasons for that could include the (urgent) need for treatment, limited mobility, or precautions due to high risk of severe illness from COVID-19. Patients might have used telemedicine because of health needs and lack of in-person services during the pandemic. In contrast, we found that the number of physical illnesses and self-rated health were not associated with telemedicine use during the pandemic in our sample. A potential reason for that could be that these determinants may not reflect the actual need for medicine or telemedicine services. For example, having ever received a diagnosis of physical illnesses such as hip fracture, high blood sugar, or high blood pressure does not indicate that there currently is a higher need for treatment. Other studies that observed German samples during the pandemic also found a nonsignificant association of the presence of chronic conditions and telemedicine use [22,23]. Moreover, necessary treatment for patients with severe diseases (eg, physical examination, cancer treatment) was potentially more likely to be in person and still available during the pandemic. Future telemedicine services might be less suitable for these patient groups. Further research is needed to gain a better understanding of the possible impact of physical illness on telemedicine service use, especially in German samples.

Since few recent studies have examined the association of psychological symptoms with telemedicine use, our findings contribute to existing knowledge concerning psychological determinants during the pandemic in Germany. We observed that symptoms of anxiety, depression, or loneliness increased the likelihood of telemedicine use in middle-aged and older adults. Similar to our results, Hajek and König [30] observed a significant positive association of loneliness and telemedicine use in middle-aged and older adults during the pandemic in Germany. Likewise, Rauschenberg et al [33] found that psychological distress was associated with the current use of mobile health apps in a representative sample of youth aged 16-25 years from the German general population. Other studies with samples from the United States also observed a positive relationship of psychological symptoms with telemedicine use during pandemic times [54,55]. Therefore, it may be the case that findings regarding higher health care use in individuals with mental illness [56-60] can be applied to the field of telemedicine and the pandemic context. These initial findings illustrate the future potential of telemedicine in the field of mental health for middle-aged and older patients, since those who experienced psychological symptoms appeared to preferentially opt for telemedicine services. Moreover, mental health problems, such as anxiety or depression, have been shown to be positively associated with fear of COVID-19 [61]. This fear could also favor increased telemedicine use due to concerns of being infected with SARS-CoV-2 during in-person health care visits—this association was also found in our sample.

Additionally, other COVID-19–related determinants that were included in our sample (ie, vaccine status, COVID-19 infection history in oneself or close others, and preventive medication), were not significantly associated with telemedicine use. This is in contrast with findings from German samples that looked at younger and adult individuals during the pandemic [23,32,33] and found significant associations of COVID-19–related factors with telemedicine use (ie, higher perceived severity of COVID-19 infection; having had COVID-19 infection; subjective COVID-19–related challenges; and COVID-19–related cognitive preoccupation, anxiety, and worries). However, when looking at a similar sample to our study, which consisted of middle-aged and older adults during the pandemic in Germany, Hajek and König [30] did not find significant associations of COVID-19–related factors with telemedicine service use. This could potentially mean that middle-aged and older individuals' decision to use telemedicine was less influenced by COVID-19–related factors than in the general adult or younger German population.

Strengths and Limitations

This study is one of only a few studies that explore determinants of use of remote medical consultations in German middle-aged and older adults. The nationally representative sample of the widely acknowledged SHARE panel study provides insight into the largest age group of the German population. The data were collected during the COVID-19 pandemic and therefore account for the unique circumstances that individuals were faced with during that time.

However, some limitations should be considered. Telemedicine service use was measured using only one item, which indicated experience with remote medical consultations over the phone, computer, or any other electronic means since the outbreak of the pandemic. Therefore, we did not differentiate between different patient groups, telemedicine modalities, or frequency of use. This should be explored further in future studies. Furthermore, the survey covered a limited selection of socioeconomic, health, and psychosocial aspects. Future studies should include more extensive instruments and variables to make more reliable and comprehensive conclusions. In addition, the majority of our sample did not use telemedicine and case numbers were small for some of the included determinants. This lack of statistical power might explain why some of the tested relationships did not reach statistical significance. Consequently, future studies with very large German samples are needed. Furthermore, this analysis was based on self-reported cross-sectional data, and it is therefore difficult to identify causal relationships. Finally, we only focused on the German context. Future research should also consider cross-cultural differences in use and determinants of telemedicine to better understand potential barriers and facilitators in different cultural contexts and improve worldwide implementations.

Conclusions

To achieve high rates of use and widespread acceptance of telemedicine, it is essential to understand determinants of telemedicine service use in middle-aged and older individuals. Our study findings stress the link between psychological symptoms and telemedicine use in Germany during the COVID-19 pandemic. Middle-aged and older adults seem to have used telemedicine services according to psychological needs and health limitations. One may conclude that, especially when they had psychological symptoms, middle-aged and older individuals accepted telemedicine as a service option. While socioeconomic and social factors were not associated with telemedicine service use, the associations of other health- and COVID-19-related determinants with use behavior remain unclear.

Future (longitudinal) studies are therefore required to confirm these initial findings and clarify whether they also apply to postpandemic circumstances, where widespread in-person visit availability returned. Some patients might have used telemedicine only because they had no other option. However, remote consultations might be especially suited for specific patient groups or forms of treatment and will remain part of postpandemic routine care. Furthermore, use of (remote) blended therapy might increase in the postpandemic context, as it combines the strengths of remote and in-person visits and can be adapted to individual patient preferences. Moreover, potential differences in determinants of telemedicine use between different service types (eg, asynchronous vs synchronous services) or patient groups (eg, mental health vs oncology patients) should be further investigated. Finally, it remains to be explored to what extent determinants of telemedicine use differ from determinants of general health care use, which could help to identify target groups and appropriate fields of application for future telemedicine services. This could be examined in the postpandemic context where both forms of services, in-person and telemedicine visits, are likely to be available to patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Results from logistic regression and Firth logistic regression for determinants of telemedicine service use during the COVID-19 pandemic.

[DOCX File, 38 KB - aging_v7i1e50938_app1.docx]

References

1. Sood S, Mbarika V, Jugoo S, et al. What is telemedicine? A collection of 104 peer-reviewed perspectives and theoretical underpinnings. Telemed J E Health 2007 Oct;13(5):573-590. [doi: 10.1089/tmj.2006.0073] [Medline: 17999619]
2. Telemedicine: opportunities and developments in member states: report on the second global survey on eHealth. World Health Organization. 2010. URL: https://iris.who.int/handle/10665/44497 [accessed 2024-04-02]
3. Kichloo A, Albosta M, Dettloff K, et al. Telemedicine, the current COVID-19 pandemic and the future: a narrative review and perspectives moving forward in the USA. Fam Med Community Health 2020 Aug;8(3):e000530. [doi: 10.1136/fmch-2020-000530] [Medline: 32816942]
4. Hjelm NM. Benefits and drawbacks of telemedicine. J Telemed Telecare 2005;11(2):60-70. [doi: 10.1258/1357633053499886] [Medline: 15829049]
5. Khemapech I, Sansrimahachai W, Toahchoodee M. Telemedicine - meaning, challenges and opportunities. Siriraj Med Bull 2019 May 1;71(3):246-252. [doi: 10.33192/Smj.2019.38]
6. Atmojo JT, Sudaryanto WT, Widiyanto A, et al. Cost effectiveness, and patients satisfaction: a systematic review. J Health Policy Manage 2020;5(2):103-107. [doi: 10.26911/thejhpm.2020.05.02.02]
7. Hailey D, Roine R, Ohinmaa A. Systematic review of evidence for the benefits of telemedicine. J Telemed Telecare 2002;8 Suppl 1:1-30. [doi: 10.1258/1357633021937604] [Medline: 12020415]
8. Goharinejad S, Hajesmaeel-Gohari S, Jannati N, Goharinejad S, Bahaadinbeigy K. Review of systematic reviews in the field of telemedicine. Med J Islam Repub Iran 2021;35:184. [doi: 10.47176/mjiri.35.184] [Medline: 36042824]
9. Eze ND, Mateus C, Cravo Oliveira Hashiguchi T. Telemedicine in the OECD: an umbrella review of clinical and cost-effectiveness, patient experience and implementation. PLoS One 2020;15(8):e0237585. [doi: 10.1371/journal.pone.0237585] [Medline: 32790752]
10. Nguyen M, Waller M, Pandya A, Portnoy J. A review of patient and provider satisfaction with telemedicine. Curr Allergy Asthma Rep 2020 Sep 22;20(11):72. [doi: 10.1007/s11882-020-00969-7] [Medline: 32959158]
11. Scott Kruse C, Karem P, Shifflett K, Vegi L, Ravi K, Brooks M. Evaluating barriers to adopting telemedicine worldwide: a systematic review. J Telemed Telecare 2018 Jan;24(1):4-12. [doi: 10.1177/1357633X16674087] [Medline: 29320966]
12. Dorsey ER, Topol EJ. State of telehealth. N Engl J Med 2016 Jul 14;375(2):154-161. [doi: 10.1056/NEJMra1601705] [Medline: 27410924]
13. Friedman AB, Gervasi S, Song H, et al. Telemedicine catches on: changes in the utilization of telemedicine services during the COVID-19 pandemic. Am J Manag Care 2022 Jan 1;28(1):e1-e6. [doi: 10.37765/ajmc.2022.88771] [Medline: 35049260]
14. Gebru AA, Birhanu T, Wendimu E, et al. Global burden of COVID-19: situational analyis and review. Hum Antibodies 2021;29(2):139-148. [doi: 10.3233/HAB-200420] [Medline: 32804122]
15. Wenger NS, Stanton AL, Baxter-King R, Sepucha K, Vavreck L, Naeim A. The impact of COVID-19 on routine medical care and cancer screening. J Gen Intern Med 2022 May;37(6):1450-1456. [doi: 10.1007/s11606-021-07254-x] [Medline: 35013931]
16. Heidemann C, Reitzle L, Schmidt C, Fuchs J, Prütz F, Scheidt-Nave C. Non-utilisation of health care services during the COVID-19 pandemic: results of the CoMoLo study. J Health Monit 2022 Mar;7(Suppl 1):2-17. [doi: 10.25646/9564] [Medline: 35356069]
17. Bollmann A, Hohenstein S, Pellissier V, et al. Utilization of in- and outpatient hospital care in Germany during the COVID-19 pandemic insights from the German-wide Helios hospital network. PLoS One 2021;16(3):e0249251. [doi: 10.1371/journal.pone.0249251] [Medline: 33765096]
18. Gesetz für eine bessere Versorgung durch Digitalisierung und Innovation (Digitale-Versorgung-Gesetz—DVG; Digital Healthcare act), BGBI I 2562. Bundesanzeiger Verlag. 2019. URL: http://www.bgbl.de/xaver/bgbl/start.xav?startbk=Bundesanzeiger_BGBl&jumpTo=bgbl119s2562.pdf [accessed 2024-04-23]
19. Gerke S, Stern AD, Minssen T. Germany’s Digital health reforms in the COVID-19 era: lessons and opportunities for other countries. NPJ Digit Med 2020 Jul;3:94. [doi: 10.1038/s41746-020-0306-7] [Medline: 32685700]
20. Omboni S, Padwal RS, Alessa T, et al. The worldwide impact of telemedicine during COVID-19: current evidence and recommendations for the future. Connect Health 2022 Jan 4;1:7-35. [doi: 10.20517/ch.2021.03] [Medline: 35233563]
21. Mangiapane S, Zhu L, Czihal T, von Stillfried D. Veränderung Der Vertragsärztlichen Leistungsinanspruchnahme Während Der COVID-Krise: Zentralinstitut für die kassenärztliche Versorgung in der Bundesrepublik Deutschland; 2021.

22. Reitzle L, Schmidt C, Färber F, et al. Perceived access to health care services and relevance of telemedicine during the COVID-19 pandemic in Germany. Int J Environ Res Public Health 2021 Jul 19;18(14):7661. [doi: 10.3390/ijerph18147661] [Medline: 34300110]
23. Hajek A, De Bock F, Merkel C, Kretzler B, König HH. Use of and satisfaction with telemedicine services during the pandemic: findings from the COVID-19 snapshot monitoring in Germany (COSMO). Healthcare (Basel) 2022 Jan 4;10(1):92. [doi: 10.3390/healthcare10010092] [Medline: 35052257]
24. Knörr V, Dini L, Gunkel S, et al. Use of telemedicine in the outpatient sector during the COVID-19 pandemic: a cross-sectional survey of German physicians. BMC Prim Care 2022 Apr 23;23(1):92. [doi: 10.1186/s12875-022-01699-7] [Medline: 35461212]
25. Dramburg S, Matricardi P, Casper I, Klimek L. Nutzung telemedizinischer anwendungen durch niedergelassene allergologen vor und während der SARS-Cov-2-pandemie: eine umfrage unter mitgliedern des ärzteverbandes deutscher allergologen (Aeda). Allergo J 2021;30(6):49-53. [doi: 10.1007/s15007-021-4866-x] [Medline: 34566269]
26. Cremers HP, Theunissen L, Hiddink J, et al. Successful implementation of eHealth interventions in healthcare: development of an eHealth implementation guideline. Health Serv Manage Res 2021 Nov;34(4):269-278. [doi: 10.1177/0951484821994421] [Medline: 33590794]
27. Meurk C, Leung J, Hall W, Head BW, Whiteford H. Establishing and governing e-mental health care in Australia: a systematic review of challenges and a call for policy-focussed research. J Med Internet Res 2016 Jan 13;18(1):e10. [doi: 10.2196/jmir.4827] [Medline: 26764181]
28. Or CKL, Karsh BT. A systematic review of patient acceptance of consumer health information technology. J Am Med Inform Assoc 2009;16(4):550-560. [doi: 10.1197/jamia.M2888] [Medline: 19390112]
29. Harju A, Neufeld J. Telehealth utilization during the COVID-19 pandemic: a preliminary selective review. Telemed Rep 2022;3(1):38-47. [doi: 10.1089/tmr.2021.0040] [Medline: 35720447]
30. Hajek A, König HH. Frequency and correlates of online consultations with doctors or therapists in middle-aged and older adults: nationally representative cross-sectional study. J Med Internet Res 2022 Apr 7;24(4):e29781. [doi: 10.2196/29781] [Medline: 35389360]
31. Uncovska M, Freitag B, Meister S, Fehring L. Patient acceptance of prescribed and fully reimbursed mHealth apps in Germany: an UTAUT2-based online survey study. J Med Syst 2023 Jan 27;47(1):14. [doi: 10.1007/s10916-023-01910-x] [Medline: 36705853]
32. Zöllner JP, Noda AH, McCoy J, et al. Use of health-related apps and telehealth in adults with epilepsy in Germany: a multicenter cohort study. Telemed J E Health 2023 Apr;29(4):540-550. [doi: 10.1089/tmj.2022.0238] [Medline: 35984859]
33. Rauschenberg C, Schick A, Goetzl C, et al. Social isolation, mental health, and use of digital interventions in youth during the COVID-19 pandemic: a nationally representative survey. Eur Psychiatry 2021 Mar 9;64(1):e20. [doi: 10.1192/j.eurpsy.2021.17] [Medline: 33686930]
34. Current population: population by age groups. Statistisches Bundesamt. 2022. URL: https://www.destatis.de/EN/Themes/Society-Environment/Population/Current-Population/Tables/lrbev01ga.html [accessed 2023-06-20]
35. Batsis JA, DiMilia PR, Seo LM, et al. Effectiveness of ambulatory telemedicine care in older adults: a systematic review. J Am Geriatr Soc 2019 Aug;67(8):1737-1749. [doi: 10.1111/jgs.15959] [Medline: 31066916]
36. Bujnowska-Fedak M, Grata-Borkowska U. Use of telemedicine-based care for the aging and elderly: promises and pitfalls. Smart Homecare Technol Telehealth 2015;3:91. [doi: 10.2147/SHTT.S59498]
37. van den Berg N, Schumann M, Kraft K, Hoffmann W. Telemedicine and telecare for older patients--a systematic review. Maturitas 2012 Oct;73(2):94-114. [doi: 10.1016/j.maturitas.2012.06.010] [Medline: 22809497]
38. Börsch-Supan A. SHARE Corona Survey 2. SHARE-ERIC. 2022. URL: https://doi.org/10.6103/SHARE.w9ca.800 [accessed 2024-04-02]
39. Börsch-Supan A, Brandt M, Hunkler C, et al. Data resource profile: the survey of health, ageing and retirement in Europe (SHARE). Int J Epidemiol 2013 Aug;42(4):992-1001. [doi: 10.1093/ije/dyt088] [Medline: 23778574]
40. Bergmann M, Kneip T, De Luca G, Scherpenzeel A. SHARE working paper series 81-2022: survey participation in the eighth wave of the survey of health, ageing and retirement in Europe (SHARE). MPGPuRe. 2022. URL: https://doi.org/10.17617/2.3390284 [accessed 2024-04-02]
41. Bergmann M, Kneip T, De Luca G, Scherpenzeel A. Survey participation in the Survey of Health, Ageing and Retirement in Europe (SHARE), wave 1-7. SHARE-ERIC. 2019. URL: https://share-eric.eu/fileadmin/user_upload/SHARE_Working_Paper/WP_Series_41_2019_Bergmann_et_al.pdf [accessed 2024-04-03]
42. Ndwabe H, Basu A, Mohammed J. Post pandemic analysis on comprehensive utilization of telehealth and telemedicine. Clinical eHealth 2024 Feb;7:5-14. [doi: 10.1016/j.ceh.2023.12.002]
43. The ongoing journey to commitment and transformation: digital health in the WHO European region, 2023. World Health Organization. URL: https://www.who.int/andorra/publications/m/item/digital-health-in-the-who-european-region-the-ongoing-journey-to-commitment-and-transformation [accessed 2024-04-03]
44. Firth D. Bias reduction of maximum likelihood estimates. Biometrika 1993;80(1):27-38. [doi: 10.1093/biomet/80.1.27]
45. Schafer JL. Multiple imputation: a primer. Stat Methods Med Res 1999 Mar;8(1):3-15. [doi: 10.1177/096228029900800102] [Medline: 10347857]

46. Dong Y, Peng CY. Principled missing data methods for researchers. Springerplus 2013 Dec;2(1):222. [doi: 10.1186/2193-1801-2-222] [Medline: 23853744]
47. Cantor JH, McBain RK, Pera MF, Bravata DM, Whaley CM. Who is (and is not) receiving telemedicine care during the COVID-19 pandemic. Am J Prev Med 2021 Sep;61(3):434-438. [doi: 10.1016/j.amepre.2021.01.030] [Medline: 33781622]
48. Rangachari P, Mushiana SS, Herbert K. A narrative review of factors historically influencing telehealth use across six medical specialties in the United States. Int J Environ Res Public Health 2021 May 8;18(9):4995. [doi: 10.3390/ijerph18094995] [Medline: 34066829]
49. Curtis ME, Clingan SE, Guo H, Zhu Y, Mooney LJ, Hser YI. Disparities in digital access among American rural and urban households and implications for telemedicine-based services. J Rural Health 2022 Jun;38(3):512-518. [doi: 10.1111/jrh.12614] [Medline: 34355427]
50. Ridic G, Gleason S, Ridic O. Comparisons of health care systems in the United States, Germany and Canada. Mater Sociomed 2012;24(2):112-120. [doi: 10.5455/msm.2012.24.112-120] [Medline: 23678317]
51. Gmunder KN, Ruiz JW, Franceschi D, Suarez MM. Demographics associated with US healthcare disparities are exacerbated by the telemedicine surge during the COVID-19 pandemic. J Telemed Telecare 2024 Jan;30(1):64-71. [doi: 10.1177/1357633X211025939] [Medline: 34160328]
52. Hsiao V, Chandereng T, Lankton RL, et al. Disparities in telemedicine access: a cross-sectional study of a newly established infrastructure during the COVID-19 pandemic. Appl Clin Inform 2021 May;12(3):445-458. [doi: 10.1055/s-0041-1730026] [Medline: 34107542]
53. Zhang D, Shi L, Han X, et al. Disparities in telehealth utilization during the COVID-19 pandemic: findings from a nationally representative survey in the United States. J Telemed Telecare 2024 Jan;30(1):90-97. [doi: 10.1177/1357633X211051677] [Medline: 34633882]
54. Choi NG, DiNitto DM, Marti CN, Choi BY. Telehealth use among older adults during COVID-19: associations with sociodemographic and health characteristics, technology device ownership, and technology learning. J Appl Gerontol 2022 Mar;41(3):600-609. [doi: 10.1177/07334648211047347] [Medline: 34608821]
55. Narcisse MR, Andersen JA, Felix HC, Hayes CJ, Eswaran H, McElfish PA. Factors associated with telehealth use among adults in the United States: findings from the 2020 National Health Interview Survey. J Telemed Telecare 2022 Jul 26:1357633X221113192. [doi: 10.1177/1357633X221113192] [Medline: 35892167]
56. Bock JO, Luppa M, Brettschneider C, et al. Impact of depression on health care utilization and costs among multimorbid patients--from the multicare cohort study. PLoS One 2014;9(3):e91973. [doi: 10.1371/journal.pone.0091973] [Medline: 24638040]
57. Horenstein A, Heimberg RG. Anxiety disorders and healthcare utilization: a systematic review. Clin Psychol Rev 2020 Nov;81:101894. [doi: 10.1016/j.cpr.2020.101894] [Medline: 32818687]
58. Koopmans GT, Donker MCH, Rutten FHH. Common mental disorders and use of general health services: a review of the literature on population-based studies. Acta Psychiatr Scand 2005 May;111(5):341-350. [doi: 10.1111/j.1600-0447.2005.00496.x] [Medline: 15819727]
59. Sirois FM, Owens J. A meta-analysis of loneliness and use of primary health care. Health Psychol Rev 2023 Jun;17(2):193-210. [doi: 10.1080/17437199.2021.1986417] [Medline: 34581240]
60. Buczak-Stec EW, Löbner M, Stein J, et al. Depressive symptoms and healthcare utilization in late life. Longitudinal evidence from the AgeMooDe study. Front Med (Lausanne) 2022;9:924309. [doi: 10.3389/fmed.2022.924309] [Medline: 35935803]
61. Şimşir Z, Koç H, Seki T, Griffiths MD. The relationship between fear of COVID-19 and mental health problems: a meta-analysis. Death Stud 2022;46(3):515-523. [doi: 10.1080/07481187.2021.1889097] [Medline: 33641626]

Abbreviations

OR: odds ratio
SHARE: Survey of Health, Ageing and Retirement in Europe
WHO: World Health Organization

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Original Paper

Barriers to and Facilitators of Older People’s Engagement With Web-Based Services: Qualitative Study of Adults Aged >75 Years

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Abstract

Background: The COVID-19 pandemic has accelerated the shift toward the digital provision of many public services, including health and social care, public administration, and financial and leisure services. COVID-19 services including test appointments, results, vaccination appointments and more were primarily delivered through digital channels to the public. Many social, cultural, and economic activities (appointments, ticket bookings, tax and utility payments, shopping, etc) have transitioned to web-based platforms. To use web-based public services, individuals must be digitally included. This is influenced by 3 main factors: access (whether individuals have access to the internet), ability (having the requisite skills and confidence to participate over the web), and affordability (ability to pay for infrastructure [equipment] and data packages). Many older adults, especially those aged >75 years, are still digitally excluded.

Objective: This study aims to explore the views of adults aged >75 years on accessing public services digitally.

Methods: We conducted semistructured qualitative interviews with a variety of adults aged ≥75 years residing in Greater Manchester, United Kingdom. We also interviewed community support workers. Thematic analysis was used to identify the key themes from the data.

Results: Overall, 24 older adults (mean age 81, SD 4.54 y; 14/24, 58% female; 23/24, 96% White British; and 18/24, 75% digitally engaged to some extent) and 2 support workers participated. A total of five themes were identified as key in understanding issues around motivation, engagement, and participation: (1) “initial motivation to participate digitally”—for example, maintaining social connections and gaining skills to be able to connect with family and friends; (2) “narrow use and restricted activity on the web”—undertaking limited tasks on the web and in a modified manner, for example, limited use of web-based public services and selected use of specific services, such as checking but never transferring funds during web-based banking; (3) “impact of digital participation on well-being”—choosing to go to the shops or general practitioner’s surgery to get out of the house and get some exercise; (4) “the last generation?”—respondents feeling that there were generational barriers to adapting to new technology and change; and (5) “making digital accessible”—understanding the support needed to keep those engaged on the web.

Conclusions: As we transition toward greater digitalization of public services, it is crucial to incorporate the perspectives of older people. Failing to do so risks excluding them from accessing services they greatly rely on and need.

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KEYWORDS

digital exclusion; digital inclusion; older people; technology; aged; web-based; internet

Introduction

Background

The shift toward digital technologies to provide access to essential and nonessential public services, such as health care, public administrative services, utilities, financial services, and leisure, has been accelerated by the COVID-19 pandemic [1-3]. In many countries, including the United Kingdom (the setting for the research reported in this paper), this shift has also been driven by national policy in attempts to maintain access to essential services during periods of social lockdown [4-6]. Many social, cultural, and economic activities, such as appointment or ticket booking, have transitioned to web-based platforms [7], whereas many COVID-19–related initiatives, such as booking and recording COVID-19 tests and vaccinations, were primarily offered through digital platforms to the public. In particular, during the COVID-19 lockdown periods, being on the web became critical for maintaining social ties and combating loneliness [8-10].

This may be convenient for many people, and there is evidence to show that digital inclusion, accelerated by the pandemic, has increased in recent years [11]. However, although in the United Kingdom, the "digital divide" (the gap between those who do and those who do not have access to new forms of information technology [12]) may have narrowed in recent years, the impact has not been felt equally and has widened for some groups [13,14]. The digital divide remains especially wide for older adults aged ≥75 years; this is further exacerbated by living alone, having a limiting long-term condition, and being financially susceptible [15,16]. An analysis of the English Longitudinal Study of Ageing data conducted early in the pandemic (June and July 2020) showed that 45% of adults aged 52 to 64 years and 41% of adults aged 65 to 74 years used the internet more since the COVID-19 outbreak, but only 24% of those aged >75 increased their use and 9% were using it less [17].

Digital exclusion, in its broadest definition [15], relates to three connected aspects: (1) access, that is, whether individuals have access to the internet at home or elsewhere; (2) ability, that is, having the skills and confidence to participate over the web; and (3) affordability, that is, the ability to pay for infrastructure (equipment) and adequate data packages [16]. In the United Kingdom, recent data from the national communications regulator (Ofcom) suggests that 6% of UK households do not have home internet access, but this figure rises to 26% of people aged ≥75 years [18]. It is also acknowledged that an additional 2 million households are experiencing financial difficulty, and this will likely increase given the cost-of-living crisis from 2021 to 2023 [19,20]. Digital exclusion is viewed as a "super" social determinant of health [21] as it impacts a variety of areas of life, including leading to poorer health outcomes [22,23] and challenges with employment, housing, education, and finance. It disproportionately affects many people, including people with low incomes, people living in social housing, people living with disabilities, people in rural areas, and people for whom English is not their first language, as well as other marginalized groups. Although all these factors are important indicators of who is likely to be digitally excluded, age remains the biggest indicator. According to data from the UK Office for National Statistics for 2020, a total of 99% of adults aged 16 to 44 years were recent internet users compared with only 54% of adults aged ≥75 years [24]. It is vital to understand the complexities of how digital exclusion exacerbates health and social inequalities so that adequate responsive action can be considered. For example, it is not simply the case that ensuring internet connectivity will mitigate digital exclusion. There is a need to understand structural challenges; financial barriers; digital literacy; and other aspects, such as the impacts of various health conditions and disabilities and concerns about privacy and data protection [25-28].

A recent scoping review explored the barriers to and facilitators of older people's digital engagement across the spectrum of nonuse through sustained use [29]. This review found that there are substantial overlaps between barriers and facilitators; for example, lack of knowledge of digital technologies is a barrier, prior knowledge is a facilitator, perceived lack of personal capability is a barrier, and a positive attitude toward oneself is a facilitator. The review also found a substantial gap regarding the determinants of technological nonuse. Although this review provides a thorough scope of the literature, it included studies involving participants with a mean age of ≥65 years and did not offer any further stratification by age. There is a need for a more nuanced focus on older groups of older people. Current insights into digital technology use often exclude a specific focus on people aged ≥75 years. The coverage of age groups in several major reports and surveys often stops at the age of 74 years or includes all people aged ≥65 years as 1 homogeneous age category [30].

Objectives

Given the increased risk of digital exclusion among older age groups and the fact that this may have been exacerbated by the COVID-19 pandemic, it is vital to gain a deeper understanding of the use, attitudes, and preferences of people aged ≥75 years.

In the United Kingdom, this gap has been recognized as a policy priority. In Greater Manchester, a city-region in North West England with a population of 2,867,800 in 2021, as many as 1.2 million residents are estimated to be limited digital users because of exclusion or personal preferences, with a substantial proportion of these being people in later life. To address this digital divide, the Greater Manchester Combined Authority (GMCA) established a Digital Inclusion Action Network and Taskforce in October 2020 [31], with the ambition to make Greater Manchester a 100% digitally enabled UK city-region. Older adults aged ≥75 years were included as a critical population group for targeted action related to digital inclusion. The aim of the paper is to report findings from a qualitative study exploring the views of adults aged ≥75 years on accessing web-based public services.

Methods

Study Design

The National Institute for Health and Care Research Applied Research Collaboration Greater Manchester was commissioned by the GMCA to gather insight into the barriers to and facilitators of older adults' (>75 y) digital participation within the region. To address this, we conducted semistructured qualitative interviews with adults aged ≥75 years residing in Greater Manchester.

Sampling, Recruitment, and Data Collection

Purposive and convenience sampling were used to identify and recruit participants. Adapting to web-based rather than face-to-face data collection during the COVID-19 pandemic lockdown meant that we had to use an approach that allowed us to use our existing networks and recruit via several third-party organizations affiliated with the GMCA Ageing Hub. We recruited a range of older adults; these included older adults who were fully engaged and participating in many web-based activities (often enrolled in a local support program), those who were just starting to receive support to get on the web, those who were previously engaged but were now lapsed users, and those who had no interest in getting on the web or using a computer or device at all. We also recruited community support workers to learn from the approaches they used to continue to engage with their communities, particularly during the COVID-19 pandemic period (from 2020 to 2022) [32].

Data were collected via semistructured interviews (conducted by AM) with a topic guide (Multimedia Appendix 1) developed from a rapid review of the literature [33] and from input from the project oversight team.

Data Analysis

Interviews were audio recorded, transcribed, and exported to NVivo Pro (version 12) software for data management [34]. Using a thematic analysis approach [35], initial themes were identified from the transcripts and indexed to develop the analytical categories. Via a process of constant comparison [36], these categories were reviewed and refined by 2 researchers (AM and DH), and any ambiguities in the coding framework were reconciled by a thorough discussion with the research team. All interviews were then fully coded using NVivo Pro for qualitative analysis (AM and DH).

Ethical Considerations

Ethics approval was granted by the University of Manchester Proportionate Research Ethics Committee (2021-12638-20811). All interviews were conducted virtually (by telephone or other remote means agreed upon with the participants) at a time convenient to the participants; the participants provided informed consent before data collection. The data were collected between October 2021 and February 2022. All data provided was anonymised by the research team with any personal identifying information removed. All participants received a £15 'Love2Shop' voucher as a thank you for their participation in the interview.

Results

Overview

The final sample comprised 26 interviews: 92% (24/26) with older adults aged >75 years and 8% (2/26) with community digital support officers. The older adult sample had a mean age of 81 (SD 4.54; range 75-91) years; 58% (14/24) of the participants were female, 96% (23/24) were White, and 4% (1/24) were of South Asian background. Participants were sampled from 4 (40%) of the 10 local authority areas in Greater Manchester, 75% (18/24) of the participants were users of the internet (to some degree), and interviews lasted on average 23 (SD 8.51; range 8-60) minutes.

A total of 5 themes were identified as being key in understanding the barriers to and facilitators of motivation, engagement, and participation in using web-based public services. The key themes and subthemes are presented in Textbox 1 and discussed in detail in the subsequent sections.

Textbox 1. Key themes and subthemes identified via thematic analysis.

- **Theme 1: initial motivation to participate digitally**
- **Theme 2: narrow use and restricted activity on the web**
    - Preference for choice of access
    - Narrow use driven by fear
    - Lack of interest in learning new digital skills and tasks
- **Theme 3: impact of digital participation on well-being**
- **Theme 4: the "last generation"?**
- **Theme 5: making digital accessible**
    - One-to-one support
    - Mitigating physical impairments

Theme 1: Initial Motivation to Participate Digitally

Among older adults who were using the internet, it was evident that their decision to do so was often driven by a particular, recent need that motivated them to go on the web. Unsurprisingly, given that COVID-19 pandemic lockdowns reduced face-to-face social contact [32], one of the major motivators related to maintaining social connections and gaining skills to be able to connect with family and friends in other parts of the world. A participant stated the following:

> *Well, I think that's vital really [being online]. It's kept me alive in that, you know, I feel as if I'm speaking to people. It's company there. I'm never isolated because I can always get in touch with somebody. So, to me, it has literally been a lifeline.* [Participant 19, female, aged 82 years]

There was also the need and convenience of being able to access certain services during the lockdown, in particular web-based ordering of prescriptions and shopping. A participant said the following:

> *That's the most brilliant thing I've ever used, Amazon. You don't even have to go outside the door.* [Participant 13, female, aged 75 years]

Theme 2: Narrow Use and Restricted Activity on the Web

Preference for Choice of Access

Although three-quarters (18/24, 75%) of the older adults interviewed were digitally engaged (to some extent), many of them were "narrow" users [11,15], in that they participated only in a handful of web-based activities or tasks. The participants reported very little interaction with web-based public administrative services (eg, local and national government services such as disabled parking applications, passport applications, driving licenses, and benefit applications). The participants were more positive about some aspects of web-based health services, particularly ordering prescriptions. When asked why they preferred to order prescriptions over the web, some commented that the system is "straightforward to use" and that they "find it very useful" to be able to order over the web, with some noting that if they did not do it over the web, it would involve them going to the surgery, "which is a bus ride away." However, when asked about the prospect of more public services moving to web-based access, most participants—both those who used the internet and those who did not—were in consensus that digital should not be the only option provided by organizations to access a service, for a variety of reasons. A participant stated the following:

> *The jabs that I had, it was telling me to go online, that's an example, and I phoned up my doctor's surgery and said, look, I can't go online, right, so they did the appointment for me. And also I had a bit of an argument with [large retail pharmacist named] and other stores like [pharmacy chain] because the flow thing, you know the flow thing, [Lateral Flow Test- rapid antigen test for COVID-19] you've got to go online although you didn't get any because they were sold out, they were out of them all the time...it's just ridiculous, nobody thinks about the older people.* [Participant 14, male, aged 83 years]

Another participant said the following:

> *Personally I don't think you can beat seeing the doctor face to face, they can pick up on your body language, colour of your skin. I think there's lots of things that you can pick up on face to face. So, I do think seeing the doctor face to face is essential for the majority, I really do. I think going online for some things is good, but I do think if you're not very sure about what you're doing, I think...I would imagine it could cause a lot of stress, if there's no alternative...* [Participant 24, female, aged 76 years]

Narrow Use Driven by Fear

Many participants adopted a granular approach to use, in which they had specific and limited web-based tasks they would undertake within particular domains of activity, such as banking or shopping. For example, many were happy to log on to banking apps or websites and view their balance—that is, to monitor their account—but stopped short of undertaking any transactions. Reasons for this limited use included a concern about having personal details "out there," pressing the wrong button and sending the money to the wrong place, and a fear of being scammed. A participant stated the following:

> *...No, I won't do finance at all, PayPal or anything, I really don't trust it because there are so many scams around, erm, I just think it's too easy, if you press the wrong button and its gone to Timbuktu, no I definitely won't have anything to do with online banking, and it's a shame because I know that I would shop online and it would save a trip to the Post Office or the bank or whatever, but I just wouldn't trust it...* [Participant 7, female, aged 79 years]

Another participant stated the following:

> *...I know I've got the banking online on the tablet if I want to use it for transactions, but I'm just quite happy seeing what I've got at the moment. I don't really feel confident enough to do transactions. I always worry, God if I do something wrong, I'm in trouble.* [Participant 24, female, aged 76 years]

In addition, another participant said the following:

> *I just feel as though I don't want to be divulging too much information about myself to the wide world, if you know what I mean.* [Participant 11, female, aged 87 years]

Community digital support officers highlighted fear and concerns around the safe sharing of personal information as a key barrier to engagement among older adults. In particular, media reports highlighting scams and frauds were deemed to exacerbate this barrier. The community officers were aware of the need to inform people of the potential risks, but "more positive campaigns about [the benefits of] using the internet [for older people] are needed" (digital support officer 2), as the negative stories reported on television were seen to deter older adults from benefiting from available web-based services. They reported that the word "scam" really "puts fear into older persons" and the media "cherry pick" the very worst scams to the point that people are convinced that these are happening on their very doorsteps:

> *...And this is no joke, I have had people say to me that they think there are people outside their house on a laptop in their car, you know they are parked on the*

> *street trying to use their Wi fi to scam them. That sort of thing.* [Digital support officer 1]

Lack of Interest in Learning New Digital Skills and Tasks

Where participants did use web-based services, once their initial needs had been met and they had gained the necessary skills to complete an activity, many lacked interest or were reluctant to undertake additional tasks or learn new activities. They were happy to maintain the skills and knowledge gained to undertake the tasks or activities that initially prompted them to get on the web. A participant stated the following:

> *I wouldn't use it for much really. I'm not ambitious about it. I have done what I wanted to do and anything else that I gained, it's a bonus.* [Participant 10, female, aged 91 years]

Another participant stated the following:

> *Are there any tasks that you haven't yet done online that you think you might want to try or you want to do in the future?* [Interviewer]
>
> *No, because I can use the computer and I can use the phone and the tablet for anything that I personally need to do.* [Participant 20, male, aged 76 years]

In addition, another participant said the following:

> *And are there things that you would want to do, that maybe you don't yet know how to do, or you'd need some support to be shown how to do it?* [Interviewer]
>
> *I don't think so. I think I do what I need to do...* [Participant 13, female, aged 75 years]

Theme 3: Impact of Digital Participation on Well-Being

For some participants, who were not digitally engaged and had no interest in getting on the web, social connections and social interaction were cited as a reason for not engaging. One participant stated the following:

> *No, I just think I've never been interested. I feel that if I did use something I'd be on my own doing it, and I don't like being on my own. Years ago I had one of these knitting machines and I had it for a while, and I hated it because it meant I was sat on my own knitting, and I don't want to do that. I like to go out and meet people while I can.* [Participant 3, female, aged 90 years]

Another participant stated the following:

> *This is the problem, lots of people don't talk anymore. They know...they don't know any other way of corresponding, getting in touch with people. I mean they go on the internet. They text, they don't talk...I mean you go out for a walk and you can more or less guarantee at least 50 per cent of people walk around with their phone.* [Participant 5, male, aged 83 years]

The participants also spoke about digital engagement in relation to aspects of physical and mental well-being. For example, for some, not using web-based services, such as to make a general practitioner (family physician in the United Kingdom) appointment, was seen as a positive because they had to get "out of the house" and, in doing so, had the benefit of getting "a little bit of exercise." For others, there was the acknowledgment of the advantages of being able to shop over the web during lockdowns, but now that restrictions had lifted, they had reverted to their preference to shop in person, which again was seen as an opportunity for exercise. Others talked about how it was sometimes "too easy" to depend on the internet to find out information that they could not immediately call to mind, and this was spoken about in terms of brain health and keeping the mind active. A participant stated the following:

> *So, in terms of doctors' appointments and things, you can still get to the surgery or you could ring. Is that something that you prefer to do?* [Interviewer]
>
> *Yes, I can ring on my landline and talk to a receptionist, or just toddle myself down to the surgery and go face to face with them, you know...Not that I would get an appointment any quicker with the doctor but, you know...And it gives me a little bit of exercise.* [Participant 18, female, aged 79 years]

Another participant stated:

> *I've gone back to going out because you get a little bit of exercise, you know. So yeah, I don't shop for groceries online anymore, no, I always go to the shop.* [Participant 20, male, aged 76 years]

Another participant stated the following:

> *...A couple of days ago, it sounds ridiculous this...I thought, what's the name of that pub at the top of Lancashire Road? I mean, what the hell I thought about that for, and I could not for the life of me, and I thought, no...remember it, because you do know it. And this morning, it's come to me, The Hinds Head it's called.* [Participant 13, female, aged 75 years]
>
> *Okay, so you resisted the urge to find out?* [Interviewer]
>
> *I did, yes, I did. I thought, no, that's too easy.* [Participant 13, female, aged 75 years]

Theme 4: The "Last Generation"?

Many participants, particularly those who were not on the web, spoke about barriers regarding generational issues and how they felt they might be the "last generation" to experience difficulty with digital participation:

> *But I do think that we're the last generation, almost the last generation that this will affect. Because from being babies now they have iPads now and what-have-you, don't they? It's just second nature to them. It puts you to shame when you watch them.* [Participant 12, female, aged 81 years]

This often went hand-in-hand with the perception that these difficulties were unique to their generation and that the younger generations experienced little difficulty in adapting to or embracing new technology. A participant stated the following:

> *Well, do you know what, to be honest with you, I could say I'm at the end of a generation. Because if you*

> *think of the youngsters today now and you think of...like my sons have no problem with this, that's another generation, and then the one below that is the youngsters, yeah, this will never happen again...it's unlucky, I'm at the end of a generation.* [Participant 14, male, aged 83 years]

Another participant stated the following:

> *The youngsters, from school onward, they know nothing but the internet. So everything is being geared toward them. And we older people, in my generation, have had to start learning various things which become harder and harder. It's second nature to younger people, to the 30s, 40s.* [Participant 5, male, aged 83 years]

Theme 5: Making Digital Accessible

For those older adults who were participating (to some extent) in web-based activities, it was important to discuss barriers and facilitators that might require consideration to keep older adults engaged and supported.

One-to-One Support

Participants emphasized the importance of having patient assistance while navigating tasks on the web. They also highlighted the value of receiving written instructions and having tasks demonstrated multiple times. The participants also valued the one-to-one support given to them but stressed that this needed to be ongoing support, noting that sometimes they would "get the hang of" one task (eg, shopping) only to find that the next time they logged on to the website, the landing page may have changed, which would "throw them off" and result in them feeling unsure whether they could continue in the manner they had been shown. A participant stated the following:

> *I'd love someone to sit and show me so I can write it down and if I get stuck I know how to do it myself.* [Participant 19, female, aged 82 years]

Other participants stated the following:

> *She writes things down for me, because I can't always remember what I've been told. If I've got it there in black and white then I can follow it. It does help.* [Participant 2, female, aged 76 years]
>
> *Yeah, sometimes it doesn't click immediately and you need them to go over it again. So you need somebody who's got a little bit of patience.* [Participant 21, male, aged 78 years]
>
> *...I could do this before and now I'm having too many problems. And it's the same with...so what it is, is what they call navigating the website becomes more difficult when they change the format, and that I find very, very annoying.* [Participant 8, male, aged 75 years]
>
> *You know, the system I have for my laptop, when they start changing things I get very annoyed and I think, oh, I've got to figure out how to get out of that or whatever it is, yes...I'm just getting really annoyed when I have to figure out how all of these things work again.* [Participant 1, female, aged 76 years]

Mitigating Physical Impairments

In addition, we asked respondents about physical impairments that might currently (or potentially in the future) make digital participation difficult. Arthritis, cataracts, Parkinson disease, diabetes, and tremors were all listed as having an effect on current internet use. Regarding future impact, although acknowledging uncertainty about how this could develop—"my eyes are not great. Yeah, I don't know how that's going to go." (participant 1, female, aged 76 y)—many of the respondents were quick to point out potential solutions to overcome these; for example, some had already been shown how to locate and use the microphone function in Google Assistant, how to use predictive text, and how to increase the font size of the text on the screen. Many respondents had already taken these issues into consideration when deciding on the type of device to use. A total of 61% (11/18) preferred to use tablets, and this was for several reasons, including their portability and ease of use. One participant stated the following:

> *I also like the fact that I can have it on my knee in the lounge or the chair that I'm in.* [Participant 19, female, aged 82 years]

Discussion

Principal Findings

The aim of this project was to explore the views of adults aged ≥75 years on accessing web-based public services in response to a policy initiative to further understand older people's digital behavior and engagement. The analysis of the semistructured interviews identified 5 themes that were key to understanding some of the barriers and facilitators experienced by the older adults participating in this project. The key facilitators included responses to meeting certain needs (particularly during national lockdowns) such as food shopping, ordering prescriptions, and staying connected with family and loved ones. The identified barriers included fear of scams and misuse of personal information, lack of ongoing support to maintain or learn new skills, preference for face-to-face interactions (especially for health appointments), and a wider generational belief (held by many) that difficulties getting on the web were "unique" to their generation and that older adults found it difficult to adapt or embrace new technology. Crucially, we also found that the potential unintended consequences of the benefits offered by digital technologies to access public services could be seen as a barrier to their use. In particular, this included their ease of access to information and their convenience, which were seen to reduce the need for people to engage cognitively elsewhere or to leave the house, thereby denying them exercise and social interaction opportunities.

Theoretically, there are several models that attempt to explain digital engagement and uptake. Two of the most well-known and widely used are the Technology Acceptance Model [37] and the Unified Theory of Acceptance and Use of Technology [38]. However, these models are primarily used to quantify the acceptance of technologies rather than to provide qualitative insights [29]. One straightforward categorization to facilitate an understanding of different "types" of older adults' digital behavior suggests they may fall into 1 of 4 groups—"engaged," "disheartened," "transitional," or "uninterested" [39]. "Engaged" refers to those older adults who believe they are capable of learning and perceive a value in using digital technology, that is, believe the internet is useful to them personally. "Disheartened" users also believe the internet to be useful and usually have more need for digital services but are worried about safety and associated risks and feel less confident in their ability and skills. "Transitional" older adults often have the highest need for use of digital services, but they are frequently lapsed users with narrow, if any, experience of digital engagement other than for social media purposes. "Uninterested" older adults do not perceive value in web-based activity and often have others access websites on their behalf. They usually have strong social connections and can be resistant to using the web. Although these categories are helpful in starting to think about digital behavior and potentially offer insights into how to support different "types" of older adults, the interviews presented here show that older adults' digital behavior may not always be neatly classified into 1 type of user versus another. A large proportion of the respondents could be classified as digitally "engaged" in the sense that they were keen to go on the web, felt capable of learning, and had many of the skills deemed "essential" [40] for digital participation.

However, it was not possible to map these older adults to 1 "type" as there was often an overlapping of categories (particularly "engaged" and "disheartened"), which required a more nuanced understanding of what digital participation means for older adults. During discussions around the motivations behind getting on the web for our older adults (particularly during the pandemic), the initial "engagement" was evident; however, this engagement for many appeared to ebb away, and subsequently, many of them fitted the descriptions for other categories, for example, "disheartened" users. Although many of our older adults admitted a perceived value in accessing the internet and participating digitally (ie, "engaged"), a lack of confidence, lack of support, or fear of sharing information would often result in them becoming "disheartened," disengaging from aspects of internet use, and not taking full advantage of the services available to them (eg, restricted use of web-based banking). Understanding that many older adults will not "fit" into 1 category highlights the need for a more individualized and nuanced approach to tailoring digital support services [41].

When considering the wider impacts of digital technology transformation, older adults' limited use of web-based activities such as banking and concerns over data protection were also amplified by a lack of confidence and skills. Added to this were the needs of older people to get out and to socialize, with health-related appointments, shopping, and banking forming part of how participants stayed active and well in their communities. Work undertaken with a range of individuals, including older adults, during the pandemic found that a move to internet-based general practitioner and health appointments was sometimes problematic for this group for a variety of reasons, including a lack of skills and confidence, no interest in engaging on the web, and a lack of trust [42-44]. In addition, web-based platforms provide a very limited 2D view of a person and their circumstances [45,46]. As such, it is critical that people are encouraged to leave their homes and are able to access and attend face-to-face appointments. We already know that far too many older people are sedentary and do not achieve the recommended levels of physical activity [47,48]. This worsened during the COVID-19 pandemic, negatively impacting health [49]. Therefore, adding to this burden by substituting physical activity with digital engagement should be avoided.

The pandemic and its successive lockdowns have moved much public and social activity to web-based platforms. Digital exclusion is often discussed in terms of "hard" (eg, never having used the internet or having no internet access) or "soft" (eg, improving digital engagement, skill level, or confidence) [7]. These changes driven by the pandemic are said to have improved "hard" exclusion for the general population. However, in terms of improving the "softer" areas of exclusion, the pandemic has done little to close the digital divide, particularly for older adults [50]. There is evidence to show rates of internet use increasing faster among younger cohorts and declining among older cohorts, demonstrating the digital divide naturally closing in time as generations who experience high levels of digital exclusion are replaced by younger generations who embrace and adapt to technological change [51,52]. This idea came through strongly in the interviews conducted, with many older adults expressing this view. However, it was not clear whether they attributed this to the impact of the rapid digitalization brought about by the pandemic or to the impact of a more general move toward digitalization over a longer period. However, the rapid development of technology combined with an individual's changes in physical health has been shown to worsen feelings of being unable to keep up or feeling too old to embrace new technology among older adults [53]. There is also the view that older adults can often internalize agism [54] and accede to the stereotype that they are not able to master technology and so do not attempt it. It seems plausible that the rapid increase in digitalization during the pandemic may have exacerbated these feelings of being left behind, but it is also important to note that inaccurate perceptions of young people as fluent technology users may be driven by a broad range of factors, including media representation, agism, and other social constructs related to digital inclusion and exclusion. Although the impact of the 2020 to 2023 COVID-19 pandemic brought many of these issues to the forefront in discussions around digital participation and the impact of the divide for older adults, these are not new issues related only to older adults' experiences during the pandemic [50].

This study highlights several digital technology features that have delivered positive outcomes for people aged ≥75 years. Among those we interviewed, there was a preference toward using tablets [55] as well as a willingness to order prescriptions and engage in web-based shopping. Shared learning across public institutions on aspects of digital technology transformation that have been delivered successfully for adults aged >75 years would be beneficial. For example, what can we learn from the experience of web-based ordering of prescriptions that could inform other public service digitalization infrastructure and processes? There is also the importance of ensuring digitalized services are fully accessible to all, including those living with long-term health conditions that may impact their ability to use digital devices (eg, arthritis) or access content easily (websites, text, etc). For older adults who wish to participate on the web, building confidence in undertaking tasks, such as banking, via support that is task focused and repeated is crucial [56,57].

Strengths and Weaknesses

Current data and insight into digital technology use may exclude people aged ≥75 years or may lack a specific focus on this age group. Often, available data on older adults' use stops around the age of 74 years or it provides information on all individuals aged ≥65 years. Given the increased risk of digital exclusion among older age groups and the fact that this may have been exacerbated by the COVID-19 pandemic, it is vital to gain a deeper understanding of the use, attitudes, and preferences of people aged >75 years. Although this research was relatively small in number, its strength is that it focuses on those aged >75 years (average respondent aged 81 years). A key message to take away from the work is one of choice: that those aged ≥75 are not digitally homogenous but rather require a range of options, both digital and nondigital, that will enable them to engage in ways that work best for them and do not further exacerbate digital inequalities [23,58-60]. A key finding adding to the literature [29] is that the benefits of technologies, such as ease of access to information and convenience, may actually have unintended consequences that put older adults off using them. This includes a desire among some participants to continue to access some public services in person for the indirect benefit of physical activity while doing so. This finding is particularly important in light of other healthy aging policies that promote physical activity to improve disability-free life expectancy [61].

Future research should investigate the experiences of older adults from ethnic minority groups. Although this study aimed to be as inclusive as possible, the recruitment of older adults from diverse ethnic minority groups proved challenging. It would also be beneficial to examine the influence of age-related sensory changes on digital inclusion. Investigating the preferences and experiences of older adults with hearing or visual impairments would provide valuable insights. Physical distancing and stay-at-home restrictions during pandemic lockdowns meant that our recruitment strategy had to be adapted to make use of our existing networks and ties with third-party organizations to be able to recruit older adults for the study. A reliance on web-based means of recruitment resulted in a more digitally engaged sample of older adults being recruited than originally intended, although the levels of engagement varied among the older adults. In an ideal setting, a study of this nature would have been conducted with older adults in a face-to-face setting rather than via telephone or video interviews [62-64]. However, data collection during the COVID-19 pandemic meant this approach was not possible, and this will have had an impact on the final sample of older adults, with a larger proportion of adults who were digitally engaged taking part.

Conclusions

The shift to digital delivery of public services, both throughout the pandemic and more generally as a driving force for future service provision, requires a focus on the needs and preferences of older people so that they are not excluded from service access. Mitigation against digital exclusion is a core component of 1 of the strategic priorities to reduce health inequalities across England [52]. It is vital that the needs and preferences of people of all ages are considered, particularly those aged >75 years, who are often underrepresented in research. Attempts to classify "types" of digital users may be a useful heuristic for thinking about digital engagement, but the boundaries between categories are permeable and complex. Those aged ≥75 years are not a digitally homogenous group but rather require a range of options, both digital and nondigital, that will enable them to access services without further exacerbating digital inequalities.

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Authors' Contributions

The conceptualization and design of the study was undertaken by AM, JM, and AH. Data collection was undertaken by AM. AM and DH coded and analyzed the data. AM drafted the original paper as first author and DH, JM, AH, CET, and CT worked on reviewing and editing subsequent drafts. All the authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview topic guides.
[PDF File (Adobe PDF File), 584 KB - aging_v7i1e46522_app1.pdf]

References

1. Global strategy on digital health 2020-2025. World Health Organization. 2021. URL: https://www.who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf [accessed 2024-02-09]
2. Contreras RR. Covid-19 and digitalisation. Eurofound. URL: https://www.eurofound.europa.eu/en/covid-19-and-digitalisation [accessed 2024-02-16]
3. OECD Digital Economy Outlook 2020. Organisation for Economic Cooperation and Development. 2020 Nov 27. URL: https://www.oecd-ilibrary.org/science-and-technology/oecd-digital-economy-outlook-2020_bb167041-en [accessed 2023-02-01]
4. NHS long term plan. National Health Service. 2019. URL: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/ [accessed 2024-02-16]
5. Build Back Better: our plan for growth (HTML). United Kingdom Government. 2021 Mar 3. URL: https://www.gov.uk/government/publications/build-back-better-our-plan-for-growth/build-back-better-our-plan-for-growth-html [accessed 2024-02-16]
6. Transforming public services, using technology and digital tools and approaches. Local Government Association. 2014 Jun 30. URL: https://www.local.gov.uk/publications/transforming-public-services-using-technology-and-digital-tools-and-approaches [accessed 2024-02-16]
7. Abey J. Bridging the divide: tackling digital inequality in a post-pandemic world. The Fabian Society. 2022 Mar. URL: https://fabians.org.uk/wp-content/uploads/2022/04/Bridging-the-Divide-web-file-Fabian-Society.pdf [accessed 2024-02-16]
8. Boulton E, Kneale D, Stansfield C, Heron P, Sutcliffe K, Hayanga B, et al. Rapid systematic review of systematic reviews: what befriending, social support and low intensity psychosocial interventions, delivered remotely, may reduce social isolation and loneliness among older adults and how? F1000Res 2021 Apr 28;9:1368. [doi: 10.12688/f1000research.27076.2]
9. COVID-19 and the digital divide. Centre for Ageing Better. 2021 Jul. URL: https://ageing-better.org.uk/sites/default/files/2021-07/COVID-19-and-the-digital-divide.pdf [accessed 2024-02-16]
10. Savage RD, Di Nicolo S, Wu W, Li J, Lawson A, Grieve J, et al. The factors associated with nonuse of social media or video communications to connect with friends and family during the COVID-19 pandemic in older adults: web-based survey study. JMIR Aging 2022 Jun 06;5(2):e34793 [FREE Full text] [doi: 10.2196/34793] [Medline: 35344502]
11. Lythreatis S, Singh SK, El-Kassar AN. The digital divide: a review and future research agenda. Technol Forecast Soc Change 2022 Feb;175:121359. [doi: 10.1016/j.techfore.2021.121359]
12. van Dijk JA. Digital divide research, achievements and shortcomings. Poetics 2006 Aug;34(4-5):221-235 [FREE Full text] [doi: 10.1016/j.poetic.2006.05.004]
13. Digital inclusion and older people – how have things changed in a Covid-19 world? Age UK. 2021 Mar. URL: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/digital-inclusion-in-the-pandemic-final-march-2021.pdf [accessed 2024-02-16]
14. Building a digital nation. Good Things Foundation. URL: https://www.goodthingsfoundation.org/insights/building-a-digital-nation/ [accessed 2024-02-16]
15. Carney F, Kandt J. Health, out-of-home activities and digital inclusion in later life: implications for emerging mobility services. J Transport Health 2022 Mar;24:101311. [doi: 10.1016/j.jth.2021.101311]
16. Gallistl V, Rohner R, Hengl L, Kolland F. Doing digital exclusion - technology practices of older internet non-users. J Aging Stud 2021 Dec;59:100973 [FREE Full text] [doi: 10.1016/j.jaging.2021.100973] [Medline: 34794717]
17. Kung CS, Steptoe A. Changes in internet use patterns among older adults in England from before to after the outbreak of the COVID-19 pandemic. Sci Rep 2023 Mar 09;13(1):3932 [FREE Full text] [doi: 10.1038/s41598-023-30882-8] [Medline: 36894600]
18. Digital exclusion: a review of Ofcom's research on digital exclusion among adults in the UK. Ofcom. 2022 Mar 30. URL: https://www.ofcom.org.uk/__data/assets/pdf_file/0022/234364/digital-exclusion-review-2022.pdf [accessed 2024-02-16]
19. UK digital poverty evidence review 2022. Digital Poverty Alliance. URL: https://digitalpovertyalliance.org/uk-digital-poverty-evidence-review-2022/introduction-myths-and-shifts/ [accessed 2024-02-16]
20. Hourston P. Cost of living crisis. Institute for Government. 2022 Feb 7. URL: https://www.instituteforgovernment.org.uk/explainer/cost-living-crisis [accessed 2024-02-16]
21. Sieck CJ, Sheon A, Ancker JS, Castek J, Callahan B, Siefer A. Digital inclusion as a social determinant of health. NPJ Digit Med 2021 Mar 17;4(1):52 [FREE Full text] [doi: 10.1038/s41746-021-00413-8] [Medline: 33731887]
22. Lu X, Yao Y, Jin Y. Digital exclusion and functional dependence in older people: findings from five longitudinal cohort studies. EClinicalMedicine 2022 Dec;54:101708 [FREE Full text] [doi: 10.1016/j.eclinm.2022.101708] [Medline: 36353265]
23. Seifert A, Cotten SR, Xie B. A double burden of exclusion? digital and social exclusion of older adults in times of COVID-19. J Gerontol B Psychol Sci Soc Sci 2021 Feb 17;76(3):e99-103 [FREE Full text] [doi: 10.1093/geronb/gbaa098] [Medline: 32672332]

24. Internet users, UK: 2020. Office for National Statistics. 2021 Apr 6. URL: https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2020 [accessed 2024-02-16]
25. Davies AR, Honeyman M, Gann B. Addressing the digital inverse care law in the time of COVID-19: potential for digital technology to exacerbate or mitigate health inequalities. J Med Internet Res 2021 Apr 07;23(4):e21726 [FREE Full text] [doi: 10.2196/21726] [Medline: 33735096]
26. Yang E, Lee KH. The moderating effects of disability on mobile internet use among older adults: population-based cross-sectional study. J Med Internet Res 2022 Apr 04;24(4):e37127 [FREE Full text] [doi: 10.2196/37127] [Medline: 35377329]
27. Poulsen A, Song YJ, Fosch-Villaronga E, LaMonica HM, Iannelli O, Alam M, et al. Digital rights and mobile health in low- and middle-income countries: protocol for a scoping review. JMIR Res Protoc 2023 Oct 03;12:e49150 [FREE Full text] [doi: 10.2196/49150] [Medline: 37788054]
28. Heponiemi T, Jormanainen V, Leemann L, Manderbacka K, Aalto AM, Hyppönen H. Digital divide in perceived benefits of online health care and social welfare services: national cross-sectional survey study. J Med Internet Res 2020 Jul 07;22(7):e17616 [FREE Full text] [doi: 10.2196/17616] [Medline: 32673218]
29. Kebede AS, Ozolins LL, Holst H, Galvin K. Digital engagement of older adults: scoping review. J Med Internet Res 2022 Dec 07;24(12):e40192 [FREE Full text] [doi: 10.2196/40192] [Medline: 36477006]
30. ICT usage in households and by individuals (isoc_i). Eurostat. URL: https://ec.europa.eu/eurostat/cache/metadata/en/isoc_i_esms.htm [accessed 2024-02-16]
31. New Digital Inclusion Taskforce launched to tackle digital divide across Greater Manchester. Greater Manchester Combined Authority. URL: https://www.greatermanchester-ca.gov.uk/news/new-digital-inclusion-taskforce-launched-to-tackle-digital-divide-across-greater-manchester/ [accessed 2024-02-16]
32. Sherrington A. 2 years of COVID-19 on GOV.UK. United Kingdom Government. 2022 Jul 25. URL: https://gds.blog.gov.uk/2022/07/25/2-years-of-covid-19-on-gov-uk/ [accessed 2024-02-16]
33. Hall A, Money A, Eost-Telling C, McDermott J. Older people's access to digitalised services - a rapid literature review. National Institute for Health and Care Research. 2022. URL: https://arc-gm.nihr.ac.uk/media/Resources/ARC/Healthy%20Ageing/Digital%20Inclusion/phase%201%20DI%20Briefing%20Note%2006%20Jan%202022.pdf [accessed 2024-02-09]
34. NVivo. Lumivero. URL: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home?_ga=2.184390499.41523644.1673345793-257720117.1673345793 [accessed 2024-02-16]
35. Boyatzis RE. Transforming Qualitative Information: Thematic Analysis and Code Development. Thousand Oaks, CA: Sage Publications; Apr 16, 1998.
36. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000 Jan 08;320(7227):114-116 [FREE Full text] [doi: 10.1136/bmj.320.7227.114] [Medline: 10625273]
37. Davis FD, Davis F. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Q 1989 Sep;13(3):319. [doi: 10.2307/249008]
38. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Q 2003 Sep;27(3):425-478. [doi: 10.2307/30036540]
39. I am connected: new approaches to supporting people in later life online. Good Things Foundation. URL: https://www.goodthingsfoundation.org/insights/i-am-connected/ [accessed 2024-02-16]
40. Essential digital skills UK 2021. Ipsos. 2021 Oct 8. URL: https://www.ipsos.com/en-uk/essential-digital-skills-uk-2021 [accessed 2024-02-16]
41. Schroeder T, Dodds L, Georgiou A, Gewald H, Siette J. Older adults and new technology: mapping review of the factors associated with older adults' intention to adopt digital technologies. JMIR Aging 2023 May 16;6:e44564 [FREE Full text] [doi: 10.2196/44564] [Medline: 37191976]
42. Tewary S, Cook N, Dezine M, Shnayder O, Pandya N. Supporting vulnerable older adults with telehealth through wellness calls and tablet distribution during COVID-19: quality improvement project. JMIR Form Res 2023 Sep 11;7:e46002 [FREE Full text] [doi: 10.2196/46002] [Medline: 37695647]
43. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021 Aug 17;21(1):1556 [FREE Full text] [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]
44. Frishammar J, Essén A, Bergström F, Ekman T. Digital health platforms for the elderly? key adoption and usage barriers and ways to address them. Technol Forecast Soc Change 2023 Apr;189:122319 [FREE Full text] [doi: 10.1016/j.techfore.2023.122319]
45. Parsons L. Study reveals lack of diagnostic accuracy in online consultations. PharmaTimes. 2021 Nov 2. URL: https://www.pharmatimes.com/news/study_reveals_lack_of_diagnostic_accuracy_in_online_consultations_1382885 [accessed 2024-02-16]
46. Kendrick K. As telemedicine replaces the physical exam, what are doctors missing? National Public Radio. 2020 Aug 31. URL: https://www.npr.org/sections/health-shots/2020/08/31/907187908/as-telemedicine-replaces-the-physical-exam-what-are-doctors-missing [accessed 2024-02-16]

47. Physical activity guidelines: UK Chief Medical Officers' report. Department of Health and Social Care United Kingdom Government. 2019 Sep 7. URL: https://www.gov.uk/government/publications/physical-activity-guidelines-uk-chief-medical-officers-report [accessed 2024-02-16]
48. Skelton DA, Mavroeidi A. How do muscle and bone strengthening and balance activities (MBSBA) vary across the life course, and are there particular ages where MBSBA are most important? JFSF 2018 Jun;03(02):74-84. [doi: 10.22540/jfsf-03-074]
49. Elliott J, Munford L, Ahmed S, Littlewood A, Todd C. The impact of COVID-19 lockdowns on physical activity amongst older adults: evidence from longitudinal data in the UK. BMC Public Health 2022 Sep 22;22(1):1802 [FREE Full text] [doi: 10.1186/s12889-022-14156-y] [Medline: 36138374]
50. Zapletal A, Wells T, Russell E, Skinner MW. On the triple exclusion of older adults during COVID-19: technology, digital literacy and social isolation. Soc Sci Humanit Open 2023;8(1):100511 [FREE Full text] [doi: 10.1016/j.ssaho.2023.100511] [Medline: 37021073]
51. Matthews K, Nazroo J, Marshall A. Digital inclusion in later life: cohort changes in internet use over a ten-year period in England. Ageing Soc 2018 Aug 02;39(9):1914-1932. [doi: 10.1017/s0144686x18000326]
52. Global report on ageism. World Health Organization. 2021 Mar 18. URL: https://www.who.int/publications/i/item/9789240016866 [accessed 2024-02-16]
53. Pirhonen J, Lolich L, Tuominen K, Jolanki O, Timonen V. “These devices have not been made for older people's needs” – older adults' perceptions of digital technologies in Finland and Ireland. Technol Soc 2020 Aug;62:101287. [doi: 10.1016/j.techsoc.2020.101287]
54. Ageism in artificial intelligence for health. World Health Organisation. 2022 Feb 9. URL: https://www.who.int/publications/i/item/9789240040793 [accessed 2024-02-16]
55. Kim S, Yao W, Du X. Exploring older adults' adoption and use of a tablet computer during COVID-19: longitudinal qualitative study. JMIR Aging 2022 Mar 08;5(1):e32957 [FREE Full text] [doi: 10.2196/32957] [Medline: 35134747]
56. Doing digital in later life: a practical guide. Good Things Foundation. URL: https://www.goodthingsfoundation.org/insights/doing-digital-in-later-life-a-practical-guide/ [accessed 2024-02-16]
57. Hunsaker A, Nguyen MH, Fuchs J, Djukaric T, Hugentobler L, Hargittai E. “He explained it to me and I also did it myself”: how older adults get support with their technology uses. Socius 2019 Dec 04;5. [doi: 10.1177/2378023119887866]
58. Mubarak F, Suomi R. Elderly forgotten? digital exclusion in the information age and the rising grey digital divide. Inquiry 2022;59:469580221096272 [FREE Full text] [doi: 10.1177/00469580221096272] [Medline: 35471138]
59. Kunonga TP, Spiers GF, Beyer FR, Hanratty B, Boulton E, Hall A, et al. Effects of digital technologies on older people's access to health and social care: umbrella review. J Med Internet Res 2021 Nov 24;23(11):e25887 [FREE Full text] [doi: 10.2196/25887] [Medline: 34821564]
60. Quan-Haase A, Williams C, Kicevski M, Elueze I, Wellman B. Dividing the grey divide: deconstructing myths about older adults' online activities, skills, and attitudes. Am Behav Sci 2018 May 29;62(9):1207-1228. [doi: 10.1177/0002764218777572]
61. Bull FC, Al-Ansari SS, Biddle S, Borodulin K, Buman MP, Cardon G, et al. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. Br J Sports Med 2020 Dec;54(24):1451-1462 [FREE Full text] [doi: 10.1136/bjsports-2020-102955] [Medline: 33239350]
62. Saarijärvi M, Bratt EL. When face-to-face interviews are not possible: tips and tricks for video, telephone, online chat, and email interviews in qualitative research. Eur J Cardiovasc Nurs 2021 May 22;20(4):392-396 [FREE Full text] [doi: 10.1093/eurjcn/zvab038] [Medline: 33893797]
63. Keen S, Lomeli-Rodriguez M, Joffe H. From challenge to opportunity: virtual qualitative research during COVID-19 and beyond. Int J Qual Methods 2022;21:16094069221105075 [FREE Full text] [doi: 10.1177/16094069221105075] [Medline: 35692956]
64. Davies L, LeClair KL, Bagley P, Blunt H, Hinton L, Ryan S, et al. Face-to-face compared with online collected accounts of health and illness experiences: a scoping review. Qual Health Res 2020 Nov;30(13):2092-2102. [doi: 10.1177/1049732320935835] [Medline: 32667257]

Abbreviations

GMCA: Greater Manchester Combined Authority

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Original Paper

Online Cognitive Stimulation Therapy for Dementia in Brazil and India: Acceptability, Feasibility, and Lessons for Implementation

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Abstract

Background: Cognitive stimulation therapy (CST) is an evidence-based, group psychosocial intervention for people with dementia, and it has a positive impact on cognition and quality of life. CST has been culturally adapted for use globally. It was developed as a face-to-face intervention but has recently been adapted for online delivery.

Objective: In this study, we aimed to explore the feasibility and acceptability of online or virtual CST (vCST) delivery in India and Brazil, emphasizing barriers and facilitators to implementation.

Methods: A single-group, multisite, mixed methods, feasibility study was conducted, with nested qualitative interviews. Primary feasibility outcomes were recruitment rate, attendance, attrition, acceptability, and outcome measure completion. Exploratory pre- and postintervention measures, including cognition and quality of life, were assessed. Qualitative interviews were conducted with people with dementia, family caregivers, and group and organizational leaders following intervention delivery, and the data were analyzed using the Consolidated Framework for Implementation Research.

Results: A total of 17 vCST group sessions with 59 participants were conducted for 7 weeks, with 53% (31/59) of participants attending all 14 sessions. Attrition rate was 7% (4/59), and outcome measure completion rate at follow-up was 68% (40/59). Interviews took place with 36 stakeholders. vCST was acceptable to participants and group leaders and enabled vital access to services during pandemic restrictions. While online services broadened geographic access, challenges emerged concerning inadequate computer literacy, poor technology access, and establishing interpersonal connections online. Exploratory, uncontrolled analyses indicated positive trends in quality of life but negative trends in cognition and activities of daily living, but these results were not statistically significant.

Conclusions: vCST demonstrated feasibility and acceptability, serving as a crucial resource during the pandemic but raised challenges related to technology access, computer literacy, and long-term implementation. The study highlights the potential of vCST while emphasizing ongoing development and solutions to address implementation challenges.

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KEYWORDS

psychosocial; intervention; technology; COVID-19; LMIC; low and middle income countries

Introduction

Background

Dementia affects more than 57.4 million people worldwide [1]. People with dementia in low- and middle-income countries (LMICs) make up 60% of all global cases [2]; however, high-income countries account for around 74% of global expenditure on dementia [3]. There are an estimated 1.8 million people >60 years of age with dementia in Brazil [4] and 8.8 million in India, representing 5.8% and 7.4% of people >60 years of age, respectively [4-6]. While demographic and socioeconomic factors differ between Brazil and India, both countries experience low diagnosis rates, limited access to specialist treatment and care, high levels of stigma, and a lack of dementia awareness [7-9].

Worldwide, pharmacological treatments for dementia remain limited, so nonpharmacological interventions are needed to address cognitive and behavioral symptoms of dementia and improve quality of life for people with dementia and their families [10]. Many interventions are developed, but only a few are delivered at large scale and have been adopted in routine practice [11].

Cognitive stimulation therapy (CST) is a brief, manualized group program which has been found to improve cognition and quality of life in people with mild to moderate dementia [12]. It comprises themed activities that stimulate and engage participants in a social group environment led by a trained facilitator through tasks such as physical activity, word association, and discussion of current affairs [13]. Despite evidence for its effectiveness [12], cost-effectiveness [14], and its successful cultural adaptation internationally in more than 35 countries [15], CST is yet to be implemented in routine practice outside of the United Kingdom [16,17]. The 2022 World Alzheimer's Report recommended further research and implementation of CST globally [18].

This study was conducted as part of the CST-International research program, which explored the implementation of CST in 3 LMICs [19]: Brazil, an upper middle-income country; (2) India, a lower middle-income country; and (3) Tanzania, a low-income country [20]. In each country, research teams had previously translated and culturally adapted CST and carried out feasibility studies of face-to-face CST [16,17].

CST was developed as a face-to-face intervention. However, during the CST-International study, access to face-to-face health care services was rapidly restricted due to the COVID-19 pandemic [21]. CST started to be delivered virtually in international settings including the United Kingdom and New Zealand [22,23], but a standardized protocol was not available. An international collaboration resulted in a framework for global delivery, which was field-tested in Brazil and India, alongside the United Kingdom, Hong Kong, and Ireland [24].

Objectives

This study aimed to build upon the initial development and field-testing of the online or virtual CST (vCST) protocol in Brazil and India, with a focus on feasibility, acceptability, and implementation. Therefore, the aims of this study were to (1) explore the acceptability of vCST to people with dementia, family caregivers, CST facilitators, and service managers in Brazil and India; (2) test the feasibility of online recruitment, delivery, and assessment for CST in Brazil and India; and (3) explore factors affecting the implementation of vCST.

Methods

Design

This study was a single-group, multisite, mixed methods, feasibility study, with pre- and postintervention outcome measures followed by semistructured interviews with people with dementia, caregivers, and intervention group leaders.

Methodological Framework

This study is guided by the Consolidated Framework for Implementation Research (CFIR) [25]. The CFIR is a determinant framework, which incorporates domains that are hypothesized or found to influence implementation outcomes and has been applied in LMIC settings [26]. The five domains relate to (1) intervention characteristics (eg, evidence strength and quality as viewed by stakeholders and its core and adaptable components); (2) outer setting (eg, local attitudes to the condition of interest as well as external partnerships and financing); (3) inner setting (eg, available organizational resources and staffing); (4) characteristics of individuals involved in implementation, their need for the intervention and their capability, availability, and motivation to be involved (based on the capability, opportunity, and motivation behavior model) [27]; and (5) process of implementation (eg, assessing needs of intervention recipients, planning, and tailoring strategies). Use of the CFIR as a deductive qualitative framework enables comparisons of barriers and facilitators in other settings and for other interventions.

Participants

People with mild to moderate dementia, supported by their family caregivers, took part in vCST group sessions. For the qualitative component, people with dementia, caregivers, group leaders, and organizational decision makers were invited to participate in qualitative interviews following the completion of the vCST groups.

Setting

In Brazil, the study site was a psychology department at a university in Rio de Janeiro. In India, the study site was a mental health nongovernmental organization (NGO) in Chennai, offering outpatient, inpatient, and day center services for people with dementia. Both sites had previously been involved in cultural and virtual adaptation of CST [16,17,24] and therefore already had access to face-to-face CST manuals, vCST guidance, and CST trainers and facilitators.

Recruitment

In Brazil, recruitment took place through partnerships with memory clinics and NGOs, advertisements on social media and local media, and snowball sampling. In India, people with dementia were recruited from the patient caseload at the NGO, with additional promotion through caregiver support groups and mobile-messaging groups.

The inclusion criteria for people with dementia at both sites were as follows: they must (1) meet the ICD-10 criteria for dementia as assessed by a trained clinician [28], (2) be rated as having mild to moderate dementia on the Clinical Dementia Rating Scale [29], (3) have sufficient hearing and vision to follow conversation and comment on visual material, and (4) have the ability to participate in a online group for 1 hour.

Intervention Procedure

People with dementia were allocated to a vCST group. The vCST intervention was delivered according to the culturally adapted CST Brazil and India manuals [16,17], which had been further adapted according to the recently developed protocol for online delivery of CST [24]. Groups took place twice weekly over 7 weeks via Zoom videoconferencing software (Zoom Video Communications) between February 2021 and September 2022. Each group consisted of 3 to 5 participants. In Brazil, participants needed to use their own devices, whereas in India, devices were loaned from the NGO if needed. In Brazil, the language of instruction was Brazilian Portuguese, and in India, it was Tamil or English. Group facilitators were trained by site leaders and worked in pairs to deliver the intervention. In Brazil, the group leaders were 2 psychologists, a gerontologist, and 8 trainee psychologists. In India, the group leaders were 3 psychologists and a nursing assistant.

Feasibility Outcomes

The following prespecified main outcomes relating to intervention acceptability were adapted from the study by Proctor et al [30]:

- Recruitment rate: the recruitment target of 50 participants in Brazil and 15 in Chennai was intended to be achieved by September 2022. This target was calculated pragmatically based on available time and resources in each site and was deemed suitable to run enough vCST groups to explore feasibility, acceptability, and implementation issues.
- Attendance: overall attendance rate of >60%, based on the international team's judgment and experience of running CST groups and supporting people with dementia in each setting.
- Attrition: retention rate of at least 75% of participants to the follow-up, again based on the team's previous experience and judgment.
- Acceptability of intervention: this will be assessed through semistructured interviews (see the Semistructured Interviews section).
- Outcome measure completion: the inclusion of cognition, quality of life, activities of daily living, and caregiver burden measures are in line with those used in previous trials and studies of CST [12]. The main goal of the outcomes was to assess the feasibility and acceptability of collecting these data.

Outcome measures were translated, back-translated, and finalized by bilingual committee review. The following pre- and postintervention measures were completed by people with dementia:

- The Alzheimer's Disease Assessment Scale-Cognitive Subscale, an internationally used 21-item measure of cognitive function [31]
- The World Health Organization Quality of Life Brief Version, a 26-item quality-of-life measure addressing 4 domains: physical health, psychological health, social relationships, and environment, which was developed for use in LMICs [32]
- Alzheimer's Disease Cooperative Study-Activities of Daily Living Scale, a 23-item scale that addresses basic and instrumental activities of daily living and has been culturally adapted for use in Brazil [33,34]. This scale was used in Brazil only
- Scale for the Instrumental Activities of Daily Living in the Elderly, an 11-item scale developed in South India that addresses cognitive and physical disability [35]. This scale was used in India only

Family caregivers completed the following:

- The Zarit Burden Interview (ZBI), a widely used 22-item self-report measure of strain and stress [36].
- Dementia Caregiver Experience Scale, a 17-item measure to assess stress and strain (personal communication by Vaitheswaran, 2023), was included due to previous issues with the cross-cultural validity of the ZBI, which has been found to underestimate burden in LMIC settings [37].

Semistructured Interviews

To gather in-depth information about intervention acceptability, feasibility, and experiences of implementation, semistructured interviews were conducted with stakeholders. People with dementia and caregivers from the first 2 vCST groups in Brazil (12 dyads) and all vCST groups in India (15 dyads) were invited to take part in dyadic interviews. A convenience sample of group leaders from Brazil and India (n=7) and organizational decision makers (n=2, India only) was invited to take part in one-to-one interviews.

Interviews with people with dementia and caregivers were conducted in the language of vCST group instruction (English, Tamil, or Brazilian Portuguese) and were led by a researcher from the respective institution who had not facilitated the group to reduce response bias. Interviews with group leaders and organizational decision makers were conducted in English. To reduce response bias, these were led by UK-based researchers who were not members of the immediate project team. All interviews took place over videoconferencing software.

On the basis of constructs from the CFIR, the interview guide was developed by researchers and clinical psychologists, with questions relating to the participants' experience of taking part in the vCST group, experience of using a online platform, and barriers and facilitators to involvement.

Analysis

Quantitative

Primary analysis was descriptive and assessed recruitment, retention, and outcome measure completion. The pre- and postintervention outcome measures, that is, means and mean differences (calculated through paired 2-tailed *t* tests), were reported descriptively. Effect sizes were calculated using Cohen *d*. Statistical analysis was performed using SPSS (version 29; IBM Corp). All data were pseudoanonymized with a unique participant identification number.

Qualitative

Transcripts in Brazilian Portuguese or Tamil were translated before analysis. First, the researchers read the transcripts for data familiarization. We used a framework analysis approach to code the transcripts using inductive thematic analysis [38] and mapped inductive themes onto the CFIR. This enabled us to capture themes that were not covered by the CFIR. Transcripts were coded independently by 2 researchers using NVivo software (Lumivero), who met regularly to ensure that they were approaching the data in a similar way and then agreed on a final coding framework. Any discrepancies were examined and resolved through discussion. An exception is the interview transcripts of caregivers in India, as it was coded by an individual reviewer using Atlas software (Observational Health Data Sciences and Informatics) and discussed with a second researcher.

Ethical Considerations

Ethics approval was granted by the relevant body in each country. In Brazil, an ethics amendment was granted by the Federal University of Rio de Janeiro Institute of Psychiatry research ethics committee (ref: 57019616.5.1001.5263). In India, approval was granted by the institutional ethics committee at Schizophrenia Research Foundation; SCARF: Chennai (SRF-CR/17/0CT-2020). Informed consent was received from people with dementia and their caregivers upon recruitment. Participants did not receive compensation.

Interviews were recorded with consent and transcribed. All transcripts were pseudoanonymized with a unique participant ID number, and any identifying information was removed during transcription.

Results

Feasibility Outcomes

Recruitment Rate

A total of 59 participants were recruited to vCST groups, which was 91% of the target figure of 65 participants. Participant demographics are outlined in Table 1. In Brazil, 12 group sessions took place with a total of 44 participants between April 2021 and November 2022. In India, 5 group sessions were conducted with 15 participants between February 2021 and February 2022. This represents an average of 3.6 participants per group across both sites.

Table 1. Participant demographics.

	Brazil (n=44)	India (n=15)	Total (N=59)
Person with dementia			
Region, n (%)			
Southeast Brazil	41 (93)	—[a]	41 (69)
South Brazil	2 (5)	—	2 (3)
Northeast Brazil	1 (2)	—	1 (2)
Chennai (India)	—	15 (100)	15 (25)
Age (y), mean (range)	77.1 (61-93)	77.3 (65-93)	77.2 (61-93)
Sex, n (%)			
Male	10 (23)	10 (67)	20 (34)
Female	34 (77)	5 (33)	39 (66)
Ethnicity, n (%)			
South Asian	—	15 (100)	15 (25)
Black	3 (7)	—	3 (5)
Mixed	6 (14)	—	6 (10)
White	35 (80)	—	35 (59)
Education (y), mean (range)	11.5 (4-20)	13.0 (10-17)	11.9 (4-20)
Type of dementia, n (%)			
Alzheimer disease	22 (50)	11 (73)	33 (60)
Vascular dementia	4 (9)	3 (2.0)	7 (12)
Mixed dementia (Alzheimer disease and vascular dementia)	1 (2)	1 (7)	2 (3)
Parkinson-related dementia	0 (0)	0 (0)	0 (0)
Dementia with Lewy bodies	1 (2)	0 (0)	1 (2)
Variant unknown	16 (36)	0 (0)	16 (27)
Caregiver			
Sex, n (%)			
Male	7 (16)	3 (20)	10 (17)
Female	37 (84)	12 (80.0)	49 (83)
Age (y), mean (range)[b]	52.5 (32-71)	53.2 (29-72)	52.7 (29-72)
Relationship to person with dementia, n (%)[c]			
Spouse	8 (19)	4 (27)	12 (20)
Daughter or son	32 (74)	11 (73)	43 (73)
Daughter-in-law or son-in-law	1 (2)	0 (0)	1 (2)
Other relative	2 (5)	0 (0)	2 (3)
Living with person with dementia, n (%)[d]			
No	11 (30)	2 (13)	13 (22)
Yes	26 (70)	13 (87)	39 (66)

[a] Not applicable.

[b] Missing data for Brazil: caregiver age, n=7.

[c] Missing data for Brazil: relationship to person with dementia, n=1.

[d] Missing data for Brazil: living with person with dementia, n=7.

Attendance

In Brazil, 52% (23/44) of participants attended all 14 sessions, and in India, 53% (8/15) of participants had full attendance.

Attrition

In Brazil, the attrition rate was 9% (4/44), denoting the percentage of participants who did not complete the vCST program due to various reasons: caregiver unavailability to support the participant (n=2, 50%), hospitalization due to COVID-19 (n=1, 25%), and to go on a vacation (n=1, 25%). There were no dropouts from vCST groups in India.

Outcome Measure Completion

Researchers completed preintervention outcome assessments with all people with dementia; however, some caregivers (3/59, 5%) were unavailable to provide preassessment measures. Retention of people with dementia to follow-up was 89% (39/44) in Brazil and 93% (14/15) in India. In India, 87% (13/15) of caregivers completed all follow-up assessments, but this figure was lower in Brazil (31/44, 70%). This was attributed to the caregivers being occupied with family and work commitments, particularly at a time of increased pressure during the pandemic. In addition, some people with dementia did not have 1 named caregiver and were supported by many family members or paid caregivers who did not always feel that they could provide accurate information. Overall, 68% (40/59) of participant dyads across both sites completed all postintervention outcome measures. No measures caused distress, and no measures had individual items missing.

Pre- and postintervention means and mean differences are outlined in Table 2. Analyses were exploratory and not powered to detect specific changes. The results suggest a small decrease in cognitive ability from baseline to follow-up. Small improvements across quality-of-life domains were observed in people with dementia. We observed moderate reductions in the activity of daily living ability across all domains in both sites. Conflicting outcomes were observed in caregiver burden outcomes, with a small reduction in burden scores on the ZBI but an increase in burden scores according to the Dementia Caregiver Experience Scale measure.

Multimedia Appendix 1 presents results by country. The direction and magnitude of change were similar across both sites; however, notable differences emerged: cognition where the decrease was smaller in India, quality-of-life score (social relationships) where the increase was smaller in India, and quality-of-life score (psychological and environment domains) where a reduction was observed in India compared with an improvement in Brazil.

Table 2. Pre- and postintervention outcome measures[a,b].

Outcome (range)	Preintervention measures		Postintervention measures		Mean improvement (pretest-posttest)			
	Values, n (%)	Values, mean (SD)	Values, n (%)	Values, mean (SD)	Values, n (%)	Mean difference (95% CI)	*P* value	Effect size (95% CI)
ADAS-Cog[c] (0-70)	59 (100)	27.11 (12.92)	52 (88)	27.36 (14.53)	52 (88)	−1.20 (−3.25 to 0.85)	.24	−0.16 (−0.44 to 0.11)
WHOQOL-BREF[d]: physical health (4-20)	59 (100)	14.48 (2.82)	51 (86)	14.80 (2.56)	51 (86)	0.38 (−0.25 to 1.01)	.23	0.17 (−0.11 to 0.45)
WHOQOL-BREF: psychological (4-20)	59 (100)	14.17 (2.13)	51 (86)	14.75 (2.02)	51 (86)	0.58 (0.04 to 1.11)	.04	0.30 (0.21 to 0.58)
WHOQOL-BREF: social relationships (4-20)	59 (100)	15.12 (1.71)	51 (86)	15.48 (1.96)	51 (86)	0.52 (−0.05 to 1.10)	.07	0.26 (−0.03 to 0.53)
WHOQOL-BREF environment (4-20)	59 (100)	15.03 (1.96)	51	15.25 (1.82)	51 (86)	0.36 (−0.12 to 0.85)	.14	0.21 (−0.07 to 0.49)
ADCS-ADL[e] (0-78)	44 (100)	44.34 (16.55)	40 (91)	42.00 (16.44)	40 (91)	−3.18 (−5.35 to −1.01)	.005	−0.47 (−0.79 to −0.14)
IADL-EDR[f]—cognitive domain (0-100)	15 (100)	37.65 (19.77)	14 (93)	43.97 (20.72)	14 (93)	−8.64 (−17.91 to 0.64)	.07	−0.54 (−1.09 to 0.03)
IADL-EDR—physical domain (0-100)	15 (100)	4.20 (7.95)	14 (93)	10.57 (15.71)	14 (93)	−7.50 (−16.61 to 1.61)	.10	−0.48 (−1.02 to 0.09)
ZBI[g] (0-88)	56 (95)	35.02 (18.04)	47 (80)	32.91 (17.69)	46 (78)	1.33 (−0.96 to 3.61)	.25	0.17 (−0.12 to 0.46)
DemCarES[h] (17-51)	53 (90)	28.94 (6.91)	46 (78)	29.35 (7.28)	43 (73)	−0.67 (−1.90 to 0.55)	.27	−0.17 (−0.47 to 0.13)

[a] Positive maximum scale scores: ADAS-Cog=0, WHOQOL-BREF (Physical health, Psychological, Social relationships, Environment)=20, ADCS-ADL=78, IADL-EDR (Cognitive domain, Physical domain)=0, ZBI=0, DemCarES=17.

[b] Effect size was calculated using Cohen *d* (complete case analysis). No adjustments were made for multiple testing because analyses are exploratory.

[c] ADAS-Cog: Alzheimer’s Disease Assessment Scale-Cognitive Subscale.

[d] WHOQOL-BREF: World Health Organization Quality of Life Brief Version.

[e] ADCS-ADL: Alzheimer’s Disease Cooperative Study-Activities of Daily Living Scale, administered in Brazil only.

[f] IADL-EDR: Instrumental Activities of Daily Living for elderly people, administered in India only.

[g] ZBI: Zarit Burden Interview.

[h] DemCarES: Dementia Caregiver Experience Scale.

Qualitative Results

Overview

A total of 36 qualitative interviews were conducted. In Brazil, 12 people with dementia and their caregivers took part. In India, interviews were conducted with 15 people with dementia and caregivers. This comprises all participants from the first 2 vCST groups in Brazil, and all participants from the 5 groups in India. In addition, 4 group leaders from Brazil took part in interviews, and from India, 3 group leaders and 2 organizational decision makers from the NGO in India. All participants who were invited to the interviews agreed to take part.

Guided by the CFIR, we explored 2 main areas in the analysis: (1) acceptability of vCST and (2) barriers and facilitators to implementation.

Acceptability of vCST

All interview participants were asked directly about their experiences of taking part in vCST and were asked to reflect on how it compared to previous face-to-face activities. Overall, participant and caregiver evaluation of vCST was positive, with key benefits relating to providing occupation, enjoyment, and social interaction at the time of isolation:

> *I liked her activeness and purposefulness...that itself is important. Earlier she used to simply sit but now she has something to do, so that kind of purposefulness is really appreciable.* [Caregiver 4, India]
>
> *We talk and such in the house, but we are only a few here. Now my family is almost just me and him...[the] television doesn’t interact.* [Caregiver 8, Brazil]

> *At first I didn't want to attend the sessions (laughs), I fought, I wanted to hit everyone, but I liked it.* [Person with dementia 1, Brazil]

The remote delivery and national recruitment in Brazil also enabled the attendance of some participants from outside the urban centers of Rio de Janeiro and São Paulo, where most services are provided:

> *You're interacting there from Rio, [name of another participant] there from Itapetininga, the other lady also from another place...with this pandemic business...we don't need to have physical contact. I think it's great.* [Caregiver 8, Brazil]

However, many, in particular, the facilitators who had had the experience of delivering both vCST and face-to-face CST, felt that the social connection and stimulation would have been stronger if the intervention had taken place face to face:

> *There are many more activities that can be done in person, rather than virtually...like for example, throwing ball to each other, doing physical activities together. Even sensory stimulation like...hearing sounds or seeing things...And I feel just physically being present and seeing other people is definitely...much more helpful.* [Group leader 3, India]

> *I think it would have been better if it could have happened in person. But during the COVID situation...this was more helpful and comfortable as anybody can attend from any place. Maybe still, I feel it would have been more beneficial for the dementia group if it were a direct session.* [Caregiver 6, India]

The participants observed additional issues with intervention acceptability that were related to the participants' access to suitable technology and computer literacy, which was compounded by cognitive impairment:

> *The main issue was internet. I would say… so we had only three participants in a group… along with a facilitator and a co-facilitator… which means that, like five different internet connections. So, the problem was if even one participant had a disruption in their internet, it tends to affect the whole group.* [Group leader 1, India]

> *At first it was more difficult, because the computer she could use at this time, I was using for work...so she had to do it on her phone...The images were too small for her to see, so that got in the way.* [Caregiver 7, Brazil]

Group leaders also reflected that it was more difficult to gauge engagement and facilitate a group virtually, as opposed to face to face:

> *Just knowing the body language, if the person is feeling sleepy, or the person's not enjoying it and stuff like that. You're not able to notice it as much because it is a virtual set up.* [Group leader 1, India]

> *Sometimes...the participants would talk over other people. We will ask someone a question, and that person...would answer, but then another person would answer also, and the two answers were colliding there, and it was hard to manage that, because it was virtual sessions.* [Group leader 2, Brazil]

Facilitators and Barriers to Implementation

Facilitators and barriers are included in Tables 3 and 4, categorized by CFIR domain with illustrative quotes. Key facilitators included the following:

- Innovation: Facilitators included the evidence base of CST and its advantage over other psychosocial interventions as a manualized intervention, which was also flexible to the needs of the participants. Some group leaders reflected that they were aware of few other interventions for people with dementia taking place virtually at the time.
- Outer setting: An international collaborative effort enabled funding and sharing of protocols and training materials. Many caregivers reflected that they were appreciative that the person with dementia could attend vCST at a time of social isolation due to COVID-19 restrictions.
- Inner setting: Staff in both sites were motivated to offer a service for people with dementia, and many participants reflected on the need for more support for people with dementia. Another facilitator to implementation was the training and supervision of staff at the NGO and trainee psychologists at the university. The NGO in India were able to appoint permanent staff members to take on vCST responsibilities as part of their role and integrate vCST into the existing services and caseload.
- Individuals: Most people with dementia relied on caregivers' support and would often miss sessions if their caregiver was unavailable. All groups also required 2 group leaders: one to lead the activities and another to provide technological support and to contact caregivers if a participant was struggling to engage. In India, group leaders reflected that adoption of vCST improved if it was suggested to participants by a clinician.
- Processes: Key implementation strategies included providing mock vCST sessions with caregivers and people with dementia to orient them to the platform and posting out activity packs to those who did not have resources at home.

Table 3. Facilitators to implementation.

CFIR[a] domain and subdomains[b]	Quotes
Innovation	
Innovation evidence-base	“In terms of evidence based published literature information… the effectiveness of CST and the cost effectiveness in other centers...That helped in choosing the most appropriate intervention.” [Decision maker 1, India]
Innovation relative advantage	“There was this one organization...a day center facility were doing... one-on-one video calls to have some sort of a social interaction during the pandemic.” [Group leader 2, Brazil]
Adaptability (of vCST[c] protocol)	“I think we had flexibility, because as I said one was the education level of patients and then the language that had to be used.” [Decision maker 2, India]
Outer setting	
Local conditions (need for socializing during lockdowns)	“He was...looking forward to the session, especially social interaction because the pandemic had obviously you know sort of cut down a lot of such interactions.” [Caregiver 1, India]
Partnerships and connections (international research partnership)	“We based it ourselves in this protocol, which was already published with some guidelines for developing the CST virtually.” [Group leader 1, Brazil]
Financing (international research funding)	“We were able to purchase the items that we need to deliver CST at our center. And for regarding technology...we were able to provide some of the participants with a tablet computer and the data for them.” [Decision maker 1, India]
Inner setting	
Tension for change (need for psychosocial treatment)	“There is no actual evidence based structured manual intervention available in India prior to this, so this provided as an opportunity to make it available for our patients.” [Decision maker 1, India]
Culture—learning centeredness (supporting trainee psychologists, Brazil)	“I really like participating on the project from my experience, in gaining experience, on like clinical experience and also a little bit of research too.” [Group leader 3, Brazil]
Compatibility (with service and caseload, India)	“We have a regular clinic so we identify participants from the clinic.” [Decision maker 1, India]
Access to knowledge and information (training and supervision)	“We had training, of course, and we also had regular supervision from our supervisor.” [Group leader 1, India]
Work infrastructure—staff (at NGO[d], India)	“Making sure that the facilitators are in substantive posts and not in fleeting positions so they are available for a longer time.” [Decision maker 1, India]
Individuals	
Opinion leaders (recommendation from doctors)	“If the doctor sometimes says, ‘you should do this, this will be beneficial for you,’ it really helps in the Indian context of the doctor’s word for you.” [Group leader 2, India]
Other implementation support—availability or capability (caregivers)	“Some of [the caregivers] would stay next to the person living with dementia...especially when the person was a little bit shy, [or] had more difficulty with technology...They were...mediating this communication.” [Group leader 2, Brazil]
Other implementation support—availability or capability (cofacilitator)	“One of the psychologists is delivering the session, and we need someone to support us at the technical end, we need someone to support us.” [Group leader 2, India]
Intervention recipient—need (person with dementia—need to stay home and subsequent isolation)	“Some of these people would not have come for in-person CST, because they could not afford transportation, did not have proper transportation, were frail, or had some kind of physical comorbidity or pain.” [Group leader 2, India]

CFIR[a] domain and subdomains[b]	Quotes
Implementation process	
Tailoring strategies (mock vCST sessions and activity packs)	• “We do have one trial session, where I sit with them individually. And then we have one group trial session, to see if they’re comfortable in a group.” [Group leader 2, India] • “We posted the materials...for number games, we had paper sheets. And colouring papers and some origami papers...We took printouts and posted it to their house.” [Group leader 1, India]

[a] CFIR: Consolidated Framework for Implementation Research.

[b] Context-specific descriptions are given in parentheses.

[c] vCST: virtual cognitive stimulation therapy.

[d] NGO: nongovernmental organization.

Table 4. Barriers to implementation.

CFIR[a] domain and subdomains[b]	Quotes
Innovation	
Adaptability (virtual delivery of CST[c])	• "I was running face-to-face sessions before they started [vCST]. Face-to-face CST was great...my group ran with eight members, six to eight, consistently. So, I had a huge group coming every Friday. It was amazing, they could form more connections, and turn taking is a little bit easier...It's a little harder like you with the Zoom." [Group leader 2, India
Innovation design (need for marketing)	• "It doesn't have much publicity. If it wasn't for chance, if this person hadn't put us in, I wouldn't have made it. So, I think in terms of dissemination it could be broader." [Caregiver 4, Brazil]
Outer setting	
Critical incidents (COVID-19 pandemic)	• "It was COVID and people are falling sick...even the facilitators are sick, at some point." [Group leader 1, India]
Local attitudes (dementia awareness)	• "In Brazil, I think it's a cultural thing to think that dementia symptoms it's part of a natural aging...So, when older people, and people living with dementia...come to a doctor to be evaluated they sometimes don't have mild symptoms anymore." [Group leader 2, Brazil]
Local attitudes (traditional focus on medical model)	• "People weren't aware of psychosocial interventions for dementia prior to this. They had very different model for working with people with dementia." [Decision maker 1, India]
Local conditions (access to technology)	• "Most of the people that we had in the groups were from the south eastern region. And that's kind of a more developed region financially...I think today most people in Brazil have access to internet. Maybe not their computer, but maybe cell phones and something like that." [Group leader 3, Brazil]
Inner setting	
Structural characteristics—work infrastructure (staff availability)	• "When we think of scaling it up, we might have to do it first of all in institutions where there is enough manpower of mental health professionals to deliver the CST...dementia care in India is still mental health care and we're still very under-resourced as far as manpower is concerned." [Decision maker 2, India]
Individuals	
High-level leaders—capability (lack of dementia awareness)	• "Some of the policymakers, who we interviewed at the beginning [in previous stakeholder engagement] weren't even aware of the issues relating to dementia." [Decision maker 1, India]
Intervention deliverers—capability (basics in clinical skills needed)	• "I think we if we didn't have the training, it would be very hard to just come to the groups...I didn't have any contact [with people with dementia] before." [Group leader 3, Brazil]
Intervention recipients—capability (sensory impairment and computer literacy)	• "So, one challenge was delivering it virtually. My mother was not able to hear very well. Now she has a hearing aid, she has the headphones but still that was a part of a problem of communication." [Caregiver 5, India] • "I don't know how to use the computer (laughs)." [Person with dementia 10, Brazil]
Implementation process	
Assessing needs—innovation recipients (severity of dementia)	• "If you have some difference in severity of dementia, because the activities demand something, and maybe it can be boring for who is not so severe." [Group leader 4, Brazil]
Assessing needs—innovation recipients (baseline assessments)	• "The first is, I think, the baseline evaluations were very long, and that was kind of hard on the, not on the people with dementia, but on their family members, the caregivers." [Group leader 3, Brazil]
Reflecting and evaluating—implementation (lack of long-term follow-up)	• "One question that most people with dementia their caregivers made was, if it was possible to have more than 14 sessions. So maybe adapting the maintenance CST for the virtual program. I think it would be a suggestion for the future." [Group leader 1, Brazil]

[a] CFIR: Consolidated Framework for Implementation Research.

[b] Context-specific descriptions are given in parentheses.

[c] CST: cognitive stimulation therapy.

Key barriers related to the 5 CFIR domains are as follows:

- Innovation. Most group leaders highlighted challenges with the online delivery of CST in terms of facilitating a group effectively, meeting individual needs, and supporting participants with the videoconferencing platform. Many leaders reflected on the comparative ease of facilitating a group in person. These issues are outlined in detail in the Acceptability of vCST
section. Finally, group leaders and caregivers highlighted the need for marketing to raise awareness of vCST
- Outer setting. While COVID-19 necessitated and possibly facilitated the online delivery of CST, staff and participant illness during the pandemic was a barrier to group delivery and attendance. Staff at both sites reflected on a lack of dementia awareness, resulting in participants presenting later to clinical services, which is a barrier to recruiting participants with mild to moderate dementia. Similarly, group leaders and decision makers reflected on a lack of awareness of psychosocial interventions for dementia, with the medical model tending to prevail. Finally, in both sites, it was highlighted that poor or limited access to technology is a barrier to involvement.
- Inner setting. The limited availability of mental health personnel was highlighted as a barrier to the wider scale-up of vCST in India.
- Individuals. People with dementia and caregivers faced barriers to taking part in vCST, including a lack of computer literacy and sensory impairment that impacted engagement. Organizational decision makers in India reflected on the lack of dementia awareness within high-level policy makers.
- Processes. One group leader reflected on the length and burden of the baseline assessments on people with dementia and caregivers. Many people with dementia and caregivers expressed a wish for the vCST groups to continue beyond the 14 sessions. At the NGO in India, it was possible to follow up with patients on the caseload; however, group leaders in Brazil wished to be able to continue to support participants and caregivers.

Discussion

Principal Findings

We found that it was feasible and acceptable to deliver CST virtually in Brazil and India. We recruited 91% (59/65) of the target sample and were able to run 17 vCST groups. Attrition was low (4/49, 7%), and attendance was moderate, with 53% (31/59) of participants attending all 14 sessions. This is in contrast to a previous trial of face-to-face CST in Brazil, where attrition was similar (6%) but attendance was high (mean 12.8 sessions, median 14 sessions) [39]. In a previous pilot study of face-to-face CST in Chennai, India, attrition was higher with 3 out of 9 participants dropping out [16]. However, these comparisons should be interpreted with care due to small sample sizes and the impact of COVID-19 in both countries.

Outcome measure completion was slightly lower than the target of 75%, as only 68% (40/59) of participant dyads completed all follow-up outcome measures, suggesting a possible measurement burden. Small improvements across all quality-of-life domains were observed in people with dementia. All results should be interpreted with care, as the study was not controlled. Any changes cannot be ascribed to the vCST intervention specifically, and the impact of COVID-19 and consequent social isolation may have played a role in pre- and postintervention measurement changes.

There were some differences in the barriers and facilitators to implementation across the 2 sites. vCST was delivered in an NGO in Chennai, where participants could be recruited from the patient caseload. In Brazil, vCST was delivered through a university where recruitment took place from the community and memory clinics and NGOs who were partnered with the study. Although staff turnover was a barrier to implementation in the NGO in India, decision makers reflected that it would be possible to build CST or vCST into services due to its compatibility with current ways of working. This may have been more of a challenge in the university setting in Brazil, where there is no patient caseload or clinic infrastructure. However, there is scope to build partnerships with community organizations and clinics to recruit participants. Upskilling trainee psychologists to deliver vCST in Brazil also presents a low-cost and scalable solution to implementing vCST in a university setting. Similar solutions have been used for other psychosocial interventions for dementia in other countries [40,41].

A major barrier in both sites was poor or limited access to technology and computer literacy. This issue was also highlighted in studies of vCST conducted in the United Kingdom [23,24]. A survey of the digital divide in India found that just 38% of households are digitally literate [42]. Access is higher in Brazil, where 80% of households have internet access [43]. In both countries, digital access intersects with age, gender, education level, and ethnicity [42-44]. While virtual interventions provide service access to those living in geographically isolated locations, the digital divide is greater in rural areas; in Brazil, only 53% of the rural population have internet access, while 88% in urban areas have internet access [43], and the figures are lower overall in India where in rural areas, only 31% of the population use the internet, while in the urban areas, the percentage rises to 67% [42]. To overcome the barriers to technology access in India, the NGO loaned tablets to participants, which required sufficient funding and resources. We addressed the issues related to digital literacy by implementing the following measures: (1) group leaders provided mock vCST sessions to familiarize participants with the videoconferencing platform, (2) a coleader was available specifically for technology support, and (3) groups sizes were smaller so that all participants could be viewed on the screen at once (average 3.6 participants compared with 6-8 according to the original CST protocol [12]).

Most people with dementia were reliant on caregivers' technical support to use the videoconferencing technology, and in some cases, caregivers remained present throughout the group sessions. This raises a key issue for those without caregivers, who could be systematically excluded from taking part in virtual psychosocial interventions. If vCST were implemented as a dyadic intervention, this could improve caregivers' awareness of dementia and person-centered approaches, which is important given the limited number of dementia awareness programs in LMIC settings [45]. However, it could also negatively impact the engagement of the person with dementia, as one of the proposed mechanisms of action of CST is the supportive learning environment, where people with dementia support each other without judgment or embarrassment [46]. If vCST is delivered dyadically, we recommend that participants are briefed at the start of the program to set expectations about the caregivers' level of involvement in the vCST sessions and that people with dementia are provided with opportunities to take part in activities and discussions alone. Further research could explore the impact of dyadic delivery on outcomes for people with dementia and their caregivers.

Limitations

In both sites, it is likely that the sample was not representative of the broader population of people living with dementia and their caregivers. Specifically, in Brazil, the sample comprised mostly White individuals (35/44, 80%), which does not reflect the majority Black and mixed Brazilian population. Most participants were from the urban region of southeast Brazil, although the remote method of recruitment did enable participation from areas outside of this region, which were underserved in terms of research and clinical services. In India, all participants were recruited from the same region and were already attending clinical services; this might have resulted in a sample skewed to those with the means to access services.

Online delivery may result in a self-selecting sample, who are more likely to be educated to a higher level and more affluent than the broader population. The mean number of years of schooling of our sample was 11.5 (SD 1.2) in Brazil and 13.0 (SD 2.6) in India. This compares to a national average of 2.5 in Brazil and 1.4 in India for the population aged ≥25 years in 1970 and 1971, respectively [47] although there is huge regional variation in education levels in both countries. To overcome issues related to digital exclusion in India, tablets were loaned to those who needed them. However, in Brazil, people without access to their own technology were excluded.

In terms of the qualitative component, most themes and quotes from a participant perspective were collected from caregivers rather than people with dementia. This is because cognitive impairment affected their recall of sessions. Despite this, caregivers and group leaders reflected on the perceived participant experience of vCST sessions. Interviews took place with all caregiver dyads from India, but only those from the first 2 vCST groups in Brazil due to staff availability. However, the reflections from group leaders and organizational decision makers relate to all vCST groups. Interviews with group leaders and decision makers were carried out in English by a UK-based researcher who was not a member of the immediate research team. This was to limit response bias and encourage honest and critical feedback; however, it limited the interview to people who speak English and may have compromised the representation of non-English speakers.

Finally, the vCST intervention was tested in 2 sites, a university in Brazil and an NGO in India, resulting in lessons for implementation that could be explored in other sites and countries; nevertheless, we acknowledge the limited generalizability of these findings.

Future Research

To date, vCST has only been trialed within a pandemic context. While this was acceptable to participants during a time of social isolation, many caregiver dyads and group leaders expressed a desire for CST to take place in person. Future research could explore the feasibility of vCST outside of the pandemic context, perhaps specifically targeting those who cannot access in-person services due to limited mobility, health issues, or geographic isolation.

In addition, although there is a strong evidence base for in-person CST, we do not know if the benefits to cognition and quality of life are conferred to the same level over online delivery. A recent feasibility study of vCST (in press Spector, 2023) has shown that a full-scale randomized controlled trial is warranted

Conclusions

The 14-session vCST program for people with dementia was successfully trialed in a university setting in Brazil and in an NGO in Chennai, India. vCST offered a feasible alternative to in-person groups during the period of pandemic restrictions with potential benefits to quality of life, but there were barriers related to technology access and computer literacy. Outside of the pandemic context, vCST could be provided to people with dementia who are geographically isolated or who have mobility- or health-related difficulties.

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Conflicts of Interest

AS delivers occasional cognitive stimulation therapy (CST) training courses on a consultancy basis. DCM provides CST training in Brazil, and SV delivers CST training in India.

Multimedia Appendix 1
Pre- and postintervention outcome measures by country.
[DOCX File , 21 KB - aging_v7i1e55557_app1.docx]

References

1. GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. Lancet Public Health 2022 Feb;7(2):e105-e125 [FREE Full text] [doi: 10.1016/S2468-2667(21)00249-8] [Medline: 34998485]
2. Global action plan on the public health response to dementia 2017 - 2025. World Health Organization. 2017 Dec. URL: https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025 [accessed 2024-04-29]
3. Wimo A, Seeher K, Cataldi R, Cyhlarova E, Dielemann JL, Frisell O, et al. The worldwide costs of dementia in 2019. Alzheimers Dement 2023 Jul 08;19(7):2865-2873 [FREE Full text] [doi: 10.1002/alz.12901] [Medline: 36617519]
4. Bertola L, Suemoto CK, Aliberti MJ, Gomes Gonçalves N, Pinho PJ, Castro-Costa E, et al. Prevalence of dementia and cognitive impairment no dementia in a large and diverse nationally representative sample: the ELSI-Brazil study. J Gerontol A Biol Sci Med Sci 2023 Jun 01;78(6):1060-1068. [doi: 10.1093/gerona/glad025] [Medline: 36682021]
5. Lee J, Meijer E, Langa KM, Ganguli M, Varghese M, Banerjee J, et al. Prevalence of dementia in India: national and state estimates from a nationwide study. Alzheimers Dement 2023 Jul;19(7):2898-2912 [FREE Full text] [doi: 10.1002/alz.12928] [Medline: 36637034]
6. Taking the pulse of the health system's response to the needs of older persons. Situational analysis Brazil. Pan American Health Organization. 2022. URL: https://www.paho.org/en/documents/taking-pulse-health-systems-response-needs-older-persons-situational-analysis-brazil [accessed 2024-04-29]
7. Nakamura AE, Opaleye D, Tani G, Ferri CP. Dementia underdiagnosis in Brazil. Lancet 2015 Jan 31;385(9966):418-419. [doi: 10.1016/S0140-6736(15)60153-2] [Medline: 25706975]
8. Calil V, Elliott E, Borelli WV, Barbosa BJ, Bram J, Silva FD, et al. Challenges in the diagnosis of dementia: insights from the United Kingdom-Brazil dementia workshop. Dement Neuropsychol 2020 Sep;14(3):201-208 [FREE Full text] [doi: 10.1590/1980-57642020dn14-030001] [Medline: 32973973]
9. Nulkar A, Paralikar V, Juvekar S. Dementia in India – a call for action. J Glob Health Rep 2019;3:1-4 [FREE Full text] [doi: 10.29392/joghr.3.e2019078]
10. Pickett J, Bird C, Ballard C, Banerjee S, Brayne C, Cowan K, et al. A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. Int J Geriatr Psychiatry 2018 Jul 22;33(7):900-906 [FREE Full text] [doi: 10.1002/gps.4868] [Medline: 29468724]
11. Vernooij-Dassen M, Moniz-Cook E. Raising the standard of applied dementia care research: addressing the implementation error. Aging Ment Health 2014 Sep 12;18(7):809-814. [doi: 10.1080/13607863.2014.899977] [Medline: 24815025]
12. Woods B, Rai HK, Elliott E, Aguirre E, Orrell M, Spector A. Cognitive stimulation to improve cognitive functioning in people with dementia. Cochrane Database Syst Rev 2023 Jan;2023(1):CD005562 [FREE Full text] [doi: 10.1002/14651858.CD005562.pub2] [Medline: 22336813]
13. Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. Br J Psychiatry 2003 Sep 02;183(3):248-254. [doi: 10.1192/bjp.183.3.248] [Medline: 12948999]
14. Cognitive Stimulation Therapy (CST) – summary of evidence on cost-effectiveness. National Health Service. URL: https://www.england.nhs.uk/publication/cognitive-stimulation-therapy-cst-summary-of-evidence-on-cost-effectiveness/ [accessed 2023-10-27]
15. CST by Country. International Cognitive Stimulation Therapy (CST) Centre. URL: https://www.ucl.ac.uk/international-cognitive-stimulation-therapy/cst-country [accessed 2023-09-15]
16. Raghuraman S, Lakshminarayanan M, Vaitheswaran S, Rangaswamy T. Cognitive stimulation therapy for dementia: pilot studies of acceptability and feasibility of cultural adaptation for India. Am J Geriatr Psychiatry 2017 Sep;25(9):1029-1032. [doi: 10.1016/j.jagp.2017.04.014] [Medline: 28545833]
17. Bertrand E, Naylor R, Laks J, Marinho V, Spector A, Mograbi DC. Cognitive stimulation therapy for Brazilian people with dementia: examination of implementation' issues and cultural adaptation. Aging Ment Health 2019 Oct 16;23(10):1400-1404 [FREE Full text] [doi: 10.1080/13607863.2018.1488944] [Medline: 30444133]
18. World Alzheimer report 2022: life after diagnosis: navigating treatment, care and support. Alzheimer's Disease International. URL: https://www.alzint.org/resource/world-alzheimer-report-2022/ [accessed 2023-11-05]

19. Spector A, Stoner CR, Chandra M, Vaitheswaran S, Du B, Comas-Herrera A, et al. Mixed methods implementation research of cognitive stimulation therapy (CST) for dementia in low and middle-income countries: study protocol for Brazil, India and Tanzania (CST-international). BMJ Open 2019 Aug 20;9(8):e030933 [FREE Full text] [doi: 10.1136/bmjopen-2019-030933] [Medline: 31434784]
20. World Bank country and lending groups. World Bank Data Help Desk. URL: https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups [accessed 2024-04-05]
21. Liu KY, Howard R, Banerjee S, Comas-Herrera A, Goddard J, Knapp M, et al. Dementia wellbeing and COVID-19: review and expert consensus on current research and knowledge gaps. Int J Geriatr Psychiatry 2021 Nov 27;36(11):1597-1639 [FREE Full text] [doi: 10.1002/gps.5567] [Medline: 34043836]
22. Cheung G, Peri K. Challenges to dementia care during COVID-19: innovations in remote delivery of group cognitive stimulation therapy. Aging Ment Health 2021 Jun 07;25(6):977-979. [doi: 10.1080/13607863.2020.1789945] [Medline: 32631103]
23. Fisher E, Proctor D, Perkins L, Felstead C, Stott J, Spector A. Is virtual cognitive stimulation therapy the future for people with dementia? An audit of UK NHS memory clinics during the COVID-19 pandemic. J Technol Behav Sci 2023 Feb 24;8(4):1-8 [FREE Full text] [doi: 10.1007/s41347-023-00306-5] [Medline: 36855467]
24. Perkins L, Fisher E, Felstead C, Rooney C, Wong GH, Dai R, et al. Delivering cognitive stimulation therapy (CST) virtually: developing and field-testing a new framework. Clin Interv Aging 2022;17:97-116 [FREE Full text] [doi: 10.2147/CIA.S348906] [Medline: 35173425]
25. Damschroder LJ, Reardon CM, Widerquist MA, Lowery J. The updated consolidated framework for implementation research based on user feedback. Implement Sci 2022 Oct 29;17(1):75 [FREE Full text] [doi: 10.1186/s13012-022-01245-0] [Medline: 36309746]
26. Means AR, Kemp CG, Gwayi-Chore MC, Gimbel S, Soi C, Sherr K, et al. Evaluating and optimizing the consolidated framework for implementation research (CFIR) for use in low- and middle-income countries: a systematic review. Implement Sci 2020 Mar 12;15(1):17 [FREE Full text] [doi: 10.1186/s13012-020-0977-0] [Medline: 32164692]
27. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr 23;6(1):42 [FREE Full text] [doi: 10.1186/1748-5908-6-42] [Medline: 21513547]
28. The ICD-10 classification of mental and behavioural disorders : diagnostic criteria for research. World Health Organization. 1993. URL: https://apps.who.int/iris/handle/10665/37108 [accessed 2023-09-15]
29. Morris JC. Clinical dementia rating: a reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. Int Psychogeriatr 1997 Jan 10;9 Suppl 1(S1):173-178. [doi: 10.1017/s1041610297004870] [Medline: 9447441]
30. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health 2011 Mar 19;38(2):65-76 [FREE Full text] [doi: 10.1007/s10488-010-0319-7] [Medline: 20957426]
31. Rosen WG, Mohs RC, Davis KL. A new rating scale for Alzheimer's disease. Am J Psychiatry 1984 Nov;141(11):1356-1364. [doi: 10.1176/ajp.141.11.1356] [Medline: 6496779]
32. Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL group. Psychol Med 1998 May;28(3):551-558. [doi: 10.1017/s0033291798006667] [Medline: 9626712]
33. Galasko D, Schmitt F, Thomas R, Jin S, Bennett D, Alzheimer's Disease Cooperative Study. Detailed assessment of activities of daily living in moderate to severe Alzheimer's disease. J Int Neuropsychol Soc 2005 Jul 01;11(4):446-453. [doi: 10.1017/s1355617705050502] [Medline: 16209425]
34. da Cunha Cintra FC, Cintra MT, Nicolato R, Bertola L, Ávila RT, Malloy-Diniz LF, et al. Functional decline in the elderly with MCI: cultural adaptation of the ADCS-ADL scale. Rev Assoc Med Bras (1992) 2017 Jul;63(7):590-599 [FREE Full text] [doi: 10.1590/1806-9282.63.07.590] [Medline: 28977084]
35. Mathuranath PS, George A, Cherian PJ, Mathew R, Sarma PS. Instrumental activities of daily living scale for dementia screening in elderly people. Int Psychogeriatr 2005 Sep 04;17(3):461-474. [doi: 10.1017/s1041610205001547] [Medline: 16252378]
36. Zarit S, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980 Dec;20(6):649-655 [FREE Full text] [doi: 10.1093/geront/20.6.649] [Medline: 7203086]
37. Brinda EM, Rajkumar AP, Enemark U, Attermann J, Jacob KS. Cost and burden of informal caregiving of dependent older people in a rural Indian community. BMC Health Serv Res 2014 May 07;14(1):207 [FREE Full text] [doi: 10.1186/1472-6963-14-207] [Medline: 24886051]
38. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019 Jun 13;11(4):589-597. [doi: 10.1080/2159676X.2019.1628806]
39. Marinho V, Bertrand E, Naylor R, Bomilcar I, Laks J, Spector A, et al. Cognitive stimulation therapy for people with dementia in Brazil (CST-Brasil): results from a single blind randomized controlled trial. Int J Geriatr Psychiatry 2021 Feb 11;36(2):286-293. [doi: 10.1002/gps.5421] [Medline: 32881071]
40. Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D, et al. Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with

dementia: pragmatic randomised controlled trial. BMJ 2013 Oct 25;347(oct25 2):f6276 [FREE Full text] [doi: 10.1136/bmj.f6276] [Medline: 24162942]

41. Cheng ST, Au A, Losada A, Thompson LW, Gallagher-Thompson D. Psychological interventions for dementia caregivers: what we have achieved, what we have learned. Curr Psychiatry Rep 2019 Jun 06;21(7):59 [FREE Full text] [doi: 10.1007/s11920-019-1045-9] [Medline: 31172302]
42. India inequality report 2022: digital divide. Oxfam India. 2022. URL: https://www.oxfamindia.org/knowledgehub/workingpaper/india-inequality-report-2022-digital-divide [accessed 2024-04-29]
43. Nakayama LF, Binotti WW, Link Woite N, Fernandes CO, Alfonso PG, Celi LA, et al. The digital divide in Brazil and Barriers to telehealth and equal digital health care: analysis of internet access using publicly available data. J Med Internet Res 2023 Jul 21;25:e42483 [FREE Full text] [doi: 10.2196/42483] [Medline: 37477958]
44. da Silva LF, Zitkus E, Freire AP. An exploratory study of the use of the internet and e-government by older adults in the countryside of Brazil. Information 2023 Apr 06;14(4):225. [doi: 10.3390/info14040225]
45. Stoner CR, Lakshminarayanan M, Mograbi DC, Vaitheswaran S, Bertrand E, Schimidt Brum P, et al. Development and acceptability of a brief, evidence-based dementia awareness for caregivers course in low- and middle-income countries. Dementia (London) 2022 Feb 09;21(2):598-617 [FREE Full text] [doi: 10.1177/14713012211055316] [Medline: 34886707]
46. Orfanos S, Gibbor L, Carr C, Spector A. Group-based cognitive stimulation therapy for dementia: a qualitative study on experiences of group interactions. Aging Ment Health 2021 Jun 10;25(6):991-998 [FREE Full text] [doi: 10.1080/13607863.2020.1746740] [Medline: 32272849]
47. Education statistics: education attainment. The World Bank. URL: https://databank.worldbank.org/Average-years-of-schooling-of-adults-(male-and-female)/id/12d63977 [accessed 2024-04-09]

Abbreviations

CFIR: Consolidated Framework for Implementation Research
CST: cognitive stimulation therapy
LMIC: low- and middle-income countries
NGO: nongovernmental organization
vCST: virtual cognitive stimulation therapy
ZBI: Zarit Burden Interview

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The Needs and Experiences of People With Early-Stage Dementia Using an Application for Cognitive and Physical Activation in Germany: Qualitative Study

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Abstract

Background: The demand for support among people with dementia is increasing, while caregiving capacity is declining. As the trend of aging at home continues, technologies can help maintain the autonomy of people with dementia, enabling them to live independently for as long as possible. Furthermore, digital applications can have numerous positive biopsychosocial effects on the health of people with dementia, enhancing their physical, cognitive, and social functioning.

Objective: This study aims to investigate the needs and experiences of people with dementia regarding a prototype tablet-based application designed to promote cognitive and physical activity.

Methods: We conducted a methodical triangulation by combining semistructured interviews with people with dementia and external overt participant observation while testing a tablet-based application. A qualitative content analysis, as outlined by Kuckartz, was used to analyze the data.

Results: Participants demonstrated varying levels of ability and prior experience with technology. While most were initially hesitant to use the tablet independently, they were more willing to try it after receiving encouragement. Some individuals required more assistance than others, indicating the need for individualized adjustments. Personal relevance to the content appeared to be crucial for cognitive tasks, as it helped to minimize overload for people with dementia. The participants appreciated social interaction with researchers and direct communication. Therefore, it is important to consider the role of personal support when developing and implementing technology.

Conclusions: The successful implementation and use of technology requires acceptance and an effective interaction between people with dementia, technology, and caregivers or caring relatives providing personal support. The acceptance of the application was found to be less influenced by the types and presentation of tasks and more by content relevance and social interaction. Ideally, one-on-one support will be provided during use, though this requires additional time and financial resources, which are often limited in caregiving settings.

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KEYWORDS

touch-based digital technology; gerontology; geriatric; older; elderly; aging; aged; tablet-based technology; tablet; digital care application; mHealth; mobile health; app; health app; home care setting; caring relatives; dementia; MCI; Alzheimer; mild cognitive impairment; cognition; prototype; digital health; telehealth; dementia; memory loss; patient care; patient health; patient support

Introduction

Dementia is a leading cause of disability and care dependency among older adults worldwide [1]. Currently, around 50 million people are living with dementia; projections indicate that dementia prevalence will increase to 152 million by 2050 [2]. Consequently, the demand for support for people with dementia is increasing. This may become a key challenge due to the simultaneous decrease in caregiving capacity. In Germany, most people with dementia live in their own homes, where they receive care from family members acting as caring relatives (CRs) and from caregivers [3]. These support systems play a crucial role in dementia care, often by acquiring the skills to manage challenging behaviors associated with dementia [4].

Given the current trend toward aging at home, technology can help people with dementia preserve their autonomy, allowing them to live independently in familiar environments for as long as possible [5]. Integrating technology into dementia care can assist in preserving physical functions [6] and strengthening cognitive functions [7]. Personalized digital technologies have the potential to enhance the well-being of people with dementia by improving behavior, mood, sense of identity, and social interactions [8]. A holistic biopsychosocial approach is essential to address the complex needs of people with dementia, especially considering the frequent occurrence of multimorbidity in this population, which presents additional challenges for care and support [9].

The aim of this study is to investigate the needs and requirements of people with dementia regarding the use of interactive videos on a tablet computer, including cognitive and physical tasks to maintain their independence.

Methods

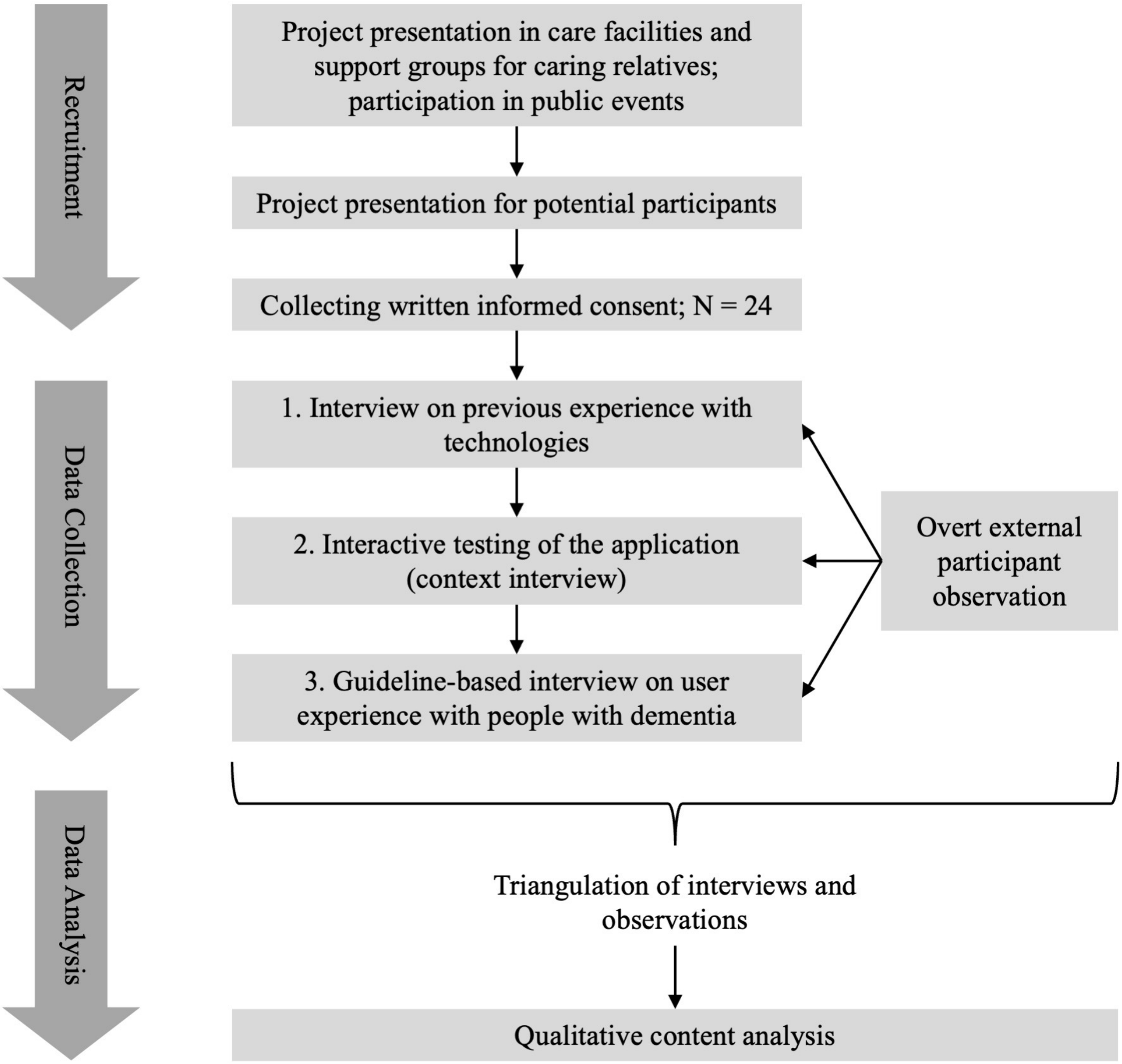
Ethical Considerations

The study was approved by the Ethics Committee of the German Society for Nursing Science (EK-22-038), and it complies with the Declaration of Helsinki. Prior to enrollment in the study, all participants provided written informed consent. All participants were anonymized. They did not receive any compensation.

Study Design

This study used a qualitative triangulation approach combining observations and interviews, with data from each method systematically aligned. The study was conducted in Germany and follows the SRQR (Standards for Reporting Qualitative Research) [10]. A summary of the study design and methodical approach is presented in Figure 1.

Figure 1. Methodical approach of presented study [11].



Sampling, Recruitment, and Field Access

The study included participants aged 50-90 years with mild cognitive impairment or early-stage dementia. They had to reside in Germany and were required to have sufficient verbal communication skills and adequate vision and hearing. Previous experience with mobile devices was intentionally not set as an inclusion criterion. Recruitment and access to participants were achieved by attending events; presentations in support groups; and visits to outpatient, semi-inpatient, and inpatient care facilities in Southwest Germany.

Data Collection

Data collection was done in day care centers or in participants' homes, using overt, external participant observations and guided context-driven interviews, which were recorded using a sound recorder. The process of data collection was divided into three phases:

1. A discussion of the participant's previous experience with digital technologies
2. Interactive testing of the application on a tablet computer (see Multimedia Appendix 1 for a section of the application's content)
3. A guideline-based interview to assess the user experience

We selected the interview questions considering the limited cognitive abilities of the participants. Therefore, they were formulated in a language that was easy to understand. Textbox 1 provides a summary of the key interview topics, along with representative examples of the types of questions posed.

Textbox 1. Key interview topics and representative questions

1. Prior experience and personal characteristics (age, ownership of a smartphone or tablet, use of a smartphone or tablet in daily life, reasons for utilisation or non-utilisation)

eg, Have you ever used a tablet computer before?

2. Overall evaluation of usage of the application (acceptance-rejection)

eg, How did you like using the tablet?

3. Usability and media presentation of the application (operability, design and layout, language)

eg, How clear was the sound?

4. Content of the application (evaluation of interaction content, evaluation of task types, personal content preferences)

eg, Which exercise did you like the most?

Each main question was followed by additional questions to gain a deeper insight into the context and motivations behind the participants' responses, ensuring a comprehensive understanding of their perspectives. We used a variety of open-ended and closed questions.

Two researchers conducted the data collection process. One researcher provided support during the use of the application by offering verbal assistance and aiding in the execution of the tasks to promote its use (Multimedia Appendix 2). The second researcher observed the process and made field notes based on predefined criteria, including attention span, facial expressions, and gestures, during the use of the application.

Data Analysis

After transcribing the meaning of the collected data, we carried out a qualitative content analysis according to Kuckartz [11]. The observation protocols were triangulated with the interviews. This allowed for unspoken aspects to be included in the analysis. Following the initial coding, related codes were grouped into categories, facilitating data organization and pattern recognition. Broader themes emerged through categorization, which was essential for understanding the data's underlying meaning. During data analysis, we supplemented deductive categories with inductive categories (Figure 1).

Results

Participants' General Perceptions of the Technology and Their Usage Patterns

The characteristics of the participants are presented in Table 1. The participants showed great heterogeneity in terms of skills and previous experience with technology, resulting in varying levels of proficiency in using a tablet computer. This is likely influenced by their prior experience, such as owning or not owning a mobile device. Overall, the participants demonstrated a high level of engagement while using the application, as indicated by focused attention on videos and comments related to the content. A majority of the participants expressed positive feedback regarding the application; however, many were unable to envision using the tablet computer independently.

Table . Profiles of people with dementia.

Study variables	Participants (N=24), n (%)
Sex	
Male	10 (42)
Female	14 (58)
Owning a smartphone or tablet	
Yes	10 (42)
No	14 (58)
Using a smartphone or tablet	
Often	5 (21)
Rarely	5 (21)
Never	14 (58)

Role of Technology Use

Most participants were proficient in recognizing visual elements, including both images and videos. However, observations regarding the varying effects of auditory stimuli on participants highlighted the challenge of designing an application that is balanced and accessible to different user groups.

Role of the Content Within the App

Cognitive Tasks

When evaluating preferences for task types, the participants demonstrated indifference toward task types, including arithmetic, pictorial, and auditory tasks. Instead, they were more engaged when the content was personally relevant to their experiences. Tasks within the application fell into three categories: those that can be solved based on personal experience, those that can only be solved in the context of the story, and those that require acquired knowledge or skills.

Personal Experiences

The individual experiences of people with dementia played a crucial role in recognizing locations depicted in the application scenes. In particular, visual and haptic experiences, such as walking through a meadow and associated memories of the perceived feeling, acted as triggers for verbal expressions from the participants. Familiar memories evoked by the content may have fostered interest and concentration.

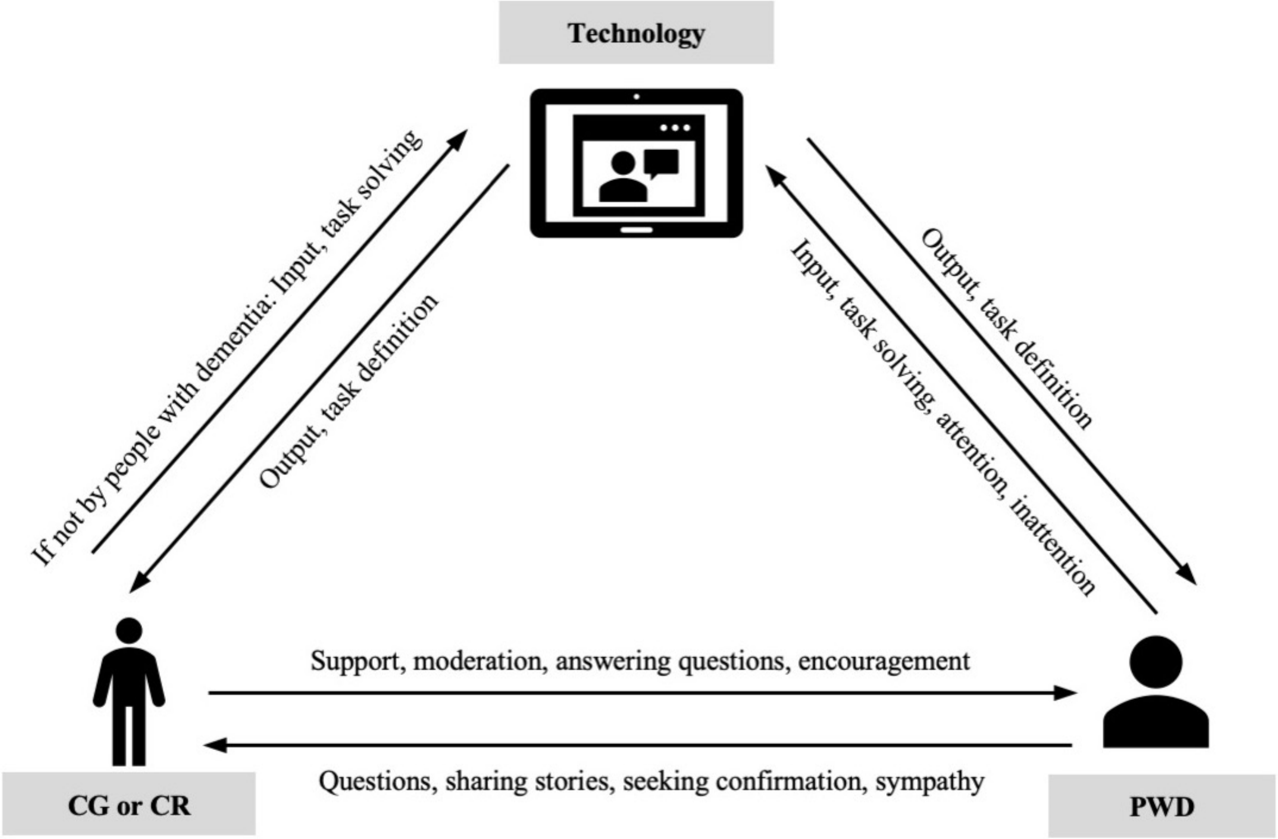
Role of Personal Support During Use

Initially, most participants were hesitant to use the tablet independently but were willing to try it after receiving positive reinforcement from the researcher.

It was noticeable that the participants often sought contact with the researchers for personal support and reassurance, frequently sharing personal stories, even while watching videos or receiving task instructions. This highlighted a strong desire for communication and social interaction while using the application.

When uncertain, the participants appreciated clear instructions from the researchers and were not hesitant to ask further questions (Figure 2). Data suggests that these positive feelings toward the researchers—whether, derived from sympathy, their presence or social interaction likely influenced their perceived acceptance and evaluation of the application positively. The participants’ politeness also contributed to their willingness to engage with the application and give positive feedback. In addition, participation in the study and the resulting change in the participants’ daily routine may have positively influenced the overall evaluation of the application.

Figure 2. Interaction between technology, PWD, and CGs or CRs [12]. CG: caregiver; CR: caring relative; PWD: people with dementia.



Discussion

Principal Results

The findings indicate that personal support is crucial for a successful overall interaction while using the application. If it is not possible for people with dementia to use the application independently, alternative scenarios for use must be considered. One such scenario is one-to-one support by CRs or caregivers, which fosters social interaction. This support can motivate users and encourage device use, highlighting the relational aspects of care that are important for people with dementia. However, providing direct support requires time, a resource that is often limited for caregivers [13]. Additionally, one-to-one support can be a financial burden, as CRs perceive the associated expenses as high and, consequently, may refrain from using the application [14].

We discovered that the type of task and the visual presentation of cognitive tasks (image-based, text-based, or auditory) were secondary in importance. Instead, the content of the tasks played a more crucial role. To develop tasks that activate cognition, it is necessary to design content that establishes an emotional connection for people with dementia with their prior experiences and interests. This approach is fundamental for the acceptance of the technology. Additionally, including relational aspects, such as sharing relevant anecdotes or engaging in social interaction, further enhances the effectiveness of the technology and its acceptance by people with dementia.

Limitations

The reliability of the study may be reduced due to participants potentially adopting a desirable response and behavior during interviews. To address this, we triangulated the data by including observations along with mutual verification among the researchers. The researchers’ reflexivity regarding their own roles in the study ensures a higher level of objectivity.

Comparison With Prior Work

In a previous study, expert interviews were conducted to analyze the requirements for an application for people with dementia. The application tested in the current study was designed based on those findings [15].

According to our study, acceptance is the base for a successful engagement with the application. A systematic review reported similar results, emphasizing the importance of acceptance [6]. For a successful engagement, social context is another crucial factor, as highlighted by our study findings. Smith et al [16] discovered that technology use is perceived more as a social event by people with dementia when they are in the presence of others or in groups. The tablet computer serves as a catalyst for conversation, facilitating the exchange of interesting anecdotes [16].

Woods et al [17] demonstrated that biographical reference plays an important role in solving cognitive tasks for people with dementia. Although they often struggle to recall recent events, they are able to retain childhood memories. Tasks that include biographical references can be easier for people with dementia, as they include leveraging their cognitive strengths and minimizing overload.

Conclusions

While designing an application for patients with dementia, it is important to consider the heterogeneity in this group and dependence on their daily fluctuating cognitive state. Therefore, providing opportunities for individualized adaptation of the technology is crucial for addressing diverse interests and abilities. Biographical content-related tasks can have a positive impact on cognitive activation. It is therefore reasonable to suggest that such interventions linked to biography could also be employed in individuals with other neurodegenerative diseases with the objective of preserving cognitive abilities and memories.

The participants in this study expressed a common interest in social interaction. Therefore, it is important to consider the significant role of personal support when developing and implementing technology, and ensuring easy access. Potential users, CRs, and caregivers should face as few barriers as possible when learning, purchasing, and using the application. This is particularly important, given the short period of use due to the changing cognitive state. If these conditions are met, this application has the potential to promote independent living among people with dementia.

Data Availability

Anonymized datasets generated or analyzed during the study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
A section of the application’s content.
[PNG File, 1476 KB - aging_v7i1e62689_app1.png]

Multimedia Appendix 2
The personal support that was provided while using the application.
[PNG File, 485 KB - aging_v7i1e62689_app2.png]

References

1. Dementia. World Health Organization. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2024-02-18]
2. World Alzheimer Report 2018: the state of the art of dementia research. Alzheimer’s Disease International. 2018. URL: https://www.alzint.org/u/WorldAlzheimerReport2018.pdf [accessed 2024-12-06]
3. Bartholomeyczik S, Halek M. Pflege von menschen mit demenz. In: Jacobs K, Kuhlmey A, Greß S, Klauber J, Schwinger A, editors. Pflege-Report 2017: Schattauer; 2017:51-62.
4. Arvanitakis Z, Shah RC, Bennett DA. Diagnosis and management of dementia: review. JAMA 2019 Oct 22;322(16):1589-1599. [doi: 10.1001/jama.2019.4782] [Medline: 31638686]
5. Shu S, Woo BKP. Use of technology and social media in dementia care: current and future directions. World J Psychiatry 2021 Apr 19;11(4):109-123. [doi: 10.5498/wjp.v11.i4.109] [Medline: 33889536]
6. Brown A, O’Connor S. Mobile health applications for people with dementia: a systematic review and synthesis of qualitative studies. Inform Health Soc Care 2020 Oct 1;45(4):343-359. [doi: 10.1080/17538157.2020.1728536] [Medline: 32237937]
7. Saragih ID, Wei CW, Batubara SO, Saragih IS, Lee BO. Effects of technology-assisted interventions for people with dementia: a systematic review and meta-analysis. J Nurs Scholarsh 2023 Jan;55(1):291-303. [doi: 10.1111/jnu.12808] [Medline: 36056586]
8. Goodall G, Taraldsen K, Serrano JA. The use of technology in creating individualized, meaningful activities for people living with dementia: a systematic review. Dementia (London) 2021 May;20(4):1442-1469. [doi: 10.1177/1471301220928168] [Medline: 32475166]
9. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 8;396(10248):413-446. [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
10. O’Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014 Sep;89(9):1245-1251. [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
11. Kuckartz U. Qualitative Text Analysis: a Guide to Methods, Practice & Using Software: SAGE; 2014. [doi: 10.4135/9781446288719]
12. Huber S, Berner R, Uhlig M, Klein P, Hurtienne J. Tangible objects for reminiscing in dementia care. Presented at: TEI ’19; Mar 17-20, 2019; Tempe, AZ. [doi: 10.1145/3294109.3295632]
13. Schultz T. Technik und demenz. In: Gebhard D, Mir E, editors. Gesundheitsförderung Und Prävention Für Menschen Mit Demenz: Grundlagen Und Interventionen: Springer; 2019:239-255. [doi: 10.1007/978-3-662-58130-8_16]

14. Sriram V, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. BMC Geriatr 2019 Jun 14;19(1):160. [doi: 10.1186/s12877-019-1169-0] [Medline: 31196003]
15. von Bosse A, Bejan A, Wessel M, Kunze C. Gestaltungs- und evaluationsmöglichkeiten von multimediaanwendungen zur unterstützung der betreuung von menschen mit leichter demenz. Z Gerontol Geriat 2024 Aug;57(5):382-388. [doi: 10.1007/s00391-023-02280-2] [Medline: 38265455]
16. Smith SK, Mountain GA, Hawkins RJ. Qualitatively exploring the suitability of tablet computers to encourage participation with activities by people with moderate stage dementia. Dem (Lon) 2020 Jul;19(5):1586-1603. [doi: 10.1177/1471301218802897] [Medline: 30269531]
17. Woods B, O'Philbin L, Farrell EM, Spector AE, Orrell M. Reminiscence therapy for dementia. Cochrane Database Syst Rev 2018 Mar 1;3(3):CD001120. [doi: 10.1002/14651858.CD001120.pub3] [Medline: 29493789]

Abbreviations

CR: caring relative
SRQR: Standards for Reporting Qualitative Research

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Baseline Smartphone App Survey Return in the Electronic Framingham Heart Study Offspring and Omni 1 Study: eCohort Study

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Abstract

Background: Smartphone apps can be used to monitor chronic conditions and offer opportunities for self-assessment conveniently at home. However, few digital studies include older adults.

Objective: We aim to describe a new electronic cohort of older adults embedded in the Framingham Heart Study including baseline smartphone survey return rates and survey completion rates by smartphone type (iPhone [Apple Inc] and Android [Google LLC] users). We also aim to report survey results for selected baseline surveys and participant experience with this study's app.

Methods: Framingham Heart Study Offspring and Omni (multiethnic cohort) participants who owned a smartphone were invited to download this study's app that contained a range of survey types to report on different aspects of health including self-reported measures from the Patient-Reported Outcomes Measurement Information System (PROMIS). iPhone users also completed 4 tasks including 2 cognitive and 2 physical function testing tasks. Baseline survey return and completion rates were calculated for 12 surveys and compared between iPhone and Android users. We calculated standardized scores for the PROMIS surveys. The Mobile App Rating Scale (MARS) was deployed 30 days after enrollment to obtain participant feedback on app functionality and aesthetics.

Results: We enrolled 611 smartphone users (average age 73.6, SD 6.3 y; n=346, 56.6% women; n=88, 14.4% Omni participants; 478, 78.2% iPhone users) and 596 (97.5%) returned at least 1 baseline survey. iPhone users had higher app survey return rates than Android users for each survey (range 85.5% to 98.3% vs 73.8% to 95.2%, respectively), but survey completion rates did not differ in the 2 smartphone groups. The return rate for the 4 iPhone tasks ranged from 80.9% (380/470) for the gait task to 88.9% (418/470) for the Trail Making Test task. The Electronic Framingham Heart Study participants had better standardized *t* scores in 6 of 7 PROMIS surveys compared to the general population mean (*t* score=50) including higher cognitive function (n=55.6) and lower fatigue (n=45.5). Among 469 participants who returned the MARS survey, app functionality and aesthetics was rated high (total MARS score=8.6 on a 1 - 10 scale).

Conclusions: We effectively engaged community-dwelling older adults to use a smartphone app designed to collect health information relevant to older adults. High app survey return rates and very high app survey completion rates were observed along with high participant rating of this study's app.

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KEYWORDS

mHealth; mobile health; mobile application; smartphone; digital health; digital technology; digital intervention; gerontology; geriatric; older adult; aging; eFHS; eCohort; smartphone app; baseline app surveys; Framingham Heart Study; health information; information collection; mobile phone

Introduction

The use of information and communication technologies (ICTs) was essential to access health care and address everyday needs during the COVID-19 pandemic. ICTs were especially important for older adults during this time, as in-person health care encounters may have placed vulnerable older adults at risk for adverse health events. A nationwide representative survey of adults aged 65 years and older reported an increase of more than 50% in use of ICTs during the COVID-19 pandemic [1]. However, gaps remained, as ICT use was lower among groups that did not learn how to use a new technology reinforcing the known age disparity in technology use [2,3]. In addition to advanced age, lower education, lower income, and reported fair or poor general health were factors associated with not learning to use new technology [1]. A smartphone study of cognition among older adults also noted that older age was associated with less familiarity with and engagement with technology [4]. However, once older adults enrolled adherence was high and furthermore adherence was not associated with gender, race, education, or technology knowledge [4]. Hence, if barriers to engagement and appropriate technologic support can be improved for those older adults that need it, digital tools may improve the lives of older adults by permitting self-monitoring of health at home outside the clinical environment.

Smartphone apps are used to monitor chronic conditions and offer opportunities for cognitive and physical function self-assessment conveniently at home but the usability of the apps are often uncertain especially among older adults [5,6]. A small study of patients with heart failure from cardiac units at an academic medical center demonstrated the feasibility of collecting health information using short questionnaires delivered by mobile app [7]. The usability scores were high, including perceived ease of use [7]. Smartphone-based tools for cognitive assessment permit more frequent assessments at home ahead of health care provider visits and may also provide information about cognitive change in adults at risk for dementia [8]. Smartphone apps and digital sensors also have the ability to record real-world measures of physical activity, gait, and mobility known to be important to independent living [9]. However, older adults have been underrepresented in electronic cohort (eCohort) [10-12] with few digital health studies including larger numbers of older adults [13].

We recruited and enrolled an eCohort of older adults, mean age 73.6 (SD 6.3) years, across the COVID-19 pandemic, embedded in the well characterized Framingham Heart Study (FHS) Offspring and Omni cohorts. We designed a smartphone app to collect health information across a range of domains using different types of smartphone surveys, and smartphone cognitive and physical function testing tasks. We report our experience with baseline smartphone survey return and completion to understand how community-dwelling older adults interact with smartphone technologies. Further, we report the survey results for representative surveys and for a cognitive testing task. Finally, participant-reported usability was assessed with the Mobile App Rating Scale (MARS) survey to better understand the older user's experience with the app. Usability was investigated by device type (iPhone and Android smartphone type), participant age, and sex. We hypothesized that iPhone users and younger participants would perceive the smartphone app more favorably. We observed iPhone users to have greater survey return in our prior work in middle-aged participants and others have reported that Apple users are more familiar with technology and more likely to use apps [14,15].

Methods

Study Sample

The Electronic Framingham Heart Study (eFHS) enrolled participants from the FHS Offspring cohort (recruited in 1971 - 1975, n=5124) and the multiethnic Omni 1 cohort (recruited from 1994 - 1998, n=506). Both cohorts were recruited in Framingham Massachusetts and have been examined every 4 to 8 years since enrollment [16]. Beginning January 25, 2021, eligible participants enrolled in eFHS during their in-person research center examination (Offspring examination 10/Omni examination 5). English-speaking participants who owned a smartphone (iPhone running iOS 10 or higher or Android version 7 or higher) were invited to download the eFHS app designed for Offspring and Omni cohort participants. If participants did not own a smartphone or the smartphone was not compatible with this study's app, they were invited to participate using a computer if they had one at home. Participants examined in a nursing home were excluded. All participants provided informed consent as part of the overall parent Offspring examination 10/Omni examination 5 and electronic informed consent was part of the eFHS app. Participants signed the consent forms electronically and were able to access the signed consent forms within this study's app. Before June 2021, participants were offered the choice of receiving surveys every 4 weeks or every 2 weeks. Starting in June of 2021, participants additionally provided consent to be randomized to one of two groups for smartphone app survey deployment (randomized controlled trial, NCT04752657). One randomized group received all surveys every 4 weeks and the other group received the same number of surveys in 2 smaller batches every 2 weeks. For the purposes of this study baseline surveys were defined as surveys that went out at enrollment (wk 0) or at week 2 after enrollment.

This study's research technician assisted participants with app download from the App store or Android Google play store. A welcome screen appeared at the initial opening of this study's app (Figure S1 in Multimedia Appendix 1), along with a request for permission to receive study notifications, and steps with instructions for enrollment. Upon the completion of the enrollment and consent process, participants received their initial smartphone app surveys. For participants who did not come to the research center for the examination, this study's research technician provided enrollment support over the telephone or via Zoom. Participants also received step-by-step written instructions on how to download this study's app and enroll in eFHS, with a brief explanation of the purpose of each app survey and contact information should technical support be needed or questions arise. Study notifications were sent through this study's app to welcome participants to this study, to thank participants for completing surveys, to remind participants when surveys were due, and to inform participants when new surveys became available. Finally, this study's technician attempted to contact all participants1 week after enrollment to provide any needed technical support and answer any questions related to this study's app.

eFHS continued to enroll participants after the completion of Offspring examination 10/Omni examination 5 in order to (1) capture participants who came into the research center examination before the start of enrollment for eFHS and (2) to invite participants who did not come into the research center for the examination but participated in the examination by televisit only (Figure 1). Offspring examination 10/Omni examination 5 (September 2019 to June 2022) occurred across the COVID-19 pandemic (March 2020 to May 2023) and the parent study permitted participants to attend the examination in-person, by televisit, or by off-site visit by sending FHS staff to the participant's home. The COVID-19 pandemic coincided with eFHS enrollment as shown in Figure 2. Active COVID cases in Massachusetts reached a peak in January in both 2021 and 2022, which coincided with the lowest enrollments in eFHS. During summer months in both years, active COVID cases dropped to the lowest and the enrollments increased [17]. In total eFHS enrolled 620 Offspring and Omni participants including 478 iPhone users, 133 Android users, and 9 computer users (Figure 1). Computer users were excluded from this study.

Figure 1. eFHS Offspring and Omni enrollment. eFHS: Electronic Framingham Heart Study.

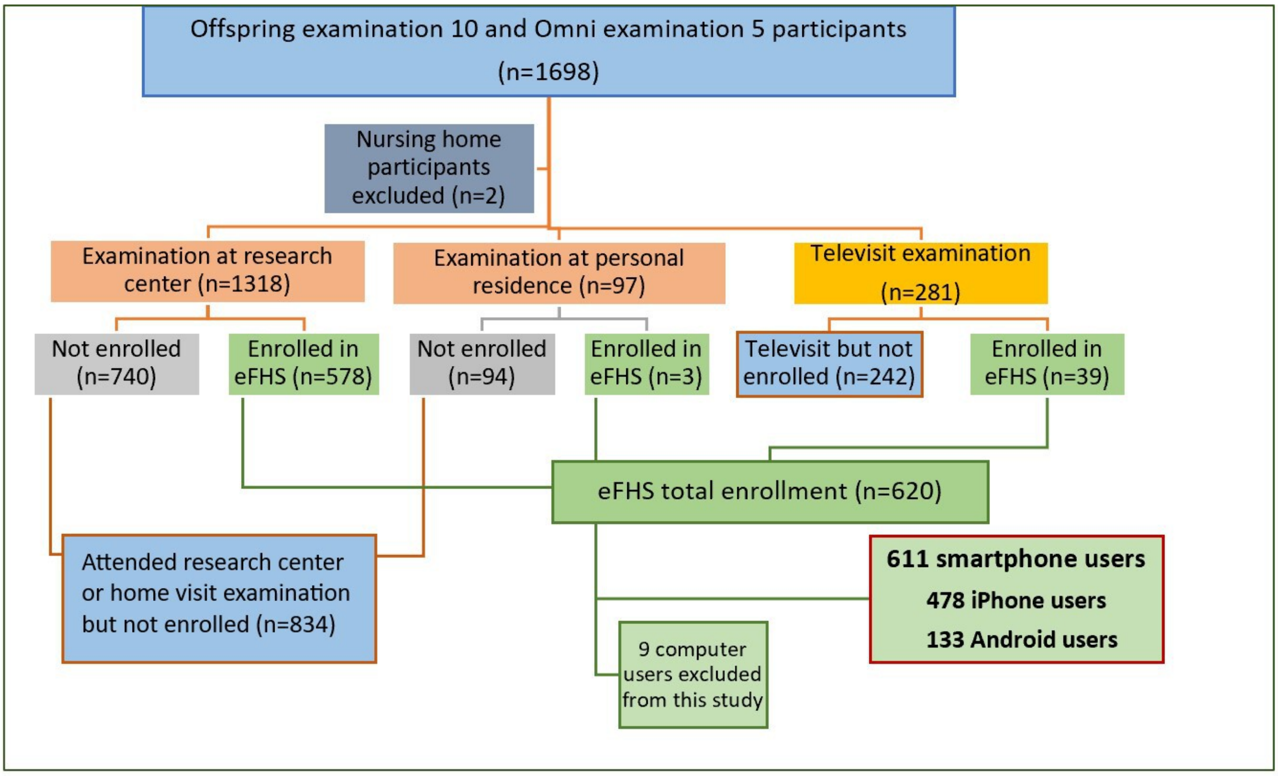
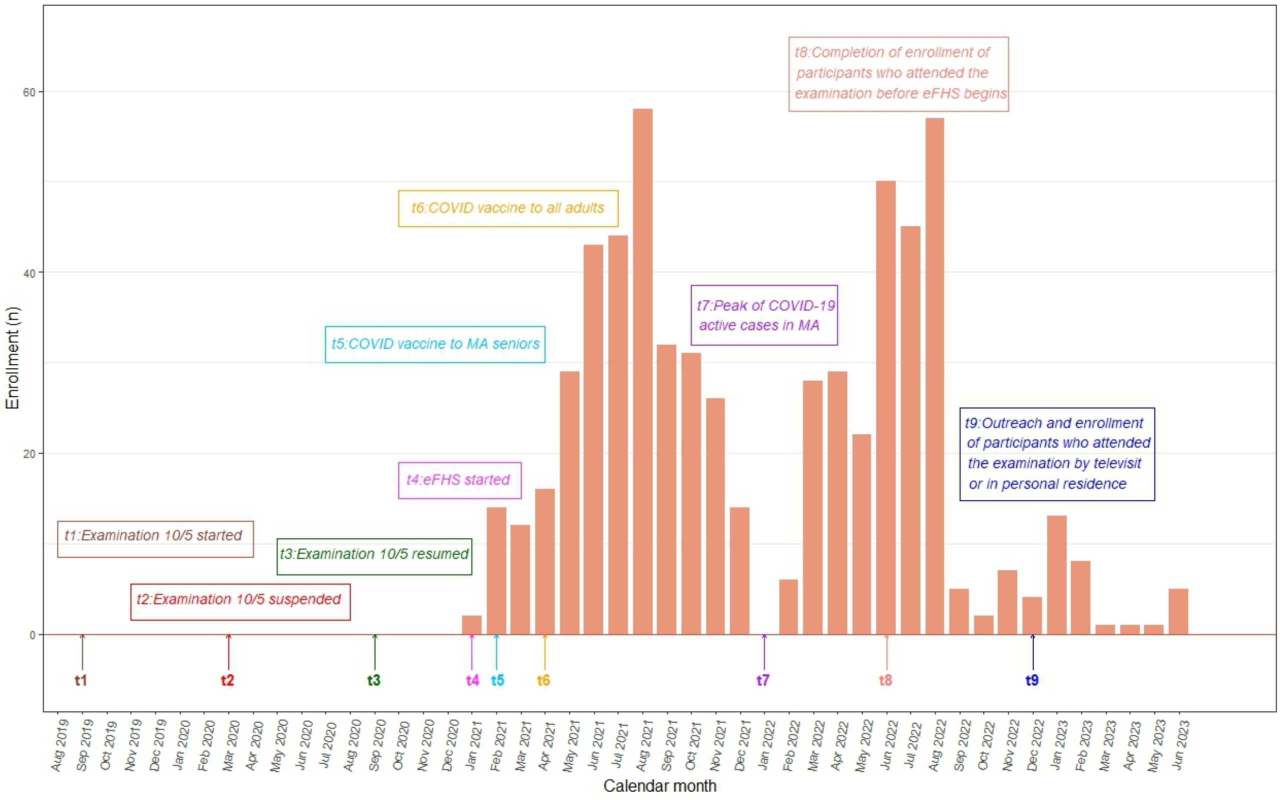


Figure 2. eFHS Offspring and Omni enrollment and timeline. eFHS: Electronic Framingham Heart Study; MA: Massachusetts.



eFHS Offspring or Omni Smartphone App

We created smartphone surveys for the eFHS Offspring and Omni participants using CareEvolution's MyDataHelps Designer platform and the MyDataHelps mobile app container (CareEvolution). The MyDataHelps app hosts different types of surveys and tasks (Figure S1 in Multimedia Appendix 1), an account where participants can see their signed consent form, and a dashboard to provide participants with survey completion status and a "thank you" message of encouragement. The surveys and tasks were designed to be sent out on enrollment (wk 0) and at various intervals after enrollment for up to 1 year. At baseline, participants were asked to complete 12 health surveys through the app and iPhone owners were asked to complete an additional 4 tasks.

Survey assessments were chosen for relevance to the health of older adults and included assessments of cognition, mood, pain, physical function, physical activity, and events such as falls and hospitalizations. Self-reported surveys from the short form of the Patient-Reported Outcomes Measurement Information System (PROMIS) were selected and included [18]: anxiety, depression [18], fatigue [19,20], sleep [21], physical function [22], pain [23], cognitive abilities, and cognitive function [24]. Most of the PROMIS surveys were 4-item multiple choice questions with response choices that ranged from "never" to "always" for the mood surveys to "never" to "very often" or "not at all " to "very much" for the cognitive assessment surveys. A modified version of the Michigan Body Pain Map [25] was additionally used to collect information on chronic pain and included a pictorial image of the front and back of the human body (Figure S2 in Multimedia Appendix 1). Participants were asked to check the places on the body where they felt persistent or recurrent pain for 3 months or longer (chronic pain). If no chronic pain was experienced, a separate box of "no chronic pain" was provided. A second survey related to mood included 3 items used to define physical frailty including unintentional weight loss, and 2 items from the Center for Epidemiologic Studies-Depression Scale [26]. The final baseline surveys queried physical activity level with the Rapid Assessment of Physical Activity Survey [27], mobility outside the home including "other rooms," "outside your home," "neighborhood," "outside your neighborhood," and "outside your town" [28], and occurrences of falls and hospitalizations.

Four smartphone testing tasks operated on the iPhone and included 2 commonly used cognitive tests, a gait task, and a motor task. The Trail Making Test [29,30] is a timed assessment that requires the participant to tap a series of dots in order alternating between numbers and letters starting with the number "1" followed by tapping the letter "A" until the number "7" is reached. The completion time and errors are recorded. The Victoria Stroop Test (Stroop) [31] includes a series of 4 increasingly more difficult tasks with a practice session provided for each of the 4 tasks. People with color blindness were excluded as the tasks require the participant to be able to distinguish colors (yellow, green, red, and blue). In each of the 4 subtasks, participants are asked to select the matching color to the block color, the word color, the font color, and the word color if the word was underlined or the font color if the word was not underlined, respectively (Figure S2 in Multimedia Appendix 1). The gait task [32], instructs the participants, in a human voice, to walk a set distance and the walking time was recorded. The 2-finger tapping [33] asked participants to tap on the screen for 20 seconds on the designated spots as quickly as possible using 2 fingers. The tapping speed and accuracy were recorded.

Six baseline surveys (2 mood surveys, pain, body pain map, cognitive function, and cognitive abilities) and all 4 cognitive and physical function testing tasks were deployed at baseline week 0. Another 6 baseline surveys (physical function, sleep, fatigue, mobility outside the home, rapid assessment of physical activity, and falls and hospitalizations) were deployed at week 0 or week 2, depending on participants' choice or randomization group (4 wk vs 2 wk, respectively).

Participant Feedback on the Smartphone App

Participants completed the MARS survey [34] and the System Usability Scale (SUS) [35] on their smartphone to obtain feedback about their experience with the eFHS study app. The MARS included questions on app functionality and aesthetics including performance, ease of use, navigation, layout, graphics, and visual appeal. Items were rated by the participant using a 5-point Likert scale from 1=inadequate to 5=excellent. The SUS included 10 multiple choice questions including "I found the app unnecessarily complex" and "I thought the app was easy to use." We modified the response options for each question from the original 5-point Likert scale to 4 response options "strongly agree," "agree," "disagree," and "strongly disagree." The 4 options were assigned scores 1, 2, 4 and 5, respectively. The total SUS score was not computed because of the modification in response choices from a 5-point Likert scale to a 4-point Likert scale. The MARS and SUS were sent to participants 30 days after enrollment to allow participants an opportunity to use the app and complete the baseline surveys and tasks.

Offspring Examination 10 or Omni Examination 5 Data Collection

As part of the routine research examination participants self-reported data was collected on education, retirement status, marital status, and subjective health (in general would you say your health is excellent, very good, good, fair, or poor). Participants were asked to bring medications in a medication bag provided to the examination and medications were recorded. Trained technicians administered the 20-item Center for Epidemiologic Studies-Depression Scale with scores that range from 0 to 60 and the Mini-Mental State Examination cognitive screen (scores range 0 - 30).

Statistical Methods

Participant characteristics were calculated as means and SDs for continuous variables and counts and percentages for categorical variables. We compared characteristics of the eFHS study sample smartphone participants (n=611) to 2 groups of nonparticipants (Table S1 in Multimedia Appendix 1), those who attended the examination in-person (n=834) and those who attended the examination via televisit (n=242). Student *t* tests were performed for continuous variables and chi-square tests were performed for categorical variables. The smartphone survey return rates and completion rates were calculated. The return rate was defined as the percentage of participants who returned a specific baseline survey among the total number of participants who returned at least 1 baseline survey.

baselinereturnrate=nreturnedindividualbaselinesurveynreturnedatleastonebaselinesurveys

The completion rate was defined as the percentage of participants who completed a survey among participants who returned the survey. The completion of a survey was defined as answering 75% of the questions if the survey had 4 or more questions, answering at least 2 questions if the survey had 3 questions. For the falls and hospitalization survey, which has 2 main questions, completion was defined as answering both questions.

baselinecompletionrateforeachsurvey=ncompletedthesurveynreturnedthesurvey

The return rate and completion rate were compared between iPhone users and Android users and between the 2 deployment groups (app surveys sent every 4 wk vs app surveys sent every 2 wk in smaller batches), using chi-square tests.

We examined baseline surveys' results from the self-reported PROMIS surveys (anxiety, depression, fatigue, sleep, cognitive abilities, cognitive function, and physical function) and results from the cognitive function testing task using the Stroop cognitive test given the interest in the research community on incorporating standardized assessments for older adults [36] and mobile cognitive testing. The individual PROMIS surveys were scored and the raw scores were converted to the PROMIS standardized *t* scores [37]. One sample *t* test (2-tailed) was performed to compare scores from our sample to the *t* score of the general population [37]. For the Stroop cognitive testing task, we calculated the completion time and errors of each of the 4 subtasks for each participant. The total completion time of the Stroop Test was calculated and compared between male and female participants, and between age groups younger than 75 years and at or older than 75 years of age.

The MARS and the SUS scores were calculated to assess the usability of the app [35,38]. The total MARS score, the functionality score, and the aesthetics score were calculated and compared between smartphone user groups (iPhone users vs Android users), men and women, and age-groups. Total MARS score is the summation of functionality score and aesthetics score. We also calculated the individual scores for each item of the MARS and SUS and conducted subgroup comparisons (phone type, age group, or sex) using chi-square tests. Due to small sample sizes for some response choices, responses were recategorized. For the MARS, responses 1, 2, and 3 were grouped together and responses 4 and 5 were grouped together. Similarly in the SUS, responses were collapsed into 2 groups: agree or strongly agree and disagree or strongly disagree. The chi-square tests were performed on the regrouped 2-level variables. We performed all analyses with RStudio in R (version 4.3.1; R Foundation) for Windows and considered 2-sided $P<.05$ as statistically significant.

Ethical Considerations

The Offspring examination 10 and Omni examination 5 and the eFHS protocols were reviewed and approved by the Institutional Review Board at Boston University Medical Center (protocol numbers H-32132, H-36586, and H-40737). iPhone users were allowed to choose to use a study Apple Watch. No compensation was given to participants. Data were anonymized for analysis.

Results

Characteristics of eFHS Smartphone Participants

Among FHS Offspring and Omni participants, 611 smartphone users enrolled in eFHS, with a mean age of 73.6 (SD 6.3) years, and included 346 (56.6%) women, 88 (14.4%) multiethnic participants, and 478 (78.2%) iPhone users. eFHS smartphone users on average were well educated (396/610, 64.9% college degree or greater) and reported very good to excellent health (428/610, 70%; Table 1). Among 526 FHS participants who did not enroll in eFHS and provided a reason for declining, 118 (22.4%) did not own a smartphone or computer, 323 (61.4%) did not have an interest in this study, 61 (11.6%) owned technology that was incompatible with the application, and 24 (4.6%) reported a health issue or other reasons. Compared to FHS participants who attended examinations at the research center but did not enroll, eFHS participants using a smartphone on average were younger (73.6, SD 6.3 vs 78.4, SD 8.1, *P*<.001), healthier (428/610, 70.2% vs 480/820, 58.5% self-reported very good or excellent in health, *P*<.001), better educated (396/610, 64.9% vs 328/823, 39.9% with a bachelor's degree and above, *P*<.001), more likely to be married (421/609, 69.1% vs 453/824, 55.0%, *P*<.001), and more likely to be an iPhone user (478/611, 78.2% vs 248/728, 34.1%, *P*<.001) as presented in Table S1 in Multimedia Appendix 1.

Table . Characteristics of the Electronic Framingham Heart Study (eFHS) smartphone users.

Variables		eFHS participants (N=611)
Age (years), mean (SD)		73.6 (6.3)
Sex (female), n (%)		346 (56.6)
Cohort, n (%)		
	Offspring	523 (85.6)
	Omni	88 (14.4)
Smartphone, n (%)		
	iPhone	478 (78.2)
	Android	133 (21.8)
Education, n (%)		
	High school graduates or lower	67 (11)
	Some college or technology certificate	147 (24.1)
	Bachelor's degree and above	396 (64.9)
Income (US $), n (%)		
	<$35,000	50 (10.2)
	$35,000-$74,999	136 (27.8)
	≥$75,000	304 (62)
Retirement status, n (%)		
	Retired and not working	322 (52.8)
	Retired but working (pay or volunteer)	103 (16.9)
	Not retired	185 (30.3)
Marital status (married), n (%)		421 (69.1)
Subjective health, n (%)		
	Poor or fair	25 (4.1)
	Good	157 (25.7)
	Very good or excellent	428 (70.2)
Depressive symptoms, mean (SD)		5.6 (6.5)
Number of medications, mean (SD)		5.1 (3.8)
Mini-Mental State Examination score, mean (SD)		28.7 (1.4)
Walk test, meters/second, mean (SD)		1.13 (0.22)

Survey Return Rates and Completion Rates

Among the 611 eFHS smartphone users, 596 (97.5%) returned at least 1 baseline survey including 470 of 478 (98.3%) iPhone users and 126 of 133 (94.7%) Android users. The iPhone users had a slightly higher return of at least 1 baseline survey compared to Android users (98.3% vs 94.7%, *P*=.02). For nearly all the individual baseline surveys, compared to the Android users, the iPhone users had a higher return rate (Tables 2 and 3). For both iPhone and Android users, the set of individual surveys sent at week 0 had higher return than the set of individual surveys sent at week 0 or week 2 (iPhone wk 0 survey return, 437/470, 93% to 462/470, 98.3% vs wk 0 or wk 2 return 402/470, 85.5% to 437/470, 93%; and Android wk 0 survey return, 109/126, 86.5% to 120/126, 95.2% vs wk 0 or wk 2 return 93/126, 73.8% to 99/126, 78.6%). Both smartphone user groups had very high completion rates for all baseline surveys, all above 90% indicating once the participant returned the surveys, they were very likely to complete them (Tables 2 and 3). Individual survey return differed by deployment group. Participants who received baseline surveys in smaller batches every 2 weeks had lower return rates for the set of individual surveys sent out at week 2 compared to participants who received the same set of surveys at week 0 (Table S2 in Multimedia Appendix 1, all *P*<.002). Baseline survey return did not differ by deployment group for the set of individual surveys sent at enrollment (wk 0). There was no difference in completion rates between the 2 deployment groups (Table S2 in Multimedia Appendix 1). The return rate for the 4 tasks ranged from 380 of 470 (80.9%) for the gait task to 418 of 470 (88.9%) for the Trail Making Test task (Table 3).

Table . Survey return rates and completion rates in iPhone and Android users who returned at least 1 baseline survey. Some participants received all baseline surveys at week 0 and some participants received some baseline surveys at week 0 and the remaining at week 2. Surveys under all week 0 were deployed at week 0. Surveys under week 0 or week 2 were deployed at week 0 or week 2. All the *P* values in comparing the completion rates are >.05.

Survey or task		Return, n (%) iPhone users (n=470)	Return, n (%) Android users (n=126)	*P* value	Completion, n (%) iPhone users (n=470)	Completion, n (%) Android users (n=126)
All week 0						
	Mood (depression and anxiety)	444 (94.5)	109 (86.5)	.002	439 (98.9)	108 (99.1)
	Mood 2	462 (98.3)	115 (91.3)	<.001	458 (99.1)	113 (98.3)
	Pain	438 (93.2)	110 (87.3)	.03	437 (99.8)	110 (100)
	Body pain map	461 (98.1)	120 (95.2)	.07	461 (100)	120 (100)
	Cognitive function	439 (93.4)	110 (87.3)	.02	437 (99.5)	109 (99.1)
	Cognitive abilities	437 (93)	109 (86.5)	.02	436 (99.8)	109 (100)
Week 0 or week 2						
	Physical function	426 (90.6)	96 (76.2)	<.001	424 (99.5)	96 (100)
	Sleep	429 (91.3)	99 (78.6)	<.001	424 (98.8)	97 (98)
	Fatigue	428 (91.1)	97 (77)	<.001	426 (99.5)	97 (100)
	Mobility outside the home	426 (90.6)	99 (78.6)	<.001	420 (98.6)	96 (97)
	Rapid assessment of physical activity	437 (93)	97 (77)	<.001	425 (97.3)	91 (93.8)
	Falls or hospitalization	402 (85.5)	93 (73.8)	.002	364 (90.6)	88 (94.6)

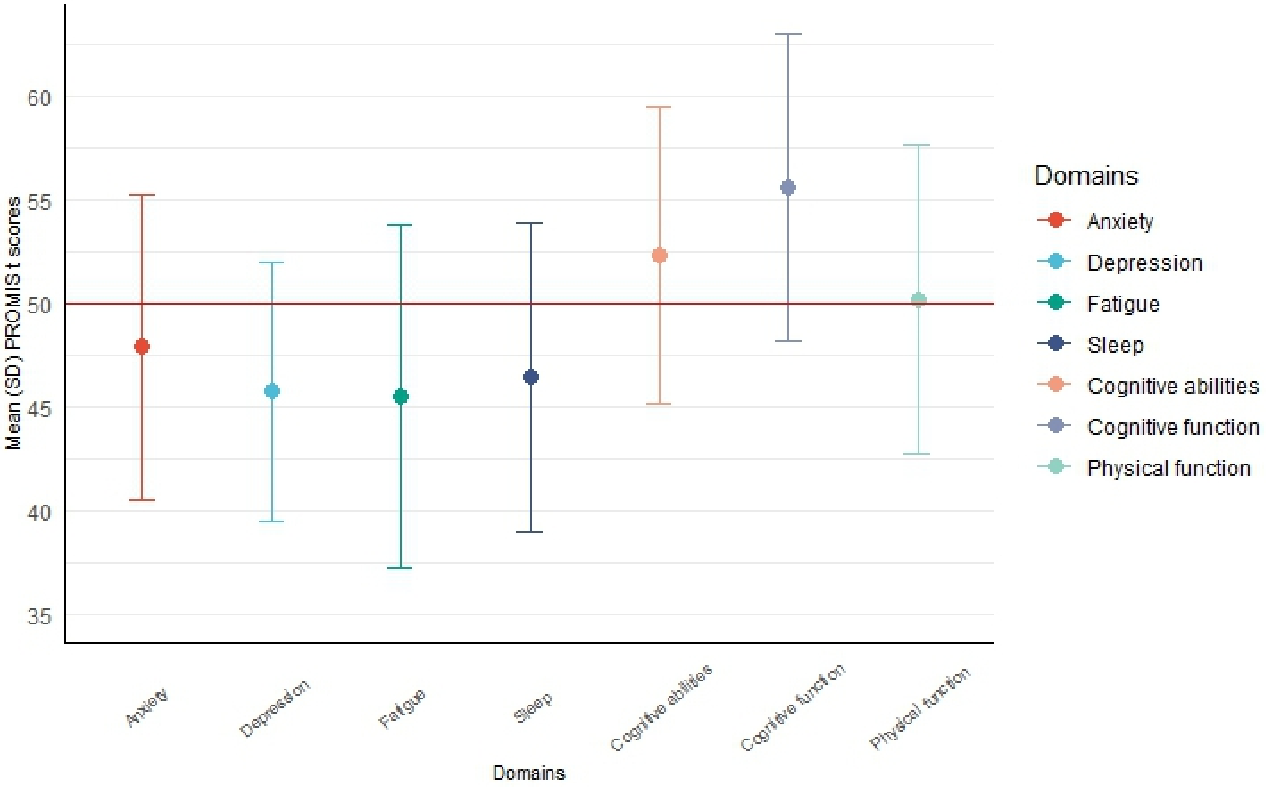
Table . iPhone only tasks, week 0.

	Returned, n (%)
Trail Making Test	418 (88.9)
Stroop	404 (86)
Two-finger tap	417 (88.7)
Gait	380 (80.9)

Distribution of PROMIS Scores Across Domains and Stroop Task Completion Time

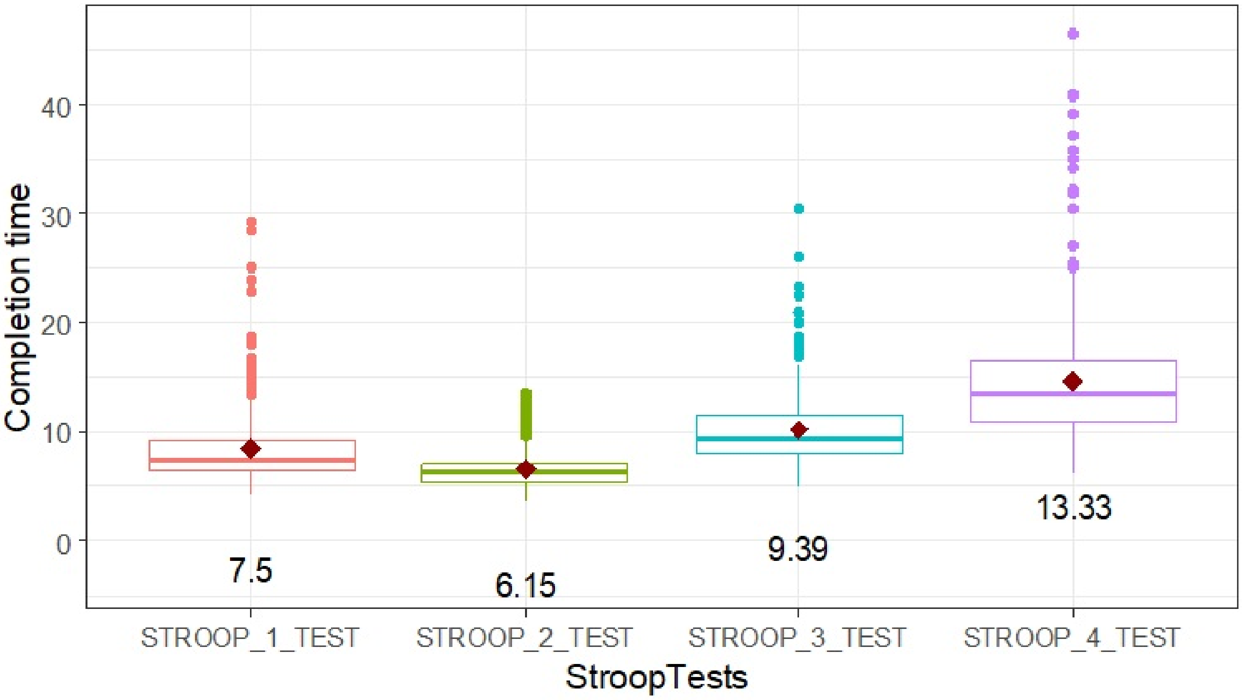
Means and SDs of each PROMIS domain survey are shown in Figure 3. Compared to the reference *t* score of 50 for the US general population, eFHS participants had lower scores in the anxiety (47.9), depression (45.7), fatigue (45.5) and sleep (46.4) domains, and higher scores in cognitive abilities (52.3) and cognitive function (55.6) domains indicating better functioning or lower symptoms (all *P*<.001).

Figure 3. Mean and SD of baseline PROMIS survey scores by domain. The red line represents the general population mean (*t* score=50) determined by PROMIS. Higher scores for cognitive abilities and cognitive function indicate better functioning whereas lower scores for anxiety, depression, fatigue, and sleep indicate better symptoms. PROMIS: Patient-Reported Outcomes Measurement Information System.



For the Stroop cognitive testing task, the mean total completion time for the 4 subtasks was 39.6 (SD 10.1) seconds. Participants spent more time on the most difficult subtask 4 than the other 3 subtasks and spent more time on subtask 3 than subtask 1 and subtask 2 (Figure 4). The mean completion times for the 4 Stroop subtasks ranged from 6.2 seconds for subtask 2 to 13.3 seconds for the most complex subtask 4. Time to complete the test was similar in males and females whereas the older age group (age 75 y and older) had longer completion times than the younger age group (under 75 y, mean 42.8, SD 11.7 vs mean 37.1, SD 7.8 s, *P*<.001).

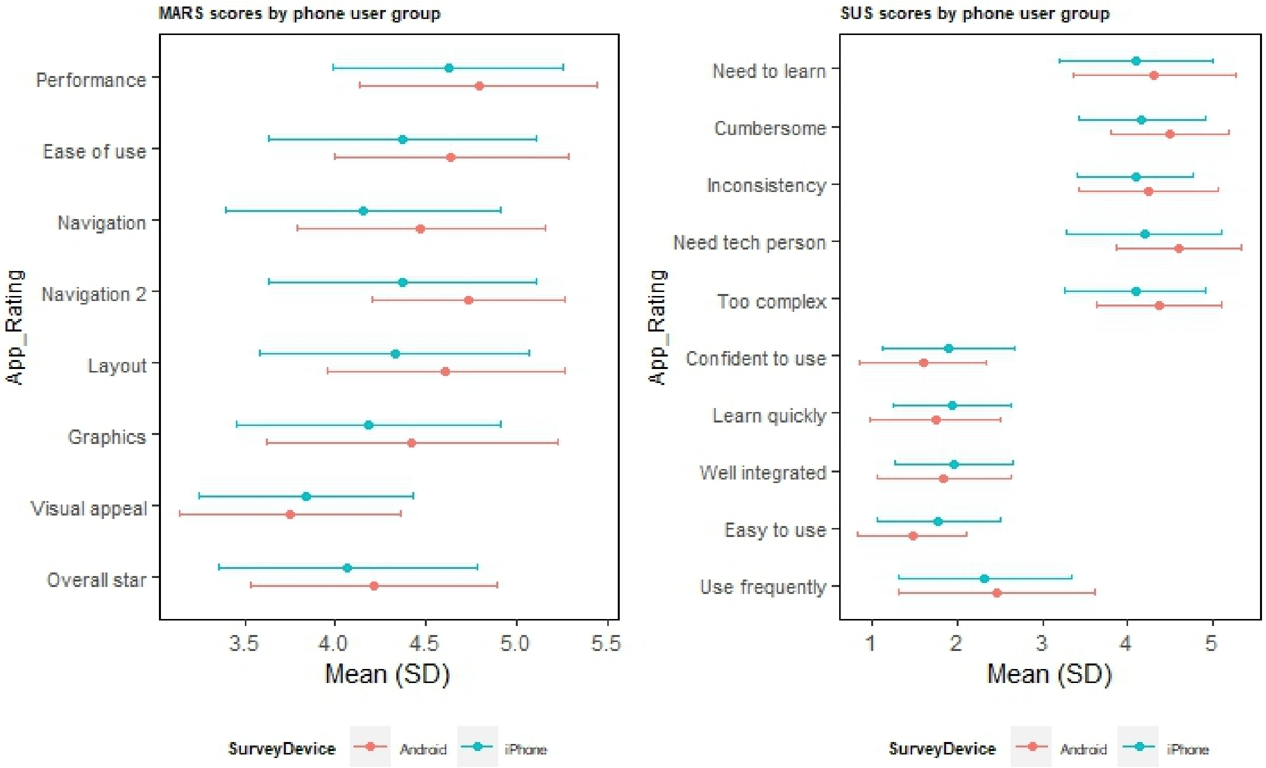
Figure 4. Stroop task distribution of test time scores in each of the 4 subtests. Completion time in seconds.



Satisfaction With the Smartphone App

There were 469 smartphone users who returned the MARS surveys including 80 Android users and 389 iPhone users. There were 475 smartphone users who returned the SUS survey including 81 Android users and 394 iPhone users. In general, eFHS participants were satisfied with the app with a mean total MARS score of 8.6 (SD 1.1), a functionality score 4.4 (SD 0.6), and aesthetics score (4.1, SD 0.6). Android users and women tended to have slightly higher functionality, aesthetics, and total MARS scores. Participants in the younger age group (<75 y) had a slightly higher functionality score (Figure S4 in Multimedia Appendix 1). Compared to iPhone users, Android users had higher scores for the individual MARS items including in performance, ease of use, navigation (navigating between screens), navigation 2 (navigating within screen and consistency across screens), layout, and graphics (Figure 5). However, only navigation (*P*=.005) was significantly different likely due to the small sample size of Android users. There was no difference for the individual MARS items between men and women or between the 2 age groups (<75 vs ≥75 y; Figure S3 in Multimedia Appendix 1).

Figure 5. MARS survey and SUS survey results by smartphone type. *P* value for navigation in MARS <.05, *P* values for all other surveys questions in MARS and SUS >.05. MARS: Mobile App Rating Scale; Navigation 2: navigating within screen and consistency across screens; SUS: System Usability Scale.



For the SUS survey, participants agreed or strongly agreed that the app was well designed or easy to use. The mean ratings were less than 2 in the 5 questions in favor of the app for which the response ratings 1 and 2 indicated "strongly agree" and "agree," respectively. They disagreed or strongly disagreed that the app was too complicated or burdensome. The mean ratings were greater than 4.1 in the 5 questions opposed to the app (too complex, cumbersome, need a technical person, inconsistent, and need to learn a lot of things), for which the response ratings of 4 and 5 indicated "disagree" and "strongly disagree" (Table S3 in Multimedia Appendix 1). In the SUS, the ratings did not differ in Android and iPhone users (Figure 5), in men and women and in the 2 age groups (Figure S3 in Multimedia Appendix 1). Participants also provided comments such as "too technical" or "tough to do without glasses" for "what were some obstacles you faced using this system?," and "very easy and convenient" or "to think more about my health & to increase my physical activity" for "what did you like the most about the system?"

Discussion

During the COVID-19 pandemic we successfully enrolled a new eCohort of community-dwelling older adults from the FHS to collect a variety of health information data using smartphone app-based surveys and tasks that the participants could complete at home at a time that was convenient for them. Survey return was high with 596 (97.5%) participants returning at least 1 survey. Importantly once surveys were returned, survey completion rates were greater than 90%. Participants who provided feedback using both the MARS and SUS surveys indicated satisfaction with the app, finding the app rather easy to use. Finally, we leveraged an in-person examination at the FHS research center to enroll most of the participants into our digital study. The in-person examination provided a touchpoint for this study's research assistant to provide one-on-one assistance with app download and the ability to answer other technologic queries the participant may have had. Our enrollment protocol was consistent with recent guidelines advocating face-to-face training to support older adults using smartphone apps [39] to improve confidence and lower potential for abandonment of technology.

Our study demonstrates the ability to collect a broad array of outcome measures and cognitive and physical function tasks important to older adults using smartphone app surveys including physical symptoms (eg, sleep and fatigue), mental health symptoms (eg, depression or anxiety), physical function, cognitive abilities, and cognitive tasks (Stroop and Trail Making). The ability to collect data remotely may facilitate inclusion of older adults in clinical trials by reducing the burden in time and cost for the participant associated with the need to travel to the clinical trial center [40]. Further, longitudinal smartphone based assessments may improve clinical care by permitting monitoring of older adults at risk for cognitive [41] or physical decline [9,42] and by empowering older adults to participate in management of chronic conditions. However persistent inequities in smartphone ownership and access to high-speed internet at home [43] will need to be addressed to ensure that technologic advances benefit all groups including older adults residing in rural locations and older adults with lower income and educational levels. Enrollment and engagement in our study differed by smartphone type with iPhone users having higher enrollment (478 of 829, 57.7% of iPhone users vs 133 of 342, 38.9% of Android users enrolled) and survey return. iPhone users had higher income compared to Android users (246 of 378, 65.1% vs 58 of 112, 51.8% reported an income of US $75,000 or more; Table S5 in Multimedia Appendix 1). The Android smartphone may be a proxy for sociodemographic factors associated with the digital divide while the iPhone may reflect a higher level of interest in digital devices and technology self-efficacy as observed in our younger eCohort [14]. Finally, others have shown technology use declines with changes in health status [44]. Consistent with this report, we observed that our eCohort of older adults had several favorable sociodemographic attributes and health metrics (lower number of self-reported medications or higher cognitive test scores). Future studies are needed to identify strategies to engage older adults with technologies they find meaningful as their health changes.

Our study had several strengths. Our eCohort was embedded in the FHS allowing us to understand the characteristics of participants who enrolled in the eCohort versus participants who did not. The high survey return rates observed may in part be due to participant loyalty to the parent FHS. Our study has some limitations that merit comment. The participants were primarily White, well-educated, and resided in New England and therefore may not be representative of older adults from more diverse backgrounds or geographic locations. However, 88 of 611 (14.4%) of our sample included older adults from more diverse racial or ethnic backgrounds (Omni cohort). Our eFHS sample had a higher proportion of iPhone users (478 of 611, 78.2%) than observed in older adults in the United States (49%) [45]. The eCohort was healthier than FHS participants who chose not to enroll and healthier than the general US population using standardized PROMIS scores (Figure 3) and may not reflect smartphone app survey use of older adults with poorer health metrics. Finally, we report survey return and completion for the baseline surveys only and more work is needed to determine longitudinal patterns of technology use.

Our study demonstrates the ability to engage older adults including those over age 75 years in the use of smartphone technology to monitor a range of health metrics. The high survey return and completion rates observed and high usability ratings suggest that smartphone app surveys may be an efficient tool to collect health data in this age group. Our study observations will be useful to researchers, clinicians, and public health professionals designing and implementing digital solutions so that older adults with highest risk for not engaging with technology can be targeted for meaningful supports. Future trials should assess the effect health-based smartphone surveys have on older adults' ability to self-monitor their own health and chronic conditions. Conducting these trials in the health care system with clinicians will be critical to the implementation of these efforts into usual clinical practice. More digital studies of older adults are needed to determine the perceived value to the older user and the health monitoring benefits from the health care provider perspective.

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Conflicts of Interest

ES is an employee of CareEvolution. The other authors have no conflicts of interest to report.

Multimedia Appendix 1
Figures and tables.
[DOCX File, 12289 KB - aging_v7i1e64636_app1.docx]

References

1. Li W, Ornstein KA, Li Y, Liu B. Barriers to learning a new technology to go online among older adults during the COVID-19 pandemic. J Am Geriatr Soc 2021 Nov;69(11):3051-3057. [doi: 10.1111/jgs.17433] [Medline: 34409589]
2. Gordon WJ, Bates DW, Fuchs D, Pappas J, Silacci S, Landman A. Comparing characteristics of patients who connect their iphones to an electronic health records system versus patients who connect without personal devices: cohort study. J Med Internet Res 2019 Aug 22;21(8):e14871. [doi: 10.2196/14871] [Medline: 31441430]
3. Rodriguez JA, Shachar C, Bates DW. Digital inclusion as health care - supporting health care equity with digital-infrastructure initiatives. N Engl J Med 2022 Mar 24;386(12):1101-1103. [doi: 10.1056/NEJMp2115646] [Medline: 35302722]
4. Nicosia J, Aschenbrenner AJ, Adams SL, et al. Bridging the technological divide: stigmas and challenges with technology in digital brain health studies of older adults. Front Digit Health 2022;4:880055. [doi: 10.3389/fdgth.2022.880055] [Medline: 35574256]
5. Sarkar U, Gourley GI, Lyles CR, et al. Usability of commercially available mobile applications for diverse patients. J Gen Intern Med 2016 Dec;31(12):1417-1426. [doi: 10.1007/s11606-016-3771-6] [Medline: 27418347]

6. Charalambous AP, Pye A, Yeung WK, et al. Tools for app- and web-based self-testing of cognitive impairment: systematic search and evaluation. J Med Internet Res 2020 Jan 17;22(1):e14551. [doi: 10.2196/14551] [Medline: 31951218]
7. Turchioe MR, Grossman LV, Baik D, et al. Older adults can successfully monitor symptoms using an inclusively designed mobile application. J Am Geriatr Soc 2020 Jun;68(6):1313-1318. [doi: 10.1111/jgs.16403] [Medline: 32157679]
8. Kaye J, Aisen P, Amariglio R, et al. Using digital tools to advance Alzheimer’s drug trials during a pandemic: the EU/US CTAD task force. J Prev Alzheimers Dis 2021;8(4):513-519. [doi: 10.14283/jpad.2021.36] [Medline: 34585227]
9. Bachman SL, Blankenship JM, Busa M, Serviente C, Lyden K, Clay I. Capturing measures that matter: the potential value of digital measures of physical behavior for alzheimer’s disease drug development. J Alzheimers Dis 2023;95(2):379-389. [doi: 10.3233/JAD-230152] [Medline: 37545234]
10. Pratap A, Neto EC, Snyder P, et al. Indicators of retention in remote digital health studies: a cross-study evaluation of 100,000 participants. NPJ Digit Med 2020;3:21. [doi: 10.1038/s41746-020-0224-8] [Medline: 32128451]
11. McConnell MV, Shcherbina A, Pavlovic A, et al. Feasibility of obtaining measures of lifestyle from a smartphone app: the MyHeart counts cardiovascular health study. JAMA Cardiol 2017 Jan 1;2(1):67-76. [doi: 10.1001/jamacardio.2016.4395] [Medline: 27973671]
12. Guo X, Vittinghoff E, Olgin JE, Marcus GM, Pletcher MJ. Volunteer participation in the health eHeart study: a comparison with the US population. Sci Rep 2017 May 16;7(1):1956. [doi: 10.1038/s41598-017-02232-y] [Medline: 28512303]
13. Golbus JR, Pescatore NA, Nallamothu BK, Shah N, Kheterpal S. Wearable device signals and home blood pressure data across age, sex, race, ethnicity, and clinical phenotypes in the Michigan Predictive Activity & Clinical Trajectories in Health (MIPACT) study: a prospective, community-based observational study. Lancet Digit Health 2021 Nov;3(11):e707-e715. [doi: 10.1016/S2589-7500(21)00138-2] [Medline: 34711377]
14. Pathiravasan CH, Zhang Y, Wang X, et al. Factors associated with long-term use of digital devices in the electronic Framingham Heart Study. NPJ Digit Med 2022 Dec 27;5(1):195. [doi: 10.1038/s41746-022-00735-1] [Medline: 36572707]
15. Taylor D, Levin M. Predicting mobile app usage for purchasing and information-sharing. Int J Retail Distrib Manag 2014 Aug 5;42(8):759-774. [doi: 10.1108/IJRDM-11-2012-0108]
16. Tsao CW, Vasan RS. Cohort profile: The Framingham Heart Study (FHS): overview of milestones in cardiovascular epidemiology. Int J Epidemiol 2015 Dec;44(6):1800-1813. [doi: 10.1093/ije/dyv337] [Medline: 26705418]
17. Massachusetts COVID - coronavirus statistics. Worldometer. URL: https://www.worldometers.info/coronavirus/usa/massachusetts/#graph-cases-daily [accessed 2024-12-19]
18. Cella D, Choi SW, Condon DM, et al. PROMIS® adult health profiles: efficient short-form measures of seven health domains. V Health 2019 May;22(5):537-544. [doi: 10.1016/j.jval.2019.02.004] [Medline: 31104731]
19. Fatigue scoring manual. HealthMeasures. URL: https://www.healthmeasures.net/images/PROMIS/manuals/Scoring_Manuals_/PROMIS_Fatigue_Scoring_Manual.pdf [accessed 2024-12-19]
20. Ameringer S, Elswick RK Jr, Menzies V, et al. Psychometric evaluation of the patient-reported outcomes measurement information system fatigue-short form across diverse populations. Nurs Res 2016;65(4):279-289. [doi: 10.1097/NNR.0000000000000162] [Medline: 27362514]
21. Yu L, Buysse DJ, Germain A, et al. Development of short forms from the PROMISTM sleep disturbance and sleep-related impairment item banks. Behav Sleep Med 2011 Dec 28;10(1):6-24. [doi: 10.1080/15402002.2012.636266] [Medline: 22250775]
22. Physical function scoring manual. HealthMeasures. URL: https://www.healthmeasures.net/images/PROMIS/manuals/Scoring_Manuals_/PROMIS_Physical_Function_Scoring_Manual.pdf [accessed 2024-12-19]
23. Pain interference. HealthMeasures. URL: https://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Pain_Interference_Scoring_Manual.pdf [accessed 2024-12-19]
24. Lai JS, Wagner LI, Jacobsen PB, Cella D. Self-reported cognitive concerns and abilities: two sides of one coin? Psychooncology 2014 Oct;23(10):1133-1141. [doi: 10.1002/pon.3522] [Medline: 24700645]
25. Brummett CM, Bakshi RR, Goesling J, et al. Preliminary validation of the Michigan Body Map. Pain 2016 Jun;157(6):1205-1212. [doi: 10.1097/j.pain.0000000000000506] [Medline: 26835782]
26. Center for epidemiologic, studies-depression scale (CES-D) - everything effort indicator. NIH CDE Repository. URL: https://cde.awsprod.nlm.nih.gov/deView?tinyId=_4Wk9uR83Gj [accessed 2024-12-19]
27. Rapid Assessment of Physical Activity (RAPA). University of Washington Health Promotion Research Center. URL: https://depts.washington.edu/hprc/programs-tools/tools-guides/rapa/ [accessed 2024-12-19]
28. Peel C, Sawyer Baker P, Roth DL, Brown CJ, Brodner EV, Allman RM. Assessing mobility in older adults: the UAB Study of Aging Life-Space Assessment. Phys Ther 2005 Oct;85(10):1008-1119. [Medline: 16180950]
29. Dahmen J, Cook D, Fellows R, Schmitter-Edgecombe M. An analysis of a digital variant of the Trail Making Test using machine learning techniques. Technol Health Care 2017;25(2):251-264. [doi: 10.3233/THC-161274] [Medline: 27886019]
30. Ashendorf L, Jefferson AL, O’Connor MK, Chaisson C, Green RC, Stern RA. Trail Making Test errors in normal aging, mild cognitive impairment, and dementia. Arch Clin Neuropsychol 2008 Mar;23(2):129-137. [doi: 10.1016/j.acn.2007.11.005] [Medline: 18178372]

31. Hankee LD, Preis SR, Piers RJ, et al. Population normative data for the CERAD word list and Victoria Stroop Test in younger- and middle-aged adults: cross-sectional analyses from the Framingham Heart Study. Exp Aging Res 2016;42(4):315-328. [doi: 10.1080/0361073X.2016.1191838] [Medline: 27410241]
32. Scura D, Munakomi S. Tinetti gait and balance test. In: StatPearls: StatPearls Publishing; 2022. [Medline: 35201709]
33. Shirani A, Newton BD, Okuda DT. Finger tapping impairments are highly sensitive for evaluating upper motor neuron lesions. BMC Neurol 2017 Mar 21;17(1):55. [doi: 10.1186/s12883-017-0829-y] [Medline: 28327094]
34. Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR mHealth uHealth 2015 Mar 11;3(1):e27. [doi: 10.2196/mhealth.3422] [Medline: 25760773]
35. Brooke J. SUS: a quick and dirty usability scale. In: Usability Evaluation in Industry: Taylor & Francis; 1996:189-194.
36. Working Group on Health Outcomes for Older Persons with Multiple Chronic Conditions. Universal health outcome measures for older persons with multiple chronic conditions. J Am Geriatr Soc 2012 Dec;60(12):2333-2341. [doi: 10.1111/j.1532-5415.2012.04240.x] [Medline: 23194184]
37. Promis adult profile instruments. HealthMeasures. URL: https://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Adult_Profile_Scoring_Manual.pdf [accessed 2024-12-19]
38. Stoyanov SR, Hides L, Kavanagh DJ, Wilson H. Development and validation of the User Version of the Mobile Application Rating Scale (uMARS). JMIR Mhealth Uhealth 2016 Jun 10;4(2):e72. [doi: 10.2196/mhealth.5849] [Medline: 27287964]
39. Gomez-Hernandez M, Ferre X, Moral C, Villalba-Mora E. Design guidelines of mobile apps for older adults: systematic review and thematic analysis. JMIR mHealth uHealth 2023 Sep 21;11:e43186. [doi: 10.2196/43186] [Medline: 37733401]
40. McDermott MM, Newman AB. Remote research and clinical trial integrity during and after the coronavirus pandemic. JAMA 2021 May 18;325(19):1935-1936. [doi: 10.1001/jama.2021.4609] [Medline: 33885728]
41. Tsoy E, Possin KL, Thompson N, et al. Self-administered cognitive testing by older adults at-risk for cognitive decline. J Prev Alzheimers Dis 2020;7(4):283-287. [doi: 10.14283/jpad.2020.25] [Medline: 32920631]
42. Omberg L, Chaibub Neto E, Perumal TM, et al. Remote smartphone monitoring of Parkinson’s disease and individual response to therapy. Nat Biotechnol 2022 Apr;40(4):480-487. [doi: 10.1038/s41587-021-00974-9] [Medline: 34373643]
43. Americans’ use of mobile technology and home broadband. Pew Research Center. URL: https://www.pewresearch.org/internet/2024/01/31/americans-use-of-mobile-technology-and-home-broadband [accessed 2024-10-24]
44. Levine DM, Lipsitz SR, Linder JA. Changes in everyday and digital health technology use among seniors in declining health. J Gerontol A Biol Sci Med Sci 2018 Mar 14;73(4):552-559. [doi: 10.1093/gerona/glx116] [Medline: 28605446]
45. Howarth J. IPhone vs android user stats (2024 data). EXPLODING TOPICS. URL: https://explodingtopics.com/blog/iphone-android-users [accessed 2024-10-24]

Abbreviations

eCohort: electronic cohort
eFHS: Electronic Framingham Heart Study
FHS: Framingham Heart Study
ICT: information and communication technology
MARS: Mobile App Rating Scale
PROMIS: Patient-Reported Outcomes Measurement Information System
SUS: System Usability Scale

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Feasibility of Measuring Smartphone Accelerometry Data During a Weekly Instrumented Timed Up-and-Go Test After Emergency Department Discharge: Prospective Observational Cohort Study

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Abstract

Background: Older adults discharged from the emergency department (ED) face elevated risk of falls and functional decline. Smartphones might enable remote monitoring of mobility after ED discharge, yet their application in this context remains underexplored.

Objective: This study aimed to assess the feasibility of having older adults provide weekly accelerometer data from an instrumented Timed Up-and-Go (TUG) test over an 11-week period after ED discharge.

Methods: This single-center, prospective, observational, cohort study recruited patients aged 60 years and older from an academic ED. Participants downloaded the GaitMate app to their iPhones that recorded accelerometer data during 11 weekly at-home TUG tests. We measured adherence to TUG test completion, quality of transmitted accelerometer data, and participants' perceptions of the app's usability and safety.

Results: Of the 617 approached patients, 149 (24.1%) consented to participate, and of these 149 participants, 9 (6%) dropped out. Overall, participants completed 55.6% (912/1639) of TUG tests. Data quality was optimal in 31.1% (508/1639) of TUG tests. At 3-month follow-up, 83.2% (99/119) of respondents found the app easy to use, and 95% (114/120) felt safe performing the tasks at home. Barriers to adherence included the need for assistance, technical issues with the app, and forgetfulness.

Conclusions: The study demonstrates moderate adherence yet high usability and safety for the use of smartphone TUG tests to monitor mobility among older adults after ED discharge. Incomplete TUG test data were common, reflecting challenges in the collection of high-quality longitudinal mobility data in older adults. Identified barriers highlight the need for improvements in user engagement and technology design.

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KEYWORDS

older adult; older adults; elder; elderly; older person; older people; ageing; aging; gait; balance; fall; falls; functional decline; fall risk; fall risks; mobility; phone; sensors; patient monitoring; monitoring; emergency department; emergency departments; ED; emergency room; ER; discharge; mobile application; mobile applications; app; apps; application; applications; digital health; digital technology; digital intervention; digital interventions; smartphone; smartphones; prediction; mobile phone

Introduction

Each year, millions of older adults are discharged from emergency departments (EDs) across the United States [1]. A growing body of evidence indicates that these individuals face high risks of adverse outcomes after ED discharge, including falls [2] and functional decline [3]. While guidelines aim to identify those at risk of poor outcomes [4], existing fall risk screening tools using data at the time of the ED encounter have limited ability to predict which patients will fall [2].

One way to improve the identification of older adults at risk for falls is to incorporate remote patient monitoring (RPM) of mobility into postdischarge care. Mobility, which includes gait and balance functions, requires the integration of sensory input, motor planning, and coordination. Gait alterations and balance issues are common in individuals aged 65 years and older [5,6] and both significantly increase the risk of falls [7]. RPM of gait and balance in home settings may identify mobility problems that are not readily apparent in controlled settings [8]. Additionally, RPM allows for examination of within-person changes over time, which can improve the discrimination of predictive models [9]. However, the success of any RPM depends heavily on the practicality and usability of the technology for older adults.

Numerous tools exist that allow for RPM of gait and balance, including external sensors (eg, cameras and force plates) and wearable sensors (eg, smartphones). Unlike external sensors, which require potentially expensive hardware and installation, wearable sensors are portable; cheaper; and in the case of smartphones, near ubiquitous [10]. Smartphones are equipped with inertial measurement units, typically composed of an accelerometer and a gyroscope. These sensors enable smartphones to accurately monitor gait mechanics [11], which can identify individuals at higher risk of falls [12]. Despite these capabilities, the potential of smartphone-based RPM of mobility after ED discharge remains largely unexplored. Describing and understanding the drivers of participants' engagement with RPM in research is necessary to determine the success of future real-world implementation of RPM in clinical services.

This study aimed to assess the feasibility of having older adults provide weekly accelerometer data from an instrumented Up-and-Go test [12] over an 11-week period after ED discharge. The Up-and-Go test (commonly referred to as the Timed Up-and-Go [TUG] test) involves an individual getting up from a chair, walking forward, turning, returning to the chair, and sitting. The TUG test was chosen because it is simple and quick and evaluates several key risk factors, including gait and balance, in a single assessment. Instrumented TUG tests using body-worn sensors can identify distinct gait patterns and balance issues [13], are validated against standard kinematic measures [14], and can distinguish between individuals who have experienced falls and those who have not [12]. To our knowledge, no prior study has reported on adherence to at-home TUG tests.

The primary focus of this study was on adherence, defined as the degree to which the user followed the program as designed [15], which involved completing weekly at-home instrumented TUG tests. Secondary aims focused on data quality, app usability, safety during at-home functional tasks, and barriers to adherence. Data quality is essential for generating meaningful gait and balance features, and various user-specific factors can negatively impact it [16,17]. Findings from this study provide foundational information for developing age-friendly RPM technologies, anticipating the increasing demand for improved postdischarge transitional care among older adults in the coming years.

Methods

Study Design

This study was a single-center, prospective, observational, cohort study of ED patients.

Ethical Considerations

This study was approved by the Stanford University institutional review board (IRB #64194), and written informed consent was obtained from all participants. The data collection app (GaitMate) was built using Stanford's Cardinal Kit and all data were stored in a secure Firebase account managed by Stanford Research IT. Participants were required to log in using a unique ID with each app task; this ID was the sole identifier linking them to the data. Compensation of up to US $90 was offered to study participants.

Study Setting and Participants

A convenience sample of patients was recruited by research associates (RAs) from a single academic ED with an annual volume of 100,000 visits. Patients were eligible for participation in the study if they were 60 years of age or older, were to be discharged home, and owned an iPhone. We excluded from the study patients currently living in a nursing home, patients with limited English proficiency, patients who could not walk unaided (ie, walking without an assistive aid), and patients without the capacity to provide informed consent. If a participant moved to a nursing home after the time of consent but during the follow-up period, they remained in the study. The study is reported in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for reporting observational studies [18].

Study Procedures

Overview

In the ED, RAs helped participants download the GaitMate app and led them through the self-report and functional baseline assessments. For 11 weeks after ED discharge, patients were asked to complete a weekly TUG test and to report any falls through the app. At 12 weeks after discharge or enrollment, we attempted to reach all participants by phone to collect data on perceived ease of app use and safety during at-home TUG tests.

Onboarding and Baseline Assessments

In the ED, each participant was guided by an RA to download the GaitMate from the Apple App Store and was assigned a unique ID they used to access the app thereafter. Next, participants were led by the RA through baseline survey questions. Subsequently, participants were presented with an in-app instructional video detailing the TUG test [19]. The RA then demonstrated the TUG procedures and helped participants complete the first task in the ED, which involved the participant standing up from a seated position, walking 2 meters, turning around, returning to the chair, and sitting down. To augment the assessment, we provided participants a waist belt equipped with a pouch to securely hold the smartphone during the TUG test. This setup enabled us to collect 3-axis accelerometer data from the phone, positioned near the body's center of mass, thereby allowing us to estimate spatial characteristics of steps. Participants who had difficulty placing the phone in the pouch and rotating to their back were instructed to keep it in the front. Multimedia Appendix 1 provides an example of the waist belt and phone placement. We chose a 2-meter walking distance for the TUG test instead of the original 3 meters given that there is limited space in the ED to perform the TUG test and concerns about the unobstructed space in patients' homes. After completing the task, participants removed the phone from the pouch and pressed the "DONE" button, prompting the transmission of the accelerometer data directly to institutional research servers for analysis. Multimedia Appendix 2 presents screenshots of the GaitMate app.

Home-Based Assessments

Each Sunday at 12 PM for 11 weeks following ED discharge, participants received a GaitMate notification prompting them to complete their weekly TUG test. After entering their ID, they were instructed to tap the "Weekly Check-in" button. Participants then viewed an instructional video on the task and were asked to complete a safety checklist. This included verification of having cleared a walking space, having set up a chair to one side, having put on regular footwear and the belt pouch, and having someone present to assist if needed. After completing the checklist, participants were asked to tap the "READY" button to start recording data. In addition, participants could log any fall by tapping the "Report a fall" button on the main screen, which would prompt the participant to record (1) the date of a fall, (2) time of fall, and (3) injury associated with fall. At-home TUG test completion was monitored by RAs. When a participant missed 3 weeks in a row, RAs attempted to reach that participant by email once and then phone to probe barriers to completing at-home tasks with open-ended questions. If a participant lost their ID, they were provided with the contact information of study investigators.

Follow-Up Phone Call

At 11 weeks following ED enrollment, a trained RA called all participants by phone, making up to 3 attempts before marking the participant as lost to follow-up. Follow-up phone calls assessed falls over the study period and whether any occurred during at-home TUG tests, perceived ease of app use, and safety while completing at-home TUG tests.

Measures

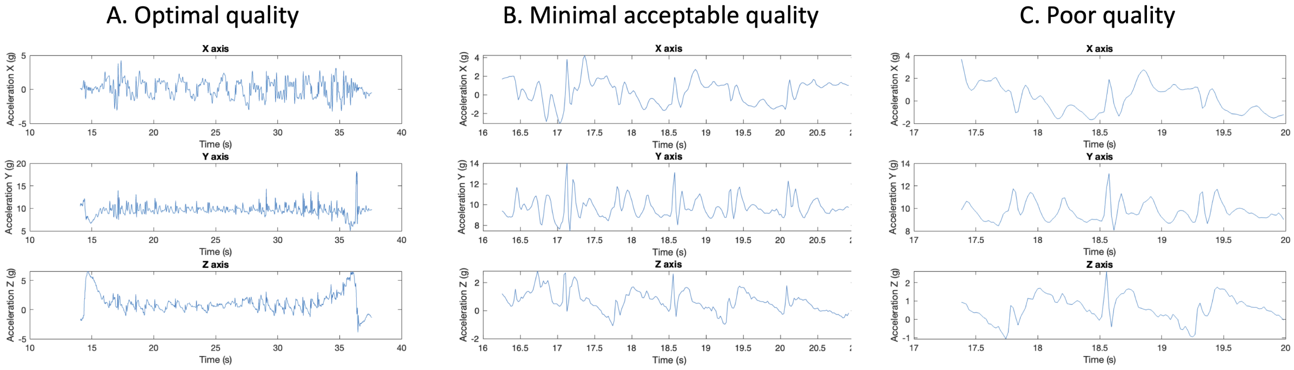
Baseline Assessments

To understand how ED patients who enrolled differ from those who did not, we collected limited information (ie, age, sex, chief complaint, and illness severity) on all prescreened patients. To understand the baseline characteristics of our participants, we additionally recorded race, ethnicity, ED chief complaints, and active medical problems.

Functional Task Completion

The primary outcome was the completion of the weekly TUG tests, defined as any transmitted accelerometer data for a given week. The secondary outcome was accelerometer data quality, assessed by 2 RAs independently, with the lead author serving as an arbiter when there was disagreement. All data-quality assessors have extensive training and experience segmenting and generating gait and balance features using accelerometer data. Each task submission was classified as one of four categories: (1) *Optimal data quality*, defined as unambiguous visual segmentation of the data into the sit-to-stand, walk-away, walk-back, and stand-to-sit portions of the gait task; (2) *Minimal acceptable data quality*, defined as whether at least 3 steps during the walk-away or walk-back segment could be visually identified; (3) *Poor data quality*, defined as cases that did not meet category 1 or 2 but where some data were transmitted; and (4) *Missing*, if no data were transmitted for active participants. Figure 1 illustrates accelerometer data in the first 3 categories.

Figure 1. Examples of accelerometer data quality. (A) Optimal quality: there are clear sit-to-stand, walk-away, walk-back, and stand-to-sit portions of the gait task as well as displacements indicative of steps. (B) Minimal acceptable quality: there is a truncated segment with a grouping of at least 3 steps. (C) Poor quality: there is a severely truncated segment without 3 consecutive displacements indicative of steps.


A. Optimal quality

B. Minimal acceptable quality

C. Poor quality

Follow-Up Assessments

To assess falls during the study period, we asked "In the past 3-months, how many times have you fallen?" followed by "Did any of these falls result in injury?" and "Did any of these falls result in the need to seek acute medical care?" Finally, we asked "Can you recall the situation that led to the fall?" To understand how participants perceived the GaitMate app, we asked "How much do you agree or disagree with the following statements: (1) Overall, the app was easy to use. (2) I felt safe completing the gait task at home." Response options ranged on a 5-point scale from strongly agree to strongly disagree. For simplicity, we collapsed the 5-point scale into 3 categories: agree, disagree, and neither agree nor disagree.

Data Analyses

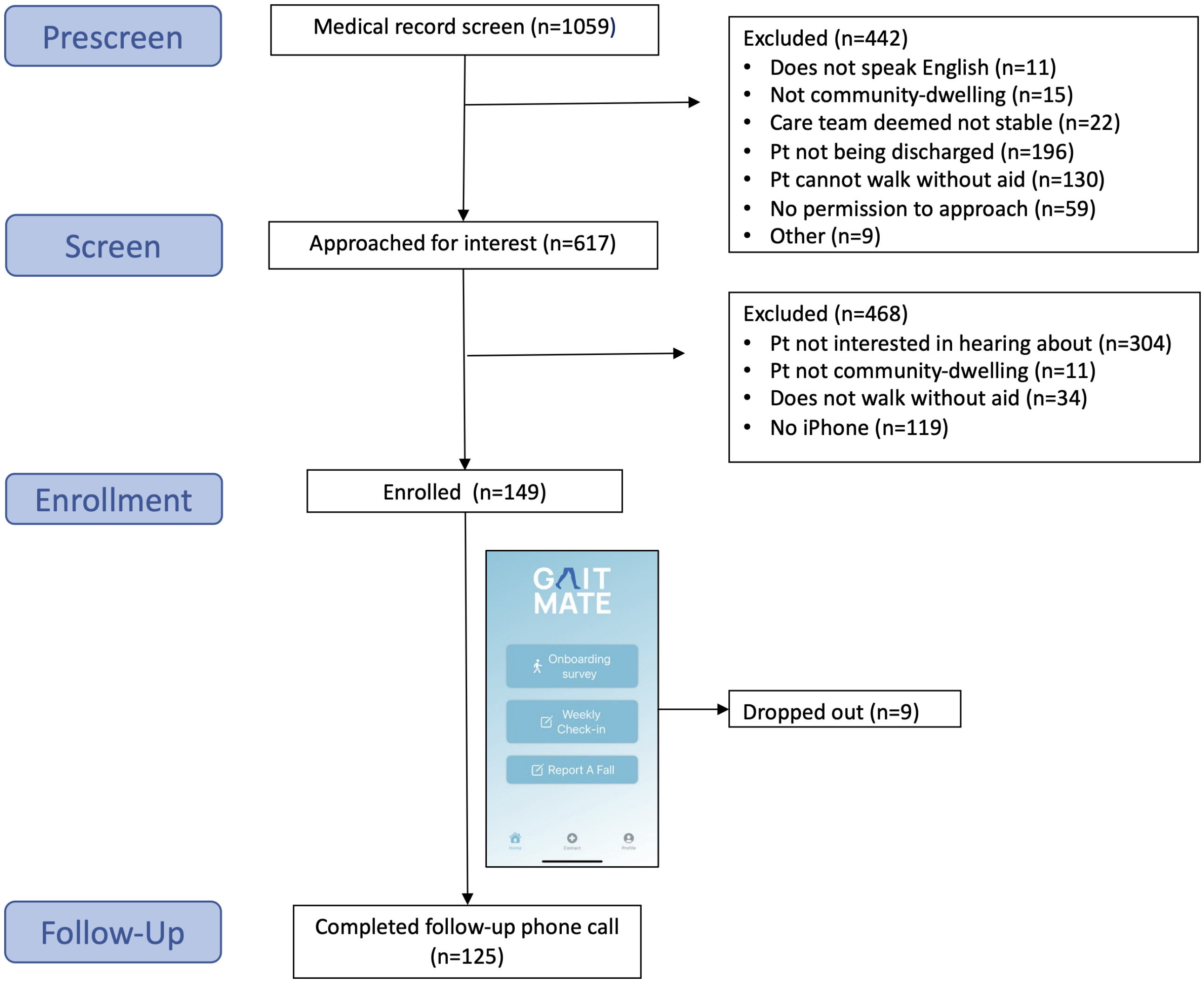
For our primary analysis, we first calculated the TUG test submission rates by week and by participant. We then categorized participants into low adherence (0%-49%), moderate adherence (50%-99%), or perfect adherence (100%) and used ordered logistic regression models to examine whether the adherence was associated with participant characteristics of age, sex, race, active medical problems, and chief complaint category. In secondary analyses, we calculated the distribution of data-quality categories for each week and by participant. To quantify older adult perceptions of GaitMate usability and safety, we calculated the percentage who agreed with the usability and safety statements. To understand barriers to adherence, we described qualitative feedback from participants when they reported difficulty with the app.

Results

Study Enrollment and Retention

Figure 2 outlines the flow of patients from enrollment through follow-up. From December 5, 2022, to August 9, 2023, we identified 1059 ED patients from the medical record who were aged 60 years or older. We excluded 442 ED patients after discussion with ED providers, with the majority excluded because they either were not being discharged to home (196/442, 44.3%) or could not ambulate unaided (130/442, 29.4%). We approached 617 patients for screening, among whom 468 (75.9%) were not interested in study participation, resulting in the recruitment of 149 participants. Common qualitative reasons for nonparticipation included feeling too sick, too busy, or lack of interest. There were no statistical differences in patient age, sex, or Emergency Severity Index between those who agreed to participate and those who did not. Of the 149 participants, 9 (6%) dropped out of the study: 4 (2.7%) participants prior to completing baseline assessments, 4 (2.7%) more participants in week 1, and 1 (0.7%) participant in week 7. Follow-up assessments at week 12 were completed by 125 (89.3%) of 140 retained participants.

Figure 2. Participant screening, enrollment, and follow-up. Pt: patient.



Participant Characteristics

Table 1 demonstrates the descriptive characteristics of the 149 enrolled participants. The mean age of the enrolled participants was 72.3 (SD 8.2) years, and the majority (n=91, 61.1%) were male. Almost half of participants (n=69, 46.3%) had fallen in the past year, indicating a fall-vulnerable cohort. The presenting ED complaints were highly varied, with only 10% (n=15) presenting for fall-related care. Participants had the comorbidity profile expected of older adults, with 63.8% (n=95) having high blood pressure, 40.9% (n=61) having heart disease, and 51.7% (n=77) reporting a past orthopedic surgery.

Table . Baseline characteristics.

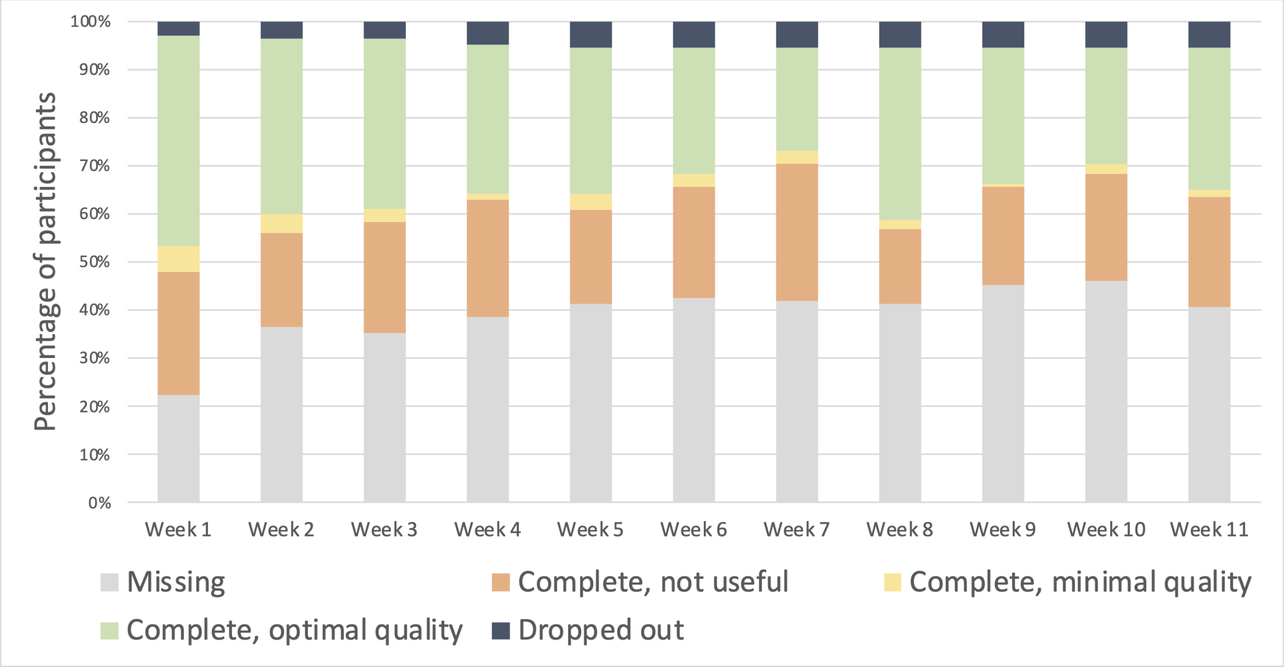
Variable	Enrolled participants (n=149)
Demographics	
Age (year), mean (SD)	72.3 (8.2)
Female, n (%)	58 (38.9)
White, non-Hispanic, n (%)	98 (65.8)
Fall history, n (%)	
Any fall in the past year	69 (46.3)
ED[a] chief complaint category, n (%)	
Cardiac	27 (18.1)
Respiratory	5 (3.4)
Gastrointestinal	20 (13.4)
Neurological	31 (20.8)
Genitourinary	6 (4)
Fall	15 (10.1)
Musculoskeletal	22 (14.8)
Other	23 (15.4)
Medical history, n (%)	
Cardiac or heart disease	61 (40.9)
Respiratory problems	26 (17.4)
Gastrointestinal problems	47 (31.5)
Vision conditions	29 (19.5)
Endocrine conditions (eg, diabetes)	51 (34.2)
Motion sickness or vertigo	54 (36.2)
High blood pressure	95 (63.8)
Orthopedic surgeries	77 (51.7)

[a] ED: emergency department.

Task Completion Rates

Figure 3 summarizes task completion and data quality over the course of the study. Accelerometer data from 55.6% (912/1639) of weekly TUG tests was transmitted over 11 weeks after discharge. The completion rates declined from 59.7% (89/149) in week 1 to 53.7% (80/149) in week 11. Overall, 23.4% (35/149) of participants completed TUG tests in all 11 weeks, 18.8% (28/149) did not complete any TUG tests, and 57.7% (86/149) of participants completed TUG test in at least 6 weeks. Adherence was similar across sex, race and ethnicity, active medical problems, and chief complaint categories.

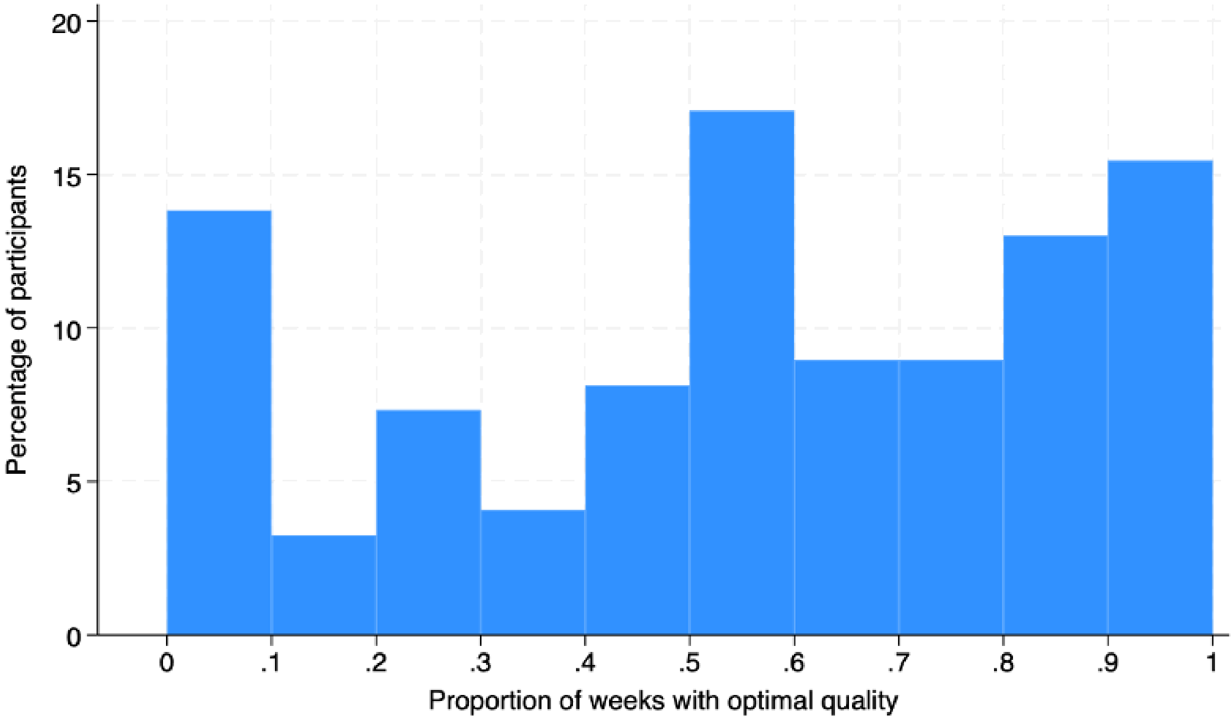
Figure 3. Gait data completeness and quality over the study period.



Data Quality

Overall, 31% (508/1639)of submitted data were rated as optimal quality, declining from 43.6% (65/149) in week 1 to 29.5% (44/149) in week 11. An additional 2.6% (42/1639) of submissions were rated as minimal acceptable quality, which remained relatively stable for the duration of the study. Almost exclusively, the submissions classified as poor quality seemed to be from truncated samples (see Figure 1 for an example). There was a high degree of variability across participants, as shown in Figure 4. For example, 14.1% (21/149) of participants did not have any weeks with optimal data quality, and 16.1% (24/149) of participants had optimal data quality in all 11 weeks.

Figure 4. Distribution of participants by proportion of weeks with optimal data.



Fall Rates

During the study period, 27 (21.6%) out of 125 participants reported falling at least once and 8 (6.4%) reported more than 1 fall. Among the 27 patients who fell, 13 (48%) reported the fall through the GaitMate app in addition to follow-up, whereas the remainder were reported through phone follow-up alone. A total of 13 (48%) out of 27 patient reported a fall injury and 2 (7%) reported needing acute medical care for the fall. None of the falls occurred during the at-home TUG tests.

Usability, Safety, and Qualitative Feedback

Among the 119 participants who completed phone follow-up, 99 (83.2%) agreed that the GaitMate app was easy to use, whereas 11 (9.2%) disagreed. A total of 114 (95.8%) agreed that they felt safe completing the at-home TUG tests, whereas only 1 (0.8%) disagreed. We identified several key barriers to completing at-home TUG tests. Several participants (n=3) related that they missed TUG test submissions because they did not have someone present with them and so could not fulfill the pretask safety checklist. A couple of participants (n=2) reported that they were busy with managing medical issues, and several (n=3) reported losing or forgetting their ID. Some participants (n=5) relayed that they either did not notice the app notification delivered each Sunday or found the “Weekly Check-in” button inactive when they had a TUG test due. Finally, some participants (n=5) stated that they accidentally tapped the “DONE” button when placing the phone in the waist belt pouch, thus prematurely ending the task for the week.

Discussion

This study explored the feasibility of collecting weekly accelerometer data during an instrumented TUG test from older adults after ED discharge using a custom iPhone app and the factors influencing adherence to this RPM technology. Our primary finding is that, among a diverse cohort of older ED patients with fall risk, the majority of weekly at-home TUG samples were submitted, with declines over 11 weeks after discharge. We also found that about a third of submitted accelerometer data were of optimal quality. Together, these findings suggest that collecting high-quality longitudinal mobility data in older adults is challenging.

To our knowledge, this is the first report of adherence to at-home functional mobility assessments in community-dwelling older adults. The adherence found in this study is better than most prior studies using app-based remote assessments. For example, a systematic review of 99 studies examining adherence to mobile health apps, most of short duration and few including older adults, found an average adherence of 56% [15]. Comparing our findings to other RPM studies is difficult given the lack of reliable reporting on longitudinal engagement in prior work [20].

Our findings provide insights into technical and human factors that may have influenced protocol adherence. For the participants who completed no weekly tasks, there seemed to be issues around technological literacy that could not be overcome in study orientation or follow-up support phone calls. For the participants with variable adherence, factors included needing assistance to perform tasks, technical issues with the app, forgetfulness, and acute health issues during the monitoring period. The GaitMate app prioritized safety by requiring participants to have another person present during task completion which was problematic for the participants who lived alone.

Other human factors influencing adherence included lost or forgotten user IDs, missed app notifications, and distracting acute health events. To meet regulatory concerns, we required re-entry of a unique ID for each app use, but several participants reported this as an undesired barrier to completion. Our finding that notifications were often missed suggests that alternative modalities such as SMS text messaging might improve task completion rates [21]. Technical difficulties such as premature TUG test closure due to accidental screen taps could be addressed by removing that design feature or requiring verification before ending. Addressing these barriers is crucial for boosting the engagement and effectiveness of RPM interventions.

We also identified human factors affecting data quality, with the majority of poor samples likely due to inadvertent button presses prematurely terminating data logging. Future versions should consider an extra verification step before stopping data capture. Variability in quality may also indicate difficulties in properly positioning or securing the smartphone in the waist-worn pouch. These findings highlight the need to carefully balance user experience with optimal data collection in RPM. Alternative wearable technologies such as Fitbits or smartwatches could allow easier data gathering but have other limitations around compliance, charging requirements, and costs. Prior work shows that older adults have high Fitbit adherence [22], but current models lack the high-resolution accelerometry needed for detailed gait or balance analysis. Smartwatches are promising [23] but limited by the costs of these devices. Further, reliably extracting high-quality gait metrics from wrist-worn sensors is technically challenging given that arm swing is uncoupled from leg motion.

Limitations of our study include the reliance on a convenience sample from a single academic ED, which may limit the generalizability of our findings. Our sample was also younger and more male than typical ED patients who fall [24]. Additionally, the study’s design did not allow for a comparison of adherence to other types of tasks and app designs, limiting the interpretation to TUG tasks with our specific app interface. Future research should aim to address these limitations by incorporating a more diverse participant pool, extending the follow-up period, and designing real-time analytics on gait and balance after discharge to focus fall prevention efforts. Further exploration into personalized interventions and feedback mechanisms within RPM technologies and how to incorporate these into health care systems could also enhance patient engagement and adherence.

In conclusion, our study contributes to growing evidence on the potential utility of RPM in postdischarge care [25], offering insights into the practical challenges and user experiences for older adults in completing smartphone functional mobility tasks at home. Addressing the human and technological barrier we identified can enable smartphone apps and RPM to play an important role in postdischarge care to reduce fall risk in older patients.

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Authors' Contributions

BS originated the project and drafted the initial manuscript. All authors participated in interpreting the results, contributed to the writing of the manuscript, provided critical feedback to the manuscript, and approved the final manuscript draft for submission.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Example of the waist belt and phone placement.
[PNG File, 1106 KB - aging_v7i1e57601_app1.png]

Multimedia Appendix 2
Screenshots of the GaitMate app.
[PNG File, 186 KB - aging_v7i1e57601_app2.png]

References

1. Ashman JJ, Schappert SM, Santo L. Emergency department visits among adults aged 60 and over: United States, 2014-2017. NCHS Data Brief 2020 Jun(367):1-8. [Medline: 32600519]
2. Carpenter CR, Avidan MS, Wildes T, Stark S, Fowler SA, Lo AX. Predicting geriatric falls following an episode of emergency department care: a systematic review. Acad Emerg Med 2014 Oct;21(10):1069-1082. [doi: 10.1111/acem.12488] [Medline: 25293956]
3. Nagurney JM, Fleischman W, Han L, Leo-Summers L, Allore HG, Gill TM. Emergency department visits without hospitalization are associated with functional decline in older persons. Ann Emerg Med 2017 Apr;69(4):426-433. [doi: 10.1016/j.annemergmed.2016.09.018] [Medline: 28069299]
4. Carpenter CR, Bromley M, Caterino JM, et al. Optimal older adult emergency care: introducing multidisciplinary geriatric emergency department guidelines from the American College of Emergency Physicians, American Geriatrics Society, Emergency Nurses Association, and Society for Academic Emergency Medicine. J Am Geriatr Soc 2014 Jul;62(7):1360-1363. [doi: 10.1111/jgs.12883] [Medline: 24890806]
5. Verghese J, LeValley A, Hall CB, Katz MJ, Ambrose AF, Lipton RB. Epidemiology of gait disorders in community-residing older adults. J Am Geriatr Soc 2006 Feb;54(2):255-261. [doi: 10.1111/j.1532-5415.2005.00580.x] [Medline: 16460376]
6. Lin HW, Bhattacharyya N. Balance disorders in the elderly: epidemiology and functional impact. Laryngoscope 2012 Aug;122(8):1858-1861. [doi: 10.1002/lary.23376] [Medline: 22645067]
7. Tinetti ME, Speechley M, Ginter SF. Risk factors for falls among elderly persons living in the community. N Engl J Med 1988 Dec 29;319(26):1701-1707. [doi: 10.1056/NEJM198812293192604] [Medline: 3205267]
8. Weiss A, Brozgol M, Dorfman M, et al. Does the evaluation of gait quality during daily life provide insight into fall risk? a novel approach using 3-day accelerometer recordings. Neurorehabil Neural Repair 2013 Oct;27(8):742-752. [doi: 10.1177/1545968313491004] [Medline: 23774124]
9. Mancini M, Horak FB. Potential of APDM mobility lab for the monitoring of the progression of Parkinson’s disease. Expert Rev Med Devices 2016 May;13(5):455-462. [doi: 10.1586/17434440.2016.1153421] [Medline: 26872510]
10. Faverio M. Share of those 65 and older who are tech users has grown in the past decade. Pew Research Center. 2022 Jan 13. URL: https://www.pewresearch.org/short-reads/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/ [accessed 2023-08-01]
11. Manor B, Yu W, Zhu H, et al. Smartphone app-based assessment of gait during normal and dual-task walking: demonstration of validity and reliability. JMIR Mhealth Uhealth 2018 Jan 30;6(1):e36. [doi: 10.2196/mhealth.8815] [Medline: 29382625]
12. Ortega-Bastidas P, Gómez B, Aqueveque P, Luarte-Martínez S, Cano-de-la-Cuerda R. Instrumented Timed Up and Go Test (ITUG)-more than assessing time to predict falls: a systematic review. Sensors (Basel) 2023 Mar 24;23(7):3426. [doi: 10.3390/s23073426] [Medline: 37050485]
13. Patel M, Pavic A, Goodwin VA. Wearable inertial sensors to measure gait and posture characteristic differences in older adult fallers and non-fallers: a scoping review. Gait Posture 2020 Feb;76:110-121. [doi: 10.1016/j.gaitpost.2019.10.039] [Medline: 31756666]

14. Petraglia F, Scarcella L, Pedrazzi G, Brancato L, Puers R, Costantino C. Inertial sensors versus standard systems in gait analysis: a systematic review and meta-analysis. Eur J Phys Rehabil Med 2019 Apr;55(2):265-280. [doi: 10.23736/S1973-9087.18.05306-6] [Medline: 30311493]
15. Jakob R, Harperink S, Rudolf AM, et al. Factors influencing adherence to mHealth apps for prevention or management of noncommunicable diseases: systematic review. J Med Internet Res 2022 May 25;24(5):e35371. [doi: 10.2196/35371] [Medline: 35612886]
16. Kobsar D, Charlton JM, Tse CTF, et al. Validity and reliability of wearable inertial sensors in healthy adult walking: a systematic review and meta-analysis. J Neuroeng Rehabil 2020 May 11;17(1):62. [doi: 10.1186/s12984-020-00685-3] [Medline: 32393301]
17. Kristoffersson A, Du J, Ehn M. Performance and characteristics of wearable sensor systems discriminating and classifying older adults according to fall risk: a systematic review. Sensors (Basel) 2021 Aug 31;21(17):5863. [doi: 10.3390/s21175863] [Medline: 34502755]
18. von Elm E, Altman DG, Egger M, et al. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. BMJ 2007 Oct 20;335(7624):806-808. [doi: 10.1136/bmj.39335.541782.AD] [Medline: 17947786]
19. Podsiadlo D, Richardson S. The timed “Up & Go”: a test of basic functional mobility for frail elderly persons. J Am Geriatr Soc 1991 Feb;39(2):142-148. [doi: 10.1111/j.1532-5415.1991.tb01616.x] [Medline: 1991946]
20. White KM, Williamson C, Bergou N, et al. A systematic review of engagement reporting in remote measurement studies for health symptom tracking. NPJ Digit Med 2022 Jun 29;5(1):82. [doi: 10.1038/s41746-022-00624-7] [Medline: 35768544]
21. Jamison RN, Jurcik DC, Edwards RR, Huang CC, Ross EL. A pilot comparison of a smartphone app with or without 2-way messaging among chronic pain patients: who benefits from a pain app? Clin J Pain 2017 Aug;33(8):676-686. [doi: 10.1097/AJP.0000000000000455] [Medline: 27898460]
22. Paolillo EW, Lee SY, VandeBunte A, et al. Wearable use in an observational study among older adults: adherence, feasibility, and effects of clinicodemographic factors. Front Digit Health 2022 Jun 10;4:884208. [doi: 10.3389/fdgth.2022.884208] [Medline: 35754462]
23. Dandapani HG, Davoodi NM, Joerg LC, et al. Leveraging mobile-based sensors for clinical research to obtain activity and health measures for disease monitoring, prevention, and treatment. Front Digit Health 2022 Jun 14;4:893070. [doi: 10.3389/fdgth.2022.893070] [Medline: 35774115]
24. Goldberg EM, Marks SJ, Resnik LJ, Long S, Mellott H, Merchant RC. Can an emergency department-initiated intervention prevent subsequent falls and health care use in older adults? a randomized controlled trial. Ann Emerg Med 2020 Dec;76(6):739-750. [doi: 10.1016/j.annemergmed.2020.07.025] [Medline: 32854965]
25. Patel MS, Volpp KG, Small DS, et al. Using remotely monitored patient activity patterns after hospital discharge to predict 30 day hospital readmission: a randomized trial. Sci Rep 2023 May 22;13(1):8258. [doi: 10.1038/s41598-023-35201-9] [Medline: 37217585]

Abbreviations

ED: emergency department
RA: research associate
RPM: remote patient monitoring
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
TUG: Timed Up-and-Go

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A Personalized and Interactive Web-Based Advance Care Planning Intervention for Older Adults (Koda Health): Pilot Feasibility Study

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Abstract

Background: Advance care planning (ACP) is a process that involves patients expressing their personal goals, values, and future medical care preferences. Digital applications may help facilitate this process, though their use in older adults has not been adequately studied.

Objective: This pilot study aimed to evaluate the reach, adoption, and usability of Koda Health, a web-based patient-facing ACP platform, among older adults.

Methods: Older adults (aged 50 years and older) who had an active Epic MyChart account at an academic health care system in North Carolina were recruited to participate. A total of 2850 electronic invitations were sent through MyChart accounts with an embedded hyperlink to the Koda platform. Participants who agreed to participate were asked to complete pre- and posttest surveys before and after navigating through the Koda Health platform. Primary outcomes were reach, adoption, and System Usability Scale (SUS) scores. Exploratory outcomes included ACP knowledge and readiness.

Results: A total of 161 participants enrolled in the study and created an account on the platform (age: mean 63, SD 9.3 years), with 80% (129/161) of these participants going on to complete all steps of the intervention, thereby generating an advance directive. Participants reported minimal difficulty in using the Koda platform, with an overall SUS score of 76.2. Additionally, knowledge of ACP (eg, mean increase from 3.2 to 4.2 on 5-point scale; *P*<.001) and readiness (eg, mean increase from 2.6 to 3.2 on readiness to discuss ACP with health care provider; *P*<.001) significantly increased from before to after the intervention.

Conclusions: This study demonstrated that the Koda Health platform is feasible, had above-average usability, and improved ACP documentation of preferences in older adults. Our findings indicate that web-based health tools like Koda may help older individuals learn about and feel more comfortable with ACP while potentially facilitating greater engagement in care planning.

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KEYWORDS

advance care planning; ACP; digital health tools; system usability; gerontology; geriatric; geriatrics; older adult; older adults; elder; elderly; older person; older people; ageing; aging; adoption; acceptance; usability; digital health; platform; website; websites

Introduction

Advance care planning (ACP) is a process by which individuals choose their goals of care, quality of life priorities, and potential future medical intervention preferences and then communicate these values [1-3]. Actions taken during ACP include choosing a surrogate decision-maker (SDM), completing advance directives, and discussing a patient's wishes with loved ones and health care providers. With increasing average lifespans, ACP is a vital component of high-quality care to ensure that patients' care when facing serious illness is concordant with their values and goals. Currently, anywhere between 3% to 47% of patients may receive medical care that is not consistent with the patient or their loved ones' wishes [4-6]. Because of these inconsistencies, it's estimated that US $75.7 billion to US $101.2 billion is spent on overtreatment or low-value care each year in the United States [7]. These findings highlight the need to increase communication regarding medical care planning.

ACP is associated with decreased anxiety among patients' family and caregivers [8], improved patient quality of life [9], decreased unwanted medical care [10-12], and decreased health care costs [13-16]. Despite the promising evidence of benefits [17], rates of ACP remain low, with many patients and families avoiding these discussions until the patient's condition has deteriorated and is suboptimal for end-of-life decision-making. In addition, less than 11% of Medicare beneficiaries discuss ACP with their medical providers [18-21]. In the United States, approximately 37% or less of individuals report having some kind of advance directive, which could include a medical power of attorney or a living will [22,23]. ACP rates are often even lower within historically marginalized communities in America [24-28].

While the majority of patients express positive views or interest in ACP [22,29], they may not know how to begin the process. Initiation of ACP conversations seems to be a major barrier, as patients may be reluctant to broach the subject with their health care providers, while clinicians report having insufficient training or time to conduct ACP discussions [22,30,31] during busy clinic visits. Though patients believe that their medical providers should initiate conversations about ACP [32,33], 17% or fewer of patients report discussing ACP with their medical team [34]. Given the barriers for many patients in learning about and completing ACP, it is important to explore alternative approaches that may better support health care providers in facilitating this vital service [29]. Digital health tools could be a potential solution to improve equitable access to ACP for patients and to engage loved ones and health care providers in the process [35,36]. Scoping reviews have concluded that currently available web-based ACP programs are feasible and generally well-received by users [37,38], but the quality of the content greatly varies [39].

Current ACP online programs are primarily static web-based forms and do not include interactive educational content, plain language, or the capability to allow for official signing of ACP documentation [40]. Other ACP programs are geared toward specific patient populations and are therefore not generalizable to all individuals. Additionally, the sections on medical interventions in many online ACP resources fail to mention some common life support treatments that an individual may experience at end of life or with serious illness [41]. Several available smartphone apps also provide some education or actionable decision-making in regard to ACP, but currently available apps lack sufficient features or have poor functionality, limiting their practicality [42].

The Koda digital ACP platform seeks to fill the gaps found in current offerings by providing a highly interactive solution that is suitable for all technological knowledge levels and more inclusive of the most common life-support treatment options. The platform guides patients through a personalized, interactive guide, which includes video-based educational content and decision-making guides for patients and their loved ones. Users are able to select health care goals and indicate their wishes regarding potential future medical interventions, all of which auto-generate into easily accessible documentation that can be shared with loved ones and health care providers. Koda was created to help facilitate informed discussions of ACP and to provide a tool that patients could use freely and effectively without an added time burden for clinicians.

A previous retrospective report on Koda [43] was conducted with a sample of patients with serious illness. The findings of that quality improvement report showed that 53% of referred patients completed their ACP through the platform. However, due to the retrospective nature of this prior study, we were unable to assess self-report usability metrics or change in opinions or knowledge after platform use. The main objective of this study was to determine the reach, adoption, and usability of Koda to conduct digital ACP within a university health system.

Methods

Population and Recruitment

This pilot study included adult patients aged 50 years or older who had an active MyChart account, defined as one that was used within the past 90 days. Participants were excluded if they were younger than 50 years, were non–English speaking, had a diagnosis of Alzheimer disease or Alzheimer disease–related dementias, or had blindness based on electronic health record (EHR) *International Classification of Diseases, 10th Edition* codes.

An EHR algorithm was created to identify eligible participants (eg, filtering for the inclusion criteria) from the Atrium Health Wake Forest Baptist network (AHWFB). The EHR included data on age, gender, race, and diagnoses. The AHWFB is a large, quaternary health system affiliated with an accountable care organization program that incorporates more than 150 primary care and multispecialty practices with more than 330 physicians and advanced practice providers in 80 different locations in communities throughout central North Carolina.

Eligible participants were sent an electronic invitation to participate via Epic MyChart with an informational message about the study and an embedded hyperlink to the Koda platform. If a participant was interested, they were directed to a web-based consent form, and electronic informed consent was obtained. Participants were instructed to create a Koda Health account, complete a preassessment survey, complete using the Koda platform, and then complete a postassessment survey. Follow-up messages were sent 2 weeks later to any nonresponders. If a participant pressed "accept" but did not create a Koda account, they were approached 2 weeks later by the research team to facilitate the process.

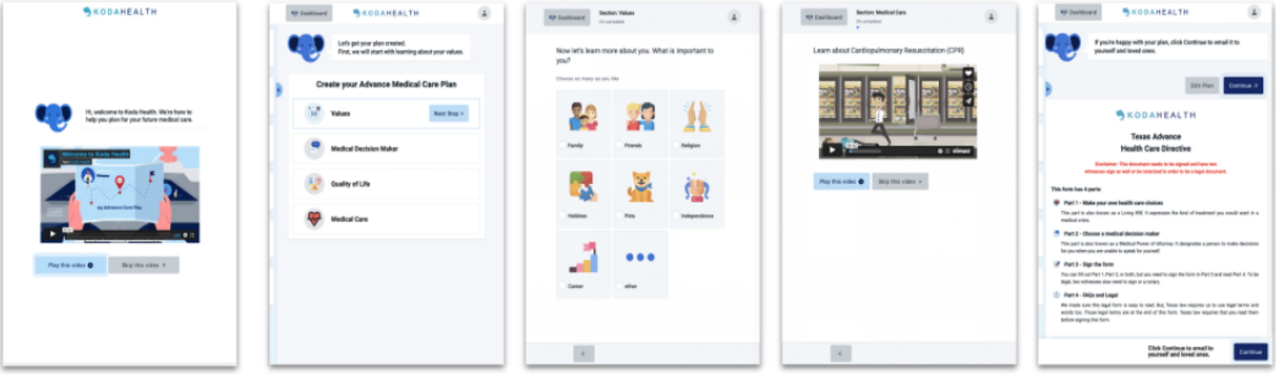
Ethical Considerations

This study was approved by the Atrium-Wake Forest Institutional Review Board (IRB00076779). All human subjects data were deidentified. Study participants were sent a US $25 gift card for completing the steps of the study.

Intervention: Koda Digital Platform

The Koda application was previously developed prior to this pilot study. Briefly, this occurred as an iterative process with input from ACP content experts (eg, geriatric and palliative medicine physicians), as well as input from end users surrounding their preferences, which was obtained by survey results. The patient-facing Koda ACP platform consists of 4 sections, focusing on values; individual definitions of quality of life; SDM preferences; and medical care preferences, with specific regard to cardiopulmonary resuscitation (CPR), mechanical ventilation, artificial nutrition via a feeding tube, and dialysis. This was in alignment with consensus recommendations on core components of ACP. Motivational interviewing techniques [44] were used to highlight the importance of planning and to motivate patients to communicate their wishes. Each section includes educational audio-video content and expandable information for additional questions users may have. For this study, platform completion progress was tracked through the Koda Health administration portal. Once the participant completed using the Koda platform by indicating their decisions within each section, their answers were autopopulated into a state-specific advance directive, which participants were able to sign or notarize online. Using the platform takes approximately 20-30 minutes. See Figure 1 for example displays directly from the platform.

Figure 1. Overview of the Koda platform interface.



Screen adaptable design runs on smartphones, tablets, or PCs.

Dashboard that shows all the sections that will be covered, including values, medical decision-maker preferences, quality of life, and medical care preferences.

Questions in the guide to help the patient understand what is important to them.

Medical care education videos, with the opportunity for the patient to input their medical care preferences.

Autogenerated plan.

Outcome Measures

Primary and secondary outcome measures consisted of reach, adoption, and usability. Reach was defined as the proportion of eligible participants who clicked on the embedded hyperlink to the Koda application. Adoption was defined as the proportion of participants who completed using the Koda platform. Usability was measured using the validated System Usability Scale (SUS) [45,46], a 10-item questionnaire. Items are rated on a 5-point (ie, 0 to 4) scale and responses to all items are summed and multiplied by 2.5. Possible scores range from 0 to 100, with scores of 68 or higher indicating above-average usability [47]. The SUS was reliable for the current sample with α=.87, which is comparable to psychometric findings from multiple studies of the SUS (ranging from α=.83 to α=.97) [48].

Exploratory outcomes included ACP knowledge and readiness using an adapted, self-report ACP engagement survey [49] and were measured before and after using the Koda platform. To assess patients' self-rated knowledge of ACP, 4 Likert-type questions were asked, which included "Do you know what Advance Care Planning is?" "How well informed are you about who can be a medical decision maker?" "How well informed are you about what makes a good medical decision maker?" and "How well informed are you about the different amounts of flexibility a person can give their medical decision maker?" The answer options were on a scale from 1 to 5, with higher scores correlating to higher ACP knowledge. Reliability for the adapted ACP Engagement Survey was good (α=.82) and comparable to previous psychometric research for other brief versions of this tool (ranging from α=.84 to α=.97) [49].

To assess patients' readiness to engage with ACP, 4 Likert-type questions were asked, which included "What describes you best when it comes to your comfort level in thinking about your care if you become seriously ill?" "How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?" and "How ready are you to talk to your healthcare provider about the kind of medical care you would want if you were very sick or near the end of life?" These answer options were on a scale from 1 to 5, with higher scores indicating greater readiness. The fourth question, "How worried are you when you think about your future illnesses?" was reverse scored so that higher scores would indicate less ACP readiness.

Statistical Analyses

Reach, adoption, and SUS scores were calculated and reported as percentages and percentiles, respectively. Success was defined a priori by having ≥40% of enrolled participants complete using the Koda platform and obtaining an above-average SUS score of 68 or higher [50-52]. For descriptive analyses, means and SDs were used to describe continuous variables and percentages and frequencies were used to describe categorical variables. Shapiro-Wilk, D'Agostino-Pearson, and Anderson-Darling tests were conducted to assess data normality, and study variables were found to have non-Gaussian distribution. Therefore, nonparametric methods were used for any inferential analyses. Changes from pre- to post-Koda use were analyzed with the 2-tailed Wilcoxon signed rank test with continuity correction. Analyses were performed using R (version 4.2; R Foundation for Statistical Computing). $P<.05$ was considered to be statistically significant.

Results

Demographics

Table 1 shows participant demographic and baseline characteristics. The mean age was 62.8 (SD 9.3) years, with ages ranging from 50-99 years. Of enrolled participants, 127 (78.9%) were female, and 46 (28.6%) were Black or African American. A total of 49 patients (30.4%) self-reported poor to fair health, 55 (35.2%) had a personal loss or misfortune in the past year, and 103 (66%) had been a caregiver of a loved one with a serious illness.

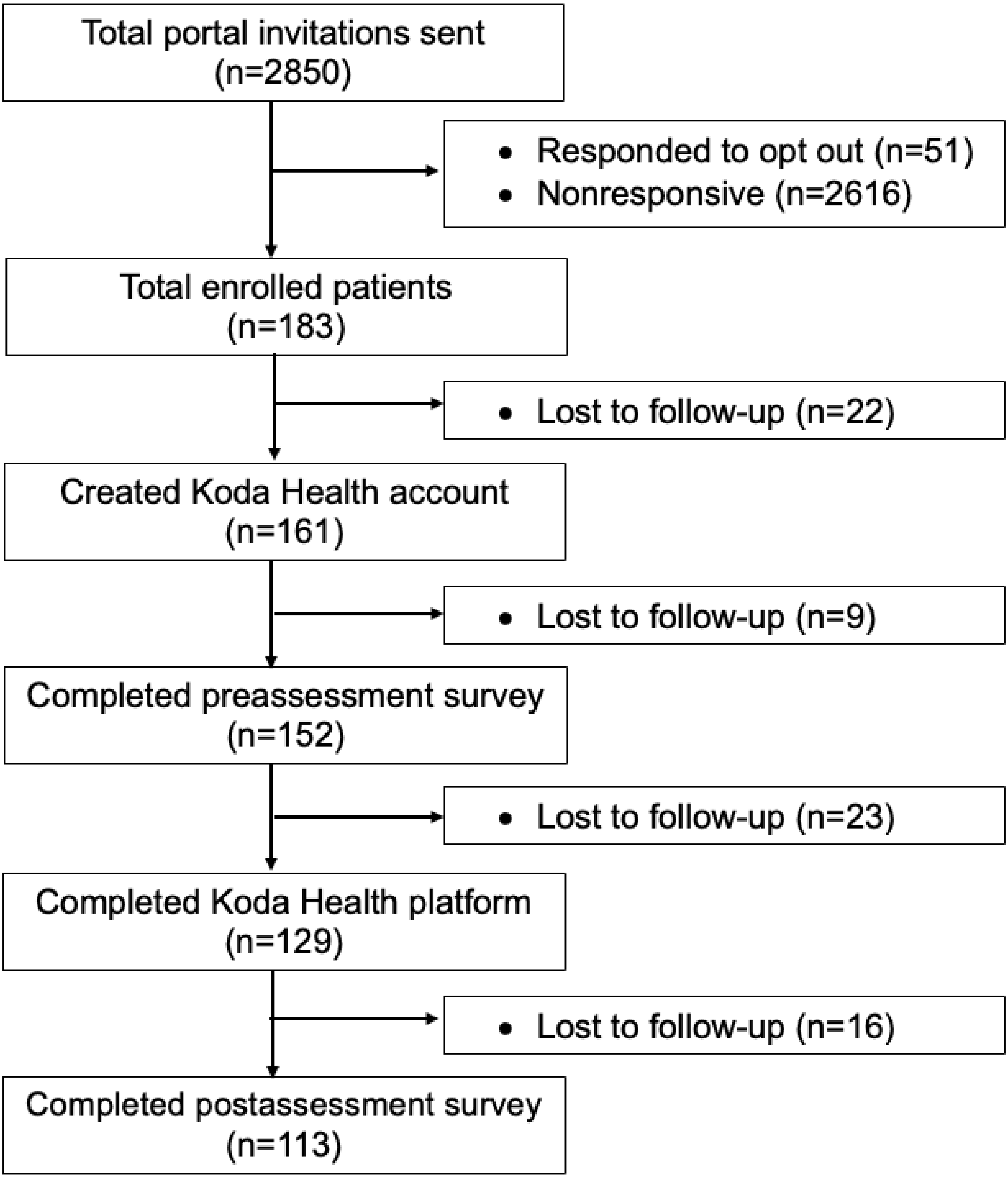
Table . Demographics of participants who created a Koda account.

Characteristics		Participants (n=161)
Age (years), mean (SD)		62.8 (9.3)
Sex , n (%)		
	Female	127 (78.9)
	Male	34 (21.1)
Ethnicity, n (%)		
	Hispanic or Latinx	1 (0.6)
	Not Hispanic or Latinx	159 (98.8)
	Not reported	1 (0.6)
Race, n (%)		
	American Indian/Alaska Native	1 (0.6)
	Black/African American	46 (28.6)
	White	113 (70.2)
Self-reportd health status, n (%)		
	Poor	10 (6.4)
	Fair	39 (25)
	Good	67 (42.9)
	Very good	36 (23.1)
	Excellent	4 (2.6)
Personal loss/misfortune in last year, n (%)		
	Yes, one	32 (20.5)
	Yes, more than one	23 (14.7)
	No	101 (64.7)
Taken care of someone seriously ill, n (%)		
	Yes	103 (66)
	No	53 (34)
Trust in the health care system, n (%)		
	Completely distrust	0 (0)
	Somewhat distrust	16 (9.9)
	Neither	23 (14.3)
	Somewhat trust	58 (36)
	Completely trust	14 (8.7)
	No response	50 (31.1)

Reach, Adoption, and Usability of the Digital Koda Platform

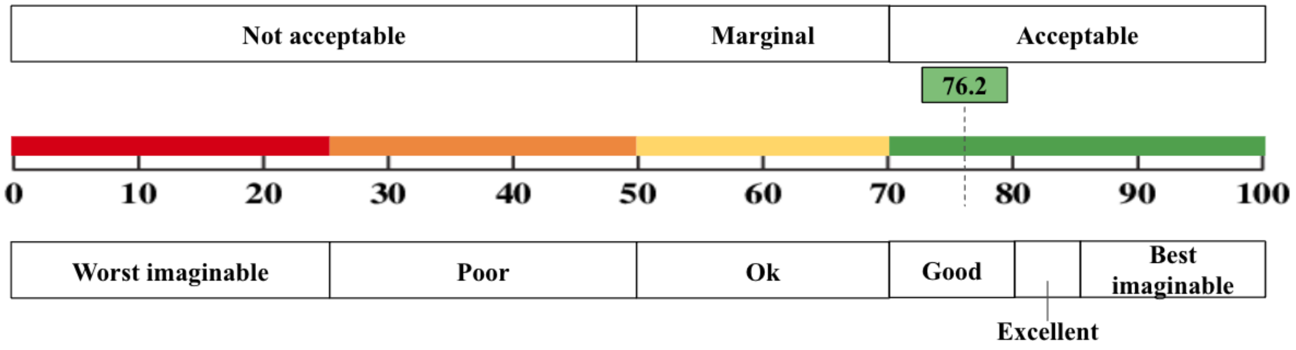
Of the 2850 patients who were sent the invitation to participate through their EHR patient portal, 183 participants read the message and clicked on the Koda link to enroll (6.4% response rate). Of those who responded to the invitation, 88% (n=161) created a Koda Health account to begin the study. Of the 161 participants who began their care plan on the platform, 129 (80.1%) completed the Koda platform intervention (Figure 2).

Figure 2. Flow diagram of participants through the study.



As measured by the SUS, the participant-reported usability of the digital Koda platform was 76.2, indicating good system usability (Figure 3). Out of possible scores from 0 to 100, the SUS scores ranged from 47.5 to 100.

Figure 3. Demonstration of the acceptability and score range interpretations for the Koda platform. The score was 76.2 on the System Usability Scale, indicating that the platform was acceptable and had a good score.



Knowledge of ACP

Wilcoxon signed-rank tests showed that there was a significant increase in knowledge of ACP after using the Koda platform compared to baseline. Ratings increased on all 4 knowledge items: knowing what ACP is (*Z*=119.5; *P*<.001), knowing who can be an SDM (*Z*=202; *P*<.001), what makes a good SDM (*Z*=235; *P*<.001), and the amount of flexibility an SDM can have (*Z*=289; *P*<.001). Table 2 shows means at each time point.

Table . Change in knowledge of advance care planning (ACP) before and after completing the digital platform (on a 5-point scale).

Knowledge items	Before Koda use, mean rating (SD)	After Koda use, mean rating (SD)	*P* value
Knowing what ACP is	3.23 (1.31)	4.19 (0.97)	<.001
Knowing who can be an SDM[a]	3.63 (1.14)	4.28 (0.93)	<.001
Knowing what makes a good SDM	3.60 (1.16)	4.28 (0.90)	<.001
Knowing what flexibility an SDM can have	3.26 (1.29)	4.19 (0.96)	<.001

[a] SDM: surrogate decision-maker.

Readiness to Make Decisions

Wilcoxon signed-rank tests showed that there was a statistically significant increase in readiness for ACP decisions after using the Koda platform compared to baseline. Ratings increased on 3 readiness items: comfort level thinking about serious illness care (*Z*=117; *P*<.001), readiness to discuss future medical care with an SDM (*Z*=316.5; *P*=.01), and readiness to discuss future medical care with a health care provider (*Z*=150; *P*<.001). The postassessment revealed a statistically significant decrease in ratings for how worried patients were about future illnesses (*Z*=536.5; *P*<.001). Table 3 shows means at each time point.

Table . Change in readiness for advance care planning (ACP) decisions and conversations before and after completing the digital platform (on a 5-point scale).

Readiness items	Before Koda use, mean rating (SD)	After Koda use, mean rating (SD)	*P* value
Comfort level thinking about serious illness care	2.89 (0.88)	3.06 (0.88)	<.001
Ready to discuss ACP with an SDM[a]	3.23 (1.46)	3.59 (1.32)	.007
Ready to discuss ACP with health care provider	2.78 (1.37)	3.26 (1.18)	<.001
Worried thinking about future illness[b]	3.32 (1.03)	3.07 (1.03)	<.001

[a] SDM: surrogate decision-maker.

[b] This item was reverse scored, so lower scores indicate higher ACP readiness.

Discussion

This pilot study assessed the feasibility and acceptability of using a web-based interactive ACP platform, Koda Health, to help older adults think about their overall health-related goals, document those goals in an advance directive, and assign an SDM. We found that the intervention was acceptable to older adults and feasible to implement. This was highlighted by the fact that 80% of enrolled participants completed the entire intervention and created an advance directive.

Our findings also suggest that the Koda platform was able to bridge the gap in ACP engagement between different racial groups. Previous reports have shown that individuals from often-marginalized racial communities are less likely to have engaged in ACP [26,28]. However, when comparing the 2 main self-identified race categories in our data, we found no substantial difference—80.95% of Black patients and 79.66% of White patients who enrolled in the study went on to complete using the Koda platform. This adds to the existing literature that indicates that digital ACP platforms have the potential to address health disparities by providing accessible, user-friendly tools to all users, regardless of their racial background [43,53].

In addition, the SUS score of 76.2 indicates that users generally found the Koda platform easy to use and had a positive overall experience. This score suggests that Koda’s interface and features were well designed, allowing users to navigate and interact with the system without substantial barriers. We also found that patient age was not correlated with system usability ratings (r=.03; P=.76), suggesting that the platform was similarly user-friendly across the sample age range (50-99 years). However, while the overall usability was rated as good, there may still be room for improvement. It will be important to analyze usability metrics in more detail to identify specific areas where the platform can be enhanced. This could involve conducting further user testing, collecting qualitative feedback, or conducting additional surveys to gather more insights.

Participants also reported learning new information about ACP and being more ready to have conversations about medical care after completing the plan. While the self-reported changes in knowledge and readiness were statistically significant, we cannot yet accurately determine the degree of clinical significance. Generally, clinically significant improvements are associated with any positive increase to an average 5-point rating. However, more research is needed to determine specific thresholds for outcomes on ACP-related metrics [17,49]. Nevertheless, these findings have positive implications for the ability of online health tools to promote ACP participation among patients and families, with the ultimate goal of bringing empowerment and peace of mind during serious illness or end-of-life care.

Despite these promising findings, several limitations must be acknowledged. First, the study intervention necessitates further validation through a randomized controlled trial. Second, the low enrollment rate compared to the total number of invitees suggest that more effective recruitment methods are needed than a single patient portal message, such as personalized ACP information from a nurse or other health care provider, posters placed in prominent areas, or additional contact methods. Additionally, as in any voluntary research, responses may have been affected by self-selection bias; those who agreed to participate in the study may be distinct from those who chose to ignore the invitation to participate. We saw evidence of this in the greater percentage of female-identifying participants in the study than in the general population. Future studies should consider appropriate sampling techniques like stratified randomization to ensure participation reflective of the larger population. Lastly, further studies should investigate the long-term impacts of the Koda platform on measures of patient and caregiver experience and goal-concordant care [54].

In conclusion, the Koda ACP platform represents a promising tool for promoting patient engagement in ACP, particularly among older adults and marginalized groups. By facilitating knowledge acquisition and readiness to engage in ACP, the Koda platform can help empower patients to make goal-informed medical decisions, especially regarding end-of-life care. Further research is needed to validate these findings and determine long-term impacts on patient and caregiver outcomes.

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Authors' Contributions

DPM, TYF, KDC, EK, JM, AM, AEB, and JG conceptualized this study. RLR, KDC, TS, and JG drafted the manuscript. JM, AM, TS, and JG contributed to the editing of the manuscript. All authors approved the final manuscript.

Conflicts of Interest

RLR, KDC, DPM, and TYF were each employed by Koda Health at the time of their work on this project. TS, EK, AM, JM, AEB, and JG have no conflicts of interest to report.

References

1. Hickman SE, Lum HD, Walling AM, Savoy A, Sudore RL. The care planning umbrella: the evolution of advance care planning. J Am Geriatr Soc 2023 Jul;71(7):2350-2356. [doi: 10.1111/jgs.18287] [Medline: 36840690]
2. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol 2017 Sep;18(9):e543-e551. [doi: 10.1016/S1470-2045(17)30582-X] [Medline: 28884703]
3. Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage 2017 May;53(5):821-832. [doi: 10.1016/j.jpainsymman.2016.12.331] [Medline: 28062339]

4. Comer AR, Hickman SE, Slaven JE, et al. Assessment of discordance between surrogate care goals and medical treatment provided to older adults with serious illness. JAMA Netw Open 2020 May 1;3(5):e205179. [doi: 10.1001/jamanetworkopen.2020.5179] [Medline: 32427322]
5. Ernecoff NC, Zimmerman S, Mitchell SL, et al. Concordance between goals of care and treatment decisions for persons with dementia. J Palliat Med 2018 Oct;21(10):1442-1447. [doi: 10.1089/jpm.2018.0103] [Medline: 29957095]
6. Khandelwal N, Curtis JR, Freedman VA, et al. How often is end-of-life care in the United States inconsistent with patients' goals of care? J Palliat Med 2017 Dec;20(12):1400-1404. [doi: 10.1089/jpm.2017.0065] [Medline: 28665781]
7. Shrank WH, Rogstad TL, Parekh N. Waste in the US health care system: estimated costs and potential for savings. JAMA 2019 Oct 15;322(15):1501-1509. [doi: 10.1001/jama.2019.13978] [Medline: 31589283]
8. Bar-Sela G, Tur-Sinai A, Givon-Schaham N, Bentur N. Advance care planning and attainment of cancer patients' end-of-life preferences: relatives' perspective. Am J Hosp Palliat Care 2023 Mar;40(3):322-328. [doi: 10.1177/10499091221099921] [Medline: 35587799]
9. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008 Oct 8;300(14):1665-1673. [doi: 10.1001/jama.300.14.1665] [Medline: 18840840]
10. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance care planning and the quality of end-of-life care in older adults. J Am Geriatr Soc 2013 Feb;61(2):209-214. [doi: 10.1111/jgs.12105] [Medline: 23350921]
11. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ 2010 Mar 23;340:c1345. [doi: 10.1136/bmj.c1345] [Medline: 20332506]
12. Levoy K, Sullivan SS, Chittams J, Myers RL, Hickman SE, Meghani SH. Don't throw the baby out with the bathwater: meta-analysis of advance care planning and end-of-life cancer care. J Pain Symptom Manage 2023 Jun;65(6):e715-e743. [doi: 10.1016/j.jpainsymman.2023.02.003] [Medline: 36764411]
13. Bond WF, Kim M, Franciskovich CM, et al. Advance care planning in an accountable care organization is associated with increased advanced directive documentation and decreased costs. J Palliat Med 2018 Apr;21(4):489-502. [doi: 10.1089/jpm.2017.0566] [Medline: 29206564]
14. Patel MI, Sundaram V, Desai M, et al. Effect of a lay health worker intervention on goals-of-care documentation and on health care use, costs, and satisfaction among patients with cancer: a randomized clinical trial. JAMA Oncol 2018 Oct 1;4(10):1359-1366. [doi: 10.1001/jamaoncol.2018.2446] [Medline: 30054634]
15. Volandes AE, Paasche-Orlow MK, Davis AD, Eubanks R, El-Jawahri A, Seitz R. Use of video decision aids to promote advance care planning in Hilo, Hawai'i. J Gen Intern Med 2016 Sep;31(9):1035-1040. [doi: 10.1007/s11606-016-3730-2] [Medline: 27194151]
16. Broom T, Rubin I. End-of-life values and value-based care. Am J Accountable Care 2022 Jun 1;10(2):4-6. [doi: 10.37765/ajac.2022.89164]
17. McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? A scoping review. J Am Geriatr Soc 2021 Jan;69(1):234-244. [doi: 10.1111/jgs.16801] [Medline: 32894787]
18. Barnato AE, O'Malley AJ, Skinner JS, Birkmeyer JD. Use of advance care planning billing codes for hospitalized older adults at high risk of dying: a national observational study. J Hosp Med 2019 Apr;14(4):229-231. [doi: 10.12788/jhm.3150] [Medline: 30933674]
19. Belanger E, Loomer L, Teno JM, Mitchell SL, Adhikari D, Gozalo PL. Early utilization patterns of the new Medicare procedure codes for advance care planning. JAMA Intern Med 2019 Jun 1;179(6):829-830. [doi: 10.1001/jamainternmed.2018.8615] [Medline: 30855641]
20. Palmer MK, Jacobson M, Enguidanos S. Advance care planning for Medicare beneficiaries increased substantially, but prevalence remained low. Health Aff (Millwood) 2021 Apr;40(4):613-621. [doi: 10.1377/hlthaff.2020.01895] [Medline: 33819084]
21. Weissman JS, Reich AJ, Prigerson HG, et al. Association of advance care planning visits with intensity of health care for Medicare beneficiaries with serious illness at the end of life. JAMA Health Forum 2021 Jul;2(7):e211829. [doi: 10.1001/jamahealthforum.2021.1829] [Medline: 35977213]
22. Genewick JE, Lipski DM, Schupack KM, Buffington ALH. Characteristics of patients with existing advance directives: evaluating motivations around advance care planning. Am J Hosp Palliat Care 2018 Apr;35(4):664-668. [doi: 10.1177/1049909117731738] [Medline: 28925295]
23. Yadav KN, Gabler NB, Cooney E, et al. Approximately one in three US adults completes any type of advance directive for end-of-life care. Health Aff (Millwood) 2017 Jul 1;36(7):1244-1251. [doi: 10.1377/hlthaff.2017.0175] [Medline: 28679811]
24. Clark MA, Person SD, Gosline A, Gawande AA, Block SD. Racial and ethnic differences in advance care planning: results of a statewide population-based survey. J Palliat Med 2018 Aug;21(8):1078-1085. [doi: 10.1089/jpm.2017.0374] [Medline: 29658817]

25. Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low completion and disparities in advance care planning activities among older Medicare beneficiaries. JAMA Intern Med 2016 Dec 1;176(12):1872-1875. [doi: 10.1001/jamainternmed.2016.6751] [Medline: 27802496]
26. Lin PJ, Zhu Y, Olchanski N, et al. Racial and ethnic differences in hospice use and hospitalizations at end-of-life among Medicare beneficiaries with dementia. JAMA Netw Open 2022 Jun 1;5(6):e2216260. [doi: 10.1001/jamanetworkopen.2022.16260] [Medline: 35679046]
27. Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. Am J Prev Med 2014 Jan;46(1):65-70. [doi: 10.1016/j.amepre.2013.09.008] [Medline: 24355673]
28. Sanders JJ, Robinson MT, Block SD. Factors Impacting advance care planning among African Americans: results of a systematic integrated review. J Palliat Med 2016 Feb;19(2):202-227. [doi: 10.1089/jpm.2015.0325] [Medline: 26840857]
29. Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AHY. Overview of systematic reviews of advance care planning: summary of evidence and global lessons. J Pain Symptom Manage 2018 Sep;56(3):436-459. [doi: 10.1016/j.jpainsymman.2018.05.016] [Medline: 29807158]
30. Hemsley B, Meredith J, Bryant L, et al. An integrative review of stakeholder views on advance care directives (ACD): barriers and facilitators to initiation, documentation, storage, and implementation. Patient Educ Couns 2019 Jun;102(6):1067-1079. [doi: 10.1016/j.pec.2019.01.007] [Medline: 30799141]
31. Blackwood DH, Walker D, Mythen MG, Taylor RM, Vindrola-Padros C. Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: a systematic review. J Clin Nurs 2019 Dec;28(23-24):4276-4297. [doi: 10.1111/jocn.15049] [Medline: 31494997]
32. Detering KM, Sinclair C, Buck K, et al. Organisational and advance care planning program characteristics associated with advance care directive completion: a prospective multicentre cross-sectional audit among health and residential aged care services caring for older Australians. BMC Health Serv Res 2021 Jul 16;21(1):700. [doi: 10.1186/s12913-021-06523-z] [Medline: 34271934]
33. Skolarus LE, Robles MC, Mansour M, et al. Low engagement of advance care planning among patients who had a stroke or transient ischemic attack. J Am Heart Assoc 2022 Mar 15;11(6):e024436. [doi: 10.1161/JAHA.121.024436] [Medline: 35229620]
34. DiJulio B, Firth J. Kaiser health tracking poll: September 2015. KFF. 2015. URL: https://www.kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/ [accessed 2024-04-11]
35. Chiarchiaro J, Arnold RM, White DB. Reengineering advance care planning to create scalable, patient- and family-centered interventions. JAMA 2015 Mar 17;313(11):1103-1104. [doi: 10.1001/jama.2015.0569] [Medline: 25781435]
36. Fine RL, Yang Z, Spivey C, Boardman B, Courtney M. Early experience with digital advance care planning and directives, a novel consumer-driven program. Proc (Bayl Univ Med Cent) 2016 Jul;29(3):263-267. [doi: 10.1080/08998280.2016.11929430] [Medline: 27365867]
37. van der Smissen D, Overbeek A, van Dulmen S, et al. The feasibility and effectiveness of web-based advance care planning programs: scoping review. J Med Internet Res 2020 Mar 17;22(3):e15578. [doi: 10.2196/15578] [Medline: 32181750]
38. Norton JM, Ip A, Ruggiano N, et al. Assessing progress toward the vision of a comprehensive, shared electronic care plan: scoping review. J Med Internet Res 2022 Jun 10;24(6):e36569. [doi: 10.2196/36569] [Medline: 35687382]
39. Dupont C, Smets T, Monnet F, et al. Publicly available, interactive web-based tools to support advance care planning: systematic review. J Med Internet Res 2022 Apr 20;24(4):e33320. [doi: 10.2196/33320] [Medline: 35442207]
40. Saunders CH, Patel K, Kang H, Elwyn G, Kirkland K, Durand MA. Serious choices: a systematic environmental scan of decision aids and their use for seriously ill people near death. J Hosp Med 2019 May;14(5):294-302. [doi: 10.12788/jhm.3110] [Medline: 30794146]
41. Ostherr K, Killoran P, Shegog R, Bruera E. Death in the digital age: a systematic review of information and communication technologies in end-of-life care. J Palliat Med 2016 Apr;19(4):408-420. [doi: 10.1089/jpm.2015.0341] [Medline: 26713368]
42. McDarby M, Llaneza D, George L, Kozlov E. Mobile applications for advance care planning: a comprehensive review of features, quality, content, and readability. Am J Hosp Palliat Care 2021 Aug;38(8):983-994. [doi: 10.1177/1049909120959057] [Medline: 32938207]
43. Roberts RL, Mohan DP, Cherry KD, et al. Deployment of a digital advance care planning platform at an accountable care organization. J Am Board Fam Med 2024 Jan 5;36(6):966-975. [doi: 10.3122/jabfm.2023.230133R2] [Medline: 37907349]
44. Hettema J, Steele J, Miller WR. Motivational interviewing. Annu Rev Clin Psychol 2005;1:91-111. [doi: 10.1146/annurev.clinpsy.1.102803.143833] [Medline: 17716083]
45. Brooke J. Usability evaluation in industry. In: SUS: A ‘Quick and Dirty’ Usability Scale: CRC Press; 1996.
46. Hyzy M, Bond R, Mulvenna M, et al. System Usability Scale benchmarking for digital health apps: meta-analysis. JMIR Mhealth Uhealth 2022 Aug 18;10(8):e37290. [doi: 10.2196/37290] [Medline: 35980732]
47. Bangor A, Kortum PT, Miller JT. An empirical evaluation of the System Usability Scale. Int J Hum Comput Int 2008 Jul 29;24(6):574-594. [doi: 10.1080/10447310802205776]
48. Lewis JR. The System Usability Scale: past, present, and future. Int J Hum Comput Int 2018 Jul 3;34(7):577-590. [doi: 10.1080/10447318.2018.1455307]

49. Sudore RL, Heyland DK, Barnes DE, et al. Measuring advance care planning: optimizing the advance care planning engagement survey. J Pain Symptom Manage 2017 Apr;53(4):669-681. [doi: 10.1016/j.jpainsymman.2016.10.367] [Medline: 28042072]
50. Blatch-Jones AJ, Pek W, Kirkpatrick E, Ashton-Key M. Role of feasibility and pilot studies in randomised controlled trials: a cross-sectional study. BMJ Open 2018 Sep 25;8(9):e022233. [doi: 10.1136/bmjopen-2018-022233] [Medline: 30257847]
51. Langford DP, Fleig L, Brown KC, et al. Back to the future - feasibility of recruitment and retention to patient education and telephone follow-up after hip fracture: a pilot randomized controlled trial. Patient Prefer Adherence 2015 Sep 22;9:1343-1351. [doi: 10.2147/PPA.S86922] [Medline: 26491262]
52. Walters SJ, Bonacho Dos Anjos Henriques-Cadby I, Bortolami O, et al. Recruitment and retention of participants in randomised controlled trials: a review of trials funded and published by the United Kingdom Health Technology Assessment Programme. BMJ Open 2017 Mar 20;7(3):e015276. [doi: 10.1136/bmjopen-2016-015276] [Medline: 28320800]
53. Skolarus LE, Brown DL, Corches CL, et al. Extending advance care planning to Black Americans in the community: a pilot study of the PREPARE program. J Pain Symptom Manage 2021 Jul;62(1):e4-e9. [doi: 10.1016/j.jpainsymman.2021.02.029] [Medline: 33647422]
54. Gabbard JL, Carpenter JG, Ernecoff NC, et al. Evaluating the pragmatic characteristics of advance care planning outcome measures in dementia clinical trials: a scoping review. J Am Geriatr Soc 2023 Nov;71(11):3595-3608. [doi: 10.1111/jgs.18495] [Medline: 37439456]

Abbreviations

ACP: advance care planning
AHWFB: Atrium Health Wake Forest Baptist
CPR: cardiopulmonary resuscitation
EHR: electronic health record
SDM: surrogate decision-maker
SUS: System Usability Scale

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Original Paper

Performance Differences of a Touch-Based Serial Reaction Time Task in Healthy Older Participants and Older Participants With Cognitive Impairment on a Tablet: Experimental Study

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Abstract

Background: Digital neuropsychological tools for diagnosing neurodegenerative diseases in the older population are becoming more relevant and widely adopted because of their diagnostic capabilities. In this context, explicit memory is mainly examined. The assessment of implicit memory occurs to a lesser extent. A common measure for this assessment is the serial reaction time task (SRTT).

Objective: This study aims to develop and empirically test a digital tablet–based SRTT in older participants with cognitive impairment (CoI) and healthy control (HC) participants. On the basis of the parameters of response accuracy, reaction time, and learning curve, we measure implicit learning and compare the HC and CoI groups.

Methods: A total of 45 individuals (n=27, 60% HCs and n=18, 40% participants with CoI—diagnosed by an interdisciplinary team) completed a tablet-based SRTT. They were presented with 4 blocks of stimuli in sequence and a fifth block that consisted of stimuli appearing in random order. Statistical and machine learning modeling approaches were used to investigate how healthy individuals and individuals with CoI differed in their task performance and implicit learning.

Results: Linear mixed-effects models showed that individuals with CoI had significantly higher error rates (b=−3.64, SE 0.86; $z=-4.25$; $P<.001$); higher reaction times ($F_{1,41}=22.32$; $P<.001$); and lower implicit learning, measured via the response increase between sequence blocks and the random block ($\beta=-0.34$; SE 0.12; $t=-2.81$; $P=.007$). Furthermore, machine learning models based on these findings were able to reliably and accurately predict whether an individual was in the HC or CoI group, with an average prediction accuracy of 77.13% (95% CI 74.67%-81.33%).

Conclusions: Our results showed that the HC and CoI groups differed substantially in their performance in the SRTT. This highlights the promising potential of implicit learning paradigms in the detection of CoI. The short testing paradigm based on these results is easy to use in clinical practice.

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KEYWORDS

serial reaction time task; SRTT; implicit learning; mobile digital assessments; cognitive impairment; neurodegeneration; tablet-based testing; mild cognitive impairment; MCI; dementia; Alzheimer; neuropsychology; aging; older individuals

Introduction

Memory, Neurodegeneration, and Aging

Overview

In an aging society, the number of individuals with neurodegenerative diseases is increasing. Alzheimer disease (AD) and Parkinson disease rank among the most prevalent neurodegenerative disorders. One of the most apparent cognitive symptoms of neurodegenerative diseases is a change in memory impairment, which can affect different cognitive and memory functions in different ways.

Memory functions differ in concepts and models [1-5]. When comparing different memory models, memory can be categorized into specific subsystems: intentional learning leads to explicit memory, and unintentional and incidental learning creates implicit memory [3-6]. Most studies on neuropsychological changes in neurodegenerative diseases focus on explicit memory, whereas studies examining the decline of implicit memory remain scarce [7-13]. Accordingly, many assessments for explicit memory are available, but only a few assessments are available for implicit memory, and most assessments are paper based. Paper-based examination of implicit memory is effortful and limited in its possibilities and test quality, although there are some digital tools available [8,14]. Still, solely examining explicit memory seems to be insufficient, as neurodegenerative disorders such as AD show changes in different cognitive domains, not just explicit memory but also implicit memory [14-19], among others. Thus, implicit memory paradigms are promising tools in addition to common explicit memory tasks in early diagnostics to assess memory dysfunctions more precisely and to determine the different causes of neuropsychological dysfunction. Reasons for reduced performance in implicit memory tasks can be independent of the reasons for deficits in regular tasks such as word lists used for explicit learning.

We introduce a digital tablet–based version of the serial reaction time task (SRTT) aimed at assessing implicit memory. We then use data gathered by this tool to develop machine learning (ML) models for predicting cognitive impairment without relying on diagnoses from comprehensive assessments such as the Montreal Cognitive Assessment or the Consortium to Establish a Registry for Alzheimer’s Disease. On the basis of computer-based studies, we developed an app for clinical application, aiming to provide results comparable with previous findings on the SRTT. This study examines a mobile touch–based SRTT on a tablet in healthy older participants and older participants with cognitive impairment (CoI).

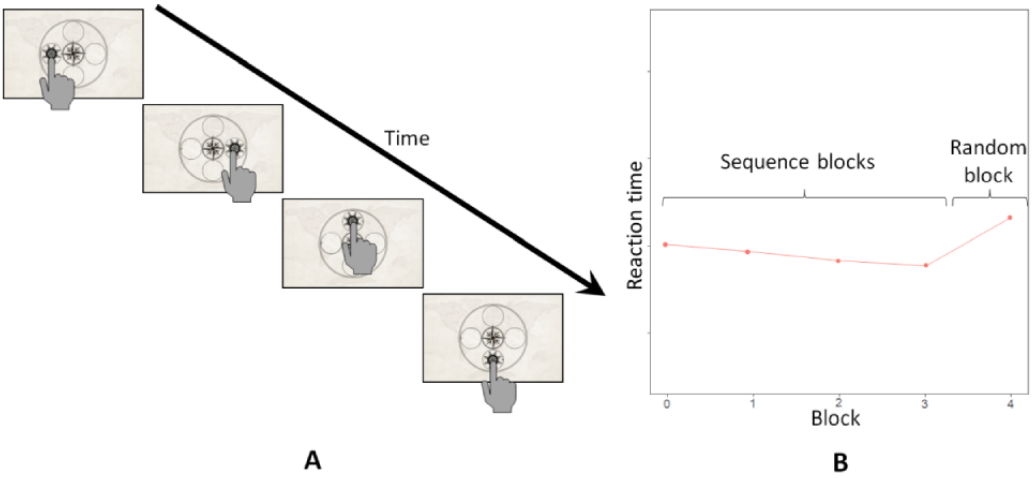
Implicit Learning

Researchers use various terms for implicit memory, referring to different concepts and processes inconsistently. Sometimes, these terms can refer to subtypes of a form of memory [8,14]. Although *implicit learning* is an umbrella term for the absence of awareness and intention, which means “a collection of abilities that are expressed through performance without requiring conscious memory content” [2], *statistical learning* “refers to the ability to detect and learn regularities in the environment” [13]. *Sequence learning* “describes the ability to incidentally acquire knowledge of sequences of events and actions” [20]. *Motor skill learning* “refers to the increasing spatial and temporal accuracy of movements with practice” [21]. *Procedural learning* is used as a synonym for sequence learning, referring to the learning of sensory-motor skills [10,13,22,23]. As we are focusing on a rather application-oriented approach, we further refer to the more general concept of implicit learning.

SRTT Paradigm

Different tasks have been used to assess implicit learning [8,14]. Among others, the SRTT was established as a widely used assessment. In the original version of the SRTT [24], participants react to stimuli presented in blocks with repeated sequences. After several blocks of repeated sequences (“sequence blocks”), a block with random sequences is presented (“random block”). Although reaction times usually improve throughout the blocks of repeated sequences, they decelerate in the blocks with a random sequence [16,24]. Implicit learning is assumed when there is a decrease in reaction time in blocks of repeated sequences and an increase in reaction time in the random block. Figure 1 shows an illustration based on the example of this study.

Figure 1. Illustration of the serial reaction task paradigm used in this study and the expected reaction times for healthy participants. (A) Touch-based variant used in the study. The participants' task was to respond with their finger to the target stimulus in the form of a ship's wheel on the tablet. (B) Expected reaction times for healthy participants. After the sequence is repeated in the first 4 blocks, leading to a decrease in participants' reaction time, a random sequence occurs in block 5, resulting in a significant increase in participants' reaction time.



SRTT Variants

There are many variations in the SRTT paradigm and ambiguous findings on the effects and results of different clinical syndromes. Variations in paradigms can significantly influence the patterns of results observed. Different versions of the SRTT may vary in factors such as the quantity and length of stimuli; number of trials and blocks; the arrangement, structure, and display of stimuli on screen; the method of response; and even the medium used. Stimuli are presented on a computer screen in most studies [14,25]. Participants are asked to indicate the position of the stimuli using buttons on a keyboard or button box. Very few studies used a touchscreen- or tablet-based presentation of the SRTT [9,26-31]. Thus, researchers have many degrees of freedom in adjusting the paradigms of the SRTT, especially when implementing a touch-based version for older participants. In this setup, the participants use their fingers to indicate the position of the stimuli directly on the touchscreen. The most appropriate specifications may vary based on the research question (RQ) and the sample under investigation.

As described by Hong et al [16], an alternating design, that is, a design with an alternating sequence and random blocks [32-34], has advantages in distinguishing between motor and cognitive learning, but progressions in sequence tasks cannot be analyzed. Moreover, alternating sequences lead to a longer overall assessment time. In contrast to laboratory studies, design decisions are limited in a clinical approach. An SRTT version suitable for clinical use with older participants should be as short as possible to meet their stamina and motivation, especially in the case of CoI. Although some researchers suggest the superiority of alternating SRTT variants because of their capacity to discriminate between sequence-specific and general skill learning [35], we decided to use the SRTT in a tablet-based version as a short SRTT version that only needs 5 blocks and thus is much shorter and more usable in clinical contexts.

Possible Distinguishing Features

The patient and control groups differ for various outcome measures. First, *reaction times* can differ between groups in general, meaning that healthy controls (HC) are faster than patient subgroups. Second, *learning curves* can vary between groups, meaning that HC participants should learn sequences faster. Third, the *response increase* between the groups may deviate. That is, the contrast in reaction times between sequence and random blocks becomes more pronounced after extensive learning of sequences, rather than just motor skill leaning or increased familiarity with the task. Finally, the *number of correct responses*, that is, the *response accuracy* (and vice versa *error rates*), is expected to differ between groups. That is, the CoI group should show more false responses than the HC group. In addition, when we combine these variables as features in a statistical model, we may discover findings not only about implicit memory but also about parameters such as limitations in task comprehension or altered reaction times, which serve as additional diagnostic information.

SRTT Findings

The SRTT and similar tasks to assess implicit learning have been used in numerous studies in different fields [25], reporting different variables, outcome measures, and results. Varying patterns of results can be explained by different design variations (eg, [32,33]) and experimental requirements and conditions [8,14]. In healthy adults, differences in response increase were found consistently between sequence and random blocks. There was a slight tendency of age-related deterioration in performance, learning, accuracy, and reaction times with higher age [20,36,37]. Worse performance can be observed in patients with strokes [38]. Numerous studies show a deterioration of performance in neurodegenerative disorders affecting the basal ganglia and the thalamus, such as Parkinson disease [25,39,40], and other neurodegenerative and neuropsychiatric diseases, such as Huntington disease [41-43] and Korsakoff syndrome [24].

Some SRTT studies were conducted with patients with AD as the clinical sample, whereas others were conducted with patients with mild cognitive impairment (MCI; for reviews, refer to the studies by de Wit et al [8] and van Halteren-van Tilborg et al [14]). Overall, there are mixed findings on the association between SRTT performance and cognitive impairment (such as AD, which can be a later stage of MCI). Comparing various studies poses a challenge because of differences in sample characteristics, such as the varying degrees of impairment severity (eg, MCI vs AD at different levels of severity), and the diverse inclusion criteria used for clinical samples (eg, specific diagnostic criteria vs various screening scores) [8]. In addition, inconsistent methodological approaches, including variations in the quantity and duration of stimuli, sequences, and blocks, further complicate comparisons between studies. Some studies revealed no significant differences in learning concerning response increase for participants with MCI compared with HC participants. That is, participants with MCI and HC participants showed similar response increases between sequence and random blocks [9,16,44,45], whereas other studies found differences [15,46]. Participants with AD, however, show less response increase than HC participants in some studies [47-49] and a comparable response increase in others [50-52].

Compared with learning curves, that is, the reduction in reaction time over sequence blocks, patients with MCI seem to have similar curves as HCs in most studies [9,15,16,44,45], whereas some studies found differences [46,48]. Patients with AD show more deficits than HCs, as indicated by a flatter learning curve in some studies [49,53], but this was not clearly evident in most studies [47,50-52].

When comparing accuracy or error rate, in some cases, no differences are found between participants with AD [41,51,52] and MCI [44,46]. In other cases, participants with AD [47,48,50] and MCI [16,45] differ from the reference groups.

In most cases, patients with MCI [16,46] and AD [47,50-53] had slower overall reaction time [54]. These differences can be explained by motoric demands, the experimental design of the tasks, and differences in sample selection. In addition, a large number of dementia diseases may be mixed pictures of different subtypes of dementia [55,56]. This phenomenon may further contribute to the divergent findings. In a review and meta-analysis, de Wit et al [8] discuss the difficulty of participants with AD in understanding and remembering the test instructions of SRTT paradigms. Most studies found differences in response accuracy and reaction times (with participants with CoI being slower than HC participants). These differences suggest that the understanding and execution of the task play a significant role in classifying differences between healthy individuals and individuals with CoI.

This Study

We developed a mobile SRTT version suitable for testing implicit memory in a clinical routine (in contrast to an extensive laboratory assessment). Working with older patients in everyday clinical routines, we recognized the need for a short, understandable, and highly accepted digital assessment that medical professionals can use in point-of-care or bedside tests without requiring additional technical equipment. We also expect a short and tablet-based variant to address the difficulties in task understanding and remembering task instructions among patients with CoI reported by de Wit et al [8]. Using a tablet in neuropsychological testing has benefits in terms of the availability of new data sources and its applicability outside the laboratory [57,58]. Furthermore, digitalized testing enables tasks and measures that are impossible in pen-and-paper testing [57]. Using a touchscreen is a considerable relief for older patients, and particularly patients with CoI, compared with using a keyboard [59-62]. Furthermore, motivational effects must be considered when designing tasks for older participants [57,63]. Not only the design of the task but also the task parameters are essential: the length of the sequence and the frequency of repetitions should capture implicit learning but should not be unnecessarily prolonged. Using ML approaches that combine various parameters, we may predict participants' cognitive status more accurately with less data than a traditional approach, which accommodates shorter assessments. Combining the SRTT with ML represents a more recent development in this research domain [9,10,16].

ML predictions based on these parameters can potentially lead to accurate predictions using fewer repetitions, which facilitate shorter assessments that are mandatory for acceptance in clinical outpatient and inpatient practice.

Research Questions

This study focuses on the following RQs, which are centered on the question of whether the findings for the computer-based version of the SRTT can be replicated and transferred to the tablet-based version of the SRTT used in this study.

We investigated the following RQs:

1. Do participants with CoI and HC participants differ significantly in response accuracy?
    - We expect participants with CoI to make more errors than HC participants.
2. Do HC participants and participants with CoI differ in their average reaction times during the learning phase?
    - We expect that participants with CoI are systematically slower than HC participants.
3. Do participants with CoI and HC participants differ in implicit learning? That is, is the response increase in the random block compared with the learning curve significantly lower for participants with CoI?
    - We expect that participants with CoI show less implicit learning than HC.
4. Do participants with CoI show a different learning curve during the learning phase than HC participants?
    - We expect HC participants to show a steeper learning curve than participants with CoI, which should show a flatter learning curve.
5. Can we reliably predict participants' groups using an ML prediction model?
    - We expect to classify participants with an accuracy comparable with that of Hong et al [16]. That is, we expect the 80.9% found by Hong et al [16] to be within our 95 % CI of prediction accuracy.

Methods

Participants

We recruited and tested 49 older participants at the Geriatric Center at the University Clinic for Psychiatry and Psychotherapy in Tübingen, Germany. A total of 2 participants discontinued the experiment. One participant had to be excluded owing to a low response accuracy of 40%, which indicates a failure to understand and complete the task appropriately. We later identified 1 participant with significantly prolonged reaction times as an outlier and had to exclude this participant. Within the scope of this project, we also collected data from 11 participants with depression, which we excluded from the analysis of this study because of the focus on neurodegeneration. The remaining 45 participants (26 female individuals), aged between 52 and 87 (mean 68.4, SD 9.82) years, consisted of 27 HC participants and 18 participants with CoI. A list of inclusion and exclusion criteria is presented in Textbox 1.

We based the allocation of groups on experienced physician examinations, confirmed by an interdisciplinary team (physicians, psychologists, specialized therapists, and nurses), as most participants were known to us as patients of our (day) hospital and their caregivers or relatives. We also recorded the participants’ educational level. Subsequently, we converted the educational levels into corresponding years representing the time typically taken to achieve them. The descriptive statistics of the demographics of the sample are provided in Table 1.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria

- Adults aged ≥50 years
- Diagnosis of cognitive impairment (for patient group), confirmed by an interdisciplinary team
- Understanding and agreement of informed consent
- Participation on a voluntary basis

Exclusion criteria

- Unable to perform or a lack of understanding of the task requirements
- Visual impairment
- Refusal or inability to give informed consent
- Acute delirious or psychotic episode
- Acute medical or physical conditions

Table 1. Demographic data of the 2 groups (HC[a] and CoI[b]; N=45).

Characteristics	HC (n=27)	CoI (n=18)	Total (N=45)	*P* value
Age (y)				.002[c]
Mean (SD)	64.89 (9.66)	73.67 (7.62)	68.40 (9.82)	
Range	52-85	55-87	52-87	
Education (y)				.52[c]
Mean (SD)	11.74 (3.21)	11.06 (3.80)	11.47 (3.43)	
Range	8-17	8-19	8-19	
Sex, n (%)				.39[d]
Female	17 (63)	9 (50)	26 (58)	
Male	10 (37)	9 (50)	19 (42)	

[a] HC: healthy controls.

[b] CoI: participants with cognitive impairment.

[c] Linear model ANOVA.

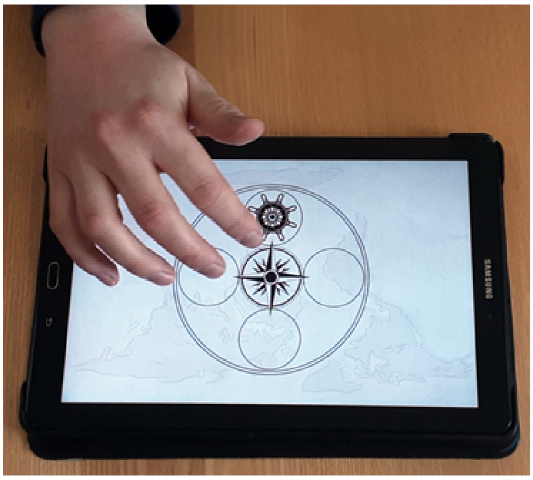
[d] Pearson chi-square test.

Materials

Overview

We used a tablet-based variant of the SRTT (described in the subsequent sections) designed for this study to meet the needs of older participants. The experiments were performed on a "Samsung Galaxy Tab A (2016) with S Pen" tablet (model SM-P580, Samsung Electronics) with a screen size of 10.1 inches, running on Android 7.0. Tablets were positioned on the table horizontally and planar in front of the participants (Figure 2). Thus, the participants were able to rest their elbows on the table. The participants' task was to repeatedly respond as quickly as possible to the target stimulus, whose position changed, with their fingers.

Figure 2. View of the setup and task in the app used for the study. Participants were allowed to rest their hands on the table.



SRTT Design

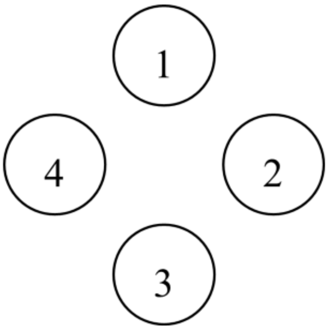
The experimental design of the SRTT used in this study is based on the study by Lum et al [64], as they used a shorter version with fewer trials than previous studies, which was necessary in working with older participants. Thus, following a 10-trial practice phase, the SRTT used in this study consisted of 5 blocks with 60 trials each. Blocks 1 to 4 are sequence blocks and contain the 10-item sequence, repeated 6 times per block. The repeated sequence 4-2-3-1-3-2-4-3-2-1 is based on the original design of Nissen and Bullemer [24] and was also used by Lum et al [64] and Lum and Kidd [65]. In the circular order we used, the top position (north) corresponds to 1, 2 corresponds to the right-hand position (east), 3 corresponds to the lowest position (south), and 4 corresponds to the left position (west; Figure 3).

When we developed the tablet-based variant, a circular order of stimuli [9,10,64,66-69] was chosen to ensure comparable spatial distances between stimuli on the screen (Figure 3). A horizontal arrangement of stimuli would lead to unequal distances between stimuli. A touchscreen-based version of the SRTT was used in only a few studies in general [26,29,31,70], specifically in samples consisting of older individuals [27]. To the best of our knowledge, apart from the study by Dominey et al [27], no study with older participants that exclusively used touchscreen versions of the SRTT on a larger sample was published. The motor skills required for responding on a tablet surface differ from those needed for pressing buttons on a response panel [29,31].

In *block 5*, based on the study by Lum et al [64], the stimulus appears in a pseudorandomized order. This order is based on 2 conditions: first, each stimulus appears as often as in the antecedent (learning) sequence blocks, and second, the probability of appearing at 1 of the 4 positions after its antecedent stimulus is the same as in the learning sequence. We precomputed 1 pseudorandomized sequence (Multimedia Appendix 1) and used the same pseudorandomized sequence for each participant. We did not inform participants about the given configuration. Using the difference between sequential and pseudorandomized trials yields a measure of skill acquisition from the SRTT that is specific and sensitive, as measuring implicit learning by only comparing improved reaction times in sequenced blocks is confounded by visuomotor association [71]. Multiple parameters captured through the app were used for statistical modeling to assess their predictive value, via the approach of Hong et al [16] using random forest classification.

After the stimulus appears at position 1, the probability that it will appear at either position 3 or position 4 is 50%, respectively. After appearing at position 2, it is equally likely that the stimulus appears next at positions 1, 2, or 4, corresponding to 33% for each position. After appearing at position 3, the probability for the stimulus to appear next is 33.33% for position 1 and 66.66% for position 2. After appearing at position 4, the probability for the stimulus to appear next at position 2 or position 3 is 50%, respectively. After a practice trial, the participants were advised to react to the stimulus, changing their position as quickly as possible throughout the blocks. The app recorded the reaction times and the correctness of the reactions.

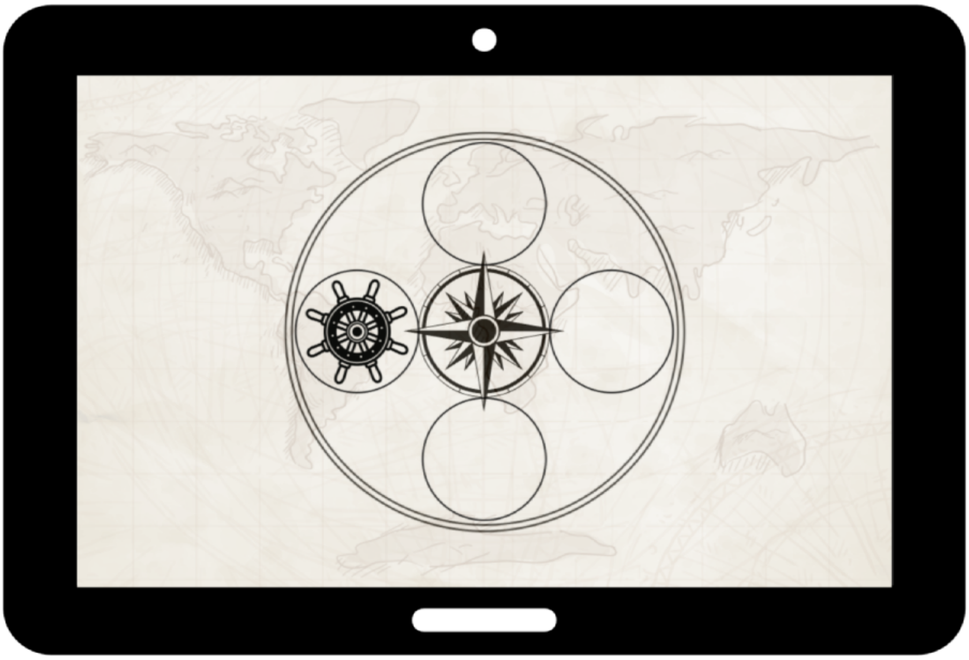
Figure 3. Circular order of the serial reaction time task.



Task Implementation

We developed the mobile touch–based SRTT in Unity 3D, version 2019.1.0f2 [72] as part of the TuCAN (Tübingen Cognitive Assessment for Neuropsychiatric Disorders) Project, which develops a tablet-based test battery app. In a first pilot study with university students, we showed that different user interface designs on the tablet are comparable and that no effects are attributable to the design. Moreover, we examined the usability and preferences of different designs with older participants in a second pilot study. The usability study is substantial for older participants to accommodate for possible low computer and tablet literacy and to ensure that an app is developed according to the needs of older participants [60,73,74]. In the preceding user tests and pilot studies described in this section, in which different designs were compared, we identified a circular compass design as the preferred design version for older participants (Figure 4). In this design, a compass dial is placed in the center of the screen and is surrounded by 4 circles. In the background, an ancient-looking map is depicted. A ship’s wheel, as the target stimulus, changes the positions between the 4 circles.

Figure 4. The compass design of the serial reaction time task developed to meet the needs of older participants.



Statistical Analysis

Overview

We performed analyses on the full sample of 45 participants. In addition, because of significant differences in age between the groups, all statistical analyses were rerun using an age-matched subsample of 36 participants (18 HCs and 18 participants with CoI). The pattern of the results remained identical, underlining the robustness of the findings to age differences. Therefore, we only report the results from the full sample in this study. The results of the matched samples are reported in the web supplement [75]. Similarly, the assumptions for all statistical models were checked. In case of assumption violation, we reran the analyses with robust models to ensure that the pattern of results remained identical. For the sake of readability, the results of the robust models are only reported in the web supplement [75].

Analyses Software

We conducted statistical analyses for RQs 1 to 4 using R software (R version 4.3.2, R Foundation for Statistical Computing) [76].

We used the *lme4* package (version 1.1-35) to fit (generalized) linear mixed-effect models [77]. The df and *P* values were calculated with the *lmerTest* package (version 3.1-3) [78] using Satterthwaite approximation for the denominator df. We calculated the CIs for logistic regressions with the *broom.mixed* package (version 0.2.9.4) [79] using Wald approximation. We used the *ggplot2* package (version 3.4.4) [80] to create plots, the *stargazer* (version 5.2.3) [81], the *arsenal* (version 3.6.3) [82], and *tab_model* from the *sjplot* (version 2.8.15) [83,84] packages to create tables.

The criterion of statistical significance was set at Cronbach α=.05. The raw data and *R* scripts detailing all analyses can be accessed in the web supplement [75].

Data Cleaning

For all analyses except for the accuracy analysis (RQ 1), we removed trials within blocks according to the following criteria in the following order: (1) the first trial of each block, as these trials succeed the fixation cross; (2) erroneous trials; (3) trials following erroneous trials; (4) trials with reaction times <200 ms; and (5) trials with reaction times deviating >2.5 SDs from the mean within a block, within participants. In total, we removed 5.36% (723/13,500) of trials.

General Modeling Approach (RQ 1+RQ 3+RQ 4)

Mixed-effect models will be hierarchically constructed from a full model (containing all fixed and random effects, including interactions) with a maximum random effects structure to the model with the best fit according to the Bayesian information criterion by removing the most complex fixed effects first (ie, interaction terms). If the complexity of the random effect structure is not supported by the data (ie, convergence issues), the random effects structure is reduced, similar to the fixed effects structure, by removing the most complex terms first.

Accuracy (RQ 1)

To contrast the difference in accuracy between the 2 groups, we ran generalized linear mixed-effects models using the logistic link function in all trials. Accuracy was computed as the proportion of correct trials to the total number of trials per participant per block. The models included group, block, their interaction, and age as fixed effects and random intercepts for the participant.

Average Reaction Time (RQ 2)

Analyses of covariance (ANCOVAs) were performed on the cleaned data (ie, correct trials only) to contrast the difference in the average reaction time across the learning phase, that is, excluding the random block. The average reaction time was computed per participant as the average of the median reaction time of each block. The fixed effects were group, with age, sex, and years of education as covariates.

On the basis of recommendations for good scientific practice for reporting ANCOVAs [85], an ANOVA comparing the average reaction times between groups was also performed, showcasing the impact of the covariates on the results.

Implicit Learning (RQ 3) and Learning Curve (RQ 4)

Linear mixed effect (LME) spline models with the last sequence block as the knot were performed on participants' median reaction times per block to contrast the influence of group, block, response increase, sex, age, education, and the interaction between block and group and response increase and group. The model included random slopes for block and response increase for the participants. The linear and quadratic effects of blocks were tested for their contribution to the model fit. To this end, orthogonal polynomials were computed to encode the linear and quadratic effects of time. The response increase between the expected reaction time in the random block, based on the estimated learning curve during the learning phase in the sequence blocks, and the measured reaction time in the random block was coded as follows: We used dummy coding for the response increase between the expected reaction time in the random block, based on the estimated learning curve during the learning phase in the sequence blocks and the measured reaction time in the random block. That is, the dummy variable for response increase is set to 0 for blocks 1 to 4, and to 1 for the last and fifth block ("Response increase = 1 if random block, else 0").

Prediction Model: Classification of Group (RQ 5)

In an exploratory step, we trained random forests to investigate how accurately the participants' group (CoI vs HC) could be predicted. The input features were participants' mean accuracy across blocks, participants' mean reaction time across the learning phase (refer to RQ 2), age, and participants' estimated learning curve and response increase. In addition, as features for learning curves (linear and quadratic effect of block) and implicit learning (response increase, coded as explained in the *Implicit Learning (RQ 3) and Learning Curve (RQ 4)* section, we extracted the predicted values of the LME model with the median of the *z*-transformed reaction time per participant per block as the response and learning curve and implicit learning as fixed effects. The model included random slopes for the learning curve and the response increase of the participants.

ML and Prediction Model (RQ 5)

ML approaches have shown promising results in predicting potential diagnoses and outcomes. These predictive models combine various parameters that were collected during the study. However, only 1 study by Hong et al [16] used an ML approach to predict participants' cognitive status. Using a random forest approach [86], they achieved a prediction accuracy of 80.9%. Thus, using ML approaches to predict participants' potential diagnoses rather than only examining group differences may improve the value of such tasks in cognitive assessments, enabling their broader use in populations of older individuals.

As explained previously, we used the random forest classifier to predict whether a participant belonged to the CoI group or the HC group. Repeated nested leave-one-out cross-validations were used to optimize hyperparameters and gain unbiased estimates of the model performance (eg, [86]). Specifically, each training data set from the initial leave-one-out cross-validation (outer cross-validation) was further split using a subsequent leave-one-out cross-validation (inner cross-validation). In the inner cross-validation, the number of trees per forest (range 10-100 in steps of 10), their maximum depth (range 1-7), and the minimum number of samples in each leaf (range 1-5) were optimized using grid search. Subsequently, to obtain an unbiased measure of accuracy, the best model from the inner cross-validation was used to predict the test set from the corresponding outer cross-validation. Finally, this procedure was repeated 15 times (ie, the same cross-validation procedure with varying random seeds) to account for random variations in the modeling procedure. These ML analyses (RQ 5) were conducted in Julia (version 1.9.3) [87] using the *Machine Learning in Julia* (MLJ, version 0.19.2) library [88].

Ethical Considerations

The study was approved by the ethics committee of the University Hospital of Tübingen (332/2016BO2). Participation was on a voluntary basis and after written informed consent and signature. Compliance with data protection and the implementation and evaluation were based on relevant regulations, guidelines, and protocols.

Results

Response Accuracy (RQ 1)

The descriptive statistics for the average response accuracy per group are shown in Figure 5. The most suitable generalized linear mixed-effects model using the logistic link function to predict participants' accuracy was obtained through hierarchical model comparisons, as outlined in the modeling approach in the *General Modeling Approach (RQ 1+RQ 3+RQ 4)* section. The final model contained block, group, and the interaction of block and group as fixed effects and a random intercept for participants. Hierarchical model analyses revealed that age did not contribute significantly to the model fit. The model revealed a significant main effect of group (*b*=−3.64, SE=0.86; *z*=−4.25; *P*<.001). We further found a significant interaction effect between block and group (*b*=0.53, SE=0.23; *z*=2.33; *P*=.02). The main effect of block was not significant (*b*=−0.18, SE=0.11; *z*=−1.54; *P*=.12). The models are listed in Table 2.

Figure 5. Average response accuracy by group and block. Bars represent the SE of the mean. CoI: participants with cognitive impairment; HC: healthy controls.

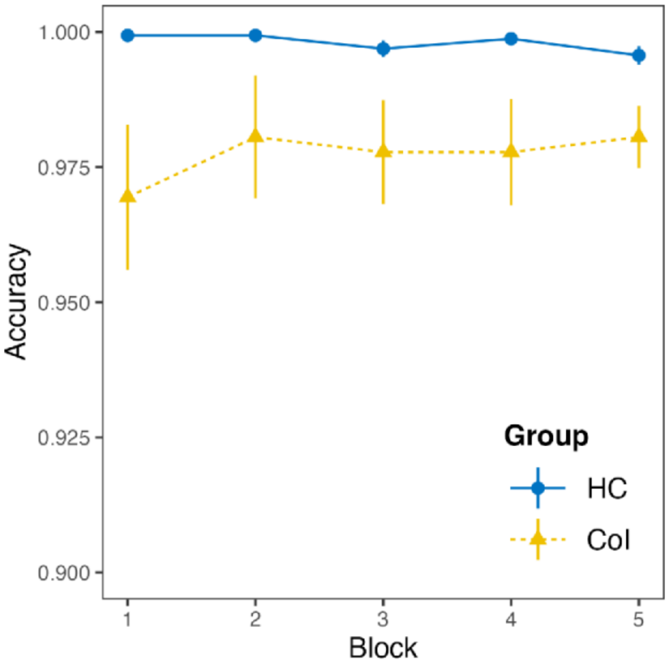


Table 2. Estimates for participants' response accuracy for the generalized linear mixed-effects models obtained in the hierarchical modeling approach. The final model is provided in the second column.

Variables	Dependent variable: response accuracy								
	R0: full model containing all fixed and random effects, including interactions[a]			R1: final model, without age as fixed effect[b]			R2: model without age and the interaction between group and block[c]		
	Odds ratio (CI)	*z* value	*P* value	Odds ratio (CI)	*z* value	*P* value	Odds ratio (CI)	*z* value	*P* value
Intercept	270.03 (2.02-36181.50)	2.24	.03	552.97 (238.66-1281.22)	14.73	<.001	332.65 (178.96-618.33)	18.36	<.001
Group	0.02 (0.004-0.15)	−4.02	<.001	0.03 (0.005-0.14)	−4.25	<.001	0.09 (0.03-0.29)	−4.10	<.001
Block	0.84 (0.67-1.05)	−1.54	.12	0.84 (0.67-1.05)	−1.54	.12	1.03 (0.91-1.16)	0.49	.63
Age (y)	1.01 (0.94-1.08)	0.29	.77	—[d]	—[d]	—[d]	—[d]	—[d]	—[d]
Group×block	1.70 (1.09-2.66)	2.33	.02	1.70 (1.09-2.66)	2.33	.02	—[d]	—[d]	—[d]

[a] Observations=225; Bayesian information criterion=420.48.

[b] Observations=225; Bayesian information criterion=415.16.

[c] Observations=225; Bayesian information criterion=416.91.

[d] Variables do not apply to a specific model.

Average Reaction Times During the Learning Phase (RQ 2)

The ANCOVA comparing participants' average reaction time (computed as the average of the median reaction times per block) during the learning phase between groups while controlling for age and education revealed a significant difference in the mean reaction times between participants with CoI and HC participants ($F_{1,41}$=22.32; P<.001), with a large effect size of Cohen $d_{estimated}$=1.61 (η_p^2=0.35). Participants with CoI were, on average, 198.57 (SE 42.03) ms slower than the HCs (during the learning phase). Furthermore, an ANOVA comparing mean reaction times between groups without covariates was conducted to test the robustness of the findings. The results showed a significant difference in reaction time between the participants with CoI and the HC groups ($F_{1,43}$=37.02; P<.001), indicating a robust effect. Descriptive statistics for the average reaction times during the learning phase are presented in Figure 6, and the results of the statistical analyses are provided in Table 3.

Figure 6. Descriptive statistics of the average reaction times per group and block. Bars represent the SE of the mean. (A) untransformed reaction times and (B) *z*-transformed reaction times. CoI: participants with cognitive impairment; HC: healthy controls.

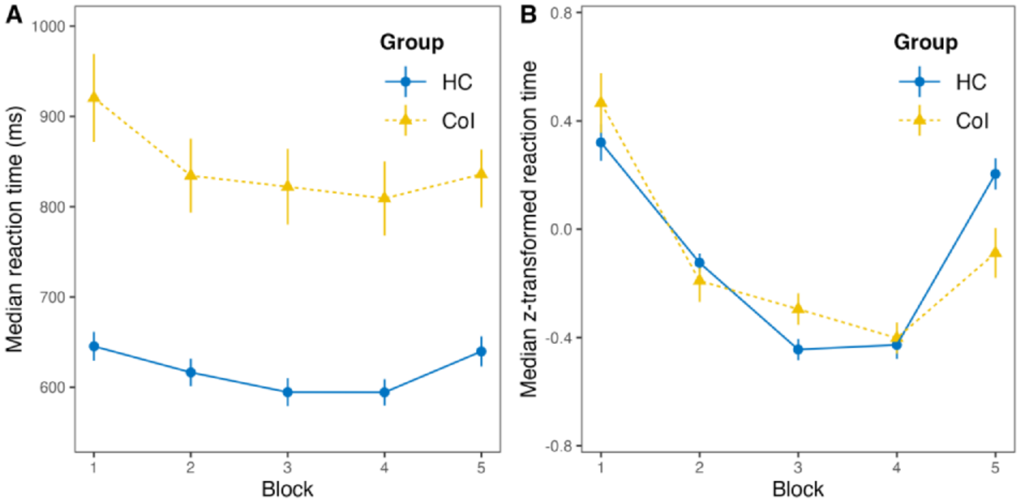


Table 3. Estimates for participants' average reaction time during the learning phase for the analysis of covariance (ANCOVA) and ANOVA models.

Variables	Dependent variable: average reaction time							
	ANCOVA[a]				ANOVA[b]			
	b (SE)	*F* test	η_p^2	*P*	*b* (SE)	*F* test	η_p^2	*P*
Intercept	526.71 (164.70)	10.23 (1,41)	—[c]	.003	729.52 (19.22)	1440.53 (1,43)	—[c]	<.001
Group	198.57 (42.03)	22.32 (1,41)	0.35	<.001	233.88 (38.44)	37.02 (1,43)	0.46	<.001
Age (y)	3.67 (2.12)	2.99 (1,41)	0.07	.09	—[d]	—[d]	—[d]	—[d]
Education (y)	-4.52 (5.48)	0.68 (1,41)	0.02	.41	—[d]	—[d]	—[d]	—[d]

[a] R^2=0.51, Adjusted R^2=0.47, $F_{3,41}$=14.18; *P*<.001.

[b] R^2=0.46, Adjusted R^2=0.45, $F_{1,43}$=37.02; *P*<.001.

[c] Not applicable.

[d] Variables do not apply to a specific model.

Implicit Learning and Learning Curve (RQ 3 and RQ 4)

The descriptive statistics of the average reaction times per group are displayed in Figure 6. As the final model predicting the raw reaction times obtained through the modeling approach outlined in the *Statistical Analysis* section in the *Methods* section resulted in nonnormally distributed residuals, we decided to use *z*-transformation of reaction times over the complete experiment per participant to reduce the effect of baseline differences in reaction times between individuals, which reduced skewness in the distribution of the residuals across participants. That is, we entered the median of the *z*-transformed reaction times per participant per block as the response into the LME. For models predicting the *z*-transformed reaction time, the visual inspection of the residual plot did not suggest a significant deviation from a normal distribution.

The final LME predicting *z*-transformed reaction times contained linear and quadratic terms of block, response increase, group, and the interaction between response increase and block, age, and education as fixed effects and random slopes for linear and quadratic terms of block as well as response increase of participants (formula: *median reaction time [z-transformed] ~ time [linear]+ time [quadratic]+response increase+group+age+education in years+response increase: group+time [linear]+ time [quadratic]+response increase|participant*). The hierarchical model analyses revealed that the interaction effect between the linear and quadratic effects of block and group did not significantly improve the model fit. The final model revealed a significant main effect of the linear effect of the block (β=−0.44, SE 0.09; *t*=−4.74; *P*<.001), a significant main effect of the quadratic effect of the block (β=0.46, SE 0.07; *t*=6.59; *P*<.001), a significant main effect of response increase (β=0.23, SE 0.11; *t*=2.21; *P*=.04), and a significant interaction effect of response increase and group (β=−0.34, SE 0.12; *t*=−2.81; *P*=.01). Regarding the interaction effect, participants with CoI had a significantly lower response increase between the random block and the last sequence block compared with HC participants. That is, there was a difference in response increase of *z*-transformed reaction times, obtained from the final model (β=−0.34, SE 0.12), and the difference in untransformed response increase between participants with CoI (mean 26.83, SD 46.09 ms) and HCs (mean 45.37, SD 35.59 ms) was 18.54 ms. The effects of group, age, and education were not significant. The final model, along with the models investigated using the hierarchical modeling approach, is provided in Table 4.

Table 4. Estimates for participants' *z*-transformed response increase of the linear mixed-effects models of the hierarchical modeling approach. The final model is listed in panel C.

Variables	Dependent variable: reaction time (*z*-transformed)		
	β (SE)	*t* test	*P* value
Panel A: R0: full model containing all fixed and random effects, including interactions[a]			
Intercept	270.03 (-0.12)	-0.95	.34
Group	0.07 (0.06)	1.18	.24
Time (linear)	−0.43 (0.09)	−4.57	<.001
Time (quadratic)	0.47 (0.07)	6.53	<.001
Response increase	0.22 (0.11)	1.97	.06
Age (y)	0.001 (0.002)	0.44	.67
Education (y)	−0.01 (0.004)	−1.63	.11
Group × response increase	−0.43 (0.23)	−1.90	.06
Group × time (linear)	0.02 (0.19)	0.12	.90
Group × time (quadratic)	0.08 (0.14)	0.57	.57
Panel B: R1: model without the interaction between group and quadratic time[b]			
Intercept	−0.12 (0.12)	−0.97	.34
Group	0.05 (0.04)	1.08	.29
Time (linear)	−0.44 (0.09)	−4.65	<.001
Time (quadratic)	0.46 (0.07)	6.59	<.001
Response increase	0.23 (0.11)	2.09	.04
Age (y)	0.001 (0.002)	0.43	.67
Education (y)	−0.01 (0.004)	−1.63	.11
Group × response increase	−0.33 (0.15)	−2.24	.03
Group × time (linear)	−0.03 (0.17)	0.15	.89
Panel C: R2: final model without the interaction between group and quadratic and linear time[c]			
Intercept	−0.12 (0.12)	−0.97	.34
Group	0.05 (0.04)	1.16	.25
Time (linear)	−0.44 (0.09)	−4.74	<.001
Time (quadratic)	0.46 (0.07)	6.59	<.001
Response increase	0.23 (0.11)	2.09	.04
Age (y)	0.001 (0.002)	0.43	.67
Education (y)	−0.01 (0.004)	−1.63	.11
Group × response increase	−0.34 (0.12)	−2.81	.007
Panel D: R3: model without the interaction between group and quadratic and linear time, and without the interaction between response increase and group[d]			
Intercept	−0.13 (0.12)	−1.04	.30
Group	−0.03 (0.03)	−1.05	.30
Time (linear)	−0.44 (0.09)	−4.74	<.001
Time (quadratic)	0.46 (0.07)	6.59	<.001
Response increase	0.27 (0.11)	2.33	.02
Age (y)	0.001 (0.002)	0.44	.66
Education (y)	−0.01 (0.004)	−1.63	.11

[a] Observations=225; Bayesian information criterion=150.74.

[b] Observations=225; Bayesian information criterion=145.66.

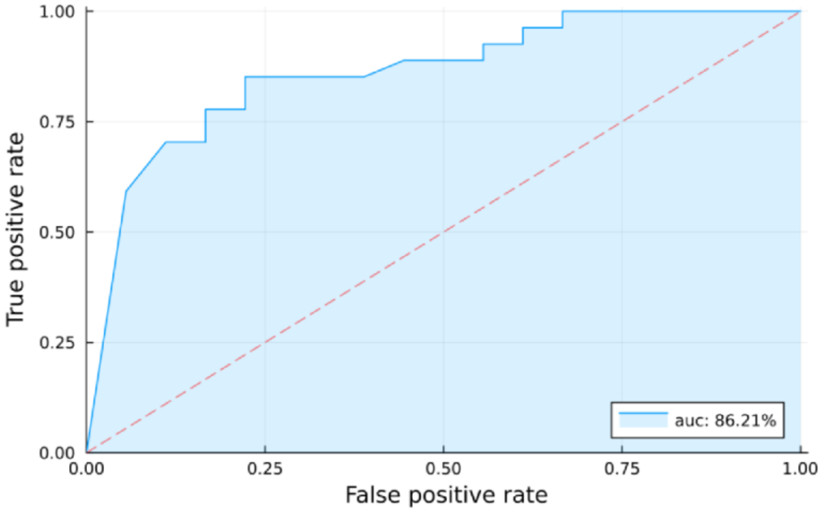
[c] Observations=225; Bayesian information criterion=140.27.

[d] Observations=225; Bayesian information criterion=142.40.

Prediction Model: Classification of Group (HC vs CoI; RQ 5)

Random forest classification predicting the group (CoI or HC) was computed using (1) standardized ordinal linear, (2) quadratic trends in reaction time for the sequence blocks, (3) standardized response increase, (4) age (years), (5) education (years), (6) response accuracy, and (7) average reaction time in milliseconds as features. To extract features 1 to 3, we refitted the LME from RQ 3 without the fixed effects of group, age, and education as well as the corresponding interaction terms. These models showed an average prediction accuracy of 77.13% (95% CI 74.67%-81.33%) across the repeated, nested leave-one-out cross-validation. The receiver operating characteristics curve is shown in Figure 7.

Figure 7. Receiver operating characteristic (ROC) curve for the prediction of cognitive impairment.



Discussion

Principal Findings

Overview

In this study, we presented and evaluated a digital tablet–based app featuring a variant of the SRTT to facilitate the diagnosis of implicit learning and memory and use it to predict the assignment of the diagnosis of CoI using an ML modeling approach. The app focuses on use in clinical routines and is based on computer-based studies and the findings of the SRTT. We evaluated our tablet-based SRTT with 27 HC participants and 18 older participants with mild to moderate CoI. We performed statistical analyses to evaluate the replicability and transfer of the results of previous (computer-based) SRTT studies with older participants with CoI to our tablet-based version of the SRTT. In addition, we deployed an ML modeling approach using a random forest classification to predict the participants' group assignments (HC vs CoI). On the basis of the RQs outlined in the *Introduction* section, the results indicate that we were able to transfer the findings of previous studies to a tablet-based implementation of the SRTT in this study. We found the same significant performance differences between HC and CoI groups, and our ML modeling approach achieves promising results in predicting participants' group assignments. In summary, our results indicate that the SRTT paradigm is transferable to (touch-based) tablet devices, and the results obtained with our app are comparable with previously published findings. The RQs and their findings are as follows:

1. Do participants with CoI and HC participants differ significantly in response accuracy? That is, do participants with CoI elicit more errors than HC participants?
    - Participants with CoI conducted, on average, significantly more errors per block than HC participants. We found no interaction between the block and the group.
2. Do participants with CoI and HC participants differ in average reaction times during the learning phase? That is, are participants with CoI systematically slower than HC participants?
    - Participants with CoI showed a significantly slower reaction time—on average, approximately 200 ms slower than HC participants (during the learning phase), with a large effect size of Cohen $d_{estimated}=1.61$ ($\eta_p^2=0.35$).
3. Do participants with CoI and HC participants differ in implicit learning? That is, is the response increase in the random block compared with the learning curve significantly lower?
    - Participants with CoI showed a significantly lower response increase than HC participants on *z*-transformed reaction times.
4. Do participants with CoI show a different learning curve during the learning phase than HC participants?

    - No significant differences were observed between participants with CoI and HC participants in terms of linear, quadratic, or cubic learning curves.
5. Can we reliably predict participants' groups using an ML prediction model?
    - A random forest classification achieved an average prediction accuracy of 77.13%.

In this study, we used a touchscreen-based version of the SRTT. Thus, our results may differ from those of previous studies using keyboard or button box input because of the change in medium. We found the same effects in our tablet-based version previously found in comparable SRTT setups [8,27]. Thus, changing the medium does not significantly change the pattern of implicit learning in older participants with little prior knowledge of technology. The analysis of the parameters of the SRTT with models predicting participants' groups allows us to make predictions about cognitive status and diagnoses with a relatively high accuracy. Even if only limited statements about isolated and pure implicit learning are possible [71,89], the app can be applied in daily clinical routines with older participants to collect diagnostic neuropsychological information.

Response Accuracy (RQ 1)

We found response accuracy to be lower in participants with CoI, in line with previous findings [8,14]. A low response accuracy may indicate difficulties in understanding and memorizing the task instruction, considering the hypothesis of difficulties with task comprehension [8,71,89]. In this study, we altogether excluded 4 participants from the analysis owing to difficulties with the task or attention and behavior difficulties or discontinuation of the examination. Among them, we excluded 2 participants who failed to complete the experiment, 1 participant because of low response accuracy, and 1 with exceptionally prolonged reaction times. This number is comparable with reported exclusions in other studies [8]. After exclusion, participants from the CoI group still had a percentage of correct trials of approximately 95%, compared with approximately 99% to 100% in the HC group. However, both numbers were still very high. Given the assumption of a strong influence of understanding the task instruction as a foremost parameter, as discussed in a recent review [8], we would suppose a lower response accuracy. Thus, the exclusion we made was in a manner that did not result in a systematic methodological error [8]. In summary, we were able to replicate previously published findings on a computer-based SRTT. At the same time, the results indicate that differences in response accuracy are not caused by task incomprehension or methodological errors, indicating the ecological reliability and applicability of our findings.

Reaction Time (RQ 2)

Similarly, we found differences in reaction times between the CoI and HC groups in the learning phase (Cohen $d_{\text{estimated}}$=1.61; η_p^2=0.35; participants with CoI were, on average, approximately 200 ms slower). This finding follows most previous studies on reaction times in general [90] and in the SRTT in particular [14,16,91]. This finding can be explained by general RT differences in participants with mild and moderate CoI and AD owing to vigilance, cognitive, and psychomotor impairments [92], for example, caused by degeneration of the locus coeruleus [90,93].

Response Increase (RQ 3)

As a third factor, we found a significant difference in the response increase between the groups, represented by the difference between the estimated reaction time of the fitted learning curve and the measured reaction time in the random block. As shown in Figure 6, we observed a response increase for both groups. However, the CoI group showed a significantly lower response increase than the HC group, which again is in line with previous findings [8,14]. A lower response increase indicates a less sustainable learning of the sequence. That is, this indicates more than just motor learning and growing familiarity with the task [71]. The response increase in the classical SRTT paradigm has been used as a valuable and verified measure for (differences in) implicit learning [8,24]. Although more basic research scholars recommend a more complex paradigm, for example, with alternating sequences to differentiate different forms of learning more precisely [71,89], we opted for the straightforward approach of contrasting sequenced blocks with a random block to gain a sensitive and specific measure of skill learning for practical use in everyday clinical practice through a short and easy-to-perform task.

Learning Curve (RQ 4)

According to RQ 4, all participants showed improved reaction times across the 4 sequence blocks, indicating learning gains in both groups. These findings align with those of previous studies with comparable paradigms and samples [8,14]. With a more differentiated group division, we may find differences in the slope of the curve, which may indicate a more distinguished learning gain in the HC group. Motor learning and familiarity with such tasks certainly interfere with this finding. To what extent motor learning and familiarity with the task affect the learning curve cannot be differentiated at this point.

Prediction Model: Classification of Group (RQ 5)

The prediction model obtained through a random forest classification showed an accuracy of 77.13% in predicting the participants' group (HC vs CoI) correctly. This performance is comparable with that of the study by Hong et al [16], who achieved an accuracy of 80.9% with a similar but lengthier version of the SRTT containing 4 learning and 4 random blocks of 48 trials each (384 trials total). In contrast, our version consisted of 5 blocks of 60 trials each, for a total of 300 trials. In addition, we achieved our results with a more robust ML approach using repeated nested cross-validation. Taken together, we achieved comparable accuracies using only the relatively short and straightforward SRTT paradigm combined with a robust random forest classification. This fact indicates the acceptable accuracy of the diagnosis classifications, despite only a coarse diagnosis classification. This insight is promising for future practical use.

Implicit Memory as a Part of Digital Neuropsychological Diagnostics

The development of neuropsychological deficits in explicit memory has been thoroughly researched and described and has become an integral part of dementia diagnostics. The role of implicit memory in the diagnosis and distinction of different subtypes of dementia has been scarcely investigated so far. In neuropsychological diagnostics and dementia research, implicit memory can be seen as an additional important domain in the entire pattern of deficits [94]. The use of digital assessment tools [57] can simplify examinations of implicit memory in clinical practice routines; even if overlaps in diseases exist, different participants show different deficit patterns in the process of neurodegeneration [95,96], partly also because of mixed subtypes of dementia [55,56]. This heterogeneity in neurodegeneration can also be seen as a relevant cause of inconsistent research outcomes [8,14] and, of course, needs further research on specific tasks such as the SRTT. On the basis of further research, differential diagnoses can be simplified using a tool similar to the one described in this study.

As different subtypes and mixed subtypes [55,56] have different progression types, paradigms such as the SRTT used for this study can help in the differential diagnosis of different dementia subtypes. When diagnosing the neuropsychological profiles of mixed dementia subtypes, a deeper and more differentiated examination at the level of explicit and implicit memory may be helpful. Using ML prediction can provide further benefit in differentiating diagnostic information based on future clinical studies that include more detailed and comprehensive diagnostics. Even this methodologically broad approach to group classification and the transdiagnostic and heterogeneous CoI group yielded significant results. Therefore, a more sophisticated approach to discriminate diagnosis groups will provide at least comparable results.

One goal of this study was to develop an assessment tool usable in clinical practice without exposing participants to unnecessary strains because of the length and complexity of the task. In developing a tablet-based tool relying on preceding user tests with older participants, we provided a short and transportable assessment instrument suitable even for older participants with CoI.

Relevance of This Study

In this study, we investigated a touch-based version of the SRTT in a sample of older participants. No control through hardware devices such as keyboards or response boxes was necessary; participants responded directly to the visual target stimuli with their fingers. The response increase and overall high response accuracy, even in participants with CoI, indicate that the paradigm we used is manageable and appropriate for older participants and that the original button-based paradigm is transferrable to tablets.

In our study, exploring an undifferentiated and roughly divided sample, significant differences between the groups were found. The application of statistical models enables the inclusion of features that exceed mere implicit memory, such as response increase. Therefore, the random forest trained achieved a prediction probability of the diagnosis groups of 77.13%. The accuracy of group prediction in our study is comparable with the accuracy reported by Hong et al [16].

Different definitions and concepts of learning are commonly used, based on different memory models, partly as different subtypes. We adhere to “implicit learning” as an umbrella term, as our task is too unspecific to distinguish more sophisticated terms and to differentiate which parts of the process can be explained through motor learning or sequence learning. Our essential objective was not to develop an experimental paradigm for the laboratory to distinguish forms of learning clearly but to provide a simple screening usable as part of a short battery of tests in clinical practice. Such tests could help to distinguish different diagnostic groups in real-life practice.

Limitations and Strengths

The study was initially part of a technical feasibility study for tablet use that did not address the conventional quality criteria of a clinical trial but had high ecological validity. Trained professional teams made the diagnoses after an extensive examination. Thus, classification into groups was based on the judgments of trained specialists and confirmed by interdisciplinary teams, as neuropsychological and depression scores were not available for all participants.

Divergent paradigms that can distinguish implicit and motor learning more sensitively are available. A more profound distinction between learning processes is not possible with the paradigm used in this study. We intended not to develop a tool for laboratory purposes but a user-centric tool that is usable in the clinic. Using statistical models, we are not limited to the exact distinction.

Taken together, the specific properties of the task partly explain the results found in our study. A pattern of stimuli alternating between random and sequence trials, for example, ensures the discrimination of explicit and implicit memory [32-34]. We chose a more focused approach without alternating patterns, as the use of statistical models for diagnostic information on implicit memory does not depend solely on accurately differentiated implicit memory processes in the experimental paradigm but on a variety of parameters. We also included parameters such as reaction times and learning gains in the statistical model. The objective of the task is not to map implicit learning as accurately as possible but to collect features that can be used in a statistical model to predict diagnostic information. The sequence length can be seen as a second factor. In this case, the well-proven and original sequence by Nissen and Bullemer [24] was used. Thus, we do not expect variations in the sequence or sequence length used in this study to result in the differences we found.

By contrast, a short tool that is easy to use in daily clinical practice is available to assess implicit memory on a tablet, for example, even at the bedside and not only in the laboratory. Because of the nature and implementation of the task, interruptions and early termination by participants who are stressed are less likely. In addition, participants do not receive negative feedback or feelings in the SRTT compared with explicit memory tasks, where they may experience failure in repeating words, drawing figures, or calculating numbers. By not only including pure reaction times but also response increase and response accuracy in a ML model, reliable predictions regarding diagnoses can be made with relatively little data and within a short time. Comparable results, as in previous studies, can be achieved with our app more quickly and simply.

Overall, a reliable assignment of the diagnoses and high ecological validity are possible with the app's relatively simple and short execution because of the use of ML algorithms. This assignment is preferable for a clinical setting, where brief assessments are essential. The data show that the short procedure is effective and yields results comparable with those obtained with more extended tests.

Future Studies

In the future, larger samples are needed to test the ability to discriminate similar conditions with heterogeneous cognitive symptom patterns such as dementia and delirium and different dementia subtypes. As implicit impairments are transdiagnostic, the SRTT and similar tasks have been examined with different samples [25]; however, only a few studies were performed with a touchscreen. Shortened versions of the task may facilitate the execution of the task to prevent cognitive overload in participants considered more impaired.

On the basis of more differentiated neuropsychological assessments, the parameters influencing test performance can be identified, especially when implementing additional information into statistical models. The SRTT can also be combined with another short task as another promising way to improve the accuracy of dementia diagnostics with the tablet. For example, this task could be a verbal task addressing different cognitive domains or a proven method such as the clock drawing test.

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Authors' Contributions

NM, HH, and CM conceptualized the study. NM programmed the app and conducted the research as part of her master's thesis under the supervision of CM, HH, FW, and KD. HH, CM, and FW performed the statistical evaluations. CM, HH, and FW wrote the first draft of the manuscript. FGM and GWE participated in the subsequent editing process. CM, HH, FW, FGM, and GWE read, reviewed, and edited the entire manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Pseudorandomized sequence used in block 5.
[DOCX File , 15 KB - aging_v7i1e48265_app1.docx]

References

1. Loprinzi PD, Edwards MK. Exercise and implicit memory: a brief systematic review. Psychol Rep 2018 Dec;121(6):1072-1085. [doi: 10.1177/0033294117745563] [Medline: 29298585]
2. Squire LR, Dede AJ. Conscious and unconscious memory systems. Cold Spring Harb Perspect Biol 2015 Mar 02;7(3):a021667 [FREE Full text] [doi: 10.1101/cshperspect.a021667] [Medline: 25731765]
3. Reber PJ, Squire LR. Parallel brain systems for learning with and without awareness. Learn Mem 1994;1(4):217-229. [Medline: 10467599]
4. Squire LR. Mechanisms of memory. Science 1986 Jun 27;232(4758):1612-1619. [doi: 10.1126/science.3086978] [Medline: 3086978]
5. Squire LR. Memory systems of the brain: a brief history and current perspective. Neurobiol Learn Mem 2004 Nov;82(3):171-177. [doi: 10.1016/j.nlm.2004.06.005] [Medline: 15464402]
6. Squire LR, Zola SM. Structure and function of declarative and nondeclarative memory systems. Proc Natl Acad Sci U S A 1996 Nov 26;93(24):13515-13522 [FREE Full text] [doi: 10.1073/pnas.93.24.13515] [Medline: 8942965]
7. Fleischman DA, Wilson RS, Gabrieli JD, Schneider JA, Bienias JL, Bennett DA. Implicit memory and Alzheimer's disease neuropathology. Brain 2005 Sep;128(Pt 9):2006-2015. [doi: 10.1093/brain/awh559] [Medline: 15975947]
8. de Wit L, Marsiske M, O'Shea D, Kessels RP, Kurasz AM, DeFeis B, et al. Procedural learning in individuals with amnestic mild cognitive impairment and Alzheimer's dementia: a systematic review and meta-analysis. Neuropsychol Rev 2021 Mar;31(1):103-114 [FREE Full text] [doi: 10.1007/s11065-020-09449-1] [Medline: 32897482]

9. de Wit L, Kessels RP, Kurasz AM, Amofa PS, O'Shea D, Marsiske M, et al. Declarative learning, priming, and procedural learning performances comparing individuals with amnestic mild cognitive impairment, and cognitively unimpaired older adults. J Int Neuropsychol Soc 2023 Feb;29(2):113-125. [doi: 10.1017/S1355617722000029] [Medline: 35225209]
10. de Wit L, Levy SA, Kurasz AM, Amofa PS, DeFeis B, O'Shea D, et al. Procedural learning, declarative learning, and working memory as predictors of learning the use of a memory compensation tool in persons with amnestic mild cognitive impairment. Neuropsychol Rehabil 2023 Aug;33(7):1278-1303. [doi: 10.1080/09602011.2022.2089697] [Medline: 35749375]
11. Ding Z, Lee TL, Chan AS. Digital cognitive biomarker for mild cognitive impairments and dementia: a systematic review. J Clin Med 2022 Jul 19;11(14):4191 [FREE Full text] [doi: 10.3390/jcm11144191] [Medline: 35887956]
12. Zabberoni S, Carlesimo GA, Perri R, Barban F, Caltagirone C, Zannino GD. Implicit prototype learning in patients with memory deficit: evidence from a study with Alzheimer's disease patients. Neuropsychology 2022 Jan;36(1):75-85. [doi: 10.1037/neu0000772] [Medline: 34735166]
13. Keith CM, McCuddy WT, Lindberg K, Miller LE, Bryant K, Mehta RI, et al. Procedural learning and retention relative to explicit learning and retention in mild cognitive impairment and Alzheimer's disease using a modification of the trail making test. Neuropsychol Dev Cogn B Aging Neuropsychol Cogn 2023;30(5):669-686. [doi: 10.1080/13825585.2022.2077297] [Medline: 35603568]
14. van Halteren-van Tilborg IA, Scherder EJ, Hulstijn W. Motor-skill learning in Alzheimer's disease: a review with an eye to the clinical practice. Neuropsychol Rev 2007 Sep;17(3):203-212 [FREE Full text] [doi: 10.1007/s11065-007-9030-1] [Medline: 17680369]
15. Nemeth D, Janacsek K, Király K, Londe Z, Németh K, Fazekas K, et al. Probabilistic sequence learning in mild cognitive impairment. Front Hum Neurosci 2013 Jul 01;7:318 [FREE Full text] [doi: 10.3389/fnhum.2013.00318] [Medline: 23847493]
16. Hong Y, Alvarado RL, Jog A, Greve DN, Salat DH. Serial reaction time task performance in older adults with neuropsychologically defined mild cognitive impairment. J Alzheimers Dis 2020;74(2):491-500. [doi: 10.3233/JAD-191323] [Medline: 32039857]
17. Harvey PD. Domains of cognition and their assessment . Dialogues Clin Neurosci 2019 Sep;21(3):227-237 [FREE Full text] [doi: 10.31887/DCNS.2019.21.3/pharvey] [Medline: 31749647]
18. Jessen F, Amariglio RE, van Boxtel M, Breteler M, Ceccaldi M, Chételat G, et al. A conceptual framework for research on subjective cognitive decline in preclinical Alzheimer's disease. Alzheimers Dement 2014 Nov;10(6):844-852 [FREE Full text] [doi: 10.1016/j.jalz.2014.01.001] [Medline: 24798886]
19. Scheurich A, Muller MJ, Siessmeier T, Bartenstein P, Schmidt LG, Fellgiebel A. Validating the DemTect with 18-fluoro-2-deoxy-glucose positron emission tomography as a sensitive neuropsychological screening test for early alzheimer disease in patients of a memory clinic. Dement Geriatr Cogn Disord 2005;20(5):271-277. [doi: 10.1159/000088248] [Medline: 16158009]
20. Meissner SN, Keitel A, Südmeyer M, Pollok B. Implicit motor sequence learning and working memory performance changes across the adult life span. Front Aging Neurosci 2016 Apr 26;8:89 [FREE Full text] [doi: 10.3389/fnagi.2016.00089] [Medline: 27199736]
21. Willingham DB. A neuropsychological theory of motor skill learning. Psychol Rev 1998 Jul;105(3):558-584. [doi: 10.1037/0033-295x.105.3.558] [Medline: 9697430]
22. Beaunieux H, Eustache F, Busson P, de la Sayette V, Viader F, Desgranges B. Cognitive procedural learning in early Alzheimer's disease: impaired processes and compensatory mechanisms. J Neuropsychol 2012 Mar;6(1):31-42 [FREE Full text] [doi: 10.1111/j.1748-6653.2011.02002.x] [Medline: 22257534]
23. Wang XP, Sun BM, Ding HL. Changes of procedural learning in Chinese patients with non-demented Parkinson disease. Neurosci Lett 2009 Jan 16;449(3):161-163. [doi: 10.1016/j.neulet.2008.10.086] [Medline: 18996168]
24. Nissen MJ, Bullemer P. Attentional requirements of learning: evidence from performance measures. Cogn Psychol 1987 Jan;19(1):1-32. [doi: 10.1016/0010-0285(87)90002-8]
25. Clark GM, Lum JA. Procedural learning in Parkinson's disease, specific language impairment, dyslexia, schizophrenia, developmental coordination disorder, and autism spectrum disorders: a second-order meta-analysis. Brain Cogn 2017 Oct;117:41-48. [doi: 10.1016/j.bandc.2017.07.004] [Medline: 28710941]
26. Dominey PF, Georgieff N. Schizophrenics learn surface but not abstract structure in a serial reaction time task. Neuroreport 1997 Sep 08;8(13):2877-2882. [doi: 10.1097/00001756-199709080-00015] [Medline: 9376523]
27. Dominey PF, Ventre-Dominey J, Broussolle E, Jeannerod M. Analogical transfer is effective in a serial reaction time task in Parkinson's disease: evidence for a dissociable form of sequence learning. Neuropsychologia 1997 Jan;35(1):1-9. [doi: 10.1016/s0028-3932(96)00050-4] [Medline: 8981372]
28. Moisello C, Crupi D, Tunik E, Quartarone A, Bove M, Tononi G, et al. The serial reaction time task revisited: a study on motor sequence learning with an arm-reaching task. Exp Brain Res 2009 Mar;194(1):143-155 [FREE Full text] [doi: 10.1007/s00221-008-1681-5] [Medline: 19104787]
29. Gabriel A, Stefaniak N, Maillart C, Schmitz X, Meulemans T. Procedural visual learning in children with specific language impairment. Am J Speech Lang Pathol 2012 Nov;21(4):329-341 [FREE Full text] [doi: 10.1044/1058-0360(2012/11-0044)] [Medline: 22846879]

30. Gabriel A, Maillart C, Guillaume M, Stefaniak N, Meulemans T. Exploration of serial structure procedural learning in children with language impairment. J Int Neuropsychol Soc 2011 Mar;17(2):336-343 [FREE Full text] [doi: 10.1017/S1355617710001724] [Medline: 21269540]
31. Lejeune C, Catale C, Willems S, Meulemans T. Intact procedural motor sequence learning in developmental coordination disorder. Res Dev Disabil 2013 Jun;34(6):1974-1981 [FREE Full text] [doi: 10.1016/j.ridd.2013.03.017] [Medline: 23584177]
32. Howard JH, Howard DV, Dennis NA, Kelly AJ. Implicit learning of predictive relationships in three-element visual sequences by young and old adults. J Exp Psychol Learn Mem Cogn 2008 Sep;34(5):1139-1157 [FREE Full text] [doi: 10.1037/a0012797] [Medline: 18763897]
33. Howard JH, Howard DV. Age differences in implicit learning of higher order dependencies in serial patterns. Psychol Aging 1997 Dec;12(4):634-656. [doi: 10.1037//0882-7974.12.4.634] [Medline: 9416632]
34. Howard DV, Howard Jr JH, Japikse K, DiYanni C, Thompson A, Somberg R. Implicit sequence learning: effects of level of structure, adult age, and extended practice. Psychol Aging 2004 Mar;19(1):79-92 [FREE Full text] [doi: 10.1037/0882-7974.19.1.79] [Medline: 15065933]
35. Janacsek K, Nemeth D. Predicting the future: from implicit learning to consolidation. Int J Psychophysiol 2012 Feb;83(2):213-221. [doi: 10.1016/j.ijpsycho.2011.11.012] [Medline: 22154521]
36. Zwart FS, Vissers CT, Kessels RP, Maes JH. Procedural learning across the lifespan: a systematic review with implications for atypical development. J Neuropsychol 2019 Jun;13(2):149-182. [doi: 10.1111/jnp.12139] [Medline: 28990357]
37. Lukács Á, Kemény F. Development of different forms of skill learning throughout the lifespan. Cogn Sci 2015 Mar;39(2):383-404 [FREE Full text] [doi: 10.1111/cogs.12143] [Medline: 25039658]
38. Kal E, Winters M, van der Kamp J, Houdijk H, Groet E, van Bennekom C, et al. Is implicit motor learning preserved after stroke? a systematic review with meta-analysis. PLoS One 2016 Dec 16;11(12):e0166376 [FREE Full text] [doi: 10.1371/journal.pone.0166376] [Medline: 27992442]
39. Siegert RJ, Taylor KD, Weatherall M, Abernethy DA. Is implicit sequence learning impaired in Parkinson's disease? a meta-analysis. Neuropsychology 2006 Jul;20(4):490-495. [doi: 10.1037/0894-4105.20.4.490] [Medline: 16846267]
40. Clark GM, Lum JA, Ullman MT. A meta-analysis and meta-regression of serial reaction time task performance in Parkinson's disease. Neuropsychology 2014 Nov;28(6):945-958. [doi: 10.1037/neu0000121] [Medline: 25000326]
41. Knopman D, Nissen MJ. Procedural learning is impaired in Huntington's disease: evidence from the serial reaction time task. Neuropsychologia 1991;29(3):245-254. [doi: 10.1016/0028-3932(91)90085-m] [Medline: 1829141]
42. Ghilardi MF, Silvestri G, Feigin A, Mattis P, Zgaljardic D, Moisello C, et al. Implicit and explicit aspects of sequence learning in pre-symptomatic Huntington's disease. Parkinsonism Relat Disord 2008 Aug;14(6):457-464 [FREE Full text] [doi: 10.1016/j.parkreldis.2007.11.009] [Medline: 18316233]
43. Kim JS, Reading SA, Brashers-Krug T, Calhoun VD, Ross CA, Pearlson GD. Functional MRI study of a serial reaction time task in Huntington's disease. Psychiatry Res 2004 May 30;131(1):23-30. [doi: 10.1016/j.pscychresns.2004.03.002] [Medline: 15246452]
44. Di Bernardi Luft C, Baker R, Bentham P, Kourtzi Z. Learning temporal statistics for sensory predictions in mild cognitive impairment. Neuropsychologia 2015 Aug;75:368-380. [doi: 10.1016/j.neuropsychologia.2015.06.002] [Medline: 26093288]
45. Baker R, Bentham P, Kourtzi Z. Learning to predict is spared in mild cognitive impairment due to Alzheimer's disease. Exp Brain Res 2015 Oct;233(10):2859-2867. [doi: 10.1007/s00221-015-4356-z] [Medline: 26105754]
46. Gobel EW, Blomeke K, Zadikoff C, Simuni T, Weintraub S, Reber PJ. Implicit perceptual-motor skill learning in mild cognitive impairment and Parkinson's disease. Neuropsychology 2013 May;27(3):314-321 [FREE Full text] [doi: 10.1037/a0032305] [Medline: 23688213]
47. Ferraro FR, Balota DA, Connor LT. Implicit memory and the formation of new associations in nondemented Parkinson's disease individuals and individuals with senile dementia of the Alzheimer type: a serial reaction time (SRT) investigation. Brain Cogn 1993 Mar;21(2):163-180. [doi: 10.1006/brcg.1993.1013] [Medline: 8442933]
48. Schmitz X, Bier N, Joubert S, Lejeune C, Salmon E, Rouleau I, et al. The benefits of errorless learning for serial reaction time performance in Alzheimer's disease. J Alzheimers Dis 2014;39(2):287-300. [doi: 10.3233/JAD-130887] [Medline: 24157724]
49. Knopman D. Long-term retention of implicitly acquired learning in patients with Alzheimer's disease. J Clin Exp Neuropsychol 1991 Nov;13(6):880-894. [doi: 10.1080/01688639108405105] [Medline: 1779028]
50. Knopman DS, Nissen MJ. Implicit learning in patients with probable Alzheimer's disease. Neurology 1987 May;37(5):784-788. [doi: 10.1212/wnl.37.5.784] [Medline: 3574677]
51. van Tilborg I, Hulstijn W. Implicit motor learning in patients with Parkinson's and Alzheimer's disease: differences in learning abilities? Motor Control 2010 Jul;14(3):344-361. [doi: 10.1123/mcj.14.3.344] [Medline: 20702895]
52. Willingham DB, Peterson EW, Manning C, Brashear HR. Patients with Alzheimer's disease who cannot perform some motor skills show normal learning of other motor skills. Neuropsychology 1997 Apr;11(2):261-271. [doi: 10.1037//0894-4105.11.2.261] [Medline: 9110332]
53. Grafman J, Weingartner H, Newhouse PA, Thompson K, Lalonde F, Litvan I, et al. Implicit learning in patients with Alzheimer's disease. Pharmacopsychiatry 1990 Mar;23(2):94-101. [doi: 10.1055/s-2007-1014490] [Medline: 2339182]

54. Chen KC, Weng CY, Hsiao S, Tsao WL, Koo M. Cognitive decline and slower reaction time in elderly individuals with mild cognitive impairment. Psychogeriatrics 2017 Nov;17(6):364-370. [doi: 10.1111/psyg.12247] [Medline: 28261945]
55. Schneider JA, Arvanitakis Z, Bang W, Bennett DA. Mixed brain pathologies account for most dementia cases in community-dwelling older persons. Neurology 2007 Dec 11;69(24):2197-2204. [doi: 10.1212/01.wnl.0000271090.28148.24] [Medline: 17568013]
56. Elahi FM, Miller BL. A clinicopathological approach to the diagnosis of dementia. Nat Rev Neurol 2017 Aug;13(8):457-476 [FREE Full text] [doi: 10.1038/nrneurol.2017.96] [Medline: 28708131]
57. Koo BM, Vizer LM. Mobile technology for cognitive assessment of older adults: a scoping review. Innov Aging 2019 Jan 01;3(1):igy038 [FREE Full text] [doi: 10.1093/geroni/igy038] [Medline: 30619948]
58. Öhman F, Hassenstab J, Berron D, Schöll M, Papp KV. Current advances in digital cognitive assessment for preclinical Alzheimer's disease. Alzheimers Dement (Amst) 2021 Jul 20;13(1):e12217 [FREE Full text] [doi: 10.1002/dad2.12217] [Medline: 34295959]
59. Joddrell P, Astell AJ. Studies involving people with dementia and touchscreen technology: a literature review. JMIR Rehabil Assist Technol 2016 Nov 04;3(2):e10 [FREE Full text] [doi: 10.2196/rehab.5788] [Medline: 28582254]
60. Kobayashi M, Hiyama A, Miura T, Asakawa C, Hirose M, Ifukube T. Elderly user evaluation of mobile touchscreen interactions. In: Proceedings of the 13th IFIP TC 13 International Conference. 2011 Presented at: IFIP TC '13; September 5-9, 2011; Lisbon, Portugal. [doi: 10.1007/978-3-642-23774-4_9]
61. Elboim-Gabyzon M, Weiss PL, Danial-Saad A. Effect of age on the touchscreen manipulation ability of community-dwelling adults. Int J Environ Res Public Health 2021 Feb 21;18(4):2094 [FREE Full text] [doi: 10.3390/ijerph18042094] [Medline: 33669980]
62. Böttinger MJ, Litz E, Gordt-Oesterwind K, Jansen CP, Memmer N, Mychajliw C, et al. Co-creating a digital life-integrated self-assessment for older adults: user experience study. JMIR Aging 2023 Sep 26;6:e46738 [FREE Full text] [doi: 10.2196/46738] [Medline: 37751274]
63. García-Casal JA, Franco-Martín M, Perea-Bartolomé MV, Toribio-Guzmán JM, García-Moja C, Goñi-Imizcoz M, et al. Electronic devices for cognitive impairment screening: a systematic literature review. Int J Technol Assess Health Care 2017 Jan;33(6):654-673. [doi: 10.1017/S0266462317000800] [Medline: 28920567]
64. Lum JA, Gelgic C, Conti-Ramsden G. Procedural and declarative memory in children with and without specific language impairment. Int J Lang Commun Disord 2010;45(1):96-107 [FREE Full text] [doi: 10.3109/13682820902752285] [Medline: 19900077]
65. Lum JA, Kidd E. An examination of the associations among multiple memory systems, past tense, and vocabulary in typically developing 5-year-old children. J Speech Lang Hear Res 2012 Aug;55(4):989-1006. [doi: 10.1044/1092-4388(2011/10-0137)] [Medline: 22232393]
66. Obeid R, Brooks PJ, Powers KL, Gillespie-Lynch K, Lum JA. Statistical learning in specific language impairment and autism spectrum disorder: a meta-analysis. Front Psychol 2016 Aug 23;7:1245 [FREE Full text] [doi: 10.3389/fpsyg.2016.01245] [Medline: 27602006]
67. Vakil E, Schwizer Ashkenazi S, Nevet-Perez M, Hassin-Baer S. Implicit sequence learning in individuals with Parkinson's disease: the added value of using an ocular version of the serial reaction time (O-SRT) task. Brain Cogn 2021 Feb;147:105654. [doi: 10.1016/j.bandc.2020.105654] [Medline: 33246230]
68. Bloch A, Shaham M, Vakil E, Schwizer Ashkenazi S, Zeilig G. Examining implicit procedural learning in tetraplegia using an oculomotor serial reaction time task. PLoS One 2020 Apr 23;15(4):e0232124 [FREE Full text] [doi: 10.1371/journal.pone.0232124] [Medline: 32324808]
69. Vakil E, Bloch A, Cohen H. Anticipation measures of sequence learning: manual versus oculomotor versions of the serial reaction time task. Q J Exp Psychol (Hove) 2017 Mar;70(3):579-589. [doi: 10.1080/17470218.2016.1172095] [Medline: 27042771]
70. Gaschler R, Zhao F, Röttger E, Panzer S, Haider H. More than hitting the correct key quickly. Exp Psychol 2019 May;66(3):207-220. [doi: 10.1027/1618-3169/a000446] [Medline: 31266432]
71. Robertson EM. The serial reaction time task: implicit motor skill learning? J Neurosci 2007 Sep 19;27(38):10073-10075 [FREE Full text] [doi: 10.1523/JNEUROSCI.2747-07.2007] [Medline: 17881512]
72. Unity 2019.1.0. Unity Technologies. 2019. URL: https://unity.com/releases/editor/whats-new/2019.1.0 [accessed 2024-01-08]
73. Nurgalieva L, Jara Laconich JJ, Baez M, Casati F, Marchese M. A systematic literature review of research-derived touchscreen design guidelines for older adults. IEEE Access 2019 Feb 12;7:22035-22058. [doi: 10.1109/access.2019.2898467]
74. Motti LG, Vigouroux N, Gorce P. Interaction techniques for older adults using touchscreen devices: a literature review. In: Proceedings of the 25th Conference on l'Interaction Homme-Machine. 2013 Presented at: IHM '13; November 12-15, 2013; Talence, France. [doi: 10.1145/2534903.2534920]
75. Mychajliw C, Holz H, Minuth N, Dawidowsky K, Eschweiler GW, Metzger FG, et al. Performance differences in Serial Reaction Time Task (SRTT) between healthy and cognitively impaired older subjects. OSF Home. 2022 Mar 18. URL: https://osf.io/d4wph/ [accessed 2024-01-08]
76. R Core Team. R: a language and environment for statistical computing. R Foundation for Statistical Computing. 2019. URL: https://www.R-project.org/ [accessed 2024-01-08]

77. Bates D, Mächler M, Bolker B, Walker S. Fitting linear mixed-effects models using lme4. J Stat Softw 2015;67(1):1-48. [doi: 10.18637/jss.v067.i01]
78. Kuznetsova A, Brockhoff PB, Christensen RH. lmerTest package: tests in linear mixed effects models. J Stat Softw 2017;82(13):1-26. [doi: 10.18637/jss.v082.i13]
79. Bolker B, Robinson D, Menne D, Gabry J, Buerkner P, Hua C, et al. broom.mixed: tidying methods for mixed models. The Comprehensive R Archive Network. 2022 Apr 17. URL: https://cran.r-project.org/web/packages/broom.mixed/index.html [accessed 2024-01-08]
80. Wickham H. ggplot2: Elegant Graphics for Data Analysis. New York, NY: Springer-Verlag; 2009.
81. Hlavac M. stargazer: well-formatted regression and summary statistics tables. The Comprehensive R Archive Network. 2022 Mar 4. URL: https://cran.r-project.org/web/packages/stargazer/index.html [accessed 2024-01-08]
82. Heinzen E, Sinnwell J, Atkinson E, Gunderson T, Votruba P, Dougherty G, et al. An arsenal of "R" functions for large-scale statistical summaries: R Package Arsenal Version 3.3.0. R Foundation for Statistical Computing. 2019. URL: https://mayoverse.github.io/arsenal/reference/arsenal.html#details [accessed 2024-01-08]
83. Lüdecke D, Bartel A, Schwemmer C, Powell C, Djalovski A, Titz J, et al. sjPlot: data visualization for statistics in social science. The Comprehensive R Archive Network. 2023 Aug 17. URL: https://cran.r-project.org/web/packages/sjPlot/index.html [accessed 2024-01-08]
84. Lüdecke D. sjPlot: Data Visualization for Statistics in Social Science. 2021. URL: https://cran.r-project.org/package=sjPlot [accessed 2024-01-09]
85. Simmons JP, Nelson LD, Simonsohn U. False-positive psychology: undisclosed flexibility in data collection and analysis allows presenting anything as significant. Psychol Sci 2011 Nov;22(11):1359-1366. [doi: 10.1177/0956797611417632] [Medline: 22006061]
86. Vabalas A, Gowen E, Poliakoff E, Casson AJ. Machine learning algorithm validation with a limited sample size. PLoS One 2019 Nov 7;14(11):e0224365 [FREE Full text] [doi: 10.1371/journal.pone.0224365] [Medline: 31697686]
87. Bezanson J, Edelman A, Karpinski S, Shah VB. Julia: a fresh approach to numerical computing. SIAM Rev 2017 Jan;59(1):65-98. [doi: 10.1137/141000671]
88. Blaom AD, Kiraly F, Lienart T, Simillides Y, Arenas D, Vollmer SJ. MLJ: a Julia package for composable machine learning. J Open Source Softw 2020;5(55):1-9. [doi: 10.21105/joss.02704]
89. Robertson E, Takács A. Motor sequence learning. Scholarpedia 2018;13(5):12319 [FREE Full text] [doi: 10.4249/scholarpedia.12319]
90. Fernaeus SE, Östberg P, Wahlund LO. Late reaction times identify MCI. Scand J Psychol 2013 Aug;54(4):283-285. [doi: 10.1111/sjop.12053] [Medline: 23782412]
91. Wallert J, Westman E, Ulinder J, Annerstedt M, Terzis B, Ekman U. Differentiating patients at the memory clinic with simple reaction time variables: a predictive modeling approach using support vector machines and Bayesian optimization. Front Aging Neurosci 2018 May 22;10:144 [FREE Full text] [doi: 10.3389/fnagi.2018.00144] [Medline: 29881341]
92. Gorus E, De Raedt R, Lambert M, Lemper JC, Mets T. Reaction times and performance variability in normal aging, mild cognitive impairment, and Alzheimer's disease. J Geriatr Psychiatry Neurol 2008 Sep;21(3):204-218. [doi: 10.1177/0891988708320973] [Medline: 18838743]
93. Grudzien A, Shaw P, Weintraub S, Bigio E, Mash DC, Mesulam MM. Locus coeruleus neurofibrillary degeneration in aging, mild cognitive impairment and early Alzheimer's disease. Neurobiol Aging 2007 Mar;28(3):327-335. [doi: 10.1016/j.neurobiolaging.2006.02.007] [Medline: 16574280]
94. Ward EV, Shanks DR. Implicit memory and cognitive aging. In: Knight BG, editor. The Oxford Encyclopedia of Psychology and Aging. Oxford, UK: Oxford University Press; 2019.
95. Lövdén M, Bäckman L, Lindenberger U, Schaefer S, Schmiedek F. A theoretical framework for the study of adult cognitive plasticity. Psychol Bull 2010 Jul;136(4):659-676. [doi: 10.1037/a0020080] [Medline: 20565172]
96. Young AL, Marinescu RV, Oxtoby NP, Bocchetta M, Yong K, Firth NC, et al. Uncovering the heterogeneity and temporal complexity of neurodegenerative diseases with subtype and stage inference. Nat Commun 2018 Oct 15;9(1):4273 [FREE Full text] [doi: 10.1038/s41467-018-05892-0] [Medline: 30323170]

Abbreviations

AD: Alzheimer disease
ANCOVA: analysis of covariance
CoI: participants with cognitive impairment
HC: healthy control
LME: linear mixed effect
MCI: mild cognitive impairment
ML: machine learning
RQ: research question
SRTT: serial reaction time task

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Original Paper

Smartwatch-Based Interventions for People With Dementia: User-Centered Design Approach

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Abstract

Background: Assistive technologies can help people living with dementia maintain their everyday activities. Nevertheless, there is a gap between the potential and use of these materials. Involving future users may help close this gap, but the impact on people with dementia is unclear.

Objective: We aimed to determine if user-centered development of smartwatch-based interventions together with people with dementia is feasible. In addition, we evaluated the extent to which user feedback is plausible and therefore helpful for technological improvements.

Methods: We examined the interactions between smartwatches and people with dementia or people with mild cognitive impairment. All participants were prompted to complete 2 tasks (drinking water and a specific cognitive task). Prompts were triggered using a smartphone as a remote control and were repeated up to 3 times if participants failed to complete a task. Overall, 50% (20/40) of the participants received *regular* prompts, and 50% (20/40) received *intensive* audiovisual prompts to perform everyday tasks. Participants' reactions were observed remotely via cameras. User feedback was captured via questionnaires, which included topics like usability, design, usefulness, and concerns. The internal consistency of the subscales was calculated. Plausibility was also checked using qualitative approaches.

Results: Participants noted their preferences for particular functions and improvements. Patients struggled with rating using the Likert scale; therefore, we assisted them with completing the questionnaire. Usability (mean 78 out of 100, SD 15.22) and usefulness (mean 9 out of 12) were rated high. The smartwatch design was appealing to most participants (31/40, 76%). Only a few participants (6/40, 15%) were concerned about using the watch. Better usability was associated with better cognition. The observed success and self-rated task comprehension were in agreement for most participants (32/40, 80%). In different qualitative analyses, participants' responses were, in most cases, plausible. Only 8% (3/40) of the participants were completely unaware of their irregular task performance.

Conclusions: People with dementia can have positive experiences with smartwatches. Most people with dementia provided valuable information. Developing assistive technologies together with people with dementia can help to prioritize the future development of functional and nonfunctional features.

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KEYWORDS

assistive technology; user-centered design; usability; dementia; smartwatch; mobile phone

Introduction

Background

Dementia is associated with a loss of autonomy and restrictions in coping with everyday tasks [1], which often lead to caregiver burden [2]. There are still no curative treatments for dementia. Assistive technologies (ATs) can help people with dementia maintain their level of everyday activity [3]. To date, digital ATs have not been broadly applied in support and care for people with dementia.

Several systematic reviews regarding digital ATs for people with dementia [4-6] indicate increasing attention being given to wearable devices, for example, smartwatches, which represent the most intimate form of noninvasive ATs. Early digital ATs were aimed at increasing a person's security by detecting falls and alerting caregivers. Current ATs interact with the wearer and address more than a single domain, for example, reminding the wearer about an event or detecting when the wearer falls [7,8]. The measurement of activities and physiological parameters and the application of user interfaces allow for more flexible support of daily living activities [7,9-12]. Despite the promising potential of ATs, many people with dementia do not use such technologies [13-15]. The reason for this could be that the needs of the target group were not adequately considered, for example, in terms of functional scope or usability of ATs [16]. According to the International Organization for Standardization and the International Electrotechnical Commission 9241-11 standard, usability is defined as the "extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" [17].

User-centered innovations address unmet needs and play an important role in breaking barriers and increasing access to ATs [14,18]. Previous studies have shown that the analysis of stakeholder needs, wishes, and values is crucial for sustainable innovations [15,19,20], and focusing on users' needs potentially prevents ATs from being nonusable or abandoned [13,21,22]. Considering the needs of future users from the beginning of development is mandatory from an ethical and a practical perspective [10,22].

However, placing people with dementia at the center of AT development can be challenging in the following ways: economically—patient involvement may increase the time and cost for organizations involved [23]; empirically—some scholars do not consider accounts of people with dementia to be reliable [24,25]; and ultimately, participation may distress or overwhelm people with dementia [25,26]. In addition, established tools for assessing user experience or usability may be insufficient and difficult to use for people with dementia because their ability to provide insight may be limited [27].

Objective

We analyzed the usability of a smartwatch application for addressing the needs of people with cognitive impairment based on a user-centered design approach together with people with mild cognitive impairment (MCI) or dementia. This study aimed to contribute to a better understanding of the values and limitations of user involvement in the development of a smartwatch to support people with dementia in their daily lives.

Methods

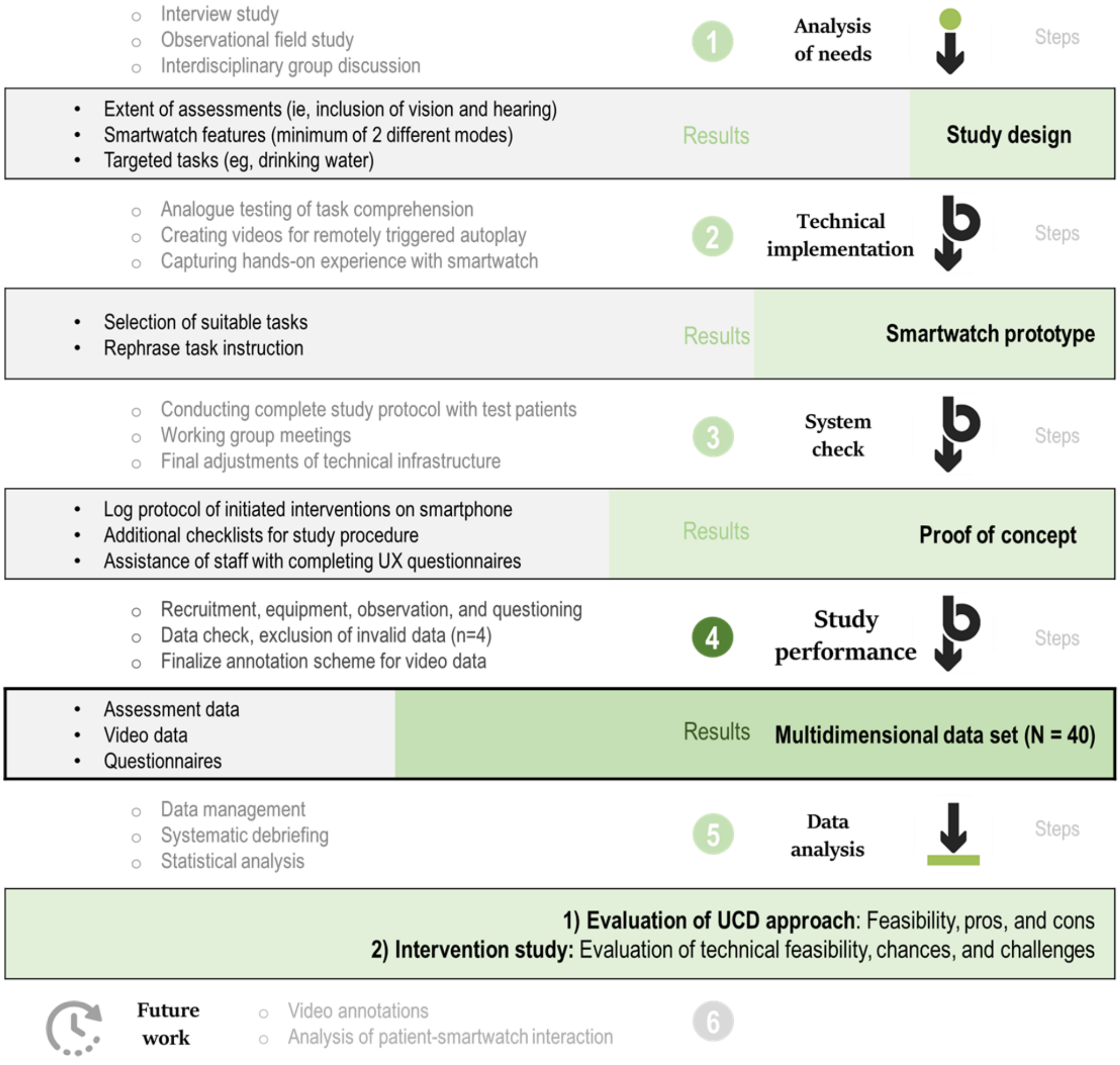
User-Centered Design Framework of the Sensor-Based Individualized Activity Management System for People With Dementia Study

The interdisciplinary *Sensor-Based Individualized Activity Management System for People With Dementia* (SAMi) study aimed to develop a mobile assistive device for people with memory impairments to support activities of daily living. The study was planned with a user-centered design approach from the beginning and included stepwise feedback from different stakeholders (Figure 1).

In step 1, we analyzed unmet needs. In a preparatory interview study, we conducted 30 semistructured interviews with stakeholders (people with dementia, health care professionals, and relatives of people with dementia) from a collaborating nursing home located in Pinnow and the geriatric ward of a hospital in Bad Doberan (both are small cities in Northeast Germany). We specifically asked about daily routines and situations in which people with dementia needed help or support. We also addressed the issue of technical assistance, design ideas, and circumstances that promote or hinder the acceptance and adoption of existing and potential future technologies. We applied qualitative content analysis according to Mayring [28] to analyze the material (refer to the study by Köhler et al [29]).

In a parallel, observational field study, we gave a passive smartwatch to 12 people with dementia residing in a nursing home and observed their behavior over a day. This smartwatch passively monitored activity via accelerometers and enabled indoor positioning via Bluetooth. It provided the users with no information except what time of day it was. During the monitoring period, participants' behavior was annotated in real time by trained observers using the Pocket observer tool (version 3.3; Noldus IT), which included a customized annotation scheme (Multimedia Appendix 1). On the basis of the analysis of needs (step 1 in Figure 1), we conducted an intervention study that aimed to increase certain daily activities by prompting the participants. We have published the results of the interviews elsewhere [29]. The core element of this paper is the results of the intervention study, which represents the final part of the SAMi study.

Figure 1. User-centered design framework. Iterative approach to study performance, with the integration of feedback from different stakeholders. Circles indicate different steps. UX: user experience.



Selection of Tasks for the Intervention Study

We decided to prompt participants to engage in 1 task each from the "activity" and "nursing" fields [29]. We implemented short instructions that completely appeared on the smartwatch's screen. Consequently, we tested different tasks and task comprehension in person with patients from the memory clinic in step 2 (Figure 1). Finally, we implemented a prompt to drink some water (task A; "nursing") and the "circling bells task" (task B; "activity") on the smartwatch, as both tasks appeared to be comprehensible and suitable. Instructions for task B explicitly included the instructions to circle bells on a sheet. Further details about step 2 can be found in Multimedia Appendix 2.

Intervention Study

Study Population

The study is registered in ClinicalTrials.gov with the brief title, "SAIN_UMR" (NCT05885620). After a short test phase for system checks (step 3), we started the intervention study (step 4). Participants were recruited from the memory clinic of the Rostock University Medical Center. The inclusion criteria were being aged >50 years, having a diagnosis of MCI or dementia, and having a Mini Mental Status Examination (MMSE) score ≥9 and ≤28 points. The exclusion criteria were presence of clinically relevant impairment of visual acuity or hearing or relevant speech or language impairment. Patients were diagnosed according to international scientific diagnostic criteria, neuropsychological testing (Consortium to Establish a Registry for Alzheimer's Disease [30]), and brain imaging; 78% (31/40) of the patients underwent cerebrospinal fluid analysis. Of the 40 patients, 12 (30%) were diagnosed with MCI [31,32], and 28 (70%) were diagnosed with dementia. Among these 28 patients, 24 (60%) were suspected to be in the Alzheimer spectrum: 18 (45%) with typical Alzheimer disease (AD) [33], 5 (13%) with mixed AD pathology [34,35], and 1 (3%) with atypical AD [33]. Of the 40 participants, 2 (5%) were diagnosed with primary progressive aphasia [36,37], 1 (3%) with a behavioral variant of frontotemporal degeneration [38], and 1 (3%) with Lewy body dementia [35].

Participants underwent clinical and neuropsychological examination—they received standardized examination of visual acuity. Near visual acuity was tested using a standardized optotype card with a decimal scale [39]. Distance acuity was assessed using a standardized eye chart at 4 to 5–m intervals (Oculus, number 4634). Both measurements were uncorrected and, when applicable, corrected with personal glasses. Hearing capabilities were assessed using a tablet-based certified app with a pure-tone threshold test (Mimi Health GmbH). Despite our efforts, we found that a standardized tablet hearing test could not be performed with our participants because they did not tap the button in time. Therefore, we decided to omit the regular test after 20 participants were assessed and did not include the results in our analysis.

As a global score for cognition, we used MMSE [40]. Visual constructive capabilities were assessed using a clock completion test [41] and the Rey complex figure direct copy (Rey Fig Copy) test [42]. Visual attention, processing speed, and task-switching abilities were measured using the Trail Making Test A (TMT-A) and Trail Making Test B (TMT-B) [43]. The results are presented in Table 1. We recruited 44 participants, 4 (9%) of whom had to be excluded. Of the 40 participants, 2 (5%) were diagnosed with subjective cognitive decline, and 1 (3%) had an MMSE score that did not match the inclusion criteria, and the trial procedure of 1 (3%) participant was incorrect because we missed repeating the intervention even though the participant did not complete the task. Finally, for the analysis, we obtained complete data sets from 40 participants. In summary, we included 50% (20/40) women and 50% (20/40) men with a mean age of 75 (SD 6.8; range 58-85) years.

Table 1. Demographics and characteristics of the participants[a]. The table includes success scores based on observations and usability scores based on 10 items of the questionnaire.

	Age (y)	MMSE[b] (points)	Rey Fig Copy[c]	CDT[d] (score)	TMT-A[e] (seconds)	TMT-B[f] (seconds)	Visual acuity–near	Visual acuity–distance	Task A[g] (score[h])	Task B[i] (score[h])	Sum success score[j]	Usability score
Values, mean (SD)	74.98 (6.68)	23.70 (3.36)	23 (9.09)	2.55 (1.28)	99.10 (66.18)	184.30 (83.56)	0.46 (0.18)	0.69 (0.29)	0.80 (0.38)	0.65 (0.32)	1.45 (0.56)	78.25 (15.22)
Values, median (IQR)	77 (69-80)	25 (22-26)	25.50 (17.5-29)	3 (1-3)	72 (57.5-120.225)	174 (105-239)	0.45 (0.3475-0.5)	0.75 (0.5-0.83)	1 (1-1)	0.50 (0.5-1)	1.50 (1.5-2)	82.50 (68.125-90)
Minimum	58	12	0	1	31	52	0.20	0.13	0	0	0	30
Maximum	85	28	35	6	329	384	1	1.66	1	1	2	100

[a] N=40; women: 20/40, 50%; men: 20/40, 50%; mild cognitive impairment diagnosis: 12/40, 30%; dementia diagnosis: 28/40, 70%; intense intervention mode: 20/40, 50%; regular intervention mode: 20/40, 50%.

[b] MMSE: Mini Mental Status Examination.

[c] Rey Fig Copy: Rey complex figure direct copy.

[d] CDT: Clock Drawing Test (Shulman score).

[e] TMT-A: Trail Making Test A.

[f] TMT-B: Trail Making Test B.

[g] Drinking water.

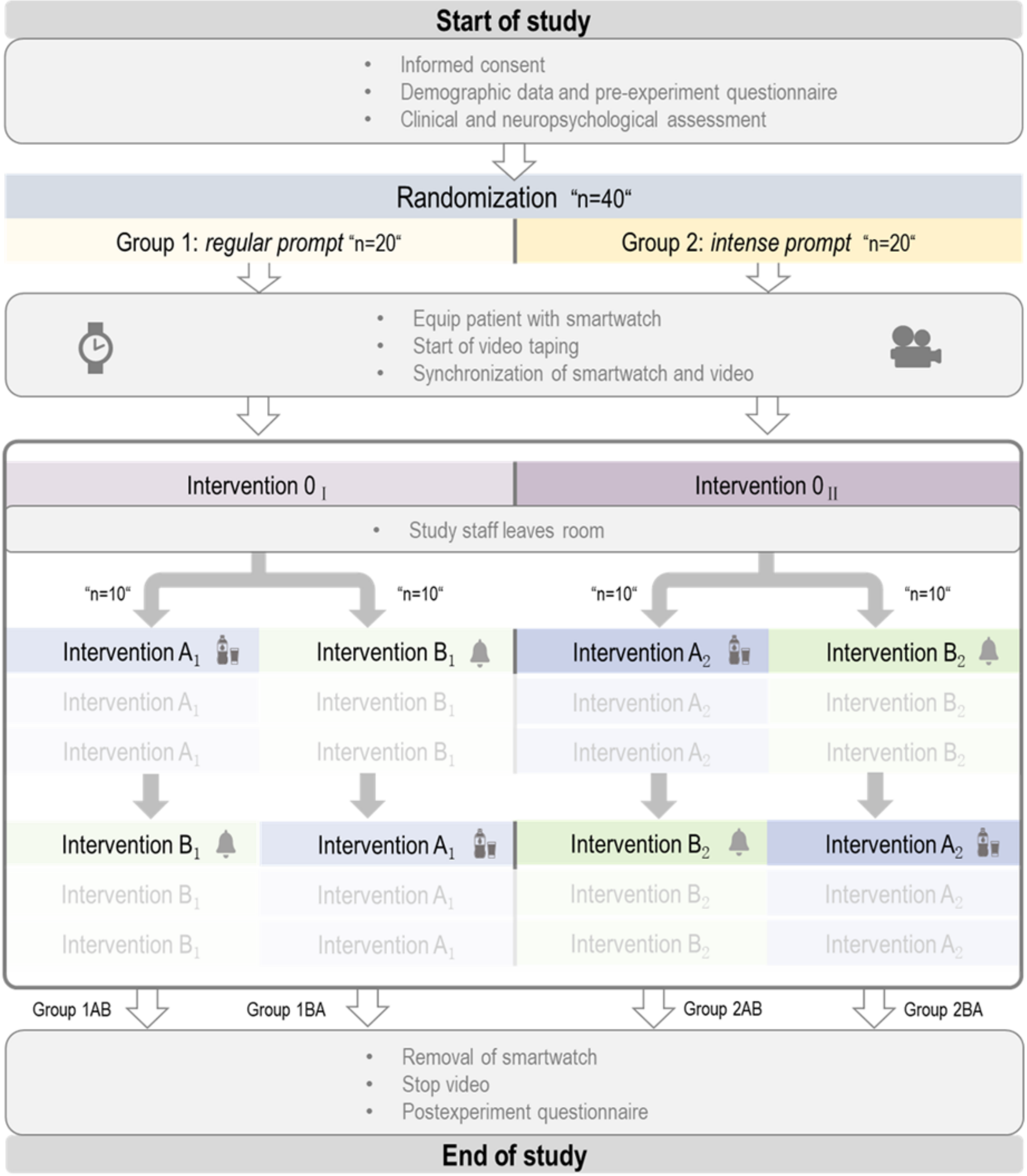
[h] Score: 0=failure, 0.5=incomplete, and 1=completed.

[i] Circling bells.

[j] Sum of task-A and task-B scores.

We conceptualized the observational intervention study based on the feedback obtained from the interview study and the experiences from the field study. Participants received interventions either in the "regular" or "intense" mode, under the observation of 2 cameras. Patients were assigned to one of the groups regardless of their neuropsychological test results. We applied an adaptive randomization procedure to balance the groups regarding participants' age and sex. Compared to those in the "regular group," the "intense group" received longer audio and vibration prompts and additional spoken output in response to the written instructions. Finally, a task-related picture appeared on both groups; this picture was animated in the "intense group." To determine whether the order of the tasks had an effect on their completion, this was tested in both groups additionally. The final result was a study with 2 intervention arms (modus: intense or regular), each consisting of 2 subgroups (order of tasks: AB or BA; Figure 2).

Figure 2. Diagram of the study design.



To avoid anxiety, all participants were introduced to the study with a trial prompt initiated by a researcher immediately next to the participant. The trial prompt instructed participants to close their eyes. Then, the participants were instructed to make themselves comfortable and feel free to move within the room. When participants were familiarized with the device and the study procedure, the researchers left the room. After a 5-minute break, the first prompt was triggered remotely. All participants were given both tasks (drinking and circling bells), and prompts were repeated a maximum of 2 times if participants failed to comply. The time delay until repetition was set as 1 minute after the previous prompt.

Participants completed 2 questionnaires. One of the questionnaires captured participants' previous experiences and affinity with technologies, and the other obtained feedback after wearing the smartwatch under camera observation. The summarized demographic information, test results, and outcomes are listed in Table 1, and additional details are provided in Multimedia Appendix 3.

Technological Specifications

A Huawei Watch 2 (4G) smartwatch was used. We designed the experiment in a Wizard-of-Oz-setting system using a smartphone as a remote control for the smartwatch (Figure 3). Consequently, we were able to repeat the interventions depending on the remotely observed participant's compliance (success or failure) or to continue with the next intervention without needing instantaneous detection of behavior via sensors. We set specifications for the smartwatch based on previous experience [44,45] and updated our prototype iteratively; refer to steps 2 and 3 Figure 1. The smartwatch was set to a maximum brightness and volume, with a display size of 1.2 inches. Loudspeakers were limited to 85 dB due to European Union restrictions. In hearing distance, we measured the volume of audio output during interventions to be 56 to 66 dB. The volume varies during signals and speech output from the male voice. We remotely triggered video playback. This approach allowed full control of the font size and audio of the prompts. The length of the videos did not vary between groups. The smartwatch displayed time with the clock hands when no intervention was displayed.

Session 'sain20' running.

Warte auf Antwort der Uhr...

Figure 3. Images and embedding of the applied prototype—smartphone with an app to manually trigger interventions on a watch, which is mounted on the patient's wrist, showing instructions (in this case, "Bitte trinken Sie etwas Wasser," which means "please drink some water").

Questionnaire

We administered 2 questionnaires to the participants, 1 before and 1 after the intervention. The preintervention questionnaire contained three parts: (1) affinity for technology, based on the Affinity for Technology Interaction scale [46]; (2) personal experiences with technologies; and (3) motivation to participate. It contains 13 items. The postintervention questionnaire was developed according to the Technology Acceptance Model [47], System Usability Scale (SUS) [48], and Technology Usage Inventory [49]. The survey included six subscales: (1) usability, (2) design, (3) perceived usefulness, (4) concerns, (5) realization, and (6) experience during the study. A translated version of the questionnaire with items assigned to the subscales and item coding is available in Multimedia Appendix 4. This questionnaire contains 40 items: 33 closed questions to be answered on a 5-point Likert scale (from strongly agree to strongly disagree), 4 multiple-choice questions, 3 open-ended questions, and 1 opportunity for closing remarks by participants and staff. When we observed participants having difficulty with using the Likert scale, for example, due to alternating positively and negatively worded items, we moderated if necessary. In the moderating questionnaires, we assisted all the respondents while they were completing the questionnaires. If a participant was unsure about what the response scale indicated and whether "agree" or "disagree" indicated their opinion about the particular item, we explained the item in more detail. We also asked participants to review their answers when they accidently skipped questions.

Internal Consistency, Usability Score, and Perceived Usefulness

Overall, 3 items of the usability subscale were adapted from the SUS [48], whereas 7 were customized. To obtain a more intuitive score for the usability measurement, we processed the results of our 10-item usability scale analogous to the SUS [48]. In other words, each item was rated 0, 1, 2, 3, or 4 according to the answer on the Likert scale in the following direction: 0 was used for the strongest disagreement and 4 was used for the strongest agreement. The sum of all the scores was subsequently multiplied by 2.5, leading to possible usability scores ranging from 0 to 100. Higher scores indicate better usability.

Answers to the "perceived usefulness" subscale were interpreted similarly. We applied the scale from 0 to 4 for each of the 3 items, resulting in a sum of 0 to 12 responses per participant. Then, the average value of all participants was converted into percentage.

For the subscales related to usability, design, usefulness, and concerns, we calculated the internal consistency as Cronbach α and McDonald ω based on principal factor analysis using Jeffrey's Amazing Statistics Program (JASP; version 0.16; JASP Team 2021; University of Amsterdam). Missing values were excluded pairwise. The reliability (α and ω) ranges between 0 and 1. Higher values indicate greater agreement among items and suggest that participants' responses throughout a set of questions were consistent. Cronbach α is a special case of McDonald ω: whereas Cronbach α is based on the assumptions of unidimensionality, equal factor loadings, and uncorrelated errors, whereas McDonald ω accounts for varying factor loadings and error variances, making ω more appropriate to use. Cronbach α also is reported to be consistent with most previous literature.

Measure of Success

We observed reactions to the manually triggered interventions via video cameras and rated behavior based on a protocol to decide whether to repeat the intervention. Task A was rated as successful and scored 1 point if the participant drank some water. Task B was rated as successful and scored 1 point if the participant circled something on the worksheet with the pencil. Actions resulting in incomplete task fulfillment were rated with 0.5 points, for example, when a participant went to the table with the worksheet but without using the pen. When no activity that could lead to task fulfillment was initiated, 0 points were assigned. Only the best performance for each task was rated. Repetitions were not scored. The scores for both tasks were summarized, resulting in success values ranging from 0 to 2 points.

Statistical Analysis

Descriptive statistics, correlations, and 2-tailed *t* tests were performed using JASP (version 0.16). To check for normality, we used the Shapiro-Wilk test. *P* value >.05 was considered to indicate normal distribution. *P* value >.05 in Leven test was considered to be consistent with the equality of variances. For variables that were not normally distributed, we calculated the Spearman rank-order correlation. Otherwise, we used Pearson correlation coefficient. For analysis of the questionnaire items, we used Kendall τ, as the answers on the Likert scale are ordinal data. We chose a significance level of .05, with a corresponding confidence level of 95%.

Ethical Considerations

Ethics approval was obtained from Rostock Ethics Committee (A 2020-0071). All participants provided written informed consent.

Results

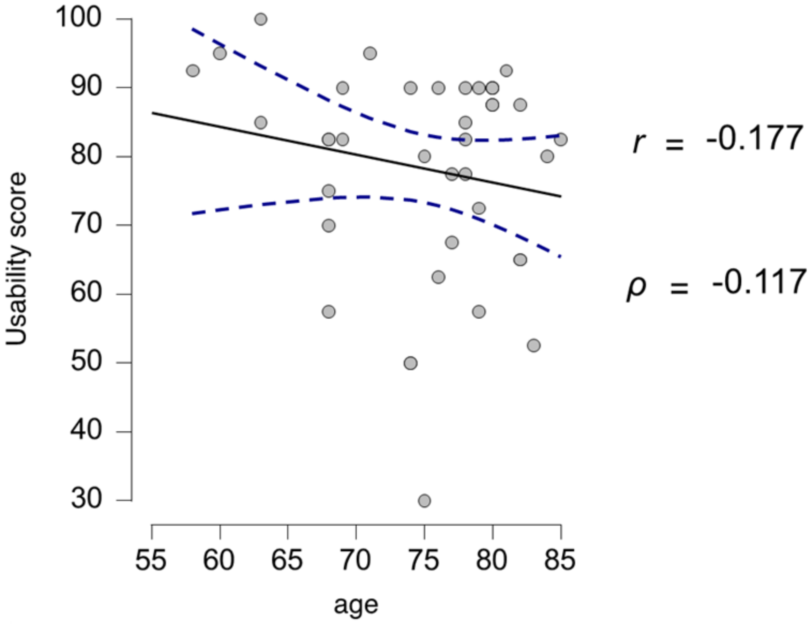
Demographics, clinical and neuropsychological test results, measures of success, and descriptive measures of the postintervention questionnaire are presented in Table 1 and Multimedia Appendix 5.

Contributions From Respondents

Results Derived From Single-Choice Items

Participants agreed very often with positively worded usability items (Multimedia Appendix 5). Most strongly agreed that they could sense vibration, hear sounds, and recognize visual cues well and had enough time to process the input. Of the 40 participants, 29 (73%) did not find the prompt disruptive. Of the 40 participants, 10 (25%) could not sense the vibration well. Interestingly, of the 40 participants, 23 (58%) agreed with the need to be supported by a technical person. Only one-third (14/40, 35%) were interested in more interactions with the smartwatch. When we processed the usability items analogously to the SUS [48], the mean usability score reached 78.3 (SD 15.4; range 30-100). The score translates as "good" usability score on the original SUS. The score did not significantly differ between men (mean 76.1) and women (mean 80.4; *P*=.39) according to the *t* test. Usability decreased with age, but the effect was not statistically significant (Figure 4).

Figure 4. Correlations and regressions between usability and age. The blue lines indicate CIs.



The design features were satisfactory to many participants. Most (30/40, 75%) found the appearance appealing, and 70% (28/40) found the watch to be properly sized. Further feedback about size was uniformly negative (12/40, 30%), with the watch being criticized for being very large. Of the 40 participants, 37 (93%) stated that the wristband was comfortable to wear. Some participants said that the wristband should be softer (user10), longer (user23), or made from a different material (user17). It was suggested that its clasp be replaced with a magnet clasp (user11). Regarding usefulness, most participants (27/40, 68%) were interested in using the smartwatch frequently and saw a personal benefit in doing so (31/40, 78%). Approximately one-third (13/40, 33%) did not have any idea how the watch could be beneficial. Regarding perceived usefulness of the tool, participants scored an average value of 8.7 (corresponds to 72%), a median value of 9.5 (corresponds to 79%, SD 3.4) Only few were concerned that other people might hear the smartwatches’ announcements (17/40, 43%) or find the watch to be very conspicuous (12/40, 30%). Of the 40 participants, 6 (15%) were concerned about stigmatization because of the watch. Overall, two-thirds of the participants (27/40, 68%) felt a sense of safety while wearing the watch. Of the 40 participants, 5 (13%) were concerned about data protection. Of the 40 participants, 4 (10%) worried about their personal health when using the smartwatch. None of them (0/40, 0%) provided further explanations about these worries. Of the 40 participants, 29 (73%) expressed the wish for a permanent contact person for service. Most (36/40, 90%) felt comfortable with using the watch. Only 8% (3/40) of the participants felt stressed during the trial.

Items to Assess Practical Implementation

Practical implementation was investigated using multiple-choice or open-ended questions. We found a preference for less intrusive notifications. A single vibration was favored over multiple vibrations (20>11 checked boxes; 20 persons ticked “single vibrations” and 11 persons ticked the box “multiple vibrations), while a single tone was preferred over ringtones (24>9). Of the 40 participants, 9 (23%) did not indicate their preferred vibration pattern, and 8 (20%) indicated no preferences for ringtones. Of the 40 participants, 24 (60%) thought that instructions should be delivered as spoken output, 20 (50%) preferred written output, and 18 (45%) preferred images. Of the 40 participants, 6 (15%) preferred animations. Of the 40 participants, 17 (43%) indicated only 1 preferred mode of instruction delivery (n=9, 53% chose speech, n=6, 35% chose text, and n=2, 12% chose animation), 18 (45%) preferred a combination of 2 modalities, and 5 (13%) preferred a combination of 3 modalities.

Elaborated feedback was given in the latter part of the questionnaire. Positive feedback was related to the “clear,” “legible,” or “well-arranged” display (user05, user07, user11, user19, and user37); the “easy to understand” audio output (user02, user08, and user41); or the “highly visible timing pointers” (user07). The issues to be optimized included the length of the text display (user04, user27, and user35) and the length of the audio and vibration (user26) files. User07 suggested that “the display should be brighter for a longer time.” The top 5 functions that were chosen for implementation were time display (38/40, 95%), emergency button (34/40, 85%), reminder function (24/40, 60%), telephone option (22/40, 55%), and alarm clock (20/40, 50%). The least useful functions were writing messages (8/40, 20%) or making notes (10/40, 25%).

The answers to the open questions confirmed the preferred functions, especially the need to be supported in navigation (and self-localization) or to be reminded about dates or appointments. In addition, vital parameters were measured. Participants expressed the wish to be directed “within an environment” (user11) and “en route” (user08) and “to find the correct path” (user10) but without further specification. Explicit ideas with points of action were provided for reminders: appointments, daily structure, anniversaries and birthdays, medication, drinking, or reminders of where the house keys are. In terms of vital parameters, people were interested in information about blood pressure, heart rate, sleep, steps, activity, and energy rate. A desired function that was not listed in the questionnaire was the interest in weather forecasting. The extent of overall assistance ranged from “never” (user05) to “for all activities” (user29).

After completing the formal part of the questionnaire, the study staff asked participants who did not respond successfully to the prompts to comment individually. The responses revealed problems with different aspects of the drinking task. User02 said they did not recognize that the watch gave them this instruction. User17 initially could not find the water bottle. User05 did not dare to drink the water provided, and user23 answered that they were not thirsty. We also asked participants for further explanation when they circled the bell on the smartwatch screen instead of the worksheet. Of the 40 participants, 2 (5%) did not think they were supposed to do something in the real world (user33 and user05). User17 indicated that they did not realize that the instructions included the specification, “circle the bells on the sheet.” User34 said they heard the instructions but could not explain why they did not follow it. In addition, user10 stated that they had no idea what to do with the worksheet.

Internal Consistency of Subscales

We hypothesized that (1) usability, (2) design factors, (3) perceived usefulness, and (4) concerns play major roles in the user experience. Therefore, we organized the questionnaires into 4 subscales. Internal consistency was determined for each scale (Table 2).

Table 2. Internal consistency of subscales.

Subscale	Items, n	McDonald ω (in descending order)	Cronbach α
Usefulness	3	0.81	.81
Concerns	7	0.79	.77
Design	6	0.75	.64
Usability	10	0.65	.64

“Good” internal consistency (ω>0.8) was achieved by the perceived usefulness scale, with concerns and design issues achieving “acceptable” consistency (ω>0.7) and usability features achieving “questionable” levels of internal consistency (ω<0.7). Overall, 3 items proved to be critical (Δ ω>0.1 if the item was excluded) for the internal consistency of their respective scales. Specifically, the items asked about the appropriate watch size, length of the instruction displayed, and desire for frequent use.

Plausibility of Statements

Approach

We evaluated the plausibility of the statements to examine the reliability of the feedback. In this paper, the term, “plausibility,” means “reasonable” or “consistent.” The responses to the items on our questionnaires were neither “right” or “wrong” nor expected by the researchers. Our approach to evaluating plausibility included 3 steps. First, we checked for discrepancies within the questionnaires; second, we compared the questionnaire responses and clinical assessments; and third, we compared the answers from the questionnaires with the observed task performance.

Discrepancies Within the Questionnaires

On an intraindividual level, we found very few inconsistencies due to contradictory answers to different items. In the first step, we checked whether positively or negatively worded items were answered consistently, that is, whether the respondent agreed with the positive items and disagreed with the negative items and vice versa. Of the 40 participants, 6 (15%) agreed (“agree” and “strongly agree”) disproportionately with all items (>mean + SD). Of those 6 participants, 5 (83%; user01, user07, user08, user11, and user28) mostly disagreed with the 8 negatively worded items, indicating a positive attitude toward the smartwatch rather than a bias toward positive answers. Only 1 respondent (1/40, 3%; user03) who agreed with the positively worded items also agreed with the negatively worded items. She exhibited an uncritical tendency to confirm statements presented to her (“acquiescence bias”), making it unclear whether her answers truly reflected her point of view or if she misunderstood the questions.

In the second step, we analyzed the participants’ answers regarding the content of their statements. The most implausible answers were found in the questionnaire of user05. She personally completed the questionnaire and indicated high usability (usability score=90) and satisfaction with the design of our smartwatch. Otherwise, she disagreed with the desire to wear the watch in daily life and disagreed with all the questions about usefulness, although she already used a smartwatch in her daily life. She used open-ended questions, for example, to suggest a smaller size but did not explain the reason for indicating high usability and satisfaction with the app design despite her concerns. She answered the question for desired domains of support with “not at all” after canceling her initial answer, “always.” Fewer inconsistencies were found in the questionnaires of user26. She preferred single vibrations and short ringtones instead of multiple or repeated vibrations and longer ringtones but recommended prolonged vibration and anticipated possible difficulties in hearing the sounds of the smartwatch for people with hearing impairment. In addition, user22 did not clearly indicate his preference regarding sounds. He selected both sound options even though they were mutually exclusive.

At a group level, it appeared implausible that less obtrusive notifications regarding audio (24>9) and vibration patterns (20>11) were favored, whereas speech output was a desired characteristic for most participants (24/40, 60%).

Correlations Between the Questionnaire and Assessment Data

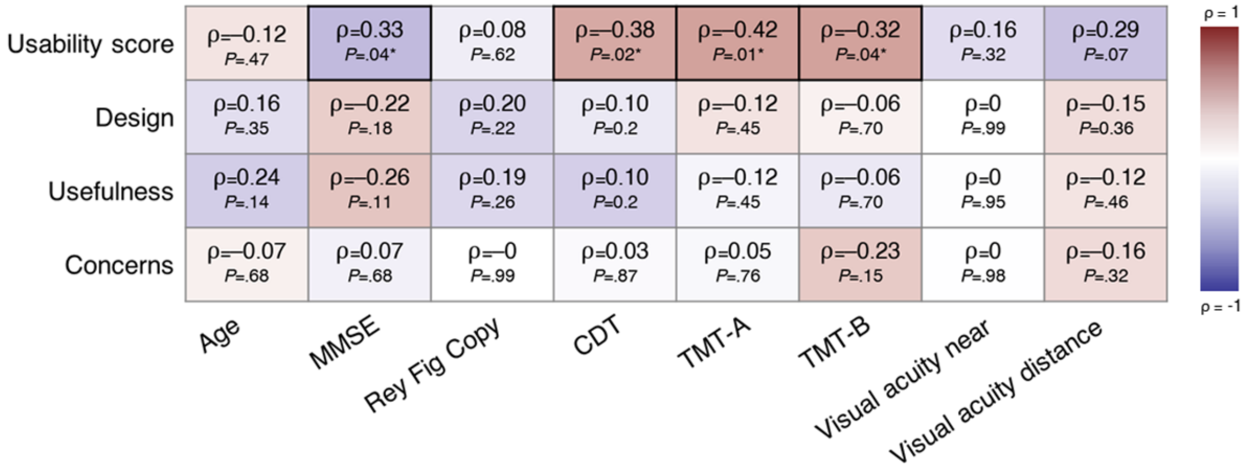
When asked to mention situations in their daily lives that should be supported by a smartwatch, 11% (3/28) of the people with dementia stated no need for support (refer to the Items to Assess Practical Implementation section), although their caregivers reported a need for help that led to the diagnosis of dementia. This implies that these participants have lost insight into their functioning in daily life, limiting their reliability in naming domains for necessary support. Otherwise, they also anticipated a decline, as indicated by the added terms, “not yet,” “not to date,” and “not at present.” In addition, there was a discrepancy between the need for support for people with dementia and the severity of their impairment. One of the patients with MCI (1/12, 8%; user29) felt the need for support “for all activities.”

We also correlated the neuropsychological test results with the results from the subscales of the questionnaire. A better usability score (the higher the score is, the more usable the smartwatch appears to be) was significantly correlated with better cognition, as suggested by a positive association with the MMSE score (*P*=.04) and negative associations with the Shulman score on the clock completion test (*P*=.02) and time on the TMT-A (*P*=.01) and TMT-B (*P*=.04; Figure 5).

This confirmed our hypothesis that neuropsychological performance is associated with usability. The 3 other subscales did not correlate significantly with any neuropsychological test. Regarding sex, the 4 subscales did not significantly differ between the 2 groups.

We also checked for conformity of single items with the clinical test results. We correlated item 5 in scale 1 (recognizability of visual prompts on the smartwatch screen) with the visual acuity test results and found no relevant correlation ($\tau_{\text{Visual acuity N}}$ –0.24, *P*=.09; $\tau_{\text{Visual acuity D}}$ –0.16, *P*=.23) Only 5% (2/40) of the participants disagreed with good visibility. Both had a visual acuity below average. The 2 items focusing on latency, asking whether participants had sufficient time to notice that the watch notified them and whether instructions were shown for an adequate time, were correlated with the results of the TMT-A and TMT-B. In addition, no correlations were found (ρ<0.3; τ<0.2; *P*>.05, respectively).

Figure 5. Heat map of Spearman correlation coefficients (ρ) and *P* values for the subscales and assessment data. Asterisks indicate statistical significance. CDT: Clock Drawing Test (Shulman score); MMSE: Mini Mental Status Examination; Rey Fig Copy: Rey complex figure direct copy; TMT-A: Trail Making Test A; TMT-B: Trail Making Test B.



	Age	MMSE	Rey Fig Copy	CDT	TMT-A	TMT-B	Visual acuity near	Visual acuity distance
Usability score	ρ=–0.12 P=.47	ρ=0.33 P=.04*	ρ=0.08 P=.62	ρ=–0.38 P=.02*	ρ=–0.42 P=.01*	ρ=–0.32 P=.04*	ρ=0.16 P=.32	ρ=0.29 P=.07
Design	ρ=0.16 P=.35	ρ=–0.22 P=.18	ρ=0.20 P=.22	ρ=0.10 P=0.2	ρ=–0.12 P=.45	ρ=–0.06 P=.70	ρ=0 P=.99	ρ=–0.15 P=0.36
Usefulness	ρ=0.24 P=.14	ρ=–0.26 P=.11	ρ=0.19 P=.26	ρ=0.10 P=0.2	ρ=–0.12 P=.45	ρ=–0.06 P=.70	ρ=0 P=.95	ρ=–0.12 P=.46
Concerns	ρ=–0.07 P=.68	ρ=0.07 P=.68	ρ=–0 P=.99	ρ=0.03 P=.87	ρ=0.05 P=.76	ρ=–0.23 P=.15	ρ=0 P=.98	ρ=–0.16 P=.32

Questionnaires and Observed Task Performance

At the group level, single vibrations and less intrusive audio were preferred (refer to the Items to Assess Practical Implementation section). Regarding completion rates, participants in the “intense” group were more often successful. Here, we can see a discrepancy between the desire for less intrusive signals and better outcomes in participants with more intense intrusiveness.

We correlated the success (for the score calculation, refer to the Measure of Success section) with the usability score (Figure 6). Here, we found a significant positive correlation between the 2 measures; however, the effect size was small to moderate (τ=0.27). The higher the usability was, the more successful the participant was.

We also checked for concordance between self-evaluations and observed behaviors at the individual level by investigating the overlap between success and specific items from the questionnaire. We divided each data set into 2 groups, resulting in 4 clusters (Figure 7). Regarding self-reflection, we distinguished between participants who agreed (clusters 1 and 3) and those who disagreed (clusters 2 and 4) based on item 7 of the usability scale, which assessed task comprehension. Regarding success, we distinguished between participants who completed no more than 1 task (clusters 2 and 3) and others (clusters 1 and 4).

We could see the concordance of self-reflection and observation in most participants (cluster 1: 26/40, 65% and cluster 2: 6/40, 15%). Of those people with appropriate self-reflection, most were successful (14/40, 35%) or almost completely successful (9/40, 23%). They correctly stated that they knew what they had to do. All the 12 people who were not completely successful had trouble with task B (circling bells). Of the 12 participants, 11 (92%) circled the bell on the smartwatch screen and 1 (8%) with the finger on the worksheet. In addition, participants from cluster 2, who were not able to complete >1 task, concordantly disagreed with good task comprehension. Interestingly, no one, including participants who did not attempt either task, strongly disagreed. Few (8/40, 20%) participants showed a discrepancy between self-reports and observations (clusters 3 and 4). We identified 3 possible reasons for the deviation in people in cluster 3. As shown previously, user05 was suspected to have had trouble in completing the questionnaire. We found inconsistencies within their questionnaire and suspected misinterpretation of questions or rating scales. Moreover, memory impairment might limit self-reflection. When completing the questionnaire, user02 indicated that she preferred to have had it handed out beforehand because she could not remember specific details (eg, vibration). User02 was diagnosed with AD dementia and had a score of 22 on the MMSE.

Finally, we found that incomplete or irregular fulfillment of tasks was not recognized by the concerned participants. Except for 1 participant (1/8, 13%; user02), all participants from clusters 3 and 4 completed task B and circled the bell image that appeared on the smartwatch screen. The individuals in cluster 3 felt that their understanding of the task was good, as they felt that they solved the task, even if they did not perform the task according to the researchers’ success protocol. This clear discrepancy between self-reflection and observation might indicate a loss of insight into their abilities and behavior. User33 explained that he did not consider using objects from the real world. User33 and user05 did not drink when prompted. Both belong to cluster 3. It is conceivable that some participants did not expect any actions involving their environment. Otherwise, all people in cluster 4 (5/5, 100%) managed the drinking task and circled the bell on the screen. It is unclear why they disagreed with task comprehension.

Figure 6. Association between success and usability. Success was rated based on observations, and usability was self-rated by participants via questionnaire.

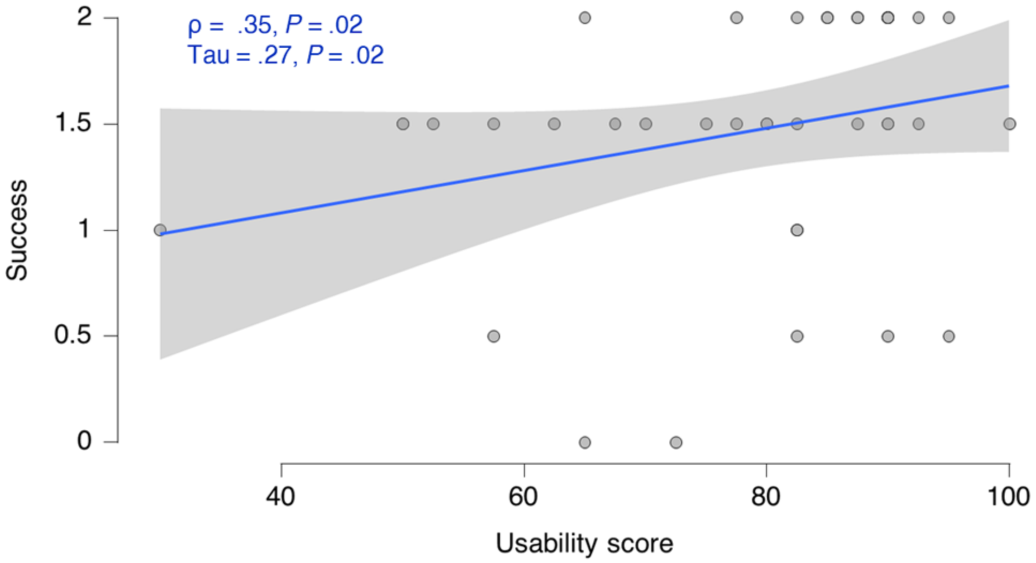
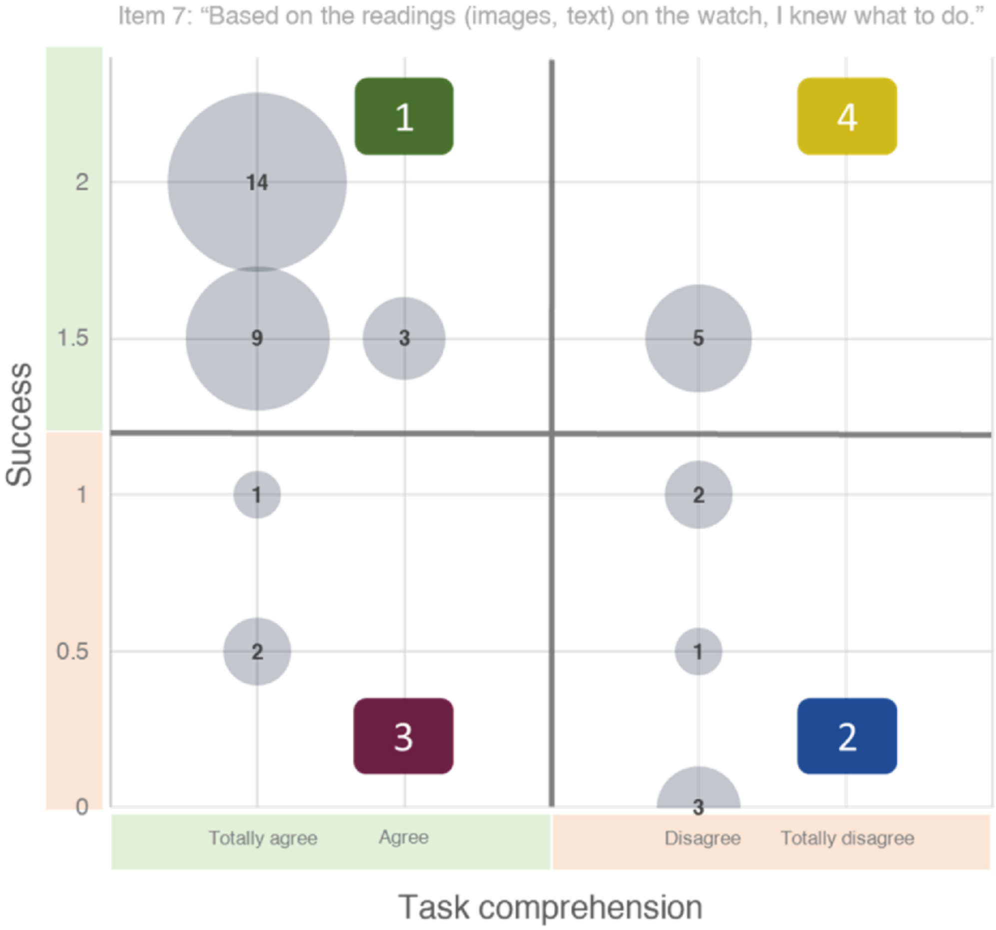


Figure 7. Matrix of self-evaluations and observed task performance. The number in gray circles corresponds to the number of participants. Cluster 1: successful participants with concordant self-reflection, cluster 2: unsuccessful participants with concordant self-reflection, cluster 3: unsuccessful participants with disconcordant self-reflection, and cluster 4: successful participants with disconcordant self-reflection.



Summary

This paper describes an interdisciplinary study to identify the needs regarding and analyze the effects of multimodal interventions using auditory, haptic, and visual information provided by a smartwatch.

We hypothesized that perceived usability, design, usefulness, and concerns would influence the user experience with our smartwatch and, consequently, included those topics using our questionnaire. We saw interest and commitment from the participants. Some participants struggled with the Likert scale, which might be avoided by guiding them or modifying the questionnaire. Usability was evaluated using complementary approaches, including questionnaire-derived measures and observational ratings of success based on completion rates. Usability, quantified through a 10-item score, reached a mean of 78 (maximum possible score=100). This finding is consistent with the remote observations: 35% (14/40) of the participants were able to complete both tasks, and 50% (20/40) of the participants solved one of both tasks. Only 15% (6/40) of the participants were unable to complete either task. Nonetheless, more than half of the respondents (23/40, 58%) thought they would need the support of a tech-savvy person to use the watch in the long term, and many (29/40, 73%) expressed the wish for a permanent contact person for maintenance. Only one-third (14/40, 35%) wanted more interaction with the smartwatch. The design was appealing to most participants, even though feedback about the size of the watch was primarily negative, with participants expressing that they felt the watch was very large. Various elements of the hardware have received suggestions for improvement. Perceived usefulness was rated high. Overall, two-thirds of the participants (27/40, 68%) had a sense of safety with the watch, and one-third of the participants (13/40, 33%) did not believe that the smartwatch would be beneficial. Only few respondents were concerned about using the watch. We also assessed nonfunctional requirements. We observed a preference for less intrusive notifications on the one hand and a desire for voice output on the other. Sophisticated feedback was provided about the wristband and the display latencies. Several specific use cases for possible reminder functions were mentioned. The internal consistency of the subscales varied between “questionable” and “good.” Lower cognitive ability was associated with lower usability.

We evaluated the plausibility of the feedback by checking for discrepancies. Only very few intraindividual inconsistencies were found within the questionnaires. There were no signs of a general acquiescence bias. When comparing self-rated task comprehension and observations, we observed concordance in 80% (32/40) of the participants. Mild deviation of self-reflection and task completion was observed in 13% (5/40) of the participants, and strong deviation was observed in 8% (3/40) of the participants. Participants seemed to lack insight into incomplete or irregular task performance. At the group level, we observed conflicting findings related to intrusiveness. Preferences for less audio and vibration conflicted with the desire for voice output, and more intrusiveness led to more successful task completion.

Discussion

Indications of Bias

Participants provided very favorable feedback. It is possible that our participants were not overly critical because they had little experience with better-designed, equivalent technologies. Older adults have a limited understanding of the potential implications for their privacy [50]. High usability could also be a sign of recruitment bias. Our recruitment strategy was not biased toward people who are interested in technology, as we invited all participants from the memory clinic. Previous experience with mobile technologies was not necessary. However, interest in the research topic is a major driver of participation; therefore, one must assume that participants were interested in technologies at least slightly.

We cannot rule out acquiescence bias, a tendency to choose the first option or a tendency to choose positive response options (agreement). We controlled for this bias by considering answers to inverted items: most of those items were consistently answered. This makes agreement bias unlikely. High levels of agreement possibly reflect a courtesy bias: the tendency to understate dissatisfaction or challenges with a system, driven by politeness. It is possible that respondents who anticipated positive feedback would be more desirable to researchers than those who provided negative feedback. At a metalevel, this poses a problem in participatory research and should be further investigated. When treated as coresearchers, people may be confused with different roles [51] and transform their commitment to science and innovations into less critical feedback in return for their empowerment. The participants were also reported to be motivated by family members and researchers [25]. Uncertainties regarding participants’ roles in participatory research have already been noted [26]. Otherwise, the participants who actively provide feedback or even participate as coresearchers are motivated to make a difference and transfer scientific results into practice [52]. Regarding ATs for people with dementia, professional researchers and coresearchers share the same need for technology transfer. Neither would benefit from spending resources for the development of unsuitable technologies as a result of uncritical evaluation. Transparency and clarification of expectations, roles, and goals could help resolve this conflict.

Rating of Usability and Review of Internal Consistency

Our calculated usability score cannot be compared directly with other scores resulting from SUS ratings, as we deviated from the original SUS by 7 items [48]. However, regarding the mean and SD, our score is similar to other SUS scores [53,54]. As described previously, usability decreases with age [53] and poorer cognition. We presented data about the internal consistency of the subscales of our questionnaire, with McDonald ω being between 0.65 and 0.81. These findings are consistent with those of previous studies about the internal consistency of usability questionnaires administered to older adults or people with cognitive impairment [54,55]; however, we found only a small number of studies regarding this topic.

Feasibility and Significance of User-Centered Design

There is an ongoing discussion about the extent to which people with dementia can be involved in research and in the development of ATs [20,25]. The ambiguous nature of participation has been examined in several recent reviews. Brett et al [23] showed many positive aspects of patient and public involvement in general; however, they also stressed that the outcomes were found more randomly than methodically. Kowe et al [26] summarized many advantages and disadvantages of participatory dementia research for researchers. Fischer et al

[20] discovered positive and negative effects of involvement of older users in technology design but were unable to determine its impact on technology adoption and acceptance. However, Bethell et al [56] focused on engagement of patients with dementia but could not determine its impact on the research process or outcomes. All of them concluded that more evidence is needed to illustrate the impacts on the involved parties. Therefore, we aimed to determine the feasibility of user-centered development of smartwatch-based interventions for people with dementia.

We based our analysis on 3 aspects: study implementation, intervention outcome (success metrics), and qualitative measures (user experience and perceived usefulness). Regarding recruitment, we had no difficulty in identifying and enrolling suitable study participants. We found participants to be interested and dedicated to this field of research. We had only a small amount of missing data. This indicates that our study addressed a problem relevant to the target group. As we wanted to evaluate the feasibility of the user-centered design approach, we do not discuss about its technical feasibility in this paper. Regarding intervention outcome, we could see that 80% (32/40) of the participants were able to completely solve task A and 40% (16/40) of the participants completely solved task B; a further 50% (20/40) of the participants completed task B at least partially. As these values are study specific and there are no values in the literature for comparison, it is difficult to determine what was to be expected. Many researchers portray older adults as technologically illiterate [20]. Many people in the target group had significant visual, hearing, and tactile impairments [57,58]; therefore, it was not clear whether a smartwatch would even be able to reach the threshold required to gain the attention and task understanding of these people. In this regard, the task completion rate in our study seems to be high. This high rate could also be explained by our interventions being common tasks requiring little effort. In addition, our tasks did not require participants to directly interact with the smartwatch.

Finally, regarding user experience, we received very positive feedback. Most participants felt comfortable with using the watch and would be willing to participate again in the study. Overall, three-fourth of the participants (31/40, 78%) could imagine having a personal benefit from using the watch, which is indicative of a high level of perceived usefulness. On the basis of the evaluation of these 3 aspects, we definitively consider the feasibility as given, but note that user involvement is more resource intensive [20].

The involvement of various stakeholders represents an additional expense [24]. On the one hand, it takes more time to conduct and, above all, evaluate interviews. On the other hand, the creation of suitable questionnaires is methodologically challenging. The scope (number of questions), the number of response levels, or the alternation of positively and negatively worded questions [59] are essential aspects that need to be considered [60]. The iterative approach [20] means that substeps and project goals cannot be defined and planned from the outset. Instead, interim evaluations and adjustments are necessary, which require consistent project management and effective team communication. In our case, the many years of expertise in this area and the commitment of the study staff contributed to our success, as did the long-term, third-party funded financial support over 3 years.

Plausibility Analyses

The second objective was to evaluate the extent to which user feedback from people with dementia regarding ATs is plausible. Our approach to evaluate plausibility included three steps: (1) analysis of discrepancies within questionnaires, (2) comparison of questionnaire responses and clinical assessments, and (3) comparison of questionnaires and observations.

Individual-based analyses revealed only isolated inconsistencies, and group-based analyses revealed inconsistencies that may indicate mutually exclusive needs. Participants showed a wish for less obtrusive notifications and dislike toward a watch that was very conspicuous but also stated a wish for speech output. This shows that there will be no technology that can address all needs equally. There can be conflicting needs both interindividually and intraindividually. This inconsistency in the statements is not due to cognitive deficits but reflects ambivalent attitudes that exist in all people to a greater or lesser extent [29]. We emphasize that unreliability in certain individual cases should not be a reason to prevent the whole group of patients with dementia from participating via self-reports [51].

Our results showed a moderate correlation between perceived usability and cognition (Figure 5). These findings were previously described [53] and confirmed our hypothesis that neuropsychological performance is associated with usability.

In contrast to previous studies [61], we observed high rates of overlap between self-reflection and success metrics such as completion rates. The concordance was evident in both directions. Objectively successful participants mostly indicated a good understanding of the task, whereas less successful participants disagreed with this statement. Only 8% (3/40) of the participants showed a clear discrepancy in the sense that they did not recognize their failure. Overall, 18% (7/40) of the participants did not recognize incomplete or irregular task fulfillment.

The answers were generally plausible and, in part, even elaborated.

Added Value of Our Study

This study is one of the few investigations of the interaction of people with dementia with an interactive smartwatch. Particularly noteworthy is the detailed clinical characterization of the study participants and the exact description of the technical features of the smartwatch interventions. The publication of the results of the survey about the wishes and needs of people with proven memory impairment regarding a smartwatch alone is valuable, even if the sample size of 40 individuals is not particularly large. Several specific use cases were mentioned, and new ideas for wishful smartwatch features were suggested.

Although there are numerous recommendations regarding the design of user interfaces of new technologies, for example, user interface design, these have rarely been tested in a scientific setting in practice on older adults or people with memory impairment. This target group is extremely heterogeneous, and it must be assumed that general recommendations are of limited value [20]. Therefore, it was not clear whether a smartwatch would even be able to reach the threshold required to gain the attention and task understanding of these people.

Most studies of smartwatches for patients with dementia have no interactive claim but, instead, use passive monitoring [62]. We could only find 3 studies that used an interactive smartwatch for people with dementia to support activities of daily life [8,63,64]. König et al [8] designed a system in which a smartwatch was embedded into an infrastructure with tablets and a web platform to evaluate usability in a 3-month trial. The authors did not observe significant changes in the quantitative measurements. They did not assess single interactions. Thorpe et al [63] tested smartwatches capable of scheduling, navigation, communication, and orientation using an off-the-shelf wearable device in 5 participants. Personalization and familiarity appeared to be key drivers of smartwatch adoption. The task completion rates varied greatly among the participants, as in our study. McCarron et al [64] tested a face recognition application for smartwatches paired with smartphones to improve the quality of social interactions and quality of life among people with dementia. The authors had no trouble with study implementation and reported no problems with feasibility. Furthermore, they found no overall impact on the quality of life of the 48 participants when they used the smartwatch for 6 months.

Compared to other studies, our study has a sound sample size [12,15] and represents great added value, as it expands the small body of scientific literature in this specific area.

At a metalevel, this study is important because it highlights the practical implications of user-centered design in the development of novel technologies together with people with cognitive impairment, for example with giving precise recommendations for usability questionnaires for people with dementia, (Multimedia Appendix 6).

Limitations

Specific reasons for discomfort or concerns could not be captured using the questionnaire. In addition, contradictory information regarding the preferred intrusiveness of smartwatch notifications could not be resolved in this study. Some other questions remain open. What authority do we ascribe to technical devices? In this study, 1 participant (1/40, 3%) commented that they would not willingly drink the water that was provided even though the smartwatch prompted them to drink it. Another user stated that they were not thirsty. Such context-related information cannot be measured by sensors. If we want users to actively interact with a device, then questions about the immersive character arise. How should users know when they should interact with the smartwatch and when they should interact with their environment? The smartwatch specifications that we applied in our study seem to match the needs of users. Minor adjustments should focus on optimizing display latencies and wristbands. Future studies should implement more functions and test those functions in practice with more participants in real-world scenarios in the long term.

Conclusions

To determine whether user-centered design featuring people with cognitive impairment in the development of digital assistive devices is worthwhile, one needs to measure the utility of the developed technology. This can be accomplished by evaluating the usability, usefulness, and success metrics. All 3 approaches provide unique challenges because the available measuring tools may be inapplicable for the technology at hand or for the group of potential users. On the basis of the results of our study, we derived specific recommendations for questionnaires for people with dementia. Measures of internal consistency should not be overrated.

To improve technology adoption, the concept of "technical dyads" might be useful: each user is assigned to a person who is willing and capable of adjusting and maintaining devices for users who are technically inexperienced. This would be consistent with the needs of our participants, who expressed the wish for a permanent contact person for service. This wish also confirms the results that have already been found by others [10].

Our study is one of few studies that examined an interactive smartwatch for people with dementia. Although there are some methodological challenges for such studies, we and others have shown that both the inclusion of future users and the use of smartwatches by people with dementia are possible.

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Data Availability

The data sets used and analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

DG and ST conceptualized and designed the study with input from SK and GB. GB built the smartwatch prototype with feedback from DG and SK. DG, ER, and SK performed the study. DG analyzed the data. DG drafted the manuscript, which was edited and critically reviewed by ER, SK, GB, AGT, IK, and ST. ER contributed to literature review. AGT focused on language editing and coherence of content. SK and IK focused on shortening the manuscript and enhancing comprehensibility. All authors read and approved the final manuscript.

Conflicts of Interest

ST is a member of the advisory boards for Lilly, Eisai, and Biogen. He is also a member of the Independent Data Safety and Monitoring Board of the study ENVISION (Biogen). All the other authors have no conflicts to declare.

Multimedia Appendix 1
Sensor-Based Individualized Activity Management System for People With Dementia observational field study.
[PDF File (Adobe PDF File), 514 KB - aging_v7i1e50107_app1.pdf]

Multimedia Appendix 2
In-person testing of intervention tasks.
[PDF File (Adobe PDF File), 196 KB - aging_v7i1e50107_app2.pdf]

Multimedia Appendix 3
Demographics and test results.
[PDF File (Adobe PDF File), 185 KB - aging_v7i1e50107_app3.pdf]

Multimedia Appendix 4
Postexperiment questionnaire used in the intervention study.
[PDF File (Adobe PDF File), 668 KB - aging_v7i1e50107_app4.pdf]

Multimedia Appendix 5
Descriptive results of the applied questionnaire.
[PDF File (Adobe PDF File), 367 KB - aging_v7i1e50107_app5.pdf]

Multimedia Appendix 6
Recommendations for usability questionnaires for people with dementia.
[PDF File (Adobe PDF File), 188 KB - aging_v7i1e50107_app6.pdf]

References

1. Dementia. World Health Organization. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2022-02-15]
2. Burlá C, Rego G, Nunes R. Alzheimer, dementia and the living will: a proposal. Med Health Care Philos 2014 Aug;17(3):389-395 [FREE Full text] [doi: 10.1007/s11019-014-9559-8] [Medline: 24737537]
3. Brookman R, Parker S, Hoon L, Ono A, Fukayama A, Matsukawa H, et al. Technology for dementia care: what would good technology look like and do, from carers' perspectives? BMC Geriatr 2023 Dec 16;23(1):867 [FREE Full text] [doi: 10.1186/s12877-023-04530-9] [Medline: 38104074]
4. Byrne C, Collier R, O’Hare G. A review and classification of assisted living systems. Information 2018 Jul 21;9(7):182. [doi: 10.3390/info9070182]
5. Moore K, O'Shea E, Kenny L, Barton J, Tedesco S, Sica M, et al. Older adults' experiences with using wearable devices: qualitative systematic review and meta-synthesis. JMIR Mhealth Uhealth 2021 Jun 03;9(6):e23832 [FREE Full text] [doi: 10.2196/23832] [Medline: 34081020]
6. Øksnebjerg L, Janbek J, Woods B, Waldemar G. Assistive technology designed to support self-management of people with dementia: user involvement, dissemination, and adoption. A scoping review. Int Psychogeriatr 2019 Nov 25;32(8):937-953. [doi: 10.1017/s1041610219001704]
7. Ienca M, Fabrice J, Elger B, Caon M, Scoccia Pappagallo A, Kressig RW, et al. Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. J Alzheimers Dis 2017;56(4):1301-1340. [doi: 10.3233/JAD-161037] [Medline: 28222516]
8. König T, Pigliautile M, Águila O, Arambarri J, Christophorou C, Colombo M, et al. User experience and acceptance of a device assisting persons with dementia in daily life: a multicenter field study. Aging Clin Exp Res 2022 Apr 11;34(4):869-879 [FREE Full text] [doi: 10.1007/s40520-021-02013-8] [Medline: 34762252]
9. Desai S, Astell A. Mixed reality technologies for people with dementia: participatory evaluation methods. arXiv Preprint posted online June 7, 2021 [FREE Full text]

10. Hassan L, Swarbrick C, Sanders C, Parker A, Machin M, Tully MP, et al. Tea, talk and technology: patient and public involvement to improve connected health 'wearables' research in dementia. Res Involv Engagem 2017;3:12 [FREE Full text] [doi: 10.1186/s40900-017-0063-1] [Medline: 29062537]
11. Liu L, Stroulia E, Nikolaidis I, Miguel-Cruz A, Rios Rincon A. Smart homes and home health monitoring technologies for older adults: a systematic review. Int J Med Inform 2016 Jul;91:44-59. [doi: 10.1016/j.ijmedinf.2016.04.007] [Medline: 27185508]
12. Palmdorf S, Stark AL, Nadolny S, Eliaß G, Karlheim C, Kreisel SH, et al. Technology-assisted home care for people with dementia and their relatives: scoping review. JMIR Aging 2021 Jan 20;4(1):e25307 [FREE Full text] [doi: 10.2196/25307] [Medline: 33470935]
13. Why do people abandon assistive technologies? Research suggests users need to be partners in design. National Institute for Health Research. 2021. URL: https://tinyurl.com/35pxxaas [accessed 2024-04-05]
14. Howard J, Fisher Z, Kemp AH, Lindsay S, Tasker LH, Tree JJ. Exploring the barriers to using assistive technology for individuals with chronic conditions: a meta-synthesis review. Disabil Rehabil Assist Technol 2022 May 14;17(4):390-408. [doi: 10.1080/17483107.2020.1788181] [Medline: 32663110]
15. Yu J, de Antonio A, Villalba-Mora E. Design of an integrated acceptance framework for older users and eHealth: influential factor analysis. J Med Internet Res 2022 Jan 28;24(1):e31920 [FREE Full text] [doi: 10.2196/31920] [Medline: 35089155]
16. Chung J, Brakey HR, Reeder B, Myers O, Demiris G. Community-dwelling older adults' acceptance of smartwatches for health and location tracking. Int J Older People Nurs 2023 Jan 12;18(1):e12490 [FREE Full text] [doi: 10.1111/opn.12490] [Medline: 35818900]
17. Bevan N. International standards for HCI and usability. Int J Hum Comput Stud 2001 Oct;55(4):533-552. [doi: 10.1006/ijhc.2001.0483]
18. WIPO technology trends 2021- assistive technology. World Intellectual Property Organization. URL: https://www.wipo.int/tech_trends/en/assistive_technology/ [accessed 2023-01-11]
19. Ummels D, Braun S, Stevens A, Beekman E, Beurskens A. Measure it super simple (MISS) activity tracker: (re)design of a user-friendly interface and evaluation of experiences in daily life. Disabil Rehabil Assist Technol 2022 Oct 24;17(7):767-777. [doi: 10.1080/17483107.2020.1815089] [Medline: 32970493]
20. Fischer B, Peine A, Östlund B. The importance of user involvement: a systematic review of involving older users in technology design. Gerontologist 2020 Sep 15;60(7):e513-e523 [FREE Full text] [doi: 10.1093/geront/gnz163] [Medline: 31773145]
21. Federici S, Borsci S. The use and non-use of assistive technology in Italy: preliminary data. In: Gelderblom GJ, Soede M, Adriaens L, Miesenberger K, editors. Everyday Technology for Independence and Care. Amsterdam, The Netherlands: IOS Press; 2011:979-986.
22. Contreras-Somoza LM, Irazoki E, Toribio-Guzmán JM, de la Torre-Díez I, Diaz-Baquero AA, Parra-Vidales E, et al. Usability and user experience of cognitive intervention technologies for elderly people with MCI or dementia: a systematic review. Front Psychol 2021 Apr 22;12:636116 [FREE Full text] [doi: 10.3389/fpsyg.2021.636116] [Medline: 33967901]
23. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. Patient 2014 Jul 18;7(4):387-395. [doi: 10.1007/s40271-014-0065-0] [Medline: 25034612]
24. Gove D, Diaz-Ponce A, Georges J, Moniz-Cook E, Mountain G, Chattat R, European Working Group of People with Dementia. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging Ment Health 2018 Jun 17;22(6):723-729. [doi: 10.1080/13607863.2017.1317334] [Medline: 28513210]
25. Hendriks N, Huybrechts L, Wilkinson A, Slegers K. Challenges in doing participatory design with people with dementia. In: Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - Volume 2. 2014 Presented at: PDC '14; October 6-10, 2014; Windhoek, Namibia p. 33-36 URL: https://dl.acm.org/doi/10.1145/2662155.2662196 [doi: 10.1145/2662155.2662196]
26. Kowe A, Panjaitan H, Klein OA, Boccardi M, Roes M, Teupen S, et al. The impact of participatory dementia research on researchers: a systematic review. Dementia (London) 2022 Apr;21(3):1012-1031. [doi: 10.1177/14713012211067020] [Medline: 35152790]
27. Huber S, Preßler J, Tung NL, Hurtienne J. Evaluating interaction-triggered emotions in people with dementia. In: Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems. 2017 Presented at: CHI EA '17; May 6-11, 2017; Denver, CO p. 2659-2667 URL: https://dl.acm.org/doi/10.1145/3027063.3053251 [doi: 10.1145/3027063.3053251]
28. Mruck K. Das beispiel der open-access-Zeitschrift forum qualitative sozialforschung / forum: qualitative social research (FQS). Forum Qual Soz Forsch Forum Qual Soc Res 2007 Oct 15;55(6):251-257. [doi: 10.17169/fqs-1.2.1089]
29. Köhler S, Görß D, Kowe A, Teipel SJ. Matching values to technology: a value sensitive design approach to identify values and use cases of an assistive system for people with dementia in institutional care. Ethics Inf Technol 2022 Jul 12;24(3):1-17. [doi: 10.1007/s10676-022-09656-9]

30. Morris JC, Heyman A, Mohs RC, Hughes JP, van Belle G, Fillenbaum G, et al. The consortium to establish a registry for Alzheimer's disease (CERAD). Part I. Clinical and neuropsychological assessment of Alzheimer's disease. Neurology 1989 Sep 01;39(9):1159-1165. [doi: 10.1212/wnl.39.9.1159] [Medline: 2771064]
31. Winblad B, Palmer K, Kivipelto M, Jelic V, Fratiglioni L, Wahlund L, et al. Mild cognitive impairment--beyond controversies, towards a consensus: report of the international working group on mild cognitive impairment. J Intern Med 2004 Sep;256(3):240-246 [FREE Full text] [doi: 10.1111/j.1365-2796.2004.01380.x] [Medline: 15324367]
32. Petersen RC. Mild cognitive impairment as a diagnostic entity. J Intern Med 2004 Sep;256(3):183-194 [FREE Full text] [doi: 10.1111/j.1365-2796.2004.01388.x] [Medline: 15324362]
33. McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA work group under the auspices of department of health and human services task force on Alzheimer's disease. Neurology 1984 Jul 01;34(7):939-944. [doi: 10.1212/wnl.34.7.939] [Medline: 6610841]
34. Román GC, Tatemichi TK, Erkinjuntti T, Cummings JL, Masdeu JC, Garcia JH, et al. Vascular dementia: diagnostic criteria for research studies. Report of the NINDS-AIREN international workshop. Neurology 1993 Feb 01;43(2):250-260. [doi: 10.1212/wnl.43.2.250] [Medline: 8094895]
35. McKeith IG, Dickson DW, Lowe J, Emre M, O'Brien JT, Feldman H, Consortium on DLB. Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. Neurology 2005 Dec 27;65(12):1863-1872. [doi: 10.1212/01.wnl.0000187889.17253.b1] [Medline: 16237129]
36. Mesulam MM. Primary progressive aphasia. Ann Neurol 2001 Apr 02;49(4):425-432. [doi: 10.1002/ana.91]
37. Gorno-Tempini ML, Hillis AE, Weintraub S, Kertesz A, Mendez M, Cappa SF, et al. Classification of primary progressive aphasia and its variants. Neurology 2011 Mar 15;76(11):1006-1014 [FREE Full text] [doi: 10.1212/WNL.0b013e31821103e6] [Medline: 21325651]
38. Rascovsky K, Hodges JR, Knopman D, Mendez MF, Kramer JH, Neuhaus J, et al. Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. Brain 2011 Sep;134(Pt 9):2456-2477 [FREE Full text] [doi: 10.1093/brain/awr179] [Medline: 21810890]
39. Steger B. Sehproben Pocketcard. Grünwald, Germany: Börm Bruckmeier; 2010.
40. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975 Nov;12(3):189-198. [doi: 10.1016/0022-3956(75)90026-6] [Medline: 1202204]
41. Shulman KI, Pushkar Gold D, Cohen CA, Zucchero CA. Clock‐drawing and dementia in the community: a longitudinal study. Int J Geriat Psychiatry 2004 Oct 13;8(6):487-496. [doi: 10.1002/gps.930080606]
42. Meyers JE, Meyers KR. Rey Complex Figure Test and Recognition Trial: Professional Manual. Lutz, FL: Psychological Assessment Ressources; 1995.
43. Tombaugh T. Trail making test A and B: normative data stratified by age and education. Arch Clin Neuropsychol 2004 Mar;19(2):203-214. [doi: 10.1016/S0887-6177(03)00039-8] [Medline: 15010086]
44. Teipel S, Babiloni C, Hoey J, Kaye J, Kirste T, Burmeister OK. Information and communication technology solutions for outdoor navigation in dementia. Alzheimers Dement 2016 Jun 14;12(6):695-707 [FREE Full text] [doi: 10.1016/j.jalz.2015.11.003] [Medline: 26776761]
45. Goerss D, Hein A, Bader S, Halek M, Kernebeck S, Kutschke A, et al. Automated sensor-based detection of challenging behaviors in advanced stages of dementia in nursing homes. Alzheimers Dement 2020 Apr;16(4):672-680 [FREE Full text] [doi: 10.1016/j.jalz.2019.08.193] [Medline: 31668595]
46. Franke T, Attig C, Wessel D. A personal resource for technology interaction: development and validation of the affinity for technology interaction (ATI) scale. Int J Hum Comput Interact 2018 Mar 30;35(6):456-467. [doi: 10.1080/10447318.2018.1456150]
47. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Manag Sci 1989 Aug;35(8):982-1003. [doi: 10.1287/mnsc.35.8.982]
48. Brooke J. SUS: a 'quick and dirty' usability scale. In: Jordan PW, Thomas B, McClelland IL, Weerdmeester B, editors. Usability Evaluation In Industry. Boca Raton, FL: CRC Press; 1996.
49. ICARUS Research Team. Technology usage inventory: manual. Information and Communication technology Applications: Research on Useroriented Solutions. 2012. URL: https://tinyurl.com/45fuzhef [accessed 2023-02-28]
50. Puri A, Kim B, Nguyen O, Stolee P, Tung J, Lee J. User acceptance of wrist-worn activity trackers among community-dwelling older adults: mixed method study. JMIR Mhealth Uhealth 2017 Nov 15;5(11):e173 [FREE Full text] [doi: 10.2196/mhealth.8211] [Medline: 29141837]
51. Mann J, Hung L. Co-research with people living with dementia for change. Action Res 2018 Jul 20;17(4):573-590. [doi: 10.1177/1476750318787005]
52. Littlechild R, Tanner D, Hall K. Co-research with older people: perspectives on impact. Qual Soc Work 2014 Nov 03;14(1):18-35. [doi: 10.1177/1473325014556791]
53. Bangor A, Kortum PT, Miller JT. An empirical evaluation of the system usability scale. Int J Hum Comput Interact 2008 Jul 30;24(6):574-594. [doi: 10.1080/10447310802205776]

54. Domingos C, Costa P, Santos NC, Pêgo JM. Usability, acceptability, and satisfaction of a wearable activity tracker in older adults: observational study in a real-life context in northern Portugal. J Med Internet Res 2022 Jan 26;24(1):e26652 [FREE Full text] [doi: 10.2196/26652] [Medline: 35080503]
55. Dietlein C, Bock O. Usability of serious games for the training of people with dementia. EAI Endorsed Trans Game Based Learn 2018 Jul 13:159946. [doi: 10.4108/eai.11-7-2019.159946]
56. Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, et al. Patient engagement in research related to dementia: a scoping review. Dementia (London) 2018 Nov 29;17(8):944-975. [doi: 10.1177/1471301218789292] [Medline: 30373460]
57. Ganesan B, Gowda T, Al-Jumaily A, Fong KN, Meena SK, Tong RK. Ambient assisted living technologies for older adults with cognitive and physical impairments: a review. Eur Rev Med Pharmacol Sci 2019 Dec;23(23):10470-10481 [FREE Full text] [doi: 10.26355/eurrev_201912_19686] [Medline: 31841201]
58. Stavropoulos TG, Lazarou I, Diaz A, Gove D, Georges J, Manyakov NV, RADAR-AD Consortium. Wearable devices for assessing function in Alzheimer's disease: a European public involvement activity about the features and preferences of patients and caregivers. Front Aging Neurosci 2021 Apr 12;13:643135 [FREE Full text] [doi: 10.3389/fnagi.2021.643135] [Medline: 33912025]
59. Sauro J, Lewis JR. When designing usability questionnaires, does it hurt to be positive? In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 2011 Presented at: CHI '11; May 7-12, 2011; Vancouver, BC p. 2215-2224 URL: https://dl.acm.org/doi/10.1145/1978942.1979266 [doi: 10.1145/1978942.1979266]
60. Gibson A, McCauley CO, Mulvenna M, Ryan A, Laird L, Curran K, et al. Assessing usability testing for people living with dementia. In: Proceedings of the 4th Workshop on ICTs for improving Patients Rehabilitation Research Techniques. 2016 Presented at: REHAB '16; October 13-14, 2016; Lisbon, Portugal p. 25-31 URL: https://dl.acm.org/doi/10.1145/3051488.3051492 [doi: 10.1145/3051488.3051492]
61. Bangor A, Kortum PT, Miller JT. Determining what individual SUS scores mean: adding an adjective rating scale. J Usability Stud 2009;4(3):114-123 [FREE Full text]
62. Boletsis C, McCallum S, Landmark BF. Smart watch and monitoring system for dementia patients. In: Proceedings of the 1st International Conference, ITAP 2015, Held as Part of HCI International on Human Aspects of IT for the Aged Population, Design for Everyday Life. 2013 Presented at: ITAP HCI '15; August 2-7, 2015; Los Angeles, CA p. 577-584 URL: https://link.springer.com/chapter/10.1007/978-3-319-20913-5_2 [doi: 10.1007/978-3-319-20913-5_2]
63. Thorpe JR, Rønn-Andersen KV, Bień P, Özkil AG, Forchhammer BH, Maier AM. Pervasive assistive technology for people with dementia: a UCD case. Healthc Technol Lett 2016 Dec;3(4):297-302 [FREE Full text] [doi: 10.1049/htl.2016.0057] [Medline: 28008366]
64. McCarron HR, Zmora R, Gaugler JE. A web-based mobile app with a smartwatch to support social engagement in persons with memory loss: pilot randomized controlled trial. JMIR Aging 2019 Jun 18;2(1):e13378 [FREE Full text] [doi: 10.2196/13378] [Medline: 31518270]

Abbreviations

AD: Alzheimer disease
AT: assistive technology
JASP: Jeffrey’s Amazing Statistics Program
MCI: mild cognitive impairment
MMSE: Mini Mental Status Examination
SAMi: Sensor-Based Individualized Activity Management System for People With Dementia
SUS: System Usability Scale
TMT-A: Trail Making Test A
TMT-B: Trail Making Test B

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Original Paper

Examining Associations Between Smartphone Use and Clinical Severity in Frontotemporal Dementia: Proof-of-Concept Study

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Abstract

Background: Frontotemporal lobar degeneration (FTLD) is a leading cause of dementia in individuals aged <65 years. Several challenges to conducting in-person evaluations in FTLD illustrate an urgent need to develop remote, accessible, and low-burden assessment techniques. Studies of unobtrusive monitoring of at-home computer use in older adults with mild cognitive impairment show that declining function is reflected in reduced computer use; however, associations with smartphone use are unknown.

Objective: This study aims to characterize daily trajectories in smartphone battery use, a proxy for smartphone use, and examine relationships with clinical indicators of severity in FTLD.

Methods: Participants were 231 adults (mean age 52.5, SD 14.9 years; n=94, 40.7% men; n=223, 96.5% non-Hispanic White) enrolled in the Advancing Research and Treatment of Frontotemporal Lobar Degeneration (ARTFL study) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS study) Longitudinal Frontotemporal Lobar Degeneration (ALLFTD) Mobile App study, including 49 (21.2%) with mild neurobehavioral changes and no functional impairment (ie, prodromal FTLD), 43 (18.6%) with neurobehavioral changes and functional impairment (ie, symptomatic FTLD), and 139 (60.2%) clinically normal adults, of whom 55 (39.6%) harbored heterozygous pathogenic or likely pathogenic variants in an autosomal dominant FTLD gene. Participants completed the Clinical Dementia Rating plus National Alzheimer's Coordinating Center Frontotemporal Lobar Degeneration Behavior and Language Domains (CDR+NACC FTLD) scale, a neuropsychological battery; the Neuropsychiatric Inventory; and brain magnetic resonance imaging. The ALLFTD Mobile App was installed on participants' smartphones for remote, passive, and continuous monitoring of smartphone use. Battery percentage was collected every 15 minutes over an average of 28 (SD 4.2; range 14-30) days. To determine whether temporal patterns of battery percentage varied as a function of disease severity, linear mixed effects models examined linear, quadratic, and cubic effects of the time of day and their interactions with each measure of disease severity on battery percentage. Models covaried for age, sex, smartphone type, and estimated smartphone age.

Results: The CDR+NACC FTLD global score interacted with time on battery percentage such that participants with prodromal or symptomatic FTLD demonstrated less change in battery percentage throughout the day (a proxy for less smartphone use) than clinically normal participants (P<.001 in both cases). Additional models showed that worse performance in all cognitive domains assessed (ie, executive functioning, memory, language, and visuospatial skills), more neuropsychiatric symptoms, and smaller brain volumes also associated with less battery use throughout the day (P<.001 in all cases).

Conclusions: These findings support a proof of concept that passively collected data about smartphone use behaviors associate with clinical impairment in FTLD. This work underscores the need for future studies to develop and validate passive digital markers sensitive to longitudinal clinical decline across neurodegenerative diseases, with potential to enhance real-world monitoring of neurobehavioral change.

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KEYWORDS

digital; technology; remote; monitoring; cognition; neuropsychology; cognitive impairment; neurodegenerative; screening; clinical trials; mobile phone

Introduction

Background

Frontotemporal lobar degeneration (FTLD) is a common cause of dementia in individuals aged <65 years [1,2]. FTLD encompasses a group of neuropathologically distinct diseases that result in an overlapping set of dementia syndromes with heterogeneous symptoms, including those defined by primary behavior, language, or sensorimotor changes [3,4]. The timely detection of neurodegenerative diseases such as FTLD is a core public health strategy to reduce the individual, caregiver, and socioeconomic burden of dementia [5-7]. As we enter the era of disease-modifying treatments for neurodegenerative diseases, early detection is critical to identify those eligible for clinical trial participation and early treatment to slow or stop disease progression [8-10].

However, current assessment practices for detecting neurobehavioral changes associated with neurodegenerative disease are limited. In-person neuropsychological and neurological evaluations are the gold standard for determining the presence of cognitive impairment and identifying clinical phenotypes suggestive of an underlying neurodegenerative process; unfortunately, their high costs and restricted availability via specialty dementia clinics and research centers limit access for those with fewer financial resources and lower health literacy as well as those who reside in more remote geographic locations. In addition, evaluating a person at a single appointment provides only a *snapshot* of neurobehavioral functioning, which does not account for the dynamic nature of human behavior that fluctuates diurnally and is influenced by other dynamic factors (eg, sleep, fatigue, mood, and medications), limiting sensitivity for detecting early subtle declines [11,12]. Traditional neuropsychological assessment also lacks ecological validity because interpretations of functioning are based on task performance in a tightly controlled testing environment, which seldom reflects a patient's typical daily experience.

Remote monitoring of health status and behavior through the use of digital health tools is a promising solution to overcome the numerous limitations of in-person assessment and has been identified as a priority by several leading health organizations, including the US Food and Drug Administration [13], the US Department of Health and Human Services [14], and the National Institutes of Health [15,16]. Passive digital monitoring in particular (ie, monitoring behavior passively and unobtrusively through remote sensors) represents a low-burden and highly scalable method for improved detection and monitoring of *real-world* neurobehavioral change in neurodegenerative disease. Naturalistic behavioral data collected via in-home remote sensors have shown sensitivity to clinical severity in Alzheimer disease [17-25]; for example, older adults with mild cognitive impairment exhibit significant declines in the number of days with computer use and daily time spent on the computer per day compared to those without cognitive impairment [18]. As an extension of this work, we aim to examine overall daily smartphone use and its association with clinical severity in FTLD. We focused on FTLD as a specific use case to study the construct of passively collected smartphone data in the context of a neurodegenerative disease that manifests with well-characterized neurobehavioral changes.

Objectives

Thus, the aims of this study were to (1) examine passively collected battery percentage trajectories as a proxy for smartphone use throughout the day and (2) test associations between daily battery percentage trajectories and measures of cognitive and functional impairment and neurodegeneration in FTLD. Time-stamped battery percentage data can be easily accessed through public application programming interfaces (APIs) for both iOS and Android devices and have previously been associated with smartphone use [26-28]. Although smartphone screen time or app use time may be a more face-valid measure of smartphone use, access to these data has historically been restricted on iOS devices. This has been a major barrier to accessibility in passive monitoring research because nearly 30% of smartphone users worldwide have iOS devices [29]. Thus, it is worthwhile to examine battery percentage as a more accessible proxy for overall smartphone use. Consistent with prior research on computer use in older adults with cognitive impairment, we hypothesized that individuals with greater FTLD overall disease severity (ie, more severe functional impairment, worse cognitive performance, greater neuropsychiatric symptoms, and more brain atrophy) would demonstrate lower levels of daily smartphone use.

Methods

Participants

Participants were enrolled in the ARTFL (Advancing Research and Treatment of Frontotemporal Lobar Degeneration) study and LEFFTDS (Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects) Longitudinal Frontotemporal Lobar Degeneration (ALLFTD) Mobile App study through the multisite ALLFTD (NCT04363684) study and University of California San Francisco studies of FTLD (AG038791, AG062422, and AG019724), as described previously [30]. The participants were those who had a referring diagnosis of an FTLD clinical syndrome or those who were members of a family with a strong family history of an FTLD syndrome. Additional inclusion criteria were as follows: (1) aged ≥18 years, (2) access to a smartphone, and (3) English reported as the primary language. Participants were asked to use their own smartphones. Recruitment primarily targeted those with Clinical Dementia Rating Dementia Staging Instrument plus National Alzheimer's Coordinating Center Frontotemporal Lobar Degeneration Behavior and Language Domains (CDR+NACC FTLD) global scores of <2, but participants who were more severely impaired were not excluded. Data for this study were collected from August 2020 to April 2023. During this period, 257 participants were enrolled and logged into the ALLFTD Mobile App on their personal smartphones. Participants were only included in this secondary analysis of the ALLFTD Mobile App study if they had at least 14 continuous days of passive smartphone monitoring data, consistent with prior digital phenotyping studies attempting to capture typical daily behavior [31]. Thus, of the initial 257 participants, 231 (89.9%) were included in the final sample after 26 (10.1%) participants were excluded because they first logged in <14 days before the date on which these data were pulled in April 2023. Of these 231 participants, 92 (39.8%) were classified as having neurobehavioral symptoms at the prodromal stage (ie, no functional impairment) or fully symptomatic (ie, with functional impairment) level of severity that are consistent with an FTLD-related clinical phenotype per conference consensus with neurologists and neuropsychologists following published criteria [32-35]. Participants who were symptomatic had either sporadic FTLD or a confirmed pathogenic or likely pathogenic variant in an autosomal dominant FTLD gene (ie, a pathogenic expansion in the chromosome 9 open reading frame 72 [C9orf72] gene or a known pathogenic or likely pathogenic variant in the progranulin (GRN) or microtubule-associated protein tau [MAPT] genes; conducted as described previously [36]). The remaining participants (139/231, 60.2%) were asymptomatic clinically normal family members of the prodromal or symptomatic individuals who (1) carried a pathogenic or likely pathogenic FTLD gene variant (55/139, 39.6%), (2) tested negative for known pathogenic or likely pathogenic FTLD variants (50/139, 36%), or (3) did not yet have results available from genetic testing (34/139, 24.5%).

Ethical Considerations

The study was approved by a centralized single institutional review board at Johns Hopkins Medicine (IRB # 20-29891), and all participants provided written informed consent.

Measures

Passively Monitored Smartphone Battery Percentage

We used the first 30 days of participants' smartphone data for this study with the goal of understanding whether approximately 1 month of smartphone monitoring could reflect baseline neurobehavioral status without capturing longitudinal disease-related decline [18,37]. Participants downloaded the

ALLFTD Mobile App onto their personal smartphones. The app is designed to deliver both active mobile cognitive assessments and passively collect smartphone use data [30], including battery percentage. The ALLFTD Mobile App was programmed to collect battery percentage every 15 minutes. Due to some variability around this timing in the actual data collected (ie, some missing data points and some data collected over shorter intervals), data were aggregated to reflect the average battery percentage per hour of each study day per participant. This resulted in a comparable number of data points per day across participants. The ALLFTD Mobile App also recorded information about participants' smartphone model, which was used to estimate the age of the smartphone (ie, calculated on the basis of the smartphone model release date and the first date of participation in this study).

Functional, Cognitive, and Neuropsychiatric Assessment

All participants underwent comprehensive functional and cognitive assessment at a parent study visit at the beginning of their smartphone monitoring study period. Informant and participant interviews were conducted to characterize the level of cognitive and everyday functioning impairment using the CDR+NACC FTLD scale [38], which is a validated, modified version of the CDR [39] that has higher sensitivity to functional impairment in FTLD. CDR+NACC FTLD global scores [40] were used to categorize participants into disease severity groups: 0=unimpaired, 0.5=prodromal, and ≥1=symptomatic. Domain-specific cognitive functioning was assessed via a comprehensive battery of well-validated neuropsychological tests. The previously published Uniform Data Set (Version 3) Executive Function composite score was used as our measure of executive functioning, comprising Trail Making Test A and B, phonemic fluency (generating words beginning with F and L), number span backwards, and category fluency (animals and vegetables) [41,42]. Sample-based *z* scores were calculated for indices of memory, including immediate and delayed free recall on the California Verbal Learning Test-3 Brief Form [43], as well as Benson Complex Figure Delayed Recall [44,45]. A composite memory *z* score was created by taking the mean of the *z* scores across these memory tests. Language functioning was assessed via the Multilingual Naming Test [46]. Visuospatial functioning was assessed via the Benson Complex Figure Copy [45]. Informants also completed the Neuropsychiatric Inventory [47] to assess the presence and severity of neuropsychiatric symptoms in participants.

Neuroimaging

Of the 231 participants, a subset (n=189, 81.8%) completed neuroimaging. Participants were scanned on 3 Tesla magnetic resonance imaging (MRI) scanners. T1-weighted images were acquired as magnetization-prepared rapid gradient echo images using the following parameters: 240×256×256 matrix; approximately 170 slices; voxel size=1.05×1.05×1.25 mm^3; and flip angle, echo time, and repetition time varied by vendor. A standard imaging protocol was used across all centers, and all images were reviewed for quality by a core group at the Mayo Clinic, Rochester, Minnesota, United States. Details of image acquisition, processing, and harmonization have been published elsewhere [48]. Total gray matter volume was used as the primary neuroimaging variable of interest. Total intracranial volumes were regressed out (using a simple linear regression with gray matter volume as outcome and total intracranial volume as the only predictor) before inclusion in analyses to account for interindividual volumetric differences in head size on gray matter volume.

Statistical Analyses

Differences in demographic and clinical characteristics across the CDR+NACC FTLD–defined disease severity groups were tested with 1-way ANOVA and chi-square tests for continuous variables and categorical variables, respectively. Raw battery percentage data were plotted against the time of day to inform statistical analysis. Linear mixed effects (LME) regression models were then used to model the linear, quadratic, and cubic effects of time (ie, hour of the day; 0=midnight; 23=11 PM) on battery percentage. Person-specific random intercepts and random effects of time (linear, quadratic, and cubic) were modeled. To determine whether daily patterns of battery percentage trajectories (ie, a proxy for smartphone use) varied as a function of FTLD disease severity, LME models examined linear, quadratic, and cubic effects of time and their interaction with each measure of disease severity separately (ie, CDR+NACC FTLD group, cognitive domain *z* scores, neuropsychiatric symptoms, and whole brain gray matter volumes). All LME models covaried for age, sex, smartphone type (iOS vs Android), and estimated smartphone age (calculated on the basis of the smartphone model release date and the first date of participation in this study). A post hoc sensitivity analysis was conducted in a subset of participants (162/231, 70.1%) whose age range was matched across the CDR+NACC FTLD groups. To understand whether subtle differences in neurobehavioral functioning related to daily smartphone battery use trajectories in an *unimpaired* sample, we conducted additional sensitivity analyses, which repeated all models in the subset of participants who were clinically normal (139/231, 60.2%). Regression estimates are reported as standardized betas, which represent the predicted change in the outcome as a function of each predictor in units of SDs. All analyses were performed using R (version 4.2.0; R Foundation for Statistical Computing). The *lme4* package was used to conduct the LME regressions [49].

Results

Participant Characteristics

Table 1 shows demographic and clinical characteristics by disease severity group. Participants had a mean age of 52.5 (SD 14.9) years and a mean of 16 (SD 2.2) years of education. Of the 231 participants, 94 (40.7%) were men, and 223 (96.5%) identified as non-Hispanic White. Nearly three-fourths of the participants (171/231, 74%) had results of genetic testing available, of whom 45% (77/171) had heterozygous pathogenic or likely pathogenic variants in an FTLD gene. Clinically normal participants were statistically significantly younger ($P<.001$) and more likely to be women ($P<.001$) than those with prodromal or symptomatic FTLD, consistent with the larger parent study samples (ALLFTD Mobile App study [30]; ALLFTD [40,50]). There were no other clear imbalances in other demographic and clinical characteristics across the 3 groups. Overall, participants had a mean of 28.3 (SD 4.19; range 14-30) days of smartphone monitoring data. On average, participants’ smartphones were 2.8 (SD 1.53; range 0-7) years old.

Table 1. Participant characteristics by disease severity group (n=231).

	A (clinically normal; n=139)	B (prodromal; n=49)	C (symptomatic; n=43)	*P* value	Pairwise comparisons[a]
Demographics					
Age (years), mean (SD)	46.3 (13.9)	59.7 (12.1)	64.3 (9.3)	<.001	A<B, C
Sex (male), n (%)	41 (29.5)	30 (61.2)	23 (53.5)	<.001	A<B, C
Education (years), mean (SD)	16.3 (2.1)	16.5 (2.4)	16.7 (2.4)	.61	N/A[b]
Race and ethnicity (non-Hispanic White), n (%)	134 (96.4)	48 (98)	41 (95.3)	.79	N/A
Study characteristics					N/A
Total study days, mean (SD)	28.3 (4.2)	28.1 (4.3)	28.6 (4.2)	.88	
Smartphone type, n (%)				.42	
iOS	97 (69.8)	37 (75.5)	27 (62.8)		
Android	42 (30.2)	12 (24.5)	16 (37.2)		
Estimated smartphone age (years), mean (SD)	2.7 (1.5)	3.0 (1.5)	2.9 (1.6)	.30	
Genetic status					
Genetic testing results, n (%)				.56	
Not available	34 (24)	13 (26.5)	13 (30.2)		
Available	105 (75.5)	36 (73.5)	30 (69.8)		
Mutation carrier	55 (52.4)	15 (41.7)	7 (23.3)		
C9orf72[c]	29 (52.7)	8 (53.3)	3 (42.9)		
GRN[d]	7 (12.7)	1 (6.7)	0 (0)		
MAPT[e]	16 (29.1)	6 (40)	3 (42.9)		
Other[f]	3 (5.5)	0 (0)	1 (14.3)		
Clinical phenotype				N/A	
Mild cognitive impairment[g]	N/A	39 (79.6)	N/A		
bvFTD[h]	N/A	N/A	25 (58.1)		
svPPA[i]	N/A	N/A	6 (14)		
nfvPPA[j]	N/A	N/A	3 (7)		
lvPPA[k]	N/A	N/A	1 (2.3)		
PSP-RS[l]	N/A	3 (6.1)	4 (9.3)		
CBS[m]	N/A	2 (4.1)	2 (4.7)		
Other[n]	N/A	5 (10.2)	2 (4.7)		

[a] Pairwise comparisons were evaluated with the Tukey honestly significant difference test.

[b] N/A: not applicable.

[c] C9orf72: chromosome 9 open reading frame 72.

[d] GRN: progranulin.

[e] MAPT: microtubule-associated protein tau.

[f] Identified pathogenic or likely pathogenic variants in genes less commonly identified as genetic causes of frontotemporal lobar degeneration (FTLD; ie, other than C9orf72, GRN, or MAPT). The specific genetic variant is not provided to protect participant anonymity.

[g] Includes behavior-, cognitive-, and language-predominant mild cognitive impairment syndromes.

[h] bvFTD: behavioral variant frontotemporal dementia.

[i] svPPA: semantic variant primary progressive aphasia.

[j] nfvPPA: nonfluent variant primary progressive aphasia.

[k] lvPPA: logopenic variant primary progressive aphasia.

[l] PSP-RS: progressive supranuclear palsy–Richardson syndrome.

[m] CBS: corticobasal syndrome.

[n] Includes FTLD-amyotrophic lateral sclerosis or a change in neurobehavior that may not meet full diagnostic criteria for any particular FTLD syndrome.

Daily Smartphone Battery Percentage

Visualization of the raw battery percentage data by the time of day (Figure 1) shows a nonlinear trajectory such that, on average, battery percentage increased from midnight to approximately 6 AM, then decreased until about 7 PM, and then increased again through 11 PM. These temporal patterns presumably represent typical patterns of charging and charge use of the smartphone throughout the day. Multimedia Appendix 1 presents raw battery percentage data by disease severity group. The shape of these raw data motivated consideration of a cubic model. Thus, we first tested the fit of the LME regression modeling the linear, quadratic, and cubic effects of the time of day on battery percentage, covarying for age, sex, smartphone type, and estimated smartphone age. The cubic model's conditional pseudo-R^2 (ie, the proportion of variance explained by both fixed and random factors) was 0.37. The likelihood ratio tests indicated that the full cubic model had statistically significantly better fit than LME regressions modeling only the linear (χ^2_2=4283.6; P<.001) and quadratic (χ^2_1=4118.8; P<.001) effects of time.

LME regression indicated that the interactions between disease severity group and the linear, quadratic, and cubic effects of the time of day were associated with battery percentage (Table 2). Visualization of model results suggests that participants with prodromal FTLD and those with symptomatic FTLD had *flatter* battery curves throughout the day (ie, shallower decreases from maximum to minimum battery percentage as well as a higher minimum battery percentage; a proxy for less smartphone use) than clinically normal participants on average (Figure 2). Examination of pairwise disease severity group contrasts showed that participants with symptomatic FTLD also had significantly less battery use than participants with prodromal FTLD (P=.003 or P<.001 in all cases).

Figure 1. Visualization of raw battery percentage data for all participants binned by time of day (0=midnight; 23=11 PM).

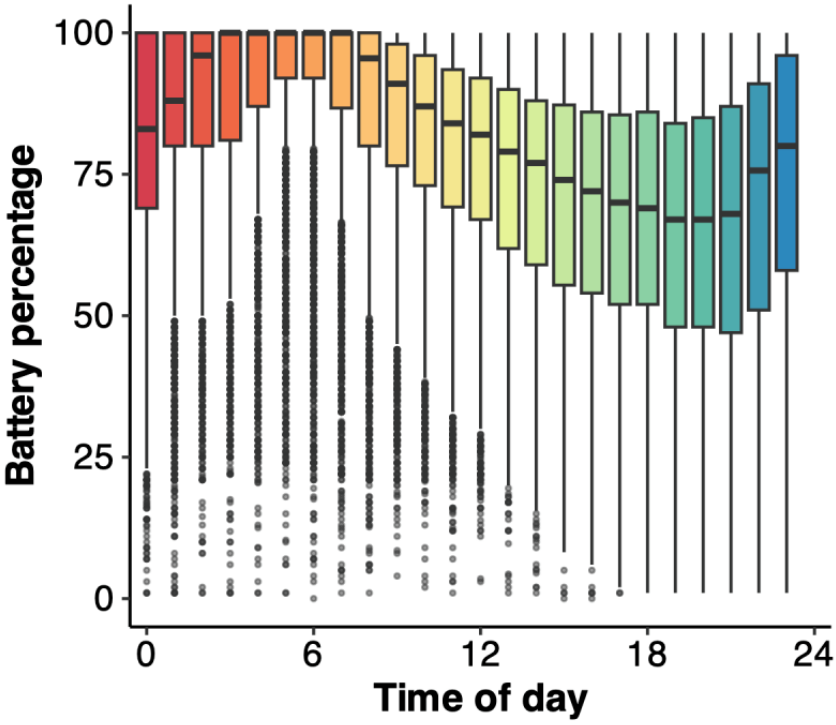
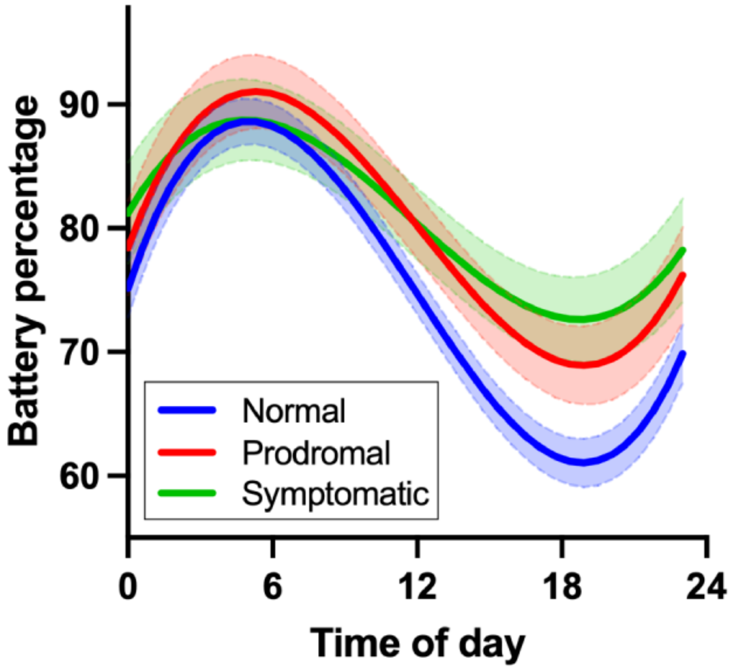


Table 2. Linear mixed effects regression results showing significant relationships between disease severity groups and battery percentage trajectories throughout the day.

	β (95% CI)	*P* value
Baseline age	.06 (.00 to .13)	.047
Sex (reference: female)	−.03 (−.14 to .08)	.62
Smartphone type (reference: Android)	.01 (−.11 to .12)	.89
Estimated smartphone age	−.04 (−.08 to −.01)	.03
Time of day (linear)	1.74 (1.66 to 1.83)	<.001
Time of day (quadratic)	−5.27 (−5.45 to −5.09)	<.001
Time of day (cubic)	3.28 (3.17 to 3.40)	<.001
Prodromal (reference: normal)	.24 (.10 to .39)	.001
Symptomatic (reference: normal)	.27 (.11 to .43)	.001
Time of day (linear)×prodromal	−.23 (−.40 to −.07)	.006
Time of day (linear)×symptomatic	−.56 (−.73 to −.38)	<.001
Time of day (quadratic)×prodromal	.88 (.53 to 1.24)	<.001
Time of day (quadratic)×symptomatic	1.65 (1.29 to 2.01)	<.001
Time of day (cubic)×prodromal	−.58 (−.81 to −.36)	<.001
Time of day (cubic)×symptomatic	−.99 (−1.22 to −.76)	<.001

Figure 2. Participants with prodromal frontotemporal lobar degeneration (FTLD) and those with symptomatic FTLD had flatter battery curves throughout the day (ie, a proxy for less smartphone use) than clinically normal participants on average. Error bands represent pointwise 95% CIs.



Similar patterns emerged when examining all other indices of clinical severity. Each cognitive domain statistically significantly moderated the relationship between the time of day and battery percentage such that participants with worse cognitive functioning had flatter battery curves throughout the day, suggesting less smartphone use (Table 3 [executive functioning, memory, language, and visuospatial skills]; Figures 3A-3D). Neuropsychiatric symptom severity also moderated the relationship between the time of day and battery percentage such that participants with higher neuropsychiatric symptom ratings had flatter battery curves throughout the day, suggesting less smartphone use (Table 3 [neuropsychiatric symptoms]; Figure 3E). Examination of each Neuropsychiatric Inventory item (*yes* or *no*) in separate LME models suggested that participants with agitation, depression, apathy, disinhibition, irritability, motor disturbance, nighttime behaviors, and changes in appetite had less smartphone use (Table 4). Delusions, hallucinations, anxiety, and elation did not statistically significantly relate to battery use trajectories throughout the day (Table 4). Finally, total gray matter volume also moderated the relationship between the time of day and battery percentage such that participants with smaller gray matter volumes had flatter battery curves throughout the day, suggesting less smartphone use (Table 3 [gray matter volume]; Figure 3F). Of all indices of clinical severity presented in Table 3, executive functioning and total gray matter volume appeared to have the largest effect sizes on smartphone battery trajectories.

Given the age difference across disease severity groups, we repeated the first LME model examining battery percentage trajectories by CDR+NACC FTLD group after restricting the age range of the clinically normal group to be identical to that of the group with prodromal FTLD and the group with symptomatic FTLD (participants aged 44-81 years in all groups; clinically normal: 70/139, 50.4%). The interactions between disease severity group and the linear, quadratic, and cubic effects of the time of day on battery percentage are fairly consistent, showing that the participants who were symptomatic had lower battery use than clinically normal participants (interaction with linear time: β=−.23, 95% CI −.40 to −.06; *P*=.009; interaction with quadratic time: β=.65, 95% CI .23 to 1.07; *P*=.003; interaction with cubic time: β=−.39, 95% CI −.66 to −.12; *P*=.004). However, the difference between the prodromal and clinically normal participants no longer reached statistical significance (interaction with linear time: β=−.05, 95% CI −.13 to .22; *P*=.586; interaction with quadratic time: β=−.07, 95% CI −.50 to .36; *P*=.76; interaction with cubic time: β=.05, 95% CI −.22 to .33; *P*=.70).

Table 3. Results of separate linear mixed effects regression models showing significant relationships between battery percentage trajectories throughout the day and executive functioning, memory, language, visuospatial skills, neuropsychiatric symptoms, and whole brain gray matter volume (lower order terms and covariates are not displayed).

	β (95% CI)	*P* value
Executive functioning		
Time of day (linear)×UDS3-EF[a] composite score	.24 (.17 to .31)	<.001
Time of day (quadratic)×UDS3-EF composite score	−.65 (−.80 to −.50)	<.001
Time of day (cubic)×UDS3-EF composite score	.38 (.28 to .47)	<.001
Memory		
Time of day (linear)×memory *z* score	.21 (.13 to .28)	<.001
Time of day (quadratic)×memory *z* score	−.58 (−.74 to −.42)	<.001
Time of day (cubic)×memory *z* score	.34 (.24 to .44)	<.001
Language		
Time of day (linear)×MINT[b]*z* score	.07 (.00 to .15)	.05
Time of day (quadratic)×MINT *z* score	−.24 (−.40 to −.08)	.002
Time of day (cubic)×MINT *z* score	.15 (.05 to .25)	.004
Visuospatial skills		
Time of day (linear)×Benson Complex Figure Copy *z* score	.10 (.04 to .16)	.001
Time of day (quadratic)×Benson Complex Figure Copy *z* score	−.28 (−.38 to −.19)	<.001
Time of day (cubic)×Benson Complex Figure Copy *z* score	.19 (.13 to .25)	<.001
Neuropsychiatric symptoms		
Time of day (linear)×NPI[c] total score	−.06 (−.13 to .01)	.08
Time of day (quadratic)×NPI total score	.25 (.10 to .39)	.001
Time of day (cubic)×NPI total score	−.15 (−.25 to −.05)	.002
Gray matter volume (n=189)		
Time of day (linear)×gray matter volume	.22 (.14 to .29)	<.001
Time of day (quadratic)×gray matter volume	−.73 (−.88 to −.57)	<.001
Time of day (cubic)×gray matter volume	.45 (.35 to .55)	<.001

[a] UDS3-EF: Uniform Data Set (Version 3) Executive Function.

[b] MINT: Multilingual Naming Test.

[c] NPI: Neuropsychiatric Inventory.

Figure 3. Daily battery percentage trajectories were significantly moderated by (A) executive functioning, (B) memory, (C) language, (D) visuospatial skills, (E) neuropsychiatric symptoms, and (F) total gray matter volumes. Participants with worse neurobehavioral outcomes had smaller daily decreases from peak to minimum battery percentage on average, suggesting less smartphone use throughout the day. GMV: gray matter volume; MINT: Multilingual Naming Test; NPI: Neuropsychiatric Inventory; TIV: total intracranial volume; UDS3-EF: Uniform Data Set (Version 3) Executive Function.

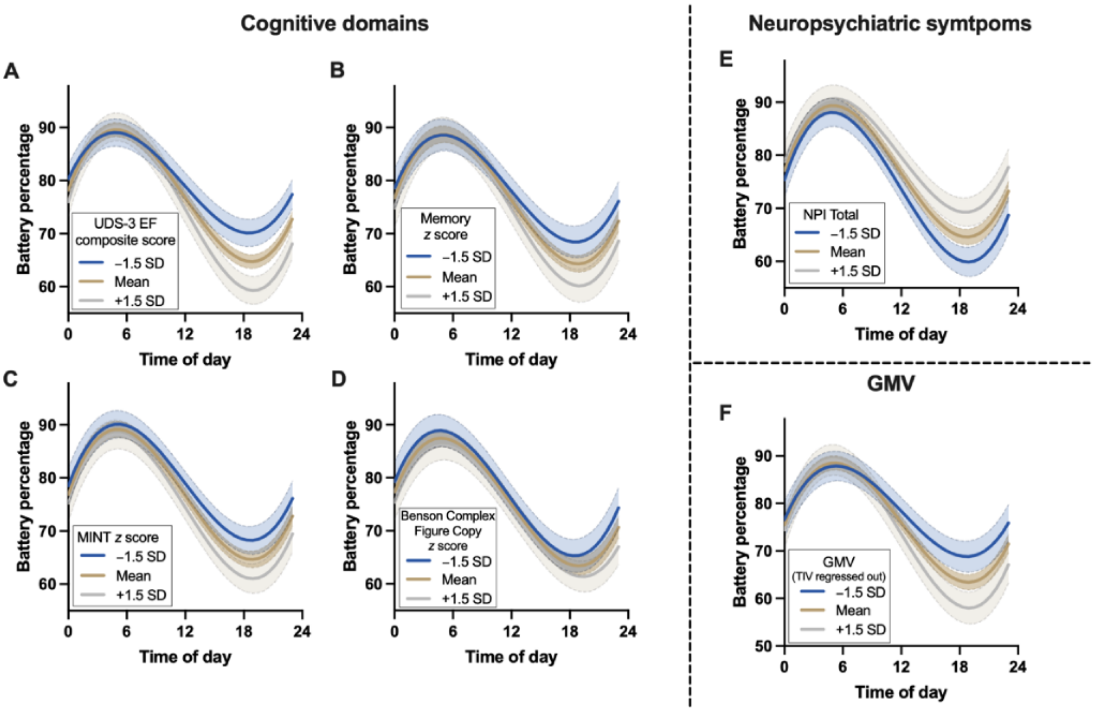


Table 4. Results of separate linear mixed effects regression models examining relationships between battery percentage trajectories throughout the day and each neuropsychiatric symptom (NPS) captured on the Neuropsychiatric Inventory. Models covaried for age, sex, smartphone type, and estimated smartphone age.

	Predictors modeling interactions with the time of day		
	NPS×time of day (linear), β (SE)	NPS×time of day (quadratic), β (SE)	NPS×time of day (cubic), β (SE)
Delusions	−.12 (.25)	−.25 (.53)	.43 (.34)
Hallucinations	−.61 (.40)	1.62 (.87)	−.78 (.55)
Agitation	−.36 (.10)[a]	1.06 (.20)[a]	−.65 (.13)[a]
Depression	−.34 (.08)[a]	.92 (.17)[a]	−.64 (.11)[a]
Anxiety	.05 (.08)	−.20 (.17)	.15 (.11)
Elation	.12 (.13)	−.38 (.26)	.29 (.17)
Apathy	−.43 (.08)[a]	1.32 (.17)[a]	−.81 (.11)[a]
Disinhibition	−.21 (.09)[a]	1.14 (.18)[a]	−.86 (.12)[a]
Irritability	−.20 (.07)[a]	.78 (.16)[a]	−.49 (.10)[a]
Motor disturbance	−.44 (.11)[a]	1.18 (.24)[a]	−.69 (.15)[a]
Nighttime behaviors	−.41 (.10)[a]	1.20 (.22)[a]	−.74 (.14)[a]
Changes in appetite	−.16 (.09)	.86 (.20)[a]	−.61 (.13)[a]

[a] *P* values met the threshold for significance.

Sensitivity analyses conducted among the 139 clinically normal participants showed that the following neurobehavioral measures were associated with daily battery percentage trajectories: executive functioning (interaction with linear time: β=.21, 95% CI .12 to .30; *P*<.001; interaction with quadratic time: β=−.57, 95% CI −.76 to −.38; *P*<.001; interaction with cubic time: β=.34, 95% CI .21 to .46; *P*<.001); memory (interaction with linear time: β=.33, 95% CI .24 to .42; *P*<.001; interaction with quadratic time: β=−.83, 95% CI −1.02 to −.63; *P*<.001; interaction with cubic time: β=.47, 95% CI .35 to .60; *P*<.001), and total gray matter volume (interaction with linear time: β=.32, 95% CI .22 to .41; *P*<.001; interaction with quadratic time:

β=−.84, 95% CI −1.03 to −.64; *P*<.001; interaction with cubic time: β=.48, 95% CI .36 to .61; *P*<.001). Language, visuospatial functioning, and neuropsychiatric symptoms did not strongly associate with daily battery percentage trajectories in clinically normal participants. The directions of associations in these clinically normal participants were consistent with relationships described in the entire sample.

Discussion

Principal Findings

This study is the first to our knowledge to examine passively collected smartphone use data in a sample with neurodegenerative disease. The results highlight an accessible, low-burden, and scalable remote monitoring method that captured behaviors associated with cognitive, neuropsychiatric, and brain health outcomes in a sample of participants with FTLD. The findings support a proof of concept that this passive digital monitoring approach, in combination with other methods, warrants further evaluation as a potential tool to augment screening and monitoring neurobehavioral change in clinical populations. Consistent with our hypotheses, we found that daily trajectories of smartphone battery use (a proxy for overall smartphone use) were associated with gold standard measures of clinical severity in FTLD such that those with more severe levels of impairment had less smartphone use throughout the day. Relationships between battery percentage trajectories and executive functioning, memory, and gray matter volume also held in the subset of clinically normal participants, suggesting potential sensitivity to subclinical neurobehavioral differences.

Comparison to Prior Work

These findings are consistent with previous studies showing that older adults with cognitive impairment have greater declines in everyday technology use compared to cognitively unimpaired older adults [18,51,52]. Other studies have shown that older adults with cognitive impairment report more difficulties using technology, representing a potential barrier to technology use [53,54]. Notably, the observed associations between battery percentage trajectories and cognitive functioning were not specific to particular cognitive domains, suggesting that the metrics of overall smartphone use may reflect a global transdiagnostic marker of functioning rather than a phenotype-specific marker (eg, executive functioning–predominant or language-predominant dysfunction). Thus, our findings may also not be specific to FTLD, and future work is needed to replicate findings in other populations with neurologic conditions. The use of a smartphone, like the use of a computer [18], is a cognitively complex task requiring the resources of many functions (eg, attention, executive function, working memory, and fine motor skill). As such, smartphone use patterns may be a particularly sensitive marker of early and subtle neurobehavioral change; however, additional research examining longitudinal changes in smartphone use over time is needed to support this hypothesis.

While this is the first study to our knowledge to report on passively collected smartphone use data in the context of neurodegenerative disease, there is a growing body of literature examining other passive streams of smartphone data as potential markers of neurobehavioral function in older adults; for example, passively collected data from smartphone accelerometers, GPS location, and touchscreen typing have been associated with symptom and disease severity in Parkinson disease, multiple sclerosis, and amyotrophic lateral sclerosis [55-64]. Future work should incorporate multiple passive smartphone data types for more comprehensive digital phenotyping and potentially improved clinical relevance in monitoring neurodegenerative disease.

Regarding the more technological aspects of passive smartphone data collection, previous studies have also reported similar variability around the frequency and timing of data collected per person. These studies have identified a number of factors that influence the collection and transfer of smartphone data to secure cloud-based servers, including smartphone hardware, data permissions, app engagement, wireless service, capacity of local data storage, data transmission limits, and even sociodemographic factors [65-67]. This has also been reported in other devices as well, including wearables [68-70]. Thus, thorough data cleaning is necessary to ensure that enough data points are captured to accurately represent activity for a given time period, as has been described previously [71,72].

Visualizing the raw battery percentage data was important for understanding daily patterns and supported the utility of daily smartphone battery percentage trajectories as a proxy for smartphone use. Average patterns in battery percentage appeared to track with typical diurnal sleep-wake rhythms: percentages increased up to morning (when mobile phones are likely charging) and decreased throughout the day (when participants were presumably awake and using their smartphones) until nighttime when percentages began to increase again. Careful examination of these raw data patterns, alongside measures of clinical severity, may support the development of specific metrics using battery percentage data that can be easily tracked over longer periods of time (eg, total battery drainage per day). Future work in this field should also consider examining the frequency and timing of smartphone battery charging as a way to track routine daily use patterns that may be clinically relevant. Tracking these metrics over many months or years would allow for future studies to examine person-specific changes in battery use over time and test longitudinal associations with neurodegenerative disease progression.

Strengths and Limitations

The strengths of this study include a large, extensively characterized cohort with FTLD; the reporting of novel smartphone use data; and the use of passive digital monitoring techniques. However, we also acknowledge several limitations. First, there are certainly caveats to our approach using battery percentage as a proxy for smartphone use, including factors that are difficult to quantify and adjust for, such as the impact of hardware, software, and service connection on battery life [73]. In addition, the ALLFTD Mobile App does not record when a smartphone may have been plugged in for charging, potentially preventing periods of battery decline even when the smartphone may have been in use. Even so, the robust relationships observed with gold standard measures of functional impairment, cognition, neuropsychiatric symptoms, and brain volumes are encouraging. Second, it is likely that the mobile cognitive testing sessions administered by the ALLFTD Mobile App contributed to some smartphone battery use and that battery use may subsequently be affected by adherence to the mobile cognitive testing protocol. However, we have previously reported on adherence to mobile cognitive testing through this app [30], which showed that cognitive testing completion rates among asymptomatic participants, participants with prodromal FTLD, and participants with symptomatic FTLD were 71.4%, 78.4%, and 59%, respectively. These adherence rates do not match the stairstep effect of battery use reported in this study whereby cognitively normal participants exhibited the highest smartphone battery use, participants with prodromal FTLD demonstrated intermediate smartphone battery use, and participants with symptomatic FTLD showed the lowest smartphone battery use, suggesting that our results are not simply driven by adherence to the mobile cognitive testing protocol. Third, although we importantly controlled for the effects of age, sex, smartphone type, and estimated smartphone age in our statistical analyses, further replication is needed in samples whose disease severity groups are demographically matched. Fourth, it is possible that a 30-day monitoring period may not be enough time to most accurately capture routine smartphone use behavior. Future studies are needed to evaluate the psychometrics of passive smartphone use metrics across different periods of time to identify optimal lengths of follow-up. Fifth, our sample was also limited in demographic diversity because participants mostly identified as non-Hispanic White and were highly educated, reflective of the cohort in the ALLFTD study [10]. This is a crucial consideration when examining new tools that require access to technology because the implementation of such digital tools may inadvertently increase disparities among those with fewer resources to obtain technology that meets required software specifications. However, with the steadily increasing rates of smartphone ownership worldwide in addition to the implementation of government-funded programs to provide access to technology (eg, the Lifeline Program or “Obama Phone” [74]), there is growing consensus that smartphone monitoring could become universally accessible.

Conclusions

In sum, our novel results demonstrate the feasibility of continuous, unobtrusive smartphone use monitoring, while also showing that smartphone use relates to the severity of neurobehavioral impairment in a sample with FTLD. We highlight these results as proof of concept because we believe that they support future research examining whether specific smartphone use metrics are clinically relevant and may have utility for monitoring clinical disease progression in FTLD and other neurodegenerative diseases. With continued validation, such passive monitoring methodologies for real-time, real-world, and remote monitoring have the potential to improve the monitoring of clinically meaningful neurobehavioral changes in individuals at risk for dementia.

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Conflicts of Interest

BA has received research funding from the National Institutes of Health (NIH), the Centers for Disease Control and Prevention, the CJD Foundation, Alector, and Ionis; consulting fees from Acadia, Ionis, Sangamo, Gate, and Merck; and royalties from Wolters Kluwer. GSD reports no conflicts of interest that are directly relevant to this work. His research is supported by the NIH (K23AG064029, U01AG057195, U01NS120901, and U19AG032438), the Alzheimer’s Association, and the Chan Zuckerberg Initiative. He serves as a consultant for Parabon Nanolabs Inc; as a topic editor (dementia) for DynaMed (EBSCO); and as the clinical director of the Anti-NMDA Receptor Encephalitis Foundation Inc, Canada (uncompensated). He is the co–project principal investigator for a clinical trial in anti–N-methyl-D-aspartate (NMDA) receptor encephalitis, which receives support from Horizon Pharmaceuticals. He has developed educational materials for PeerView, and Continuing Education Inc. He owns stock in ANI Pharmaceuticals. His institution has received support from Eli Lilly for development and participation in an educational event promoting early diagnosis of symptomatic Alzheimer disease and in-kind contributions of radiotracer precursors for tau–positron emission tomography (PET) neuroimaging in studies of memory and aging (via Avid Radiopharmaceuticals, a wholly owned subsidiary of Eli Lilly). NG has participated, or is currently participating, in clinical trials of antidementia drugs sponsored by Bristol Myers Squibb, Eli Lilly and Avid Radiopharmaceuticals, Janssen Immunotherapy, Novartis, Pfizer, and Wyeth, as well as the Study of Nasal Insulin to Fight Forgetfulness (SNIFF) and the Anti-Amyloid Treatment in Asymptomatic Alzheimer’s Disease (A4) trial. She receives research support from the Tau Consortium and the Association for Frontotemporal Dementia and is funded by the NIH. IL’s research is supported by the NIH (2R01AG038791-06A, U01NS100610, R25NS098999, U19 AG063911-1, and 1R21NS114764-01A1), the Michael J Fox Foundation, the Parkinson’s Foundation, the Lewy Body Dementia Association, CurePSP, Roche, Abbvie, Biogen, Centogene, EIP Pharma, Biohaven Pharmaceuticals, Novartis, United BioPharma, and UCB. She is a member of the scientific advisory board for Amydis but does not receive funds and from the Rossy Progressive Supranuclear Palsy Program at the University of Toronto. She receives her salary from the University of California San Diego and as chief editor of Frontiers in Neurology. JCR is the site principal investigator for clinical trials sponsored by Eli Lilly and Eisai. He receives consulting fees from Roon. LVV is the site principal investigator for clinical trials sponsored by Biogen and has consulted for Retrotope. All other authors declare no other conflicts of interest.

Multimedia Appendix 1

Visualization of raw battery percentage data binned by time of day (0=midnight; 23=11 PM) by disease severity group: (A) clinically normal, (B) prodromal frontotemporal lobar degeneration (FTLD), and (C) symptomatic FTLD.

[DOCX File , 137 KB - aging_v7i1e52831_app1.docx]

References

1. Knopman DS, Roberts RO. Estimating the number of persons with frontotemporal lobar degeneration in the US population. J Mol Neurosci 2011 Nov 17;45(3):330-335 [FREE Full text] [doi: 10.1007/s12031-011-9538-y] [Medline: 21584654]
2. Hendriks S, Peetoom K, Bakker C, van der Flier WM, Papma JM, Koopmans R, Young-Onset Dementia Epidemiology Study Group, et al. Global prevalence of young-onset dementia: a systematic review and meta-analysis. JAMA Neurol 2021 Sep 01;78(9):1080-1090 [FREE Full text] [doi: 10.1001/jamaneurol.2021.2161] [Medline: 34279544]
3. Perry D, Brown JA, Possin KL, Datta S, Trujillo A, Radke A, et al. Clinicopathological correlations in behavioural variant frontotemporal dementia. Brain 2017 Dec 01;140(12):3329-3345 [FREE Full text] [doi: 10.1093/brain/awx254] [Medline: 29053860]
4. Seo SW, Thibodeau MP, Perry DC, Hua A, Sidhu M, Sible I, et al. Early vs late age at onset frontotemporal dementia and frontotemporal lobar degeneration. Neurology 2018 Mar 20;90(12):e1047-e1056. [doi: 10.1212/wnl.0000000000005163]
5. Black CM, Fillit H, Xie L, Hu X, Kariburyo MF, Ambegaonkar BM, et al. Economic burden, mortality, and institutionalization in patients newly diagnosed with Alzheimer’s disease. J Alzheimers Dis 2017 Nov 28;61(1):185-193. [doi: 10.3233/jad-170518]
6. Rasmussen J, Langerman H. Alzheimer's disease - why we need early diagnosis. Degener Neurol Neuromuscul Dis 2019 Dec;9:123-130 [FREE Full text] [doi: 10.2147/DNND.S228939] [Medline: 31920420]
7. Wong W. Economic burden of Alzheimer disease and managed care considerations. Am J Manag Care 2020 Aug 17;26(8 Suppl):S177-S183 [FREE Full text] [doi: 10.37765/ajmc.2020.88482] [Medline: 32840331]
8. van Dyck CG, Swanson CJ, Aisen P, Bateman RJ, Chen C, Gee M, et al. Lecanemab in early Alzheimer's disease. N Engl J Med 2023 Jan 05;388(1):9-21. [doi: 10.1056/NEJMoa2212948] [Medline: 36449413]

9. A study of PBFT02 in patients with frontotemporal dementia and progranulin mutations (FTD-GRN) (upliFT-D). National Institutes of Health U.S. National Library of Medicine. 2021. URL: https://clinicaltrials.gov/ct2/show/NCT04747431 [accessed 2024-04-03]
10. Staffaroni AM, Quintana M, Wendelberger B, Heuer HW, Russell LL, Cobigo Y, et al. Temporal order of clinical and biomarker changes in familial frontotemporal dementia. Nat Med 2022 Oct;28(10):2194-2206 [FREE Full text] [doi: 10.1038/s41591-022-01942-9] [Medline: 36138153]
11. Valdez P, Ramírez, García A. Circadian rhythms in cognitive performance: implications for neuropsychological assessment. ChronoPhysiol Ther 2012 Dec;2:81-92. [doi: 10.2147/cpt.s32586]
12. McDermott LM, Ebmeier KP. A meta-analysis of depression severity and cognitive function. J Affect Disord 2009 Dec;119(1-3):1-8. [doi: 10.1016/j.jad.2009.04.022] [Medline: 19428120]
13. Framework for FDA's real-world evidence program. U.S. Food & Drug Administration. 2018 Dec. URL: https://www.fda.gov/media/120060/download [accessed 2024-04-03]
14. National plan to address Alzheimer's disease: 2022 update. U.S. Department of Health and Human Services. 2022 Dec 30. URL: https://aspe.hhs.gov/reports/national-plan-2022-update [accessed 2024-04-03]
15. Workshop on applying digital technology for early diagnosis and monitoring of Alzheimer's disease and related dementias. National Institutes of Health National Institute on Aging. URL: https://www.nia.nih.gov/research/dn/workshops/workshop-applying-digital-technology-early-diagnosis-and-monitoring [accessed 2024-04-03]
16. National advisory neurological disorders and stroke council. National Institutes of Neurological Disorders and Stroke. URL: https://www.ninds.nih.gov/about-ninds/who-we-are/national-advisory-neurological-disorders-and-stroke-council [accessed 2024-04-03]
17. Bernstein JP, Dorociak KE, Mattek N, Leese M, Beattie ZT, Kaye JA, et al. Passively-measured routine home computer activity and application use can detect mild cognitive impairment and correlate with important cognitive functions in older adulthood. J Alzheimers Dis 2021 Jun 01;81(3):1053-1064. [doi: 10.3233/jad-210049]
18. Kaye J, Mattek N, Dodge HH, Campbell I, Hayes T, Austin D, et al. Unobtrusive measurement of daily computer use to detect mild cognitive impairment. Alzheimers Dement 2014 Jan 20;10(1):10-17 [FREE Full text] [doi: 10.1016/j.jalz.2013.01.011] [Medline: 23688576]
19. Seelye A, Hagler S, Mattek N, Howieson DB, Wild K, Dodge HH, et al. Computer mouse movement patterns: a potential marker of mild cognitive impairment. Alzheimers Dement (Amst) 2015 Dec 01;1(4):472-480 [FREE Full text] [doi: 10.1016/j.dadm.2015.09.006] [Medline: 26878035]
20. Stringer G, Couth S, Heuvelman H, Bull C, Gledson A, Keane J, et al. Assessment of non-directed computer-use behaviours in the home can indicate early cognitive impairment: a proof of principle longitudinal study. Aging Ment Health 2023 Jan 30;27(1):193-202. [doi: 10.1080/13607863.2022.2036946] [Medline: 35352597]
21. Gledson A, Asfiandy D, Mellor J, Ba-Dhfari TO, Stringer G, Couth S, et al. Combining mouse and keyboard events with higher level desktop actions to detect mild cognitive impairment. In: Proceedings of the IEEE International Conference on Healthcare Informatics (ICHI). 2016 Presented at: ICHI 2016; October 4-7, 2016; Chicago, IL. [doi: 10.1109/ichi.2016.22]
22. Stringer G, Couth S, Brown LJ, Montaldi D, Gledson A, Mellor J, et al. Can you detect early dementia from an email? A proof of principle study of daily computer use to detect cognitive and functional decline. Int J Geriatr Psychiatry 2018 Jul 09;33(7):867-874 [FREE Full text] [doi: 10.1002/gps.4863] [Medline: 29424087]
23. Piau A, Wild K, Mattek N, Kaye J. Current state of digital biomarker technologies for real-life, home-based monitoring of cognitive function for mild cognitive impairment to mild Alzheimer disease and implications for clinical care: systematic review. J Med Internet Res 2019 Aug 30;21(8):e12785 [FREE Full text] [doi: 10.2196/12785] [Medline: 31471958]
24. Bayat S, Babulal GM, Schindler SE, Fagan AM, Morris JC, Mihailidis A, et al. GPS driving: a digital biomarker for preclinical Alzheimer disease. Alzheimers Res Ther 2021 Jun 14;13(1):115 [FREE Full text] [doi: 10.1186/s13195-021-00852-1] [Medline: 34127064]
25. Di X, Shi R, DiGuiseppi C, Eby DW, Hill LL, Mielenz TJ, et al. Using naturalistic driving data to predict mild cognitive impairment and dementia: preliminary findings from the longitudinal research on aging drivers (LongROAD) study. Geriatrics (Basel) 2021 Apr 23;6(2):45 [FREE Full text] [doi: 10.3390/geriatrics6020045] [Medline: 33922735]
26. Li H, Liu X, Mei Q. Predicting smartphone battery life based on comprehensive and real-time usage data. arXiv. Preprint posted online January 12, 2018 2024 [FREE Full text]
27. Gower AD, Moreno MA. A novel approach to evaluating mobile smartphone screen time for iPhones: feasibility and preliminary findings. JMIR Mhealth Uhealth 2018 Nov 19;6(11):e11012 [FREE Full text] [doi: 10.2196/11012] [Medline: 30455163]
28. Rahmati A, Tossell C, Shepard C, Kortum P, Zhong L. Exploring iPhone usage: the influence of socioeconomic differences on smartphone adoption, usage and usability. In: Proceedings of the 14th International Conference on Human-Computer Interaction with Mobile Devices and Services. 2012 Presented at: MobileHCI '12; September 21-24, 2012; San Francisco, CA. [doi: 10.1145/2371574.2371577]
29. Market share of mobile operating systems worldwide from 2009 to 2023, by quarter. Statista. URL: https://www.statista.com/statistics/272698/global-market-share-held-by-mobile-operating-systems-since-2009/ [accessed 2024-04-03]

30. Taylor JC, Heuer HW, Clark AL, Wise AB, Manoochehri M, Forsberg L, et al. Feasibility and acceptability of remote smartphone cognitive testing in frontotemporal dementia research. Alzheimers Dement (Amst) 2023 May 9;15(2):e12423 [FREE Full text] [doi: 10.1002/dad2.12423] [Medline: 37180971]
31. Bufano P, Laurino M, Said S, Tognetti A, Menicucci D. Digital phenotyping for monitoring mental disorders: systematic review. J Med Internet Res 2023 Dec 13;25:e46778 [FREE Full text] [doi: 10.2196/46778] [Medline: 38090800]
32. Rascovsky K, Hodges JR, Knopman D, Mendez MF, Kramer JH, Neuhaus J, et al. Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. Brain 2011 Sep;134(Pt 9):2456-2477 [FREE Full text] [doi: 10.1093/brain/awr179] [Medline: 21810890]
33. Gorno-Tempini ML, Hillis AE, Weintraub S, Kertesz A, Mendez M, Cappa SF, et al. Classification of primary progressive aphasia and its variants. Neurology 2011 Mar 15;76(11):1006-1014. [doi: 10.1212/wnl.0b013e31821103e6]
34. Höglinger GU, Respondek G, Stamelou M, Kurz C, Josephs KA, Lang AE, et al. Clinical diagnosis of progressive supranuclear palsy: the movement disorder society criteria. Mov Disord 2017 Jun;32(6):853-864 [FREE Full text] [doi: 10.1002/mds.26987] [Medline: 28467028]
35. Armstrong MJ, Litvan I, Lang AE, Bak TH, Bhatia KP, Borroni B, et al. Criteria for the diagnosis of corticobasal degeneration. Neurology 2013 Jan 29;80(5):496-503. [doi: 10.1212/wnl.0b013e31827f0fd1]
36. Ramos EM, Dokuru DR, Van Berlo V, Wojta K, Wang Q, Huang AY, ARTFL/LEFFTDS consortium, et al. Genetic screening of a large series of North American sporadic and familial frontotemporal dementia cases. Alzheimers Dement 2020 Jan;16(1):118-130 [FREE Full text] [doi: 10.1002/alz.12011] [Medline: 31914217]
37. Wakim NI, Braun TM, Kaye JA, Dodge HH, for ORCATECH. Choosing the right time granularity for analysis of digital biomarker trajectories. Alzheimers Dement (N Y) 2020 Dec 18;6(1):e12094 [FREE Full text] [doi: 10.1002/trc2.12094] [Medline: 33354618]
38. Knopman DS, Weintraub S, Pankratz VS. Language and behavior domains enhance the value of the clinical dementia rating scale. Alzheimers Dement 2011 May;7(3):293-299 [FREE Full text] [doi: 10.1016/j.jalz.2010.12.006] [Medline: 21575870]
39. Morris JC. Clinical dementia rating: a reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. Int Psychogeriatr 1997 Jan 10;9 Suppl 1(S1):173-6; discussion 177. [doi: 10.1017/s1041610297004870] [Medline: 9447441]
40. Miyagawa T, Brushaber D, Syrjanen J, Kremers W, Fields J, Forsberg LK, et al. Utility of the global CDR plus NACC FTLD rating and development of scoring rules: data from the ARTFL/LEFFTDS Consortium. Alzheimers Dement 2020 Jan;16(1):106-117 [FREE Full text] [doi: 10.1002/alz.12033] [Medline: 31914218]
41. Staffaroni AM, Asken BM, Casaletto KB, Fonseca C, You M, Rosen HJ, et al. Development and validation of the Uniform Data Set (v3.0) executive function composite score (UDS3-EF). Alzheimers Dement 2021 Apr 20;17(4):574-583 [FREE Full text] [doi: 10.1002/alz.12214] [Medline: 33215852]
42. Weintraub S, Besser L, Dodge HH, Teylan M, Ferris S, Goldstein FC, et al. Version 3 of the Alzheimer disease centers' neuropsychological test battery in the uniform data set (UDS). Alzheimer Dis Assoc Disord 2018;32(1):10-17 [FREE Full text] [doi: 10.1097/WAD.0000000000000223] [Medline: 29240561]
43. Delis DC, Kramer JH, Kaplan E, Ober BA. California Verbal Learning Test. San Antonio, TX: The Psychological Corporation; 1987.
44. Kramer JH, Jurik J, Sha SJ, Rankin KP, Rosen HJ, Johnson JK, et al. Distinctive neuropsychological patterns in frontotemporal dementia, semantic dementia, and Alzheimer disease. Cogn Behav Neurol 2003 Dec;16(4):211-218. [doi: 10.1097/00146965-200312000-00002] [Medline: 14665820]
45. Possin KL, Laluz VR, Alcantar OZ, Miller BL, Kramer JH. Distinct neuroanatomical substrates and cognitive mechanisms of figure copy performance in Alzheimer's disease and behavioral variant frontotemporal dementia. Neuropsychologia 2011 Jan;49(1):43-48 [FREE Full text] [doi: 10.1016/j.neuropsychologia.2010.10.026] [Medline: 21029744]
46. Gollan TH, Weissberger GH, Runnqvist E, Montoya RI, Cera CM. Self-ratings of spoken language dominance: a Multilingual Naming Test (MINT) and preliminary norms for young and aging Spanish–English bilinguals. Bilingualism 2011 Aug 01;15(3):594-615. [doi: 10.1017/s1366728911000332]
47. Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, et al. Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. J Neuropsychiatry Clin Neurosci 2000 May 1;12(2):233-239. [doi: 10.1176/appi.neuropsych.12.2.233]
48. Olney NT, Ong E, Goh SY, Bajorek L, Dever R, Staffaroni AM, et al. Clinical and volumetric changes with increasing functional impairment in familial frontotemporal lobar degeneration. Alzheimers Dement 2020 Jan;16(1):49-59 [FREE Full text] [doi: 10.1016/j.jalz.2019.08.196] [Medline: 31784375]
49. Bates D, Mächler M, Bolker B, Walker S. Fitting linear mixed-effects models using lme4. J Stat Softw 2015;67(1):1-48. [doi: 10.18637/jss.v067.i01]
50. Toller G, Cobigo Y, Callahan P, Appleby BS, Brushaber D, Domoto-Reilly K, et al. Multisite ALLFTD study modeling progressive empathy loss from the earliest stages of behavioral variant frontotemporal dementia. Alzheimers Dement 2023 Jul 02;19(7):2842-2852. [doi: 10.1002/alz.12898] [Medline: 36591730]

51. Hedman A, Nygård L, Almkvist O, Kottorp A. Patterns of functioning in older adults with mild cognitive impairment: a two-year study focusing on everyday technology use. Aging Ment Health 2013 Apr 03;17(6):679-688. [doi: 10.1080/13607863.2013.777396] [Medline: 23550598]
52. Hedman A, Nygård L, Almkvist O, Kottorp A. Amount and type of everyday technology use over time in older adults with cognitive impairment. Scand J Occup Ther 2015 May 12;22(3):196-206. [doi: 10.3109/11038128.2014.982172] [Medline: 25580938]
53. Ikeda Y, Maruta M, Shimokihara S, Nakamura A, Han G, Tabira T. Difficulties in the use of everyday technology among older adults with subjective memory complaint and cognitive decline. Gerontology 2022 Sep 2;68(6):655-663. [doi: 10.1159/000518390] [Medline: 34515123]
54. Malinowsky C, Almkvist O, Kottorp A, Nygård L. Ability to manage everyday technology: a comparison of persons with dementia or mild cognitive impairment and older adults without cognitive impairment. Disabil Rehabil Assist Technol 2010 Jun 15;5(6):462-469. [doi: 10.3109/17483107.2010.496098] [Medline: 20545577]
55. Chen MH, Leow A, Ross MK, DeLuca J, Chiaravalloti N, Costa SL, et al. Associations between smartphone keystroke dynamics and cognition in MS. Digit Health 2022 Dec 05;8:20552076221143234 [FREE Full text] [doi: 10.1177/20552076221143234] [Medline: 36506490]
56. Hoeijmakers A, Meijer KA, Alfonso N, McConchie H, Lam KH, Killestein J. Motor- and non-motor symptoms can be passively and remotely monitored in people with multiple sclerosis by measuring keyboard interactions on a smartphone (4142). Neurology 2021 Apr 13;96(15_supplement). [doi: 10.1212/wnl.96.15_supplement.4142]
57. Lam KH, Meijer KA, Loonstra FC, Coerver E, Twose J, Redeman E, et al. Real-world keystroke dynamics are a potentially valid biomarker for clinical disability in multiple sclerosis. Mult Scler 2021 Aug;27(9):1421-1431 [FREE Full text] [doi: 10.1177/1352458520968797] [Medline: 33150823]
58. Lam KH, Twose J, Lissenberg-Witte B, Licitra G, Meijer K, Uitdehaag B, et al. The use of smartphone keystroke dynamics to passively monitor upper limb and cognitive function in multiple sclerosis: longitudinal analysis. J Med Internet Res 2022 Nov 07;24(11):e37614 [FREE Full text] [doi: 10.2196/37614] [Medline: 36342763]
59. Arroyo-Gallego T, Ledesma-Carbayo MJ, Sanchez-Ferro A, Butterworth I, Mendoza CS, Matarazzo M, et al. Detection of motor impairment in Parkinson's disease via mobile touchscreen typing. IEEE Trans Biomed Eng 2017 Sep;64(9):1994-2002. [doi: 10.1109/tbme.2017.2664802]
60. Iakovakis D, Hadjidimitriou S, Charisis V, Bostantzopoulou S, Katsarou Z, Hadjileontiadis LJ. Touchscreen typing-pattern analysis for detecting fine motor skills decline in early-stage Parkinson's disease. Sci Rep 2018 May 16;8(1):7663 [FREE Full text] [doi: 10.1038/s41598-018-25999-0] [Medline: 29769594]
61. Lipsmeier F, Taylor KI, Postuma RB, Volkova-Volkmar E, Kilchenmann T, Mollenhauer B, et al. Reliability and validity of the Roche PD Mobile Application for remote monitoring of early Parkinson's disease. Sci Rep 2022 Jul 15;12(1):12081 [FREE Full text] [doi: 10.1038/s41598-022-15874-4] [Medline: 35840753]
62. Papadopoulos A, Iakovakis D, Klingelhoefer L, Bostantjopoulou S, Chaudhuri K, Kyritsis K, et al. Unobtrusive detection of Parkinson's disease from multi-modal and in-the-wild sensor data using deep learning techniques. Sci Rep 2020 Dec 07;10(1):21370 [FREE Full text] [doi: 10.1038/s41598-020-78418-8] [Medline: 33288807]
63. Johnson SA, Karas M, Burke KM, Straczkiewicz M, Scheier ZA, Clark AP, et al. Wearable device and smartphone data quantify ALS progression and may provide novel outcome measures. NPJ Digit Med 2023 Mar 06;6(1):34 [FREE Full text] [doi: 10.1038/s41746-023-00778-y] [Medline: 36879025]
64. Karas M, Olsen J, Straczkiewicz M, Johnson SA, Burke KM, Iwasaki S, et al. Tracking ALS disease progression using passively collected smartphone sensor data. SSRN. Preprint posted online August 3, 2023 2024. [doi: 10.2139/ssrn.4526533]
65. Kiang MV, Chen JT, Krieger N, Buckee CO, Alexander MJ, Baker JT, et al. Sociodemographic characteristics of missing data in digital phenotyping. Sci Rep 2021 Jul 29;11(1):15408 [FREE Full text] [doi: 10.1038/s41598-021-94516-7] [Medline: 34326370]
66. Currey D, Torous J. Increasing the value of digital phenotyping through reducing missingness: a retrospective review and analysis of prior studies. BMJ Ment Health 2023 Feb 17;26(1):e300718 [FREE Full text] [doi: 10.1136/bmjment-2023-300718] [Medline: 37197799]
67. Barnett I, Torous J, Reeder HT, Baker J, Onnela JP. Determining sample size and length of follow-up for smartphone-based digital phenotyping studies. J Am Med Inform Assoc 2020 Dec 09;27(12):1844-1849 [FREE Full text] [doi: 10.1093/jamia/ocaa201] [Medline: 33043370]
68. Paolillo EW, Lee SY, VandeBunte A, Djukic N, Fonseca C, Kramer JH, et al. Wearable use in an observational study among older adults: adherence, feasibility, and effects of clinicodemographic factors. Front Digit Health 2022 Jun 10;4:884208 [FREE Full text] [doi: 10.3389/fdgth.2022.884208] [Medline: 35754462]
69. Di J, Demanuele C, Kettermann A, Karahanoglu FI, Cappelleri JC, Potter A, et al. Considerations to address missing data when deriving clinical trial endpoints from digital health technologies. Contemp Clin Trials 2022 Feb;113:106661 [FREE Full text] [doi: 10.1016/j.cct.2021.106661] [Medline: 34954098]
70. Tackney MS, Cook DG, Stahl D, Ismail K, Williamson E, Carpenter J. A framework for handling missing accelerometer outcome data in trials. Trials 2021 Jun 05;22(1):379 [FREE Full text] [doi: 10.1186/s13063-021-05284-8] [Medline: 34090494]

71. Barnett I, Onnela JP. Inferring mobility measures from GPS traces with missing data. Biostatistics 2020 Apr 01;21(2):e98-112 [FREE Full text] [doi: 10.1093/biostatistics/kxy059] [Medline: 30371736]
72. Langener AM, Stulp G, Jacobson NC, Costanzo A, Jagesar RR, Kas MJ, et al. It's all about timing: exploring different temporal resolutions for analyzing digital-phenotyping data. Adv Method Pract Psychol Sci 2024 Jan 19;7(1). [doi: 10.1177/25152459231202677]
73. Pereira R, Matalonga H, Couto M, Castor F, Cabral B, Carvalho P, et al. GreenHub: a large-scale collaborative dataset to battery consumption analysis of android devices. Empir Softw Eng 2021 Mar 20;26:38. [doi: 10.1007/s10664-020-09925-5]
74. Ford GS. Subsidies and substitution: an empirical study of the lifeline program. Telecommun Policy 2021 Feb;45(1):102075. [doi: 10.1016/j.telpol.2020.102075]

Abbreviations

ALLFTD: Advancing Research and Treatment of Frontotemporal Lobar Degeneration (ARTFL study) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS study) Longitudinal Frontotemporal Lobar Degeneration
API: application programming interface
ARTFL: Advancing Research and Treatment of Frontotemporal Lobar Degeneration
C9orf72: chromosome 9 open reading frame 72
CDR+NACC FTLD: Clinical Dementia Rating Dementia Staging Instrument plus National Alzheimer's Coordinating Center Frontotemporal Lobar Degeneration Behavior and Language Domains
FTLD: frontotemporal lobar degeneration
GRN: progranulin
LEFFTDS: Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects
LME: linear mixed effects
MAPT: microtubule-associated protein tau
MRI: magnetic resonance imaging

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Original Paper

Optimizing Technology-Based Prompts for Supporting People Living With Dementia in Completing Activities of Daily Living at Home: Experimental Approach to Prompt Modality, Task Breakdown, and Attentional Support

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Abstract

Background: Assistive technology is becoming increasingly accessible and affordable for supporting people with dementia and their care partners living at home, with strong potential for technology-based prompting to assist with initiation and tracking of complex, multistep activities of daily living. However, there is limited direct comparison of different prompt features to guide optimal technology design.

Objective: Across 3 experiments, we investigated the features of tablet-based prompts that best support people with dementia to complete activities of daily living at home, measuring prompt effectiveness and gaining feedback from people with dementia and their care partners about their experiences.

Methods: Across experiments, we developed a specialized iPad app to enable data collection with people with dementia at home over an extended experimental period. In experiment 1, we varied the prompts in a 3 (visual type: text instruction, iconic image, and photographic image) × 3 (audio type: no sound, symbolic sound, and verbal instruction) experimental design using repeated measures across multiple testing sessions involving single-step activities. In experiment 2, we tested the most effective prompt breakdown for complex multistep tasks comparing 3 conditions (1-prompt, 3-prompt, and 7-prompt conditions). In experiment 3, we compared initiation and maintenance alerts that involved either an auditory tone or an auditory tone combined with a verbal instruction. Throughout, we asked people with dementia and their care partners to reflect on the usefulness of prompting technology in their everyday lives and what could be developed to better meet their needs.

Results: First, our results showed that audible verbal instructions were more useful for task completion than either tone-based or visual prompts. Second, a more granular breakdown of tasks was generally more useful and increased independent use, but this varied across individuals. Third, while a voice or text maintenance alert enabled people with dementia to persist with a multistep task for longer when it was more frequent, task initiation still frequently required support from a care partner.

Conclusions: These findings can help inform developers of assistive technology about the design features that promote the usefulness of home prompting systems for people with dementia as well as the preferences and insights of people with dementia and their care partners regarding assistive technology design.

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KEYWORDS

assistive technology; accessible technology; accessibility technology; assistive technologies; accessible technologies; assistive device; assistive devices; dementia; people living with dementia; dementia care; person-centered technology; patient-centered technology; person-centered technologies; patient-centered technologies; memory support; prompting; user-computer interface; user interface; UI; app; apps; digital health; digital technology; digital intervention; digital interventions; mobile phone

Introduction

Background

Dementia is a progressive neurological condition that results in a range of cognitive and motor impairments that can have an impact on an individual's well-being and capacity to live independently. These impacts include difficulties with orientation in time and space; noticing body signals such as hunger, thirst, or temperature; initiating activities; and keeping track of a sequence of tasks [1]. Assistive technology that provides prompts for activities of daily living (ADLs) is a form of environmental support that can help people living with dementia by reducing the impact of their cognitive impairment and enabling active living and independence [2]. In daily practical terms, a prompting device could be an effective way to support people with dementia to first notice that an ADL needs to be done; then initiate the ADL; and, finally, undertake each step of the ADL in the necessary sequence to see it through to completion. In this way, assistive technology has strong potential to support people with dementia compensate for their cognitive disability. However, the cognitive, sensory, and motor changes associated with aging and dementia may have an impact on design features of technology interfaces that are useful for this user group [3]. So far, little research has directly compared the outcomes of different types of prompts (eg, visual vs auditory) to test what is most useful for people with dementia. Across 3 experiments, we addressed this gap, with the aim of informing general assistive technology design for people with dementia.

ADLs are functional, multistep, complex tasks related to self-care, domestic duties, socialization, and leisure. Difficulties with completing ADLs can arise for a range of reasons, and these difficulties have a substantial impact on quality of life for people with dementia. People with dementia often experience reduced ability to initiate activities as well as executive functioning changes that make accurate tracking of multistep activities challenging [4,5]. These difficulties with ADLs increase dependence on others for support [6] and are a common reason for moving to residential care [7]. Supporting people with dementia to both initiate activities and accurately and independently complete the steps involved in daily tasks has the potential to improve well-being for both people with dementia and their family care partners [6,8]. Therefore, cognitive rehabilitation approaches emphasize the potential for the right support tools and strategies to enable successful ADL completion and support people with dementia in living independently for longer [9].

Assistive technology has increasingly received attention for its potential to reduce the impact of cognitive impairments on an individual's day-to-day functioning [10]. However, existing research on prompting technology for people with dementia has adopted a wide range of approaches, which makes drawing general conclusions and developing recommendations challenging. Technology solutions vary in several ways, including what kinds of tasks they aim to support, what kind of device they adopt, prompt features, and the amount of user involvement required. Typically, a single version of the prompting system is developed and then user tested, often involving small feasibility trials [11]. Studies that directly compare design features in terms of their outcomes for people with dementia are scarce [11]. More broadly, technological research and development at the cutting edge of innovation has to date been unable to generate solutions that are readily available on the market. One reason is that people with dementia and family care partners experience barriers and challenges in incorporating assistive technology into daily care practice, contributing to the low uptake of existing devices [12-14]. Therefore, experimental work and an evidence base with end users is required to inform general technology design for people with dementia to ensure that assistive technology solutions go beyond research studies and become part of everyday life [15,16].

Device Types and User Involvement

A recent review identified 30 published studies of prompting systems to support people with a cognitive impairment in completing ADLs [11]. The authors classified 6 broad types of devices, with varying hardware approaches and corresponding variance in the extent to which users were involved in mediating prompt delivery. Technology solutions ranged from fully autonomous sensor-based home systems designed to detect completed steps in a sequence and provide prompts when needed to social robots and prompts delivered in readily available consumer devices such as tablets and smartphones. Systems that are autonomous, without user input, typically use sensors and smart technology to monitor a person's activity and detect where they are up to in a sequence of steps [17] to determine when a prompt may need to be given. Examples of these systems tend to focus on supporting a specific ADL for which the system is designed and trained, such as the Cognitive Orthosis for Assisting Activities in the Home (COACH) system for handwashing [18]. Alternative approaches involve input from either people with dementia or care partners to determine when tasks are initiated and when prompts are delivered. Examples of these include app-based prompting software where the user themselves selects *next* to move through steps and receive the next prompt in a sequence [19], although these solutions may not align with people with dementia's need for support with activity initiation. Interestingly, in a recent version of the COACH handwashing system [20], researchers reported that voice-based interaction with the system was much more effective for users with dementia than the previous iterations that had used a camera to detect step completion, indicating that a human-in-the-loop system may be more effective than a fully automated one. Across these varying device types and technologies—from apps to sensors to social robots—the features of effective prompts have not yet been taxonomized. We aimed to test general principles about the optimal design features of effective prompts for people with dementia in ways that could be applied to these widely ranging device types, technologies, and intended tasks.

Optimizing Prompt Design: Modality, Timing, and Breakdown

Existing research provides a limited evidence base on how to optimize prompts for people with dementia in terms of features such as modality, timing, and task breakdown. Prompting technologies in the published literature have adopted a range of modalities for prompt delivery, including a visual (eg, image- or video-based instruction) or auditory (eg, verbal instruction [21]) element or a combination of both [22,23]. Prompt modality has been frequently determined by device design, although some researchers have provided the individual user with a choice [12,24]. In the subset of studies in which outcomes have been measured and reported, studies that have compared a *prompting* to a *no prompting* condition generally have demonstrated some advantage to using prompts [11]. For example, a recent experimental study tested a smartphone app that prompted water drinking and found significantly better performance in the prompted than in the unprompted condition [25]. Reviews have identified benefits of step-based prompting in other populations (eg, those with an intellectual disability [26]). The social robot Tessa has been used to provide people with dementia with support to complete a predetermined ADL goal [27]. The eWare system integrates the social robot Tessa with sensor monitoring technology (eg, door contact sensors) with the aim of using the sensor data to generate verbal reminders and motivating comments for people with dementia. A small pilot study of 9 dyads who were monitored over 6 months [28] found promising results of this system but with limited benefits for carer burden and the need for further research identified.

Despite promising evidence that technology-based prompting can support ADL completion for people with dementia, few studies have directly compared different prompt modalities, timings, and task breakdown options to determine which design features are the most useful and direct future technology development. In one exception, a study directly comparing prompt features found that text-based and verbal prompts were more effective than image-based prompts for a card-and-envelope task but not for putting on a CD to play music [19]. The authors concluded that the most effective prompt modality may depend on aspects of the task, including complexity and familiarity (see also the study by Braley et al [22]). In a qualitative study with the social robot Tessa, people with a cognitive disability and their carers preferred prompts with an auditory element compared to visual-only prompts [29]. Conversely, other research has suggested no advantage in adding verbal instructions to visual (pictorial or video) prompts, albeit with small sample sizes [30,31]. Overall, although there is some evidence that the presence of prompts is better than no prompts, there are limited data to guide choices about optimal prompt design, including prompt modality, task breakdown, and timing.

Task Types and Task Breakdown

Within the literature, a number of prompting systems have been developed that are specialized to support 1 key activity of ranging complexity, including washing hands [32,33], putting on prosthetic limbs [34], making pizza [35], morning routine [36], and cooking tasks [37]. Some prompting systems could theoretically be applied to any task but were tested with a small range of predetermined tasks for the purposes of evaluation [23,25,30,31]. Other devices have focused on a generic interface that can support any kind of user-chosen task. For instance, research that examined a personalized tablet-based prompter found that people with dementia and their care partners could select and load their own tasks and steps based on their own goals [24]. Tasks chosen by users included using the television or a camera, remembering to take required objects when leaving the house, and basic ADLs such as table setting or making a sandwich [24]. In our own research conducting detailed interviews with people with dementia and their care partners, we identified a great deal of individual variation in what tasks were valued by individuals as well as idiosyncratic reasons for task incompletion and which steps within tasks needed more support [38]. Despite the technological challenges of an open-ended system in which people can choose their own tasks and prompts, this personalized approach appears to more closely match the needs of users within their everyday context.

This Research

A number of recent studies of home prompting systems for people with dementia have focused on implementing prompts via mainstream, tablet-based devices. Research indicates good potential for the usability of these systems such that people with dementia and their care partners can interact with a touch-screen tablet by, for example, advancing to the next step in a sequence via pressing an on-screen button [19]. However, a recent review concluded that general conclusions could not be drawn about the effectiveness of prompting technology for people with dementia because many studies were very small and did not have an experimental design with comparisons and control groups [11].

To address this gap, we conducted a series of 3 iterative studies aiming to advance assistive technology design by examining the potential of prompts to support people with dementia with 2 key aspects of ADL completion. First, people with dementia often experience loss of initiative and could benefit from technology that activates them to commence a task through effective reminders. Second, people with dementia experience difficulties with executive functioning, making multistep activities more difficult to perform and keep track of, so that complex tasks may need multiple prompts provided in a sequence to be completed successfully. The 3 studies integrated experimental design and both quantitative and qualitative methods and examined prompt modality (experiment 1), task breakdown (experiment 2), task initiation (experiment 3), and attention maintenance (experiment 3). At the conclusion of each study, we gained detailed user experiences and feedback to contextualize our findings and provide user recommendations for future technology development.

Ethical Considerations

All studies were conducted with approval from the Western Sydney University Human Research Ethics Committee (reference H14632). All participants provided extended consent for both primary data collection and secondary analyses of the research data. Additional proxy consent was obtained from family members in situations in which participants with dementia—through cognitive screening or specialist advice—were assessed to have reduced capacity to provide informed consent depending on their degree of cognitive impairment. In all three experiments, both participants with dementia and care partners were reimbursed (Aus $50 [US $33.74] per hour e-gift card) in recognition of their time and specialist expertise due to their lived experience of dementia. All methods were carried out in accordance with relevant guidelines and regulations. Data were deidentified for analyses and stored securely on Western Sydney University infrastructure.

Experiment 1

Methods

Participants

Participants were 11 people with dementia, 10 (91%) of whom were supported by a care partner to complete the research. Participants with dementia (n=5, 45% female; n=6, 55% male) ranged in age from 58 to 82 years, with an average age of 73 (SD 7.20) years. Participants who were care partners (10 female) ranged in age from 34 to 77 years, with an average age of 58 (SD 13.59) years. A total of 55% (6/11) of the participants with dementia spoke English as a first language, and 45% (5/11) spoke a language other than English. Participants with dementia had been diagnosed between 9 months and 9 years before the study, with an average of 3.5 years. The relationship of care partners to the participants with dementia included 50% (5/10) spouses, 40% (4/10) adult children, and 10% (1/10) siblings. Participants were recruited through care partner support groups, Dementia Australia, and the StepUp for Dementia Research participant database [39]. We did not formally record additional medical information regarding comorbidities beyond the participants' dementia diagnosis, but participants were required to have sufficient visual and hearing ability to be able to see and hear the iPad prompts as part of our inclusion criteria.

Design and Materials

Software for Prompt Delivery

We developed a method for remote data collection to accommodate restrictions on face-to-face research associated with the COVID-19 pandemic. A dedicated iPad app was developed to enable data collection in participants' homes. An iPad was issued to each participant, with reliance on collaboration between researchers and care partners who facilitated data collection with participants with dementia. Using the iPad app, we established 9 conditions to test what visual and auditory features would make prompts most useful. We varied prompts in a 3 (visual content: text instruction, iconic image, and photographic image)×3 (audio content: no sound, symbolic sound, and verbal instruction) experimental design. We also included 5 different tasks developed to sample a range of daily activities that a seated participant could complete with a single action (ie, not involving moving around the home). These tasks were (1) *drink some water*, (2) *brush your teeth*, (3) *wear a mask*, (4) *put on something warm*, and (5) *turn on the television*. The 5 different tasks were completed in each of the 9 conditions, resulting in 45 trials for each participant.

Visual Prompt Content

For the visual prompts, photo images representing each task were sourced from Unsplash (Getty Images [40]), and icon images representing each task were sourced from Flat Icon (Freepik Company SL; Figure 1).

Figure 1. Example item—the icon image for "Wear a mask.".

Auditory Prompt Content

For the auditory content, symbolic sounds were developed and recorded by the research team. Verbal instructions were recorded in an Australian-accented female voice as high quality, clearly presented audio clips.

Pilot-Testing

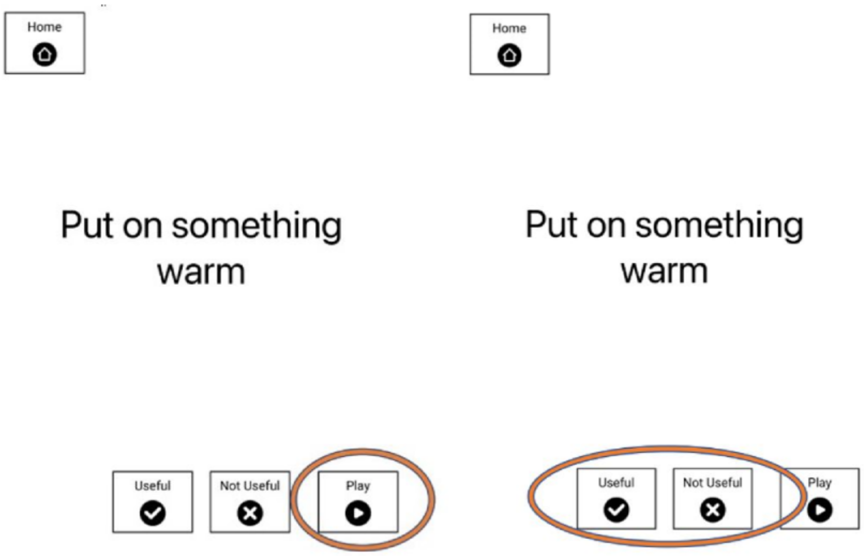
The associations among the images, sounds, and the target tasks were pilot-tested by conducting a survey of 55 Australian older adults (aged ≥65 years). We used the responses of these participants to refine our final stimuli selection by presenting a variety of stimuli and selecting the images and sounds rated as having the strongest association with the target task.

Measures and Scoring

Prompt Usefulness

Our key dependent variable was prompt usefulness. For each prompt, immediately following its presentation, care partners rated whether it was *useful* or *not useful* by selecting the appropriate button on the iPad (Figure 2). For a scoring of useful carers were instructed that this should be selected if the participant with dementia completed or approximated the target task (ie, initiated the task by selecting the correct target item from the table and then followed through by completing the prompted action with it). When tasks were not completed or the prompt could not be understood by the participant with dementia, carers were instructed to rate the prompt as not useful (Figure 2).

Figure 2. An example item for “Put on something warm” in the text and verbal instruction condition. The prompt screen included the option to press “play” to repeat the auditory content (either symbolic sound or verbal instruction). Carers rated the usefulness of each prompt by pressing the appropriate button.


Put on something warm

Put on something warm

Time to Respond

The time between prompt onset and the care partner indicating whether it was useful or not useful was recorded automatically via the iPad app. Response times were then compared across prompt conditions.

Care Partner Support

To understand the extent to which care partners were involved in supporting the participant with dementia in engaging with the prompts and completing tasks, the iPad app captured audio and video during each trial using the in-built camera. Independent coders scored the videos for verbal assistance from care partners at 3 time points (using the iPad, engaging with the objects on the table, and performing the action) and across 2 levels of assistance (*asking for attention* or *direct telling*). All videos were scored for the presence of support in the resulting 6 categories by 2 raters who were blind to the prompting condition. Agreement between raters was substantial (84.92%), and the ratings of the first rater were retained for analysis.

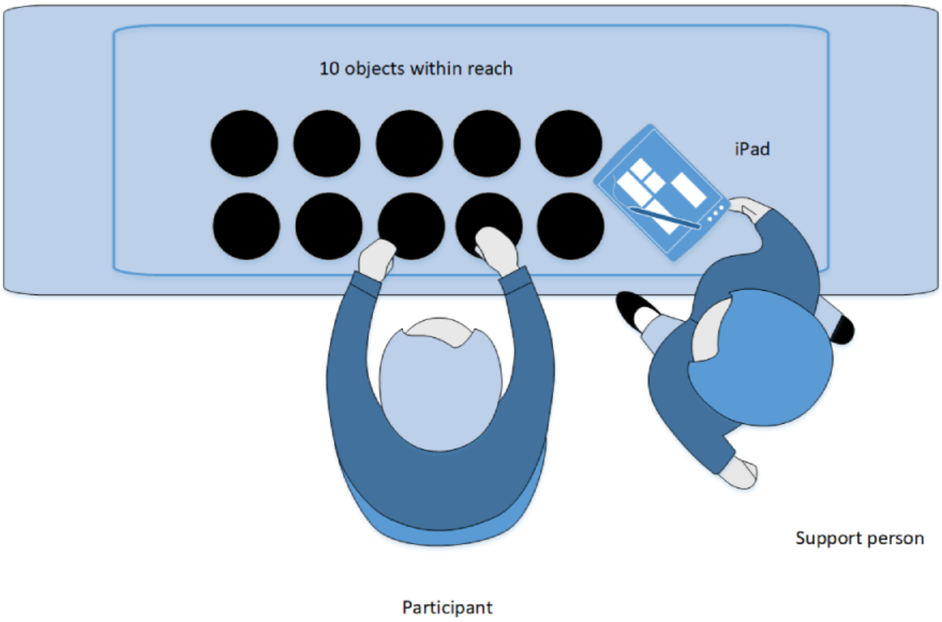
Procedure

Baseline

During an initial video call, participants were oriented as to the project. They provided informed consent and proxy consent where appropriate. If participants with dementia had not had a recent cognitive assessment with their health care provider, a Mini-Mental State Examination (MMSE) [41] was conducted to assess the cognitive status of participants with dementia and determine the consent pathway. Participants provided demographics, including age, gender, and cultural and language background, and information about their dementia diagnosis, including when it was received, by whom, and what type of dementia they were diagnosed with (if known).

Participants were given a detailed printed manual as well as verbal phone instructions about how to set up and conduct the tasks. Care partners were instructed that participants with dementia should sit comfortably at a table with 10 preselected objects in front of them within easy reach. Objects included 5 target objects (a glass of water, toothbrush, mask, an item of warm clothing like a scarf or woolen hat, and a television remote control) and 5 distractor objects (other familiar objects from around the home). The iPad was placed to the side of the participant with dementia to enable them to see and interact with it while being able to reach the objects on the table (Figure 3).

Figure 3. A visual representation of the at-home setup provided within the care partner manual, including positioning of the objects and iPad.



Experimental Phase

On each research participation day, care partners supported participants with dementia to work through a set of 5 prompts for the 5 target tasks. Each of the 5 task types appeared once each day in a different condition, with the condition associated with each task varying in a fixed random order. Across the whole experiment, each of the 5 tasks appeared in each of the 9 conditions, and conditions were spread across the 45 trials (Table 1). For each prompt, participants with dementia were to respond by selecting the appropriate object from in front of them and completing the task. There was a button labelled *play* that enabled care partners and participants with dementia to replay the symbolic sound or verbal instruction if they wished to have it repeated (Figure 2). Care partners were asked to allow participants with dementia to respond to the prompt themselves without assistance. For each prompt, care partners rated whether it was useful (the participant with dementia completed or approximated the task) or not useful (the participant with dementia did not complete the task) by selecting the appropriate button on the iPad (Figure 2). Once rated, the next task was presented on the iPad until the 5 tasks for that day were completed. This procedure was repeated over 9 separate sessions (typically one session each day for consecutive days) until all 45 trials were completed. The iPad automatically captured video and audio during the experimental sessions while the prompts were on the screen using the front-facing iPad camera. In the case of partial completion of the 5 tasks on a particular day, participants and care partners continued the tasks at their next session.

Table 1. The 9 experimental conditions for each of the 5 activity of daily living tasks[a].

Audio condition	Visual condition		
	Text instruction	Iconic image	Photographic image
No sound	Tasks 1-5	Tasks 1-5	Tasks 1-5
Symbolic sound	Tasks 1-5	Tasks 1-5	Tasks 1-5
Verbal instruction	Tasks 1-5	Tasks 1-5	Tasks 1-5

[a] Task 1: “Have a drink of water”; task 2: “Brush your teeth”; task 3: “Wear a mask”; task 4: “Put on something warm”; task 5: “Turn on the television.”

Experience and Feedback Interview

After completion of the 9-day experimental phase, a semistructured interview was conducted with both the participant with dementia and the care partner together. Questions included the following: “How did you and the person you care for engage with the system? What worked and what didn’t work?”; “What did you think of the images, sounds, and text?”; and “What would you use a system like this for in your daily life?” The interviews were approximately 15 to 20 minutes in duration. Due to restrictions on face-to-face interactions with participants, all interviews were conducted via web-based videoconference and recorded for transcription and analysis. The transcripts were checked and edited for accuracy. Transcripts were stored and analyzed by the research team in the NVivo qualitative analysis software (QSR International) using a coding rubric as a guide to code. A thematic approach was taken to identify, analyze, and interpret patterns of meaning [42].

Results

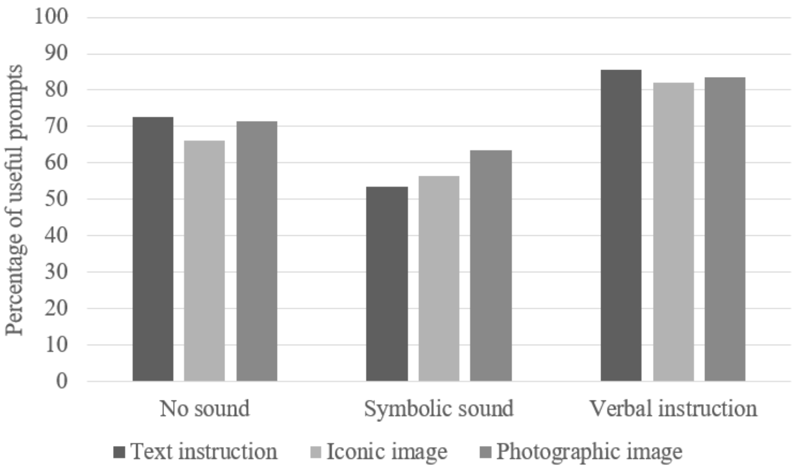
Prompt Usefulness

To determine what kinds of prompts were most useful, we first examined the frequency with which care partners responded *useful* versus *not useful* for each task type. A chi-square analysis indicated that prompt usefulness was significantly different across task types (χ^2_4=35.3; *P*<.001), with "drink some water" (79/100 trials, 79%), "brush your teeth" (80/100 trials, 80%), and "put on a mask" (82/100 trials, 82%) being more successful than "turn on the TV" (53/100 trials, 53%) and "put on something warm" (59/100 trials, 59%). These differences in usefulness may be due to the direct correspondence between the stimuli and the item in front of the participants with dementia that they were to select. For example, compared with the other target objects (glass, toothbrush, and mask), the link between the target objects for "turn on the TV" (television remote control) and "put on something warm" (item of clothing) was more abstract, without a direct correspondence between the visual prompt (eg, a television) and the item on the table (eg, the television remote control).

Participants varied in their stage of dementia and degree of cognitive impairment. Therefore, we examined any differences in prompt usefulness depending on dementia severity, which was self-reported by care partners as mild, mild to moderate, moderate, or severe. Self-reporting was also corroborated, where possible, through administration of the MMSE [41]. Data indicated a difference in prompt usefulness depending on the participants' dementia severity (χ^2_3=61.9; *P*<.001). Frequencies of prompts being rated as useful were comparable for participants who had mild (67/90 trials, 74%), mild to moderate (73/90 trials, 81%), and moderate (180/230 trials, 78.3%) dementia symptoms, and these participants found more of the prompts useful than did participants with severe dementia (33/90 trials, 37%).

Most importantly for our research questions, we examined what combinations of visual and verbal stimuli were the most effective in yielding useful prompts. Across tasks, the type of visual content made little difference to prompt usefulness. The most important prompt feature that impacted usefulness was the presence of the verbal instruction (compared to a symbolic sound or no sound). A chi-square analysis confirmed that the spoken verbal instruction was more useful than the other auditory conditions of a symbolic sound or no sound (χ^2_2=27.2; *P*<.001), whereas the different visual conditions (text instruction, iconic image, and photographic image) did not make a significant difference regarding prompt usefulness (χ^2_2=0.9; *P*=.65; Figure 4).

Figure 4. Percentage of useful prompts by prompt visual and auditory content.



Prompt Success Across Time

We examined whether there was a difference in prompt success across trials to see whether useful prompts were more frequent on later trials (indicating learning) or early trials (indicating fatigue). To achieve this, we compared the average day number (1-9) and the average trial number (1-45) for useful versus not useful prompts. This analysis indicated no significant difference in average day or task number of useful versus not useful prompts (t_{498}=0.85 and *P*=.20 vs t_{498}=0.93 and *P*=.18, respectively). This suggests no evidence that people found the prompts more or less useful with practice and experience.

Combining All Predictors

Given that there was wide variation in the usefulness ratings across participants and that participants contributed multiple trials to the data set, we followed up these trial-based analyses with a stepwise (forward, likelihood ratio) logistic regression, with predictors added in order of participant, degree of dementia, task content, day number (1-9), trial number (1-45), auditory condition, and visual condition. Usefulness on each trial was the binary dependent variable. This analysis yielded a model with 4 significant predictors, confirming a significant effect of auditory condition (*B*=0.37; *P*=.004) over and above the significant contributions of participant (*B*=0.068; *P*<.001), dementia severity (*B*=−0.55; *P*<.001), and task content (*B*=0.21; *P*=.006). There was no significant contribution of visual condition (*B*=.26; *P*=.61). Overall, auditory prompt content predicted prompt usefulness over and above participant variance, but visual prompt content did not.

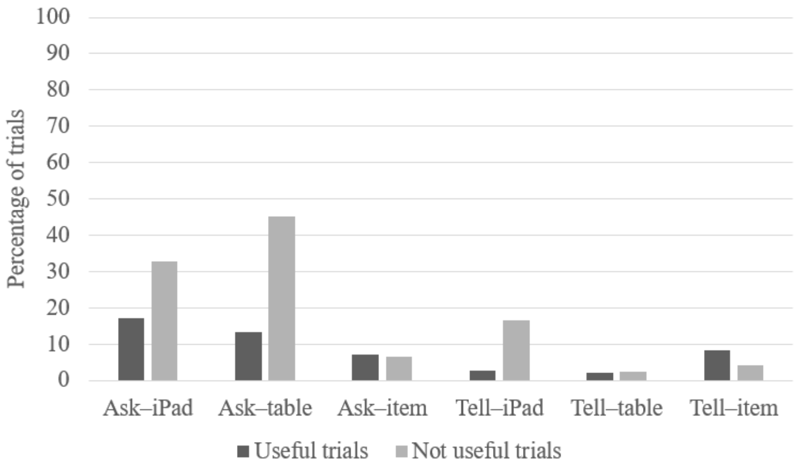
Time to Respond to Prompts

The time to respond to prompts was examined to understand which prompts elicited the quickest comprehension of information. In general, it took significantly longer for participants to select not useful (mean 30.70; SD 25.26 s) than useful (mean 19.19, SD 18.72 s; $t_{498}=5.62$; $P<.001$). This may be due to care partners giving participants with dementia more time to consider the prompt before declaring that it was not useful. We examined whether auditory or visual content resulted in a faster response by conducting a 3 (auditory content)×3 (visual content) ANOVA on response times for the 353 trials in which the prompt was useful. This analysis yielded no main effects or interactions between auditory and visual content on response time (F values of <0.93 in all cases; $P>.44$ in all cases). Overall, auditory and visual prompt features did not impact time to respond to prompts.

Care Partner Support

To understand how much care partners were involved in helping participants with dementia engage with the prompts and complete the tasks, independent raters scored the video recordings captured by the iPad during each trial for the presence of care partners providing additional verbal support or instructions. Care partners were observed giving assistance by *asking for attention* when they asked the participant with dementia questions such as the following: “what is on the iPad?”; “what is on the table?”; and “what do you do with it?” Care partners were observed to provide assistance through *direct telling* when they told the participant with dementia what was on the iPad (eg, “it’s a toothbrush”), what was on the table (eg, “see the toothbrush on the table”), and what to do with the item (eg, “now brush your teeth”). Across the categories of support, *asking for attention* and *direct telling* were much more likely in trials rated as not useful compared to useful (chi-square values of >13.1 in all cases; $P<.001$ in all cases; Figure 5). Support in drawing attention was more frequent, whereby care partners scaffolded the participant with dementia by sensitively drawing attention if the prompts alone were not successful. The lower frequency of the direct telling form of support suggests that the content of the prompts was useful for participants with dementia and could be understood and acted upon once their attention was drawn to the task (Figure 5).

Figure 5. Percentage of trials in which support was given by support type.



Experiment 2

Overview

In experiment 1, we focused on simple tasks that could be completed with a single object by participants seated at a table. This approach enabled us to compare the specific visual and auditory features of the tasks while holding other aspects such as complexity constant. In experiment 2, we extended our findings to more complex multistep tasks that were a better match for ADLs, which are likely to involve a sequence of interactions with multiple objects. We wanted to determine whether people with dementia would be able to follow a multistep task through to completion with an appropriate sequence of prompts, noting that, in experiment 1, care partners were involved in maintaining participants’ attention to the task.

Methods

Participants

Participants were 9 people with dementia, all of whom were supported by a female care partner to complete the research. All participants in experiment 2 had previously completed experiment 1. Participants with dementia (4/9, 44% female; 5/9, 56% male) ranged in age from 58 to 82 years, with an average age of 74 (SD 7.43) years. Participants who were care partners (4/9, 44% spouses; 4/9, 44% adult children; 1/9, 11% siblings) ranged in age from 34 to 77 years, with an average age of 61 (SD 13.31) years. A total of 44% (4/9) of the participants with dementia spoke English as a first language, and 56% (5/9) spoke a language other than English. Participants had received a diagnosis of dementia between 9 months and 9 years before, with an average of 3.5 (SD 2.79) years. We did not formally record additional medical information regarding comorbidities beyond the participants’ dementia diagnosis, but participants were required to have sufficient visual and hearing ability to be able to see and hear the iPad prompts as part of our inclusion criteria.

Materials

Software for Prompt Delivery

As with experiment 1, software development was conducted to produce an iPad app for displaying prompts and collecting data. An iPad was issued to each participant, with the reliance on collaboration between researchers and care partners to facilitate data collection with participants with dementia in their home.

Prompting Conditions

To examine the best way to break down prompts for multistep tasks, we selected 2 common everyday tasks (“wash and dry hands” and “make a sandwich”) that were relevant for all participants and in which the same set of steps to complete the tasks could be used for all participants. Care partners confirmed the suitability of the 2 tasks before participation. Care partners were issued a detailed manual together with verbal phone instructions to assist with the standardization and delivery of the experimental tasks in the participants’ homes.

Prompt Content

To develop a uniform set of custom-designed icons for prompts, we worked with a professional graphic designer to create visual stimuli that were simple and clear, used high contrasting colors, and included all relevant components of the task in the image (Figure 6).

For each of the 2 tasks, we developed 1-prompt, 3-prompt, and 7-prompt versions (Table 2). Each visual image was combined with a text instruction and a verbal instruction. The verbal instructions were recorded by the research team in an Australian-accented female voice. Stimuli were designed to include images, text, and audible verbal instructions so that prompt content represented the most useful condition from experiment 1. The iPad automatically captured video and audio during the experimental sessions while the prompts were on the screen using the front-facing iPad camera.

Figure 6. Visual stimuli for the 1-prompt version of the tasks.

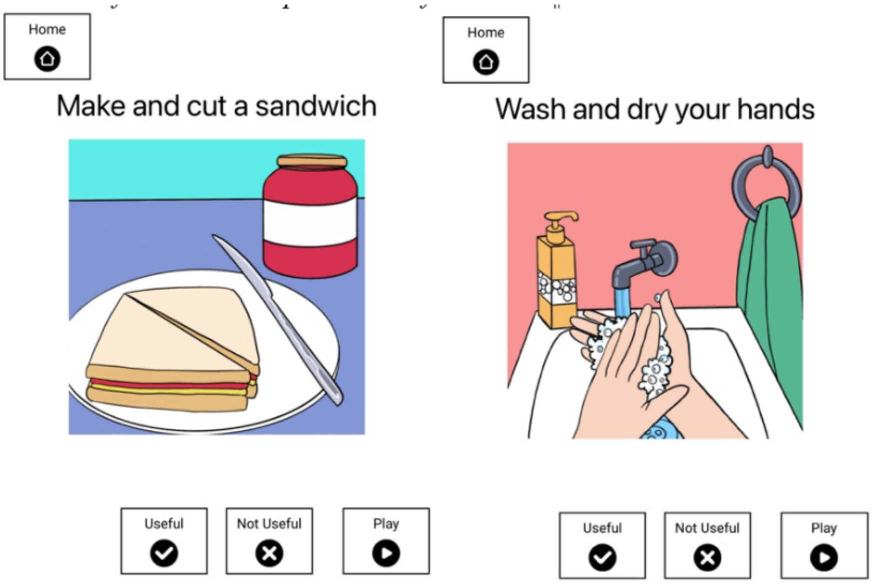


Table 2. Prompt conditions (1, 3, and 7 prompts) for the 2 tasks.

Daily task	Prompt condition		
	1 prompt	3 prompts	7 prompts
Wash hands	- Wash and dry your hands.	- Wet your hands under the water. - Wash your hands with soap. - Dry your hands.	- Turn on the tap. - Wet your hands. - Put soap on your hands. - Wash your hands with soap. - Rinse your hands. - Dry your hands. - Turn off the tap.
Make a sandwich	- Make and cut a sandwich.	- Get bread and fillings. - Put the fillings in the sandwich. - Cut the sandwich.	- Put 2 pieces of bread on a plate. - Butter 1 piece of bread. - Choose your fillings. - Put your fillings on the buttered bread. - Put the second piece of bread on the top. - Cut the sandwich. - Put the sandwich on the plate.

Measures

Prompt Usefulness

For each prompt, care partners rated whether it was “useful” or “not useful” by selecting the appropriate button on the iPad.

Task Quality

To understand the quality of task completion in the different prompting conditions, care partners completed a task checklist during the experimental task and noted any relevant observations. The task checklist itemized all 7 steps involved in the 2 tasks, and on each trial, care partners checked which steps were performed by participants with dementia in response to the 1-, 3-, and 7-prompt versions. As such, care partners could score that a prompt was “useful” overall (via button pressing on the iPad) but could also identify when some steps of the task may have been omitted (eg, using soap), especially during the more condensed prompting conditions.

Care Partner Support

As in experiment 1, we scored the video recordings of each trial for care partner involvement. Independent coders scored the frequency and type of verbal assistance from care partners classified according to 2 domains (asking for attention or direct telling). All videos were scored for the presence of support in the 2 categories by 2 raters who were blind to the prompting condition. Agreement between raters was substantial (86.9%), and the ratings of the first rater were retained for analysis.

Procedure

Baseline and Setup

During an initial video call, participants were oriented as to the project. They provided informed consent and proxy consent where appropriate. If participants with dementia had not had a recent cognitive assessment with their health care provider, an MMSE [41] was conducted to assess the cognitive status of the participants with dementia and determine the consent pathway. Participants were given a detailed printed manual as well as verbal phone instructions about how to set up and conduct the tasks. Care partners were instructed that participants with dementia would be prompted to complete 1 multistep task each day, either washing their hands or making a sandwich. Care partners were asked to indicate the usefulness of each step by pressing “useful” or “not useful” depending on whether participants with dementia understood the prompt and completed the action. In addition, care partners were asked to complete a checklist each day to indicate the quality of activity completion in each prompting condition.

Experimental Phase

On each research participation day, care partners supported participants with dementia in working through 1 of the 2 activities in each of 3 prompting conditions for a total of 6 experimental trials. Conditions and tasks varied in a fixed random order so that, across the whole experiment, each of the 2 tasks appeared in each of the 3 conditions. For each activity, participants first viewed a screen that stated what activity was scheduled for the day and how many steps it would have. Once participants pressed “start,” the prompt sequence began. Care partners were asked to allow participants with dementia to respond to the prompt themselves without assistance. For each prompt, care partners rated whether it was *useful* (the participant with dementia completed or approximated the task) or *not useful* (the participant with dementia did not complete the task) by selecting the appropriate button on the iPad. Once rated, the next step appeared on the screen, with a final screen to indicate when the activity was completed. The iPad automatically captured video and audio during the experimental sessions while the prompts were on the screen using the front-facing iPad camera. Care partners used a hard-copy notebook to record the checklist of completed steps and any other observations regarding each day’s task.

Experience and Feedback Interview

After completion of the 6-day experiment, a semistructured interview was conducted with both the participants with dementia and the care partners together using the same core questions as those for experiment 1. The interviews were approximately 15 to 20 minutes in duration. Due to restrictions on face-to-face interactions with participants, all interviews were conducted via web-based videoconference and were recorded for transcription and analysis.

Results

Prompt Usefulness

To examine the benefit of breaking down an activity into multiple steps, we first examined the frequency of useful versus not useful care partner ratings in each of the conditions.

The 7-prompt sequence obtained the highest ratings of useful for both the sandwich and handwashing tasks. However, usefulness ratings were high across steps in all conditions (Table 3). We also noted that washing hands appeared to reach maximum effectiveness after 3 prompts, with no additional benefit gained from the 7-prompt version. Separate chi-square analyses confirmed no statistically significant difference in frequency of useful versus not useful ratings for steps in the 1-step, 3-step, and 7-step conditions in the 2 different tasks (χ^2_2=1.2 and *P*=.54 vs χ^2_2=1.5 and *P*=.48, respectively).

Table 3. Percentage of “useful” steps in the 3 prompt conditions (1, 3, and 7 prompts) for the 2 tasks.

Daily task	Prompt condition, n/N (%)		
	1 prompt	3 prompts	7 prompts
Wash hands	9/11 (82)	28/32 (88)	71/77 (92)
Make a sandwich	9/11 (82)	26/33 (79)	67/77 (87)

Prompt Usefulness and Dementia Stage

We examined any differences in prompt usefulness depending on stage of dementia. Data indicated a difference in the frequency of prompts being useful versus not useful depending on participants' dementia severity (χ^2_2=26.8; P<.001). Participants with mild (80/88 steps, 91% useful) and moderate (102/109 steps, 93.6% useful) dementia had comparable results, whereas participants with more severe dementia found the prompts less useful (28/44 steps, 64% useful). In general, prompts in experiment 2 were more frequently rated as useful compared to those in experiment 1 regardless of participants' dementia severity. This was perhaps because experiment 2 used the most effective prompting condition identified in experiment 1, combining a visual prompt with both an audible verbal instruction and a written text instruction.

Task Quality

The task checklist and care partner observations from each day were analyzed to understand the quality of task completion in the different prompting conditions and gain feedback on how we had chosen to break down the tasks into steps and whether there were steps missing. Across all participants, care partners indicated that most steps were performed in all prompting conditions. However, there were individual differences in care partners' observations about which versions of the prompts were most effective. Some participants found that the 1-prompt condition was sufficient to support the participant with dementia in completing the activity. For example, some observations recorded in the 1-prompt condition included the following: "[participant with dementia] did it naturally, even rushed the steps," "Washing hands is something my mother knows very well, so she is able to perform it very easily when prompted," and "all instructions were performed." However, some participants mentioned that the 1-prompt sequence did not include enough instructions. For example, observations in the 1-prompt condition included the following: "[The participant with dementia] left tap running on a drip, [it] was not turned off properly," "I think the additional step 'eat your sandwich' may be beneficial as the sequence of steps does not state what to do with the sandwich once complete!" and "[participant with dementia] needed a prompt to find [the] hand towel."

The 7-prompt sequence worked well for many participants. For example, an observation in the 7-prompt condition was as follows: "all of the above steps are easy to follow." For some participants with dementia, the explicit instructions in the 7-prompt sequence encouraged them to stay focused on each step of the activity rather than rushing. For example, an observation in the 7-prompt condition was that the participant with dementia had "used more fillings" when making a sandwich compared to the 1- and 3-prompt conditions. Similarly, participants with dementia were observed by care partners to spend more time thoroughly washing their hands when following the 7-prompt sequence. However, for some participants with dementia, 7 prompts were too many. For example, observations in the 7-prompt condition were as follows: "At times...the 7 steps might have a few steps too many [as] mum was ahead of time doing the activity. She wanted to turn on [the] tap to rinse before the step was prompted" and "[participant with dementia]...pre-empts commands."

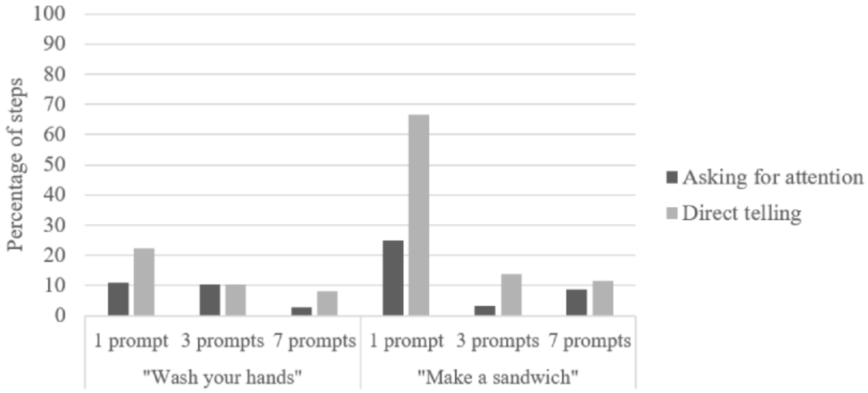
The completed checklists and observations made by care partners highlighted the personalization of prompts necessary to benefit each person. They also helped to contextualize the useful and not useful ratings, reflecting different degrees of quality or thoroughness in task completion. Overall, findings suggest that, for some participants with dementia, more granular prompt breakdown facilitated more thorough completion of the ADL. However, for others, the additional prompts may have caused confusion. Ideal task breakdown may also vary for different tasks. For example, some tasks familiar to the person with dementia may only need a single-step prompt, whereas less familiar tasks may need more explicit and finely grained multistep prompts, suggested by the different patterns between handwashing and sandwich making.

Care Partner Support

Similar to experiment 1, we measured the extent to which care partners used verbal statements to help participants with dementia notice and understand the prompts and complete the prompted tasks. Statistical analysis indicated that the frequency of both "asking for attention" and "direct telling" was relatively higher when the prompt was unsuccessful than when it was successful, indicating that care partners provided support when they perceived that it was needed (χ^2_1=10.7 and P=.006 vs χ^2_1=10.1 and P=.004, respectively), as in experiment 1. Substantially higher levels of support were provided in the 1-prompt condition, particularly for the less familiar task of making a sandwich (Figure 7), and this mostly involved direct instruction, unlike in experiment 1.

To examine the impact of condition given the association with prompt success and that participants contributed multiple trials to the data set, we followed up these trial-based analyses with a stepwise (forward, likelihood ratio) logistic regression, with predictors added in order of participant number, prompt success, task content, and number of prompts (1, 3, or 7). The presence of care partner assistance in the form of "asking for attention" or "direct telling" on each trial was the binary dependent variable for the 2 separate regressions. For "asking for attention," this analysis yielded a model with only 1 significant predictor, confirming prompt success as impacting the likelihood of drawing attention (B=1.71; P=.003). For "direct telling," this analysis yielded a model with 2 significant predictors of prompt success (B=1.27; P=.008) and number of steps (B=0.21; P=.02). The negative relationships indicate that tasks with fewer steps had higher frequencies of direct telling over and above the effect of prompt success. This provides evidence that breaking tasks down into more granular steps increased the independence of people with dementia in using the prompting system.

Figure 7. Percentage of steps in which care partners provided support by task type and condition.



Experiment 3

Overview

Experiment 3 aimed to follow up our observation in experiments 1 and 2 that care partners frequently supported participants with dementia in responding to prompts by drawing their attention or directly telling them what to do, especially at the outset of the task to draw attention to the iPad, consistent with the challenges that people with dementia experience with task initiation. In experiment 3, we addressed two key questions about how to better support people with dementia in independently initiating and completing ADLs: (1) what kind of auditory alerts are most effective for gaining people with dementia's attention so that they initiate a new task? (2) What kind of auditory alerts and what frequency are most effective for maintaining people with dementia's attention to complete multistep tasks? While various kinds of alerts (audio and vibration) have been found to be effective in gaining the attention of people with an acquired brain injury [43,44], little is known about the potential role of alerts in supporting people with dementia to initiating and accurately completing everyday tasks [45].

Methods

Participants

A total of 17 people with dementia were recruited for this study, including 16 (94%) who participated with a care partner and 1 (6%) person with dementia who participated alone. Participants living with dementia (n=6, 35% female; n=11, 65% male) were aged 58 to 90 years, with a mean age of 76 (SD 8.76) years. Care partner participants (15/16, 94% female; 1/16, 6% male) were aged 25 to 88 years, with a mean age of 61 (SD 18.89) years. In total, 65% (11/17) of the participants with dementia spoke English as their native language; 35% (6/17) communicated most of the time in a language other than English. Time since diagnosis ranged from 3 months to 9 years, with an average of 3 (SD 2.30) years. Care partners were 56% (9/16) spouses, 38% (6/16) adult children, and 6% (1/16) formal carers of the participants with dementia. We did not record additional medical information regarding comorbidities beyond participants' dementia diagnosis, but participants were required to have sufficient visual and hearing ability to be able to see and hear the iPad prompts as part of our inclusion criteria. The experiment ran over a 14-day period, and not all participants completed all trials. However, partially complete data were retained for analysis.

Materials

Software for Prompt Delivery

As previously, software development was conducted to produce an iPad app for prompt delivery and data collection, and an iPad was issued to each participant. Researchers and care partners collaborated to facilitate data collection with participants with dementia in their everyday home environment.

Coloring-In Activity

We designed a coloring-in activity to provide an experimental, multistep task that could be standardized across all participants. Our findings from experiment 2 emphasized the heterogeneity in the natural steps and sequence for completing ecological everyday tasks. Coloring pictures were selected from dementia-friendly coloring books, with a new picture provided each day in a physical printed booklet. We provided each participant with a coloring book and pencils with the same instructions and number of steps across all participants, enabling experimental control and an objective scoring system to determine task completeness and accuracy (Figure 8).

Figure 8. Example coloring prompt combining text, visual icon, and "Repeat" option for verbal instruction.

Colour the roses in red

Prompt Content

The prompt for each of the 6 steps was multimodal based on the most effective conditions from experiments 1 and 2, combining a text instruction, verbal instruction, and visual icon of the colored pencil that the participant was instructed to use. Participants pressed *repeat* on the iPad if they wanted to hear the verbal instruction again. Participants pressed *next* on the iPad to receive the next step in the coloring activity (Figure 8).

Auditory Attention Alerts

A melodic tone called "Blackberry Spirit" was used for both the initiation and the attention maintenance alerts. This tone was selected based on evidence that receiving a soft tone notification is preferred for receiving noncritical messages than notifications with loud tones, which are deemed more intrusive [46]. We judged Blackberry Spirit to have a soft tone with a "happy" emotional association. Verbal instructions were recorded in an Australian-accented female voice for both initiation ("You have a new activity on iPad. Press 'start' to begin") and maintenance ("When you have finished this step, press 'next' to continue") alerts.

Care Partner Notebook

In experiment 3, we asked care partners to sit in the next room during the experimental sessions and allow the participant with dementia to navigate the task and the prompts by themselves. To facilitate this and score the usefulness of the different prompts, care partners received a notebook with a series of questions to answer on each day of the activity, including recording whether they had provided assistance with initiating or completing the task, rating the participant with dementia's mood, indicating the other activities of the day, and recording any other observations or comments.

Procedure

Baseline and Setup

Care partners were given a detailed manual as well as verbal phone instructions regarding how to set up the at-home experimental task. Care partners were instructed to ensure that the participant with dementia was able to sit comfortably at a table, with the iPad, coloring-in book, and pencils within reach. The iPad was placed to the side of the participant with dementia to enable them to see and interact with it while being able to reach the objects on the table (Figure 9).

Figure 9. A visual representation of the at-home setup provided within the care partner manual, including positioning of the coloring task and iPad.

Task Initiation

At the beginning of each trial, an initiation alert played on the iPad. To test which initiation alert might be most useful for drawing the participant with dementia's attention to the iPad task, we adopted a 2×2 within-subject design with Alert Type as the first independent variable. The initiator alert was either the Blackberry Spirit tone alone (tone-only condition) or Blackberry Spirit followed by the verbal instruction (tone+verbal condition). The second independent variable manipulated whether the iPad screen repeatedly flashed bright white while the initiation alert was playing to add a visual cue for gaining attention. Care partners were asked to allow the participant with dementia to notice and initiate the task themselves but, if they did not, to then direct them to commence the task for the day by drawing their attention to the iPad. Care partners recorded in their notebook whether they had provided assistance for task initiation.

Task Maintenance

Following task initiation, participants with dementia were presented with a sequence of 6 prompts to complete that day's coloring-in activity. For each step, participants pressed *next* when it was complete and they wished to move to the next step. To examine whether alerts were useful for supporting participants with dementia to maintain focus and continue through the full sequence of steps in the activity, maintenance alerts were tested in a 2×3 experimental design varying 2 alert conditions (tone only vs tone+verbal) and 3 timing conditions (no alert vs 30-second interval vs 60-second interval). The resulting 6 conditions were presented in a fixed random order across days 2 to 13, with each condition appearing twice. Days 1 and 14 were always the no-alert condition to provide a baseline and a posttest of task completion. The iPad automatically captured video and audio during the experimental sessions while the prompts were on the screen using the front-facing iPad camera.

Experience and Feedback Interview

After completion of the 2-week experiment, a semistructured interview was conducted with both participants with dementia and the care partners together. Example questions included core questions from the previous experiments as well as some additional specific questions about the alerts, including the following: "Did the participant start the activity by themselves in response to the alert? Why or why not?" and "Did the alert during the task help the participant maintain focus?" The interviews lasted approximately 15 to 20 minutes. The interviews were conducted via web-based videoconference or in person and were audio recorded and transcribed for later analysis. Written transcripts were reviewed to identify common themes within and across participants.

Results

Task Initiation

We examined how often the participants initiated the task independently versus with assistance from their care partners by examining and coding the videos captured by the iPad and scoring the care partner reports recorded in their daily notebooks. Of the 210 initiation trials that had video data captured by the iPad, independent raters scored 91 (43.3%) trials as involving participants with dementia initiating the day's task themselves and 119 (56.7%) trials as involving support from the care partner to commence the day's activity. A total of 12.1% (29/239) of the presented trials were missing or could not be coded. Reports from care partners contrasted slightly with coded video results. Of the 204 trials with notebook entries, care partners reported that 129 (63.2%) trials involved participants with dementia initiating the day's task themselves and 75 (36.8%) trials involved support from care partners to commence the day's activity. Participants with dementia took between 1 and 299 seconds to initiate the task after the alert sounded. The average time taken to commence the task was 26 seconds. Taken together, these findings suggest that participants with dementia sometimes initiated the task themselves and sometimes relied on the care partner to do it for them. Coders also noted in the videos that participants with dementia were often seated at the iPad waiting for the task to commence and this may have influenced these findings.

To examine whether the nature of initiation alerts influenced the likelihood of trials being person with dementia initiated versus care partner initiated, we conducted 2 stepwise (forward, likelihood ratio) logistic regression analyses examining the impact of condition as well as accounting for participant-related variance. Predictors were added in order of participant, participant's dementia category, experimental day (1-14), alert type (tone only or tone+verbal), and screen flash (present or absent). Whether the task was initiated by the participant with dementia or by the care partner was the binary dependent variable for the 2 separate regressions, one using the independent video coding and the second using the care partner ratings of who initiated the task. A significant model emerged (χ^2_1=28.3; P<.001; R^2=0.169), with only 1 significant predictor of dementia category (B=−0.751; P<.001). These results suggested that the auditory and visual nature of the initiation alert had no impact on the likelihood of the participant with dementia initiating the activity independently and that people with more severe dementia were less likely to independently initiate the task. Both tone-only and tone+verbal alerts were similar in effectiveness, with no advantage of adding a voice to the tone and no impact of the additional visual cue of the flashing screen. Overall, initiation alerts were moderately effective, with participants with dementia independently initiating the task 43% to 63% of the time regardless of auditory and visual condition.

Task Maintenance and Completion

To assess the value of attention maintenance alerts, we scored participant performance on the coloring task by examining the coloring books and assigning each step on each task a score for *accuracy* (whether the correct color was used) and *completeness* (score from 1 to 5 indicating degree of coverage). Participants with dementia used the correct color on 78.97% (1093/1384) of the steps and the incorrect color on the remaining 21.02% (291/1384) of the steps. Participants received an average completeness score of 3.85 (SD 1.67), indicating 60% to 80% coverage on each step. However, the modal score was 5 (>80% completeness), which was achieved on 57.08% (790/1384) of the steps. Overall, these data suggest that participants with dementia could follow the prompts and complete the coloring task successfully and accurately, although their completion and accuracy varied across individuals and days. Participants with more severe dementia had lower accuracy and completeness scores than those with milder dementia. The average coloring step lasted for 378 (SD 297.65) seconds (just over 5 minutes), although this varied across participants and days.

Most importantly for our research questions, we examined whether the likelihood of participants with dementia pressing *next* independently, accuracy, completion, and time spent on each coloring step varied systematically as a function of the content and timing of maintenance alerts. We conducted 3 stepwise (forward, likelihood ratio) logistic regressions, with predictors added in order of participant number, dementia category, prompt presence (present or absent), prompt content (none, tone, or tone+verbal), and timing (none, 30 seconds, and 60 seconds) Binary dependent variables were whether participants with dementia pressed *next* independently (yes or no), accurate color choice (yes or no), and completeness (>80% or <80%) for 3 separate regressions. A fourth linear regression was conducted with the same predictors for the continuous dependent variable of time taken on each step (Table 4). Across dependent variables in all 3 logistic regressions, the only significant predictors were participant ID and dementia category. Overall, there were individual differences in independence and task completion, but these were associated with individual differences and task familiarity rather than with the presence, content, or timing of the maintenance alerts. The only exception was timing. The regression yielded alert type as a positive predictor of time spent on each step, indicating an advantage for sound+verbal trials, as well as alert trigger as a negative predictor, indicating an advantage for alerts at shorter intervals.

To better understand the impact of alert type and alert trigger on the time spent on each step, we compared mean time spent on each coloring step across conditions. A 1-way ANOVA across the 3 alert type conditions (none vs sound only vs sound+verbal) indicated no significant effect ($F_{2,\ 880}$=1.40; *P*=.25). A 1-way ANOVA across the 3 alert timing conditions (none vs 30 seconds vs 60 seconds) indicated a significant effect of timing ($F_{2,\ 880}$=9.43; *P*<.001). Follow-up comparisons indicated that participants with dementia spent significantly longer on steps that had maintenance alerts at 30-second intervals (mean 453.31 seconds; SE 15.36) than on steps that had no alerts (mean 371.18 seconds; SE 21.49; *P*=.006) and alerts at 60-second intervals (mean 364.35 seconds; SE 15.84; *P*<.001), with no significant difference between 60-second alerts and no alerts.

Overall, the findings from experiment 3 supported that people with dementia could accurately complete a sequence of multiple task steps supported by audiovisual prompts delivered on the iPad to both initiate and persist through a sequence of steps. Although there was some heterogeneity in whether people with dementia initiated the task independently and operated the iPad to move through the steps independently, we did not find clear evidence that the nature of auditory initiation or maintenance alerts made a difference regarding independent engagement with the prompts. Instead, individual differences, and particularly dementia severity, as well as experience with the task over the course of the experiment had a bigger impact. These findings suggest the value of iPad-delivered prompts as people with dementia could engage with them and use them to complete a sustained activity, with high rates of accuracy and completeness. We did find some evidence that maintenance alerts at 30-second intervals might help people with dementia persist with a task for longer. However, as people with dementia were supported to initiate the tasks approximately half the time regardless of alert condition, future work is needed to test alternative ways of initiating and maintaining attention if independent use of a prompting system without care partner support is a valued goal.

Table 4. Regression analyses predicting independent use, color accuracy, color completeness, and time spent on each step.

Dependent variable	Significant predictors	Model chi-square (*df*)	Model *R*	Model R^2	*P* value	Correctness (%)
Independent initiation	Participant ID, dementia (negative), and day (positive)	123.65 (3)	—[a]	0.185	<.001	66.4
Color accuracy	Participant ID, dementia (negative), day (positive), and step (negative)	85.54 (4)	—	0.134	<.001	80.8
Color completeness	Participant ID, dementia (negative), day (positive), and step (negative)	139.46 (4)	—	0.180	<.001	66
Time spent on each step	Day (positive), step (positive), alert type (positive), and alert trigger (negative)	—	0.235	0.055	<.001	—

[a] Not applicable.

A Synthesis of Experiences and Feedback Across all 3 Experiments

Overview

In all 3 experiments, we conducted detailed interviews with care partners alongside participants with dementia to discuss their experiences of the prompts and the tasks. We explored what participants found most useful about the prompting system and what features they would like to see in future assistive technology devices. As the questions and resulting themes were similar across all experiments, we present a synthesis of the interview findings in the following sections. These insights nuance our experimental findings and inform key recommendations for future assistive technology development.

What Aspects Did Participants Find Useful and Not Useful?

Care partners provided mixed reports on the usefulness of the prompting system. Most carers found the prompts to be useful to at least some degree. However, the perceived usefulness of the system varied according to the participants' dementia severity, consistent with our behavioral data. Participants in the early (mild) stages of dementia were less likely to report difficulties following the prompts and were able to complete the task independently. Care partners reported variability in participant mood and, therefore, the usefulness of the prompting from day to day (eg, "There are days he [enjoyed it]. There are days he [got] frustrated" [experiment 3]). Overall, findings highlighted the importance of customizability and personalization of the system to manage variability in preferences and abilities of people with dementia both across individuals and across time. Despite this variability, there were common themes regarding the benefits and challenges associated with the different prompts tested across the 3 experiments, which are detailed in the following sections along with care partner suggestions for further development and uses of a prompting system.

Useful Features

Care partner participants reported that the prompts were useful and practical and they generally liked the design of the visual pictures and icons (eg, "nice, simple pictures" [experiment 1]). Concerning auditory prompts (verbal instructions and symbolic sounds) in experiment 1, care partners reflected that the verbal instructions were more useful than the symbolic sounds as the association between the target object and action and the symbolic sound was more abstract, consistent with behavioral data. The verbal instructions were also perceived as helpful by care partners in later experiments:

> *The [verbal] instructions did [motivate him]. Yes, he would wait to hear "Colour the lady's hair green" or whatever. And then that was like "Oh, I have a task," and then he would do it.* [Experiment 3]

In experiments 2 and 3, some care partners found that the person with dementia's ability to complete the multistep tasks and associated activity improved over time and with repetition. This effect encouraged these care partners to continue with the activities at home. For example, as a result of watching her husband make a sandwich independently with prompts, one care partner (experiment 2) reported an intention to continue supporting him with prompts to prepare his own lunch instead of making it for him as she had done previously. Similarly, in interviews following experiment 3, some care partners reported that the person with dementia enjoyed the coloring in and they were continuing the activity at home:

> *Yeah and [Dad's] still doing it actually.... Now, when his carers come, they draw things or do writing, and he colours it in. So it started something that's entertaining for him. So that was very useful.* [Experiment 3]

In this way, participating in the research led to a focus on retained abilities and benefited day-to-day quality of life. It also demonstrated the potential for a prompting system to connect people with dementia with meaningful leisure activities in addition to the completion of ADL tasks.

In experiment 2, care partners observed that the granular nature of the prompts for the multistep tasks resulted in a more thorough completion of the ADL task, improving task quality in a way that was not always captured by our binary scoring of success. For example, several care partners reported that, with the support of the prompting system, the participant with dementia had used soap when washing their hands, a step usually omitted when not prompted, or had washed their hands more thoroughly. In addition, across experiments, participants reported that they appreciated the simple app interface and the ease of pressing the "home" button to return to the start. They also reported the value of having a dedicated device that only contained the prompting program ("without all that other stuff on it") to increase the simplicity of interacting with it.

Challenges

Some care partners reported that the need to locate buttons on the iPad was a mismatch with their family member's abilities due to their stage of dementia (eg, "So [the verbal instructions] part did motivate him. [but], pushing buttons and messages on the screen—no" [experiment 3]). Some care partners mentioned that the participant with dementia would have more success completing even simpler tasks if multiple, more granular prompts were given. For example, at times, even simple 1-step tasks needed multiple prompts to complete (eg, "He knows where the remote is, but has difficulty finding the right button to press" [experiment 1]). Similarly, in experiment 3, a care partner reported the following:

> *[The task] "colouring the leaves green" involves both finding the right colour pencil and identifying the correct part of the picture.*

This feedback suggests that the "right number" and granularity of steps may vary depending on the individual and the degree of support they need for a particular task.

Care partner responses indicated that the usefulness of the prompts was impacted by how well the prompt content matched an individual's experiences and preferences. For instance, one care partner in experiment 1 commented that the generic picture of the television was too old-fashioned and, therefore, was hard to recognize as referring to the participant with dementia's own television. These complexities highlight the need to personalize prompt content and structure to ensure that it matches the needs and experiences of the individual user.

Independent Use and Initiation by People With Dementia

Care partners of people with dementia in later stages generally expressed doubt about whether they would initiate and use a prompting device on their own:

> *I think maybe for somebody with very early dementia it might [be] useful, but I think for my mother's stage it's not so useful...it becomes just noise telling her to do something, and she's not able to grasp [what to do].* [Experiment 3]

An overarching theme from carer feedback across the experiments, consistent with our behavioral data, was that care partners felt the need to be involved in directing the attention of people with dementia to the iPad prompts. For example, carers noted that their presence was needed to provide repetitions of the prompt, break the prompt down into smaller steps, or focus the participant with dementia's attention. They also reported that participant with dementia found the initiation of the activity difficult and their ability to complete it was improved with scaffolding and support from the care partner. For example, some reported that screen-based prompts or activities were unsuccessful in capturing the attention of the participant with dementia, and others were unsure of whether the participant with dementia would understand the prompts and content on their own:

> *So it was that motivation to get started, and so I'm just not sure how it would work in practice. If she was alone, using the iPad, whether she would actually turn it on or not, I don't know.* [Experiment 1]

Despite these concerns, some care partners were more optimistic about people with dementia being able to use a home assistant device through strategies such as developing a routine of checking a device in the morning to orient themselves for the day or learning to use the prompts independently over time with practice and familiarity (eg, "It might take a few goes, but she would probably be able to do it on her own" and "by the end, she was able to do it much faster; at the beginning, where she was unsure she would look to me" [experiment 1]). Others also discussed whether the participant with dementia would advance to the next step without the care partner there to press the button and suggested considering a timed system that automatically advanced to the next prompt to reduce the demands. Participants with dementia also reflected on the anxiety of getting things wrong and a worry that the "machine" would break or freeze if they pressed the wrong thing. However, care partners observed that participants with dementia became less anxious and more accomplished with using the prompts with practice and repetition and enjoyed the opportunity to interact with technology. Although we were concerned with the time demands of the repeated experimental sessions, some participants expressed that the experiments were too short and the person with dementia was just becoming familiar and comfortable with the tasks at the point in which they ended:

> *Because at the beginning she's a bit nervous, so it's about getting used to the technology and it's hard to judge how well she's doing via the prompts. So, it's almost like, [the] last couple of days, where she's starting to get it, especially some of the similar ones that keep coming up like brushing your teeth, drinking water, the ones she could become familiar with. Towards the end the minute she sees it she knows what it is.* [Experiment 1]

Auditory Alerts as Attention Grabbers

Given that there was a great deal of variation in whether participants with dementia initiated the task and that it did not depend on the nature of the initiation alert in experiment 3, we sought to understand the reasons for this variation by asking care partners during interviews about whether the alerts were effective at grabbing attention for the participant with dementia. Interviews with care partners identified that a common reason given for participants with dementia not initiating the task was confusion related to understanding and interpreting the alerts and prompts:

> *When it first started...when it's buzzed...she knows something's buzzing...so she knows she needs to get started but then I think the first step she tries, and then I think she gets caught up and not know what to do. And also, like, I think it's a bit complicated for her in terms of that she doesn't know where to press, whether it's pressing on the colouring book or pressing on the iPad.* [Experiment 3]
>
> *But no, those alerts be it on the iPad or on the handheld, did not work [for mum]. It just didn't work.* [Experiment 3]

Suggestions for Future Device Development

Across experiments, care partners were given the opportunity to suggest improvements to the prompts and prompting system. Suggestions included ways of improving the hardware and user interface, such as the use of a larger device, potentially mounted or fixed in place so that it could not get lost or misplaced. They also suggested making the attention-grabbing prompts deliverable on a more portable device rather than requiring users to be in front of the iPad or noticing a new task from across the room. For example, several care partners suggested incorporating a wearable to bring the participant with dementia's attention to the task even if they were not in front of the iPad or so that reminders could be provided in nonhome locations (eg, taking medication while out at a friend's house). Such a wearable would be too small for the screen display to be useful but could emit voice instructions. One care partner participant suggested that videos or active prompts showing the movement and the action involved in a task would be helpful for people with dementia to copy compared to the static visual images that we tested. Finally, participants mentioned that the device could be voice activated rather than requiring a button press on the screen to interact with it and progress through tasks.

Suggested ADL Tasks for Prompting

On the basis of their experience of the prompting system, we asked care partners to reflect on what ADL tasks could be potentially supported using home prompting devices. Although we received a range of suggestions, common responses included health and self-care activities such as taking medication, drinking water, and eating; hygiene activities such as taking a shower and brushing teeth; and well-being and recreation, such as doing some exercise, listening to music, and calling a friend or family member. Care partners found our approach of breaking tasks into substeps useful and suggested that additional ADL tasks could be broken down and prompted in similar ways. Care partners also suggested having options to display (and schedule) set tasks for some days and not others or to orient people with dementia with a list of reminders each morning (eg, "today we are doing..."). Care partners also noted that even short periods within the day (eg, "20 minutes") while the person with dementia independently showers or shaves would be a valued source of independence and respite for both parties.

General Discussion

Principal Findings

We aimed to compare the usefulness of different features of tablet-based prompts to support people with dementia in completing everyday ADLs at home. Across 3 experiments, we found that people with dementia could engage with tablet-based prompts and use them to complete activities. Prompts were more useful for people with mild and moderate dementia compared to those with severe dementia, but even participants with severe dementia could understand and respond to prompts on most trials, particularly when prompts combined auditory and visual modalities. In experiment 1, we found that the most effective prompts included an auditory verbal instruction regardless of their visual content. In experiment 2, we found that breaking complex tasks into substeps could support task completion as well as task quality and independence. Although the ideal granularity of steps depended on the individual and the task, people with dementia were observed to need less support when there was more than a single prompt. In experiment 3, we found some benefit of auditory prompts for drawing and maintaining attention but no difference between a tone alone and a tone combined with a verbal call to action. Combined with feedback from care partners, these findings suggest that fully independent use of prompting technology may be a challenging goal and that different hardware choices beyond a touch-screen tablet may be better suited to this user group to facilitate attention and engagement. Regardless, a degree of independence and engagement supported by the prompting system was valued by both people with dementia and care partners even if care partners were involved at times in facilitating its use.

Prompt Modality

Our experimental research comparing different kinds of visual and verbal stimuli to each other found that the presence of an audible verbal instruction was associated with task success. The nature of the visual content, whether text, icon, or photo, did not appear to influence prompt usefulness over and above the presence of an auditory verbal instruction. This was consistent with care partner observations and feedback as well as with other studies that combined auditory and visual components when designing prompts, suggesting the particular effectiveness of direct verbal and text-based prompts [19]. Direct instruction, provided both verbally and visually via text, appeared to be the most effective, removing ambiguity about what the task was.

There was also evidence that prompting was more effective for people in early to moderate stages of dementia, with less success for those whose dementia was more severe, although even those with severe dementia could respond to the prompts at least half the time. However, gaining experience and familiarity with a prompting device during the earlier stages of dementia may enable people to continue using it as their dementia progresses. We did not find a learning effect in experiment 1, but regression analyses in experiment 3 suggested that the accuracy and completion of the coloring task increased across the 14 days. Participants also reported that they appreciated the prolonged experimental period that allowed people with dementia to overcome their initial anxiety and gain confidence and familiarity with the tasks. This is consistent with other research showing that those who were more successful responding to a prompting device used it for longer, over more days, and on more occasions [24], emphasizing the role of confidence building and successful use in motivating further use. A longer period of regular use may have even more advantages and may have boosted performance for those with more severe dementia, but future research is needed to examine this question.

Prompts for Complex Tasks

Generally, increasing the number of substeps within a task increased the success of the prompts and the likelihood of task completion and reduced the extent to which care partner support was needed. Observations indicated that the ideal breakdown varied according to the individual and their degree of cognitive impairment as well as with the task complexity and familiarity. These factors are likely to combine to make the optimal breakdown of steps idiosyncratic to the individual such that the ability to tailor or select and deselect substeps may be ideal for prompt usefulness. We did not identify any previous research examining the optimal granularity for breaking down tasks when providing prompts to people with dementia, although some of the prompting devices reported in previous literature did break tasks down into substeps. For instance, the COACH handwashing system provided 5 steps for washing hands [47]. We found that breaking tasks down into multiple steps could be critical for ensuring their completion and increased independence. For instance, one participant could not wash his hands independently because he would forget to turn off the tap, and others would neglect to use soap if not reminded. In cases such as these, single prompts may be insufficient or even counterproductive for task completion. However, the optimal granularity and the specific step content varied depending on the individual and the specific task, making personalization essential for success [24,48,49].

Grabbing and Maintaining Attention

Our analysis of the videos indicated that care partners were often involved in drawing the attention of people with dementia to the task and ensuring task completion. Moreover, although we trialed different methods for the system to gain and maintain attention, we did not identify a particular type of alert that made independent initiation and task maintenance more likely than another as the tone alone and the tone combined with a verbal call to action had similar outcomes. On the basis of feedback, auditory alerts were reported to be difficult to interpret for people with dementia even when accompanied by a verbal reminder. Future research is needed to test other ways to support people with dementia to notice and initiate the task and persist through the steps of complex ADLs. One suggestion from care partners was the inclusion of an associated wearable device to tell people with dementia when there was a new task. Other suggestions included using the person with dementia's name in the verbal call to action to gain and maintain attention across multiple steps, which was the approach adopted in a previous study [47]. Another study used a Bluetooth earpiece to directly provide verbal prompts to people with dementia wherever they were without relying on them being close to a device; however, this approach may not be suitable for all people with dementia

[21]. Further research is needed to determine how to support people with dementia to independently notice and initiate a task when prompted by a home-based system. However, we noted that care partners and people with dementia still valued the partial independence provided by the prompting system even when care partners scaffolded its use.

User Experiences and Avenues for Future Development

Generally, care partners were positive about the prompting system and the characteristics and content of the prompts. They had a range of specific feedback, some of which was idiosyncratic to the individual participant. Feedback that generalized across participants was the need for a custom, dedicated device, potentially including a wearable to enhance portability. Consistent with our analysis, care partners reported that success at the different tasks and usefulness of the prompts was impacted by how well the prompt matched an individual's experiences and preferences. Care partners reflected lack of certainty regarding whether such a system could be used independently, but both care partners and people with dementia valued the potential for independent use.

There was a range of specific recommendations that should be incorporated into future device development. This included the need for large display screens and large buttons. In addition, buttons should be clearly marked and kept to a minimum, and voice control may be more successful. Care partners suggested that the system may need multiple devices or screens in different rooms so that they could be in fixed, predictable locations and "plugged in" rather than needing to be charged. In addition, the system could be customized to deliver prompts automatically at set times. A recent review also noted the potential benefit of time-based prompts, especially as dementia progressed, but noted that the timing of transitions would need to be tailored and calibrated for the individual [11]. Overall, engagement remains a key challenge, particularly with remembering to use an assistive device and maintain attention to multiple steps in a sequence.

A major emerging consideration regards customizability and tailoring built into the prompting system [24,48]. We noted that much of the feedback about the usefulness of specific steps or prompts was idiosyncratic to the individual, their capacity, the specific task, and the home environment. It was challenging to generalize regarding the prompt content provided for people with dementia, and it varied depending on the individual and the task. Small mismatches between needs and expectations of the user and how the device behaves can render a system useless by creating confusion or uncertainty. Future development could focus on a technological solution that allows care partners or people with dementia to choose or edit the tasks and the steps that they want displayed to them (as in the study by Harris et al [24]). We also noted the wide range of content that care partners and people with dementia were interested in having supported through prompts. This included a focus on instrumental ADLs but also a focus on more meaningful activities, such as music listening, and facilitating social connection and reminiscing. Although much assistive technology development has focused on ADLs and safety [50], richer, meaningful activities are crucial for promoting positive quality of life for people with dementia and supporting relationships between people with dementia and care partners, and these should be considered in the development of prompting technology.

Limitations and Future Directions

Our research had a range of strengths, seeking generalizability by examining a set of prompts that were fixed and standardized across participants to examine how prompt features impacted their usefulness. However, this necessarily meant that the visual and auditory content of the prompts was generic rather than personalized. Although we made attempts to select the optimal content based on pilot-testing, it may have provided a poor match for some individuals, and this may have particularly disadvantaged the visual prompting condition in experiment 1. Future research is needed to examine whether there is more benefit from the visual prompt content when it is personalized to the individual, matching their own environment (ie, depicting their own television or their own bathroom sink) instead of being generic. Relatedly, we relied on care partners to indicate prompt usefulness. This meant that the research could be conducted in an ecological, everyday home setting over a long testing period rather than requiring the presence of researchers. However, carers may have been biased to support "good" performance and indicate that a prompt was useful when it was not. We deliberately framed our research questions regarding the usefulness of the prompts rather than the performance of people with dementia to reduce this bias, and we emphasized to participants that we wanted to know about prompts that were not useful just as much as those that were. However, future research could consider other ways of recording the outcomes of prompting, especially as pandemic-related restrictions on face-to-face testing have eased. Finally, we did not record detailed information about participants' comorbidities, including limitations to their mobility, vision, or hearing. These individual differences are likely to shape needs and what kind of prompting is best suited to whom, and this would be a fruitful avenue for future research.

Conclusions and Recommendations

Overall, our findings suggest promise for future development of assistive technology to support people with dementia and their care partners. Participants with dementia could become familiar with and use a touch screen–based prompting device to complete a range of activities, especially when prompted with a combination of verbal and visual information and when activities were broken down into more granular substeps. We found that participants with dementia responded to prompts more than half the time across experiments, including people with more severe cognitive impairment when prompts combined visual content with direct verbal instructions. Therefore, we recommend that future prompting technologies include both a direct verbal instruction alongside visual prompts to maximize task success and that they enable complex tasks to be broken down into customizable substeps. Care partners were often involved in scaffolding task initiation and drawing the attention of people with dementia to ensure task completion, and additional attentional alerts did not appear to influence this. Overall, people with dementia and their care partners are interested in assistive technology that is intuitive and able to be personalized for the individual to make it work for their needs and context, prompt valued tasks, promote independence and self-esteem, and enhance quality of life. Our findings highlight the value of working meaningfully with intended users within their everyday settings to understand the reasons why assistive technology is experienced as useful or not useful as well as the need to move away from one-size-fits-all solutions to support people with dementia.

Conflicts of Interest

None declared.

References

1. Wherton JP, Monk AF. Problems people with dementia have with kitchen tasks: the challenge for pervasive computing. Interact Comput 2010 Jul;22(4):253-266. [doi: 10.1016/j.intcom.2010.03.004]
2. Wilson G, Pereyda C, Raghunath N, de la Cruz G, Goel S, Nesaei S, et al. Robot-enabled support of daily activities in smart home environments. Cogn Syst Res 2019 May;54:258-272 [FREE Full text] [doi: 10.1016/j.cogsys.2018.10.032] [Medline: 31565029]
3. Dixon E, Lazar A. The role of sensory changes in everyday technology use by people with mild to moderate dementia. ASSETS 2020 Oct;2020:41 [FREE Full text] [doi: 10.1145/3373625.3417000] [Medline: 34308427]
4. Giebel CM, Sutcliffe C, Challis D. Hierarchical decline of the initiative and performance of complex activities of daily living in dementia. J Geriatr Psychiatry Neurol 2017 Mar;30(2):96-103 [FREE Full text] [doi: 10.1177/0891988716686835] [Medline: 28073326]
5. Regier NG, Hodgson NA, Gitlin LN. Characteristics of activities for persons with dementia at the mild, moderate, and severe stages. Gerontologist 2017 Oct 01;57(5):987-997 [FREE Full text] [doi: 10.1093/geront/gnw133] [Medline: 27986794]
6. Andersen CK, Wittrup-Jensen KU, Lolk A, Andersen K, Kragh-Sørensen P. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. Health Qual Life Outcomes 2004 Sep 21;2:52 [FREE Full text] [doi: 10.1186/1477-7525-2-52] [Medline: 15383148]
7. Thoma-Lürken T, Bleijlevens MH, Lexis MA, de Witte LP, Hamers JP. Facilitating aging in place: a qualitative study of practical problems preventing people with dementia from living at home. Geriatr Nurs 2018;39(1):29-38 [FREE Full text] [doi: 10.1016/j.gerinurse.2017.05.003] [Medline: 28624128]
8. Giebel CM, Sutcliffe C. Initiating activities of daily living contributes to well-being in people with dementia and their carers. Int J Geriatr Psychiatry 2018 Jan;33(1):e94-102. [doi: 10.1002/gps.4728] [Medline: 28467006]
9. Poulos CJ, Bayer A, Beaupre L, Clare L, Poulos RG, Wang RH, et al. A comprehensive approach to reablement in dementia. Alzheimers Dement (N Y) 2017 Sep;3(3):450-458 [FREE Full text] [doi: 10.1016/j.trci.2017.06.005] [Medline: 29067351]
10. Jamieson M, Cullen B, McGee-Lennon M, Brewster S, Evans JJ. The efficacy of cognitive prosthetic technology for people with memory impairments: a systematic review and meta-analysis. Neuropsychol Rehabil 2014;24(3-4):419-444. [doi: 10.1080/09602011.2013.825632] [Medline: 23957379]
11. Lancioni G, Desideri L, Singh N, O'Reilly M, Sigafoos J. Technology options to help people with dementia or acquired cognitive impairment perform multistep daily tasks: a scoping review. J Enabling Technol 2021 May 25;15(3):208-223. [doi: 10.1108/jet-11-2020-0048]
12. Evans N, Boyd H, Harris N, Noonan K, Ingram T, Jarvis A, et al. The experience of using prompting technology from the perspective of people with dementia and their primary carers. Aging Ment Health 2021 Aug;25(8):1433-1441. [doi: 10.1080/13607863.2020.1745145] [Medline: 32223428]
13. Lariviere M, Poland F, Woolham J, Newman S, Fox C. Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: findings from an embedded ethnography of a national dementia trial. BMC Geriatr 2021 Feb 15;21(1):121 [FREE Full text] [doi: 10.1186/s12877-020-01896-y] [Medline: 33588768]
14. Sriram V, Jenkinson C, Peters M. Carers' experience of using assistive technology for dementia care at home: a qualitative study. BMJ Open 2020 Mar 18;10(3):e034460 [FREE Full text] [doi: 10.1136/bmjopen-2019-034460] [Medline: 32193267]
15. Boger J, Jackson P, Mulvenna M, Sixsmith J, Sixsmith A, Mihailidis A, et al. Principles for fostering the transdisciplinary development of assistive technologies. Disabil Rehabil Assist Technol 2017 Jul;12(5):480-490. [doi: 10.3109/17483107.2016.1151953] [Medline: 27052793]
16. Wilson M, Doyle J, Turner J, Nugent C, O'Sullivan D. Designing technology to support greater participation of people living with dementia in daily and meaningful activities. Digit Health 2024 Jan 15;10:20552076231222427 [FREE Full text] [doi: 10.1177/20552076231222427] [Medline: 38235415]
17. Enshaeifar S, Zoha A, Markides A, Skillman S, Acton ST, Elsaleh T, et al. Health management and pattern analysis of daily living activities of people with dementia using in-home sensors and machine learning techniques. PLoS One 2018;13(5):e0195605 [FREE Full text] [doi: 10.1371/journal.pone.0195605] [Medline: 29723236]

18. Jean-Baptiste EM, Mihailidis A. Benefits of automatic human action recognition in an assistive system for people with dementia. In: Proceedings of the IEEE Canada International Humanitarian Technology Conference. 2017 Presented at: IHTC 2017; July 21-22, 2017; Toronto, ON URL: https://ieeexplore.ieee.org/abstract/document/8058201/authors#authors
19. Boyd HC, Evans NM, Orpwood RD, Harris ND. Using simple technology to prompt multistep tasks in the home for people with dementia: an exploratory study comparing prompting formats. Dementia (London) 2017 May;16(4):424-442 [FREE Full text] [doi: 10.1177/1471301215602417] [Medline: 26428634]
20. Dharan NM, Alam MR, Mihailidis A. Speech-based prompting system to assist with activities of daily living: a feasibility study. Gerontechnology 2021;20(2):1-12. [doi: 10.4017/gt.2021.20.2.436.06]
21. Lancioni GE, Singh NN, O'Reilly MF, Sigafoos J, D'Amico F, Laporta D, et al. Technology-based behavioral interventions for daily activities and supported ambulation in people with Alzheimer's disease. Am J Alzheimers Dis Other Demen 2018 Aug;33(5):318-326 [FREE Full text] [doi: 10.1177/1533317518775038] [Medline: 29742903]
22. Braley R, Fritz R, Van Son CR, Schmitter-Edgecombe M. Prompting technology and persons with dementia: the significance of context and communication. Gerontologist 2019 Jan 09;59(1):101-111 [FREE Full text] [doi: 10.1093/geront/gny071] [Medline: 29897450]
23. Lancioni GE, Perilli V, Singh NN, O'Reilly MF, Sigafoos J, Cassano G, et al. Technology-aided pictorial cues to support the performance of daily activities by persons with moderate Alzheimer's disease. Res Dev Disabil 2012;33(1):265-273. [doi: 10.1016/j.ridd.2011.09.017] [Medline: 22093673]
24. Harris N, Boyd H, Evans N, Cheston R, Noonan K, Ingram T, et al. A preliminary evaluation of a client-centred prompting tool for supporting everyday activities in individuals with mild to moderate levels of cognitive impairment due to dementia. Dementia (London) 2021 Apr;20(3):867-883 [FREE Full text] [doi: 10.1177/1471301220911322] [Medline: 32249596]
25. Hackett K, Lehman S, Divers R, Ambrogi M, Gomes L, Tan CC, et al. Remind me to remember: a pilot study of a novel smartphone reminder application for older adults with dementia and mild cognitive impairment. Neuropsychol Rehabil 2022 Jan;32(1):22-50 [FREE Full text] [doi: 10.1080/09602011.2020.1794909] [Medline: 32684106]
26. Desideri L, Lancioni G, Malavasi M, Gherardini A, Cesario L. Step-instruction technology to help people with intellectual and other disabilities perform multistep tasks: a literature review. J Dev Phys Disabil 2020 Nov 17;33(6):857-886. [doi: 10.1007/S10882-020-09781-7]
27. Casaccia S, Revel GM, Scalise L, Bevilacqua R, Rossi L, Paauwe RA, et al. Social robot and sensor network in support of activity of daily living for people with dementia. In: Proceedings of the Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context. 2019 Presented at: D-Lab 2019; October 21-22, 2019; Eindhoven, The Netherlands. [doi: 10.1007/978-3-030-33540-3_12]
28. Amabili G, Cucchieri G, Margaritini A, Benadduci M, Barbarossa F, Luzi R, et al. Social robotics and dementia: results from the eWare project in supporting older people and their informal caregivers. Int J Environ Res Public Health 2022 Oct 16;19(20):13334 [FREE Full text] [doi: 10.3390/ijerph192013334] [Medline: 36293915]
29. van Dam K, Gielissen M, Reijnders R, van der Poel A, Boon B. Experiences of persons with executive dysfunction in disability care using a social robot to execute daily tasks and increase the feeling of independence: multiple-case study. JMIR Rehabil Assist Technol 2022 Nov 03;9(4):e41313 [FREE Full text] [doi: 10.2196/41313] [Medline: 36326800]
30. Lancioni GE, Singh NN, O'Reilly MF, Sigafoos J, Tatulli E, Rigante V, et al. Technology-aided verbal instructions to help persons with mild or moderate Alzheimer's disease perform daily activities. Res Dev Disabil 2010;31(6):1240-1250. [doi: 10.1016/j.ridd.2010.07.021] [Medline: 20696547]
31. Perilli V, Lancioni GE, Hoogeveen F, Caffó A, Singh N, O'Reilly M, et al. Video prompting versus other instruction strategies for persons with Alzheimer's disease. Am J Alzheimers Dis Other Demen 2013 Jun 17;28(4):393-402 [FREE Full text] [doi: 10.1177/1533317513488913] [Medline: 23687181]
32. Hoey J, Poupart P, Bertoldi AV, Craig T, Boutilier C, Mihailidis A. Automated handwashing assistance for persons with dementia using video and a partially observable Markov decision process. Comput Vision Image Understand 2010 May;114(5):503-519. [doi: 10.1016/j.cviu.2009.06.008]
33. Czarnuch S, Cohen S, Parameswaran V, Mihailidis A. A real-world deployment of the COACH prompting system. J Ambient Intell Smart Environ 2013;5(5):463-478. [doi: 10.3233/ais-130221]
34. O'Neill B, Moran K, Gillespie A. Scaffolding rehabilitation behaviour using a voice-mediated assistive technology for cognition. Neuropsychol Rehabil 2010 Aug;20(4):509-527. [doi: 10.1080/09602010903519652] [Medline: 20182951]
35. Chang YJ, Chou LD, Wang FT, Chen SF. A kinect-based vocational task prompting system for individuals with cognitive impairments. Pers Ubiquit Comput 2011 Dec 17;17(2):351-358. [doi: 10.1007/S00779-011-0498-6]
36. O Neill B, Best C, O Neill L, Ramos SD, Gillespie A. Efficacy of a micro-prompting technology in reducing support needed by people with severe acquired brain injury in activities of daily living: a randomized control trial. J Head Trauma Rehabil 2018;33(5):E33-E41. [doi: 10.1097/HTR.0000000000000358] [Medline: 29194177]
37. Pinard S, Bottari C, Laliberté C, Pigot H, Olivares M, Couture M, et al. Design and usability evaluation of COOK, an assistive technology for meal preparation for persons with severe TBI. Disabil Rehabil Assist Technol 2021 Oct;16(7):687-701. [doi: 10.1080/17483107.2019.1696898] [Medline: 31846395]

38. Brookman R, Parker S, Hoon L, Ono A, Fukayama A, Matsukawa H, et al. Technology for dementia care: what would good technology look like and do, from carers' perspectives? BMC Geriatr 2023 Dec 16;23(1):867 [FREE Full text] [doi: 10.1186/s12877-023-04530-9] [Medline: 38104074]
39. Jeon YH, Shin M, Smith A, Beattie E, Brodaty H, Frost D, et al. Early implementation and evaluation of StepUp for dementia research: an Australia-wide dementia research participation and public engagement platform. Int J Environ Res Public Health 2021 Oct 28;18(21):11353 [FREE Full text] [doi: 10.3390/ijerph182111353] [Medline: 34769871]
40. Unsplash homepage. Unsplash. URL: https://unsplash.com/ [accessed 2024-07-29]
41. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975 Nov;12(3):189-198. [doi: 10.1016/0022-3956(75)90026-6] [Medline: 1202204]
42. Clarke V, Braun V. Thematic analysis. J Posit Psychol 2016 Dec 09;12(3):297-298. [doi: 10.1080/17439760.2016.1262613]
43. Evans JJ, Emslie H, Wilson BA. External cueing systems in the rehabilitation of executive impairments of action. J Int Neuropsychol Soc 1998 Jul;4(4):399-408. [Medline: 9656613]
44. Manly T, Hawkins K, Evans J, Woldt K, Robertson IH. Rehabilitation of executive function: facilitation of effective goal management on complex tasks using periodic auditory alerts. Neuropsychologia 2002;40(3):271-281. [doi: 10.1016/s0028-3932(01)00094-x] [Medline: 11684160]
45. McGoldrick C, Crawford S, Evans JJ. MindMate: a single case experimental design study of a reminder system for people with dementia. Neuropsychol Rehabil 2021 Jan;31(1):18-38 [FREE Full text] [doi: 10.1080/09602011.2019.1653936] [Medline: 31429370]
46. Caroux L, Consel C, Merciol M, Sauzéon H. Acceptability of notifications delivered to older adults by technology-based assisted living services. Univ Access Inf Soc 2019 Jul 6;19(3):675-683. [doi: 10.1007/s10209-019-00665-y]
47. Mihailidis A, Boger JN, Craig T, Hoey J. The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study. BMC Geriatr 2008 Nov 07;8:28 [FREE Full text] [doi: 10.1186/1471-2318-8-28] [Medline: 18992135]
48. Gibson G, Dickinson C, Brittain K, Robinson L. Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. Ageing Soc 2018 Jun 27;39(11):2502-2519. [doi: 10.1017/s0144686x18000661]
49. Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, et al. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR Rehabil Assist Technol 2017 Jan 16;4(1):e1 [FREE Full text] [doi: 10.2196/rehab.6376] [Medline: 28582262]
50. Evans J, Brown M, Coughlan T, Lawson G, Craven MP. A systematic review of dementia focused assistive technology. In: Proceedings of the 17th International Conference on Human-Computer Interaction: Interaction Technologies. 2015 Presented at: HCI International 2015; August 2-7, 2015; Los Angeles, CA. [doi: 10.1007/978-3-319-20916-6_38]

Abbreviations

ADL: activity of daily living
COACH: Cognitive Orthosis for Assisting Activities in the Home
MMSE: Mini-Mental State Examination

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Original Paper

Digital Storytelling for People With Cognitive Impairment Using Available Mobile Apps: Systematic Search in App Stores and Content Analysis

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Abstract

Background: Growing evidence suggests cognitive and social health benefits can be derived from digital storytelling for older adults with cognitive impairment. Digital storytelling apps offer the potential to serve as an on-demand, easy-to-access platform for enhancing cognitive abilities and promoting social well-being. Yet, despite the increasing quantity of such apps being available on the market, there is a gap in research investigating their quality.

Objective: This app review aims to assess the digital storytelling apps available in the Chinese market and evaluate them in accordance with the Mobile Application Rating Scale (MARS). The goal was to identify key features and evaluate the overall quality in the context of cognitively impaired users.

Methods: A systematic search was conducted in both the Google Play store (Google LLC) and iTunes store (Apple Inc), using English and Chinese keywords. Apps were chosen according to specific criteria that included features, including (but not limited to) memory capture, story saving, cue-based reminiscing, and the ability to share stories or memories with others. The MARS was used by 3 individual researchers to independently assess app quality across several domains, such as engagement, functionality, aesthetics, and information quality, for both Android and iOS apps.

Results: From an initial screening of 297 apps, only 9 (3%) met the criteria for detailed evaluation using MARS. The reviewed apps featured *capture memory*, *save*, *reminisce*, and *share* functions, which are critical in supporting cognitive functions and enhancing user engagement. The analysis revealed patterns in platform diversity and geographical distribution of developers, with apps available on both iOS and Android. Memoirs of Life and Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories (Fair Apps Mobile) had the highest mean MARS scores of 3.35, indicating strong engagement, functionality, and information quality, while the lowest score was 2.33. The overall mean score across all apps was only 3.03 (SD 0.60), highlighting significant variation, particularly in information quality. User feedback also showed considerable variability, ranging from 0 comments for apps such as Grand Storyteller (VarIT Inc) and PWI Storyteller (Project World Impact, LLC) to as many as 5361 comments for FamilySearch, which received extensive positive reviews. This wide range of user feedback underscores the importance of continuous improvement and user-centered design, particularly in enhancing information quality and content accuracy.

Conclusions: The systematic search and evaluation highlight the diverse capabilities yet variable quality of digital storytelling apps available within the Chinese market, reflecting user experiences, satisfaction levels, and efficacy in supporting cognitively impaired users. While some apps excel in engagement and functionality, others need significant improvements in information quality and user interface design to better serve those with cognitive impairments. Future research is recommended to investigate regional limitations and features that would result in more inclusive and effective digital storytelling apps.

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KEYWORDS

mobile apps; digital storytelling; older adults; mobile phone; cognitive impairment

Introduction

Background

Storytelling, as a practice of therapeutic intervention, has been shown to empower people with cognitive impairment engaged in chronic disease self-management, facilitating recovery by allowing them to actively identify needs and knowledge gaps while fostering connections with peers who share similar experiences [1]. For instance, a storytelling-based intervention resulted in significant improvements in blood pressure [2] among older adults diagnosed with uncontrolled hypertension. Despite the demonstrable physical benefits, storytelling apps designed for people with cognitive impairment offer a range of mental health and general well-being benefits. First, these apps serve as powerful tools for memory enhancement, with empirical studies demonstrating positive improvements in long-term and short-term memory [3,4] as well as older adults recollection and improved cognitive functions via leveraging narratives and visuals [5,6]. By engaging users in personalized and meaningful activities, including story-editing activities [7] and story-sharing activities [8], these apps contribute to a sense of purpose and accomplishment, aiding positive psychosocial and cognitive recovery. In the context of communication and social interaction, these apps play a crucial role by facilitating meaningful connections between their caregivers (including spouses) [8,9], family members [10], and peers [11,12]. Moreover, emotional connections fostered through storytelling have been found to be integral in promoting overall well-being [13], mitigating symptoms of depression and anxiety [14], and even linking older adults with dementia to personal histories, thereby aiding memory recall. These systems are crafted to evoke memories, enhance communication, and foster social engagement by leveraging digital media technologies [15,16]. There are key differences between fictional storytelling and reminiscence-based storytelling, both of which have distinct impacts on cognitive, emotional, and social processes. Fictional storytelling, for instance, has been shown to enhance cognitive engagement by transporting individuals into the narrative, thus deepening their emotional involvement and promoting cognitive stimulation [17]. By contrast, reminiscence-based storytelling plays a crucial role in memory enhancement and emotional well-being, particularly among older adults, by encouraging the recall of personal memories and fostering a sense of identity and continuity [18]. The emotional processing involved in these 2 types of storytelling also differs significantly. Fictional storytelling often leads to the creation of new emotional experiences, while reminiscence-based storytelling is more likely to evoke past emotions, reinforcing a person's narrative identity [19]. In addition, the social benefits of reminiscence-based storytelling are well documented, with research showing that it can improve social interactions and contribute to overall well-being in older populations [15]. Research shows that individuals with cognitive impairments, including those with dementia, retain the ability to generate creative stories through structured programs. For instance, the TimeSlips program is an arts-based, creative storytelling initiative designed for people with dementia. In this program, participants collaboratively create stories using their imaginations and respond to staged pictures, guided by a facilitator [20]. This approach not only fosters creativity but also encourages meaningful social interactions among participants, highlighting their capacity to engage in generative activities despite cognitive challenges. This evidence supports the notion that even individuals with cognitive impairments can actively participate in creative storytelling, contributing to collective narratives and maintaining social connections. Thus, using the process of storytelling, these apps catalyze effective communication, supporting cognitive and psychosocial recovery, as well as enriching the lives of older adults with cognitive impairment.

Despite this potential, the plethora of storytelling apps available on the market—and their utility and efficacy for the cognitively impaired—remains woefully understudied. With a lack of concrete evidence regarding their quality, a need to fill this research gap emerges [21]. While the potential benefits for those with cognitive impairment are well understood in theory, the commercial digital storytelling apps available remain largely untested; instead, the academic focus has thus far been commercial software, primarily instant-messaging apps [22] and video editing software [7]. Given the uncertainty deriving from the plethora of available apps, consumers and older adults often turn to reviews and ratings on app stores or published on developer websites to inform their decision-making process [23]. However, reliance on such reviews brings forth the challenge of ensuring these apps are genuinely suitable for individuals with cognitive impairment. Indeed, despite the theoretical utility of such apps for older adults who are cognitively impaired, no specific measure or ranking system exists designed specifically for that user group. Extant consumer ratings were found to be poor indicators of clinical utility or usability, with a significant number of apps exhibiting potentially misleading and dangerous health information entered by users [21].

A scoping review explored studies related to digital storytelling apps published in 2023 [6], wherein only 1 study was found to have undertaken a randomized controlled trial, predominantly focused on academic apps that were not readily available in the commercial market [11]. A few exceptions were observed where commercial software, such as WeChat (Tencent) [22] and WeVideo (WeVideo, Inc) [7], were used. However, these commercial apps were used merely as auxiliary tools, limiting their capacity to support specific phases of the digital storytelling process. Bridging the gap between the lack of empirical proof of app utility and consumer reliance on potentially inaccurate reviews is crucial. An up-to-date and comprehensive review of apps offers an informative and much-needed benchmark in assessing the appropriateness and efficacy of digital storytelling apps, furnishing individuals and caregivers with valuable insights when selecting apps that genuinely cater to the unique needs of those with cognitive impairment. Simultaneously, this research aims to systematically review mobile apps for digital storytelling, evaluating their suitability for people with cognitive impairment. To do so, app quality is evaluated via an expert rating scale, delineating the features of the apps that received the highest scores.

On the basis of the extant body of academic literature [20,23], digital storytelling is conceptualized as comprising 4 components—*capture memory*, *save*, *reminisce*, and *share*—components which can be integrated into 2 prevailing theoretical frameworks: narrative psychology focuses on how individuals construct and understand their experiences through stories, making it particularly relevant for understanding the *capture memory* and *reminisce* functionalities. By contrast, life span developmental psychology emphasizes the importance of preserving memories and social connections at different stages of life, which aligns well with the *save* and *share* functionalities. The decision to use both theoretical approaches is grounded in their complementary nature. While narrative psychology offers insights into the personal and emotional aspects of storytelling, life span developmental psychology provides a broader context for understanding how these activities support cognitive and social well-being across the life span. These frameworks are epistemologically compatible, as both are concerned with understanding human development and behavior through the lens of memory and narrative. By integrating them, we can offer a more holistic understanding of how digital storytelling can be optimized for users with cognitive impairments.

First, narrative psychology studies how individuals construct and understand their experiences through stories. When translated to storytelling apps, this theoretical framework offers great potential for explaining the *capture memory* and *reminisce* functionalities. According to Bruner [24], people form and express their identity by recording and reconstructing their experiences. In digital storytelling apps, the *capture memory* functionality allows users to document life events through photos, videos, and text—transposing a cognitive function into a digital device. This not only helps users construct and understand their stories but also provides rich material for future reminiscence. In addition, narrative psychology emphasizes that individuals can better understand and construct their personal narratives by recalling and reflecting on past experiences [25]. In parallel, the *reminisce* functionality in digital storytelling apps allows users to revisit and reflect on their past, helping strengthen self-identity and promoting emotional health and social interaction [26].

Second, life span developmental psychology is focused on understanding how individuals handle and preserve memories at different life stages. This theoretical framework can correspond to and explain the *save* and *share* functionalities. Significant autobiographical memories shape an individual’s identity, reflect age-related themes of psychosocial development, and contribute to life satisfaction, particularly when these memories are emotionally positive [27]. In digital storytelling apps, the *save* functionality ensures that users can store their memories and stories indefinitely. This is especially important for older adults and individuals suffering from memory-related impairments, as it helps them maintain a sense of continuity in their personal history and narrative as memory declines.

In addition, life span developmental psychology emphasizes the importance of social relationships and emotional support at different life stages. By sharing personal memories and stories, users can enhance social connections and support [22]. The *share* functionality in digital storytelling apps also enables users to share their stories and memories with family and friends, catalyzing social relationships and maintaining social networks, thereby facilitating emotional support—which in turn helps improve psychological health and social well-being [13]. By integrating narrative psychology and life span developmental psychology, we can comprehensively explain the 4 functionalities—*capture memory*, *save*, *reminisce*, and *share*—offered by digital storytelling apps. These functionalities collectively promote cognitive functions, emotional expression, and social interaction, providing older adult-users with greater opportunities for social support, psychosocial betterment, and cognitive recovery. Using this integrated framework not only helps our understanding of the effectiveness of these apps but can also guide future app development to better serve users with cognitive impairments.

Objectives

This study evaluates the features and quality of digital storytelling apps tailored for individuals with cognitive impairment within the Chinese cultural context. The primary research question focuses on determining the overall effectiveness of these apps in supporting cognitive functions and enhancing user engagement. This study investigates the key features of digital storytelling apps that are designed to support cognitive abilities and stimulate user engagement among a research population of users who are cognitively impaired in China. In addition, the research will investigate how these apps may aid in reminiscence and potentially promote social interactions. Through a systematic analysis of these aspects, the study aims to identify the potential benefits and adaptability of digital storytelling tools in the context of cognitive impairment. The research questions are as follows:

1. What are the features of digital storytelling apps for users who are cognitively impaired?
2. What are the qualities of those apps?
3. What are the users’ recommendations for an effective and engaged digital storytelling app?

Methods

Search Process

A systematic search was carried out across China’s Apple Store (Apple Inc) and Google Play (Google LLC). The search encompassed a carefully selected array of keywords in both English and Mandarin, relevant to this study’s focus. These keywords include *storytelling*, *life memories*, *life stories*, *life review*, *reminiscence*, *mild cognitive impairment*, *dementia*, *cognitive impairment*, and *Alzheimer’s disease*. Multimedia Appendix 1 presents the search outcome.

In total, 3 research assistants systematically conducted the searches, downloaded all apps that fell within the inclusion criteria, and independently evaluated each one. For every app, 2 reviewers were assigned to evaluate its relevance; in cases of discrepancy, a thorough discussion ensued to reach a consensus. The Mobile Application Rating Scale (MARS) was then used by the research assistants to assign a score to each screened app.

App Screening

The inclusion criteria were as follows: (1) a smartphone-based app, (2) compatible with Android or iOS operating systems, (3) the language of the app should be either English or Chinese, (4) the app should have features that contribute to assisted storytelling or reminiscence for those with cognitive impairment, and (5) the app must be available for download in the China app store via iTunes and Google Play.

During the preliminary screening process, the following exclusion criteria were applied, with duplicates removed: (1) app content is merely for information, education, reference, or reading only (ie, no data entry capability); (2) the app only comprises treatment algorithms; (3) the app only supports media editing or saving; (4) original story creation is not supported; and (5) it was explicitly designed for use by clinicians only.

Android apps were downloaded (via the China Google Play store) and tested, capturing memory, saving memory, reminiscence, and sharing features using Huawei P30Pro phones equipped with Android (version 5.1.1; Harmony OS). Similarly, iOS apps were downloaded (via the China iTunes store). Android apps were rated and reviewed using Huawei P30Pro on Harmony OS and Samsung S9 using the Android system. Apple apps were rated and reviewed using iPhone 11 on iOS 13. Each app was tested in a real-world environment for no less than 20 minutes by 3 researchers and scored together after testing was completed. (the PRISMA-ScR checklist is attached in Multimedia Appendix 2).

Data Collection

A total of 9 digital storytelling apps were evaluated by the research team from December 17, 2023, all of which declared their potential to support individuals with cognitive impairments. During this period, each team member independently documented information gathered from extensive user reviews and feedback available in the Ratings and Reviews sections of the iTunes App store and Google Play platform for each app. The data were extracted and organized using Excel (Microsoft Corp), which allowed for systematic categorization and analysis of user feedback across multiple parameters relevant to our study. This tool facilitated the efficient management and analysis of the large volume of user-generated data. This included fun mental app details (such as its name, country of origin, developers, and user ratings), as well as more in-depth data, such as app description, first launch time, pricing, overall comments, and the number of user comments. Additional data captured include the app's stated aims, its main features, its target users, user experience, and interaction logic, as well as functionalities related to the cognitive support features of Capture Memory, Save, Reminisce, and Share mentioned earlier. User interface and visual design elements (such as color, imagery, and screenshots) were also recorded and analyzed.

Data Analysis

Textbox 1 details the analytic methods applied to the collected data; we used a methodological approach designed to focus on different aspects of digital storytelling apps. Thematic analysis was used to identify and report patterns or themes within the description of apps, summarizing key features and evaluating commonalities across apps [28]. Similarly, thematic analysis was used to categorize and interpret platform diversity, geographic origins of app developers, and app ratings, helping to ascertain the spread and focus areas of app development across different regions and platforms. Thematic was then used to systematically categorize specific features of digital storytelling apps, allowing a structured comparison of more nuanced functionalities, such as *capture memory*, *save*, *reminisce*, and *share*, highlighting how these features support cognitive functions and user engagement. Statistical analysis was conducted based on the MARS [29] ratings to evaluate app quality. Mean scores were calculated across 4 domains: engagement, functionality, esthetics, and information quality. MARS is a validated tool widely used in other studies to assess mobile health apps. MARS is structured as a Likert-type scale, with items rated from 1 (inadequate) to 5 (excellent) across 4 domains: engagement, functionality, aesthetics, and information quality [29]. MARS showed strong internal consistency and interrater reliability, offering a dependable approach for rating and comparing mobile apps [30,31].

Textbox 1. Data collected and type of analysis used.

Analysis and data collected

- Thematic analysis
  - Description of apps: platform diversity, geographical distribution of develope, and features of digital storytelling apps
  - User feedback and engagement
- Descriptive statistics
  - App rating and quality assessment of digital storytelling apps: Mobile Application Rating Scale rating

All collected data were collaboratively reviewed by the 3 research assistants to ensure accuracy, consistency, and impartiality in the final evaluation. The data analysis process was structured to ensure a comprehensive and accurate evaluation of the apps. Initially, key areas for app development and improvement were highlighted through data summarization using Excel, where the research team organized and extracted essential data points from the app stores. Following this, each research assistant independently analyzed the data, assessing the apps' features and performance.

The team engaged in group discussions to review the independently analyzed data to ensure consistency and minimize individual biases. Discrepancies were resolved through these discussions, leading to a consensus on the final data extraction. This collaborative approach not only enhanced the reliability of the findings by incorporating diverse perspectives but also provided a foundation for identifying areas where the apps could be further developed and improved.

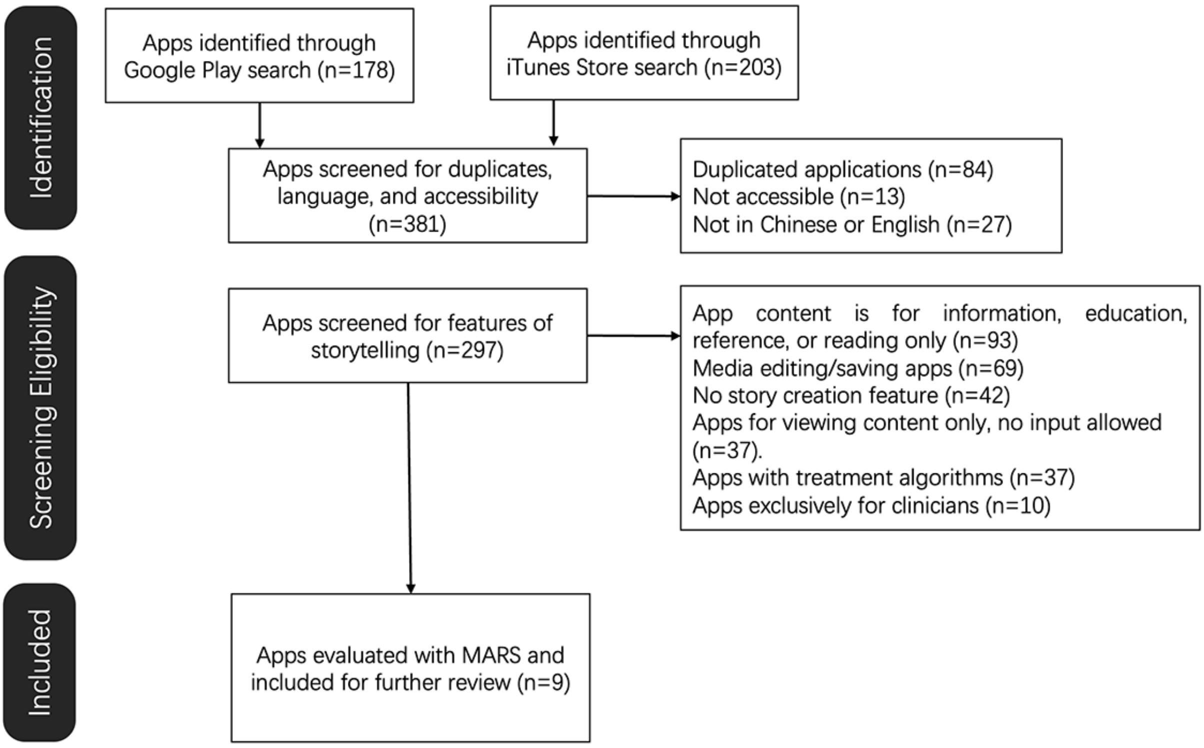
The research team used a detailed coding framework to systematically categorize feedback and MARS scores, ensuring a thorough and structured analysis. Regular cross-checks and validation steps were integrated throughout the review process to maintain data integrity and validity. Periodic meetings were also held to discuss emerging themes and refine the analysis methodology where necessary. This rigorous review process not only ensured the accuracy and consistency of the final evaluation, but also yielded comprehensive insights into the strengths and weaknesses of each app, thereby informing targeted recommendations for future app development vis-à-vis users who are cognitively impaired.

Results

Search Outcome

As depicted in Figure 1, Google Play yielded 46.7% (178/381) apps, while iTunes had a slightly higher yield with 53.3% (203/381) apps. After removing duplicates, the aggregate number of unique apps stood at 77.9% (297/381). The screening process then ensued, during which 4.3% (13/297) apps were found to be inaccessible; another 9.1% (27/297) apps did not offer Chinese or English language options. This filtration culminated in the inclusion of 9 apps that met all the stipulated criteria for further consideration.

Figure 1. Flow diagram of systematic search and selection of apps from the Google Play and iTunes stores. MARS: Mobile Application Rating Scale.



Overview of Digital Storytelling Apps

Table 1 provides an overview of the included storytelling and memory apps, detailing their platform compatibility, developer origins, user ratings, and feedback across both iOS and Android platforms.

Table 1. Overview of digital storytelling apps.

App name	Description	Country	Platform	Rating	Pricing	Number of comments
Story Dice: Story Telling	Game with 40 dice, 240 images, and unlimited stories. Mixed categories such as mystery or Star Wars.	Netherlands	Both iOS and Android	iOS: 4.6 and Android: 4.5	Free	iOS: 8 and Android: 0
Grand Storyteller	Create and share multimedia stories and convert stories into videos.	United States	iOS	No score provided	Free	—[a]
Memoirs of Life	Record daily life with documents, labels, and stickers. Add and edit photos.	China	Android	4	Free with membership	—
Spicy Memories	AI[b] selects and crops photos, sets time ranges, and shares photos as wallpapers or collages.	China	iOS	4.6	Free	245
PWI Storyteller	Share stories with nonprofits to help them tell their stories more effectively.	United States	iOS	No score provided	Free	—
Brief Memories of Photos	Simple Photo app groups photos with labels for easy retrieval.	China	iOS	3.6	Free	5
FamilySearch	Preserve and share family memories, create digital scrapbooks, capture important moments, identify relatives in photos, and sync across devices.	United States	Both iOS and Android	iOS: 4.9 and Android: 5.0	Free	iOS: 234 and Android: 47,400
Reminisce	Trivia game on American pop culture with categories such as television shows, movies, sports, history, and commercials.	China	Android	—	Free	—
Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories	Diary app for recording memories, thoughts, and events. Features include adding photos, voice notes, PIN[c] or fingerprint security, multiple themes, and backup or restore.	Unknown	Android	3.8	Free	3892

[a] Not applicable.

[b] AI: artificial intelligence.

[c] PIN: personal identification number.

All the apps included in our analysis are available (at least initially) for free, a common strategy used to increase user initial engagement without requiring a financial commitment. Only Memories of Life has a paid membership feature, which is necessary for users to export memories. Another shared aspect is their focus on storytelling or memory recording. This indicates a targeted market interest: users who are keen on documenting personal experiences, storytelling, or creatively engaging with content over periods. All these apps aim to preserve and share personal memories, stories, and experiences in a creative and engaging manner. They provide tools for users to manually record, organize, and share content, such as text, images, audio, and video. By and large, the apps are designed to be user-friendly and offer features such as tagging, categorizing, and integrating with other platforms for seamless sharing and retrieval of memories. They also emphasize personalization, enabling users to add their unique touches to their memories and stories.

Story Telling and Grand Storyteller, both encourage creative storytelling. The Story Telling app highlights its function of randomly displaying images, which prompts users to create imaginative stories. Story Telling uses dice with images to inspire the creation of fictional stories, encouraging users to craft narratives that are entirely imaginative and creative. The app's design promotes storytelling as a fun and interactive family activity, where participants use the random images provided by the dice to generate unique and inventive fictional stories. Grand Storyteller encourages detailed multimedia stories with text, images, audio, and video, which is perfect for documenting personal experiences and creating personalized audio storybooks. Memoirs of Life and Memorize both serve as digital diaries. Memoirs of Life is a simple app for documenting daily activities, moods, and thoughts with stickers and photos, whereas Memorize offers more features, including secure detailed memory recording with photos, voice notes, categories, tags, and themes, catering to a wide range of diary-keeping needs. Spicy Memories and Brief Memories of Photos function more like tools for organizing and curating photos.

Spicy Memories uses artificial intelligence (AI) to help users select and crop photos for rediscovery and sharing as wallpapers or photo collages. Brief Memories of Photos allows users to label photos for easy searching and revisiting, helping users efficiently manage photo collections. PWI Storyteller offers an innovative approach by connecting users with nonprofits, enabling them to share personal stories that organizations can use to promote their causes and engage audiences, fostering meaningful connections for social impact. FamilySearch helps preserve and share family memories by creating digital scrapbooks of important moments, enabling integration with other platforms for ease of access and sharing, making it ideal for documenting family heritage. The Reminisce app incorporates cultural elements by offering predefined story prompts that reflect various aspects of American pop culture, including African American heritage. This feature allows users to engage with culturally relevant content, which could include trivia about television shows, movies, sports, and historical events. In addition, users have the option to create their own stories, which provides a way to personalize their experience further. By integrating these elements, the app not only offers an engaging and educational platform but also allows users to explore and connect with cultural memories, potentially using their own photos to enhance and personalize the storytelling process.

Platform Diversity, Geographical Distribution of Developers, and App Ratings

The 9 apps sampled in this research exhibit significant diversity in terms of platform availability. About 44% (4/9) of the apps are exclusive to iOS, reflecting a preference (or perhaps a strategic decision) to target Apple's ecosystem, which is known for its more controlled user experience. In contrast, 22% (2/9) are exclusive to Android, which may cater to a broader user base given Android's larger global market share. Another 22% (2/9) are available on both iOS and Android, ensuring the widest possible accessibility. About 11% (1/9) of the total app's platform is unknown.

The geographical distribution of the app developers also exhibits significant variance, with China producing 33% (3/9) of the apps, reflecting significant input from Chinese developers in the app market. The United States is responsible for 22% (2/9) of the apps, demonstrating its continued influence in the global tech scene. About 11% (1/9) comes from the Netherlands, and the remaining 33% (3/9) have developers listed as global or unknown. All in all, this composition reflects a range of diverse or multinational development efforts.

About 67% (6/9) of the apps have a user rating of 4.0 or above, suggesting generally positive user feedback (where ratings are provided). Furthermore, 22% (2/9) of the apps have a high level of user engagement, with >200 comments on their respective platforms, highlighting significant interactive participation by users with those apps.

Features of Digital Storytelling Apps

The 9 sampled apps boast 4 principal functionalities: *capture memory*, *save*, *reminisce*, and *share* (Table 2). The *capture memory* feature allows users to take notes, snap pictures, or record videos directly through their smartphones, as well as upload existing media. The *save* function ensures that stories are not only displayed but also preserved for future access, transcending ephemeral experiences. *Reminisce* leverages these materials to facilitate the recollection of memories, enriching the user's reflective experience, such as via playback functionalities. Finally, *share* extends the reach of users' stories, enabling them to connect with a broader audience through digital or social media sharing. All apps incorporate reminiscence and outputting stories in the form of words or pictures.

Table 2. Comparative features of storytelling apps: capturing, saving, reminiscing, and sharing memories.

App	Capture memory	Save	Reminiscence	Share
Story Dice: Story Telling			✓[a]	
Grand Storyteller	✓	✓	✓	✓
Memoirs of Life		✓	✓	✓
Spicy Memories		✓	✓	
PWI Storyteller	✓	✓	✓	✓
Brief Memories of Photos		✓	✓	✓
FamilySearch	✓	✓	✓	✓
Reminisce			✓	
Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories	✓	✓	✓	✓

[a] Supported the features from the app.

Most apps (7/9, 78%) offer saving memories or stories, and 67% (6/9) apps support sharing the stories. About 22% (2/9) apps did not have *store memory stories* (Story Dice: Story Telling, and Reminisce), and 33% (3/9) did not have user tips (Grand Storyteller, Memoirs of Life, and Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories). Around 44% (4/9) apps provided memory themes (Grand Storyteller, PWI Storyteller, FamilySearch, and Reminisce). Grand Storyteller was unique in that it offered some broader story themes, which are illustrated by a cartoon picture and a sentence. PWI Storyteller is classified by some specific items or activities (potentially diseases for older adults-users) to determine the theme of the story. FamilySearch automatically determines the theme of memory through some very detailed guiding questions, whereby user answers influence the automated formation of stories. In *reminisce*, under each memory theme, an actual photo is in the foreground and questions about important life events are asked.

Table 3 synthesizes the findings from our analysis of the storytelling apps. The main columns in the table were created through thematic analysis of the features and functionalities identified across the apps. The "app community" column refers to the social features within each app that allow users to share their memory stories with others, fostering a sense of community. Memory Theme represents the categorization or thematic organization of the stories, which may be guided by the apps to help users focus on specific types of memories, such as childhood or significant life events. Classification denotes how the apps organize the content, whether by media type (text, photo, and video) or by chronological or thematic order. Usage Tips refers to the guidance or suggestions provided by the apps to enhance user engagement, such as best practices for creating and sharing stories or ways to use the app more effectively. These columns capture the core features shared across the storytelling apps. For instance, all the apps require users to upload and edit their memory-derived stories, providing materials for engaging in reminiscence. In addition, 89% (8/9) apps allow users to present their stories in multiple formats, such as text, photos, or videos.

Table 3. Shared features across storytelling apps.

App	App community	Memory theme	Classification	Use tips
Story Dice: Story Telling				✓[a]
Grand Storyteller		✓		
Memoirs of Life	✓		✓	
Spicy Memories			✓	✓
PWI Storyteller	✓	✓		✓
Brief Memories of Photos			✓	✓
FamilySearch		✓	✓	✓
Reminisce		✓		✓
Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories			✓	

[a] Supported the features from the app.

First, it can be seen that these storytelling apps all require users to upload their own memory-derived stories and use their own memories to edit and generate stories, providing materials for users to engage in reminiscence. Users can use the apps to browse through their own memory stories. Second, when using these apps (8/9, 89%), users can usually choose to present their memory stories in text, photos, or video form.

When engaged in creating their own memory stories, different apps use different methods for selecting the story's theme. For instance, Story Dice inspires users' creativity by letting them roll the dice in the app to create fictional stories, allowing users to invent characters, settings, and plots based on the outcomes of the dice rolls. Pela Memory uses AI technology to automatically select and crop photos uploaded by users to create collages. This kind of story generating method reduces the user's learning cost (which may be better suited for older adults who are cognitively impaired) and can guide users to pay attention to details in their photos that they have never noticed before, making user engagement with memory stories more fun and potentially aiding memory recall. In addition, these apps also differ in how they can classify user memories. There are 2 main ways of classification. One is to enable users to add tags themselves to classify their memories, whereby users edit memory classification tags manually, making it more flexible when using this kind of storytelling app. The other is that the app itself already has classifications, and users only need to add their own stories or photos under the preexisting classifications. This second approach may be more convenient and easier for cognitively impaired users to learn.

Quality Assessment of Digital Storytelling Apps: MARS Rating

To provide a systematic quality assessment, our research evaluated a sample of the available storytelling apps using the MARS across 4 domains: engagement, functionality, aesthetics, and information, culminating in an overall score (Table 4). The range of the mean score of MARS is 2.33 to 3.35, (SD 0.60). The reliability of the MARS was assessed using intraclass correlation coefficients (ICCs) across various categories. The results indicate that information quality demonstrated the highest reliability with an ICC of 0.81, suggesting substantial agreement among raters. Similarly, overall app quality also showed substantial reliability with an ICC of 0.71. The engagement category had moderate reliability with an ICC of 0.49, while the functionality and aesthetics categories exhibited fair reliability with ICCs of 0.37 and 0.38, respectively. The evaluation of digital storytelling apps using MARS yielded varied results across the 9 apps sampled, with scores reflecting different strengths and weaknesses regarding engagement, functionality, esthetics, and information quality. Memoirs of Life obtained a score of 3.6, 3.75, 3.3, and 2.4 over each of the domains, respectively, with a mean score of 2.33. Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories exhibited a slightly more consistent performance across domains, with scores of 3.4, 3, 3, and 2.9 (respectively), resulting in a mean of 3.06. Grand Storyteller emerged as a stronger contender for use by older adults who are cognitively impaired, with scores of 3.8, 3.75, 3.3, and 2.3 (respectively) and a mean score of 3.35. Spicy Memories and PWI Storyteller were found to be midrange, with mean scores of 3.18 and 3.05, respectively. Brief Memories of Photos and FamilySearch both demonstrated modest scores across all 4 domains, with a mean of 3.02 and 3.17 (respectively). Reminisce and Story Dice: Story Telling rounded out the evaluation, recording mean scores of 3.10 and 3.04 (respectively). The outcome of this assessment demonstrates the diverse capabilities and varying quality of digital storytelling apps currently available, reflecting a broad spectrum of user experiences and satisfaction levels.

Table 4. Average Mobile Application Rating Scale rating.

App	Engagement	Functionality	Aesthetics	Information	Scores, mean (SD)
Memoirs of Life	3.6	3.75	3.3	2.4	2.33 (0.77)
Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories	3.4	3	3	2.9	3.06 (0.70)
Grand Storyteller	3.8	3.75	3.3	2.3	3.35 (0.60)
Spicy Memories	3.4	3.5	3.7	2	3.18 (0.78)
PWI Storyteller	3	3.5	3.3	2.3	3.05 (0.53)
Brief Memories of Photos	3.2	3.25	3	2.3	3.02 (0.44)
FamilySearch	3.2	3.75	3.3	2.3	3.17 (0.61)
Reminisce	3.4	3.25	3.3	2.4	3.10 (0.46)
Story Dice: Story Telling	3	3.5	3	1.7	3.04 (0.22)

User Feedback and Engagement

User feedback and engagement across the digital storytelling apps reveal a diverse range of experiences and sentiments, which can be grouped into several key themes.

Overview of Comments

Despite the diverse range of comments, the overall comment across these apps is slightly positive, with 5231 positive reviews compared with 4280 negative ones. User feedback also showed considerable variability, ranging from 0 comments for apps such as Grand Storyteller and PWI Storyteller to as many as 5361 comments for FamilySearch, which received extensive positive reviews. This suggests a generally mediocre reception, with some apps, such as FamilySearch and Memorize, receiving high praise for their functionalities, while others, such as Spicy Memories, show room for improvement, particularly in user interface and flexibility. The diversity in feedback highlights the importance of continuous updates and improvements to meet user needs and enhance satisfaction, particularly for cognitively impaired users.

Ease of Use and User Interface

Users frequently mentioned the importance of a user-friendly interface. For example, Story Dice: Story Telling was generally found enjoyable, particularly for both adult and child users. However, criticisms arose regarding advertisements that could not be closed, which detracted from the overall user experience and could potentially confuse cognitively impaired users. Similarly, Spicy Memories faced criticism for becoming less user-friendly over time, as updates made the app more restrictive in editing options.

Content and Feature Satisfaction

Several apps received praise for specific features that enhance the user experience. FamilySearch garnered extensive positive feedback, with users appreciating its ability to collect and preserve family memories by adding photos, documents, and recordings to their family tree. This app also had the highest number of comments, indicating significant user engagement. By contrast, Brief Memories of Photos was highlighted for its effective tagging and organizing functionalities, though more detailed feedback was scarce.

Customization and Flexibility

Customization options were a point of contention for users. While Spicy Memories was praised for its innovative AI-driven features, such as rediscovering old photos and photo cropping options, users expressed dissatisfaction with the app's growing restrictions, reflecting challenges in balancing feature development with user flexibility. In addition, Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories received generally favorable reviews, particularly for its diary and note-taking functions, but users suggested improvements, such as enhanced data backup options, better security settings, and additional synchronization options.

Market Penetration and User Engagement

The level of user engagement varied widely among the apps. Grand Storyteller, PWI Storyteller, and Reminisce had no user comments available, which could indicate either low user engagement or limited market penetration. Memoirs of Life also lacked specific user feedback, making it challenging to assess user satisfaction or identify areas for improvement. The scarcity of comments for these apps suggests a relatively small target audience or recent entry into the market.

Discussion

Principal Findings

The principal findings from the evaluation of 9 digital storytelling apps using the MARS offer significant insights into the app landscape. Among the apps evaluated, Memoirs of Life and Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories scored the highest, with Grand Storyteller also performing well, indicating a balance in user engagement, functionality, esthetics, and information quality. Story Dice: Story Telling yielded the lowest mean score at 3.04, primarily due to its deficiencies in information quality. Apps with lower information quality scores are likely to struggle with user retention and credibility, which are critical for maintaining user interest. Users' feedback on specific app features and innovative features such as the photo classification functionality received positive feedback, contrasting with criticisms of Story Dice for its lack of innovation.

Apps, such as FamilySearch, have received extensive positive feedback and high user engagement, whereas others, such as Grand Storyteller, have received minimal feedback, highlighting market penetration inconsistencies and varying user interest levels. The geographical distribution of app developers, with significant contributions from China and the United States, indicates a global interest in digital storytelling technologies.

In summary, while certain apps set benchmarks for excellence in the digital storytelling domain, others lag, particularly in crucial areas, such as information quality. This disparity accentuates the need for ongoing improvements in app functionality and user interface to better cater to specific user groups, particularly those with cognitive impairments.

Features of Storytelling Apps

Traditional photo organization features on mobile devices often fall short of more complex or customizable sorting, making the structured and intuitive classification functions provided by storytelling apps highly beneficial [32,33]. These apps simplify the management of photos, offering a supportive user experience for the cognitively impaired. In addition, some apps incorporate AI to automatically generate photo albums and recall key life milestones, which can further support users in selecting appropriate materials for reminiscence [8]. This innovative use of technology simplifies data interaction as well as encourages sharing memories within social groups, which can improve social relationships and foster new connections, especially among older adults [34]. The effective use of AI and organization features in storytelling apps plays a crucial role in supporting cognitive functions and enhancing social engagement among users. AI can perform an automated role in curating, summarizing, linking, and presenting vast amounts of image data in a manner that is particularly helpful for the cognitively impaired. In this context, storytelling emerges as a fitting metaphor, adept at capturing and illustrating the narratives and insights hidden within the relationships among data scattered across various repositories. The difference, however, lies in the fact that commercial apps have introduced AI for automatic filtering and reminders.

In addition, helping users to share their memories or stories in a group by offering preset themes is also one of the ways to increase positive user engagement and, by extension, positive emotions. Such an approach is not only innovative but also instrumental in making complex data interactions more accessible and engaging for users, especially for older adults or those who are cognitively impaired. This underscores the untapped potential of commercial apps that could leverage AI to transform how we interact with and interpret image data, turning it into compelling and informative digital narratives that are particularly valuable in enhancing cognitive engagement among older adults. This form of sharing in a group, by contrast, can also support users in maintaining or enhancing their social relationships and making new social connections. Academic research has shown that the choice of story themes is limited, and there is little support for group activities [6,7], revealing a research and operational gap. Finally, the sample analyzed herein revealed how some apps focus on the entertainment value they provide. These apps often achieve this through some special interaction or interactive logic. For instance, by shaking the phone to simulate a dice roll, the app reads the contents of a photo album to automatically generate memories or to locate people nearby who have similar experiences, thereby encouraging face-to-face meetings or walks together.

Quality of Digital Storytelling Apps

The quality of these apps, as assessed using established methods such as the MARS, shows considerable variation. For instance, apps such as Memoirs of Life and Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories rank highly due to their comprehensive features and user-friendly interfaces, all of which are conducive to supporting cognitive functions [32,33]. In contrast, other apps may have lower scores due to less effective implementation of features or poorer information quality, aspects that are crucial for users who rely on accurate reminiscence triggers and social interaction support [35-37]. The effectiveness of digital storytelling apps, particularly within the Chinese cultural context and for individuals with cognitive impairments, such as dementia, reveals a high degree of potential yet varied outcomes [4]. This statistical approach provided a quantifiable measure of app utility and quality, facilitating objective comparisons. Thematic analysis was additionally used to gauge user feedback and engagement levels, a process that entailed an examination of user reviews to identify common sentiments, areas of satisfaction, and points of contention. This layer of analysis helps us to understand the user experience and the impact of app updates on user satisfaction.

These apps, which aim to engage users—especially older adults—often suffer from a gap in quality and a lack of specialized features. This results in an overall scarcity of intuitive and cognitively engaging apps, as is demonstrated by the limited user comments and a lack of engagement. These factors suggest a need for apps more tailored to specific user needs. Moreover, there is a clear oversight in the accessibility and practicality of these apps for public use, highlighting an urgent need for focused development and rigorous evaluation to enhance their relevance and effectiveness in promoting cognitive engagement. This finding is supported by various studies that demonstrate the benefits of digital reminiscence therapy, which can facilitate significant enhancements in cognitive function and emotional well-being among participants. Studies by Moon and Park [38], Mulvenna et al [39], Derbring et al [40], and Sarne-Fleischmann et al [41] illustrate how these interventions not only improve engagement and interaction among older adults and caregivers but also emphasize the importance of personalized digital systems in improving recall abilities among older adults who are cognitively impaired, especially among older adults with Alzheimer. Collectively, these findings provide an empirical basis to support the continued development and integration of digital storytelling tools in therapeutic and care settings, highlighting the potential of these technologies to significantly improve cognitive functions, emotional well-being, and interpersonal interactions, thereby enhancing the overall quality of life for cognitively impaired users. While this research has filled a gap in the academic literature, it has also revealed an important gap between empirical findings and commercially available solutions for the cognitively impaired.

Recommendations for Effective and Engaged Digital Storytelling

Synthesizing the user feedback indicates that there is a need for more interactive and personalized features in digital storytelling apps to improve engagement and effectiveness in cognitive and social support. Digital storytelling apps facilitate reminiscence and social interaction among users with cognitive impairment by providing functions that are both engaging and relatively easy to navigate. For instance, apps such as FamilySearch and Memoirs of Life offer functionalities that not only allow users to store and recall memories but also share these with others. This sharing capability is advantageous and yields therapeutic benefits, as it enables users to connect with family and friends, fostering social interactions that are vital for mental health and social well-being. Moreover, the integration of AI technologies in apps such as Spicy Memories enhances the curation and presentation of personal content, making it more accessible and engaging for users; this not only supports cognitive engagement through interactive reminiscence but also makes the apps easier to use and thus less burdensome for the cognitively impaired. Digital memory books that incorporate personal photos, videos, and narratives can improve the emotional and social well-being of older adults.

The strategies of these apps in terms of functionality are almost identical and offer little differentiation. For instance, some apps allow memories to be cataloged according to life events or specific topics, providing a structured approach (ie, timeline) to storytelling [11]. Moreover, there are apps that index memories by locations and dates, offering strategies to track recollections over time. These features enhance the user experience by simplifying the process of memory retrieval and organization, aiding in memory recall. In addition to the timeline organization strategy used in the reminiscence phase of digital storytelling, these apps offer significant potential for the integration of other stages and behavioral change strategies. These include setting behavior goals and outcome objectives, which can play a crucial role in structuring the storytelling process [42] and encouraging cognitive exercises. Specifically, in the reminiscence phase, the introduction of scaffolding techniques can significantly aid older users in recalling memories [43]. This could involve the use of guided questions or prompts that help in fleshing out stories more comprehensively. By incorporating such strategies, digital storytelling apps can become more than just tools for memory capture; they can actively assist users in weaving richer, more detailed narratives, thereby enhancing the overall storytelling experience for older adults.

Regarding story-sharing functionalities, in academic settings, sharing is found to be more oriented, toward family members and participants who are involved, which is understandable given the personal nature of photographs [14,44]. Narrating personal experiences and events offers a wealth of subjects for discussion and chances to establish connections with others [45]. Discussing our own life experiences is recognized as integral to forming relationships and is a primary method through which we pursue and establish connections with others. In this research, we observed distinct technical features across various storytelling apps, each designed to enhance the user experience in unique ways. Memoirs of Life stands out with its sharing capability, necessitates user login, and requires internet access for its functionality. PWI Storyteller similarly offers a sharing feature that requires internet access. A notable aspect of FamilySearch is its facilitation of family members sharing a common database, with the added advantage of memory sharing through networking. This app seamlessly synchronizes with FamilySearch, which facilitates a fluid experience across different devices by enabling users to pick up where they left off (a reduction in the necessary steps, thereby increasing accessibility for the cognitively impaired). Memorize offers a robust solution for journaling, with features for permanent storage, backup to Google's cloud storage, and the ability to import and export memories in different formats, including ZIP files. By contrast, some apps did not exhibit specific technical features.

Commercial apps offer several advantages in supporting story sharing, particularly for older adults or cognitively impaired users. A promising feature is the ability to invite family members to collaborate and edit stories together, fostering a sense of community and intergenerational connection [45]. Furthermore, research into the mediating effects of internet use reveals that it enhances the propensity of older adults to engage with their communities, partly due to the improvement in their subjective health perceptions [46]. By providing an easy and accessible platform for sharing personal narratives, commercial storytelling apps not only promote social interaction but also potentially improve the overall well-being of older adults, which is conducive to psychosocial and cognitive therapy.

Research Implications and Future Directions

This research identifies a need for more comprehensive studies that not only explore commercially available digital storytelling tools but also examine their adaptability and relevance for older and cognitively impaired users. Such studies should aim to address the usability challenges these apps often present and explore how AI-enhanced features can further support cognitive functioning, mental health, and social well-being. By focusing on these aspects, future research can significantly contribute to the development of digital storytelling apps that are more inclusive, effective, and tailored to meet the unique needs of this population segment. Ongoing research is needed to further explore the long-term effects of digital storytelling apps, the best practices for their design and usability, and how they can be integrated into broader dementia care strategies.

Strength and Limitations

This study offers an initial exploratory review of digital storytelling apps, assessing their quality and suitability through a newly developed multidimensional expert rating scale. This scale provides a comprehensive measure of app quality across 4 objective domains (engagement, functionality, aesthetics, and information quality) and incorporates a subjective aspect. These objective quality dimensions, which contribute to the overall app quality score, offer a quantitative means for comparative analysis and can set a benchmark for future research.

Nonetheless, this study has a few limitations. First, while the rating scale is effective in evaluating the current milieu of apps, it cannot replace the need for user-centered design and evidence-based practices in app development, especially within the health behavior sector. A significant limitation of this study is its geographic restriction to the Chinese market, meaning that apps that may be available in other regions have not been considered. This limitation may have resulted in the exclusion of potentially relevant apps that are not accessible within the Chinese market, thus limiting the scope of this review. Future research would do well to increase the geographic scope of analysis. Future studies should also focus on evaluating specific storytelling features and guided content within these apps, as there is currently no established standard for optimal storytelling practices or their efficacy in mitigating symptoms of cognitive impairment. This study did not establish a standard for optimal storytelling practices, particularly regarding the use of fictional versus reminiscence-based storytelling in digital apps for older adults. The differences between these 2 types of storytelling and their respective impacts on cognitive function remain underexplored. Future research should aim to delineate the cognitive benefits of each storytelling approach, particularly for older adults with cognitive decline.

Conclusions

This systematic search and evaluation of digital storytelling apps in the Chinese app ecosystem reveals a gap in the quality and features of these apps, particularly for users with cognitive impairment. Our findings, derived from an extensive search in both English and Chinese on the Google Play Store and iTunes Store, identified 297 unique apps, with only 9 (3%) meeting our criteria for further evaluation. The apps sampled herein and evaluated using MARS, exhibited varied levels of quality. Key functionalities such as capture memory, save, reminisce, and share were not uniformly present across all apps. The highest-rated apps were Memoirs of Life and Memorize: Diaries, Memories, Notes, Ideas, Timelines, Categories, indicating a balance in engagement, functionality, and information quality. However, overall, many apps reveal significant room for improvement, especially in the information domain (where user complaints were concentrated). This exploratory study lays the foundation for future research and development in digital storytelling apps, aiming to enhance user experience and effectiveness. The significance of these results lies in guiding the development of more effective digital storytelling apps to maximize their therapeutic potential with a focus on the cognitively impaired. In parallel, the findings emphasize the need for improved content accuracy, user interface design, and the integration of AI technologies to enhance cognitive support and user engagement by aiding in photo restoration and material selection.

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Authors' Contributions

AAM and DZ conceptualized the study. DZ collected and analyzed the data. AAM directed several rounds of feedback and contributed significantly to the manuscript's writing and revision. AAM, WL, and DW supervised the project. All authors examined and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search outcome.
[XLSX File (Microsoft Excel File), 6406 KB - aging_v7i1e64525_app1.xlsx]

Multimedia Appendix 2
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.
[DOCX File , 91 KB - aging_v7i1e64525_app2.docx]

References

1. Gucciardi E, Jean-Pierre N, Karam G, Sidani S. Designing and delivering facilitated storytelling interventions for chronic disease self-management: a scoping review. BMC Health Serv Res 2016 Jul 11;16(1):249 [FREE Full text] [doi: 10.1186/s12913-016-1474-7] [Medline: 27401836]
2. Houston TK, Allison JJ, Sussman M, Horn W, Holt CL, Trobaugh J, et al. Culturally appropriate storytelling to improve blood pressure: a randomized trial. Ann Intern Med 2011 Jan 18;154(2):77-84 [FREE Full text] [doi: 10.7326/0003-4819-154-2-201101180-00004] [Medline: 21242364]
3. Hashim A, Rias RM, Kamaruzaman MF. The use of personalized digital memory book as a reminiscence therapy for Alzheimer's disease (AD) patients. In: Proceedings of the 2013 International Visual Informatics Conference on Advances in Visual Informatics. 2013 Presented at: IVIC '13; November 13-15, 2013; Selangor, Malaysia p. 508-515 URL: http://link.springer.com/10.1007/978-3-319-02958-0_46 [doi: 10.1007/978-3-319-02958-0_46]
4. Rios Rincon AM, Miguel Cruz A, Daum C, Neubauer N, Comeau A, Liu L. Digital storytelling in older adults with typical aging, and with mild cognitive impairment or dementia: a systematic literature review. J Appl Gerontol 2022 Mar 19;41(3):867-880 [FREE Full text] [doi: 10.1177/07334648211015456] [Medline: 34009053]
5. Evans SC, Garabedian C, Bray J. 'Now he sings'. The my musical memories reminiscence programme: personalised interactive reminiscence sessions for people living with dementia. Dementia (London) 2019 Apr 29;18(3):1181-1198. [doi: 10.1177/1471301217710531] [Medline: 28554224]
6. Chang H, Do Y, Ahn J. Digital storytelling as an intervention for older adults: a scoping review. Int J Environ Res Public Health 2023 Jan 11;20(2):1344 [FREE Full text] [doi: 10.3390/ijerph20021344] [Medline: 36674100]
7. Park E, Owens H, Kaufman D, Liu L. Digital storytelling and dementia. In: Proceedings of the 3rd International Conference on Human Aspects of IT for the Aged Population, Applications, Services and Contexts. 2017 Presented at: ITAP '17; July 9-14, 2017; Vancouver, BC p. 443-451 URL: https://link.springer.com/10.1007/978-3-319-58536-9_35 [doi: 10.1007/978-3-319-58536-9_35]
8. Critten V, Kucirkova N. 'It brings it all back, all those good times; it makes me go close to tears'. Creating digital personalised stories with people who have dementia. Dementia (London) 2019 Apr 05;18(3):864-881. [doi: 10.1177/1471301217691162] [Medline: 28161989]
9. Sweeney L, Wolverson E, Clarke C. Understanding the shared experiences of creating a digital life story with individuals with dementia and their spouse. Dementia (London) 2021 Jul 31;20(5):1791-1813. [doi: 10.1177/1471301220970403] [Medline: 33131329]
10. Karlsson E, Axelsson K, Zingmark K, Fahlander K, Sävenstedt S. Supporting conversations between individuals with dementia and their family members. J Gerontol Nurs 2014 Feb;40(2):38-46. [doi: 10.3928/00989134-20130916-07] [Medline: 24066788]

11. Elfrink TR, Ullrich C, Kunz M, Zuidema SU, Westerhof GJ. The online life story book: a randomized controlled trial on the effects of a digital reminiscence intervention for people with (very) mild dementia and their informal caregivers. PLoS One 2021 Sep 15;16(9):e0256251 [FREE Full text] [doi: 10.1371/journal.pone.0256251] [Medline: 34525105]
12. Zhu D, Al Mahmud A, Liu W. Digital storytelling intervention for enhancing the social participation of people with mild cognitive impairment: co-design and usability study. JMIR Aging 2024 Jan 17;7:e54138 [FREE Full text] [doi: 10.2196/54138] [Medline: 38231541]
13. Xu L, Fields NL, Highfill MC, Troutman BA. Remembering the past with today's technology: a scoping review of reminiscence-based digital storytelling with older adults. Behav Sci (Basel) 2023 Dec 04;13(12):998 [FREE Full text] [doi: 10.3390/bs13120998] [Medline: 38131854]
14. Filoteo JV, Cox EM, Split M, Gross M, Culjat M, Keene D. Evaluation of ReminX as a behavioral intervention for mild to moderate dementia. Annu Int Conf IEEE Eng Med Biol Soc 2018 Jul;2018:3314-3317. [doi: 10.1109/EMBC.2018.8513049] [Medline: 30441098]
15. Smith KL, Crete-Nishihata M, Damianakis T, Baecker RM, Marziali E. Multimedia biographies: a reminiscence and social stimulus tool for persons with cognitive impairment. J Technol Hum Serv 2009 Nov 09;27(4):287-306. [doi: 10.1080/15228830903329831]
16. Zhu D, Al Mahmud A, Liu W. Social connections and participation among people with mild cognitive impairment: barriers and recommendations. Front Psychiatry 2023 Jul 5;14:1188887 [FREE Full text] [doi: 10.3389/fpsyt.2023.1188887] [Medline: 37476544]
17. Green MC, Brock TC. The role of transportation in the persuasiveness of public narratives. J Pers Soc Psychol 2000 Nov;79(5):701-721. [doi: 10.1037//0022-3514.79.5.701] [Medline: 11079236]
18. Chueh KH, Chang TY. Effectiveness of group reminiscence therapy for depressive symptoms in male veterans: 6-month follow-up. Int J Geriatr Psychiatry 2014 Apr 15;29(4):377-383. [doi: 10.1002/gps.4013] [Medline: 23946260]
19. Waller A, Seltzer G, Eates W. ‘Life goes through in a book’: a case study of a co-creative narrative enquiry involving older adults living with early-stage dementia. J Audience Recept Stud 2021;18(2):1-23 [FREE Full text]
20. Fritsch T, Kwak J, Grant S, Lang J, Montgomery RR, Basting AD. Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers. Gerontologist 2009 Feb 18;49(1):117-127. [doi: 10.1093/geront/gnp008] [Medline: 19363009]
21. Singh K, Drouin K, Newmark LP, Lee J, Faxvaag A, Rozenblum R, et al. Many mobile health apps target high-need, high-cost populations, but gaps remain. Health Aff (Millwood) 2016 Dec 01;35(12):2310-2318. [doi: 10.1377/hlthaff.2016.0578] [Medline: 27920321]
22. Zheng M, Zhang X, Xiao H. Effects of a WeChat-based life review program for patients with digestive system cancer: 3-arm parallel randomized controlled trial. J Med Internet Res 2022 Aug 25;24(8):e36000 [FREE Full text] [doi: 10.2196/36000] [Medline: 36006665]
23. Azad-Khaneghah P, Neubauer N, Miguel Cruz A, Liu L. Mobile health app usability and quality rating scales: a systematic review. Disabil Rehabil Assist Technol 2021 Oct 08;16(7):712-721. [doi: 10.1080/17483107.2019.1701103] [Medline: 31910687]
24. Bruner J. The narrative construction of reality. Crit Inq 1991 Oct;18(1):1-21. [doi: 10.1086/448619]
25. Green MC, Appel M. Narrative transportation: how stories shape how we see ourselves and the world. Adv Exp Soc Psychol 2024;70(1):1-82 [FREE Full text] [doi: 10.1016/bs.aesp.2024.03.002]
26. Cuevas PE, Davidson PM, Mejilla JL, Rodney TW. Reminiscence therapy for older adults with Alzheimer's disease: a literature review. Int J Ment Health Nurs 2020 Jun 26;29(3):364-371. [doi: 10.1111/inm.12692] [Medline: 31984570]
27. Nusser L, Zimprich D, Wolf T. Themes of trust, identity, intimacy, and generativity in important autobiographical memories: associations with life periods and life satisfaction. J Pers 2023 Oct 31;91(5):1110-1122. [doi: 10.1111/jopy.12786] [Medline: 36256457]
28. Byrne D. A worked example of Braun and Clarke’s approach to reflexive thematic analysis. Qual Quant 2021 Jun 26;56(3):1391-1412. [doi: 10.1007/S11135-021-01182-Y]
29. Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M. Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR Mhealth Uhealth 2015 Mar 11;3(1):e27 [FREE Full text] [doi: 10.2196/mhealth.3422] [Medline: 25760773]
30. Grainger R, Townsley H, White B, Langlotz T, Taylor WJ. Apps for people with rheumatoid arthritis to monitor their disease activity: a review of apps for best practice and quality. JMIR Mhealth Uhealth 2017 Feb 21;5(2):e7 [FREE Full text] [doi: 10.2196/mhealth.6956] [Medline: 28223263]
31. McKay F, Chan L, Cerio R, Rickards S, Hastings P, Reakes K, et al. Assessing the quality and behavior change potential of vaping cessation apps: systematic search and assessment. JMIR Mhealth Uhealth 2024 Mar 15;12:e55177 [FREE Full text] [doi: 10.2196/55177] [Medline: 38532616]
32. Nair V, Yunus MM. A systematic review of digital storytelling in improving speaking skills. Sustainability 2021 Sep 01;13(17):9829. [doi: 10.3390/SU13179829]
33. Quah CY, Ng KH. A systematic literature review on digital storytelling authoring tool in education: January 2010 to January 2020. Int J Hum Comput Interact 2021 Sep 14;38(9):851-867. [doi: 10.1080/10447318.2021.1972608]

34. Lotfi F, Beheshti A, Farhood H, Pooshideh M, Jamzad M, Beigy H. Storytelling with image data: a systematic review and comparative analysis of methods and tools. Algorithms 2023 Mar 02;16(3):135. [doi: 10.3390/A16030135]
35. Castilla D, Suso-Ribera C, Zaragoza I, Garcia-Palacios A, Botella C. Designing ICTs for users with mild cognitive impairment: a usability study. Int J Environ Res Public Health 2020 Jul 17;17(14):5153 [FREE Full text] [doi: 10.3390/ijerph17145153] [Medline: 32708861]
36. Holthe T, Halvorsrud L, Karterud D, Hoel KA, Lund A. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. Clin Interv Aging 2018;13:863-886 [FREE Full text] [doi: 10.2147/CIA.S154717] [Medline: 29765211]
37. Wildenbos GA, Jaspers MW, Schijven MP, Dusseljee-Peute LW. Mobile health for older adult patients: using an aging barriers framework to classify usability problems. Int J Med Inform 2019 Apr;124:68-77. [doi: 10.1016/j.ijmedinf.2019.01.006] [Medline: 30784429]
38. Moon S, Park K. The effect of digital reminiscence therapy on people with dementia: a pilot randomized controlled trial. BMC Geriatr 2020 May 06;20(1):166 [FREE Full text] [doi: 10.1186/s12877-020-01563-2] [Medline: 32375661]
39. Mulvenna M, Gibson A, McCauley C, Ryan A, Bond R, Laird L, et al. Behavioural usage analysis of a reminiscing app for people living with dementia and their carers. In: Proceedings of the 2017 European Conference on Cognitive Ergonomics. 2017 Presented at: ECCE '17; September 19-22, 2017; Umeå, Sweden p. 35-38 URL: https://dl.acm.org/doi/10.1145/3121283.3121289 [doi: 10.1145/3121283.3121289]
40. Derbring S, Barbos Nordström M, Svenningsson JA, Ekström A, Ingebrand E, Samuelsson C, et al. Effects of a digital reminiscing intervention on people with dementia and their care-givers and relatives. Ageing Soc 2021 Oct 27;43(9):1983-2000. [doi: 10.1017/S0144686X21001446]
41. Sarne-Fleischmann V, Tractinsky N, Dwolatzky T, Rief I. Personalized reminiscence therapy for patients with Alzheimer's disease using a computerized system. In: Proceedings of the 4th International Conference on PErvasive Technologies Related to Assistive Environments. 2011 Presented at: PETRA '11; May 25-27, 2011; Heraklion Crete, Greece p. 1-4 URL: http://dl.acm.org/citation.cfm?doid=2141622.2141679 [doi: 10.1145/2141622.2141679]
42. Abraham C, Michie S. A taxonomy of behavior change techniques used in interventions. Health Psychol 2008 May;27(3):379-387. [doi: 10.1037/0278-6133.27.3.379] [Medline: 18624603]
43. Cerna K, Müller C, Randall D, Hunker M. Situated scaffolding for sustainable participatory design: learning online with older adults. Proc ACM Hum Comput Interact 2022 Jan 14;6(GROUP):1-25. [doi: 10.1145/3492831]
44. Lancioni GE, Singh NN, O'Reilly MF, Sigafoos J, Ferlisi G, Zullo V, et al. A computer-aided program for helping patients with moderate Alzheimer's disease engage in verbal reminiscence. Res Dev Disabil 2014 Nov;35(11):3026-3033. [doi: 10.1016/j.ridd.2014.07.047] [Medline: 25124700]
45. Fels DI, Astell AJ. Storytelling as a model of conversation for people with dementia and caregivers. Am J Alzheimers Dis Other Demen 2011 Nov 07;26(7):535-541 [FREE Full text] [doi: 10.1177/1533317511429324] [Medline: 22155895]
46. Xiaobing H, Meng C. The impact of internet use on community participation of older adults: evidence from China. SAGE Open 2022 May 17;12(2):215824402210973. [doi: 10.1177/21582440221097387]

Abbreviations

AI: artificial intelligence
ICC: intraclass correlation coefficient
MARS: Mobile Application Rating Scale

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Comparison of the Burdens and Attitudes Between Standard and Web-Based Remote Programming for Deep Brain Stimulation in Parkinson Disease: Survey Study

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Abstract

Background: Remote programming enables physicians to adjust implantable pulse generators over the internet for patients with Parkinson disease who have undergone deep brain stimulation (DBS) surgery. Despite these technological advances, the demand for and attitudes toward remote programming compared with standard programming among patients with Parkinson disease are still not well understood.

Objective: This study aims to investigate the preferences and perceptions associated with these 2 programming methods among patients with Parkinson disease through a web-based survey.

Methods: A web-based survey was administered to 463 patients with Parkinson disease who have undergone DBS surgery. The survey aimed to assess the burdens associated with postoperative programming and to compare patients' attitudes toward the 2 different programming methods.

Results: A total of 225 patients completed the survey, all of whom had undergone standard programming, while 132 patients had also experienced remote programming. Among those who received standard programming, 191 (85%) patients required the support of more than 1 caregiver, 129 (58%) patients experienced over 2 days of lost work time, 98 (42%) patients incurred expenses ranging from US $42 to US $146, and 14 (6%) patients spent over US $421. Of the 132 patients who had used remote programming, 81 (62%) patients indicated a preference for remote programming in the future. However, challenges with remote programming persisted, including difficulties in obtaining official prescriptions, a lack of medical insurance coverage, and limited medical resources.

Conclusions: Postoperative programming of DBS imposes significant burdens on patients and their caregivers during standard programming sessions—burdens that could be mitigated through remote programming. While patient satisfaction with remote programming is high, it is imperative for clinicians to develop personalized programming strategies tailored to the needs of different patients.

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KEYWORDS

remote programming; Parkinson disease; deep brain stimulation; telemedicine; economic evaluation

Introduction

Deep brain stimulation (DBS) is recognized as a cost-effective, invasive treatment for patients with Parkinson disease [1]. DBS aims to regulate neural activity through controllable electrical currents generated by an implantable pulse generator (IPG) [2], which can be finely adjusted during programming sessions to optimize treatment effects [3]. However, the frequent long-distance travel required to access specialized medical centers often imposes significant costs and logistical challenges on patients [4], and may vary among different Parkinson disease subtypes [5].

Introduced as a viable alternative, internet-based remote programming first became operational in China in 2015. Its use expanded significantly during the COVID-19 pandemic, and it continues to be widely used, with over 10,000 sessions conducted annually [6,7]. Previous research has confirmed the satisfaction, necessity, and effectiveness of remote programming for patients with Parkinson disease with DBS implants [8-10]. However, most of these studies were conducted during the pandemic, when travel restrictions limited access to standard programming. With the lifting of COVID-19 restrictions, standard programming has resumed without these obstacles, prompting a reevaluation of the value of remote programming.

To explore the long-term value of remote programming, we conducted a comprehensive web-based survey focusing on patients with Parkinson disease who had received DBS. This study aimed to assess the burdens and factors associated with different programming methods and to compare patient attitudes toward each. The findings are intended to serve as an essential reference for specialized centers when making informed decisions about IPG selection prior to DBS surgery.

Methods

Study Design and Participants

A retrospective, cross-sectional, web-based survey was conducted from September 25, 2023, to October 15, 2023, following the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) guidelines and CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth) checklist [11,12]. A total of 463 patients are invited to participate through messages sent via WeChat (Tencent Co, Ltd), leveraging the platform’s extensive reach and accessibility. The message includes a brief overview of the study and an invitation link to the survey.

All participants met the following inclusion criteria: (1) diagnosed with Parkinson Disease and received DBS surgery at our center; (2) implanted with an IPG capable of a remote programming function, specifically from manufacturers SceneRay and PINS [13,14] (detailed information about the remote programming procedure can be found elsewhere [15]); (3) experienced at least one session of standard programming; and (4) was willing to participate in the survey.

In 2019, our center created a clinical database for patients with Parkinson disease to record the results of preoperative assessment and postoperative follow-up. The preoperative motor assessment of patients in this study was extracted from this database. The process of screening valid questionnaires and matching them with the database is provided in Multimedia Appendix 1.

Questionnaire Design

We developed a comprehensive 49-item questionnaire divided into five sections: (1) basic information (Q1-10: including name, age, gender, etc), (2) burdens of standard programming (Q11-19: exploring transportation needs, caregiver requirements per session, etc), (3) burdens of remote programming (Q22-29: detailing caregiver involvement and workdays lost per remote session, etc), (4) satisfaction with remote programming (Q31-43: assessing factors such as ease of use and therapeutic effects on a 5-point Likert scale, from strongly disagree to strongly agree), and (5) open-ended questions (Q46-49: eliciting views on the pros and cons of both programming methods). A preliminary test of the questionnaire was conducted with 12 patients to refine its content. The English version of the questionnaire is available in Multimedia Appendix 2. The cost was converted to US dollars, based on the exchange rate of US $1≈¥7.12.

Section 4 of the questionnaire was adapted from a previously validated questionnaire on telemedicine in movement disorders [16]. This part was designed to compare remote programming with standard programming directly. Respondents were prompted to assess their perceptions of remote programming compared with standard programming, providing comparative insights that formed the basis of our analysis and discussion.

Data Analysis

Demographic characteristics were summarized using median values, IQR, and frequencies (percentage). Group comparisons were conducted using the Mantel-Haenszel chi-aquare test for categorical data and either the 2-tailed *t* test or Wilcoxon rank-sum test for continuous data, depending on their distribution.

Ordinal logistic regression was used to identify factors influencing the burden of each standard programming session, including caregiver needs, lost working time, and travel costs. Variable selection for the regression model followed a stepwise (both forward and backward) approach. Statistical significance was set at a 2-tailed *P* value of less than .50.

Data analysis was performed using SAS (version 9.4; SAS Institute Inc), with all data stored and managed in Excel (Microsoft). Responses to open-ended questions were categorized and analyzed using a web-based tool (Weiciyun). Detailed processes for logistic regression and the analysis of open-ended questions are provided in Multimedia Appendix 3.

Ethical Considerations

The study protocol was approved by the Ethics Committee of the Ruijin Hospital (Clinical Ethics Review [2023] No 231) and adhered to the principles of the Declaration of Helsinki. All patients were informed about the scientific purpose and their right to decline participation. Web-based informed consent was obtained at the beginning of the questionnaire.

Results

Overview of Participants

After excluding 7 records due to repeated submissions and 6 due to inaccurate names, 225 returned questionnaires were included in the analysis, resulting in a response rate of 49%. All patients had experienced standard programming, and 132 patients had also undergone remote programming (Table 1). Among those using remote programming, 54 (41%) had IPGs implanted by PINS, while the remaining 78 (59%) had devices from SceneRay.

The demographic profile was as follows: 105 (47%) were female, and the median distance from their residence to our center was 194 km, with an IQR of 91 - 513 km. The median age was 66 years (IQR 59 - 70), and the median disease duration was 11 years (IQR 8 - 15). Additionally, 51 (23%) patients had attained at least a junior college education, 195 (87%) were married, and only 18 (8%) were still employed.

Using the Unified Parkinson Disease Rating Scale III, we categorized 135 patients as having the tremor-dominant subtype. Additionally, 42 patients were classified under the postural instability/gait disorder subtype, 13 were deemed to have an indeterminate subtype, and scores were unavailable for the remaining 35 patients.

Table . Characteristics of the respondents.

Characteristics		All (n=225)	TD[a] (n=135)	PIGD[b] (n=42)	*P* value (TD versus PIGD)
Age (year), median (IQR)		66 (59 - 70)	66 (59 - 69)	68 (57 - 71)	.37
Sex (female), n (%)		105 (47)	63 (47)	19 (45)	.87
Disease duration (year), median (IQR)		11 (8 - 15)	11 (8 - 15)	11 (8 - 14)	.71
Follow-up period (year), median (IQR)		2 (0 - 3)	2 (0 - 2)	2 (1-3)	.20
Distance (km), median (IQR)		194 (91 - 513)	207 (98 - 567)	152 (34 - 367)	.09
Education, n (%)					.78
	Elementary school and below	61 (27)	37 (27)	12 (29)	
	High school and below	113 (50)	70 (51)	19 (45)	
	Junior college and above	51 (23)	29 (21)	11 (26)	
Marital status, n (%)					.56
	Married	195 (87)	114 (84)	37 (88)	
	Single, divorced, or widowed	30 (13)	21 (16)	5 (12)	
Employment status, n (%)					.36
	Employed	18 (8)	10 (7)	5 (11)	
	Unemployed, retired, or underage	207 (92)	125 (93)	37 (88)	

[a] TD: tremor-dominant.

[b] PIGD: postural instability/gait disorder.

Comparison of Programming Burdens Between 2 Methods

For standard programming sessions (n=225), 191 (85%) patients reported requiring more than 1 caregiver for accompaniment, 129 (57%) patients indicated that more than 2 days of work were lost for themselves or their caregivers, 98 (44%) patients stated that the cost for each session ranged from US $42 to US $146, and 14 (6%) patients incurred costs exceeding US $421. Furthermore, 159 (71%) patients experienced waiting times of over 60 minutes (Figure 1). No significant differences in these burdens were observed between the tremor-dominant and postural instability/gait disorder groups (not shown).

In remote programming sessions (n=115; Figure 2), 115 (87%) patients needed more than 1 caregiver, 38 (29%) patients reported more than 2 days of lost working time, and 93 (70%) patients perceived their costs of remote programming to be lower than standard programming. The lost working time was significantly reduced in remote programming compared with standard programming (*P*<.001), although no significant difference was noted in the number of required caregivers (*P*=.51).

Figure 1. Burden of programming in standard programming with deep brain stimulation (n=225). Data are presented as numbers (center of the bar) and percentages (vertical coordinate).

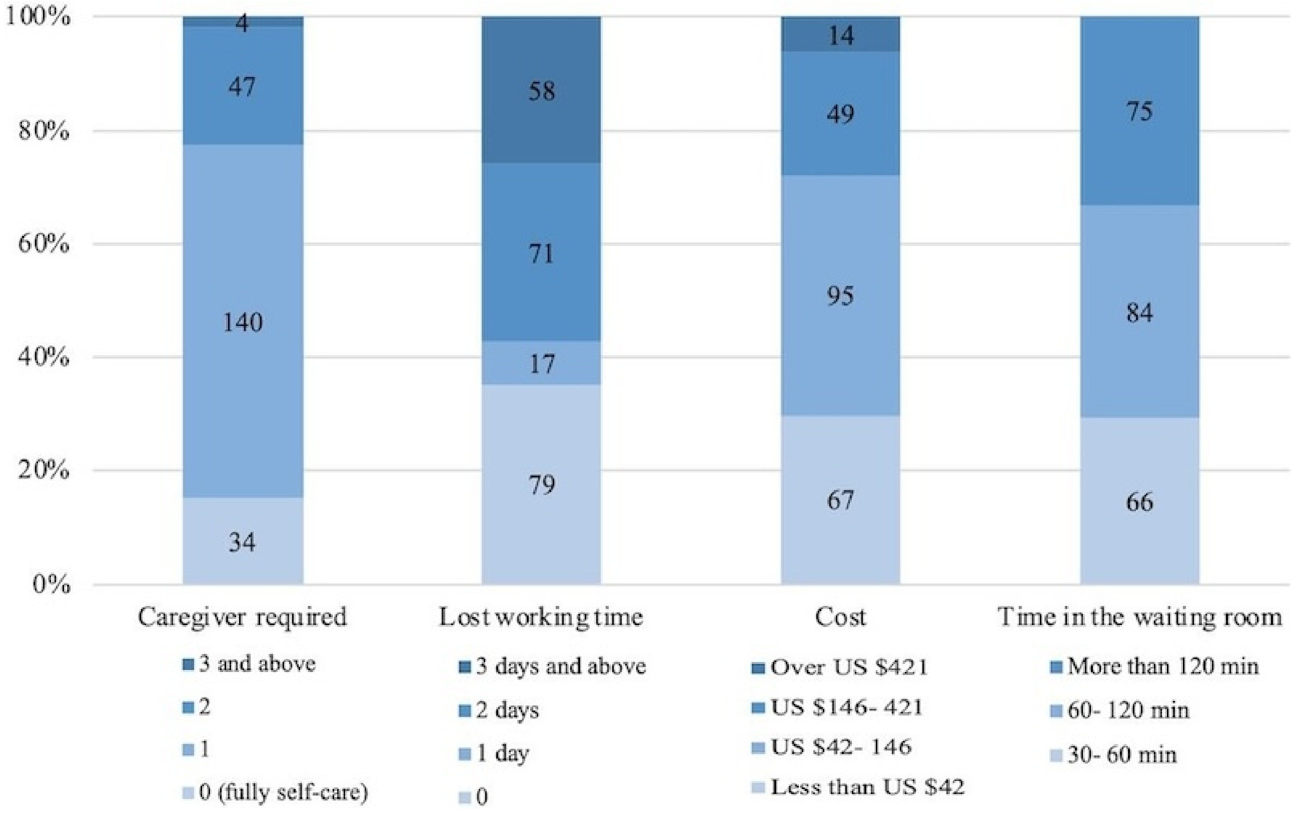
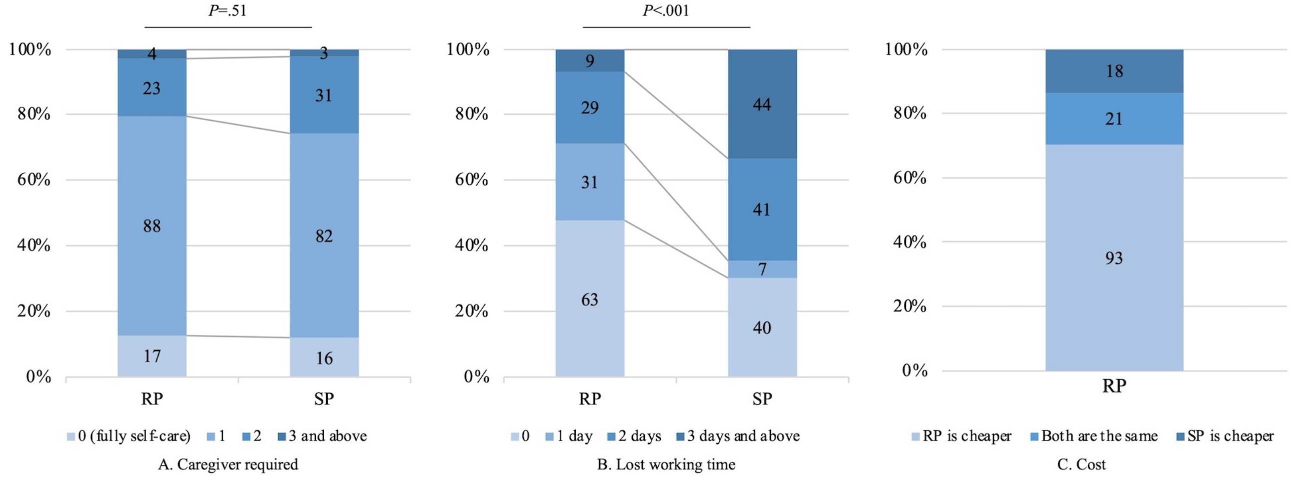


Figure 2. Burden between 2 programming methods (n=132). Data are presented as numbers (center of the bar) and percentages (vertical coordinate). *P*<.05 is considered statistically significant. RP: remote programming; SP: standard programming.



Factors Associated With Standard Programming Burdens

In the regression analysis, covariates of age, gender, distance, marital status, and education level were considered (Table 2). The requirement for caregivers was positively correlated with age (odds ratio [OR] 1.070, 95% CI 1.038 - 1.103, *P*<.001) and correlated with being female (OR 0.519, 95% CI 0.300 - 0.900, *P*=.02) as well as being single (OR 0.302, 95% CI 0.131 - 0.695, *P*=.005). Lost working time was positively correlated with distance (OR 1.001, 95% CI 1.000 - 1.001, *P*=.003) and negatively correlated with education level (high school and below: OR 0.312, 95% CI 0.153 - 0.636, *P*=.001; junior college and above: OR 0.446, 95% CI 0.250 - 0.796, *P*=.006). Additionally, the travel cost was also positively correlated with distance (OR 1.002, 95% CI 1.001 - 1.003, *P*<.001). No significant associations were observed between the preoperative Unified Parkinson Disease Rating Scale III score and any of the burden aspects (not shown).

Table . Factors associated with burdens of standard programming.

Factors	Caregiver required		Lost working time		Travel cost	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Age	1.070 (1.038 - 1.103)	<.001[b]	—[c]	—	—	—
Sex (reference=male)	0.519 (0.300 - 0.900)	.02[b]	—	—	—	—
Distance	—	—	1.001 (1.000 - 1.001)	.003[b]	1.002 (1.001 - 1.003)	<.001[b]
Marital status (reference=married)	0.302 (0.131 - 0.695)	.005[b]	—	—	—	—
Education: H[d] (reference=E[e])	—	—	0.312 (0.153 - 0.636)	.001[b]	—	—
Education: J[f] (reference=E)	—	—	0.446 (0.250 - 0.796)	.006[b]	—	—

[a] OR: odds ratio.

[b] *P*<.05 is considered statistically significant.

[c] Not applicable.

[d] H: High school and below.

[e] E: Elementary school and below.

[f] J: Junior college and above.

Attitude Toward 2 Programming Methods

Attitudes toward the 2 programming methods were reflected in the questionnaire results (satisfaction with remote programming section of the questionnaire). Among 132 patients with experience in remote programming (Figure 3), 53 (40%) patients disagreed (strongly) that using the remote programming system was difficult, and 75 (57%) patients disagreed (strongly) that communicating with doctors during remote sessions was challenging. A small percentage of respondents (8/132, 6%) viewed remote programming as an intrusion of their privacy, and a similar number (10/132, 7%) were (strongly) dissatisfied with the efficacy of remote programming. In addition, a significant majority appreciated the convenience (92/132, 69%) and the diagnostic accuracy (83/132, 63%) of remote programming.

When comparing remote to standard programming, 62 (47%) patients agreed (strongly) that doctors could better resolve their issues in standard programming, while 44 (33%) patients expressed a neutral opinion. Half of the patients (66/132, 50%) agreed (strongly) that the quality of remote programming matched that of standard programming. However, a substantial majority (102/132, 77%) believed their trust in doctors would increase with standard programming. Regarding their preferred method for future programming, 81 (62%) patients opted for remote programming. These results showed no significant differences between the 2 manufacturers (not shown).

Among 93 patients who had never used remote programming, those individuals typically lived closer to the medical center and had different educational levels compared with those who had used it. The top 3 reasons cited for not using remote programming were as follows: (1) a belief that remote programming might not be as convenient as hospital visits; (2) concerns about the effectiveness of remote programming; and (3) perceptions that remote programming was more expensive than hospital visits (Tables S1 and S2 in Multimedia Appendix 4).

The open-ended questions underscored the advantages and disadvantages of each programming method (Table 3). Remote programming was favored for its convenience and cost-effectiveness, though there were concerns about personal payment costs and the need for more scheduling resources. Conversely, standard programming was valued for direct doctor interaction and insurance coverage of fees, but issues like limited appointment availability and long waiting times were frequent complaints.

Figure 3. Perception of remote programming among patients (n=132). RP: remote programming; SP: standard programming.

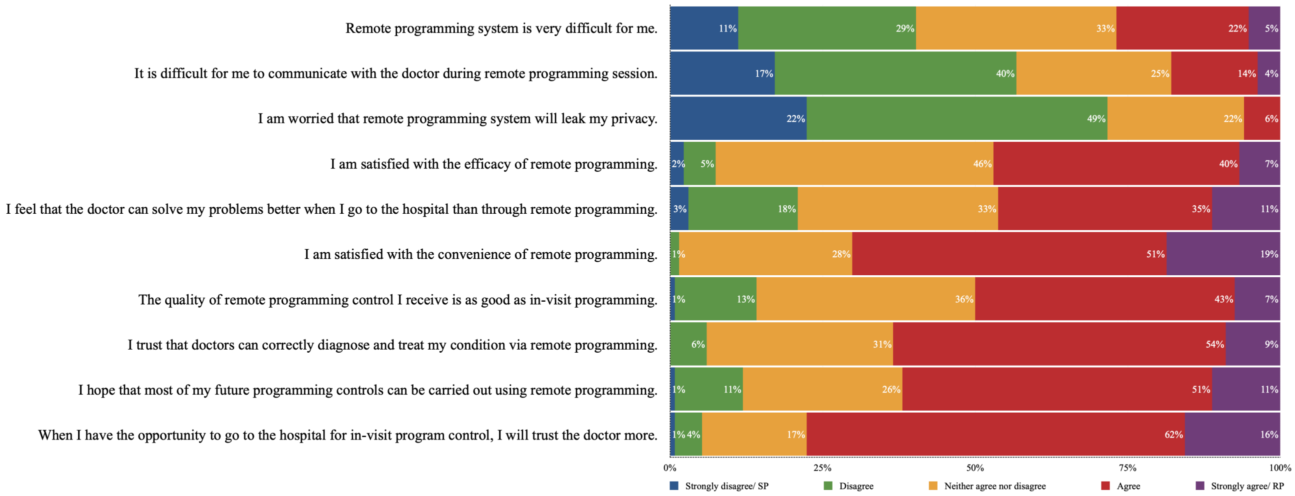


Table . Word frequency analysis of the pros and cons between 2 programming methods.

Programming method and category and comments ranked by frequency (top 3)			Count
Remote programming			
	Neg [a]		
		Hope the cost of personal payment can be reduced.	85
		Hope there are more appointment resources.	55
		Hope the remote programming system will be easier to use.	38
	Pos [b]		
		Remote programming is very convenient.	107
		Remote programming avoids long queue times for standard programming.	106
		Remote programming is cheaper.	40
Standard programming			
	Neg		
		It’s difficult to get an appointment for standard programming.	139
		Waiting too long in the waiting room.	117
		I hope the programming session can be longer at each time.	92
	Pos		
		I can communicate with the doctor face to face about my condition.	168
		The fee of programming could be paid through medical insurance.	40
		The doctor can give me a prescription directly for me to get the medication.	39

[a] Neg: negative comment.

[b] Pos: positive comment.

Discussion

Principal Findings

This survey study is the first to comprehensively examine the burdens associated with postoperative programming sessions of DBS from multiple perspectives. It also compares attitudes toward 2 different programming methods. Key findings include the following: (1) significant burdens were observed in terms of the number of required caregivers, lost working time, and travel costs, which heavily impacted patients and their caregivers; (2) patients facing higher risks of in-clinic programming burdens, such as those related to travel distance, age, and education level, might benefit more from remote programming; and (3) although remote programming has generally received positive feedback, there are specific areas where improvements are necessary.

As the coverage rate of DBS in standard programming increases annually [7], the associated costs are also expected to rise. A nationwide study from Hungary revealed that travel expenses could average €922.7 (≈US $1028) over 10 years following DBS [4]. Considering the median disposable income in China is US $4398 per year [17], the travel costs become significant for the 63 patients (28% of this study's cohort) who spend more than US $421 per standard programming session, especially assuming the need for 2 - 3 sessions annually post-surgery [18]. In this study, 93 (70%) patients confirmed that the costs of remote programming were lower than those of standard programming. Furthermore, a recent study indicated that, with the adoption of remote programming, 18 patients with Parkinson disease living farther from medical facilities received the same number of postoperative procedures as those residing nearby but at a lower average cost per programming session [15].

In addition to cost savings, the flexibility in time and space provided by remote programming is another substantial benefit. According to our survey, 159 (71%) patients reported needing to wait in the waiting room for more than an hour. Long waiting times coupled with short programming durations were common complaints about standard programming, as highlighted in the open-ended responses (Table 3). In China, the average waiting time for outpatient consultations in public hospitals is approximately 24.2 minutes [19]. The prolonged waiting times in DBS programming can be attributed to the time needed to observe symptom response to DBS stimulation [20], as well as the discrepancy between the high demand for postoperative programming and the limited availability of neurology specialists for programming. The web-based appointment system used in remote programming can eliminate excessive waiting times, and the home environment also provides a more comfortable and familiar setting for remote programming compared with a crowded hospital waiting room.

Patients at risk of high postoperative programming burdens are more likely to benefit from remote programming. In this study, for each standard programming session, factors such as longer distances and lower education levels were associated with increased lost working time as well as travel costs. An IPG capable of remote programming would be recommended for these patients. However, not all patients perceived remote programming to have these advantages. Ninety-three participants had never used remote programming; they believed that traditional in-person programming was a cheaper and more convenient option for them and expressed concerns about the effectiveness of remote programming. Living closer to our center may be the primary reason these individuals prefer standard programming, and varying education may also be caused by regional differences.

A previous British study highlighted that 174 (82%) patients with movement disorders preferred in-person medical treatment over telemedicine approaches once COVID-19 restrictions were lifted [16]. However, in our study, 81 (62%) patients expressed a willingness to continue using remote programming as their primary method. The contrast can be attributed to 2 factors. First, patients in this survey had undergone DBS surgery at our center and were familiar with the programming physicians, which could increase their trust in the doctor. In fact, 83 (63%) patients expressed trust in the doctor's diagnosis, compared with only 32 (15%) patients in the previous study. Second, telephone consultations were mostly used in the previous study, while during the remote programming sessions, patients and physicians communicated through real-time videoconferencing, which may have facilitated better communication compared with the telephone.

Highlighted in the open-ended responses, remote programming was favored for its convenience and cost-effectiveness, though concerns about out-of-pocket costs and the lack of appointment resources were noted. While remote programming reduces travel expenses and is especially beneficial for patients living far from medical facilities, some still perceive it as prohibitively expensive. In China, telemedicine fees are determined by doctors based on demand and their business volume. Although most outpatient procedures are covered by medical insurance, services provided by internet hospitals typically are not, leading many patients to view these as direct expenses. Conversely, standard programming was valued for its direct communication with doctors and coverage of programming fees by insurance, but it also drew complaints regarding the availability of appointments and long waiting times (Table 3). Clinicians need to carefully consider these factors to recommend the most suitable programming method for each patient, ensuring that both medical and personal needs are effectively met. This personalized approach will help maximize the benefits of DBS therapy while minimizing its burdens.

As DBS has been increasingly used among patients with Parkinson disease, labor-intensive postoperative management is increasingly burdensome for both clinicians and patients. To enhance the programming workflow, advanced technologies like closed-loop stimulation, which relies on various input signals [21], and image-guided programming based on visualization of DBS leads [22] are being developed. Patient feedback is still indispensable in these advancements. Although indirectly, remote programming offers a convenient method for clinicians to communicate with and gather feedback from patients. The integration of remote programming with these emerging technologies holds significant potential for improving post-DBS management.

Limitation

Several limitations of this study warrant consideration. The first is the single-center design with a low response rate. This survey was conducted at a single center and achieved a response rate of only 49%. This relatively low response rate could limit the generalizability of the findings and suggests caution when interpreting the applicability of the results to other settings. The variations in postoperative management strategies and the experience levels of programming physicians across different centers could influence the outcomes. The second limitation is the short follow-up duration. The median follow-up duration for participants in this study was 2 years. Considering that DBS has been shown to be cost-effective over a 15-year period for advanced standard programming in China [23], this limited follow-up may underestimate the long-term burdens faced by patients and their families. The third limitation is missing preoperative motor assessments. Preoperative motor assessment was not available for 32 patients, potentially compromising the validity of related conclusions. This missing data limits the strength of our findings concerning preoperative conditions and postoperative outcomes.

Conclusion

DBS postoperative programming places burdens on patients in standard programming and their caregivers in many aspects, and remote programming could alleviate such burdens in terms of the lost working time and total costs. Identifying patients at risk of such burdens before surgery and choosing IPGs with remote programming functions would help reduce the overall postoperative burden. Although the overall satisfaction of remote programming is high, a more complete and sounder system is still required to improve postoperative management.

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Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Authors' Contributions

XW was responsible for writing the original draft. ZL handled the formal analysis and contributed to reviewing and editing the manuscript. ZZ, CD, and CZ all participated in reviewing and editing the manuscript, with CZ also contributing to the conceptualization. DL oversaw conceptualization and supervision and was involved in reviewing and editing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data processing and cybersecurity.
[DOCX File, 57 KB - aging_v7i1e57503_app1.docx]

Multimedia Appendix 2
Full questionnaire.
[DOCX File, 25 KB - aging_v7i1e57503_app2.docx]

Multimedia Appendix 3
Process of logistic regression and open-ended question analysis.
[DOCX File, 71 KB - aging_v7i1e57503_app3.docx]

Multimedia Appendix 4
Analysis for patients who never used remote programming.
[DOCX File, 16 KB - aging_v7i1e57503_app4.docx]

References

1. McIntosh E, Gray A, Daniels J, et al. Cost-utility analysis of deep brain stimulation surgery plus best medical therapy versus best medical therapy in patients with Parkinson's: economic evaluation alongside the PD SURG trial. Mov Disord 2016 Aug;31(8):1173-1182. [doi: 10.1002/mds.26423] [Medline: 26846185]

2. Neumann WJ, Steiner LA, Milosevic L. Neurophysiological mechanisms of deep brain stimulation across spatiotemporal resolutions. Brain (Bacau) 2023 Nov 2;146(11):4456-4468. [doi: 10.1093/brain/awad239] [Medline: 37450573]
3. Picillo M, Lozano AM, Kou N, Puppi Munhoz R, Fasano A. Programming deep brain stimulation for Parkinson's disease: the Toronto Western Hospital algorithms. Brain Stimul 2016;9(3):425-437. [doi: 10.1016/j.brs.2016.02.004] [Medline: 26968806]
4. Pintér D, Járdaházi E, Janszky J, Kovács N. Potential clinical and economic benefits of remote deep brain stimulation programming. Sci Rep 2022 Oct 19;12(1):17420. [doi: 10.1038/s41598-022-22206-z] [Medline: 36261678]
5. Chase A. Parkinson disease: treatment needs vary between Parkinson disease subtypes. Nat Rev Neurol 2015 Mar;11(3):123. [doi: 10.1038/nrneurol.2015.19] [Medline: 25708392]
6. Zhang C, Zhu K, Lin Z, et al. Utility of deep brain stimulation telemedicine for patients with movement disorders during the COVID-19 outbreak in China. Neuromodulation 2021 Feb;24(2):337-342. [doi: 10.1111/ner.13274] [Medline: 33006811]
7. Meng F, Hu W, Wang S, et al. Utilization, surgical populations, centers, coverages, regional balance, and their influential factors of deep brain stimulation for Parkinson's disease: a large-scale multicenter cross-sectional study from 1997 to 2021. Int J Surg 2023 Nov 1;109(11):3322-3336. [doi: 10.1097/JS9.0000000000000603] [Medline: 37463002]
8. Esper CD, Merola A, Himes L, et al. Necessity and feasibility of remote tele-programming of deep brain stimulation systems in Parkinson's disease. Parkinsonism Relat Disord 2022 Mar;96:38-42. [doi: 10.1016/j.parkreldis.2022.01.017] [Medline: 35151948]
9. Nie P, Zhang J, Yang X, et al. Remote programming in patients with Parkinson's disease after deep brain stimulation: safe, effective, and economical. Front Neurol 2022;13:879250. [doi: 10.3389/fneur.2022.879250] [Medline: 35592473]
10. Wan X, Lin Z, Zeng Z, et al. Telemedicine in patients with obsessive-compulsive disorder after deep brain stimulation: a case series. Front Hum Neurosci 2024;18:1296726. [doi: 10.3389/fnhum.2024.1296726] [Medline: 38419962]
11. Eysenbach G. Improving the quality of web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res 2004 Sep 29;6(3):e34. [doi: 10.2196/jmir.6.3.e34] [Medline: 15471760]
12. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of web-based and mobile health interventions. J Med Internet Res 2011 Dec 31;13(4):e126. [doi: 10.2196/jmir.1923] [Medline: 22209829]
13. Li D, Zhang C, Gault J, et al. Remotely programmed deep brain stimulation of the bilateral subthalamic nucleus for the treatment of primary Parkinson disease: a randomized controlled trial investigating the safety and efficacy of a novel deep brain stimulation system. Stereotact Funct Neurosurg 2017;95(3):174-182. [doi: 10.1159/000475765] [Medline: 28571034]
14. Chen Y, Hao H, Chen H, Tian Y, Li L. The study on a real-time remote monitoring system for Parkinson's disease patients with deep brain stimulators. Annu Int Conf IEEE Eng Med Biol Soc 2014;2014:1358-1361. [doi: 10.1109/EMBC.2014.6943851] [Medline: 25570219]
15. Wan X, Duan C, Lin Z, Zeng Z, Zhang C, Li D. Motor improvement of remote programming in patients with Parkinson's disease after deep brain stimulation: a 1-year follow-up. Front Neurol 2024;15:1398929. [doi: 10.3389/fneur.2024.1398929] [Medline: 38962477]
16. Rajapakshe I, Menozzi E, Cunha I, Lees AJ, Bhatia KP, Mulroy E. Patients' postjudice of tele-neurology for movement disorders. Mov Disord Clin Pract 2022 May;9(4):446-451. [doi: 10.1002/mdc3.13434] [Medline: 35586530]
17. Residents' income and consumption expenditure in 2022 [Article in Chinese]. Central People's Government of the People's Republic of China. 2023. URL: https://www.gov.cn/xinwen/2023-01/17/content_5737487.htm [accessed 2024-10-16]
18. Chen S, Gao G, Feng T, et al. Chinese expert consensus on programming deep brain stimulation for patients with Parkinson's disease. Transl Neurodegener 2018;7:11. [doi: 10.1186/s40035-018-0116-x] [Medline: 29719720]
19. Fan Z, Hao J, Gu H, et al. Satisfaction analysis on outpatient experience in 136 tertiary public hospital in China. Chin J Hosp Admin 2021;37(6):460-464. [doi: 10.3760/cma.j.cn111325-20210510-00417]
20. Koeglsperger T, Palleis C, Hell F, Mehrkens JH, Bötzel K. Deep brain stimulation programming for movement disorders: current concepts and evidence-based strategies. Front Neurol 2019;10:410. [doi: 10.3389/fneur.2019.00410] [Medline: 31231293]
21. Wang S, Zhu G, Shi L, et al. Closed-loop adaptive deep brain stimulation in Parkinson's disease: procedures to achieve it and future perspectives. J Parkinsons Dis 2023;13(4):453-471. [doi: 10.3233/JPD-225053] [Medline: 37182899]
22. Waldthaler J, Bopp M, Kühn N, et al. Imaging-based programming of subthalamic nucleus deep brain stimulation in Parkinson's disease. Brain Stimul 2021;14(5):1109-1117. [doi: 10.1016/j.brs.2021.07.064] [Medline: 34352356]
23. Guo X, Feng C, Pu J, et al. Deep brain stimulation for advanced Parkinson disease in developing countries: a cost-effectiveness study from China. Neurosurgery 2023 Apr 1;92(4):812-819. [doi: 10.1227/neu.0000000000002274] [Medline: 36729808]

Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth
DBS: deep brain stimulation

IPG: implantable pulse generator
OR: odds ratio

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Predicting Adherence to Computer-Based Cognitive Training Programs Among Older Adults: Study of Domain Adaptation and Deep Learning

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Abstract

Background: Cognitive impairment and dementia pose a significant challenge to the aging population, impacting the well-being, quality of life, and autonomy of affected individuals. As the population ages, this will place enormous strain on health care and economic systems. While computerized cognitive training programs have demonstrated some promise in addressing cognitive decline, adherence to these interventions can be challenging.

Objective: The objective of this study is to improve the accuracy of predicting adherence lapses to ultimately develop tailored adherence support systems to promote engagement with cognitive training among older adults.

Methods: Data from 2 previously conducted cognitive training intervention studies were used to forecast adherence levels among older participants. Deep convolutional neural networks were used to leverage their feature learning capabilities and predict adherence patterns based on past behavior. Domain adaptation (DA) was used to address the challenge of limited training data for each participant, by using data from other participants with similar playing patterns. Time series data were converted into image format using Gramian angular fields, to facilitate clustering of participants during DA. To the best of our knowledge, this is the first effort to use DA techniques to predict older adults' daily adherence to cognitive training programs.

Results: Our results demonstrated the promise and potential of deep neural networks and DA for predicting adherence lapses. In all 3 studies, using 2 independent datasets, DA consistently produced the best accuracy values.

Conclusions: Our findings highlight that deep learning and DA techniques can aid in the development of adherence support systems for computerized cognitive training, as well as for other interventions aimed at improving health, cognition, and well-being. These techniques can improve engagement and maximize the benefits of such interventions, ultimately enhancing the quality of life of individuals at risk for cognitive impairments. This research informs the development of more effective interventions, benefiting individuals and society by improving conditions associated with aging.

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KEYWORDS

domain adaptation; adherence; cognitive training; deep neural networks; early detection of cognitive decline

Introduction

Background

Cognitive decline in the aging population presents an unprecedented challenge for the United States and the world. The World Health Organization predicts that the global population of those 60 years and older will double from 1.4 billion in 2020 to 2.1 billion in 2050 and will triple for those 80 years and older reaching 426 million [1]. While some cognitive changes are normal with aging, impacting the performance of some everyday tasks, individuals experiencing nonnormative cognitive declines face even greater challenges. The risk of developing dementia and Alzheimer disease is substantial, with dementia being the seventh leading cause of death worldwide [1]. As the population continues to age, and despite declines in dementia prevalence [2] the number of people affected by dementia is projected to triple by 2050, along with the associated costs [3].

Addressing age-related cognitive changes is crucial for individuals' well-being and independence, and has broader societal impact. Cognitive training interventions, such as technology-based exercises targeting specific cognitive functions, have been widely used. However, research on their effectiveness has yielded both positive [4-6] and negative [7-9] results. Adherence to these training programs is essential for understanding and maximizing their benefits, but factors influencing adherence are not fully understood [10,11]. The ongoing Adherence Promotion with Person-Centered Technology project aims to understand adherence barriers, develop predictive algorithms, and support early detection of age-related cognitive decline. By predicting adherence, personalized reminders can be sent to encourage participants to adhere to the prescribed training schedule.

Our work differs from previous related research in 2 fundamental ways. Previous research efforts mostly used personality traits and metacognitive beliefs of each participant for predicting their adherence to training regimes [12-15]. These are static "distal" features, which quantify the personality and attitudes of a participant, and are unlikely to bear as much information about their continuing engagement to the training program as more proximal dynamic features such as aspects of current adherence behavior. Advances in computing technologies and computational approaches allow us to tailor interventions based on more objective, automatically collected data rather than on mostly subjective, self-reported measures, as well as to create highly adaptive, dynamic systems that can support different types of behavior change interventions [16,17]. We used relevant information about the engagement of a participant to the training schedule (eg, engagement time, number of tasks performed) for N consecutive days to predict their adherence for the (N+1)th day. These predictors contain richer and fine-grained contextual information about the participant's engagement and may thus be much more informative in predicting adherence. Further, while previous research mostly used naïve regression models for predicting the adherence of a participant [12-15], we used sophisticated deep learning models for the same purpose.

In our recent research, we demonstrated the potential of deep convolutional neural networks (CNNs) to predict adherence for a particular participant based on their past behavior, using data from previous computer-based cognitive intervention studies [18,19]. To capture the individualistic differences in participation, we developed a separate prediction model for each participant, rather than a single model for all participants. While our empirical results were promising, one challenge we faced was the limited amount of labeled training data per participant (30 days only) to train a reliable deep neural network. Our main objective in this research was to address this practical challenge by using relevant training data from other participants to train a prediction model for a given participant. This is a challenging task, as each participant has a unique pattern of engagement with the training schedule, and directly using the training data from other participants, without addressing the individualistic variabilities, may not produce the optimal model for a given participant.

Domain adaptation (DA) techniques are instrumental in leveraging ample training data from source domains to train a reliable model for a related target domain of interest, where labeled data are scarce, when the data of each domain are derived from a different probability distribution [20,21]. Through DA, the disparity between the source and target domains can be minimized, so that the training data from the source domains can also be used to train a model for the target domain, thereby addressing the challenge of limited labels. We used state-of-the-art adversarial DA techniques [22], together with advanced signal processing algorithms to overcome the challenge of limited training data for each participant.

Our study highlights the potential of using deep neural networks and DA techniques to predict adherence lapses and develop personalized support systems for cognitive training interventions. Such a prediction system can improve engagement and help maximize the benefits of such interventions, ultimately enhancing the quality of life for individuals with cognitive impairments. To the best of our knowledge, this research is the first of its kind to use advanced deep DA techniques to predict older adults' daily adherence to cognitive training programs.

Objectives

This study sought to (1) explore the potential of deep learning to predict a participant's adherence to cognitive training programs, based on their past behavior; (2) investigate if applying DA techniques can help improve the accuracy of predicting adherence for a given participant, by using relevant information from other participants in the same or different clinical trial; and (3) determine if time series data can be presented in a more meaningful and understandable way, and if it can be used to cluster the participants based on their adherence to a cognitive training program.

Methods

Research Design

We used the Mind Frontiers (Aptima Inc) cognitive training software package in this study. The video game application included 7 Wild West–themed mini-video games. These games were designed to improve memory, attention, spatial processing, task-switching, reasoning ability, and problem-solving, and were played on a Lenovo 10 tablet. Participants were trained on how to use the tablet and play each game; after each game, participants received feedback and the difficulty of the game was adjusted based on their previous performance.

Ethical Considerations

Florida State University Institutional Review Board approved this study's protocol (2017.20622) and informed consent form. Informed consent was obtained from all participants, and participants were given the opportunity to opt out at any time. This consent process included institutional review board–approved language that collected data could be made available for secondary analysis by other research teams and that any shared data would not include personal identifiers. Data were labeled with participant IDs, meaning that data were deidentified in this study. Participants were compensated a total of US $200 (study 1) or US $75 (study 2) for their participation, with the difference driven by the shorter commitment involved in study 2.

Datasets

In total, 2 datasets were used in this study, which we will refer to as the study 1 and study 2 datasets. Study 1 data [13] came from a cognitive training study that involved 2 phases. In phase 1, participants were asked to follow a prescribed schedule for 12 weeks, playing for 5 days each week, for at least 45 minutes per day. Phase 2 was unstructured, where participants were encouraged to play as frequently as they wanted to, for 6 weeks. In this study, only the data collected during the structured phase was analyzed, as adherence cannot be defined without the proposed game-playing instructions given in phase 1. This study had 118 participants, with an overall mean age of 72.6 years and an SD of 5.5 years. Further, 78 (66.2%) participants were female and 40 (33.8%) were male. The cognitive training program consisted of 7 different tasks with 5 possible outcomes (defeat, stalemate, victory, abandonment, or not yet completed). Participants were also given a custom user manual on how to operate the tablet and play each game within the intervention and were provided information on how to access technical support.

The study 2 dataset came from a similar but independent study [12]. Here, in phase 1, participants were asked to follow a prescribed schedule for 8 weeks, playing for 5 days each week, for at least 60 minutes per day. Phase 2 was unstructured and lasted for 4 weeks. A total of 120 adults aged 64 years and older were recruited from Leon County, Florida, and the surrounding area for this study. Among the participants, 116 completed the structured phase of this study. The average age of the participants was 72.6 (SD 5.5) years, with a range of 64 - 84 years. In total, 77 (64.2%) participants were female and 43 (35.8%) were male. The intervention also involved use of the tablet-based Mind Frontiers app (version 2.4.11), which included 7 gamified neuropsychological tasks targeting working memory, processing speed, executive control, and spatial reasoning. While the intent was for participants to complete both phases of this study, the second phase of this study did not require participants to engage with the gaming intervention for any predetermined length of time. Therefore, we only used the data from the first phase of this study. To increase the comparability of datasets, all analyses focus on the first 8 weeks of intervention engagement. Note that variations in study parameters make the datasets slightly different (eg, 45 min vs 60 min sessions).

Deep Neural Networks for Adherence Prediction

We used deep CNNs to predict adherence from the multivariate time series data. While CNNs are well-suited for image recognition tasks, they have also been successfully used for time series data classification [23-25]. The primary mechanism used by these models is convolution, which allows the network to extract essential features from the raw data. In 1D convolution, the kernel slides unidirectionally from the start of the time series to its end. If we have input vector f of length n and a kernel g of length m, the convolution $f \times g$ of f and g is defined as follows:

$$(1)(f\times g)(i)=\sum_{j=1}^{m} g(j)\cdot f(i-j+\frac{m}{2})$$

In this research, we used 2 convolution blocks consisting of a convolution layer and a maximum pooling layer for feature extraction. The maximum pooling layer moves a pool of predetermined size across the input and calculates the maximum of the region. These blocks are followed by a dense and an output layer. Figure 1 shows the architecture of the CNN used in this research.

Following the setup in our previous research [18,19], we used the first 30 days of data for each participant for training and the next 30 days for testing. We used 4 time-dependent variables obtained through game interface interactions as our predictors, namely, (1) duration for which a participant played, (2) number of sessions, (3) maximum level reached, and (4) the number of tasks performed. Session refers to daily session, the number of days on which gameplay occurred. Participants were asked to play 5 sessions (on different days) each week. A session, however, was comprised of the completion of a number of tasks (or games). The participants were said to be satisfying the minimal adherence criterion if they played for at least 10 minutes on a given day. This minimal adherence criterion was selected to ensure that the participants spent a reasonable amount of time playing the game and to avoid cases where they may have accidentally opened the app and then backed out. Hence, this was considered as the threshold to define the 2 classes (adherent and nonadherent) in our study. Based on the values of these predictors for a given participant for N days, our goal was to predict the adherence class of the participant for the (N+1)th day, N being the window size. This is depicted in Figure 2. Note that participants were asked to play on 5 out of 7 days per week. As such, nonengagement was permitted 2 days per week, and a participant could still be classified as adherent overall for the week by not playing for 2 days. The ability to predict whether participants engage or not on a specific day, however, is crucial for facilitating the early detection of adherence lapses so that our system under development can provide just-in-time adherence support. In this paper, we focus on the artificial intelligence aspect of the problem, predicting whether a participant will adhere to the training schedule on any given day, given their past N days of data (as shown in Figure 2). A separate, personalized deep neural network was trained for each participant to capture the individual playing patterns, rather than attempting to fit a single model for all participants.

Figure 1. The convolution neural architecture used in this study (adapted from Singh et al [19], which is published under Creative Commons Attribution 4.0 International License [26]). Conv: convolution.

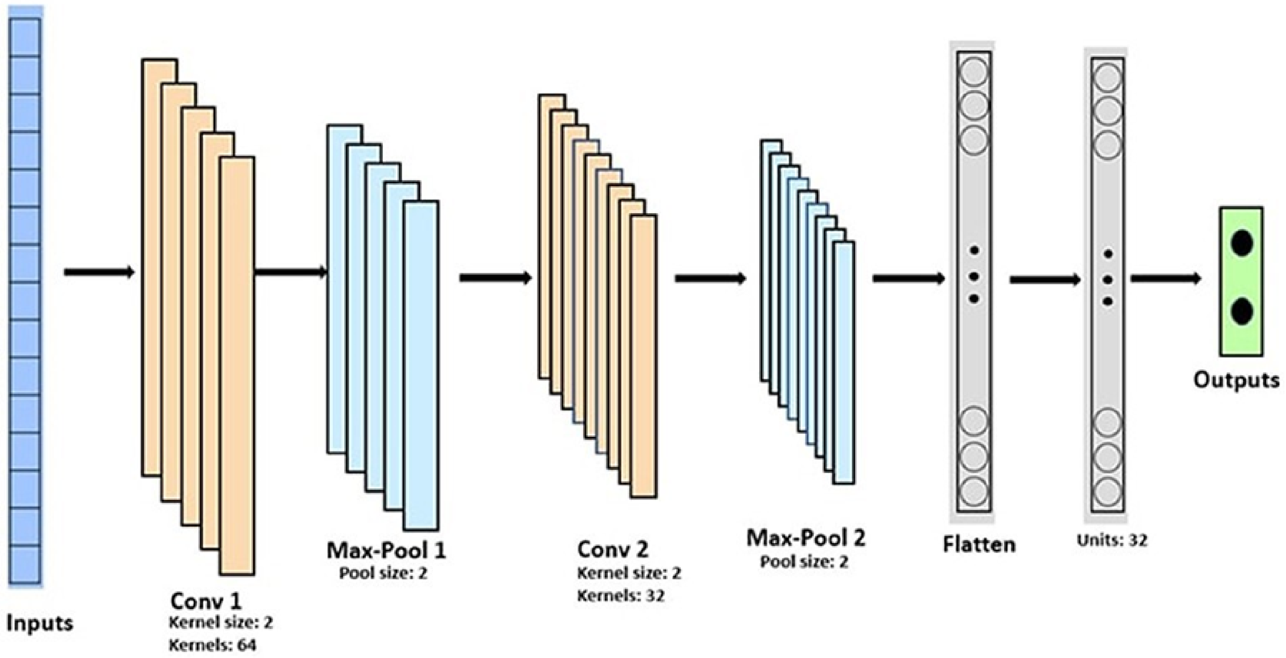
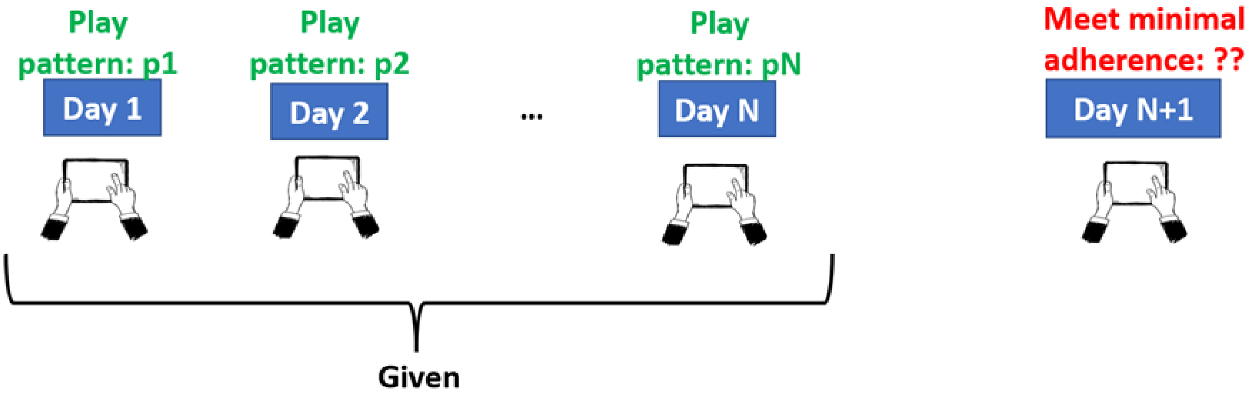


Figure 2. Given the play patterns of a participant for N consecutive days, our goal was to predict whether the participant will meet the minimal adherence criterion on the (N+1)th day (adapted from Singh et al [19], which is published under Creative Commons Attribution 4.0 International License [26]).



DA for Adherence Prediction

One of the main challenges in our problem setup was the limited amount of labeled data per participant (30 d) to train a reliable deep neural network. DA or transfer learning is a technique used in machine learning to address the challenge of model training with limited labeled data. The fundamental premise of DA is to leverage abundant labeled training data in one or more source domains to train a model for a target domain of interest, where labeled data are scarce [20-22]. The source and the target data are derived from different probability distributions and thus a model trained on the source domains may not generalize directly to the target domain. This necessitates a strategy to address the disparity between the probability distributions of the source and target domains so that the labeled source samples can be used to train a robust model for the target domain. While extensively used in computer vision, DA has also been successfully used with time series data [27,28].

DA techniques based on adversarial training have depicted promising empirical performance. We used the domain adversarial network in our study (please refer to [22] for further details). The architecture includes a deep feature extractor, together with 2 classification heads: one to classify the label y of a given sample (adherent or nonadherent in our case) and the other to classify the domain d from which a given sample is derived (source or target). During model training, the label classifier was trained to achieve high accuracy (so that the test samples are accurately classified), but the domain classifier was trained to achieve minimal accuracy. This ensures that the deep model learns domain invariant features and a classifier trained to distinguish between the source and target domain samples has high error. This also ensures that the disparity between the 2 domains is addressed, and the labeled source samples can be used to train a model for the target domain. The conventional cross-entropy loss is used to train the label classifier; the domain classifier is connected to the feature extractor via a gradient reversal layer that multiplies the gradient by a certain negative constant during the backpropagation-based training so that the domain classifier is trained to have a high error. Please refer to Ganin et al [22] for more details about this method.

In our problem setup, a particular participant constitutes the target domain and each of the other participants constitutes the source domain. Each participant had a unique playing pattern, which implies that the data for each participant is derived from a different probability distribution. Our objective was to use data from the source participants to augment the training data for the target participant and to train a better adherence prediction model for the target participant. To deal with the scale of the data, and to ensure that the source participants had similar playing patterns as the target participant (so that only relevant information is transferred), we exploited a clustering technique based on Gramian angular fields (GAFs), as described below. We clustered the participants based on their playing patterns and the DA scheme was applied cluster-wise; that is, a particular participant was considered as the target, and all the other participants in the same cluster (instead of the whole dataset) were considered as the source participants.

Clustering Time Series Data Using GAFs

Directly clustering temporal cognitive training data can be challenging due to its complex and dynamic nature. We hence used GAFs to transform the univariate time series data (time spent in playing games) into images [29-31]. GAF images provide a more intuitive representation of the data, making it easier to interpret and analyze. As mentioned before, the adherence classes were defined based on how long each participant engaged in the training schedule on a particular day. We therefore used the variable "time spent in playing games" to transform the (univariate) time series data into images and cluster them, instead of the other variables: "number of sessions," "maximum level reached," and "number of tasks performed." This ensured that participants with similar adherence patterns belonged to the same cluster; thus, during DA, only participants with similar playing patterns as the target participant can be used to transfer relevant knowledge.

The process of converting time series to GAFs involves several steps, as detailed below (the complete pipeline is depicted in Figure 3):

- Normalizing the time series data: The time series data are first normalized to have a mean of 0 and an SD of 1. This step is important to ensure that the resulting GAF images capture the underlying patterns and trends in the data.
- Conversion to polar coordinates: The time series data were then mapped to the polar coordinate system where each point on the plane is determined by its distance from a reference point and an angle from a reference direction. Assuming our time series is composed of T timestamps with corresponding values x_i, then the angles are computed as $arccos(x_i)$. They lie within $[0, \pi]$. The radius is computed using time stamp i, where $i \in T$ represents the timestamp of data point x_i.

Mathematically it translates to,

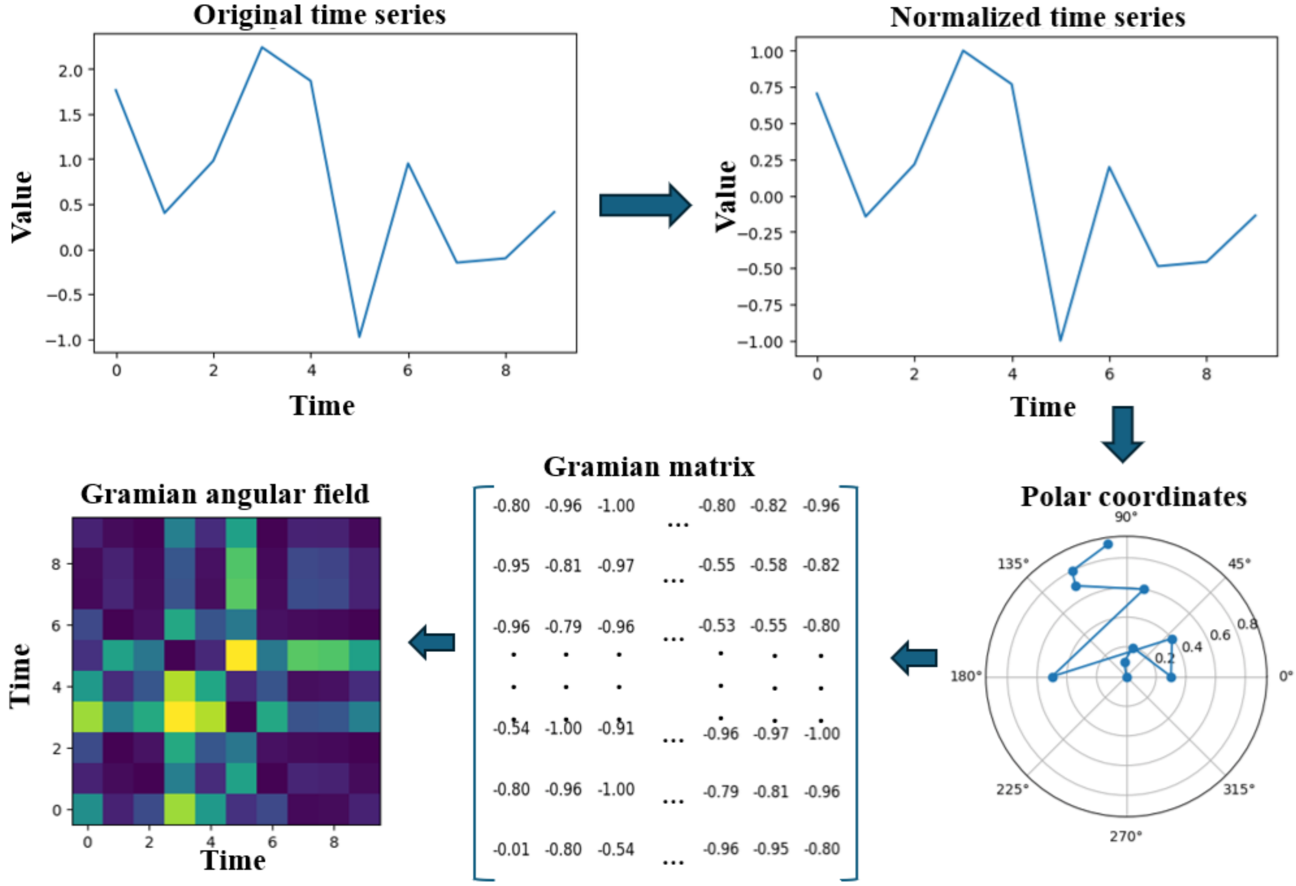
$$(2)\{r=i/T\ \theta_i=\arccos(x_i), -1\leq x_i\leq 1$$

- Generating a Gramian matrix: The normalized and converted time series data were then used to generate a Gramian matrix using a chosen mathematical function, such as the cosine or sine function. The Gramian matrix captures the pairwise inner products between the time series data points, which provides a measure of the similarity between different points in the time series.5

$$(3) GAF=[\cos(\theta_1+\theta_1)\ldots\cos(\theta_T+\theta_1)\cos(\theta_1+\theta_2)\ldots\cos(\theta_T+\theta_2)\cos(\theta_1+\theta_T)\ldots\cos(\theta_T+\theta_T)]$$

- Mapping the Gramian matrix to an image: The Gramian matrix was then mapped to a 2D image using a color mapping scheme, such as a grayscale or rainbow colormap as shown in Figure 3. The resulting image captures the underlying patterns and trends in the time series data.

Figure 3. Pipeline for converting time series data into GAF images. GAF: Gramian angular field.

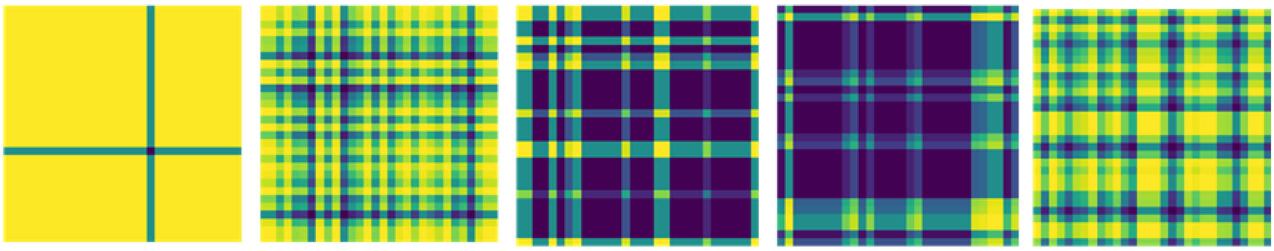


Clustering of Images

We converted the univariate time series data of the length of playtime for each participant into GAF images using the cosine function, to capture the underlying patterns in cognitive training performance [32,33]. We then used the pretrained Visual Geometry Group 16 deep neural network to extract features from the GAF images, which were fed into the K-means clustering algorithm to group the participants into distinct clusters based on their daily playing time. Sample images from different clusters are shown in Figure 4. The GAFs are symmetrical along the diagonal, and the colors vary from yellow to blue with green gradients in between. The yellow or lighter color means that the participant did not play or spent much less time playing, while the increase in the gradient from yellow to blue implies that the participant spent more time playing. The first image in Figure 4 comes from a participant who did not play at all (GAF image is mostly yellow). The third and fourth images come from participants who played more consistently; however, there were some days in between where they either did not play or played for a short duration, which explains the yellow regions in between. The second and fifth images come from participants who were erratic in their playing patterns.

The advantages of converting the time series data into images and clustering them were twofold: (1) the resulting clusters allowed for a more visually interpretable understanding of the data and enabled us to identify distinct trends in the playing patterns of the participants, which can be used to tailor cognitive training programs to specific groups of individuals; and (2) it enabled us to identify the relevant source participants (who have similar playing patterns) for a given target participant, while applying DA to train a model for the target participant.

Figure 4. Examples of generated GAF images. GAF: Gramian angular field.



Experimental Setup

For each participant, we used the first 30 days of data for training and the next 30 days for testing. This split was selected to strike a balance between the training and testing samples. Further, there is evidence in the psychology literature showing that the median time to develop different health-related habits asymptotes around 30 days [34]. The proposed split can thus be useful to assess long-term adherence. The input to the CNN was the multivariate time series data consisting of the maximum task level reached, number of sessions played, time spent playing, and number of tasks completed each day. A threshold of 10 minutes on the play time on a particular day was used to determine the classes (adherent or nonadherent); that is, if a participant played for more than 10 minutes on a given day, they were considered to adhere to the training program on that day; otherwise, they were considered to be nonadherent to the program on that day. Given the playing data of a particular participant over N days, our goal was to train deep neural networks to predict the adherence class on the (N+1)th day. As detailed in our previous research [19], we used the fast Fourier transform to detect the presence of any seasonality in the time series data. Fast Fourier transform was applied to transform the time series training data into the frequency domain and derive the corresponding amplitude and frequency. The highest amplitude frequencies represent seasonal patterns and the lowest amplitude frequencies represent noise. The inverse fast Fourier transform was then applied to the frequency with maximum amplitude to obtain the time interval for the most prominent cycle (periodic pattern). This cyclic period was used as the window size N, which was computed as *7* in our study. A separate deep model was trained for each participant to capture individualistic playing patterns. After every epoch, the error of the model on the validation set was noted to avoid overfitting.

The data from a particular clinical trial were first clustered using GAFs. We experimented with different numbers of clusters and manually inspected the GAFs within each cluster. With 4 clusters, the GAFs within each cluster visually appeared to be similar, denoting that participants with similar playing patterns were grouped in each cluster; with other values of *k*, each cluster had mixed GAFs, denoting that each cluster had participants with varied playing patterns. We therefore performed K-means clustering with (K=4) clusters in our empirical studies. Further, 1 participant from a given cluster was selected as the target participant, and all the other participants in the same cluster were designated as the source participants. A deep model was trained for the target participant and was evaluated on the test data for the same participant. The process was repeated for all participants across all the clusters and the final score was computed as the average score over all the participants. In total, 4 evaluation metrics were used: precision, recall, F_1-score, and accuracy. Precision, recall [35], and F_1-score [36] were used to measure the model's performance on positive predictions, while accuracy was used to evaluate the overall model performance. We conducted 3 different sets of experiments:

1. No source, no DA: In this setup, only the 30 days of training data for the target participant was used to train a model for that participant; the data from the other participants was not used at all.
2. With source, no DA: here, in addition to the training data of the target participant, the training data from the source participants (in the same cluster as the target participant) was also used to train a model for the target participant. However, the training data from the source participants was used directly, without applying any DA.
3. With source, with DA: In this setup, DA was used to address the domain disparity between the target and source participants, and the training data from the source participants (in the same cluster) was used to train a model for the target participant.

In all 3 setups, the trained model was tested on the test data of the target participant. For the experiments without DA, the CNN architecture in Figure 1 was used, while for experiments with DA, the layers before the flatten layer were used as the feature extractor as in .

Results

Experiments With a Single Dataset

The results on the study 1 and study 2 datasets are depicted in Tables 1 and 2, respectively. Note that all the evaluation metrics referred to in this section are the average values of all the participants across all clusters. For the study 1 dataset (Table 1), using training data only from the target participant, without any source or DA, resulted in an accuracy of 63% (the accuracy was computed as the percentage of times our model correctly predicted whether a given participant will meet the minimal adherence criterion on day N+1, as illustrated in Figure 2; this was averaged across all the participants). Using training data from the other participants (source) in the same cluster as the target participant, but without DA, resulted in an improved accuracy of 67.9%. Using training data from the source participants together with DA produced the best accuracy of 71.7%. The superior performance of DA is also reflected in all the other evaluation metrics. The same pattern is evident for the study 2 dataset (Table 2), where using the training data from the source participants (in the same cluster as the target participants) together with DA consistently furnished the best performance. Notably, using DA, both the accuracy and F_1-score improved by more than 8% compared to the "no source, no DA" experiment.

We also note that the "with source, no DA" experiment produced slightly better results than the "no source, no DA" experiment. This shows that using training data from the source participants can improve the adherence prediction performance; however, using the data directly without addressing the domain disparity may not produce optimal results. The best results were obtained when the training data from the source participants were used, and the difference in probability distribution between the source and the target participants was addressed through DA.

We also conducted statistical tests of significance on the F_1-score using the ANOVA repeated measures (the F_1-score may be a better indicator of the overall performance than accuracy, to address the presence of any class imbalance in the data). We compared the performance of the CNN models for the following two experimental setups: (1) with source, no DA, and (2) with source, with DA. A statistically significant difference (P=.004) was found between the results of using DA compared to not using DA for the study 2 dataset. A sign test was also conducted on the F_1-score of the individual participants to test for consistent differences in the results with and without using DA. A significant difference (P=.003) was found in the results for the study 2 dataset. These results corroborate the potential of DA algorithms to develop personalized deep learning models for predicting adherence to cognitive training programs in older adults.

Table . Results (in percentage) on the study 1 dataset. Italicized values represent the best performance. The scores are calculated by averaging the respective scores over all the participants.

Experiment type	Accuracy, mean (SD)	Precision, mean (SD)	Recall, mean (SD)	F_1-score (SD)
No source, no DA[a]	63 (0.2)	58.3 (0.2)	57.1 (0.2)	54.3 (0.3)
With source, no DA	67.9 (0.3)	61.1 (0.3)	60.2 (0.3)	58.7 (0.3)
With source, with DA	*71.7 (0.3)*	*63.2 (0.3)*	*62.3 (0.3)*	*59.4 (0.3)*

[a] DA: domain adaptation.

Table . Results (in percentage) on the study 2 dataset. Italicized values represent the best performance. The scores are calculated by averaging the respective scores over all the participants.

Experiment type	Accuracy, mean (SD)	Precision, mean (SD)	Recall, mean (SD)	F_1-score (SD)
No source, no DA[a]	57.3 (0.2)	54.1 (0.2)	52.4 (0.2)	49.6 (0.2)
With source, no DA	61.8 (0.2)	54.5 (0.2)	53.4 (0.2)	50.1 (0.2)
With source, with DA	*66.6 (0.2)*	*60 (0.2)*	*60.4 (0.2)*	*57.6 (0.2)*

[a] DA: domain adaptation.

Experiments With a Combination of the Two Datasets

Having validated the usefulness of DA on single trial datasets, we conducted an experiment to study whether data from participants from a different clinical trial can also help in training a predictive model for a target participant in a given clinical trial. To this end, we segregated all the participants in both datasets together, into 4 clusters using the GAF method. Within each cluster, for a given target participant, only participants from the other dataset (different from the target participant's dataset) were considered as source participants. This was accomplished to mimic the following challenging real-world scenario: a participant enrolls in a cognitive intervention program, and we desire to train a deep neural network to predict adherence for this participant; we have access to a limited amount of training data from this participant. However, we do not have any training data available from other participants in the same program; rather, we have access to data from other participants from a similar (previously conducted) intervention program. Our goal, therefore, was to leverage data from a similar intervention program, in addition to the limited labeled data for the target participant, to develop an adherence prediction model for the target participant. Note that, the only objective of clustering the participants in both datasets together, was to identify the source participants for a given target participant. Once the source participants were identified, the prediction model was trained for the target participant using data from the source participants; no prediction model was trained on the combination of the 2 datasets. The same 3 experiments were conducted, and the results are presented in Table 3.

The results depict a similar pattern, with DA comprehensively outperforming the other 2 experiments. The F_1-score increased by almost 8% compared to the scenario where the source data are used directly without applying DA. As before, a statistical test of significance was conducted on the F_1-score using the ANOVA repeated measures. A significant trend (P=.08) was found between the results of using DA compared to using the source data directly for training without DA. A sign test was also conducted on the F_1-score of the individual participants; a significant difference (P=.004) was found in the results with and without using DA. We also conducted a sign test on the combined results obtained from the 3 experiments (study 1, study 2, and study 1 and study 2 combined). A significant difference (P<.001) was found in the results of the individual participants with and without using DA. These findings suggest that incorporating other participants' data by using DA techniques can improve the generalization capability of a deep neural network trained to predict adherence of a particular participant, even when the other participants' data are derived from a different (but similar) intervention program.

Overall, the findings of this study suggest that DA has tremendous promise in improving the performance of a deep neural network trained to predict adherence to a cognitive training program of a given participant, by appropriately leveraging training data from other participants. Such a framework can be immensely useful in situations where only a limited amount of training data is available for the target participant. DA consistently produced better performance compared to baseline methods which did not incorporate data from other participants (source participants) at all or used the data directly without DA. Additionally, ANOVA repeated measures analyses demonstrated a statistical trend toward significance in the F_1-score between experiments with and without DA while using the source data, further corroborating the efficacy of DA on adherence prediction accuracy.

Table . Results (in percentage) on study 1 and study 2 datasets. In this experiment, for each cluster, a participant is selected as the target and all the participants, from the other dataset, in the same cluster are considered as source. Italicized values represent the best performance. The scores are calculated by averaging the respective scores over all the participants.

Experiment type	Accuracy, mean (SD)	Precision, mean (SD)	Recall, mean (SD)	F_1-score (SD)
No source, no DA[a]	64.2 (0.3)	57.1 (0.3)	58.2 (0.2)	54.2 (0.3)
With source, no DA	66.9 (0.3)	51.3 (0.3)	57.3 (0.2)	50.9 (0.3)
With source, with DA	*68.5 (0.2)*	*61.3 (0.2)*	*60.4 (0.2)*	*58.7 (0.2)*

[a]DA: domain adaptation.

Discussion

Principal Results

The results of this study have several important implications for the field of adherence prediction in the context of gamified cognitive intervention programs. Our findings suggest that CNNs can be a powerful tool for analyzing time series data and predicting adherence and can have important implications for the field of cognitive neuroscience. By using CNNs to predict adherence, we were able to identify patterns and trends in the data that could be used to improve cognitive training interventions, ultimately leading to enhanced quality of life for individuals with cognitive impairments. This research has implications for the development of more effective intervention approaches that can benefit individuals and society by improving conditions associated with aging and the life course.

More importantly, each participant has a unique playing pattern, and it is important to address the individualistic variabilities when developing adherence prediction models for cognitive gaming programs. Our study demonstrated that DA techniques can effectively reduce domain shift and improve the accuracy of CNN models in predicting adherence. The results of the experiments conducted on the study 1 and study 2 datasets demonstrated the effectiveness of DA in improving adherence prediction performance. This suggests that appropriately leveraging information from participants with similar playing patterns can enhance the accuracy of adherence pattern predictions. To the best of our knowledge, this is the first research effort to study the performance of advanced deep DA techniques to predict adherence to cognitive training programs for older adults.

Our study also suggests that GAFs can be a valuable tool for preprocessing time series data and clustering participants based on their playing patterns. The findings indicate that GAFs can aid in identifying participants with similar behaviors and interpret the patterns visually. They also enable us to identify source participants that have similar playing patterns as the target participant, so that relevant information can be transferred during DA.

Conclusions

In conclusion, this study highlights the potential of deep neural networks and DA techniques in predicting adherence lapses and developing personalized support systems for cognitive training interventions. The findings contribute to the advancement of the field and provide valuable insights for improving engagement and maximizing the benefits of such interventions for individuals with cognitive impairments. Future research will further explore the application of these techniques in other contexts and populations with the fundamental goal of improving the effectiveness of cognitive training interventions.

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Conflicts of Interest

None declared.

References

1. Dementia. World Health Organization. 2023 Mar 15. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2024-07-24]
2. Langa KM, Larson EB, Crimmins EM, et al. A comparison of the prevalence of dementia in the United States in 2000 and 2012. JAMA Intern Med 2017 Jan 1;177(1):51-58. [doi: 10.1001/jamainternmed.2016.6807] [Medline: 27893041]
3. Fong TG, Inouye SK. The inter-relationship between delirium and dementia: the importance of delirium prevention. Nat Rev Neurol 2022 Oct;18(10):579-596. [doi: 10.1038/s41582-022-00698-7] [Medline: 36028563]
4. Lampit A, Hallock H, Valenzuela M. Computerized cognitive training in cognitively healthy older adults: a systematic review and meta-analysis of effect modifiers. PLoS Med 2014 Nov;11(11):e1001756. [doi: 10.1371/journal.pmed.1001756] [Medline: 25405755]

5. Hill NTM, Mowszowski L, Naismith SL, Chadwick VL, Valenzuela M, Lampit A. Computerized cognitive training in older adults with mild cognitive impairment or dementia: a systematic review and meta-analysis. Am J Psychiatry 2017 Apr 1;174(4):329-340. [doi: 10.1176/appi.ajp.2016.16030360] [Medline: 27838936]
6. Basak C, Qin S, O'Connell MA. Differential effects of cognitive training modules in healthy aging and mild cognitive impairment: a comprehensive meta-analysis of randomized controlled trials. Psychol Aging 2020 Mar;35(2):220-249. [doi: 10.1037/pag0000442] [Medline: 32011155]
7. Gobet F, Sala G. Cognitive training: a field in search of a phenomenon. Perspect Psychol Sci 2023 Jan;18(1):125-141. [doi: 10.1177/17456916221091830] [Medline: 35939827]
8. Gray N, Yoon JS, Charness N, et al. Relative effectiveness of general versus specific cognitive training for aging adults. Psychol Aging 2022 Mar;37(2):210-221. [doi: 10.1037/pag0000663] [Medline: 34968102]
9. Melby-Lervåg M, Redick TS, Hulme C. Working memory training does not improve performance on measures of intelligence or other measures of "far transfer": evidence from a meta-analytic review. Perspect Psychol Sci 2016 Jul;11(4):512-534. [doi: 10.1177/1745691616635612] [Medline: 27474138]
10. Adherence to long-term therapies: evidence for action. World Health Organization. 2003. URL: https://apps.who.int/iris/handle/10665/42682 [accessed 2024-07-24]
11. Turunen M, Hokkanen L, Bäckman L, et al. Computer-based cognitive training for older adults: determinants of adherence. PLoS One 2019 Jul 10;14(7):e0219541. [doi: 10.1371/journal.pone.0219541] [Medline: 31291337]
12. Harrell ER, Roque NA, Boot WR. Comparing the effectiveness of two theory-based strategies to promote cognitive training adherence. J Exp Psychol Appl 2023 Dec;29(4):782-792. [doi: 10.1037/xap0000485] [Medline: 37471032]
13. Harrell ER, Roque NA, Boot WR, Charness N. Investigating message framing to improve adherence to technology-based cognitive interventions. Psychol Aging 2021 Dec;36(8):974-982. [doi: 10.1037/pag0000629] [Medline: 34460281]
14. Double KS, Birney DP. The effects of personality and metacognitive beliefs on cognitive training adherence and performance. Pers Individ Dif 2016 Nov;102:7-12. [doi: 10.1016/j.paid.2016.04.101]
15. Boot W, Souders D, Charness N, Blocker K, Roque N, Vitale T. The gamification of cognitive training: older adults' perceptions of and attitudes toward digital game-based interventions. In: Zhou J, Salvendy G, editors. Human Aspects of IT for the Aged Population Design for Aging: Second International Conference, ITAP 2016, Held as Part of HCI International 2016, Toronto, ON, Canada, July 17–22, 2016, Proceedings, Part I: Springer; 2016:290-300. [doi: 10.1007/978-3-319-39943-0_28]
16. Gonul S, Namli T, Huisman S, Laleci Erturkmen GB, Toroslu IH, Cosar A. An expandable approach for design and personalization of digital, just-in-time adaptive interventions. J Am Med Inform Assoc 2019 Mar 1;26(3):198-210. [doi: 10.1093/jamia/ocy160] [Medline: 30590757]
17. Wang L, Miller LC. Just-in-the-moment adaptive interventions (JITAI): a meta-analytical review. Health Commun 2020 Nov;35(12):1531-1544. [doi: 10.1080/10410236.2019.1652388] [Medline: 31488002]
18. He Z, Tian S, Singh A, et al. A machine-learning based approach for predicting older adults' adherence to technology-based cognitive training. Inf Process Manag 2022 Sep;59(5):103034. [doi: 10.1016/j.ipm.2022.103034] [Medline: 35909793]
19. Singh A, Chakraborty S, He Z, et al. Deep learning-based predictions of older adults' adherence to cognitive training to support training efficacy. Front Psychol 2022 Nov 17;13:980778. [doi: 10.3389/fpsyg.2022.980778] [Medline: 36467206]
20. Pan SJ, Yang Q. A survey on transfer learning. IEEE Trans Knowl Data Eng 2010 Oct 16;22(10):1345-1359. [doi: 10.1109/TKDE.2009.191]
21. Tzeng E, Hoffman J, Zhang N, Saenko K, Darrell T. Deep domain confusion: maximizing for domain invariance. arXiv. Preprint posted online on Dec 10, 2014. [doi: 10.48550/arXiv.1412.3474]
22. Ganin Y, Ustinova E, Ajakan H, et al. Domain-adversarial training of neural networks. J Mach Learn Res 2016;17(59):1-35 [FREE Full text]
23. Chen JF, Chen WL, Huang CP, Huang SH, Chen AP. Financial time-series data analysis using deep convolutional neural networks. Presented at: 2016 7th International Conference on Cloud Computing and Big Data (CCBD); Nov 16-18, 2016; Macau, China. [doi: 10.1109/CCBD.2016.027]
24. Kim TY, Cho SB. Predicting residential energy consumption using CNN-LSTM neural networks. Energy 2019 Sep;182:72-81. [doi: 10.1016/j.energy.2019.05.230]
25. Liu S, Zhang C, Ma J. CNN-LSTM neural network model for quantitative strategy analysis in stock markets. In: Liu D, Xie S, Li Y, Zhao D, El-Alfy ESM, editors. Neural Information Processing: 24th International Conference, ICONIP 2017, Guangzhou, China, November 14-18, 2017, Proceedings, Part II: Springer; 2017:198-206. [doi: 10.1007/978-3-319-70096-0_21]
26. Creative Commons. Attribution 40 International (CC BY 40). URL: https://creativecommons.org/licenses/by/4.0/ [accessed 2024-09-09]
27. Wilson G, Doppa JR, Cook DJ. Multi-source deep domain adaptation with weak supervision for time-series sensor data. Presented at: 26th ACM SIGKDD International Conference on Knowledge Discovery & Data Mining; Jul 6-10, 2020. [doi: 10.1145/3394486.3403228]

28. Hu H, Tang M, Bai C. Datsing: data augmented time series forecasting with adversarial domain adaptation. Presented at: 29th ACM International Conference on Information & Knowledge Management; Oct 19-23, 2020. [doi: 10.1145/3340531.3412155]
29. Wang Z, Oates T. Imaging time-series to improve classification and imputation. arXiv. Preprint posted online on Jun 1, 2015. [doi: 10.48550/arXiv.1506.00327]
30. Fan J, Wen J, Lai Z. Myoelectric pattern recognition using Gramian angular field and convolutional neural networks for muscle-computer interface. Sensors (Basel) 2023 Mar 1;23(5):2715. [doi: 10.3390/s23052715] [Medline: 36904918]
31. Yousuf A, Hafiz R, Riaz S, Farooq M, Riaz K, Rahman MMU. Myocardial infarction detection from ECG: a gramian angular field-based 2D-CNN approach. arXiv. Preprint posted online on Feb 25, 2023. [doi: 10.48550/arXiv.2302.13011]
32. Li X, Li T, Wang Y. GW-DC: a deep clustering model leveraging two-dimensional image transformation and enhancement. Algorithms 2021;14(12):349. [doi: 10.3390/a14120349]
33. Dhanachandra N, Manglem K, Chanu YJ. Image segmentation using K -means clustering algorithm and subtractive clustering algorithm. Procedia Comput Sci 2015;54:764-771. [doi: 10.1016/j.procs.2015.06.090]
34. Lally P, van Jaarsveld CHM, Potts HWW, Wardle J. How are habits formed: modelling habit formation in the real world. Euro J Social Psych 2010 Oct;40(6):998-1009. [doi: 10.1002/ejsp.674]
35. Goutte C, Gaussier E. A probabilistic interpretation of precision, recall and F-score, with implication for evaluation. In: Losada DE, Fernández-Luna JM, editors. Advances in Information Retrieval: 27th European Conference on IR Research, ECIR 2005, Santiago de Compostela, Spain, March 21-23, 2005, Proceedings: Springer; 2005:345-359. [doi: 10.1007/978-3-540-31865-1_25]
36. Sokolova M, Japkowicz N, Szpakowicz S. Beyond accuracy, F-score and ROC: a family of discriminant measures for performance evaluation. In: Sattar A, Kang BH, editors. AI 2006: Advances in Artificial Intelligence: 19th Australian Joint Conference on Artificial Intelligence, Hobart, Australia, December 4-8, 2006, Proceedings: Springer; 2006:1015-1021. [doi: 10.1007/11941439_114]

Abbreviations

CNN: convolutional neural network
DA: domain adaptation
GAF: Gramian angular field

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A Serious Game for Cognitive Stimulation of Older People With Mild Cognitive Impairment: Design and Pilot Usability Study

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Abstract

Background: Cognitive stimulation of older people helps prevent, and even treat, age-related diseases, such as mild cognitive impairment. Playing games reduces the probability of experiencing this pathology, which is related to the loss of the ability to carry out some instrumental activities of daily living.

Objective: This work describes the design and development of a serious game for the cognitive stimulation of older people, with exercises related to the daily life task of shopping. A pilot study for its preliminary usability validation is also presented.

Methods: The designed serious game includes 4 exercises consisting of shopping in a hypermarket, ordering products, making payments, and organizing the purchase, thus dealing with the most frequent cognitive problems of older people associated with episodic declarative memory, naming, calculation, and organization, respectively.

Results: A total of 19 older people participated in the pilot study for the usability validation of the serious game. They indicated that they like the aesthetic and interesting topic of the game. They reported that it provides a high level of entertainment and could be useful in daily life for mental stimulation. The participants found the serious game to be intuitive, but the ease of use and readability of the instructions could be improved.

Conclusions: This study suggests that the innovative serious game developed could be accepted by older people for their cognitive stimulation to prevent or treat mild cognitive impairment, although a long-term intervention study should be performed as future work. Its ecological validity design, with everyday tasks, adaptable levels of difficulty, and motivational mechanisms, is a differentiating factor compared to similar serious games.

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KEYWORDS

serious game; mild cognitive impairment; cognitive stimulation; design; pilot study; older people; activities of daily living; shopping; ecological validity

Introduction

The increase in life expectancy means that we can live with age-related pathologies, such as dementia. However, the prevalence of this pathology is clearly on the rise, and there are currently about 55 million people affected worldwide [1] and around 11 million for the broad European region [2]. This acquired syndrome is characterized by a progressive deterioration of cognitive functions, which influences activities of daily living (ADL) and decreases the level of independence of individuals. For this reason, dementia is classified into grades, where simple activities can be performed in the mild stage but the severity of symptoms increases as the impairment progresses [2-4]. Mild cognitive impairment (MCI) is the term used for individuals whose cognitive changes fall between those of aging and early dementia and is considered a precursor to early dementia in around 30% of cases; thus, those with MCI are much more likely to progress to this type or level of dementia, especially in older people [4]. Treatment usually includes drugs that aim to reduce or delay cognitive, psychological, and behavioral symptoms [5], but nonpharmacological treatments are also very important. These include reality orientation, reminiscence and validation therapies, or cognitive stimulation [6].

Cognitive stimulation includes techniques that focus on treating cognitive aspects through activities that allow them to be worked on globally and simultaneously [6,7]. Cognitive and reminiscence activities, multisensory activities, as well as those that work on social aspects are used, along with group activities that facilitate integration and social participation among users [8]. In fact, several studies confirm an improvement in different aspects of the cognitive sphere and in the quality of life of people with dementia who have participated in this type of therapies [9,10]. We also found improvements in mood and ADL maintenance [11].

Currently, information and communication technology (ICT) instruments and tools are incorporated into nonpharmacological treatments. These technological devices facilitate performance, which can lead to a greater sense of self-efficacy and improve one's own perception of functionality, as well as reduce the burden of caregivers. Some of the devices that are commonly used with people with dementia are tele-assistance, devices that improve cognitive functions, and robotics [12]. Among them, the most widely used are those that can be connected to the internet (tablets, mobile phones, computers, and video game consoles), which provides a wide variety of resources that allow the diversification of therapies and increase motivation and adherence to treatment [8,13]. The use of ICTs as therapeutic tools requires a previous study of the person's abilities and skills for their use and management, to avoid feelings of frustration that can lead to discouragement from therapy or rejection of the device [9]. Therefore, it is essential to gradually approach the device and its applications, looking for intuitive tasks that the user can easily carry out independently [9,13].

Serious games are ICT games whose main objective is to give a therapeutic or diagnosis value to the playful action of the games. They have been tested in different areas of intervention in pathologies with cognitive impairment [14,15], particularly dementia [16]. Through serious games, we can work to delay deficits, increase autonomy and relationships with their social environment, and improve the quality of life of people with dementia [17]. For this intervention, the occupational therapist may include in their individual intervention plans games to work on physical, cognitive, and social aspects. The literature reveals that there are already a number of well-established serious games that could improve older people's cognitive health. Some examples of these are focused on sport simulations, quizzes with text and images, music tools, arithmetic and reading calculations, etc [17]. Others instead use a fantasy world setting, minigames, puzzles, or scenarios to cope with stressful or negative situations [18]. However, few serious games have been developed that incorporate tasks focused on ADL, such as cooking [19]. Once cognitive impairment becomes perceptible in ADL, the disease has usually progressed, so the analysis of ADL performance would help to assess cognitive status during the course of cognitive impairment [19]. In this sense, serious games can be a valuable tool for achieving this in a motivating and enjoyable way for older people with ecological scenarios.

In this study, we describe the design and development process of a serious game developed for the cognitive stimulation of older people, with exercises related to the daily life task of shopping. We also present the results of a usability validation from a pilot study of the game.

Methods

Game Development Process and Design Requirements

In the process of designing and developing this serious game, researchers with a bioengineering profile, game designers and developers (computer and telecommunication engineers), and health care professionals (neuropsychologists, psychologists, and occupational therapists) participated to fulfill the essential collaboration of an interdisciplinary team [20].

First, 2 focus groups were performed with 11 psychologists and 6 occupational therapists from Extremadura, Spain, to identify the needs, limitations, and motivations of older people to use cognitive stimulation programs. The selection criteria of participants in both focus groups were the geographical location (working in rural and urban areas) and the kind of institutions in which they work (public and private). The focus groups were conducted by 2 engineers with extensive experience in conducting interviews. After the presentation of the study and the objectives, a previously created guide with topics of interest and questions was followed to conduct the session in a semistructured way. With the participants' consent, all conversations were recorded for subsequent transcription and analysis. NVivo 2017 (QSR International) software was used to carry out this analysis to facilitate the drawing of conclusions. Four thematic areas were identified: (1) the most frequent cognitive problems of older people are mainly focused on memory loss, disorientation, difficulty in performing executive tasks, or difficulty in concentrating; (2) motivation is the fundamental element for the success of new training exercises; (3) technological barriers are mainly related to interface design problems and cultural level; and (4) the low degree of awareness of older people regarding the importance of leading an active life. This served as a basis for designing the new tool to promote the cognitive training that directly stimulates memory and executive tasks, as well as orientation and concentration skills.

In the implementation of this serious game for Android OS, Unity 3D (C#, Visual Studio 2017) was used, following the design recommendations established in previous studies [21]. In this sense, the game interface was designed while taking into account that the target audience is older people and adapted to their needs, including the minimum necessary information in a clear and concise way, which allows the older people to understand the objective of the game. Regarding user interaction, the game was designed to be used on a tablet instead of the standard keyboard and mouse to provide a more natural interaction and facilitate the acceptance by older people [22].

Two fundamental characteristics were taken into account in the design of this serious game. First, a shopping task with high ecological validity was included, that is, a day-to-day activity of older people. In this way, a greater interest and acceptance by older people should be achieved, due to the high utility of this tool in their daily lives. The concept of ecological validity is determined by the degree of representativeness, that the game is represented in a form and context that correspond to its occurrence in everyday life, as well as by the level of generalization that the results are able to explain similar tasks in everyday life [23]. Second, the difficulty level of the game was customized by professionals according to the needs of each older person, as detailed in the description of each game in the following sections.

An additional characteristic included in the design of the game was that immediate feedback is provided to the user at the end of each game, showing the attempts, hits, and failures made after the user performance. Moreover, positive feedback with encouragement messages is showed to the user during the completion of the game, such as "Come on, you're about to get it," "You almost got it. Try again," "Surely you have the name on the tip of your tongue," and "Don't worry. Let's go with another product."

Game Description

First Exercise: Shopping in a Hypermarket

Episodic declarative memory is the neurocognitive function that is affected the earliest in Alzheimer disease due to the initial involvement of the hippocampal formation in the medial temporal lobe, so the stimulation of episodic declarative memory in people with MCI who are affected by mnesic impairment is of utmost importance.

This exercise is designed with the specific aim of stimulating verbal intentional episodic declarative memory at the level of the 3 mnesic processes of encoding or fixation, consolidation or storage, and recall or retrieval of information, thus consisting of 3 phases:

- *1.1 Learning Phase*: memorization of a shopping list
- *1.2 Interference Phase*: preparation of the money to pay for the purchase
- *1.3 Recall Phase*: purchase of products from the shopping list

The level of difficulty can be adjusted by the number of products on the shopping list, the number of product categories, the memorization and interference times, the number of attempts, or the total allowed time.

Second Exercise: Ordering Products in a Hypermarket

On the one hand, expressive language impairment manifests itself very frequently and early in the form of anomia, a naming deficit that consists of the difficulty to recall the names of objects. Due to the great frustration caused by this early expressive language difficulty for people with MCI, it is essential to include naming stimulation tasks within the global stimulation of expressive language in cognitive stimulation programs.

On the other hand, complex visual gnosias, in which the visual recognition and identification of objects is hindered by a modification of the characteristics of the objects' images, are one of the cognitive functions that are affected in the early stages of several primary cortical degenerative dementias, hence the importance of their stimulation.

This exercise is designed with the specific aim of stimulating language at the level of naming and complex visual gnosias in 2 phases:

- *2.1 Phase 1*: hypermarket product naming
- *2.2 Phase 2*: visual recognition and identification of hypermarket products

The difficulty can be customized by adjusting the product familiarity percentage, the number of products that appears, whether or not to provide help to recognize the products, or the allowed time.

Third Exercise: Making Payments

Executive attentional control processes are affected early in several types of primary and secondary dementias such as subcortical vascular dementia. Working memory, a key element of executive attentional control, is the ability to maintain and manipulate information in on-going cognitive activity, such as money management for shopping. It is therefore very important to place great emphasis on the stimulation of these cognitive processes to maintain the highest possible level of functional independence of each person.

This exercise consists of 3 phases and is designed with the specific aim of stimulating the working memory through calculation tasks by simulating purchase payments:

- *3.1 Phase 1*: payment of the purchase
- *3.2 Phase 2*: check the change (money returned)
- *3.3 Phase 3*: check the price of products on the purchase receipt with the catalog of offers

Professionals can adapt the difficulty by adjusting whether or not to include decimals in the amount to be paid or the change, the number of attempts, the allowed time, the number of correct banknotes or coins in the change, the number of products, pages and sections in the catalog of offers, or the rate of products with erroneous price.

Fourth Exercise: Organizing the Purchase

Executive functions, such as planning and organization, reasoning, cognitive flexibility, or monitoring when problem-solving, are crucial functions for a good performance of any adult in advanced and instrumental ADL. In the context of cognitive treatments for MCI, the stimulation of executive functions is a compulsory subject given their close interdependence with the maintenance of a high level of functional independence and personal autonomy in ADL.

This exercise is designed with the specific objective of stimulating this executive function of organization, as well as abstract reasoning, performance monitoring, visual gnosias, semantic memory, and visuospatial function.

The only phase of this exercise consists of the arrangement of the purchase products in the corresponding rooms of the house.

In this case, the adaptation of the difficulty can be achieved by adjusting the number of products on the list and the maximum time allowed to complete the task.

Acceptance and Usability Study

A preliminary validation of the serious game was carried out by 4 participants from the Association of Friends of the Minimally Invasive Surgery Centre in Cáceres, Spain; 5 participants from senior centers in Castelo Branco, Portugal; and 10 participants who attended the FEHISPOR fair held in Badajoz, Spain. The nonprobability intentional sampling technique was used to conduct the recruitment of participants, with inclusion criteria of older people aged 60-80 years with MCI. Through this method, older people from those attending various demonstrations of the game at the aforementioned events and venues were recruited to voluntarily participate in the study.

Participants tested the game until all exercises were completed and then filled in a questionnaire. The questionnaire consisted of questions scored on a 5-value Likert scale (1=lowest value, 5=highest value) about the acceptance and usability of the game, assessing (1) the user's perception and degree of satisfaction when using the game and (2) the design and layout of the game. A descriptive analysis with the average values of the answers provided by the participants was performed.

Ethical Considerations

Both ethical approval and written participants consent were waived for this study because they were not within the scope of Law 14/2007 of 3rd July on Biomedical Research, due to this study not involving any invasive procedure on the participants. Only verbal informed consent was considered sufficient. All data have been deidentified, and there was no compensation for participation.

Results

Game Implementation

First Exercise: Shopping in a Hypermarket

This exercise consists of 3 phases.

In *1.1 Learning Phase*, the user must learn a series of products from a shopping list in 3 subphases (Figure 1): (1) organization of the list by categorization, since the structure of the information facilitates its deep encoding; (2) identification of specific characteristics that differentiate the products, since better fixation of information with clues optimizes recall; and (3) intentional memorization of the list in a specific time frame.

Figure 1. The first exercise stimulates episodic declarative memory with 3 mnesic processes: encoding, consolidation, and recall. The user must learn a series of products from a shopping list.

In *1.2 Interference Phase*, the task simulates the preparation of the wallet with the money to pay for the purchase. It activates the processes of attentional control at the level of selective attention to choose the correct banknotes or coins, working memory to sum the money, and monitoring of the execution to avoid errors.

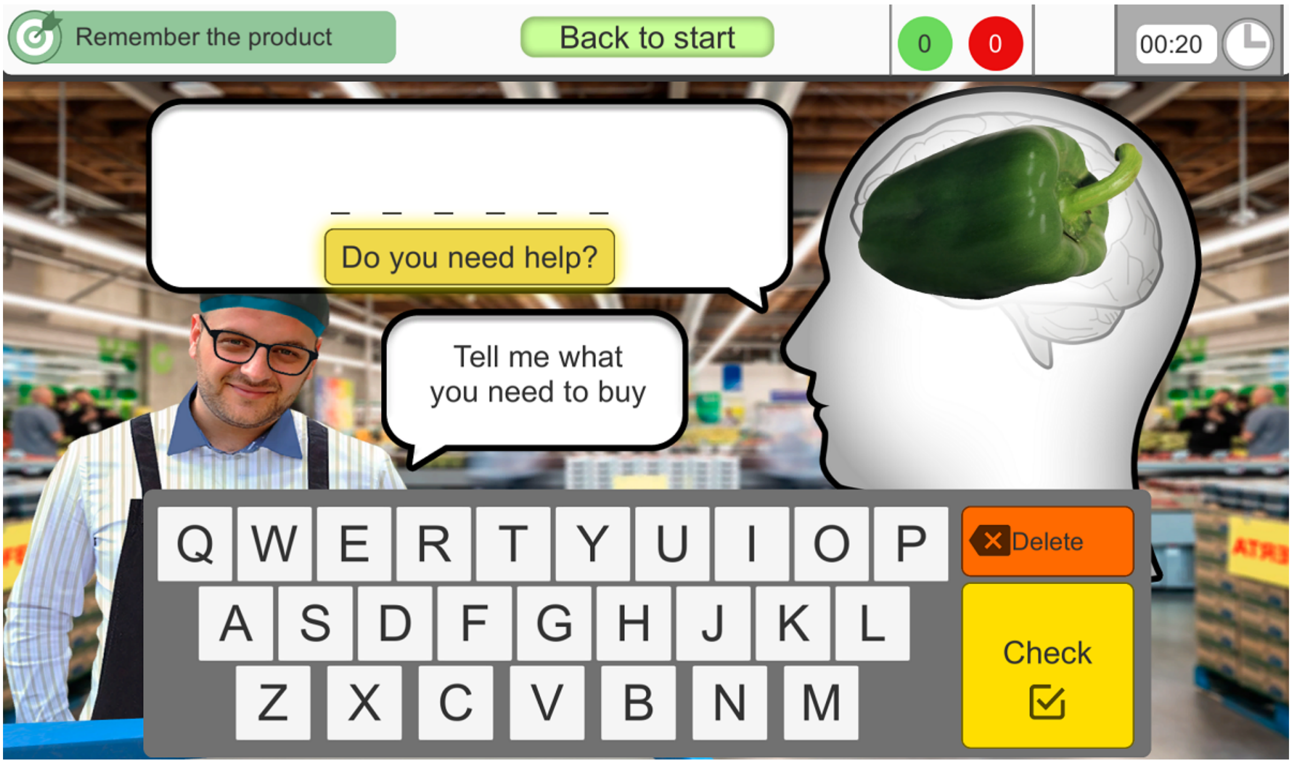
In *1.3 Recall Phase*, the user is presented with a map of a hypermarket where the sections are marked out, and the user has to fill a shopping basket with those products from the shopping list studied in the *1.1 Learning Phase* among distracting products. The aim is to stimulate the mnesic process of recalling short-term episodic declarative memory.

Second Exercise: Ordering Products in a Hypermarket

This exercise consists of 2 phases.

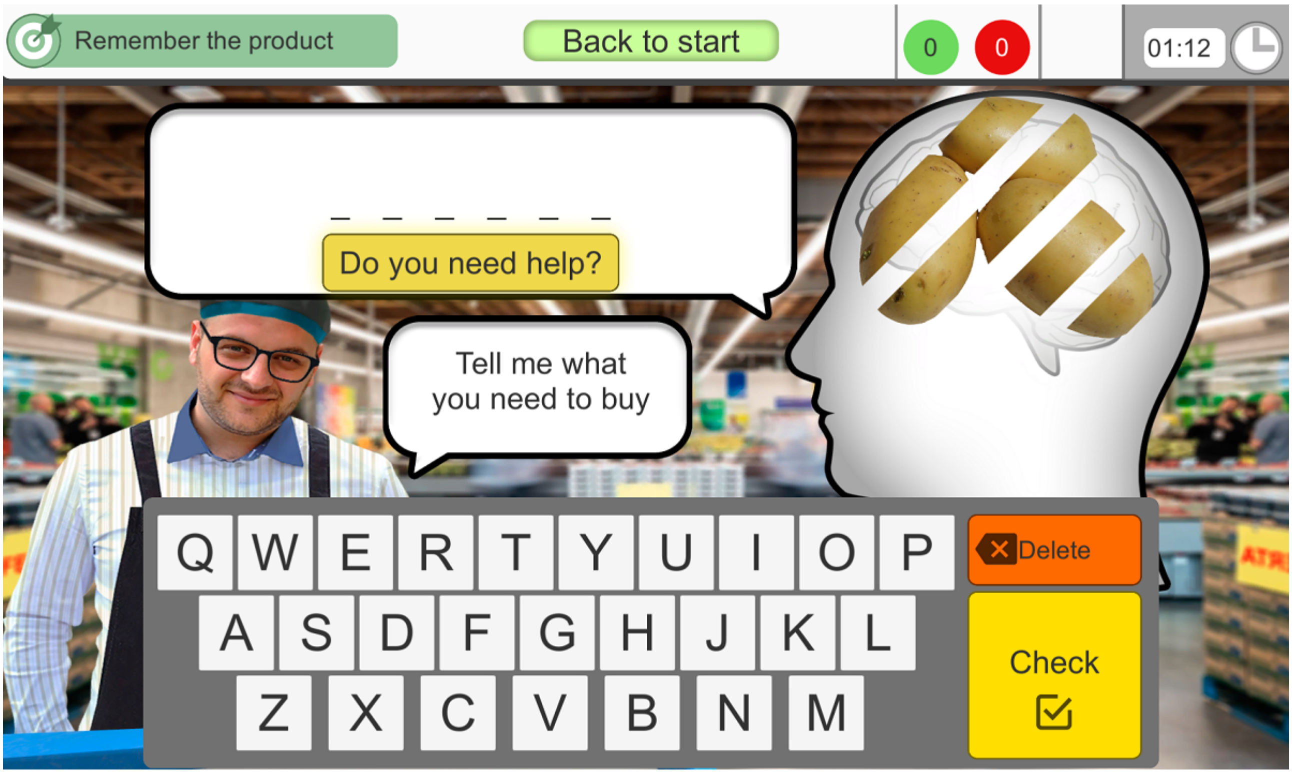
In *2.1 Phase 1*, the user has to write the names of the hypermarket products that appear in the images (Figure 2).

Figure 2. The second exercise (2.1) stimulates expressive language. The user has to write the names of the products that appear in the images.



In *2.2 Phase 2*, the user has to recognize and identify the hypermarket products through their distorted images and subsequently name these products (Figure 3). The emphasis is placed on the stimulation of complex visual gnosias, making it difficult to recognize and identify the objects to be named.

Figure 3. The second exercise (2.2) stimulates complex visual gnosias. The user has to recognize and write the names of the products through their distorted images.



Third Exercise: Making Payments

This exercise consists of 3 phases.

In *3.1 Phase 1*, the user has to use banknotes or coins to make the exact payment of the purchase (Figure 4).

Figure 4. The third exercise stimulates executive attentional control. The user has to use banknotes or coins to make the exact payment of the purchase.

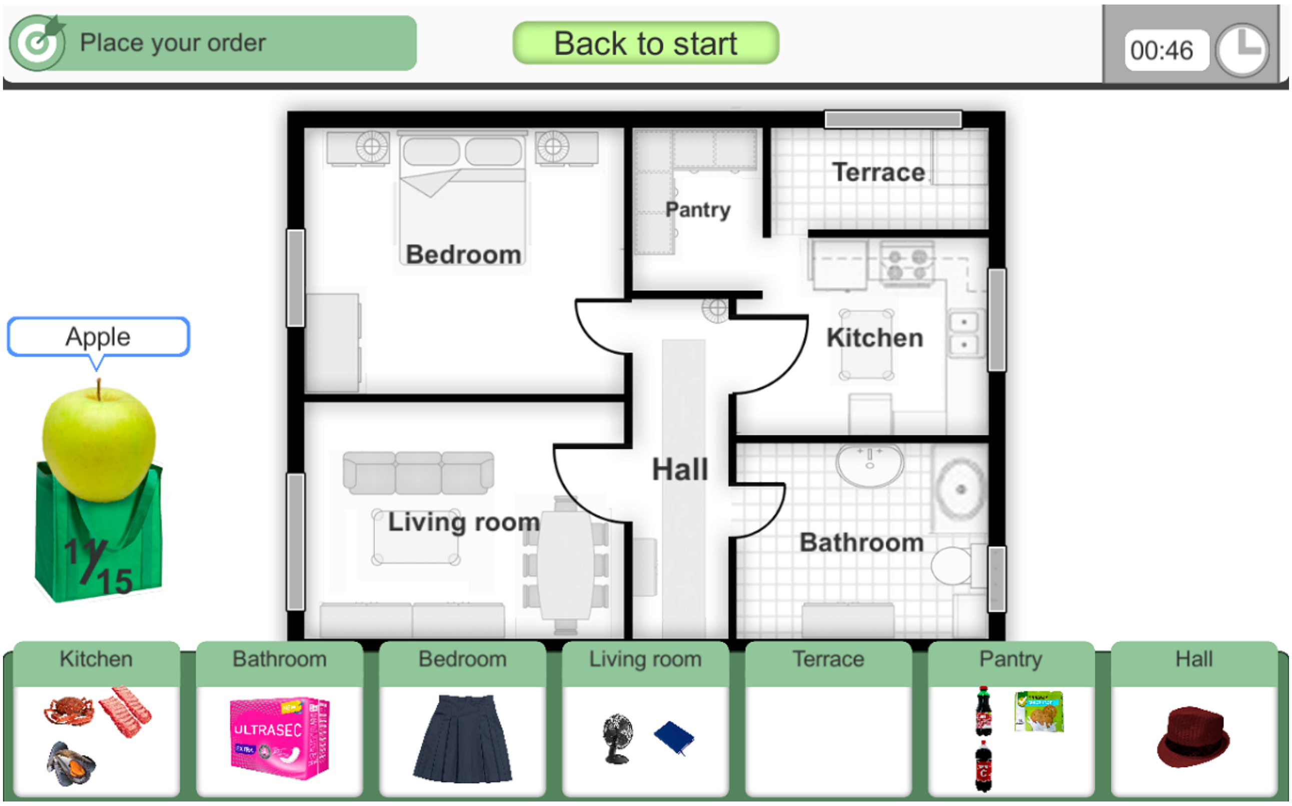
In *3.2 Phase 2*, the user must check whether the change (money returned) received is correct, and if not, he or she must select the banknotes or coins necessary to make the change amount correct.

In *3.3 Phase 3*, the user has to check the price charged for each product on the purchase receipt to verify whether it corresponds to the price for that product in the catalog, and in the case of error, to mark on the receipt the products for which the amount on the receipt is erroneous.

Fourth Exercise: Organizing the Purchase

In this exercise, the user must arrange the products of a purchase into the rooms of a house, whose floor plan appears on the screen and consists of the following spaces: kitchen, terrace, bathroom, pantry, living room, and bedroom (Figure 5). Within each of these house spaces, the correct storage location is flexible according to each product.

Figure 5. The fourth exercise stimulates executive functions. The user must arrange the products of a purchase into the rooms of a house.



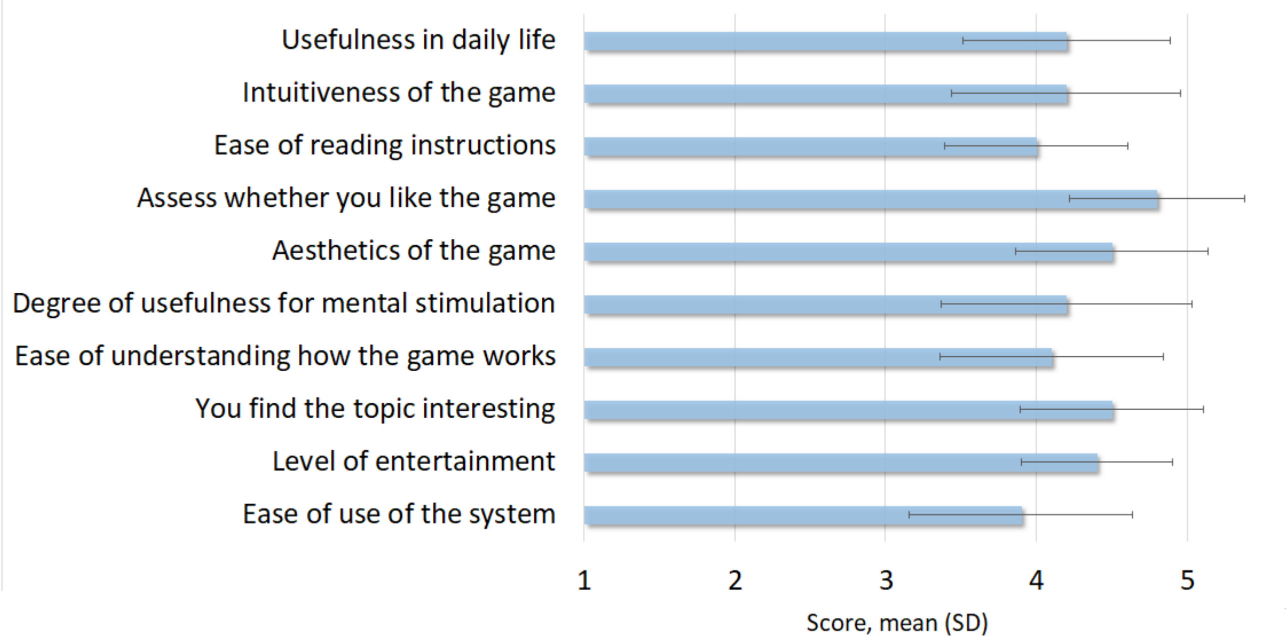
Acceptance and Usability

A total of 19 people participated in the study (Table 1) and provided their opinions regarding the serious game, which are shown in Figure 6.

Table . Demographic characteristics of participants.

Characteristics		Value (N=19)
Age (years), mean (SD)		75.3 (1.4)
Gender, n (%)		
	Woman	16 (84)
	Man	3 (16)
Level of education, n (%)		
	Secondary (high school)	19 (100)
Smartphone experience (frequency of use), n (%)		
	Once a week	19 (100)

Figure 6. Scores of older people who participated in the validation.



All items were highly valued with a score over 3.5 out of 5, which is the threshold for an item to be considered as positively validated, and the average value was 4.28 (SD 0.67). On the one hand, the most valued aspects were that participants like the game (mean 4.8, SD 0.58), both from the aesthetics point of view (mean 4.5, SD 0.64) and the interesting topic (mean 4.5, SD 0.61) of the game. On the other hand, the items that had the lowest score were the ease of use of the system (mean 3.9, SD 0.74) and the ease of reading the instructions (mean 4.0, SD 0.61).

Discussion

Principal Findings

From a cognitive point of view, the first effects of deterioration in older adults are directly related to the loss of the ability to carry out some instrumental ADL. However, there are multiple studies showing that people who read or play games are less likely to develop dementia or even Alzheimer disease [24,25]. In particular, the use of serious games has proven its value as a cognitive therapy for older people [26]. In the literature, different games have been designed and validated for cognitive stimulation [17,18], but it is not common for these games to use tasks focused on ADL. The aim of this work has been to describe how a serious game has been designed and implemented for cognitive stimulation of older adults by means of memory, naming, calculation, and organization exercises, which are key in ADL such as shopping. In this way, this serious game deals with the most frequent cognitive problems of older people indicated by health professionals.

According to the literature, it is not completely clear to what extent existing health care research explicitly distinguishes between gamification and serious games [27]. Serious games refer to the use of games and gaming technology for purposes other than just entertainment or fun, including health purposes. They can have direct or indirect positive physiological and psychological effects on people, which is precisely the objective of serious games in health and health care [28]. Our work applies to this definition because our serious game was designed for cognitive stimulation of older people with MCI and could have direct positive psychological effects on older people for the prevention or treatment of such cognitive impairment.

The preliminary pilot study carried out to validate the usability of the serious game showed that participants had a great opinion of this game and considered the theme interesting, entertaining, and useful for mental stimulation, so we can think a priori that the game could be well accepted among older people. Users found the serious game intuitive and aesthetically appealing; therefore, it meets the principles of simplicity and intuitiveness for the design of user interfaces for older people to avoid extracognitive load for the user [29].

Taking into account preferences of older people, game themes should meet their interest because they have a predilection for games related to real life [30]. In this sense, ecological validity was considered in the design of our serious game, since it is important for the validation of cognitive skills that influence functional tasks in real-world contexts [31]. Moreover, the fact that the difficulty of the game can be set by the professional to provide an achievable difficulty for each older adult user is important to motivate them to play and avoid frustration, anxiety, or negative emotions when playing [30].

Previous studies have described the benefits of using tablets for cognitive stimulation [32], but at the same time, rejection and barriers for older people in the use of these technologies have also been described [33]. In this regard, the results obtained in this study indicate that the game is easy to use and understand. However, these are preliminary findings as the study participants use smartphones in their daily live, which greatly reduces the rejection of this type of technology. Nevertheless, as future work, it is necessary to improve the interaction and facilitate the use of the game to avoid the rejection by older people, since results obtained from the questionnaires regarding the ease of use and instructions of the game were positive, but there was room for improvement.

In relation to the use of technologies by older adults and to digital health, the European Commission encourages improving the digitalization of health systems to fight health inequalities [34]. However, digital health services and devices are useless if consumers, in this case older people, do not have the skills or understanding to use them. For that, in the digital age, more than ever, literacy in digital health is a critical first step to improve the quality of life.

A feature of this serious game is that it provides feedback to the user at the end of each stage of the game, indicating whether the task was correctly completed or not and the type of mistake that was made. This agrees with Brox et al [35], who stated that when older people achieve their goal, feedback should be immediately provided. Moreover, to avoid frustration, which is another key aspect of the game, the system also provides encouraging messages during the completion of the game, so that the user can try again. This positive feedback for encouragement favors a successful experience of older user with the game [36], allowing them to achieve the goal with high motivation [30]. The use of narratives and the low complexity of the game are factors that motivate older people to play [37,38]. In this way, motivational mechanisms have been included in this serious game, which is the fundamental element for success of new training exercises.

According to the literature [39], game design features related to the game genre (GG), game nature (GN), and game development strategy (GDS) are necessary to develop a serious game. The GG covers sports, simulation, and strategy, among others. GN features include player perspective taking (first-person perspective vs third-person perspective), gameplay mode (multiplayer vs single player), type of scenery or in-game environment (realistic, fantasy themed, or simple), the presence or absence of playable characters, and the level of immersion applied to the use of immersive or nonimmersive virtual reality. GDS refers to custom-made serious games developed specifically for the study in question or direct-to-consumer approaches. In our work, regarding the GG, we can associate gender to the simulation of ADL, such as shopping, thus meeting this design criterion. In the case of GN, a first-person perspective, single-player experience, realistic scenario, the absence of playable characters, and no immersion was implemented. According to these design features, those of interest that have not been included in our serious game and could be implemented and tested in the future works are as follows: (1) a multiplayer gameplay mode: in this way, older people could simulate going shopping together with their loved one, family member, or friend, which is something they are probably used to in their life, thus increasing the feeling of sociability; and (2) changing the level of immersion to include the use of virtual reality: the use of virtual reality could be of interest, so that the older person is immersed in the game and can feel as if they are actually doing the shopping task, especially in the exercises that involve going to the supermarket, such as asking the shop assistant for the products, moving through the sections of the supermarket and filling the shopping basket with the products on the list, or even arriving home with the shopping basket and moving through the different sections of the house to place the products. All of these features would involve older people in a more realistic environment. However, the effort (human and material resources) involved in implementing these features, as well as the acceptance of older people to the use of this type of virtual reality technologies, either with glasses or simulating on a PC with a keyboard and mouse, would have to be carefully studied. Finally, regarding the third game design feature of GDS, our serious game has been implemented solely for our study, but it will be freely available for download and use by older people and health care institutions who wish to use it.

This serious game presents an alternative format to traditional interventions for older people, so we suggest defining a protocol to assess the effects on the cognitive function of older adults with a long-term intervention after a period of time to test the effectiveness of this serious game.

Limitations

The study has the limitation that the pilot study used a small sample size belonging to a limited geographical area, which may influence the generalizability of results. Therefore, it is necessary to extend these results with a larger sample size, including people of different cultural levels, with different experiences in the use of tactile devices, as well as people with different levels of cognitive impairment, to test the robustness of our findings.

Comparison With Prior Work

Ecological validity has been taken into account in the design of the serious game in this work, with tasks focused on ADL such as shopping. This is not common in the different games designed and validated for cognitive stimulation found in the literature, some of which focused on sport simulations, quizzes with text and images, music tools, arithmetic and reading calculations, etc [17], whereas others use a fantasy world setting, minigames, puzzles, or scenarios to cope with stressful or negative situations [18]. The innovative factor of including ecological scenarios of ADL tasks favors a greater interest and acceptance by older people and could help to assess the cognitive status to prevent or control the progress of the cognitive impairment.

Conclusions

In this work, an innovative serious game for cognitive stimulation of older people has been designed and developed, focusing on the ADL of shopping, incorporating motivational elements, and allowing for difficulty adaptability. The set of exercises included in the serious game have been described, including the theoretical basis on which each exercise has been implemented, which deal with the most frequent cognitive problems of older people associated with episodic declarative memory, naming, calculation, and organization. This study could serve as a basis for future serious games for cognitive stimulation of older people that may benefit from the knowledge obtained about the design strategies followed.

A pilot usability study carried out with older adults has shown that this serious game is intuitive, provides a high level of entertainment, and is useful for its application in daily life. In conclusion, according to the preliminary results obtained, we think that the serious game could be widely accepted by older people and, therefore, could become a tool that contributes to delaying their deterioration and increasing their independence. In this way, the serious game developed could contribute to increase the low degree of awareness of older people regarding the importance of leading an active life.

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Conflicts of Interest

None declared.

References

1. Dementia. World Health Organization. 2023 Mar 15. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2024-03-25]
2. Prevalence of dementia in Europe. Alzheimer Europe. 2019. URL: https://www.alzheimer-europe.org/dementia/prevalence-dementia-europe [accessed 2024-03-25]
3. Slachevsky A. Las demencias: historia, concepto, clasificación y dificultades diagnósticas. In: Guajardo G, editor. Salud Mental y Personas Mayores: Reflexiones Teórico-Conceptuales para la Investigación Social de las Demencias: FLACSO-Chile; 2016:45-63 URL: https://biblio.flacsoandes.edu.ec/libros/digital/56111.pdf#page=38 [accessed 2024-03-25]
4. Knopman DS, Petersen RC. Mild cognitive impairment and mild dementia: a clinical perspective. Mayo Clin Proc 2014 Oct;89(10):1452-1459. [doi: 10.1016/j.mayocp.2014.06.019] [Medline: 25282431]
5. Holmes C, Amin J. Dementia. Medicine 2020 Nov;48(11):742-745. [doi: 10.1016/j.mpmed.2020.08.014]
6. Subirana Mirete J, Crusat Basté M, Cullell Gómez N, Cuevas Pérez R, Signo Miguel S, et al. Capítulo |18| - demencias y enfermedad de Alzheimer. In: Bruna O, Roig T, Puyuelo M, editors. Rehabilitación Neuropsicológica: Intervención y Práctica Clínica: Elsevier España; 2011:289-318. [doi: 10.1016/B978-84-458-2066-7.00018-5]
7. López Núñez AE. Instrumentos Lúdicos para la Estimulación Cognitiva del Adulto Mayor con Demencia Tipo Alzheimer DTA [thesis].: Pontificia Universidad Católica del Ecuador; 2021 URL: https://repositorio.pucesa.edu.ec/handle/123456789/3093 [accessed 2024-03-25]
8. García Santelesforo R, Pérez Sáez E. Intervención con Nuevas Tecnologías en Centros de Personas con Demencia: Guía para la Implantación del Uso de tablet. : Instituto de Mayores y Servicios Sociales (Imserso); 2017 URL: https://cendocps.carm.es/documentacion/2018_Intervencion_nuevas_tecnologias_personas_demencia.pdf [accessed 2024-03-25]
9. Miranda-Castillo C, Mascayano Tapia F, Roa Herrera A, Maray Ghigliotto F, Serraino Guerra L. Implementación de un programa de estimulación cognitiva en personas con demencia tipo Alzheimer: un estudio piloto en Chilenos de la tercera edad [Article in Spanish]. Universitas Psychologica 2013;12(2):445-455. [doi: 10.11144/Javeriana.UPSY12-2.ipec]
10. Saragih ID, Tonapa SI, Saragih IS, Lee BO. Effects of cognitive stimulation therapy for people with dementia: a systematic review and meta-analysis of randomized controlled studies. Int J Nurs Stud 2022 Apr;128:104181. [doi: 10.1016/j.ijnurstu.2022.104181] [Medline: 35149325]
11. Sánchez Vélez D, Baiz Restrepo NA. Revisión Sistemática de la Intervención Neuropsicológica en el Deterioro Cognitivo Leve y la Demencia Alzheimer [term paper].: Universidad de Antioquia; 2016 URL: https://bibliotecadigital.udea.edu.co/bitstream/10495/14698/1/SanchezDaniela_2016_RevisionSistematicaIntervencion.pdf [accessed 2024-03-25]
12. Blasco SV, Moreno MJC. Las nuevas tecnologías en el tratamiento de enfermos con demencias y la conveniencia de incluir estos contenidos en los estudios de disciplinas de ciencias de la salud [Article in Spanish]. Psiquiatria 2021;25 [FREE Full text]
13. Brossard B. Situating words: what grounded theory brings to dementia research and vice versa. Sociological Focus 2019 Apr 3;52(2):117-130. [doi: 10.1080/00380237.2018.1544518]
14. Glynn K, O’Callaghan M, Hannigan O, et al. Clinical utility of mild cognitive impairment subtypes and number of impaired cognitive domains at predicting progression to dementia: a 20-year retrospective study. Int J Geriatr Psychiatry 2021 Jan;36(1):31-37. [doi: 10.1002/gps.5385] [Medline: 32748438]

15. Valladares-Rodríguez S, Pérez-Rodríguez R, Anido-Rifón L, Fernández-Iglesias M. Trends on the application of serious games to neuropsychological evaluation: a scoping review. J Biomed Inform 2016 Dec;64:296-319. [doi: 10.1016/j.jbi.2016.10.019] [Medline: 27815228]
16. Asad J, Kousar S, Mehmood NQ. Dementia-related serious games: a comparative study. University of Sindh Journal of Information and Communication Technology 2019;3(4):171-177 [FREE Full text]
17. Mccallum S, Boletsis C. Dementia games: a literature review of dementia-related serious games. In: Ma M, Oliveira MF, Petersen S, et al, editors. Serious Games Development and Applications. SGDA 2013. Lecture Notes in Computer Science: Springer; 2013, Vol. 8101. [doi: 10.1007/978-3-642-40790-1_2]
18. Fleming TM, Bavin L, Stasiak K, et al. Serious games and gamification for mental health: current status and promising directions. Front Psychiatry 2016 Jan 10;7:215. [doi: 10.3389/fpsyt.2016.00215] [Medline: 28119636]
19. Vallejo V, Wyss P, Chesham A, et al. Evaluation of a new serious game based multitasking assessment tool for cognition and activities of daily living: comparison with a real cooking task. Comput Human Behav 2017 May;70:500-506. [doi: 10.1016/j.chb.2017.01.021]
20. Kato PM. The role of the researcher in making in serious games for health. In: Arnab S, Dunwell I, Debattista K, editors. Serious Games for Healthcare: Applications and Implications: IGI-Global; 2012:213-231. [doi: 10.4018/978-1-4666-1903-6.ch010]
21. Ben-Sadoun G, Manera V, Alvarez J, Sacco G, Robert P. Recommendations for the design of serious games in neurodegenerative diseases. Front Aging Neurosci 2018 Feb 2;10:13. [doi: 10.3389/fnagi.2018.00013] [Medline: 29456501]
22. Vasconcelos A, Silva PA, Caseiro J, Nunes F, Teixeira L. Designing tablet-based games for seniors: the example of CogniPlay, a cognitive gaming platform. In: FnG '12: Proceedings of the 4th International Conference on Fun and Games: Association for Computing Machinery; 2012:1-10. [doi: 10.1145/2367616.2367617]
23. Kvavilashvili L, Ellis J. Ecological validity and twenty years of real-life/laboratory controversy in memory research: a critical (and historical) review. History and Philosophy of Psychology 2004;6:59-80 [FREE Full text]
24. Wang Y, Wang S, Zhu W, et al. Reading activities compensate for low education-related cognitive deficits. Alzheimers Res Ther 2022 Oct 14;14(1):156. [doi: 10.1186/s13195-022-01098-1] [Medline: 36242017]
25. Udjaja Y, Rumagit RY, Gazali W, Deni J. Healthy elder: brain stimulation game for the elderly to reduce the risk of dementia. Procedia Comput Sci 2021;179:95-102. [doi: 10.1016/j.procs.2020.12.013]
26. Wouters P, van Nimwegen C, van Oostendorp H, van der Spek ED. A meta-analysis of the cognitive and motivational effects of serious games. J Educ Psychol 2013;105(2):249-265. [doi: 10.1037/a0031311]
27. Warsinsky S, Schmidt-Kraepelin M, Rank S, Thiebes S, Sunyaev A. Conceptual ambiguity surrounding gamification and serious games in health care: literature review and development of Game-Based Intervention Reporting Guidelines (GAMING). J Med Internet Res 2021 Sep 10;23(9):e30390. [doi: 10.2196/30390] [Medline: 34505840]
28. Abd-Alrazaq A, Abuelezz I, AlSaad R, et al. Serious games for learning among older adults with cognitive impairment: systematic review and meta-analysis. J Med Internet Res 2023 Apr 12;25:e43607. [doi: 10.2196/43607] [Medline: 37043277]
29. Boletsis C, McCallum S. Smartkuber: a serious game for cognitive health screening of elderly players. Games Health J 2016 Aug;5(4):241-251. [doi: 10.1089/g4h.2015.0107] [Medline: 27192473]
30. Li J, Xu X, Pham TP, Theng YL, Katajapuu N, Luimula M. Exergames designed for older adults: a pilot evaluation on psychosocial well-being. Games Health J 2017 Dec;6(6):371-378. [doi: 10.1089/g4h.2017.0072] [Medline: 29131678]
31. Tarnanas I, Schlee W, Tsolaki M, Müri R, Mosimann U, Nef T. Ecological validity of virtual reality daily living activities screening for early dementia: longitudinal study. JMIR Serious Games 2013 Aug 6;1(1):e2778. [doi: 10.2196/games.2778] [Medline: 25658491]
32. Chan MY, Haber S, Drew LM, Park DC. Training older adults to use tablet computers: does it enhance cognitive function? Gerontologist 2016 Jun;56(3):475-484. [doi: 10.1093/geront/gnu057] [Medline: 24928557]
33. Heinz M, Martin P, Margrett JA, et al. Perceptions of technology among older adults. J Gerontol Nurs 2013 Jan;39(1):42-51. [doi: 10.3928/00989134-20121204-04] [Medline: 23244061]
34. Maiso Fontecha L. The European Pillar of Social Rights. ERA Forum 2017 Jun;18(2):149-153. [doi: 10.1007/s12027-017-0473-4]
35. Brox E, Fernandez-Luque L, Evertsen G, González-Hernández J. Exergames for elderly: social exergames to persuade seniors to increase physical activity. Presented at: 5th International ICST Conference on Pervasive Computing Technologies for Healthcare; May 23-26, 2011; Dublin, Ireland p. 546-549. [doi: 10.4108/icst.pervasivehealth.2011.246049]
36. Planinc R, Nake I, Kampel M. Exergame design guidelines for enhancing elderly's physical and social activities. Presented at: The Third International Conference on Ambient Computing, Applications, Services and Technologies; Sep 29 to Oct 3, 2013; Porto, Portugal p. 58-63 URL: https://cvl.tuwien.ac.at/wp-content/uploads/2014/12/Planinc_AMBIENT2013.pdf [accessed 2024-03-25]
37. Naul E, Liu M. Why story matters: a review of narrative in serious games. J Educ Comput Res 2020 Jun;58(3):687-707. [doi: 10.1177/0735633119859904]
38. Cota TT, Ishitani L. Motivation and benefits of digital games for the elderly: a systematic literature review. Revista Brasileira de Computação Aplicada 2014 Nov;7(1):2-16. [doi: 10.5335/rbca.2015.4190]

39. Vieira C, Ferreira da Silva Pais-Vieira C, Novais J, Perrotta A. Serious game design and clinical improvement in physical rehabilitation: systematic review. JMIR Serious Games 2021 Sep 23;9(3):e20066. [doi: 10.2196/20066] [Medline: 34554102]

Abbreviations

ADL: activities of daily living
GDS: game development strategy
GG: game genre
GN: game nature
ICT: information and communication technology
MCI: mild cognitive impairment

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Home-Based Cognitive Intervention for Healthy Older Adults Through Asking Robots Questions: Randomized Controlled Trial

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Abstract

Background: Asking questions is common in conversations, and while asking questions, we need to listen carefully to what others say and consider the perspective our questions adopt. However, difficulties persist in verifying the effect of asking questions on older adults' cognitive function due to the lack of a standardized system for conducting experiments at participants' homes.

Objective: This study examined the intervention effect of cognitive training moderated by robots on healthy older adults. A focus on the feasibility of the intervention at participants' homes was also maintained. Feasibility was evaluated by considering both the dropout rate during the intervention and the number of questions posed to each participant during the experiment.

Methods: We conducted a randomized controlled trial with 81 adults older than 65 years. Participants were recruited through postal invitations and then randomized into 2 groups. The intervention group (n=40) received sessions where participants listened to photo-integrated stories and posed questions to the robots. The control group (n=41) received sessions where participants listened to photo-integrated stories and only thanked the robots for confirming participation. The participants participated in 12 dialogue sessions for 2-3 weeks. Scores of global cognitive functioning tests, recall tests, and verbal fluency tasks measured before and after the intervention were compared between the 2 groups.

Results: There was no significant intervention effect on the Telephone Interview for Cognitive Status-Japanese scores, recall tests, and verbal fluency tasks. Additionally, our study successfully concluded with no participant dropouts at follow-up, confirming the feasibility of our approach.

Conclusions: There was no statistically significant evidence indicating intervention benefits for cognitive functioning. Although the feasibility of home-based interventions was demonstrated, we identified areas for improvement in the future, such as setting up more efficient session themes. Further research is required to identify the effectiveness of an improved cognitive intervention involving the act of asking questions.

Trial Registration: University Hospital Medical Information Network Center UMIN000039489; https://center6.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000045027

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KEYWORDS

cognitive intervention; home-based experiment; robots; older adults; technology adoption; digital health

Introduction

The aging of the world's population has led to a growing interest in maintaining a healthy lifestyle and enhancing the quality of life in later years. Previous studies have suggested that a healthy lifestyle can prevent or delay age-related cognitive decline [1,2].

Social interaction is a key component of a healthy lifestyle in later years. The social isolation attributed to social distancing during the COVID-19 pandemic may have particularly impacted older adults. For example, the impact of loneliness due to isolation on mental health is concerning [3].

Another concern is that reduced social participation can increase the risk of cognitive decline [4]. Conversations with a variety of people can be a trigger for understanding others' perspectives and acquiring new information, which plays an important role in maintaining and improving older adults' cognitive function

[5]. Sharifian et al [6] showed that older adults with a higher proportion of family members in their social networks have less contact with friends, which is negatively associated with their episodic memory. As the aforementioned study conjectured, contact with family members is usually restricted to obligatory tasks. In contrast, contact with friends is more likely to involve new conversations and information exchanges, which may be cognitively beneficial. Thus, cognitive maintenance and improvement mechanisms may be absent for older adults whose social participation is limited, such as those who only communicate with family members or caregivers or those who are completely isolated. The lives of older adults often involve factors that prevent social participation, such as the COVID-19 pandemic [7]. Therefore, methods to safely and remotely deliver cognitive training programs have been developed [8,9]. Dodge et al [8] have reported the effect of improving language-based executive function for older adults who have mild cognitive impairments through discussion intervention. However, previous studies still indicate a need for conversational human partners; hence, full automation of conversations needs further study.

Another issue in providing cognitive training for older adults is the limited available human resources for performance [10]. For example, a software agent that learns user characteristics, such as an intelligent assistant [11], could help older adults manage their health based on personal data collected automatically [12]. Furthermore, socially assistive robots may reduce the burden on caregivers to continuously monitor older adults who live alone with cognitive impairments and are at daily risk of various accidents [13].

Hence, our goal is to develop assistive robots that enable older adults' remote participation in conversational cognitive training with the same degree of effectiveness as in-person social interaction for cognitive function. Home-based cognitively assistive robots aim to conduct cognitive training for older adults at home. A previous study has suggested that cognitively assistive robots have the potential to benefit older adults and society [14,15]; however, few studies have rigorously evaluated their benefits [16]. The challenge to overcome in promoting such research is the difficulty in controlling users' characteristics related to speech. For example, depending on personality and familiarity with device use, the amount of conversation with the robot may differ from person to person. Therefore, the training effects provided by the robot cannot be accurately evaluated without controlling for such factors.

Similarly, we developed a conversational intervention program, Photo-Integrated Conversation Moderated by Robots (PICMOR), and examined its effect on healthy older adults' cognitive function [17]. Briefly, the PICMOR program is a group conversation that uses photos taken by the participants beforehand. The program consists of 2 parts. First, the participants elaborate on the photos. Second, the participants receive questions about the photos from other participants and answer them. Each part has a time limit and is controlled by a robot facilitator. Notably, the questioning time for each participant is controlled by the robot. It has the function of encouraging participants who talk too much or too little to reduce or promote their speech as needed.

In a randomized controlled trial (RCT), we observed the beneficial effects of PICMOR on performance in a letter fluency task [17]. A follow-up experiment using multimodal magnetic resonance imaging provided candidate brain metrics that could be associated with the intervention effects on phonemic verbal fluency [18-20]. For instance, resting-state functional connectivity between the left inferior frontal gyrus, one of the most important brain regions for verbal fluency, and the right temporal pole, a semantic-related brain region, positively correlated with enhanced verbal fluency performance [18]. Moreover, we conducted another RCT using PICMOR and examined whether the intervention effects on verbal fluency varied as a function of neuronal states estimated from blood-based biomarkers, such as plasma neurofilament light chain [21]. The results showed that individuals with lower neurofilament light chain, indicating a relatively intact neuronal state, performed better in a category fluency task.

Despite these observed benefits, we could not accurately identify the components of this intervention program that contribute to the enhancement of verbal fluency [18]. This is because the intervention methodology included a variety of cognitive and mental activities, such as preparing a short presentation within a certain length of time, flexibly asking and answering questions among participants, intentionally storing and manipulating information to ask questions, and refraining from interrupting other participants' utterances.

As merely developing methods to improve performance on specific tasks is not enough to improve cognitive function generally applicable to daily life, intervention strategies that bundle multiple components are being researched [22-25]. However, distinguishing these components to clarify the mechanisms underlying the intervention effects and develop more effective intervention methods is also important. In this study, we explored the effects of "asking questions" on cognitive functions among healthy older adults, assuming that it would be an important factor in verbal fluency enhancement.

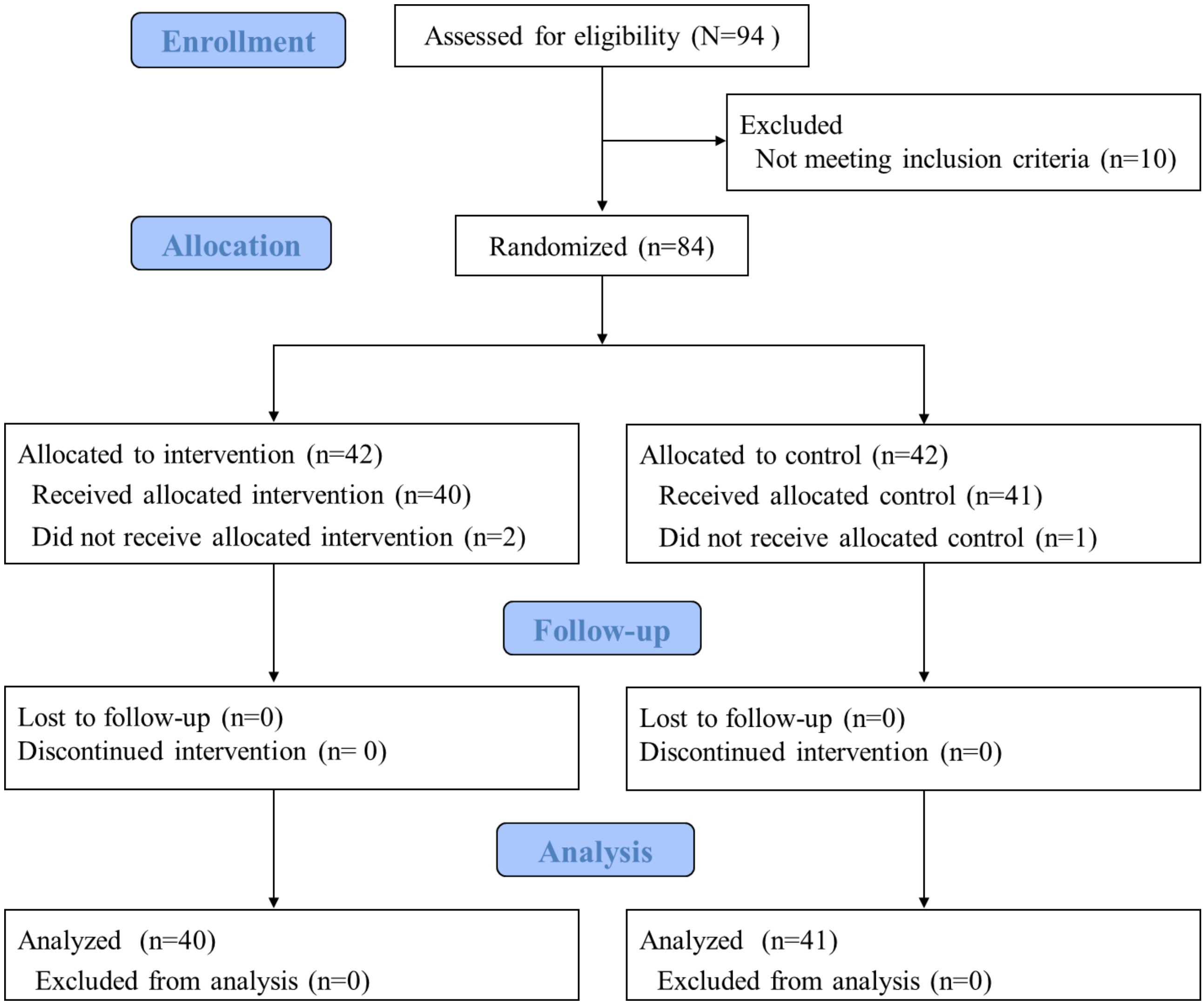
This study conducted an RCT to collect evidence on the feasibility of asking questions to robots at home and its effect on the cognitive functions of healthy older adults. Our hypothesis is that cognitive function will improve in the intervention group compared to the control group. Additionally, the effects and future improvements of the intervention program are discussed.

Methods

Trial Design

This study used an RCT with a two-parallel-arm design and 1:1 allocation. All RCT procedures were conducted from February to November 2021 at the participants' homes. Figure 1 presents the CONSORT (Consolidated Standards of Reporting Trials) flowchart of this trial. No participants dropped out of the intervention at follow-up.

Figure 1. The CONSORT (Consolidated Standards of Reporting Trials) diagram flowchart.



Ethical Considerations

The studies involving human participants were reviewed and approved by the RIKEN Ethical Committee. All participants provided written informed consent to participate in the study. The study is registered with ClinicalTrials.gov (UMIN000039489).

Participants

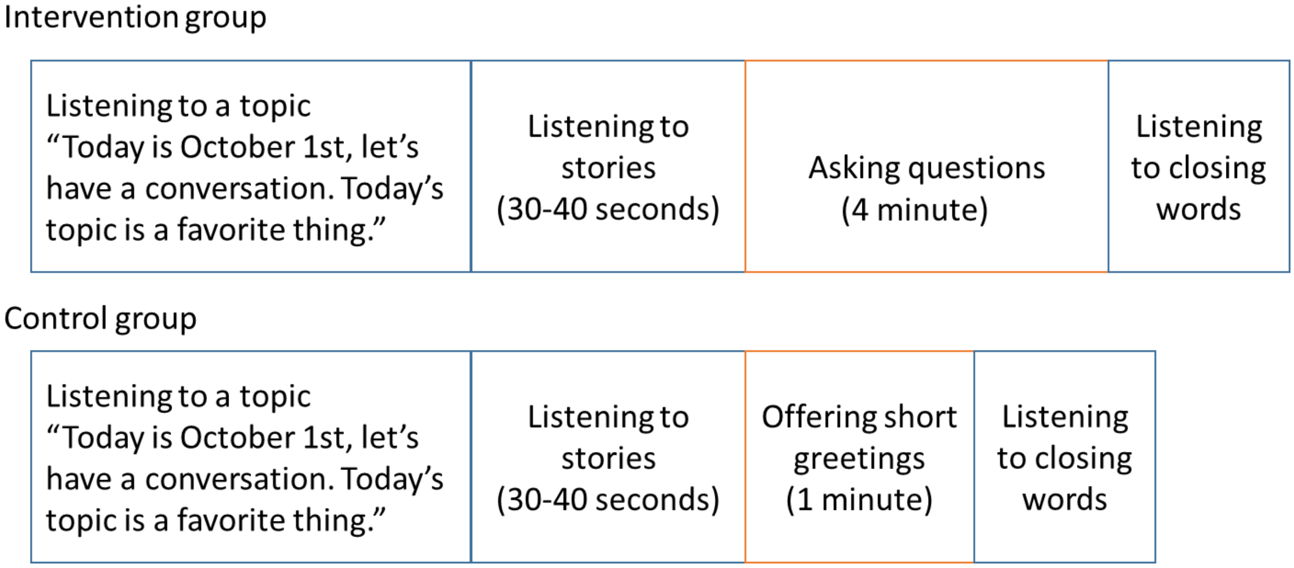
Participants were community-dwelling older adults with subjective memory concerns living in an urban city (Wako-shi) in Japan. They were recruited through postal invitations. In total, 92 participants were screened for eligibility. The eligibility criteria for the trial were as follows: (1) age ≥65 years, (2) Telephone Interview for Cognitive Status-Japanese (TICS-J) score ≥33, and (3) complaints of cognitive concern. The exclusion criteria were as follows: (1) any neurological impairment known to affect the central nervous system, (2) any serious complicating disorder, (3) any history of serious head injury, (4) any disease or medication known to affect the central nervous system, (5) medical history of stroke, and (6) need for care. We defined the term “need for care” as certification of care needs levels or “support need levels” in the Japanese public long-term care insurance system, and participants were screened based on their self-report.

Intervention Design

In the intervention group, participants listened to stories and subsequently asked the dialogue robots as many questions as possible during the experiment. In the control group, participants listened to the stories and subsequently offered short greetings to the robots as evidence of participation. Participants received 2-3 intervention sessions weekly; we arranged the schedules with participants individually to complete 12 dialogue sessions. The theme of each session was based on our previous studies [17,26]. The training and intervention procedure is described as follows: before the experiment, all the experimental devices were mailed to each participant. The system was preliminarily set up for each participant, eliminating the need for them to log in to the system. On the first day of the experiment, participants learned how to use the robot and tablets through Zoom. Then, a practice session was conducted via Zoom. In addition, 2 sessions were conducted with the administrator’s face hidden so that participants could become familiar with the devices. Finally, the participants were asked to answer questionnaires on the last day. For other experimental dates, participants received an intervention program.

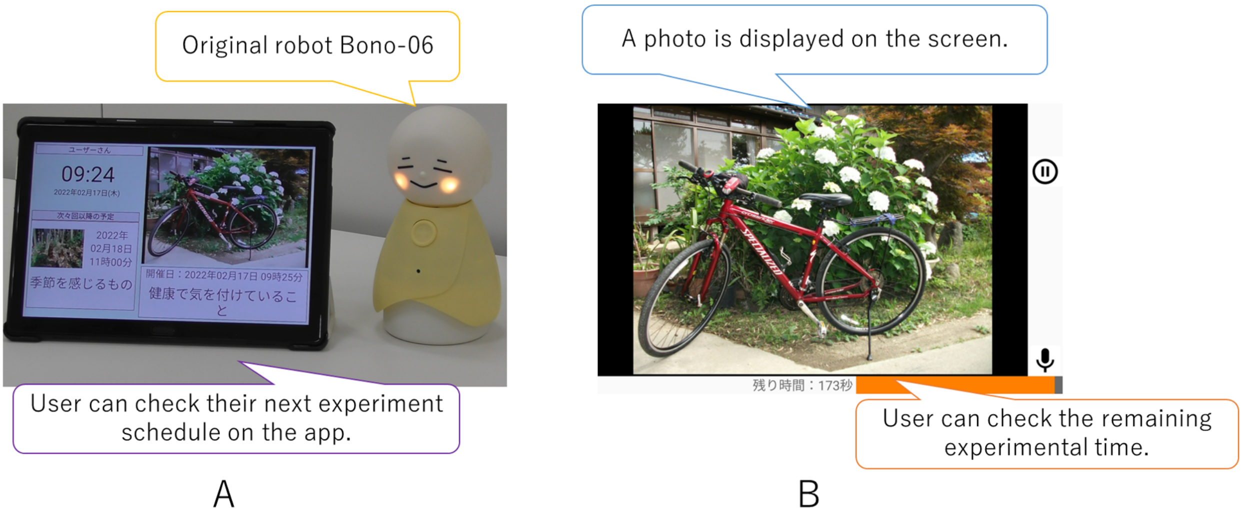
The experimental procedure for both groups included listening to a story and subsequently asking questions to robots while looking at a photo. Both the photos and a summary of the older adults' conversation (called a story) were preliminarily collected from 2 older adults [27]. For storytelling, the length of the story was adjusted to 30-40 seconds, referring to the logical memory task of the Wechsler Memory Scale-Revised (WMS-R) [28]. In the intervention group, participants posed as many questions as possible within 4 minutes. When the participants asked questions, the robots provided a plausible response from a list of approximately 550 responses collected beforehand. Contrastingly, in the control group, participants indicated their participation by simply saying "Thank you for the conversation" within 1 minute. Participants were required to push a switch before each utterance, as the pushing switch had a trigger function for the robots to activate question-answering mode. Further details are presented in Figure 2. Therefore, the difference between the intervention and control groups was whether questions were asked during the dialogue session.

Figure 2. Session timelines for the intervention and control groups.



For the experimental devices in our experimental setting, we used an original robot called Bono-06 [29] as a user interface for older adults (shown in Figure 3A). Bono-06 has 1 degree of freedom for nodding its head. Red, green, and blue full-color LEDs on its cheeks indicate the system's status, such as whether it has successfully connected to a tablet. Additionally, a push switch on the chest allows intuitive interaction with older adults. In this study, the robots were designed to enable older adults to ask them questions by only pushing a switch. We also developed an original app that manages participants' experimental schedules and displays photos and experimental time in dialogue sessions (shown in Figure 3B). The app was designed to display participants' experimental schedules and run them automatically so that participants could participate in the experiment by turning on their tablets and robots at home without cumbersome operations, such as taps and swipes.

Figure 3. Experimental devices for participants. (A) Android app and original dialogue with robot Bono-06. (B) App screen during the experiment.



Finally, the system's operation in home-based experiments was also considered [26]. A delivery and reporting function was implemented in our system so that the experiment administrator could remotely set up each experimental session as scheduled and observe the system report of each session, including the number of utterances and errors. In addition, the experiment report, including the transcribed audio, namely utterances for each dialogue session, was stored in a database on the cloud server. Thus, the experiment administrator could remotely monitor and download the results. In other words, the administrator monitored the experiment while the actual experiment was being conducted in the participants' homes.

Outcome

Our primary concern was to examine the extent to which our intervention program improved cognitive function. The TICS-J [30], recall tests, and verbal fluency tasks [31] were assessed before and after the intervention as primary outcomes by well-trained psychologists.

The TICS-J, an 11-item cognitive test, was used to assess global cognition [30]. TICS-J included the immediate recall test, in which the participants were asked to recall a 10-word list. In addition to that, we also conducted a delayed recall test 5 minutes after the immediate recall test. The numbers of words recalled were the scores of these tests. For comparison with a previous RCT [17], the results of the immediate recall test were also reported separately from the total TICS-J score.

Verbal fluency tests were conducted to assess verbal and executive control abilities. Two types of verbal fluency tasks were performed: letter and category [31]. In the letter fluency task, participants were required to produce as many words as possible, beginning with a given letter ("ka" in Japanese) within 1 minute. In the category fluency task, they were asked to produce as many words as possible belonging to a specific category (animals) within 1 minute. The number of words generated was the score for each task. All tests were conducted via telephone interviews.

As a secondary aim, we also investigated the intervention effect on the suboutcomes using questionnaires, including the World Health Organization's 26-item Quality of Life questionnaire [32], the Japanese version of the Geriatric Depression Scale (short form) [33], and the Tokyo Metropolitan Institute of Gerontology-Index of Competence [34], to assess quality of life, depression symptoms, and functional capacity.

We also examined the factors of our intervention program that should be improved in the future to increase its effectiveness, which will be mainly reported in the *Ancillary Analysis* section. First, we counted the total number of utterances to measure the extent to which our intervention prompted participants to speak. In this study, the number of turns taken by a participant in a conversation with the robot was defined as the number of utterances. Second, we related it to participants' cognitive test scores to examine how much the intervention worked differently, depending on their cognitive functions. Third, we investigated the extent to which participants's use of digital devices affected their total amount of utterances. This was achieved by asking participants to answer a 4-item questionnaire about the frequency of their use of PCs, emails, smartphones, and flip phones in their daily lives (1: usually; 2: sometimes; 3: rare; 4: never).

The reason for the distinction between smartphones and flip phones lies in the history of the cell phone market in Japan [35]. Although flip phones used to be popular in Japan, smartphone use began to exceed that of flip phones in 2013. The difference in the time of popularization between the two could result in different user demographics; in other words, those who still frequently use flip phones may be less likely to switch to a new device compared to those who use smartphones. This has particular implications among older adults, the target population of our study. In fact, in 2020, the percentage of Japanese people in their sixties using flip phones was about 26%, while that of Japanese people in their twenties was about 12%. Considering the possibility that these differences between both users might affect their attitude toward the device used in our intervention, we decided to ask them separately about their use.

Randomization Implementation

Stratified block randomization with a 1:1 allocation was implemented. Participants were stratified into male and female groups and then sorted based on total TICS-J scores. Subsequently, blocks of size 2 were created and randomized. The coding was performed in R 4.3.2 (R Foundation for Statistical Computing). This determined which participants belonged to the intervention or control group. The experimenter assigned participants to the 2 groups based on this result. The person who conducted the randomization was different from the experimenter and had no information other than IDs, TICS-J scores, and gender at the time of randomization. The assessors were blinded to the allocation results.

Statistical Analysis

As explained in the *Outcome and Estimation* section, we used linear mixed models with random intercepts to examine the effects of the intervention on cognitive function. The models included total TICS-J scores, immediate and delayed recall test scores, letter fluency test scores, and category fluency scores as outcome variables, with time (1: end point; 0: baseline), group (1: intervention group; 0: control group), and their interaction terms as independent variables. We interpreted the regression coefficients associated with the interaction terms as the degree of the intervention effects. We also reported the sizes of intervention effects measured by f^2 [36].

For the ancillary analysis, we applied linear mixed models with random intercepts to the intervention group, which included cognitive function scores as outcome variables; time, the number of utterances, and their interaction terms as explanatory variables; and gender, age, and education as control variables. For these models, we reported regression coefficients associated with the number of utterances to understand the relationship between cognitive function scores at baseline and the number of utterances; we also reported regression coefficients associated with the interaction term to understand the relationship between the number of utterances and change in scores before and after the intervention. In addition, we reported the relationship between participants' digital device use in the intervention group and their total number of utterances using 2-tailed t tests.

All analyses were performed using R. To implement the linear mixed models, the lmer function in the R package (lme4) was used [37].

Results

Baseline Data

A total of 40 participants in the intervention group and 41 in the control group underwent cognitive testing, both at baseline and end point, and were included in the analysis. Table 1 shows the baseline characteristics of the participants. For all demographic and cognitive variables (Table 1 and Table 2), there were no major differences between the intervention and control groups, namely, participant attributes were balanced at baseline.

Table . Baseline characteristics of the intervention and control groups (N=81).

Characteristics		Intervention (n=40)	Control (n=41)
Age (year), mean (SD)		73.9 (3.8)	74.0 (4.1)
Gender (female), n (%)		24 (60)	25 (61)
Education (≥13 years), n (%)		19 (48)	30 (73)
WHO[a] QOL26[b] questionnaire, mean (SD)		3.68 (0.38)	3.67 (0.41)
GDS-15[c], mean (SD)		2.17 (2.00)	2.05 (2.32)
TMIG-IC [d] , mean (SD)			
	Total score	11.93 (1.1)	11.73 (1.3)
	Instrumental activity of daily living	5.00 (0.0)	4.95 (0.2)
	Intellectual activity	3.62 (0.7)	3.73 (0.6)
	Social role	3.30 (0.9)	3.05 (1.0)

[a] WHO: World Health Organization.

[b] QOL26: Quality of Life 26-item. For the WHO QOL26, 2 participants who selected multiple items were excluded from the intervention group.

[c] GDS-15: Geriatric Depression Scale-15.

[d] TMIG-IC: Tokyo Metropolitan Institute of Gerontology Index of Competence.

Table . Comparison of cognitive test scores at baseline and end point between the intervention and control groups.

Cognitive test	Intervention (n=40)		Control (n=41)	
	Baseline, mean (SD)	End point, mean (SD)	Baseline, mean (SD)	End point, mean (SD)
TICS-J[a]	36.30 (2.03)	36.80 (2.57)	36.07 (1.82)	37.07 (2.24)
Category fluency	15.47 (4.49)	17.27 (5.09)	16.34 (3.66)	16.78 (4.34)
Letter fluency	13.93 (3.55)	14.43 (3.97)	14.27 (4.14)	14.37 (3.79)
Immediate recall	7.20 (1.40)	7.90 (1.39)	6.80 (1.42)	7.61 (1.46)
Delayed recall	6.30 (1.94)	7.17 (1.82)	5.98 (1.51)	6.95 (1.61)

[a] TICS-J: Telephone Interview for Cognitive Status-Japanese.

Outcome and Estimation

Table 3 shows the results of the linear mixed models used to examine the intervention effects on cognitive function. No significant intervention effects were found for the total TICS-J score, immediate and delayed recall, and verbal fluency. The regression coefficient associated with the time-group interaction term for the category fluency test score was the largest among the study outcomes (1.361), but the effect was not significant (P=.09; effect sizes of f^2<0.01 for all outcomes). We found no significant intervention effects on any of the secondary outcomes. Table 4 shows the conversation theme of each session and the descriptive statistics for the number of participants' utterances therein.

Table . Results of the linear mixed models used to examine the intervention effects on cognitive function.

Category	Time				Group				Time × group			
	Coefficients (95%CI)	SE	*t* (df)[a]	*P* value	Coefficients (95%CI)	SE	*t* (df)[a]	*P* value	Coefficients (95%CI)	SE	*t* (df)[a]	*P* value
TICS-J[b]	1.00 (0.32 to 1.68)	0.35	2.89 (79)	.005	0.23 (–0.72 to 1.17)	0.49	0.47 (127.98)	.64	–0.50 (–1.46 to 0.46)	0.49	–1.02 (79)	.31
Category fluency	0.44 (–0.65 to 1.53)	0.56	0.79 (79)	.43	-0.87 (–2.78 to 1.05)	0.98	–0.88 (108.5)	.38	1.36 (–0.19 to 2.91)	0.79	1.72 (79)	.09
Letter fluency	0.10 (–1.00 to 1.19)	0.56	0.17 (79)	.86	-0.34 (–2.02 to 1.33)	0.86	–0.40 (119.1)	.69	0.40 (–1.16 to 1.96)	0.80	0.51 (79)	.62
Immediate recall	0.80 (0.34 to 1.27)	0.24	3.39 (79)	.001	0.40 (–0.22 to 1.01)	0.32	1.25 (133.8)	.21	–0.10 (–0.77 to 0.56)	0.34	–0.31 (79)	.76
Delayed recall	0.98 (0.41 to 1.54)	0.29	3.38 (79)	.001	0.32 (–0.42 to 1.07)	0.38	0.85 (133.5)	.40	–0.10 (–0.90 to 0.70)	0.41	–0.25 (79)	.81

[a] Satterthwaite degree of freedom.

[b] TICS-J: Telephone Interview for Cognitive Status-Japanese.

Table . Descriptive statistics of the number of utterances per session. The participant count in the intervention group is 40. Mean, SD, minimum, and maximum are at the participant level.

Theme	Total, n	Mean (SD)	Minimum	Maximum
1. Favorite things	291	7.28 (2.20)	1	10
2. Neighborhood landmarks	344	8.60 (1.85)	2	11
3. I try to get off the train at a station that I seldom use	346	8.65 (2.05)	2	11
4. Favorite foods	346	8.65 (1.70)	4	12
5. For my health	335	8.38 (1.23)	5	10
6. Found on a 10-minute walk	363	9.07 (1.94)	4	11
7. Saving energy	317	7.92 (1.67)	4	11
8. Funny stories and mistakes	328	8.20 (1.92)	4	11
9. Things to get rid of	323	8.07 (1.83)	2	11
10. Tips for daily living	353	8.82 (1.80)	3	12
11. Feeling the season	359	8.97 (1.75)	5	12
12. Starting something new	366	9.15 (1.72)	5	12

Ancillary Analysis

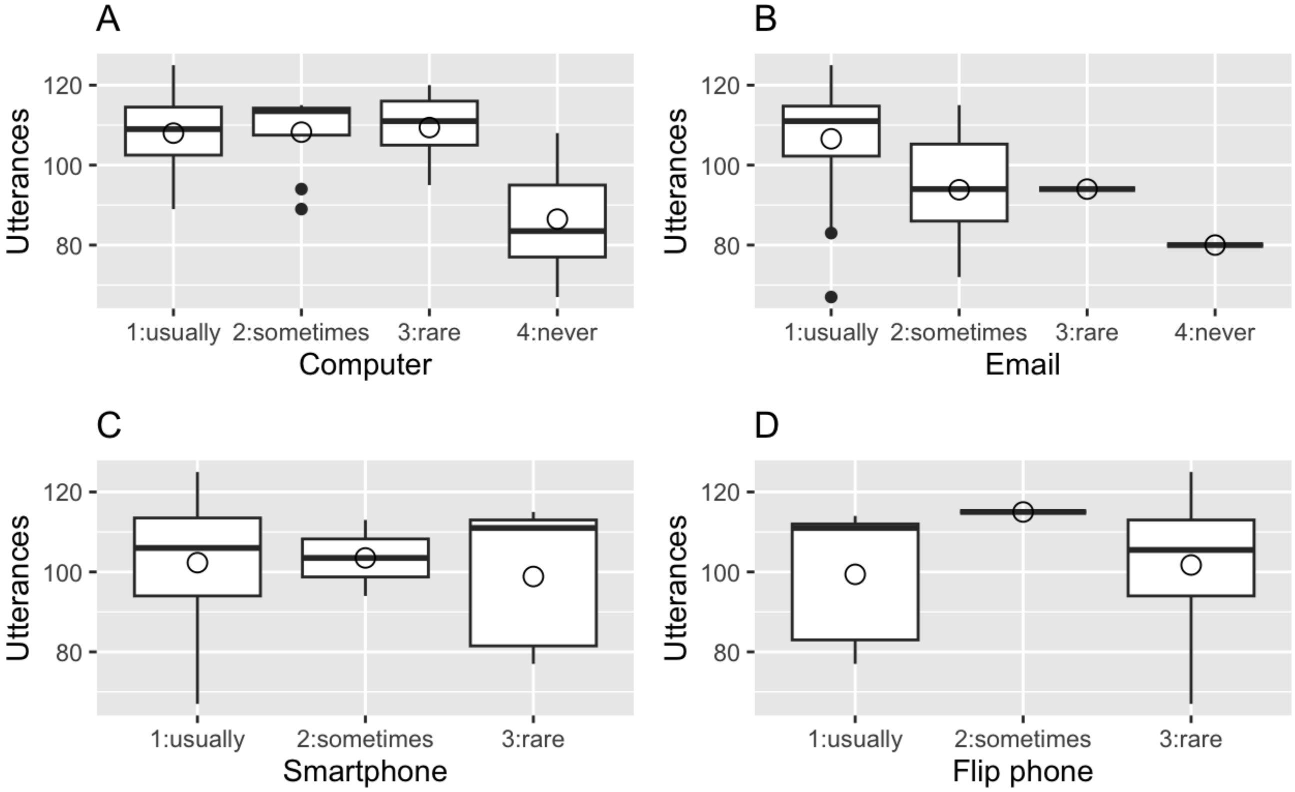
The average total number of utterances of the participants in the intervention group was 101.78 (SD 14.72). The number of utterances was positively correlated with a higher letter fluency score at baseline (letter fluency: B=0.11, SE 0.04; *P*=.01), while no significant associations were found for the other outcomes (TICS-J: B=0.03, SE 0.03; *P*=.30; category fluency: B=0.10, SE 0.06; *P*=.07; immediate recall: B=−0.01, SE 0.02; *P*=.64; delayed recall: B=0.01, SE 0.02; *P*=.55).

There was no significant association between the number of utterances and change in scores for any of the outcomes (TICS-J: B=−0.03, SE 0.03; *P*=.31; category fluency: B=−0.01, SE 0.04; *P*=.79; letter fluency: B=0.02, SE 0.03; *P*=.63; immediate recall: B=−0.003, SE 0.02; *P*=.85; delayed recall: B=−0.01, SE 0.02; *P*=.76).

Figure 4 shows the relationship between the digital device use of participants in the intervention group and their total number of utterances. In Figure 4A, we notice that participants who never used a computer had fewer utterances. In fact, the average number of utterances for participants who chose “4: never” was

86.50, compared to 108.32 for participants who chose options other than “4: never.” This difference was significant (*P*<.001). In Figure 4B, we observe that participants who usually used email had more utterances. In fact, the average number of utterances for participants who chose “1: usually” was 106.58, compared to 92.8 for participants who chose options other than “1: usually.” This difference was significant (*P*=.005). No significant associations were found between the frequency of smartphone use and flip phone use and the number of utterances (Figure 4C and 4D). This result persisted in regression analyses, even after controlling for age, gender, and education years. Associate regression coefficients were 19.69 (SE 4.15; *P*<.001) for computer use, 12.06 (SE 4.44; *P*=.01) for email use, 3.74 (SE 5.39; *P*=.49) for smartphone use, and −2.89 (SE 6.75; *P*=.67) for flip phone use.

Figure 4. Box plots for the relationship between the frequency of device use by participants in the intervention group (horizontal axis) and the total amount of their utterances (vertical axis). Boxes represent IQRs. White circles indicate the mean values. Black lines in boxes indicate the median values. Observations outside the first (third) quartile (i.e., outside of 1.5 × IQR) are indicated by black circles. No participant selected “4: never” for C and D.



Discussion

Overview of This Study

This paper presented the intervention effect of asking questions to improve cognitive function in healthy older adults. The intervention involved an RCT conducted at participants’ homes. There were no significant intervention effects on scores of TICS-J, recall tests, and verbal fluency tasks. Notably, the feasibility of the intervention was confirmed, as all participants were able to ask at least 1 question in every session, with no participants dropping out.

Principal Results

This study identified no significant intervention effect in category fluency task scores and letter fluency task scores. In both types of verbal fluency tasks, the number of words produced per unit of time is commonly used as a behavioral index. However, the mechanisms of word production are supposedly quite different. The category fluency test requires retrieval of content included in a given semantic category, which involves access to semantic memory. This mechanism helps one use existing links between related concepts, such as those between the categorical label and its contents and among associated category members [38]. In contrast, the letter fluency task demands retrieval from a phonemic category in which the association of semantically related words should be suppressed [38]. This strategy depends on an effortful exploration of lexical systems. To ask questions, one must understand the meanings of others’ utterances and identify what is unclear with reference to one’s knowledge. A series of these processes would inevitably involve access to semantic memory.Nonetheless, no intervention effect was found on category verbal fluency and letter fluency.

This result may have been influenced by the short duration of the intervention. Other studies have involved longer experimental periods, lasting 6 [8] and 12 weeks [17]. Therefore, further studies are needed to clarify the effectiveness of asking questions, for example, by setting up a program with a longer intervention period. Another reason why the results did not show any significant intervention effects may pertain to various elements included in the conversations. We solely focused on asking questions and did not incorporate other elements into the intervention. Older adults who are more inclined to compare opinions with others display higher cognitive function [5]. Therefore, thinking about things from the perspective of others during conversations and thinking about the similarities and differences between oneself and others may be important for improving or maintaining cognitive function. Considering this, simply asking questions is not an adequately strong intervention to affect cognitive function, and combining questions with other cognitive elements, such as thinking about questions from the other person's point of view or asking questions based on the similarities and differences between one's thoughts and those of others, may be effective in strengthening future interventions.

Another area of interest is the feasibility of home-based interventions and their improvement. As shown in Table 4, all participants asked at least 1 question in every session, and no participants dropped out. These results indicate the feasibility of this intervention method.

The result that the frequency of device use was positively correlated with the number of questions asked during the intervention, even after controlling for age, gender, and years of education, suggests that future improvements to the usability of our system may enhance intervention effectiveness. One could be optimistic about this point. As Table 4 further indicates, the average number of utterances increased slightly more in the latter half of the intervention period compared to the former. This may have occurred because participants became accustomed to the system through repeated session participation. A more extended intervention period may compensate for the disadvantage owing to the lower frequencies of device use.

However, in terms of the social implementation of intervention programs, such a view may be too optimistic. This is because users may want to discontinue use of the program before becoming accustomed to it. From this perspective, we need to continue improving usability and developing appropriate evaluation methods, keeping in mind that our target population is older adults [39]. For example, it would be helpful to investigate which individuals, among those who use less frequently digital devices at baseline, are more likely to experience higher intervention effectiveness.

Furthermore, it would be important to have a perspective on what kind of interface to provide and how to personalize it according to the user's preferences or personality as well as the characteristics of the user's daily conversations [40], to keep them motivated to continue with the intervention program. This could lead to an overall increase in the effectiveness of the intervention, benefiting even those who are already accustomed to using the device.

Strengths

This study has some strengths. One strength is that we presented a technical framework for examining the impact of "asking questions," an important factor for conversation-based interventions for cognitive function, which was lacking in our previous studies [17,21]

Another strength of this study is that we successfully conducted home-based interventions while most intervention studies, including our previous ones [17,21], have been conducted on-site. Notably, this study demonstrated that home-based interventions are feasible even though some participants were unfamiliar with digital devices.

Finally, a strength of our study is that the system is fully automated after human-assisted training, requiring fewer human resources compared to previous methods. The impact of automation on participants' satisfaction needs further investigation.

Limitations

This study has several limitations. First, this study is limited by the diversity and sample size of the participants. Currently, this program only supports Japanese people; therefore, this study was conducted in an urban city in Japan for feasibility. Second, this study was conducted during the COVID-19 pandemic; hence, the research was designed to reduce communication as much as possible to keep the participants safe. To achieve this, we did not collect magnetic resonance imaging data from participants, unlike our previous intervention study [17]. Therefore, from a neural perspective, this study could not obtain useful information about the impact of asking questions on improving the intervention effect on cognitive function. The importance of asking questions in conversation-based intervention programs should be reevaluated in future research after accounting for these issues.

Finally, we did not sufficiently examine the effects of session topics and their order on the number of participants' utterances. The topics suitable for improving cognitive function through conversation must be neither so challenging that participants cannot generate questions nor so easy that they do not train cognitive function. There has already been a study that identified the characteristics of utterances by older adults with higher cognitive functioning in group conversations, and then, identified conversation topics in which such utterances are likely to be observed [41]. However, this has not been examined in terms of encouraging participants to ask questions and enriching the conversation. Future studies should consider setting up efficient session themes for improving cognitive function.

Conclusions

This study evaluated the possible improvements associated with introducing a dialogue-based robot in cognitive interventions, aiming to verify the training effects of asking questions in healthy older adults.

We did not observe any significant differences in global cognition between the 2 groups. The feasibility of our study was identified by (1) no loss in the intervention and (2) all participants asking at least 1 question in every session. We also recommend improvements to the intervention program, such as setting up more efficient session themes for cognitive training. This study has provided future directions for cognitive training studies of older adults at home.

Acknowledgments

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Conflicts of Interest

None declared.

Checklist 1
CONSORT (Consolidated Standards of Reporting Trials)-eHEALTH checklist (version 1.6.1).
[PDF File, 316 KB - aging_v7i1e47229_app1.pdf]

References

1. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 8;396(10248):413-446. [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
2. Murman DL. The impact of age on cognition. Semin Hear 2015 Aug;36(3):111-121. [doi: 10.1055/s-0035-1555115] [Medline: 27516712]
3. Hwang TJ, Rabheru K, Peisah C, Reichman W, Ikeda M. Loneliness and social isolation during the COVID-19 pandemic. Int Psychogeriatr 2020 Oct;32(10):1217-1220. [doi: 10.1017/S1041610220000988] [Medline: 32450943]
4. Tomioka K, Kurumatani N, Hosoi H. Social participation and cognitive decline among community-dwelling older adults: a community-based longitudinal study. J Gerontol B Psychol Sci Soc Sci 2018 Jun 14;73(5):799-806. [doi: 10.1093/geronb/gbw059] [Medline: 27194753]
5. Sugimoto H, Sekiguchi T, Otake-Matsuura M. Association between social comparison orientation and hippocampal properties in older adults: a multimodal MRI study. Soc Neurosci 2022 Dec;17(6):544-557. [doi: 10.1080/17470919.2023.2166580] [Medline: 36692233]
6. Sharifian N, Kraal AZ, Zaheed AB, Sol K, Zahodne LB. The longitudinal association between social network composition and episodic memory in older adulthood: the importance of contact frequency with friends. Aging Ment Health 2020 Nov;24(11):1789-1795. [doi: 10.1080/13607863.2019.1660850] [Medline: 33076685]
7. Otaki N, Yokoro M, Yano M, et al. Social contact impacts physical activity and sedentary behavior among older adults in Japan due to COVID-19. BMC Geriatr 2022 Jun 8;22(1):491. [doi: 10.1186/s12877-022-03188-z] [Medline: 35676622]
8. Dodge HH, Zhu J, Mattek N, et al. Web-enabled conversational interactions as a method to improve cognitive functions: results of a 6-week randomized controlled trial. Alzheimers Dement (N Y) 2015 May;1(1):1-12. [doi: 10.1016/j.trci.2015.01.001] [Medline: 26203461]
9. Yu K, Wild K, Potempa K, et al. The Internet-based Conversational Engagement Clinical Trial (I-CONECT) in socially isolated adults 75+ years old: randomized controlled trial protocol and COVID-19 related study modifications. Front Digit Health 2021 Aug 25;3:714813. [doi: 10.3389/fdgth.2021.714813] [Medline: 34713183]
10. Ho A. Are we ready for artificial intelligence health monitoring in elder care. BMC Geriatr 2020 Sep 21;20(1):358. [doi: 10.1186/s12877-020-01764-9] [Medline: 32957946]
11. Azvine B, Djian D, Tsui KC, Wobcke W. The intelligent assistant: an overview. In: Intelligent Systems and Soft Computing: Springer Berlin Heidelberg; 2000:215-238. [doi: 10.1007/10720181]
12. Martin-Hammond A, Vemireddy S, Rao K. Exploring older adults' beliefs about the use of intelligent assistants for consumer health information management: a participatory design study. JMIR Aging 2019 Dec 11;2(2):e15381. [doi: 10.2196/15381] [Medline: 31825322]
13. Lee H, Chung MA, Kim H, Nam EW. The effect of cognitive function health care using artificial intelligence robots for older adults: systematic review and meta-analysis. JMIR Aging 2022 Jun 28;5(2):e38896. [doi: 10.2196/38896] [Medline: 35672268]
14. Tanaka H, Adachi H, Ukita N, et al. Detecting dementia through interactive computer avatars. IEEE J Transl Eng Health Med 2017;5:2200111. [doi: 10.1109/JTEHM.2017.2752152] [Medline: 29018636]
15. Lee EH, Kim BR, Kim H, et al. Four-week, home-based, robot cognitive intervention for patients with mild cognitive impairment: a pilot randomized controlled trial. Dement Neurocogn Disord 2020 Sep;19(3):96-107. [doi: 10.12779/dnd.2020.19.3.96] [Medline: 32985149]
16. Van Patten R, Keller AV, Maye JE, et al. Home-based cognitively assistive robots: maximizing cognitive functioning and maintaining independence in older adults without dementia. Clin Interv Aging 2020;15:1129-1139. [doi: 10.2147/CIA.S253236] [Medline: 32764900]

17. Otake-Matsuura M, Tokunaga S, Watanabe K, et al. Cognitive intervention through Photo-Integrated Conversation Moderated by Robots (PICMOR) program: a randomized controlled trial. Front Robot AI 2021;8:633076. [doi: 10.3389/frobt.2021.633076] [Medline: 33969003]
18. Sugimoto H, Kawagoe T, Otake-Matsuura M. Characteristics of resting-state functional connectivity in older adults after the PICMOR intervention program: a preliminary report. BMC Geriatr 2020 Nov 20;20(1):486. [doi: 10.1186/s12877-020-01892-2] [Medline: 33218309]
19. Sugimoto H, Otake-Matsuura M. Tract-based spatial statistics analysis of diffusion tensor imaging in older adults after the PICMOR intervention program: a pilot study. Front Aging Neurosci 2022;14:867417. [doi: 10.3389/fnagi.2022.867417] [Medline: 35721023]
20. Sugimoto H, Otake-Matsuura M. A pilot voxel-based morphometry study of older adults after the PICMOR intervention program. BMC Geriatr 2022 Jan 19;22(1):63. [doi: 10.1186/s12877-021-02669-x] [Medline: 35045810]
21. Otake-Matsuura M, Sugimoto H, Sekiguchi T, et al. Cognitive intervention effects vary as a function of plasma Neurofilament light chain levels: a PICMOR randomized controlled trial. medRxiv. Preprint posted online on Mar 31, 2023. [doi: 10.1101/2023.03.30.23287976]
22. Lustig C, Shah P, Seidler R, Reuter-Lorenz PA. Aging, training, and the brain: a review and future directions. Neuropsychol Rev 2009 Dec;19(4):504-522. [doi: 10.1007/s11065-009-9119-9] [Medline: 19876740]
23. Ranganath C, Flegal KE, Kelly LL. Can cognitive training improve episodic memory? Neuron 2011 Dec 8;72(5):688-691. [doi: 10.1016/j.neuron.2011.10.022] [Medline: 22153366]
24. Gross AL, Parisi JM, Spira AP, et al. Memory training interventions for older adults: a meta-analysis. Aging Ment Health 2012;16(6):722-734. [doi: 10.1080/13607863.2012.667783] [Medline: 22423647]
25. Wenger E, Shing YL. Episodic memory. In: Strobach T, Karbach J, editors. Cognitive Training: An Overview of Features and Applications: Springer International Publishing; 2016:69-80. [doi: 10.1007/978-3-319-42662-4_7]
26. Tokunaga S, Tamura K, Otake-Matsuura M. A dialogue-based system with photo and storytelling for older adults: toward daily cognitive training. Front Robot AI 2021;8:644964. [doi: 10.3389/frobt.2021.644964] [Medline: 34268339]
27. Tokunaga S, Seaborn K, Tamura K, Otake-Matsuura M. Cognitive training for older adults with a dialogue-based, robot-facilitated storytelling system. In: Cardona-Rivera RE, Sullivan A, Young RM, editors. Interactive Storytelling: 12th International Conference on Interactive Digital Storytelling, ICIDS 2019, Little Cottonwood Canyon, UT, USA, November 19–22, 2019, Proceedings: Springer International Publishing; 2019:405-409. [doi: 10.1007/978-3-030-33894-7]
28. Wechsler D. WMS-R: Wechsler Memory Scale-Revised: Psychological Corporation; 1987.
29. Tokunaga S, Otake-Matsuura M. Development of a dialogue robot Bono-06 for cognitive training of older adults. Gerontechnology 2020 Oct 3;19:1 [FREE Full text] [doi: 10.4017/gt.2020.19.s.69666]
30. Konagaya Y, Watanabe T, Takata K, Ohta T. Cognitive function screening of community-dwelling elderly by Telephone Interview of Cognitive Status in Japanese (TICS-J). Nihon Ronen Igakkai Zasshi 2008 Sep;45(5):532-538. [doi: 10.3143/geriatrics.45.532] [Medline: 19057107]
31. Lezak MD, Howieson DB, Bigler ED, Tranel D. Neuropsychological Assessment, 5th edition: Oxford University Press; 2012.
32. Tasaki M, Nakane Y. WHOQOL26 Manual Improved Edition: Kaneko Shobou; 2007.
33. Sugishita K, Sugishita M, Hemmi I, Asada T, Tanigawa T. A validity and reliability study of the Japanese Version of the Geriatric Depression Scale 15 (GDS-15-J). Clin Gerontol 2017;40(4):233-240. [doi: 10.1080/07317115.2016.1199452] [Medline: 28452641]
34. Koyano W, Shibata H, Nakazato K, Haga H, Suyama Y. Measurement of competence: reliability and validity of the TMIG Index of Competence. Arch Gerontol Geriatr 1991;13(2):103-116. [doi: 10.1016/0167-4943(91)90053-s] [Medline: 15374421]
35. Ministry of Internal Affairs and Communications. Report on Survey Regarding Usage Time and Information Behavior of Information and Communication Media [Article in Japanese]. 2021. URL: https://www.soumu.go.jp/main_content/000708016.pdf [accessed 2024-04-02]
36. Selya AS, Rose JS, Dierker LC, Hedeker D, Mermelstein RJ. A practical guide to calculating Cohen's f(2), a measure of local effect size, from PROC MIXED. Front Psychol 2012;3:111. [doi: 10.3389/fpsyg.2012.00111] [Medline: 22529829]
37. Bates D, Mächler M, Bolker B, Walker S. Fitting linear mixed-effects models using lme4. J Stat Softw 2015;67(1). [doi: 10.18637/jss.v067.i01]
38. Shao Z, Janse E, Visser K, Meyer AS. What do verbal fluency tasks measure? Predictors of verbal fluency performance in older adults. Front Psychol 2014;5:772. [doi: 10.3389/fpsyg.2014.00772] [Medline: 25101034]
39. Sinabell I, Ammenwerth E. Challenges and recommendations for eHealth usability evaluation with elderly users: systematic review and case study. Univ Access Inf Soc 2022 Nov 23;23:455-474. [doi: 10.1007/s10209-022-00949-w]
40. Seaborn K, Sekiguchi T, Tokunaga S, Miyake NP, Otake-Matsuura M. Voice over body? Older adults' reactions to robot and voice assistant facilitators of group conversation. Int J Soc Robot 2023;15(2):143-163. [doi: 10.1007/s12369-022-00925-7] [Medline: 36406778]
41. Sekiguchi T, Sugimoto H, Tokunaga S, Otake-Matsuura M. Time-orientations of older adults in group conversations and their association with memory functioning. Curr Psychol 2023 May 27;43:5854-5867. [doi: 10.1007/s12144-023-04545-w]

Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
PICMOR: Photo-Integrated Conversation Moderated by Robots
RCT: randomized controlled trial
TICS-J: Telephone Interview for Cognitive Status-Japanese
WMS-R: Wechsler Memory Scale-Revised

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Review

Markerless Motion Capture to Quantify Functional Performance in Neurodegeneration: Systematic Review

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Abstract

Background: Markerless motion capture (MMC) uses video cameras or depth sensors for full body tracking and presents a promising approach for objectively and unobtrusively monitoring functional performance within community settings, to aid clinical decision-making in neurodegenerative diseases such as dementia.

Objective: The primary objective of this systematic review was to investigate the application of MMC using full-body tracking, to quantify functional performance in people with dementia, mild cognitive impairment, and Parkinson disease.

Methods: A systematic search of the Embase, MEDLINE, CINAHL, and Scopus databases was conducted between November 2022 and February 2023, which yielded a total of 1595 results. The inclusion criteria were MMC and full-body tracking. A total of 157 studies were included for full-text screening, out of which 26 eligible studies that met the selection criteria were included in the review.

Results: Primarily, the selected studies focused on gait analysis (n=24), while other functional tasks, such as sit to stand (n=5) and stepping in place (n=1), were also explored. However, activities of daily living were not evaluated in any of the included studies. MMC models varied across the studies, encompassing depth cameras (n=18) versus standard video cameras (n=5) or mobile phone cameras (n=2) with postprocessing using deep learning models. However, only 6 studies conducted rigorous comparisons with established gold-standard motion capture models.

Conclusions: Despite its potential as an effective tool for analyzing movement and posture in individuals with dementia, mild cognitive impairment, and Parkinson disease, further research is required to establish the clinical usefulness of MMC in quantifying mobility and functional performance in the real world.

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KEYWORDS

markerless motion capture; motion analysis; movement analysis; motion; neurodegeneration; neurodegenerative; systematic review; movement; body tracking; tracking; monitoring; clinical decision making; decision; decision making; dementia; neurodegenerative disease; mild cognitive impairment; Parkinson's disease; tool; mobility

Introduction

Markerless motion capture (MMC) technology uses sensors and advanced software algorithms to track and analyze human movement, without the attachment of physical markers to individuals or the use of external devices such as pressure sensors or wearables. There is growing use of MMC to provide highly accurate quantitative parameters of physical function including mobility [1,2], balance [3], upper extremity tasks [4], and activities of daily living (ADL) [5].

While 3D motion capture systems using markers are considered the gold standard for movement analysis, they have several limitations including their lack of portability, the need for trained staff, and the requirement for reflective markers to be placed precisely on participants' bodies [6]. In contrast, the use of MMC provides several advantages: being easier to operate, requiring less space, and being more economical than traditional marker-based systems [7]. Importantly, their ability to capture movement unobtrusively is a key benefit for user compliance [8], particularly when working with individuals with cognitive impairments.

MMC is attractive for health care and research use, such as monitoring functional performance loss or improvement in neurodegenerative diseases. While traditional movement analyses are based on subjective clinical assessments, MMC can be used to generate objective and quantifiable digital biomarkers that can help detect a decline in functional performance by capturing movement unobtrusively [9]. Variations in these digital biomarkers could indicate underlying impairment and enable earlier support. The fact that MMC can be deployed in home environments may avoid unnecessary hospital visits for patients, as well as detect subtle changes in functional ability that may only be apparent in everyday home-based settings rather than within a clinic.

Several MMC devices can provide cost-effective assessments of functional performance in research and clinical settings. Broadly, the 2 main types of MMC camera hardware are depth cameras and standard red-green-blue (RGB) video cameras, used in single or multicamera systems. Commonly used and widely accessible depth cameras are the Kinect (Microsoft) devices, which use standard RGB color video as well as depth estimation by recording the distance between the camera and each pixel through the emission of structured light patterns [10]. Machine learning algorithms can be used to reconstruct 3D skeletal models in real-time from the RBG+depth (RBG-D) image. Alternatively, deep learning can be used with standard video cameras or mobile phone cameras to record limb location and orientation. This method uses deep neural networks trained from large datasets to estimate body segment position and orientation (pose) and motion tracking, without explicit depth sensing. It requires specific body segment positions known as the 6 degrees of freedom: 3 rotational (flexion or extension, abduction or adduction, and rotation about the longitudinal axis) and 3 translational (sagittal, frontal, and transverse) [11]. Both forms of MMC have shown promising use thus far.

A scoping review of single-camera MMC models used in health care highlighted the significant potential for use in clinical applications but also noted the need to improve their tracking accuracy [12]. A previous systematic review of MMC-based training devices used in neurological rehabilitation found that these devices improve motivation and enable better functional performance potentially due to the gaming element [13]. Another systematic review of MMC-based devices in rehabilitation found that balance training with the support of MMC resulted in better outcomes potentially due to more dynamic training conditions [14]. While those systematic reviews explored the use of MMC specifically in rehabilitation training, this review focuses on the technology-based evaluation of functional tasks. The recent increase in the number of studies involving MMC-based movement analysis in neurodegenerative diseases offers a strong rationale for this review. This trend includes the use of MMC to track gait decline [9], assess fall risks [15,16], detect disease traits [17], estimate disease severity [18], and detect cognitive impairment from gait features [19].

Neurodegenerative diseases such as dementia and Parkinson disease (PD) lead to declining functional performance. Detecting problems in everyday functional tasks in these patient groups can help provide early, timely, and clinically appropriate interventions that may help maintain independence, decrease caregiver burden, and potentially slow the rate of functional decline [20,21]. MMC can provide digitally measured functional performance data that could be used to enhance clinical decision-making and remote monitoring; identify risks such as falls; and better capture the impact of rehabilitative, pharmacological, and surgical interventions. Although MMC technology could offer the potential for detecting functional changes in neurodegenerative diseases, a model that is comparable to established gold-standard motion capture systems is essential for deployment in real-world applications. This study aimed to complete a systematic review of published literature on the use of MMC with full-body tracking for quantifying functional performance in people with dementia, mild cognitive impairment (MCI), and PD.

Methods

Study Design

The web-based Covidence (Veritas Health Innovation) software platform was used in this review, and the titles and abstracts were screened by 2 independent reviewers. The full text of the relevant studies was reviewed, and the quality of the studies was assessed by 2 independent reviewers. Data extraction was also performed by 2 independent reviewers, and any conflicts were resolved through discussion.

Search Strategy

The search strategy was designed to include all types of studies that used MMC with full-body tracking in individuals with dementia, MCI, or PD. To identify relevant studies, a combination of both the Medical Subject Headings thesaurus and free-text terms related to the 3 conditions and MMC technology were used. The search included publications from all years in the CINAHL, Embase, MEDLINE, and Scopus databases using the terms "Motion Capture," "Motion Analysis," "Movement Analysis," and "Pose Estimation" in combination with "Dementia," "Mild cognitive impairment," and

"Parkinson's disease." The details of the search activity can be found in Multimedia Appendix 1.

Inclusion and Exclusion Criteria

The inclusion criteria for the systematic review were as follows: (1) markerless optical motion capture; (2) full-body tracking; (3) involving participants with dementia, MCI, or PD; (4) original research; and (5) English language studies. Studies with the following characteristics were excluded: (1) motion capture with markers, inertial measurement units, body-worn sensors, or pressure sensors; (2) movement analysis of specific parts of the body or symptoms such as tremor and rigidity; (3) evaluating interventions such as exercises, deep brain stimulation, medication, rehabilitation protocol, dance, and gaming; and (4) pose estimation of videos found on the internet.

Data Extraction

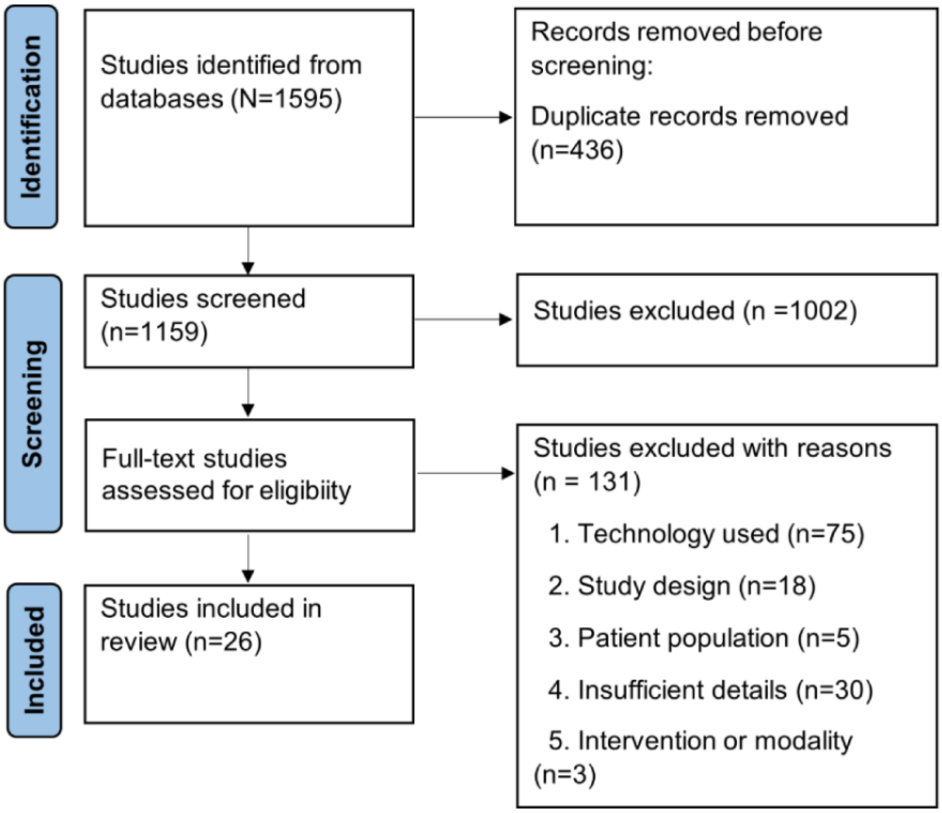
The general information extracted from the studies included: the center and country where the study took place; study characteristics; funding sources; age, sex, and number of participants; number and duration of visits; study aims; inclusion and exclusion criteria; and the main disease condition evaluated. Methodological information extracted included technical details of the MMC system used; functional performance area evaluated, for example, gait or sit to stand; software used for feature extraction; and the method of analysis. The results information extracted included the following: statistically significant movement features, whether they were measured under single or dual task (motor or cognitive) conditions, whether compared to established gold standard models or a relevant clinical measure, and key outcomes including the level of accuracy obtained.

Results

Study Selection

The literature search yielded 1595 results; after removing duplicates, 1159 studies remained for title or abstract screening. Subsequently, 131 studies were identified for full-text screening, of which 26 studies met the inclusion criteria and were included in the review. A PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart [22] outlining the selection process can be found in Figure 1.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flow diagram for new systematic reviews.



Quality Assessment

The 26 selected studies were assessed for quality using the Specialist Unit for Review Evidence questions to assist with the critical appraisal of the cross-sectional studies tool [23]. While no studies were excluded from the review based on this assessment, issues pertaining to quality were identified within several of the studies. Table 1 shows that all studies included in this review used appropriate outcome measures (n=26, 100%).

Most studies clearly stated the study design (n=20, 77%); provided information on the study setting, location, and dates (n=20, 77%); described the results well (n=19, 73%); and provided participant characteristics (n=16, 62%). However, few studies reported if participants were fairly selected (n=10, 38%) or provided information on participant eligibility (n=2, 8%) and handling of missing data and control of potential biases (n=1, 4%).

Table 1. Quality assessment summary.

Study	Is the study design clearly stated?	Are the setting, location, and relevant dates provided?	Were participants fairly selected?	Are participant characteristics provided?	Are the measures of exposures and outcomes appropriate?	Is there a description of how the study size was arrived at?	Is there information on how missing data was handled and whether sources of bias were controlled for?	Is information provided on participant eligibility?	Are the results well described?
Cimolin et al (2022) [24]	✓	✓	✓	✓	✓	X	X	X	X
Kaur et al (2023) [25]	✓	✓	Not reported	✓	✓	X	X	X	✓
Khan et al (2021) [26]	✓	✓	Not reported	✓	✓	X	X	X	X
Khan et al (2013) [27]	X	✓	Not reported	X	✓	X	X	X	X
Kondraguntа et al (2020) [19]	X	✓	Not reported	X	✓	X	X	X	X
Lai et al (2022) [28]	✓	✓	✓	✓	✓	X	X	X	✓
Li et al (2018) [29]	X	✓	Not reported	X	✓	X	X	X	✓
Mehdizadeh et al (2021) [9]	✓	✓	✓	✓	✓	X	X	✓	✓
Mehdizadeh et al (2021) [15]	✓	✓	✓	✓	✓	✓	X	✓	✓
Morinan et al (2022) [30]	✓	✓	X	X	✓	X	X	X	X
Muñoz-Ospina et al (2022) [31]	✓	✓	Not reported	✓	✓	X	X	X	✓
Ng et al (2020) [16]	✓	✓	✓	✓	✓	X	X	X	✓
Ospina et al (2021) [32]	✓	✓	✓	✓	✓	X	X	X	✓
Otte et al (2020) [33]	✓	✓	✓	✓	✓	✓	✓	X	✓
Pedro et al (2020) [34]	X	X	Not reported	✓	✓	X	X	X	X
Procházka et al (2015) [35]	X	X	Not reported	X	✓	X	X	X	✓
Rupprechter et al (2021) [36]	✓	X	Not reported	X	✓	X	X	X	✓
Sabo et al (2022) [18]	✓	✓	✓	✓	✓	X	X	X	✓
Sabo et al (2022) [37]	✓	✓	Not reported	✓	✓	X	X	X	✓
Sabo et al (2021) [17]	✓	✓	Not reported	X	✓	X	X	X	X
Sabo et al (2020) [38]	✓	X	Not reported	✓	✓	X	X	X	✓
Seifallahi et al (2022) [39]	✓	X	Not reported	X	✓	X	X	X	✓

Study	Is the study design clearly stated?	Are the setting, location, and relevant dates provided?	Were participants fairly selected?	Are participant characteristics provided?	Are the measures of exposures and outcomes appropriate?	Is there a description of how the study size was arrived at?	Is there information on how missing data was handled and whether sources of bias were controlled for?	Is information provided on participant eligibility?	Are the results well described?
Shin et al (2021) [40]	✓	✓	✓	✓	✓	X	X	X	✓
Soltaninejad et al (2018) [41]	X	✓	Not reported	X	✓	X	X	X	✓
Tan et al (2019) [42]	✓	X	✓	✓	✓	✓	X	X	✓
Ťupa et al (2015) [43]	✓	✓	Not reported	X	✓	X	X	X	✓

Patient Groups

The 26 studies comprised 18 involving participants with PD, 6 involving participants with dementia, and 2 involving participants with MCI. Most (18/26, 69%) of the studies used Kinect sensors for MMC. All studies that included participants with dementia (n=6) used the Kinect sensor and were conducted in inpatient settings. The Kinect was used to quantify gait decline over 10 weeks [9], propose a prognostic model for fall risk [15], and demonstrate the association with clinical gait measures and future falls [16]. In inpatients with dementia and drug-induced Parkinsonism, the Kinect was used to capture Parkinsonian traits [17]; quantify Parkinsonian gait [38]; and along with pose estimation of recordings from a video camera, estimate Parkinsonian severity [18]. It was also used in the MCI studies reviewed (n=2), as a tool to detect MCI from gait features [19,39].

Of the 18 studies that included participants with PD, 10 (56%) reported the use of the Kinect sensor for analyzing gait, including its feasibility to extract relevant features [34,42], ability to detect PD [24,32,41,43], and ability to measure clinical disease severity [28,31,33]. Alternative MMC models that use image processing for pose estimation of videos from RGB cameras have also been used with participants with PD, demonstrating the feasibility of these models in quantifying gait impairment and disease severity [18,25-27,29,30,36,40].

Functional Performance Components

Most studies (24/26, 92%) evaluated aspects of gait, although there were significant variations in the features extracted and methods used for analysis, with some of them lacking statistical significance. Other functional performance components evaluated were sit to stand (n=5) and stepping in place (n=1). Table 2 shows functional performance components by study.

Table 2. Patient groups, functional performance components, and feature extraction categories.

Study	Patient group	Functional performance component	Feature category
Cimolin et al (2022) [24]	PD[a]	Gait	Spatiotemporal and stability
Kaur et al (2023) [25]	PD	Gait	Spatiotemporal and symmetry
Khan et al (2021) [26]	PD	Gait	Spatiotemporal
Khan et al (2013) [27]	PD	Gait	Gait posture and spatiotemporal
Kondragunta et al (2020) [19]	MCI[b]	Gait	Spatiotemporal
Lai et al (2022) [28]	PD	Gait	Spatiotemporal and ROM[c]
Li et al (2018) [29]	PD	Sit to stand and gait	Spatiotemporal
Mehdizadeh et al (2021) [9]	Dementia	Gait	Spatiotemporal, ROM, and stability
Mehdizadeh et al (2021) [15]	Dementia	Gait	Spatiotemporal, stability, and symmetry
Morinan et al (2022) [30]	PD	Sit to stand	Spatiotemporal
Muñoz-Ospina et al (2022) [31]	PD	Gait	Spatiotemporal and symmetry
Ng et al (2020) [16]	Dementia	Gait	Stability
Ospina et al (2021) [32]	PD	Gait	Spatiotemporal and symmetry
Otte et al (2020) [33]	PD	Stepping in place	Spatiotemporal, symmetry, and rhythmicity
Pedro et al (2020) [34]	PD	Gait	Spatiotemporal
Procházka et al (2015) [35]	PD	Gait	Spatiotemporal
Rupprechter et al (2021) [36]	PD	Gait	Spatiotemporal
Sabo et al (2022) [37]	PD	Gait	Spatiotemporal
Sabo et al (2022) [18]	Dementia	Gait	Spatiotemporal, stability, and symmetry
Sabo et al (2021) [17]	Dementia	Gait	Spatiotemporal, stability, and symmetry
Sabo et al (2020) [38]	Dementia	Gait	Spatiotemporal, stability, and symmetry
Seifallahi et al (2022) [39]	MCI	Gait	Spatiotemporal
Shin et al (2021) [40]	PD	Gait and sit to stand	Spatiotemporal
Soltaninejad et al (2018) [41]	PD	Gait and sit to stand	Spatiotemporal
Tan et al (2019) [42]	PD	Gait and sit to stand	Spatiotemporal and stability
Ťupa et al (2015) [43]	PD	Gait	Spatiotemporal

[a] PD: Parkinson disease.

[b] MCI: mild cognitive impairment.

[c] ROM: range of motion.

Feature Categories

Table 2 shows extraction feature categories by study. Spatiotemporal features of gait that were reported as having statistical significance included spatial parameters, such as step length (n=8), step width (n=5), and stride length (n=4), and temporal parameters, such as cadence (n=5), gait velocity (n=4), step time (n=4), stance duration (n=1), double support duration (n=1), stride time (n=1), turning time (n=1), turning speed (n=1), swing time (n=1), step velocity (n=1), and stride velocity (n=1). Other extracted feature categories included symmetry (n=9), stability (n=8), range of motion (n=2), and rhythmicity (n=1).

MMC Devices and Feature Extraction Methods

Table 3 shows that most studies (18/26, 69%) used Kinect depth cameras (4 used V1; 12 used V2; 1 used Kinect eMotion; and the latest version, the Azure Kinect, was used in 1 study), while the remainder used regular video or mobile phone cameras. Common camera positioning included frontal views (n=4), ceiling-mounted (n=4), and multiple cameras from different angles (n=3). However, camera position was not reported in 7 of the study papers. The majority of studies have developed their own custom programs (n=10, 38%) or have used open-source libraries (n=8, 31%) to identify bodies in frame and extract movements. The use of propriety software was less common (n=5).

Table 3. Markerless motion capture devices and feature extraction methods used.

Study	Device (camera or sensor)	Devices, n	Frames per second (fps or Hz)	Position of cameras	Extraction methods
Cimolin et al (2022) [24]	Kinect V2	1	30	Tripod in front	Custom algorithm
Kaur et al (2023) [25]	Video camera	2	30	Front and right side	OpenPose
Khan et al (2021) [26]	Video camera	1	25	Front	Custom algorithm
Khan et al (2013) [27]	Video camera	1	5	Not reported	Custom algorithm
Kondragunta et al (2020) [19]	Kinect V2	1	20	Not reported	OpenPose
Lai et al (2022) [28]	Kinect V2	Not reported	30	Not reported	GaitBEST (LongGood Meditech)
Li et al (2018) [29]	Video camera	1	25	Not reported	Iterative Error Feedback and OpenPose
Mehdizadeh et al (2021) [9]	Kinect V2	1	Not reported	Ceiling in hallway	Custom algorithm
Mehdizadeh et al (2021) [15]	Kinect V2	1	Not reported	Ceiling in hallway	Custom algorithm
Morinan et al (2022) [30]	Mobile phone camera and KELVIN-PD (Machine Medicine) mobile app	Not reported	Not reported	Not reported	OpenPose
Munoz-Ospina et al (2022) [31]	Kinect eMotion	1	Not reported	Not reported	Custom algorithm
Ng et al (2020) [16]	Kinect V2	1	30	Ceiling at the end of a hallway	OpenPose
Ospina et al (2021) [32]	Kinect V1	1	Not reported	Participants walking toward the camera	Custom algorithm
Otte et al (2020) [33]	Kinect V1	1	30	1.4 m height in front	Custom algorithm
Pedro et al (2020) [34]	Azure Kinect	3	30	Each end of walkway and halfway between	Azure Kinect SDK to extract joint positions to estimate 32 body joint poses from depth color recordings
Procházka et al (2015) [35]	Kinect V1	1	30	60 cm above floor	Custom algorithm
Rupprechter et al (2021) [36]	Mobile phone camera and KELVIN-PD (Machine Medicine) mobile app	1	Not reported	Patients walking directly toward or away from the camera in hallways or office settings	OpenPose
Sabo et al (2022) [37]	Logitech C920	1	30	Tripod mounted, at one end of walkway	AlphaPose (Shanghai Jiao Tong University), Detectron (Facebook AI Research), OpenPose, and ROMP (Regress All Meshes in a One-Stage Fashion for Multiple 3D People; JD AI research)
Sabo et al (2022) [18]	Kinect V2 and mobile phone cameras	1	30	Kinect: hallway ceiling; stationary mobile phone camera: participants walked toward and away from	OpenPose, Detectron, and AlphaPose
Sabo et al (2021) [17]	Kinect V2	1	30	Ceiling in hallway	AlphaPose and engineered 2D gait features from joint trajectories
Sabo et al (2020) [38]	Kinect V2	1	30	Ceiling in hallway	OpenPose

Study	Device (camera or sensor)	Devices, n	Frames per second (fps or Hz)	Position of cameras	Extraction methods
Seifallahi et al (2022) [39]	Kinect V2	1	Not reported	On a tripod at a suitable distance from an oval path	Custom algorithm
Shin et al (2021) [40]	Video camera	1	30	Frontal view from a tripod-mounted camera 1.5 m from the horizontal line of the turning point	OpenPose, OpenCV
Soltaninejad et al (2018) [41]	Kinect V2	Not reported	30	Not reported	Graph model of body skeleton
Tan et al (2019) [42]	Kinect V2	1	Not reported	End of walkway	Custom algorithm
Ťupa et al (2015) [43]	Kinect V1	1	30	60 cm above floor	Custom algorithm

Key Findings

Tables 4-6 summarize the key findings of the 26 studies that used MMC to study movement features in people with dementia, MCI, and PD. Stride length, cadence, gait stability, step length, arm swing, and number of steps were the primary features investigated in these studies. Notably, several studies [26,28,33,37] found that stride length and cadence are commonly affected in those with PD. Other studies [15,31,38] highlighted the potential of MMC for predicting fall risk and discriminating between individuals with PD and controls.

Most studies (20/26, 77%) used some form of clinical validation for the assessment of disease, and patients were referred to or assessed within a clinical research facility by a clinician. The most common clinical measures used were the Unified Parkinson's Disease Rating Scale (UPDRS) for assessing Parkinsonism symptoms in those with PD and dementia and the Performance Oriented Mobility Assessment–gait and Performance Oriented Mobility Assessment–balance assessments for evaluating mobility characteristics. Many of the studies (23/26, 88%) used the MMC features to classify patients from control participants and to classify symptom severity (eg, UPDRS scores in PD) using various techniques, including support vector machines, random forest models, multivariate ordinal logistic regression, and adaptive neuro-fuzzy inference system classifiers. Several studies reported excellent classification accuracy, with some achieving 100% accuracy [26,27,41]. For instance, Seifallahi et al [39] achieved an accuracy of over 90% for differentiating between people with MCI and controls using an adaptive neuro-fuzzy inference system classifier. Khan et al [26] reported a 70.83% accuracy in predicting UPDRS-gait scores using a support vector machine model, with an area under the receiver operating characteristic curve of 80.88%.

Conversely, most studies included within this review (20/26, 77%) did not evaluate their MMC system or algorithms against an established gold-standard motion capture model, making it difficult to conclude whether their derived features for monitoring functional performance characteristics were comparable to an accepted measure of movement analysis. Some notable exceptions such as Cimolin et al [24] compared their Kinect setup to a Vicon system, which is an accepted and clinically validated method for assessing gait. Other studies used established and clinically validated spatiotemporal measures including the GAITRite system [34,40] and the Zeno Walkway system [37], although the study by Pedro et al [34] only had 2 participants. Li et al [29] had experts manually annotate videos, which, while subjective, proved effective for creating labels to train machine learning algorithms for task segmentation. They also used automated labeling to generate subtask segmentation, which could help automate larger-scale studies and clinical assessments.

MMC models showed moderate to strong positive correlations with Vicon [24], Zeno [37], and GAITRite [40]. However, some of the studies also identified limitations of MMC. For example, Pedro et al [34] found that Kinect cameras may overestimate step length variation in people with PD due to inherent smoothing, while Sabo et al [37] found that automated heel strike algorithms may struggle to identify short steps. Some studies [19,29] reported challenges with data processing and interpretation, highlighting the need for more standardized methods in this field.

Despite these limitations, the findings suggest that MMC is a promising tool for studying characteristics of functional performance in people with dementia, MCI, and PD. It is worth noting that specialized depth cameras may not be necessary for extracting suitable joint positions in camera space [37]. However, further research in this field is warranted to fully understand the potential of MMC.

Table 4. Key findings from studies that used the Kinect.

Study	Primary features	Main results
Cimolin et al (2022) [24]	• Gait cadence, mediolateral sway, and step width	• Strong positive correlation between Kinect and Vicon systems for gait cadence and mediolateral sway (ICC[a] 0.94-0.97) and a weak correlation for step width (ICC 0.44) in people with PD[b]
Kondragunta et al (2020) [19]	• Gait cycle (dynamic time warping)	• SVM[c] for classifying between controls, persons with possible MCI[d], and persons with MCI: 74.6%-87.3%
Lai et al (2022) [28]	• Stride length, straight walking speed, and turning speed	• Mediation analysis demonstrates decreased stride length, walking speed, and turning speed are associated with increased falls prediction model score (*r*=–0.58, *r*=–0.52, and *r*=–0.46, respectively; *P*<.001) • UPDRS[e] negatively correlated with features (*r*=–0.65, *r*=–0.56, and *r*=–0.37, respectively; *P*<.001) but positively with fall prediction model score (*r*=.53, *P*<.001) • UPDRS serves as a mediator for features and higher fall prediction model scores

Mehdizadeh et al (2021) [9]	• Gait stability, step time, step length, step time variability, and step length variability	• Mixed effects models over 10 weeks show:
		  • Decrease in primary features and an increase in variability over time for people with dementia
		  • Gait stability decreased more in men
		  • Mediolateral range of motion decreased in those with mild neuropsychiatric symptoms but increased in those with more severe symptoms

Mehdizadeh et al (2021) [15]	• Gait stability.	• Cox proportional hazard regressions show gait stability predicts time to fall in people with dementia (ROC[f] 0.80 at 7 days, 0.67 at 30 days)
Muñoz-Ospina et al (2022) [31]	• Left and right arm and ankle swing (magnitude and speed), stance time, gait speed, total time, and number of steps	• Random forest model was most accurate for discriminating between people with PD and controls (85% using all gait features)
Ng et al (2020) [16]	• Gait: cadence, symmetry, CV[g] of step time, step width (average and CV), and eMOS[h]	• Univariate linear regression: cadence associated with POMA[i]-gait scores (*P*<.001) • Poisson regression: cadence, eMOS, average step width associated with the number of future falls (*P*<.001)
Ospina et al (2021) [32]	• Arm swing: magnitude, time, and arm swing asymmetry	• Age influenced arm movement • People with PD showed significant reductions in arm swing magnitude (left, *P*=.002; right, *P*=.006) and speed (left, *P*=.002; right, *P*=.004) • Arm swing asymmetry differentiated people living with PD from controls (ROC: 78%)
Otte et al (2020) [33]	• Cadence, knee amplitude, asymmetry, average step time, longest step time, arrhythmicity, average stance time, and longest stance time	• Knee amplitude and longest stance time correlated with UPDRS (–0.51, *P*=.003 and 0.52, *P*=.002, respectively) • Postural instability (pull test) correlated with longest stance time (0.47, *P*=.008) • Knee amplitude, asymmetry, and average step time differed between on- and off-medication states (*P*=.002, *P*=.007, and *P*=.007, respectively)
Pedro et al (2020) [34]	• Step length	• In comparison with the GAITRite (CIR Systems, Inc) system, the Kinect camera overestimated the average variation in step length for the 2 people with PD potentially due to inherent smoothing
Procházka et al (2015) [35]	• Average step length	• In total, 91.7% classification accuracy for determining between controls and those with people with PD. Decrease in step length (regression coefficient=–0.0082 m/year)
Sabo et al (2022) [18]	• Number of steps, cadence, velocity, step length, CV of stride width, and step and swing time	• Moderate or strong positive correlations between steps, cadence, step width from 2D pose-estimation, and Zeno in people with PD • Automated heel strike algorithm struggled to identify short steps

Study	Primary features	Main results
Sabo et al (2021) [17]	- Cadence, steps, average step width, average margin of stability, CV of step width and time, and symmetry	- ST-GCN[j] using 2D joint trajectories and gait features outperforms ST-GCN using only gait features - Regression models for predicting UPDRS-gait over 94% if off by 1 is allowed
Sabo et al (2020) [38]	- 2D: steps, cadence, symmetry, and CV of step time - 3D: walking speed, step length or width, step width, step length symmetry angle, RMS[k] of ML[l] velocity, margin of stability, and CV step width	- Multivariate ordinal logistic regression models achieved 61.4% and 62.1% for 2D and 3D features for predicting UPDRS-gait in people with dementia
Seifallahi et al (2022) [39]	- Steps and stride	- Adaptive neuro-fuzzy inference system classifier accuracy >90% for differentiating between MCI and controls
Soltaninejad et al (2018) [41]	- Stride and tremor	- Random forest classifier accuracy for differentiating controls and people with dementia: 93.33% stride and 81% tremor
Tan et al (2019) [42]	- Step length, step time, vertical pelvic displacement, and gait speed	- Multivariable regression: step length during TUG[m] and vertical pelvic displacement during the gait speed were associated with postural instability and gait disorder (*P*=.01 and *P*<.05, respectively) in people with PD
Ťupa et al (2015) [43]	- Step length and average speed	- Combining gait features improves classification accuracy relative to single features - 2-layer neural network achieved an accuracy of 97.2% in classifying people with PD from controls

[a] ICC: intraclass correlation coefficient.

[b] PD: Parkinson disease.

[c] SVM: support vector machine.

[d] MCI: mild cognitive impairment.

[e] UPDRS: Unified Parkinson’s Disease Rating Scale.

[f] ROC: receiver operating characteristic.

[g] CV: coefficient of variation.

[h] eMOS: estimated margin of stability.

[i] POMA: Tinetti Performance Oriented Mobility Assessment.

[j] ST-GCN: spatiotemporal graph convolutional networks.

[k] RMS: root mean squared.

[l] ML: mediolateral.

[m] TUG: Timed Up and Go.

Table 5. Key findings from studies that used video cameras.

Study	Primary features	Main results
Kaur et al (2023) [25]	Stride (91 derived features based on variation and asymmetry speed)	- Logistic regression, random forest, deep learning–based classifiers 75% (walking and talking) and 78.1% (walking) - Multi-scale residual neural network: 100% accuracy for classifying people with controls, multiple sclerosis, and people with PD[a] during walking and walking-while-talking, and 78% for new subjects walking - 1D convolutional neural network: 75% walking-while-talking and 79.3% when generalizing to new subjects in different tasks
Khan et al (2021) [26]	Slow walking short-shuffling steps gait festination	- SVM[b] classification predicts UPDRS[c]: gait scores with 70.83% accuracy and area under ROC[d] curve 80.88%
Khan et al (2013) [27]	Stride cycles and posture lean	- SVM classification of 100% for differentiating between people with PD and controls
Li et al (2018) [29]	Subtask segmentation based on selected body points: neck, R/L[e] shoulder, R/L hip, R/L knee, or R/L ankle	- Accuracies for subtask segmentation of TUGg: OpenPose+LSTM[f]=93.10% and OpenPose+LSTM=92.8% - Correlations between OpenPose+LSTM and experts on timed reduction rates: turn (0.93), walk-back (0.98), and sit-back (0.98)
Sabo et al (2022) [37]	Cadence, steps, average step width, average margin of stability, CV[g] of step width and time, symmetry, and stability	- ST-GCN[h] operating on 3D joint trajectories outperform 2D models - Best model prediction of UPDRS-gait and SAS[i]-gait scores are 53% and 40%, respectively.
Shin et al (2021) [40]	Step length, gait velocity, number of steps, and turning time	- Features correlated with Freezing of Gait Questionnaire, UPDRS part III total score, HY[j], and postural instability in people with PD - Features measured improvements following medication

[a] PD: Parkinson disease.

[b] SVM: support vector machine.

[c] UPDRS: Unified Parkinson’s Disease Rating Scale.

[d] ROC: receiver operating characteristic.

[e] R/L: right or left.

[f] LSTM: long short-term memory (machine learning model).

[g] CV: coefficient of variation.

[h] ST-GCN: spatiotemporal graph convolutional networks.

[i] SAS: Simpson-Angus Scale.

[j] HY: Hoehn and Yahr scale.

Table 6. Key findings from studies that used mobile phone cameras.

Study	Primary features	Main results

Morinan et al (2022) [30]	- D_{body}: distance between nose and 2 ankles
	- Standard of D_{body}, proportional increase in D_{body}, and percentage jerk of D_{body}
	- D_{hand}: distance between 2 wrists
	- U: hands used (Boolean)
		- Ordinal random forest classifiers:
		  - U=99.6% accuracy for hands used to push up from chair
		  - UPDRS[a] ratings estimated by models agree by 79.2% with clinicians’ ratings for people with PD[b]

Rupprechter et al (2021) [36]	- Steps, arm swing, postural control, and smoothness	- Step frequency highly correlated with labeled steps (*P*<.001) - Ordinal random forest: 50% prediction

[a] UPDRS: Unified Parkinson’s Disease Rating Scale.

[b] PD: Parkinson disease.

Discussion

Principal Findings

This systematic review has shown that there is a paucity of studies exploring the use of MMC in people with dementia and models exploring the performance of ADL. Moreover, there is a lack of standardization in the used MMC models and clinical validation in real-world applications. The absence of standardization among the models used posed a significant challenge, precluding the possibility of conducting a meta-analysis to compare and synthesize study results.

The review findings suggest that there is more evidence of the use of MMC with full-body tracking in patients with PD (n=18) compared to those with dementia (n=6) and MCI (n=2). This demonstrates a bias toward movement disorders, where the motor symptoms are more prominent, and highlights a significant knowledge gap in the feasibility and effectiveness of using MMC models in quantifying functional performance in people with dementia and MCI. Moreover, the studies that included patients with dementia [9,15-18,38] were all conducted in inpatient dementia units, indicating a lack of research involving this patient group in real-world settings. This underscores the need for further investigation in this area.

While MMC models based on gait features extracted mainly from straight-line walking may provide useful preliminary data for model development, they have less scope in quantifying functional performance in a real-world context, particularly in people with cognitive impairment. In contrast, the evaluation of ADL tasks could potentially provide more comprehensive insights into real-world functional performance from routine daily activities. Previous research suggests that dual-task tests of mobility are more effective in detecting cognitive decline as well as predicting cognitive impairment and falls [44-46], potentially due to the increased cognitive demand on the individual. However, just 1 study included in this review [19] used dual tasks for the classification of MCI from control, and it was not reported how the completion of dual tasks impacted the results. Feature extraction of ADL tasks that require planning and organization could potentially facilitate the measurement of dual-task performance. Therefore, analysis of ADL tasks could help provide a more accurate assessment of neurodegenerative impairment.

The findings of this review suggest a lack of consensus on the most effective features used. Some spatiotemporal features of mobility such as step length are commonly used, but other features vary widely between studies, making it difficult to determine which are most effective. Additionally, some unique features such as vertical pelvic displacement [42] and D_{body}, the distance between nose and 2 ankles [30], have been identified in individual studies, but their effectiveness is unknown without further evaluation. Moreover, it is important to note that the effectiveness of several of these feature extraction models has not been tested in real-world settings which therefore requires further evaluation.

Several studies included in the review (n=10) reported machine learning classifier outcomes for identifying people living with dementia, MCI, or PD from control [19,25-27,31,32,35,39,41,43], whereas several others (n=8) reported models that computed clinical assessment scores [17,18,29,30,33,36,38,40]. Although these are useful outcomes, it is important to note that models that help detect gait impairment and predict falls (n=5) [9,15,16,28,42] could potentially be more useful in practical applications for assessing functional performance. It must also be noted that these models were all based on the Kinect cameras demonstrating the potential of RGB-D cameras for detecting and predicting functional impairment.

Accurate feature extraction and classification are crucial for improving the quality of MMC-based functional assessment [47]. The accuracy rates of MMC models reported in the reviewed studies ranged from 40% for a model predicting a clinical assessment score [18] to 100% for machine learning classification of PD from control [27]. Those numbers cannot be compared directly due to the different number of classes and the resulting chance level, as well as the task difficulty between classifying patients from control participants to rating symptoms. However, it is important to ensure that any clinical applications of these models are consistent and accurate because inaccurate predictions could potentially have consequences for patient care. Further validation and refinement of the models may therefore be necessary before they can be safely used in practical applications.

It is important to note that the accuracy of a model does not only depend on its ability to correctly identify a condition but also on its capacity to detect features of functional performance consistently in various real-world settings. Potential real-world applications include the detection of problems in functional performance in clinical settings and functional deterioration in home settings. The effectiveness of several feature extraction models reviewed in this study has not been tested in such settings, and therefore, the accuracy in practical applications remains unclear. Moreover, devices used in clinical applications must be subjected to a rigorous clinical validation process to ensure safety and efficacy before use on patients [48]. Many of the studies reviewed seem to have primarily focused on the technical aspects of the MMC models, such as feature extraction and analysis, with less focus on their clinical utility. Therefore, further MMC research should objectively evaluate the practical clinical and real-world mobility applications of this technology. If a standard MMC movement analysis protocol could be established, functional performance could be compared across diagnoses.

Additionally, the cross-sectional nature of most of the included studies may limit their ability to evaluate and track functional performance over time. Longitudinal studies would be necessary to assess the performance of these models for tracking functional changes caused by factors such as disease progression, infections, and treatment effects or recovery. Despite these limitations, the effectiveness of MMC models using the Kinect [24] and 2D pose estimation [37] in comparison to established gold-standard motion capture systems within experimental settings suggests they may be suitable for testing in real-world applications such as remote monitoring. However, further research is required to explore and address ethical and privacy considerations when deploying MMC devices that capture video and movement within people's homes. Managing consent where patients lack mental capacity and safeguarding the privacy of patient data that is stored or shared with clinical teams will also need to be carefully addressed while deploying MMC in remote monitoring applications.

It is important to consider the overall quality of studies included in this review, as shown in Table 1, which summarizes key questions to consider when assessing quality. Most studies had a clear study design and focused research questions with appropriate measures of exposures and outcomes. However, only 1 of the studies reported if potential sources of bias from confounders such as musculoskeletal comorbidities, were controlled which could have significant implications for clinical applications. Moreover, few studies provided information on participant eligibility and whether they were selected fairly which could have implications for generalization of study results. The suboptimal quality observed in the included studies in key aspects such as bias control and participant selection suggests these MMC models need to be further evaluated potentially using more rigorous study designs before deployment in real-world applications. Studies that have attempted to create MMC models for fall prediction have primarily focused on retrospective analyses, for example, the number of falls in the past few months. While it is useful to examine historical patterns, future studies should aim to develop prospective studies. Testing the algorithms for MMC models in a prospective study would offer the capability to analyze more detailed information on fall events and contextual associated factors therefore making them more generalizable and valid for predicting falls.

The main findings of this review highlight the potential of MMC in assessing components of functional performance including gait and sit-to-stand characteristics in individuals with dementia, MCI, and PD. Notably, high classification accuracies in several studies demonstrate the potential for clinical applications, such as identifying, monitoring, and predicting outcomes in these populations. However, it is crucial to address the limitations and challenges, such as overestimation of step length variation and difficulty in identifying short steps, as well as the need for standardized methodologies and further research.

A segment of motion analysis research will likely continue to focus on simplified, discrete tasks executed within the controlled setting of a laboratory. However, advancements in technology are progressively enabling the expansion of movement analysis into real-world environments [49]. While the current body of literature predominantly centers on gait analysis, the potential applications of MMC extend far beyond this domain, particularly within the realm of ADL. The integration of knowledge gleaned from analyzing various types of functional tasks will empower clinicians to better assist individuals with neurodegeneration in enhancing their quality of life.

Limitations

It was not feasible to conduct a meta-analysis of the reviewed studies due to significant heterogeneity in the MMC models evaluated, the features extracted, and the analysis methods used. The use of search terms that are not specific to MMC such as motion capture and movement analysis may have introduced the possibility of inherent biases in the search results. However, the adoption of these broad search terms facilitated a more comprehensive screening of studies, encompassing a wider spectrum of the literature. Furthermore, it is important to acknowledge a potential constraint inherent in the search strategy, specifically about the inclusion criterion of full-body tracking MMC models. This led to the exclusion of studies that analyzed the movement of specific body parts. Another limitation of this review is that only a small number of studies met the inclusion criteria limiting the generalizability of this study's results.

Conclusion

The findings of this review illustrate that the use of MMC technology with full-body tracking has the potential to quantify functional performance in people living with dementia, MCI, and PD. However, the lack of consistency in evaluating these models presents a challenge. Standardization of the extracted features and analysis methods may help overcome the heterogeneity of the evaluation process and propose a framework for assessing future models. The findings further suggest that MMC models based on both RGB-D and standard video cameras are viable options for analyzing movement, yielding similar outcomes. Nonetheless, RGB-D cameras have been favored in models intended to detect gait impairment and predict instances of falling.

It is worth noting that the majority of the reviewed studies evaluated aspects of gait, with no evidence of ADL tasks being analyzed. Future studies should incorporate ADL tasks, as this would be more representative of real-world scenarios, particularly for individuals with cognitive impairment. Moreover, longitudinal studies are required to develop models that could track functional impairment over time and potentially predict decline.

Although accuracy is an important factor to consider when evaluating MMC models for clinical applications, other factors such as comparability to established gold-standard motion capture models and capability for analyzing routine tasks and reproducibility in the natural environment are also important. Therefore, a more holistic approach to model development and evaluation with a clear focus on real-world clinical utility may be necessary to ensure that the models are suitable for use in practical applications.

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Data Availability

No new or unpublished data are included within this study and all data are freely available. All code relating to summary figure development is available on request to the corresponding authors.

Authors' Contributions

JJ-J and SH wrote the review protocol, JJ-J, MC-R, HS, and TJ conducted the literature searches and performed data extraction. JJ-J, MC-R, and SH wrote this paper. All authors read and critically commented on drafts of this study, including the latest version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search activity record.
[DOCX File , 38 KB - aging_v7i1e52582_app1.docx]

References

1. Mentiplay BF, Perraton LG, Bower KJ, Pua YH, McGaw R, Heywood S, et al. Gait assessment using the Microsoft Xbox One Kinect: concurrent validity and inter-day reliability of spatiotemporal and kinematic variables. J Biomech 2015;48(10):2166-2170. [doi: 10.1016/j.jbiomech.2015.05.021] [Medline: 26065332]
2. Vernon S, Paterson K, Bower K, McGinley J, Miller K, Pua YH, et al. Quantifying individual components of the Timed Up and Go using the Kinect in people living with stroke. Neurorehabil Neural Repair 2015;29(1):48-53. [doi: 10.1177/1545968314529475] [Medline: 24743227]
3. Clark RA, Pua YH, Oliveira CC, Bower KJ, Thilarajah S, McGaw R, et al. Reliability and concurrent validity of the Microsoft Xbox One Kinect for assessment of standing balance and postural control. Gait Posture 2015;42(2):210-213. [doi: 10.1016/j.gaitpost.2015.03.005] [Medline: 26009500]
4. Ma Y, Liu D, Cai L. Deep learning-based upper limb functional assessment using a single Kinect v2 sensor. Sensors (Basel) 2020;20(7):1903 [FREE Full text] [doi: 10.3390/s20071903] [Medline: 32235436]
5. Rammer JR, Krzak JJ, Riedel SA, Harris GF. Evaluation of upper extremity movement characteristics during standardized pediatric functional assessment with a Kinect®-based markerless motion analysis system. Annu Int Conf IEEE Eng Med Biol Soc 2014;2014:2525-2528 [FREE Full text] [doi: 10.1109/EMBC.2014.6944136] [Medline: 25570504]
6. Klöpfer-Krämer I, Brand A, Wackerle H, Müßig J, Kröger I, Augat P. Gait analysis—available platforms for outcome assessment. Injury 2020;51 Suppl 2:S90-S96. [doi: 10.1016/j.injury.2019.11.011] [Medline: 31767371]
7. Bonnechère B, Jansen B, Salvia P, Bouzahouene H, Omelina L, Moiseev F, et al. Validity and reliability of the Kinect within functional assessment activities: comparison with standard stereophotogrammetry. Gait Posture 2014;39(1):593-598. [doi: 10.1016/j.gaitpost.2013.09.018] [Medline: 24269523]
8. van Dellen F, Hesse N, Labruyère R. Markerless motion tracking to quantify behavioral changes during robot-assisted gait training: a validation study. Front Robot AI 2023;10:1155542 [FREE Full text] [doi: 10.3389/frobt.2023.1155542] [Medline: 36950282]
9. Mehdizadeh S, Faieghi M, Sabo A, Nabavi H, Mansfield A, Flint AJ, et al. Gait changes over time in hospitalized older adults with advanced dementia: predictors of mobility change. PLoS One 2021;16(11):e0259975 [FREE Full text] [doi: 10.1371/journal.pone.0259975] [Medline: 34788342]
10. Wade L, Needham L, McGuigan P, Bilzon J. Applications and limitations of current markerless motion capture methods for clinical gait biomechanics. PeerJ 2022;10:e12995 [FREE Full text] [doi: 10.7717/peerj.12995] [Medline: 35237469]
11. Nakano N, Sakura T, Ueda K, Omura L, Kimura A, Iino Y, et al. Evaluation of 3D markerless motion capture accuracy using OpenPose with multiple video cameras. Front Sports Act Living 2020;2:50 [FREE Full text] [doi: 10.3389/fspor.2020.00050] [Medline: 33345042]
12. Scott B, Seyres M, Philp F, Chadwick EK, Blana D. Healthcare applications of single camera markerless motion capture: a scoping review. PeerJ 2022;10:e13517 [FREE Full text] [doi: 10.7717/peerj.13517] [Medline: 35642200]
13. Knippenberg E, Verbrugghe J, Lamers I, Palmaers S, Timmermans A, Spooren A. Markerless motion capture systems as training device in neurological rehabilitation: a systematic review of their use, application, target population and efficacy. J Neuroeng Rehabil 2017;14(1):61 [FREE Full text] [doi: 10.1186/s12984-017-0270-x] [Medline: 28646914]
14. Lam WWT, Fong KNK. The application of markerless motion capture (MMC) technology in rehabilitation programs: a systematic review and meta-analysis. Virtual Real 2022;27(4):3363-3378. [doi: 10.1007/s10055-022-00696-6]
15. Mehdizadeh S, Sabo A, Ng KD, Mansfield A, Flint AJ, Taati B, et al. Predicting short-term risk of falls in a high-risk group with dementia. J Am Med Dir Assoc 2021;22(3):689-695. [doi: 10.1016/j.jamda.2020.07.030] [Medline: 32900610]

16. Ng KD, Mehdizadeh S, Iaboni A, Mansfield A, Flint A, Taati B. Measuring gait variables using computer vision to assess mobility and fall risk in older adults with dementia. IEEE J Transl Eng Health Med 2020;8:1-9 [FREE Full text] [doi: 10.1109/JTEHM.2020.2998326] [Medline: 32537265]
17. Sabo A, Mehdizadeh S, Iaboni A, Taati B. Prediction of parkinsonian gait in older adults with dementia using joint trajectories and gait features from 2D video. : IEEE; 2021 Presented at: 2021 43rd Annual International Conference of the IEEE Engineering in Medicine & Biology Society (EMBC) IEEE; 2021.?5703; 2021 Nov 01; Mexico p. 5700-5703. [doi: 10.1109/embc46164.2021.9630563]
18. Sabo A, Mehdizadeh S, Iaboni A, Taati B. Estimating parkinsonism severity in natural gait videos of older adults with dementia. IEEE J Biomed Health Inform 2022;26(5):2288-2298. [doi: 10.1109/JBHI.2022.3144917] [Medline: 35077373]
19. Kondragunta J, Seidel R, Hirtz G. Machine learning based identification of elderly persons with cognitive impairment using dynamic time warping. Current Directions in Biomedical Engineering 2020;6(3):360-363. [doi: 10.1515/cdbme-2020-3093]
20. Graff MJL, Vernooij-Dassen MJM, Thijssen M, Dekker J, Hoefnagels WHL, Rikkert MGMO. Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. BMJ 2006;333(7580):1196 [FREE Full text] [doi: 10.1136/bmj.39001.688843.BE] [Medline: 17114212]
21. Suzuki T, Shimada H, Makizako H, Doi T, Yoshida D, Ito K, et al. A randomized controlled trial of multicomponent exercise in older adults with mild cognitive impairment. PLoS One 2013;8(4):e61483-e63013 [FREE Full text] [doi: 10.1371/journal.pone.0061483] [Medline: 23585901]
22. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71 [FREE Full text] [doi: 10.1136/bmj.n71] [Medline: 33782057]
23. Questions to assist with the critical appraisal of cross-sectional studies. Specialist Unit for Review Evidence (SURE). 2018. URL: https://www.cardiff.ac.uk/__data/assets/pdf_file/0010/1142974/SURE-CA-form-for-Cross-sectional_2018.pdf [accessed 2024-07-24]
24. Cimolin V, Vismara L, Ferraris C, Amprimo G, Pettiti G, Lopez R, et al. Computation of gait parameters in post stroke and Parkinson's disease: a comparative study using RGB-D sensors and optoelectronic systems. Sensors (Basel) 2022;22(3):824 [FREE Full text] [doi: 10.3390/s22030824] [Medline: 35161570]
25. Kaur R, Motl RW, Sowers R, Hernandez ME. A vision-based framework for predicting multiple sclerosis and Parkinson's disease gait dysfunctions—a deep learning approach. IEEE J Biomed Health Inform 2023;27(1):190-201. [doi: 10.1109/JBHI.2022.3208077] [Medline: 36126031]
26. Khan T, Zeeshan A, Dougherty M. A novel method for automatic classification of Parkinson gait severity using front-view video analysis. Technol Health Care 2021;29(4):643-653 [FREE Full text] [doi: 10.3233/THC-191960] [Medline: 33427697]
27. Khan T, Westin J, Dougherty M. Motion cue analysis for parkinsonian gait recognition. Open Biomed Eng J 2013;7:1-8 [FREE Full text] [doi: 10.2174/1874120701307010001] [Medline: 23407764]
28. Lai YR, Lien CY, Huang CC, Lin WC, Chen YS, Yu CC, et al. Clinical disease severity mediates the relationship between stride length and speed and the risk of falling in Parkinson's disease. J Pers Med 2022;12(2):192 [FREE Full text] [doi: 10.3390/jpm12020192] [Medline: 35207680]
29. Li T, Chen J, Hu C, Ma Y, Wu Z, Wan W, et al. Automatic Timed Up-and-Go sub-task segmentation for Parkinson's disease patients using video-based activity classification. IEEE Trans Neural Syst Rehabil Eng 2018;26(11):2189-2199. [doi: 10.1109/TNSRE.2018.2875738] [Medline: 30334764]
30. Morinan G, Peng Y, Rupprechter S, Weil RS, Leyland LA, Foltynie T, et al. Computer-vision based method for quantifying rising from chair in Parkinson's disease patients. Intell Based Med 2022;6:100046. [doi: 10.1016/j.ibmed.2021.100046]
31. Muñoz-Ospina B, Alvarez-Garcia D, Clavijo-Moran HJC, Valderrama-Chaparro JA, García-Peña M, Herrán CA, et al. Machine learning classifiers to evaluate data from gait analysis with depth cameras in patients with parkinson's disease. Front Hum Neurosci 2022;16:826376 [FREE Full text] [doi: 10.3389/fnhum.2022.826376] [Medline: 35664343]
32. Ospina BM, Chaparro JAV, Paredes JDA, Pino YJC, Navarro A, Orozco JL. Objective arm swing analysis in early-stage Parkinson's disease using an RGB-D camera (Kinect®). J Parkinsons Dis 2021;11(1):375 [FREE Full text] [doi: 10.3233/JPD-200001] [Medline: 32144997]
33. Otte K, Ellermeyer T, Vater TS, Voigt M, Kroneberg D, Rasche L, et al. Instrumental assessment of stepping in place captures clinically relevant motor symptoms of Parkinson's disease. Sensors (Basel) 2020;20(19):5465 [FREE Full text] [doi: 10.3390/s20195465] [Medline: 32977647]
34. Pedro A, Kirsten H, Sebastian F, Kathrin J, Karsten W, Andreas H. Preliminary viability test of a 3-D-consumer-camera-based system for automatic gait feature detection in people with and without Parkinson's disease. 2020 Presented at: 2020 IEEE International Conference on Healthcare Informatics (ICHI); 2020 Nov 30; Germany. [doi: 10.1109/ichi48887.2020.9374363]
35. Procházka A, Vyšata O, Vališ M, Ťupa O, Schätz M, Mařík V. Use of the image and depth sensors of the Microsoft Kinect for the detection of gait disorders. Neural Comput Appl 2015;26(7):1621-1629. [doi: 10.1007/s00521-015-1827-x]
36. Rupprechter S, Morinan G, Peng Y, Foltynie T, Sibley K, Weil RS, et al. A clinically interpretable computer-vision based method for quantifying gait in Parkinson's disease. Sensors (Basel) 2021;21(16):5437 [FREE Full text] [doi: 10.3390/s21165437] [Medline: 34450879]

37. Sabo A, Gorodetsky C, Fasano A, Iaboni A, Taati B. Concurrent validity of Zeno instrumented walkway and video-based gait features in adults with Parkinson's disease. IEEE J Transl Eng Health Med 2022;10:2100511 [FREE Full text] [doi: 10.1109/JTEHM.2022.3180231] [Medline: 35795874]
38. Sabo A, Mehdizadeh S, Ng KD, Iaboni A, Taati B. Assessment of Parkinsonian gait in older adults with dementia via human pose tracking in video data. J Neuroeng Rehabil 2020;17(1):97 [FREE Full text] [doi: 10.1186/s12984-020-00728-9] [Medline: 32664973]
39. Seifallahi M, Hassani Mehraban A, Khamseh F, Salehi M, Hajati G, Khansari M, et al. Detection of mild cognitive impairment from gait using adaptive neuro-fuzzy inference system. Biomed Signal Process Control 2022;71:103195. [doi: 10.1016/j.bspc.2021.103195]
40. Shin JH, Yu R, Ong JN, Lee CY, Jeon SH, Park H, et al. Quantitative gait analysis using a pose-estimation algorithm with a single 2D-video of Parkinson's disease patients. J Parkinsons Dis 2021;11(3):1271-1283. [doi: 10.3233/JPD-212544] [Medline: 33935106]
41. Soltaninejad S, Rosales-Castellanos A, Ba F, Ibarra-Manzano M, Cheng I. Body movement monitoring for Parkinson's disease patients using a smart sensor based non-invasive technique. 2018 Presented at: 2018 IEEE 20th International Conference on e-Health Networking, Applications and Services (Healthcom); 2018 Sep 17; Czech Republic p. 1-6. [doi: 10.1109/healthcom.2018.8531197]
42. Tan D, Pua YH, Balakrishnan S, Scully A, Bower KJ, Prakash KM, et al. Automated analysis of gait and modified Timed Up and Go using the Microsoft Kinect in people with Parkinson's disease: associations with physical outcome measures. Med Biol Eng Comput 2019;57(2):369-377. [doi: 10.1007/s11517-018-1868-2] [Medline: 30123947]
43. Ťupa O, Procházka A, Vyšata O, Schätz M, Mareš J, Vališ M, et al. Motion tracking and gait feature estimation for recognising Parkinson's disease using MS kinect. Biomed Eng Online 2015;14:97 [FREE Full text] [doi: 10.1186/s12938-015-0092-7] [Medline: 26499251]
44. Bridenbaugh SA, Kressig RW. Motor cognitive dual tasking: early detection of gait impairment, fall risk and cognitive decline. Z Gerontol Geriatr 2015;48(1):15-21. [doi: 10.1007/s00391-014-0845-0] [Medline: 25633391]
45. Montero-Odasso MM, Sarquis-Adamson Y, Speechley M, Borrie MJ, Hachinski VC, Wells J, et al. Association of dual-task gait with incident dementia in mild cognitive impairment: results from the gait and brain study. JAMA Neurol 2017;74(7):857-865 [FREE Full text] [doi: 10.1001/jamaneurol.2017.0643] [Medline: 28505243]
46. Åhman HB, Cedervall Y, Kilander L, Giedraitis V, Berglund L, McKee KJ, et al. Dual-task tests discriminate between dementia, mild cognitive impairment, subjective cognitive impairment, and healthy controls—a cross-sectional cohort study. BMC Geriatr 2020;20(1):258 [FREE Full text] [doi: 10.1186/s12877-020-01645-1] [Medline: 32727472]
47. Ye M, Yang C, Stankovic V, Stankovic L, Cheng S. Gait phase classification for in-home gait assessment. 2017 Presented at: 2017 IEEE International Conference on Multimedia and Expo (ICME); 2017 July 10; Hong Kong, China p. 1524-1529. [doi: 10.1109/icme.2017.8019500]
48. Park SH, Choi J, Byeon JS. Key principles of clinical validation, device approval, and insurance coverage decisions of artificial intelligence. Korean J Radiol 2021;22(3):442-453 [FREE Full text] [doi: 10.3348/kjr.2021.0048] [Medline: 33629545]
49. Tsay J, Steadman N, Fleming M, Gann M, Di Giulio I, Graef C, et al. Bridging the gap between experimental control and ecological validity in human sensorimotor science. J Physiol 2024. [doi: 10.1113/JP287037] [Medline: 38970623]

Abbreviations

ADL: activities of daily living
MCI: mild cognitive impairment
MMC: markerless motion capture
PD: Parkinson disease
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RGB: red-green-blue
RGB-D: red-green-blue+depth
UPDRS: Unified Parkinson’s Disease Rating Scale

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Original Paper

Developing a Life Story Intervention for Older Adults With Dementia or at Risk of Delirium Who Were Hospitalized: Multistage, Stakeholder-Engaged Co-Design Study

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Abstract

Background: Older adults with chronic or acute cognitive impairment, such as dementia or delirium, who are hospitalized face unique barriers to person-centered care and a higher risk for negative outcomes stemming from hospitalizations. There is a need for co-designed interventions adapted for these patients to the hospital setting to improve care and outcomes. Patient life storytelling interventions have demonstrated promise in enhancing person-centered care by improving patient–care team relationships and providing information to enable care tailored to individual needs and values.

Objective: This study aims to engage patients, care partners, and clinical stakeholders in a co-design process to adapt an existing life storytelling model for use with older adults with dementia and at risk of delirium in the acute care hospital setting.

Methods: We recruited patients with dementia or at risk of delirium who were hospitalized, their care partners, clinicians, and informaticists. A 3-stage co-design process that used a mixed methods data collection approach including in-depth interviews and surveys was completed. We used content analysis to analyze qualitative data and descriptive statistics to summarize quantitative data.

Results: In total, 27 stakeholder informants (ie, patients, care partners, and interdisciplinary care team [IDT] members) participated. Stakeholders were unanimously interested in using patient life stories as a tool for hospital care through electronic health record (EHR) integration. Stakeholders shared potential topics for life stories to cover, including social support, information on patients’ key life events, and favorite activities. Participants provided insights into the logistics of integrating life stories into acute care, including interview arrangement, story-sharing methods, and barriers and facilitators. IDT members shared preferences on EHR integration, resulting in 3 co-designed mock-ups of EHR integration options. Stakeholders shared ways to optimize future acceptability and uptake, including engaging with the care team and promoting awareness of life stories, ensuring suitability to the acute environment (eg, distilling information in an easily digestible way), and addressing concerns for patient capacity and privacy (eg, engaging care partners when appropriate). Thoughts on potential impacts of life stories were also elicited, including improving patient- and care partner–IDT member relationships; humanizing patients; increasing clinical team, patient, and caregiver satisfaction; and enabling more specific, tailored care for patients with dementia and at risk of delirium.

Conclusions: This study resulted in a co-designed life storytelling intervention for patients with dementia and at risk for delirium in an acute care hospital setting. Stakeholders provided valuable information to ensure future intervention acceptability and uptake, including potential benefits, facilitators, and challenges in the acute care setting.

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KEYWORDS

co-design; storytelling; dementia; delirium; older adults; person-centered care

Introduction

Background

Between 25% and 40% of patients aged ≥65 years have acute or chronic cognitive impairment during a hospitalization, which can greatly affect their experience, care, and ability to communicate [1]. This impairment can be a chronic deteriorating impairment as is seen in Alzheimer or other dementias, or it can be an acute and likely reversible impairment which happens in hospital-induced delirium. For older adults with dementia or at risk of delirium, hospitalizations are often dehumanizing and disorienting [2,3]. No matter if it is a chronic cognitive impairment or an acute delirium episode, it is often difficult for these patients to communicate their needs and preferences in a new environment such as the hospital.

These challenges, coupled with a hospital's limited set of resources, tools, and time to provide person-centered care can contribute to loss of patient dignity and autonomy [2,4] and result in negative quality and clinical outcomes, including increased restraint use, longer hospital stays, and higher hospital mortality compared to patients without cognitive impairment [1,5-7]. In addition, hospital interdisciplinary care team (IDT) members report feeling moral distress and low satisfaction when they are unable to provide high-quality, person-centered care for patients with dementia and delirium [8]. Care partners for older adults with dementia and delirium experience increased caregiver strain and negative health outcomes from the stress of caregiving [9-13].

Addressing the complexities associated with high-quality, person-centered care for patients with dementia or at risk of delirium requires co-designed solutions that accommodate the workplace demands of the hospital IDTs and prioritize the well-being and individual needs of patients and care partners. Co-design is a dynamic process, endorsed by leading health agencies [14], that involves active engagement of stakeholders in intervention development to produce sustainable, acceptable interventions [15,16].

By acknowledging the unique demands and requirements of multiple clinical roles within the IDT, we can develop interventions that fit into the existing resource-limited care context, resulting in more effective and efficient health care delivery. Engaging IDT members in intervention development can improve their satisfaction and ultimate uptake of the intervention [16]. Co-design has been used to improve the use of electronic information exchange tools (eg, patient portals) by eliciting patient, care partner, care team, and other stakeholders' perspectives on barriers and facilitators to engagement with these tools [17].

In addition, co-designing with older adults with dementia or at risk of delirium presents an opportunity to understand their needs and wishes [18] but comes with logistical and ethical challenges regarding capacity to consent and participate in research. There is a paucity of research including patients with dementia or at risk of delirium who were hospitalized, in co-design. A recent review identified only 8 published co-design studies in the acute care setting, and none focused specifically on patients with dementia or at risk of delirium [19]. Interviewing the older adults in the presence of their care partner can help with communication [18].

Given the unique barriers to providing person-centered care for older adults facing cognitive issues who were hospitalized, co-designed interventions adapted to this setting and population are sorely needed. Life stories and similar narratives have emerged as a powerful strategy to enhance person-centered care by improving patient–care team relationships and communication. Life stories include information about patients' values, preferences, and personal experiences that enable the delivery of personalized care aligned with patients' unique needs. Research on life stories and similar narratives has shown improvements in patient–care team relationships and communication, as well as patient well-being [20-24]. However, life stories have yet to be tailored to the acute care setting for older adult patients with dementia and at risk of delirium.

This Study

Because of negative hospital experiences (eg, experiencing confusion and disorientation), communication challenges, and barriers to person-centered care in the hospital, these populations may similarly stand to benefit from patient life storytelling. The aim of this study was to describe a stakeholder-engaged co-design process to adapt an existing life storytelling model for older adults with dementia or at risk of delirium in the acute care hospital setting.

Methods

Study Design

The co-design process involved using a mixed methods data collection approach including in-depth individual interviews and survey.

Setting

This study took place in the Acute Care for Elders (ACE) Unit at the University of California San Francisco (UCSF) Medical Center between May and December 2022. The UCSF ACE Unit provides a specialized acute care environment for older adult patients to promote independence and function and prevent complications such as delirium that are common for older adults who are hospitalized [25].

Ethical Considerations

This study was reviewed by the Advarra Institutional Review Board (Pro00056445) and deemed exempt in accordance with the US Department of Health and Human Services regulations at Title 45 Code of Federal Regulations Part 46. Participants provided written informed consent. Patients were able to participate if their legally authorized representative or surrogate provided written informed consent. Participants were remunerated with Visa gift cards for participating; US $20 for surveys and US $50 for qualitative interviews. All data were deidentified before analysis.

Intervention Development and Description

MemoryWell life stories, which have been used primarily in long-term care settings since 2017, were developed by expert interviewers (JN-S and MC) with backgrounds in journalism. They developed the life story questionnaire drawing from evidence-based, dementia-friendly interview strategies [26] as well as user experience at long-term care and palliative care settings at 45 sites in more than 20 states. MemoryWell's life stories have demonstrated improved experiences for patients, care partners, and care staff; in one 30-story pilot at a skilled nursing facility (SNF), patients and family members reported feeling better understood because of the life story, and family members reported improved relationships with care staff [27]. Staff reported increased satisfaction and ability to care for patients considering their needs and wishes after life story intervention [27].

Life stories include information about patients' life stages (eg, childhood and early adulthood), achievements, challenges, religion and spirituality, favorite activities, and social support. MemoryWell's life storytelling model consists of a 30- to 45-minute interview conducted by trained interviewers with a patient or their care partner, or both together. The life story interview format is dependent on the patient's cognitive capacity, care needs, and family preference and availability. When possible, patients participate in all or part of the life story interview independently, and the interviewer can contact their care partner to provide additional information if needed. Otherwise, the interview is conducted with the patient and a care partner present. Questions are addressed to the patient, and the care partner fills in and supports the interview as needed. For patients who are unable to recall or communicate their life stories or whose care needs interfere with the ability to give an interview, a care partner can provide the interview on their behalf. This interview is audio recorded and automatically transcribed. On the basis of this interview, a professional writer writes an approximately 500- to 700-word life story narrative, which takes approximately 1 to 2 hours. The story is then reviewed by an editor for clarity, which takes about half an hour, before being shared with the family and care team. The story is intended to inform care for this particular patient. This study's goal was to adapt MemoryWell's SNF life story intervention to the acute care setting for older adults with dementia or at risk of delirium, reflecting setting differences in patient continuity, workflow, and time constraints.

Participants and Recruitment

Patient and Care Partner Recruitment

We used purposeful sampling [28] to identify eligible patients and care partners to participate in in-depth interviews for the co-design process. Eligible patients were English-speaking adults aged ≥65 years, admitted to the ACE Unit, with a diagnosis of dementia documented in their medical chart or a positive AWOL score [29], a validated hospital admission-screening tool that determines the risk of acquiring hospital delirium. The AWOL score uses a person's age (A), ability to spell "world" backward (W), orientation to environment (O), and a nurse assessment of illness severity (L) to determine not only an increased risk of delirium during their hospitalization but also it gives the medical team general information about a patient's current cognitive status (whether it is acute delirium or a more chronic cognitive issue, although it does not distinguish the difference). A positive score indicates an increased risk for hospital delirium. English-speaking care partners aged ≥18 years of eligible patients were also invited to participate. If a care partner spoke English but the patient did not, care partners were invited to participate. Non-English speakers were not enrolled due to constraints in translation resources for consent and interviews.

Eligible patients and care partners were identified daily through the electronic health record (EHR). Eligible patients and care partners were then invited to participate in the study in person during their hospitalization or via telephone shortly after their hospital discharge.

IDT Members and EHR Informaticist Recruitment

Inpatient IDT members were eligible if they delivered care to an eligible patient in the ACE Unit. Using purposive sampling [28], inpatient IDT members were invited to participate via email. To address different clinical perspectives, IDT members from a variety of roles on the ACE Unit were invited, including geriatricians, hospitalists, physical therapists, chaplains, social workers, case managers, nurse practitioners, registered nurses, and pharmacists. To explore the potential utility of life stories in the patients' care transitions after hospitalization, eligible outpatient geriatric primary care and postacute care providers were invited by email. These participants included physicians, geriatricians, nurse practitioners, and a SNF medical director.

Eligible EHR informaticists and programmers from the UCSF APeX Enabled Research (AER) program were invited to participate. APeX is the name of the Epic EHR used at UCSF. The AER program supports the use of APeX for faculty-initiated research projects and provided consultation and technical services for this project [30].

Data Collection and Co-Design Process

Figure 1 demonstrates our 3-stage co-design process with stakeholders and methods used.

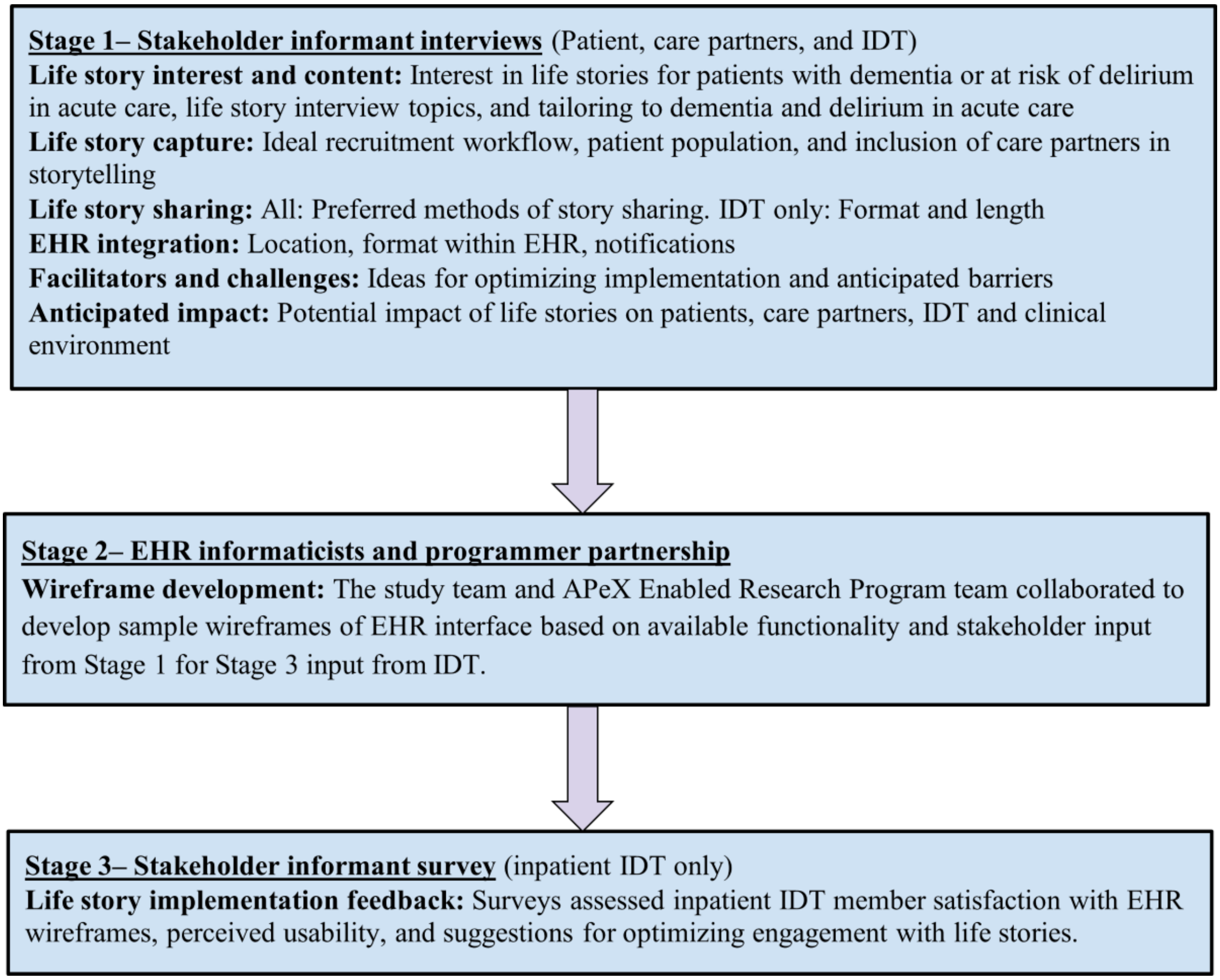

Figure 1. Co-design of life storytelling intervention for patients with dementia or at risk of delirium who were hospitalized, in acute care. EHR: electronic health record; IDT: interdisciplinary care team.

Stage 1– Stakeholder informant interviews (Patient, care partners, and IDT)

Life story interest and content: Interest in life stories for patients with dementia or at risk of delirium in acute care, life story interview topics, and tailoring to dementia and delirium in acute care

Life story capture: Ideal recruitment workflow, patient population, and inclusion of care partners in storytelling

Life story sharing: All: Preferred methods of story sharing. IDT only: Format and length

EHR integration: Location, format within EHR, notifications

Facilitators and challenges: Ideas for optimizing implementation and anticipated barriers

Anticipated impact: Potential impact of life stories on patients, care partners, IDT and clinical environment

Stage 2– EHR informaticists and programmer partnership

Wireframe development: The study team and APeX Enabled Research Program team collaborated to develop sample wireframes of EHR interface based on available functionality and stakeholder input from Stage 1 for Stage 3 input from IDT.

Stage 3– Stakeholder informant survey (inpatient IDT only)

Life story implementation feedback: Surveys assessed inpatient IDT member satisfaction with EHR wireframes, perceived usability, and suggestions for optimizing engagement with life stories.

Stage 1: Stakeholder Informant Interviews

Stage 1 involved in-depth qualitative interviews with stakeholder informants. We developed a study-specific interview guide, based on our previous experience interviewing patients with dementia in long-term care, to assess the feasibility and acceptability of integrating life stories into acute care for patients with dementia or at risk of delirium (Multimedia Appendix 1). At the beginning of each interview, stakeholders were given an overview of the purpose of the study which included the overarching goal of developing a life story intervention for implementation in the acute care setting. The questions explored the stakeholder's level of interest in life stories and anticipated impacts on care. Interviews elicited preferred topics for life stories as well as content that stakeholders did not want to be included in life story interviews. We also explored stakeholders' views on how life stories could be implemented into hospital clinical practice such as preferences on the life story interview process, including timing (eg, in relation to hospital stay and time of day) and method (eg, in-person vs remote and who participates in the interview). Barriers and facilitators to life story implementation and workflows were also assessed. Inpatient and outpatient IDT members were also asked about their preferences for integrating life stories into the EHR. Questions included life story format, preferred location within EHR, and strategies for integrating life stories into clinical workflows. All interviews were digitally recorded.

Stage 2: EHR Informaticists and Programmer Partnership

Data from stage 1 interviews were then used to inform the design of the life story intervention and implementation workflow in partnership with informaticists and EHR programmers. We identified opportunities for feasible and functional EHR integration. The AER team created sample wireframes (2D illustrations of the EHR interface) to demonstrate EHR integration options to stakeholders.

Stage 3: Stakeholder Informant Survey

Stage 3 involved asking stakeholder informants to provide additional feedback and insights on the intervention and implementation workflow using the wireframes as potential examples. We developed a survey for inpatient IDT members using study-created measures and measures adapted from the American Customer Satisfaction Index to assess their satisfaction with EHR wireframes, perceived usability, and suggestions for optimizing engagement. Measures were rated on a scale of 1 to 10, with 1 being the least desirable and 10 being the most desirable (eg, convenience of accessing: 1=very difficult and 10=very easy; satisfaction: 1=very dissatisfied and 10=very satisfied). Surveys were administered via email using SurveyMonkey (SurveyMonkey Inc) [31].

Analysis

Qualitative interviews (stage 1) were deidentified and professionally transcribed verbatim. We used a combination of qualitative and quantitative content analysis for interview data [32,33]. Transcripts were reviewed independently by 2 members of the research team (SJF and JDH). We first used qualitative content analysis to systematically examine the transcripts to obtain a condensed understanding and description of the content [33]. We used a data-driven (inductive) approach to analysis whereby open coding was performed to identify salient and elevated topics of importance within the data set. Reviewers (SJF and JDH) met to define and refine coding categories to ensure trustworthiness throughout the analysis. Negotiated consensus was used to resolve disparities and coding categories [34]. We then organized codes around key study questions: interest and content, story capture, story sharing and EHR integration, anticipated impact, and facilitators and challenges to implementation. Quantitative content analysis was then performed to count coding categories. This was conducted for the purpose of providing a more detailed assessment of how frequently certain codes or themes were mentioned. Data analysis was managed in Dedoose (SocioCultural Research Consultants, LLC) [35]. Stage 3 surveys were analyzed using descriptive statistics.

Results

Stage 1: Stakeholder Informant Interviews

Of the 27 individuals interviewed, 3 (11%) were patients, 6 (22%) were care partners, and 18 (67%) were IDT members. Table 1 shows stakeholder *interest* in life stories and potential *topics to include* in life stories for patients, care partners, and IDT members. All stakeholders were interested in implementing patient life stories in the acute care setting. Care partners and patients focused on wanting to share who the patient is as a person outside of their current state, including reviewing the patient's life stages (eg, education, former occupations, and places they have lived) and favorite activities. Several IDT members indicated that while they suspected certain preselected topics could be useful, they would want to know what patients and care partners prefer to share in each story. All IDT members wanted to know about the patient's social support, as this was deemed to be critical knowledge for tailoring care plans.

Table 1. Life story level of interest and potential topics to include[a].

	Total (N=27), n (%)	Patients (n=3), n (%)	Caregivers (n=6), n (%)	IDT[b] (n=18), n (%)
Interested in life stories for acute care	27 (100)	3 (100)	6 (100)	18 (100)
Topics[c]				
Life stages	23 (92)	1 (100)	6 (100)	16 (89)
Social support	23 (92)	1 (100)	4 (67)	18 (100)
Spirituality	6 (24)	0 (0)	2 (33)	4 (22)
Hobbies and activities	20 (80)	1 (100)	5 (83)	14 (78)
Preferred foods	5 (20)	0 (0)	3 (50)	2 (11)
Legacy and achievements	11 (44)	0 (0)	3 (50)	8 (44)
SDOH[d], mental health, and trauma	14 (56)	0 (0)	2 (33)	12 (67)
Care preferences	7 (28)	0 (0)	1 (17)	6 (33)
What brings joy	11 (44)	1 (100)	2 (33)	8 (44)

[a] Where data do not equal 100%, data are missing due to nonresponse.

[b] IDT: interdisciplinary care team.

[c] Only one patient answered about topics to include, so N=25 for these rows and n=1 for the patient.

[d] SDOH: social determinants of health.

Life Story Interview Process

Patient and Care Partner Perspectives on Life Story Interview Timing and Format

Timing of Life Story Interview

Most patients and care partners indicated they would be willing to complete a life story interview during hospitalization if the interview would not interrupt daily activities, including medical procedures or favorite television programs. In addition, 1 care partner said that there was too much going on while the patient was hospitalized, so it would be preferable to capture stories before hospitalization.

Life Story Interview Format

Patients and care partners responded that in-person or virtual interviews were preferred; 1 care partner noted that because internet connectivity was poor in some patient rooms, Wi-Fi hot spots would need to be provided to conduct Zoom (Zoom Video Communications, Inc) interviews.

IDT Member Perspectives on Life Story Interview Timing and Format

Timing of Life Story Interview

Themes from IDT members regarding life story interview scheduling include challenges navigating short lengths of stay, ensuring patients are medically stable, and finding a time of day that fits the hospital workflow and patient needs. To ensure the story is used within short lengths of stay, IDT members suggested collecting stories as soon as possible once the patient is out of the emergency department on the hospital floor. Life story interviews must fit the clinical workflow, in between medication administration, testing, specialist visits, procedures, and mealtimes. The optimal time between these tasks, when patients are most alert, was noted to be between 10 AM and 5 PM.

Life Story Interview Format

IDT members highlighted that life story interviews must be responsive to COVID-safety considerations as well as technology and visual and hearing needs of patients and families. They cautioned that Zoom interviews may be difficult for patients if they have issues with hearing or vision. For patients with cognitive impairment, they recommended care partners be involved in life story interviews. Care partners supported having an interviewer from outside of the care team conduct the life story interview and write the life story if they were made aware that the interviewer was from an outside organization, noting that professional writers would be “the right people for the job.” They felt MemoryWell conducting interviews would save time and resources for the care team while helping fill in information gaps; MemoryWell was described as a “bridge to patients for the care team.”

Life Story Sharing

Life Story Sharing With Patients and Care Partners

Patients and care partners suggested a variety of methods to personally receive their stories after they had been completed, including via email, paper copies, and UCSF’s patient portal, MyChart.

Life Story Sharing With IDT Members

Life Story Format

Most IDT members indicated that they would prefer a story format that includes both paragraphs and bullet points. Bullet points were perceived to skim information quickly when IDT members have limited time while paragraphs can offer more detailed context. IDT members prioritized ease of reading, and several suggested that communicating valuable information in a concise manner was more vital to ensuring use than the exact length of the story. IDT members emphasized the importance of keeping the stories brief to ensure that they would not get overwhelmed and avoid reading stories. Most suggested 1 to 2 pages and others preferred even briefer stories at just 2 to 3 paragraphs or 350 words.

EHR Integration

IDT members emphasized the importance of ease of access to life stories in the EHR to ensure they could incorporate life stories into their workflow. Most IDT members suggested integrating life stories into the social history section because the life story content intuitively aligns with this section and most clinicians would be able to find it. Further, the social history EHR section automatically pulls into notes and is a static location that can be viewed as an inpatient or outpatient IDT member. Others suggested locations that would be visible immediately upon opening the patient’s chart or integrating into the EHR’s Daily Rounds tab. IDT members stressed avoiding information overload in clinical notes or other important EHR pages and suggested potentially storing a summary in some sections (ie, social history) with an option to click to another location for the full life story.

IDT members said that making the story easy to find is the most significant priority, preferable to creating alerts or notifications that a story is available; several suggested an icon next to the patient’s name that would change colors to indicate that the story was available. Other suggestions included only flagging for especially critical information, such as trauma history, through a pop-up notification.

Anticipated Impact of Life Story Integration Into EHR and Patient Care

Overview

Themes and exemplary quotes about the anticipated impact of life stories can be found in Table 2.

Table 2. Anticipated impact of life story integration into EHR[a] and patient care.

Stakeholder, theme, and theme description	Quotes
Patients and care partners	
Theme 1: Life stories can help the care team see patient as a person beyond their medical issues.	• “One doctor came in and he was very kind of brusque and fast talking, didn’t even really look that much at us at the beginning...I felt like saying, hey...my mom is a person, not just a patient, she’s a person.”
Theme 2: Life stories may support patient and IDT[b] relationship building.	• “I think the best would be if the doctor can have the capacity to take on this patient,...and have that kind of personal time to get to know the patient. Because caring, the feeling is so complicated. There’s magic to it, and it can only come from like a true...kind of collaboration...when a doctor makes a connection with a patient.”
Theme 3: Life stories can provide context that could help prevent discrimination based on age and race.	• “Not enough credit is given to the elderly to be able to think and express themselves. That throws them into a depressed state of mind, thinking that it’s over for me. But if they are involved and respected, it’s a better transition.” • “I think they would treat her differently. It’s unfortunate that when people perceive you, the outside of you, they have a limited view of what you’re really like as a person...For example, people of other cultures tend to look at African Americans as not being knowledgeable, not being experienced with the other parts of the world.” • “I just think that... people have a really limited view of older people. I think especially with older people that if they know... she’s really sharp and she’s usually really active, I think that... it would make a difference—if they actually wanted to know. I just have a lot of doubt about them really actually wanting to know.”
IDT members	
Theme 1: Life stories could help improve person-centered care by (1) humanizing patients, (2) fostering patient- and care partner–IDT relationships and communication, and (3) enabling care tailored to what matters the most to patients.	• “I think that the humanizing element is really important. In the hospital specifically... there are many dangers of having a narrow track mind, and we want people to fit in the narrow track... and so the more ways that we can bring out the individuality, the intriguing parts of a person’s story, I think that can soften our approach and actually make it easier to do our jobs.” • “You have all the tests and you have all the medications available, but really don’t have the time to sit down and know them. So maybe working as a team would be helpful, where maybe the care team there could be a champion saying okay, this is a person who is going to make sure this person’s wishes are done, and inform everybody in the team. It could be an email, as you said, like where the case manager sends an email. Oh, just wanted to let you know this other thing is on the person’s life story, just for the team to know.” • “Our providers are working in an increasingly busy care environment. They want more support, because we’re being asked...to see more patients with less support...it is a moral distress as an inpatient provider. You want to spend time with patients, you want to get to know them. So the value proposition for this is like, this is a tool that allows your providers to get to know your patients, starting off instead of at first base on third base, with all this information about them in a very easy way that’s user friendly, that’s right in front of them, that’s readable, where you don’t have to spend time as a provider sifting through the chart.”
Theme 2: Life stories could be especially helpful for caring for patients with CI[c] or delirium.	• “It gives us things to talk about with the patients, and it’s helpful in cases of delirium or dementia to know what was important to that person so that we can kind of help ground them and give them more context, just make them feel less lost in the alien atmosphere of being in the hospital.” • “When you do medical interventions to this type of patient it can be very challenging sometimes because of their behavior. So I think it gives an in to the clinicians of how to soothe the patient and making sure oh, this patient can still make a little bit of decision with guidance. If we have that in the life story of the medical records, then we know already...the patient is not a stranger to us...we already know the patient’s background.” • “I think it’s extremely important to connect with your patient, especially because people with dementia are usually older and frail and scared in the hospital. And they do best, a lot of times they do best when they’re around familiar surroundings, which they can’t be around, so familiar conversation always helps provide some comfort.”
Theme 3: Life stories help improve stakeholder satisfaction.	• “And knowing more about who our patients are and what they’ve done with their lives and what was important to them really humanizes them and I think facilitates staff to have greater empathy for their situation. Frankly, I think it improves care for everybody. I think the staff feels more satisfied, feeling like they know who they’re taking care of.” • “I imagine that in general people like to feel known and seen for who they are.” • “I feel like families often feel more comfortable with their loved one being in the hospital if they feel like we know their loved one well, we care about trying to make them comfortable.”

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[a] EHR: electronic health record.

[b] IDT: interdisciplinary care team.

[c] CI: cognitive impairment.

Patient and Care Partner Themes About the Anticipated Impact of Life Stories

Theme 1: Life Stories Can Help Care Team See Patient as a Person Beyond Their Medical Issues

Patients and care partners said that life stories could be helpful in encouraging the IDT to see the patient as a full person.

Theme 2: Life Stories May Support Patient and IDT Relationship Building

Care partners expressed the importance of care teams taking the time to build genuine relationships with patients and that life stories could help foster these relationships by helping IDT members get to know their patients.

Theme 3: Life Stories Can Provide Context That Could Help Prevent Discrimination Based on Age and Race

Care partners also shared that life stories could help prevent ageism and discrimination, arguing that if the IDT understood patients' life experiences and social context, they could be less quick to judge them based on their age or race. They also expressed that life stories could help with suboptimal care team communication and rapport.

IDT Member Themes About the Anticipated Impact of Life Stories

Theme 1: Life Stories Could Help Improve Person-Centered Care by (1) Humanizing Patients, (2) Fostering Patient- and Care Partner–IDT Member Relationships, and (3) Enabling Care Tailored to What Matters Most

IDT members said that knowing more about their patients as people could help humanize the patients. They expressed that in a setting with limited time and background information on patients, life stories could be a valuable *time-saver* in jump-starting the patient- and care partner–IDT relationship by providing context for building rapport and communication. Several IDT members also said that giving social and cultural context and knowing about trauma history and root causes of social needs can help "decrease bias and promote respect and cultural competency."

IDT members expressed that life stories could be beneficial for tailoring their care around "*what matters most* to the patient." Further, knowing about family dynamics and if there is a designated health care proxy can help the care team know whom to involve in decision-making. Knowing about previous functional status and current social support can help optimize care and discharge planning. IDT members expressed that providing better person-centered care could lead to better patient outcomes, such as reduced delirium and readmissions.

Theme 2: Life Stories Could Be Especially Helpful for Caring for Patients With Dementia and Delirium

IDT members said that information from life stories could be especially helpful for patients with dementia or at risk of delirium by helping orient patients in an unfamiliar, often scary environment. This could help prevent the use of physical and chemical restraints in response to challenging behaviors. Furthermore, when these patients are unable to speak for themselves, a life story could help document important information and give them a voice in the medical record.

Theme 3: Improved Satisfaction for Each Stakeholder

IDT members shared that building better relationships and providing optimized person-centered care could lead to satisfaction for patients, care partners, and IDT. The story can be given as a gift for the family, which offers a chance to reflect on the patient's life during a difficult time. IDT members anticipated that patients and care partners could feel seen and heard by someone in the medical setting taking the time to listen to and document their stories. IDT members explained that they often feel moral distress in not being able to provide the care that they want to and that life stories could help them take a step back and remind them of the meaning of their work.

Facilitators and Challenges to Implementation

Table 3 shows IDT member–reported potential barriers and facilitators to life story implementation. IDT members emphasized the importance of training the full IDT around life stories to ensure life story use by everyone who cares for the patient. They also raised concerns about the time constraints within acute care and the necessity for life stories to be easily accessible. IDT members said that while patients with dementia and delirium could be uniquely well-suited for a life story intervention, care must be taken to adapt to patient capacity, involve care partners when appropriate, and ensure understanding of how information is being shared and with whom.

Table 3. IDT[a]-reported potential implementation barriers and facilitators.

Barriers and facilitators	Description of barriers and facilitators
Engaging care team and awareness of life stories	
Potential barriers	• Need cultural buy-in to treat the whole person • Life stories must be available for enough patients to become a part of the regular workflow • Some specialties may be less likely to want to engage with life stories (eg, surgery and pharmacy) or see components as outside of the scope of their role (eg, social determinants of health)
Potential facilitators	• Providing training regarding (1) the existence of life stories, (2) how to access stories, and (3) the potential benefits of reading life stories • Some specialties may be more apt to see the benefit of life stories (eg, geriatricians well-versed in dementia and delirium care)
Suitability to acute environment	
Potential barriers	• Short length of stay • Story may not be a priority in comparison to acute needs • Resource intensive
Potential facilitators	• Distill information into an easily digestible format • Must be easily accessible in EHR[b]
Concerns for patient capacity and privacy	
Potential barriers	• Privacy concerns: some patients may not want to share personal information, especially for populations at risk of potential legal system involvement (eg, undocumented patients) • Ensuring patients are aware all IDT members can access life story in EHR • Patient capacity to consent and communicate is dependent on cognitive impairment and illness severity
Potential facilitators	• Engaging with care partners as appropriate • Working with patients to find an appropriate time to conduct life story interviews within day and stay • Patients with dementia and at risk of delirium stand to benefit the most

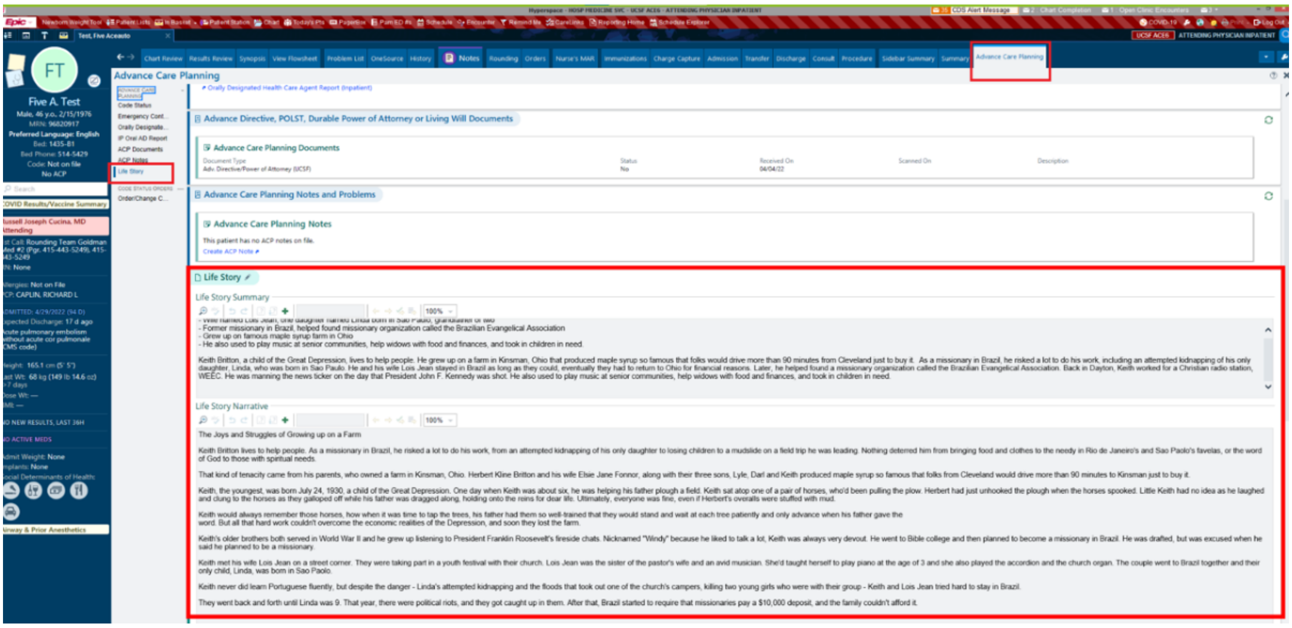
[a] IDT: interdisciplinary care team.

[b] EHR: electronic health record.

Stage 2: EHR Informaticists and Programmer Partnership

We partnered with 3 members of the UCSF AER team who provided insights into feasible EHR integration. Moreover, 3 sample wireframes focusing on available functionalities, intended behaviors, and space allocation with prioritization of content were created incorporating options of how the life story would look in the EHR. Figures 2-4 present these wireframes in 3 potential EHR locations, including the Daily Rounds tab (used to quickly collect basic clinical information before rounds), Advance Care Planning (ACP) tab (which summarizes all ACP discussions and documents), and Social History section (the section to input a patient’s social history).

Figure 2. Advance Care Planning (ACP) tab. Life story summary and narrative on ACP tab. This page summarizes all ACP discussions and documents.



Advance Care Planning

Orally Designated Health Care Agent Report (Inpatient)

Advance Directive, POLST, Durable Power of Attorney or Living Will Documents

Advance Care Planning Documents

Document Type	Status	Received On	Scanned On	Description
Adv. Directive/Power of Attorney (UCSF)	No	04/04/22		

Advance Care Planning Notes and Problems

Advance Care Planning Notes

This patient has no ACP notes on file.

Create ACP Note

Life Story

Life Story Summary

- Wife named Lois Jean, one daughter named Linda born in Sao Paulo, grandfather of two
- Former missionary in Brazil, helped found missionary organization called the Brazilian Evangelical Association
- Grew up on famous maple syrup farm in Ohio
- He also used to play music at senior communities, help widows with food and finances, and took in children in need.

Keith Britton, a child of the Great Depression, lives to help people. He grew up on a farm in Kinsman, Ohio that produced maple syrup so famous that folks would drive more than 90 minutes from Cleveland just to buy it. As a missionary in Brazil, he risked a lot to do his work, including an attempted kidnapping of his only daughter, Linda, who was born in Sao Paulo. He and his wife Lois Jean stayed in Brazil as long as they could, eventually they had to return to Ohio for financial reasons. Later, he helped found a missionary organization called the Brazilian Evangelical Association. Back in Dayton, Keith worked for a Christian radio station, WEEC. He was manning the news ticker on the day that President John F. Kennedy was shot. He also used to play music at senior communities, help widows with food and finances, and took in children in need.

Life Story Narrative

The Joys and Struggles of Growing up on a Farm

Keith Britton lives to help people. As a missionary in Brazil, he risked a lot to do his work, from an attempted kidnapping of his only daughter to losing children to a mudslide on a field trip he was leading. Nothing deterred him from bringing food and clothes to the needy in Rio de Janeiro's and Sao Paolo's favelas, or the word of God to those with spiritual needs.

That kind of tenacity came from his parents, who owned a farm in Kinsman, Ohio. Herbert Kline Britton and his wife Elsie Jane Fonnor, along with their three sons, Lyle, Darl and Keith produced maple syrup so famous that folks from Cleveland would drive more than 90 minutes to Kinsman just to buy it.

Keith, the youngest, was born July 24, 1930, a child of the Great Depression. One day when Keith was about six, he was helping his father plough a field. Keith sat atop one of a pair of horses, who'd been pulling the plow. Herbert had just unhooked the plough when the horses spooked. Little Keith had no idea as he laughed and clung to the horses as they galloped off while his father was dragged along, holding onto the reins for dear life. Ultimately, everyone was fine, even if Herbert's overalls were stuffed with mud.

Keith would always remember those horses, how when it was time to tap the trees, his father had them so well-trained that they would stand and wait at each tree patiently and only advance when his father gave the
word. But all that hard work couldn't overcome the economic realities of the Depression, and soon they lost the farm.

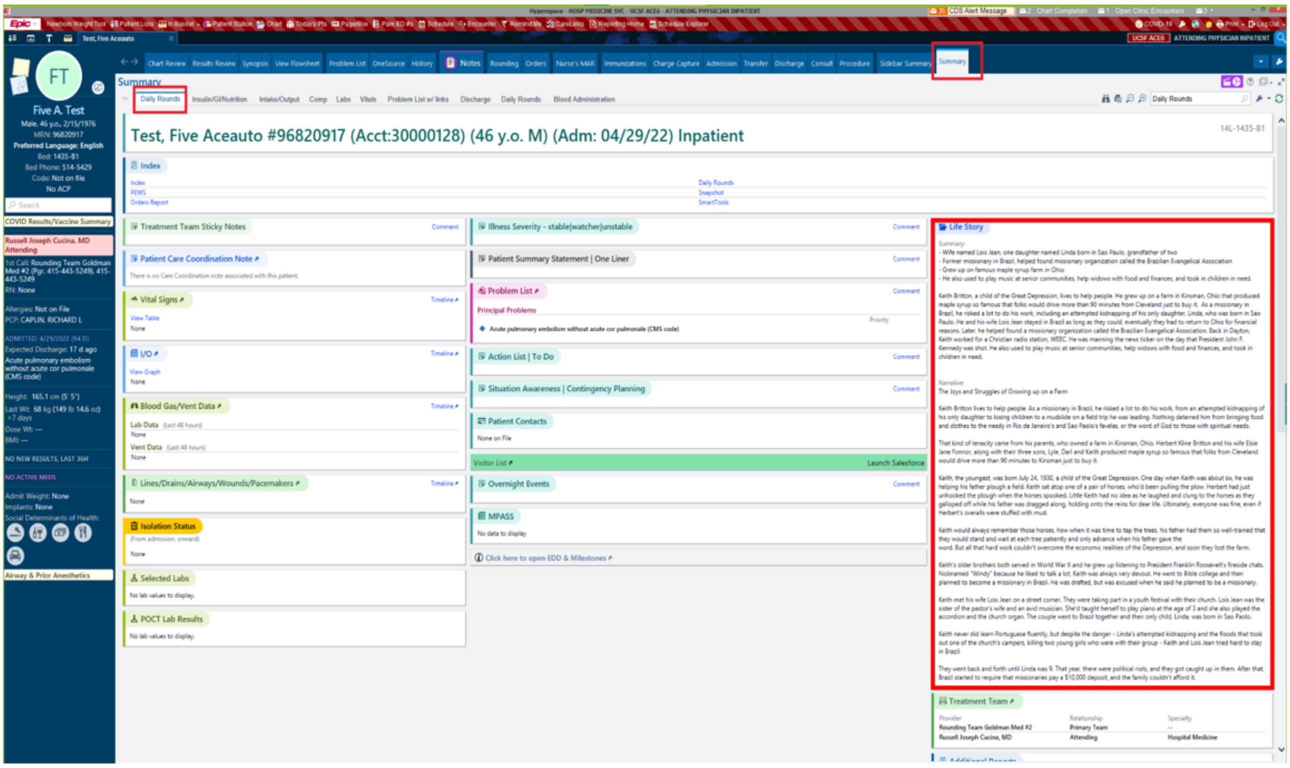
Keith's older brothers both served in World War II and he grew up listening to President Franklin Roosevelt's fireside chats. Nicknamed "Windy" because he liked to talk a lot, Keith was always very devout. He went to Bible college and then planned to become a missionary in Brazil. He was drafted, but was excused when he said he planned to be a missionary.

Keith met his wife Lois Jean on a street corner. They were taking part in a youth festival with their church. Lois Jean was the sister of the pastor's wife and an avid musician. She'd taught herself to play piano at the age of 3 and she also played the accordion and the church organ. The couple went to Brazil together and their only child, Linda, was born in Sao Paolo.

Keith never did learn Portuguese fluently, but despite the danger - Linda's attempted kidnapping and the floods that took out one of the church's campers, killing two young girls who were with their group - Keith and Lois Jean tried hard to stay in Brazil.

They went back and forth until Linda was 9. That year, there were political riots, and they got caught up in them. After that, Brazil started to require that missionaries pay a $10,000 deposit, and the family couldn't afford it.

Figure 3. Daily Rounds tab. Life story summary and narrative on the Daily Rounds tab. This page is used to quickly collect basic clinical information before rounds.



Summary

Test, Five Aceauto #96820917 (Acct:30000128) (46 y.o. M) (Adm: 04/29/22) Inpatient

14L-1435-B1

Index

Index
PEWS
Orders Report
Daily Rounds
Snapshot
SmartTools

Treatment Team Sticky Notes

Patient Care Coordination Note

There is no Care Coordination note associated with this patient.

Vital Signs

View Table
None

I/O

View Graph
None

Blood Gas/Vent Data

Lab Data (Last 48 hours)
None
Vent Data (Last 48 hours)
None

Lines/Drains/Airways/Wounds/Pacemakers

None

Isolation Status

(From admission, onward)
None

Selected Labs

No lab values to display.

POCT Lab Results

No lab values to display.

Illness Severity - stable|watcher|unstable

Patient Summary Statement | One Liner

Problem List

Principal Problems

Priority

- Acute pulmonary embolism without acute cor pulmonale (CMS code)

Action List | To Do

Situation Awareness | Contingency Planning

Patient Contacts

None on File

Visitor List

Overnight Events

MPASS

No data to display

Click here to open EDD & Milestones

Life Story

Summary:

- Wife named Lois Jean, one daughter named Linda born in Sao Paulo, grandfather of two
- Former missionary in Brazil, helped found missionary organization called the Brazilian Evangelical Association
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Narrative:

The Joys and Struggles of Growing up on a Farm

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word. But all that hard work couldn't overcome the economic realities of the Depression, and soon they lost the farm.

Keith's older brothers both served in World War II and he grew up listening to President Franklin Roosevelt's fireside chats. Nicknamed "Windy" because he liked to talk a lot, Keith was always very devout. He went to Bible college and then planned to become a missionary in Brazil. He was drafted, but was excused when he said he planned to be a missionary.

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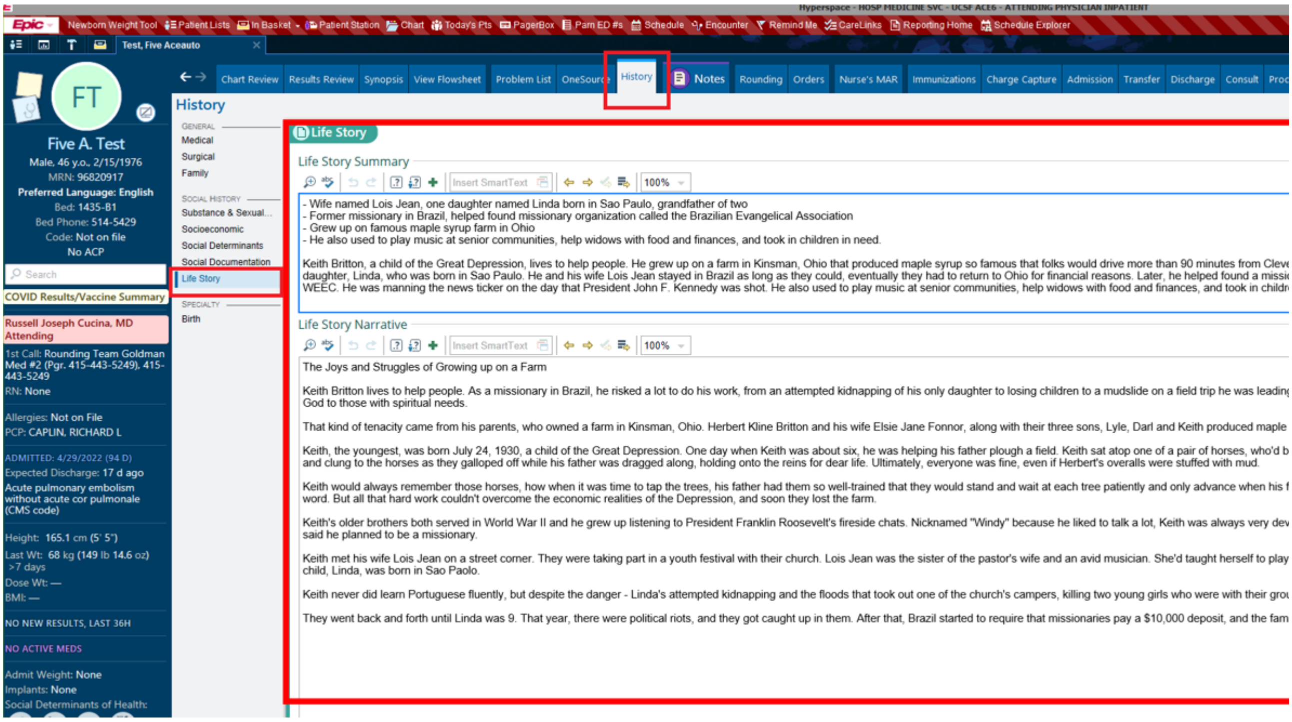
They went back and forth until Linda was 9. That year, there were political riots, and they got caught up in them. After that, Brazil started to require that missionaries pay a $10,000 deposit, and the family couldn't afford it.

Treatment Team

Provider	Relationship	Specialty
Rounding Team Goldman Med #2	Primary Team	--
Russell Joseph Cucina, MD	Attending	Hospital Medicine

Figure 4. Social History section. Life story summary and narrative in the Social History section of overall History tab. This section is used to input information regarding the patient's social history.



Five A. Test
Male, 46 y.o., 2/15/1976
MRN: 96820917
Preferred Language: English
Bed: 1435-B1
Bed Phone: 514-5429
Code: Not on file
No ACP

Russell Joseph Cucina, MD
Attending
1st Call: Rounding Team Goldman Med #2 (Pgr. 415-443-5249), 415-443-5249
RN: None

Allergies: Not on File
PCP: CAPLIN, RICHARD L

ADMITTED: 4/29/2022 (94 D)
Expected Discharge: 17 d ago
Acute pulmonary embolism without acute cor pulmonale (CMS code)

Height: 165.1 cm (5' 5")
Last Wt: 68 kg (149 lb 14.6 oz) >7 days
Dose Wt: —
BMI: —

NO NEW RESULTS, LAST 36H

NO ACTIVE MEDS

Admit Weight: None
Implants: None
Social Determinants of Health:

Life Story Summary

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Stage 3: Stakeholder Informant Survey

Stage 3 involved asking inpatient IDT stakeholder informants to provide feedback on EHR wireframes and life story implementation, including perceived usability and suggestions for optimizing engagement. Table 4 presents findings from the stakeholder informant survey, where 10 inpatient IDT members were surveyed with a 100% response rate. The Daily Rounds tab was rated highest on convenience of access and satisfaction (out of 10), followed by the Social History and ACP sections, respectively. The Daily Rounds tab was the most common top choice, followed by Social History. The majority (7/10, 70%) of IDT members responded they would review the story for all patients.

Table 4. Stakeholder informant survey of 3 sample EHR[a] wireframe examples (N=10).

Location	Daily Rounds tab	Advance Care Planning tab	Social History section
Convenience, mean (SD)	8.3 (1.6)	5.5 (1.7)	5.5 (2.1)
Satisfaction, mean (SD)	7.7 (1.8)	5.7 (1.8)	6 (1.9)
Respondents who ranked top choice, n (%)	7 (70)	1 (10)	2 (20)
Respondents who ranked second choice, n (%)	1 (10)	2 (20)	7 (70)

[a] EHR: electronic health record.

Outputs of Co-Design Process: Co-Designed Life Story and EHR Wireframe Selection

Co-Designed Life Story for Acute Care

On the basis of the feedback from stages 1 to 3, the resulting Life Story section of the wireframe was divided into 2 sections: Life Story Short-Form and Life Story Narrative. The Life Story Short Form is intended to provide concise information about the patient's life story if a clinical team member is time-constrained. The The Life Story Short Form is formatted in bullet points and short-form questions were selected based on stakeholder input to include information deemed most readily applicable to acute care, including evidence-based commonly unmet needs for patients with dementia or at risk of delirium (eg, boredom, discomfort, and loneliness) [36,37], as well as what matters to align with the Age-Friendly Health Systems framework [38]. These short-form unmet needs questions are at the beginning of the co-designed life story interview guide and the life story interviewer outlines the responses in bullet points to allow for immediate sharing. Topics included social support, previous occupation, favorite entertainment (eg, television, reading, and music) and foods, religion or spirituality, what a good day at home might entail, and what matters most to the patient.

The Life Story Narrative is approximately 400 to 500 words and in paragraph format. This is written by a professional writer based on the life story interview recording and transcript and takes approximately 1 to 2 hours to write. It builds upon the summary to provide a rich description of the patient's life experiences and covers life stages, achievements, challenges, and other information the patient or care partner wanted to share that is not covered in the summary. This narrative form is intended to provide a longer summary in case clinical team members want to spend more time getting to know a patient on a less busy clinical day.

EHR Wireframe Selection

After stages 1 to 3, both the Daily Rounds (Figure 3) and the Social History (Figure 4) locations were chosen for future piloting and EHR integration. These 2 options provided a static location that can be viewed in both the inpatient and outpatient context (Social History) and for ease of daily inpatient access (Daily Rounds and Social History pulling into notes), thus giving more opportunities for clinical care team members to read the stories in their usual daily clinical workflow. The Daily Rounds tab would include the Life Story Short-Form section for quick access, while the Social History would include the full life story (both the Life Story Short-Form and Life Story Narrative sections).

Discussion

Principal Findings

This co-design process found that integrating life stories into the acute care setting for patients with dementia or at risk of delirium is a highly acceptable intervention to patients, care partners, and the IDT. Stakeholders were unanimously supportive of the idea of using a life storytelling intervention in acute care. They described potential benefits to integrating life storytelling into acute care including humanizing patients, building patient- and care partner–IDT relationships, sharing information about patients with dementia or at risk of delirium, and addressing potential biases based on age, race, or other factors. Stakeholders described potential challenges including the necessity to focus on acute patient needs, short lengths of stay, the need for IDT member buy-in, and patient capacity and privacy concerns.

The existing MemoryWell life storytelling intervention, previously used in long-term care in the form of 500- to 700-word narratives providing care teams information about patient’s personal histories and preferences, was adapted to meet stakeholder preferences and to best fit the acute care setting needs. These modifications include focusing the life story interview guide to cover stakeholder-selected topics (eg, significant focus on social support), the creation of a brief, bullet point summary to help clinicians quickly learn information most applicable to caring for acute needs and discharge planning, and a multipronged approach to story EHR integration. Stakeholders shared their perspectives on ideal timing for life story interviews, including interviewing the patient as soon as possible while ensuring clinical workflow and medical procedures are not interrupted.

The study resulted in the creation of a co-designed life storytelling interview guide and format for EHR integration and wireframes depicting future EHR integration, and ideas to fit a life storytelling intervention into acute hospital workflows, to be piloted in a future study. A future pilot is needed to explore the actual implementation of the co-designed intervention, including logistics, usability, and impact on the patient, IDT, and care partner outcomes.

Comparison With Prior Work

This study is the first to our knowledge that has co-designed a life storytelling intervention for patients with dementia and at risk of delirium in the hospital setting. Our findings mirror previous patient narrative interventions aimed at sharing patients’ personal histories, values, and beliefs with their care teams in other clinical settings in terms of acceptability, challenges to implementation, and anticipated benefits. Though some life story work has focused on older adults with dementia, none has focused specifically on those with or at risk of delirium. Life story work has most often been implemented in long-term care settings [24,39-41] and has been acceptable among staff, patients, and care partners [20,21,24,39-41]. Evaluations of the My Life My Story program at the Veterans Administration have found that most staff read narratives [21]. One study involving patients with serious illness and without dementia in acute care found a narrative intervention to be acceptable to patients and bedside nurses [20].

The potential challenges to life story implementation uncovered in this study, including barriers to care team engagement, suitability to the acute care environment, and concerns for patient capacity and privacy are similar to previous studies [20]. One feasibility study of life stories for older adults with dementia in the United Kingdom on acute care National Health Service wards found similar time barriers and a need for prioritizing acute needs [42]. Approaches to the involvement of care partners in storytelling varied by study; some studies caution against using care partners to tell patients’ stories [43], while others acknowledge the need for care partner participation dependent on patients’ cognitive status [24]. We found that to co-design a life storytelling intervention for this population in acute care, care partners must be involved for patients with dementia and those at risk of delirium.

The anticipated benefits in our study are similar to anticipated and actual benefits in previous work, including improving individually tailored care; promoting relationships and communication among patients, care partners, and care teams; and particular benefits for people with dementia or risk of delirium, including serving as a communication tool for patients who are unable to communicate for themselves. Life story studies involving older adults with dementia have also shown that stories humanize patients, improve patient- and care partner–care staff relationships, and aid patient care [42-44].

Limitations

This study has several limitations. The primary limitation is that it was difficult to recruit and interview patients with dementia or at risk of delirium while they were in the hospital, due to acute illness, consistent clinical interventions, and limited cognitive capacity. Another limitation was the lack of cultural diversity patients recruited, as we were only able to recruit English-speaking patients and care partners. We did allow for English-speaking care partners to participate even if the patient did not speak English, to include perspectives from families with non-English speakers. Our recruitment was limited to 1 unit at 1 hospital and used only the APeX EHR, which means findings may not be generalizable to other EHRs, which could be a barrier to expanding the intervention. Finally, we experienced challenges in recruitment as the ACE Unit beds were delegated to patients who tested positive for COVID-19 of all ages during the study. As the pandemic numbers waxed and waned, this limited the number of available beds for older eligible patients, thus restricting the pool of eligible patients to recruit for our study.

Conclusions

In this study, we have co-designed with patients, care partners, and interdisciplinary team members, an adapted MemoryWell life story intervention for patients with dementia or at risk of delirium in an acute care hospital setting. This study highlights the anticipated impact of life stories for improving person-centered care in this setting, which often has limited resources and tools to do so. Future studies should be conducted to assess implementation feasibility and if these anticipated impacts on quality clinical and person-centered care can be made.

Acknowledgments

The authors would like to thank all stakeholder informants who took part in this study. The authors would also like to thank Tajalei Willard for her work in recruitment. This study was funded by the National Institute on Aging under award R43AG074775. JDH is supported in part by the National Institute on Aging of the National Institutes of Health (NIH; award K01AG073533) and the National Center for Advancing Translational Sciences of the NIH (award KL2TR001870).

Conflicts of Interest

This study was a partnership between University of California San Francisco and MemoryWell, a patient life storytelling company. Authors SJF and MC were employees of MemoryWell at the time the research was being completed. JN-S is the chief executive officer of MemoryWell. JN-S and MC own stock in MemoryWell.

Multimedia Appendix 1
Study-specific qualitative interview guides used in stage 1.
[PDF File (Adobe PDF File), 192 KB - aging_v7i1e59306_app1.pdf]

References

1. Fogg C, Griffiths P, Meredith P, Bridges J. Hospital outcomes of older people with cognitive impairment: an integrative review. Int J Geriat Psychiatry 2018 Jun 26;33(9):1177-1197. [doi: 10.1002/gps.4919]
2. Bridges J, Collins P, Flatley M, Hope J, Young A. Older people's experiences in acute care settings: systematic review and synthesis of qualitative studies. Int J Nurs Stud 2020 Feb;102:103469. [doi: 10.1016/j.ijnurstu.2019.103469] [Medline: 31862528]
3. Preserving your brain health during illness or surgery: GCBH recommendations to prevent and treat delirium. Global Council on Brain Health. 2020. URL: https://www.researchgate.net/publication/342976332_Preserving_Your_Brain_Health_During_Illness_or_Surgery_GCBH_Recommendations_to_Prevent_and_Treat_Delirium [accessed 2024-04-29]
4. Tay FH, Thompson CL, Nieh CM, Nieh CC, Koh HM, Tan JJ, et al. Person-centered care for older people with dementia in the acute hospital. Alzheimers Dement (N Y) 2018 Dec 04;4(1):19-27 [FREE Full text] [doi: 10.1016/j.trci.2017.11.003] [Medline: 29955648]
5. Reynish EL, Hapca SM, De Souza N, Cvoro V, Donnan PT, Guthrie B. Epidemiology and outcomes of people with dementia, delirium, and unspecified cognitive impairment in the general hospital: prospective cohort study of 10,014 admissions. BMC Med 2017 Jul 27;15(1):140 [FREE Full text] [doi: 10.1186/s12916-017-0899-0] [Medline: 28747225]
6. Witlox J, Eurelings L, de Jonghe JF, Kalisvaart KJ, Eikelenboom P, van Gool WA. Delirium in elderly patients and the risk of postdischarge mortality, institutionalization, and dementia: a meta-analysis. JAMA 2010 Jul 28;304(4):443-451. [doi: 10.1001/jama.2010.1013] [Medline: 20664045]
7. Inouye SK, Westendorp RG, Saczynski JS. Delirium in elderly people. Lancet 2014 Mar 08;383(9920):911-922 [FREE Full text] [doi: 10.1016/S0140-6736(13)60688-1] [Medline: 23992774]
8. Gwernan-Jones R, Lourida I, Abbott RA, Rogers M, Green C, Ball S. Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews. Health Serv Deliv Res 2020 Nov;8(43):1-248. [doi: 10.3310/hsdr08430] [Medline: 33237687]
9. Del-Pino-Casado R, Rodríguez Cardosa M, López-Martínez C, Orgeta V. The association between subjective caregiver burden and depressive symptoms in carers of older relatives: a systematic review and meta-analysis. PLoS One 2019 May 29;14(5):e0217648 [FREE Full text] [doi: 10.1371/journal.pone.0217648] [Medline: 31141556]
10. Meyer K, Gassoumis Z, Wilber K. The differential effects of caregiving intensity on overnight hospitalization. West J Nurs Res 2022 Jun;44(6):528-539 [FREE Full text] [doi: 10.1177/01939459211002907] [Medline: 33764207]
11. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. N Engl J Med 2006 Feb 16;354(7):719-730. [doi: 10.1056/NEJMsa050196] [Medline: 16481639]

12. Schmitt EM, Gallagher J, Albuquerque A, Tabloski P, Lee HJ, Gleason L, et al. Perspectives on the delirium experience and its burden: common themes among older patients, their family caregivers, and nurses. Gerontologist 2019 Mar 14;59(2):327-337 [FREE Full text] [doi: 10.1093/geront/gnx153] [Medline: 30870568]
13. Tabloski PA, Arias F, Flanagan N, Webb M, Gregas M, Schmitt EM, et al. Predictors of caregiver burden in delirium: patient and caregiver factors. J Gerontol Nurs 2021 Sep;47(9):32-38. [doi: 10.3928/00989134-20210803-03] [Medline: 34432572]
14. AHRQ research priorities and compliance guidance. Agency for Healthcare Research and Quality. URL: https://www.ahrq.gov/funding/policies/nofoguidance/index.html [accessed 2024-04-29]
15. Savoy A, Patel H, Shahid U, Offner AD, Singh H, Giardina TD, et al. Electronic co-design (ECO-design) workshop for increasing clinician participation in the design of health services interventions: participatory design approach. JMIR Hum Factors 2022 Sep 22;9(3):e37313. [doi: 10.2196/37313] [Medline: 36136374]
16. Pallesen KS, Rogers L, Anjara S, De Brún A, McAuliffe E. A qualitative evaluation of participants' experiences of using co-design to develop a collective leadership educational intervention for health-care teams. Health Expect 2020 Apr;23(2):358-367 [FREE Full text] [doi: 10.1111/hex.13002] [Medline: 31999883]
17. Dukhanin V, Wolff JL, Salmi L, Harcourt K, Wachenheim D, Byock I, Shared Access Project Team. Co-designing an initiative to increase shared access to older adults' patient portals: stakeholder engagement. J Med Internet Res 2023 Nov 22;25:e46146 [FREE Full text] [doi: 10.2196/46146] [Medline: 37991827]
18. Wang G, Marradi C, Albayrak A, van der Cammen TJ. Co-designing with people with dementia: a scoping review of involving people with dementia in design research. Maturitas 2019 Sep;127:55-63 [FREE Full text] [doi: 10.1016/j.maturitas.2019.06.003] [Medline: 31351521]
19. Subbe CP, Goodman A, Barach P. Co-design of interventions to improve acute care in hospital: a rapid review of the literature and application of the BASE methodology, a novel system for the design of patient centered service prototypes. Acute Med 2022;21(4):182-189. [doi: 10.52964/AMJA.0922] [Medline: 36809449]
20. Coats H, Meek PM, Schilling LM, Akard TF, Doorenbos AZ. “Connection”: the integration of a person-centered narrative intervention into the electronic health record: an implementation study. J Palliat Med 2020 Jun 01;23(6):785-791. [doi: 10.1089/jpm.2019.0376]
21. Roberts TJ, Ringler T, Krahn D, Ahearn E. The my life, my story program: sustained impact of veterans' personal narratives on healthcare providers 5 years after implementation. Health Commun 2021 Jun 30;36(7):829-836. [doi: 10.1080/10410236.2020.1719316] [Medline: 31999933]
22. Chang H, Do Y, Ahn J. Digital storytelling as an intervention for older adults: a scoping review. Int J Environ Res Public Health 2023 Jan 11;20(2):1344. [doi: 10.3390/ijerph20021344] [Medline: 36674100]
23. Subramaniam P, Woods B, Whitaker C. Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. Aging Ment Health 2014 Sep 24;18(3):363-375 [FREE Full text] [doi: 10.1080/13607863.2013.837144] [Medline: 24063317]
24. Subramaniam P, Thillainathan P, Mat Ghani NA, Sharma S. Life story book to enhance communication in persons with dementia: a systematic review of reviews. PLoS One 2023;18(10):e0291620. [doi: 10.1371/journal.pone.0291620] [Medline: 37796820]
25. Palmer RM. The acute care for elders unit model of care. Geriatrics (Basel) 2018 Sep 11;3(3):59 [FREE Full text] [doi: 10.3390/geriatrics3030059] [Medline: 31011096]
26. Tips for dementia-friendly 1-2-1 conversations and interviews. Alzheimer's Society. URL: https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/tips-dementia-friendly-conversations-and-interviews [accessed 2024-04-29]
27. Heersink D, Flessa S, Blankenmyer J, Chandler M, Newton-Small J. Life storytelling to improve person-centered care in long-term care. J Am Med Dir Assoc 2023 May;24(5):B22-B23. [doi: 10.1016/j.jamda.2023.02.063]
28. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health 2015 Sep;42(5):533-544 [FREE Full text] [doi: 10.1007/s10488-013-0528-y] [Medline: 24193818]
29. Douglas VC, Hessler CS, Dhaliwal G, Betjemann JP, Fukuda KA, Alameddine LR, et al. The AWOL tool: derivation and validation of a delirium prediction rule. J Hosp Med 2013 Sep;8(9):493-499. [doi: 10.1002/jhm.2062] [Medline: 23922253]
30. APeX-enabled research program. UCSF Technology Services. URL: https://tech.ucsf.edu/apex-enabled-research-program [accessed 2024-04-29]
31. Home page. SurveyMonkey Inc. URL: https://www.surveymonkey.com/ [accessed 2024-04-29]
32. Krippendorff K. Content Analysis: An Introduction to Its Methodology. Thousand Oaks, CA: Sage Publications; 2018.
33. Schreier M. Qualitative Content Analysis in Practice. Thousand Oaks, CA: Sage Publications; 2012.
34. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. Health Serv Res 2007 Aug;42(4):1758-1772 [FREE Full text] [doi: 10.1111/j.1475-6773.2006.00684.x] [Medline: 17286625]
35. Dedoose version 9.0.17, web application for managing, analyzing, and presenting qualitative and mixed method research data. Dedoose. URL: https://www.dedoose.com/ [accessed 2024-04-29]

36. Cohen-Mansfield J. Nonpharmacologic treatment of behavioral disorders in dementia. Curr Treat Options Neurol 2013 Dec;15(6):765-785. [doi: 10.1007/s11940-013-0257-2] [Medline: 24136714]
37. Cohen-Mansfield J, Dakheel-Ali M, Marx MS, Thein K, Regier NG. Which unmet needs contribute to behavior problems in persons with advanced dementia? Psychiatry Res 2015 Jul 30;228(1):59-64 [FREE Full text] [doi: 10.1016/j.psychres.2015.03.043] [Medline: 25933478]
38. Cacchione PZ. Age-friendly health systems: the 4Ms framework. Clin Nurs Res 2020 Mar;29(3):139-140. [doi: 10.1177/1054773820906667] [Medline: 32036695]
39. Doran C, Noonan M, Doody O. Life-story work in long-term care facilities for older people: an integrative review. J Clin Nurs 2019 Apr;28(7-8):1070-1084. [doi: 10.1111/jocn.14718] [Medline: 30431682]
40. McKeown J, Clarke A, Ingleton C, Ryan T, Repper J. The use of life story work with people with dementia to enhance person-centred care. Int J Older People Nurs 2010 Jun;5(2):148-158. [doi: 10.1111/j.1748-3743.2010.00219.x] [Medline: 20925716]
41. Qu J, Goldman LN, Wilkinson JE. Effect of patients' life stories in bringing meaning to nursing home care. PRiMER 2019;3:11. [doi: 10.22454/PRiMER.2019.181832] [Medline: 32537582]
42. Gridley K, Brooks JC, Birks YF, Baxter CR, Parker GM. Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care. Health Serv Delv Res 2016;4(23):1-298 [FREE Full text] [Medline: 27559566]
43. Nathan S, Fiore LL, Saunders S, Vilbrun-Bruno Pa- CO, Hinrichs KL, Ruopp MD, et al. My life, my story: teaching patient centered care competencies for older adults through life story work. Gerontol Geriatr Educ 2022 Sep 09;43(2):225-238. [doi: 10.1080/02701960.2019.1665038] [Medline: 31498034]
44. Parker G, Gridley K, Birks Y, Glanville J. Using a systematic review to uncover theory and outcomes for a complex intervention in health and social care: a worked example using life story work for people with dementia. J Health Serv Res Policy 2020 Oct;25(4):265-277. [doi: 10.1177/1355819619897091] [Medline: 32237911]

Abbreviations

ACE: Acute Care for Elders
ACP: Advance Care Planning
AER: Apex Enabled Research
EHR: electronic health record
IDT: interdisciplinary care team
SNF: skilled nursing facility
UCSF: University of California San Francisco

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Association Between Sleep Efficiency Variability and Cognition Among Older Adults: Cross-Sectional Accelerometer Study

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Abstract

Background: Sleep efficiency is often used as a measure of sleep quality. Getting sufficiently high-quality sleep has been associated with better cognitive function among older adults; however, the relationship between day-to-day sleep quality variability and cognition has not been well-established.

Objective: We aimed to determine the relationship between day-to-day sleep efficiency variability and cognitive function among older adults, using accelerometer data and 3 cognitive tests.

Methods: We included older adults aged >65 years with at least 5 days of accelerometer wear time from the National Health and Nutrition Examination Survey (NHANES) who completed the Digit Symbol Substitution Test (DSST), the Consortium to Establish a Registry for Alzheimer's Disease Word-Learning subtest (CERAD-WL), and the Animal Fluency Test (AFT). Sleep efficiency was derived using a data-driven machine learning algorithm. We examined associations between sleep efficiency variability and scores on each cognitive test adjusted for age, sex, education, household income, marital status, depressive symptoms, diabetes, smoking habits, alcohol consumption, arthritis, heart disease, prior heart attack, prior stroke, activities of daily living, and instrumental activities of daily living. Associations between average sleep efficiency and each cognitive test score were further examined for comparison purposes.

Results: A total of 1074 older adults from the NHANES were included in this study. Older adults with low average sleep efficiency exhibited higher levels of sleep efficiency variability (Pearson *r*=−0.63). After adjusting for confounding factors, greater average sleep efficiency was associated with higher scores on the DSST (per 10% increase, β=2.25, 95% CI 0.61 to 3.90) and AFT (per 10% increase, β=.91, 95% CI 0.27 to 1.56). Greater sleep efficiency variability was univariably associated with worse cognitive function based on the DSST (per 10% increase, β=−3.34, 95% CI −5.33 to −1.34), CERAD-WL (per 10% increase, β=−1.00, 95% CI −1.79 to −0.21), and AFT (per 10% increase, β=−1.02, 95% CI −1.68 to −0.36). In fully adjusted models, greater sleep efficiency variability remained associated with lower DSST (per 10% increase, β=−2.01, 95% CI −3.62 to −0.40) and AFT (per 10% increase, β=−.84, 95% CI −1.47 to −0.21) scores but not CERAD-WL (per 10% increase, β=−.65, 95% CI −1.39 to 0.08) scores.

Conclusions: Targeting consistency in sleep quality may be useful for interventions seeking to preserve cognitive function among older adults.

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KEYWORDS

aging; cognition; accelerometer; sleep; sleep efficiency; geriatrics; gerontology; actigraphy; digital health; mhealth; cognitive impairments; mobile health; efficiency; variability; older adult; older adults; elder; elderly; older person; sleep quality; machine learning; quality of sleep; sleep

Introduction

Healthy sleep habits protect memory and cognitive function [1,2]. Sleep quality deteriorates with age, but older adults with cognitive impairments have worse sleep quality than their counterparts without impairments [3-5]. Lower sleep efficiency, a proxy for sleep quality, is associated with worse cognition among older adults [6]. The importance of getting sufficiently high-quality sleep to reduce individual risk of cognitive impairments has been reported [3,7]; however, the relationship between consistent sleep quality and cognition remains understudied. Because it is unreasonable to assume that older adults strictly adhere to a consistent sleep schedule on a nightly basis, the relationship between day-to-day sleep efficiency variability and cognition must be examined.

This cross-sectional accelerometer study aimed to quantify associations between sleep efficiency variability and performance on 3 cognitive tests assessing memory, categorical verbal fluency, and sustained attention while adjusting for demographic factors, chronic diseases, smoking habits, alcohol consumption, cardiovascular risk factors, depressive symptoms, and measures of activities of daily living (ADL) and instrumental activities of daily living (IADL). We additionally fit models using average sleep efficiency metrics to compare any observed relationships between sleep efficiency variability and cognition to those between average sleep efficiency and cognition.

Methods

Data Source and Study Design

Data from the US National Health and Nutrition Examination Survey (NHANES) 2011-2014 waves [8] were used, during which a subset of participants wore an ActiGraph GT3X+ device that objectively measured activity levels over 7 consecutive days immediately after all nonaccelerometer data were collected. Participants aged >60 years were also administered cognitive tests during the 2011-2014 waves. We excluded participants aged <65 years, without complete cognitive test data, or without at least 5 days of accelerometer wear time.

Ethical Considerations

All NHANES participants provided informed consent, and ethics approval was granted by the National Center for Health Statistics Research Ethics Review Board (protocol #2011-17).

Measuring Cognition

The NHANES 2011-2014 waves include 3 cognitive tests: the Digit Symbol Substitution Test (DSST), the Consortium to Establish a Registry for Alzheimer’s Disease Word-Learning subtest (CERAD-WL), and the Animal Fluency Test (AFT; Table 1) [9]. For the AFT, CERAD-WL, and DSST, higher scores correspond to better cognition.

Table . The 3 cognitive tests included in the 2011-2014 waves of the US National Health and Nutrition Examination Survey.

Cognitive test	Description
DSST[a]	Tests processing speed, sustained attention, and working memory. Scores range from 0 to 133 where 1 point is awarded for each symbol correctly written below its corresponding number based on a key mapping the symbols to the numbers.
CERAD-WL[b]	Measures immediate and delayed word recall. Three rounds of immediate recall and 1 round of delayed recall using lists of 10 unrelated words comprise the CERAD-WL. Scores on the CERAD-WL correspond to the number of correctly recalled words across all 3 rounds.
AFT[c]	Measures verbal categorical fluency and requires participants to name as many animals as possible in a 1-minute period.

[a] DSST: Digit Symbol Substitution Test.

[b] CERAD-WL: Consortium to Establish a Registry for Alzheimer’s Disease Word-Learning subtest.

[c] AFT: Animal Fluency Test.

Deriving Sleep Metrics

Sleep efficiency—a proxy for sleep quality—is the ratio of time asleep to the total time between sleep onset and final sleep offset; possible values range 0-1 with higher values corresponding to better-quality sleep. Nightly sleep efficiency values were derived using an unsupervised hidden Markov model that identifies sleep-wake states using a data-driven machine learning approach [10]. The hidden Markov model algorithm has been validated against gold-standard polysomnography with 85.7% accuracy, 99.3% sensitivity, and better performance than commonly used supervised algorithms [10]. Sleep efficiency variability was defined as the SD of sleep efficiency across all nights of valid accelerometer data. For comparison purposes, we further derived each participant’s average sleep efficiency.

Additional Covariates

To account for potential confounders, we gathered each participant’s age, sex, education, marital status, household income, smoking habits, current alcohol consumption, depressive symptoms, measures of functional independence, history of heart attack, history of stroke, and diagnoses of arthritis, heart disease, and diabetes. Depressive symptoms were quantified using Patient Health Questionnaire-9 scores [11]. A functional independence score was derived by summing responses to 20 ADL and IADL questions. Participants were categorized as current, former, or never smokers and drinkers. An explicit explanation of how each covariate was defined can be found in Multimedia Appendix 1. Participants with missing data were excluded to enable a complete-case analysis.

Statistical Analysis

Participant characteristics were reported using the means and SDs for numeric variables and counts and percentages for categorical variables. We first examined the relationship between mean and day-to-day sleep efficiency variability using the Pearson r correlation coefficient and a scatterplot. Thereafter, using cutoffs from previous studies [12], we plotted the distribution of sleep efficiency variability stratified by normal versus low (≥0.85 vs <0.85) sleep efficiency.

We first examined univariable associations between sleep efficiency variability and DSST, CERAD-WL, and AFT scores. Demographic models were adjusted for age, sex, education, marital status, and household income. Finally, the full models in this study were further adjusted for depressive symptoms, ADL and IADL scores, smoking habits, alcohol consumption, diabetes, arthritis, heart disease, history of stroke, and history of heart attack. All univariable, demographic, and full models were refit using average sleep efficiency instead of day-to-day variability for comparison purposes. A sensitivity analysis was then conducted where we excluded extreme outliers (observations ≤1st or ≥99th quantile) for both average sleep efficiency and day-to-day variability. Models with both average and sleep efficiency variability were also examined (Multimedia Appendix 2).

Results

Descriptive Statistics

In total, 1074 NHANES participants were included (mean age 72.3, SD 5.2 years; females: n=528, 49%), among whom 97.8% (n=1051) had ≥7 nights of sleep data (Table 2 and Table S1 and Figure S1 in Multimedia Appendix 1). The average sleep efficiency in the cohort was 0.94 (SD 0.05), while the average DSST, CERAD-WL, and AFT scores were 46.7 (SD 16.0), 25.0 (SD 6.29), and 16.8 (SD 5.25), respectively. The correlation between mean and day-to-day sleep efficiency variability was −0.63 (Figure 1). We found that older adults with low average sleep efficiency had higher levels of sleep efficiency variability than those with normal sleep efficiency levels (Figure 2).

Table . Demographic, sleep, and cognitive characteristics of older adults (N=1074) with valid accelerometer and cognitive test data who were part of the National Health and Nutrition Examination Survey.

Characteristic		Participants
Number of nights of sleep data, mean (SD)		7.8 (0.47)
Age (years), mean (SD)		72.3 (5.2)
Sex, n (%)		
	Male	546 (0.51)
	Female	528 (0.49)
Education, n (%)		
	Less than ninth grade	95 (0.09)
	Some high school	141 (0.13)
	High school graduate or GED[a]	245 (0.23)
	Some college or associate’s degree	307 (0.29)
	College graduate or above	286 (0.27)
Marital status, n (%)		
	Married	613 (0.57)
	Widowed	230 (0.21)
	Divorced	145 (0.14)
	Separated	19 (0.02)
	Never married	42 (0.04)
	Living with partner	25 (0.02)
Sleep efficiency variability, mean (SD)		0.04 (0.05)
Average sleep efficiency, mean (SD)		0.94 (0.05)
DSST[b] score, mean (SD)		46.7 (16.0)
CERAD-WL[c] score, mean (SD)		25.0 (6.29)
AFT[d] score, mean (SD)		16.8 (5.25)

[a] GED: General Educational Development.

[b] DSST: Digit Symbol Substitution Test.

[c] CERAD-WL: Consortium to Establish a Registry for Alzheimer’s Disease Word-Learning subtest.

[d] AFT: Animal Fluency Test.

Figure 1. Scatterplot with a fitted regression line of average versus day-to-day variability for sleep efficiency.

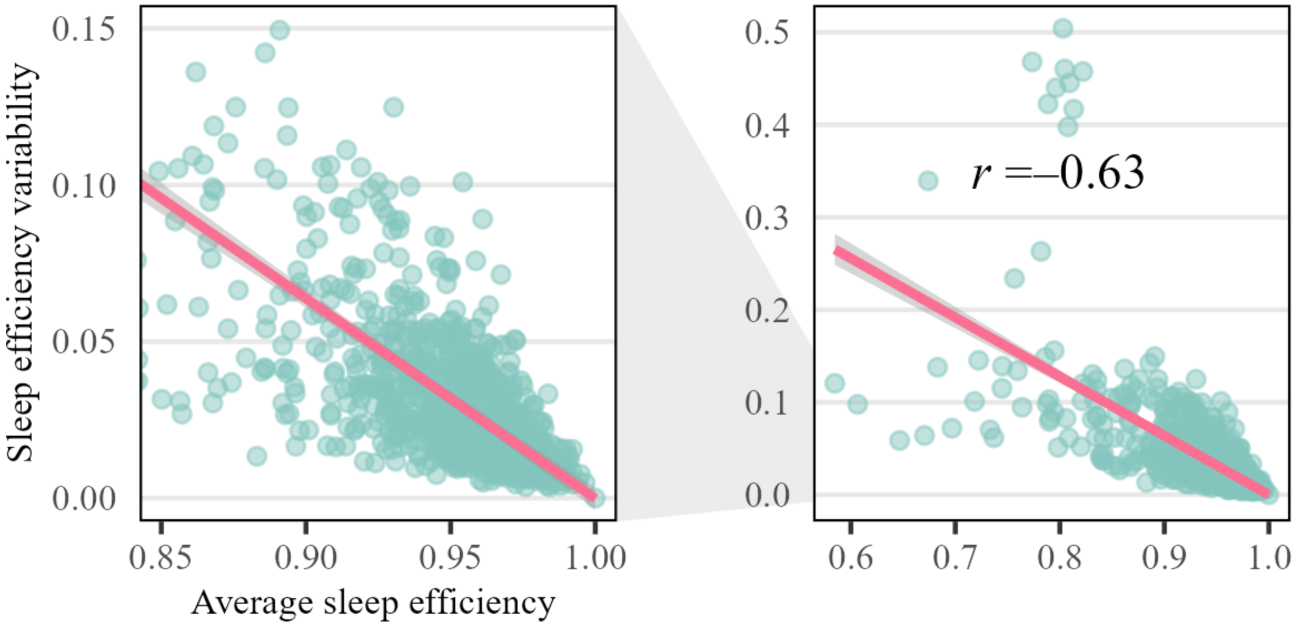
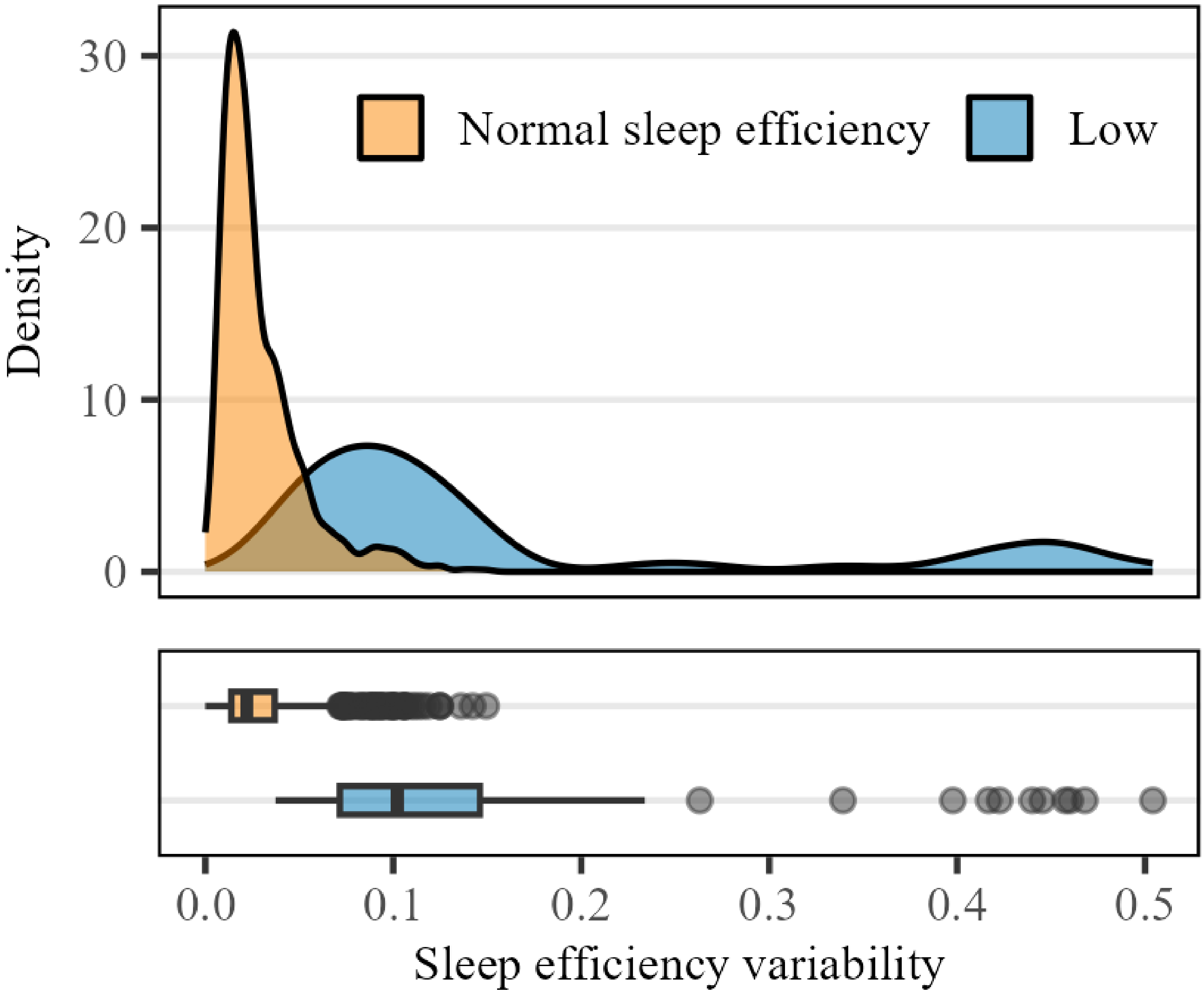


Figure 2. Distribution of day-to-day sleep efficiency variability stratified by average sleep efficiency.



Associations

In the univariable models, greater sleep efficiency variability was associated with lower scores on the DSST (per 10% increase, β=−3.34, 95% CI −5.33 to −1.34), CERAD-WL (per 10% increase, β=−1.00, 95% CI −1.79 to −0.21), and AFT (per 10% increase, β=−1.02, 95% CI −1.68 to −0.36). In the full models, greater sleep efficiency variability was associated with lower scores on the DSST (per 10% increase, β=−2.01, 95% CI −3.62 to −0.40) and AFT (per 10% increase, β=−.84, 95% CI −1.47 to −0.21) but not the CERAD-WL (per 10% increase, β=−.65, 95% CI −1.39 to 0.08; Tables 3-5). Conversely, greater average sleep efficiency was associated with higher scores on the DSST (per 10% increase, β=2.25, 95% CI 0.61-3.90) and AFT (per 10% increase, β=.91, 95% CI 0.27-1.56) but not the CERAD-WL (per 10% increase, β=.46, 95% CI −0.29 to 1.21) in the full models. In the sensitivity analysis, after excluding extreme averages and sleep efficiency variability outliers, all significant results observed in the full models remained significant (Multimedia Appendix 3).

Table . Associations between day-to-day variability and average sleep efficiency with Digit Symbol Substitution Test (DSST) scores.

Model covariates	Association with DSST scores	
	β (95% CI)[a]	*P* value
Sleep efficiency variability	−3.34 (−5.33 to −1.34)	.001
Mean sleep efficiency	4.28 (2.27 to 6.28)	<.001
Demographics + sleep efficiency variability	−2.04 (−3.69 to −0.39)	.02
Demographics + mean sleep efficiency	2.65 (0.97 to 4.32)	.002
Full model + sleep efficiency variability	−2.01 (−3.62 to −0.40)	.02
Full model + average sleep efficiency	2.25 (0.61 to 3.90)	.007

[a] Coefficients are reported per 10% increase.

Table . Associations of day-to-day variability and average sleep efficiency with Consortium to Establish a Registry for Alzheimer’s Disease Word-Learning subtest (CERAD-WL) scores.

Model covariates	Association with CERAD-WL scores	
	β (95% CI)[a]	*P* value
Sleep efficiency variability	−1.00 (−1.79 to –0.21)	.01
Mean sleep efficiency	0.85 (0.06 to 1.65)	.04
Demographics + sleep efficiency variability	−0.70 (−1.43 to 0.03)	.06
Demographics + mean sleep efficiency	0.52 (−0.23 to 1.26)	.18
Full model + sleep efficiency variability	−0.65 (−1.39 to 0.08)	.08
Full model + average sleep efficiency	0.46 (−0.29 to 1.21)	.23

[a] Coefficients are reported per 10% increase.

Table . Associations of day-to-day variability and average sleep efficiency with Animal Fluency Test (AFT) scores.

Model covariates	Association with AFT scores	
	β (95% CI)[a]	*P* value
Sleep efficiency variability	−1.02 (−1.68 to −0.36)	.002
Mean sleep efficiency	1.08 (0.42 to 1.74)	.001
Demographics + sleep efficiency variability	−0.85 (−1.48 to −0.22)	.009
Demographics + mean sleep efficiency	1.02 (0.38 to 1.66)	.002
Full model + sleep efficiency variability	−0.84 (−1.47 to −0.21)	.009
Full model + average sleep efficiency	0.91 (0.27 to 1.56)	.005

[a] Coefficients are reported per 10% increase.

Discussion

Principal Results and Comparisons With Prior Work

This study shows that older adults with higher sleep efficiency variability scored worse on the DSST and AFT after adjusting for demographic factors, chronic diseases, smoking habits, alcohol consumption, depressive symptoms, cardiovascular risk factors, and ADL and IADL scores. Effect sizes for average and sleep efficiency variability were similar in magnitude but in opposite directions, with greater variability being associated with lower DSST and AFT scores, while greater average sleep efficiency was associated with higher scores.

A previous accelerometer study found that greater sleep efficiency variability was associated with lower scores on serial subtraction tests and memory questionnaires [13]. However, the study was limited by a small sample (n<50) and did not consider relevant confounders such as chronic diseases, ADL and IADL, smoking habits, and alcohol consumption. Another study found that greater sleep efficiency variability was associated with a greater β-amyloid burden—a biomarker for Alzheimer disease—but was again limited by a small sample (n=52) [14]. Compared to existing studies, our work, using a larger cohort accounting for more confounders, provides evidence that greater sleep efficiency variability is associated with worse cognitive function among older adults. Furthermore, we found that effect sizes for sleep efficiency variability and average sleep efficiency were similar but in opposite directions, suggesting that getting sufficient and consistent high-quality sleep may be useful targets for interventions seeking to preserve cognitive function among older adults.

Limitations

Given the cross-sectional nature of this study, we could not examine causal relationships. Bidirectional associations exist between certain forms of cognitive impairment and sleep disturbances [15], but they could not be examined herein. Future studies with longitudinal designs are therefore needed to further examine whether high sleep efficiency variability causally influences cognitive function or vice versa. Future studies may also benefit from collecting accelerometer data over longer durations, which more reliably measures sleep parameters [16], and from analyzing data across different countries to assess the generalizability of the findings presented herein. Lastly, polysomnography, the gold standard for measuring sleep parameters, was not used in this study. However, the use of wrist-worn accelerometers helped us assess sleep under natural living conditions, which intrusive polysomnography does not permit.

Conclusions

Greater day-to-day sleep efficiency variability was associated with lower scores on 2 cognitive tests in this study. Our work may motivate future causal inference studies seeking to determine if consistency in sleep quality is a viable target for preserving cognitive function among older adults.

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Authors' Contributions

CS, XL, and JL designed the study. CS and TL performed the statistical analyses with supervision from XL and JL. The manuscript was primarily written by CS with oversight from XL, CY, and JL.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Participant flowchart, cohort chartacteristics, covariate definitions.
[DOCX File, 106 KB - aging_v7i1e54353_app1.docx]

Multimedia Appendix 2
Additional models including both average and sleep efficiency variability
[DOCX File, 26 KB - aging_v7i1e54353_app2.docx]

Multimedia Appendix 3
Sensitivity analysis.
[DOCX File, 26 KB - aging_v7i1e54353_app3.docx]

References

1. Scullin MK, Bliwise DL. Sleep, cognition, and normal aging: integrating a half century of multidisciplinary research. Perspect Psychol Sci 2015 Jan;10(1):97-137. [doi: 10.1177/1745691614556680] [Medline: 25620997]

2. Qin S, Leong RLF, Ong JL, Chee MWL. Associations between objectively measured sleep parameters and cognition in healthy older adults: a meta-analysis. Sleep Med Rev 2023 Feb;67:101734. [doi: 10.1016/j.smrv.2022.101734] [Medline: 36577339]
3. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 8;396(10248):413-446. [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
4. Unruh ML, Redline S, An MW, et al. Subjective and objective sleep quality and aging in the sleep heart health study. J Am Geriatr Soc 2008 Jul;56(7):1218-1227. [doi: 10.1111/j.1532-5415.2008.01755.x] [Medline: 18482295]
5. Casagrande M, Forte G, Favieri F, Corbo I. Sleep quality and aging: a systematic review on healthy older people, mild cognitive impairment and Alzheimer’s disease. Int J Environ Res Public Health 2022 Jul 11;19(14):8457. [doi: 10.3390/ijerph19148457] [Medline: 35886309]
6. D’Rozario AL, Chapman JL, Phillips CL, et al. Objective measurement of sleep in mild cognitive impairment: a systematic review and meta-analysis. Sleep Med Rev 2020 Aug;52:101308. [doi: 10.1016/j.smrv.2020.101308] [Medline: 32302775]
7. Mellow ML, Crozier AJ, Dumuid D, et al. How are combinations of physical activity, sedentary behaviour and sleep related to cognitive function in older adults? A systematic review. Exp Gerontol 2022 Mar;159:111698. [doi: 10.1016/j.exger.2022.111698] [Medline: 35026335]
8. Johnson CL, Dohrmann SM, Burt VL, Mohadjer LK. National health and nutrition examination survey: sample design, 2011-2014. Vital Health Stat 2 2014 Mar(162):1-33. [Medline: 25569458]
9. Brody DJ, Kramarow EA, Taylor CA, McGuire LC. Cognitive performance in adults aged 60 and over: National Health and Nutrition Examination Survey, 2011-2014. Natl Health Stat Report 2019 Sep(126):1-23. [Medline: 31751207]
10. Li X, Zhang Y, Jiang F, Zhao H. A novel machine learning unsupervised algorithm for sleep/wake identification using actigraphy. Chronobiol Int 2020 Jul;37(7):1002-1015. [doi: 10.1080/07420528.2020.1754848] [Medline: 32342702]
11. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001 Sep;16(9):606-613. [doi: 10.1046/j.1525-1497.2001.016009606.x] [Medline: 11556941]
12. Brindle RC, Yu L, Buysse DJ, Hall MH. Empirical derivation of cutoff values for the sleep health metric and its relationship to cardiometabolic morbidity: results from the Midlife in the United States (MIDUS) study. Sleep 2019 Sep 6;42(9):zsz116. [doi: 10.1093/sleep/zsz116] [Medline: 31083710]
13. Balouch S, Dijk DAD, Rusted J, Skene SS, Tabet N, Dijk DJ. Night-to-night variation in sleep associates with day-to-day variation in vigilance, cognition, memory, and behavioral problems in Alzheimer’s disease. Alzheimers Dement (Amst) 2022;14(1):e12303. [doi: 10.1002/dad2.12303] [Medline: 35603140]
14. Fenton L, Isenberg AL, Aslanyan V, et al. Variability in objective sleep is associated with Alzheimer’s pathology and cognition. Brain Commun 2023;5(2):fcad031. [doi: 10.1093/braincomms/fcad031] [Medline: 36895954]
15. Ju YE, Lucey BP, Holtzman DM. Sleep and Alzheimer disease pathology--a bidirectional relationship. Nat Rev Neurol 2014 Feb;10(2):115-119. [doi: 10.1038/nrneurol.2013.269] [Medline: 24366271]
16. Lau T, Ong JL, Ng BKL, et al. Minimum number of nights for reliable estimation of habitual sleep using a consumer sleep tracker. Sleep Adv 2022;3(1):zpac026. [doi: 10.1093/sleepadvances/zpac026] [Medline: 37193398]

Abbreviations

ADL: activities of daily living
AFT: Animal Fluency Test
CERAD-WL: Consortium to Establish a Registry for Alzheimer’s Disease Word-Learning subtest
DSST: Digit Symbol Substitution Test
IADL: instrumental activities of daily living
NHANES: National Health and Nutrition Examination Survey

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Original Paper

Brief Video-Delivered Intervention to Reduce Anxiety and Improve Functioning in Older Veterans: Pilot Randomized Controlled Trial

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Abstract

Background: Older veterans with anxiety disorders encounter multiple barriers to receiving mental health services, including transportation difficulties, physical limitations, and limited access to providers trained to work with older persons. To address both accessibility and the shortage of available providers, evidence-based treatments that can be delivered via guided self-management modalities are a potential solution.

Objective: This study aims to determine the feasibility and acceptability of a randomized controlled trial of 2 guided self-management interventions. This study compared the treatment effects of these 2 interventions (relaxation and health psychoeducation) on anxiety symptom severity and functioning in older veterans with anxiety disorders. Our exploratory aims examined factors related to home practices and treatment engagement and perceptions of the practices.

Methods: Participants were randomized to one of two video-delivered interventions: (1) Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment (BREATHE)—breathing and progressive relaxation or (2) Healthy Living for Reduced Anxiety—psychoeducation about lifestyle changes. Telephone coaching calls were conducted weekly. Measures of anxiety, depression, and functioning were obtained at baseline, week 4 (end of treatment), week 8, and week 12. Participants completed a semistructured interview at week 12. Analyses included descriptive statistics to summarize measures of intervention engagement; mixed-effects models to characterize symptom change, and qualitative analyses.

Results: Overall, 56 participants (n=48, 86% men; n=23, 41% from ethnic or racial minority groups; mean age 71.36, SD 6.19 y) were randomized. No difference in retention between study arms was found. The Healthy Living group (29/56, 52%) completed significantly more lessons (mean 3.68, SD 0.86) than the BREATHE group (27/56, 48%; mean 2.85, SD 1.43; t_{53}=2.60; P=.01) but did not differ in completion of coaching calls. In the BREATHE group, greater baseline anxiety scores (r=–0.41; P=.03) and greater severity of medical comorbidity (r=–0.50; P=.009) were associated with fewer completed practices. There was no effect of intervention on change in total anxiety scores or functioning. For specific anxiety subtypes, Healthy Living produced a greater decline in somatic anxiety compared with BREATHE. Qualitative analyses found barriers to practicing, including difficulty setting time aside to practice, forgetting, or having other activities that interfered with BREATHE practices. Some participants described adapting their practice routine to fit their daily lives; some also used relaxation skills in everyday situations.

Conclusions: These findings suggest that a larger randomized controlled trial of guided self-management approaches to treating late-life anxiety is feasible; however, BREATHE was not effective in reducing anxiety compared with Healthy Living. Possible contributing factors may have been the reliance on a single technique. Progressive relaxation was reported to be enjoyable for most participants, but maintaining home practices was challenging. Those with milder anxiety severity and fewer health problems were better able to adhere to practices.

Trial Registration: ClinicalTrials.gov NCT02400723; https://clinicaltrials.gov/study/NCT02400723

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KEYWORDS

guided self-management; internet; progressive relaxation; technology; anxiety; telehealth; veterans; older adults

Introduction

Background

Anxiety disorders are pervasive among older adults and especially common in older military veterans. These disorders include generalized anxiety disorder (GAD), social anxiety disorder, panic disorder, agoraphobia, and unspecified anxiety disorders [1]. A meta-analytic review estimated that nearly 1 in 10 (9.1%) older military veterans met the criteria for one of these anxiety disorders [2]. Not only do late-life anxiety symptoms and disorders contribute to detrimental outcomes such as functional and cognitive decline [3-5], but the presence of an anxiety disorder (ie, GAD) is a risk factor for suicide ideation among older non–combat-exposed veterans [6,7]. Thus, access to mental health services for anxiety in older veterans is critical.

Numerous barriers impede older veterans with anxiety from receiving mental health services. These barriers include mental health stigma and beliefs, lack of knowledge about available mental health services, mobility limitations, transportation challenges, and residing in rural areas [8]. Another barrier is the impact of anxiety diagnoses on referral for treatment. Older veterans with anxiety are more likely to receive nonspecific anxiety disorder diagnoses and less likely to receive mental health services compared with younger veterans who receive specific anxiety diagnoses and more subsequent mental health services [9]. Thus, accessible and brief nonpharmacological interventions for late-life anxiety are needed to address the barriers to accessing mental health care faced by older veterans with anxiety disorders. Furthermore, conclusions from a recent systematic review and meta-analysis suggest that these brief interventions may show promise for reducing anxiety symptoms in older adults [10]. One such brief behavioral intervention, progressive relaxation [11], also known as progressive muscle relaxation (PMR), has been shown to be an efficacious behavioral intervention for the treatment of late-life anxiety [12]. PMR is often included as a component within cognitive behavioral therapy (CBT) for anxiety treatments, as well as being a component of digital mental health interventions such as self-management mobile apps. We focused on this skill and developed a 4-week video-delivered intervention that teaches PMR and diaphragmatic breathing and encourages the application of these skills to help patients engage in activities in which anxiety or other types of stress may arise. Activity engagement was selected as a treatment target as discomfort and distress from anxiety symptoms prompt individuals to use coping strategies such as escape from and avoidance of anxiety-evoking situations in the short term [13]. This process (ie, negative reinforcement) makes it more likely for avoidance to be relied upon in the long term and is particularly detrimental to older patients because reduced engagement in activities often leads to isolation and functional decline [7].

This intervention—Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment (BREATHE)—is organized with weekly video lessons, daily practice videos, and telephone coaching to encourage adherence to the practices. It was initially tested in a proof-of-concept study comparing the 4-week BREATHE intervention to a waitlist control in older adults with anxiety disorders [14]. The BREATHE intervention was found to be superior to the waitlist control in reducing anxiety, depressive, and somatic symptoms; however, the attrition in BREATHE (35%) warranted further investigation. To address these attrition issues, we sought feedback on BREATHE from older veterans and made iterative revisions to the intervention in a second study [15]. The revised BREATHE intervention was then tested in a small feasibility study with 10 older veterans with anxiety disorders [16] in which BREATHE was found to be feasible and acceptable in that 90% (n=9) completed the intervention and 100% felt that BREATHE somewhat or completely met their expectations. While BREATHE is a guided self-management approach to anxiety, it differs from other similar approaches that either rely on manuals and bibliotherapy or are entirely internet delivered (see the study by Cremers et al [17] for a review). BREATHE falls between these 2 approaches, uses familiar technology (web-based videos or DVDs), and focuses on a single skill (PMR) rather than multiple skills (eg, CBT).

Objectives

In this study, we conducted a pilot randomized controlled trial (RCT) comparing 2 guided self-management interventions in older veterans with anxiety disorders. This study was conducted in part to determine the feasibility of conducting an RCT by documenting willingness to be randomized, engagement with the interventions assigned, and dropout. We also examined the preliminary efficacy of BREATHE compared with a psychoeducation intervention (Healthy Living for Reduced Anxiety) on anxiety symptoms and functioning in older veterans. We hypothesized that (1) BREATHE would result in greater reduction in anxiety symptoms compared with psychoeducation at 12 weeks and (2) BREATHE would result in significantly greater improvements in functioning compared with psychoeducation at 12 weeks. Our exploratory aims were to examine whether home practices and treatment engagement were related to patient characteristics or to intervention outcomes and examine participants’ perceptions of the home practices via qualitative interviews.

Methods

A 2-group pilot RCT (ClinicalTrials.gov NCT02400723) was conducted over the course of 12 weeks. The interventions lasted 4 weeks, with data collected at baseline, week 4 (end of treatment), week 8 (4 weeks after treatment), and 12 weeks (8 weeks after treatment).

Ethical Considerations

This study was reviewed and approved by the Stanford University Institutional Review Board (IRB-32454), the institutional review board of record for the US Department of Veterans Affairs (VA) Palo Alto Health Care System. Informed consent was obtained at the baseline visit. Participants were paid US $60 for the initial assessment and the 12 week assessment. Participants were paid US $10 for completing the telephone assessments at weeks 4 and 8. Data were deidentified prior to data entry and analysis.

Recruitment

Participants were recruited from a large VA health care system via posted flyers and brochures. Informational letters were also sent to patients who had at least one encounter during the past year that was related to a diagnosis of anxiety. Recruitment took place from February 2019 to March 2020 (before the COVID-19 pandemic) and from July 2020 to November 2020 (after the COVID-19 pandemic). Participants were eligible if they were aged ≥60 years and proficient in English and exhibited a diagnosis of an anxiety disorder (ie, GAD, panic disorder, agoraphobia, social anxiety disorder, or unspecified anxiety disorder). Participants were excluded if they were currently enrolled in other intervention research studies or were currently involved in individual therapy or group therapy more frequently than once per month. Those with possible cognitive impairment per a brief cognitive assessment or those who reported a diagnosis of bipolar disorder, psychotic disorder, schizophrenia, or other serious psychiatric disorders were excluded during the telephone screening process. If participants were taking psychotropic medications, they needed to be on a stable dose for 1 month before enrollment.

Measures

The following sections describe measures for inclusion and exclusion criteria assessment, outcome assessment, and measurement of covariates.

Assessment of Inclusion and Exclusion Criteria

The Short Blessed Test (SBT), derived from the Blessed Orientation-Memory-Concentration Test, was included as a brief cognitive assessment to ascertain possible cognitive impairment [18]. Participants obtaining scores of ≥6 on the SBT were excluded from the study [18,19]. The Structured Clinical Interview for the DSM-V (SCID-5 [20]), was administered to assess mental health diagnoses and exclude participants with serious psychiatric disorders, as mentioned previously. Those participants exhibiting an anxiety disorder were included if they met all other inclusion criteria.

Demographic Questionnaire

A questionnaire was administered at baseline to assess basic demographic, employment, and health information. Additional questions inquired about participants' previous experience with relaxation, breathing training, meditation, tai chi, and any other similar techniques.

Anxiety Measures

The Geriatric Anxiety Scale (GAS [21]) is a 30-item measure of anxiety that served as a primary outcome measure. The first 25 items measure the frequency of somatic, cognitive, and affective anxiety symptoms and are summed to obtain a total score. The last 5 items assess specific anxiety and fear content and are not included in the total score. Items are scored on a scale from 0 (*not at all*) to 3 (*all of the time*), with total scores ranging from 0 to 75; higher scores indicate greater anxiety. The GAS and its somatic, cognitive, and affective symptom subscales have good internal consistency and convergent validity compared with other anxiety measures [22]. The GAS was administered at baseline, week 4, week 8, and week 12.

The Hamilton Anxiety Rating Scale (HAM-A [23]) assesses the severity of anxiety using clinician ratings of 14 items on a 5-point scale and was included as a secondary outcome measure of anxiety. It has adequate internal consistency, high interrater reliability, and good to adequate concurrent validity [24,25]. The HAM-A was administered at baseline and week 12.

The Patient-Reported Outcomes Measurement Information System 7-item anxiety scale assesses the frequency of experiencing anxiety symptoms within the previous week [26]. Psychometric support for this measure has been found in adult populations [27,28] and in our previous work [16]. The Patient-Reported Outcomes Measurement Information System anxiety scale was administered at baseline and week 12.

The Anxiety Control Questionnaire (ACQ [29]) is a 30-item self-report measure assessing one's perceived ability to control anxiety-evoking situations and emotional reactions to these situations. Gerolimatos et al [30] found good internal consistency in older adults. The ACQ was administered at baseline and week 12.

Functioning

The Activity Card Sort (ACS) [31] was selected as a measure of activity engagement as it assesses the presence and the loss of activities using 80 photographs that depict instrumental, leisure, and social activities. We used an interactive sorting task to calculate lifestyle-adjusted function, which excludes activities that people have never performed in their lifetime [32]. The lifestyle-adjusted function is the number of easy activities divided by the sum of easy activities, hard activities, and no-longer-performed activities. Thus, the lifestyle-adjusted function score accurately reflects loss, gain, or changes in activity participation. This measure was obtained at baseline and week 12. Due to this being an in-person task, the lifestyle-adjusted function scores were only obtained from participants who completed the study before the COVID-19 pandemic.

We also used an individualized scoring of the ACS [33]. In this approach, we asked participants to select 5 activities that they would like to do more frequently if not experiencing anxiety. We ascertained participants' goals for the number of times they would like to do the activity, and we obtained the frequency of performing the activity at baseline, week 4, week 8, and week 12.

The Veterans RAND 12-item Health Survey (VR-12) [34] examines health-related quality of life and generates 2 scores: a physical component summary and a mental component summary (MCS). The MCS was used as a functioning outcome measure. The VR-12 was administered at baseline, week 4, week 8, and week 12.

Additional Measures

The 9-item Patient Health Questionnaire (PHQ-9 [35]) was used to assess participants' depression symptoms. The questionnaire asks about symptoms during the previous 2 weeks, and each item is scored from 0 (*not at all*) to 3 (*nearly every day*), with total scores ranging from 0 to 27. This measure was administered at baseline and week 12.

The Cumulative Illness Rating Scale–Geriatric [36] measures medical illness burden. Retrospective chart review was used to obtain the ratings and drew on recorded history, physical examination, and laboratory tests, consistent with previous work [37,38].

A semistructured interview and brief survey about the BREATHE or Healthy Living intervention was administered to participants at week 12. The survey included a question in which participants ranked the intervention components (video lessons, practices, and coaching calls) from most helpful to least helpful. The semistructured interview encompassed 7 questions about different domains, including changes made in one's life as a result of the intervention, effects on one's well-being, changes in activities and function, when improvement was first noticed, sustainability of the practices, recommended changes to the intervention, and whether the intervention would be recommended to other patients. Herein, we focus on questions related to the home practices in the BREATHE participants.

Procedures

Telephone Screening and Baseline Assessment

Participants completed a brief telephone screen to assess for potential cognitive impairment using the SBT, concurrent psychotherapy, presence of serious mental illness, or recent changes to psychotropic medications (if taking any). Eligible participants based on the telephone screen were invited to a baseline assessment that included obtaining informed consent. Baseline assessments were conducted in person up to February 2020 and via telephone after the onset of the COVID-19 pandemic. During the baseline assessment, a structured psychiatric interview was conducted to ascertain the presence of a current anxiety disorder (ie, GAD, panic disorder, agoraphobia, social anxiety disorder, or unspecified anxiety disorder). Participants who did not meet the criteria for an anxiety disorder or individuals who had a potential psychotic disorder or bipolar disorder were excluded at baseline. The remainder of the assessment consisted of completing the clinical interviews (SCID-5 and HAM-A), ACS, and questionnaires (demographics and health questionnaire, GAS, PHQ-9, ACQ, and VR-12).

Randomization

Eligible participants were randomized to BREATHE or psychoeducation in a blocked randomization scheme with blocks of varying sizes (2 to 8), as recommended by the statistician who created the randomization scheme. Each assignment was concealed in an envelope that a research team member opened in sequential order at the time of randomization.

Interventions

BREATHE Intervention

In the BREATHE intervention, participants watched 1 lesson video each week and then were instructed to practice relaxation 1 to 2 times a day. Participants were able to select whether they viewed the videos from a DVD or from a website. Participants also received weekly calls from their BREATHE coaches during which adherence was ascertained (ie, the lesson video viewed and practices completed). Anxiety ratings for each practice were reviewed, questions were addressed, and encouragement for practice adherence was provided. During weeks 2 to 4, patients were instructed to apply the skills during everyday life. In total, 2 team members (CG and LA) with a master's to PhD level of training in psychology served as coaches for both the BREATHE and Healthy Living interventions. Coaches used a coaching manual (available upon request) for each intervention and questions tailored to each week's content to guide the coaching calls. Both BREATHE and Healthy Living coaches addressed any participant challenges with using the DVD or website. Table 1 provides an overview of the intervention components, including the mean duration of the completed coaching calls.

Table 1. Summary of intervention components.

Week	BREATHE[a] components	Healthy Living components
1	• Video lesson: "What is anxiety? Diaphragmatic breathing & progressive relaxation" (37 min 35 s) • Video-guided daily practice: 16-muscle group relaxation (20 min 50 s) • Coaching call: mean 10 min, SD 4 min 42 s	• Video lesson: "What is anxiety?" (18 min 45 s) • Readings: "Coping with Stress and Aging" and "Stress: Causes and Effects" • Coaching call: mean 7 min, SD 3 min 29 s
2	• Video lesson: review 16-muscle group relaxation • Video-guided daily practice: 16-muscle group relaxation (20 min 50 s) • Skill application: use breathing in daily life • Coaching call: mean 11 min, SD 4 min 50 s	• Video lesson: "Coping with Stress and Aging" (19 min 27 s) • Readings: "Sleep Tips" and "Age Page: A Good Night's Sleep" • Coaching call: mean 10 min, SD 5 min 24 s
3	• Video lesson: brief relaxation (7-muscle group; 19 min 31 s) • Video-guided daily practice: 7-muscle group relaxation (11 min 32 s) • Skill application: use progressive relaxation in daily life • Coaching call: mean 12 min, SD 4 min 42 s	• Video lesson: "Taking care of your body through physical activity" (31 min 20 s) • Readings: "Age Page: Exercise and Physical Activity" and "Getting Fit for Life" • Coaching call: mean 7 min, SD 4 min 49 s
4	• Video lesson: review brief relaxation • Video-guided daily practice: 7-muscle group relaxation (11 min 32 s) • Skill application: use progressive relaxation in daily life • Coaching call: mean 14 min, 7 min 42 sec	• Video lesson: "Taking Care of Your Body Through Healthy Eating" (19 min 30 s) • Readings: "Healthy Eating & Physical Activity Across Your Lifespan" and "What's on your plate?" (optional) • Coaching call: mean 8 min, SD 3 min, 46 s

[a] BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment.

Psychoeducation (Healthy Living for Reduced Anxiety)

In the psychoeducation intervention (ie, active control), participants viewed 30-minute video lessons once a week for 4 weeks. The videos provided information about what anxiety is, coping with anxiety and sleep tips, benefits of exercise and a gentle stretching routine, and healthy eating. A Healthy Living coach (see the aforementioned description) called participants each week to ascertain adherence (ie, the lesson video viewed) and answer specific questions about the materials. Practice assignments consisted only of brief supplemental readings (Table 1).

Assessments at Weeks 4, 8, and 12

At weeks 4 and 8, a total of 4 questionnaires were completed with participants via phone: the GAS, PHQ-9, VR-12, and activity goal frequency (ACS). At week 12 (8 weeks after completion of the 4-week intervention), participants returned for a posttreatment assessment. The posttreatment assessment included the GAS, PHQ-9, HAM-A, ACS, VR-12, and ACQ. A feedback survey for the BREATHE and Healthy Living conditions was completed followed by a semistructured interview. The survey asked participants to rank the helpfulness of each part of the program: video lessons, practices for BREATHE or readings for Healthy Living, and coaching calls. Then, the survey had 5 statements with which participants rated their agreement on a Likert-type scale ranging from *strongly disagree* (1) to *strongly agree* (5). The items asked about the usability of the DVDs, website log-in, and watching of web-based videos and about the frequency of coaching calls and duration of the program. The semistructured interview was recorded with participants' permission, and the recordings or notes (if not recorded) were then transcribed. During the COVID-19 pandemic, the posttreatment assessment was completed by telephone. Assessors were not blinded to participant condition.

Power

An a priori sample power analysis was calculated with an α of .05 and power of 0.80. On the basis of previous research, the controlled effect size (Hedges *g*) for relaxation therapy's effect on anxiety was 0.90 (95% CI 0.44-1.44) [12]. The total estimated sample size was 30 (15 per group; Cohen *f*=0.41). Because of expected attrition and use of self-directed treatment, we estimated a smaller effect of the primary measure of anxiety and, thus, aimed for a sample of at least 26 participants per group (*f*=0.35).

Statistical Analysis

Descriptive statistics were used to help characterize the sample; *t* tests (2-tailed) and chi-square analyses were used to test whether the 2 groups differed on any characteristics. Correlation analyses were conducted to examine whether baseline anxiety or medical comorbidity were associated with homework completion. Analyses were conducted using SPSS Statistics (version 29.0; IBM Corp) [39].

To examine the hypotheses regarding the primary outcomes of anxiety (GAS) and functioning (VR-12 MCS), mixed-effects models, also known as linear growth models or multilevel models [40], were used. Missing data points due to participant dropout were handled assuming that the data were missing at random and conditional on observed information. Mixed models were used to examine the change in outcomes across 4 time points (baseline [T1], 4 weeks and end of treatment [T2], 8 weeks [T3], and 12 weeks [T4]). Growth models with just time were estimated first followed by the fully specified models that included a between factor of treatment group (BREATHE vs psychoeducation); a within factor of time; and an interaction of treatment by time, which was the estimate of the treatment effect over the course of the study.

A total of 3 mixed-effects models with 2 time points (baseline [T1] and 12 weeks [T4]) were conducted on (1) anxiety as measured using the HAM-A, (2) perceived anxiety control as measured using the ACQ, and (3) lifestyle-adjusted functioning using the ACS. Sensitivity analyses were conducted to evaluate the change in anxiety symptoms (GAS) from baseline to 4 weeks.

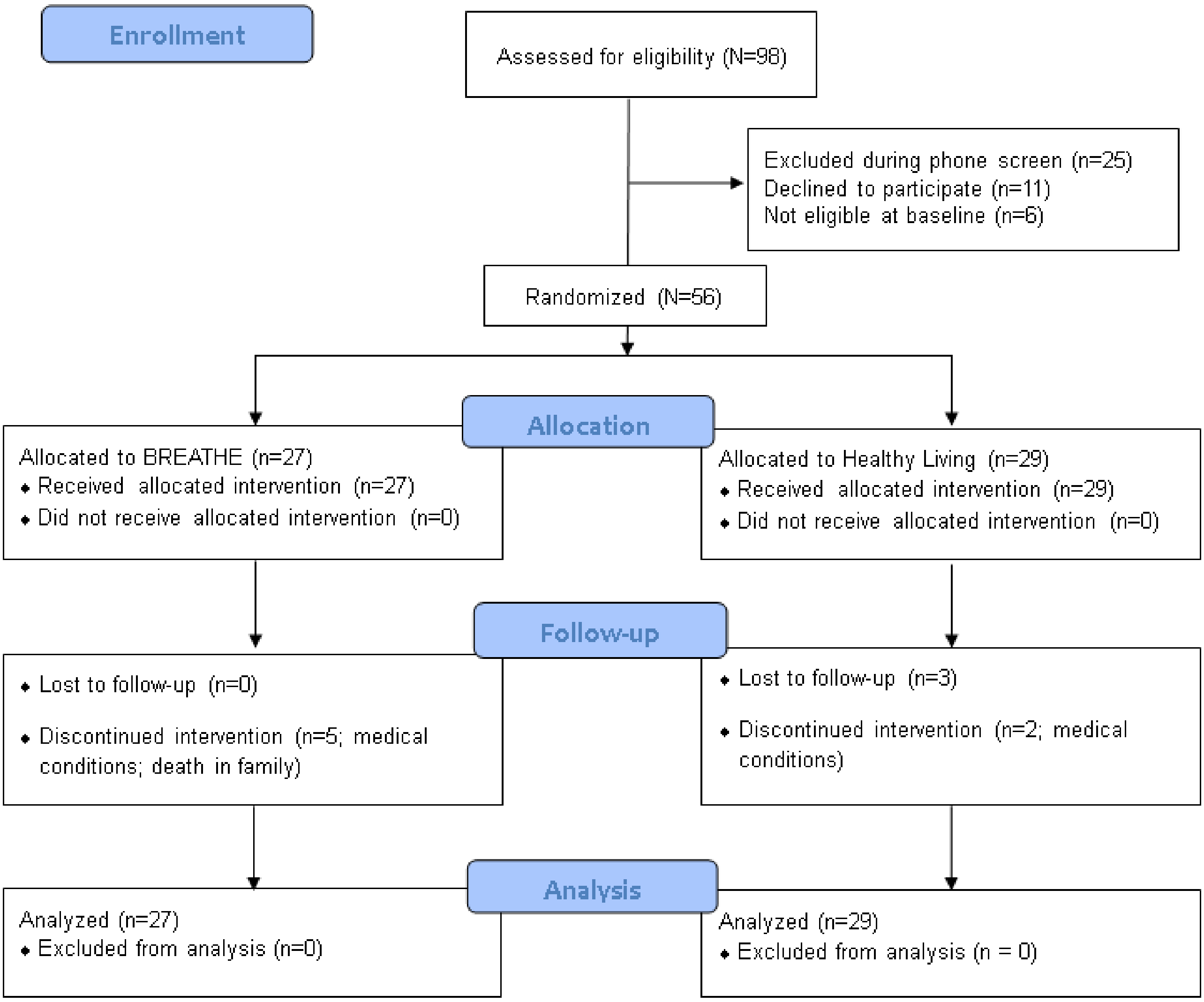
Rapid qualitative analysis [41,42] was used to investigate perceptions of the home practices among the participants assigned to the BREATHE intervention. Interview transcripts were summarized using templates, and then domain summaries were created by 2 authors trained in qualitative techniques (CG and CC). The summaries were reviewed for themes.

Results

Overview

Of the 98 participants assessed for eligibility, 56 (57%) were eligible and were all subsequently randomized. Figure 1 shows the participant flow throughout the study.

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) flow diagram. BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment.



Randomized participants had a mean age of 71.36 (SD 6.19) years and ranged in age from 60 to 88 years. Table 2 shows the characteristics of participants at baseline. Participants were diagnosed with a current anxiety disorder at baseline using the SCID-5. A total of 16% (9/56) of the participants had more than one concurrent anxiety disorder, 29% (16/56) had co-occurring depression, and 14% (8/56) had subthreshold posttraumatic stress disorder (PTSD; other specified trauma disorder). The most frequently occurring disorders were other specified anxiety disorder (30/56, 54%), GAD (18/56, 32%), social anxiety disorder (11/56, 20%), agoraphobia (2/56, 4%), and panic disorder (2/56, 4%).

Table 2. Baseline characteristics of randomized participants (N=56)[a].

Characteristic	Total	BREATHE[b] (n=27)	Healthy Living (n=29)	Test of significance		
				t test (*df*)	Chi-square (*df*)	*P* value
Age (years), mean (SD)	71.4 (6.2)	72.8 (6.2)	70.0 (6.0)	–1.73 (54)	—[c]	.09
Education years, mean (SD)	15.6 (3.0)	15.8 (3.2)	15.5 (2.7)	–0.48 (53)	—	.63
CIRS-G[d] medical comorbidity, mean (SD)	13.2 (4.6)	13.8 (5.4)	12.6 (3.8)	–1.01 (53)	—	.32
Gender, n (%)				—	1.2 (2)	.56
Men	48 (86)	23 (85)	25 (86)			
Women	7 (12)	3 (11)	4 (14)			
Nonbinary	1 (2)	1 (4)	0 (0)			
Race and ethnicity, n (%)				—	4.1 (4)	.40
Asian	1 (2)	0 (0)	1 (3)			
Black	7 (12)	5 (19)	2 (7)			
Hispanic, any race	10 (18)	5 (19)	5 (17)			
White	33 (59)	16 (59)	17 (59)			
Other or multiracial	5 (9)	1 (4)	4 (14)			
Marital status, n (%)				—	8.0 (4)	.09
Single	7 (12)	6 (22)	1 (3)			
Married	24 (43)	10 (37)	14 (48)			
Separated or divorced	21 (38)	8 (30)	13 (45)			
Widowed	4 (7)	3 (11)	1 (3)			
Employment status, n (%)				—	1.8 (3)	.61
Working full time	6 (11)	2 (7)	4 (14)			
Working part time	5 (9)	2 (7)	3 (10)			
Unemployed	4 (7)	3 (11)	1 (3)			
Retired	41 (73)	20 (74)	21 (72)			
Health status, n (%)				—	2.7 (4)	.61
Excellent	5 (9)	3 (11)	2 (7)			
Very good	8 (14)	3 (11)	5 (17)			
Good	23 (41)	12 (44)	11 (38)			
Fair	18 (32)	9 (33)	9 (31)			
Poor	2 (4)	0 (0)	2 (7)			
Psychotropic medication, n (%)				—	0.0 (1)	.85
Yes	31 (55)	15 (56)	16 (55)			
No	24 (43)	11 (41)	13 (45)			
Missing	1 (2)	1 (4)	0 (0)			
Previous psychological counseling, n (%)				—	0.0 (1)	.83
Yes	43 (77)	20 (74)	23 (79)			
No	12 (21)	6 (22)	6 (21)			
Missing	1 (2)	1 (4)	0 (0)			
Previous complementary health experience, n (%)						
Meditation	10 (18)	7 (26)	3 (10)	—	2.3 (1)	.13
Yoga	5 (9)	2 (7)	3 (10)	—	0.2 (1)	.70

Characteristic	Total	BREATHE[b] (n=27)	Healthy Living (n=29)	Test of significance		
				t test (*df*)	Chi-square (*df*)	*P* value
Tai chi	4 (7)	1 (4)	3 (10)	—	0.9 (1)	.34
Regular exercise	17 (30)	6 (22)	11 (38)	—	1.9 (1)	.17

[a] No significant differences were found for the Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment and Healthy Living participants. Fisher exact tests confirmed chi-square results in variables with <5 per cell.

[b] BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment.

[c] Not applicable.

[d] CIRS-G: Cumulative Illness Rating Scale–Geriatric.

Retention and Engagement

Completion of the assessment at 4 weeks and after treatment was 81% (22/27) for BREATHE and 93% (27/29) for Healthy Living (χ^2_2=1.7; *P*=.19). The retention at week 12 was similar across groups, with 81.5% (22/27) of BREATHE participants and 82.8% (24/29) of Healthy Living participants completing the assessment at 12 weeks (T4). The groups did not differ with regard to which modality they used for the delivery of the videos (χ^2=2.4; *P*=.30). Across both groups, 66% (37/56) used DVD delivery, 21% (12/56) used web delivery, 7% (4/56) used both, and 5% (3/56) had missing data on modality due to dropout from the study.

Most of the weekly coaching calls were completed for both interventions, with no differences found in the number of weekly calls completed for each intervention (t_{54}=0.92; *P*=.36). On average, BREATHE participants completed 3.48 (SD 1.05) of 4 (87%) weekly coaching calls. Healthy Living participants completed 3.72 (SD 0.92) of 4 (93%) weekly coaching calls.

With regard to engagement with the intervention as self-reported to coaches, the Healthy Living group completed significantly more lessons (mean 3.55, SD 1.09) than the BREATHE group (mean 2.85, SD 1.43; t_{54}=2.07; *P*=.04). In addition to the weekly lessons, the BREATHE group had daily home practices and 3 assignments to apply the skills in real life. Pearson correlation analyses found that greater baseline anxiety scores (GAS) were associated with fewer completed practices in the BREATHE group (*r*=–0.41; *P*=.03). In addition, greater severity of medical comorbidity (Cumulative Illness Rating Scale–Geriatric) was associated with fewer completed practices in BREATHE (*r*=–0.50; *P*=.009). On average, BREATHE participants completed 23.07 (SD 17.38) practices during the 4-week intervention. A total of 22% (6/27) of the participants completed 1 application of the skills, 19% (5/27) completed 2 applications of the skills, and 30% (8/27) completed ≥3 applications.

Participants shared feedback about the interventions through a postsurvey (Table 3). Participants generally agreed to strongly agreed regarding the ease of use and the usability of the DVD and website to access the videos. Most participants agreed to strongly agreed that the coaching calls were frequent enough and the program length was sufficient.

Table 3. Intervention feedback survey[a].

Survey item	BREATHE[b], mean (SD)	Healthy Living, mean (SD)	Test of significance	
			t test (*df*)	*P* value
The DVDs were easy to use.[c]	4.67 (0.69)	4.35 (0.93)	1.18 (36)	.25
The log-in for the website was easy.[d]	4.17 (0.72)	4.79 (0.43)	–2.72 (24)	.01
It was easy to watch the videos on the website.[e]	4.33 (0.71)	4.69 (0.63)	–0.13 (20)	.23
The calls from my coach were frequent enough.[f]	4.30 (0.66)	4.21 (0.83)	0.40 (42)	.69
The program was the right length of time.[f]	4.25 (0.79)	4.29 (0.75)	–0.18 (42)	.86

[a] Responses ranged from *strongly disagree* (1) to *strongly agree* (5). Due to some participants choosing to use DVDs and others using web delivery, the number of responses to the postsurvey question varied.

[b] BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment.

[c] BREATHE: n=18; Healthy Living: n=20.

[d] BREATHE: n=12; Healthy Living: n=14.

[e] BREATHE: n=9; Healthy Living: n=13.

[f] BREATHE: n=20; Healthy Living: n=24.

Primary and Secondary Analyses

Treatment effects were examined using mixed-effects models conducted on total anxiety scores as measured using the GAS. The models were best fitted with a fixed effect of time and group and random intercept. Table 4 shows the means for the BREATHE and Healthy Living groups across 4 time points (baseline [T1], 4 weeks and end of treatment [T2], 8 weeks [T3], and 12 weeks [T4]). Notably, there was substantial variability for baseline GAS scores, with some participants reporting low symptoms in the previous week despite meeting the criteria for an anxiety disorder. There were no differences in the rates of decline in anxiety between the groups. That is, the effects of time (*P*=.07), group (*P*=.64), and interaction of treatment by group (*P*=.07) were not significant. An inspection of the subscales revealed that there was a significant time by group interaction for somatic anxiety symptoms ($F_{3, 145.6}$=2.81; *P*=.04) but not for affective or cognitive anxiety symptoms. This significant interaction indicated that the Healthy Living group experienced a significant decline in somatic anxiety over time compared with the BREATHE group.

Table 4. Means and SDs for outcome measures at 4-week intervals.

	BREATHE[a], mean (SD)	Healthy Living, mean (SD)	Test of significance	
			t test (*df*)	*P* value
Baseline[b]				
GAS[c]	17.07 (10.35)	18.79 (10.50)	0.62 (54)	.54
GAS somatic	7.37 (4.33)	7.31 (4.75)	–0.05 (54)	.96
GAS cognitive	4.56 (3.67)	5.41 (3.31)	0.92 (54)	.36
GAS affective	5.15 (4.29)	6.07 (3.87)	0.84 (54)	.40
PHQ-9[d]	7.37 (6.07)	6.69 (4.64)	–0.47 (54)	.64
VR-12[e] MCS[f]	16.07 (3.10)	14.93 (3.83)	–1.22 (54)	.23
End of treatment (week 4)[g]				
GAS	17.86 (10.04)	14.11 (9.51)	–1.35 (48)	.18
GAS somatic	8.22 (4.06)	5.61 (4.11)	–2.08 (48)	.04
GAS cognitive	4.73 (3.49)	3.67 (2.93)	–1.15 (48)	.25
GAS affective	5.00 (4.19)	4.54 (3.50)	–0.26 (48)	.80
PHQ-9	7.64 (5.80)	5.14 (4.27)	–1.75 (48)	.09
VR-12 MCS	16.00 (3.55)	14.04 (3.31)	–2.02 (48)	.05
Week 8[h]				
GAS	14.19 (6.46)	14.73 (11.35)	0.19 (45)	.85
GAS somatic	7.10 (3.73)	6.15 (5.03)	–0.71 (45)	.48
GAS cognitive	3.43 (2.79)	4.04 (4.05)	0.59 (45)	.56
GAS affective	3.67 (2.33)	4.54 (3.50)	0.98 (45)	.33
PHQ-9	6.86 (5.35)	6.27 (6.53)	–0.33 (45)	.74
VR-12 MCS	15.10 (3.13)	13.65 (3.24)	–1.54 (45)	.13
Week 12[i]				
GAS	18.41 (10.96)	15.67 (9.19)	–0.92 (44)	.36
GAS somatic	8.64 (4.74)	6.58 (4.03)	–1.59 (44)	.12
GAS cognitive	4.64 (3.16)	4.04 (3.63)	–0.59 (44)	.56
GAS affective	5.14 (4.44)	5.04 (2.79)	–0.09 (44)	.93
PHQ-9	6.92 (5.66)	5.96 (4.62)	–0.63 (44)	.53
VR-12 MCS	15.82 (3.42)	13.42 (3.82)	–2.24 (44)	.03

[a] BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment.

[b] BREATHE: n=27; Healthy Living: n=29.

[c] GAS: Geriatric Anxiety Scale.

[d] PHQ-9: 9-item Patient Health Questionnaire.

[e] VR-12: Veterans RAND 12-item Health Survey.

[f] MCS: mental component summary.

[g] BREATHE: n=22; Healthy Living: n=28.

[h] BREATHE: n=21; Healthy Living: n=26.

[i] BREATHE: n=22; Healthy Living: n=24.

No difference was found with regard to a difference in BREATHE or Healthy Living effect on mental functioning over time as measured using the VR-12. In addition, no difference was found between treatment groups with regard to depressive symptoms as measured using the PHQ-9 (Table 4), anxiety symptoms as measured using the HAM-A, lifestyle-adjusted functioning as measured using the ACS, or anxiety control as measured using the ACQ (Table 5).

Table 5. Means and SDs for outcome measures at baseline and week 12[a].

	BREATHE[b], mean (SD)	Healthy Living, mean (SD)	Test of significance	
			t test (*df*)	*P* value
Baseline[c]				
ACS[d] lifestyle-adjusted function[e]	42.66 (14.05)	45.65 (13.81)	0.74 (45)	.47
PROMIS[f] anxiety	17.74 (6.91)	18.97 (6.40)	0.69 (54)	.49
ACQ[g]	91.48 (23.87)	84.24 (21.00)	–1.21 (54)	.22
HAM-A[h]	18.04 (7.57)	16.59 (7.10)	–0.74 (54)	.46
Week 12[i]				
ACS lifestyle-adjusted function[j]	46.30 (13.02)	49.77 (15.51)	0.69 (31)	.50
PROMIS anxiety[k]	17.64 (6.74)	16.25 (6.47)	–0.71 (44)	.48
ACQ	97.96 (30.06)	91.08 (21.97)	–0.91 (46)	.37
HAM-A[k]	15.55 (7.30)	15.54 (7.17)	–0.002 (44)	.99

[a] With the exception of the Activity Card Sort and Anxiety Control Questionnaire, higher scores indicate worse symptom severity. On the Activity Card Sort, higher scores indicate a greater percentage of activities that are easy to do. On the Anxiety Control Questionnaire, higher scores indicate greater perceived anxiety control. Due to missing data, the number of participants at baseline varied.

[b] BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment.

[c] BREATHE: n=27; Healthy Living: n=29.

[d] ACS: Activity Card Sort.

[e] BREATHE: n=23; Healthy Living: n=24.

[f] PROMIS: Patient-Reported Outcomes Measurement Information System.

[g] ACQ: Anxiety Control Questionnaire.

[h] HAM-A: Hamilton Anxiety Rating Scale.

[i] BREATHE: n=23; Healthy Living: n=25.

[j] BREATHE: n=22; Healthy Living: n=23.

[k] BREATHE: n=15; Healthy Living: n=18.

Effects at Week 4 and Association With Engagement Measures

As shown in Table 4, the BREATHE and Healthy Living groups did not differ in effects at week 4 and end of treatment with the exception of GAS somatic scale scores, which were lower for Healthy Living compared with BREATHE at this time point. We also investigated whether changes in scores from baseline to week 4 were associated with home practice completion. Using Pearson correlation analyses, we found the association with practice completion to be nonsignificant (r=0.33; P=.13). Reduction in GAS scores from baseline to week 4 (end of treatment) was not associated with completion of lessons (r_s=–0.09; P=.53) or coaching calls (r_s=–0.009; P=.95) across the BREATHE and Healthy Living combined samples.

Individual Activity Goals

Individual activity goals set by participants were examined with regard to the number of goals identified, types of goals, and change in individualized goal frequencies from baseline to 4 weeks. On average, participants selected at least 4 activities to focus on (mean 4.7, SD 1.2; range 2-7). Of 263 total activities identified, the 3 most frequently selected activity categories were social activities (72/263, 27.4%); high-demand leisure activities (70/263, 26.6%) such as hiking or swimming; and low-demand leisure activities (63/263, 24%) such as photography, reading, or playing a musical instrument. The remaining activities were instrumental activities (35/263, 13.3%) or other activities identified by participants (23/263, 8.7%).

Change scores for each activity goal were calculated from 0 to 4 weeks. Scores were then collapsed into 2 categories: increase in activity frequency (change score of >0) or no change or decrease in activity frequency (change score of ≤0). The BREATHE and Healthy Living groups did not differ in their distribution of increased activities at 4 weeks (χ^2=0.2; P=.64). A total of 79% (23/29) of Healthy Living participants and 74% (20/27) of BREATHE participants reported an increase in frequency of one or more goals at 4 weeks. On average, participants in both groups attained ≥1 goal at 4 weeks (BREATHE: mean 1.6, SD 1.4; Healthy Living: mean 1.6, SD 1.3; consistent with an intention-to-treat approach, all participants were retained in these analyses. Those individuals who were lost to follow-up were coded as not attaining their goal).

Qualitative Feedback Regarding Practice Routine and Challenges

Feedback regarding the experience of the practices in the BREATHE group, including the overall experience of the practices, mechanics and frequency of practices, challenges encountered, and application of skills to real-world situations, was analyzed to better understand participants' experience with the BREATHE intervention (22/27, 81% completed the interviews). While Healthy Living participants relayed the same type of information, in this section, we focus on the BREATHE intervention as the condition of interest.

Experience With Practices

Participants expressed varied experiences with the practice components of the BREATHE intervention, that is, the diaphragmatic breathing and the PMR exercises. Overall, most participants ranked the practices as the most (9/21, 43%) or second (9/21, 43%) most helpful component of the intervention compared with the weekly coaching calls and video lessons. Some described the diaphragmatic breathing exercises as the most effective part of the intervention and the easiest skill to use outside of home. One participant (BR1) noted the following:

> *The breathing definitely was important. That's probably a big part of it. The breathing practices, because I didn't normally do this before, but by doing breathing exercises, it definitely helped me.*

Participants described adjustments made to PMR exercises. These included tensing for less time (BR12); adjusting for physical issues (BR18), which could include imagined tensing as specified in the videos; and grouping some muscles together (eg, lower extremities and facial muscles; BR18). Another participant liked tensing from the waist up (ie, face and upper torso) "because I get a lot of tension there" (BR4). A smaller number of participants felt that the practices and skills were not helpful in that breathing would not solve the problems they were facing. One individual explained the following:

> *I don't think learning how to breathe a certain way is gonna make anything go away that I'm dealing with.* [BR5]

Another participant noted that tensing their muscles was not helpful "because I'm tense already" (BR3).

Mechanics and Frequency of Practices

The mechanics of how and when people practiced varied. Creating a practice habit through timing, frequency (eg, once or twice a day), or location seemed to help with accomplishing the practices without stress or feeling pressured. One participant described the following:

> *...that the only time that I could do this was lying down—was in bed, lying down. And I thought—Oh, gosh, it's not going to be as effective. But after life quieted down somewhat, I was able to attain my goal and start to do it twice a day. Attempt to do it twice a day. But it was still lying down, and I loved it.* [BR8]

For some, setting a schedule to practice was stressful and, instead, practicing during a block of time (eg, mornings and evenings) helped:

> *It's like I like to do stretching exercises every day and I would kind of keep myself physically fit and this was more kind of a mental exercise of imposing discipline on myself to be able to do this twice a day.* [BR6]

With regard to the frequency of practice, participants described practicing once or twice a day for the first month or 2; however, many participants described that their practice frequency decreased after the first 4 weeks, which coincided with the weekly check-in calls ending after the first 4 weeks. For some participants, the relaxation procedures may have been too static (ie, the same video used to guide practice), and after several weeks, this contributed to diminished engagement. In contrast, some described returning to the practices to help with anxiety. One participant explained the following:

> *I didn't do it [progressive relaxation] as much for a while. And then out of necessity I said, "This is what I need to do," and I have done it more in the past months.* [BR16]

Another individual expressed an intention to continue practicing:

> *I will keep doing this 'cause I enjoy setting aside a time for a disciplined approach to trying to relax.* [BR6]

Personalization of the practices seemed to facilitate continued use of the techniques. One participant described adjusting their practice over time:

> *I changed it from watching the videos to just actually sitting, closing my eyes, and going through the process. I felt most comfortable doing it that way.* [BR1]

The guidance helped one participant "keep my mind on track" (BR8).

Challenges

Participants identified several challenges with completing the practices. Setting time aside to practice daily was a challenge due to timing, forgetting (BR2 and BR15), traveling (BR7), having visitors (BR6), or other activities. One participant described the following:

> *So, carving out the time is a little bit of a challenge. It's not overwhelming, because the program is really not that demanding, really, when you think about the time. But you just get busy.* [BR2]

Health and other life challenges deprioritized the study for some participants (BR5). Technology difficulties were noted by 9% (2/22) of the participants, and 5% (1/22) encountered difficulties, but described learning the technology. Documenting anxiety scores was identified as tedious by another individual.

Application of Skills in the Real World

Participants described multiple applications of the relaxation and breathing practice in the real world. The most common applications were using the skills when experiencing anxiety, tension, or stress or whenever a situation dictated it. Some described noticing tense or anxious feelings and then using the practices to alleviate the symptoms:

> *...when I began to feel periods of anxiety, I would either go to immediately and practice, or I'd set time aside [to practice].* [BR10]

Others described specific situations in which they applied the skills, including dentist appointments (BR4), at the hospital

(BR9), or when having an operation (BR11). Some used the breathing or tensing and releasing tools while driving and in traffic or while waiting for VA appointments (eg, BR8 and BR13). Another veteran described deep breathing when a task became more complicated or frustrating:

> *What helps me is that if I'm sitting there making breakfast and I see that it's getting complicated, something is frustrating me that maybe I dropped something that immediately I will just close my eyes and breathe slow. And sometimes I can only breathe three and then, if I feel I need it, I just go into doing more. And it's not a big conversation, I just do it.* [BR16]

Discussion

Principal Findings

The findings of this pilot RCT of BREATHE compared with Healthy Living demonstrate the feasibility of conducting an RCT in that all participants were willing to be randomized and retention was similar between study arms at 12 weeks. Some variation in engagement with and acceptability of the interventions emerged, as discussed in the following sections, but does not decrease the feasibility of conducting an RCT. The hypotheses were not supported with regard to the greater reduction in total anxiety symptoms or improvement in functioning (as measured using the VR-12 MCS score) in BREATHE compared with the psychoeducation control of Healthy Living. On the anxiety symptom subscales, participants in the Healthy Living condition experienced a greater reduction in somatic anxiety symptoms, but no other differences were found for the other 2 subscales of cognitive and affective anxiety symptoms. There are several reasons for these findings. First, as observed in most previous late-life intervention studies [43], the inclusion of an active control may have diminished the potential effect of relaxation. Furthermore, a growing body of research has focused on the importance of well-being–focused interventions, including yoga [44], nutrition [45], and other alternative interventions [46], and the presence of some of these factors may have contributed to the benefits that participants achieved in the Healthy Living intervention. This intervention did include gentle stretching and some basic sleep and coping tips in addition to nutritional information, which all may relate to physical and mental health while aging. It is possible that a single-component intervention was not effective for engaging participants across a 4-week period. Recent studies have demonstrated that CBT for depression and anxiety is effective at not only reducing anxiety but also preventing relapse over a 10-year period [47]. In addition, the heterogeneity of anxiety disorders, as detected using structured interviews, and the range in anxiety severity based on baseline GAS scores may lead to attenuated findings with a single-component intervention rather than a multicomponent intervention to address varied facets of anxiety (ie, cognitive, somatic, and affective symptoms).

Our exploratory aim examined factors related to home practices in the BREATHE condition or related to intervention outcomes which revealed that greater self-reported anxiety symptom severity and greater medical comorbidity at baseline were associated with fewer progressive relaxation practices completed during the 4-week intervention. The qualitative findings helped us further probe the potential effect of practices. Qualitative findings suggested that, for some, practicing breathing, relaxation, or both breathing and relaxation was not viewed as enough to manage their anxiety and stress, thus dovetailing with the quantitative finding of those participants with greater anxiety practicing less. Accordingly, BREATHE or Healthy Living may be better suited for individuals with mild to moderate anxiety, which should be tested directly in a future study. It is possible that older veterans with greater distress would have preferred having access to group or individual psychotherapy and may have had previous exposure to these modalities as a function of the integration of mental health into the Veterans Health Administration [48].

Other challenges to practicing were recounted by participants, including difficulty finding the time to practice, having other things to do (eg, visitors and other activities), or worsening of health problems and experiencing acute health changes. Some participants reported a decline in practices after the coaching calls ended at the 4-week mark. Thus, the challenges with practices were 2-fold and included both adhering to the practices and maintaining a practice routine over time, which parallels the challenges of having sustained engagement with digital mental health interventions [49] and with any behavioral intervention requiring practice. Perhaps improvements and variations in the types of relaxation are needed to maintain interest in practices over time.

These findings led to the question of whether home practice is the issue itself. Integrating an ongoing relaxation practice into daily life while facing multiple medical conditions may have required extra effort and motivation from participants. The qualitative interview findings revealed that participants were able to personalize their practices based on their own needs, tailor their routine, and implement the relaxation procedures in their daily life when they needed it. Another possible future direction would be to provide multiple skills in a modular approach consistent with digital mental health interventions [50] or consider adding a session focused on motivational interviewing to the intervention.

Participants described using the skills in a myriad of settings, including when facing worries or anxiety, when in a stressful situation, or when simply waiting for an appointment, and they achieved one or more goals on average. Future studies should clarify the dose of PMR needed and whether preferences for psychotherapy compared with technology [51] play a role in practice completion and overall adherence. Alternatively, while these interventions were designed to be widely accessible and scalable, it is possible that a more mechanistic consideration of breathing approaches for specific individuals may be needed (ie, precision medicine approaches [52]). In addition, more engaging and adaptive technology–based interventions could be of benefit for late-life anxiety and lead to more sustained engagement with practices. Further refinement of goal setting to promote intervention engagement alongside skills to cope with anxiety is needed. On average, BREATHE and Healthy Living participants attained at least one goal at the end of treatment, but this could be strengthened using more directed, individualized outcome measures for the goals (eg, goal attainment scaling approaches [53]).

Limitations

This study is not without limitations. One of the key limitations may be the heterogeneity of anxiety disorders and symptom presentation in a relatively small pilot study. Rather than including multiple types of anxiety disorders, focusing on specific symptoms (eg, worry that exceeds a particular threshold on a questionnaire) may be a better approach, as used with other studies [44,54]. As this sample included veterans, we likely encountered higher rates of co-occurring PTSD compared with other nonveteran samples. This particular comorbidity of PTSD may have made the anxiety presentation more complex and difficult to treat using guided self-management interventions. Additional limitations include the small sample size as the study was designed to be a pilot, the use of nonblinded assessors, and the absence of a validated measure of acceptability. Another limitation to our design was that only a portion of the outcome measures were assessed at the end of treatment (T2). This study took place earlier in the COVID-19 pandemic, which led to some modifications in data collection methods and limited our ability to collect complete data, in particular from the lifestyle-adjusted ACS.

Comparison With Prior Work

These findings differ from those of earlier studies on progressive relaxation for late-life anxiety in that the effects of progressive relaxation were not as robust as those found in earlier studies [55]. The use of a primarily male, ethnically and racially diverse military veteran sample may have contributed to some differences compared with earlier studies, in which older nonveteran White women made up much of the samples. The benefits derived from the Healthy Living intervention fit with the evidence for complementary and integrated health approaches for late-life anxiety [44] and the Whole Health program in the Veterans Health Administration [56].

Conclusions

These findings suggest that guided self-management approaches to treating late-life anxiety in older veterans are feasible but that further refinement and study are needed to identify what works best for whom using a video-delivered format with remote coaching. Our findings suggest that a psychoeducation-based approach may help older adults with somatic anxiety symptoms. While progressive relaxation was deemed to be feasible and enjoyable to most participants, those with mild to moderate anxiety symptom severity and fewer health problems were more likely to adhere to the recommended home practice. Thus, based on the qualitative feedback, the BREATHE intervention in particular might not be a good match for all older adults with anxiety disorders due to some participants needing a higher-intensity treatment and others experiencing negative reactions to progressive relaxation, primarily “relaxation-induced anxiety” [57]. Further work is needed to delineate the role of intervention design factors and individual participant baseline characteristics on the effect of guided self-management approaches on late-life anxiety.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 441 KB - aging_v7i1e56959_app1.pdf]

References

1. American Psychiatric Association. Diagnostic And Statistical Manual Of Mental Disorders, 5th edition. Washington, DC: American Psychiatric Association Publishing; 2013.
2. Williamson V, Stevelink SA, Greenberg K, Greenberg N. Prevalence of mental health disorders in elderly U.S. military veterans: a meta-analysis and systematic review. Am J Geriatr Psychiatry 2018 May;26(5):534-545. [doi: 10.1016/j.jagp.2017.11.001] [Medline: 29221697]
3. Karim HT, Ly M, Yu G, Krafty R, Tudorascu DL, Aizenstein HJ, et al. Aging faster: worry and rumination in late life are associated with greater brain age. Neurobiol Aging 2021 May;101:13-21 [FREE Full text] [doi: 10.1016/j.neurobiolaging.2021.01.009] [Medline: 33561786]
4. Beaudreau SA, O'Hara R. The association of anxiety and depressive symptoms with cognitive performance in community-dwelling older adults. Psychol Aging 2009 Jun;24(2):507-512 [FREE Full text] [doi: 10.1037/a0016035] [Medline: 19485667]
5. Petkus AJ, Reynolds CA, Wetherell JL, Kremen WS, Pedersen NL, Gatz M. Anxiety is associated with increased risk of dementia in older Swedish twins. Alzheimers Dement 2016 Apr 05;12(4):399-406 [FREE Full text] [doi: 10.1016/j.jalz.2015.09.008] [Medline: 26549599]

6. Karsten J, Penninx BW, Verboom CE, Nolen WA, Hartman CA. Course and risk factors of functional impairment in subthreshold depression and anxiety. Depress Anxiety 2013 Apr 16;30(4):386-394. [doi: 10.1002/da.22021] [Medline: 23165799]
7. Fanning JR, Pietrzak RH. Suicidality among older male veterans in the United States: results from the National Health and Resilience in Veterans Study. J Psychiatr Res 2013 Nov;47(11):1766-1775. [doi: 10.1016/j.jpsychires.2013.07.015] [Medline: 23992768]
8. Karel MJ, Wray LO, Adler G, Hannum AO, Luci K, Brady LA, et al. Mental health needs of aging veterans: recent evidence and clinical recommendations. Clin Gerontol 2022 Jan 23;45(2):252-271. [doi: 10.1080/07317115.2020.1716910] [Medline: 31971092]
9. Barrera TL, Mott JM, Hundt NE, Mignogna J, Yu HJ, Stanley MA, et al. Diagnostic specificity and mental health service utilization among veterans with newly diagnosed anxiety disorders. Gen Hosp Psychiatry 2014 Mar;36(2):192-198. [doi: 10.1016/j.genhosppsych.2013.10.013] [Medline: 24268573]
10. Wuthrich VM, Dickson SJ, Pehlivan M, Chen JT, Zagic D, Ghai I, et al. Efficacy of low intensity interventions for geriatric depression and anxiety - a systematic review and meta-analysis. J Affect Disord 2024 Jan 01;344:592-599 [FREE Full text] [doi: 10.1016/j.jad.2023.10.093] [Medline: 37858732]
11. Bernstein DA, Borkovec TD, Hazlett-Stevens H. New Directions in Progressive Relaxation Training: A Guidebook for Helping Professionals. Santa Barbara, CA: Greenwood Publishing Group; 2000.
12. Thorp SR, Ayers CR, Nuevo R, Stoddard JA, Sorrell JT, Wetherell JL. Meta-analysis comparing different behavioral treatments for late-life anxiety. Am J Geriatr Psychiatry 2009 Feb;17(2):105-115. [doi: 10.1097/jgp.0b013e31818b3f7e]
13. Barlow DH. Anxiety and Its Disorders: The Nature and Treatment of Anxiety and Panic. New York, NY: Guilford Press; 2004.
14. Gould CE, Kok BC, Ma VK, Zapata AM, Owen JE, Kuhn E. Veterans affairs and the department of defense mental health apps: a systematic literature review. Psychol Serv 2019 May;16(2):196-207. [doi: 10.1037/ser0000289] [Medline: 30431306]
15. Gould CE, Zapata AM, Bruce J, Bereknyei Merrell S, Wetherell JL, O'Hara R, et al. Development of a video-delivered relaxation treatment of late-life anxiety for veterans. Int Psychogeriatr 2017 Oct 08;29(10):1633-1645. [doi: 10.1017/S1041610217000928] [Medline: 28592349]
16. Gould CE, Carlson C, Wetherell JL, O'Hara R, Goldstein MK, Loup JR, et al. Guided self-management targeting anxiety and activity participation in older veterans. Aging Ment Health 2021 Oct 13;25(10):1913-1922. [doi: 10.1080/13607863.2020.1758905] [Medline: 32397822]
17. Cremers G, Taylor E, Hodge L, Quigley A. Effectiveness and acceptability of low-intensity psychological interventions on the well-being of older adults: a systematic review. Clin Gerontol 2022 Sep 11;45(2):214-234. [doi: 10.1080/07317115.2019.1662867] [Medline: 31507251]
18. Katzman R, Brown T, Fuld P, Peck A, Schechter R, Schimmel H. Validation of a short orientation-memory-concentration test of cognitive impairment. Am J Psychiatry 1983 Jun;140(6):734-739. [doi: 10.1176/ajp.140.6.734] [Medline: 6846631]
19. Meiran N, Stuss DT, Guzman DA, Lafleche G, Willmer J. Diagnosis of dementia. Methods for interpretation of scores of 5 neuropsychological tests. Arch Neurol 1996 Oct 01;53(10):1043-1054. [doi: 10.1001/archneur.1996.00550100129022] [Medline: 8859067]
20. First M, Williams J, Karg R, Spitzer R. Structured Clinical Interview for DSM-5® Disorders - Clinician Version (SCID-5-CV). 2nd edition. NewYork, NY: American Psychiatric Publishing; 2015.
21. Segal DL, June A, Payne M, Coolidge FL, Yochim B. Development and initial validation of a self-report assessment tool for anxiety among older adults: the Geriatric Anxiety Scale. J Anxiety Disord 2010 Oct;24(7):709-714. [doi: 10.1016/j.janxdis.2010.05.002] [Medline: 20558032]
22. Gould CE, Segal DL, Yochim BP, Pachana NA, Byrne GJ, Beaudreau SA. Measuring anxiety in late life: a psychometric examination of the geriatric anxiety inventory and geriatric anxiety scale. J Anxiety Disord 2014 Dec;28(8):804-811. [doi: 10.1016/j.janxdis.2014.08.001] [Medline: 25271176]
23. Hamilton M. The assessment of anxiety states by rating. Br J Med Psychol 1959;32(1):50-55. [doi: 10.1111/j.2044-8341.1959.tb00467.x] [Medline: 13638508]
24. Diefenbach GJ, Stanley MA, Beck JG. Worry content reported by older adults with and without generalized anxiety disorder. Aging Ment Health 2001 Aug;5(3):269-274. [doi: 10.1080/13607860120065069] [Medline: 11575066]
25. Stanley MA, Wilson NL, Novy DM, Rhoades HM, Wagener PD, Greisinger AJ, et al. Cognitive behavior therapy for generalized anxiety disorder among older adults in primary care: a randomized clinical trial. JAMA 2009 Apr 08;301(14):1460-1467 [FREE Full text] [doi: 10.1001/jama.2009.458] [Medline: 19351943]
26. Bjorner JB, Rose M, Gandek B, Stone AA, Junghaenel DU, Ware JE. Difference in method of administration did not significantly impact item response: an IRT-based analysis from the Patient-Reported Outcomes Measurement Information System (PROMIS) initiative. Qual Life Res 2014 Feb 23;23(1):217-227 [FREE Full text] [doi: 10.1007/s11136-013-0451-4] [Medline: 23877585]
27. Cella D, Yount S, Rothrock N, Gershon R, Cook K, Reeve B, PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH roadmap cooperative group during its first two years. Med Care 2007 May;45(5 Suppl 1):S3-11 [FREE Full text] [doi: 10.1097/01.mlr.0000258615.42478.55] [Medline: 17443116]

28. Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, PROMIS Cooperative Group. Psychometric evaluation and calibration of health-related quality of life item banks: plans for the Patient-Reported Outcomes Measurement Information System (PROMIS). Med Care 2007 May;45(5 Suppl 1):S22-S31. [doi: 10.1097/01.mlr.0000250483.85507.04] [Medline: 17443115]
29. Rapee RM, Craske MG, Brown TA, Barlow DH. Measurement of perceived control over anxiety-related events. Behav Ther 1996;27(2):279-293. [doi: 10.1016/S0005-7894(96)80018-9]
30. Gerolimatos LA, Gould CE, Edelstein BA. Exploratory factor analysis of the Anxiety Control Questionnaire among older adults. Behav Modif 2012 Jul 03;36(4):600-616. [doi: 10.1177/0145445512443982] [Medline: 22563044]
31. Baum CM, Edwards D. ACS: Activity Card Sort. 2nd edition. NewYork, NY: American Occupational Therapy Association; 2008.
32. Albert SM, Bear-Lehman J, Burkhardt A. Lifestyle-adjusted function: variation beyond BADL and IADL competencies. Gerontologist 2009 Dec 08;49(6):767-777 [FREE Full text] [doi: 10.1093/geront/gnp064] [Medline: 19506030]
33. Wetherell JL, Bower ES, Johnson K, Chang DG, Ward SR, Petkus AJ. Integrated exposure therapy and exercise reduces fear of falling and avoidance in older adults: a randomized pilot study. Am J Geriatr Psychiatry 2018 Aug;26(8):849-859 [FREE Full text] [doi: 10.1016/j.jagp.2018.04.001] [Medline: 29754811]
34. Kazis LE, Selim A, Rogers W, Ren XS, Lee A, Miller DR. Dissemination of methods and results from the veterans health study: final comments and implications for future monitoring strategies within and outside the veterans healthcare system. J Ambul Care Manage 2006;29(4):310-319. [doi: 10.1097/00004479-200610000-00007] [Medline: 16985389]
35. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001 Sep;16(9):606-613 [FREE Full text] [doi: 10.1046/j.1525-1497.2001.016009606.x] [Medline: 11556941]
36. Miller MD, Towers A. A manual of guidelines for scoring the Cumulative Illness Rating Scale for Geriatrics (CIRS-G). University of Pittsburgh. 1991. URL: https://www.anq.ch/fileadmin/redaktion/deutsch/20121211_CIRSG_Manual_E.pdf [accessed 2024-04-29]
37. Gould CE, Loup J, Kuhn E, Beaudreau SA, Ma F, Goldstein MK, et al. Technology use and preferences for mental health self-management interventions among older veterans. Int J Geriatr Psychiatry 2020 Mar 29;35(3):321-330. [doi: 10.1002/gps.5252] [Medline: 31854029]
38. Salvi F, Miller MD, Grilli A, Giorgi R, Towers AL, Morichi V, et al. A manual of guidelines to score the modified cumulative illness rating scale and its validation in acute hospitalized elderly patients. J Am Geriatr Soc 2008 Oct;56(10):1926-1931. [doi: 10.1111/j.1532-5415.2008.01935.x] [Medline: 18811613]
39. IBM SPSS statistics for Windows. IBM Corp. URL: https://www.ibm.com/products/spss-statistics [accessed 2024-04-29]
40. Singer JD, Willett JB. Applied Longitudinal Data Analysis: Modeling Change and Event Occurrence. Oxford, UK: Oxford University Press; 2003.
41. Beebe JR. Rapid Qualitative Inquiry: A Field Guide to Team-Based Assessment. Lanham, MD: Rowman & Littlefield; 2014.
42. Hamilton AB, Finley EP. Reprint of: qualitative methods in implementation research: an introduction. Psychiatry Res 2020 Jan;283:112629 [FREE Full text] [doi: 10.1016/j.psychres.2019.112629] [Medline: 31735374]
43. Wuthrich VM, Johnco CJ, Wetherell JL. Differences in anxiety and depression symptoms: comparison between older and younger clinical samples. Int Psychogeriatr 2015 Sep;27(9):1523-1532. [doi: 10.1017/S1041610215000526] [Medline: 25892278]
44. Brenes GA, Divers J, Miller ME, Anderson A, Hargis G, Danhauer SC. Comparison of cognitive-behavioral therapy and yoga for the treatment of late-life worry: a randomized preference trial. Depress Anxiety 2020 Dec 27;37(12):1194-1207. [doi: 10.1002/da.23107] [Medline: 33107666]
45. Marx W, Moseley G, Berk M, Jacka F. Nutritional psychiatry: the present state of the evidence. Proc Nutr Soc 2017 Nov 25;76(4):427-436. [doi: 10.1017/S0029665117002026] [Medline: 28942748]
46. Nguyen SA, LAvretsky H. Emerging complementary and integrative therapies for geriatric mental health. Curr Treat Options Psychiatry 2020 Sep 01;7(4):447-470 [FREE Full text] [doi: 10.1007/s40501-020-00229-5] [Medline: 32904865]
47. Johnco CJ, Zagic D, Rapee RM, Kangas M, Wuthrich VM. Long-term remission and relapse of anxiety and depression in older adults after Cognitive Behavioural Therapy (CBT): a 10-year follow-up of a randomised controlled trial. J Affect Disord 2024 Aug 01;358:440-448 [FREE Full text] [doi: 10.1016/j.jad.2024.05.033] [Medline: 38723682]
48. Kearney LK, Post EP, Pomerantz AS, Zeiss AM. Applying the interprofessional patient aligned care team in the Department of Veterans Affairs: transforming primary care. Am Psychol 2014 May;69(4):399-408. [doi: 10.1037/a0035909] [Medline: 24820689]
49. Lipschitz JM, Van Boxtel R, Torous J, Firth J, Lebovitz JG, Burdick KE, et al. Digital mental health interventions for depression: scoping review of user engagement. J Med Internet Res 2022 Oct 14;24(10):e39204 [FREE Full text] [doi: 10.2196/39204] [Medline: 36240001]
50. Gould CE, Carlson C, Alfaro AJ, Chick CF, Bruce ML, Forman-Hoffman VL. Changes in quality of life and loneliness among middle-aged and older adults participating in therapist-guided digital mental health intervention. Front Public Health 2021;9:746904 [FREE Full text] [doi: 10.3389/fpubh.2021.746904] [Medline: 34957011]

51. Ma F, Carlson C, Gomez R, Gould CE. Older veterans' treatment preferences: psychotherapy and self-management treatment modalities. Clin Gerontol 2023 May 26;46(3):413-423. [doi: 10.1080/07317115.2022.2079447] [Medline: 35616145]
52. Lavretsky H, Feldman JL. Precision medicine for breath-focused mind-body therapies for stress and anxiety: are we ready yet? Glob Adv Health Med 2021 Jan 13;10:2164956120986129 [FREE Full text] [doi: 10.1177/2164956120986129] [Medline: 33489480]
53. Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: a practical guide. Clin Rehabil 2009 Apr;23(4):362-370. [doi: 10.1177/0269215508101742] [Medline: 19179355]
54. Lenze EJ, Hickman S, Hershey T, Wendleton L, Ly K, Dixon D, et al. Mindfulness-based stress reduction for older adults with worry symptoms and co-occurring cognitive dysfunction: MBSR in older adults. Int J Geriatr Psychiatry 2014 Oct 18;29(10):991-1000 [FREE Full text] [doi: 10.1002/gps.4086] [Medline: 24677282]
55. DeBerry S. The effects of meditation-relaxation on anxiety and depression in a geriatric population. Psychother Theory Res Pract 1982;19(4):512-521. [doi: 10.1037/H0088465]
56. Gaudet T, Kligler B. Whole health in the whole system of the veterans administration: how will we know we have reached this future state? J Altern Complement Med 2019 Mar;25(S1):S7-11. [doi: 10.1089/acm.2018.29061.gau] [Medline: 30870023]
57. Lazarus AA, Mayne TJ. Relaxation: some limitations, side effects, and proposed solutions. Psychother Theory Res Pract Train 1990;27(2):261-266. [doi: 10.1037/0033-3204.27.2.261]

Abbreviations

ACQ: Anxiety Control Questionnaire
ACS: Activity Card Sort
BREATHE: Breathing, Relaxation, and Education for Anxiety Treatment in the Home Environment
CBT: cognitive behavioral therapy
GAD: generalized anxiety disorder
GAS: Geriatric Anxiety Scale
HAM-A: Hamilton Anxiety Rating Scale
MCS: mental component summary
PHQ-9: 9-item Patient Health Questionnaire
PMR: progressive muscle relaxation
PTSD: posttraumatic stress disorder
RCT: randomized controlled trial
SBT: Short Blessed Test
SCID-5: Structured Clinical Interview for the DSM-V
VA: US Department of Veterans Affairs
VR-12: Veterans RAND 12-item Health Survey

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Original Paper

Evaluating a Smart Textile Loneliness Monitoring System for Older People: Co-Design and Qualitative Focus Group Study

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Abstract

Background: Previous studies have explored how sensor technologies can assist in in the detection, recognition, and prevention of subjective loneliness. These studies have shown a correlation between physiological and behavioral sensor data and the experience of loneliness. However, little research has been conducted on the design requirements from the perspective of older people and stakeholders in technology development. The use of these technologies and infrastructural questions have been insufficiently addressed. Systems generally consist of sensors or software installed in smartphones or homes. However, no studies have attempted to use smart textiles, which are fabrics with integrated electronics.

Objective: This study aims to understand the design requirements for a smart textile loneliness monitoring system from the perspectives of older people and stakeholders.

Methods: We conducted co-design workshops with 5 users and 6 stakeholders to determine the design requirements for smart textile loneliness monitoring systems. We derived a preliminary product concept of the smart wearable and furniture system. Digital and physical models and a use case were evaluated in a focus group study with older people and stakeholders (n=7).

Results: The results provided insights for designing systems that use smart textiles to monitor loneliness in older people and widen their use. The findings informed the general system, wearables and furniture, materials, sensor positioning, washing, sensor synchronization devices, charging, intervention, and installation and maintenance requirements. This study provided the first insight from a human-centered perspective into smart textile loneliness monitoring systems for older people.

Conclusions: We recommend more research on the intervention that links to the monitored loneliness in a way that addresses different needs to ensure its usefulness and value to people. Future systems must also reflect on questions of identification of system users and the available infrastructure and life circumstances of people. We further found requirements that included user cooperation, compatibility with other worn medical devices, and long-term durability.

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KEYWORDS

loneliness; smart textiles; wearable technology; health monitoring; older people; co-design; design requirement; mobile phone

Introduction

Background

Loneliness is a common experience in later life and describes a subjective feeling, whereas social isolation is an objective state that is not necessarily associated with felt loneliness [1,2]. While people can be alone and lonely, they can also be lonely while cohabiting with their families [3]. Risk factors for loneliness and difficulties dealing with loneliness at an older age include physical health issues; lack of social resources, such as quality and frequency of contacts; lower educational attainment; and loss of a partner [3-6]. Loneliness can have health implications for individuals and economic impacts on the health care system. Loneliness has been shown to affect stress responses by increasing fibrinogen levels and diastolic blood pressure [5], risk of malnutrition [7], frailty [8], sleep deterioration [5], greater sensitivity toward self-rated health [2], depressive symptoms [9], and higher mortality risk [10].

Loneliness monitoring can help older people communicate with health care providers [11,12] and provide reassurance to family members. Another motivation is to assess loneliness objectively and understand its relation to health outcomes [11,13]. Previous systems used sensors at home, in corridors, and on doors and monitored phone and computer activities [11,12]. In this paper, we focus on the use of smart textiles in wearables and furniture for loneliness monitoring. Smart textiles have the potential to support a comfortable, accessible method of detection for physiological and behavioral data [14-16]. No previous systems designed to detect and systematically assess loneliness have used smart textiles for detection. Only 1 study detected the frequency of speech through a textile band; however, it did not evaluate whether this could be associated with the experience of loneliness [17].

Lessons From Loneliness Monitoring Systems for Older People

Loneliness has been associated with depressive symptoms [18], sleep disturbance [19], sleep dysfunction, lower sleep quality, and differences in heart rate [20] and blood pressure [21]. Previous monitoring systems for loneliness also found associations with decreased daily phone use and incoming calls [13], time spent outside the home [11,12], the number of computer sessions [11], and speech characteristics [22]. Some of these symptoms could potentially be detected with smart textile sensors positioned on beds [23], embedded electrocardiogram sensors [24], sensors in insoles [25], or pressure sensors [26] on seat covers.

Design considerations for current loneliness monitoring systems concern the need for privacy, system unobtrusiveness [11,12], and durability (ie, battery efficiency) [27]. Having sensors installed intuitively on walls or devices was considered more comfortable and could be more easily remembered by older people than those on wearables [11]. There have been a few proposals for the application of a loneliness monitoring system. One proposal was to implement the technology in community settings to raise awareness for people who are on the verge of becoming lonely and to address the issue or share the data with physicians or nurses [11]. There is also a need to gain consent from older people to use the proposed technology [11]. Furthermore, a consideration is the question of how to serve lower-income and rural populations in accessing this technology [12]. No studies have presented in-depth findings on the needs and preferences of older people or stakeholders in loneliness monitoring systems using smart textiles. Thus, we drew on user studies and insights into design requirements from the literature on smart textile technologies.

Lessons From Smart Textile Wearable Technologies for Older People

Compared to pervasive computing systems, smart textile systems are predicted to acquire denser data, be less obtrusive, and reduce the number of devices required to detect diverse symptoms simultaneously [28]. Greater privacy is also a reason for positioning sensors in insoles for monitoring falls compared to alternative video cameras [25]. Positioning of sensors in furniture, such as a mattress topper, has previously been considered less invasive than worn sensors [23]. Positioning sensors on wearables, such as socks, allows for continuous monitoring including at home [29]. Even in older patient groups, there was a high adherence to the continuous use of wearable sensors, helping continuous monitoring of potential health risks [30]. Other examples of textile sensors include Taekwondo suits (pants and jackets) [26], floor mats [31], waistbands [24], and head ornaments [32]. Previous applications have contributed to the development of strain, pressure [26], electrocardiogram textile sensors, and explored the possibility of sensors with combined functions [26]. There has been a proposal for “intelligent health agents” based on smart textiles, which can support monitoring and treatment through textile technologies, such as thermotherapy, electrical stimulation, or phototherapy [33].

The commonly mentioned requirements are comfort [34-36] and wearables being made of breathable [34,37], lightweight, and permeable materials [34]. Furthermore, smart textile applications would need to function during daily and sports activities [35], be discrete [36], be safe on the body, and resist bodily fluids [35]. Aesthetic properties, such as color, fit, and diverse choices, to adapt clothing to the cultural context of the wearer and the possibility of mass production of such design choices should be further considered for greater acceptance [35,38]. Moreover, smart textile wearables must adapt to different body measures, genders, postures, and movements [35]. Further requirements include greater accuracy, reliability, privacy, and safety of the transmitted information [38]. The requirements for the material can vary according to the application context, but they did involve resisting large deformations and strikes in sports [26] and resisting abrasions from moving a topper on a mattress [23].

Furthermore, washability is considered an essential requirement for smart textiles [34]. Current applications can range from approximately 5 washing cycles by hand [26] to 40 cycles at 25 °C by a machine [36]. This implies potential additional requirements for washing [39]. One proposed solution to protect the textile sensors was microelectronic systems that could “be detached from the clothing component before washing” [40].

However, this might also contradict being a user-friendly washing process [38]. Thus, it is recommended that smart textiles are machine washable, support known washing processes, and do not require complicated washing instructions [38]. Power sources are also vital as currently available power sources are often too bulky [41]. Hence, one requirement is reduced energy consumption as one way to use less bulky power sources and the option to use energy from motion and body heat [34,35,38]. Enough power should be provided to last throughout monitoring activities [35]. Another important consideration is the recyclability and potential biodegradability of smart textiles produced without using harmful materials [34,41].

We are an interdisciplinary research group consisting of experts in gerontology, psychology, design, sensor technology, and machine learning, aiming to develop a loneliness monitoring and communication system from a human-centered design perspective [42]. This study aims to understand the needs of older individuals and the expectations of stakeholders to inform the system design.

Methods

Overview

We obtained user and stakeholder feedback from workshops and focus groups to develop the design requirements and initial design concept of the smart textile loneliness monitoring system for older adults. The study design and topic guides were developed in collaboration with team members who are developing the textile sensors and explored symptoms of loneliness in previous interviews [40]. For instance, sensor development required an understanding of user expectations in the positioning of sensors, washing, and charging. In addition, our initial prototypes developed and presented during the studies were informed by insights from interviews on potential symptoms of loneliness.

On March 27, 2023, and April 12, 2023, we conducted 2 co-design workshops with people aged ≥65 years who had experienced loneliness (n=5). On June 7, 2023, and June 15, 2023, we conducted a second co-design workshop with stakeholders (n=7). Therefore, we derived a set of design requirements implemented in an initial service system scenario and a smart home wearable system prototype. In October 2023, the design requirements were evaluated in a focus group study that included older people and stakeholders (n=7).

Participants

Participants for the workshop and focus group studies were contacted based on their previous expression of interest in the DELONELINESS project, as specified by Rees et al [4]. Invitations were sent via email newsletters within a housing network specialized for older people. We engaged individuals who had previously responded through a newsletter in a study involving older participants. Participants were also contacted through a study pool on wearable technologies from the Remote Assessment of Disease and Relapse-Major Depressive Disorder program focused on the passive monitoring of depressive disorders through smartphone data and wearables. Older participants were eligible for the workshops if they were aged ≥65 years, spoke fluent English, and experienced loneliness within the last 10 years since reaching the age of 65. Participants were ineligible if they had any cognitive impairment or dementia.

The severity of loneliness measured by the University of California, Los Angeles 3-item Loneliness Scale [43] has been associated with various health effects and restrictions. Higher and medium levels of loneliness were associated with a higher risk for frailty than lower levels of loneliness [8]. Another study showed that higher levels of loneliness were associated with greater mortality risk [9]. Higher levels of loneliness were also associated with people who might face functional restrictions, which have potential difficulties in engaging in activities [44]. Severe loneliness might have different requirements for a monitoring system and linked interventions. When participants were unable to attend on the day due to ill health, follow-up sessions were organized.

For both the workshop and focus group, stakeholders were recruited through the People in Research website by the National Institute for Health and Care Research to offer opportunities for public engagement and through the researchers' professional networks. The eligibility criterion for stakeholders was being aged >18 years. We searched for family members of older people who had experienced loneliness, industry representatives, carers, social workers, social prescribers, housing providers, and charity workers.

Participant characteristics in the studies have been summarized in Table 1 and Textbox 1.

We chose a qualitative approach with the aim of gaining more in-depth insights into participant perspectives and needs, which serves well to inform the initial system design. Previous qualitative research on design requirements for technologies for susceptible people and with stakeholders have been based on sample sizes such as 12 patients and 4 stakeholders [45], 10 experts to develop and 4 to evaluate a system [46], or 15 stakeholders [47]. For a qualitative evaluation in user research, we followed the recommended participant number of 3 to 15 [48].

Table 1. Older participant demographics in the co-design and focus group study.

Characteristic	Study 1: co-design workshop (2 groups; n=5)	Study 2: focus group (2 groups; n=4)
Age (y), mean (SD; range)	74.6 (3.8; 70-83)	73.3 (5.4; 68-78)
Sex, n (%)		
Female	4 (80)	2 (50)
Male	1 (20)	2 (50)
Hughes Scale for Loneliness, mean (SD; range)	6.2 (1.7; 3-8)	5.8 (2.2; 3-9)
Experience in using health monitoring technology, n (%)		
Yes	3 (60)	2 (50)
No	2 (40)	2 (50)
Living circumstances, n (%)		
Living alone	3 (60)	2 (50)
Living with others	2 (40)	2 (50)

Textbox 1. Stakeholder characteristics in the co-design and focus group study.

Stakeholders in study 1: co-design workshop (2 groups; n=7)

- Family member and private carer
- Representative for a housing network for older people
- Company founder for housing for older people
- Representative for a smart textile company
- Social prescriber and social worker
- Charity founder for loneliness
- Public contributor with non-English, international family background

Stakeholders in study 2: focus group (1 group; n=3)

- Family member and private carer
- Family member and care home manager
- Health and well-being coordinator (social housing)

Procedure

Study 1: Co-Design With Older People

The first co-design sessions were held with older people to discuss their design preferences for the function and positioning of a textile monitoring system on the body and in the home environment. The session involved the activities mentioned subsequently, which were relevant to the overall system development. Topics include the positioning of sensors; what to detect; overall system components; and washing, charging, and service requirements.

Initially, participants were asked to brainstorm about behaviors indicative of loneliness and the strategies to detect them. They were also asked what objects they surrounded themselves with and in which situations they experienced loneliness. This served as a basis for further thought on how a system for monitoring loneliness could be positioned.

Participants received preprinted outlines of a human figure and a home environment in a task. They were asked to indicate through red and green markers where they would accept or avoid the positioning of sensors. The previously discussed and exemplary symptoms were added. Subsequently, each person shared their materials and presented them to the group. This first indicated how the system would be positioned and what should be detected. For the positioning, they were not presented with symptoms or preferred sensor positions from a technical perspective to avoid influencing them.

Afterward, a presentation by the researchers summarized specific questions relevant to the sensor development. Pictures and questions prompted the discussion on existing wearables (eg, t-shirts, underwear, and leggings), charging and washing requirements, and whether participants would accept detachable electronic components for wearables and furniture. They were also asked to comment on some proposed positionings for the system based on initially hypothesized symptoms and preferred sensor positionings as recommended by experts in our team.

Study 2: Co-Design With Stakeholders

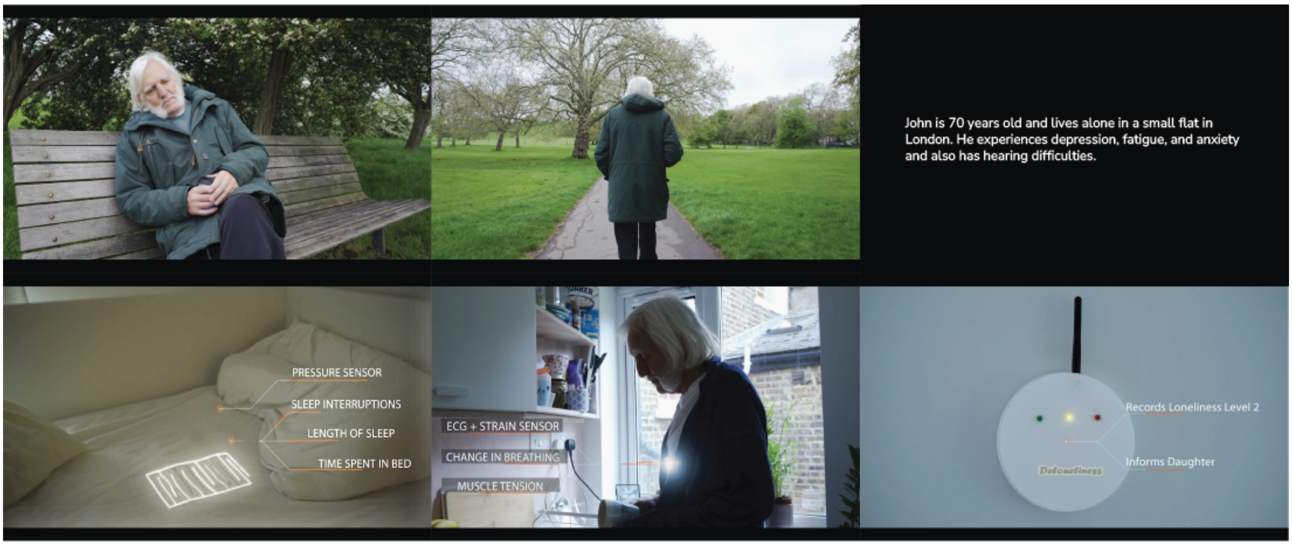
The workshop with stakeholders was built on the previous co-design session with older adults, which helped inform and develop the first concept and use case and elicited further discussion (Figure 1). In addition, the stakeholder's workshop aimed to explore the overall device implementation in the existing health care and personal environment. Therefore, the session involved additional activities mentioned subsequently.

First, participants were shown a video scenario (Figure 1). The video presents the case of John, an older man living with the loneliness monitoring system. It displays the locations where sensors are positioned, what symptoms are sensed, and what response is expected. The video shows that if a medium level of loneliness is detected, a family member will be informed, and they will initiate a call. A dedicated expert or social prescriber will be informed if severe loneliness is recognized. On the basis of the video, the stakeholder participants were provided materials to brainstorm about initial questions or concerns from their perspectives.

Afterward, stakeholders were presented with the human shape and home environment previously provided to older people to indicate how they suppose such a system should be positioned.

Finally, participants were asked to envision the implementation and installation of the system and the process while the researcher summarized comments in a sketch with preprinted elements.

Figure 1. A short film about the main character, John, who experiences loneliness and uses the developed monitoring device. ECG: electrocardiogram.



Study 3: Focus Group Evaluation

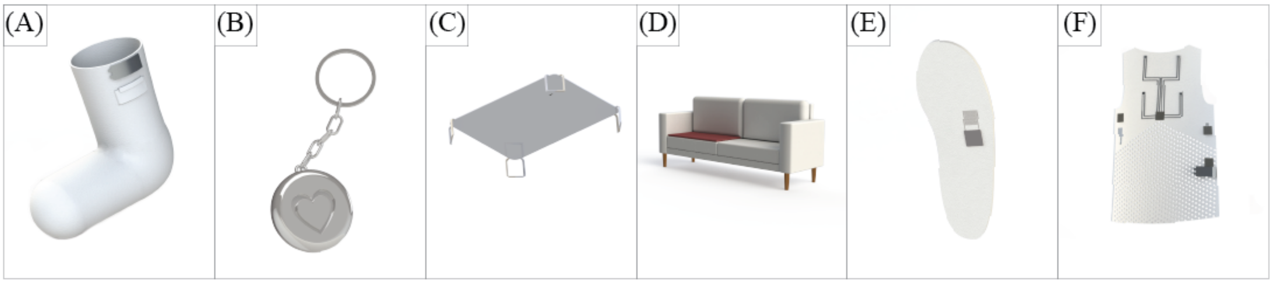
A list of design requirements was developed based on the analysis of previous co-design sessions. These were implemented in digital and physical models (Figure 2) with materials recommended by the team members developing smart textile sensors. The focus group evaluated whether the proposed system design and requirement implementation were perceived as valuable and easy to use, which are predicting variables for older people's use of new technologies [49].

The session was divided into 3 main parts. First, we presented the system's physical components, showing its function and use process over time. Participants were asked to interrupt at any time to express their thoughts [50]. Afterward, open-ended questions followed, such as "What are your initial thoughts on the system?" "What are the benefits and drawbacks of how the system is positioned on the body and in the home?" and "Do you believe the system will be more or less useful to older people that were identified to experience loneliness?" In addition, a set of Likert-type questions (5-point items) was presented to get responses from everyone on the usefulness and expected ease of use (Textbox 2). The questions were inspired by the System Usability Scale [51] and measures for perceived usefulness [52]. Although participants had not yet tested the system's usability, the rating was intended as the first evaluation step before the system was implemented and tested in the field.

In the second part, methods of washing and charging were presented. Washing would need to take place as efficiently as possible, as was determined by the previous co-design sessions. Participants were asked to rate the expected ease of washing, ease of remembrance, and comfort. Then, participants were asked open-ended questions, such as "What do you like or dislike about the way of washing proposed?" and "Would it be easy or difficult for an older person to maintain these forms of charging?"

Finally, participants were presented with 4 personas based on the previous interview data [4]. Participants were asked to comment on interventions that might be helpful to support the personas (Multimedia Appendix 1). Afterward, an initial proposal for a mobile app was shown and discussed (Figure 3).

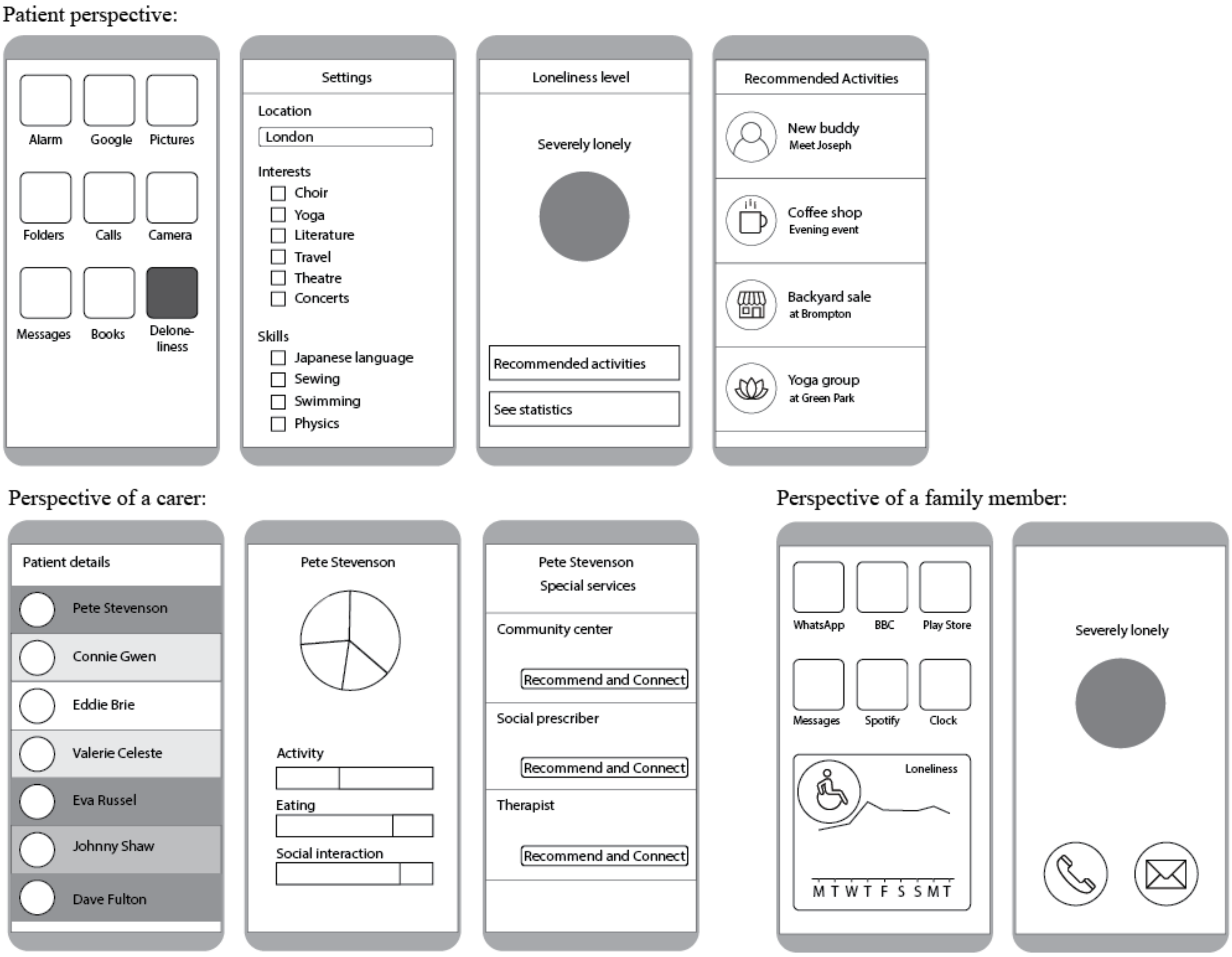
Figure 2. 3D model of system components. From left to right: (A) a sock with a battery, (B) a sensor synchronization device shaped as a key charm, (C) a mattress cover, (D) a seating cover, (E) a shoe insole with an integrated pressure sensor, and (F) a vest that indicates the positioning of sensors and microchips.



Textbox 2. Rating questions asked in the focus group evaluation and 5-point scales.

- The system can be used intuitively by older people: strongly disagree to strongly agree
- The system is useful to reduce loneliness for older people: strongly disagree to strongly agree
- How do you rate the comfort of the sensing (socks or mattress cover or seat cushion or vest or insoles)? not at all comfortable to very comfortable (1-5)
- How easily would older people remember to use the sensing (socks or mattress cover or seat cushion or vest or insoles)? not at all easily to very easily (1-5)
- The system is easy to wash for the older adult: strongly disagree to strongly agree (1-5)

Figure 3. Proposed mobile app linked to the loneliness monitoring system.



Analysis

The workshops and focus groups were transcribed by the first author and, in part, by a professional transcription service with the consent of the participants. Our analytical approach was an inductive qualitative content analysis [53]. Content analysis is a "technique for making replicable and valid inferences from texts...to the contexts of their use" [50]. A qualitative approach differs in coding, the determination of categories, and how researchers interpret data frequencies [54,55]. Categories are often developed inductively close to the dataset at hand and reading data in depth rather than by applying automated analysis approaches based on predetermined codes [54,55]. According to the approach [53], we first applied open coding by reading the material, assigning codes, and developing categories with the help of NVivo (Lumivero) software. Then, the codes were classified and grouped into categories (eg, "accuracy in detection," "economical inclusivity," and "instructions for carers"). The categories developed were further grouped into superordinate categories (eg, "general system requirements," "wearable requirements," "installation and maintenance requirements," "material requirements—wearable," and "material requirements—furniture"). For part of the material, the coding was done independently by a second researcher. Differences in coding were resolved through discussion. This led to additional codes in a few categories. The categories were further presented to 2 coauthors. This led to the summary and further grouping of codes, such as soft and lightweight materials. Moreover, it led to renaming some categories, such as "machine washing" rather than "direct washing." We considered frequencies and how often different participants mentioned a concept. The detailed quotes and frequencies in each category are enlisted in Multimedia Appendix 2. This served to structure the observed requirements. The frequency count is not intended to be statistically significant or generalizable but to better compare different requirements and their potential importance.

Ethical Considerations

The study was approved by the research ethics committee at King's College London (LRS/DP-22/23-34602) on January 16, 2023. Participants were provided with an information sheet and the consent form before the initiation of the study for their information and they were informed about being able to opt out at any time in the study and asked to sign the consent form on the day the study started. In all data processing, data were labelled with a unique non–personally identifiable participant identification number. This made the data pseudoanonymous. A password-protected file contained the name and contact details with an ID that is stored separately. Participants were not provided with any direct incentives to participate. However, travel and lunch costs were reimbursed.

Results

General System Requirements

The general system requirements addressed the overall system function or were mentioned concerning multiple aspects of the system.

Accuracy of Detection

Older people and stakeholders wished for the system's effectiveness. Some older participants were skeptical about how a subjective feeling of loneliness could be associated with physical symptoms or behaviors:

> *A sensor's not gonna pick up my feelings of emptiness.*

They were also incredulous that sensors could accurately detect the intended symptoms:

> *I wonder if that would work with my dog. I talk to my dog all the time.*

A couple of stakeholders suggested that sensors would need to be able to differentiate data from home visitors:

> *But when other people come to visit you or use your house or even if their care workers or something. Then they would they might access the toilet, the kitchen sink. They wouldn't be in your bed though, you tend to have your own side of the bed don't you. So, I think bed probably works well. But what about towels? I don't know if in a towel would work.*

The company representative and expert in smart textiles also noted the importance of data detection during the wearable's movement.

Economic Inclusivity

Stakeholders with a background in charity, social work, or housing provision raised the question of how such a system could become affordable to more people. They recommended a tiered system:

> *Being a tiered service, a basic service, open to all. And if I can afford it and can afford to pay a subscription maybe a better-quality service or a wider range of monitoring.*

People could choose from a basic or more elaborate sensor system and intervention for loneliness based on their financial possibilities and individual needs.

Cultural Inclusivity

Some stakeholders questioned the compatibility of such a system for different cultures. For instance, some cultures might prefer seats on the floor rather than a traditional settee:

> *Some people might not use settees but sit on the floor.*

The monitoring system and linked interventions would also need to be delivered in multiple languages or visual symbols that are universally understood:

> *Different cultures respond to different phrases.*

Flexibility to Change

An expert on housing provision to older adults mentioned the importance of system flexibility concerning future technological developments:

> *Builders and housing developers want something flexible. Because if you look at things like the existing, the old-fashioned emergency call systems, a lot of providers had difficulties retrofitting.*

Previous emergency call systems had proved challenging to replace in care housing. Thus, systems need to avoid becoming integrated into the home infrastructure.

Comfort

Comfort was mentioned by some older participants in workshops, describing it as a crucial element of wearable acceptability:

> *But then surely we are back to the Velcro thing, aren't we, which we discussed, and we don't really like because it is stiff and uncomfortable.*

It was a key argument for where they wished the sensor system to become positioned on the body. Older adults expressed concerns regarding wearables with detachable components, with 1 participant describing Velcro as "stiff" and "uncomfortable." The mattress cover and seating cushion were rated most comfortable (mean 4.5, SD 0.56). The vest was perceived as less comfortable (mean 3, SD 0.71). One participant felt he would be unwilling to wear a vest but would accept a watch:

> *I could see being prepared to wear a watch.*

It also seemed related to the fact that participants felt concerned about the comfort of such a vest:

> *It might go underneath of their own vest or if it can go on top of their vest, there are two sides there. Their own vest is comfortable, and they are used to it so the other one could be on top of it, if it still works.*

Environmental Consciousness

Concerns about the environmental impact of the technology were expressed by 3 of the older participants. Environmental consciousness affected peoples' charging and material preferences. Moreover, a stakeholder with experience in providing smart textile applications emphasized the importance of enabling the exchange of batteries at the end of their life span to avoid the wastefulness of the overall technology. It needs to be outweighed whether people want easier washing or longer durability of the components. Participants disagreed that it would be acceptable to dispose of a vest after 3 months of use (mean 2, SD 1.41). In addition, participants disagreed with disposing of the detachable sensors after 3 months of use (mean 2, SD 1.50), indicating environmental and economic consciousness.

Cooperation With Other People

The social worker reported cases where people liked manipulating activity monitoring and supporting systems:

> *It's actually critical, is accuracy. I think you mentioned earlier that, you know, if people are given a walking stick with G.P.S. monitoring, they can give the walking stick to somebody else and wander off.*

A family member reported that their relative misused a sensing doormat to call staff more frequently, so it had to be unplugged:

> *My mother is actually in a residential home. She started off with a mattress cover and a floor mat, but when she gets annoyed at the staff, she consciously hits it to make sure that the staff are required to come and see her. And they have given up with using them because she does it so often and they have to respond to her.*

Thus, the monitoring system's functioning will need people to cooperate, and developers need to expect that some people are willing to trick or use a system in unintended ways.

Aesthetics

In response to the presented digital and physical system concepts, focus group participants felt that aesthetics and a gentle appearance were missing. The system components were found to be too sterile and cold in appearance:

> *It does remind me of the original cars in America when everything was black, black, or black and this feels like it's surgical. It doesn't have a pretty pattern for example.*

The indication of loneliness in graphics or visual data also needs to convey information more sensitively. A red color or light on a display or device might indicate a lower level of physical and mental well-being or a need to charge the device. However, this needs to be designed in a more sensitive and friendly manner. According to an older participant, red colors should be avoided and instead, more friendly, soothing colors should be used:

> *That one goes red, they wouldn't like that. Now they know that I feel lonely, you know, because there is a stigma attached as well, so sweet colors, you know the meaning of them, but you don't want to scare them.*

Requirements for Wearables and Furniture

Compatibility With Existing Clothing and Furniture

A few stakeholders asked how a wearable would integrate with people's existing wardrobe and how it would match the broad range of clothing styles. They felt that everyone had their preferences and style in clothing. Two older women also expressed how certain wearables, such as socks, would not suit dresses or tighter shoes, and a wearable would need to be compatible with different outfits and match one's wardrobe:

> *If you are wearing skirt or dress you are not going to want to wear socks, aren't you?*

Many participants preferred the system's attachability to existing furniture (eg, cushions). Due to sentimental and financial reasons, older adults expressed that it was unlikely that people would be willing to exchange their existing furnishing:

> *I can't see people being able to afford to have new furniture.*

Seasonal, Intuitive, and Unisex

Participants from both interviews and workshops noted that a wearable must function in different seasons:

> *On a summer's day you wouldn't have it on the sleeve.*

Interview participants frequently mentioned underwear (ie, brassiere and pants) as an item of clothing that is close to the skin and intuitively worn daily:

> *I think the picture with this attached to your bra makes the most sense to me, because it is something*

> *you automatically put on and you wear under your clothing.*

Older adults in workshops expressed the importance of integrating a wearable sensor into clothing that would be habitually worn to avoid additional burdens. While most women in the first co-design session agreed to have sensors positioned on bras, they felt it would not be adequate for men:

> *It would be a problem for men, presumably men, I mean we are all female.*

Thus, unisex options for the wearables would need to be available, such as vests and socks.

Discretion

The device's conspicuous design or positioning could risk drawing unwanted attention. A few workshop participants expressed concern that a conspicuous design or positioning (eg, wrist-worn wearable) could also feel stigmatizing or become the subject of conversation:

> *I think people would ask you what it was. I think you would draw attention to it if it was on your wrist.*

The loneliness sensing system would need to be presented inconspicuously.

No Detachable Components on Wearables

Detachable sensor components were proposed to support the sensor's durability over washing cycles. The detachability of sensors could also enhance the recycling of the sensors on the garment and reduce waste. Multiple participants argued against attachments to apparel and clothing due to comfort, cleanability, and the risk of breaking the sensors. There was a risk that Velcro would feel “bulky,” and detachable components would still need to be cleaned, as they were close to the skin. Furthermore, people could easily forget to remove the detachable components and accidentally break the device:

> *People will forget to remove stuff...Things will break because of that.*

Material Requirements

Lightweight and Soft Materials

Older adults from workshops mentioned the need for lightweight materials to increase the discretion of the device (“You want to make it seamless”) and the need for greater comfort. Participants recommended soft materials or materials that are not rough. It is important to select a preferred and comfortable material, particularly for textiles worn close to the skin continuously.

Natural and Antiallergic Materials

Most participants preferred natural materials for comfort and mentioned the likelihood of allergic reactions to synthetic fabrics:

> *And cotton I suppose because some people are allergic to, if I wear something artificial over a certain percentage, I get rashes all over the place.*

Nonmagnetic Materials

A private carer mentioned the potential interference of sensors with pacemakers worn to regulate one's heart rhythm. Thus, all components embedded in clothing will need to be noninterfering.

Wrinkle-Free Materials

One older participant also wished for a material that does not wrinkle, to avoid ironing it. Otherwise, it would need to be a material that resists ironing:

> *Because some shirts nowadays, you know, you don't really need to iron them.*

Positioning Requirements

Privacy

Privacy was a key determinant in how participants positioned the sensing textiles on the body and in the home. Most participants mentioned they would not position any wearables closer to the lower torso region, excluding shorter pants or underwear in that area. Moreover, some individuals found the positioning of sensors in the bed or bedroom unfitting due to privacy issues. Conversely, 4 participants found positioning in the bed and bedroom reasonable and acceptable. Therefore, privacy needs vary from person to person.

Use in Daily Activities

The preferred positioning of smart textile wearables on the body and furniture also depends on people's daily activities. Some participants felt that a sensor positioning on longer sleeves, socks, or in the bathroom would pose a risk of getting the sensors wet. This would lead to a more frequent need to wash the wearable or home-based device. Interview participants also highlighted the importance of the wearable being discreet and unnoticeable, with specific reference to its use, and not being inconvenient or impacting daily activities. A wearable must be integrated to appear subtle, hidden, imperceptible, and inconspicuous.

Washing Requirements

Washability of All System Parts

Older adults in workshops discussed how any textile would need to be regularly washed as they would be in close contact with the skin. In terms of furniture, covers must be regularly washable, for instance, in cases of incontinence or spills, whereas clothing wearables, specifically underwear, would need to be washed daily. Workshop participants also discussed how any detachable components close to the skin would need to be clean and washable. Therefore, the detachable components would take more effort to clean than when directly printed on the wearable, but they could be treated more sensitively.

Machine Washing

The device or wearable should be machine washable as not everyone might like to do a separate washing, as mentioned by few individuals. More individuals preferred a wearable that allows a washing without having to remove any detachable components beforehand (eg, batteries and sensors). This also means that the sensors must resist stronger kinds of detergent and need printed batteries. Participants were neutral (mean 3, SD 1.07) regarding whether they found the system easy to wash. Some were happier to apply a special washing cycle:

> *I like doing hand washing. I hand wash a couple of times a week.*

Others were more critical and unwilling to introduce a separate gentle washing cycle:

> *I only use one cycle on my washing machine and it's going to destroy this. I use the hand washing cycle about once every five months.*

Life Span of 2 Years

A wearable would have an expected life span; however, it was difficult for participants to determine an exact period. The industry representative suggested 2 years after an estimation of yearly washing cycles. This was deemed an acceptable life span for consumers.

Requirements for the Sensor Synchronization Device

Memory Support and Prevention of Loss

The sensor synchronization device is a technical component that helps collect and transmit sensor data outside the home. This could be integrated into a phone or kept as a separate device that an older person can carry. The device should be easily remembered when going outside:

> *It is much less likely that they forget about it if it is attached to their key or to their trousers.*

The industry expert on smart wearable textile applications found a synchronizing device could be easily forgotten and this should be fixed so that people automatically carry outside with them. Alternatively, they could be reminded by a light or noise. One older participant felt a device of a smaller size could be more easily lost. In the evaluation, the mattress cover was rated highest for being easily remembered (mean 4, SD 0). The insoles and socks were considered less easy to remember for an older person (mean 3, SD 0.71). Participants were neutral (mean 2.8, SD 0.75) when asked whether the system is easy to use, also due to potentially forgetting to use it: people "might forget or not bother using it."

Charging Requirements

Little Cognitive Strain and Notifications

A couple of stakeholders also mentioned that older people might forget how to change batteries. Carers would potentially be supportive of charging and exchanging batteries for the devices. Notifications were a recommended feature by the industry expert. A display, light, or notification sound could help inform older adults and carers about the charging status. On average, participants in the focus groups disagreed on whether it would be acceptable to remove a battery before washing (mean 2, SD 1.06). Written comments included "too fiddly," "not practical at all," and "dexterity." This is particularly relevant for batteries attached to the vest or socks, due to more frequent washing. When questioned about their thoughts regarding an inductive charging station, participants wished for a dedicated area to place all device components to be loaded:

> *If there was a single place that you could throw the whole lot and they be charged in the morning.*

Fewer Plugs

The industry expert who had previous experience working with older people with disabilities mentioned that there can be few plugs in apartments. Therefore, the system should not require too many plugs:

> *We have a project with older people who also have learning disabilities. People don't necessarily have a lot of power, lot of plugs.*

Accessibility

Some charging processes can require the agility of the hands. While many found the idea of smaller batteries preferable, participants were concerned about the size and process of replacing batteries:

> *I would have a comment about removable batteries and everything because I know of at least two people who have problems with hearing aids putting batteries in, and it depends how like fiddly it is. For people who don't have the dexterity.*

Older people could have arthritis and might find certain charging processes difficult. Simple charging methods that require less precision, such as inductive charging, might be an appropriate solution.

Requirements for the Linked Intervention

Providing a Linked Intervention

Participants were neutral on whether they considered the system useful to help address loneliness (mean 2.7, SD 1.25). Many older participants found it difficult to comprehend the value of the monitoring system, as they did not see how it could immediately help them address their loneliness. A notification about their loneliness was not perceived as valuable. Few older participants determined that they were already aware of when they felt alone. One participant also did not have any children or family members to be contacted. Thus, determining how the interventions are valuable to different individuals is important to their perceived value. This finding was also reflected in the focus group evaluation, where it became apparent that people were pressing on what happened due to the detection of loneliness. One participant expressed as follows:

> *I am not sure what help I will be for this research. If I know I am isolated or lonely, why do I need that? I don't need that to tell me.*
>
> *It is useful to use the system as an older person that experiences loneliness. Yes, it depends on what you do about it... The system is useful to reduce loneliness for older people, not in itself. It depends on what is done because you are just monitoring.*

Personalization

Multiple stakeholders mentioned the importance of personalization concerning the linked intervention. A personalized intervention could better appeal to people who might feel discouraged from engaging in activities:

> *All of your interests. Something that really interests you and you will make the effort.*

Avoiding Burden on Family Members

The monitoring system could communicate data to family members. However, a few older participants expressed concern about how such a system could burden their family members:

> *I don't want it to be family because I think I mean I've got this memory of my grandmother guilt tripping people all the time. And I think this would be a very formal way of guilt tripping. And you know, they've got their own lives.*

Infrastructure

Some stakeholders were concerned about not only the functioning of the technology but also the infrastructure requirements:

> *You felt you were having a heart attack and you phoned nine, nine, nine, it still might take six hours. So, I suppose that's not that this doesn't change that, does it. That's an extra thing.*

In addition, from the perspective of a family member, it was also noted that older people might be in a carer position themselves, which restricts their time and resources to take action to address their loneliness. One participant recalled previous experiences with dedicated staff for loneliness and long waiting times for being contacted. Infrastructural requirements are particularly relevant for interventions that respond to detected loneliness.

Motivation

One difficulty addressed by a few stakeholders was how to help with "chronic" or almost paralyzing loneliness. In such cases, older people might struggle to find motivation or see purpose in acting to change their situation:

> *For people who are lonely or who are isolated, it's generalized again but they are not necessarily, they are in that situation because they potentially aren't the type of person...or there aren't the opportunities to go and do something. Actually, stepping through the door of some kind of group activity for some people they just wouldn't do it.*

Installation and Maintenance Requirements

Identification

One of the first questions to be addressed is identifying people most in need of receiving such a system:

> *You need to know whether they're likely to be lonely in the first place.*

The monitoring system could become privately acquired, but it could also become part of housing schemes. Stakeholders discussed that identification should occur through individuals in regular closer contact with the older person, ranging from medical staff to people in the community and delivery service staff, as they can sometimes identify changes over time or be the only existent touchpoint. The social worker drew attention to the potential stigmatization connected to revealing one's feelings of loneliness, and it might be preferable to make such a system the norm and offer it to everyone as part of the housing scheme.

Consent

Consent needs to be acquired before installation. Consent should confirm that people are willing to have such a system installed in their homes, and it should indicate who can access the data collected. Further considerations need to be made in case someone cannot make an informed decision for themselves:

> *The person whose data people are accessing, they need to give people permission, and they might not want to share certain things with the carer, they might not want to share with the family.*

Easy Installation, Instructions for Carers, and Continuous Support Provision

The system needs to be easily installable, as recommended by an expert in textile wearables. It should ideally function readily when it arrives ("plug and play"). Carers will likely be involved in helping to charge the system or washing the textile wearables and furniture covers. Therefore, clear instructions need to be provided at the older person's home. The instructions should be visibly placed as one needs to expect a regular change in carers, who will need to be directed. According to the industry expert, a technology provider would also need to have a customer service facility that can be called to provide help in case people have technical difficulties.

Discussion

Principal Findings

This research aimed to understand user and stakeholder requirements for a smart textile loneliness monitoring system. Overall, a key finding is the participants' concern regarding what applications and interventions become linked to the sensor monitoring system for loneliness. Previous work found that older adults' acceptance of smart textile technology and smart home devices depends strongly on perceived usefulness [56-58]. Whether the monitoring system was perceived as useful often depended on what actions would be taken in response to the monitoring. Previous rationales for developing loneliness monitoring provided in the literature were the importance of loneliness as a health concern [11,59]; the identification of loneliness, as directly communicating it might be associated with stigma [11,12,22]; potential bias in self-reporting and the nonobjective reporting of one's state, also due to cognitive decline, to help prevent loneliness early on [11]; and research purposes to better understand the relationship between loneliness and health outcomes [11,13]. While questioning older participants and stakeholders, we found that participants perceived particular applicability in dementia, particularly as family members who wished to be notified of the status of loneliness of their loved ones. This might require future research to better involve such susceptible populations in the development of loneliness monitoring systems for accuracy. In contrast, it raises issues of consent and the state at which it would be achievable. Other potential applications considered by participants were buddy systems, being part of a group to improve technology development for older people to provide agency, and an artificial intelligence–recommendation system.

A proposition has also been made to potentially detect changes in individuals earlier on, in terms of loneliness, than is currently possible [13]. These suggestions elicit questions about available infrastructure and about an efficient distribution of the system. In case a loneliness monitoring system is intended warn people of loneliness in its early states [13], it could require a wider distribution than what might be affordable. A suggestion was to involve people who are in regular contact with potentially affected people to support a more targeted distribution.

Our findings showed that some older adults felt that the monitoring process did not solve their loneliness directly. Some also thought that they would not need a system to tell them when they are lonely.

Other propositions are informing family members or caregivers [12], overcoming stigma to receive help where necessary, and assessing current risks for greater mental health consequences [12]. Some declined the idea of contacting their family members in response to detected loneliness due to fears of burdening them. Stakeholders also noted that time constraints by health care professionals or social work professionals would not change via the introduction of a monitoring system. In contrast, 2 family members wished they had such a system to inform them about the well-being of susceptible family members (eg, those with mild dementia) across distance.

Similar to previous literature, participants expressed a preference for natural, soft, and lightweight materials useful in daily activities [34,37]. They also expressed a need for comfort [34-36] and discretion [36]. We found that furniture-embedded smart textiles (on a mattress or sofa) were rated more positively regarding comfort and ease of remembrance than smart apparel (eg, a smart vest), which has been predicted in previous literature on loneliness monitoring systems [11,23]. This was not only due to the individual preferences in clothing (whether one was used to wearing a vest or a watch) but also due to the greater potential effort in washing and charging. Therefore, it should be possible to consider individual preferences in the choice of sensor devices for monitoring [58]. In addition to the cultural sensitivity for clothing and wearable styles [35,38], we observed the same considerations in the context of textiles on furniture. In our study, we observed that colors that could elicit negative emotions should also be avoided, particularly for mental health applications. This aligns with findings from previously developed websites, robots, and devices to address the loneliness of older people [60-63]. Many vests and smart textiles developed for older people do have a plain design [64]; however, there have been exceptions that experimented with more friendly motifs of cats and flowers on smart textiles for patients with dementia [65]. Participants required the current system to function along with their existing furniture and clothing as they were unlikely to be replaced. Embedded electronics and their positioning must be compatible with other wearable health care devices, such as pacemakers or stoma bags. Regarding considerations of reliability and accuracy [37,38], participants also noted the possibilities of manipulation by them and the potential impact through people's movement.

Washing and charging procedures are key concerns for the usability of the proposed technology. Current washing cycles [26,36] are not sufficient for user requirements, as participants did not agree with a life span of approximately 3 months. Most people did not accept special washing requirements, such as hand washing, or the use of a special washing cycle [39]. The proposed solution of detachable components [38,40,65], which could protect electronics from being washed as part of the overall textile, appeared more reasonable for furniture but less applicable for wearables that must be washed often. Participants emphasized the importance of washability of all parts (in particular, the materials close to the skin). Smart textile wearables and furniture covers are required to be washed frequently, due to the risk of spilling liquids at an older age or the possibility of incontinence. For maintenance, there will also need to be notifications and instructions for charging and washing and the requirement for fewer plugs, which is supported by previous findings from technologies addressing loneliness for older people. While current charging options are developed for smart textiles to become less obtrusive, they need to consider the potential limited dexterity of older people to handle them while washing or charging.

Strengths and Limitations

There has been little understanding of the needs of stakeholders and older people for the development of smart textile loneliness monitoring systems. Our insights were based on people envisioning the system by presenting a prototype and use case. Therefore, it was not possible to determine the proposed system's actual usability. In the future, we would like to undertake system testing in the field.

Conclusions

This study presented key design requirements for a loneliness monitoring system embedded in smart textiles in wearables and smart home furniture from the perspectives of older people and stakeholders, touching on questions of usefulness and usability. Sensors on smart home furniture seem to face fewer difficulties in terms of individual habits, washing, and charging than applications that are wearable. Overall, the linked intervention in response to monitored loneliness remains a question that needs more in-depth understanding, including what individuals perceive as most valuable in connection with such a sensing system. We found additional aspects in the system design that have not found much consideration in previous work, such as the need for user cooperation, compatibility with other worn medical devices, user expectations regarding life span and washing requirements, questions about identifying the recipients of the system, and initial insights into possible linked interventions and purposes of loneliness monitoring systems.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Personas used to inspire the discussion on interventions.
[DOCX File , 15 KB - aging_v7i1e57622_app1.docx]

Multimedia Appendix 2
Categories and frequencies (each participant is only counted once in each category) of quotes for the co-design and focus group study.
[DOCX File , 47 KB - aging_v7i1e57622_app2.docx]

References

1. Perlman D, Peplau LA. Toward a social psychology of loneliness. In: Personal Relationships: Personal Relationships in Disorder. Cambridge, MA: Academic Press; 1981.
2. Svensson M, Rosso A, Elmståhl S, Ekström H. Loneliness, social isolation, and health complaints among older people: a population-based study from the "Good Aging in Skåne (GÅS)" project. SSM Popul Health 2022 Nov 07;20:101287 [FREE Full text] [doi: 10.1016/j.ssmph.2022.101287] [Medline: 36387019]
3. Hemberg J, Nyqvist F, Näsman M. "Homeless in life" - loneliness experienced as existential suffering by older adults living at home: a caring science perspective. Scand J Caring Sci 2019 Jun;33(2):446-456. [doi: 10.1111/scs.12642] [Medline: 30566252]
4. Rees J, Liu W, Ourselin S, Shi Y, Probst F, Antonelli M, et al. Understanding the psychological experiences of loneliness in later life: qualitative protocol to inform technology development. BMJ Open 2023 Jun 19;13(6):e072420 [FREE Full text] [doi: 10.1136/bmjopen-2023-072420] [Medline: 37336536]
5. Steptoe A, Owen N, Kunz-Ebrecht SR, Brydon L. Loneliness and neuroendocrine, cardiovascular, and inflammatory stress responses in middle-aged men and women. Psychoneuroendocrinology 2004 Jun;29(5):593-611. [doi: 10.1016/s0306-4530(03)00086-6]
6. Balki E, Hayes N, Holland C. The indirect impact of educational attainment as a distal resource for older adults on loneliness, social isolation, psychological resilience, and technology use during the COVID-19 pandemic: cross-sectional quantitative study. JMIR Aging 2023 Nov 24;6:e47729 [FREE Full text] [doi: 10.2196/47729] [Medline: 37999938]
7. Eskelinen K, Hartikainen S, Nykänen I. Is loneliness associated with malnutrition in older people? Int J Gerontol 2016 Mar;10(1):43-45. [doi: 10.1016/j.ijge.2015.09.001]
8. Davies K, Maharani A, Chandola T, Todd C, Pendleton N. The longitudinal relationship between loneliness, social isolation, and frailty in older adults in England: a prospective analysis. Lancet Health Longev 2021 Feb;2(2):e70-e77. [doi: 10.1016/s2666-7568(20)30038-6]
9. Luo Y, Hawkley LC, Waite LJ, Cacioppo JT. Loneliness, health, and mortality in old age: a national longitudinal study. Soc Sci Med 2012 Mar;74(6):907-914. [doi: 10.1016/j.socscimed.2011.11.028] [Medline: 22326307]
10. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci 2015 Mar;10(2):227-237. [doi: 10.1177/1745691614568352] [Medline: 25910392]
11. Austin J, Dodge HH, Riley T, Jacobs PG, Thielke S, Kaye J. A smart-home system to unobtrusively and continuously assess loneliness in older adults. IEEE J Transl Eng Health Med 2016 Jun 10;4:2800311. [doi: 10.1109/JTEHM.2016.2579638] [Medline: 27574577]
12. Huynh S, Tan HP, Lee Y. Towards unobtrusive mental well-being monitoring for independent-living elderly. In: Proceedings of the 4th International on Workshop on Physical Analytics. 2017 Presented at: WPA '17; June 19, 2017; New York, NY. [doi: 10.1145/3092305.3092311]
13. Petersen J, Thielke S, Austin D, Kaye J. Phone behaviour and its relationship to loneliness in older adults. Aging Ment Health 2016 Oct;20(10):1084-1091. [doi: 10.1080/13607863.2015.1060947] [Medline: 26133745]
14. Palamutcu S, Goren I. Functional textile preferences of elderly people. Mediterr J Soc Sci 2015 May 1;6(2 S5):279. [doi: 10.5901/mjss.2015.v6n2s5p279]
15. Avellar L, Stefano Filho C, Delgado G, Frizera A, Rocon E, Leal-Junior A. AI-enabled photonic smart garment for movement analysis. Sci Rep 2022 Mar 08;12(1):4067 [FREE Full text] [doi: 10.1038/s41598-022-08048-9] [Medline: 35260746]

16. Yang K, Isaia B, Brown LJ, Beeby S. E-textiles for healthy ageing. Sensors (Basel) 2019 Oct 15;19(20):4463 [FREE Full text] [doi: 10.3390/s19204463] [Medline: 31618875]
17. Ejupi A, Menon C. Detection of talking in respiratory signals: a feasibility study using machine learning and wearable textile-based sensors. Sensors (Basel) 2018 Jul 31;18(8):2474 [FREE Full text] [doi: 10.3390/s18082474] [Medline: 30065177]
18. Cacioppo JT, Hughes ME, Waite LJ, Hawkley LC, Thisted RA. Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. Psychol Aging 2006 Mar;21(1):140-151. [doi: 10.1037/0882-7974.21.1.140] [Medline: 16594799]
19. Griffin SC, Williams AB, Mladen SN, Perrin PB, Dzierzewski JM, Rybarczyk BD. Reciprocal effects between loneliness and sleep disturbance in older Americans. J Aging Health 2020 Oct;32(9):1156-1164 [FREE Full text] [doi: 10.1177/0898264319894486] [Medline: 31868077]
20. Cacioppo JT, Hawkley LC, Crawford LE, Ernst JM, Burleson MH, Kowalewski RB, et al. Loneliness and health: potential mechanisms. Psychosom Med 2002;64(3):407-417. [doi: 10.1097/00006842-200205000-00005] [Medline: 12021415]
21. Hawkley LC, Thisted RA, Masi CM, Cacioppo JT. Loneliness predicts increased blood pressure: 5-year cross-lagged analyses in middle-aged and older adults. Psychol Aging 2010 Mar;25(1):132-141. [doi: 10.1037/a0017805] [Medline: 20230134]
22. Yamada Y, Shinkawa K, Nemoto M, Arai T. Automatic assessment of loneliness in older adults using speech analysis on responses to daily life questions. Front Psychiatry 2021 Dec 13;12:712251 [FREE Full text] [doi: 10.3389/fpsyt.2021.712251] [Medline: 34966297]
23. Hudec R, Matúška S, Kamencay P, Benco M. A smart IoT system for detecting the position of a lying person using a novel textile pressure sensor. Sensors (Basel) 2020 Dec 31;21(1):206 [FREE Full text] [doi: 10.3390/s21010206] [Medline: 33396203]
24. Gwon D, Cho H, Shin H. Feasibility of a waistband-type wireless wearable electrocardiogram monitoring system based on a textile electrode: development and usability study. JMIR Mhealth Uhealth 2021 May 11;9(5):e26469 [FREE Full text] [doi: 10.2196/26469] [Medline: 33973860]
25. Hu KJ, Chang CW, Chang YS. Application for detecting falls for elderly persons through internet of things combined with pulse sensor. Sens Mater 2023;35(11(2)):3655-3669. [doi: 10.18494/SAM4641]
26. Ma Y, Ouyang J, Raza T, Li P, Jian A, Li Z, et al. Flexible all-textile dual tactile-tension sensors for monitoring athletic motion during taekwondo. Nano Energy 2021 Jul;85:105941. [doi: 10.1016/j.nanoen.2021.105941]
27. Ji X, Li X, Yuh A, Kendell C, Watson A, Weimer J, et al. Short: integrated sensing platform for detecting social isolation and loneliness in the elderly community. In: Proceedings of the 8th ACM/IEEE International Conference on Connected Health: Applications, Systems and Engineering Technologies. 2023 Presented at: CHASE '23; June 21-23, 2023; Orlando, FL. [doi: 10.1145/3580252.3586983]
28. Chen M, Liu J, Li P, Gharavi H, Hao Y, Ouyang J, et al. Fabric computing: concepts, opportunities, and challenges. Innovation (Camb) 2022 Oct 14;3(6):100340 [FREE Full text] [doi: 10.1016/j.xinn.2022.100340] [Medline: 36353672]
29. Zhu M, Shi Q, He T, Yi Z, Ma Y, Yang B, et al. Self-powered and self-functional cotton sock using piezoelectric and triboelectric hybrid mechanism for healthcare and sports monitoring. ACS Nano 2019 Feb 26;13(2):1940-1952. [doi: 10.1021/acsnano.8b08329] [Medline: 30741521]
30. Scholten HJ, Shih CD, Ma R, Malhotra K, Reyzelman AM. Utilization of a smart sock for the remote monitoring of patients with peripheral neuropathy: cross-sectional study of a real-world registry. JMIR Form Res 2022 Mar 01;6(3):e32934 [FREE Full text] [doi: 10.2196/32934] [Medline: 35230248]
31. Kim H, Jang SJ, Lee HD, Ko JH, Lim JY. Smart floor mats for a health monitoring system based on textile pressure sensing: development and usability study. JMIR Form Res 2023 Aug 07;7:e47325. [doi: 10.2196/47325] [Medline: 37548993]
32. Chen M, Ouyang J, Jian A, Liu J, Li P, Hao Y, et al. Imperceptible, designable, and scalable braided electronic cord. Nat Commun 2022 Nov 19;13(1):7097 [FREE Full text] [doi: 10.1038/s41467-022-34918-x] [Medline: 36402785]
33. Chen M, Li P, Wang R, Xiang Y, Huang Z, Yu Q, et al. Multifunctional fiber-enabled intelligent health agents. Adv Mater 2022 Dec;34(52):e2200985. [doi: 10.1002/adma.202200985]
34. Júnior HL, Neves RM, Monticeli FM, Dall Agnol L. Smart fabric textiles: recent advances and challenges. Textiles 2022 Nov 21;2(4):582-605. [doi: 10.3390/textiles2040034]
35. Fernández-Caramés TM, Fraga-Lamas P. Towards the internet of smart clothing: a review on IoT wearables and garments for creating intelligent connected e-textiles. Electronics 2018 Dec 07;7(12):405. [doi: 10.3390/electronics7120405]
36. Fan W, He Q, Meng K, Tan X, Zhou Z, Zhang G, et al. Machine-knitted washable sensor array textile for precise epidermal physiological signal monitoring. Sci Adv 2020 Mar 13;6(11):eaay2840 [FREE Full text] [doi: 10.1126/sciadv.aay2840] [Medline: 32201720]
37. Tsai TH, Lin WY, Chang YS, Chang PC, Lee MY. Technology anxiety and resistance to change behavioral study of a wearable cardiac warming system using an extended TAM for older adults. PLoS One 2020 Jan 13;15(1):e0227270 [FREE Full text] [doi: 10.1371/journal.pone.0227270] [Medline: 31929560]
38. Kan CW, Lam YL. Future trend in wearable electronics in the textile industry. Appl Sci 2021 Apr 26;11(9):3914. [doi: 10.3390/app11093914]

39. Gaubert V, Gidik H, Bodart N, Koncar V. Investigating the impact of washing cycles on silver-plated textile electrodes: a complete study. Sensors (Basel) 2020 Mar 20;20(6):1739 [FREE Full text] [doi: 10.3390/s20061739] [Medline: 32245027]
40. Muhammad Sayem AS, Hon Teay S, Shahariar H, Fink PL, Albarbar A. Review on smart electro-clothing systems (SeCSs). Sensors (Basel) 2020 Jan 21;20(3):587 [FREE Full text] [doi: 10.3390/s20030587] [Medline: 31973123]
41. Meena JS, Choi SB, Jung SB, Kim JW. Electronic textiles: new age of wearable technology for healthcare and fitness solutions. Mater Today Bio 2023 Jan 28;19:100565 [FREE Full text] [doi: 10.1016/j.mtbio.2023.100565] [Medline: 36816602]
42. Rees J, Matcham F, Probst F, Ourselin S, Shi Y, Antonelli M, et al. Wearables, sensors and the future of technology to detect and infer loneliness in older adults. Gerontechnology 2023;22(2):1-4. [doi: 10.4017/gt.2023.22.2.ree.08]
43. Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A short scale for measuring loneliness in large surveys: results from two population-based studies. Res Aging 2004;26(6):655-672. [doi: 10.1177/0164027504268574] [Medline: 18504506]
44. Czaja SJ, Moxley JH, Rogers WA. Social support, isolation, loneliness, and health among older adults in the PRISM randomized controlled trial. Front Psychol 2021 Oct 05;12:728658 [FREE Full text] [doi: 10.3389/fpsyg.2021.728658] [Medline: 34675843]
45. Kosch T, Woźniak PW, Brady E, Schmidt A. Smart kitchens for people with cognitive impairments: a qualitative study of design requirements. In: Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems. 2018 Presented at: CHI '18; April 21-26, 2018; Montreal, QC. [doi: 10.1145/3173574.3173845]
46. Gibson RC, Bouamrane MM, Dunlop M. Design requirements for a digital aid to support adults with mild learning disabilities during clinical consultations: qualitative study with experts. JMIR Rehabil Assist Technol 2019 Mar 04;6(1):e10449 [FREE Full text] [doi: 10.2196/10449] [Medline: 30829575]
47. Dick S, O'Connor Y, Thompson MJ, O'Donoghue J, Hardy V, Wu TS, et al. Considerations for improved mobile health evaluation: retrospective qualitative investigation. JMIR Mhealth Uhealth 2020 Jan 22;8(1):e12424. [doi: 10.2196/12424] [Medline: 32012085]
48. Baxter K, Courage C, Caine K. Understanding Your Users: A Practical Guide to User Research Methods. Burlington, MA: Morgan Kaufmann; May 20, 2015.
49. Li J, Ma Q, Chan AH, Man SS. Health monitoring through wearable technologies for older adults: smart wearables acceptance model. Appl Ergon 2019 Feb;75:162-169. [doi: 10.1016/j.apergo.2018.10.006]
50. Krippendorff K. Content Analysis: An Introduction to Its Methodology. Thousand Oaks, CA: SAGE Publications; 2004.
51. Brooke J. SUS: a 'quick and dirty' usability scale. In: Usability Evaluation In Industry. Boca Raton, FL: CRC Press; 1996.
52. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Q 1989 Sep;13(3):319-340. [doi: 10.2307/249008]
53. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115. [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]
54. Morgan DL. Qualitative content analysis: a guide to paths not taken. Qual Health Res 1993 Feb;3(1):112-121. [doi: 10.1177/104973239300300107] [Medline: 8457790]
55. Forman J, Damschroder L. Qualitative content analysis. In: Jacoby L, Siminoff LA, editors. Empirical Methods for Bioethics: A Primer. Bingley, UK: Emerald Group Publishing Limited; 2007:39-62.
56. Mahmood N, Lee YA. Factors influencing older adults’ acceptance of health monitoring smart clothing. Fam Consum Sci Res J 2021 Jun 04;49(4):376-392. [doi: 10.1111/fcsr.12404]
57. Brauner P, van Heek J, Ziefle M. Age, gender, and technology attitude as factors for acceptance of smart interactive textiles in home environments: towards a smart textile technology acceptance model. In: Proceedings of the 3rd International Conference on Information and Communication Technologies for Ageing Well and e-Health. 2017 Presented at: ICT4AWE 2017; April 28-29, 2017; Porto, Portugal. [doi: 10.5220/0006255600130024]
58. Choi YK, Thompson HJ, Demiris G. Use of an internet-of-things smart home system for healthy aging in older adults in residential settings: pilot feasibility study. JMIR Aging 2020 Nov 10;3(2):e21964 [FREE Full text] [doi: 10.2196/21964] [Medline: 33170128]
59. Site A, Vasudevan S, Afolaranmi SO, Lastra JL, Nurmi J, Lohan ES. A machine-learning-based analysis of the relationships between loneliness metrics and mobility patterns for elderly. Sensors (Basel) 2022 Jun 30;22(13):4946 [FREE Full text] [doi: 10.3390/s22134946] [Medline: 35808440]
60. Al Mahmud A, Long KM, Harrington KD, Casey K, Bhar S, Curran S, et al. Developing a digital psychoeducational tool to reduce loneliness in older adults: a design case study. Int J Hum Comput Interact 2021 Aug 04;38(6):499-528. [doi: 10.1080/10447318.2021.1949854]
61. Demaeght A, Miclau C, Hartmann J, Markwardt J, Korn O. Multimodal emotion analysis of robotic assistance in elderly care. In: Proceedings of the 15th International Conference on PErvasive Technologies Related to Assistive Environments. 2022 Presented at: PETRA '22; June 29-July 1, 2022; Corfu, Greece. [doi: 10.1145/3529190.3529194]
62. Yamazaki R, Nishio S, Ishiguro H, Nørskov M, Ishiguro N, Balistreri G. Acceptability of a teleoperated android by senior citizens in Danish society. Int J of Soc Robot 2014 Jul 15;6:429-442. [doi: 10.1007/s12369-014-0247-x]

63. Chen SC, Jones C, Moyle W. The impact of engagement with the PARO therapeutic robot on the psychological benefits of older adults with dementia. Clin Gerontol 2024;47(5):909-921. [doi: 10.1080/07317115.2022.2117674] [Medline: 36062840]
64. Lin CC, Yang CY, Zhou Z, Wu S. Intelligent health monitoring system based on smart clothing. Int J Distrib Sens Netw 2018 Aug 13;14(8):1550147718794318. [doi: 10.1177/1550147718794318]
65. Oatley G, Choudhury T, Buckman P. Smart textiles for improved quality of life and cognitive assessment. Sensors (Basel) 2021 Nov 30;21(23):8008 [FREE Full text] [doi: 10.3390/s21238008] [Medline: 34884010]

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Review

The Implementation Success of Technology-Based Counseling in Dementia Care: Scoping Review

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Abstract

Background: Implementing technology-based counseling as a complex intervention in dementia care poses challenges such as adaptation to stakeholders’ needs and limited resources. While studies have examined the effectiveness of technology-based counseling, its successful implementation remains largely unexplored.

Objective: We aimed to review the knowledge about the implementation success of technology-based counseling interventions for people with dementia and their informal caregivers.

Methods: We conducted a scoping review and systematically searched CINAHL, the Cochrane Library including the Cochrane Central Register of Controlled Trials, MEDLINE, PsycINFO, and Web of Science Core Collection databases (April 2021) in combination with citation searching and web searching (November 2021). Studies reporting on technology-based counseling interventions for people with dementia or their informal caregivers were included, irrespective of the design. We used the conceptual framework for implementation outcomes to operationalize *implementation success* and applied the outcomes acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability as categories to inform data extraction. We identified dimensions within the categories and synthesized results narratively and graphically.

Results: We included 52 publications reporting on 27 technology-based counseling interventions. The studies were conducted in 9 countries and published between 1993 and 2021. As the design of the included studies varied, the number of participants and the type of data reported varied as well. The intervention programs were heterogeneous and ranged from single counseling interventions (such as helpline services) to counseling as part of a multicomponent program. Telephone, email, videoconferencing, social media (respectively chats), and web-based platforms were used for delivering counseling. We found data on appropriateness for all interventions and data on acceptability for most interventions, describing aspects such as consumer-perceived usefulness and helpfulness of services, as well as satisfaction. Information on the other categories of adoption, feasibility, fidelity, implementation cost, penetration, and sustainability was fragmented.

Conclusions: The scope and depth of information on conceptual categories of the implementation success of technology-based counseling for people with dementia and informal caregivers varied. The data only partially covered the concept of *implementation success*, which highlights the need for a systematic evaluation accompanying the implementation. The application of theoretical approaches for implementation and adherence to the framework for developing and evaluating complex interventions are required to promote the implementation of complex interventions and to comprehensively assess implementation success.

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KEYWORDS

implementation success; implementation outcomes; counseling; technology; dementia

Introduction

During the course of dementia, people with dementia, their families, and informal caregivers may need professional support to deal with the consequences of the disease [1-4]. Supportive interventions [5] are complex in their development, delivery, and impact, as they involve multiple components, aim at multiple outcomes, and are delivered in different settings. In addition, a broad range of skills are required of those who deliver the interventions [6] in dementia care.

Counseling for people with dementia and their informal caregivers is a supportive intervention that can be defined as conversational therapy in which a trained therapist listens to the person, enhances the individual's ability to cope with the effects of dementia, and provides information and education [7,8]. Counselors provide information about the disease and support service options, offer the opportunity to share and discuss feelings or problems, and can enhance problem-solving and coping skills [9,10]. In the context of dementia, counseling services provided by professionals and tailored to individuals aim at various outcomes, such as reducing depressive symptoms and perceived burden, improving quality of life and self-efficacy, and encouraging the uptake of support services in the community [11]. Counseling interventions are therefore complex interventions comprising several components, such as specific training for providers, tools and instruments to individualize services, or different ways to access the available services [9,11]. Information and communication technologies may improve accessibility to counseling [12,13], and this aspect gained importance during the COVID-19 pandemic when remote counseling offered the possibility of providing support without the risk of infection [10,14].

To successfully translate complex interventions into practice, various challenges need to be overcome. Implementation can be defined as an "actively planned and deliberately initiated effort with the intention to bring a given intervention into policy and practice within a particular setting" [15]. The challenges described in implementing eHealth interventions in dementia care include adapting the interventions to match the skills and abilities of the target population, achieving user friendliness in the context of rapidly evolving technology, and addressing users' concerns about security issues, especially when personal information is disclosed [16]. In implementing organizations, the lack of staff resources or the lack of interaction with staff as well as the reluctance of the provider to use the technology may impede implementation [16]. Furthermore, financial and time constraints can also act as barriers to implementation [16]. In the wider context, aspects such as stakeholders' limited capabilities to support innovation or preferences for classically delivered care were identified as significant barriers [16].

Another challenge in the implementation of complex interventions is to operationalize and measure the success or effectiveness of implementation efforts. In a Cochrane Review on remotely delivered information, training, and support (including counseling) for informal caregivers of people with dementia, the authors found information on various aspects indicating implementation success such as acceptability, user satisfaction, or fidelity of implementation. As the indicators and assessment areas varied substantially across studies, data synthesis could not be conducted [9]. There are theoretical approaches that facilitate a comprehensive evaluation of implementation efforts [15]. One of them is the conceptual framework for implementation outcomes introduced by Proctor et al [17], which provides implementation-specific outcomes for assessing implementation success.

While there are studies investigating the effectiveness of technology-based counseling [8,9,11], the extent to which these interventions are successfully implemented remains unexplored. To address this gap in knowledge, we aimed to review the evidence and pursue the question of what is known about the implementation success of technology-based counseling interventions for people with dementia or their informal caregivers.

Methods

Design

According to the methodological approach of scoping reviews [18], we aimed at mapping evidence of implementation success to provide a comprehensive overview. We followed the methodological guidance [18] of the Joanna Briggs Institute and structured our report according to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) [19].

Protocol and Registration

This scoping review is embedded in the project "Technology-based counselling in dementia (TeCoDem)," for which a protocol has been developed [7] and registered with the international prospective register of systematic reviews (PROSPERO CRD42021245473; see the section *Deviations From the Protocol*).

Eligibility Criteria

We included studies, irrespective of their design in English and German, that reported on technology-based counseling interventions for people with any type and severity of dementia or their informal caregivers. Interventions had to be tailored to individuals and provided remotely by professionals using various information technologies. Studies on people with mild cognitive impairment as well as studies on standardized interventions, such as cognitive behavioral therapy, on genetic counseling, and on counseling regarding diagnostics or screening for dementia were excluded. We also excluded studies describing interventions that focus mainly on care coordination or case management. Furthermore, publications reporting exclusively on the development of interventions were excluded [7].

Information Sources and Search Strategy

We searched CINAHL, the Cochrane Library including the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE via PubMed, PsycINFO via Ovid, and the Web of Science Core Collection databases (last search: April 22, 2021) without any filters and limiters. We systematically developed a search strategy that contained 3 components: *dementia*, *technology*, and *counseling*. Corresponding search terms and synonyms (eg, dementia/Alzheimer, technology/electronic, counselling/counseling/consultation) were identified through an orienting search using MEDLINE via PubMed, and we checked entry terms given in the Medical Subject Headings browser. The strategy was peer-reviewed by applying the Peer Review of Electronic Search Strategies [20]. In addition, we performed forward and backward citation searches of included studies and pertinent reviews via Scopus (last search: October 7, 2021) and a web search via Google and Google Scholar (last search: November 26, 2021) [21,22]. Full database-specific search strategies are provided elsewhere [7].

Selection of Sources of Evidence

Titles, abstracts, and full texts were independently screened by 2 reviewers (out of AB, JH, and DB) using the Rayyan web application (Rayyan) [23]. Any discrepancies in the decisions were resolved by discussions within the review team.

Data Charting Process and Data Items

A targeted and uniform extraction sheet was developed and consented to by the research team. We extracted study and design characteristics (year of publication, country where the study was conducted, objectives, number of participants or contacts) and assessed the technology-based counseling interventions by applying criteria from the Template for Intervention Description and Replication checklist [24] and from the revised Criteria for Reporting the Development and Evaluation of Complex Interventions guideline [25] to obtain a comprehensive overview of the interventions and their components. Data extraction on implementation success was guided by the conceptual framework for implementation outcomes, which comprises the implementation outcomes acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability [17]. We adapted the definitions of the outcomes by specifying the intervention of interest and adjusting it to the research interest of our scoping review. Adaptations were consented to by the review team. The original and adapted definitions are listed in Table 1.

Table 1. Original and adapted definitions of implementation outcomes.

Outcome	Original definition according to Proctor et al [17]	Adapted definition for our review
Acceptability	"*Acceptability* is the perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory."	*Acceptability* is the perception among implementation stakeholders of technology-based counseling that the intervention is agreeable, palatable, or satisfactory.
Adoption	"*Adoption* is defined as the intention, initial decision, or action to try or employ an innovation or evidence-based practice."	*Adoption* is defined as the intention, initial decision, or action to try or employ a technology-based counseling intervention.
Appropriateness	"*Appropriateness* is the perceived fit, relevance, or compatibility of the innovation or evidence based practice for a given practice setting, provider, or consumer; and/or perceived fit of the innovation to address a particular issue or problem."	*Appropriateness* is the perceived fit, relevance, or compatibility of the technology-based counseling intervention for the given practice setting, provider, and consumer; and/or perceived fit of the intervention to address a particular issue or problem.
Feasibility	"*Feasibility* is defined as the extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting (Karsh 2004)."	*Feasibility* is defined as the extent to which the technology-based counselling intervention can be successfully used or carried out within a given agency or setting.
Fidelity	"*Fidelity* is defined as the degree to which an intervention was implemented as it was prescribed in the original protocol or as it was intended by the program developers (Dusenbury et al. 2003; Rabin et al. 2008)."	*Fidelity* is the degree to which a technology-based counseling intervention was implemented as it was prescribed in the original protocol or as it was intended by the program developers.
Implementation cost	"*Cost (incremental or implementation cost)* is defined as the cost impact of an implementation effort."	*Implementation cost* is the cost impact of an implementation effort.
Penetration	"*Penetration* is defined as the integration of a practice within a service setting and its subsystems."	*Penetration* is defined as the integration of a technology-based counseling intervention within a service setting.
Sustainability	"*Sustainability* is defined as the extent to which a newly implemented treatment is maintained or institutionalized within a service setting's ongoing, stable operations."	*Sustainability* is defined as the extent to which an implemented technology-based counseling intervention is maintained or institutionalized within an organization's ongoing, stable operations.

Quotations from the included studies were extracted and assigned to the outcomes by 1 reviewer (out of DB or JW) and cross-checked for accuracy by another reviewer (out of DB or JW). Any discrepancies were resolved by consensus between these 2 reviewers.

Synthesis of Results

Data on the implementation success of technology-based counseling interventions were summarized by applying the framework mentioned in the preceding section [17]. The following 8 conceptually distinct implementation outcomes were used as conceptual categories to operationalize *implementation success*: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability.

Our approach to data synthesis involved the following steps:

1. Concept specification: identification of dimensions in the definition of each conceptual category: as these conceptual categories incorporate various aspects [17] and therefore represent multidimensional concepts, a concept specification was performed by determining the dimensions of the categories [26,27]. Dimensions are defined as characteristics according to which empirical facts can be distinguished [28]. The 2 reviewers (DB and JW) independently identified dimensions matching the attributes of the conceptual categories [27] described by Proctor et al [17] with the characteristics of the extracted data. Consensus on the dimensions was reached through discussion between the 2 reviewers.
2. Reduction of data and assignment to dimensions in analysis matrices: the extracted data were reduced without paraphrasing and assigned to the dimensions using tables as analysis matrices.
3. Specification of the level of analysis: we specified the level at which data were provided (level of analysis: consumer, provider or providing institution, organization, setting, and administration), as indicated by Proctor et al [17].
4. Narratively synthesizing of findings and graphical presentation: findings were narratively synthesized and presented in the form of a net diagram.

Each synthesis step was cross-checked (DB and JW) and consent was obtained from the review team.

Study characteristics and characteristics of the included interventions are presented in narrative and tabular forms.

Deviations From the Protocol

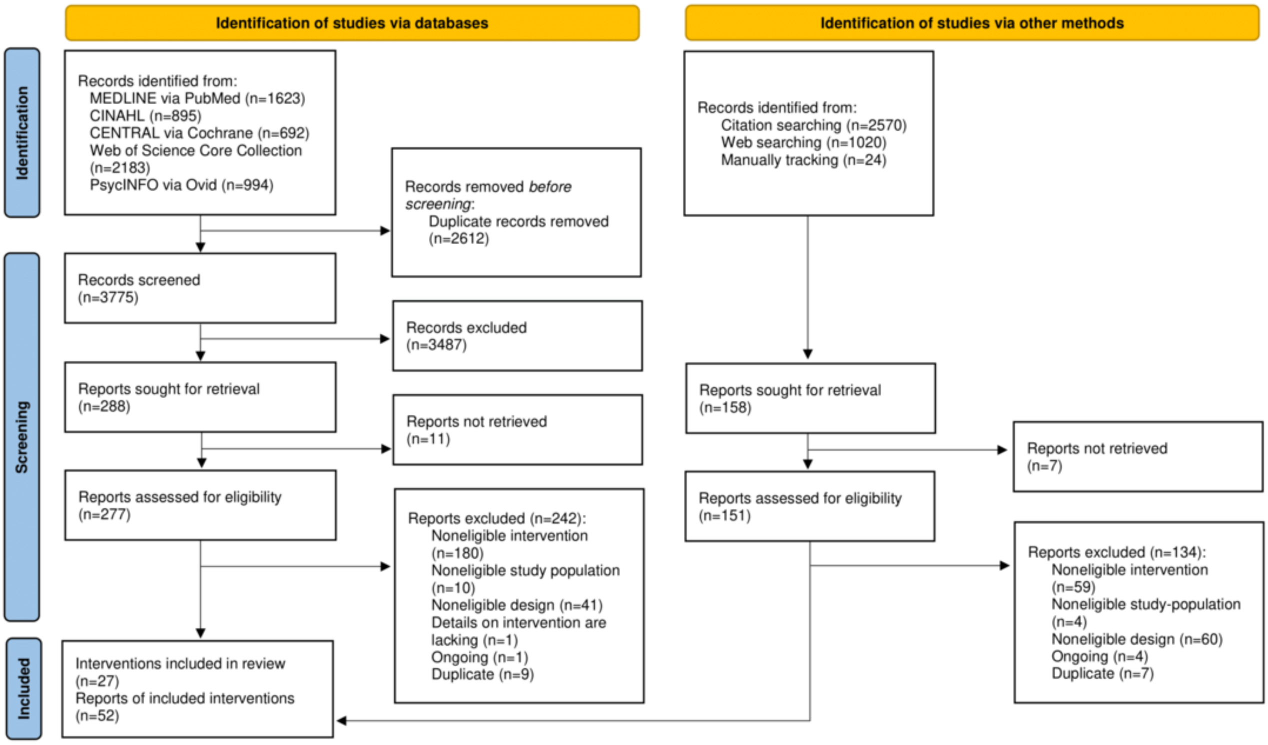
The prespecified method of conducting a Qualitative Comparative Analysis on the conditions of successful implementation of technology-based counseling interventions [7] could not be realized because of the heterogeneity of the data found in the literature. In addition, reports that were not written in English or German were excluded because of a lack of professional translation resources.

Results

Selection of Sources of Evidence

The electronic database yielded 6387 records. After removing duplicates, we screened the titles and the abstracts of 3775 records, reviewed 277 full texts for eligibility, and included 35 records. We identified 3614 records from additional sources and assessed 151 full texts, of which 17 were included. Finally, 52 publications [29-80] reporting on 27 technology-based counseling interventions were included (Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of study selection.



Characteristics of Sources of Evidence

Interventions ranged from single counseling interventions, such as helpline services, to multicomponent programs combining nontechnology-based components, such as day care for people with dementia, with technology-based counseling for informal caregivers. All 27 interventions [29-80] focused on informal caregivers, mostly in combination with people with dementia, and 4 also addressed professional caregivers [29-32,34,35,37,40]. Counseling was provided by professionals from different disciplines, such as psychologists, geriatricians, or nurses. If volunteers were involved, they were professionally supervised or had received training. The technologies used for delivery included telephone, email, videoconferencing, social media, and chats, as well as web-based platforms. Additional (personalized) information material was frequently offered and delivered via email or postal mail. We differentiated the following types of interventions (refer to Table S1 in Multimedia Appendix 1): counseling via telephone or email and counseling via videoconferencing; web-based psychosocial intervention: information, communication, and counseling; videoconference- or telephone-based counseling combined with tele-monitoring or psychoeducation; and technology-based counseling as part of a comprehensive program with nontechnology-based components.

The design of the included studies varied (refer to Table S2 in Multimedia Appendix 1). Studies applying a quantitative descriptive design mostly focused on users' demographics, topics discussed and advice provided in counseling sessions, and satisfaction with services. Few of the included studies exclusively focused on implementation, and we found process evaluation reports [79,80] related to 2 interventions. Furthermore, the publication type of the included reports varied greatly, as we aimed to depict the broad spectrum of interventions. In addition to research reports, we identified abstracts, letters to the editor, and practical project reports.

The interventions are displayed in Table S2 in Multimedia Appendix 1 and characteristics of the included studies are described in Table S3 in Multimedia Appendix 1.

Results of Individual Sources of Evidence

Table 2 provides an overview of the data extracted from the included studies.

The label ("✓") indicates the presence of data without any information on content or scope. None of the interventions included reported data in all categories. The information available ranged from 1 to 7 conceptual categories for each intervention (also refer to the analysis matrices in Multimedia Appendix 1).

Table 2. Overview of reported data on conceptual categories.

Intervention	References	Data extracted for conceptual categories							
		Acceptability	Adoption	Appropriateness	Feasibility	Fidelity	Implementation cost	Penetration	Sustainability
Admiral Nurse Helpline	[29-32]	✓	✓	✓	✓	✓		✓	✓
ADS[a] Helpline	[33]	✓		✓				✓	✓
Alzheimer Helpline	[34,35]	✓		✓				✓	✓
Alz i-Connect	[36]	✓	✓	✓	✓		✓	✓	✓
CANDID[b]	[37]		✓	✓		✓		✓	✓
Care Consultation	[38]								✓
Care Consultation Plus	[38]	✓		✓					
Care Consultation/Care Consultation Plus[c]	[38]			✓		✓			
Coyne[d] comparator	[39]								
Coyne[d] experimental	[39]			✓	✓				
Coyne[c,d]	[39]			✓					
Helpline Alz Ass East Massa[e]	[40]	✓	✓	✓	✓	✓		✓	✓
Natale[d]	[41]			✓					
ODCC[f]	[42]		✓	✓					✓
Sabat[d]	[43]	✓		✓	✓				
Salfi[d] nonanonym	[44-46]			✓					
Salfi[d] anonym	[44-46]			✓					
Salfi[c,d]	[44-46]	✓		✓					
FITT-C[g]	[47-53]	✓	✓	✓	✓	✓			✓
FITT-D[h]	[54]	✓	✓	✓	✓	✓			
NVAMP[i]	[55]	✓		✓	✓				
ICSS[j]	[56-61]	✓		✓	✓				
InformCare	[62-64]	✓		✓	✓	✓	✓	✓	✓
Link2Care	[65]	✓	✓	✓				✓	✓
Online Coaching	[66]	✓		✓					✓
De Cola[d]	[67]	✓	✓	✓				✓	✓
Laver[d]	[68,69]	✓	✓	✓	✓	✓			
RCTM[k]	[70-73]			✓	✓				
Dementelcoach	[74-79]	✓	✓	✓	✓		✓	✓	

Intervention	References	Data extracted for conceptual categories							
		Acceptability	Adoption	Appropriateness	Feasibility	Fidelity	Implementation cost	Penetration	Sustainability
Nomura[d]	[80]	✓	✓	✓				✓	

[a] ADS: Alzheimer's Disease Society.

[b] CANDID: Counseling and Diagnosis in Dementia.

[c] Assignment of the quotes to experimental and comparator intervention is not possible; we assume that the information is applicable for both interventions.

[d] When no name was reported, the name of the first author was assigned to the intervention.

[e] *Helpline Alz Ass East Massa*: Helpline of the Alzheimer's Association of Eastern Massachusetts.

[f] ODCC: Okayama Dementia Call Center.

[g] FITT-C: Family Intervention: Telephone Tracking – Caregiver.

[h] FITT-D: Family Intervention: Telephone Tracking – Dementia.

[i] NVAMP: Nurse Video With Assisted Modeling Program.

[j] ICSS: Internet-based Caregiver Support Service.

[k] RCTM: Residential Care Transition Module.

Synthesis of Results

Acceptability

We defined *acceptability* as the perception among implementation stakeholders of technology-based counseling that the intervention is agreeable, palatable, or satisfactory [17]. Within the data related to the conceptual category (reported for 20 interventions [29-36,38,40,43-69,74-80]; refer to Table 2), we identified the dimensions *measures to promote acceptability* and *impact*, which can be further differentiated into *impact of parts of the service* and *impact of the overall service*. Measures to promote acceptability were reported, specifically from the perspective of the organizations. These were mainly aimed at promoting acceptability among providers, for example, through supervision, debriefings, or training. The impact on parts of the respective intervention or service was described from the perspective of both the provider and the consumer. The provider reported satisfaction with their role, whereas the consumer described individual parts of the service, including the helpfulness of the conversations, the competence of counselors, accessibility, materials, etc. The impact on the overall service was reported from the provider's perspective, namely, satisfaction with the experience of the team members. Other interventions reported on the impact of the overall service from the consumer's perspective, illustrated by relief, satisfaction with the intervention, or comfort with the service.

Adoption

Adoption is defined as the intention, decision, or action to use an intervention [17] (reported for 12 interventions [29-32,36,37,40,42,47-54,65,67-69,74-80]; refer to Table 2). Dimensions of adoption were *organizational motive*, *mode of decision*, and *uptake of interventions motivated internally or externally*. The motives of organizations included their commitment to helping families affected by dementia, connecting individuals to helpful information, providing access to support services, and providing support. Some authors described organizational motives in more general terms by referring to aspects that need to be addressed, for example, increased service demands or restrictions in the living conditions of people with dementia in the community. The mode of decision was characterized in different ways: as a response to developments in the setting, such as mobility restrictions or the increasing use of the internet in the target groups; as consent to participate at the organizational level; or as permission sought and obtained to implement the program. External reasons for the uptake of the specific intervention were evidence of the effectiveness of the intervention found in the literature or evidence indicating that the previously used mode of delivery needed to be adapted. Internally motivated uptake is based on the development, modification, or advancement of one's own interventions.

Appropriateness

Appropriateness is understood as the perceived fit [17] of technology-based counseling for stakeholders, the setting, and the problems addressed. We defined the dimensions *overall compatibility with stakeholder needs*, *tailoring to individuals*, *skills and instruments for enhancing fit*, and *concepts for fit* for this conceptual category and found extensive information for all interventions [29-80]. If assignment of the quotes to experimental and comparator interventions was not possible, we assumed that the information was applicable for both interventions (refer to Table 2).

The dimension *overall compatibility with stakeholder needs* comprises information on accessibility, availability, tailoring to consumer groups, and usefulness of service. In the area of accessibility, the ways to access were described, ranging from the use of a single technology to multiple ways via email, telephone, and videoconferencing, or in combination with home visits. The availability of counseling in terms of service hours, for instance, permanently or during regular working hours on weekdays, was discussed against the background of availability when needed or in times of crisis. From the perspective of organizations, providers, and consumers, technology-based counseling was viewed as a mode of delivery that can solve logistical issues such as making appointments or long-distance travel. People who are homebound can access support without leaving their homes, and caregivers do not have to arrange substitute care. The limitations of remote delivery, such as the loss of context or consumers' different capacities for using technology, were discussed from the perspective of the provider and the consumer. In addition, the advantages and disadvantages of anonymous services and services in which providers know the caregiver or the person with dementia are debated. Tailoring to consumer groups included services focusing on early-onset dementia or rare diseases, considering cultural and ethnic backgrounds, and providing multilingual services. To ensure the usefulness of the services, the appropriate amount and delivery of information were discussed. Tailoring to individuals included statements from the perspective of the provider that services were individualized, personalized, adapted, or flexible and aimed at responding to or addressing individual clients' needs by offering the most appropriate intervention or the best approach to resolve problems. Providers' skills for enhancing fit were described as specialist communication or counseling skills based on the training, knowledge, or experience of the person providing the service. Instruments used in organizations for enhancing fit comprise assessment instruments, information material, or written summaries of counseling sessions, such as letters, scripts, or proposals for individual use. Concepts for fit were reported from the providers' perspective and described in terms of person-centered and holistic approaches by applying techniques such as validation or empathetic understanding and psychological strategies to enhance coping and problem-solving processes.

Feasibility

We defined *feasibility* as the extent to which technology-based counseling can be successfully used [17] and identified the dimensions *practicability*, *factors impeding feasibility*, and *factors promoting feasibility* (reported for 13 interventions [29-32,36,39,40,43,47-64,68-79]; refer to Table 2). The practicability of the interventions was stated from the perspective of the provider, the organization, or the setting. The quotes refer to the general practicability of the intervention, stating its successful application or conceptual clarity. Practicability was also discussed with reference to the use of technology. Factors impeding feasibility comprised general aspects such as lack of financial and staff resources, technology-related aspects such as legal standards and technical challenges, and the lack of visual and nonverbal cues when counseling was delivered via telephone. Special training of providers to overcome technical problems or to compensate for technology-related issues was reported as a factor promoting feasibility.

Fidelity

Fidelity is the degree to which an intervention was implemented as prescribed or intended [17] (reported for 9 interventions [29-32,37,38,40,47-54,62-64,68,69]; refer to Table 2). We determined *formalization of intervention* and *quality assurance in delivering the intervention* as dimensions of fidelity. *Formalization of intervention* was addressed by mentioning standardized manuals, guidelines, frameworks, protocols, or assessments. Proceedings for *quality assurance in delivering the intervention* comprised senior staff supervision to ensure adherence to the protocol and monitor fidelity, the analysis of audiotaped counseling sessions, and the use of adherence and competence scales.

Implementation Cost

On the basis of Proctor et al [17], we defined the conceptual category *implementation cost* as the cost impact of an implementation effort reported from the perspective of a provider or the providing institution (reported for 3 interventions [36,62-64,74-79]; refer to Table 2). We identified the dimensions *cost impact of delivery because of complexity of intervention*, *cost impact of implementation because of complexity of implementation strategy*, and *cost impact because of varying complexity of settings*. Data on the first dimension comprised the costs of delivering the complex intervention and its financing through previously paid travel costs. The costs of the implementation strategy were illustrated by the impact of existing and lacking financial resources for staffing on the implementation process. Within the third dimension, failed expansion or implementation because of a lack of resources was exemplified.

Penetration

Within the conceptual category of *penetration*, defined as a step of integrating the technology-based counseling intervention into the service setting ([17] reported for 11 interventions [29-37,40,62-65,67,74-80]; refer to Table 2), we identified 3 dimensions: *collaboration with stakeholders*, *access to the service*, and *spread*. Data from interventions describe cooperation with stakeholders to implement the intervention, initiated either by the implementing organization itself or jointly through cooperation with other stakeholders in the setting. Access to the service occurred through referrals from other stakeholders in the setting, for example, physicians, or through information from other sources, such as telephone books or newspapers. From the perspective of the implementing organization, the degree of utilization of the intervention by different professional groups (eg, physicians, social workers, and nurses) was described. The level of spread was reported from the perspective of the implementing organization as well as the setting and is often reflected as the regional spread of interventions, for example, at the national or international level.

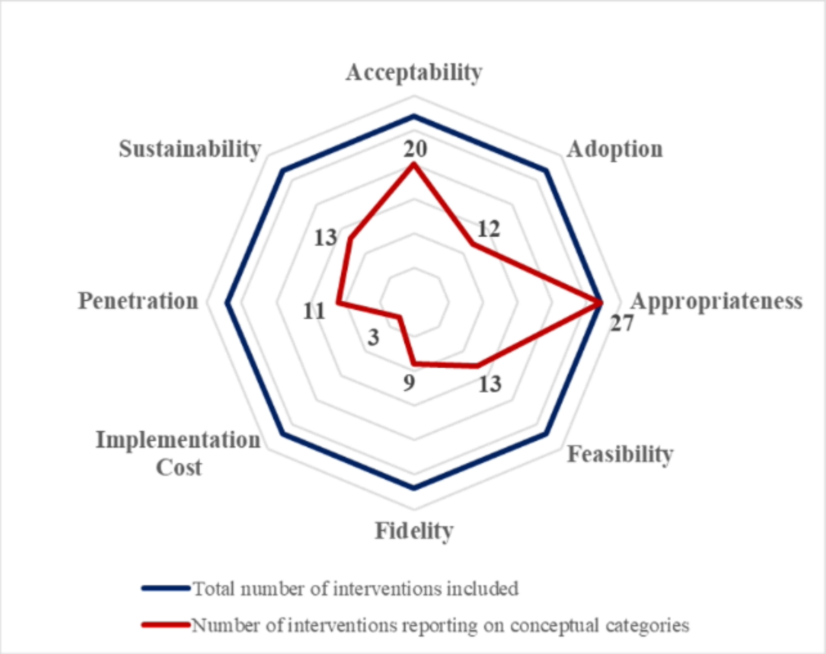
Sustainability

Following Proctor et al [17] and consequently Steckler et al [81], we understand *sustainability* (reported for 13 interventions [29-38,40,42,47-53,62-67]; refer to Table 2) as the final phase of the diffusion process in which innovations become entrenched in organizations. We were able to identify specifications of the data in 3 dimensions: *routinization*, *passage*, and *incorporation*. These dimensions were mainly reported from the perspective of the implementing organization; once, the perspective of the administration was also taken. The data on the dimension *routinization* provided information on the permanence and the degree to which the intervention was established, especially related to the number of versions of the intervention developed, the stakeholders involved, or the period from the start of the program. The duration varied greatly, ranging from a recent introduction to a multiyear build-up with many contacts. Statements were found in the interventions indicating maintained procedures, with the (planned) transition to expand the intervention often explained from the perspective of the organization with the aim of maintaining the intervention. An administrative perspective was also taken, referring to the discontinuation of support after the end of the research project and, thus, the termination of the program. For example, this dimension was clarified by the integration of another target group or expansion to another region. Incorporation, for example, the final integration into (existing) organizational structures with the aim of maintaining the intervention, was mentioned, describing the dissemination of the service within existing structures.

Graphical Presentation of Synthesized Data

Figure 2 shows the graphical synthesis of the data. Data on the conceptual categories of *implementation success* were sought for 27 interventions (blue line). The number of interventions for which data were extracted is indicated by the red line. While the categories *appropriateness* and *acceptability* are largely covered, substantial parts of the other areas remain unconsidered (refer to Figure 2).

Figure 2. Net diagram on reported data of conceptual categories.



Discussion

Principal Findings

We aimed to review the knowledge about the implementation success of technology-based counseling interventions for people with dementia or their caregivers. In our scoping review, we included 52 publications that reported 27 interventions. Interventions were heterogeneous and ranged from single counseling interventions, such as helplines, to counseling as part of multicomponent programs. To operationalize *implementation success*, we used the 8 outcomes of the conceptual framework for implementation outcomes [17] as conceptual categories. Only a few studies evaluated the implementation. Reporting on implementation outcomes was found to be fragmentary, and the comprehensiveness of the information varied widely. Overall, the focus of reporting was on the outcomes of *appropriateness* and *acceptability*, which may be because great efforts were made to adapt the interventions to a vulnerable target population.

As our data show, reporting on *acceptability* is inconsistent in terms of the perspective taken: data reports on measures to promote acceptability, but only from the perspective of the provider. At the same time, reporting on impact from this perspective was underrepresented. As already discussed in the literature, there are difficulties in unifying the wealth of perspectives in the context of implementation research [16].

The information reported on the dimension of *adoption* illustrates the importance of the fit between organizational motives and the type of intervention chosen for successful implementation. Little data are available on the mode of decision but differences in organizational culture can be identified that may influence the success of implementation efforts. We found data indicating that decisions from administrative stakeholders had an impact on sustainability by limiting the duration of the implementation of an intervention. Increasing the administrators' enthusiasm for implementing the intervention by promoting familiarity with the specific intervention and using the effect of name-brand recognition may facilitate long-term commitment [82]. In some cases, the uptake of a specific intervention was based on evidence of its effectiveness, and there is a need for further effectiveness trials to expand the evidence base for decision-making regarding the implementation of technology-based counseling interventions.

The data provided on *appropriateness* comprised the largest amount of information extracted for categories and document the efforts undertaken to fit the target population. In addition to general measures to enhance the perceived fit of individualized support services, providers' skills and instruments, as well as concepts applied by individual providers, were described. Tailoring and personalizing counseling services to individuals' needs has been associated with the usefulness of information and support [55-65]. The benefits and limitations of using technology for delivering counseling are discussed against the background of statements by consumers who would have preferred a different mode of communication with counselors [36]. On the basis of participants' attrition, González-Fraile et al [9] reported that remote support or training interventions appear to be less acceptable to informal caregivers of people with dementia than control interventions, which may limit their applicability in community settings. Further research is needed to determine whether services that are accessible both face to face and technology-based can provide appropriate accessibility and improve the perceived fit of the target populations.

Information on *feasibility* comprised the successful implementation of interventions. Although factors impeding feasibility, such as legal issues and technical challenges, were reported, we found no information on failed or unsuccessful implementation. Barriers to the implementation of eHealth interventions described in the literature are, among others, the lack of digital literacy in the target population and staff's uncertainties and insecurities about their coaching competences [83]. According to Proctor et al [17], the concept of *feasibility* is typically "invoked retrospectively as a potential explanation of an initiative's success or failure." Thus, a more comprehensive reporting of factors promoting or impeding feasibility may inform the implementation of interventions in future projects and may contribute to increasing the implementation success of technology-based counseling interventions.

Ways of formalizing the interventions to ensure fidelity in the delivery of interventions were mentioned, but manuals or guidelines were not made accessible along with publications. In addition, measurements to ensure fidelity were described for some interventions, but the results of assessments, as well as details on aspects where deviations occurred, were not reported. After critically reviewing the literature on the use of fidelity implementation frameworks in early intervention, Lemire et al [84] also stated gaps in defining and assessing implementation fidelity. Drawing on preexisting conceptualizations, the authors proposed a definition of fidelity that comprises the 4 components: adherence, exposure, quality, and participant responsiveness [84].

The cost impact of implementation efforts was rarely reported for the included interventions. Factors that influence the costs are the complexity of the specific intervention, the strategy used for implementation, and the delivery setting [17]. Despite the costs incurred in setting up the technical infrastructure, the costs for remote delivery were lower than when counseling was provided face to face [36,68,69]. Owing to the lower costs, eHealth interventions are considered suitable for widespread implementation [16]. The provision of information on implementation costs is essential to compare the cost impact of different interventions and to inform decisions regarding the uptake of a specific intervention [17].

The data reported on *penetration* often indicates access to the service in multiple ways, which seems to match the preferences and capabilities of consumers. As reported by Jelly et al [85], caregivers use dementia support services primarily when services are able to meet consumers' individual needs. However, it is important to keep in mind that, from an organizational point of view, these extended access options need to be served simultaneously. In particular, cooperation with other stakeholders seems to be central to integrating counseling services into a service setting, but this was only highlighted by some authors in the included publications.

The sustainable anchoring of diffusion processes is described as a difficult phase in the implementation process of support services for caregivers of people with dementia. The reasons for this include a lack of understanding of the barriers to sustainable implementation in practice and a lack of long-term funding [86]. The problem is substantiated in that, as long as researchers focus on measuring the effectiveness of the interventions, the potential goal is not fully realized. However, there are models that can support this sustainable implementation [87].

There are several theoretical approaches, such as generalized theories, models, or frameworks, that address different aspects of implementation [88]. Frameworks "describe more loosely structured constellations of theoretical constructs... or prescriptive approaches for accomplishing implementation goals" [88]. By providing clarity in terms and definitions [88], frameworks contribute to shared language in implementation research. There are different types of frameworks focusing on processes or determinants or evaluations [88]. Evaluation frameworks, such as the conceptual framework for implementation outcomes introduced by Proctor et al [17] and the Reach, Efficacy, Adoption, Implementation, Maintenance (RE-AIM) planning and evaluation framework [89,90], offer guidance on identifying results that can be used to evaluate implementation efforts [88]. While the RE-AIM framework describes outcomes across 5 domains (reach, effectiveness, adoption, implementation, and maintenance) [90], Proctor et al [17] present the concept of 8 implementation outcomes, which are differentiated from service system and treatment outcomes. Implementation outcomes are defined as "the effects of deliberate and purposive actions to implement new treatments, practices, and services" and are reported from different levels of analysis (eg, the provider or the consumer perspective) [17]. Serving as conceptual categories of the implementation success [17], these outcomes provided the appropriate approach to operationalize the object of interest—the implementation success of technology-based counseling interventions in dementia—in our review.

To increase the clarity of terminology used in implementation research, Proctor et al [17] proposed the definitions of 8 conceptually distinct implementation outcomes as a "working taxonomy," including different aspects of implementation success and thus creating a comprehensible framework.

The use of outcomes as conceptual categories was sometimes challenging in our case. The mapping of the extracted data, in particular, was sometimes difficult because of the conceptual similarity of some outcomes, for example, penetration and sustainability, and the inconsistent use of terminology found in the literature. When determining the levels of analysis, we sometimes included additional perspectives, as described by Proctor et al [17].

Altogether, the lack of process evaluation studies, the fragmented reporting, and the unclear use of terms and concepts made it impossible to determine the extent of implementation success of technology-based counseling interventions in dementia care. Because of the impaired comparability of data, we were not able to assess how the different types of interventions affect the conceptual categories of acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability. For instance, we found data on *appropriateness* for all interventions, but the consumer-perceived usefulness of services was referred to for only 5 interventions. These 5 interventions comprised helplines that provided counseling via telephone [29-32,55] and web-based psychosocial interventions that provided information, communication, and counseling [56-65]. The reported information does not allow any conclusions to be drawn on how the types or components of interventions have an impact on implementation success. Gaining further insight into this issue is important for developing future interventions that can be implemented successfully.

Adherence to the framework for developing and evaluating complex interventions [6] may help overcome these problems, as proper process evaluation and exploration of conditions for implementation are recommended. The update to the Medical Research Council guidance states that "[e]arly consideration of implementation increased the potential of developing an intervention that can be widely adopted and maintained in real-world settings" [6] and thus can increase the success of implementation efforts. In addition, the conceptual clarity of the terms and concepts used in implementation research is needed to enhance transparency. This can be achieved by applying theoretical approaches that are "encapsulated as generalized theories, models, or frameworks" [88]. The consistent use of terms not only creates clarity but also forms the basis for better reporting on the success of implementation efforts, as Lengnick-Hall et al [91] proposed as the first of 6 practical recommendations for improved implementation outcomes reporting.

Strengths and Limitations

We followed a theory-driven approach to review the available evidence on implementation success. As we examined a broad topic with evidence emerging from studies in various designs, a scoping review proved appropriate. We performed a comprehensive and methodologically rigorous systematic literature search and included a variety of technology-based counseling interventions for people with dementia and their informal caregivers. Differentiating counseling from interventions focusing on education and information or from psychotherapeutic approaches brought challenges that we overcame through intensive discussions in the review team. Although we were able to include a considerable number of publications, it was not possible to make reliable statements about the implementation success of technology-based counseling interventions in dementia because of the inconsistent database as well as the heterogeneity in terminology and concepts.

Conclusions

We applied 8 conceptually distinct categories to operationalize the implementation success of technology-based counseling interventions for people with dementia and their informal caregivers. We found considerable data for the categories *appropriateness* and *acceptability*, and limited data on *sustainability*, *feasibility*, *adoption*, *penetration*, *fidelity*, and *implementation cost*. There is an imbalance in the scope and depth of the reported data on the conceptual categories, and the data extracted from the included publications only partially covered the concept of *implementation success*.

This highlights the need for a systematic evaluation accompanying the implementation of technology-based counseling interventions in the context of dementia. Adherence to guidelines for the development and evaluation of interventions and to guidelines or recommendations for reporting conceptualizations, measurements, and results on implementation outcomes is needed to expand knowledge on the effectiveness of implementation efforts and may foster the implementation of complex interventions in diverse contexts.

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Authors' Contributions

DB, JW, JH, GM, and AB conceived the idea of the manuscript and made substantial contributions to this scoping review. JH and AB conducted the literature search. DB, JW, JH, and AB conducted study selection and data extraction. DB, JW, JH, and AB conceptualized and operationalized the object of interest. DB and JW conducted the data analysis and synthesis. DB and JW were involved in the drafting of the manuscript. DB, JW, JH, GM, and AB revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Description of included intervention programs, description of studies reporting on included intervention programs, and analysis matrices.

[DOCX File , 181 KB - aging_v7i1e51544_app1.docx]

Multimedia Appendix 2

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

[DOCX File , 89 KB - aging_v7i1e51544_app2.docx]

References

1. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. BMJ Support Palliat Care 2020 Oct 14:1-12 (forthcoming). [doi: 10.1136/bmjspcare-2020-002242] [Medline: 33055092]
2. Miller LM, Kaye JA, Lyons KS, Lee CS, Whitlatch CJ, Caserta MS. Well-being in dementia: a cross-sectional dyadic study of the impact of multiple dimensions of strain on persons living with dementia and their family care partners. Int Psychogeriatr 2019 May;31(5):617-626 [FREE Full text] [doi: 10.1017/S104161021800203X] [Medline: 30722800]
3. Gauthier S, Rosa-Neto P, Morais JA, Webster C. World Alzheimer report 2021: journey through the diagnosis of dementia. Alzheimer’s Disease International. 2021 Sep. URL: https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf [accessed 2022-10-25]
4. Gilsenan J, Gorman C, Shevlin M. Explaining caregiver burden in a large sample of UK dementia caregivers: the role of contextual factors, behavioural problems, psychological resilience, and anticipatory grief. Aging Ment Health 2023;27(7):1274-1281. [doi: 10.1080/13607863.2022.2102138] [Medline: 35881027]
5. Cheng ST, Zhang F. A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. BMC Geriatr 2020 Apr 15;20(1):137 [FREE Full text] [doi: 10.1186/s12877-020-01547-2] [Medline: 32293325]
6. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of medical research council guidance. BMJ 2021 Sep 30;374:n2061 [FREE Full text] [doi: 10.1136/bmj.n2061] [Medline: 34593508]
7. Hirt J, Langer G, Wilde F, Bauernschmidt D, Meyer G, Bieber A. Technology-based counselling in dementia (TeCoDem): study protocol of a mixed-methods systematic review with qualitative comparative analysis and meta-analysis. BMJ Open 2021 Dec 08;11(12):e054157 [FREE Full text] [doi: 10.1136/bmjopen-2021-054157] [Medline: 34880025]
8. Lins S, Hayder-Beichel D, Rücker G, Motschall E, Antes G, Meyer G, et al. Efficacy and experiences of telephone counselling for informal carers of people with dementia. Cochrane Database Syst Rev 2014 Sep 01;2014(9):CD009126 [FREE Full text] [doi: 10.1002/14651858.CD009126.pub2] [Medline: 25177838]
9. González-Fraile E, Ballesteros J, Rueda JR, Santos-Zorrozúa B, Solà I, McCleery J. Remotely delivered information, training and support for informal caregivers of people with dementia. Cochrane Database Syst Rev 2021 Jan 04;1(1):CD006440 [FREE Full text] [doi: 10.1002/14651858.CD006440.pub3] [Medline: 33417236]
10. Saragih ID, Tonapa SI, Porta CM, Lee BO. Effects of telehealth intervention for people with dementia and their carers: a systematic review and meta-analysis of randomized controlled studies. J Nurs Scholarsh 2022 Nov;54(6):704-719. [doi: 10.1111/jnu.12797] [Medline: 35769007]
11. Bauernschmidt D, Hirt J, Langer G, Meyer G, Unverzagt S, Wilde F, et al. Technology-based counselling for people with dementia and their informal carers: a systematic review and meta-analysis. J Alzheimers Dis 2023;93(3):891-906 [FREE Full text] [doi: 10.3233/JAD-221194] [Medline: 37125549]
12. Jackson D, Roberts G, Wu ML, Ford R, Doyle C. A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community. Arch Gerontol Geriatr 2016;66:218-236. [doi: 10.1016/j.archger.2016.06.013] [Medline: 27372903]
13. Lucero RJ, Fehlberg EA, Patel AG, Bjarnardottir RI, Williams R, Lee K, et al. The effects of information and communication technologies on informal caregivers of persons living with dementia: a systematic review. Alzheimers Dement (N Y) 2018 Dec 31;5:1-12 [FREE Full text] [doi: 10.1016/j.trci.2018.11.003] [Medline: 30623020]
14. Lai FH, Yan EW, Yu KK, Tsui WS, Chan DT, Yee BK. The protective impact of telemedicine on persons with dementia and their caregivers during the COVID-19 pandemic. Am J Geriatr Psychiatry 2020 Nov;28(11):1175-1184 [FREE Full text] [doi: 10.1016/j.jagp.2020.07.019] [Medline: 32873496]
15. Pfadenhauer LM, Gerhardus A, Mozygemba K, Lysdahl KB, Booth A, Hofmann B, et al. Making sense of complexity in context and implementation: the context and implementation of complex interventions (CICI) framework. Implement Sci 2017 Feb 15;12(1):21 [FREE Full text] [doi: 10.1186/s13012-017-0552-5] [Medline: 28202031]

16. Christie HL, Bartels SL, Boots LM, Tange HJ, Verhey FJ, de Vugt ME. A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. Internet Interv 2018 Jul 07;13:51-59 [FREE Full text] [doi: 10.1016/j.invent.2018.07.002] [Medline: 30206519]
17. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health 2011 Mar;38(2):65-76 [FREE Full text] [doi: 10.1007/s10488-010-0319-7] [Medline: 20957426]
18. Peters MD, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Implement 2021 Mar;19(1):3-10. [doi: 10.1097/XEB.0000000000000277] [Medline: 33570328]
19. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018 Oct 02;169(7):467-473 [FREE Full text] [doi: 10.7326/M18-0850] [Medline: 30178033]
20. McGowan J, Sampson M, Salzwedel DM, Cogo E, Foerster V, Lefebvre C. PRESS peer review of electronic search strategies: 2015 guideline statement. J Clin Epidemiol 2016 Jul;75:40-46 [FREE Full text] [doi: 10.1016/j.jclinepi.2016.01.021] [Medline: 27005575]
21. Cooper C, Booth A, Varley-Campbell J, Britten N, Garside R. Defining the process to literature searching in systematic reviews: a literature review of guidance and supporting studies. BMC Med Res Methodol 2018 Aug 14;18(1):85 [FREE Full text] [doi: 10.1186/s12874-018-0545-3] [Medline: 30107788]
22. Lefebvre C, Glanville J, Briscoe S, Littlewood A, Marshall C, Metzendorf MI, et al. Searching for and selecting studies. In: Higgins JP, Thomas J, Higgins J, Chandler J, Cumpston M, Li T, et al, editors. Cochrane Handbook for Systematic Reviews of Interventions, Second Edition. London, UK: The Cochrane Collaboration; Sep 20, 2019:67-108.
23. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan-a web and mobile app for systematic reviews. Syst Rev 2016 Dec 05;5(1):210 [FREE Full text] [doi: 10.1186/s13643-016-0384-4] [Medline: 27919275]
24. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ 2014 Mar 07;348:g1687 [FREE Full text] [doi: 10.1136/bmj.g1687] [Medline: 24609605]
25. Möhler R, Köpke S, Meyer G. Criteria for reporting the development and evaluation of complex interventions in healthcare: revised guideline (CReDECI 2). Trials 2015 May 03;16:204 [FREE Full text] [doi: 10.1186/s13063-015-0709-y] [Medline: 25935741]
26. Stein P. Forschungsdesigns für die quantitative Sozialforschung. In: Baur N, Blasius J, editors. Handbuch Methoden der empirischen Sozialforschung. Wiesbaden, Germany: Springer VS; Aug 28, 2022:143-162.
27. Wonka A. Concept specification in political science research. In: Gschwend T, Schimmelfennig F, editors. Research Design in Political Science. London, UK: Palgrave Macmillan; 2007:41-61.
28. Kromrey H. Empirische Sozialforschung: Modelle und Methoden der standardisierten Datenerhebung und Datenauswertung. Opladen, Germany: Leske + Budrich; 2002.
29. Wilkinson S. An analysis and evaluation of the Admiral Nurse Dementia Helpline. Dementia UK. 2016. URL: https://dementiauk.org/wp-content/uploads/2017/09/Admiral-Nurse-dementia-helpline-report_MED-RES.compressed.pdf [accessed 2022-12-05]
30. Brown P, Oliver E, Dening KH. Increasing need for telehealth services for families affected by dementia as a result of Covid-19. J Community Nurs 2020;34(5):59-64.
31. Brown P, Oliver E, Dening KH. Supporting family carers via the admiral nurse dementia helpline: reflection on a case study. Nurs Older People 2020 Sep 22;32(5):16-20. [doi: 10.7748/nop.2020.e1248] [Medline: 32400141]
32. Drayton S, Dening KH. Achieving positive outcomes in complex cases: the admiral nurse dementia helpline (innovative practice). Dementia (London) 2020 May;19(4):1308-1315. [doi: 10.1177/1471301217740005] [Medline: 29132219]
33. Gilliard J, Keady J, Evers C, Milton S. Telephone helplines for people with dementia. Int J Geriatr Psychiatry 1998 Oct;13(10):734-735. [doi: 10.1002/(sici)1099-1166(1998100)13:10<734::aid-gps846>3.0.co;2-x] [Medline: 9818311]
34. Jansen S. Fünf Jahre Alzheimer-Telefon der Deutschen Alzheimer Gesellschaft. Nervenheilkunde 2007;26(08):685-689. [doi: 10.1055/s-0038-1626915]
35. Pendergrass A, Weiß S, Gräßel E. Zu welchen Themen suchen Angehörige von Demenzbetroffenen telefonische oder emailbasierte Beratung auf? Aktuelle Ergebnisse des bundesweiten Beratungsangebots der Deutschen Alzheimer Gesellschaft e.V. Gesundheitswesen 2019 Dec;81(12):1018-1021. [doi: 10.1055/a-0586-8809] [Medline: 29672813]
36. Tousi B, Kanetsky C, Udelson N. ALZ i-Connect: A Novel Audiovisual Care Consultation for Caregivers. Am J Alzheimers Dis Other Demen 2017 Feb;32(1):63-66 [FREE Full text] [doi: 10.1177/1533317516677615] [Medline: 27899432]
37. Harvey R, Roques PK, Fox NC, Rossor MN. CANDID - counselling and diagnosis in dementia: a national telemedicine service supporting the care of younger patients with dementia. Int J Geriatr Psychiatry 1998 Jun;13(6):381-388. [doi: 10.1002/(sici)1099-1166(199806)13:6<381::aid-gps777>3.0.co;2-m] [Medline: 9658273]
38. Hodgson NA, Petrovsky DV, Finegan K, Kallmyer BA, Pike J, Fazio S. One call makes a difference: an evaluation of the Alzheimer's association national helpline on dementia caregiver outcomes. Patient Educ Couns 2021 Apr;104(4):896-902 [FREE Full text] [doi: 10.1016/j.pec.2020.09.026] [Medline: 33004235]

39. Coyne AC, Potenza M, Nose MA. Caregiving and dementia: the impact of telephone helpline services. Am J Alzheimers Dis Other Demen 1995;10(4):27-32. [doi: 10.1177/153331759501000407]
40. Silverstein NM, Kennedy K, McCormick D. A telephone helpline for Alzheimer 's disease: information, referral, and support. Am J Alzheimer's Care Relat Disord Res 1993;8(5):28-36. [doi: 10.1177/153331759300800507]
41. Natale G, Zigoura E, Carpaneto V, D'Angelo MG, Massone L, De Pasquale R, et al. Telephone calls provide effective support for most caregivers of patients with dementia but not for all. Int J Geriatr Psychiatry 2012 Feb;27(2):215-216. [doi: 10.1002/gps.2710] [Medline: 22223146]
42. Nakano Y, Hishikawa N, Sakamoto K, Myoraku Y, Ozaki Y, Takemoto M, et al. A unique telephone support system for dementia patients and their caregivers managed in Japan (Okayama Dementia Call Center, ODCC). Neurol Clin Neurosci 2018 May 26;6(4):100-103. [doi: 10.1111/ncn3.12200]
43. Sabat SR. Flourishing of the self while caregiving for a person with Dementia: a case study of education, counseling, and psychosocial support via email. Dementia 2011;10(1):81-97. [doi: 10.1177/1471301210392986]
44. Salfi J. Seeking to understand telephone support for dementia caregivers: a qualitative case study. McMaster University. 2004 Sep. URL: https://macsphere.mcmaster.ca/bitstream/11375/7569/1/fulltext.pdf [accessed 2022-12-05]
45. Salfi J, Ploeg J, Black ME. Seeking to understand telephone support for dementia caregivers. West J Nurs Res 2005 Oct;27(6):701-721. [doi: 10.1177/0193945905276882] [Medline: 16157943]
46. Spilsbury K. Commentary: Telephone support met the perceived needs of dementia caregivers for convenient access to information, referral, and emotional support. Evid Based Nurs 2006 Jul;9(3):94. [doi: 10.1136/ebn.9.3.94] [Medline: 16865845]
47. Telephone support for dementia caregivers. NCT00735800. National Institutes of Health. 2008. URL: https://clinicaltrials.gov/ct2/show/NCT00735800 [accessed 2022-11-08]
48. Tremont G, Davis J, O'Connor K, Grover C, Bishop D, Ott B, et al. Relationship between expectancy/credibility and early response to telephone ‐ based dementia caregiver interventions. Alzheimers Dement 2011 Jul;7(4):S435. [doi: 10.1016/j.jalz.2011.05.1257]
49. Tremont G, Davis J, Grover C, Bryant K, Ott B, Papandonatos G, et al. Randomized controlled trial of a telephone ‐ delivered intervention (FITT ‐ Caregiver) for dementia caregivers. Alzheimers Dement 2013 Jul;9(4):P324-P325. [doi: 10.1016/j.jalz.2013.04.161]
50. Tremont G, Davis J, Papandonatos GD, Grover C, Ott BR, Fortinsky RH, et al. A telephone intervention for dementia caregivers: background, design, and baseline characteristics. Contemp Clin Trials 2013 Nov;36(2):338-347 [FREE Full text] [doi: 10.1016/j.cct.2013.07.011] [Medline: 23916916]
51. Tremont G, Davis J, Bryant K, Ott BR, Papandonatos G, Fortinsky R, et al. Effect of a telephone-based dementia caregiver intervention on use of community support services and health care resources. Alzheimers Dement 2014 Jul;10(4):P226-P227. [doi: 10.1016/j.jalz.2014.04.319]
52. Tremont G, Davis JD, Papandonatos GD, Ott BR, Fortinsky RH, Gozalo P, et al. Psychosocial telephone intervention for dementia caregivers: a randomized, controlled trial. Alzheimers Dement 2015 May;11(5):541-548 [FREE Full text] [doi: 10.1016/j.jalz.2014.05.1752] [Medline: 25074341]
53. Tremont G, Davis JD, Ott BR, Galioto R, Crook C, Papandonatos GD, et al. Randomized trial of the family intervention: telephone tracking-caregiver for dementia caregivers: use of community and healthcare resources. J Am Geriatr Soc 2017 May;65(5):924-930 [FREE Full text] [doi: 10.1111/jgs.14684] [Medline: 28008609]
54. Tremont G, Davis JD, Bishop DS, Fortinsky RH. Telephone-delivered psychosocial intervention reduces burden in dementia caregivers. Dementia (London) 2008;7(4):503-520 [FREE Full text] [doi: 10.1177/1471301208096632] [Medline: 20228893]
55. Chang BL, Nitta S, Carter PA, Markham YK. Perceived helpfulness of telephone calls: providing support for caregivers of family members with dementia. J Gerontol Nurs 2004 Sep;30(9):14-21. [doi: 10.3928/0098-9134-20040901-05] [Medline: 15471059]
56. Chiu T, Lottridge D. Development and iterative refinement of an internet-based service for Chinese family caregivers of people with Alzheimer disease. AMIA Annu Symp Proc 2005;2005:919 [FREE Full text] [Medline: 16779206]
57. Chiu TM. Usage and non-usage behaviour of eHealth services among Chinese Canadians caring for a family member with dementia. University of Toronto. 2008. URL: https://tspace.library.utoronto.ca/bitstream/1807/11189/1/Chiu_Teresa_ML_200806_PhD_Thesis.pdf [accessed 2022-11-08]
58. Chiu T, Marziali E, Colantonio A, Carswell A, Gruneir M, Tang M, et al. Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia. Can J Aging 2009 Dec;28(4):323-336. [doi: 10.1017/S0714980809990158] [Medline: 19925698]
59. Chiu TM, Eysenbach G. Stages of use: consideration, initiation, utilization, and outcomes of an internet-mediated intervention. BMC Med Inform Decis Mak 2010 Nov 23;10:73 [FREE Full text] [doi: 10.1186/1472-6947-10-73] [Medline: 21092275]
60. Chiu TM, Marziali E, Tang M, Colantonio A, Carswell A. Client-centred concepts in a personalized e-mail support intervention designed for Chinese caregivers of family members with dementia: a qualitative study. Hong Kong J Occup Ther 2010 Dec;20(2):87-93. [doi: 10.1016/s1569-1861(11)70008-0]

61. Chiu TM, Eysenbach G. Theorizing the health service usage behavior of family caregivers: a qualitative study of an internet-based intervention. Int J Med Inform 2011 Nov;80(11):754-764. [doi: 10.1016/j.ijmedinf.2011.08.010] [Medline: 21958550]
62. Barbabella F, Poli A, Andréasson F, Salzmann B, Papa R, Hanson E, et al. A web-based psychosocial intervention for family caregivers of older people: results from a mixed-methods study in three European countries. JMIR Res Protoc 2016 Oct 06;5(4):e196 [FREE Full text] [doi: 10.2196/resprot.5847] [Medline: 27713113]
63. Lamura G, Poli A, Yghemonos S, Barbabella F. InformCare: the European information hub on family care. Int J Care Caring 2017;1(3):409-413. [doi: 10.1332/239788217X15018371295074]
64. Barbabella F, Poli A, Hanson E, Andréasson F, Salzmann B, Döhner H, et al. Usage and usability of a web-based program for family caregivers of older people in three European countries: a mixed-methods evaluation. Comput Inform Nurs 2018 May;36(5):232-241. [doi: 10.1097/CIN.0000000000000422] [Medline: 29505433]
65. Kelly K. Link2Care: internet-based information and support for caregivers. Generations 2003;27(4):87-88.
66. Rentz ML, Hoene AV. Online coaching for caregivers: using technology to provide support and information. Alzheimer's Care Today 2010 Jul;11(3):206-209. [doi: 10.1097/ACQ.0b013e3181ebc878]
67. De Cola MC, De Luca R, Bramanti A, Bertè F, Bramanti P, Calabrò RS. Tele-health services for the elderly: a novel southern Italy family needs-oriented model. J Telemed Telecare 2016 Sep;22(6):356-362. [doi: 10.1177/1357633X15604290] [Medline: 26377125]
68. Does telehealth delivery of the COPE program provide a non-inferior alternative to face-to-face treatment for community dwelling people with cognitive impairment? ACTRN12617000117314. Australian New Zealand Clinical Trials Registry. 2017. URL: https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=372140&isReview=true [accessed 2022-11-08]
69. Laver K, Liu E, Clemson L, Davies O, Gray L, Gitlin LN, et al. Does telehealth delivery of a dyadic dementia care program provide a noninferior alternative to face-to-face delivery of the same program? A randomized, controlled trial. Am J Geriatr Psychiatry 2020 Jun;28(6):673-682 [FREE Full text] [doi: 10.1016/j.jagp.2020.02.009] [Medline: 32234275]
70. The residential care transition module (RCTM). NCT02915939. National Institutes of Health. 2016. URL: https://clinicaltrials.gov/ct2/show/NCT02915939 [accessed 2022-12-06]
71. Gaugler JE, Statz TL, Birkeland RW, Louwagie KW, Peterson CM, Zmora R, et al. The Residential Care Transition Module: a single-blinded randomized controlled evaluation of a telehealth support intervention for family caregivers of persons with dementia living in residential long-term care. BMC Geriatr 2020 Apr 15;20(1):133 [FREE Full text] [doi: 10.1186/s12877-020-01542-7] [Medline: 32293314]
72. Statz TL, Peterson CM, Birkeland RW, McCarron HR, Finlay JM, Rosebush CE, et al. "We moved her too soon": navigating guilt among adult child and spousal caregivers of persons living with dementia following a move into residential long-term care. Couple Family Psychol 2022 Dec;11(4):300-314 [FREE Full text] [doi: 10.1037/cfp0000150] [Medline: 36743783]
73. Zmora R, Statz TL, Birkeland RW, McCarron HR, Finlay JM, Rosebush CE, et al. Transitioning to long-term care: family caregiver experiences of dementia, communities, and counseling. J Aging Health 2021 Jan;33(1-2):133-146 [FREE Full text] [doi: 10.1177/0898264320963588] [Medline: 32990494]
74. van Mierlo LD, Meiland FJ, Dröes RM. Dementelcoach: effect of telephone coaching on informal and professional carers of community dwelling people with dementia. Int Psychogeriatr 2011;23(S1):378-379. [doi: 10.1017/S1041610211001293]
75. van Mierlo LD, Meiland FJ, Dröes RM. Dementelcoach: effect of telephone coaching on carers of community-dwelling people with dementia. Int Psychogeriatr 2012 Feb;24(2):212-222. [doi: 10.1017/S1041610211001827] [Medline: 21995966]
76. Meeting Centers3.0: evaluation of the implementation and costeffectiveness of three new tailored interventions for people with dementia and their carers: DemenTalent, Dementelcoach and STAR-online training. NTR5521. Netherlands Trial Register. 2015 Nov 9. URL: https://www.trialregister.nl/trial/5396 [accessed 2022-12-06]
77. Dröes R, van Rijn A, Bosmans J, Meiland F. The individualized meeting centers support program: evaluation of benefits and costs. In: Proceedings of the 19th IPA International Congress. 2019 Presented at: 19th IPA International Congress; August 31-September 3, 2019; Santiago de Compostela, Spain. [doi: 10.1017/S1041610219001339]
78. Dröes RM, van Rijn A, Rus E, Dacier S, Meiland F. Utilization, effect, and benefit of the individualized meeting centers support program for people with dementia and caregivers. Clin Interv Aging 2019;14:1527-1553 [FREE Full text] [doi: 10.2147/CIA.S212852] [Medline: 31692559]
79. van Rijn A, Meiland F, Dröes RM. Linking two new e-health caregiver interventions to meeting centres for people with dementia and their carers; a process evaluation. Aging Ment Health 2020 Aug;24(8):1316-1325. [doi: 10.1080/13607863.2019.1617243] [Medline: 31119946]
80. Nomura M, Makimoto K, Kato M, Shiba T, Matsuura C, Shigenobu K, et al. Empowering older people with early dementia and family caregivers: a participatory action research study. Int J Nurs Stud 2009 Apr;46(4):431-441. [doi: 10.1016/j.ijnurstu.2007.09.009] [Medline: 17983619]
81. Steckler A, Goodman RM, McLeroy KR, Davis S, Koch G. Measuring the diffusion of innovative health promotion programs. Am J Health Promot 1992;6(3):214-224. [doi: 10.4278/0890-1171-6.3.214] [Medline: 10148679]
82. Christie HL, Schichel MC, Tange HJ, Veenstra MY, Verhey FR, de Vugt ME. Perspectives from municipality officials on the adoption, dissemination, and implementation of electronic health interventions to support caregivers of people with

dementia: inductive thematic analysis. JMIR Aging 2020 May 13;3(1):e17255 [FREE Full text] [doi: 10.2196/17255] [Medline: 32401217]
83. Christie HL, Boots LM, Tange HJ, Verhey FR, de Vugt ME. Implementations of evidence-based eHealth interventions for caregivers of people with dementia in municipality contexts (Myinlife and partner in balance): evaluation study. JMIR Aging 2021 Feb 05;4(1):e21629 [FREE Full text] [doi: 10.2196/21629] [Medline: 33544085]
84. Lemire C, Rousseau M, Dionne C. A comparison of fidelity implementation frameworks used in the field of early intervention. Am J Eval 2022 Nov 10;44(2):236-252. [doi: 10.1177/10982140211008978]
85. Jelley H, Kerpershoek L, Verhey F, Wolfs C, de Vugt M, Bieber A, et al. Carers' experiences of timely access to and use of dementia care services in eight European countries. Ageing Soc 2019 Sep 16;41(2):403-420. [doi: 10.1017/s0144686x19001119]
86. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. Gerontologist 2015 Apr;55(2):210-226 [FREE Full text] [doi: 10.1093/geront/gnu123] [Medline: 26035597]
87. Feldstein AC, Glasgow RE. A practical, robust implementation and sustainability model (PRISM) for integrating research findings into practice. Jt Comm J Qual Patient Saf 2008 Apr;34(4):228-243. [doi: 10.1016/s1553-7250(08)34030-6] [Medline: 18468362]
88. Damschroder LJ. Clarity out of chaos: use of theory in implementation research. Psychiatry Res 2020 Jan;283:112461 [FREE Full text] [doi: 10.1016/j.psychres.2019.06.036] [Medline: 31257020]
89. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health 1999 Sep;89(9):1322-1327. [doi: 10.2105/ajph.89.9.1322] [Medline: 10474547]
90. Glasgow RE, Harden SM, Gaglio B, Rabin B, Smith ML, Porter GC, et al. RE-AIM planning and evaluation framework: adapting to new science and practice with a 20-year review. Front Public Health 2019 Mar 29;7:64 [FREE Full text] [doi: 10.3389/fpubh.2019.00064] [Medline: 30984733]
91. Lengnick-Hall R, Gerke DR, Proctor EK, Bunger AC, Phillips RJ, Martin JK, et al. Six practical recommendations for improved implementation outcomes reporting. Implement Sci 2022 Feb 08;17(1):16 [FREE Full text] [doi: 10.1186/s13012-021-01183-3] [Medline: 35135566]

Abbreviations

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
RE-AIM: Reach, Efficacy, Adoption, Implementation, Maintenance

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Review

Patient and Public Involvement in Technology-Related Dementia Research: Scoping Review

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Abstract

Background: Technology-related research on people with dementia and their carers often aims to enable people to remain living at home for longer and prevent unnecessary hospital admissions. To develop person-centered, effective, and ethical research, patient and public involvement (PPI) is necessary, although it may be perceived as more difficult with this cohort. With recent and rapid expansions in health and care–related technology, this review explored how and with what impact collaborations between researchers and stakeholders such as people with dementia and their carers have taken place.

Objective: This review aims to describe approaches to PPI used to date in technology-related dementia research, along with the barriers and facilitators and impact of PPI in this area.

Methods: A scoping review of literature related to dementia, technology, and PPI was conducted using MEDLINE, PsycINFO, Embase, and CINAHL. Papers were screened for inclusion by 2 authors. Data were then extracted using a predesigned data extraction table by the same 2 authors. A third author supported the resolution of any conflicts at each stage. Barriers to and facilitators of undertaking PPI were then examined and themed.

Results: The search yielded 1694 papers, with 31 (1.83%) being analyzed after screening. Most (21/31, 68%) did not make clear distinctions between activities undertaken as PPI and those undertaken by research participants, and as such, their involvement did not fit easily into the National Institute for Health and Care Research definition of PPI. Most of this mixed involvement focused on reviewing or evaluating technology prototypes. A range of approaches were described, most typically using focus groups or co-design workshops. In total, 29% (9/31) described involvement at multiple stages throughout the research cycle, sometimes with evidence of sharing decision-making power. Some (23/31, 74%) commented on barriers to or facilitators of effective PPI. The challenges identified often regarded issues of working with people with significant cognitive impairments and pressures on time and resources. Where reported, the impact of PPI was largely reported as positive, including the experiences for patient and public partners, the impact on research quality, and the learning experience it provided for researchers. Only 4 (13%) papers used formal methods for evaluating impact.

Conclusions: Researchers often involve people with dementia and other stakeholders in technology research. At present, involvement is often limited in scope despite aspirations for high levels of involvement and partnership working. Involving people with dementia, their carers, and other stakeholders can have a positive impact on research, patient and public partners, and researchers. Wider reporting of methods and facilitative strategies along with more formalized methods for recording and reporting on meaningful impact would be helpful so that all those involved—researchers, patients, and other stakeholders—can learn how we can best conduct research together.

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KEYWORDS

dementia; technology; patient and public involvement and engagement; co-design; coproduction

Introduction

Background

Worldwide incidence of dementia is increasing. In the United Kingdom alone, there are approximately 1 million people living with dementia, with this figure expected to double by 2050 [1]. The total cost of care for people with dementia in the United Kingdom in 2019 was £34.7 billion (US $44.1 billion), with an expected increase to approximately £94 billion (US $119.5 billion) by 2040 [2]. Technology is increasingly cited as a means of supporting people with dementia and their formal and informal carers and reducing some of this economic burden. "Digitally enabled care" is a core component of the National Health Service Long Term Plan [3]—it is felt that technology has the potential to facilitate aging in place and reduce unplanned hospital admissions, with consequent economic benefits as well as improved health outcomes and quality of life [4,5]. Smart home systems, assistive technology devices, and other technologies are being developed with aims including supporting safety in people's homes; enabling early detection of deterioration or ill health; supporting activities of daily living; and facilitating access to treatment, leisure activities, or social participation [5-8].

Despite rapid advancements in technology, the implementation of health and care–related technology for people with dementia has been slow, and there is increasing recognition of the many challenges in this area [9-11]. These challenges include ethical issues regarding privacy, autonomy, safety, and trust and the risk of creating or exacerbating health-related bias and inequality [12-16]. Researchers and technology developers must also understand the complex and changing needs of individual circumstances—there is a need for research to center on the person and their support network rather than on the technology itself if it is to be successful [17]. Therefore, understanding users' perspectives is fundamental if we are to develop technologies that are acceptable, effective, and ethical [5,10,18,19]. One way to achieve this is through patient and public involvement (PPI).

PPI describes a partnership between patients, the public, and researchers in the research process itself. It is often described as research conducted "with" or "by" service users rather than research "about" or "for" them [20]. In addition to being seen as an ethical imperative, PPI aims to improve the efficiency and value of health research, recognizing that those with lived experience of health conditions or services will bring knowledge and experience that may increase the relevance of studies, improve recruitment and retention of participants, and improve dissemination of research findings [20-22]. PPI is now seen as an essential part of health and social care research—the Health Research Authority strongly advises PPI because of its likelihood of improving research quality and addressing the Research Ethics Committee's key considerations [23]. Stakeholder engagement is a key part of the guidance from the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use [24], and the National Institute for Health and Care Research (NIHR) makes it a condition of research funding [21]. The NIHR describes different approaches to involvement with increasing levels of power and influence for members of the public, from consultation (least power) to coproduction and user controlled (most power) [20].

PPI in dementia-related research has been gathering pace in recent years. Historically focusing more on the involvement of carers or other stakeholders, this has changed with more studies involving people with dementia themselves [25,26]. It is now well established that this supports and promotes a person-centered model of health care [27-31]. PPI should be conducted in a manner that promotes equality, diversity, and inclusion [20]. The NIHR emphasizes the need for researchers to enable the involvement of underrepresented groups and adapt their PPI approaches and activities to ensure accessibility for all groups affected by the project [32]. When planning and carrying out PPI in dementia research, this means the consideration of all groups affected by aging and dementia from diverse ethnic, racial, linguistic, geographic, and socioeconomic backgrounds.

The principle of stakeholder involvement is not unique to PPI. To understand the principles of terms such as "co-design" and "coproduction" within PPI, it is important to appreciate the context in which these terms have developed beyond just the health care sector. Within technology innovation, there has been a steady and increasing emphasis over the past 50 years on ensuring that a "human-centered" approach is taken to developing a new product or service [33]. Human-centered design emphasizes the need for fostering deep empathy with the people one is designing with, bringing end users into the design process as early as possible. Co-design can be a method of human-centered design. Co-design also stems from the 1970s, from a Scandinavian movement of participatory design, in which scientists, technologists, and design researchers acknowledged that "the people destined to use the system [must] play a critical role in designing it" [34]. Wider adoption of these human-centered design approaches has been seen in the last 15 years with methodologies such as the Design Council's "Double Diamond" [35] helping visualize this iterative approach to innovation and widen adoption across nondesigners.

Considering the context of technology within health and social care, it is not surprising that practitioners from health and social care, design, and technology research have found themselves discussing what best practice should look like and what approaches or methods might facilitate meaningful innovation [36]. Regardless of the background, researchers across these disciplines agree on the need to move from a patient-centered or user-centered approach to a "co-production" approach in which users not only are observed or consulted but also work jointly as partners, with mutual respect and understanding of each other's different knowledge and experiences and the contributions they can make [21,37,38]. The NIHR outlines 5 key principles of coproduction as part of a research project (Textbox 1).

Textbox 1. National Institute for Health and Care Research "Guidance on co-producing a research project"—key principles.

1. Sharing of power—the research is jointly owned and people work together to achieve a joint understanding
2. Including all perspectives and skills—making sure the research team includes all those who can make a contribution
3. Respecting and valuing the knowledge of all those working together on the research—everyone is of equal importance
4. Reciprocity—everyone benefits from working together
5. Building and maintaining relationships—an emphasis on relationships is key to sharing power" [32]

Despite the recognition of the value of PPI and the recommendation of coproduction approaches [10,19], patient or other stakeholder involvement in technology-related dementia research is known to be variable in breadth and depth and sometimes absent altogether [11]. Older reviews show that the involvement of people with dementia has usually been as passive participants to be observed or at most as a group to consult but without any sharing of decision-making power [19,39,40]. A review of the literature published between 2011 and 2017 by Suijkerbuijk et al [41] demonstrated that, although there has been an increase in the involvement of people with dementia in technology research, reporting on the methods, barriers, facilitators, and impact remains minimal, making progress in this field challenging. This mirrors issues with PPI reporting (especially of impact) in the wider field of dementia research [25,42,43]. Given the increased attention that PPI has received in recent years as well as the rapid advances in technology-related health research, we anticipated that there would be many more papers published in the period from 2017 to 2022 worthy of review. In addition, the review by Suijkerbuijk et al [41] included papers with a broad range of methodologies to cover the concept of "involvement," including the involvement of people with dementia as participants in qualitative research. To our knowledge, no review to date has explored the specific concept of PPI in technology-related dementia research.

Objectives

Therefore, the objectives of this scoping review were as follows:

1. To describe the approaches to PPI used to date in technology-related dementia research, exploring who is involved, when, and how,
2. To describe the reported barriers to and facilitators of effective PPI in this area, and
3. To examine and report on the impact of PPI in this area.

Methods

Review Type

To gather the available literature in this area, a scoping review was conducted. Scoping reviews are often used in preference to systematic reviews in cases in which the body of literature is likely to be large and heterogeneous and to answer broad questions (such as "what is known about this concept?") [44]. They are a useful way to map out the evidence, as opposed to systematic reviews, which often bring together literature on a particular subject with a more defined question, for example, about the efficacy of interventions [45]. The PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) guidelines [44] were followed to ensure appropriate reporting.

Search Strategy and Eligibility Criteria

A search strategy was developed and used a search string consisting of words related to dementia; technology designed to support health, care, or well-being; and PPI. Knowing that the terminology used varies considerably, definitions were kept broad, in particular of "patient and public involvement," adapting and building on existing search strings from previous reviews [11,19,25,41,42]. Our definition of technology was similarly broad. Assistive technology may be described as "products or systems that support and assist individuals with disabilities, restrict mobility or other impairments to perform functions that might otherwise be difficult or impossible" [46]. We included any type of assistive technology as well as, more broadly, any technology that could be deemed to be a part of technology-enabled care (such as telehealth systems, telecare, telemedicine, and self-care apps) [47]. Inclusion criteria were developed (Textbox 2). PPI activities do not usually require ethics approval [20], yet we did not exclude those who sought ethics approval so as to ensure that we captured a range of approaches.

Textbox 2. Inclusion and exclusion criteria.

Inclusion criteria

- Research about dementia (any type) or mild cognitive impairment
- Research focused on technology designed to support the health, care, or well-being of people with dementia or their carers
- Research describing ways in which patients or other stakeholders were actively involved in the research process itself (not only as research participants)
- Full text available in English
- Any publication date up to the end of 2022

Exclusion criteria

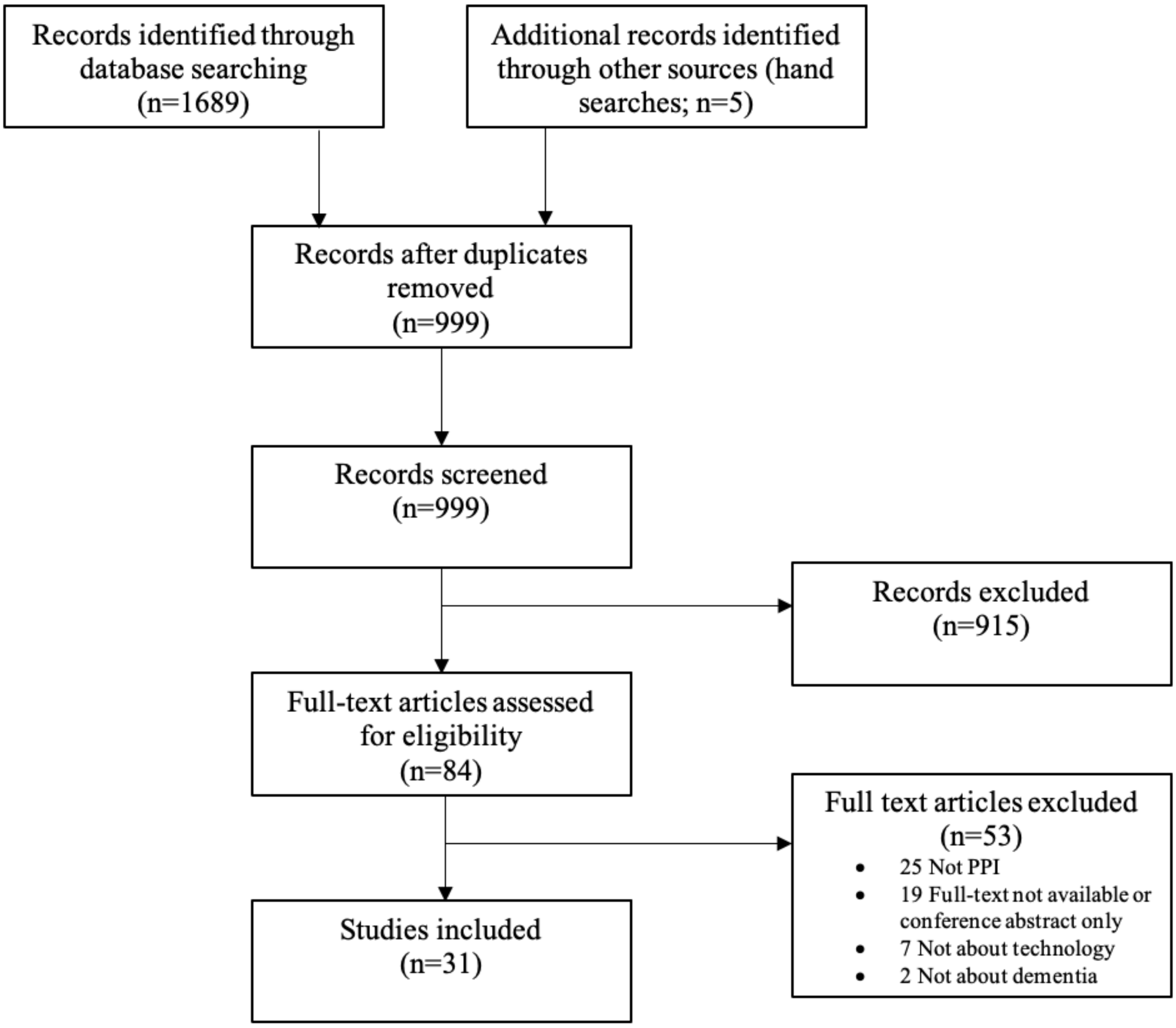
- Dementia only mentioned incidentally (eg, primary focus was Parkinson disease)
- Technology in which target beneficiaries are not people with dementia, family or carers (eg, web-based education programs for health care workers)
- Studies in which the patients or stakeholders are positioned as research participants only (eg, participants in a qualitative study) and are not actively involved in conducting the research
- Reviews
- Opinion pieces
- Conference abstracts

Data Sources and Charting Process

The search was conducted in 4 databases: MEDLINE, PsycINFO, Embase (using Ovid), and CINAHL (using EBSCO). All papers published until the end of 2022 were included. Abstracts had to be available in English, and opinion pieces and reviews were excluded (refer to Multimedia Appendix 1 for the full MEDLINE search string). The search was last conducted in January 2023. References were exported to EndNote (Clarivate Analytics) and then to Covidence (Veritas Health Information) [48] for screening. After the removal of duplicates, 2 reviewers (PK and HL) screened the titles and abstracts against the eligibility criteria. The full texts were then further screened for eligibility. The 2 reviewers then independently charted the data from the included studies using a predesigned extraction table. For the first 10 papers, detailed discussions were held to clarify interpretations of PPI. Subsequent discussions were held to reach a consensus where required. A third author (CMA) was available if a consensus was not reached. As the purpose of this review was to provide an overview of existing evidence regardless of quality, no formal appraisal of methodological quality was conducted, in line with guidance [45]. Facilitators of and barriers to effective PPI were grouped and analyzed by the first author to draw out themes, which were then refined in discussion with the other authors. The impact of PPI, where described, was summarized and categorized into impact on the study, impact on the patient and public partners, and impact on the research team.

Initial database searching identified 1689 records, with an additional 5 found through hand searches following references from papers identified in the initial search. After removal of 695 (41%) duplicates, the remaining 999 abstracts were screened. Most of these (915/999, 91.6%) did not meet the eligibility criteria (were not about dementia, involvement in research, or technology). Determining whether papers described active involvement in the research process or merely involvement as participants was frequently unclear from the abstracts alone, and the authors erred on the side of inclusion here, in line with guidance. When analyzing full texts (84/999, 8.4%), not meeting the “involvement in research” criteria was the most common reason for exclusion (25/53, 47% of the papers excluded at this stage). A total of 31 papers were included in the scoping review. Figure 1 shows the flow of information for this process.

Figure 1. Record identification and screening process. PPI: patient and public involvement.



Results

Study Characteristics

Of the 31 papers included in the review (Table 1), most (n=18, 58%) were published between 2020 and 2022. Only 13% (4/31) were published before 2010. Most papers were authored by groups from multiple disciplines, for example, authors from design engineering backgrounds and health sciences and health care professionals. A total of 13% (4/31) of the studies included patient or public partners as coauthors [17,49-51]. In total, 21 of the studies originated in Europe, including 10 (48%) from the United Kingdom. Others were from Canada (7/31, 23%) and Australia (3/31, 10%), and 1 of the studies (1/31, 3%) included discussions of collaborations with groups in Ireland, Hong Kong, Brazil, and India [52].

Table 1 also outlines the stakeholders involved, the stage or stages of the research they were involved in, and the methods used for this involvement. When determining which stage of research stakeholders were involved in, the authors mapped involvement onto NIHR stages of research in which PPI might typically take place (eg, “design of the research”). Where Table 1 states “did not fit model,” this was because participants were positioned as both coresearchers and research participants. This is explored further in the following sections (Table 2).

A range of technologies were described with varied purposes (Textbox 3), apart from in Liddle et al [17], which did not focus on any one type.

Table 1. Study characteristics describing the technology, stakeholder involvement, stage of the research process in which the involvement took place, role of the stakeholder, and methods used to involve patients and the public.

Study, year	Origin	Technology type and purpose	Stakeholders involved	NIHR[a] stage of research in which PPI[b] took place	Role of stakeholders involved	PPI methods
Davies et al [53], 2019	United Kingdom	Website to provide information and peer and professional support for caregivers of people with dementia toward end of life	Research development group including 6 HCPs[c], 2 members of a dementia charity organization, and 1 carer	Design of the research, undertaking and management of the research, and analysis of data	Refining the aims of the wider project and steering the project throughout	Steering group, group meetings, and 1:1 meetings
Kort and van Hoof [54], 2014	The Netherlands	Website with information about home modifications for people with dementia and their family caregivers	3 dyads (people with dementia+carer) and, separately, a group of 20 (carers or residential home staff)	Did not fit model	Contributing to the iterative design process	Observations, consultation rounds, and questionnaire
Schikhof et al [55], 2010	The Netherlands	Monitoring system in residential home for people with dementia to detect anomalies (eg, panicking and falls)	8 nursing home staff members and 13 family representatives (as proxies for people with dementia)	Did not fit model	Contributing to the iterative design process	Interviews, workshops for prototype testing, informal group meetings, and focus groups
Muñoz et al [56], 2022	Canada	Virtual reality game to support engagement in exercise for people with dementia	7 people with dementia or MCI[d], 5 older adults without dementia, industry partners, and HCPs	Design of the research and undertaking and management of the research; elements did not fit model	Contributing to the iterative design process; HCPs and industry representatives also had a role in designing and managing the study	Prototype testing and interviews (people with dementia or MCI and older adults), research group meetings (HCPs), and focus group (older adults without dementia, members of the research team, and industry representatives)
Eisapour et al [57], 2020, also with reference to Eisapour et al [58], 2018, and Eisapour [59], 2018	Canada	Virtual reality game to support engagement in exercise for people with dementia	HCPs and 3 people with dementia	One PPI representative involved in the main research team, presumed to be throughout; other elements did not fit model	Contributing to the iterative design process and involved in the main research team	Focus groups, observations, informal discussions in care home, and prototype testing; one member of the original focus group subsequently joined the research team
Hanson et al [60], 2007	Sweden	Home computer-based education and support program providing information, support tools, and exercises for people with dementia and their carers	7 people with dementia	Did not fit model	Contributing to the iterative design process	Group meetings to develop support program content and computer skills tuition for group members
Orpwood et al [61], 2004	Finland and others part of the ENABLE project	Various assistive technology devices: picture gramophone, calendar, tap monitor, lost object locator, gas cooker monitor, and night-light	Family carers (as proxies for people with dementia), paid carers, and older adults without dementia	Did not fit model	Contributing to the iterative design process	Informal group meetings and focus groups

Study, year	Origin	Technology type and purpose	Stakeholders involved	NIHR[a] stage of research in which PPI[b] took place	Role of stakeholders involved	PPI methods
Kort et al [62], 2019	The Netherlands	Various projects described: a smart pill box and real-time location systems (also a website as documented separately [51])	People with dementia and carers (past or current)	Did not fit model	Contributing to the iterative design process	Varied between projects: observations, consultations, storytelling, focus groups, and "thinking aloud" sessions
Hendriks et al [63], 2017, also with reference to Hendriks et al [64], 2014	Belgium	System for monitoring the mealtimes of people with dementia in a care home using sensors and data input by carers into the app	Industry representatives, academics and HCPs, professional carers, people with dementia, and informal carers	Did not fit model	Contributing to the iterative design process	Meetings, feedback sessions with HCPs or professional carers, integration of research team into daily life at care home, and group "mapping" sessions with people with dementia and carers
Orpwood et al [65], 2007	United Kingdom	Various technology projects: music player, video streaming of outside world scenes into the homes of people with dementia, conversation prompter for people with dementia, and "sequence support" tool for prompting ADLs[e]	Varied across projects: people with dementia; carers; and other "user representatives," including academics from the social sciences, engineering, and dementia organizations	Did not fit model	Contributing to the iterative design process	Varied across projects: user survey, co-design workshops, observations, 1:1 user testing, and interviews
Savitch et al [66], 2012	United Kingdom	Website providing information about assistive technology for people with dementia	People with dementia and, separately, a steering group that also included 1 person with dementia	Steering group: detail not given; elements did not fit model	Contributing to the iterative design process (people with dementia); steering group also provided input throughout	Interviews, focus groups, co-design workshops, and involvement in steering group meetings
Perkins et al [52], 2022	United Kingdom, Ireland, Hong Kong, India, and Brazil	Web-based delivery of CST[f]	4 people with dementia, 4 family carers, 4 service managers, and 8 CST group facilitators from the United Kingdom and Hong Kong; additional stakeholders in India	Design of the research and undertaking and management of the research	Designing and developing a protocol (people with dementia, carers, service managers, and CST facilitators) and field-testing of the protocol and subsequently giving feedback following testing (CST facilitators)	Focus groups (web-based); CST facilitators then tested the protocol with people with dementia in 5 countries; interviews with CST facilitators following field-testing
Hwang et al [67], 2015	Canada	Animated videos for prompting people with dementia with ADLs	6 family carers	Did not fit model	Contributing to the iterative design process	Co-design workshops first to develop the concept and then refine the designs; 2 home visits for paper prototype evaluation
Oksnebjerg et al [68], 2019	Denmark	An app to support self-management for people with dementia, including a calendar and diary	4 people with dementia, 4 family carers, and 4 paid carers	Did not fit model	Contributing to the iterative design process	Co-design workshops

Study, year	Origin	Technology type and purpose	Stakeholders involved	NIHR[a] stage of research in which PPI[b] took place	Role of stakeholders involved	PPI methods
Hung et al [50], 2021	Canada	PARO, a commercially available robot seal that uses AI[g] to support the social and emotional needs of the people with dementia interacting with it	5 "patient and family partners"	Undertaking and managing the research, analysis of data, and dissemination of research findings	Supporting data collection, thematic analysis of data, and authoring of the paper	Supporting data collection with some patients or particular settings, analysis (4 × 1-h thematic analysis group sessions), and coauthoring the paper
Rathnayake et al [37], 2021	Australia	A mobile health app that provides information about dementia, care strategies, and tips for managing ADLs	Carers, HCPs, and IT experts	Did not fit model	Contributing to the iterative design process	Web-based survey, interviews, and co-design workshops
Kowe et al [69], 2021, also with reference to Kowe et al [70], 2022	Germany	Sensor-based activity management system	6 family carers	Analysis of data	Supporting thematic analysis of interview data	30-min group analysis session or workshop
Daly Lynn et al [51], 2021, also with reference to Daly Lynn et al [71], 2019, and Daly Lynn et al [72], 2022	United Kingdom	Smart home system for people with dementia in supported living	Peer researchers: 7 older adults without dementia; steering group: including 2 people with dementia, 1 family carer, and 2 dementia organization employees	Undertaking and management of the research, analysis of data, and dissemination; steering group: detail not given	Peer researchers: conducting interviews with research participants and supporting data analysis; steering group: ensuring that the voice of older people was central to the project and coauthoring the paper	2-d training for peer researchers, conducting interviews jointly with a member of the research team, group thematic analysis session, and evaluation forms
Banbury et al [73], 2021	Australia	Virtual support program to provide information and peer support for carers of people with dementia	6 family carers	Did not fit model	Contributing to the iterative design process	Co-design workshops and group meetings (all virtual) following the Double Diamond approach
Fox et al [74], 2022	United Kingdom	A mobile health app that delivers memory tests throughout the day to monitor cognition changes	7 people with dementia, 7 family carers, and a PPI officer	Did not fit model	PPI officer as "proxy patient representative" in the research team; people with dementia and carers contributed to the iterative design process	Co-design workshops; PPI officer part of the main research group
Rai et al [75], 2020	United Kingdom	Virtual delivery of CST	People with dementia and family carers	Did not fit model	Contributing to the iterative design process	Consultation meetings and co-design workshops
Owens et al [76], 2020	Consortium spanning organizations in Europe and the United States	Remote monitoring and measurement technologies for people with dementia	People with dementia and family carers	Design of the research	Patient advisory board—supporting research planning and design and feedback on relevance and priorities	Provision of feedback on researchers' literature review, group discussions, workshops, and other meetings of the patient advisory board

Study, year	Origin	Technology type and purpose	Stakeholders involved	NIHR[a] stage of research in which PPI[b] took place	Role of stakeholders involved	PPI methods
Stavropoulos et al [77], 2021	Greece, with involvement from multiple countries across Europe	A range of commercially available wearable devices	11 people with dementia and 10 carers from 11 countries across Europe	Design of the research	Reviewing devices and providing information to guide the design of future research, aiming to make it more relevant and accessible and improve participant experience	One-off 2.5-h session including presentations, roundtable discussions, hands-on experimentation, and voting
Liddle et al [17], 2022	Australia	No specific technology discussed—study explored factors related to engagement with technology for people with dementia and carers	15 people with dementia and carers (living experience expert reference group); 4 of them (2 people with dementia and 2 carers) were also members of the core research team and were listed as coauthors	Design of the research, undertaking and management of the research, analysis of data, and dissemination of research findings	Setting research priorities, supporting the design of interviews and developing the topic guide, thematic analysis of data, reflexivity sessions with the research team, and writing up of the study	Group sessions, discussions and meetings with reference group, group analysis sessions, and discussions of reflexivity
Hassan et al [78], 2017	United Kingdom	A range of commercially available wearable devices	>30 in total: people with dementia or MCI, carers, people with early-onset dementia (aged <65 y), and older adults without dementia	Design of the research	Contributing to research design (producing guidelines to optimize design and improve acceptability) and informing procurement decisions	Exploratory workshops in groups according to diagnosis (people with dementia+carers, people with early-onset dementia, and older adults without dementia), individual 1:1 meetings (people with MCI), and opportunities for stakeholders to try the devices at home
Jacklin et al [79], 2020	Canada	A wearable (wristband) for capturing movement-related behaviors (eg, falls, wandering, and agitation)	Indigenous community representatives, carers, community elders, and health and social care workers	Did not fit model	Informing the design of the research to ensure that culturally appropriate and inclusive methods are used	Community-based participatory research approach, focus groups (with carers), and preparation meetings with the Community Advisory Council to plan the research and ensure that appropriate methods are used
Ghafurian et al [80], 2022	Canada	App to support professional carers in communicating with people with dementia in nursing homes	17 professional carers and 1 nurse	Did not fit model	Contributing to the iterative design process	Survey, focus groups, and co-design workshops
Berge et al [81], 2022	Norway	Tablet-based music app primarily used as a relational tool to support positive interactions between people with dementia and carers	People with dementia or other psychiatric conditions, carers, and HCPs	Did not fit model	Contributing to the iterative design process	Observations, interviews, and 2 focus groups; user testing of a prototype with 4 older adults with dementia or other psychiatric conditions

Study, year	Origin	Technology type and purpose	Stakeholders involved	NIHR[a] stage of research in which PPI[b] took place	Role of stakeholders involved	PPI methods
Shadarevian et al [49], 2020	Canada	Tablet for sharing family videos in hospital with people with dementia to support care provision, reduce social isolation, and reduce aggression	People with dementia, family carers, HCPs, and students	Undertaking and management of the research, analysis of data, and dissemination of research findings	Positioned as part of the research team throughout, guiding the research process; thematic analysis of interview data; creating a toolkit to support wider dissemination and adoption of the intervention; and coauthoring the paper	Monthly research project meetings, making videos, interviews, group thematic analysis session, manuscript reviewing and editing
Tiersen et al [82], 2021	United Kingdom	Smart home system for people with dementia in their own homes	People with dementia, carers, and HCPs	Did not fit model	Contributing to the iterative design process	Various across 9 substudies: semistructured interviews, focus groups, co-design workshops, surveys, home visits, online group meetings, and observations
van der Roest et al [83], 2008	The Netherlands	Website with customized information for people with dementia and their carers about health care and welfare services	People with dementia, carers, and HCPs	Did not fit model	Contributing to the iterative design process	Workshop exploring user needs (people with dementia, carers, and HCPs), further co-design workshops (HCPs), prototype testing, and questionnaire (family carers)

[a] NIHR: National Institute for Health and Care Research.

[b] PPI: patient and public involvement.

[c] HCP: health care professional.

[d] MCI: mild cognitive impairment.

[e] ADL: activity of daily living.

[f] CST: cognitive stimulation therapy.

[g] AI: artificial intelligence.

Table 2. Patient and public involvement (PPI) in the different stages of research as recommended by the National Institute for Health and Care Research [21] (n=31).

Stage of research	Studies with PPI at this stage, n (%)	Example
Design of the research and development of the grant application	7 (23)	PPI representatives (here a “Patient Advisory Board”) supported research planning and design, giving feedback on relevance and priorities [76].
Undertaking and management of the research	7 (23)	PPI representatives, here termed “peer researchers,” collected data for the study interviewing people with dementia [51].
Analysis of data	6 (19)	PPI representatives were part of interview data analysis and discussions of reflexivity [17].
Dissemination of research findings	4 (13)	PPI representatives coauthored the paper [49].
Did not fit model	21 (68)	PPI representatives were positioned both as co-designers along with the research team and as research participants testing the prototype [81].

Textbox 3. Types of technologies and their purposes.

Sensor monitoring systems (including smart home monitoring systems) [51,55,63,69,76,82]

- Safety alerts
- Monitoring (of health, activity, behavior, and cognition)

Wearables [77-79]

- Safety alerts
- Monitoring (of health, activity, behavior, and cognition)

Apps [37,60,68,74,80,81]

- Monitoring (of health, activity, behavior, and cognition)
- Self-management
- Exercises
- Information provision or education
- Supporting social interaction
- Social and emotional well-being

Miscellaneous assistive technology devices (not wearables and not app based, eg, gas cooker monitor or smart pill box) [50,61,62,65,67]

- Safety alerts
- Self-management
- Leisure access
- Supporting social interaction
- Social and emotional well-being

Websites [53,54,66,83]

- Information provision and education
- Accessing peer support
- Accessing professional support

Videoconferencing platforms [73,75]

- Therapy delivery
- Information provision and education
- Accessing peer support

Virtual reality games [56,57]

- Exercises

Who Was Involved?

Studies involving only 1 stakeholder group in their PPI activities were in the minority (5/31, 16%), and many (17/31, 55%) involved ≥3 different stakeholder groups, with the range of these shown in Multimedia Appendix 2. Family carers were the most frequently involved group (27/31, 87% of the studies), followed by people living with dementia (23/31, 74%). Most papers gave little detail about recruitment methods or the background of their PPI representatives. Where papers mentioned attempts to recruit diverse viewpoints, this generally referred to involving different stakeholder perspectives (eg, patients as well as carers and health care professionals), and where inclusivity was dwelled on, this usually referred to the involvement of people living with dementia. Some papers mentioned the linguistic mix or geographical spread of those involved, in particular [52,76,77]. Discussions of racial or ethnic diversity within PPI groups were almost entirely absent. There was one exception [79] in which the inclusion of First Nations representatives was central to the study.

When Were They Involved?

The NIHR recommends PPI throughout the research cycle, highlighting in particular 4 key areas where PPI can take place [21]. The studies in this review were mapped to these stages, as shown in Table 2. In total, 29% (9/31) of the studies had involvement from patient and public partners at multiple stages throughout the research cycle [17,49-53,56,57,66], although sometimes a lack of detail on methods meant that this multistage involvement was presumed (eg, description of a steering group providing oversight "at key milestones" [66] without further description).

As shown in Table 2, a total of 68% (21/31) of the sources did not fit into this NIHR description. These were papers describing a co-design or participatory design process in which the stakeholders involved were both the "co-researchers" or "co-designers" and yet were also positioned as research participants. Typically, these studies involved stakeholders in the iterative design process of a technology prototype. Participants collaborated with the research team on the design process while also being positioned as study participants, for example, being observed testing prototypes or providing feedback as part of interviews. Their involvement could not clearly be classified as designing the research (the study protocol having been designed before their input) or quite as "undertaking/managing the research" as they were the targets of data collection, not involved in the process of collecting them themselves. However, as the authors positioned these stakeholders as collaborators or co-designers along with the research team, these studies were not excluded in the same way that others were when they were more clearly set up as qualitative studies (eg, a focus group to collect end users' views on technology where ethics approval had been sought for this research process).

How Were They Involved?

Approaches to PPI varied (Table 1). Every paper mentioned at least one form of group activity for their involvement work. Varying terms were used for this—co-design workshops and focus groups were the most frequently mentioned, along with group meetings, group discussions, prototype testing sessions, consultation rounds, group consultations, informal meetings, group feedback sessions, and workshops. Most papers (26/31, 84%) described more than 1 type of activity. In addition to group activities, many conducted interviews [37,49,51,52,55,56,65,66,81,82], observations [54,57,62,65,81,82], or surveys or questionnaires [37,54,65,80,82,83]. A total of 19% (6/31) of the studies set up steering groups that were regularly involved in the research process, described variously as a research development group [53], living experience expert reference group [17], steering group [51,66,71], and patient advisory board [76,77], although details were minimal or absent about what this entailed. A total of 19% (6/31) of the papers [17,49-51,57,74] described some form of integration of patient and public partners (or, in 1 case, a PPI officer as proxy for the PPI group itself [74]) into the main research team, although, again, details were often very minimal about what this entailed. In total, 13% (4/31) of the papers were coauthored by patient and public partners [17,49-51].

Barriers to and Facilitators of Effective PPI

A total of 74% (23/31) of the papers included at least some reporting of either facilitators or barriers faced when conducting PPI. In many cases, this reporting was minimal, for example, listing one challenge the team faced. Only 26% (8/31) of the papers had what we considered to be a more thorough discussion of barriers or facilitators [51,56,60,63,64,69,70,73,74,78] (the papers by Hendriks et al [63,64] refer to the same study, as do those by Kowe et al [69,70]). Barriers and facilitators were grouped into themes (Textboxes 4 and 5). Facilitators often focused on ways to achieve richer, more meaningful involvement, for example, working with multiple stakeholder groups and creating a trusting, supportive group dynamic. The barriers identified principally regarded issues with working with dementia as a condition as well as practical issues such as time and budget.

Textbox 4. Facilitating effective patient and public involvement (PPI).

A person-centered approach: choices and adaptability in involvement

1. Prioritizing the well-being and positive experience of those involved [60,77]
2. Offering choices and being led by those involved (how to take part, methods, environment, and level of involvement) [17,69,82]
3. Use of extra time and flexibility for people with dementia, including modification of activities to make them more accessible, acknowledging that there will be no *one-size-fits-all* [60,77]

Building the group: rapport, trust, and equality

1. Spending time developing group relationships, finding commonalities, and building connections within the team [51,73,77]
2. Building time for chatting and eating together. Informality helps build rapport and flatten hierarchies [60,63,65]
3. Use of a nonresearcher as facilitator [69]
4. Being face-to-face rather than web-based [77]
5. Use of small groups [60]

Multiple viewpoints

1. Including views from multiple stakeholder groups as a way of improving the quality of involvement work and the richness of the data gathered [78,82]
2. Planning a range of methods to recruit and work with different groups (carers, people with dementia, health care professionals, and others) seen as important [82]
3. Considering ways of involving seldom heard groups—from practical adaptations (researchers traveling and not asking patient and public partners to do so) [80] to cultural considerations [79]
4. Group members from different backgrounds learning from each other [65]
5. Support to access different groups was beneficial (eg, working with community organizations or having managerial support to enable staff to take time away from their main role [56])

The right environment

1. Considering accessibility and proximity to local amenities and transport [60,78]
2. Considering who owns the environment—researchers going to those involved (eg, integrating into nursing home environment) may help create a greater sense of equality, flatten hierarchies, and support researchers' understanding of the group they are working with [56,63,80]
3. Being face-to-face enabled hands-on workshops, improved group dynamics, and reduced technology barriers [77,78]
4. Web-based environments enable geographically diverse groups to come together and may keep discussions more focused [73]

Support and training

1. Having facilitators or members of the research team who are skilled and experienced working with people with dementia [60,78]
2. Providing training for patient and public partners (eg, data collection, thematic analysis, and computer skills) [51,60]
3. Supporting patient and public partners with adequate time to reflect and debrief with members of the academic research team [51]
4. Using paper prototypes to overcome technology barriers [66]
5. Providing adequate support for people with dementia (family carers [60] or modified activities [60,77,78])

Pragmatism and compromise

1. Proxy involvement (of family, PPI officers, and nursing home staff) used in place of people with dementia (or people with moderate to severe dementia) in cases in which their involvement was not seen as feasible [55,61,74]
2. One-to-one sessions found to be easier to organize than group sessions [53]
3. Virtual meetings may be easier to organize than face-to-face meetings [73]

Textbox 5. Barriers to effective patient and public involvement (PPI).

The nature of dementia

1. Cognitive impairments seen as too great a barrier to attempt PPI with people with dementia [55,61]
2. Input from people with dementia described as very minimal [62]
3. Attempts at adaptations unsuccessful [63,64]
4. Variations in presentation making it difficult to plan a particular approach or manage a group [63,64]
5. Carers and people with dementia both overestimating the abilities of the latter [63,64]
6. Unreliable historians— for example the challenge of interpreting someone’s account of their ability to participate in activities of daily living while they also recount recent interactions with long-dead relatives [63,64]
7. The emotional load faced by researchers working with this group, including challenges such as being asked for support or advice out of their scope [63,64]

Inequality of relationships within the group

1. Some authors highlighted issues with patient and public partners feeling undervalued or not equal within the team; this applied to those without dementia [51,63], though dementia was also seen as an additional barrier to a sense of equality [63,64]
2. Lack of payment for PPI also contributed to this, as well as the limited scope or lack of defined roles and responsibilities for patient and public partners [63,69]

Time pressures

1. Researchers’ time pressures—co-design or other involvement activities as time-consuming processes that can be difficult to manage alongside the time pressures of a research study [75,81,83]
2. Family carers’ time pressures—busy schedules and stressful lives [37,69]
3. Staff time pressures—nursing home staff and health care professionals’ strict shift patterns and limited flexibility for time away from work [80], in some cases exacerbated by the COVID-19 pandemic [52]
4. Limited time resulting in reduced or inadequate training for patient and public partners [51,69]
5. Rapport building in the group suffering as a result of lack of time [51,56]

Recruitment and diversity

1. Small numbers of people involved resulting in reduced diversity of opinions and a poorer representation of stakeholders [56,57,75]
2. Challenges with generating interest in the study or reaching particular groups [74,78] and COVID-19 causing staffing pressures [52] and a lack of face-to-face options for people with dementia [82]

Processes and communication

1. Communicating complex content (the ethics of smart homes, technology use, and design processes) was particularly challenging for people with dementia [62,68]
2. Use of jargon terminology by researchers was a barrier for all patient and public partners (not only those with dementia) [63,69]
3. Methods of communication—use of phone for people with dementia was limiting [82], and sending too many emails was unpopular [56]
4. Processes for PPI members experienced as boring or repetitive (eg, completing multiple assessments), especially when combined with a lack of communication about the purpose or the results of their input [56]
5. Lack of involvement and communication early in the study resulting in stakeholders having less of a connection or understanding of the project or feeling that their contributions were less valued [51,63]

Impact of PPI

Although most papers (28/31, 90%) implied or briefly commented that stakeholder involvement had some impact on their study (usually on the iterative design process), this was sometimes without any description of what the impact was. Where any details were given, as was the case in 52% (16/31) of the papers [51,54-57,60,61,63,69,73-79], the results are summarized in Textbox 6.

Textbox 6. Impact of patient and public involvement (PPI) activities.

Impact on the research

- PPI activities helped set groups' research agendas, with clearly defined stakeholder priorities for research [76,77]. PPI data were identified as something that can be shared with and used by the wider research community when planning research [77].
- Involvement in research design resulted in a set of recommendations that the authors hope will improve the acceptability for research participants [78] and in specific cultural adaptations and approaches [79].
- Involvement in data collection was reported as adding richness to the data on account of the rapport and connections that peer researchers built with the people with dementia they were interviewing [51].
- Many papers (21/31, 68%) commented that the methods used (eg, co-design and participatory design) had an end result that was in some way grounded in the views or priorities of users but often with minimal detail. In total, 13% (4/31) of the papers [55,57,74,75] gave detail about the extent to which user groups drove the development or design of technology, reflecting on the value of their input.
- Coresearcher involvement in a thematic analysis workshop made for a more robust analysis, with differing perspectives between the research team and coresearchers showing the need for more PPI at the analysis stage in the future [69]. The limited impact that PPI activities had at the analysis stage was also reflected on, citing inadequate time and training for coresearchers resulting in brief and surface-level group analysis sessions [51,69].

Impact on patient and public partners

- Feedback on positive experiences of patient and public partners was provided in general terms [74,78]. Positive relationships between team members were developed, with feelings of mutual respect as well as the value of finding connections being reported [51,56,73].
- Some reported empowerment and satisfaction with the project and their role in it [54,60,61].
- Patient and public partners developed new skills [51].
- Negative experiences were reported on, including finding tasks boring or repetitive or processes complex [56]. Some papers also reported that patient and public partners felt underinvolved [51] or not treated as equal partners [63].

Impact on the academic research team

- Researchers gained a deeper understanding of the needs and priorities of the group they were seeking to conduct research with and for [79].
- Researchers developed a sense of connection with and respect for other disciplines or stakeholders they had not previously worked with [60,65].
- One paper reflected on the emotional burden associated with close working with people with dementia and the need for support for researchers as well as the people with dementia themselves [64].
- The initial challenges of stepping back when sharing responsibility with peer researchers was reported on, which became easier with experience [51].

In general, no formal methods were used for evaluating the impact of PPI activities. Where papers reported on impact, it was usually limited to the authors' reflections, including when reporting on the impact on patient and public partners. In the case of 13% (4/31) of the papers [51,56,63,73], the authors reported seeking direct feedback from those who had been involved, for example, in the form of interviews; evaluation forms; or, in 3% (1/31) of the studies, a much more extensive retrospective analysis using formalized methods [63].

Discussion

Principal Findings

In this scoping review, we set out to explore the concept of PPI in technology-related dementia research. The papers reviewed in this study revealed that dementia researchers are embracing PPI, with varied and sometimes ambitious methods, values centered on inclusivity and coproduction, and involvement of a range of stakeholder groups. We found that approaches often blurred boundaries between those involved as "researchers" and those involved as "participants" so that most studies' (21/31, 68%) PPI activities did not fit into a strict definition of PPI, for example, as set out by the NIHR [32]. Although the involvement activities being undertaken demonstrate this to be a rapidly expanding and developing field, the brevity in the reporting of such activities (often without comments on the impact of PPI) perhaps highlights the need for clearer reporting guidelines. Where mentioned, the impact of PPI was generally reported as being positive on research quality, patient and public experience, and the learning experiences provided to researchers. We comment further on our objectives in the following sections.

Objective 1: To Describe the Approaches to PPI Used to Date in Technology-Related Dementia Research (Exploring Who Is Involved, When, and How)

We found that there was a narrative across many of the included papers about the value of involvement and coproduction methods, with many authors describing their aspiration for high levels of involvement with a sense of partnership and equality with stakeholders. A few consciously excluded people with dementia from this aspiration, citing cognitive impairments as making it either practically or ethically too challenging to involve this group. These views were chiefly expressed in older papers (before 2010). More recent papers were broadly inclusive, with some describing their efforts to involve people with dementia along with other stakeholder groups such as carers, health care professionals, and older adults without dementia. Sometimes, these groups were involved in similar ways, and sometimes, there were 2 very separate approaches, for example, a set of workshops with people with dementia and carers and more extensive involvement of health care professionals or others without dementia in the research process (eg, playing a role in designing the protocol or as members of a steering group). The fact that a significant majority (26/31, 84%) involved more than one stakeholder group, with many involving ≥3 groups (17/31, 55%), reflects the value placed on hearing from multiple viewpoints.

Despite this widespread acknowledgment of the value of collaborative or coproduction methods, it was not always clear from the papers to what extent their methods reflected these values. Some used methods that perhaps lend themselves better to a consultative approach (such as one-off focus groups or surveys) rather than a collaboration or coproduction approach [20]. Consultative methods have some value in enabling researchers to find out more about people's views and experiences. They are also relatively easy to organize (often one-off events as opposed to longer-term involvement), meaning that they are a practical way of hearing from a wide range of stakeholders [20]. However, these methods mean that involvement will always be more limited in scope—there is no 2-way discussion, and there is the risk of disengagement from stakeholders who feel that their views are not being listened to [20], as indeed was reported by Hendriks et al [63]. Where stated methods or approaches may have enabled more of a partnership approach to take place (eg, the use of a series of co-design workshops or involvement of a steering group), the brevity of the write-up often prevented us from understanding whether or how this happened.

The most common methods of involvement were through some form of group activity such as focus groups, workshops, prototype testing sessions, or roundtable discussions. Every paper mentioned some form of group activity such as these, with or without other methods. Involvement often occurred at just one stage of research—most commonly, this was contributing to the design of a prototype but with no involvement either before or after this (eg, in protocol design, recruitment, analysis, or dissemination), although there were exceptions to this, with studies involving patients or the public throughout multiple stages of the research.

Most studies (26/31, 84%) used multiple methods of involvement. There will be practical reasons for using different methods, some suiting particular groups or settings more than others, especially when we consider involving people with dementia and the flexibility of approach that this requires. Tiersen et al [82] described many different methods in their paper, reflecting that this "resulted in triangulation of investigators, methods and data sources to develop a more comprehensive understanding of the phenomena being studied." The use of multiple methods also allowed for more flexibility of involvement, with some able to take on a more active or sustained role than others as able or desired. This was cited as an aspiration or suggestion for future PPI by groups who did not have such flexible approaches, such as Kowe et al [69]. The paper by Liddle et al [17] described the flexibility of roles and high levels of involvement. Their "Living Experience Expert Reference Group" involved 15 people with dementia and carers, of whom 4 (2 people with dementia and 2 carers) were also integrated into the main investigator team. Roles included helping set research priorities, developing the interview topic guide, analysis of data, reflexivity sessions, and the write-up of the study. Shadarevian et al [49] and Hung et al [50] also described the integration of stakeholders into the main research group, mentioning roles in undertaking and managing the research along with analysis and dissemination, although there was little detail about the methods used for this involvement. PPI in data collection was rare. It was described in most depth by Daly Lynn et al [51], who worked with "peer researchers" (older adults without dementia) to interview research participants with dementia about their experiences with smart home living, with an insightful write-up detailing both the positive experiences and the challenges they faced.

Finally, although the notion of diverse viewpoints being included in PPI was often celebrated, this almost always referred to the inclusion of a variety of stakeholder groups (eg, patients, carers, and health care professionals). In general, there was very little explicit discussion of the demographics of PPI representatives. To reduce health-related inequalities and bias, researchers should consider not only how to involve people with dementia but also the demographics of this heterogeneous population, explicitly seeking ways to involve underrepresented groups.

Objective 2: To Describe the Reported Barriers to and Facilitators of Effective PPI in This Area

The general lack of evaluation or reflections on barriers to and facilitators of involvement means that the themes described in this paper result from a minority of studies, with most derived from just 26% (8/31) of the studies [51,56,60,63,69,73,74,78]. Themes drawn out broadly matched those frequently documented in the literature [11,25,41,42], in particular barriers such as time and budget, recruitment issues, and the specific challenges of adapting activities to be suitable for people with dementia.

Facilitators tended to focus on the manner in which activities were carried out (eg, how informality helped flatten hierarchies) rather than on specific methods or approaches, such as focus groups or interviews. The themes here mirror the key principles of coproduction outlined by the NIHR [21,32]. The NIHR emphasizes that coproduction does not require a specific method but a more nuanced focus on interpersonal skills, relationship building, and power sharing (Textbox 1) [32]. However, although many papers stated the need for approaches using these principles or claimed to have worked with such values in mind, details about what was done were often limited. We would welcome further and more detailed reporting on these activities so as to build the knowledge base among research teams and enable more high-quality PPI to be conducted in the future with this population. As also emphasized by Hendriks et al [64], there is a need for more than anecdotal evidence in the literature about how to involve people with dementia—the lack of guidelines or a strong evidence base makes progression challenging.

The barriers identified reflect the challenging nature of PPI in technology-related dementia research. Time and resources were frequently cited as limiting factors. Some studies avoided the challenge of making PPI activities accessible to people with dementia by not involving them at all. Hendriks et al [64] detailed the challenges of involving people with dementia in a particularly frank manner. They reported on the difficulty of sufficiently modifying activities to make them accessible, difficulties with variability in dementia presentations, and overestimation of abilities by people with dementia and their family carers. They went as far as to say that "the differences between the designer and the person to design for are too big to speak about equality in participation" [64]. A few papers highlighted the complex topics under discussion (eg, smart home technology, ethics, and design processes) and the difficulty of translating these issues into something someone with dementia could understand and contribute to [62,63,68]. Kort et al [62] went as far as to say that the complexity of content meant that input from people with dementia was very basic, commenting that "the actual participation in the project was deemed more important than the actual contribution." Although pessimistic sounding in tone at times, these honest admissions of the challenges faced and the inability of researchers to overcome them to a meaningful degree help the research community understand the current landscape of PPI in technology-related dementia research. They reinforce the need for significant investment to be made for the involvement of people with dementia to be successful. This is not merely in the creation of accessible resources or the provision of the right environment. Rather, it may be that significant cultural shifts need to take place for researchers to be able to plan and conduct effective coproduction based on the key principles of power sharing, inclusivity, respect, reciprocity, and relationship building [32]. It seems likely that researchers would benefit from significant training and support in understanding power dynamics and coproduction as well as support to learn more about how to work with people with cognitive impairments.

Objective 3: To Examine and Report on the Impact of PPI in This Area

Papers with more than a brief comment on the impact of involvement were scarce in this review, mirroring the findings by Suijkerbuijk et al [41] as well as the findings of those studies considering PPI in dementia research more broadly [25,26,42,84]. A few papers, notably those by Daly Lynn et al [51], Muñoz et al [56], Banbury et al [73], and Hendriks et al [63,64], provided valuable discussions and evaluations of impact.

Where papers reported on the impact of their involvement work, the results were largely positive. The studies demonstrated that PPI can have a positive impact on research quality at multiple stages of the research cycle as well as on those taking part. To achieve this, the authors reflected on the need to involve multiple stakeholder groups and use multiple methods of involvement to provide a person-centered and flexible approach in which people feel well supported and valued for their contribution. To do this evidently requires significant investment of time and resources. Even those papers detailing what we considered to be relatively high levels of involvement spoke about the need for more time and resources, for example, to improve levels of training or offer more formalized PPI roles [51,69].

It was helpful to see negative experiences with PPI also reported [56,63,64]. These are often missing from the literature [85] but provide helpful learning points. Another area that received little attention is the emotional impact of PPI on researchers. This was commented on briefly by Hendriks et al [64] but otherwise did not feature in the studies we reviewed, although it has been noted as a feature of PPI in dementia research more broadly [43,84]. The emotional impact on researchers might be seen as both positive and negative—as a research community, it would be helpful to recognize and value the learning and increased empathy that can come from close working with patient and public partners. It is also important to recognize the potential distress or emotional burden felt by researchers, which might be associated with this relationship, in particular for those unused to working with people in cognitive decline [43]. It is important that future studies consider these impacts and that researchers as well as patient and public partners have access to adequate training and support.

Across most studies (27/31, 87%), formal or standardized methods were not used to capture impact. Reporting was generally limited to the authors' personal reflections. In only 13% (4/31) of the papers did the authors report seeking direct feedback from those who had been involved, for example, in the form of interviews or evaluation forms [51,56,63,73]. Hendriks et al [63] included a detailed evaluation of impact. This team retrospectively analyzed their participatory design process, mapping out the decision-making process at each stage of the project and considering the extent to which coresearchers had been involved and, therefore, whether participation had been truly meaningful. They also interviewed some of those who had been involved and analyzed themes that emerged. There is a risk that reporting on the impact of PPI can lead to an overvaluing of that which is easily measured but of little meaning (such as the number of people involved) instead of these more complex issues such as research culture or power relations [85]. Therefore, this example by Hendriks et al [63] reflecting on and evaluating the power dynamics at play and the processes that took place is particularly commendable.

In the future, it would be helpful for all involved—researchers, patients, and the public—if there were more recording and reporting of the impact of involvement to help all parties understand if, when, how, and why partnership working is beneficial [20,43]. Capturing this in a meaningful way is the challenge ahead of us [85,86]. A focus on the dialogue and the learning is felt to be helpful—Russell et al [85] recommend exploring "the complexity and richness of this relationship, using methods that emphasise illumination rather than measurement, and asking when, why, and with whom the dialogue happens or fails to happen."

Defining PPI: Challenges We Faced in This Review

One of the challenges we faced was the varying terminology and approaches used to involve groups in research. We applied a broad definition of "involvement" and, therefore, included papers using co-design or participatory design processes, as described, for example, by Hendriks et al [63]. Within a participatory design approach, there is a deliberate blurring of the roles of "designer" and "end user." When written up in a research context, this can lead to a blurring of the roles of researcher, designer, end user, and research participant. From a PPI perspective, it is not usually considered appropriate for people involved in research to also be research participants as this can compromise both the researcher and person involved [20]. However, the NIHR gives the example of participatory or action research as a possible exception to this rule, and it was often these types of studies that we reviewed. Nevertheless, it was often difficult to determine which studies met our inclusion criteria, in part because of this mixing of roles and because of lack of detail in the methodology sections. Where studies explicitly used qualitative research methods (stating a qualitative approach and collecting data for analysis with appropriate ethics approval), they were excluded from this review. However, details were often missing, or sometimes subsections of a study appeared to be qualitative, whereas other sections were framed more like PPI activities. Terminology could not be relied on as it was applied inconsistently among studies. Similarly, information about ethics applications was not always available, and we did not use this as part of the inclusion and exclusion criteria. Had we used a stricter definition of PPI, we would have excluded a significant portion of the literature (21/31, 68% of the studies in this review). We felt that doing this would result in a misrepresentation of the type of involvement work being carried out and in missing key learning points from these studies.

Strengths

We used a comprehensive search strategy considering all types of technology, all types of dementia, and many terms for "patient and public involvement" to reflect the different types of involvement in the field, building on search strategies from other reviews [11,19,25,41,42] that at times had been narrower in scope (eg, looking at "patient and public involvement" but not "co-design"). The 2 reviewers overcame the difficulty of defining PPI through regular communication and close working throughout the screening stages, consulting with a third member of the team where required. The review is further strengthened by multidisciplinary team input, with representatives from health care and health sciences as well as from design and technology backgrounds, which we hope ensures that our reflections and conclusions are of interest and applicable to a wide range of disciplines.

Limitations

We did not conduct a gray literature search. Doing so might have resulted in a broader range of accounts of involvement being included. In addition, we did not involve patients or the public in this review, which may have contributed additional perspective and depth. However, we have planned and started recruitment for a much broader PPI strategy for our research center. The results of this review will be shared with our steering group so as to jointly consider how the findings should inform our PPI work as a center.

Conclusions

At present, most involvement in technology-related dementia research is limited in breadth (often to just 1 stage in the research cycle) and depth (often consultative rather than with any sharing of power). We see across the literature shared aspirations of high levels of meaningful involvement in research, and it is encouraging to see some evidence of this being put into practice, with some reporting on methods used for involvement and the impact this has. Where papers gave details, it appears that a flexible approach with multiple methods used at different stages of the research cycle may be the most successful, tailoring methods to the various groups or individuals involved and facilitating greater depth or breadth of involvement according to people's wishes and abilities. When this is done well, PPI can have a positive impact on both the research and those involved. This evidently will take significant time and resources, particularly if the approaches used are to move beyond consultations to collaboration or coproduction. Wider reporting of methods and facilitative strategies along with more formalized methods for recording and reporting on meaningful impact would be helpful so that all those involved—researchers, patients, and other stakeholders—can understand and learn how best to jointly conduct research.

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Authors' Contributions

PK wrote the manuscript. PK and HL developed the protocol with supervision from CMA and SD. PK and HL screened the results and extracted the data with third-author support where necessary from CMA. All authors reviewed and contributed to the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Detailed search strings used for the different databases.
[DOCX File , 22 KB - aging_v7i1e48292_app1.docx]

Multimedia Appendix 2

Stakeholder groups included as part of patient and public involvement activities.

[PNG File , 76 KB - aging_v7i1e48292_app2.png]

Multimedia Appendix 3

PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.

[DOCX File , 83 KB - aging_v7i1e48292_app3.docx]

References

1. Dementia statistics hub. Alzheimer's Research UK. URL: https://dementiastatistics.org/ [accessed 2023-03-30]
2. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. Care Policy and Evaluation Centre, London School of Economics and Political Science. 2019 Nov. URL: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf [accessed 2023-03-30]
3. The NHS long term plan. National Health Service. URL: https://www.longtermplan.nhs.uk/ [accessed 2023-03-30]
4. Moyle W, Murfield J, Lion K. The effectiveness of smart home technologies to support the health outcomes of community-dwelling older adults living with dementia: a scoping review. Int J Med Inform 2021 Sep;153:104513. [doi: 10.1016/j.ijmedinf.2021.104513] [Medline: 34116363]
5. Astell AJ, Bouranis N, Hoey J, Lindauer A, Mihailidis A, Nugent C, et al. Technology and dementia: the future is now. Dement Geriatr Cogn Disord 2019;47(3):131-139 [FREE Full text] [doi: 10.1159/000497800] [Medline: 31247624]
6. Gagnon-Roy M, Bourget A, Stocco S, Courchesne AL, Kuhne N, Provencher V. Assistive technology addressing safety issues in dementia: a scoping review. Am J Occup Ther 2017;71(5):7105190020p1-710519002010. [doi: 10.5014/ajot.2017.025817] [Medline: 28809655]
7. Moyle W. The promise of technology in the future of dementia care. Nat Rev Neurol 2019 Jun 9;15(6):353-359. [doi: 10.1038/s41582-019-0188-y] [Medline: 31073242]
8. Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M, Damant J. Technology-based tools and services for people with dementia and carers: mapping technology onto the dementia care pathway. Dementia (London) 2019 Feb 08;18(2):725-741. [doi: 10.1177/1471301217691617] [Medline: 28178858]
9. Liu L, Stroulia E, Nikolaidis I, Miguel-Cruz A, Rios Rincon A. Smart homes and home health monitoring technologies for older adults: a systematic review. Int J Med Inform 2016 Jul;91:44-59. [doi: 10.1016/j.ijmedinf.2016.04.007] [Medline: 27185508]
10. Ienca M, Fabrice J, Elger B, Caon M, Scoccia Pappagallo A, Kressig RW, et al. Intelligent assistive technology for Alzheimer’s disease and other dementias: a systematic review. J Alzheimer's Dis 2017 Feb 20;56(4):1301-1340. [doi: 10.3233/jad-161037]
11. Øksnebjerg L, Janbek J, Woods B, Waldemar G. Assistive technology designed to support self-management of people with dementia: user involvement, dissemination, and adoption. A scoping review. Int Psychogeriatr 2019 Nov 25;32(8):937-953. [doi: 10.1017/s1041610219001704]
12. Sánchez VG, Taylor I, Bing-Jonsson PC. Ethics of smart house welfare technology for older adults: a systematic literature review. Int J Technol Assess Health Care 2017 Nov 20;33(6):691-699. [doi: 10.1017/s0266462317000964]
13. Birchley G, Huxtable R, Murtagh M, Ter Meulen R, Flach P, Gooberman-Hill R. Smart homes, private homes? an empirical study of technology researchers' perceptions of ethical issues in developing smart-home health technologies. BMC Med Ethics 2017 Apr 04;18(1):23 [FREE Full text] [doi: 10.1186/s12910-017-0183-z] [Medline: 28376811]
14. Hine C, Nilforooshan R, Barnaghi P. Ethical considerations in design and implementation of home-based smart care for dementia. Nurs Ethics 2022 Jun 01;29(4):1035-1046 [FREE Full text] [doi: 10.1177/09697330211062980] [Medline: 35105196]
15. Predel C, Timmermann C, Ursin F, Orzechowski M, Ropinski T, Steger F. Conflicting aims and values in the application of smart sensors in geriatric rehabilitation: ethical analysis. JMIR Mhealth Uhealth 2022 Jun 23;10(6):e32910 [FREE Full text] [doi: 10.2196/32910] [Medline: 35737429]
16. Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B. Ethical design of intelligent assistive technologies for dementia: a descriptive review. Sci Eng Ethics 2018 Aug;24(4):1035-1055. [doi: 10.1007/s11948-017-9976-1] [Medline: 28940133]
17. Liddle J, Worthy P, Frost D, Taylor E, Taylor D, Beleno R, et al. Personal and complex: the needs and experiences related to technology use for people living with dementia. Dementia (London) 2022 Jul;21(5):1511-1531. [doi: 10.1177/14713012221084521] [Medline: 35420505]
18. Novitzky P, Smeaton AF, Chen C, Irving K, Jacquemard T, O'Brolcháin F, et al. A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. Sci Eng Ethics 2015 Jun;21(3):707-765. [doi: 10.1007/s11948-014-9552-x] [Medline: 24942810]

19. Holthe T, Halvorsrud L, Karterud D, Hoel KA, Lund A. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. Clin Interv Aging 2018 May 04;13:863-886 [FREE Full text] [doi: 10.2147/CIA.S154717] [Medline: 29765211]
20. Briefing notes for researchers - public involvement in NHS, health and social care research. National Institute for Health and Care Research. 2021 Apr 05. URL: https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371 [accessed 2023-03-30]
21. Patient and public involvement in health and social care research: a handbook for researchers. National Institute for Health Research. 2014. URL: https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf [accessed 2022-07-15]
22. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. Health Expect 2019 Aug;22(4):785-801 [FREE Full text] [doi: 10.1111/hex.12888] [Medline: 31012259]
23. What do I need to do? National Health Service Health Research Authority. URL: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/what-do-i-need-do/ [accessed 2023-04-04]
24. ICH E8 General considerations for clinical studies - scientific guideline. European Medicines Agency. 2021 Oct 14. URL: https://www.ema.europa.eu/en/ich-e8-general-considerations-clinical-studies-scientific-guideline [accessed 2023-04-04]
25. Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, et al. Patient engagement in research related to dementia: a scoping review. Dementia (London) 2018 Nov 29;17(8):944-975. [doi: 10.1177/1471301218789292] [Medline: 30373460]
26. Burton A, Ogden M, Cooper C. Planning and enabling meaningful patient and public involvement in dementia research. Curr Opin Psychiatry 2019 Nov;32(6):557-562. [doi: 10.1097/YCO.0000000000000548] [Medline: 31306247]
27. Collins R, Hunt A, Quinn C, Martyr A, Pentecost C, Clare L. Methods and approaches for enhancing communication with people with moderate-to-severe dementia that can facilitate their inclusion in research and service evaluation: findings from the IDEAL programme. Dementia (London) 2022 May;21(4):1135-1153 [FREE Full text] [doi: 10.1177/14713012211069449] [Medline: 35156412]
28. Cheston R, Bender M, Byatt S. Involving people who have dementia in the evaluation of services: a review. J Ment Health 2000;9(5):471-479. [doi: 10.1080/09638230020005200]
29. Gove D, Diaz-Ponce A, Georges J, Moniz-Cook E, Mountain G, Chattat R, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging Ment Health 2018 Jun;22(6):723-729. [doi: 10.1080/13607863.2017.1317334] [Medline: 28513210]
30. Beresford P. From ‘other’ to involved: user involvement in research: an emerging paradigm. Nord Soc Work Res 2013;3(2):139-148. [doi: 10.1080/2156857x.2013.835138]
31. Volkmer A, Broomfield K. Seldom Heard Voices in Service User Involvement: The How and Why of Meaningful Collaboration. Havant, UK: J&R Press Ltd; May 2022.
32. NIHR guidance on co-producing a research project. National Institute for Health and Care Research. URL: https://www.learningforinvolvement.org.uk/?opportunity=nihr-guidance-on-co-producing-a-research-project [accessed 2023-03-30]
33. Ideo design thinking homepage. Ideo Design Thinking. URL: https://designthinking.ideo.com/ [accessed 2023-03-15]
34. Robert G, Locock L, Williams O, Cornwell J, Donetto S, Goodrich J. Co-Producing and Co-Designing. Cambridge, UK: Cambridge University Press; Sep 2022.
35. Design council homepage. Design Council. URL: https://www.designcouncil.org.uk/our-work/skills-learning/tools-frameworks/framework-for-innovation-design-councils-evolved-double-diamond/ [accessed 2023-03-14]
36. Simonse L, Albayrak A, Starre S. Patient journey method for integrated service design. Des Health 2019;3(1):82-97. [doi: 10.1080/24735132.2019.1582741]
37. Rathnayake S, Moyle W, Jones C, Calleja P. Co-design of an mHealth application for family caregivers of people with dementia to address functional disability care needs. Inform Health Soc Care 2021 Mar 02;46(1):1-17. [doi: 10.1080/17538157.2020.1793347] [Medline: 32706282]
38. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Qual Saf Health Care 2006 Oct;15(5):307-310 [FREE Full text] [doi: 10.1136/qshc.2005.016527] [Medline: 17074863]
39. Topo P. Technology studies to meet the needs of people with dementia and their caregivers: a literature review. J Appl Gerontol 2009;28(1):5-37. [doi: 10.1177/0733464808324019]
40. Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C. Involving people with dementia in the development of supportive IT applications: a systematic review. Ageing Res Rev 2013 Mar;12(2):535-551. [doi: 10.1016/j.arr.2013.01.002] [Medline: 23318684]
41. Suijkerbuijk S, Nap HH, Cornelisse L, IJsselsteijn WA, de Kort YA, Minkman MM. Active involvement of people with dementia: a systematic review of studies developing supportive technologies. J Alzheimers Dis 2019;69(4):1041-1065 [FREE Full text] [doi: 10.3233/JAD-190050] [Medline: 31156158]

42. Miah J, Dawes P, Edwards S, Leroi I, Starling B, Parsons S. Patient and public involvement in dementia research in the European Union: a scoping review. BMC Geriatr 2019 Aug 14;19(1):220 [FREE Full text] [doi: 10.1186/s12877-019-1217-9] [Medline: 31412788]
43. Miah J, Parsons S, Lovell K, Starling B, Leroi I, Dawes P. Impact of involving people with dementia and their care partners in research: a qualitative study. BMJ Open 2020 Oct 27;10(10):e039321 [FREE Full text] [doi: 10.1136/bmjopen-2020-039321] [Medline: 33109666]
44. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018 Oct 02;169(7):467-473 [FREE Full text] [doi: 10.7326/M18-0850] [Medline: 30178033]
45. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. Int J Evid Based Healthc 2015 Sep;13(3):141-146. [doi: 10.1097/XEB.0000000000000050] [Medline: 26134548]
46. Assistive technology: definition and safe use. United Kingdom Government. 2023 Jul 1. URL: https://www.gov.uk/government/publications/assistive-technology-definition-and-safe-use/assistive-technology-definition-and-safe-use [accessed 2023-08-15]
47. Technology enabled care services (TECS). National Health Service England. URL: https://www.england.nhs.uk/tecs/ [accessed 2023-08-15]
48. Covidence systematic review software. Veritas Health Innovation. URL: https://www.covidence.org/ [accessed 2022-12-12]
49. Shadarevian J, Chan C, Berndt A, Son C, Gregorio M, Horne N, et al. Creating a toolkit with stakeholders for leveraging tablet computers to support person-centred dementia care in hospitals. J Rehabil Assist Technol Eng 2020 Nov 23;7:2055668320960385 [FREE Full text] [doi: 10.1177/2055668320960385] [Medline: 33282336]
50. Hung L, Gregorio M, Mann J, Wallsworth C, Horne N, Berndt A, et al. Exploring the perceptions of people with dementia about the social robot PARO in a hospital setting. Dementia (London) 2021 Feb;20(2):485-504 [FREE Full text] [doi: 10.1177/1471301219894141] [Medline: 31822130]
51. Daly Lynn J, Washbrook M, Ryan A, McCormack B, Martin S. Partnering with older people as peer researchers. Health Expect 2021 Oct;24(5):1879-1889 [FREE Full text] [doi: 10.1111/hex.13331] [Medline: 34337838]
52. Perkins L, Fisher E, Felstead C, Rooney C, Wong GH, Dai R, et al. Delivering cognitive stimulation therapy (CST) virtually: developing and field-testing a new framework. Clin Interv Aging 2022 Feb 09;17:97-116 [FREE Full text] [doi: 10.2147/CIA.S348906] [Medline: 35173425]
53. Davies N, Hopwood J, Walker N, Ross J, Iliffe S, Walters K, et al. Designing and developing a co-produced theoretical and evidence-based online support for family caregivers of people with dementia at the end of life. BMC Palliat Care 2019 Aug 13;18(1):71 [FREE Full text] [doi: 10.1186/s12904-019-0455-0] [Medline: 31409329]
54. Kort HS, van Hoof J. Design of a website for home modifications for older persons with dementia. Technol Disabil 2014 Jul 09;26(1):1-10. [doi: 10.3233/TAD-140399]
55. Schikhof Y, Mulder I, Choenni S. Who will watch (over) me? humane monitoring in dementia care. Int J Hum Comput Stud 2010 Jun;68(6):410-422. [doi: 10.1016/j.ijhcs.2010.02.002]
56. Muñoz J, Mehrabi S, Li Y, Basharat A, Middleton LE, Cao S, et al. Immersive virtual reality exergames for persons living with dementia: user-centered design study as a multistakeholder team during the COVID-19 pandemic. JMIR Serious Games 2022 Jan 19;10(1):e29987 [FREE Full text] [doi: 10.2196/29987] [Medline: 35044320]
57. Eisapour M, Cao S, Boger J. Participatory design and evaluation of virtual reality games to promote engagement in physical activity for people living with dementia. J Rehabil Assist Technol Eng 2020 May 21;7:2055668320913770 [FREE Full text] [doi: 10.1177/2055668320913770] [Medline: 32499921]
58. Eisapour M, Cao S, Domenicucci L, Boger J. Participatory design of a virtual reality exercise for people with mild cognitive impairment. In: Proceedings of the Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems. 2018 Presented at: CHI EA '18; April 21-26, 2018; Montreal, QC. [doi: 10.1145/3170427.3174362]
59. Eisapour M. Design and evaluation of virtual reality exergames for people living with dementia. University of Waterloo. 2018. URL: https://uwspace.uwaterloo.ca/handle/10012/13694 [accessed 2022-12-12]
60. Hanson E, Magnusson L, Arvidsson H, Claesson A, Keady J, Nolan M. Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. Dementia 2016 Jul 26;6(3):411-434. [doi: 10.1177/1471301207081572]
61. Orpwood R, Bjørneby S, Hagen I, Mäki O, Faulkner R, Topo P. User involvement in dementia product development. Dementia 2016 Jul 25;3(3):263-279. [doi: 10.1177/1471301204045160]
62. Kort HS, Steunenberg B, van Hoof J. Methods for involving people living with dementia and their informal carers as co-developers of technological solutions. Dement Geriatr Cogn Disord 2019 Jun 27;47(3):149-156 [FREE Full text] [doi: 10.1159/000497802] [Medline: 31247623]
63. Hendriks N, Slegers K, Wilkinson A. Lessons learned from participatory design in dementia care: placing care partners at the centre. Stud Health Technol Inform 2017;233:63-77. [Medline: 28125414]
64. Hendriks N, Huybrechts L, Wilkinson A, Slegers K. Challenges in doing participatory design with people with dementia. In: Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - Volume 2. 2014 Presented at: PDC '14; October 6-10, 2014; Windhoek, Namibia.

65. Orpwood R, Sixsmith A, Torrington J, Chadd J, Gibson G, Chalfont G. Designing technology to support quality of life of people with dementia. Technol Disabil 2007 Apr 13;19(2-3):103-112. [doi: 10.3233/TAD-2007-192-307]
66. Savitch N, Brooks D, Wey S. AT guide: developing a new way to help people with dementia and their carers find information about assistive technology. J Assist Technol 2012;6(1):76-80. [doi: 10.1108/17549451211214391]
67. Hwang AS, Truong KN, Cameron JI, Lindqvist E, Nygård L, Mihailidis A. Co-Designing Ambient Assisted Living (AAL) environments: unravelling the situated context of informal dementia care. Biomed Res Int 2015;2015:720483 [FREE Full text] [doi: 10.1155/2015/720483] [Medline: 26161410]
68. Øksnebjerg L, Woods B, Waldemar G. Designing the ReACT app to support self-management of people with dementia: an iterative user-involving process. Gerontology 2019 Jul 2;65(6):673-685 [FREE Full text] [doi: 10.1159/000500445] [Medline: 31266031]
69. Kowe A, Köhler S, Teipel S. Improving the depth of data quality or increasing confusion? reflections on a data analysis involving members of a self-help group for relatives of people living with dementia. Health Expect 2021 Aug;24(4):1516-1523 [FREE Full text] [doi: 10.1111/hex.13298] [Medline: 34101956]
70. Kowe A, Köhler S, Görß D, Teipel S. The patients' and caregivers' perspective: in-hospital navigation aids for people with dementia- a qualitative study with a value sensitive design approach. Assist Technol 2023 May 04;35(3):248-257. [doi: 10.1080/10400435.2021.2020378] [Medline: 34919023]
71. Daly Lynn J, Quinn E, Ryan A, Mccormack B, Martin S. TESA: technology enriched supported accommodation for people living with dementia and their caregivers. HSC Public Health Agency, Research and Development Division. 2019 Mar. URL: https://research.hscni.net/sites/default/files/TESA%20-Brief%20%20Executive%20Summary%20%28FINAL%29_0.pdf [accessed 2022-12-12]
72. Daly-Lynn J, Ryan A, McCormack B, Martin S. A qualitative exploration of living with dementia in supported living environments using a peer researcher approach. Aging Health Res 2022 Mar;2(1):100055. [doi: 10.1016/j.ahr.2022.100055]
73. Banbury A, Pedell S, Parkinson L, Byrne L. Using the Double Diamond model to co-design a dementia caregivers telehealth peer support program. J Telemed Telecare 2021 Nov 02;27(10):667-673. [doi: 10.1177/1357633x211048980]
74. Fox S, Brown LJ, Antrobus S, Brough D, Drake RJ, Jury F, et al. Co-design of a smartphone app for people living with dementia by applying agile, iterative co-design principles: development and usability study. JMIR Mhealth Uhealth 2022 Jan 14;10(1):e24483 [FREE Full text] [doi: 10.2196/24483] [Medline: 35029539]
75. Rai HK, Schneider J, Orrell M. An individual cognitive stimulation therapy app for people with dementia: development and usability study of thinkability. JMIR Aging 2020 Nov 16;3(2):e17105 [FREE Full text] [doi: 10.2196/17105] [Medline: 33196451]
76. Owens AP, Hinds C, Manyakov NV, Stavropoulos TG, Lavelle G, Gove D, et al. Selecting remote measurement technologies to optimize assessment of function in early Alzheimer's disease: a case study. Front Psychiatry 2020;11:582207 [FREE Full text] [doi: 10.3389/fpsyt.2020.582207] [Medline: 33250792]
77. Stavropoulos TG, Lazarou I, Diaz A, Gove D, Georges J, Manyakov NV, et al. Wearable devices for assessing function in Alzheimer's disease: a European public involvement activity about the features and preferences of patients and caregivers. Front Aging Neurosci 2021;13:643135 [FREE Full text] [doi: 10.3389/fnagi.2021.643135] [Medline: 33912025]
78. Hassan L, Swarbrick C, Sanders C, Parker A, Machin M, Tully MP, et al. Tea, talk and technology: patient and public involvement to improve connected health 'wearables' research in dementia. Res Involv Engagem 2017;3:12 [FREE Full text] [doi: 10.1186/s40900-017-0063-1] [Medline: 29062537]
79. Jacklin K, Pitawanakwat K, Blind M, Lemieux AM, Sobol A, Warry W. Peace of mind: a community-industry-academic partnership to adapt dementia technology for Anishinaabe communities on Manitoulin Island. J Rehabil Assist Technol Eng 2020;7:2055668320958327 [FREE Full text] [doi: 10.1177/2055668320958327] [Medline: 32999732]
80. Ghafurian M, Francis L, Tao Z, Step M, Hoey J. VIPCare: understanding the support needed to create affective interactions between new caregivers and residents with dementia. J Rehabil Assist Technol Eng 2022;9:20556683211061998 [FREE Full text] [doi: 10.1177/20556683211061998] [Medline: 35096413]
81. Berge LI, Gedde MH, Torrado Vidal JC, Husebo B, Hynninen KM, Knardal SE, et al. The acceptability, adoption, and feasibility of a music application developed using participatory design for home-dwelling persons with dementia and their caregivers. The "Alight" app in the LIVE@Home.Path trial. Front Psychiatry 2022 Aug 18;13:949393 [FREE Full text] [doi: 10.3389/fpsyt.2022.949393] [Medline: 36061298]
82. Tiersen F, Batey P, Harrison MJ, Naar L, Serban AI, Daniels SJ, et al. Smart home sensing and monitoring in households with dementia: user-centered design approach. JMIR Aging 2021 Aug 11;4(3):e27047 [FREE Full text] [doi: 10.2196/27047] [Medline: 34383672]
83. van der Roest HG, Meiland FJ, Haaker T, Reitsma E, Wils H, Jonker C, et al. Finding the service you need: human centered design of a Digital Interactive Social Chart in DEMentia care (DEM-DISC). Stud Health Technol Inform 2008;137:210-224. [Medline: 18560083]
84. Kowe A, Panjaitan H, Klein OA, Boccardi M, Roes M, Teupen S, et al. The impact of participatory dementia research on researchers: a systematic review. Dementia (London) 2022 Apr;21(3):1012-1031. [doi: 10.1177/14713012211067020] [Medline: 35152790]

85. Russell J, Fudge N, Greenhalgh T. The impact of public involvement in health research: what are we measuring? why are we measuring it? should we stop measuring it? Res Involv Engagem 2020 Oct 27;6(1):63 [FREE Full text] [doi: 10.1186/s40900-020-00239-w] [Medline: 33133636]
86. Staley K, Barron D. Learning as an outcome of involvement in research: what are the implications for practice, reporting and evaluation? Res Involv Engagem 2019;5:14-19 [FREE Full text] [doi: 10.1186/s40900-019-0147-1] [Medline: 30915234]

Abbreviations

NIHR: National Institute for Health and Care Research
PPI: patient and public involvement
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Review

Strategies to Mitigate Age-Related Bias in Machine Learning: Scoping Review

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Abstract

Background: Research suggests that digital ageism, that is, age-related bias, is present in the development and deployment of machine learning (ML) models. Despite the recognition of the importance of this problem, there is a lack of research that specifically examines the strategies used to mitigate age-related bias in ML models and the effectiveness of these strategies.

Objective: To address this gap, we conducted a scoping review of mitigation strategies to reduce age-related bias in ML.

Methods: We followed a scoping review methodology framework developed by Arksey and O'Malley. The search was developed in conjunction with an information specialist and conducted in 6 electronic databases (IEEE Xplore, Scopus, Web of Science, CINAHL, EMBASE, and the ACM digital library), as well as 2 additional gray literature databases (OpenGrey and Grey Literature Report).

Results: We identified 8 publications that attempted to mitigate age-related bias in ML approaches. Age-related bias was introduced primarily due to a lack of representation of older adults in the data. Efforts to mitigate bias were categorized into one of three approaches: (1) creating a more balanced data set, (2) augmenting and supplementing their data, and (3) modifying the algorithm directly to achieve a more balanced result.

Conclusions: Identifying and mitigating related biases in ML models is critical to fostering fairness, equity, inclusion, and social benefits. Our analysis underscores the ongoing need for rigorous research and the development of effective mitigation approaches to address digital ageism, ensuring that ML systems are used in a way that upholds the interests of all individuals.

Trial Registration: Open Science Framework AMG5P; https://osf.io/amg5p

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KEYWORDS

age; ageing; ageism; aging; algorithm; algorithmic bias; artificial intelligence; bias; digital ageism; elder; elderly; geriatric; gerontology; machine learning; older adult; older people; older person; review methodology; review methods; scoping; search; searching; synthesis

Introduction

The rapid progress of machine learning (ML) has revolutionized health care decision-making, medical diagnosis, and other domains [1]. However, as the influence of ML systems expands, so do concerns regarding potential fairness issues that may arise from ML systems encoding human biases [2]. As an example, population health management systems have been found to underestimate the health risks facing Black patients, who are typically underrepresented in health care data due to systemic challenges accessing health care [3]. Concurrent with the rise of ML, there has also been a growing demand for efforts to improve the fairness of ML systems by better representing systemically disadvantaged groups in their data [4,5], such as gender and ethnic minority individuals [6-8]. To better understand the scope of this problem, frameworks to classify the various forms of bias present in ML have been developed. Our previous work used the framework developed by Mehrabi et al [5], which classified numerous types of bias according to the characteristics of each bias as well as where it would be introduced into an ML system in the cycle of providing training data (data to algorithm), the ML model interacting with the public (algorithm to user), and the public's data being used for future testing (user to data). In our earlier investigation, we delineated 9 distinct categories of ML bias that could provide avenues for age-related bias to affect ML systems [9], using the conceptual framework by Mehrabi et al [5]. In this investigation, the prevalent forms of bias from their framework were: (1) representation bias, which emerges when the data set used for training the ML model inadequately reflects the diversity of the user population compromising the performance for specific demographic groups; (2) evaluation bias, which can occur when the model is tested with unrepresentative data and inappropriate evaluation benchmarks are used; (3) aggregation bias, in which distinct demographics within a larger sample are categorized in a way that makes their unique characteristics indistinguishable; (4) algorithmic bias, where the algorithm itself is the origin of the bias leading to distorted outcomes; and (5) measurement bias, which arises from how certain features are selected, measured, and used. When data are measured or gathered using improper tools or techniques, the resulting evaluation of the data by an ML model does not reflect the relevant variables within the data [5,9]

Digital ageism is a form of ageism perpetuated through the development, use, and deployment of technology and ML models [10,11]. Recently, the World Health Organization released a brief report about age-related bias in ML models and raised critical questions about the equitable treatment of older people across various sectors [12]. The rising concerns about digital ageism highlight the pressing need for further research and policy interventions to address the potential biases and discriminatory practices that may affect older adults in the digital era [13-15]. Recent studies have demonstrated instances of digital ageism, emphasizing the urgency of designing and deploying technologically inclusive solutions to ensure equitable treatment and opportunities for individuals of all ages [16]. The exclusion of older adults from the development of digital technologies has been previously researched [15,17,18] and can manifest in many ways. Older adults may not be adequately represented in training and testing data for ML models, resulting in models with reduced accuracy for older adult data and being vulnerable to multiple intersecting disadvantages [19]. For example, older adults who live in long-term care homes may have limited access to the internet and may be excluded from technological advances [20]. Data may also aggregate older adults into arbitrary age blocks, replicating problematic assumptions that link functional decline with age and failing to represent the diversity of the older adult population [10]. The marketing strategies for these ML systems often highlight their use in health care, reinforcing the idea of aging as a period of physical and mental decline [21]. As ML models and technologies become inextricably part of accessing opportunities and services, older adults' risk of being left behind by a growing digital divide increases [22]. This is particularly alarming considering that the older population represents the fastest-growing demographic worldwide [23].

The topic of digital ageism is gaining prominence in scholarly discussions, leading researchers to investigate these phenomena from various perspectives [9,19,24,25]. Previous investigations have focused on developing conceptual frameworks to comprehend and define the nature and implications of digital ageism [13]. Previous reviews of facial image data sets have also found that older adults, particularly older adults aged 85 years or older, are underrepresented in a majority of data sets [18]. While this research has been foundational in identifying and characterizing these biases, there is now a critical need to focus on the mitigation strategies that can address age-related bias in ML models. The purpose of this scoping review is to advance this crucial discussion by shedding light on the mitigation strategies currently being used to address age-related bias in ML models. By bridging the gap between theory and practice, this research aims to pave the way for meaningful and impactful interventions that can rectify biases and promote inclusivity in the digital age. Our research focuses on two main questions: (1) Which mitigation strategies have been used to address age-related bias in artificial intelligence, and how successful were these strategies? and (2) Specifically, what types of biases were targeted and mitigated during these efforts?

Methods

Overview

This review is part of a larger scoping review about digital ageism that follows a 6-stage methodology framework developed by Arksey and O'Malley [26] and further refined by Levac et al [27]. A scoping review was appropriate to explore the study's aims of summarizing the available evidence, identifying gaps, and establishing future directions regarding mitigation strategies. As the breadth and depth of the literature are unclear, a wide and interdisciplinary approach was used [10]. The description of the review was published elsewhere [28] and registered in the Open Science Framework database [29]. This review also followed the PRISMA-ScR (Preferred Reporting for Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) format [30].

Information Sources and Search

An information specialist helped develop the search strategy in Scopus, which was then translated into 5 other databases (Web of Science, CINAHL, EMBASE, IEEE Xplore, and the ACM digital library). The search strategy included the terms "machine learning," "artificial intelligence," "algorithms," "neural networks," "deep learning," "algorithmic bias," "biased," "discrimination," "ageism," "age," and "older people."

Eligibility Criteria

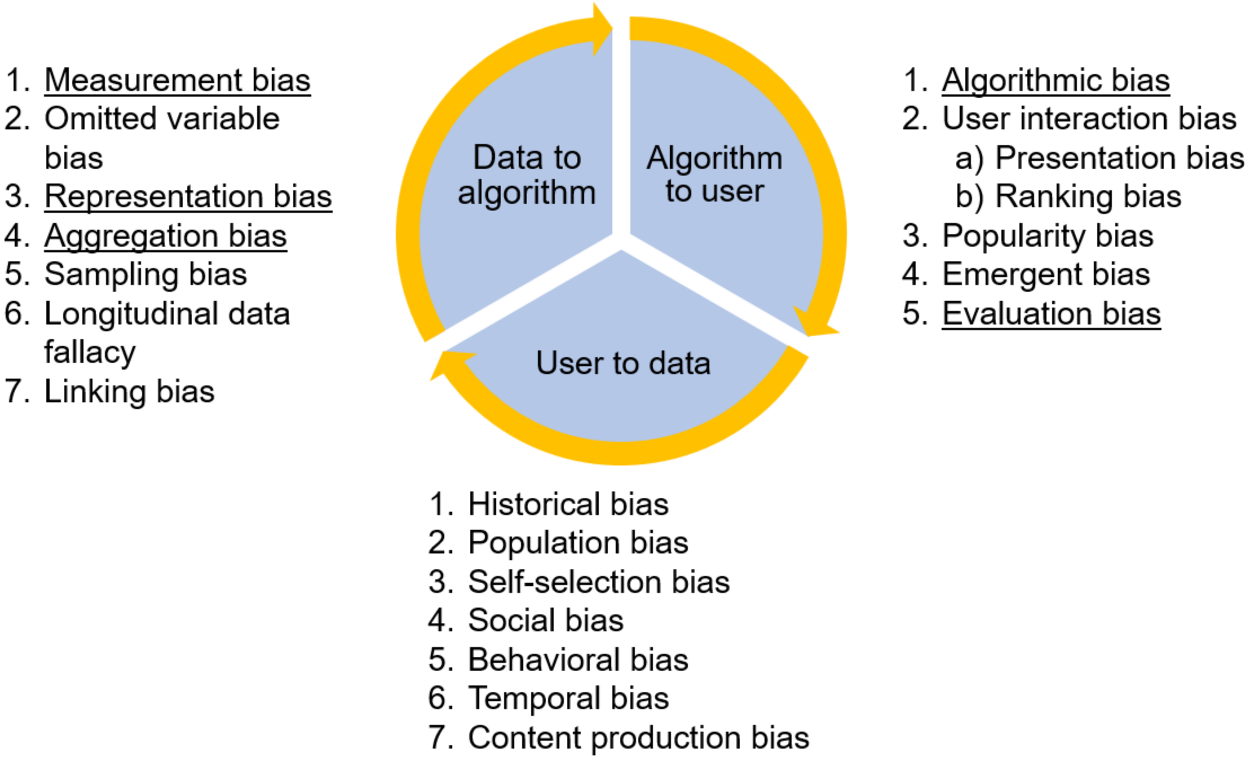
Articles were included if they were published in English and focused on "artificial intelligence" in the context of algorithms that make predictions and classifications about data; "bias"; and age-related terms such as "aging," "older," and "demographic." As the term "artificial intelligence" is over 50 years old [31], the search strategy was also not restricted by publication date, and databases were searched from inception. Papers were excluded if they included nonhuman topics. Theses, conference abstracts, dissertations, nonpeer-reviewed conference proceedings, books and book chapters, perspectives, editorials, and editorial letters were also excluded.

Selection of Sources of Evidence and Charting the Data

The academic literature search was completed in January 2022. All citations were uploaded to Covidence (Veritas Health Innovation), a systematic review software, and duplicates were removed. The titles and abstracts of all articles were screened by 2 independent reviewers according to the eligibility criteria. Once the abstract screening was complete, the full text of each article was reviewed by 2 independent reviewers to judge the article's relevance to the research questions. Data extraction included the manuscript information (title, authors, year, and location), study design, type of ML model and purpose, database used, type of data, presence of age-related bias, mitigation strategy used, and effectiveness of the strategy if reported. The framework by Mehrabi et al [5] (Figure 1 [5]), which identified different sources of biases that can affect ML according to the data-to-algorithm (data), algorithm-to-user (modeling), and user-to-data (deployment) interaction loops, was used in this review to identify the different types of bias in the included studies [5]. A total of 5 of the 19 different types of biases in the framework by Mehrabi et al [5] (Figure 1) were included in the extraction table, including representation and evaluation bias, aggregation bias, measurement bias, and algorithmic bias.

Studies were selected if they acknowledged the presence of any bias against older adults in either their data or results, and the researchers then took any action to correct that bias, regardless of its effectiveness. For example, publications were selected based on whether authors attempted to enhance the performance of their model on older demographics, regardless of the success of their efforts. Biweekly meetings were held to discuss the progress of the charting process. Disagreements were resolved through discussion or by having the first author (CC) act as a third reviewer. The extracted information was converted into table format, which allowed the authors to develop a narrative description according to the type of mitigation strategy (Table S1 in Multimedia Appendix 1 [32-42]). The team conducted additional analysis of the databases in the included studies to identify data disparities among older adults and provide further directions for future studies in the field of digital ageism. The results of the literature search are reported in tables. One of the challenges involved in assessing the inclusion of older adults involves defining the age at which someone is considered "old." While the commonly accepted age for legal recognition as a "senior citizen," based on general eligibility for a public pension, is 65 years [43], the data sets and articles we reviewed grouped older adults into a much wider range of age categories (Table S2 in Multimedia Appendix 1), starting with adults aged 50 or older. When we refer to "older adults" throughout this paper, we are referring to either (1) the participants in the data set aged 60 years or older, or else (2) the oldest age category found in the data set or publication being discussed.

Figure 1. The framework by Mehrabi et al for bias in machine learning. The specific biases discussed in this review are underlined.



Ethical Considerations

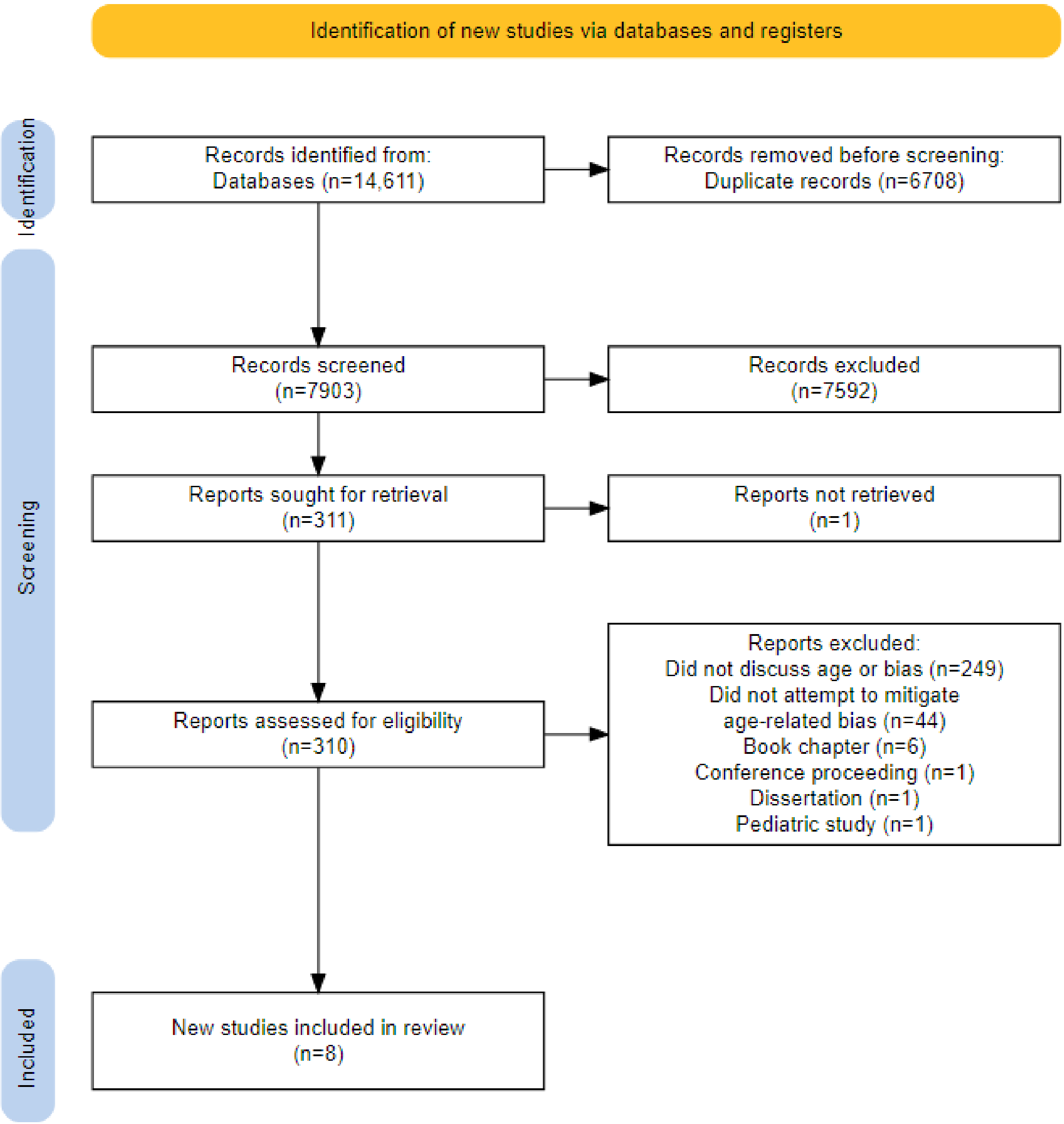
Ethics approval was obtained from the (University of Toronto) Research Ethics Board (REB #40095) for a larger study on the same topic. This study does not contain any studies with human participants performed by any of the authors.

Results

Overview

From our search, 14,611 academic publications were identified. After removing duplicates, we screened the abstracts of the remaining 7903 publications. During the abstract screening process, we excluded 7592 publications. Subsequently, we conducted a full-text screening of 310 articles, ultimately including 8 academic publications in this review (Figure 2).

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of the literature review.



Types of Ageist Bias in the Selected Publications, per the Framework by Mehrabi et al

After reviewing the full text of each of the 8 publications, 5 types of bias found in the framework by Mehrabi et al [5] (Figure 1) were identified. Representation bias occurs when the data set underrepresents or misrepresents specific demographics within the overall population, resulting in a nonrepresentative data set [5]. Evaluation bias is similar to representation bias: it occurs when inappropriate evaluation benchmark data are selected to assess ML models [5]. In this review, this amounted to using the same underrepresentative data sets for training as well as testing the model, which was found to be the case in 7 publications [32-38]. Aggregation bias occurs when conclusions are drawn based on observations about a larger group, overriding unique characteristics about a smaller demographic within that group [5]. As a result, the data set fails to account for the unique characteristics of more specific demographics within the overall data set. Aggregation bias was found in 2 publications in this review [34,35]. Algorithmic bias occurs when the bias is generated at the level of the algorithm's calculation itself rather than being a by-product of biased data or measurement tools being provided to that algorithm. Algorithmic bias was found in 2 papers in this review [36,39]. Measurement bias occurs when the data being processed by the algorithm fail to represent the variable of interest accurately. It can often arise from the methods used to collect or measure the data or respective variables. Measurement bias was demonstrated in 1 publication in this review [35]. A complete list of each type of bias found in each publication, along with a rationale, can be found in Table S1 in Multimedia Appendix 1.

Data Sets Used in the Included Studies

Table S2 in Multimedia Appendix 1 presents the demographic breakdown of the data based on age to determine the extent of underrepresentation of older adults in common data sets. Overall, there was a large data disparity between the data of older adults compared with younger individuals in all the databases in this review. In the FG-Net data set, the oldest age group was "aged 61 years old or older." In this age group, the FG-Net data set only had 7 images (0.7%) [40]. In the MORPH Academic data set, there were only 3933 (7.1%) images of individuals in the "aged between 50 and 77 years" category [44], and in the MORPH Longitudinal data set, only 5615 (1.4%) of the data set's 402,055 images were from the "aged between 60 and 69 years" (5021 images) and "aged 70 years or older" (594 images) categories [45]. The CACD data set contains 163,446 images, divided into age groups of 10 years (0-10 years, 10-20 years, 20-30 years, 30-40 years, 40-50 years, 50-60 years, and 60 years or older). However, only 2912 (1.78%) of these images depict participants older than 60 years (the fifth figure in Georgopoulos et al [34]). Grouping all older adults into one 60+ demographic category also raises the risk for aggregation bias [5].

The APPA-Real data set contains 7591 images (from public internet repositories), aged between 10 and 95 years. When we combine the APPA-Real data set's 4 oldest age groups: between 60 and 70 years (254 images), between 70 and 80 years (111 images), between 80 and 90 years (68 images), and between 90 and 95 years (13 images), the combined total of 446 images accounts for just 6% of the entire data set [41]. Lastly, the 100 Celebrities data set created by Jung et al [35] has a smaller-sized balanced data set to offset the imbalances in the IMDB-Wiki and Twitter (subsequently rebranded as X) Profile data sets also used in the same study. Participants were divided into 3 age groups: between 14 and 34 years (33 images), between 35 and 55 years (34 images), and 55 years or older (33 images), with the "55 years or older" age group having equal representation with the other demographics, although grouping all older adults into 1 category of aged 55 years or older increases the likelihood of aggregation bias [5].

For the other data sets present in this review (11,000 Hands, ABIDE, CoRR, DLBS, NKI Rockland, Pilots Parliament Benchmark, and a data set comprised of Twitter Profile data), the exact data for the age demographics in each data set was not readily available (Table S2 in Multimedia Appendix 1).

Bias Mitigation Strategies

We found 8 studies that attempted to mitigate bias against older adults. The studies were all related to "computer vision" systems, systems that rely on an ML model's processing and interpretation of images, although with varying aims: 1 study focused on hand images [32], another study focused on radiological scan interpretation [36], and 6 others focused on facial images [33-35,37-39]. A complete list of the papers, the data sets that were used, and the strategies used to mitigate bias and their outcomes can be found in Table S1 in Multimedia Appendix 1. We identified 3 broad categories of bias mitigation strategies: data set balancing, data set augmentation, and algorithm alterations. This section will provide a comprehensive overview of each bias mitigation strategy and its effectiveness [34,36].

Data Set Balancing

Data set balancing involves the practice of ensuring balance within the data sets used for training and testing ML models [5]. This strategy aims to address representation bias due to the imbalance in the representation of older adults and subsequent evaluation bias against different age groups in the data set, which can lead to biased predictions and unfair outcomes [5]. By ensuring a more balanced distribution of samples across age groups, the model can learn from a more diverse and representative set of examples, reducing the potential for age-related bias. A total of 4 papers used data set balancing techniques to achieve an equitable distribution of data across different classes or categories within the data sets, such as altering their data set or creating a new data set (as was the case for Jung et al [35]) that would balance their previously unrepresentative data.

For their study to demonstrate the effect of bias on older adults with dementia on facial expression analysis models, Taati et al [39] developed a data set of test participants comprised entirely of older adults for their study. This data set was comprised of images of 86 older adults (aged 65 years or older), of whom 42 were affected by dementia and 44 were cognitively healthy, creating a balanced data set with the target population [39]. Frontal and profile photos of each participant's face were taken at baseline, and a physiotherapist guided each participant through a series of exercises to identify painful positions. Images were then annotated manually according to the facial action coding system (FACS) and the "Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II" (PACSLAC-II) pain scales. This method helped avoid potential representation biases that could arise from an imbalanced representation of different cognitive states. Taati et al [39] also used a fine-tuning method, in which they pretrained their models with images of cognitively healthy older adults and then fine-tuned their models with images of cognitively impaired older adults. They found that when this strategy was tested on active appearance models (AAMs), the number of images in the fine-tuning data set with a normalized root-mean square error (NRMSE) of <5% improved from 87% to 91% accuracy. However, when fine-tuned with the same strategy, facial alignment networks (FANs) performance remained around 90% (for an NRMSE threshold of 5%). When the NRMSE threshold was lowered to 4%, the performance disparity became even more significant: AAMs and FANs both started between 65% to 70%, but the number of fine-tuning images with an NRMSE of <4% continually increased into the 75% to 80% range when the AAM was fine-tuned, while FANs did not see any increase (second and third figures in Taati et al [39]). The gaps in performance between AAMs and FANs indicate that the bias present in these results is at least partially algorithmic in nature, as both models were tested using the same strategy but only the AAMs showed any improvement [5].

In another paper, Zou et al [38] tested a model intended for cost-sensitive facial age estimation using the FG-Net and MORPH data sets, along with an image database of 14,238 images taken from Wikipedia Commons. They modified the FG-Net data set by adding images from their Wikipedia data set to balance it for age, particularly for the groups aged between 40 and 49 years and between 50 and 59 years. Doing this corrected the representation bias in the FG-Net database, 87% of which consists of participants aged 30 years or younger [38]. This mitigation strategy effectively resulted in a significant reduction in mean absolute error (MAE) for those age groups, along with a smaller reduction in MAE for the other age groups in their test. The balanced data set using the cost-sensitive function showed the lowest MAE in age predictions (MAE 8.25, SD 0.03) versus the cost-insensitive data set (MAE 9.31, SD 0.4) and an unmodified data set (MAE 8.6). This approach effectively reduced the MAE for the groups aged between 40 and 49 years and between 50 and 59 years, so it was similar to the younger groups aged between 20 and 29 years and between 30 and 39 years. However, the representation of the groups aged between 60 and 69 years and 70 and 79 years appear to have been largely unchanged (fifth figure in Zou et al [38]), with every other age category receiving a substantial number of additional images except for the 2 oldest, and as a result, the MAE for these groups seems to be substantially higher, even using the cost-sensitive model (eg, for the group aged between 60 and 69 years, the MAE was 17, and for the group aged between 70 and 79 years, the MAE was 30), while the younger age groups did not have an MAE above 10 [38].

Jung et al [35] worked with several databases on facial recognition, including the IMDB-Wiki data set, a data set composed of Twitter profile images, and the 100 Celebrities data set. Jung et al [35] created the 100 Celebrities data set after noticing that the other data sets were imbalanced for age and ethnicity. Celebrity images were selected due to the wide availability of high-quality images of celebrities from a wide range of angles and the simplicity of establishing the participant’s true age when the photo was taken (celebrity birthdates are easily determined). Creating this data set would help mitigate the representation and evaluation bias found in the IMDB-Wiki data set, although using those data sets without balancing them would still expose the outcomes to those biases [5]. Age detection by the Face++, IBM Bluemix Visual Recognition, AWS Rekognition, and Microsoft Azure Face API detection systems found that on the balanced 100 Celebrities data set, age was underestimated by 15.2 years. The highest accuracy of all the models trained on the 100 Celebrities data set was the IBM model, at 53% (although the Microsoft model achieved 66% accuracy when trained on the Twitter-Age data set). However, it is worth noting that the 100 Celebrities data set is comprised of celebrities who fall under entertainment-industry beauty standards, which may explain the large variance. While the creation of a balanced data set is a step toward mitigating biases, the fact that the age detection models still exhibited significant inaccuracies in this study raises questions about the overall effectiveness of the strategy with this specific data set. By grouping all older adults into a single category (aged 55 years or older), the 100 Celebrities data set may also increase the likelihood of aggregation bias, as mentioned in the previous section.

Finally, Liang et al [36] attempted to balance their combined data set that originally contained magnetic resonance imaging (MRI) scans of the brain from 2026 participants. These were comprised of samples from the ABIDE, CoRR, DBLS, and NKI Rockland data sets that had a higher number of participants aged 40 years or younger. To help balance representation bias within this sample, the authors resampled the full data set in 5-year age intervals to address overrepresentation and underrepresentation of age groups. They duplicated samples from overrepresented age groups to match the number of samples in underrepresented age groups (ie, participants aged 75 years or younger), resulting in a more balanced distribution of age groups within the new data set (n=782), reducing the bias toward certain age ranges, and ensuring a more representative representation of the population [26]. However, the researchers noted that a significant bias persisted even after training their model on their more balanced data set. Testing their model on the imbalanced data set returned r=.91 and an MAE of 6.77 years, while the balanced data sample returned r=.91 and an MAE of 8.02 years. The correlation between the brain-age gap and chronological age remained the same (–0.52) for both the imbalanced full data set and the balanced data sample. This indicates that, despite accounting for representation bias by balancing the data set, the strategy alone did not achieve the desired reduction in bias. Moreover, the MAE increased from 6.7 years to 8 years; although the correlation remained the same, the higher MAE suggests a decrease in the accuracy of the model’s predictions when using the balanced data set. These findings suggest that additional strategies or factors may need to be considered to further mitigate bias and improve the accuracy of the model. It is possible that the resampling strategy, while addressing representation bias to some extent, may not have fully addressed other sources of bias present in the data set. Therefore, this strategy had limited effectiveness in addressing bias while aiming to improve accuracy.

Data Augmentation

Data augmentation strategies can mitigate bias related to ageism in ML models by enhancing the diversity and representativeness of the data set. This enables the model to learn from a wide range of age groups, reducing potential bias toward specific age categories. In 3 papers that applied data augmentation techniques, the actual images in their data set were modified without adding images from an external source. For example, Georgopoulos et al [34] applied digital age progression methods to the images in the data sets selected for their study, generating realistic images of what their participants may look like as they age but modified images of the participant. Smith and Ricanek [37] used random cropping and Gaussian tinting, and Abderrahmane et al [32] used an unspecified technique.

Using the MORPH, Cross-Age Celebrities data set (CACD), and FG-Net data sets, Georgopoulos et al [34] tested the ability of a generative adversarial network (GAN) to synthesize aging patterns realistically. They divided the participants’ images from each data set into 4 groups: those aged 30 years or younger, between 31 and 40 years, between 41 and 50 years, and 51 years or older. For each data set, their model would then take an image from these data sets and either age or de-age new images for each of the other 3 categories to which the participant did not belong, creating new images for each of the other 3 age groups and balancing the data set in the process. The approach was effective in creating a data set 4 times the size of the original data set, and their results were able to significantly improve both the data set diversity (measured using the Shannon D and Simpson H metrics) and overall balance (measured using the Shannon E and Simpson E metrics) of the data sets they studied, demonstrating superior performance over contemporary models (Conditional Adversarial Auto Encoders [CAAEs] and Identity-Preserved Conditional Generative Adversarial Networks [IPCGANs]). While CAAEs generated the most accurate images for the group aged between 31 and 40 years after being trained on the MORPH data set (MAE 1.18), and IPCGANs generated the most accurate images for the demographic aged between 31 and 40 years after being trained on the CACD data set (MAE 0.04), the novel method presented in the paper was most accurate for the groups aged between 41 and 50 years and 51 years or older, for both the MORPH and CACD (MAE of 1.21 and 1.69, and MAE of 1.33 and 1.04, respectively). The images generated by the novel method also produced the best scores on the Simpson and Shannon data diversity indices after augmenting the MORPH, CACD, and FG-Net databases. This approach effectively reduced the representation and evaluation bias against older adults in these data sets. In doing so, the researchers acknowledged the possibility of their model enabling researchers to overcome demographic bias in facial image data sets, the most popular of which heavily underrepresent older adults [34]. The method used could also have the impact of increasing aggregation bias, as all older adults were grouped into a single group (aged 51 years or older) [5].

Smith and Ricanek [37] studied age and gender prediction models using data sets taken from IMDB, Wikipedia, and the MORPH data sets, which underrepresent older adults and present representation and evaluation bias [37]. They sought to expand the robustness of their data sets by applying random data-augmentation policies, which are transformation techniques used to modify existing data. For instance, they used random cropping and Gaussian tinting techniques to increase the diversity of the images in the data set. After training and testing, they also composed a separate challenge data set, which applied the data-augmentation policies to images from categories that their model had difficulty identifying accurately, including female individuals, older adults, and individuals with darker skin. The MORPH data set lacks images of older adults, so adding additional images was effective in addressing representation and evaluation bias in the data set [5]. The data augmentation policies would be randomly applied to these images as they were loaded during training [37]. This method to augment the training data was effective, as the overall MAE fell from 4.62 to 4.21, with a final MAE of 4.13 for male individuals and 4.90 for female individuals. The overall gender prediction accuracy increased slightly, from 98.44% to 98.92%.

Abderrahmane et al [32] developed an algorithm for age prediction based on hand images. They acknowledged that their data set initially had a highly imbalanced age distribution, which could introduce bias in their model. To address this, they used data augmentation techniques to create a more balanced data set from the 11,000 Hands Database, which contained 11,000 images of hands from 190 participants, showing the dorsal and palmar aspects. The authors recognized that the data set was underrepresentative of older adults and appeared to use data augmentation to balance the data set. There were no specific details regarding the augmentation processes used, but the figures suggest that additional images were added to the data set to address the underrepresentation of certain age groups. The underrepresentation of older adults in the 11,000 Hands data set is noteworthy in light of the significant use of hand images to represent older adults (more details on this issue have been provided in the *Discussion* section).

Algorithmic Alteration

Papers were listed under algorithmic alteration if the researchers adjusted the calculations of their algorithm itself and applied statistical methods to their algorithms to reduce the bias in their outcomes [5]. We found that 2 papers had adjusted their algorithms to improve performance [33,36]. Liang et al [36] applied linear regression to correct for the bias produced by their model after balancing the data set, which proved unsuccessful. Noticing a bias in age prediction based on MRI scans, which resulted in less accurate predictions for older participants, they unsuccessfully attempted to balance their combined data set, as was previously discussed. After examining multiple possible additional sources of the bias, including noise within the data, heterogeneity of the data sets, and the use of specific ML models, they were able to correct the bias statistically with a linear regression, fitting a linear regression model for predicted age to the chronological age and sex that improved MAE. By ruling out the other sources of bias (such as representation and evaluation bias, which they corrected for by balancing their data set), they were able to determine that the algorithm itself was the source of the issue (algorithmic bias, per the framework by Mehrabi et al [5]). The study by Liang et al [36] is unique in that they attempted to correct for more than one type of bias: first working on representation bias, and then solving for algorithmic bias (biases introduced by the algorithm itself) after balancing their data set was unsuccessful, which was an overall effective approach.

In the second paper, Clapes et al [33] sought to correct the bias between estimated age and true age by dividing participants into smaller groups based on mutually exclusive image categories and recalculating the estimated age for each real age. This produced a fitted curve for the difference between estimated and real ages, which was then used to correct the bias between the estimated and real ages. Linear interpolation was used to correct bias for ages that had fewer examples. This effectively addressed the measurement bias in the study. Clapes et al [33] also added labels for expression, ethnicity, makeup, gender, and the age of the photograph itself to the APPA real database. The resultant model's overall performance improved, reducing the MAE from 13.57 to 12.07. The reduced representation of older adults is mirrored by trends in the consistency between age predictions in Clapes et al [33], where the difference between real age and estimated age widens as age increases (panels A-F in the eighth figure in Clapes et al [33]), which they theorized was due to the decreasing representation of older age groups (ie, representation bias).

Discussion

Overview

Our review included 8 publications that used mitigation strategies to address age-related bias. To our knowledge, this is the first review to examine this topic. Our analysis revealed that age-related bias predominantly stemmed from the underrepresentation of older adults in the data sets used to build the models (representation bias). Notwithstanding the 100 Celebrities data set, the data sets in this study (for which data were available) contained only 0.05% to 7% of data representing older adults. Our first research question explored the variety of strategies used to address this bias and their effectiveness. Researchers used three approaches: (1) creating a smaller yet more balanced data sample from their existing data set (n=4) [35,36,38,39], (2) augmenting and supplementing the available data (n=3) [32,34,37], and (3) modifying the algorithm directly to account for bias specifically (n=2) [33,36]. There was heterogeneity in the outcome measures, so a meta-analysis was not possible. Our findings emphasize the multifaceted nature of bias in ML models and the strategies available to address it, as well as the critical imperative of identifying and mitigating age-related bias in ML models to ensure fairness and equity for older adults in society [32-39].

The effectiveness of mitigation strategies aimed at reducing age-related bias in ML models varied based on several factors, including the types of data used, the ML approaches used, and the specific purpose of the ML model. While the included papers covered a range of uses, including facial and age recognition and MRI brain-scan interpretation, it is crucial for researchers to recognize that the solutions that may apply to one type of model may not apply to others due to qualitative differences in the data each model depends on. While many researchers reported successful outcomes with their methods, some encountered challenges and limitations. Jung et al [35] conducted experiments with a more balanced data set but found that the accuracy of their model reached a peak of only 53%. This suggests that achieving complete mitigation of age-related bias may be difficult, even with an improved data set balance. Taati et al [39] explored a mitigation strategy that showed mixed results and discovered that adding images of older adults affected by dementia to the training data for models trained on cognitively healthy older adults improved landmark detection significantly, but this approach improved the performance of AAMs significantly more than FANs. This highlights how specific types of algorithms can affect outcomes and how that must be considered when selecting which models to use when attempting to reduce bias. In a follow-up study, Asgarian et al [40] also identified performance differences in models intended to identify facial landmarks between healthy older adults and older adults with dementia [46]. In another example, Liang et al [36] encountered challenges in their attempts to balance data set representation and ultimately settled on a linear regression alteration for their algorithm. Making algorithmic alterations appears to have been most effective at mitigating measurement bias, but this is an extremely small sample (n=2) [33,36]. Overall, these findings highlight the complexity and context-dependence of mitigating age-related bias in ML models. While some strategies showed promising results, achieving complete elimination of bias remains challenging, and alternative approaches may need to be explored. Researchers must consider how both the data and the models they are using may affect outcomes.

Our second research question explored the types of bias being mitigated. Our previous work has demonstrated that age-related bias is present across the ML life cycle [9]. Bias affects ML models at multiple levels, including the data that trains the models (data to algorithm), the models themselves (algorithm to user), and the people who rely on the models (user to data) [5]. Our results found that researchers who attempted to correct for bias primarily focused on representation bias (n=7), with algorithmic bias (n=2) and measurement bias (n=1) being far less common targets of mitigation efforts. Representation and evaluation bias and measurement bias were most commonly mitigated by data set balancing [35,36,38,39], but this method did not consistently achieve the desired reduction in bias [35,36], while algorithmic bias [33,36] was resolved by algorithmic alterations, to the satisfaction of their respective authors.

Moreover, we noted that 2 papers may have aggregation bias [34,35], which occurs when a demographic is grouped in a way that does not account for its heterogeneity [5]. Many data sets in this review grouped all older adults into arbitrarily large categories (eg, those who were aged 55 years or older and 60 years or older). For example, Georgopoulos et al [34] aggregated the oldest participants into a single category of those aged 50 years or older [34]. While this worked to address one type of bias (representation bias), it reinforced another type of bias (aggregation bias), which impacts older adults significantly and essentially erases older adults as a distinct group, given that the legal cutoff to be considered a senior citizen is usually 65 years old [5]. While the 100 Celebrities data set by Jung et al [35] offered older adults equal representation compared with other age groups, it also grouped all older adults into a single category (ie, aged 55 years or older). This point of discussion holds significance but is often not fully acknowledged when tackling bias in ML. It highlights that bias can manifest in various interconnected ways, and while addressing the most prominent and evident forms of bias remains crucial, it may not completely eradicate bias from a model. Much of the discussion of bias in ML focuses on representation bias of specific demographics (it was the most common type of bias in this review), but there are other forms of bias that may be more easily neglected (such as aggregation bias, which was not addressed in the included studies). Sometimes, efforts to mitigate bias did not reach the data set's oldest demographics. Panel 5A from the fifth figure in Zou et al [38] shows that the authors only balanced the FG-Net data set, and while they balanced the representation for all other age groups, they did not significantly improve the representation of the groups aged between 60 and 69 years and 70 and 79 years, which remained underrepresented. There are also ageist contradictions that emerge when representation is examined, with the strongest example in these papers being how even the images of the hands of older people were underrepresented in the 11,000 Hands data set, despite the prominence of wrinkled, disembodied hands as a dominant social representation of older people in media and societal images [47]. Such imagery may have a dehumanizing effect by portraying older adults as a pair of hands rather than a face or a whole person, which could result in their apparent exclusion from a data set of images with similar subject matter being compiled for practical purposes [48].

An important implication is for developers to consider the practical significance or real-world impact of the mitigation strategy. For example, Clapes et al [33] reduced their MAE from 13.6 to 12.1, while Smith and Ricanek [37] reduced their overall MAE from 4.6 to 4.2, with a final MAE of 4.1 for male individuals and 4.9 for female individuals. While these are quantifiable improvements, it is also important to consider the extent of an improvement and whether it has practical meaning or relevance in decision-making processes.

To address age-related bias in ML, researchers and designers can take steps from research design, methodology, and technical perspectives to ensure that technology is accessible and inclusive. From a research design perspective, an alternative mitigation strategy for developers collecting their data sets is to provide a representative sample of participants. Jung et al [35] created an age prediction training data set using celebrity images from IMDB. The researchers intended to create balanced data sets for their target populations, which aimed to prevent representation and evaluation bias, reducing the potential for age-related biases in the analysis and evaluation of the data. Although the effectiveness of this specific approach is not explicitly stated, the use of balanced data sets likely played a role in mitigating potential biases stemming from an imbalanced representation of age groups. Consequently, their study results may be more reliable and less susceptible to age-related biases, contributing to a more unbiased understanding of age recognition algorithms (although they may still be affected by other varieties of bias, as was previously discussed). By emphasizing the importance of representative sampling and the creation of balanced data sets, researchers can minimize the risk of introducing age-related biases into artificial intelligence systems and foster more accurate and equitable results.

Lastly, promoting the consideration of age as a variable of interest could help draw the attention of researchers and developers to digital ageism and disparities within their data sets. Recognizing age as a crucial factor requires a multidisciplinary approach that involves educational institutions, industry leaders, and policy makers. Within educational curricula, emphasizing the significance of critical demographic parameters can sensitize future engineers and computer scientists to the diverse needs of populations, including older adults. Technical approaches that use robust statistical approaches can begin to minimize age-related bias in ML. Techniques such as stratification and oversampling can ensure adequate representation of older adults in training data sets, attenuating the risk of underperformance or misclassification for this demographic group. These techniques are particularly relevant where the intersections of social locations of age and known underrepresentations of disability, race, and sexual orientation in ML models are concerned for 3 reasons. First, many of these types of bias (racism, sexism, and ageism) have their roots in similar problems, such as underrepresentation [4,9]. For example, a 2022 study of 21 age-recognition systems found that artificial intelligence systems consistently identified age with less accuracy across all age, gender, and ethnic categories, which the authors speculated was due to older adults being underrepresented in training data [49]. Second, the methods used to balance age-related bias in these papers may also have applications for other types of bias. For example, Sixta et al [50] reported a combination of strategies to reduce bias, including balancing their data for underrepresented demographics using external data and then further augmenting the data with different lighting and image quality adjustments. Third, the discussion around these types of bias in ML is much broader than the focus on digital ageism, making them an effective tool for drawing attention to these issues and advancing work in this area [9]. In a comparison of commercial facial emotional recognition (FER) systems, Kim et al [51] found that performance did improve for all demographics from 2019 to 2020, but that FER systems still performed best on younger adults and most poorly on older adults. The “black box” nature of these commercial systems, in which the method’s underlying algorithm is inaccessible, makes it impossible for external reviewers to assess the source of these improvements from an algorithmic standpoint [51]. However, digital ageism is not limited to ML and is a broader issue that stems from societal biases in the design, development, and deployment of ML models [9,16]. The multivalent nature of age-related bias in ML requires solutions from multiple sectors of society, including the public, private developers, government, and academic research [24]. Future research should focus on developing a global consensus of priorities that can mobilize the multitude of players from these sectors to advance knowledge about age-related bias and best practices to address this bias.

Limitations

One limitation of this study is the exclusion of publications in languages other than English, potentially excluding the viewpoints and solutions to these challenges found within other cultures. Also, our review would not have captured all examples of implicit age-related bias, only in papers that mentioned the keyword “bias.” However, the studies included in this review can serve as exemplars of implicit and explicit bias. The implicit nature of ageism in the context of the technology sector with limited ethical oversight and regulations underscores the importance of further research and policy development. Our review also only examined papers that attempted to mitigate age-related bias, not other types of bias (such as gender- or ethnicity-related biases). One major concern is that these biases and omissions may continue to produce exclusion and push older people whose experiences are not read as “youthful” further outside the peripheries of shared social and cultural everyday spaces, including (but not limited to) those mediated through technological systems. This is perhaps especially the case where age intersects with locations already known to experience bias, such as gender, race, and ethnicity.

Conclusion

This study explored and synthesized mitigation strategies for age-related bias in ML. The results underscore the value of 3 primary strategies for bias mitigation: data set balancing, data augmentation, and statistical techniques. However, the efficacy of these tactics demonstrated variability contingent upon factors such as data type, ML methodologies, and the intended purpose of the ML model. Although some researchers reported successful outcomes by diversifying their data sets, achieving complete elimination of bias remains challenging, and alternative approaches should be explored. The practical significance of the intervention should also be considered, as improvements in bias reduction may not always have substantial real-world impact, and further bias reduction and mitigation may still be required. A greater understanding of how digital ageism and age-related bias are propagated in ML and reproduced is needed across multiple sectors, including researchers and policy makers. Future research and policy agendas should include developing collaborative, comprehensive transdisciplinary strategies to foster fairness and inclusivity in the digital landscape.

Data Availability

Data sharing is not applicable to this article as no data sets were generated or analyzed during this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Extracted information. The following data sets appeared in publications included in this review, but subject demographic data was not readily available; thus, they were not included in the tables: 11k Hands, ABIDE, CoRR, DLBS, NKI Rockland, Pilots Parliament Benchmark, and a data set comprised of Twitter Profile data.

[XLSX File (Microsoft Excel File), 17 KB - aging_v7i1e53564_app1.xlsx]

Multimedia Appendix 2

PRISMA Checklist.

[PDF File (Adobe PDF File), 273 KB - aging_v7i1e53564_app2.pdf]

References

1. Devakunchari R. Analysis on big data over the years. International Journal of Scientific and Research Publications 2014;4(1):383-389 [FREE Full text]
2. Howard A, Borenstein J. The ugly truth about ourselves and our robot creations: the problem of bias and social inequity. Sci Eng Ethics 2018;24(5):1521-1536 [FREE Full text] [doi: 10.1007/s11948-017-9975-2] [Medline: 28936795]
3. Obermeyer Z, Powers B, Vogeli C, Mullainathan S. Dissecting racial bias in an algorithm used to manage the health of populations. Science 2019;366(6464):447-453 [FREE Full text] [doi: 10.1126/science.aax2342] [Medline: 31649194]
4. Zou J, Schiebinger L. AI can be sexist and racist - it's time to make it fair. Nature 2018;559(7714):324-326. [doi: 10.1038/d41586-018-05707-8] [Medline: 30018439]
5. Mehrabi N, Morstatter F, Saxena N, Lerman K, Galstyan A. A survey on bias and fairness in machine learning. ACM Comput Surv 2021;54(6):1-35 [FREE Full text] [doi: 10.1145/3457607]
6. Dawson D, Schleiger E, Horton J, McLaughlin J, Robinson C, Quezada G, et al. Artificial intelligence: Australia's ethics framework - a discussion paper. Analytics and Policy Observatory. 2019. URL: https://apo.org.au/node/229596 [accessed 2022-09-05]
7. Digital decisions. Center for Democracy & Technology. 2018. URL: https://cdt.org/wp-content/uploads/2018/09/Digital-Decisions-Library-Printer-Friendly-as-of-20180927.pdf [accessed 2024-01-09]
8. Machine learning: the power and promise of computers that learn by example. The Royal Society. 2017. URL: https://royalsociety.org/~/media/policy/projects/machine-learning/publications/machine-learning-report.pdf [accessed 2024-01-09]
9. Chu CH, Donato-Woodger S, Khan SS, Nyrup R, Leslie K, Lyn A, et al. Age-related bias and artificial intelligence: a scoping review. Humanit Soc Sci Commun 2023;10(1):gnab167 [FREE Full text] [doi: 10.1057/s41599-023-01999-y]
10. Chu CH, Nyrup R, Leslie K, Shi J, Bianchi A, Lyn A, et al. Digital ageism: challenges and opportunities in artificial intelligence for older adults. Gerontologist 2022;62(7):947-955 [FREE Full text] [doi: 10.1093/geront/gnab167] [Medline: 35048111]
11. Nyrup R, Chu CH, Falco E. Digital ageism, algorithmic bias, and feminist critical theory. In: Drage E, Browne J, McInerney K, Cave S, editors. Feminist AI: Critical Perspectives on Data, AlgorithmsIntelligent Machines. Oxford: Oxford University Press; 2023:309-327.
12. Ageism in artificial intelligence for health. World Health Organization. 2022. URL: https://www.who.int/publications-detail-redirect/9789240040793 [accessed 2022-10-06]
13. Stypinska J. AI ageism: a critical roadmap for studying age discrimination and exclusion in digitalized societies. AI Soc 2023;38(2):665-677 [FREE Full text] [doi: 10.1007/s00146-022-01553-5] [Medline: 36212226]

14. Peine A, Neven L. The co-constitution of ageing and technology – a model and agenda. Ageing Soc 2020;41(12):2845-2866 [FREE Full text] [doi: 10.1017/s0144686x20000641]
15. Rosales A, Fernández-Ardèvol M. Structural ageism in big data approaches. Nordicom Rev 2019;40(S1):51-64 [FREE Full text] [doi: 10.2478/nor-2019-0013]
16. Rosales A, Fernández-Ardèvol M, Svensson J, editors. Digital Ageism: How it Operates and Approaches to Tackling it. 1st Edition. Abingdon, Oxon: Routledge; 2023.
17. Rosales A, Fernández-Ardèvol M. Beyond WhatsApp: older people and smartphones. Romanian J Commun Public Relat 2016;18(1):27-47. [doi: 10.21018/rjcpr.2016.1.200]
18. Park JS, Bernstein MS, Brewer RN, Kamar E, Morris MR. Understanding the representation and representativeness of age in AI Data Sets. USA: Association for Computing Machinery; 2021 Presented at: AIES '21: AAAI/ACM Conference on AI, Ethics, and Society; May 19-21, 2021; Virtual Event USA p. 834-842. [doi: 10.1145/3461702.3462590]
19. Berridge C, Grigorovich A. Algorithmic harms and digital ageism in the use of surveillance technologies in nursing homes. Front Sociol 2022;7:957246 [FREE Full text] [doi: 10.3389/fsoc.2022.957246] [Medline: 36189442]
20. Chu CH, Ronquillo C, Khan S, Hung L, Boscart V. Technology recommendations to support person-centered care in long-term care homes during the COVID-19 pandemic and beyond. J Aging Soc Policy 2021;33(4-5):539-554 [FREE Full text] [doi: 10.1080/08959420.2021.1927620] [Medline: 34278980]
21. Chu C, Nyrup R, Donato-Woodger S, Leslie K, Khan S, Bernett C, et al. Examining the technology-mediated cycles of injustice that contribute to digital ageism: advancing the conceptualization of digital ageismvidence and implications. 2022 Presented at: PETRA '22: The15th International Conference on PErvasive Technologies Related to Assistive Environments; 29 June-1 July, 2022; Corfu Greece p. 545-551 URL: https://dl.acm.org/doi/10.1145/3529190.3534765 [doi: 10.1145/3529190.3534765]
22. McDonough CC. The effect of ageism on the digital divide among older adults. J Gerontol Geriatr Med 2016;2(1):1-7 [FREE Full text] [doi: 10.24966/ggm-8662/100008]
23. Anderson M, Perrin A. Tech adoption climbs among older adults. Pew Research Center. 2017. URL: https://www.pewresearch.org/internet/2017/05/17/tech-adoption-climbs-among-older-adults/ [accessed 2022-09-05]
24. Rosales A, Svensson J, Fernández-Ardèvol M, editors. Digital Ageism: How it Operates and Approaches to Tackling it. London: Routledge; 2023.
25. Global report on ageism. World Health Organization. 2022. URL: https://www.who.int/publications-detail-redirect/9789240016866 [accessed 2022-10-06]
26. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;8(1):19-32 [FREE Full text] [doi: 10.1080/1364557032000119616]
27. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010;5:69 [FREE Full text] [doi: 10.1186/1748-5908-5-69] [Medline: 20854677]
28. Chu CH, Leslie K, Shi J, Nyrup R, Bianchi A, Khan SS, et al. Ageism and artificial intelligence: protocol for a scoping review. JMIR Res Protoc 2022;11(6):e33211 [FREE Full text] [doi: 10.2196/33211] [Medline: 35679118]
29. Scoping review protocol. Open Science Framework. URL: https://osf.io/amg5p [accessed 2024-02-28]
30. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018;169(7):467-473 [FREE Full text] [doi: 10.7326/M18-0850] [Medline: 30178033]
31. Smith C, McGuire B, Huang T, Yang G. The history of artificial intelligence. University of Washington. 2006. URL: https://courses.cs.washington.edu/courses/csep590/06au/projects/history-ai.pdf [accessed 2024-01-09]
32. Abderrahmane MA, Guelzim I, Abdelouahad AA. Hand image-based human age estimation using a time distributed CNN-GRU. 2020 Presented at: International Conference on Data Analytics for Business and Industry: Way Towards a Sustainable Economy (ICDABI); October 26-27, 2020; Sakheer, Bahrain p. 1-5. [doi: 10.1109/icdabi51230.2020.9325667]
33. Clapés A, Anbarjafari G, Bilici O, Temirova D, Avots E, Escalera S. From apparent to real age: gender, age, ethnic, makeup, and expression bias analysis in real age estimation. 2018 Presented at: IEEE Computer Society Conference on Computer Vision and Pattern Recognition Workshops (CVPRW); June 18-22, 2018; Salt Lake City, UT, USA p. 2436. [doi: 10.1109/cvprw.2018.00314]
34. Georgopoulos M, Oldfield J, Nicolaou MA, Panagakis Y, Pantic M. Enhancing facial data diversity with style-based face aging. ArXiv Preprint posted online on June 06 2020 [FREE Full text] [doi: 10.1109/cvprw50498.2020.00015]
35. Jung S, An J, Kwak H, Salminen J, Jansen B. Assessing the accuracy of four popular face recognition tools for inferring gender, age, and race. 2018 Presented at: Twelfth International AAAI Conference on Web and Social Media (ICWSM-18); June 25-28, 2018; Palo Alto, California USA. [doi: 10.1609/icwsm.v12i1.15058]
36. Liang H, Zhang F, Niu X. Investigating systematic bias in brain age estimation with application to post-traumatic stress disorders. Hum Brain Mapp 2019;40(11):3143-3152 [FREE Full text] [doi: 10.1002/hbm.24588] [Medline: 30924225]
37. Smith P, Ricanek K. Mitigating algorithmic bias: evolving an augmentation policy that is non-biasing. 2020 Presented at: IEEE Winter Applications of Computer Vision Workshops (WACVW); March 01-05, 2020; Snowmass, CO, USA p. 90-97. [doi: 10.1109/wacvw50321.2020.9096905]

38. Zou M, Niu J, Chen J, Liu Y, Zhao X. Facial age estimation with images in the wild. Cham: Springer International Publishing; 2016 Presented at: MultiMedia Modeling: 22nd International Conference; January 4-6, 2016; Miami, FL, USA p. 454-465. [doi: 10.1007/978-3-319-27671-7_38]
39. Taati B, Zhao S, Ashraf AB, Asgarian A, Browne ME, Prkachin KM, et al. Algorithmic bias in clinical populations—evaluating and improving facial analysis technology in older adults with dementia. IEEE Access 2019;7:25527-25534 [FREE Full text] [doi: 10.1109/access.2019.2900022]
40. Asgarian A, Zhao S, Ashraf AB, Browne ME, Prkachin KM, Mihailidis A, et al. Limitations and biases in facial landmark detection — an empirical study on older adults with dementia. ArXiv Preprint posted online on May 17 2019 [FREE Full text]
41. MORPH 4.0 statistics. University of North Carolina Wilmington. 2022. URL: https://web.archive.org/web/20230516225206/https://uncw.edu/oic/tech/morph-4.0-statistics.pdf [accessed 2024-01-09]
42. Eidinger E, Enbar R, Hassner T. Age and gender estimation of unfiltered faces. IEEE Trans.Inform.Forensic Secur 2014 Dec;9(12):2170-2179 [FREE Full text] [doi: 10.1109/tifs.2014.2359646]
43. The world Factbook. Central Intelligence Agency. URL: https://www.cia.gov/the-world-factbook/ [accessed 2023-08-15]
44. Panis G, Lanitis A, Tsapatsoulis N, Cootes TF. Overview of research on facial aging using the FG-NET aging database. IET Biometrics 2015;5(2):37-46 [FREE Full text] [doi: 10.1049/iet-bmt.2014.0053]
45. MORPH non-commercial release whitepaper. University of North Carolina Wilmington. 2021. URL: https://web.archive.org/web/20211104050403/http://people.uncw.edu/vetterr/MORPH-NonCommercial-Stats.pdf [accessed 2024-01-09]
46. Agustsson E, Timofte R, Escalera S, Baro X, Guyon I, Rothe R. Apparent and real age estimation in still images with deep residual regressors on appa-real database. USA: IEEE; 2017 Presented at: 12th IEEE International Conference on Automatic Face & Gesture Recognition (FG 2017); 30 May-03 June, 2017; Washington, DC, USA p. 87-94. [doi: 10.1109/fg.2017.20]
47. Wernick A, Featherstone M, editors. Images of Aging: Cultural Representations of Later Life. London: Routledge; 1995.
48. Loos E, Ivan L. Visual ageism in the media. In: Tesch-Römer C, Ayalon L, editors. Contemporary Perspectives on Ageism. Cham: Springer International Publishing; 2018:163-176.
49. Ganel T, Sofer C, Goodale MA. Biases in human perception of facial age are present and more exaggerated in current AI technology. Sci Rep 2022;12(1):22519 [FREE Full text] [doi: 10.1038/s41598-022-27009-w] [Medline: 36581653]
50. Sixta T, Jacques JCSJ, Buch-Cardona P, Vazquez E, Escalera S. FairFace challenge at ECCV 2020: analyzing bias in face recognition. In: Computer Vision – ECCV 2020 Workshops. Cham: Springer International Publishing; 2020 Presented at: ECCV: European Conference on Computer Vision; August 23–28, 2020; Glasgow, UK p. 463-481 URL: https://link.springer.com/chapter/10.1007/978-3-030-65414-6_32 [doi: 10.1007/978-3-030-65414-6_32]
51. Kim E, Bryant D, Srikanth D, Howard A. Age bias in emotion detection: an analysis of facial emotion recognition performance on young, middle-aged, and older adults. USA: Association for Computing Machinery; 2021 Presented at: AIES '21: AAAI/ACM Conference on AI, Ethics, and Society; May 19-21, 2021; Virtual Event USA p. 638-644 URL: https://doi.org/10.1145/3461702.3462609 [doi: 10.1145/3461702.3462609]

Abbreviations

AAM: active appearance model
CAAE: Conditional Adversarial Auto Encoder
CACD: Cross-Age Celebrities data set
FACS: facial action coding system
FAN: facial alignment network
FER: facial emotional recognition
GAN: generative adversarial network
IPCGAN: Identity-Preserved Conditional Generative Adversarial Network
MAE: mean absolute error
ML: machine learning
MRI: magnetic resonance imaging
NRMSE: normalized root-mean square error
PACSLAC-II: Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II
PRISMA-ScR: Preferred Reporting for Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Review

Adoption of Artificial Intelligence–Enabled Robots in Long-Term Care Homes by Health Care Providers: Scoping Review

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Abstract

Background: Long-term care (LTC) homes face the challenges of increasing care needs of residents and a shortage of health care providers. Literature suggests that artificial intelligence (AI)–enabled robots may solve such challenges and support person-centered care. There is a dearth of literature exploring the perspectives of health care providers, which are crucial to implementing AI-enabled robots.

Objective: This scoping review aims to explore this scant body of literature to answer two questions: (1) what barriers do health care providers perceive in adopting AI-enabled robots in LTC homes? (2) What strategies can be taken to overcome these barriers to the adoption of AI-enabled robots in LTC homes?

Methods: We are a team consisting of 3 researchers, 2 health care providers, 2 research trainees, and 1 older adult partner with diverse disciplines in nursing, social work, engineering, and medicine. Referring to the Joanna Briggs Institute methodology, our team searched databases (CINAHL, MEDLINE, PsycINFO, Web of Science, ProQuest, and Google Scholar) for peer-reviewed and gray literature, screened the literature, and extracted the data. We analyzed the data as a team. We compared our findings with the Person-Centered Practice Framework and Consolidated Framework for Implementation Research to further our understanding of the findings.

Results: This review includes 33 articles that met the inclusion criteria. We identified three barriers to AI-enabled robot adoption: (1) perceived technical complexity and limitation; (2) negative impact, doubted usefulness, and ethical concerns; and (3) resource limitations. Strategies to mitigate these barriers were also explored: (1) accommodate the various needs of residents and health care providers, (2) increase the understanding of the benefits of using robots, (3) review and overcome the safety issues, and (4) boost interest in the use of robots and provide training.

Conclusions: Previous literature suggested using AI-enabled robots to resolve the challenges of increasing care needs and staff shortages in LTC. Yet, our findings show that health care providers might not use robots because of different considerations. The implication is that the voices of health care providers need to be included in using robots.

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KEYWORDS

artificial intelligence; robot; long-term care home; health care provider; scoping review; person-centered care

Introduction

Background

Long-term care (LTC) provides various services designed to meet the chronic health and personal care needs of those who can no longer perform daily activities independently [1]. LTC health care providers face challenges to meet the increased demand from older adults and their family caregivers due to a dramatically increasing aging population and growing chronic disease burden [2]. Health care providers in LTC homes often engage in repetitive tasks, many involving physical labor, which could lead to a high risk of job stress, physical or emotional exhaustion, burnout, and high turnover, all of which contribute to a lower quality of care [3-5]. Thus, innovative solutions are required to meet LTC home residents' health care needs and reduce the workload for health care providers.

Artificial intelligence (AI)–enabled robots have been perceived as a solution to the crisis in LTC homes, where significant labor shortages will accompany rapidly increasing care demand [6-8]. AI-enabled robots have been used to support person-centered care for older adults and attend to the emotional, social, and physical needs of older adults. For example, PARO, a socially assistive robot, can interact with and provide emotional support for patients with dementia [9]. Physically assistive robots can perform tasks such as dressing and sit-to-stand support [10]. Evidence has suggested that using AI-enabled robots in LTC homes could optimize resources, enhance resident outcomes, create patient-centered care, satisfy residents' needs, and improve health care providers' workflow [2]. While AI-enabled robots may potentially alleviate the burden on health care workers and enhance efficiency in LTC homes, they also pose risks. Issues associated with AI-enabled robot use were explored in the literature. In LTC homes, the adoption and use of robotics are associated with ethical issues and technological risks such as safety, privacy and data security, liability, and effects on the incumbent workforce [11]. Accordingly, research has been focusing on examining attitudes and perceptions of AI-enabled robots [12].

Recent AI-enabled robot studies evaluate the acceptance of this technology in older users, including in the settings of care facilities, as well as private homes and living lab contexts [13-18]. Findings of the literature show that older adults are generally open to robot assistants, while robots provide social interactions, cognitive stimulation, home-based tasks, personal care, and information management [19,20]. However, very few studies have been focused on measuring the health care providers' perception of AI use, although their acceptance of AI-enabled robots is crucial to future research and development and the implementation of AI-enabled robots in LTC homes [21]. Some studies have shown that approximately 40% of technologies, such as home health care robots and information systems, have been abandoned in the last 2 decades [22,23]. Several barriers to health care providers' adoption of AI-enabled robots were explored, including clinicians' inadequate knowledge [24] and lack of understanding of the sociotechnical aspects of the technology [24]. These barriers lead to a fear of job loss among health care staff, who are concerned about being replaced by robots for repetitive or manual tasks, even when robots are intended to assist rather than replace workers [21,24]. Therefore, understanding the perspectives of health care providers on AI-enabled robot use is crucial, as they can offer the most pertinent insights into the risks and impacts, as well as to understand users' needs and expectations [25].

This scoping review aims to synthesize and analyze the existing literature on the potential barriers and the strategies to overcome these barriers by adopting AI-enabled robots in LTC homes from the perspectives of health care providers. Two research questions guided the review: (1) what barriers do health care providers perceive in adopting AI-enabled robots in LTC homes? (2) What strategies can be taken to overcome these barriers to the adoption of AI-enabled robots in LTC homes?

To our knowledge, no scoping review has been conducted on this topic. Existing scoping reviews focus on using AI in older adult care or health care, such as promoting shared health care decision-making [26], monitoring diabetes-related parameters [27], and facilitating digital health care interventions [28]. However, these settings are not LTC homes. There are also scoping reviews on LTC homes, such as making decisions about moving into LTC homes [29] and physical rehabilitation in LTC homes [30]. Yet, they are not related to the use of technology. There are scoping reviews about technologies in LTC homes, such as using eHealth to support assessment and decision-making with residents living with dementia in LTC homes [31] and defining the concepts of smart nursing homes and technology-assisted LTC homes [32]. Nevertheless, these reviews are not specifically about AI. Lukkien et al [33] conducted a scoping review about responsible AI, that is, using AI ethically in LTC homes. Yet, the review is from the perspectives of researchers, not health care providers.

The paper addresses the critical gap concerning LTC health care providers' perspectives in adopting AI robots. Staff perspectives are essential as they directly impact the acceptance, use, and effectiveness of AI technologies in care settings. Our findings highlight the importance of an inclusive approach to engaging LTC staff in robot development and implementation. The practical insights and strategies can empower staff to support the integration of AI technologies into LTC.

To begin with, we will define some terms used in this paper. We have published a protocol for this scoping review and will refer to the definitions of *robot*, *AI*, and *AI-enabled robot* as outlined in the protocol [34]: "*Robots* are mechanical devices that can be of various physical forms and are designed to perform a wide range of tasks.... *AI* is known as 'the science of making [a] machine or computer to act intelligently'.... The *AI-enabled robot*, or intelligence robot, can be defined as 'a physically situated intelligent agent in the "real world," regardless of shape, that can sense and act on its operational environment.' AI allows robots to (a) present the world symbolically in a way that can be easily understood by computers, (b) understand natural language and explore clear communication required for comfortable social interaction between humans and robots, (c) learn by self-iterative trials and apply that learning to a range of functions, (d) plan and solve problems, (e) generate an answer without complete information,

(f) use search algorithms to generate solutions in navigation or search for optimal knowledge representation and (g) improve robotic actions with vision systems in the robots" [35]. *Health care providers* refer to paid staff caring for LTC home residents (eg, nurses, care aides, and allied health professionals). *LTC* refers to "care settings that provide 24-hour personal care support for people with complex needs who are unable to remain at home" [34].

Theoretical Frameworks

In this scoping review, the Person-Centered Practice Framework (PCPF) [36] and Consolidated Framework for Implementation Research (CFIR) [37] are the supplementary theoretical frameworks that guided our synthesis and analysis of results to explore the barriers and the strategies to overcome these barriers to the adoption of AI-enabled robots in LTC homes.

PCPF Philosophy

McCormack and McCance [38] coined *PCPF*. Person-centered care is a care philosophy with people living with dementia [39]. Despite cognitive impairment, person-centered care recognizes that a person living with dementia still has personhood; should be seen as a person; and has diverse needs, such as psychosocial needs, which need to be met by care to achieve the person's holistic well-being. PCPF provides a framework for understanding the factors influencing the practice of person-centered care with people living with dementia [38,40]. Our review focuses on adopting AI-enabled robots to care for people with dementia. PCPF is, therefore, a good fit for our review. PCPF initially focuses on nursing practice with people living with dementia [38]. However, gradually, it has been adopted by other disciplines, such as social work [41] and rehabilitation [39]. PCPF is an evolving framework since its first publication in 2001; its author continues to enhance it over the years by absorbing lessons from new research and practice [36,38,40]. We have adopted the latest version of PCPF as published by the authors in 2023 [36].

PCPF comprises 5 domains: prerequisite, practice environment, person-centered process, outcome, and macrocontext. Figure 1 presents the framework from the authors' recent publication in 2023 [36].

Figure 1. Developing healthful cultures through the development of person-centered practice. Reproduced from McCance and McCormack [36] with permission from Elsevier.

PCPF considers that person-centered care practice is shaped not only by factors at the level of the patient and the health care provider but also by factors at the level of organization and society. These domains are interrelated with each other, as elaborated by the authors [36]: "to reach the centre of the framework, one must first take account of the *macrocontext*, followed by consideration of the attributes of staff, as a *prerequisite* to managing the practice *environment*, and in order to engage effectively through the *person-centred processes*. This ordering ultimately leads to the achievement of the *outcome*." Under each of the 5 domains, there are constructs. There is no hierarchy among the constructs; constructs in the same domain can be related or even overlap [36].

The *prerequisite* domain examines the "attributes" of health care providers required to provide person-centered care, and the constructs under this domain are "being professionally competent, having developed interpersonal skills, being committed to the job, being able to demonstrate clarity of beliefs and values, and knowing self" [36]. The practice *environment* domain looks into "the context," that is, the care setting and organization, where person-centered care is provided, and under this domain, the constructs include "appropriate skill mix; systems that facilitate shared decision making; the sharing of power; effective staff relationships; organisational systems that are supportive; potential for innovation and risk taking; and the physical environment" [36]. The *person-centered process* domain explores health care providers' "ways of engaging that are necessary to create connections between persons (living with dementia)," and the constructs under this domain include "working with the person's beliefs and values; engaging authentically; being sympathetically present; sharing decision making; and working holistically" [36]. The *outcome domain* looks into the "result of effective person-centred practice," and the authors suggest that effective person-centered practice should "enable human flourishing for those who give care and for those who receive care" [36]. Under this domain, the constructs are that "decision-making is shared, relationships are collaborative, leadership is transformational, and innovative practices are supported" [36]. The *macrocontext* domain refers to regional, national, and international "factors that are strategic and political in nature that influence the development of person-centred cultures" [36]. The constructs under this domain include "policy frameworks, strategic frameworks, workforce developments, and strategic leadership" [36].

CFIR Framework

Damschroder et al [42] developed the CFIR by consolidating constructs from 19 implementation frameworks or theories in 2009. The authors updated it by incorporating new literature and feedback in 2022 [43,44]. Our review will refer to the latest version of CFIR, which is freely accessible on the CFIR website [45]. CFIR is a framework for understanding the contextual factors that influence implementation in a clinical setting or organization [44]. Our review concerns the implementation of AI-enabled robots in LTC. Thus, CFIR and our review are a good match. In addition, previous literature suggested that CFIR can be used with other frameworks [44]. In our review, we are using it with PCPF.

According to the authors, one way to use CFIR is to better understand the findings on implementation [44]. We will use CFIR to understand the findings from the literature on health care providers' perspectives on the barriers to implementing AI-enabled robots and the strategies for overcoming them. The authors suggested 2 approaches to using CFIR to understand the findings on implementation: deductive and inductive. Our study will use a mixed approach, which will be further elaborated.

CFIR comprises 5 domains: innovation, inner setting, outer setting, individuals, and implementation process; there are constructs under each domain, and CFIR has 48 constructs in total [37]. The *innovation domain* explores "the 'thing' being implemented," such as research, programs, policies, and innovations [37]. The constructs under this domain include "innovation source, innovation evidence-base, innovation relative advantage, innovation adaptability, innovation trialability, innovation complexity, innovation design, and innovation cost" [37]. The *outer setting domain* examines "the setting in which the inner setting exists," such as the health and community organizations [37]. Under this domain, the constructs are "critical incidents, local attitudes, local conditions, partnerships and connections, policies and laws, financing, and external pressure" [37]. The *inner setting domain* looks into "the setting in which the innovation is implemented," such as an LTC home or a hospital [37]. The constructs under this domain are "structural characteristics, relational connections, communications, culture, tension for change, compatibility, relative priority, incentive systems, mission alignment, available resources, and access to knowledge and information" [37]. The *individuals domain* explores "the roles and characteristics of individuals" involved in implementation [37]. Under this domain, the constructs include "high-level leaders, midlevel leaders, opinion leaders, implementation facilitators, implementation leads, implementation team members, other implementation support, innovation deliverers, and innovation recipients" [37]. The *implementation process domain* examines "the activities and strategies used to implement the innovation" [37]. The constructs under this domain are "teaming, assessing needs, assessing context, planning, tailoring strategies, engaging, doing, reflecting and evaluating, and adapting" [37].

Methods

Overview

Scoping reviews are pivotal for identifying and summarizing evidence in emergent fields and highlighting significant themes, contexts, and research gaps [46]. Given the nascent stage of AI-enabled robots in LTC homes, a scoping review was apt for our study. Our interdisciplinary review team was comprised 3 researchers, 2 health care providers, 2 research trainees, and 1 older adult partner. We each brought different expertise: researchers and research trainees brought research knowledge and skills, health care providers brought frontline experiences, and the older adult partner brought in lived expertise. Our group represented diverse backgrounds: nursing, social work, engineering, and medicine. Diverse expertise and backgrounds enriched our team discussions, especially during data analysis. We followed the guidelines on scoping reviews outlined by the Joanna Briggs Institute [47]. We published the objectives, inclusion criteria, and methods of this scoping review in a protocol [34]. We conducted the scoping review over 6 months. As data were synthesized solely from existing literature, ethics approval was not required for this scoping review.

Search Strategy

We followed the three-step search approach recommended by Joanna Briggs Institute: (1) conducting a preliminary search using 2 databases (MEDLINE and CINAHL) to identify keywords and index terms; (2) using keywords and index terms from the previous step to search selected databases (CINAHL, MEDLINE, PsycINFO, Web of Science, ProQuest, and Google Scholar); and (3) hand-searching the reference lists of selected items.

The participants, context, and concept of our scoping review were as follows: participants were health care providers working with older adults in LTC, the context was LTC, and the concept was AI-enabled robots. The search string was based on these participants, context, and concept, that is, “healthcare provider” AND “older adult” AND “LTC” AND “AI.” Our search was limited to the items published in the last 10 years (2013-2023), and we only included publications in English.

Item Selection

We used a web-based software platform, Covidence (Veritas Health Innovation), to assist us in conducting the scoping review. Initially, we identified 279 items and uploaded them to Covidence. Subsequently, we performed 2 screening levels according to the inclusion and exclusion criteria (Textbox 1).

We adopted an inclusive approach to how we considered a robot an AI-enabled robot. We considered a robot an AI-enabled robot if it has AI features according to our AI-enabled robot definition as mentioned in the Introduction section. Textbox 2 explains how each robot included in this scoping review is related to our AI-enabled definition.

Textbox 1. Eligibility criteria.

Inclusion criteria

- Includes health care providers working with older adults in long-term care (LTC) homes
- Includes artificial intelligence (AI)–enabled robots
- Includes LTC home setting
- Published in English language
- All study designs (eg, qualitative, quantitative, and mixed methods)
- All sources (eg, peer-reviewed journal articles, books and book chapters, conference proceedings, reports, theses, and dissertations)
- Include data that address the 2 objectives of our paper

Exclusion criteria

- Does not include health care providers working with older adults
- Does not include AI-enabled robots
- Acute care or community settings other than LTC home (eg, home care, older adult care centers, and adult day health care programs)
- Published in language other than English
- Do not include data that address the 2 objectives of our paper

Textbox 2. How robots are related to artificial intelligence (AI) by definition.

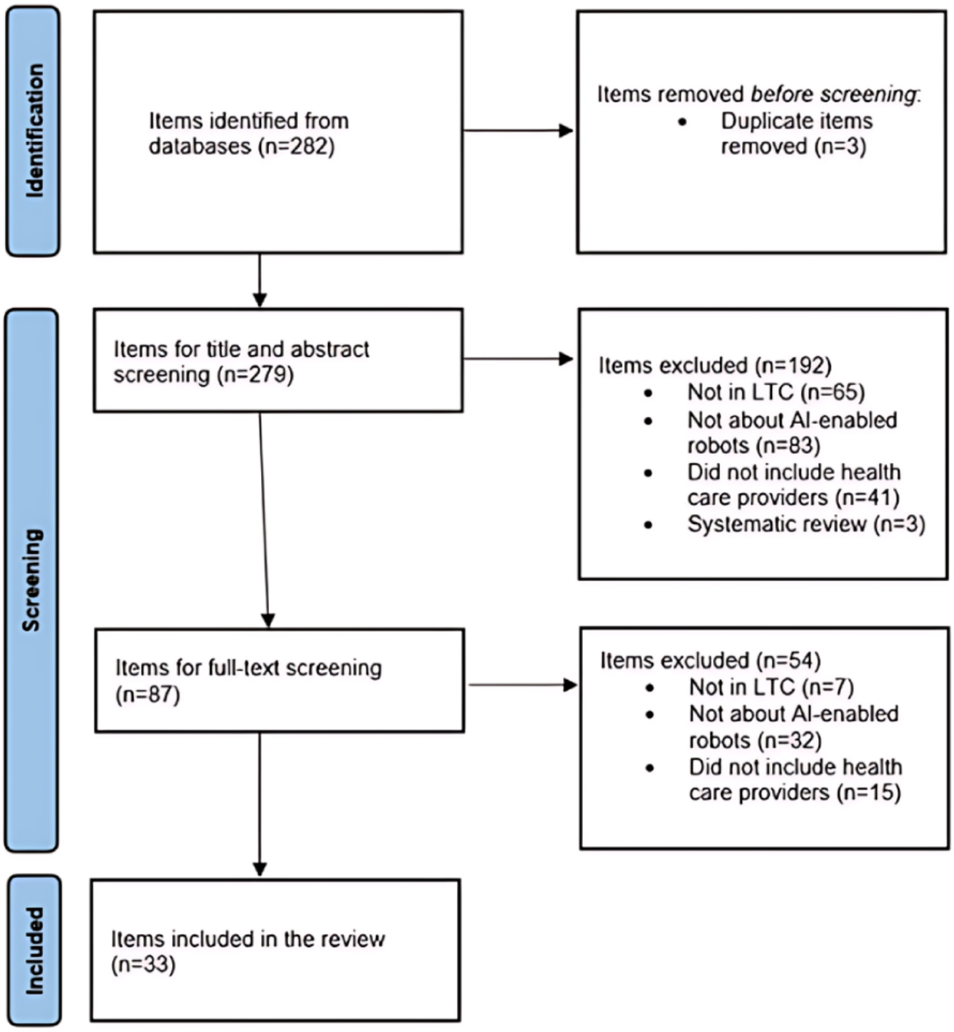
Robot name and how it is related to AI by definition

- Stevie [48,49]
    - Stevie is a social robot designed to be used in care settings for older adults. The robot incorporates AI to enhance its functionality and communication abilities. Like other AI-enabled robots, Stevie II can autonomously map and navigate 3D environments in real time. Unlike other robots, Stevie uses AI to support its enhanced communication functionality. Through the use of humanlike speech, gestures, and facial expressions, the robot is able to engage in clear communication required for social interaction. Furthermore, the robot leverages AI to perform various tasks such as setting reminders, entertaining older adults, and problem-solving.
- PARO [50]
    - PARO is a seal-shaped interactive robot that incorporates sensory receptors to interface with its environment. The robot is used in various health care environments to reduce stress anxiety, improve socialization, and so on by replicating the effects of animal therapy. PARO can be held, spoken to, and stroked as if it were an actual animal. AI enables PARO to remember users' actions and learn to adapt its behavior accordingly. Actions that result in positive user feedback will be repeated, while actions resulting in negative user feedback will not.
- NAO [51]
    - NAO is a bipedal interactive humanoid robot designed for various applications, including education and research. The robot supports open-source functionality, allowing users to curate the robot to their specific needs. NAO uses AI at the lowest level to perceive the surrounding environment, understand and respond to human emotion, solve tasks, navigate using advanced vision systems, and so on.
- Pepper [52]
    - Pepper is a humanoid robot designed for social interaction and customer service. Leveraging its ability to recognize faces and human emotions, Pepper is available in businesses and schools as a helpful assistant. The robot uses AI to map and navigate its environment and solve tasks, among many other things. Above all, Pepper uses AI to recognize and respond to human emotions, making it capable of humanlike communication. It also learns from interactions, allowing it to adapt and improve its responses over time.
- SCITOS [53]
    - The SCITOS is an autonomous robot designed to be used in various applications such as research and many customer service positions. The robot is designed to interact with people through its voice, head movements, and touch display, as well as guide people in various settings. It uses AI to map and navigate its environment, avoiding obstacles and identifying its position in a 3-D space. AI is also used for effective communication, equipping SCITOS with the ability to interact with and understand humans. This AI-enabled emotional recognition allows the robot to guide visitors, provide explanations, and play fun games such as hide and seek.
- Tangy [54]
    - Tangy is a social robot designed to assist with social and interactive tasks. The main use case for Tangy is as a bingo assistant in long-term care settings. Using AI, Tangy can autonomously support older adults in playing bingo. The robot is able to call bingo numbers, help individuals, ensure the accuracy of winning bingo cards, and congratulate winners. These functionalities are supported by AI, which enables Tangy to perceive and influence its surrounding environment. AI also allows the robot to recognize certain bingo cards as winners, an ability made possible with improved computer vision systems. Tangy also uses AI to integrate information from different sensors, and this allows it to identify and communicate when certain bingo numbers are called out.
- MARIO [55,56]
    - The MARIO robot is a social robot that builds on existing Kompai architecture with the purpose of providing companionship and support. The robot is intended for use with individuals who have dementia in long-term care settings. The robot applies AI at various levels to supplement its predetermined functionalities. Simultaneous mapping and navigation are possible through the AI-driven integration of sensor data, although this requires more constant environments. It is also able to understand and respond to human communication, and this allows it to effectively engage with residents. The robot supports various applications, including fall or hazard detection, which are facilitated by AI.
- Roomba [57]
    - The Roomba is a robotic vacuum cleaner designed to automate the floor cleaning process. There are several iterations of the device that support different types of cleaning and more efficient automation. At the lowest level, the Roomba uses AI to perceive and influence its surrounding environment. Advanced sensor and mapping technology is leveraged to create a computer-readable rendition of a 3D space, enabling systematic and efficient cleaning patterns.
- TUG [58]
    - The TUG autonomous mobile robot is made specifically to deliver linens, medications, and meals in hospital settings. The robot functions to maintain order in the hospital and reduce the physical workload that the staff are required to manage. The TUG robot uses AI to enhance its computer vision capabilities, allowing it to map and navigate 3D environments and make use of existing navigation infrastructures (eg, elevator). The AI-enabled robot also can identify hazards in real time, which is integral in health care settings that may contain patients, caregivers, and other individuals.

- PaPeRo [59]
    - PaPeRo is a social robot that was developed to appeal to various populations, with the intention of providing companionship. The robot uses AI to engage in human conversation, recognizing >200 words and speaking in a natural voice. The robot can also perceive the volume of sounds in the environment and adjust its behavior accordingly. Furthermore, the robot makes use of image-recognition technology to identify faces. While not actively engaging with individuals, the robot makes use of AI to map and traverse through its environment while dancing and singing on its own. PaPeRo is also able to identify hazards in its environment.
- Temi [60]
    - Temi is a social robot designed for home and business applications. The robot acts as an autonomous personal assistant following users, saving locations, setting tasks, and providing Face Time functionalities. Temi uses AI to map and navigate its environment, facilitating autonomous motion. The robot can also identify environmental hazards and adapt its movement to suit different types of surfaces to suit different types of surfaces (wood, carpet, etc). It can also understand and respond to voice commands, demonstrating an ability to engage in humanlike communication while also learning and adapting to users' behaviors over time.
- Grace [61]
    - Grace is an advanced humanoid robot designed for health care applications. The robot emulates health care professionals with a humanlike appearance and its ability to interact with patients, record key vitals (temperature and responsiveness), engage in therapeutic conversation, and help other health care professionals. AI is deeply embedded into almost all components of Grace, allowing for autonomous movement, diagnosing of some conditions, and most of all, humanlike communication. The robot uses AI in conjunction with electrical components to replicate facial expressions, and this facilitate its ability to communicate and provide companionship. The robot is mainly used to provide social stimulation to older adults and others isolated in health care settings.
- PR2 [62]
    - PR2 is a service robot that supports a wide array of use cases and can be adapted to fit different environments. PR2 robots have the dexterity to fold towels, grab drinks, pick up various items, and even make purchases in stores. The robot relies heavily on AI to perform these tasks. A variety of sensors are integrated through AI tools to create 3D representations of environments, allowing for real-time mapping and navigation. The robot also supports complex problem-solving skills that allow it to adapt to complete many different tasks. AI also enables the robot to interact with humans through voice and gesture recognition.
- Sota [63]
    - Sota is a social robot optimized for social interaction and communication. Sota is designed to give PowerPoint presentations, making use of its versatile communication skills. The robot has a unique communication style, making use of its tone of voice, arm gestures, expressions, body language, and other sounds to convey certain emotions. Sota uses AI to integrate its different skills in a coherent way suitable for presentations. For example, the 3D environment is mapped in real time, and this allows Sota to move around while speaking and point to key features in the presentation. Sota's voice and gestures are all decided on using AI algorithms that can learn and adapt to audience reactions over time.
- Smart Walker [64]
    - The Smart Walker is an AI-assistive device that is intended to aid individuals with mobility challenges. The robot can precisely detect users' movements and adjust its own behavior accordingly by moving forward, stopping, or adjusting its speed. AI allows the robot to map and navigate its environment while also detecting hazards in real time. The hazard detection functionality uses AI to detect objects in the path of the user and stop the walker, preventing collisions. Furthermore, the robot also supports gait detection and health monitoring, a feature enabled by the integration of various sensor data through AI.
- Artificial Intelligence Lightweight Android (AILA) [65]
    - AILA is an autonomous robot designed as a research platform for autonomous mobile dual-arm manipulation. The robot can understand and navigate its environment in real time, a feature facilitated by integrating AI technologies with various sensor modalities. Moreover, AI enables AILA to recognize specific objects in its environment through feature matching and 3D pose estimation. On the basis of this information, AILA can autonomously adjust its arms and determine the best orientation to grasp different objects. Furthermore, AILA can use different strategies to lift and relocate objects depending on their characteristics (fragile, soft, and hard).

In the first screening level, 2 research trainees of our team independently screened the titles and abstracts of the 279 identified items. We removed 192 (68.8%) items that were not conducted in LTC homes, were not about AI-enabled robots, did not include health care providers, or were systematic reviews, and 87 (31.2%) items remained. In the second screening level, the 2 research trainees independently reviewed the full text of the 87 selected items. Subsequently, we removed 54 items (reasons for removing were the same as those in the first screening level), and 33 items remained. We used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [66] to record the selection process (Figure 2). When the 2 research trainees did not agree with each other, the researcher (LH) made the final decision.

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) chart. AI: artificial intelligence; LTC: long-term care.



Data Extraction and Analysis

We extracted data from the chosen items by domain and documented the data extracted in the data extraction table (Multimedia Appendix 1 [11,49,67-97]). The domain included "author, year, and place" of the literature; "literature type and study design/method"; "setting, population, and sample size (if mentioned)" of the study; "type of AI-enabled robot and use of the robot" mentioned in the literature; "barriers to the use of the AI-enabled robot (from healthcare providers' perspectives)"; and "strategies to overcome the barriers." The data extraction tool was an enhanced version compared with the one we published in the protocol: most of the categories of the tool in the enhanced version were similar to the protocol version. The main difference was that we removed the category on "results and implications" and added a category on "the type of AI-enabled robot and use of the robot." We initially had a category on "results and implications," just in case we needed additional information to help us address the review questions. However, after we started data extraction, we realized that the category on "results and implications" did not provide additional information to help us address the review questions and might even divert our attention away from addressing the review questions. Therefore, after discussion, we removed this category. By contrast, during data extraction, we found that the differences in the types and uses of AI-enabled robots might relate to the review questions on the barriers and the strategies to overcome them. Therefore, after discussion, we added this category.

Each team member was randomly assigned items for data extraction. Since our older adult partner expressed interest in helping with data extraction despite being less familiar with academic work, he was assigned fewer items (3 items) than other members. We met to discuss the challenges we encountered during the data extraction process and resolve them together under the guidance of the researcher (LH), who is experienced in the scoping review. For items that include both health care provider participants and non–health care provider participants (eg, residents and families), we only extracted the data on the barriers and the strategies to overcome these barriers from the perspectives of health care providers. For items that include AI-enabled and non–AI-enabled robots, we only extracted the data on AI-enabled robots.

After data extraction, a research trainee of our team did a preliminary thematic analysis of the extracted data using NVivo (version 12; Lumivero), a qualitative data analysis software [98]. The trainee coded the data, grouped similar codes into categories, grouped similar categories into themes, and then presented the findings to the team. The team members gave inputs to refine the findings, which were finalized through team analysis. When differing opinions on the themes arose, we reached a consensus through discussion. Team members then compared the findings with PCPF and CFIR to see how the frameworks further our understanding of the findings. We followed a mixed inductive and deductive approach in data analysis. The research trainees coded the data, and the team developed the themes inductively. However, we also compared the findings with PCPF and CFIR to further our understanding of the findings deductively.

Results

Overview

In our review, we included 33 studies conducted across 16 different countries. Most studies were from Canada and Australia, with 12% (5/33) of the studies from each country [11,72,78,80,84,85,90,94,96]. Moreover, 9% (3/33) of the studies were conducted in Austria, and the United States [49,68,75,89,91,95]. There were 4 (12%) studies that took place in Japan [74,86,93,97]. The remaining countries contributed to either 3% (1/33) of the studies (China, the Netherlands, New Zealand, Turkey, and the United Kingdom) or 6% (2/33) of the studies (Finland, Germany, Switzerland, and Taiwan), while 1 (3%) [67,69-71,73,81,82,87-89,92] study involved >1 country (Italy, Ireland, and the United Kingdom) [81]. Most of the studies (20/33, 61%) were journal articles [11,49,67-72,74-77,79,80,82,83,86,87,92,97]. Furthermore, 24% (8/33) of the studies were conference proceedings, and 9% (3/33) of the studies were book chapters [73,78,81,84,85,88,89,91,93,95,96]. There was 1 (3%) web-based news article and 1 (3%) dissertation [90,94]. The most frequently researched robot among the studies was the social robot PARO, mentioned in 33% (11/33) of the studies [11,69,73,77,80,81,84-86,89,96]. The humanoid robots NAO and Pepper were mentioned by 15% (5/33) of the studies and 12% (4/33) of the studies, respectively [67,70-72,79,84,86,97]. While 2 (6%) studies were found mentioning the following robots: SCITOS, Sota, and Tangy, 1 (3%) study mentioned the remaining robots [49,68,73-76,78,83,87,88,90,91,93,94].

Barriers to the Use of AI-Enabled Robots

Overview

One of our primary research questions is to explore the barriers that health care providers perceive in adopting AI-enabled robots in LTC homes. After reviewing and analyzing the existing literature, 3 barriers related to this regard were identified (Textbox 3).

Textbox 3. A summary of the barriers to the use of artificial intelligence (AI)–enabled robots.

Barriers and summary

- Perceived technical complexity and limitation
  - Perceived using AI-enabled robots complex or troublesome
  - Reported not having the knowledge and skills to use the robots
- Negative impact, doubted usefulness, and ethical concerns
  - Worried about the AI-enabled robots’ negative impacts on residents
  - Worried about the AI-enabled robots’ negative impacts on staff
  - Doubted residents’ interests in the AI-enabled robots
  - Doubted the usefulness of the AI-enabled robots to residents
  - Doubted that the robots would fit the LTC home context
  - Worried about the potential ethical issues of using AI-enabled robots
  - Raised ethical concerns on privacy
- Resource limitations
  - Lack of human and time resources
  - Not enough robots
  - A lack of infrastructure
  - Worried about maintenance costs

Perceived Technical Complexity and Limitation

Health care providers perceived the technical complexity and limitations of robots as a barrier to adopting robots. For example, in the study by Huisman and Kort [67], using the humanoid robot NAO to entertain residents and stimulate them to do physical exercises, health care providers expressed frustration with the complex robot’s operation steps and the robot’s short battery life. In the study by Hebesberger et al [68], the autonomous robot SCITOS was used to perform safety checks around the LTC home (eg, checking if doors were closed and fire extinguishers were in place) and greet visitors at the LTC home’s lobby. Nevertheless, health care providers reported that the robot’s slow response and rigid system discouraged their use of it. In the study by Pfadenhauer and Dukat [69] on the social robot PARO, health care providers mentioned that as the robot could not move independently, they had to carry it around the LTC home for residents' use, which was inconvenient.

In addition, a lack of knowledge and skills contributes to the reluctance to adopt these technologies. For example, in the study by Papadopoulos et al [70], using the humanoid robot Pepper to interact with residents socially, health care providers reported not being fully equipped to operate and maintain the robot. In the study by Melka et al [71], using the humanoid robot NAO for rehabilitation and recreational assistance, health care providers hesitated to use the robot as they feared making mistakes because of a lack of knowledge and skills using it. Even if there is training, the willingness to participate is low due to existing heavy workloads. For instance, referring to the study by Li et al [72], using humanoid robots Pepper and NAO to entertain residents, health care providers expressed concerns about the time needed to join training as they already had heavy workloads.

Negative Impact, Doubted Usefulness, and Ethical Concerns

Health care providers have expressed concerns, including potential negative impacts, doubts about their usefulness, and ethical implications.

Potential Negative Impacts

Some health care providers are concerned that AI-enabled robots might negatively impact residents. For example, one of the robots used in the ethnographic study by Chang and Šabanović [73] was the robotic vacuum Roomba, and health care providers expressed concerns about residents' risk of falling. In the study by McGinn et al [49], using the social robot Stevie to communicate with residents, health care providers were worried about hygiene hazards, such as the robot not being adequately sterilized after use and the potential spread of germs among residents. The study by Obayashi et al [74] used the social robot Sota; The health care providers were concerned that the robot's flashing eyes might scare residents.

Some health care providers were concerned that the AI-enabled robots might negatively impact them. For example, in the study by Hung et al [11], on the use of robots, including social robot PARO, in LTC, health care providers expressed their concerns that using these robots increased their workloads, such as teaching and assisting residents to use the robots, cleaning and charging the robots, and handling technical glitches. The study by Mitzner et al [75] used service robot PR2 to assist in caregiving tasks such as medication dispensing and transferring residents. Health care providers were concerned that the robot would replace human functions. In the study by Melkas et al [71], using the humanoid robot NAO to assist in rehabilitation and recreation, health care providers were reluctant to use it as they had established workflows, and including the robot would interrupt how they had been doing things. Erebak and Turgut [76] studied health care providers' attitudes toward robots, such as the autonomous robot Artificial Intelligence Lightweight Android (AILA). They found that the health care providers did not trust robots to be fully autonomous in decision-making. Instead, they preferred robots that allowed them to make certain decisions as humans (although the authors did not specify what these decisions would be).

Doubted Usefulness

Some health care providers have raised doubts about the usefulness of AI-enabled robots for residents in LTC homes. Some providers doubted whether residents would be interested in robots. For example, in the study by Robinson et al [77], on social robotic pet PARO as a companion with residents, health care providers raised doubts that residents would be interested in it because residents preferred real pets, and PARO looked like a toy. In the study by Louie et al [78], using the social robot Tangy, health care providers said residents preferred humans, and Tangy's appearance and voice were too mechanical. In the study by Huisman and Kort [67], using the humanoid robot NAO, health care providers said that residents would be bored by the lack of choices of programs that the robots could offer for recreation and physical exercise.

Other health care providers doubted the practicality of AI-enabled robots for residents. For instance, in the study by Louie et al [78], the primary function of the social robot Tangy was to speak to residents and interact with them. However, Tangy could not speak the languages of some residents. Some health care providers pointed out that these residents could not understand and interact with Tangy. The study by Bäck et al [79] used humanoid robot NAO to demonstrate physical exercise to residents. However, health care providers hesitated to use the robot because its size was too small for residents with eyesight impairment to see it, its voice was too soft for residents with hearing impairment to hear its instructions, and residents with cognitive impairment could not follow its demonstration.

Furthermore, providers doubted that the robots would fit the LTC home context. For instance, one robot used in the study by Chang and Šabanović [73] was the autonomous mobile robot, TUG, which was designed to help health care providers deliver care and medical supplies and clean the LTC home. However, health care providers did not find it helpful because its size was too large to navigate the LTC home's narrow hallways.

Potential Ethical Issues

Health care providers have expressed ethical concerns about using AI-enabled robots in LTC settings. For example, in the study by Moyle et al [80], social robot PARO was used to interact with residents. Health care providers raised concerns that the use might infantilize residents due to the robot's toy-like appearance. In the study by Lehmann et al [81], PARO was used as a robotic pet for companionship with residents. Health care providers expressed concerns that the robot could deceive residents with cognitive impairment as a real pet.

Privacy concerns have also been raised, particularly concerning surveillance. For instance, Christoforou et al [82] looked into different types of nursing and social and physical assistive robots. Some health care providers expressed the feeling that the robots were monitoring their work. In the study by Papadopoulos et al [70], using the humanoid robot Pepper to communicate with residents, health care providers worried about residents' privacy, especially since Pepper had cameras on its forehead.

Resource Limitations

The last barrier expressed by health care providers is that LTC homes lack the resources to use AI-enabled robots. The types of resources that LTC homes lack include time, robots, infrastructure, and maintenance costs. First, as suggested, health care providers expressed concerns about the lack of time to learn, maintain, and assist residents using the robots [11]. Second, some health care providers said that their LTC homes did not have sufficient robots. In the study by Hung et al [11], a nurse recalled how 2 residents fought with each other for 1 social robot PARO. Third, some health care providers mentioned that their LTC homes lacked infrastructure for robot use. Melkas et al [71] used a humanoid robot NAO for diverse purposes (eg, rehabilitation and recreation), and NAO needed Wi-Fi. However, some health care providers mentioned that their LTC home had a poor internet connection. They also added that their LTC home did not have sufficient physical space to store the robot. Finally, keeping a robot is expensive, and some health care providers were worried about the maintenance costs. In the study by Casey et al [83], using the social robot MARIO to stimulate residents' cognition and memories, such as giving them updates on news, health care providers were concerned about the costs of keeping the robot and suggested that it would be a better idea to spend money hiring more health care providers than keeping the robot.

Strategies to Overcome the Barriers to the Use of AI-Enabled Robots

Overview

To overcome the barriers, another primary question of our review is to identify the strategies suggested in the literature, including (1) accommodate the various needs of residents and health care providers, (2) increase the understanding of the benefits of using robots, (3) review and overcome the safety issues, and (4) boost interests in the use of robots and provide training. The strategies can be summarized in an acronym, "AI-ROBOT" (Textbox 4).

Textbox 4. Summary of the strategies to overcome barriers.

AI-ROBOT and illustrative examples from literature

- Accommodate various needs of residents and health care providers
    - Incorporate songs in languages other than English to meet the language needs of residents [84]
- Increase the understanding of the benefits of using robots
    - Health care staff found that the robot could enhance residents' emotional well-being and bring them joy [67]
- Review and overcome the safety issues with staff
    - Incorporate safety designs suggested by staff into robots [88]
- Boost interests in the use of robots
    - Dress up the robots to make them more attractive [90]
- Provide training and involve staff in the planning and implementation
    - Set up a help desk for health care staff to contact by phone or email when they encounter any challenge using the robot [67]

Accommodate the Various Needs of Residents and Health Care Providers

One strategy is to collect feedback from health care providers to design AI-enabled robots that better accommodate the various needs of residents and health care providers. For example, one of the robots used in the study by Yuan et al [84] was the humanoid robot NAO for communication with residents. Health care providers raised a concern that some residents could not understand English. In response to this feedback, Yuan et al [84] suggested incorporating songs in languages other than English into the robot to meet these residents' language needs better. The study by Bäck et al [79] used NAO for demonstration of physical exercise. In response to the feedback from health care providers that residents with sight impairment could hardly see the robot and the residents with hearing impairment could not hear the instructions by the robot clearly, Bäck et al [79] recommended painting the arms of the robot in sharp color and giving it a loud and clear voice to accommodate the visual and hearing needs. In the study by Cavenett et al [85] who used the social robot PARO for social interaction with residents, corresponding to health care providers' concerns that using the robot would add to their workload and interrupt their established workflow, Cavenett et al [85] proposed acknowledging the concerns and discussing with health care providers to understand their work needs and explore how the use of robot could address these needs and fit with their existing workflow.

Increase the Understanding of the Benefits of Using Robots

Another strategy is to increase health care providers' understanding of the benefits of using robots. The authors of the literature reviewed mentioned that when health care providers better understand the benefits of using robots, they will accept and use them more. For example, in the study by Huisman and Kort [67], some health care providers supported using the humanoid robot NAO because they found that it could enhance the emotional well-being of residents and bring them joy. In the study by Kolstad et al [86], some health care providers welcomed the social robot PARO because they found that it could stimulate residents' functions, such as interactions with people. In the study by Follmann et al [87], the social robot Temi was used to contact residents' relatives. Health care providers welcomed the robot because they found different benefits to it: it was easy for residents to use and health care providers did not need to transport the robots between residents, did not need to stand by to provide supervision when residents were using the robot, and did not need to disinfect the robot.

In addition, the reviewed literature suggests letting health care providers learn that the relationship between health care providers and robots is not competitive but complementary, emphasizing that humans perform certain tasks better than robots. A collaborative approach leverages the strengths of robots and humans, ensuring a higher quality of care. For example, Cavenett et al [85] used social robots to communicate with residents. Corresponding to health care providers' worry that robots would replace their communication role, the authors suggested that robots only complemented health care providers' communication role because robots were not as capable as humans to catch the nonverbal cues of residents.

Review and Overcome the Safety Issues With Staff

The third strategy is to review the safety issues with staff and address their concerns. The study by Shin et al [88] used the robot SmartWalker to guide residents to walk. The health care providers asked if the robot was safe, considering that the residents were prone to falling. Shin et al [88] recommended incorporating safety designs into the robot. For example, when there were obstacles and stairs in front of residents, the robot would give audio warnings to the residents. In the study by Hung et al [11], in response to health care providers' concerns about residents' safety that residents might fight over the robots, Hung et al [11] proposed having risk assessment and management guidelines in place to avoid conflicts and violence over robots and guide health care providers on what to do in case these happen.

Boost Interests in the Use of Robots

It is crucial to boost interests in using the AI-enabled robots from both the health care providers and the residents. The authors of the reviewed literature suggested increasing health care providers' interest in using robots. For instance, in the study by Chang and Šabanović [89], the researchers used the social robot PARO with residents in public areas of LTC so that health care providers could see the process of using the robot and witness how the robot provided therapeutic effects to residents. The researchers found that this raised the health care providers' interest in using the robot because they told the researchers that seeing how the researchers used the robot with the residents stimulated them to think about how they could use it in their work.

Since health care providers expressed concerns that residents might not be interested in using the robot, the authors of the reviewed literature also suggested increasing residents' interest in using robots to address their concerns. Robinson et al [77], who used the social robot PARO, proposed changing the robot's color from white to a more appealing color. Louie [90] recommended dressing up the social robot Tangy so that it looked more attractive. In the study by Hebesberger et al [91], using the robot SCITOS to accompany residents doing walking exercises, the researchers suggested giving the robot a name so that residents felt the robot was more personalized and thus more interested in it. In addition, in response to health care providers' comments that SCITOS's voice was too mechanical, they proposed giving the robot a more attractive, more natural voice.

Provide Training and Involve Staff in the Planning and Implementation

The last strategy is to provide training. The authors of the reviewed literature recommended training and support to health care providers. Huisman and Kort [67], who used the humanoid robot NAO, proposed that the training should give health care providers clear instructions on how to use the robot for physical and recreational activities with residents. They added that time needed to be reserved for training. Otherwise, health care providers could not find time to do the training within their busy work schedules. They also recommended setting up a help desk, which health care providers could contact by phone or email when they encountered any challenges using the robot. When health care providers were more familiar with using the robot, they recommended peer learning (ie, encouraging the health care providers to support each other in using the robot). Yuan et al [84], who used the social robot PARO and humanoid robot NAO for interaction and communication with residents, raised the need for an instruction manual in place so that health care providers could refer to it after training.

Comparing Findings With Theoretical Frameworks

Overview

As suggested, we compared our findings with PCPF and CFIR to further our understanding of the findings. The authors of PCPF [40] and CFIR [99] suggested that discussing all constructs in 1 paper is not feasible, so they recommended that the users of their framework select a few most relevant constructs to the research. We selected constructs most relevant to our review through team discussions.

Comparing Findings With PCPF

In our review, one barrier to adopting AI-enabled robots is that health care providers feel that they lack the knowledge and skills to use the robots [70]. One strategy is providing training to health care providers so that they can improve their knowledge and skills [67]. The knowledge and skills needed to use robots to provide care may be part of "professional competence," a construct under the "prerequisite" domain of PCPF. This construct refers to "the knowledge, skills and attitudes of the person to negotiate care options and effectively provide holistic care" [36].

Another barrier mentioned in our review is that health care providers are concerned that robots might replace human functions [75]. One strategy is to let health care providers know that they are better at providing these human functions, such as communication, than robots, as they are humans [75]. The constructs “engaging authentically” and “being sympathetically present” under the “person-centered process” domains of PCPF help us further understand why health care providers are better than robots. “Engaging authentically” refers to “the connectedness between people, determined by knowledge of the person, clarity of beliefs and values, knowledge of self and professional expertise” [22]. Robots cannot engage with residents “authentically” because robots are not authentic humans, despite being equipped with AI. “Being sympathetically present” means “an engagement that recognizes the uniqueness and value of the patient by appropriately responding to cues that maximize coping resources through the recognition of important agendas in the person’s life” [36]. The study by Cavenett et al [85] in our review mentioned that humans are better than robots at responding to nonverbal “cues” of residents, which are a crucial element to show residents “being sympathetically present.”

The “shared decision-making” construct under the “person-centered process” domain of PCPF refers to “engaging persons in decision-making by considering values, experiences, concerns and future aspirations” [36]. This construct made us wonder why health care providers did not mention too much about how the lack of residents’ involvement in decision-making was a barrier to the adoption of robots or suggest involving residents’ voices in the adoption process, especially since many barriers that the health care providers mentioned were related to the residents, such as potential negative impacts of robots to residents [49,73,74], perceived lack of usefulness of robots to residents [67,77,78], and ethical concerns related to residents [70,80,81]. One explanation might be that health care providers thought that they knew the residents well and could represent the voices of residents, so involving residents in decision-making was not a concern from their perspective. Future studies might examine this further. Another construct is “health and social care/policy” under the “macrocontext” domain of PCPF, which refers to “the decisions, plans, and actions that are undertaken to achieve specific health and social care goals within a society” [36]. Health care providers in our review did not mention too much about the influence of health and social policy on their adoption of AI-enabled robots, although there were international and national policies about the use of AI, such as the guidelines by the World Health Organization [100] and Health Canada [101].

Comparing Findings With CFIR

One barrier to adopting the AI-enabled robots mentioned in our review is health care providers’ perceived technical complexity [68]. CFIR has a construct of “innovation complexity” under the “innovation” domain, which resonated with our findings. This construct states that “the innovation is complicated, which may be reflected by its scope and/or the nature and number of connections and steps” [37].

Another barrier is a lack of resources, such as time for health care providers to learn, maintain, and assist residents in using robots [11]; infrastructure such as Wi-Fi and storage place [71]; and maintenance costs [83]. CFIR has the construct “available resources” under the “inner setting” domain [37]. “Available resources” means “resources (that) are available to implement and deliver the innovation” [37]. This construct helps us think that the lack of resources is an organizational-level barrier, as the “inner setting” in our review context means the LTC home (ie, the organization). In other words, the organization needs to be involved in resolving these barriers.

The construct “need” is under the “individuals” domain of CFIR [37]. The “need” construct refers to the following: “the individual(s) has deficits related to survival, well-being, or personal fulfillment, which will be addressed by implementation and/or delivery of the innovation” [37]. Our findings include barriers such as health care providers’ doubted usefulness [79] and ethical concerns [81] about using robots for residents. The “need” construct helps us realize that these barriers are related to health care providers’ concerns about the “needs” of residents. For example, in the study by Bäck et al [79], health care providers doubted the usefulness of the humanoid robot NAO in facilitating exercises because its size was too small for residents with visual impairment to see it, and its voice was too soft for residents with hearing impairment to hear it. It does not meet the visual and hearing “needs” of residents. In the study by Papadopoulos et al [70] on the humanoid robot Pepper, health care providers were worried about residents’ privacy as the robot had a camera on its forehead: they were concerned about the privacy “need” of residents.

In our review, some health care providers hesitated to use robots because they were concerned that doing so would interrupt their existing workflow [71]. One strategy identified was to discuss with health care providers how to integrate the robot into their workflow [85]. The construct “compatibility” under the “inner setting” domain of CFIR helps us to understand that these are “compatibility” concerns [37]. “Compatibility” refers to the following: “the innovation fits with workflows, systems, and processes” [37].

Discussion

Principal Findings

This scoping review addressed two review questions: (1) health care providers’ perceived barriers to using AI-enabled robots in LTC and (2) the strategies to overcome the barriers to the adoption of robots. We identified the barriers to adopting AI-enabled robots in LTC homes, including (1) perceived technical complexity and limitation; (2) negative impact, doubtfulness, and ethical concerns; and (3) resource limitations. We also identified the strategies to overcome these barriers to adopting AI-enabled robots: (1) accommodate various needs of residents and health care providers, (2) increase the understanding of the benefits of using robots, (3) review and overcome the safety issues, and (4) boost interest in the use of robots and provide training.

As suggested in the Introduction section, LTC homes face the challenges of increased resident care needs and a shortage of health care providers [3-5]. Researchers and technology developers expect that AI-enabled robots could address these challenges by sharing the workload of health care providers [6-8]. However, according to the results of our review, health care providers had a different opinion. For example, some suggested that using robots would increase instead of reducing their workload, such as assisting residents in using the robots and cleaning them [11]. Some suggested that using robots would interrupt their existing workflow [71]. An explanation for the gap between researchers or technology developers' expectations and health care providers' opinions might be health care providers' lack of involvement in developing and researching AI-enabled robots. Therefore, health care providers' opinions did not align with researchers' and technology developers' expectations that robots could address the challenges in LTC homes.

In this scoping review, health care providers identified a few ethical concerns about using AI-enabled robots. Frennert and Östlund [102] summarized the main ethical concerns of using robots with older adults from previous literature. Although the literature summarized by Frennert and Östlund [102] did not specifically address AI-enabled robots or LTC contexts, it could still be a good reference for understanding the findings on ethical concerns in our review. Some ethical concerns mentioned in the paper by Frennert and Östlund [102] were found in our review, including concerns about the privacy of residents [70] and health care providers [82]; deception to residents [81]; infantilization of residents (as many robots, especially social robots, look like a toy) [80]; equitable distribution of the use of robots in a group setting [11]; and residents' attachment to the robots and negative emotions triggered when they break down [70]. However, when Frennert and Östlund [102] mentioned the ethical concern of humans' loss of control of the robot, they did not specify the particular aspects of control involved. In our scoping review, for example, in the study by Erebak and Turgut [76], health care providers mentioned specifically the control of decision-making. One possible reason health care providers in our scoping review highlighted the control of decision-making is that among different aspects of control of AI-enabled robots, decision-making is a key feature of AI that is widely discussed in society [103].

In our review, health care providers had different opinions on whether the AI-enabled robots should look real. Some providers suggested that residents preferred real people or pets and doubted that residents would be interested in robots if they were not real enough [77,78]. Corresponding to this feedback, some literature proposed making the robot more real by adding features (eg, a more natural human voice) [91]. However, some health care providers had an ethical concern that residents with cognitive impairment would be deceived that the robots were real [81]. The concern about deception was also previously discussed in the literature on non–AI-enabled robots. For example, in the study by Koh et al [104], health care providers raised their concern that residents misperceived a Joy for All companion cat as a real cat. We considered that the opinion divide would be even more intense as AI-enabled robots develop. Compared with non–AI-enabled robots, AI-enabled robots could be even more "real" due to AI technology. Future research might further explore this topic.

Recommendations

As suggested, a possible explanation for the gap between researchers or technology developers' expectations and health care providers' opinions on using AI-enabled robots is health care providers' lack of involvement in developing and researching AI-enabled robots. Previous literature on using technologies in older adults care highlighted the importance of involving health care providers [105]: working on the frontline, health care providers use technologies according to the context. Their experiences with technologies may differ from what researchers and technology developers expect. Thus, researchers and technology developers need to work with health care providers to understand, for example, their training requirements, how technologies can support their work, and how these technologies can be integrated into their established work routines and workflows. Involving health care providers and understanding their perspectives should increase their acceptability and sense of ownership and reduce their concerns about using technologies.

We propose that administrators be involved in addition to health care providers. Some barriers to using AI-enabled robots found in this scoping review could not be resolved without administrators' involvement. For example, health care providers said that they did not have time for training [72], and the administrators are responsible for reserving time for them for training. Some health care providers are worried about the safety risks of using robots [49,73]. Administrators need to implement protocols for assessing and managing the risks.

We propose that residents be involved in addition to health care providers and administrators. When we compared our findings with PCPF, it was interesting that the health care providers in our review did not mention much about residents' involvement, although they provided person-centered care. Residents are the users of the robots, and they can give feedback on using them.

All stakeholders, researchers, technology developers, health care providers, administrators, and residents need to get involved in developing and implementing AI-enabled robots. Each stakeholder has strengths to contribute: health care providers know the potential day-to-day challenges of using robots as they work on the front line, while administrators know the policies and regulations of LTC, so they can advise on how to ensure that the use of robots aligns with these policies and regulations. Technology developers have technical knowledge about robots, and residents provide feedback as users of the robots. This scoping review explored the barriers and the strategies to overcome the barriers to the use of robots from the perspectives of health care providers. Future scoping reviewers may consider conducting scoping reviews on other stakeholders' perspectives.

Limitations of the Review

This scoping review included only English-language studies because of the limited language capacity of our team. However, in many parts of the world, there is rapid development in the use of AI-enabled robots in LTC homes. Relevant studies published in languages other than English may have been omitted. Future scoping reviews should consider how to search for and include items in languages other than English, such as including team members with language capacity other than English or using translation tools. Furthermore, a quality assessment of the included studies was not conducted. However, the scoping review methodology mainly focuses on identifying the breadth of existing research rather than evaluating the quality of evidence [106]. Finally, the review only examined the point of view of health care providers, not residents. Future researchers may consider conducting a scoping review on the same topic but from residents' perspectives.

Conclusions

This scoping review examined the barriers to using AI-enabled robots in LTC homes from health care providers' perspectives and identified the strategies to overcome these barriers to the adoption of such robots. We anchored our analysis in established theories, specifically the PCPF and the CFIR, to guide our further understanding of the findings. By addressing the barriers and identifying the strategies to overcome them, we hope to foster the effective deployment of AI-enabled robots in LTC homes.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data extraction table.
[DOCX File , 44 KB - aging_v7i1e55257_app1.docx]

Multimedia Appendix 2
Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.
[PDF File (Adobe PDF File), 100 KB - aging_v7i1e55257_app2.pdf]

References

1. Wang G, Albayrak A, Mattace-Raso F, van der Cammen TJ. Technologies in long-term care and nursing homes. In: Pilotto A, Maetzler W, editors. Gerontechnology: A Clinical Perspective. Cham, Switzerland: Springer; 2023:45-59.
2. Boamah SA, Weldrick R, Havaei F, Irshad A, Hutchinson A. Experiences of healthcare workers in long-term care during COVID-19: a scoping review. J Appl Gerontol 2023 May;42(5):1118-1136 [FREE Full text] [doi: 10.1177/07334648221146252] [Medline: 36541274]
3. Costello H, Walsh S, Cooper C, Livingston G. A systematic review and meta-analysis of the prevalence and associations of stress and burnout among staff in long-term care facilities for people with dementia. Int Psychogeriatr 2019 Aug 13;31(8):1203-1216. [doi: 10.1017/S1041610218001606] [Medline: 30421691]
4. Schaefer JA, Moos RH. Effects of work stressors and work climate on long-term care staff's job morale and functioning. Res Nurs Health 1996 Feb;19(1):63-73. [doi: 10.1002/(SICI)1098-240X(199602)19:1<63::AID-NUR7>3.0.CO;2-J] [Medline: 8552804]
5. Dhaini SR, Zúñiga F, Ausserhofer D, Simon M, Kunz R, De Geest S, et al. Care workers health in Swiss nursing homes and its association with psychosocial work environment: a cross-sectional study. Int J Nurs Stud 2016 Jan;53(12):105-115 [FREE Full text] [doi: 10.1016/j.ijnurstu.2015.08.011] [Medline: 26363704]
6. Osterland A. Aging baby boomers raise the risk of a long-term-care crisis in the U.S. CNBC. URL: https://www.cnbc.com/2021/11/08/aging-baby-boomers-raise-the-risk-of-a-long-term-care-crisis-in-the-us.html [accessed 2023-08-12]
7. Spetz J, Trupin L, Bates T, Coffman JM. Future demand for long-term care workers will be influenced by demographic and utilization changes. Health Aff (Millwood) 2015 Jun;34(6):936-945. [doi: 10.1377/hlthaff.2015.0005] [Medline: 26056198]
8. Tan SY, Taeihagh A. Smart city governance in developing countries: a systematic literature review. Sustainability 2020 Jan 25;12(3):899. [doi: 10.3390/su12030899]
9. Kelly PA, Cox LA, Petersen SF, Gilder RE, Blann A, Autrey AE, et al. The effect of PARO robotic seals for hospitalized patients with dementia: a feasibility study. Geriatr Nurs 2021 Jan;42(1):37-45. [doi: 10.1016/j.gerinurse.2020.11.003] [Medline: 33221556]
10. Camilleri A, Dogramadzi S, Caleb-Solly P. Learning from carers to inform the design of safe physically assistive robots - insights from a focus group study. In: Proceedings of the 2022 17th ACM/IEEE International Conference on Human-Robot Interaction. 2022 Presented at: HRI '22; March 7-10, 2022; Sapporo, Japan p. 703-707 URL: https://ieeexplore.ieee.org/document/9889658 [doi: 10.1109/HRI53351.2022.9889658]
11. Hung L, Mann J, Perry J, Berndt A, Wong J. Technological risks and ethical implications of using robots in long-term care. J Rehabil Assist Technol Eng 2022;9:20556683221106917 [FREE Full text] [doi: 10.1177/20556683221106917] [Medline: 35733613]
12. Krägeloh CU, Bharatharaj J, Sasthan Kutty SK, Nirmala PR, Huang L. Questionnaires to measure acceptability of social robots: a critical review. Robotics 2019 Oct 21;8(4):88. [doi: 10.3390/robotics8040088]

13. Heerink M, Kröse B, Evers V, Wielinga B. Assessing acceptance of assistive social agent technology by older adults: the Almere model. Int J of Soc Robotics 2010 Sep 4;2(4):361-375. [doi: 10.1007/S12369-010-0068-5]
14. Stafford RQ, MacDonald BA, Jayawardena C, Wegner DM, Broadbent E. Does the robot have a mind? Mind perception and attitudes towards robots predict use of an eldercare robot. Int J of Soc Robotics 2013 Apr 23;6(1):17-32. [doi: 10.1007/S12369-013-0186-Y]
15. Takayanagi K, Kirita T, Shibata T. Comparison of verbal and emotional responses of elderly people with mild/moderate dementia and those with severe dementia in responses to seal robot, PARO. Front Aging Neurosci 2014;6:257 [FREE Full text] [doi: 10.3389/fnagi.2014.00257] [Medline: 25309434]
16. Smarr CA, Mitzner TL, Beer JM, Prakash A, Chen TL, Kemp CC, et al. Domestic robots for older adults: attitudes, preferences, and potential. Int J Soc Robot 2014 Apr 01;6(2):229-247 [FREE Full text] [doi: 10.1007/s12369-013-0220-0] [Medline: 25152779]
17. Smarr CA, Prakash A, Beer JM, Mitzner TL, Kemp CC, Rogers WA. Older adults' preferences for and acceptance of robot assistance for everyday living tasks. Proc Hum Factors Ergon Soc Annu Meet 2012 Sep 20;56(1):153-157 [FREE Full text] [doi: 10.1177/1071181312561009] [Medline: 25284971]
18. Körtner T, Schmid A, Batko-Klein D, Gisinger C, Huber A, Lammer L, et al. How social robots make older users really feel well – a method to assess users' concepts of a social robotic assistant. In: Proceedings of the 4th International Conference on Social Robotics. 2012 Presented at: ICSR '12; October 29-31, 2012; Chengdu, China p. 138-147 URL: https://link.springer.com/chapter/10.1007/978-3-642-34103-8_14 [doi: 10.1007/978-3-642-34103-8_14]
19. Louie WY, McColl D, Nejat G. Acceptance and attitudes toward a human-like socially assistive robot by older adults. Assist Technol 2014 Jun 26;26(3):140-150. [doi: 10.1080/10400435.2013.869703] [Medline: 26131794]
20. Wu YH, Cristancho-Lacroix V, Fassert C, Faucounau V, de Rotrou J, Rigaud AS. The attitudes and perceptions of older adults with mild cognitive impairment toward an assistive robot. J Appl Gerontol 2016 Jan 09;35(1):3-17. [doi: 10.1177/0733464813515092] [Medline: 24652924]
21. Sierra Marín SD, Gomez-Vargas D, Céspedes N, Múnera M, Roberti F, Barria P, et al. Expectations and perceptions of healthcare professionals for robot deployment in hospital environments during the COVID-19 pandemic. Front Robot AI 2021;8:612746 [FREE Full text] [doi: 10.3389/frobt.2021.612746] [Medline: 34150856]
22. Alaiad A, Zhou L. The determinants of home healthcare robots adoption: an empirical investigation. Int J Med Inform 2014 Nov;83(11):825-840. [doi: 10.1016/j.ijmedinf.2014.07.003] [Medline: 25132284]
23. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. J Med Internet Res 2017 Nov 01;19(11):e367 [FREE Full text] [doi: 10.2196/jmir.8775] [Medline: 29092808]
24. Servaty R, Kersten A, Brukamp K, Möhler R, Mueller M. Implementation of robotic devices in nursing care. Barriers and facilitators: an integrative review. BMJ Open 2020 Sep 21;10(9):e038650 [FREE Full text] [doi: 10.1136/bmjopen-2020-038650] [Medline: 32958491]
25. Broadbent E, Stafford R, MacDonald B. Acceptance of healthcare robots for the older population: review and future directions. Int J of Soc Robotics 2009 Oct 3;1(4):319-330. [doi: 10.1007/S12369-009-0030-6]
26. Abbasgholizadeh Rahimi S, Cwintal M, Huang Y, Ghadiri P, Grad R, Poenaru D, et al. Application of artificial intelligence in shared decision making: scoping review. JMIR Med Inform 2022 Aug 09;10(8):e36199 [FREE Full text] [doi: 10.2196/36199] [Medline: 35943793]
27. Ahmed A, Aziz S, Abd-Alrazaq A, Farooq F, Sheikh J. Overview of artificial intelligence-driven wearable devices for diabetes: scoping review. J Med Internet Res 2022 Aug 09;24(8):e36010 [FREE Full text] [doi: 10.2196/36010] [Medline: 35943772]
28. Maaß L, Pan CC, Freye M. Mapping digital public health interventions among existing digital technologies and internet-based interventions to maintain and improve population health in practice: protocol for a scoping review. JMIR Res Protoc 2022 Mar 31;11(3):e33404 [FREE Full text] [doi: 10.2196/33404] [Medline: 35357321]
29. Lapp L, Egan K, McCann L, Mackenzie M, Wales A, Maguire R. Decision support tools in adult long-term care facilities: scoping review. J Med Internet Res 2022 Sep 06;24(9):e39681 [FREE Full text] [doi: 10.2196/39681] [Medline: 36066928]
30. McArthur C, Gibbs JC, Patel R, Papaioannou A, Neves P, Killingbeck J, et al. A scoping review of physical rehabilitation in long-term care: interventions, outcomes, tools. Can J Aging 2017 Dec 13;36(4):435-452. [doi: 10.1017/S071498081700040X] [Medline: 29130428]
31. Gillam J, Davies N, Aworinde J, Yorganci E, Anderson JE, Evans C. Implementation of eHealth to support assessment and decision-making for residents with dementia in long-term care: systematic review. J Med Internet Res 2022 Feb 03;24(2):e29837 [FREE Full text] [doi: 10.2196/29837] [Medline: 35113029]
32. Zhao Y, Rokhani FZ, Sazlina SG, Devaraj NK, Su J, Chew BH. Defining the concepts of a smart nursing home and its potential technology utilities that integrate medical services and are acceptable to stakeholders: a scoping review. BMC Geriatr 2022 Oct 07;22(1):787 [FREE Full text] [doi: 10.1186/s12877-022-03424-6] [Medline: 36207705]
33. Lukkien DR, Nap HH, Buimer HP, Peine A, Boon WP, Ket JC, et al. Toward responsible artificial intelligence in long-term care: a scoping review on practical approaches. Gerontologist 2023 Jan 24;63(1):155-168 [FREE Full text] [doi: 10.1093/geront/gnab180] [Medline: 34871399]

34. Hung L, Wong KL, Wong J, Park J, Mousavi H, Zhao H. Facilitators and barriers to using AI-enabled robots with older adults in long-term care from staff perspective: a scoping review protocol. BMJ Open 2023 Oct 30;13(10):e075278 [FREE Full text] [doi: 10.1136/bmjopen-2023-075278] [Medline: 37903609]
35. Murphy R. Introduction To AI Robotics. 2nd edition. Cambridge, MA: MIT Press; 2019.
36. McCance T, McCormack B. Developing healthful cultures through the development of person-centred practice. Int J Orthop Trauma Nurs 2023 Nov;51:101055. [doi: 10.1016/j.ijotn.2023.101055] [Medline: 37857103]
37. Updated CFIR constructs. Consolidated framework for implementation research (CFIR). 2023. URL: https://cfirguide.org/constructs/ [accessed 2023-05-31]
38. McCormack B, McCance T. Person ‐ Centred Nursing: Theory and Practice. Hoboken, NJ: John Wiley & Sons; 2017.
39. Morris JH, Kayes N, McCormack B. Editorial: person-centred rehabilitation - theory, practice, and research. Front Rehabil Sci 2022 Jul 20;3:980314 [FREE Full text] [doi: 10.3389/fresc.2022.980314] [Medline: 36189058]
40. McCormack B, McCance T. The person-centred nursing framework. In: Dewing J, McCormack B, McCance T, editors. Person-centred Nursing Research: Methodology, Methods and Outcomes. Cham, Switzerland: Springer; 2021:13-27.
41. Wong KL. The value of knowledge and persons living with dementia: a healthcare professional’s reflection. Int Pract Develop J 2022 Nov 23;12(2):1-6. [doi: 10.19043/ipdj.122.011]
42. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009 Aug 07;4:50 [FREE Full text] [doi: 10.1186/1748-5908-4-50] [Medline: 19664226]
43. Damschroder LJ, Reardon CM, Widerquist MA, Lowery J. The updated consolidated framework for implementation research based on user feedback. Implement Sci 2022 Oct 29;17(1):75 [FREE Full text] [doi: 10.1186/s13012-022-01245-0] [Medline: 36309746]
44. Damschroder LJ, Reardon CM, Opra Widerquist MA, Lowery J. Conceptualizing outcomes for use with the Consolidated Framework for Implementation Research (CFIR): the CFIR outcomes addendum. Implement Sci 2022 Jan 22;17(1):7 [FREE Full text] [doi: 10.1186/s13012-021-01181-5] [Medline: 35065675]
45. Home page. Consolidated Framework for Implementation. 2023. URL: https://cfirguide.org/ [accessed 2023-12-01]
46. Armstrong R, Hall BJ, Doyle J, Waters E. Cochrane Update. 'Scoping the scope' of a cochrane review. J Public Health (Oxf) 2011 Mar;33(1):147-150. [doi: 10.1093/pubmed/fdr015] [Medline: 21345890]
47. Peters MD, Godfrey-Smith P, Mcinerney P, Munn Z, Tricco AC, Khalil H. Scoping reviews. In: Aromataris E, Lockwood C, Porritt C, Pilla B, Jordan Z, editors. JBI Manual for Evidence Synthesis. Adelaide, South Australia: Joanna Briggs Institute; 2024.
48. Design of embodied social robot v2.0 'Stevie'. Department of Mechanical, Manufacturing & Biomedical Engineering, Trinity College Dublin. 2021. URL: https://www.tcd.ie/mecheng/research/robotics/projects/stevie.php [accessed 2024-05-29]
49. McGinn C, Bourke E, Murtagh A, Donovan C, Cullinan MF. Meeting Stevie: perceptions of a socially assistive robot by residents and staff in a long-term care facility. In: Proceedings of the 2019 14th ACM/IEEE International Conference on Human-Robot Interaction. 2019 Presented at: HRI '19; March 11-14, 2019; Daegu, South Korea p. 602-603 URL: https://ieeexplore.ieee.org/document/8673161 [doi: 10.1109/hri.2019.8673161]
50. PARO therapeutic robot. PARO. 2024. URL: http://www.parorobots.com/ [accessed 2024-05-20]
51. NAO: the educational robot. United Robotics Group. 2024. URL: https://unitedrobotics.group/en/robots/nao [accessed 2024-05-20]
52. Pepper the humanoid and programmable robot. Aldebaran. 2022. URL: https://www.aldebaran.com/en/pepper [accessed 2024-05-20]
53. Interaktiver roboter SCITOS A5. MetraLabs. URL: https://www.metralabs.com/de/scitos-a5/ [accessed 2024-05-20]
54. Thompson C, Mohamed S, Louie WY, He JC, Li J, Nejat G. The robot tangy facilitating trivia games: a team-based user-study with long-term care residents. In: Proceedings of the 2017 IEEE Conference on International Symposium on Robotics and Intelligent Sensors. 2017 Presented at: IRIS '17; October 5-8, 2017; Ottawa, ON p. 173-178 URL: https://ieeexplore.ieee.org/document/8250117 [doi: 10.1109/iris.2017.8250117]
55. 1-MARIO services robots. MARIO consortium. 2016. URL: http://www.mario-project.eu/PORTAL/images/deliverables/D2.1-MARIO-Services-Robots.pdf [accessed 2024-04-29]
56. KOMPAI-assist. Kompai Robotics. URL: https://www.kompairobotics.com/kompai-assist [accessed 2024-05-20]
57. Roomba robot vacuum cleaners. iRobot. 2023. URL: https://www.irobot.com/en_US/us-roomba.html [accessed 2024-05-20]
58. TUG robot. Mercy. 2024. URL: https://www.mercy.net/about/mercy-technology-services/tug-robot [accessed 2024-05-20]
59. PaPeRo - razor robotics. Razor Robotics. 2020. URL: https://www.razorrobotics.com/robots/papero/ [accessed 2024-05-20]
60. Temi - AI in motion. Robotemi. 2023. URL: https://www.robotemi.com/product/temi/ [accessed 2024-05-20]
61. Meet grace, the healthcare robot COVID-19 created. Reuters. 2021. URL: https://www.reuters.com/business/healthcare-pharmaceuticals/meet-grace-healthcare-robot-covid-19-created-2021-06-09/ [accessed 2024-05-20]
62. PR2. ROBOTS. 2024. URL: https://robotsguide.com/robots/pr2 [accessed 2024-05-20]
63. Sota – smart robot “presenter” from Japan. Personal Robots. URL: https://www.personalrobots.biz/sota-smart-robot-presenter-from-japan/ [accessed 2024-05-20]

64. Shin J, Rusakov A, Meyer B. SmartWalker: an intelligent robotic walker. J Ambient Intell Smart Environ 2016 Jul 21;8(4):383-398. [doi: 10.3233/ais-160383]
65. Lemburg J, de Gea Fernández J, Eich M, Mronga D, Kampmann P, Vogt A, et al. AILA - design of an autonomous mobile dual-arm robot. In: Proceedings of the 2011 IEEE International Conference on Robotics and Automation. 2011 Presented at: ICRA '11; May 9-11, 2011; Shanghai, Chaina p. 5147-5153 URL: https://ieeexplore.ieee.org/document/5979775 [doi: 10.1109/icra.2011.5979775]
66. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ 2009 Jul 21;339:b2535 [FREE Full text] [doi: 10.1136/bmj.b2535] [Medline: 19622551]
67. Huisman C, Kort H. Two-year use of care robot Zora in Dutch nursing homes: an evaluation study. Healthcare (Basel) 2019 Feb 19;7(1):31 [FREE Full text] [doi: 10.3390/healthcare7010031] [Medline: 30791489]
68. Hebesberger D, Koertner T, Gisinger C, Pripfl J. A long-term autonomous robot at a care hospital: a mixed methods study on social acceptance and experiences of staff and older adults. Int J of Soc Robotics 2017 Jan 31;9(3):417-429. [doi: 10.1007/S12369-016-0391-6]
69. Pfadenhauer M, Dukat C. Robot caregiver or robot-supported caregiving? Int J of Soc Robotics 2015 Jan 30;7(3):393-406. [doi: 10.1007/S12369-015-0284-0]
70. Papadopoulos I, Ali S, Papadopoulos C, Castro N, Faulkes N, Koulouglioti C. A qualitative exploration of care homes workers' views and training needs in relation to the use of socially assistive humanoid robots in their workplace. Int J Older People Nurs 2022 May 22;17(3):e12432. [doi: 10.1111/opn.12432] [Medline: 34679219]
71. Melkas H, Hennala L, Pekkarinen S, Kyrki V. Impacts of robot implementation on care personnel and clients in elderly-care institutions. Int J Med Inform 2020 Feb;134:104041 [FREE Full text] [doi: 10.1016/j.ijmedinf.2019.104041] [Medline: 31838291]
72. Li Y, Liang N, Effati M, Nejat G. Dances with social robots: a pilot study at long-term care. Robotics 2022 Sep 13;11(5):96. [doi: 10.3390/robotics11050096]
73. Chang WL, Šabanović S. Potential use of robots in Taiwanese nursing homes. In: Proceedings of the 2013 8th ACM/IEEE International Conference on Human-Robot Interaction. 2013 Presented at: HRI '13; March 3-6, 2013; Tokyo, Japan p. 99-100 URL: https://ieeexplore.ieee.org/document/6483520 [doi: 10.1109/hri.2013.6483520]
74. Obayashi K, Kodate N, Masuyama S. Can connected technologies improve sleep quality and safety of older adults and care-givers? An evaluation study of sleep monitors and communicative robots at a residential care home in Japan. Technol Soc 2020 Aug;62:101318. [doi: 10.1016/j.techsoc.2020.101318]
75. Mitzner TL, Tiberio L, Kemp CC, Rogers WA. Understanding healthcare providers' perceptions of a personal assistant robot. Gerontechnology 2018 Mar 26;17(1):48-55 [FREE Full text] [doi: 10.4017/gt.2018.17.1.005.00] [Medline: 31178672]
76. Erebak S, Turgut T. Caregivers’ attitudes toward potential robot coworkers in elder care. Cogn Tech Work 2018 Jul 24;21(2):327-336. [doi: 10.1007/s10111-018-0512-0]
77. Robinson H, Broadbent E, MacDonald B. Group sessions with Paro in a nursing home: structure, observations and interviews. Australas J Ageing 2016 Jun 09;35(2):106-112. [doi: 10.1111/ajag.12199] [Medline: 26059390]
78. Louie WY, Li J, Vaquero T, Nejat G. A focus group study on the design considerations and impressions of a socially assistive robot for long-term care. In: Proceedings of the 23rd IEEE International Symposium on Robot and Human Interactive Communication. 2014 Presented at: ROMAN '14; August 25-19, 2014; Edinburgh, UK p. 237-242 URL: https://ieeexplore.ieee.org/document/6926259 [doi: 10.1109/ROMAN.2014.6926259]
79. Bäck I, Makela K, Kallio J. Robot-guided exercise program for the rehabilitation of older nursing home residents. Ann Longterm Care 2013;21(6):38 [FREE Full text]
80. Moyle W, Bramble M, Jones C, Murfield J. Care staff perceptions of a social robot called Paro and a look-alike Plush Toy: a descriptive qualitative approach. Aging Ment Health 2018 Mar 14;22(3):330-335. [doi: 10.1080/13607863.2016.1262820] [Medline: 27967207]
81. Lehmann S, Ruf E, Misoch S. Using a socially assistive robot in a nursing home: caregivers’ expectations and concerns. In: Proceedings of the 23rd HCI International Conference. 2021 Presented at: HCII '21; July 24–29, 2021; Virtual Event p. 2021 URL: https://link.springer.com/chapter/10.1007/978-3-030-78642-7_20 [doi: 10.1007/978-3-030-78642-7_20]
82. Christoforou EG, Avgousti S, Ramdani N, Novales C, Panayides AS. The upcoming role for nursing and assistive robotics: opportunities and challenges ahead. Front Digit Health 2020;2:585656 [FREE Full text] [doi: 10.3389/fdgth.2020.585656] [Medline: 34713058]
83. Casey D, Barrett E, Kovacic T, Sancarlo D, Ricciardi F, Murphy K, et al. The perceptions of people with dementia and key stakeholders regarding the use and impact of the social robot MARIO. Int J Environ Res Public Health 2020 Nov 20;17(22):8621 [FREE Full text] [doi: 10.3390/ijerph17228621] [Medline: 33233605]
84. Yuan S, Coghlan S, Lederman R, Waycott J. Social robots in aged care: care staff experiences and perspectives on robot benefits and challenges. Proc ACM Hum Comput Interact 2022 Nov 11;6(CSCW2):1-23. [doi: 10.1145/3555220]
85. Cavenett W, Baker S, Waycott J, Carrasco R, Robertson E, Vetere F, et al. Deploying new technology in residential aged care: staff members' perspectives. In: Proceedings of the 30th Australian Conference on Computer-Human Interaction.

2018 Presented at: OzCHI '18; December 4-7, 2018; Melbourne, Australia p. 200-204 URL: https://dl.acm.org/doi/10.1145/3292147.3292214 [doi: 10.1145/3292147.3292214]

86. Kolstad M, Yamaguchi N, Babic A, Nishihara Y. Integrating socially assistive robots into Japanese nursing care. Stud Health Technol Inform 2020 Jun 26;272:183-186 [FREE Full text] [doi: 10.3233/SHTI200524] [Medline: 32604631]
87. Follmann A, Schollemann F, Arnolds A, Weismann P, Laurentius T, Rossaint R, et al. Reducing loneliness in stationary geriatric care with robots and virtual encounters-a contribution to the COVID-19 pandemic. Int J Environ Res Public Health 2021 May 01;18(9):4846 [FREE Full text] [doi: 10.3390/ijerph18094846] [Medline: 34062776]
88. Shin J, Itten D, Rusakov A, Meyer B. SmartWalker: towards an intelligent robotic walker for the elderly. In: Proceedings of the 2015 International Conference on Intelligent Environments. 2015 Presented at: IE '15; July 15-17, 2015; Prague, Czech Republic p. 9-16 URL: https://ieeexplore.ieee.org/document/7194265 [doi: 10.1109/ie.2015.10]
89. Chang WL, Šabanović S. Interaction expands function: social shaping of the therapeutic robot PARO in a nursing home. In: Proceedings of the 2015 10th ACM/IEEE International Conference on Human-Robot Interaction. 2015 Presented at: HRI '15; March 2-5, 2015; Portland, OR p. 343-350 URL: https://ieeexplore.ieee.org/document/8520628 [doi: 10.1145/2696454.2696472]
90. Louie WY. A learning based robot interaction system for multi-user activities [thesis]. University of Toronto. 2017. URL: https://www.proquest.com/dissertations-theses/learning-based-robot-interaction-system-multi/docview/1995372926/se-2?accountid=14656 [accessed 2024-04-28]
91. Hebesberger D, Koertner T, Gisinger C, Pripfl J, Dondrup C. Lessons learned from the deployment of a long-term autonomous robot as companion in physical therapy for older adults with dementia a mixed methods study. In: Proceedings of the 2016 11th ACM/IEEE International Conference on Human-Robot Interaction. 2016 Presented at: HRI '16; March 7-10, 2016; Christchurch, New Zealand p. 27-34 URL: https://ieeexplore.ieee.org/document/7451730 [doi: 10.1109/hri.2016.7451730]
92. Chen N, Song J, Li B. Providing aging adults social robots' companionship in home-based elder care. J Healthc Eng 2019;2019:2726837 [FREE Full text] [doi: 10.1155/2019/2726837] [Medline: 31281615]
93. Doi T, Kuwahara N, Morimoto K, Tsutsumimoto K, Lee S, Hotta R, et al. Questionnaire survey result of the use of communication robots for recreational activities at nursing homes. In: Proceedings of the AHFE 2016 International Conference on Affective and Pleasurable Design. 2013 11 Presented at: AHFE '13; July 27-31, 2016; Orlando, FL p. 3-13 URL: https://link.springer.com/chapter/10.1007/978-3-319-41661-8_1 [doi: 10.3390/ijerph120303002]
94. Jonas SJ. Meet Grace, the humanoid robot offering companionship in a Montreal nursing home. CBC. URL: https://www.cbc.ca/news/canada/montreal/grace-humanoid-robot-montreal-seniors-study-1.6623292 [accessed 2023-10-20]
95. Kriegel J, Grabner V, Tuttle-Weidinger L, Ehrenmüller I. Socially assistive robots (SAR) in in-patient care for the elderly. Stud Health Technol Inform 2019;260:178-185. [Medline: 31118335]
96. Pedell S, Constantin K, Muñoz D, Sterling L. Designing meaningful, beneficial and positive human robot interactions with older adults for increased wellbeing during care activities. In: Lim CP, Chen YW, Vaidya A, Mahorkar C, Jain LC, editors. Handbook of Artificial Intelligence in Healthcare. Vol 2: Practicalities and Prospects. Cham, Switzerland: Springer; 2022:85-108.
97. Tanioka R, Sugimoto H, Yasuhara Y, Ito H, Osaka K, Zhao Y, et al. Characteristics of transactive relationship phenomena among older adults, care workers as intermediaries, and the pepper robot with care prevention gymnastics exercises. J Med Invest 2019;66(1.2):46-49 [FREE Full text] [doi: 10.2152/jmi.66.46] [Medline: 31064953]
98. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. In: Liamputtong P, editor. Handbook of Research Methods in Health Social Sciences. Singapore, Singapore: Springer; 2019:843-860.
99. Damschroder LJ, Reardon CM, Lowery JC. Consolidated framework for implementation research (CFIR). In: Ho EY, Bylund CL, Van Weert JC, editors. The International Encyclopedia of Health Communication. New York, NY: Wiley-Blackwell; 2022:1-9.
100. Ethics and governance of artificial intelligence for health. World Health Organization. 2021. URL: https://iris.who.int/bitstream/handle/10665/341996/9789240029200-eng.pdf?sequence=1 [accessed 2024-04-29]
101. Good machine learning practice for medical device development: guiding principles. Health Canada. 2021. URL: https://www.canada.ca/content/dam/hc-sc/documents/services/drugs-health-products/medical-devices/good-machine-learning-practice-medical-device-development/good-machine-learning-practice-medical-device-development-eng.pdf [accessed 2024-04-29]
102. Frennert S, Östlund B. Review: seven matters of concern of social robots and older people. Int J of Soc Robotics 2014 Jan 29;6(2):299-310. [doi: 10.1007/s12369-013-0225-8]
103. Ahmad SF, Han H, Alam MM, Rehmat MK, Irshad M, Arraño-Muñoz M, et al. Correction: impact of artificial intelligence on human loss in decision making, laziness and safety in education. Humanit Soc Sci Commun 2023 Jun 29;10(1):1-14. [doi: 10.1057/S41599-023-01842-4]
104. Koh WQ, Ang FX, Casey D. Impacts of low-cost robotic pets for older adults and people with dementia: scoping review. JMIR Rehabil Assist Technol 2021 Feb 12;8(1):e25340 [FREE Full text] [doi: 10.2196/25340] [Medline: 33497349]
105. Schwennesen N, Peine A, Marshall B, Martin W, Neven L. Between repair and bricolage: digital entanglements and fragile connections in dementia care work in Denmark. In: Schwennesen N, editor. Socio-gerontechnology. New York, NY: Taylor & Francis Group; 2021.

106. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005 Feb;8(1):19-32. [doi: 10.1080/1364557032000119616]

Abbreviations

AI: artificial intelligence
AILA: Artificial Intelligence Lightweight Android
CFIR: Consolidated Framework for Implementation Research
LTC: long-term care
PCPF: Person-Centered Practice Framework
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Review

Nursing Staff’s Perspectives of Care Robots for Assisted Living Facilities: Systematic Literature Review

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Abstract

Background: Care robots have been proposed in response to nursing shortages in assisted living facilities (ALFs) and the growing population of older adults. While the use of care robots may improve the general health and well-being of older adults, their introduction changes the work of nursing staff fundamentally, and it has implications for the entire health care system. In developing such technology, it is important to include end users, but so far, the nursing staff’s perspectives have largely been ignored.

Objective: This study aims to examine the literature on nursing staff’s attitudes, needs, and preferences related to the use of care robots in ALFs, in order to discover gaps in the literature and guide future research.

Methods: This review follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 protocol. On May 12, 2023, we searched PubMed, CINAHL Plus with Full Text, PsycINFO, the IEEE Xplore Digital Library, and the ACM Digital Library using predetermined search terms. Included publications, written in English, focused on the predevelopment phase, in which information was gathered on nursing staff’s attitudes, needs, and preferences regarding care robots for ALFs. Publications were excluded if they did not provide peer-reviewed empirical data. The studies’ findings were summarized, coded, and analyzed into major themes using thematic analysis and narrative synthesis. Their quality was assessed using McGill University’s Mixed Methods Appraisal Tool and the Joanna Briggs Institute’s critical appraisal tools.

Results: The final sample included 15 studies. Most of the studies (n=11, 73%) were rated as good quality; however, there was a general lack of reporting on important methodological decisions and sample characteristics. Nursing staff desired care robots that could assist with physically demanding tasks and reduce their workload but had mixed feelings on whether robots could or should assist with social tasks. In addition, nursing staff are concerned about the ethics of care robots, as well as about their safety, accessibility, and operability. The nursing staff’s culture, qualification, and role in the facility may influence their perspectives of care robots. The studies lacked theory-driven designs and large sample sizes. Eight (53%) studies mentioned using a participatory design approach, but a lack of established criteria for what constitutes participatory design leads to varying degrees of methodological quality.

Conclusions: There was consensus among nursing staff that care robots should serve as nursing assistants to reduce workload. Whether robots could or should assist with social tasks remains a question. Further research is needed to mitigate nursing staff’s concerns and understand the socioecological factors that influence their perspectives of care robots and their adoption in ALFs. In addition, theory-driven and large sample size study designs are necessary, as well as work to develop clear criteria for related participatory design research.

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KEYWORDS

robots; nursing staff; nursing home; senior living; systematic review; aging; older adults; gerontology; participatory design; user needs; nurses; nursing; retirement; long-term care; geriatrics; elderly; older people; syntheses; review methods; review methodology; searches; searching; systematic; experiences; attitudes; opinions; perceptions; perspectives; preferences; needs; preference

Introduction

Across the world, the population of older adults is growing at an unprecedented rate. It is estimated that the US population of older adults—those aged 65 years and older—will grow from 49 million in 2016 to 95 million in 2060 [1]. This trend in aging will be associated with increased care demands: 70% of older adults will eventually require some form of long-term care, including residential care facilities [2]. Older adults who reside in these facilities rely on nursing staff as their primary caregivers. Depending on the level of care the facility provides, the nursing staff can include advanced practice registered nurses, registered nurses, licensed vocational or practical nurses, certified nursing aids or assistants, patient care technicians or assistants, and unlicensed paid caregivers.

At the same time as care demands rise, assisted living facilities (ALFs), or residential settings that provide long-term care to older adults, face a severe nurse staffing shortage. It is estimated that the number of professional care workers will need to increase by 60% globally (or 13.5 million new care workers) by 2040 just to maintain the current ratio of caregivers to older adults [3]. The COVID-19 pandemic exacerbated this staffing crisis, and the US Bureau of Labor Statistics estimates that an additional 245,600 employees are needed just to return ALFs to prepandemic levels [4]. Nurse burnout has contributed to this shortage and also resulted from it; burnout is associated with increased turnover, high workload, and inadequate staffing [5,6]. In fact, some argue that the staffing crisis is not due to a shortage of available nurses, but to a shortage of nurses willing to work under unsafe conditions [7]. The nurse burnout thus has far-reaching implications for the health of nurses, patients, and health care systems. Burnout is significantly related to poor nurse health; poor quality of care and adverse events for patients; and increased nurse turnover, costing hospital systems US $16,736 per nurse per year employed [6,8,9]. ALFs show higher rates of nurse burnout and turnover than do all other health care settings [4,5].

Care robots, which include both social and assistive robots, show promise for addressing the mismatch between the aging population and the shortage of professional caregivers in ALFs. Interest in care robotics is growing, with a 585% increase in publications on health care robots from 2011 to 2021 [10]. Social robots, which include companion robots, perform work tasks based on "interactional performances" between humans (eg, caregivers and patients) or with pets [11]. Assistive robots (also referred to as mobility or service robots) perform physical work tasks such as lifting patients, helping with activities of daily living, or assisting at mealtimes [11]. Some evidence suggests that care robots may improve the general well-being of older adults [12-14]. In a scoping review of 69 studies, the most commonly reported therapeutic benefits consisted of improved mood and emotional states and increased social interaction [13].

Despite the positive effects for older adults and the frequently stated objective of addressing the nursing shortage, very few studies have managed to reduce workload [15]. Furthermore, the perspectives of nursing staff on the use of care robots have been largely ignored. In the previously mentioned review of 69 studies, only 15 included nursing staff as participants [13]. In those 15 studies, the robots relieved nurses of certain tasks (eg, responding to call lights [16]), but they often required the assistance of staff for operation (27/69, 39%) and thereby increased workload [13,17,18]. A scoping review on the effects of care robots on professional caregivers supports these findings: the introduction of care robots had both positive and negative effects, reducing physical and mental demands in some scenarios and increasing workload in others [11]. These examples highlight the fact that although care robots have the potential to improve the health of older adults, such benefits are in part due to skilled use by nursing staff [19]. Further, the implications of introducing care robots into ALFs extend beyond the recipient of care (ie, older adults) to the entire health care system. Care robots will fundamentally change the nature of nursing work. These findings are important, given today's climate of widespread nursing shortages and burnout.

Although this research topic is gaining popularity, the usability and acceptability of care robots remain a barrier to widespread adoption. High workloads and negative attitudes have been identified as barriers to staff's adoption of care robots [20,21]. In their scoping reviews on robots in nursing, Maalouf et al [22] and Ohneberg et al [23] identified usability and acceptance issues, the need for further research on the psychological barriers to acceptance, and the need to improve collaboration between nurses and robots [22,23]. Successful deployment of care robots into health care systems and facilities requires a comprehensive understanding of multiple stakeholders' perspectives of their use, and their design must be informed by an awareness of the context in which they will be used [24,25].

Participatory design is a research approach that actively involves stakeholders in the design process of emergent technologies to ensure that their needs and preferences are addressed by the developed technology [26-28]. Previous literature reviews have been conducted to examine the participatory design and other similar research approaches for the design and development of care robots for ALFs, but they have mainly included the receivers of care (ie, older adults), leaving the perspectives of nursing staff underexplored [29-31]. In addition, these reviews have aimed to evaluate and compare different research methodologies, not to synthesize participants' perspectives [29-31]. A 2018 scoping review explored the views of nurses and other health care providers on the use of assistive humanoid and animal-like robots and identified mixed opinions, but more positive than negative, and concerns related to patient safety and privacy [32]. While this review did focus on the perspectives of health care providers, including nurses, the authors excluded robots without a social or interactive element and did not focus on older adults or the ALF setting. Furthermore, this scoping review did not include a quality assessment of the selected articles, which limits its ability to offer suggestions for practice. Our review builds on these findings by including all types of care robots, focusing on the assisted living setting, and including a quality assessment of the reviewed publications. We have chosen to focus on the ALF setting because the world's growing population of older adults and subsequent rising need for residential long-term care, coupled with widespread staffing shortages, has led to a growing interest in care robots for ALFs [13]. Additionally, it is important robots are customized to the specific end user and health care setting, as the needs of staff and care receivers differ greatly between different care settings [33].

Nurses' perspectives have not been fully implicated in the design, development, and implementation of care robots. Without consideration of nursing staff and the care environment of ALFs, care robots may further exacerbate the nurse staffing crisis and are unlikely to be adopted into care. To address these research gaps, we have conducted a systematic literature review in order to answer the following research questions: (1) What is known about the attitudes, needs, and preferences of nursing staff in ALFs in relation to the use of care robots? (2) What research methods, designs, and populations have been used in this research? (3) What are the gaps in the literature that warrant future research? The results of this systematic literature review were originally published as part of the 2024 ACM/IEEE (Association for Computing Machinery/ Institute of Electrical and Electronics Engineers) International Conference on Human-Robot Interaction [34]. This study expands on those findings and provides additional methodological details, as well as a quality assessment of the included publications.

Methods

Study Design

This literature review follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 protocol for systematic literature reviews [35]. The PRISMA 2020 checklist is provided in Multimedia Appendix 1. A protocol was not registered for this systematic literature review.

Round 1: Keyword Search

The topic of care robots in ALFs is an interdisciplinary concern; therefore, we searched databases in engineering, computer science, and health sciences: PubMed, CINAHL Plus with Full Text, PsycINFO, the IEEE Xplore Digital Library, and the ACM Digital Library. On May 12, 2023, these databases were searched using the following search terms: ("robot*") AND ("senior living facilit*" OR "residential facilit*" OR "independent living" OR "assisted living" OR "senior living center*" OR "nursing home*" OR "skilled nursing facilit*" OR "intermediate care facilit*") AND ("aged" OR "older" OR "elderly") AND ("nurse*" OR "nursing" OR "staff" OR "professional caregiver*" OR "professional carer*") AND ("perspective*" OR "preference*" OR "need*" OR "user-centered design" OR "user-driven design" OR "participatory design" OR "co-design" OR "usability" OR "universal design" OR "user experience*"). These search terms build on a previous literature review and were informed by the authors' previous experience and other relevant literature in the field [13]. To retrieve the full scope of literature on our topic, we imposed no limit for years of publication. PubMed, CINAHL Plus with Full Text, and PsycINFO were searched by titles and abstracts, the IEEE Xplore Digital Library was searched by metadata (titles, abstracts, and indexing terms), and the ACM Digital Library was searched using the 2012 ACM Computing Classification System with the filter "Robotics." This strategy was adopted from a previous review [13]. A detailed search strategy for each database is provided in Multimedia Appendix 2.

Round 2: Screening of Titles and Abstracts

Next, the first author screened the retrieved publications by title and abstract using predetermined inclusion and exclusion criteria. To be included, the publications had to meet the following criteria: (1) full text written in English, and (2) focus on the predevelopment phase, on gathering information on nursing staff's attitudes, needs, and preferences regarding care robots for ALFs. Following a previous literature review [13], we adopted the National Library of Medicine's MeSH (Medical Subject Headings) definition of robotics: "the application of electronic, computerized control systems to mechanical devices designed to perform human functions" [36]. Smart assistive devices (eg, walkers, canes, and transfer devices) and ambient assisted living technologies without a robotic platform were thus excluded from the review. Studies of the implementation of a care robot or of perspectives of an already developed care robot were also excluded. We defined "assisted living facility" as any residential setting that provides long-term care to older adults, consistent with prior literature reviews [12]. Publications that did not focus on such facilities (eg, aging in place) were excluded. Publications were also excluded if they were not peer-reviewed empirical studies (eg, literature reviews, opinion pieces, system architectures, and dissertations). We included all other research designs: quantitative, qualitative, and mixed methods.

Round 3: Screening of Full Text

The remaining papers were screened by full text using the same inclusion and exclusion criteria.

Round 4: Coding and Analysis of Full Text

The final 15 publications for review were coded by publication year, study aim, research method, sample characteristics, country and setting where data collection occurred, and key findings. Qualitative study findings were synthesized using applied thematic analysis to understand the main themes regarding nursing staff's perspectives of care robots for ALFs [37]. Quantitative data were examined using narrative synthesis to gain a richer understanding of the perspectives of nursing staff, as well as methodological trends and limitations of the existing literature.

In addition, we assessed the levels of evidence reported in the 15 publications. To assess studies with a mixed methods design, McGill University's Mixed Methods Appraisal Tool was used [38]. For all other study designs, the critical appraisal tools developed by the Joanna Briggs Institute were used to evaluate study quality [39]. To compute scores, questions answered as “Yes” received 1 point and questions answered as “No” or “Unclear” received no points. The total score was then divided by the number of questions and multiplied by 100. Depending on the score, studies were rated as very poor (0%-30%), poor (31%-50%), fair (51%-70%), good (71%-90%), and excellent (>90%). Two reviewers (KT, a doctoral student in Nursing, and JL, a doctoral student in Robotics) independently completed the checklist for each study; their interrater reliability reached 87%; disagreements were resolved through discussion.

Results

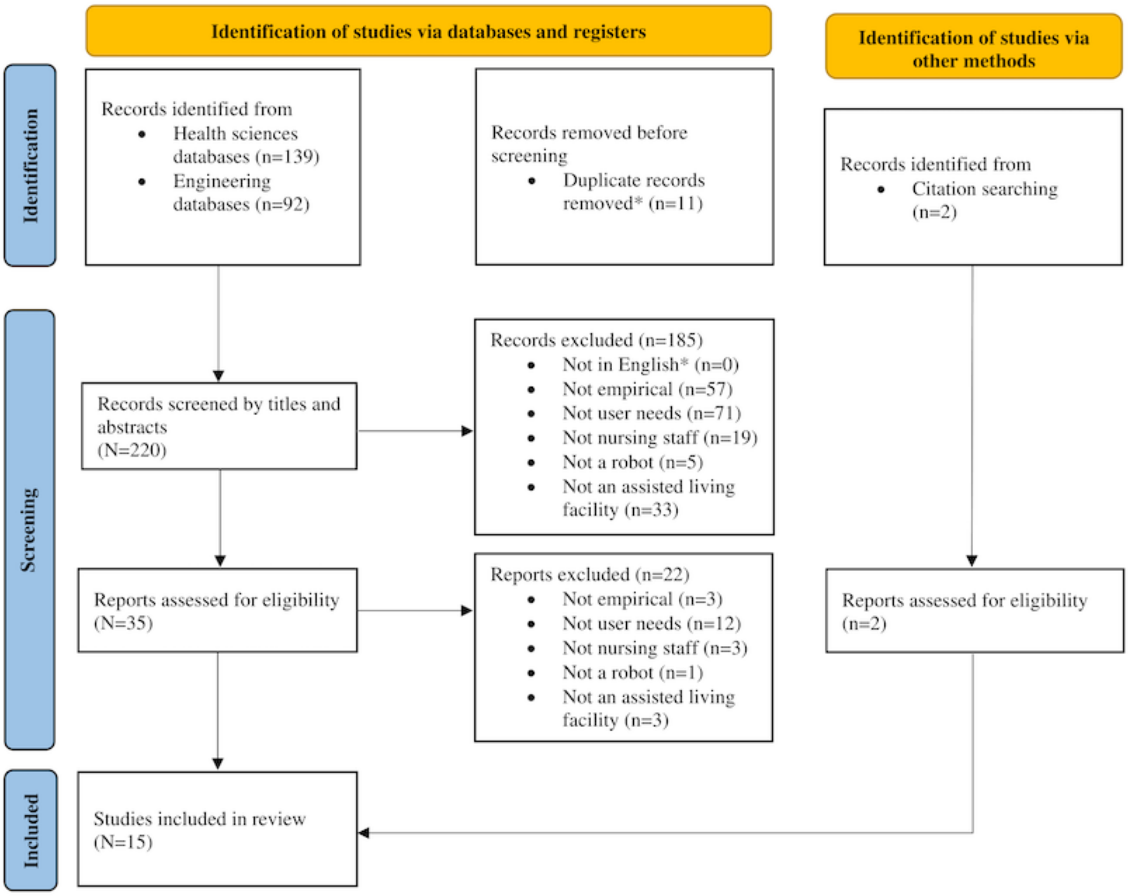
Search and Screening Results

During round 1, keyword search, the 5 databases yielded 231 publications (n=53, 23% from PubMed; n=44, 19% from PsycINFO; n=42, 18% from CINAHL; n=35, 15% from IEEE; and n=57, 25% from ACM). When these publications were combined, 11 duplicates were identified and removed using Rayyan, an electronic screening tool [40]; a total of 220 nonduplicate publications remained for screening.

During round 2, screening of titles and abstracts, a total of 185 publications were excluded (Figure 1), resulting in 35 publications for full-text review.

In round 3, screening of full text, 22 additional publications were excluded; a total of 13 remained. Additionally, 2 publications were added via citation searches of the included studies, for a total of 15 publications. Figure 1 presents the full search and screening process.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram. *Records that were excluded by automation tools.



Quality Assessment Results

Multimedia Appendix 3 [41-55] shows the results of the quality assessment. From the results, 2 (13%) publications were rated excellent, 11 (73%) were rated good, and 2 (13%) were rated fair. The qualitative publications overall lacked philosophical and theoretical frameworks. With regard to the quantitative publications, points were deducted for a lack of valid and reliable instruments, as well as a lack of consideration of confounding variables. Although the majority of studies were rated good, there was a general lack of reporting on important methodological decisions and sample characteristics.

Descriptive Results Based on the Coding of Full Text

A summary of the 15 studies is presented in Multimedia Appendix 4 [41-55]. The 15 studies in our final sample were published from 2007 to 2023; the majority (8/15, 53%) were published in the last 5 years. They were conducted in 11 countries—in North America (7/15, 47%), Europe (5/15, 33%), Asia (2/15, 13%), and Oceania (2/15, 13%). One study was conducted in both Europe and Asia, so it is accounted for twice [45]. Qualitative designs were most common (8/15, 53%); the remaining studies used mixed methods (3/15, 20%), a cross-sectional approach (3/15, 20%), or quasi-experimental designs (1/15, 6%). Qualitative data collection included interviews (6/15, 40%), focus groups (8/15, 53%), and observation (3/15, 20%). The cross-sectional studies relied on questionnaires. The Robot Anxiety Scale was used in 2 of the 15 (13%) studies; this scale has high reliability (Cronbach α=0.92) [42,43]. Others included A Questionnaire for the Use of a Social Robot in Care for Older Persons [54], which has high reliability (Cronbach α=0.95; intraclass correlation coefficient 0.88) [56], and the Positive and Negative Affect Schedule [42], which has also demonstrated high reliability (Cronbach α=0.84-0.90) and validity [57]. The quasi-experimental study developed new scales from existing literature and calculated high reliability for each scale (Cronbach α=0.70-0.92) [49]. The remaining questionnaires were study-specific and were developed from the literature, from focus groups, or by an undisclosed method, without any reliability or validity testing.

Most of the studies (11/15, 73%) lacked theoretical guidance. Four of the studies included a theoretical framework: the social-ecological model [48], the technology acceptance model [47], the model for the ethical evaluation of sociotechnical arrangements [46], and Forlizzi product ecology [44]. The 4 studies adopted a more holistic approach, exploring the social, environmental, and organizational aspects of ALFs (eg, nursing workflows) in relation to care robots [44,48,52,53]. In addition, 8 studies mentioned using a participatory design or related approach [44,46,48-50,52,53,55]. An overview of how these studies defined and facilitated user participation is presented in Table 1, as well as at which stage of the innovation process the users were involved. Seven studies (47%) used a predetermined definition of "care robot," meaning that aspects of the robot had been decided before the study took place. Three of these studies focused respectively on robots for a specific task or purpose: robot-assisted feeding systems [48], a robotic shower system [46], and robots to address personal mobility challenges [55]. Five studies involved demonstrations with robotic prototypes [44,49,53-55].

All 15 studies relied on convenience samples. Only 2 focused exclusively on nursing staff [49,52]; the remaining included older adults (10/15, 67%), relatives (4/15, 27%), other staff members (4/15, 27%), or experts in the field (4/15, 27%). Nursing staff included registered nurses (10/15, 67%); certified care workers (eg, certified nursing assistants/aides, licensed vocational nurses, or licensed practical nurses; 3/15, 20%); unspecified caregivers or nursing staff members (10/15, 67%); nurse practitioners (2/15, 13%); and nursing supervisors (2/15, 13%). Participants in 1 study were nursing and medical students [54], and another study included roboticists [55]. Sample sizes ranged from 3 to 286 nursing staff members; a majority (8/15, 53%) had fewer than 10 participants. Four studies provided no additional demographic information besides the participants' roles in the ALF [41,47,50,55]. Of the studies that did provide additional demographic information, all but one [49] had mainly female participants; the average age of participants ranged from 22.2 to 50 years, and average years of experience ranged from 2.5 to 12 years. Level of education, reported in only 3 studies, ranged from 26% to 43% college educated [43,45,54]. Most studies were conducted in a single setting, but 6 included participants from multiple facilities [42-45,51,55]. Eight of the studies focused on not-for-profit or government-funded facilities [41-43,47,50-53]. Participants were recruited in 1 study through a medical university [54]. Three studies, in addition to investigating ALFs, also examined community-based care for older adults [45,46,55]. Key characteristics of the 15 studies are provided in Table 2.

Table 1. Overview of participatory design or related approaches.

Author (year)	Definition/facilitation of user participation	Stage of innovation
Chang and Šabanović (2014) [44]	User-centered design approach: emphasis is on the perspectives of users instead of technology development. Uses task analysis, interviews, field observations, and focus groups.	Predesign
Klein and Schlömer (2018) [46]	User-centered requirements analysis: users are involved in all relevant stages of development. Uses interviews and focus groups to analyze requirements for the shower system, discuss renderings and mock-ups, and identify sociotechnical arrangements and ethical problems.	Predesign; postrenderings and mock-ups
Bhattacharjee et al (2019) [48]	Community-led relational approach shifts away from focusing on a single user to supporting multiple users at multiple layers of the social network. Uses contextual inquiry and surveys.	Postinitial design
Erebak and Turgut (2019) [49]	Human-centered technology approach: human and robot are evaluated as a team to understand the work prior to implementing technology. Participants evaluated existing robots.	Preproduction
Johnson et al (2020) [50]	Need finding design approach prioritizes the needs of older adults first and caregivers and clinicians second. Uses focus groups and surveys.	Predesign
Fiorini et al (2021) [55]	Cocreation or co-design: older adults and caregivers are the principal investigators. Uses interviews.	During design or development
Stegner and Mutlu (2022) [52]	Co-design: to help understand caregivers' work and guide the design of care robots. Uses observations and interviews.	Predesign
Stegner et al (2023) [53]	Situated participatory design enables the design and testing of use scenarios through interaction with the robot prototype. Uses focus groups.	During design or development

Table 2. Key characteristics of the 15 studies in the final sample (N=15).

Characteristic	Frequency, n (%)
Year of publication	
2009 and earlier	2 (13)
2010-2014	2 (13)
2014-2018	3 (20)
2019-2023	8 (53)
Country of publication[a]	
North America	7 (47)
Europe	5 (33)
Asia	2 (13)
Oceania	2 (13)
Sample size	
Less than 10	8 (53)
11-60	4 (27)
61-110	2 (13)
111 and greater	1 (6)
Method	
Qualitative methods	8 (53)
Mixed methods	4 (27)
Cross-sectional methods	2 (13)
Quasi-experimental methods	1 (6)
Sample background[a]	
Exclusively nursing staff	2 (13)
Older adults	10 (67)
Relatives	4 (27)
Other staff members	4 (27)
Content experts	4 (27)

[a] Studies were accounted for multiple times if met the criteria.

Nursing Staff Desired Robot Characteristics

Across the 15 studies, nursing staff described their ideal robot as one that could assist with their high workload. The most desired capability of a care robot was to assist with physically demanding tasks (9/15, 60%) [41,43-45,47,48,50,52,55]. These tasks included activities of daily living (eg, bathing, toileting, and feeding) and transferring or lifting patients. The nursing staff also desired a robot that could assist with monitoring patients and alerting staff when patients were in danger (8/15, 53%) [43,45-47,50,52,54,55], physical therapy or mobility exercises (5/15, 33%) [43,45,47,50,54], and medication administration and reminders (3/15, 20%) [45,50,54]. Less commonly desired capabilities included cognitive interventions [47,54], assessments [43], entertainment [44], and assistance with visual or hearing deficits [47].

Although assisting with physical tasks was the most desired function of care robots, participants in 2 studies discussed care that is lost when such work is delegated to robots [46,48]. In one of those studies, the nursing staff discussed how bathing patients involves more than just hygiene—staff used this time to connect with patients and establish relationships, to motivate patients to participate in the bathing process, and to monitor health changes (eg, skin breakdown) [46]. In the other study, staff expressed concerns about the robot replacing important bonding time that occurs during meals [48].

Opinions on whether a care robot could provide social support were mixed. In a few studies, nursing staff believed that care robots were capable of providing such care [51] or a limited version of it [44]. In 1 study, staff had a “wait and see” attitude about robots’ abilities [55]. Although their thoughts about robots’ ability to provide social care were inconclusive, nursing staff agreed that delegating such care to a robot would have serious implications [44-46,51,52,54,55]. In 3 (20%) studies, staff were adamant that robots should not provide social care [46,52,55]. In 3 other studies (20%), staff were less decisive about whether robots should provide social support and feared that their introduction could lead to inhumane or subpar care; however, these participants saw robots as a potential mediator of human social interaction [44,51,54]. For example, participants in 1 study discussed the benefit of using care robots to connect residents with loved ones during the COVID-19 pandemic [51]. In 1 study, beliefs about whether care robots could or should provide social support differed on the basis of the staff's cultural background [45].

Finally, the nursing staff desired robots personalized to older adults' abilities, routines, preferences, and needs [46-48,52-54]. To achieve personalized robots, 1 study suggested "end user programming" where nursing staff (ie, the domain experts) could easily customize robots for older adults [52]. This study also suggested that robots should have the ability to learn and adapt from previous experiences [52]. Another study suggested that nursing staff's intimate relationships with residents could be used to gain knowledge and personalize robots for specific older adults [47].

Concerns

Nursing staff members voiced several concerns about adopting care robots in ALFs. Ethically, there was disagreement about who should control the robots—the older adults or the nursing staff. In 2 (13%) studies, staff argued that they should supervise and have ultimate control over robots, instead of the older adults [52,54]. Their primary argument for needing control of the robots was to ensure older adults' safety. In other studies, however, nursing staff were concerned about maintaining the older adults' autonomy and dignity [46,51,53]. An emergency shutoff button was suggested as a method to increase autonomy and safety [43,44,46-48,51]. In 2 (13%) studies, staff were concerned about surveillance and emphasized the importance of protecting the privacy of older adults and staff [51,54]. Finally, nursing staff worried that robots could replace human caregivers and take away their jobs [42,45,46].

Accessibility was also a common concern across studies. Caregivers in one of the studies thus advocated for "distributive justice," meaning that everyone should have access to care robots [46]. Care robots can be extremely expensive, but finances (whether those of the older adult or of the facility) should not prevent someone from accessing these devices [46,51]. A staff member in 1 study commented that the high cost of care robots can lead to extreme precautions in order to keep the robots in good working order [51]. As a result, the robots were often locked up when they were needed most (ie, when family or staff were unavailable) [51]. In addition to being financially accessible, robots must be easy to hear and see for those with deficits [43].

Finally, nursing staff were concerned about operability. Nursing staff were concerned that care robots might increase workload, and so they desired robots that would be easy to use [44,51,55], easy to clean and maintain [43,51], flexible [44], and reliable [43]. Three of the studies emphasized that robots should save nursing staff time, which could then be invested into providing relational care [43,46,51]. Also related to operability, 3 (20%) studies pointed to a lack of education and training on care technologies in nursing curricula [43,44,54].

Potential Factors Influencing Robot Perspectives

In 5 (33%) studies, the authors examined potential factors in participants' perspectives of care robots—culture, qualification, and the participant's role in the facility. In 1 study, Finnish staff reported significantly greater fear that robots would cause inhuman care and increase loneliness; whereas, Japanese staff were more likely to believe that robots could reduce anxiety and loneliness [45]. In another study, clinicians (therapists and registered nurses) desired robots to help with medications, safety, and mobility tasks, whereas caregivers (certified nursing assistants and other formal caregivers) desired robots to assist with activities of daily living [50]. Medical students in 1 study were concerned about privacy, whereas nursing students were concerned about robots' social functions [54]. In 2 studies with residents and nursing staff, the residents felt more positively toward the robots than did the nursing staff [42,43]. Both the residents and nursing staff desired assistance from care robots: residents desired assistance with managing their health (eg, medication reminders), and nursing staff desired job assistance (eg, escorting residents to meals) [42].

Discussion

Overview of Findings

In this systematic literature review, we have examined 15 studies of nursing staff's attitudes, needs, and preferences regarding the use of care robots in ALFs. We have synthesized our findings into three major themes: (1) desired robot characteristics, (2) concerns, and (3) methodological approaches.

Nursing Staff Desired Robot Characteristics

There was a consensus among nursing staff that care robots should serve as nursing assistants to help reduce high workload; they should not replace nursing work. Assistance with physical tasks was the most desired function. Whether robots could or should assist with social tasks remains a question. However, a previous literature review has identified an overrepresentation of social robots as opposed to assistive robots: 60 of the 69 (87%) included studies in that review investigated social robots [13]. This discrepancy illustrates the necessity of involving stakeholders at the early stages of care robots' development. Whether robots can provide social assistance is a technical question and will require collaboration with roboticists. Whether robots should provide social assistance is an ethical question that requires the involvement of older adults and their caregivers. Existing participatory research in this field has focused on older adults as the key stakeholders [29-31]; however, it is important that future research involve a wide range of perspectives (including nursing staff) to gain a holistic understanding of care robots for ALFs.

In addition, our findings call for future research on what constitutes nursing work in ALFs. The reviewed studies demonstrate that nursing work is extremely diverse, and much of nursing's most essential care work goes unseen or is taken for granted, due to gender and power dynamics [58-60]. In a literature review of 121 articles on this topic, the authors describe nursing work as multifaceted and a composite of physical, emotional, cognitive, and organizational labor [60].

Many important yet invisible aspects of care cannot be accounted for by the technical affordances of a robot. In the included study that investigated a robotic showering system, nursing staff suggest that while a robot may be useful for the functional aspects of washing a patient, it may not replace the interpersonal nor observational labor involved in their work [46]. The same is true of the electronic health care record, which has been widely adopted throughout the health care system but reduces nurses' face-to-face interactions [61]. These examples highlight the unexamined and incomplete notions of what nursing work is today—aspects that developers of such technologies may fail to address [62]. Topol [63] describes a future where medicine harnesses the power of artificial intelligence and robotics to support tasks better suited for automation, freeing nurses and other health care providers to focus on providing real care to patients [63]. To develop ethical, effective, and useful robots, thoughtful discussion and study is necessary on the nature of work that nurses do in ALFs (visible and invisible) and what constitutes good care with robotic systems.

Concerns

Nursing staff had concerns about the ethics, safety, accessibility, and operability of care robots in ALFs. Opinions about who should have control over the robots were mixed. On the one hand, giving older adults control over a care robot may enhance autonomy, but, on the other, nursing staff are responsible for ensuring residents' safety. Further research on how to preserve older adults' autonomy while balancing it with safety is needed. Care robots should be accessible to those who need them, and this should be factored into care robot design, development, and implementation. Accessibility includes financial, physical, and cognitive accessibility. Robots' operability was especially important to nursing staff, who did not want robots to increase their already high workloads. Future research should consider nurse workflows and how to thoughtfully implement robots in a way that does not increase workload. In addition, in the context of the COVID-19 pandemic and widespread staffing shortages, where nurses already feel undervalued, it is important that robots be introduced as assistants to nurses, rather than replace nursing work.

Methodological Approaches

Several methodological limitations were identified across the 15 studies.

First, 7 (47%) studies used predetermined definitions of care robots, which limited the implications of their participants' comments. Participatory design is intended to address the power imbalance between researchers and participants. By involving participants at the very beginning of technology design, stakeholders are empowered to take part in the conceptualization of technologies [27]. When participants act solely as informants, however, study findings are biased by the researchers' assumptions about end users and the types of robots they would prefer, and participants are limited to thinking only within predetermined definitions, which may lead to incomplete or misleading findings [64]. To fully understand the perspectives of nursing staff at the early stages of robot design, future research should use participatory design to empower nurses to describe their ideal robot without any preconceived ideas. Although a majority of the included studies (8/15, 53%) claimed to take a participatory design or related approach, there is a lack of established criteria for what constitutes participatory design, which leads to varying degrees of participants' involvement. To increase rigor and strengthen the quality of research in this field, there is a need for future work to develop protocols for participatory design.

Second, the sample sizes were small; 53% (8/15) of the studies had fewer than 10 participants. In addition, the studies provided very limited demographic information on the nursing staff or facilities. This lack of empirical reporting is a common limitation in health informatics research and has been noted in previous literature reviews on care robots [13] and artificial intelligence for caregivers of persons with Alzheimer disease [65]. Only 5 studies included demographic factors in the interpretation of their results, and findings differed across culture, qualification, and role in the facility. To understand the factors that influence attitudes toward and needs or preferences for the use of care robots, it is important to collect and consider demographic information on nursing staff as well as other end-user groups. This can promote the development of care robots that are personalized and useful, as well as increase the likelihood that care robots will be adopted into practice. Six of the studies included multiple facilities but with little exploration of how differences among facilities might influence users' perspectives of care robots. Studying a single facility may allow detailed exploration, but the inclusion of multiple facilities allows comparisons, with greater potential for generalization. This is especially important in the United States, where licensure and regulations differ greatly between different types of facilities and from state to state.

Finally, several different questionnaires were used to assess nursing staff's attitudes, needs, and preferences, making it difficult to compare findings across studies, and although some of these instruments have been validated, many have not. Further research is needed to develop and validate relevant instruments for understanding nursing staff's perspectives of care robots.

Limitations

The systematic literature review has several limitations. First, only 5 electronic databases were searched, so it is possible that important and relevant studies were missed. To mitigate this possibility, we chose an interdisciplinary selection of databases representing engineering, computer sciences, and health sciences. We also searched the citations of our final sample to reduce the chances of missing pertinent studies and added 2 publications. Second, we included only publications with full text written in English, so it is possible that we missed studies written in other languages. Third, our search terms were not exhaustive, and the language used to describe the participatory design and related research approaches is diverse; therefore, it is possible that we missed important relevant articles. To mitigate this possibility, we reviewed the search terms of previous similar literature reviews. In addition, the language used to describe nursing staff varies, and it is possible that we missed studies that used different terms. Notably, after the conclusion of this review, the authors became aware of a study by Chen et al [66], which investigated the attitudes of Taiwanese health professionals in ALFs toward the use of social robots. The authors validated the Chinese version of attitudes toward the use of social robot questionnaire and found that most participants had positive attitudes toward social robots, these attitudes were positively and significantly correlated with their awareness of robots, and staff working in nursing homes (as opposed to lower-acuity, residential aged care) were significantly more positive toward social robots [66]. These findings support our statement that in order to customize robots to the specific care setting and end user, which in turn will promote the robots' usefulness and adoption, future research is needed on the different individual- and facility-level factors that influence nursing staff's attitudes toward care robots.

Conclusions

In this systematic review of 15 studies on nursing staff's attitudes, needs, and preferences related to the use of care robots in ALFs, we have found that nursing staff desire care robots that will assist with physically demanding tasks and reduce workload. But the nurses wanted to be able to preserve their interpersonal caring work too. Consideration of ethics, safety, accessibility, and operability informed nurses' concerns across the studies. Further research is needed to mitigate these concerns and understand the demographic, social, environmental, and organizational factors that influence individuals' perspectives of care robots and their adoption in ALFs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.
[DOCX File , 30 KB - aging_v7i1e58629_app1.docx]

Multimedia Appendix 2
Detailed search strategy.
[DOCX File , 15 KB - aging_v7i1e58629_app2.docx]

Multimedia Appendix 3
Quality assessment of the 15 studies in the final sample.
[DOCX File , 27 KB - aging_v7i1e58629_app3.docx]

Multimedia Appendix 4
Summary of the 15 studies in the final sample.
[DOCX File , 32 KB - aging_v7i1e58629_app4.docx]

References

1. Vespa J, Armstrong DM, Medina L. Demographic turning points for the United States: population projections for 2020 to 2060. United States Census Bureau. 2020. URL: https://www.census.gov/library/publications/2020/demo/p25-1144.html [accessed 2022-04-25]
2. How much care will you need? LongTermCare.gov. 2020. URL: https://acl.gov/ltc/basic-needs/how-much-care-will-you-need [accessed 2022-07-29]
3. Organisation for Economic Co-Operation and Development. Who cares? Attracting and retaining care workers for the elderly. Organisation for Economic Co-Operation and Development. 2020. URL: https://doi.org/10.1787/92c0ef68-en [accessed 2023-03-02]
4. Long Term Care Jobs Report: May 2023. American Health Care Association and National Center for Assisted Living. 2023 May. URL: https://tinyurl.com/2yamt4vd [accessed 2024-08-14]
5. McHugh MD, Kutney-Lee A, Cimiotti JP, Sloane DM, Aiken LH. Nurses' widespread job dissatisfaction, burnout, and frustration with health benefits signal problems for patient care. Health Aff 2011;30(2):202-210 [FREE Full text] [doi: 10.1377/hlthaff.2010.0100] [Medline: 21289340]
6. Dall'Ora C, Ball J, Reinius M, Griffiths P. Burnout in nursing: a theoretical review. Hum Resour Health 2020;18(1):41 [FREE Full text] [doi: 10.1186/s12960-020-00469-9] [Medline: 32503559]

7. National Nurses United sets the record straight on nurse staffing. National Nurses United. 2021. URL: https://www.nationalnursesunited.org/press/national-nurses-united-sets-record-straight-on-nurse-staffing [accessed 2023-09-29]
8. Muir KJ, Wanchek TN, Lobo JM, Keim-Malpass J. Evaluating the costs of nurse burnout-attributed turnover: a Markov modeling approach. J Patient Saf 2022;18(4):351-357. [doi: 10.1097/PTS.0000000000000920] [Medline: 35617593]
9. White EM, Aiken LH, McHugh MD. Registered nurse burnout, job dissatisfaction, and missed care in nursing homes. J Am Geriatr Soc 2019;67(10):2065-2071 [FREE Full text] [doi: 10.1111/jgs.16051] [Medline: 31334567]
10. Morgan AA, Abdi J, Syed MAQ, Kohen GE, Barlow P, Vizcaychipi MP. Robots in healthcare: a scoping review. Curr Robot Rep 2022;3(4):271-280 [FREE Full text] [doi: 10.1007/s43154-022-00095-4] [Medline: 36311256]
11. Persson M, Redmalm D, Iversen C. Caregivers' use of robots and their effect on work environment—a scoping review. J Technol Hum Serv 2022;40(3):251-277. [doi: 10.1080/15228835.2021.2000554]
12. Budak KB, Atefi G, Hoel V, Laporte Uribe F, Meiland F, Teupen S, et al. Can technology impact loneliness in dementia? A scoping review on the role of assistive technologies in delivering psychosocial interventions in long-term care. Disabil Rehabil Assist Technol 2023;18(7):1107-1119. [doi: 10.1080/17483107.2021.1984594] [Medline: 34752177]
13. Trainum K, Tunis R, Xie B, Hauser E. Robots in assisted living facilities: scoping review. JMIR Aging 2023;6:e42652 [FREE Full text] [doi: 10.2196/42652] [Medline: 36877560]
14. Neal I, du Toit SHJ, Lovarini M. The use of technology to promote meaningful engagement for adults with dementia in residential aged care: a scoping review. Int Psychogeriatr 2020;32(8):913-935. [doi: 10.1017/S1041610219001388] [Medline: 31547900]
15. Huter K, Krick T, Domhoff D, Seibert K, Wolf-Ostermann K, Rothgang H. Effectiveness of digital technologies to support nursing care: results of a scoping review. J Multidiscip Healthc 2020;13:1905-1926 [FREE Full text] [doi: 10.2147/JMDH.S286193] [Medline: 33328736]
16. Obayashi K, Masuyama S. Pilot and feasibility study on elderly support services using communicative robots and monitoring sensors integrated with cloud robotics. Clin Ther 2020;42(2):364-371.e4. [doi: 10.1016/j.clinthera.2020.01.001] [Medline: 31987582]
17. Tulsulkar G, Mishra N, Thalmann NM, Lim HE, Lee MP, Cheng SK. Can a humanoid social robot stimulate the interactivity of cognitively impaired elderly? A thorough study based on computer vision methods. Vis Comput 2021;37(12):3019-3038 [FREE Full text] [doi: 10.1007/s00371-021-02242-y] [Medline: 34345091]
18. Pou-Prom C, Raimondo S, Rudzicz F. A conversational robot for older adults with Alzheimer's disease. J Hum Robot Interact 2020;9(3):1-25. [doi: 10.1145/3380785]
19. Sharkey A. Robots and human dignity: a consideration of the effects of robot care on the dignity of older people. Ethics Inf Technol 2014;16(1):63-75. [doi: 10.1007/s10676-014-9338-5]
20. Kolstad M, Yamaguchi N, Babic A, Nishihara Y. Integrating socially assistive robots into Japanese nursing care. Stud Health Technol Inform 2020;272:183-186 [FREE Full text] [doi: 10.3233/SHTI200524] [Medline: 32604631]
21. Kidd CD, Taggart W, Turkle S. A sociable robot to encourage social interaction among the elderly. 2006 Presented at: Proceedings 2006 IEEE International Conference on Robotics and Automation, 2006 (ICRA 2006); May 15-19, 2006; Orlando, FL p. 3972-3976.
22. Maalouf N, Sidaoui A, Elhajj IH, Asmar D. Robotics in nursing: a scoping review. J Nurs Scholarsh 2018;50(6):590-600. [doi: 10.1111/jnu.12424] [Medline: 30260093]
23. Ohneberg C, Stöbich N, Warmbein A, Rathgeber I, Mehler-Klamt AC, Fischer U, et al. Assistive robotic systems in nursing care: a scoping review. BMC Nurs 2023;22(1):72 [FREE Full text] [doi: 10.1186/s12912-023-01230-y] [Medline: 36934280]
24. Šabanović S. Robots in society, society in robots. Int J Soc Robot 2010;2(4):439-450. [doi: 10.1007/s12369-010-0066-7]
25. Christoforou EG, Avgousti S, Ramdani N, Novales C, Panayides AS. The upcoming role for nursing and assistive robotics: opportunities and challenges ahead. Front Digit Health 2020;2:585656 [FREE Full text] [doi: 10.3389/fdgth.2020.585656] [Medline: 34713058]
26. Antony VN, Cho SM, Huang CM. Co-designing with older adults, for older adults: robots to promote physical activity. 2023 Presented at: Proceedings of the 2023 ACM/IEEE International Conference on Human-Robot Interaction; March 13, 2023; Stockholm, Sweden p. 506-515.
27. Lee HR, Šabanović S, Chang WL, Nagata S, Piatt J, Bennett C, et al. Steps toward participatory design of social robots: mutual learning with older adults with depression. 2017 Presented at: Proceedings of the 2017 ACM/IEEE International Conference on Human-Robot Interaction; March 06, 2016; Vienna, Austria p. 244-253.
28. Spinuzzi C. The methodology of participatory design. Technical Commun 2005 May;52(2):163-174 [FREE Full text]
29. Merkel S, Kucharski A. Participatory design in gerontechnology: a systematic literature review. Gerontologist 2019;59(1):e16-e25. [doi: 10.1093/geront/gny034] [Medline: 29788319]
30. Rogers WA, Kadylak T, Bayles MA. Maximizing the benefits of participatory design for human-robot interaction research with older adults. Hum Factors 2022;64(3):441-450 [FREE Full text] [doi: 10.1177/00187208211037465] [Medline: 34461761]
31. Sumner J, Chong L, Bundele A, Wei Lim Y. Co-designing technology for aging in place: a systematic review. Gerontologist 2021;61(7):e395-e409 [FREE Full text] [doi: 10.1093/geront/gnaa064] [Medline: 32506136]

32. Papadopoulos I, Koulouglioti C, Ali S. Views of nurses and other health and social care workers on the use of assistive humanoid and animal-like robots in health and social care: a scoping review. Contemp Nurse 2018;54:425-442. [doi: 10.1080/10376178.2018.1519374] [Medline: 30200824]
33. Fennelly O, Cunningham C, Grogan L, Cronin H, O'Shea C, Roche M, et al. Successfully implementing a national electronic health record: a rapid umbrella review. Int J Med Inform 2020;144:104281 [FREE Full text] [doi: 10.1016/j.ijmedinf.2020.104281] [Medline: 33017724]
34. Trainum K, Liu J, Hauser E, Xie B. Nursing staff's attitudes, needs, and preferences for care robots in assisted living facilities: a systematic literature review. 2024 Presented at: HRI '24: Companion of the 2024 ACM/IEEE International Conference on Human-Robot Interaction; March 11, 2024; Boulder, CO.
35. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71 [FREE Full text] [doi: 10.1136/bmj.n71] [Medline: 33782057]
36. National Center for Biotechnology Information. Robotics. URL: https://www.ncbi.nlm.nih.gov/mesh?term=Robotics [accessed 2022-04-25]
37. Guest G, MacQueen KM, Namey EE. Applied Thematic Analysis. Thousand Oaks, CA: SAGE Publications, Inc; 2012.
38. Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Dagenais P, et al. Mixed Methods Appraisal Tool (MMAT) version 2018: user guide. McGill University. 2018. URL: http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf [accessed 2023-11-14]
39. Joanna Briggs Institute. Critical appraisal tools. URL: https://jbi.global/critical-appraisal-tools [accessed 2023-11-14]
40. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. Syst Rev 2016;5(1):210 [FREE Full text] [doi: 10.1186/s13643-016-0384-4] [Medline: 27919275]
41. Cohen-Mansfield J, Biddison J. The scope and future trends of gerontechnology: consumers' opinions and literature survey. J Technol Hum Serv 2008;25(3):1-19. [doi: 10.1300/j017v25n03_01]
42. Broadbent E, Tamagawa R, Kerse N, Knock B, Patience A, MacDonald B. Retirement home staff and residents? Preferences for healthcare robots. 2009 Presented at: RO-MAN 2009—The 18th IEEE International Symposium on Robot and Human Interactive Communication; October 02, 2009; Toyama, Japan p. 645-650.
43. Broadbent E, Tamagawa R, Patience A, Knock B, Kerse N, Day K, et al. Attitudes towards health-care robots in a retirement village. Australas J Ageing 2012;31(2):115-120. [doi: 10.1111/j.1741-6612.2011.00551.x] [Medline: 22676171]
44. Chang WL, Šabanović S. Exploring Taiwanese nursing homes as product ecologies for assistive robots. 2014 Presented at: IEEE International Workshop on Advanced Robotics and its Social Impacts; September 11-13, 2014; Evanston, IL.
45. Coco K, Kangasniemi M, Rantanen T. Care personnel's attitudes and fears toward care robots in elderly care: a comparison of data from the care personnel in Finland and Japan. J Nurs Scholarsh 2018;50(6):634-644. [doi: 10.1111/jnu.12435] [Medline: 30354007]
46. Klein B, Schlömer I. A robotic shower system: acceptance and ethical issues. Z Gerontol Geriatr 2018;51(1):25-31 [FREE Full text] [doi: 10.1007/s00391-017-1345-9] [Medline: 29230538]
47. Sefcik JS, Johnson MJ, Yim M, Lau T, Vivio N, Mucchiani C, et al. Stakeholders' perceptions sought to inform the development of a low-cost mobile robot for older adults: a qualitative descriptive study. Clin Nurs Res 2018;27(1):61-80 [FREE Full text] [doi: 10.1177/1054773817730517] [Medline: 28918654]
48. Bhattacharjee T, Cabrera ME, Caspi A, Cakmak M, Srinivasa SS. A community-centered design framework for robot-assisted feeding systems. 2019 Presented at: ASSETS '19: Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility; October 21-25, 2019; Pittsburgh, PA.
49. Erebak S, Turgut T. Caregivers' attitudes toward potential robot coworkers in elder care. Cognit Technol Work 2018;21(2):327-336. [doi: 10.1007/s10111-018-0512-0]
50. Johnson MJ, Johnson MA, Sefcik JS, Cacchione PZ, Mucchiani C, Lau T, et al. Task and design requirements for an affordable mobile service robot for elder care in an all-inclusive care for elders assisted-living setting. Int J Soc Robot 2017;12(5):989-1008. [doi: 10.1007/s12369-017-0436-5]
51. Hung L, Mann J, Perry J, Berndt A, Wong J. Technological risks and ethical implications of using robots in long-term care. J Rehabil Assist Technol Eng 2022;9:20556683221106917 [FREE Full text] [doi: 10.1177/20556683221106917] [Medline: 35733613]
52. Stegner L, Mutlu B. Designing for caregiving: integrating robotic assistance in senior living communities. 2022 Presented at: DIS '22: Proceedings of the 2022 ACM Designing Interactive Systems Conference; June 13, 2022; Virtual event, Australia p. 1934-1947.
53. Stegner L, Senft E, Mutlu B. Situated participatory design: a method for in situ design of robotic interaction with older adults. 2023 Presented at: CHI '23: Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems; April 19, 2023; Hamburg, Germany.
54. Łukasik S, Tobis S, Kropińska S, Suwalska A. Role of assistive robots in the care of older people: survey study among medical and nursing students. J Med Internet Res 2020;22(8):e18003 [FREE Full text] [doi: 10.2196/18003] [Medline: 32784187]

55. Fiorini L, De Mul M, Fabbricotti I, Limosani R, Vitanza A, D'Onofrio G, et al. Assistive robots to improve the independent living of older persons: results from a needs study. Disabil Rehabil Assist Technol 2021;16(1):92-102. [doi: 10.1080/17483107.2019.1642392] [Medline: 31329000]
56. Tobis S, Neumann-Podczaska A, Kropinska S, Suwalska A. UNRAQ—a questionnaire for the use of a social robot in care for older persons. A multi-stakeholder study and psychometric properties. Int J Environ Res Public Health 2021;18(11):6157 [FREE Full text] [doi: 10.3390/ijerph18116157] [Medline: 34200294]
57. Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: the PANAS scales. J Pers Soc Psychol 1988;54(6):1063-1670. [doi: 10.1037//0022-3514.54.6.1063] [Medline: 3397865]
58. Allen D. The Invisible Work of Nurses: Hospitals, Organisation and Healthcare. Abingdon, Oxon: Routledge; 2014.
59. Andrist LA, Nicholas PK, Wolf K. The history of the relationship between feminism and nursing. In: A History of Nursing Ideas. Sudbury, MA: Jones and Bartlett Publishers; 2006.
60. Jackson J, Anderson JE, Maben J. What is nursing work? A meta-narrative review and integrated framework. Int J Nurs Stud 2021;122:103944 [FREE Full text] [doi: 10.1016/j.ijnurstu.2021.103944] [Medline: 34325358]
61. Forde-Johnston C, Butcher D, Aveyard H. An integrative review exploring the impact of electronic health records (EHR) on the quality of nurse-patient interactions and communication. J Adv Nurs 2023;79(1):48-67 [FREE Full text] [doi: 10.1111/jan.15484] [Medline: 36345050]
62. Hülsken-Giesler M, Daxberger S. Robotics in Nursing from a Nursing Science Perspective. Wiesbaden, Germany: Springer Gabler; 2018:125-139.
63. Topol EJ. Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again. Illustrated Edition. New York, NY: Basic Books; 2019.
64. de Saille S, Greenwood A, Law J, Ball M, Levine M, Vallejos EP, et al. Using LEGO® SERIOUS® play with stakeholders for RRI. J Responsib Technol 2022;12:100055. [doi: 10.1016/j.jrt.2022.100055]
65. Xie B, Tao C, Li J, Hilsabeck RC, Aguirre A. Artificial intelligence for caregivers of persons with Alzheimer's disease and related dementias: systematic literature review. JMIR Med Inform 2020;8(8):e18189 [FREE Full text] [doi: 10.2196/18189] [Medline: 32663146]
66. Chen SC, Jones C, Moyle W. Health professional and workers attitudes towards the use of social robots for older adults in long-term care. Int J Soc Robot 2019;12(5):1135-1147. [doi: 10.1007/s12369-019-00613-z]

Abbreviations

ACM/IEEE: Association for Computing Machinery/Institute of Electrical and Electronics Engineers
ALF: assisted living facility
MeSH: Medical Subject Headings
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Review

Exploring the Landscape of Standards and Guidelines in AgeTech Design and Development: Scoping Review and Thematic Analysis

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Abstract

Background: AgeTech (technology for older people) offers digital solutions for older adults supporting aging in place, including digital health, assistive technology, Internet of Things, medical devices, robotics, wearables, and sensors. This study underscores the critical role of standards and guidelines in ensuring the safety and effectiveness of these technologies for the health of older adults. As the aging demographic expands, the focus on robust standards becomes vital, reflecting a collective commitment to improving the overall quality of life for older individuals through thoughtful and secure technology integration.

Objective: This scoping review aims to investigate the current state of standards and guidelines applied in AgeTech design and development as reported in academic literature. We explore the existing knowledge of these standards and guidelines and identify key gaps in the design and development of AgeTech guidelines and standards in scholarly publications.

Methods: The literature review adhered to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) guidelines. Searches were carried out across multiple databases, including Scopus, IEEE, PubMed, Web of Science, EBSCO, CINAHL, Cochrane, and Google Scholar, using a search string incorporating concepts such as “older people,” “technology,” and “standards or guidelines.” Alternative terms, Boolean operators, and truncation were used for comprehensive coverage in each database. The synthesis of results and data analysis involved both quantitative and qualitative methods.

Results: Initially, 736 documents were identified across various databases. After applying specific inclusion and exclusion criteria and a screening process, 58 documents were selected for full-text review. The findings highlight that the most frequently addressed aspect of AgeTech standards or guidelines is related to “design and development,” constituting 36% (21/58) of the literature; “usability and user experience” was the second most prevalent aspect, accounting for 19% (11/58) of the documents. In contrast, “privacy and security” (1/58, 2%) and “data quality” (1/58, 2%) were the least addressed aspects. Similarly, “ethics,” “integration and interoperability,” “accessibility,” and “acceptance or adoption” each accounted for 3% (2/58) of the documents. In addition, a thematic analysis identified qualitative themes that warrant further exploration of variables.

Conclusions: This study investigated the available knowledge regarding standards and guidelines in AgeTech design and development to evaluate their current status in academic literature. The substantial focus on assistive technologies and ambient assisted living technologies confirmed their vital role in AgeTech. The findings provide valuable insights for interested parties and point to prioritized areas for further development and research in the AgeTech domain.

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KEYWORDS

aging in place; technology; gerontechnology; AgeTech; assistive technology; older adult; aging; ambient assisted living; active assisted living

Introduction

Background

As the global population ages, the number of people aged ≥60 years is expected to double, reaching 2.1 billion by 2050, while the number of those aged ≥80 years is expected to triple, reaching 426 million [1-3]. This trend is mirrored in Canada, where older adults are projected to make up approximately 25% of the population by 2050 [4,5]. Notably, >95% of older Canadians would prefer to age in their own homes and communities [6,7]. However, many older adults contend with multiple chronic health conditions that can necessitate long-term care to manage their activities of daily living. A recent Canadian study suggests that between 11% and 22% of older adults transitioning into long-term care could have remained in their homes or community-based care settings with the appropriate supports in place [8].

Addressing the needs of this rapidly aging population requires innovative solutions to overcome the unique social, fiscal, and medical challenges of providing health and social care. Assistive technologies, including a range of devices, equipment, software, or adaptations to the physical environment, offer the potential to improve functional ability, social participation, and well-being, making them a valuable part of the solution. Within this broad category, AgeTech—technology for older people, a specialized subset of assistive technologies—is designed to meet the unique needs and preferences of older adults and their care partners, focusing on preserving and enhancing independence and inclusion for individuals aged ≥65 years [9-11]. For the purposes of this study, a broad definition of AgeTech is used [9]: "AgeTech refers to digital technologies or digitally enabled products designed explicitly for or with the potential to provide benefit to older adults and care partners. This will include a range of innovations supporting aging in place, healthy aging, staying connected, and more. It is expected that technologies in the program will include digital health, assistive technologies, Internet of Things, medical devices/diagnostics, robotics, wearables, and other sensor-based technologies."

Despite the potential of AgeTech to help older adults age longer in the homes and communities of their choice, many technologies have not achieved the expected success rates [12]. Challenges include the development of fit-for-purpose technologies that address the real needs of older adults and that are subsequently adopted by them and their care partners [12,13]. Recent studies have revealed evidence of the potential impact of technology in supporting older adults to age in place [9,14]. Still, AgeTech innovators can struggle with the adoption of AgeTech products or services by older people, their caregivers, and the systems that help care for them. One factor contributing to this translational challenge is the lack of standards-based solutions for AgeTech design and evaluation, which can result in products that are either unfit for purpose or fail to address real needs [13,15]. Standards and guidelines are crucial in AgeTech development for ensuing support for safety, efficacy, reliability, interoperability, and regulatory compliance [16,17]. They address the specific needs of older adults, mitigate risks, and foster user trust. In addition, standards promote seamless integration, improving care coordination and decision-making. Consistency and quality across AgeTech solutions are maintained, fostering innovation and reliability. Compliance with standards streamlines regulatory processes and enhances market acceptance, benefiting older adults and caregivers. Overall, standards are essential in advancing AgeTech, enhancing aging-related care, and improving the well-being of older populations [9,15-19].

Objectives

This scoping review aims to explore the current state of standards and guidelines used in the design and development of AgeTech in the academic peer-reviewed literature and highlights the importance of these frameworks in advancing the field [9,15-19]. The decision to initially focus on academic peer-reviewed literature allows for a rigorous, systematic exploration of the foundational research in AgeTech design and development standards and guidelines. This approach ensures that the review is grounded in scientifically validated findings, providing a robust framework from which to explore the broader, practical implications and innovations captured within the gray literature in a subsequent review. This phased methodology strategically broadens the scope of analysis to include a comprehensive spectrum of insights, from theoretical underpinnings to practical applications in the field. Two research questions helped to guide the search strategy and data extraction process in the academic literature:

1. Research question 1: What is the existing knowledge about standards or guidelines in the design and development of AgeTech?
2. Research question 2: What are the key gaps in the design and development of standards or guidelines for AgeTech?

Methods

Study Design

A scoping review was chosen as the systematic method to comprehensively map the available evidence and provide an overview of the scientific literature concerning existing guidelines and standards for the development of AgeTech [20-22]. The scoping review followed a five-step process: (1)

identifying an initial research question; (2) identifying relevant studies; (3) selecting the studies; (4) charting the data; and (5) collating, summarizing, and reporting the findings [20]. To establish an effective search strategy and search strings, our research team engaged in 3 consultations with a librarian subject matter expert. Following these consultations and using an iterative approach to test database and search terms, a search strategy was finalized. Article selection adhered to the guidelines outlined in the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews).

Information Sources and Study Selection

The research team performed the scoping review search in October 2023. A subsequent search was conducted before submission for publication on January 20, 2024. We searched 8 databases, including Scopus, IEEE, PubMed, Web of Science, EBSCO, CINAHL, Cochrane, and Google Scholar, to identify academic, peer-reviewed journal articles and conference papers. Reflective of the interdisciplinary nature of our research, we searched a broad range of databases and knowledge repositories in the health sciences and engineering disciplines. This strategy was designed to ensure a comprehensive review of relevant literature. The retrieval period for the search was not limited. The search strategy, including keywords and search strings, is summarized in Textbox 1.

Articles were imported into Covidence (Veritas Health Innovation Ltd) screening and data extraction software for conducting systematic reviews. All titles and abstracts were screened by at least 2 members of the research team (SA, TR, or JM) using the inclusion and exclusion criteria detailed in Textbox 2. Any discrepancies were reviewed by a member who was not an original reviewer.

Articles identified in the title and abstract screening as relevant were included in a full-text review using the same inclusion and exclusion criteria and review process. To identify any studies that may have been missed during the initial search, we conducted both forward and backward searching.

Textbox 1. Academic peer-reviewed journal search strategy.

Search strategy

- Databases: Scopus, IEEE, PubMed, Web of Science, EBSCO, CINAHL, Cochrane, and Google Scholar
- Limits: language (only resources in English) and species (studies on human)
- Date: all literature till January 20, 2024
- Search string: #1 AND #2 AND #3
  - #1 “standards” OR “guideline*”
  - #2 “Agetech” OR “ambient assisted living” OR “active assisted living” OR “wearables” OR “mobile digital technology” OR “remote patient monitoring” OR “telemedicine” OR “telehealth” OR “gerontology” OR “digital technology” OR “mhealth” OR “mobile health” OR “assistive technology” OR “internet of things” OR “virtual reality” OR “voice recognition” OR “artificial intelligence” OR “smart technology” OR “smart assistive technology” OR “digital” OR “technology”
  - #3 “Aging” OR “ageing” OR “elderly” OR “seniors” OR “aging in place” OR “older adult” OR “care partner” OR “senior citizens” OR “aging population” OR “gerentol*” OR “geriatric” OR “care givers”

Textbox 2. Inclusion and exclusion criteria.

Inclusion criteria

- English language
- Only peer-reviewed scholarly articles and conference papers (In this study, we limited the inclusion criteria to peer-reviewed journal articles and full conference papers to ensure a high level of quality and academic rigor. We excluded book chapters, dissertations, and conference abstracts as they often lack the comprehensive detail, consistency, and peer-review standards needed for robust analysis, thereby maintaining the relevance and feasibility of our scoping review.)
- Subject matter
    - AgeTech-related technology standards or guidelines (using the definition outlined in the third paragraph of the Background section)
- No restrictions on publication date

Exclusion criteria

- Non-English
- Article types
    - Book chapters
    - Dissertations
    - Conference abstracts
    - Reports
- Subject matter
    - Standards or guidelines that do not emphasize age-related technology
    - Standards or guidelines intended for devices specifically aimed at children aged <18 years
    - Standards or guidelines intended for medical devices delivering clinical health care services within a clinical setting that require professional or medical expertise for use, monitoring, and interpretation (includes all class II, III, and IV medical devices and some class I medical devices if they are intended for medical use)
    - Documents addressing frameworks and models

Data Extraction

Data were extracted into an Excel worksheet with a variety of categories that systematically captured information relevant to the studies' objectives and research questions. Details extracted from documents included author and year, journal or conference name and scope, country, type of study, the document's type, aim of study, AgeTech type, developer of the standard or guideline, the old or new feature of the standard or guideline (the meaning of this variable is the response to the question: was the standard or guideline developed for the first time in this study, or was it developed previously?), methodology of standard or guideline development, target stakeholders of the standard or guideline (the meaning of this variable is the response to the question: who is going to use these standards and guidelines in AgeTech development?), characteristics of older adults as end users of AgeTech, main aspects of the standards or guidelines, results of the evaluation of the developed standard or guideline, important conclusions of the study, main limitations of the study, and gap of the study and recommendations for future studies.

Data Analysis and Presentation of Results

Both quantitative and qualitative methods were used for data analysis. We used descriptive methods to analyze quantitative variables and then conducted a thematic analysis on data from 3 qualitative variables.

For quantitative analysis, extracted data were imported into SPSS (version 26; IBM Corp), and basic descriptive statistics were calculated, representing information on the publication year, country, journal or conference name, scope of the journal or conference, type of study, the document's type, the old or new feature of the standard or guideline, AgeTech type, developer of the standard or guideline, target stakeholders of the standard or guideline, characteristics of older adults as end users of AgeTech, and main aspects of the standard or guideline.

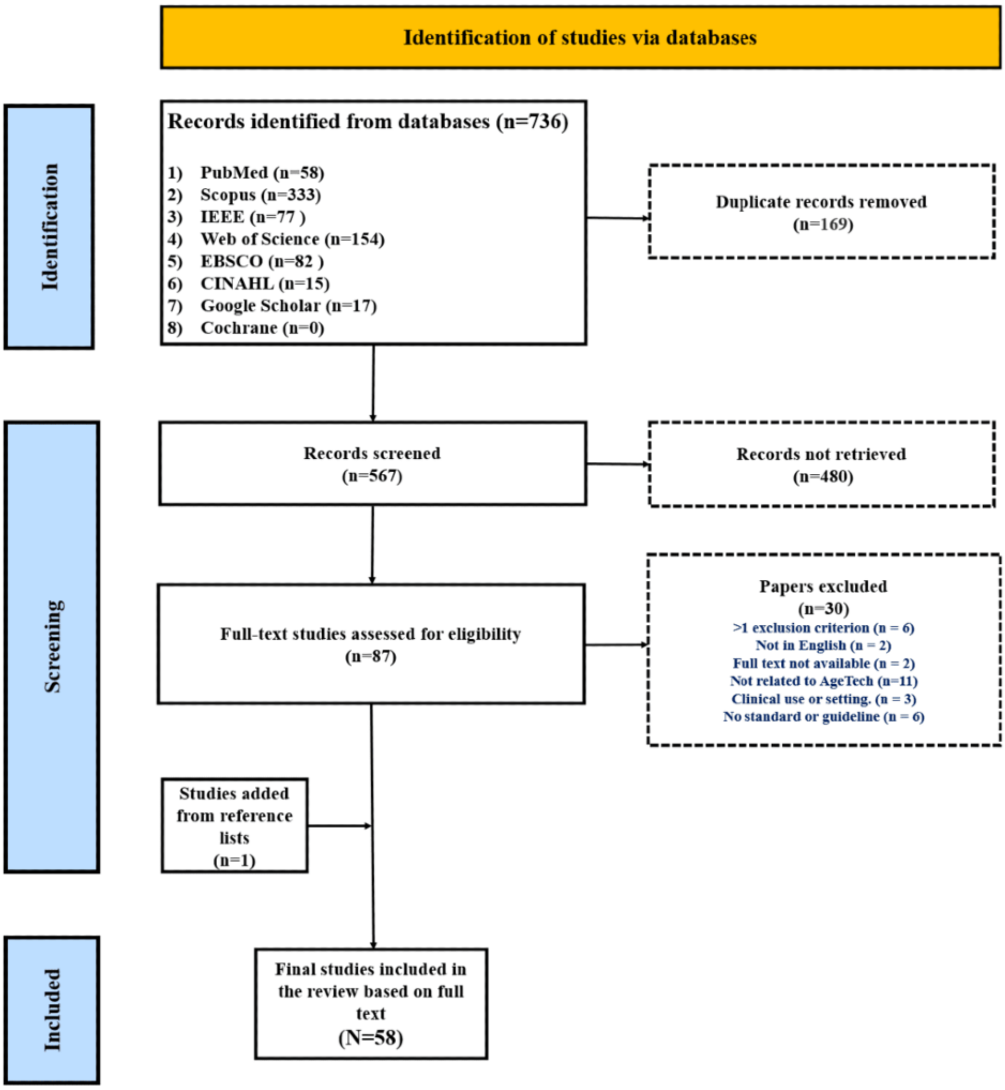
For qualitative analysis, we used thematic analysis to examine 3 qualitative variables: the aim of the study, the main limitations of study, and gap of the study and recommendations for future studies. Thematic analysis is a widely recognized method in both scoping and systematic reviews and has been applied in numerous studies to provide a deeper understanding of qualitative data [23-26]. Data from each variable were individually imported into NVivo (version 14; QSR International). Two coders conducted a thematic analysis following the guidelines established by Thomas and Harden [27]. Thematic analysis was conducted in 3 stages: free coding of primary study findings, organization of these "free codes" into related areas to form "descriptive" themes, and the development of "analytical'" themes.

Results

Overview

We selected 58 research papers [19,28-84] from an initial pool of 736 studies identified through the database search. We organized the information extracted from the 58 included documents into Multimedia Appendices 1-3. Figure 1 outlines the full process based on PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.

Figure 1. Inclusion flowchart for peer-reviewed articles, based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.



Multimedia Appendix 1 [19,28-84] presents a summary of the studies, detailing 6 variables: publication year, country, journal or conference name, scope of the journal or conference, type of study, and document's type. Multimedia Appendix 2 [19,28-84] compiles variables that most of them analyzed through quantitative analysis in the subsequent stage, featuring 8 columns: the old or new feature of the standard or guideline, AgeTech type, developer of the standard or guideline, methodology of standard or guideline development, target stakeholders of the standard or guideline, characteristics of older adults as end users of AgeTech, main aspects of the standard or guideline, and results of the evaluation of the developed standard or guideline. Finally, Multimedia Appendix 3 [19,28-84] summarizes variables that 3 of them analyzed using qualitative analysis in the next stage, including aim of the study, important conclusions, main limitations of the study, and gaps in the study, along with recommendations for future research.

In the following sections, we will present the analysis results for Multimedia Appendices 1-3.

Characteristics of the Study and Literature Distribution

Conference papers made up the majority of publications at 59% (34/58), while journal papers accounted for 41% (24/58). The field of computer science accounted for 69% (40/58). Other areas included health sciences (5/58, 9%), management and business sciences (2/58, 3%), multidisciplinary studies (9/58, 15%), and various other fields (2/58, 3%). Most of the publications were original research (46/58, 79%), while review articles constituted 21% (12/58) of the total. The research methods varied, with qualitative methods being the most common (37/58, 64%). Review articles also incorporated a review methodology (12/58, 21%), while quantitative methods (6/58, 10%) and mixed methods (3/58, 5%) were less commonly used (Multimedia Appendix 1). Table 1 provides a summary of the retrieved publications' characteristics.

Most of the papers (28/58, 48%) were published from 2019, as illustrated in Figure 2.

The United States was the leading source of publications (8/58, 14%), while Germany and Portugal each contributed to 9% (5/58) of the publications (Table 2).

Table 1. Summary of the retrieved publications' characteristics (N=58).

	Publications, n (%)
Document type	
Conference paper	34 (59)
Journal paper	24 (41)
Scope of journals or conferences	
Computer sciences	40 (69)
Health sciences	5 (9)
Management and business sciences	2 (3)
Multidisciplinary	9 (15)
Other	2 (3)
Research type	
Original	46 (79)
Review	12 (21)
Research methods	
Review	12 (21)
Qualitative	37 (64)
Quantitative	6 (10)
Mixed	3 (5)

Figure 2. Distribution of documents by year.

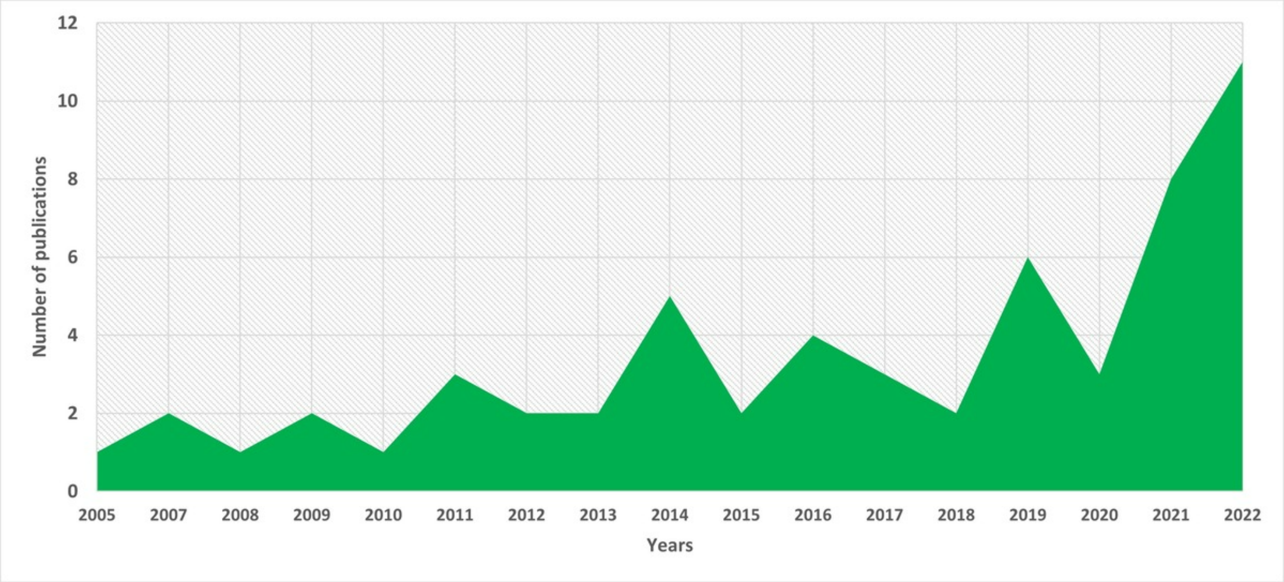


Table 2. Source of publications by country (N=58).

	Publications, n (%)
Australia	2 (3)
Austria	1 (2)
Belgium	3 (5)
Brazil	1 (2)
Canada	3 (5)
China	1 (2)
Denmark	1 (2)
Finland	3 (5)
France	1 (2)
Germany	5 (9)
Greece	3 (5)
India	1 (2)
Italy	2 (3)
Japan	2 (3)
Malaysia	1 (2)
Mexico	2 (3)
The Netherlands	3 (5)
Poland	1 (2)
Portugal	5 (9)
Saudi Arabia	1 (2)
South Korea	1 (2)
Spain	1 (2)
Sweden	1 (2)
Switzerland	1 (2)
Taiwan	1 (2)
Thailand	1 (2)
United Kingdom	2 (3)
United States	8 (14)

Findings From the Descriptive Quantitative Analysis

The analysis of the data included in Multimedia Appendix 2, regarding the status of standards or guidelines as “new” or “old,” indicated that a majority, 55% (32/58) instances, were classified as “new.” In contrast, 24% (14/58) of the instances were labeled as “N/A” (not applicable), indicating that the development status was either not applicable or not specified. The “old” category, signifying previously established standards or guidelines, accounted for 21% (12/58) of the instances.

In categorizing AgeTech types, we adopted a classification framework developed by AGE-WELL [10,85]. This framework includes 9 categories: “supportive homes and communities,” “health care and health service delivery,” “autonomy and independence,” “cognitive health and dementia,” “mobility and transportation,” “healthy lifestyles and wellness,” “staying connected,” “financial wellness and employment,” and “other.” Two authors with expertise in health informatics independently coded the AgeTech types using predefined AGE-WELL categories, achieving a high intercoder reliability with a Cohen κ score of 0.9, indicating strong agreement. Results indicate that the most prevalent AgeTech types with corresponding standards or guidelines are associated with the “staying connected” category (which includes mobile apps, social games, social and telepresence robots, friendly caller programs, and virtual reality technology), with a frequency of 31% (18/58). The “supportive homes and communities” category (encompassing smart homes, socially assistive robots, and age-friendly communities) was the second most frequent (16/58, 28%). Table 3 illustrates these findings.

Table 3. Distribution of studies based on AgeTech type (N=58).

	Studies, n (%)
Supportive homes and communities	16 (28)
Health care and health service delivery	7 (12)
autonomy and independence	5 (9)
Cognitive health and dementia	2 (3)
Mobility and transportation	1 (2)
Healthy lifestyles and wellness	4 (7)
Staying connected	18 (31)
Financial wellness and employment	1 (2)
Other	4 (7)

A substantially finding from the analysis pertains to the primary focus of the standards or guidelines mentioned in the selected publications. For clarity, we organized these into 11 categories. The results show that "design and development" is the most addressed aspect in AgeTech standards or guidelines, accounting for 36% (21/58) of the instances. "Usability and user experience" is the second most frequent area (11/58, 19%). In contrast, aspects receiving the least attention in AgeTech standards or guidelines in the academic literature were "ethics," "integration and interoperability," "accessibility," and "acceptance or adoption," each accounting for 3% (2/58) of the instances, and "privacy and security" and "data quality," each accounting for 2% (1/58) of the instances. These findings are presented in Table 4. It should be noted that in this classification "design and development" encompasses all technical aspects that are important in technology design. We could classify "usability and user experience" under the "design and development" category. However, we decided not to do so because of the significance of "usability and user experience" in technology design as well as the explicit focus of studies on this aspect. Therefore, we preferred to separate them from the broader "design and development" aspect. Furthermore, it should be noted that "not applicable" refers to documents where we could not identify specific aspects related to the standards or guidelines they addressed. In contrast, "others" refers to aspects that did not fit into these categories.

The most frequently targeted stakeholders for whom standards or guidelines were developed were "designers and developers," constituting 33% (19/58). Multiple stakeholders were the second most frequently mentioned, representing 28% (16/58) of the occurrences. Table 5 illustrates this discovery.

"General older adult population" was the largest group of end users for AgeTech, accounting for 71% (41/58). This classification was applied to end users of AgeTech in cases where the study did not define or describe the specific characteristics of older adults but only mentioned older adults or older population. Table 6 presents these results.

Table 4. The focus of guidelines or standards in studies based on frequencies (N=58).

	Studies, n (%)
Not applicable	9 (16)
Usability and user experience	11 (19)
Ethics	2 (3)
Accessibility	2 (3)
Data quality	1 (2)
Design and development	21 (36)
Cultural competence	3 (5)
Acceptance or adoption	2 (3)
Privacy and security	1 (2)
Integration and interoperability	2 (3)
Other	4 (7)

Table 5. Frequency of target stakeholders of guidelines or standards (N=58).

	Studies, n (%)
Not applicable	12 (21)
Various stakeholders	16 (28)
Designers and developers or companies	19 (33)
Health care providers	1 (2)
Older adults	7 (12)
Researchers	2 (3)
Other	1 (2)

Table 6. Frequency of end users of AgeTech demographics (N=58).

	Studies, n (%)
General older population	41 (71)
Older adults with cognitive problems such as dementia	5 (9)
Older adults who require residential care	5 (9)
Older adults with chronic conditions	2 (3)
Other	5 (9)

Findings From the Thematic Analysis of Qualitative Data

The thematic analysis, which focused on 3 qualitative variables: “the aim of the study,” “the main limitations,” and “recommendations for future research” (summarized in Table 7). This can also be seen in Multimedia Appendix 3.

In the thematic analysis for the “aim of the study,” certain themes, namely, “usability studies and design guidelines,” “assistive technologies for aging,” and “human-centered design and cultural considerations,” were the most frequently referenced in the identified literature. Conversely, critical aspects such as privacy and security, ethical considerations, accessibility considerations, integration and interoperability, user adoption, and data quality had the fewest references in the literature. This finding suggests a noteworthy emphasis within the academic literature on specific themes related to the “aims of the study” in the field of AgeTech. The recurrent references to these 3 main themes indicate a predominant focus on practical and user-centric aspects of technology development, particularly those tailored to aging populations. In contrast, the fewer references to the mentioned aspects indicate potential gaps in the current research landscape. This could imply that the existing literature may not adequately address these crucial dimensions, and there might be a need for more research and attention in these areas to ensure a comprehensive and ethically sound approach to AgeTech development. The findings underscore the importance of a balanced and holistic perspective when conducting research in AgeTech, urging scholars and practitioners to broaden their focus beyond usability and design guidelines to also address ethical, privacy, and accessibility considerations essential for the responsible and inclusive development of technologies for aging populations. In addition, these results indicate that assistive technologies and ambient assisted living (AAL) technologies constitute a significant portion of references in the AgeTech domain. It also suggests that one of the most crucial subsections within the AgeTech domain is associated with solutions related to AAL. These results align with the findings derived from our quantitative analysis. In addition, regarding the thematic analysis for the “aim of the study,” we can summarize all themes into 3 general domains: “inclusive design and accessibility,” “technology-enabled health and well-being,” and “ethics, security, and digital governance.” Textbox 3 illustrates this summary of themes for the aim of the study.

Table 7. Summary of results from the thematic analysis of qualitative data for 3 qualitative variables.

Goal and key emergent themes	Publications defining this theme, n	A short explanation of the theme	Single quotes from literature
Aim of study			
Usability studies and design guidelines	34	Numerous studies aimed to enhance the usability of mobile devices for older adults through the development of comprehensive design guidelines. For instance, 1 study emphasized the creation of a robust set of design guidelines based on 4 design strategies to ensure the usability of mobile devices for older users.	"The purpose of this research study was to develop a robust, integrative set of design guidelines based on the four design strategies to ensure usability of mobile devices by older adults." [35]
Assistive technologies for aging	14	A significant theme emerged around the exploration of assistive technologies for aging individuals. Studies within this theme proposed procedures and guidelines to support further research projects, contributing to internal quality control for testing assistive technologies in real-life settings, such as living laboratories at home.	"The procedure is suggested as a guideline to support further research projects and to contribute to an internal quality control of testing involving people 65+ testing assistive technologies in Living Labs at home." [59]
Human-centered design and cultural considerations	12	This theme delved into the incorporation of culturally competent assistive behaviors in robots. Studies discussed how guidelines could be encoded in robots to effectively adjust their actions, gestures, and communication to align with diverse cultural contexts.	"This paper discussed how guidelines describing culturally competent assistive behaviors can be encoded in a robot to effectively tune its actions, gestures and words." [39]
AAL[a]	5	In this theme, researchers aimed to understand the standards and policy guidelines used by companies in creating AAL technologies. The goal was to identify gaps between available technologies, standards, and policies and what should be available for use in AAL applications.	"The aim of this study was to understand the standards and policy guidelines that companies use in the creation of AAL technologies and to highlight the gap between available technologies, standards, and policies and what should be available for use." [19]
Cognitive stimulation and health software	7	This theme focused on gaining insight into the mistakes made by individuals with mild dementia during wayfinding on independent walks. The objective was to understand cognitive stimulation and the impact of health software in addressing these challenges.	"The goal of our study is to gain insight into frequently made mistakes that people with mild dementia make in wayfinding, while taking an independent walk." [28]
Digital impact on older adults	6	This theme explored the global survey on aging-inclusive digital economy and related standards. The studies aimed to clarify the influence and challenges of the digital economy on the older population, emphasizing the expectations and demands of building an aging-inclusive digital economy.	"This paper introduces the global survey on ageing-inclusive digital economy and related standards conducted in early 2021, which aimed to clarify the influence and challenges of the digital economy on the elderly, and the expectations and demands of building an ageing-inclusive digital economy." [26]
Ethical guidelines and considerations	5	This theme addresses ethics, wherein studies reviewed literature on ethics and home monitoring technology. They proposed ethical models for technology development, discussed issues for reviewers to consider, and recommended ethical guidelines to direct the research and implementation process.	"This paper aims to 1) review the relevant literature specific to ethics and home monitoring technology, 2) present an ethical model for technology development, 3) raise pertinent issues for reviewers to consider in assessing applications, 4) discuss strategies to address IRB concerns, and 5) recommend ethical guidelines to direct the research and implementation process." [54]
Security considerations	2	This theme focused on analyzing the security requirements and challenges of eHealth IoT[b] applications. Studies proposed complete architectures to address security concerns in eHealth IoT applications.	"Analyze the security requirements and challenges of e-Health Internet of Things (IoT) applications and propose a complete architecture to address them." [63]
Telehealth and remote monitoring	3	This theme aimed at developing telehealth principles and guidelines specifically tailored for older adults.	"Development of telehealth principles and guidelines for older adults." [34]
Accessibility considerations	1	This theme contains 1 study that emphasized the unique accessibility issues for persons with disabilities and older adults in online communities.	"The primary goals of this article are to raise awareness of the unique issues of accessibility for persons with disabilities and older adults in online communities and to identify key considerations for future development and research." [32]
Main limitations of study			

Goal and key emergent themes	Publications defining this theme, n	A short explanation of the theme	Single quotes from literature
Scope limitations	9	In this theme, studies acknowledged limitations concerning the scope of proposed guidelines. Notably, some topics crucial to care delivery, such as HIPAA[c] adherence, data privacy, and reimbursement, were not directly addressed. A representative quote emphasized the need for a more comprehensive approach.	"A limitation is that the proposed guidelines are not all-encompassing and certain topics important to care delivery were not directly addressed. These topics include Health Insurance and Portability Accountability Act adherence, data privacy, and reimbursement." [34]
Sample size and recruitment	7	This theme highlighted the limitation associated with sample size and recruitment. Studies frequently acknowledged small sample sizes, as illustrated by 1 study that mentioned a small interviewee sample of 28 participants as a potential constraint.	"The interviewee sample was small at 28 participants." [77]
Validation and bias	7	This theme emerged in studies using design guidelines primarily intended for web applications. In some cases, these guidelines may not be directly applicable to mobile platforms, and there may be bias in the interpretation of the transition from Culture Interface Design Matrix to design decisions. The quote reflects this concern.	"Aaron Marcus's design guidelines are mainly for web, so the design guidelines may not be applicable on mobile in some cases. In addition, the transition from Culture Interface Design Matrix to design decision is interpreted by the research team. Thus, potential bias may exist." [41]
Data collection and analysis limitations	4	This theme highlights studies pointing out limitations in the current approach to interface analysis, which often involve manual processes. This was recognized as time consuming due to multiple scopes and technical debt. Recommendations were made for the automation of the process to enhance efficiency, reduce costs, and maximize test coverage.	"The current approach to interface analysis involves manual analysis, which is time-consuming due to multiple scopes and technical debt. To streamline the process, automation is recommended, offering benefits like cost reduction and test coverage maximization." [29]
Technology and interface limitations	4	This theme highlights the challenges of integrating nonstandardized and standardized wearable activity trackers. Although the approach provided a broad integration, there were difficulties in incorporating proprietary interfaced devices, as they were either unreadable or inaccessible.	"Although the approach provided a very broad integration of nonstandardized as well as standardized wearable activity trackers, it was challenging to integrate existing proprietary interfaced devices as they could not be read or be accessed." [80]
Methodological and research design	3	In this theme, the practical circumstances associated with evaluation studies were acknowledged as potential sources of deviation from standards, leading to heterogeneity in evaluation methodologies. This theme emphasized the impact of real-world circumstances on the adherence to predefined standards in evaluation studies.	"The practical circumstances of an evaluation study can cause deviations in the standards, thus producing heterogeneity in the evaluation methodologies. [65]
External factors impacting the study	2	In this theme, the analysis identified external factors impacting studies in the AAL field. Despite extensive research efforts, the proliferation of AAL technologies into real-world use has not matched expectations. This limitation was attributed to various research and industry organizations active in the field.	"This review has identified a high number of research and industry organizations who are currently active within the AAL field. However, the extensive research effort has not yet led to a significant proliferation of technologies into real world usage." [25]
Main study recommendations for future research			
Refinement and iteration of guidelines	10	This theme predominantly focused on refining and iterating guidelines for various domains, such as psychotherapy, special needs education therapy, jobs screening, and occupational therapy. The aim is to enhance intervention practices, achieve more accurate measurements through game-based approaches, and explore different types of evaluations involving psychotherapy experiments using intelligent methods.	"The proposed criteria and guidelines can be adapted to other psychotherapy domain, such as special needs education therapy, jobs screening, and occupational therapy. Furthermore, this could possibly improve the existing intervention practices by having more accurate measurement through a game-based approach. Future works might consider different type of evaluation involving psychotherapy experiments using intelligent manners." [42]
Future plans for evaluation and trials	9	This theme contained studies highlighting the need for future evaluations and trials of the proposed guidelines. These included user testing, proofs of concept, experiments with developers and older adults, and other assessment methods to ensure the effectiveness of the guidelines in real-world scenarios.	"As future work, new studies will be considered to evaluate the set of guidelines (AGE 1.2.), such as: user testing, proof of concepts, experiments with developers and seniors, among others." [27]

Goal and key emergent themes	Publications defining this theme, n	A short explanation of the theme	Single quotes from literature
Design for aging and user-centered technologies	9	This theme emphasized the evaluation of persuasive strategies and their impact on the motivation of older adults to exercise. Long-term goals include further guideline development to assist researchers and practitioners in designing user-centered assistive persuasive technologies for and with older people.	“As future work, we plan to evaluate the effectiveness of our persuasive strategies and their influence on the elderly’s motivation to exercise. In long-term perspective, we aim to develop our guidelines further in order to help other researchers and practitioners to design user-centered assistive persuasive technologies for and together with elderly.” [45]
Dissemination, implementation, and engagement	8	This theme highlighted the next steps in research that involve investigating older adults’ opinions of robotic assistance, assessing the length of engagement, and exploring robot assistance for older adults with impairments. In addition, this theme suggests a focus on real-world engagement and practical applications of assistive technologies.	“The next step in this line of research would be to investigate older adults’ opinions of seeing the robot in person, length of engagement, or robot assistance for older adults with impairments.” [36]
Development of assistive technologies	6	This theme emphasized future plans to develop an editing tool for therapists, allowing them to customize exercises based on user preferences. Additionally, the goal is to expand mobile games to include more complex exercises related to daily living activities, enhancing the transfer of learning to real-world contexts.	“Future plans involve creating an edition tool for therapists that allows for customization of exercises to fit user preferences. The game will be developed for mobile devices and expanded with more complex exercises related to daily living activities, such as shopping, money management, and social relationships, to enhance learning transfer to real contexts.” [30]
Ethical awareness and AI[d] decision-making	4	This theme contained studies recommending further exploration of the effectiveness of ethical guidelines and a comparison of methods for promoting ethical awareness in the context of AI decision-making.	“One subject for the further studies could be to study the effectiveness of the ethical guidelines or to compare different methods of promoting ethical awareness.” [31]
Refinement of design and data	4	This theme highlighted the need for extending the proposed data format beyond body-worn sensors to include signals from other sources, such as video cameras and ambient sensors. Further efforts were deemed necessary to enhance the applicability of the presented consensus.	“The presented consensus focused only on data recorded with body-worn sensors. The proposed data format should be applicable to other type of signals, for example, from video cameras and ambient sensors, but further efforts are needed to extend the concept.” [33]
Aging inclusivity	3	This theme included recommendations focusing on standards and conformity assessment activities for an aging society and the silver economy. The goal of this theme is to promote research on standardization in the silver economy, encourage stakeholder involvement, and establish a long-term dialogue mechanism.	“The paper recommends a focus on standards and conformity assessment activities for the ageing society and silver economy, discussing problems and solutions, and sharing best practices among countries, territories, and organizations. It also suggests conducting research on standardization of the silver economy, encouraging more involvement, and creating a long-term dialogue mechanism.” [26]
Universal accessibility of online communities	2	This theme urged researchers to contribute to creating universally accessible online communities by developing accessibility guidelines, conducting studies on barriers faced by different groups, and exploring features that provide equal access.	“Researchers can contribute to creating universally accessible online communities by developing accessibility guidelines, conducting studies on barriers faced by these groups, and exploring features that would provide equal access.” [32]
Developing best practices	1	These themes include a single publication that covered various topics, such as developing best practices, ethnography and co-design sessions, privacy and security in AAL technology, safety and instructions in navigational aids, and validation and user experience studies.	“The paper recommends a focus on standards and conformity assessment activities for the ageing society and silver economy, discussing problems and solutions, and sharing best practices among countries, territories, and organizations.” [26]
Ethnography and co-design sessions	1	These themes include a single publication that covered various topics, such as developing best practices, ethnography and co-design sessions, privacy and security in AAL technology, safety and instructions in navigational aids, and validation and user experience studies.	“An ethnography could give us a much better understanding of how well seniors would be able to use the system in real conditions. Future work should also include the perspective of the rest of the stakeholders, as they can provide a more comprehensive view on this strategic application domain.” [40]

Goal and key emergent themes	Publications defining this theme, n	A short explanation of the theme	Single quotes from literature
Focus on standards and conformity assessment activities	1	These themes include a single publication that covered various topics, such as developing best practices, ethnography and co-design sessions, privacy and security in AAL technology, safety and instructions in navigational aids, and validation and user experience studies.	"The paper recommends a focus on standards and conformity assessment activities for the ageing society and silver economy, discussing problems and solutions, and sharing best practices among countries, territories, and organizations." [26]
Privacy and security in AAL technology	1	These themes include a single publication that covered various topics, such as developing best practices, ethnography and co-design sessions, privacy and security in AAL technology, safety and instructions in navigational aids, and validation and user experience studies.	"In terms of Privacy by Design guidelines, future work could include data minimization and anonymization." [63]
Safety and instructions in navigational aids	1	These themes include a single publication that covered various topics, such as developing best practices, ethnography and co-design sessions, privacy and security in AAL technology, safety and instructions in navigational aids, and validation and user experience studies.	"In further studies one could concentrate on adding safety and warning instructions to the default left and right instructions of the current navigational aids for pedestrians." [28]
Validation and user experience studies	1	These themes include a single publication that covered various topics, such as developing best practices, ethnography and co-design sessions, privacy and security in AAL technology, safety and instructions in navigational aids, and validation and user experience studies.	"We found that more validation and user experience studies are required to produce better AAL systems with additional user feedback and participatory development approaches." [25]

[a] AAL: ambient assisted living.

[b] IoT: Internet of Things.

[c] HIPAA: Health Insurance and Portability Accountability Act.

[d] AI: artificial intelligence.

Textbox 3. Summary of themes for the aim of the study.

Inclusive design and accessibility

- Usability studies and design guidelines
- Assistive technologies for Aging
- Human-centered design and cultural
- Accessibility considerations

Technology-enabled health and well-being

- Ambient assisted living
- Cognitive stimulation and health software
- Telehealth and remote monitoring

Ethics, security, and digital governance

- Ethical guidelines and considerations
- Security considerations
- Digital impact on the older adults

In the thematic analysis for the "main limitations of study," the results revealed that certain themes, including "scope limitations," "sample size and recruitment," and "validation and bias," were more frequently referenced in the included documents. On the basis of this finding, 1 hypothesis could be that the limitations mentioned in the literature are likely linked to the complex nature of developing standards or guidelines. Furthermore, it would be advisable for researchers to strive to mitigate these limitations in their future studies. In addition, regarding the thematic analysis for the "main limitations of study," we can summarize all themes into 3 general domains: "scope and applicability limitations," "methodological limitations," and "external and contextual factors." Textbox 4 illustrates this summary of themes for the main limitations of the study.

In the thematic analysis of “recommendations for future research” within the main study, we found that specific themes, such as “refinement and iteration of guidelines;” “evaluation and trials of standards or guidelines;” “design for aging and user-centered technologies;” and “dissemination, implementation, and engagement” were more frequently referenced in the examined literature. These suggestions indicate a forward-thinking and comprehensive approach, addressing not only the theoretical aspects of guideline development but also emphasizing the practical facets of implementation and user engagement. In addition, regarding the thematic analysis for the “recommendations for future research,” we can summarize all themes into 6 general domains: “guideline development and refinement;” “evaluation, trials, and testing;” “user-centered and inclusive design;” “assistive and ethical technology development;” “dissemination, implementation, and real-world engagement;” and “specialized research methods.” Textbox 5 illustrates this summary of themes for the recommendations for future research.

Textbox 4. Summary of themes for the main limitations of study.

Scope and applicability limitations

- Scope limitations
- Technology and interface limitations

Methodological limitations

- Sample size and recruitment
- Validation and bias
- Data collection and analysis limitations
- Methodological and research design

External and contextual factors

- External factors impacting the study

Textbox 5. Summary of themes for the recommendations for future research.

Guideline development and refinement

- Refinement and iteration of guidelines
- Refinement of design and data
- Developing best practices

Evaluation, trials, and testing

- Future plans for evaluation and trials
- Validation and user experience studies

User-centered and inclusive design

- Design for aging and user-centered technologies
- Aging inclusivity
- Universal accessibility of online communities

Assistive and ethical technology development

- Development of assistive technologies
- Ethical awareness and artificial intelligence decision-making
- Privacy and security in ambient assisted living technology

Dissemination, implementation, and real-world engagement

- Dissemination, implementation, engagement
- Focus on standards and conformity assessment activities

Specialized research methods

- Ethnography and co-design sessions
- Safety and instructions in navigational aids

Discussion

Overview

In response to the global trend of an aging population and the call for increasing reliance on technology to address the challenges associated with aging, this academic literature review aims to provide a comprehensive overview of the current state of design and development guidelines and standards for AgeTech to key stakeholders in this field, such as policy makers, developers, researchers, and third parties. Our discussion is structured to reflect the findings across 3 main areas: the characteristics of the study and literature distribution, the evidence of quantitative analysis, and insights from qualitative analysis.

Characteristics of the Study and Literature Distribution

Our analysis showed that most research studies on AgeTech standards and guidelines come from the field of computer science, particularly those focused on technical development aspects such as usability and user interface design.

In examining the characteristics of retrieved publications, the results indicated that the majority were original research. Furthermore, given that the research and development processes related to standards or guidelines tend to be qualitative in nature, this study highlighted the extensive use of qualitative methods in most publications. This finding is consistent with both previous research and our predictions.

Examining the distribution of publications over the years, there has been an increased focus on research in standards or guidelines in the AgeTech and AAL domains, particularly in the years from 2019. This trend is influenced by the growing development of AgeTech and AAL. In addition, in examining the distribution of publications by country, it is observed that scientists from the United States and several European countries, including Germany, Portugal, the Netherlands, Belgium, Finland, and Canada, contributed more publications in this domain. This finding may be associated with the varying levels of technological development and aging challenges present in these countries. It is also possible that these countries view standards and guidelines as a means to better frame AgeTech development, thereby facilitating adoption. It may also be due to the availability of AgeTech standards that are more specific to those regions.

Evidence of Quantitative and Qualitative Analysis

Regarding the findings on the type of AgeTech referenced, the results revealed that the most frequently referenced standards and guidelines were associated with the “staying connected” category, encompassing mobile apps, social games, social and telepresence robots, friendly caller programs, and virtual reality technology, accounting for 31% (18/58) of the instances. Following closely, the "supportive homes and communities" domain, covering smart homes, socially assistive robots, and age-friendly communities, accounted for 28% (16/58) of the instances. The results also indicated a lack of standards and guidelines in existing knowledge within the academic literature in certain AgeTech domains or types such as "mobility and transportation" (including smart wheelchairs, autonomous vehicles, and transportation service mobile apps), "financial wellness and employment" (encompassing financial mobile apps, cybersecurity enhancement programs, technology-based vocational programs, and workplace accommodations), "cognitive health and dementia" (covering diagnostic and predictive tools, wandering detection, and locator and GPS tracking devices), and "health care and health service delivery" (involving nanotechnologies, wearable health technologies, telemedicine, and medication management systems). The lack of standards and guidelines in the academic literature in these specific AgeTech categories may be attributed to 2 factors. The first could be the limited development in these areas of AgeTech, and the second could be the lack of attention to creating standards or guidelines in these specific AgeTech domains. In line with the first reason, a scoping review by Bergschöld et al [11] published in 2024, which included 344 documents exploring the characteristics and range of reviews about technologies for aging in place, found that assistive technologies were the most frequently discussed AgeTech type. This finding probably corresponds with the results of our own study, where AgeTech related to assistive technologies emerged as the second most prevalent category.

A significant finding revolves around the primary aspects of AgeTech standards and guidelines: "design and development" along with "usability and user experience" emerges as the predominant focus, underscoring the industry's emphasis (or literature's focus) on these domains. In simpler terms, most efforts are directed toward developing or addressing standards and guidelines in these specific areas of AgeTech. Conversely, areas such as "privacy and security," "data quality," "ethics," "integration and interoperability," "accessibility," and "acceptance or adoption" receive limited attention, indicating potential gaps in the current landscape of AgeTech standards and guidelines. In light of these findings, there is a need for increased attention to developing or addressing standards and guidelines in these domains. While it is important to clarify that the findings relate to the use of standards and guidelines in academic literature, this does not necessarily signify an absence of standards or guidelines but rather a lack of their documented use in these publications. Furthermore, it is plausible that they are being used in the industry during the development of AgeTech, but their implementation might not be documented in the published literature. In their study, Memon et al [28] conducted a literature survey to explore state-of-the-art AAL frameworks, systems, and platforms, aiming to identify essential aspects and investigate critical issues from various perspectives including design, technology, quality-of-service, and user experience. The main aspects identified in AAL systems include medical device interoperability and integration; AAL system architectures, security, privacy, and data protection; design and development methodologies for AAL systems and services; frameworks and open solutions; quality attributes such as usability, accuracy, dependability, availability, reliability, technology standards, and specifications; and user experience as well as miscellaneous research in AAL systems and reviews or surveys in AAL. These findings offer valuable insights for this study in identifying the main aspects within the ALL and AgeTech domains. It is important to emphasize that a significant area of focus for researchers is the development of guidelines for designing user interfaces and improving user experience specifically for older adults. Numerous studies and systematic reviews have focused on this domain [38,41,54,71,75,81].

Concerning the frequency of stakeholders for whom standards or guidelines were developed, it appears that due to the primary focus on "design and development" along with "usability and user experience," it is logical that the most frequently targeted stakeholders were "designers and developers," accounting for 33% (19/58) of the instances. Furthermore, multiple stakeholders were mentioned in 28% (16/58) of the documents.

Regarding the demographic classification of adults targeted by AgeTech standards or guidelines, the results indicate that the category "general older adult population" is the most prevalent, comprising 71% (41/58) of the studies. Other older adult categories, such as "older adults living with chronic conditions," "older adults living in residential care," and "older adults living with cognitive impairment," have lower frequencies. Although these results align with the early stages of AgeTech standards or guidelines development, it is advisable for scientists, standards development organizations, or associations to focus more on specific groups or populations of older adults in the future, such as those with chronic diseases, aging in place and residential care, cognitive health, and dementia. Each specific group has distinct needs, requirements, and conditions, necessitating the development of tailored standards or guidelines. It is noteworthy that the results of Bergschöld et al [11] are consistent with our study. They reported that in most review studies on AgeTech, the general population of older adults was the most frequently mentioned type of population. This finding aligns with the results of our study.

Limitations

First and foremost, it is essential to emphasize the importance of conducting both a gray literature review and an academic literature review to comprehensively assess the current state of standards and guidelines in the AgeTech field and identify any critical gaps. To clarify, in this project, "gray literature" specifically refers to the collection of relevant practical standards and guidelines for AgeTech design and development, typically published by standardization organizations or other reputable institutions. The gray literature review is currently underway, and the findings will be presented in a subsequent publication by our research team. In addition, despite the robust methodological aspects of the scoping review design, certain limitations should be acknowledged. While we collaborated with an information specialist and conducted pilot tests with various terms to optimize the comprehensiveness of our search strategy, and searched multiple databases using relevant keywords, it is possible that not all pertinent search terms have been included. In addition, during the search process, we only considered English-language articles. Despite our efforts, which included manual searches and consultations with experts, there may still be missing documents. Hence, it is essential to acknowledge the potential risk of overlooking relevant articles.

Conclusions

This review aimed to comprehensively outline the current state of standards and guidelines used in AgeTech design and development as reported in academic literature. Its primary focus was to explore existing knowledge and identify key gaps in AgeTech guidelines and standards. Using a scoping review and thematic analysis, we evaluated 58 academic sources using both quantitative and qualitative methods. Our primary finding emphasizes the predominant focus on "design and development" and "usability and user experience" within AgeTech standards and guidelines, reflecting the industry's concentrated efforts in these domains. Conversely, areas such as "privacy and security," "data quality," "ethics," "integration and interoperability," "accessibility," and "acceptance or adoption" receive limited attention, revealing potential gaps in the use and implementation of standards and guidelines across the academic landscape. Furthermore, the study highlights significant references to the "staying connected" and "supportive homes and communities" categories within AgeTech types, whereas categories such as "mobility and transportation," "financial wellness and employment," "cognitive health and dementia," and "health care and health service delivery" lack sufficient standards and guidelines in academic literature. Moreover, the study highlights the notable presence of assistive technologies and AAL technologies in AgeTech, underscoring the prevalence of these solutions within the field. These insights are valuable for stakeholders, including AgeTech innovators, policy makers, health and social care providers, researchers, and experts by experience, as they guide efforts toward priority areas within AgeTech.

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Authors' Contributions

SA, JM, HM, FM, PD, JT, and PPM conceived the idea of the manuscript and made substantial contributions to this scoping review. SA conducted the literature search. SA, JM, TR, GBN, and TH-P conducted study selection and data extraction. SA, JM, TR, GBN, and TH-P conceptualized and operationalized the object of interest. SA and TR conducted the data analysis and synthesis. SA was involved in the drafting of the manuscript. SA, JM, HM, FM, PD, JT, GBN, TH-P, and PPM revised the manuscript for important intellectual content. PPM, JM, HM, FM, PD, and JT supervised the project and allocated resources accordingly. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Overview of study characteristics.
[XLSX File (Microsoft Excel File), 24 KB - aging_v7i1e58196_app1.xlsx]

Multimedia Appendix 2
Raw data and key variables for quantitative analysis.
[XLSX File (Microsoft Excel File), 33 KB - aging_v7i1e58196_app2.xlsx]

Multimedia Appendix 3
Raw data and key variables for qualitative analysis.
[XLSX File (Microsoft Excel File), 43 KB - aging_v7i1e58196_app3.xlsx]

Multimedia Appendix 4
Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.
[DOCX File , 84 KB - aging_v7i1e58196_app4.docx]

References

1. World report on ageing and health. World Health Organization (WHO). 2015. URL: https://www.who.int/publications/i/item/9789241565042 [accessed 2024-04-29]
2. Rudnicka E, Napierała P, Podfigurna A, Męczekalski B, Smolarczyk R, Grymowicz M. The World Health Organization (WHO) approach to healthy ageing. Maturitas 2020 Sep;139:6-11 [FREE Full text] [doi: 10.1016/j.maturitas.2020.05.018] [Medline: 32747042]
3. Wilmoth JR, Bas D, Mukherjee S, Hanif N. World social report 2023: leaving no one behind in an ageing world. World Health Organization (WHO). URL: https://desapublications.un.org/publications/world-social-report-2023-leaving-no-one-behind-ageing-world [accessed 2024-04-29]
4. Consultations on the social and economic impacts of ageism in Canada: "what we heard" report. Federal/Provincial/Territorial Seniors Forum. URL: https://www.canada.ca/content/dam/esdc-edsc/documents/corporate/seniors/forum/reports/consultation-ageism-what-we-heard/UWBC-FinalDraftReport-WWH-EN-20230411-withISBN.pdf [accessed 2024-04-29]
5. Rosenberg MW, Puxty J, Crow B. Enabling older adults to age in community: employment and social development Canada. Government of Alberta. URL: https://open.alberta.ca/dataset/793bf56c-1788-4076-bae6-5d23e0adc073/resource/813e9fe4-3818-430c-8d4e-8f2ea0cdf2c4/download/sh-fpt-enabling-older-adults-to-age-in-community-2022.pdf [accessed 2024-04-29]
6. Nearly all Canadians 45+ years want to age at home, but only 1 in 10 (12%) say they can afford the cost of a personal support worker. Ipsos. URL: https://www.ipsos.com/en-ca/news-polls/Nearly-All-Canadians-45-Want-Age-Home-But-Only-1-in-10-Afford-Cost-PSW [accessed 2024-04-22]
7. Iciaszczyk N, Neuman K, Brierley A, MacDonald BJ, Sinha S. Perspectives on growing older in Canada: the 2022 NIA ageing in Canada survey. National Institute on Ageing, Canada. 2022. URL: https://www.niageing.ca/2022-annual-survey#:~:text=In%20less%20than%2010%20years,data%20from%20older%20Canadians%20themselves [accessed 2024-04-29]
8. 1 in 9 new long-term care residents potentially could have been cared for at home. Canadian Institute for Health Information. 2020. URL: https://www.cihi.ca/en/1-in-9-new-long-term-care-residents-potentially-could-have-been-cared-for-at-home [accessed 2024-09-26]
9. Genge C, McNeil H, Debergue P, Freeman S. Technology to support aging in place: key messages for policymakers and funders. Front Psychol 2023 Nov 16;14:1287486 [FREE Full text] [doi: 10.3389/fpsyg.2023.1287486] [Medline: 38078234]
10. Sixsmith A. AgeTech: technology-based solutions for aging societies. In: Rootman I, Edwards P, Levasseur M, Grunberg F, editors. Health of Older Adults: The Canadian Experience. Toronto, ON: Canadian Scholars Press; 2023:135.
11. Bergschöld JM, Gunnes M, Eide AH, Lassemo E. Characteristics and range of reviews about technologies for aging in place: scoping review of reviews. JMIR Aging 2024 Jan 22;7:e50286 [FREE Full text] [doi: 10.2196/50286] [Medline: 38252472]
12. Pirhonen J, Lolich L, Tuominen K, Jolanki O, Timonen V. "These devices have not been made for older people's needs" – older adults' perceptions of digital technologies in Finland and Ireland. Technol Soc 2020 Aug;62:101287. [doi: 10.1016/j.techsoc.2020.101287]
13. Ollevier A, Aguiar G, Palomino M, Simpelaere IS. How can technology support ageing in place in healthy older adults? A systematic review. Public Health Rev 2020 Nov 23;41(1):26 [FREE Full text] [doi: 10.1186/s40985-020-00143-4] [Medline: 33292707]
14. Kondratova I, Fournier H, Rajabiyazdi F. Aging in place virtual care technology from the user experience perspective. In: Proceedings of the 9th International Conference, ITAP 2023, Held as Part of the 25th HCI International Conference. 2023 Presented at: HCII '23; July 23-28, 2023; Copenhagen, Denmark p. 131-144 URL: https://dl.acm.org/doi/10.1007/978-3-031-34917-1_10 [doi: 10.1007/978-3-031-34917-1_10]
15. Bartlett L, Fowler HS. A Canadian roadmap for an aging society: current trends, opportunities and implications for standards. CSA Group. 2019. URL: https://www.csagroup.org/wp-content/uploads/CSA-Group-Research-Aging-Society-Standard-Roadmap.pdf [accessed 2024-04-29]
16. Florez-Revuelta F, Chaaraoui AA. Active and Assisted Living: Technologies and Applications. London, UK: Institution of Engineering and Technology; 2016.
17. Fadrique LX, Rahman D, Morita PP. The active assisted living landscape in Canada: insights for standards, policies, and governance. CSA Group. 2019. URL: https://www.csagroup.org/wp-content/uploads/CSA-Group-Research-AAL.pdf [accessed 2024-04-29]
18. Khaemba N, Traoré I, Mamun M. A Framework for synthetic AgeTech attack data generation. J Cybersecur Priv 2023 Oct 09;3(4):744-757. [doi: 10.3390/jcp3040033]
19. Fadrique LX, Rahman D, Vaillancourt H, Boissonneault P, Donovska T, Morita PP. Overview of policies, guidelines, and standards for active assisted living data exchange: thematic analysis. JMIR Mhealth Uhealth 2020 Jun 22;8(6):e15923 [FREE Full text] [doi: 10.2196/15923] [Medline: 32568090]
20. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005 Feb;8(1):19-32. [doi: 10.1080/1364557032000119616]
21. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010 Sep 20;5(1):69 [FREE Full text] [doi: 10.1186/1748-5908-5-69] [Medline: 20854677]

22. Tricco AC, Lillie E, Zarin W, O'Brien K, Colquhoun H, Kastner M, et al. A scoping review on the conduct and reporting of scoping reviews. BMC Med Res Methodol 2016 Feb 09;16(1):15 [FREE Full text] [doi: 10.1186/s12874-016-0116-4] [Medline: 26857112]
23. Murad C, Candello H, Munteanu C. What’s the talk on VUI guidelines? A meta-analysis of guidelines for voice user interface design. In: Proceedings of the 5th International Conference on Conversational User Interfaces. 2023 Presented at: CUI '23; July 19-21, 2023; Eindhoven, Netherlands p. 1-16 URL: https://dl.acm.org/doi/abs/10.1145/3571884.3597129#:~:text=A%20Meta%2DAnalysis%20of%20Guidelines%20for%20Voice%20User%20Interface%20Design,-Christine%20Murad%2C%20University&text=Over%20the%20past%20decade%2C%20voice,established%20guidelines%20for%20VUI%20design [doi: 10.1145/3571884.3597129]
24. Shafi S, Mallinson DJ. The potential of smart home technology for improving healthcare: a scoping review and reflexive thematic analysis. Hous Soc 2021 Oct 13;50(1):90-112. [doi: 10.1080/08882746.2021.1989857]
25. Capper TS, Williamson M, Chee R. How is cultural safety understood and translated into midwifery practice? A scoping review and thematic analysis. Nurse Educ Pract 2023 Jan;66:103507. [doi: 10.1016/j.nepr.2022.103507] [Medline: 36410133]
26. Salm M, Ali M, Minihane M, Conrad P. Defining global health: findings from a systematic review and thematic analysis of the literature. BMJ Glob Health 2021 Jun 03;6(6):e005292 [FREE Full text] [doi: 10.1136/bmjgh-2021-005292] [Medline: 34083243]
27. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol 2008 Jul 10;8(1):45 [FREE Full text] [doi: 10.1186/1471-2288-8-45] [Medline: 18616818]
28. Memon M, Wagner SR, Pedersen CF, Beevi FH, Hansen FO. Ambient assisted living healthcare frameworks, platforms, standards, and quality attributes. Sensors (Basel) 2014 Mar 04;14(3):4312-4341 [FREE Full text] [doi: 10.3390/s140304312] [Medline: 24599192]
29. Hou F, Cao L, Wang Q. Call for the ageing-inclusive digital economy and related standards: based on a global survey. In: Proceedings of the 13th International Conference on E-business, Management and Economics. 2022 Presented at: ICEME '22; July 16-18, 2022; Beijing, China p. 157-162 URL: https://dl.acm.org/doi/abs/10.1145/3556089.3556175 [doi: 10.1145/3556089.3556175]
30. de Oliveira Sestito CD, Fioravanti ML, Scatalon LP, de Mattos Fortes RP, Barbosa EF. Catalog of pedagogical practices, theories and teaching procedures for the elderly: contributions to the development of m-learning guidelines. In: Proceedings of the 2022 IEEE Frontiers in Education Conference. 2022 Presented at: FIE '22; October 8-11, 2022; Uppsala, Sweden p. 1-8 URL: https://ieeexplore.ieee.org/document/9962402 [doi: 10.1109/fie56618.2022.9962402]
31. Hagethorn F, Kröse B, de Greef P, Helmer M. Creating design guidelines for a navigational aid for mild demented pedestrians. In: Proceedings of the 2008 Conference on Ambient Intelligence. 2008 Presented at: Ami '08; November 19-22, 2008; Nuremberg, Germany p. 276-289 URL: https://link.springer.com/chapter/10.1007/978-3-540-89617-3_18 [doi: 10.1007/978-3-540-89617-3_18]
32. Romeiro C, Araújo P. Definition of guideline-based metrics to evaluate AAL ecosystem’s usability. Hum Behav Emerg Technol 2022 Nov 14;2022:1-19. [doi: 10.1155/2022/8939072]
33. Acosta CO, Palacio RR, Borrego G, García R, Rodríguez MJ. Design guidelines and usability for cognitive stimulation through technology in Mexican older adults. Inform Health Soc Care 2022 Jan 02;47(1):103-119. [doi: 10.1080/17538157.2021.1941973] [Medline: 34157914]
34. Nevanperä M, Rajamäki J, Helin J. Design science research and designing ethical guidelines for the SHAPES AI developers. Procedia Comput Sci 2021;192:2330-2339. [doi: 10.1016/j.procs.2021.08.223]
35. Jaeger PT, Xie B. Developing online community accessibility guidelines for persons with disabilities and older adults. J Disabil Policy Stud 2008 Oct 17;20(1):55-63. [doi: 10.1177/1044207308325997]
36. Klenk J, Chiari L, Helbostad JL, Zijlstra W, Aminian K, Todd C, FARSEEING Consortiumthe FARSEEING Meta-Database Consensus Group. Development of a standard fall data format for signals from body-worn sensors: the FARSEEING consensus. Z Gerontol Geriatr 2013 Dec 24;46(8):720-726. [doi: 10.1007/s00391-013-0554-0] [Medline: 24271252]
37. Wardlow L, Leff B, Biese K, Roberts C, Archbald-Pannone L, Ritchie C, Collaborative for Telehealth and Aging. Development of telehealth principles and guidelines for older adults: a modified Delphi approach. J Am Geriatr Soc 2023 Feb 19;71(2):371-382. [doi: 10.1111/jgs.18123] [Medline: 36534900]
38. Ruzic L, Lee ST, Liu YE, Sanford JA. Development of universal design mobile interface guidelines (UDMIG) for aging population. In: Proceedings of the 10th International Conference on Universal Access in Human-Computer Interaction, Methods, Techniques, and Best Practices. 2016 Presented at: UAHCI '16; July 17-22, 2016; Toronto, ON p. 98-108 URL: https://link.springer.com/chapter/10.1007/978-3-319-40250-5_10 [doi: 10.1007/978-3-319-40250-5_10]
39. Beer JM, Smarr CA, Chen TL, Prakash A, Mitzner TL, Kemp CC, et al. The domesticated robot: design guidelines for assisting older adults to age in place. Proc ACM SIGCHI 2012 Mar;2012:335-342 [FREE Full text] [doi: 10.1145/2157689.2157806] [Medline: 31240279]
40. Money AG, Lines L, Fernando S, Elliman AD. e-Government online forms: design guidelines for older adults in Europe. Univ Access Inf Soc 2010 May 19;10(1):1-16. [doi: 10.1007/s10209-010-0191-y]
41. Carmien S, Manzanares AG. Elders using smartphones – a set of research based heuristic guidelines for designers. In: Proceedings of the 8th International Conference on Universal Access in Human-Computer Interaction: Universal Access

to Information and Knowledge. 2014 Presented at: UAHCI '14; June 22-27, 2014; Crete, Greece p. 26-37 URL: https://link.springer.com/chapter/10.1007/978-3-319-07440-5_3 [doi: 10.1007/978-3-319-07440-5_3]
42. Sgorbissa A, Papadopoulos I, Bruno B, Koulouglioti C, Recchiuto C. Encoding guidelines for a culturally competent robot for elderly care. In: Proceedings of the 2018 IEEE/RSJ International Conference on Intelligent Robots and Systems. 2018 Presented at: IROS '18; October 1-5, 2018; Madrid, Spain p. 1988-1995 URL: https://ieeexplore.ieee.org/document/8594089 [doi: 10.1109/iros.2018.8594089]
43. Panagopoulos C, Kalatha E, Tsanakas P, Maglogiannis I. Evaluation of a mobile home care platform: lessons learned and practical guidelines. In: Proceedings of the 12th European Conference on Ambient Intelligence. 2015 Presented at: AmI '15; November 11-13, 2015; Athens, Greece p. 328-343 URL: https://link.springer.com/chapter/10.1007/978-3-319-26005-1_22 [doi: 10.1007/978-3-319-26005-1_22]
44. Chiao WL, Hong YJ, Tsai HP, Wang YH, Chou YJ, Chen WL. Exploring the role of culture-centric design guidelines in the design of mHealth application for senior informal caregivers: lessons learned in a field study. In: Proceedings of the 24th International Conference on Human-Computer Interaction. 2022 Presented at: HCII '22; June 26-July 1, 2022; Virtual Event p. 399-406 URL: https://link.springer.com/chapter/10.1007/978-3-031-06394-7_50 [doi: 10.1007/978-3-031-06394-7_50]
45. ChePa N, Sie-Yi LL, Adetunmbi S. Game-based technology for elderly with memory disorder: criteria and guideline of mobile psychotherapy games. J Adv Res Appl Sci Eng Technol 2022 Oct 17;28(2):162-180. [doi: 10.37934/araset.28.2.162180]
46. Moshnyaga V. Guidelines for developers of smart systems. In: Proceedings of the 8th International Conference on Intelligent Systems. 2016 Presented at: IS '16; September 4-6, 2016; Sofia, Bulgaria p. 455-460 URL: https://ieeexplore.ieee.org/document/7737461 [doi: 10.1109/is.2016.7737461]
47. Thach KS, Lederman R, Waycott J. Guidelines for developing the VR program in residential aged care: a preliminary study from staff members' perspective. In: Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems. 2021 Presented at: CHI EA '21; May 8-13, 2021; Yokohama, Japan p. 1-6 URL: https://dl.acm.org/doi/10.1145/3411763.3451706 [doi: 10.1145/3411763.3451706]
48. Zach J, Lorenz K, Joost G. Guidelines for technology that supports physical activity by elderly. In: Proceedings of the 2014 International Conference on Universal Design. 2014 Presented at: UD '14; June 16-18,2014; Lund, Sweden p. 429-430 URL: https://dl.acm.org/doi/10.1145/2384916.2384923
49. Groen EC, Polst S. Guidelines for validation interviews with senior citizens. In: Proceedings of the 29th International Requirements Engineering Conference Workshops. 2021 Presented at: REW '21; September 20-24, 2021; Dame, IN p. 258-267 URL: https://ieeexplore.ieee.org/document/9582326 [doi: 10.1109/rew53955.2021.00047]
50. Romeiro C, Araújo P. Guidelines' parametrization to assess AAL ecosystems' usability. In: Proceedings of the Proceedings of the 24th International Conference on Enterprise Information Systems. 2022 Presented at: ICEIS '22; April 25-27, 2022; Virtual Event p. 309-316 URL: https://www.scitepress.org/PublishedPapers/2022/110438/110438.pdf [doi: 10.5220/0011043800003179]
51. Wisniewski Z, Polak-Sopinska A. HCI standards for handicapped. In: Proceedings of the 5th International Conference on Universal Access in Human-Computer Interaction, Addressing Diversity. 2009 Presented at: UAHCI '09; July 19-24, 2009; San Diego, CA p. 5 URL: https://link.springer.com/chapter/10.1007/978-3-642-02707-9_76 [doi: 10.1007/978-3-642-02707-9_76]
52. Veloso A, Costa LV. Heuristics for designing digital games in assistive environments: applying the guidelines to an ageing society. In: Proceedings of the 1st International Conference on Technology and Innovation in Sports, Health and Wellbeing. 2016 Presented at: TISHW '16; December 1-3, 2016; Vila Real, Portugal p. 1-8 URL: https://ieeexplore.ieee.org/document/7847789 [doi: 10.1109/tishw.2016.7847789]
53. Lim JH, Park C, Park SJ. Home healthcare settop-box for senior chronic care using ISO/IEEE 11073 PHD standard. Annu Int Conf IEEE Eng Med Biol Soc 2010;2010:216-219. [doi: 10.1109/IEMBS.2010.5627845] [Medline: 21097184]
54. D'Haeseleer I, Gielis K, Abeele VV. Human-centred design of self-management health systems with and for older adults: challenges and practical guidelines. In: Proceedings of the 7th International Conference on Information and Communication Technologies for Ageing Well and e-Health. 2021 Presented at: ICT4AWE '21; April 24-26, 2021; Prague, Czech Republic p. 90-102 URL: https://www.scitepress.org/Papers/2021/105291/105291.pdf [doi: 10.5220/0010529100002931]
55. Martins N, Ralha S, Simoes R. ICT4Silver: design guidelines for the development of digital interfaces for elderly users. In: Machado J, Soares F, Trojanowska J, Yildirim S, editors. Innovations in Mechatronics Engineering. Cham, Switzerland: Springer; 2022:1780-1788.
56. Abeele VV, Schraepen B, Huygelier H, Gillebert C, Gerling K, Van Ee R. Immersive virtual reality for older adults: empirically grounded design guidelines. ACM Trans Access Comput 2021 Aug 19;14(3):1-30. [doi: 10.1145/3470743]
57. Mahoney DF, Purtilo RB, Webbe FM, Alwan M, Bharucha AJ, Adlam TD, Working Group on Technology of the Alzheimer's Association. In-home monitoring of persons with dementia: ethical guidelines for technology research and development. Alzheimers Dement 2007 Jul;3(3):217-226. [doi: 10.1016/j.jalz.2007.04.388] [Medline: 19595941]
58. Kascak LR, Rébola CB, Sanford JA. Integrating Universal Design (UD) principles and mobile design guidelines to improve design of mobile health applications for older adults. In: Proceedings of the 2014 on IEEE International Conference on

Healthcare Informatics. 2014 Presented at: ICHI '14; September 15-17, 2014; Washington, DC p. 1 URL: https://www.researchgate.net/publication/305730189_Integrating_Universal_Design_UD_principles_and_mobile_design_guidelines_to_improve_design_of_mobile_health_applications_for_older_adults [doi: 10.1109/ichi.2014.54]
59. Ostrowski AK, Breazeal C, Park HW. Long-term co-design guidelines: empowering older adults as co-designers of social robots. In: Proceedings of the 30th IEEE International Conference on Robot & Human Interactive Communication. 2021 Presented at: RO-MAN '21; August 8-12, 2021; Vancouver, BC p. 1165-1172 URL: https://ieeexplore.ieee.org/document/9515559 [doi: 10.1109/ro-man50785.2021.9515559]
60. Rupal BS, Rafique S, Singla A, Singla E, Isaksson M, Virk GS. Lower-limb exoskeletons: research trends and regulatory guidelines in medical and non-medical applications. Int J Adv Robot Syst 2017 Dec 04;14(6):172988141774355. [doi: 10.1177/1729881417743554]
61. de Belen RA, Bednarz T. Mixed reality and internet of things (MRIoT) interface design guidelines for elderly people. In: Proceedings of the 23rd International Conference in Information Visualization. 2019 Presented at: IV-2 '19; July 16-19, 2019; Adelaide, Australia p. 82-85 URL: https://ieeexplore.ieee.org/document/8811967 [doi: 10.1109/iv-2.2019.00025]
62. Lehmann S, Ruf E, Misoch S. Older adults testing assistive technologies in living labs: guidelines. In: Proceedings of the 6th International Conference on Information and Communication Technologies for Ageing Well and e-Health. 2020 Presented at: ICT4AWE '20; May 3-5, 2020; Virtual Event p. 85-92 URL: https://www.scitepress.org/Papers/2020/94641/94641.pdf [doi: 10.5220/0009464100850092]
63. Woodward AT, Freddolino PP, Wishart DJ, Bakk L, Kobayashi R, Tupper C, et al. Outcomes from a peer tutor model for teaching technology to older adults. Ageing Soc 2012 Jun 18;33(8):1315-1338. [doi: 10.1017/S0144686X12000530]
64. Grimaldo A, Morán AL, Gamez EC, Cairns P, Palacio RR, Meza-Kubo V. Promoting elderly-children interaction in digital games: a preliminary set of design guidelines. In: Proceedings of the 20th International Conference on Collaboration and Technology. 2014 Presented at: CRIWG '14; September 7-10, 2014; Santiago, Chile p. 169-176 URL: https://link.springer.com/chapter/10.1007/978-3-319-10166-8_15 [doi: 10.1007/978-3-319-10166-8_15]
65. Hyry J, Yamamoto G, Pulli P. Requirements guideline of assistive technology for people suffering from dementia. In: Proceedings of the 4th International Symposium on Applied Sciences in Biomedical and Communication Technologies. 2011 Presented at: ISABEL '11; October 26-29, 2011; Barcelona, Spain p. 1-5 URL: https://dl.acm.org/doi/10.1145/2093698.2093737 [doi: 10.1145/2093698.2093737]
66. Koutli M, Theologou N, Tryferidis A, Tzovaras D, Kagkini A, Zandes D. Secure IoT e-Health applications using VICINITY framework and GDPR guidelines. In: Proceedings of the 15th International Conference on Distributed Computing in Sensor Systems. 2019 Presented at: DCOSS '19; Santorini, Greece; May 29-31, 2019 p. 263-270 URL: https://ieeexplore.ieee.org/document/8804811 [doi: 10.1109/dcoss.2019.00064]
67. Ma C, Guerra-Santin O, Mohammadi M. Smart home modification design strategies for ageing in place: a systematic review. J Hous and the Built Environ 2021 Aug 27;37(2):625-651. [doi: 10.1007/s10901-021-09888-z]
68. Jurkeviciute M. Standards as applied in reality: a case study on the translation of standards in eHealth evaluation practice. BMC Med Inform Decis Mak 2019 Nov 29;19(1):247 [FREE Full text] [doi: 10.1186/s12911-019-0975-9] [Medline: 31783847]
69. Wissemann AK, Pit SW, Serafin P, Gebhardt H. Strategic guidance and technological solutions for human resources management to sustain an aging workforce: review of international standards, research, and use cases. JMIR Hum Factors 2022 Jul 21;9(3):e27250 [FREE Full text] [doi: 10.2196/27250] [Medline: 35862177]
70. Nurgalieva L, Jara Laconich JJ, Baez M, Casati F, Marchese M. A systematic literature review of research-derived touchscreen design guidelines for older adults. IEEE Access 2019;7:22035-22058. [doi: 10.1109/access.2019.2898467]
71. Chirayus K, Nanthaamornphong A. A systematic mapping review: mobile user interface design guidelines for the elderly with cognitive impairments. In: Proceedings of the 23rd International Computer Science and Engineering Conference. 2019 Presented at: ICSEC '19; October 30-November 1, 2019; Phuket, Thailand p. 35-42 URL: https://ieeexplore.ieee.org/document/8974698 [doi: 10.1109/icsec47112.2019.8974698]
72. Marziali E, Serafini JM, McCleary L. A systematic review of practice standards and research ethics in technology-based home health care intervention programs for older adults. J Aging Health 2005 Dec 01;17(6):679-696. [doi: 10.1177/0898264305281100] [Medline: 16377767]
73. Young KL, Koppel S, Charlton JL. Toward best practice in human machine interface design for older drivers: a review of current design guidelines. Accid Anal Prev 2017 Sep;106:460-467. [doi: 10.1016/j.aap.2016.06.010] [Medline: 27374247]
74. Lindberg RS, De Troyer O. Towards a reference model of guidelines for the elderly based on technology adoption factors. In: Proceedings of the 6th EAI International Conference on Smart Objects and Technologies for Social Good. 2020 Presented at: GoodTechs '20; September 14-16, 2020; Antwerp, Belgium p. 30-35 URL: https://dl.acm.org/doi/10.1145/3411170.3411240 [doi: 10.1145/3411170.3411240]
75. Lindberg RS, De Troyer O. Towards an up to date list of design guidelines for elderly users. In: Proceedings of the 1st International Conference of the ACM Greek SIGCHI Chapter. 2021 Presented at: CHI Greece '21; November 25-27, 2021; Virtual Event p. 1-7 URL: https://dl.acm.org/doi/10.1145/3489410.3489418 [doi: 10.1145/3489410.3489418]
76. Patel A, Shah J. Towards enhancing the health standards of elderly: role of ambient sensors and user perspective. Int J Eng Syst Mod Simul 2022;13(1):96. [doi: 10.1504/ijesms.2022.122739]

77. Niemelä M, van Aerschot L, Tammela A, Aaltonen I, Lammi H. Towards ethical guidelines of using telepresence robots in residential care. Int J of Soc Robotics 2019 Feb 22;13(3):431-439. [doi: 10.1007/s12369-019-00529-8]
78. Takadama K. Towards guideline for applying machine learning into care support systems. In: Proceedings of the 2017 AAAI Conference on Spring Symposium Series. 2017 Presented at: AAAI '17; March 27-29, 2017; Stockholm, Sweden p. 740-745 URL: https://cdn.aaai.org/ocs/15284/15284-68315-1-PB.pdf
79. Palacio RR, Acosta CO, Morán A, Cortez J. Towards videogame design guidelines to promote significant leisure activities in Mexican older adults. In: Proceedings of the 4th Mexican Conference on Human-Computer Interaction. 2012 Presented at: MCHCI '12; October 3-5, 2012; Mexico City, Mexico p. 43-46 URL: https://dl.acm.org/doi/10.1145/2382176.2382186 [doi: 10.1145/2382176.2382186]
80. Alkhomsan MN, Alturayeif N, Alwadei S, Baslyman M. UsAge guidelines: toward usable Saudi m-government applications for elderly users. J King Saud Univ Comput Inf Sci 2023 Jan;35(1):202-218. [doi: 10.1016/j.jksuci.2022.11.011]
81. Niman BV, Rodríguez-Ascaso A, Brown S, Sund T. User experience design guidelines for telecare (e-health) services. interactions 2007 Sep;14(5):36-40. [doi: 10.1145/1288515.1288537]
82. Benner M, Schope L. Using continua health alliance standards - implementation and experiences of IEEE 11073. In: Proceedings of the 12th International Conference on Mobile Data Management. 2011 Presented at: MDM '11; June 6-9, 2011; Lulea, Sweden p. 40-45 URL: https://ieeexplore.ieee.org/document/6068492 [doi: 10.1109/mdm.2011.25]
83. Urbauer P, Frohner M, David V, Sauermann S. Wearable activity trackers supporting elderly living independently: a standards based approach for data integration to health information systems. In: Proceedings of the 8th International Conference on Software Development and Technologies for Enhancing Accessibility and Fighting Info-exclusion. 2018 Presented at: DSAI '18; June 20-22, 2018; Thessaloniki, Greece p. 302-309 URL: https://dl.acm.org/doi/10.1145/3218585.3218679 [doi: 10.1145/3218585.3218679]
84. Silva PA, Holden K, Jordan P. Towards a list of heuristics to evaluate smartphone apps targeted at older adults: a study with apps that aim at promoting health and well-being. In: Proceedings of the 48th Hawaii International Conference on System Sciences. 2015 Presented at: HICSS '15; January 5-8, 2015; Kauai, HI p. 3237-3245 URL: https://ieeexplore.ieee.org/document/7070205 [doi: 10.1109/hicss.2015.390]
85. The future of technology and aging research in Canada. Canada's Technology and Aging Network. 2023. URL: https://agewell-nce.ca/wp-content/uploads/2019/01/Booklet_8_Challenges_English_5_final_PROOF_rev.pdf [accessed 2024-04-29]

Abbreviations

AAL: ambient assisted living
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Increasing Older Adults' Social Connectedness: Development and Implementation of a Web-Assisted Acceptance and Commitment Therapy–Based Intervention

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Abstract

In this article, we will provide a rationale for a web-assisted acceptance and commitment therapy (ACT) approach to loneliness among older adults, drawing upon theories from the literature on adult development and aging, emotion regulation, and loneliness. The intervention program was developed using the principles of ACT, which is a cognitive behavioral approach and unified model of human behavior change and psychological growth. The ACT intervention focuses on developing nonjudgmental present-focused awareness of internal experiences (thoughts, emotions, and memories) through strategies such as acceptance and mindfulness rather than directly modifying or removing them per se. The ACT intervention appears well-suited to assist older adults in coping with the challenges of aging, as the focus is on an individual's willingness to sit with internal experiences out of one's control (ie, acceptance), stepping back from negative or critical thoughts and developing greater kindness toward oneself (ie, defusion), discerning what is most important to one's true self (ie, values), and building larger patterns of effective action based on such values (ie, committed action). The ACT intervention was developed as a resource for older adults who are socially isolated or having difficulty with social connectedness. Eight modules comprise the web-assisted ACT intervention program, which includes reading materials, video clips, and activities. Each module is followed by a summary, a homework assignment, a short quiz to assess learning, and a moderated discussion with a coach. The intervention program begins with reconnecting participants with their values. The goal of the ACT intervention program is to foster flexibility in a participant's behavior so they can behave consistently with their chosen values, rather than becoming locked into a pattern of behavior that is driven by avoiding distress or discomfort. The ACT intervention approach is both novel and innovative, as it is based on ACT and leverages a behavioral health web platform that is flexible and inclusive in its design. The ACT intervention aims to help older adults become more socially connected, less lonely, and more satisfied with their relationships with other people. The emphasis that ACT places on values and living life in accordance with one's values renders it an approach ideally suited to older adults. Finally, recommendations for future research regarding this approach to addressing loneliness among older adults is addressed.

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KEYWORDS

acceptance and commitment therapy; psychotherapy; loneliness; technology; lonely; older adults; older adult; gerontology; geriatric; geriatrics; emotion regulation; mental health; elder; elderly; isolation; aging; mHealth; digital health; digital mental health; online health; online support; eHealth; internet; depression

Introduction

Loneliness, the subjective experience of feeling socially isolated, occurs at all stages of the life span [1]. Loneliness has been observed to impact older adults' experience of depressive symptoms and lead to functional limitations [2,3]. In addition, loneliness has been found to impact older adults' cognition, with loneliness positively associated with dementia [4-6]. Individuals who score high on loneliness visit physicians more frequently [7]. Loneliness has also been associated with cardiovascular risk and risk of mortality [3,8-10]. The crucial point from these studies is that across the life span, loneliness or lack of social relationships puts individuals at greater likelihood of mortality [11].

Older adults are an underserved population; the majority of older adults in need of mental health treatment do not receive care [12]. During the COVID-19 outbreak in early 2020, older adults were disproportionately affected with high rates of mortality and difficulty accessing telemedicine services [13]. COVID-19 has increased calls for the adoption of technology-based approaches to ensure older adults are able to access mental health services [14]. If older adults do receive treatment, it is typically pharmacological, despite the fact that many prefer counseling [15]. Reasons why older adults do not receive treatment include lack of knowledge about mental health services, lack of perceived need for services, and stigma [16,17]. In addition, provider factors such as biases and misconceptions about aging also contribute to mental health services being underused by older adults [12,18].

To date, most research examining the effectiveness of psychosocial treatments with older adults has examined cognitive behavioral approaches. Studies have shown that these types of treatments are effective in treating depression in older adults in the community and primary care [19]. However, studies have produced mixed findings on their effectiveness with some subpopulations, such as depressed, medically ill, homebound older adults [20,21]. Cognitive behavioral therapy (CBT) approaches may also be suboptimal in the treatment of anxiety in later life [22,23]. Thus, there is a need to further develop and test psychosocial treatments to provide better care to older adults.

The purpose of this paper is to present an acceptance and commitment therapy (ACT)–based intervention program comprising a cognitive-behavioral web-assisted intervention to enhance social connectedness in older adults. We will review the literature on evidence-based programs for older adults and provide the theoretical basis for our ACT-based intervention program [24]. We will review the rationale for such an approach and provide a brief description of the ACT intervention program, as well as describe current evaluation efforts and future directions for the work.

Ethical Considerations

The study was approved by the New England Institutional Review Board (IRB tracking number: 120180244).

Loneliness Interventions

The deleterious impact of loneliness on physical and mental health points to the need for evidence-based intervention programs for older adults. Few evidence-based interventions have been developed for older adults, and creative approaches are needed. There have been various intervention approaches for addressing loneliness. Interventions approached at the individual level have included CBT, interpersonal therapies, and psychoanalytic therapies; interventions at the group level have focused on social skills training and groups centered around addressing shyness and depressive symptoms [25]. For older adults, interventions that may lessen the experience of loneliness have focused on social resources (eg, family and friends) and individual pursuits (eg, spending time on meaningful activities) [26].

Meta-analyses on the effectiveness of loneliness interventions have pointed to the effectiveness of psychological interventions [27,28]. A recent meta-analysis was conducted to specifically examine the effectiveness of psychological interventions in reducing loneliness [27]. The effectiveness of the various types of interventions did not significantly differ; however, reminiscence therapy had the largest effect size, followed by social identity interventions; CBT had the lowest effect size [27]. Similar results were observed in another meta-analysis where reminiscence therapy and social skills training had the largest effect size, followed by CBT [28]. However, there was only 1 study that used reminiscence therapy. In addition, the meta-analysis found higher effect sizes for intervention studies that (1) used the UCLA Loneliness Scale to assess loneliness, (2) used technology (telephone or computer) to deliver the intervention, and (3) addressed maladaptive social cognition [28]. This meta-analysis indicated that the use of technology (ie, telephone or computer) in delivering the intervention can be an effective way to address loneliness [28].

A major challenge in developing evidence-based programs for older adults has been access. Telehealth, the use of video conferencing to provide social support for older adults, is one approach that has been used during COVID-19 [29]. Interventions delivered through technology (ie, telephone or computer) have been found to be effective at reducing loneliness for older adults. One study examined the effectiveness of delivering a web-assisted intervention to older adults with chronic illness or handicap and found that computer and internet use significantly reduced loneliness among older adults [30]. In addition, lower mean levels of loneliness and depressive symptoms were found in a videoconferencing program for older adults in nursing homes after administering the intervention for 3 months [31]. Educational programs aimed at teaching older adults to use computers and the internet have also been found to significantly reduce loneliness [32]. In addition, a recent randomized controlled trial during COVID-19 examining the effectiveness of a web-assisted group intervention via Zoom found that it was effective in reducing loneliness and depressive symptoms among older adults [32]. A qualitative study examining the impact of a web-assisted intervention on loneliness among adults aged 18 to 64 years found that technology was viewed as a means of social connection. Web-assisted interventions have the ability to have a positive impact, as reviewed above. They can present information in a simple format (eg, video, graphics, audio), reach people in their homes and in rural areas, and reduce stigma related to seeking treatment. However, too much use of technology can lead to videoconferencing fatigue, and face-to-face communication is preferred [33].

Cognitive Approach to Loneliness

Theoretical perspectives on loneliness have encompassed a wide range of approaches. Weiss [34] presented an interactionist view of loneliness that focused on the types of relationship deficits in people's social networks. He described 2 types of loneliness: emotional loneliness (absence of a close partner) and social loneliness (absence of friendships and community). Other scholars have advocated for a cognitive approach to loneliness, which emphasizes the discrepancy between individuals' *subjective perceptions* of their social life and their *desired quantity or quality* of social relationships [35]. That is, loneliness is hypothesized to occur when individuals' networks of social relationships do not meet their expectations [35]. Cognition can act as a mediator between perceived loneliness and the intensity of the experience. For example, loneliness is often increased or decreased based on one's thoughts and beliefs about one's social skills. If a person believes that they are awkward and drive other people away, they may view every failed social encounter as their fault and as something that cannot be improved in the future. Thus, the cognitive approach emphasizes causal attributions for social difficulties, as well as behavioral and personality traits.

Based on the cognitive theory of loneliness and past research examining the effectiveness of psychological interventions, a new approach to loneliness is warranted that uses technology to deliver the intervention components. The use of technology (ie, telephone or computer) has been observed to be an effective means of delivering an intervention [27,28]. Psychosocial interventions (ie, reminiscence therapy, social identity interventions, and CBT) have been observed to be effective in reducing the experience of loneliness [27,28]. A systematic review of communication technology interventions suggested a need for further studies in the fields of loneliness and web-based technologies to identify opportunities to reduce loneliness in older people [36]. We propose that ACT, an emerging evidence-based approach to the treatment of emotional distress, is a viable new intervention approach for addressing loneliness among older adults, delivered via computer or the internet [24].

ACT-Based Intervention

The intervention program was developed by drawing upon basic research on loneliness in older adults and using the principles of ACT. ACT is a cognitive-behavioral approach and unified model of human behavior change and psychological growth. ACT interventions focus on developing nonjudgmental present-focused awareness of internal experiences (thoughts, emotions, and memories); willingness to sit with internal experiences that are out of one's control (ie, acceptance); stepping back from negative or critical thoughts and developing greater kindness toward oneself (ie, defusion); discerning what is most important to one's true self (ie, values); and building larger patterns of effective action based on such values (ie, committed action). Compared to traditional CBT, ACT pays greater attention to the context and functions of private events and emphasizes helping individuals respond to them with greater flexibility through strategies such as acceptance and mindfulness rather than directly modifying or removing them per se.

There are several lines of evidence that support the use of ACT with older adults who are socially isolated or having difficulty with social connectedness. First, theories of adult development and successful aging suggest that an ACT approach to treatment could be useful for older adults [37]. It is well established that older adults experience a change in life dynamics due to shifts in gains and losses. Older adulthood has a higher proportion of losses and many of those are out of one's control and unable to be changed [38]. Given that research has consistently shown that loneliness in older adults can be exacerbated by losses such as disability [39,40], decreased mobility [41-43], and widow- or widowerhood [43-45], it may prove fruitful to consider intervention approaches that assist older adults to respond flexibly to these relatively unmodifiable aspects of later life. The use of interventions was proposed to enhance psychological acceptance among older adults in response to findings of higher levels of well-being among older adults who showed greater psychological acceptance [46]. Also, in a study in which treatment response was defined as a reduction in the amount of interference with life due to pain, older people were more likely to respond to ACT compared to CBT [22].

Second, althought CBT approaches have been used with some success, there is reason to doubt their effectiveness for all individuals. Traditional CBT strategies that involve challenging the validity of thoughts may not be beneficial to older adults because the thoughts and feelings that arise after losses, while unhelpful, may not be unrealistic. Moreover, because older adults often have beliefs about aging that have solidified over a long period of time, modifying them may not be an efficient use of time [47].

This is consistent with research on CBT for mental health problems, which has revealed that the cognitive restructuring components of CBT do not significantly improve therapeutic outcomes [48]. Such techniques may be invalidating, futile, or cause iatrogenic effects. For example, there are data to show that cognitions are not directly modifiable and that deliberate attempts to change or suppress thoughts can increase their occurrence and behavioral impact [49]. Furthermore, some evidence suggests that older adults who make active efforts to eliminate problems that cannot be solved are at a higher risk for depression and other negative outcomes, and that disengaging from commitments or goals that are unattainable—followed by choosing an attainable alternative—is associated with better emotional well-being [50,51]. An acceptance approach in which individuals learn to focus on their remaining resources may be more beneficial than an approach in which they are encouraged to modify their thinking about loss or disability.

Third, the goal of an ACT intervention is to live life in accordance with deeply held values. ACT may be particularly appropriate for older adults because individuals experiencing declines associated with aging may limit their goals to those that are most highly valued, work harder to strive toward achieving those goals, and use alternative strategies to compensate for formerly used strategies that may no longer be workable. This perspective is articulated in the Selective Optimization with Compensation Model of successful aging [52]. This is the essence of ACT and psychological flexibility. Such a model of treatment may resonate with older adults, which in turn may make it more likely they will actively engage in treatment. For example, there is some evidence to suggest that attrition rates may be lower among older adults treated with ACT when compared to those who received CBT [22].

In sum, ACT appears well-suited to assist older adults in coping with the challenges of aging, such as losses in functioning and changes in social connections. ACT has been shown to be effective for older adults in other areas, such as reducing depression and anxiety and improving symptoms of chronic pain [53-55]. ACT interventions have been adapted for web-assisted delivery and have been shown to be effective in teaching ACT-based skills to manage conditions such as overweight, fibromyalgia, and stress [56-58]. Recent research indicates even 4 web sessions can have a positive impact [59].

Development of a Web-Based ACT Intervention for Older Adults

Table 1 provides an overview of the ACT intervention program components. The ACT intervention program begins with reconnecting the client with their values, defined as intrinsic reinforcers, which provide a chosen direction for their behaviors and actions despite obstacles faced [60]. First, a list of relationships is provided (friendships, romantic or intimate relationships, family relationships, acquaintances or neighbors, and new people) and participants are asked to indicate how much they value each of those relationships. Importantly, indicating the level of importance means what the participants would like to see in their life, and does not necessarily mean that those relationships are currently matching up with that desired level. Next, a list of potential characteristics and qualities that people often value in their relationships is provided, and the client chooses the 5 that are most important to them. The list includes qualities such as being trustworthy, accepting, spontaneous, kind, open, sincere, forgiving, and loyal. The ultimate goal of the ACT intervention program is to foster flexibility in the participant's behavior so they can behave consistently with their chosen values, rather than becoming locked into a pattern of behavior that is driven by avoiding distress or discomfort.

Table . Acceptance and commitment therapy intervention program modules.

Module	Purpose
(1) Introduction and values	• Education about loneliness and why it is important to address loneliness • Education about values • Identifying and connecting with values and what the older person wants relationships to look like, to enhance motivation
(2) Exploring coping	• Awareness of triggers and consequences • Identifying how one copes with distress • Evaluating the workability of one's coping strategies
(3) Awareness of thoughts	• Learning how the mind works and how thoughts influence behavior • Learning how some people are often sensitive to certain social situations
(4) The impact of thoughts	• Identifying one's own sticky thoughts and how they keep one stuck
(5) Changing the impact of one's thoughts	• Stepping back from thoughts • Labeling thoughts
(6) Changing the impact of ones' thoughts	• Acceptance • Self-compassion
(7) Social stuck points	• Identifying one's interpersonal patterns and identifying where one might need skills • Learning different skills for finding the relationships one wants
(8) Putting it all together	• Integrating education and skills from modules 1-7 • Identifying barriers and setbacks and making a plan for skill use
Homework	• Self-assignments after each module on behavioral tasks to provide exposure to previously avoided situations, with the goal of increasing skill use and increasing adaptive thought patterns

This intervention program is an interactive, dynamic web-based intervention for social isolation and loneliness that delivers ACT over 8 interactive modules. The web-assisted modules are largely self-paced. The ACT intervention includes reading materials, video clips, and activities; each module is followed by a summary and homework assignment, a short quiz to assess learning, and a moderated discussion with a coach. Participants also have access to supplementary materials and email reminders. Participants are instructed to work through the modules in sequential order, approximately one module per week. Each module begins with a brief review of the content from the previous module before introducing a new concept. The homework includes self-assigned behavioral activities to complete each week (eg, "set a specific behavioral goal to engage in this week where you practice the skill learned in this week's module"), and the participant is prompted to enter a description of the self-assignment after the module. Before starting the next module, participants are prompted to complete an "activity recap," where they enter whether or not they completed the behavioral exercise, and to indicate their satisfaction with the exercise. Finally, they are asked to share any challenges that arose while engaging in the activity, and if this kept them from completing it. Participants are sent reminders if they have not logged on to the system for over a week.

The exercises in the first modules of the ACT intervention program attempt to increase clarity about what participants truly value in relationships and social connections, examine the ways in which current behaviors are either helping or hurting these values, and help participants begin to take concrete steps toward behaving consistently with their social values. This is important to set the stage for the rest of the program. All educational and skill-building activities in the ACT intervention program are linked to participants' values, and the module content is aligned with living life in accordance with their own personally chosen values. For example, an increased willingness to experience one's distressing thoughts and emotions (instead of trying to change them) is a skill that is explored as a way to facilitate progress in areas of one's life that provide meaning and personal fulfillment. Participants' self-identified values are also used to set values-consistent goals. For example, if they have an overall goal to have more friendships, their specific goal might be to participate in more social activities where they can meet new people. Most importantly, the homework assignments at the end of each module (ie, self-identified behavioral tasks) are based on what is personally meaningful for each participant. For example, one participant cited being open, friendly, and active as key values. Her homework assignment was to attend the community's senior center game night and talk to a person she had not met previously. Fostering these patterns of committed action is highly important, as this is what helps the participant increase their ability to engage in behaviors consistent with their values and increase social connectedness.

Next, the participants reflect on their use of coping strategies (ie, avoidance and control-based strategies) and evaluate if these are helpful. The goal of this module is to help the participants recognize that avoidance often does not work, and in fact may be their primary problem. For example, isolating oneself at home to control the uncomfortable feelings that arise when attempting to meet new people is an avoidant and unhelpful coping strategy. To address maladaptive coping strategies, participants are guided through several activities to identify positive and active coping strategies. It is even better if their active coping strategies also involve building social connections.

The next several modules focus on thoughts, particularly how the mind works in social situations and how thoughts might influence participants' behavior. These modules also emphasize how some people are vulnerable to experiencing certain thoughts more often, especially in social situations (eg, sensitivity to rejection). Participants identify "sticky thoughts," which are thoughts that tend to stick around and control one's behavior, even when they are unhelpful. For example, a sticky thought might be "Nobody wants to get to know me." Participants are encouraged to increase awareness of how these thoughts get in the way of relationships with other people. Participants are then introduced to several strategies for changing the impact of their sticky thoughts, such as defusion (ie, stepping back from thoughts), acceptance, and self-compassion. One session is then devoted to recognizing social situations in which to use their newly learned skills (eg, when meeting someone new, making conversation with someone, or experiencing conflict with someone). In the final part of the program, participants reflect on their values and set further goals to live their lives according to these values, solving problems related to any perceived barriers.

Several adaptations were made to the program to ensure that it was appropriate for older adults. Changes in cognitive functioning with aging are not universal and older adults show extensive variability, but it is important to make programming flexible and inclusive for all learning abilities and types. Older adults may experience a decline in cognitive speed, working memory, selective attention, and fluid intelligence. Research indicates that for people with cognitive impairment, information should be presented slowly and with frequent repetitions and summaries.

In the ACT intervention program, information is presented in multiple ways, and participants are encouraged to notice what does and does not work for them. To accommodate for a decline in some aspects of executive functioning, such as memory, new information is presented in the context of the previous module's material. Participants can revisit module content at any time, including readings, videos, and assignments. Phone prompts or alarms can remind participants in the program to carry out certain activities, such as behavioral homework tasks.

Conclusion

The desire for fulfilling social connections is a universal need and essential to well-being. Involvement in satisfying social relationships contributes to enhanced emotional and physical health throughout the life span. The fulfillment of this need looks different for older adults, as they navigate the developmental changes of later life and adjust to gains and losses that occur in their social networks. Furthermore, factors such as fear of intimacy, low self-esteem, and behavioral struggles such as difficulty with social skills may exacerbate feelings of loneliness and also make it more difficult to recover from loneliness.

This intervention aims to help participants become more socially connected, less lonely, and more satisfied with their relationships with other people. Researchers and clinicians collaborated on the ACT intervention program, leveraging a behavioral health platform to deliver the intervention. Most existing web-assisted interventions for loneliness that have been tested for efficacy are therapist-based and require extensive involvement by mental health professionals, and they are therefore neither anonymous nor self-directed [27]. Unlike therapist-assisted programs on the web, the ACT intervention program is an interactive, dynamic web-based intervention for social isolation and loneliness that delivers material over 8 modules and can be done largely at one's own pace and anonymously. A trained wellness coach is available to chat (voice or web-assisted) after each module to assist the user with processing program content or answering questions.

The ACT intervention approach is both novel and innovative, as it is based on ACT and leverages a behavioral health web-assisted platform that is flexible and inclusive in its design. The session content of the ACT intervention program is reflective of current knowledge of loneliness presented in the literature, as well as the extant evidence on ACT for older adults.

The emphasis that ACT places on values and living life in accordance with one's values renders it an approach ideally suited to older adults. Furthermore, some of the basic notions of ACT (eg, that pain and suffering are inevitable in human experience and that trying to avoid pain and suffering leads to problems) are highly compatible with this developmental stage of the life span and consistent with basic research on older adults and well-being.

Future studies should include randomized controlled trials of the ACT intervention program that include an attention control group, rater-blind assessments, and a systematic investigation of possible mechanisms of action (eg, acceptance). Measures of treatment adherence will need to be established, and interactions with coaches should be monitored and assessed for treatment fidelity and competency. Using mediator-moderator analyses, physical and cognitive functioning should be evaluated as moderators, and intrinsic motivation and homework adherence as mediators of the ACT intervention program's effectiveness. Additional research may include determination of optimal "dosages" (frequency and duration) of the program for different subgroups of participants. Finally, an examination of treatment components via dismantling studies may reveal the program activities that are most potent in reducing loneliness. For example, the extent to which chat with coaches is essential to the program's success will need to be studied.

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Conflicts of Interest

None declared.

References

1. Luhmann M, Hawkley LC. Age differences in loneliness from late adolescence to oldest old age. Dev Psychol 2016 Jun;52(6):943-959. [doi: 10.1037/dev0000117] [Medline: 27148782]
2. Luanaigh CO, Lawlor BA. Loneliness and the health of older people. Int J Geriatr Psychiatry 2008 Dec;23(12):1213-1221. [doi: 10.1002/gps.2054] [Medline: 18537197]
3. Luo Y, Hawkley LC, Waite LJ, Cacioppo JT. Loneliness, health, and mortality in old age: a national longitudinal study. Soc Sci Med 2012 Mar;74(6):907-914. [doi: 10.1016/j.socscimed.2011.11.028] [Medline: 22326307]
4. Rafnsson SB, Orrell M, d'Orsi E, Hogervorst E, Steptoe A. Loneliness, social integration, and incident dementia over 6 years: prospective findings from the English Longitudinal Study of Ageing. J Gerontol B Psychol Sci Soc Sci 2020 Jan 1;75(1):114-124. [doi: 10.1093/geronb/gbx087] [Medline: 28658937]
5. Sundström A, Adolfsson AN, Nordin M, Adolfsson R. Loneliness increases the risk of all-cause dementia and Alzheimer's disease. J Gerontol B Psychol Sci Soc Sci 2020 Apr 16;75(5):919-926. [doi: 10.1093/geronb/gbz139] [Medline: 31676909]
6. Sutin AR, Stephan Y, Luchetti M, Terracciano A. Loneliness and risk of dementia. J Gerontol B Psychol Sci Soc Sci 2020 Aug 13;75(7):1414-1422. [doi: 10.1093/geronb/gby112] [Medline: 30365023]
7. Gerst-Emerson K, Jayawardhana J. Loneliness as a public health issue: the impact of loneliness on health care utilization among older adults. Am J Public Health 2015 May;105(5):1013-1019. [doi: 10.2105/AJPH.2014.302427] [Medline: 25790413]
8. Berg-Weger M, Morley JE. Loneliness in old age: an unaddressed health problem. J Nutr Health Aging 2020;24(3):243-245. [doi: 10.1007/s12603-020-1323-6] [Medline: 32115602]
9. Hawkley LC, Burleson MH, Berntson GG, Cacioppo JT. Loneliness in everyday life: cardiovascular activity, psychosocial context, and health behaviors. J Pers Soc Psychol 2003 Jul;85(1):105-120. [doi: 10.1037/0022-3514.85.1.105] [Medline: 12872887]
10. Hawkley LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. Ann Behav Med 2010 Oct;40(2):218-227. [doi: 10.1007/s12160-010-9210-8] [Medline: 20652462]
11. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. PLoS Med 2010 Jul 27;7(7):e1000316. [doi: 10.1371/journal.pmed.1000316] [Medline: 20668659]
12. Segal DL, Coolidge FL, Mincic MS, O'Riley A. Beliefs about mental illness and willingness to seek help: a cross-sectional study. Aging Ment Health 2005 Jul;9(4):363-367. [doi: 10.1080/13607860500131047] [Medline: 16019293]
13. Vahia IV, Jeste DV, Reynolds CF. Older adults and the mental health effects of COVID-19. JAMA 2020 Dec 8;324(22):2253-2254. [doi: 10.1001/jama.2020.21753] [Medline: 33216114]
14. Egede LE, Ruggiero KJ, Frueh BC. Ensuring mental health access for vulnerable populations in COVID era. J Psychiatr Res 2020 Oct;129:147-148. [doi: 10.1016/j.jpsychires.2020.07.011] [Medline: 32912595]
15. Gum AM, Iser L, Petkus A. Behavioral health service utilization and preferences of older adults receiving home-based aging services. Am J Geriatr Psychiatry 2010 Jun;18(6):491-501. [doi: 10.1097/JGP.0b013e3181c29495] [Medline: 21217560]

16. Klap R, Unroe KT, Unützer J. Caring for mental illness in the United States: a focus on older adults. Am J Geriatr Psychiatry 2003;11(5):517-524. [doi: 10.1097/00019442-200309000-00006] [Medline: 14506085]
17. Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. Soc Sci Med 2010 Dec;71(12):2150-2161. [doi: 10.1016/j.socscimed.2010.09.030] [Medline: 21051128]
18. Kessler EM, Agines S, Bowen CE. Attitudes towards seeking mental health services among older adults: personal and contextual correlates. Aging Ment Health 2015;19(2):182-191. [doi: 10.1080/13607863.2014.920300] [Medline: 24898327]
19. Bell AC, D'Zurilla TJ. Problem-solving therapy for depression: a meta-analysis. Clin Psychol Rev 2009 Jun;29(4):348-353. [doi: 10.1016/j.cpr.2009.02.003] [Medline: 19299058]
20. Ayalon L, Fialová D, Areán PA, Onder G. Challenges associated with the recognition and treatment of depression in older recipients of home care services. Int Psychogeriatr 2010 Jun;22(4):514-522. [doi: 10.1017/S1041610209991797] [Medline: 20149271]
21. Gellis ZD, Bruce ML. Problem solving therapy for subthreshold depression in home healthcare patients with cardiovascular disease. Am J Geriatr Psychiatry 2010 Jun;18(6):464-474. [doi: 10.1097/jgp.0b013e3181b21442] [Medline: 20871804]
22. Wetherell JL, Petkus AJ, Alonso-Fernandez M, Bower ES, Steiner ARW, Afari N. Age moderates response to acceptance and commitment therapy vs cognitive behavioral therapy for chronic pain. Int J Geriatr Psychiatry 2016 Mar;31(3):302-308. [doi: 10.1002/gps.4330] [Medline: 26216753]
23. Thorp SR, Ayers CR, Nuevo R, Stoddard JA, Sorrell JT, Wetherell JL. Meta-analysis comparing different behavioral treatments for late-life anxiety. Am J Geriatr Psychiatry 2009 Feb;17(2):105-115. [doi: 10.1097/JGP.0b013e31818b3f7e] [Medline: 19155744]
24. Hayes SC, Strosahl KD, Wilson KG. Acceptance and Commitment Therapy: An Experiential Approach to Behavior: Guilford Press; 1999.
25. Andersson L. Loneliness research and interventions: a review of the literature. Aging Ment Health 1998 Nov;2(4):264-274. [doi: 10.1080/13607869856506]
26. Pettigrew S, Roberts M. Addressing loneliness in later life. Aging Ment Health 2008 May;12(3):302-309. [doi: 10.1080/13607860802121084] [Medline: 18728942]
27. Hickin N, Käll A, Shafran R, Sutcliffe S, Manzotti G, Langan D. The effectiveness of psychological interventions for loneliness: a systematic review and meta-analysis. Clin Psychol Rev 2021 Aug;88:102066. [doi: 10.1016/j.cpr.2021.102066] [Medline: 34339939]
28. Masi CM, Chen HY, Hawkley LC, Cacioppo JT. A meta-analysis of interventions to reduce loneliness. Pers Soc Psychol Rev 2011 Aug;15(3):219-266. [doi: 10.1177/1088868310377394] [Medline: 20716644]
29. Zubatsky M, Berg-Weger M, Morley J. Using telehealth groups to combat loneliness in older adults through COVID-19. J Am Geriatr Soc 2020 Aug;68(8):1678-1679. [doi: 10.1111/jgs.16553] [Medline: 32392617]
30. Fokkema T, Knipscheer K. Escape loneliness by going digital: a quantitative and qualitative evaluation of a Dutch experiment in using ECT to overcome loneliness among older adults. Aging Ment Health 2007 Sep;11(5):496-504. [doi: 10.1080/13607860701366129] [Medline: 17882587]
31. Tsai HH, Tsai YF. Changes in depressive symptoms, social support, and loneliness over 1 year after a minimum 3-month videoconference program for older nursing home residents. J Med Internet Res 2011 Nov 15;13(4):e93. [doi: 10.2196/jmir.1678] [Medline: 22086660]
32. Shapira N, Barak A, Gal I. Promoting older adults' well-being through internet training and use. Aging Ment Health 2007 Sep;11(5):477-484. [doi: 10.1080/13607860601086546] [Medline: 17882585]
33. Boucher EM, McNaughton EC, Harake N, Stafford JL, Parks AC. The impact of a digital intervention (Happify) on loneliness during COVID-19: qualitative focus group. JMIR Ment Health 2021 Feb 8;8(2):e26617. [doi: 10.2196/26617] [Medline: 33498011]
34. Weiss RS. Loneliness: The Experience of Emotional and Social Isolation: First MIT Press; 1973.
35. Peplau LA, Perlman D. Theoretical approaches to loneliness. In: Peplau LA, Perlman D, editors. Loneliness: A Sourcebook of Current Theory, Research and Therapy: John Wiley and Sons; 1982:123-134.
36. Chen YR, Schulz PJ. The effect of information communication technology interventions on reducing social isolation in the elderly: a systematic review. J Med Internet Res 2016 Jan 28;18(1):e18. [doi: 10.2196/jmir.4596] [Medline: 26822073]
37. Petkus AJ, Wetherell JL. Acceptance and commitment therapy with older adults: rationale and considerations. Cogn Behav Pract 2013 Feb;20(1):47-56. [doi: 10.1016/j.cbpra.2011.07.004] [Medline: 26997859]
38. Baltes PB. On the incomplete architecture of human ontogeny: selection, optimization, and compensation as foundation of developmental theory. Am Psychol 1997 Apr;52(4):366-380. [doi: 10.1037//0003-066x.52.4.366] [Medline: 9109347]
39. Wormald AD, McCallion P, McCarron M. The antecedents of loneliness in older people with an intellectual disability. Res Dev Disabil 2019 Feb;85:116-130. [doi: 10.1016/j.ridd.2018.11.009] [Medline: 30551091]
40. Burholt V, Windle G, Morgan DJ, CFAS Wales Team. A social model of loneliness: the roles of disability, social resources, and cognitive impairment. Gerontologist 2017 Nov 10;57(6):1020-1030. [doi: 10.1093/geront/gnw125] [Medline: 27831482]

41. Rantakokko M, Iwarsson S, Vahaluoto S, Portegijs E, Viljanen A, Rantanen T. Perceived environmental barriers to outdoor mobility and feelings of loneliness among community-dwelling older people. J Gerontol A Biol Sci Med Sci 2014 Dec;69(12):1562-1568. [doi: 10.1093/gerona/glu069] [Medline: 24864307]
42. von Soest T, Luhmann M, Gerstorf D. The development of loneliness through adolescence and young adulthood: its nature, correlates, and midlife outcomes. Dev Psychol 2020 Oct;56(10):1919-1934. [doi: 10.1037/dev0001102] [Medline: 32852969]
43. Dahlberg L, Andersson L, McKee KJ, Lennartsson C. Predictors of loneliness among older women and men in Sweden: a national longitudinal study. Aging Ment Health 2015;19(5):409-417. [doi: 10.1080/13607863.2014.944091] [Medline: 25126996]
44. King BM, Carr DC, Taylor MG. Loneliness following widowhood: the role of the military and social support. J Gerontol B Psychol Sci Soc Sci 2021 Jan 18;76(2):403-414. [doi: 10.1093/geronb/gbz164] [Medline: 31899492]
45. Freak-Poli R, Kung CSJ, Ryan J, Shields MA. Social isolation, social support, and loneliness profiles before and after spousal death and the buffering role of financial resources. J Gerontol B Psychol Sci Soc Sci 2022 May 5;77(5):956-971. [doi: 10.1093/geronb/gbac039] [Medline: 35373252]
46. Butler J, Ciarrochi J. Psychological acceptance and quality of life in the elderly. Qual Life Res 2007 May;16(4):607-615. [doi: 10.1007/s11136-006-9149-1] [Medline: 17268930]
47. Sarkisian CA, Hays RD, Mangione CM. Do older adults expect to age successfully? The association between expectations regarding aging and beliefs regarding healthcare seeking among older adults. J Am Geriatr Soc 2002 Nov;50(11):1837-1843. [doi: 10.1046/j.1532-5415.2002.50513.x] [Medline: 12410903]
48. Longmore RJ, Worrell M. Do we need to challenge thoughts in cognitive behavior therapy? Clin Psychol Rev 2007 Mar;27(2):173-187. [doi: 10.1016/j.cpr.2006.08.001] [Medline: 17157970]
49. Cioffi D, Holloway J. Delayed costs of suppressed pain. J Pers Soc Psychol 1993 Feb;64(2):274-282. [doi: 10.1037//0022-3514.64.2.274] [Medline: 8433273]
50. Isaacowitz DM, Seligman MEP. Cognitive style predictors of affect change in older adults. Int J Aging Hum Dev 2002;54(3):233-253. [doi: 10.2190/J6E5-NP5K-2UC4-2F8B] [Medline: 12148688]
51. Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: goal disengagement, goal reengagement, and subjective well-being. Pers Soc Psychol Bull 2003 Dec;29(12):1494-1508. [doi: 10.1177/0146167203256921] [Medline: 15018681]
52. Baltes PB, Baltes MM. Psychological perspectives on successful aging: the model of selective optimization with compensation. In: Baltes PB, Baltes MM, editors. Successful Aging: Perspectives from the Behavioral Sciences: Cambridge University Press; 1990:1-34. [doi: 10.1017/CBO9780511665684]
53. Davison TE, Eppingstall B, Runci S, O'Connor DW. A pilot trial of acceptance and commitment therapy for symptoms of depression and anxiety in older adults residing in long-term care facilities. Aging Ment Health 2017 Jul;21(7):766-773. [doi: 10.1080/13607863.2016.1156051] [Medline: 26942691]
54. Witlox M, Garnefski N, Kraaij V, et al. Blended acceptance and commitment therapy versus face-to-face cognitive behavioral therapy for older adults with anxiety symptoms in primary care: pragmatic single-blind cluster randomized trial. J Med Internet Res 2021 Mar 26;23(3):e24366. [doi: 10.2196/24366] [Medline: 33769293]
55. McCracken LM, Jones R. Treatment for chronic pain for adults in the seventh and eighth decades of life: a preliminary study of acceptance and commitment therapy (ACT). Pain Med 2012 Jul;13(7):860-867. [doi: 10.1111/j.1526-4637.2012.01407.x] [Medline: 22680627]
56. Barrett K, Stewart I. A preliminary comparison of the efficacy of online acceptance and commitment therapy (ACT) and cognitive behavioural therapy (CBT) stress management interventions for social and healthcare workers. Health Soc Care Community 2021 Jan;29(1):113-126. [doi: 10.1111/hsc.13074] [Medline: 32613644]
57. Levin ME, Petersen JM, Durward C, et al. A randomized controlled trial of online acceptance and commitment therapy to improve diet and physical activity among adults who are overweight/obese. Transl Behav Med 2021 Jun 17;11(6):1216-1225. [doi: 10.1093/tbm/ibaa123] [Medline: 33289785]
58. Simister HD, Tkachuk GA, Shay BL, Vincent N, Pear JJ, Skrabek RQ. Randomized controlled trial of online acceptance and commitment therapy for fibromyalgia. J Pain 2018 Jul;19(7):741-753. [doi: 10.1016/j.jpain.2018.02.004] [Medline: 29481976]
59. Carvalho SA, Skvarc D, Barbosa R, Tavares T, Santos D, Trindade IA. A pilot randomized controlled trial of online acceptance and commitment therapy versus compassion-focused therapy for chronic illness. Clin Psychol Psychother 2022 Mar;29(2):524-541. [doi: 10.1002/cpp.2643] [Medline: 34269493]
60. Wilson KG, DuFrene T. Mindfulness for Two: An Acceptance and Commitment Therapy Approach to Mindfulness in Psychotherapy: New Harbinger; 2009.

Abbreviations

ACT: acceptance and commitment therapy
CBT: cognitive behavioral therapy

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Viewpoint

The Best of Two Worlds to Promote Healthy Cognitive Aging: Definition and Classification Approach of Hybrid Physical Training Interventions

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Abstract

A healthy lifestyle can be an important prerequisite to prevent or at least delay the onset of dementia. However, the large number of physically inactive adults underscores the need for developing and evaluating intervention approaches aimed at improving adherence to a physically active lifestyle. In this regard, hybrid physical training, which usually combines center- and home-based physical exercise sessions and has proven successful in rehabilitative settings, could offer a promising approach to preserving cognitive health in the aging population. Despite its potential, research in this area is limited as hybrid physical training interventions have been underused in promoting healthy cognitive aging. Furthermore, the absence of a universally accepted definition or a classification framework for hybrid physical training interventions poses a challenge to future progress in this direction. To address this gap, this article informs the reader about hybrid physical training by providing a definition and classification approach of different types, discussing their specific advantages and disadvantages, and offering recommendations for future research. Specifically, we focus on applying digital technologies to deliver home-based exercises, as their use holds significant potential for reaching underserved and marginalized groups, such as older adults with mobility impairments living in rural areas.

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KEYWORDS

physical activity; dementia prevention; cognitive health; hybrid: aging in place; active; exercises; exercising; healthy lifestyle; dementia; dementia onset; dementia care; preventive; prevention; cognitive health; cognition; cognitive; hybrid; hybrid model

Introduction

Dementia is a brain disease that is characterized by an acquired loss of cognitive abilities in different domains which is sufficiently severe to interfere with both activities of daily living and the ability of an individual to live independently [1,2]. As a result, individuals affected by dementia cause high health care expenditures [3-6]. Given the expected worldwide rise in dementia cases from 57.4 million cases in 2019 to 152.8 million cases in 2050 [7], it seems reasonable to assume that the already relatively high health care–related expenditures for dementia (ie, US $1313.4 in 2019 [3]) will dramatically increase in the upcoming years. Thus, preventing dementia should be a priority of public health actions [8,9]. Based on the evidence that the individual dementia risk is substantially influenced by several lifestyle factors (eg, regular engagement in physical activity), a positive modification of these is important to lower the global prevalence and, in turn, the societal and economic costs of dementia [3,8,9]. This assumption is reinforced by the fact that the effectiveness of pharmacological interventions to treat dementia is limited [10,11]. Although lifestyle-related interventions (eg, targeting physical activity, sedentary behavior, diet, or sleep) can be effective and implemented along the entire continuum of dementia [9,12-14], preventive approaches should focus on healthy middle-aged and older adults, and preclinical stages of dementia including adults at-risk (eg, adults with subjective cognitive decline [SCD], mild cognitive impairment [MCI], or with the motoric cognitive risk syndrome [MCR]) [9,15-20] to avoid that cognitive impairment and neurodegenerative changes of the central nervous system become too serious which, in turn, might negatively influence adherence and increase the cost of the implementation of the intervention. At-risk groups for dementia comprise, among others, adults with SCD who have a self-reported or informant-reported worsening of cognitive performance (especially memory) but normal performance on specific clinical cognitive tests [21,22], adults with MCI who have objective cognitive deficits determined by a clinical cognitive test battery [23-25], and adults with MCR who have subjective cognitive complaints and a slow gait speed [17,20,26-28]. SCD, MCI, and MCR are preclinical stages of dementia that are unrelated to an acute event, do not interfere with activities of daily living, and thus allow the individual to live independently [17,20,21,24-27]. Current estimates suggest that worldwide 315 million individuals aged 50 years or older are in a preclinical stage of dementia [29] emphasizing the pressing need to develop and implement appropriate intervention strategies to prevent or at least delay the onset of dementia in the general and at-risk populations.

In the literature, there is some evidence showing that among other factors such as sedentary behavior, sleep, and diet, especially regular physical activity including planned and structured forms such as physical exercise and physical training [6,30-35] can be an important factor to preserve cognitive functions [36-44] and to prevent or at least delay the onset of dementia in older adults [6,9,45,46] although future high-quality randomized controlled trials (RCTs) are required to further substantiate the evidence in this direction [47,48]. Hence, the high prevalence of physical inactivity among the general adult population [6,49] which increases with age [50-52] and low cognitive status [53], necessitates the development of new, more efficient, and sustainable intervention approaches to preserve and maintain cognitive health across the life span, especially in adults-at-risk to develop dementia (eg, adults with MCI) [9,16].

Concerning new approaches to support healthy cognitive aging, there is the opinion in the literature that using digital technologies is a promising and cost-saving option that can support healthy aging in place (eg, by providing lifestyle interventions) [54-56]. In this context, digital technologies can be a valuable instrument to remotely assess and monitor changes in cognitive health [57-63] and to facilitate positive lifestyle changes [57,63-65] by fostering a higher level of regular physical activity (eg, via wearable physical activity trackers [66,67] or via apps or online classes to remotely deliver home-based exercise sessions [64]), which is especially relevant for adults living in rural and remote areas [64,68-71].

Digital technologies can be applied in a wide range of contexts and in recent years they have become a popular instrument for delivering physical exercises and physical training to the general population [64,72-75]. For instance, in center-based exercise sessions, the application of digital technologies encompasses but, is not limited to (1) monitoring and controlling exercise intensity (eg, via wearables recording heart rate) [76-78], or (2) delivering specific physical exercises (eg, via exergames [79-81] or videoconference-based online classes, in which the exercise professional is remotely connected to the groups of trainees being located in a center [82]). However, digital technologies provide also several advantages making them extremely well-situated for delivering home-based exercise sessions. This assumption is supported by the latest editions of the Worldwide Survey of Fitness Trends revealing that digital applications such as wearable technologies, online training, and mobile exercise apps are among the top 20 fitness trends in recent years [72-75]. More specifically, the Worldwide Survey of Fitness Trends also showed that exercising at home is the number 2 trend for 2022 [73] probably due to the consequences of the COVID-19 pandemic (eg, home confinement). Even from a more general point of view, exercising at home provides some benefits for older adults (eg, no need to commute to a training facility) because home-based approaches can help to circumvent frequently mentioned barriers to engaging in planned and structured forms of physical activity (eg, the lack of opportunity or transport [83-86]).

Compared with traditional options, the use of digital technologies can be a promising alternative (1) to remotely recruit and assess a large number of (diverse) participants (eg, in decentralized trials instead of centralized trials) [87], and (2) to deliver home-based interventions (eg, via video capsules instead of booklets) [64]. In particular, remotely delivered home-based interventions via digital technologies can provide several advantages such as better visualization of exercises or gamification (eg, exergames) as compared with nondigital solutions (eg, booklets) [64]. Thus, digital technologies can play an important role in reducing inequalities arising from various reasons (eg, living in a rural area without a driving license) which, in turn, might contribute to increased robustness of the findings of the trials because of the inclusion of larger and more diverse samples of older adults at-risk or with cognitive impairment [87-91]. Further empirical data supporting our claims have been published recently [90-93]. However, using digital technologies and home-based interventions does not come without limitations [87,94]. For instance, home-based physical exercise sessions provided via digital technologies are typically associated with lower levels of supervision, and social interaction (ie, social support and relatedness such as the feelings of belonging to a group) [95] although the level of supervision and social interaction depends on the type of digital technology used for that purpose [64]. Given that the social factors are important for adhering to an intervention [96], the unique characteristics of different types of digital technologies being used for delivering home-based physical exercises should be considered when designing and implementing future trials [87] and suggest that establishing a classification framework to improve the structuring of knowledge is required (eg, as started in [64]) to better inform the application in practical settings.

Since factors such as supervision, social support, and relatedness can be more easily promoted in center-based physical exercise sessions (eg, in clinical settings) because of the interaction with health professionals (eg, certified trainers, physiotherapists) and peers, several studies have combined both center-based physical exercise sessions and home-based physical exercise sessions. For instance, especially in rehabilitative settings such as cardiac rehabilitation [97-99] or orthopedic rehabilitation (eg, hip or knee osteoarthritis [100]) interventions that combine center- and home-based physical exercise sessions are widely used. Such interventions are typically referred to as hybrid. With regard to healthy cognitive aging, hybrid physical training interventions have been somewhat neglected [64] but have been highlighted as a promising option for future studies (eg, for older adults at risk or with cognitive impairment) [87]. Moreover, neither a generally accepted definition nor a classification framework for hybrid physical training interventions is available. As such a classification framework allows for better structuring of knowledge and might foster research in the field of healthy cognitive aging (eg, by increasing the awareness of research in which different types of hybrid physical training interventions exist), this article aims to inform the reader about this intervention approach by providing a definition and classification approach of hybrid physical training and by narratively summarizing the current state of the literature. In accordance with the literature [31-35,101], we use in the forthcoming sections of this article the term “physical training” to refer to chronic forms of planned and structured forms of physical activity. Furthermore, we focus on hybrid physical training approaches that use digital technologies for delivering home-based exercises because their application holds great potential to reach needy but underserved and marginalized groups (eg, older adults with mobility impairments living in rural areas). The latter is related to the facts (1) that reaching and including such cohorts is highly relevant from a public health perspective given the paucity of research in this direction and the existing rural health disparities [68-71,102], and (2) that research in this direction will improve our understanding of whether the effects of physical training on cognitive health typically observed in laboratory setting extend to ecologically valid settings (eg, community-dwelling older adults living in rural areas) for which the evidence base is currently relatively scant [103].

Hybrid Physical Training: A Definition and Classification Approach

Overview

Hybrid interventions have been recently highlighted as a promising option to improve health-related outcomes, especially in rehabilitation settings [87,98,100,104] but, to the best of our knowledge, neither a generally accepted definition nor a classification approach exists. To address this issue and avoid ambiguity which can be a major source of difficulty in scientific communication, we define the term “hybrid physical training” as an intervention that combines center-based physical exercise sessions, that is, conducted in a clinical setting (eg, health care facility) or community setting (eg, local gym) [105] and home-based physical exercise sessions, that is, undertaken inside or within the immediate vicinity of the home (eg, apartment, park) [100,104,105].

To derive a classification approach for different types of hybrid physical training interventions, we orient on recommendations on constructing, conducting, and analyzing physical interventions [105,106] and recent literature in this field [64,107]. In this context, we propose that hybrid physical training interventions can be differentiated based on (1) temporal characteristics, that is, how the center-based exercise sessions and home-based physical exercise sessions are combined, and (2) specific intervention-related characteristics, that is, how center-based physical exercise sessions and home-based physical exercise sessions are delivered.

Temporal Characteristics

Concerning the temporal characteristics, we propose that hybrid physical training can be differentiated as (1) alternating hybrid physical training interventions, and (2) subsequent hybrid physical training interventions (Figures 1A and 1B). First, in alternating hybrid physical training interventions, center-based physical exercise sessions are alternated with home-based physical exercise sessions. While this alternation provides, on the one hand, the advantage that the participant has frequent contact with health professionals and peers fostering higher levels of supervision and social interaction (ie, especially in center-based physical exercise sessions) that might positively influence compliance and adherence to the intervention [108], it is, on the other hand, a clear disadvantage because it demands the participants to commute to attend the center-based physical exercise sessions. However, the alternating hybrid physical training can also unburden the participants because it reduces the number of travels (eg, 1 travel per week if there are 2 sessions per week) and thus allows for a higher frequency (eg, 2 exercise sessions instead of 1 per week), which has been linked to larger improvements of cognitive performance in adults aged 50 years or older [44]. Second, in subsequent hybrid physical training interventions, a phase of center-based exercise sessions is followed by a phase of home-based exercise sessions (Figure 1B). This type of intervention can be further divided into (1) subsequent hybrid physical training interventions with alternating follow-up or (2) subsequent hybrid physical training interventions with home-based follow-up. The advantages and disadvantages of subsequent hybrid physical training interventions strongly depend on the type of follow-up (Figure 1B) and the implementation of the home-based physical exercise sessions (Figure 2B). For instance, subsequent hybrid training interventions with alternating follow-up can enable relatively high levels of supervision and social interactions due to frequent contact with health professionals and peers during the center-based physical exercise sessions. On the downside, to attend center-based physical exercise sessions, the participants are obliged to commute to the training facility, which is in some studies mentioned as a barrier, especially by older women [84]. A home-based follow-up offers the advantage that the participants are not obliged to commute to the training facility but comes at the cost of lower levels of supervision (eg, by the health professional) and limited social interactions (ie, with peers) during the home-based physical exercise sessions in the follow-up, although the latter can be influenced by the implementation (eg, higher levels of supervision and social interaction may be achievable via online classes [64]; Figure 2B).

Figure 1. Overview of possible temporal organizations of hybrid physical training interventions which can be divided into (A) alternating hybrid physical training interventions and (B) subsequent hybrid physical training interventions.

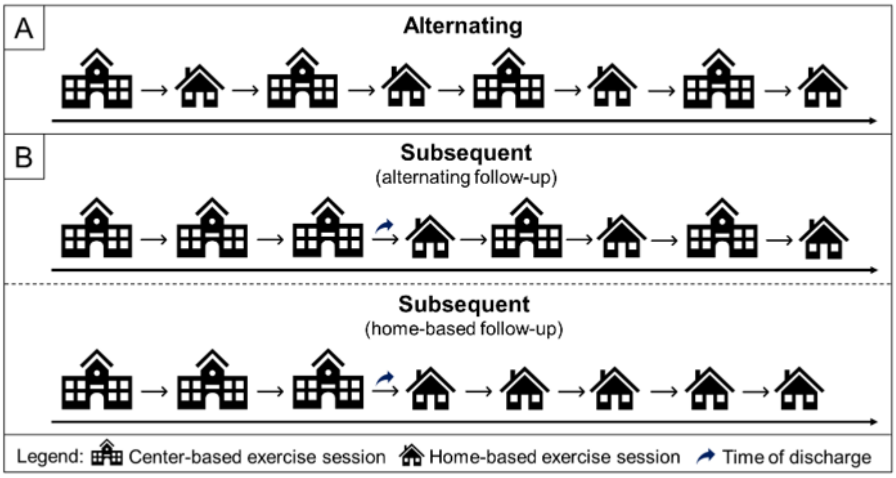
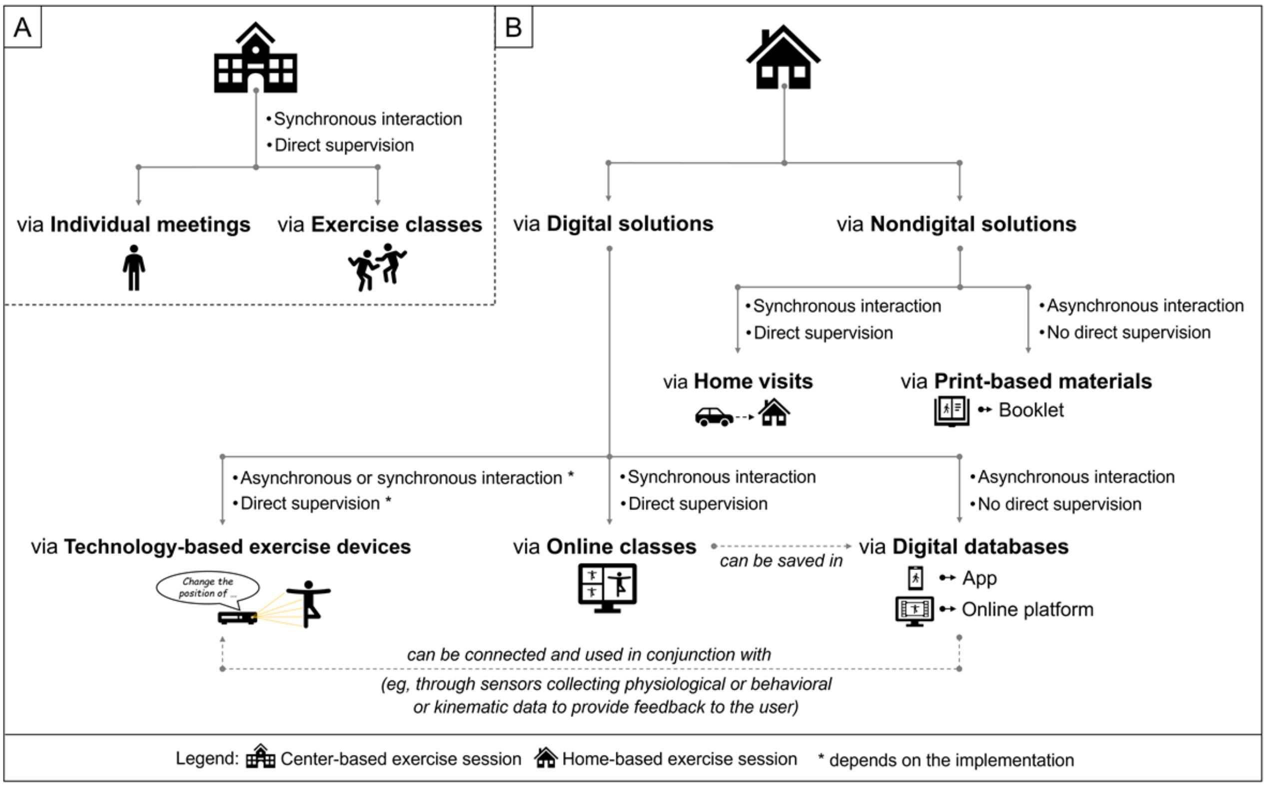


Figure 2. Overview by which means (A) center-based physical exercise sessions and (B) home-based physical exercise sessions can be delivered.



Specific Intervention-Related Characteristics

Based on a recent systematic review of our group, in which we propose a classification approach for digital- and home-based physical training interventions [64], we used the type of interaction and the level of supervision to differentiate between different types of hybrid physical training interventions.

Before we discuss the different types of hybrid physical training interventions and their strengths and limitations in more detail, we provide the reader with a brief description of the different types of interaction and the different levels of supervision.

Regarding the type of interaction, one can distinguish between asynchronous interaction and synchronous interaction. Synchronous interaction refers to an interaction that occurs in real-time, whereas asynchronous interaction refers to a decoupled interaction (eg, at different times) [64,109-113]. Thus, a synchronous interaction allows for the immediate exchange of information (eg, immediate feedback on specific exercises—direct supervision) but is limited concerning time flexibility [64,109]. Vice versa, asynchronous interaction provides the advantage of on-demand information exchange at the convenience of the participating parties but bears—as a consequence of the decoupled communication—the risk that specific information is not received on time (eg, short-term adjustment of a physical exercise session due to quality of exercise execution or acute pain of the trainee is difficult) [64,109].

Regarding supervision, one can distinguish between direct supervision (ie, each exercise session is monitored by a health professional or digitally via sensors allowing for immediate feedback on exercise execution), general supervision (ie, no direct supervision of each exercise session but regular in-person or web-based contact with a health professional to support the trainee; also referred to as “facilitated”), and no supervision (ie, the trainee has no direct contact with a health professional throughout the intervention period; also referred to as “unsupervised”) [64,105]. In general, there is some evidence suggesting that higher levels of supervision (ie, direct supervision) can facilitate adherence to physical training interventions [96,114,115] although, on the downside, higher levels of direct supervision can increase the cost of the intervention (ie, to pay the health professional who supervises the physical exercise sessions) and lower the time flexibility (ie, as result of the synchronous interaction) [96].

As shown in Figure 2A, center-based exercise sessions are typically supervised and are based on synchronous interactions with health professionals and other peers. In addition, center-based exercise sessions can be conducted individually or in a group. Individual meetings provide the advantage that a high level of individualization can be achieved because of close contact with the health professional. In individual meetings, the social interaction with peers, in contrast, to exercise classes, might be somewhat limited. In this context, it is worth noting that in older adults’ social factors such as loneliness are associated with worse cognitive functioning [116-119] and increased risk of dementia [8,120-123]. Furthermore, in a cross-sectional study of older adults with MCI, a higher level of perceived loneliness was observed as compared with age-, sex-, and education-matched controls with slightly less pronounced cognitive deficits [124]. In addition, social factors are also important promotors for regular engagement in specific forms of physical training (eg, sports) [84,125-127] and long-term adherence to interventions [96,128]. Accordingly, promoting social participation (eg, via group-based physical training), especially in at-risk cohorts for dementia (eg, older adults with MCI), seems to be an important factor for fostering adherence to physical training interventions [96,128], preventing cognitive decline, and potentially reducing the risk of dementia [129]. Indeed, there is evidence that in healthy older adults’ group-based physical training interventions can counteract social isolation and loneliness [130,131]. Moreover, there is evidence from cross-sectional studies that older adults who exercise alone and exercise with others (eg, team or partner sports activities) showed better cognitive performance and have a lower risk of cognitive impairment, but that exercising with others is slightly more beneficial than exercising alone [132-134] even after adjusting for important influencing factors (eg, accelerometer-derived physical activity or time spent for other social engagements [133]). Based on these findings, group-based physical training, which can lead to a higher level of social interaction (ie, with peers) and perhaps trigger specific psychosocial-related changes [133] on multiple levels of analysis [129,135-137], might provide some additional benefits to preserve cognitive health as compared with exercising alone or without peers (eg, individual meetings).

The level of social interaction (eg, with peers) depends, among other factors, on the type of digital technology that is used to deliver the home-based physical exercise sessions. As shown in Figure 2B, home-based physical exercise sessions can be broadly categorized based on the instruments being used to deliver and prescribe the physical exercises—namely digital and nondigital solutions.

Nondigital Solutions to Deliver Home-Based Physical Exercise Sessions

We propose that nondigital solutions can be divided into two different types: (1) the term “home visits” refers to physical training interventions in which the health professional provides the physical training at the participant’s home. Although home visits ensure a high level of individualization because of the direct supervision (ie, synchronous interaction), they are relatively costly as the health professional provides 1:1 supervision and needs to commute to the participant’s home [96]; and (2) the term “print-based materials” characterize interventions in which the exercise and training prescription is provided via nondigital solutions such as booklets. This type of intervention provides the advantage that it can be disseminated on a broad scale even in low-resource settings (eg, with limited access to digital technologies). Owing to the asynchronous interaction, this intervention type is, in general, unsupervised, and thus it cannot be controlled for a proper exercise execution [64].

Digital Solutions to Deliver Home-Based Physical Exercise Sessions

In general, digital solutions, as compared with nondigital solutions, can be less costly (ie, online communication in comparison to home visits), allow for better visualization of how the exercises should be conducted (ie, by video instructions which provide more appropriate exercise execution cues than print-based material), allow clinician-based digital care to replace or complement traditional in-person visits in a health care center due to synchronous video or audio visits, and potentially allow for a "gamification" of exercise programs (ie, in comparison to print-based materials) [64]. For instance, there is some evidence that "gamification" can positively influence the promotion of physical activity [138,139]. Because of the aforementioned advantages especially digital solutions to deliver home-based exercise sessions within a hybrid physical training intervention seem to be a promising approach to facilitate the implementation and improve the effectiveness of such an intervention program. In the following, we will discuss in more detail the different types of digital solutions to deliver home-based physical training using a classification approach that has been previously proposed by our group [64]. For a more comprehensive overview of the physical exercise and training characteristics and effectiveness of digital and home-based physical training interventions to improve cognitive functions, we refer the interested reader to a recent systematic review of our group [64].

First, the term "digital databases" comprises digital and home-based physical training interventions that rely on the storage of the exercise prescriptions (eg, via video capsules) on specific digital media platforms (eg, smartphone or tablet-based apps) [64] and thus, can be considered as the digital alternative to print-based materials (eg, booklets). This type of digital and home-based physical training provides the advantage that it can be delivered to a relatively large number of individuals and allows for on-demand training based on asynchronous interaction [64]. A drawback of asynchronous interaction, the inherent feature of digital databases, typically no direct supervision of the single exercise sessions during the home-based training exists [64]. Concerning the implementation of digital databases to support healthy cognitive aging, different digital platforms or applications such as YouTube video capsules [140,141], DVDs [142,143], and tablet-based [144-147] or smartphone-based app [148] have so far been used to deliver a wide range of different types of physical exercises (eg, endurance, resistance, flexibility, or coordinative exercise such balance, or dancing exercises) to diverse cohorts including healthy-middle-aged and older adults [141] or middle-aged and older adults with MCI [144], cardiovascular disorders [140], or Parkinson disease [147,148]. Given that hand-eye coordination, visual acuity, and mental acuity are frequently reported barriers to the use of digital health technologies in older adults [149], commercially available devices with voice-controlled intelligent personal assistants (eg, Amazon Alexa) can be a promising alternative to remotely delivering physical exercises because the voice control helps older adults to access the exercise instructions more easily. Indeed, several small-scale studies (n=15) showed that applying voice-controlled digital solutions to remotely deliver physical exercise instruction and feedback is feasible in older adults [150-152] and is associated with high completion adherence (ie, 100%) and attendance adherence rates (ie, 115% of the prescribed exercise sessions) [152]. Thus, investigating the cognitive health effects of remotely delivered physical training, which uses devices with voice-controlled intelligent personal assistants (eg, Amazon Alexa), seems to be a promising area for further investigation.

Second, the term "online classes" refers to digital and home-based physical training interventions that are characterized by a synchronous and remote interaction of the trainees with the health professional via videoconference software [64]. Hence, it can be considered as some kind of digital alternative to home visits, typically used to supervise a single trainee or a group of trainees who exercise individually at their homes. In this context, it is worth noting that online classes can be delivered via static videoconferencing (eg, PC with camera) or dynamic videoconference (eg, via a mobile telepresence robot [MTR]) [153,154]. MTRs are typically wheeled devices that are remotely controlled by the operator (eg, exercise professional) and which allows them to be present through the robotic embodiment at remote locations, move throughout the environment, and interact with persons (eg, trainee) in the environment by 2-way audio-visual communication [154,155]. Using MTRs to deliver online classes provides the advantage of superior mobility that enables the remote controller (ie, exercise professional) to change the point of view (eg, when the trainee leaves the field of view of the camera) and thus allows for better direct supervision of single trainees or the direct supervision of several trainees exercising as a group at the same location (eg, gym in a retirement home) as compared with static videoconferencing [153,154]. While online classes provide a relatively high level of direct supervision, they are, on the downside, limited with regard to the number of trainees (eg, to ensure an appropriate level of direct supervision) and time flexibility (ie, because of fixed time schedules) [64]. In intervention studies that implement physical training via online classes (ie, static videoconference) to support healthy cognitive aging, different types of directly supervised physical exercises including endurance exercises such as cycling [156], resistance exercises [157], chair-based motor-cognitive exercises [158], or Tai Ji Quan [159] were remotely delivered to healthy older adults [157] or older adults with SCD [156], MCI [159], and Alzheimer disease [158]. In future studies, dynamic videoconference solutions using MTR could be a promising alternative to static videoconference because of their specific advantages over static videoconferencing (eg, the opportunity to change the point of view by moving the robot), and the findings (1) that older adults found MTRs useful, easy to use, and pleasant for remote supervision of physical exercises [153] and (2) that MTRs can be as effective as face-to-face interaction with an exercise professional to learn a new motor cognitive task within a single session [154]. Although these findings are encouraging, future long-term studies are needed to substantiate the evidence on the applicability of MTRs to deliver and supervise physical exercise sessions before they can be unreservedly recommended.

Third, the term “technology-based exercise devices” covers a wide range of instruments that can be used to remind individuals to be physically active (eg, just-in-time adaptive physical activity interventions using real-life data of wearables such as smartwatches or smartphones to provide real-time recommendations for opportunities to be physically active [160-162]) or that are used to conduct physical exercises (eg, virtual reality–enhanced stationary ergometer [163-166]) [64]. Such technology-based exercise devices include but are not limited to exergames. The term “exergames” (ie, also referred to as active video games or gamercizing) is a portmanteau consisting of the terms “physical exercise” and “gaming” [167] and refers to technology-driven physical activities in a gaming environment requiring participants to become physically active to play the game [168-170]. Technology-based exercise devices offer the advantage that they allow for on-demand training, but the level of direct supervision is constrained by the implementation of technical features (eg, integration of different sensors or camera-based information allowing for the assessment of behavioral, physiological, and kinematic data) [64]. In this regard, technology-based exercise devices fulfill the criteria of asynchronous interaction (eg, can be used on-demand) and synchronous interaction (ie, can provide immediate feedback to the user through integrated sensors or camera-based information), although the latter strongly depends on the technological features of the device [64]. Studies aiming to support healthy cognitive aging via technology-based exercise devices typically used specifically designed step-based exergames [171-178] or cycling-based exergames [163-166] in older adults with different health statuses (eg, in healthy older adults [171-175,178], older adults with Parkinson disease [163,164,176], multiple sclerosis [177], or MCI [165,166]), whereas the application of other technology-based exercise devices (eg, wearables such as activity trackers) is less common [64]. Given (1) that wearables (eg, activity trackers) can increase the level of regular physical activity [66,67] and (2) that physical activity is an important factor for preserving cognitive performance [36-44] and lowering dementia risk in older adults [6,9,45,46], wearables (eg, to deliver just-in-time adaptive physical activity interventions [160-162]) may hold some promise to support healthy cognitive aging, although they have so far been underused to prescribe and monitor physical activity in the context of healthy cognitive aging [64].

In summary, we proposed a classification framework and provided definitions for different types of nondigital and digital solutions to remotely deliver home-based physical exercise sessions that can guide future research in the field of healthy cognitive aging. In this context, we wish to acknowledge that in practical and research settings different nondigital and digital solutions (eg, home visits and online classes), different nondigital solutions (eg, home visits and booklet [179]), or different digital solutions (eg, digital database and online classes [180,181]) can be combined to deliver home-based physical exercises but we intentionally refrained from discussing or visualizing all possible combinations (Figure 2) for reasons of clarity and comprehensibility.

Challenges of Implementing Hybrid Physical Training Interventions Using Digital Technologies to Deliver Physical Exercise Sessions Remotely

Digital technologies provide several advantages when they are used to remotely deliver physical exercise sessions (see *Digital Solutions to Deliver Home-Based Physical Exercise Sessions* section) [64]. However, the use of digital technologies in older adults without and with cognitive impairment is also associated with some challenges including but not limited to (1) infrastructural- and device-related factors (eg, absence of stable internet coverage and unequal availability of digital technology or devices in rural or socioeconomically deprived areas), and (2) user-related factors (eg, digital literacy, privacy concerns, perceived usefulness and ease of use of the digital application, support of the social network) [57,94,150,182-188]. In this context, there is, on the one hand, some evidence that older adults with cognitive complaints or decline and who did not regularly use a computer show a lower engagement in a digital intervention aiming to reduce dementia risk through lifestyle changes [189]. On the other hand, several studies provided evidence that digital technologies can be successfully used to remotely deliver physical exercise sessions in diverse cohorts [64] including healthy older adults [142,143,145,171-175,190-192], older adults with MCI [144,159,180] and SCD [146], and even older adults with dementia [193,194]. Although the latter evidence clearly supports the feasibility of such approaches, future studies aiming to implement hybrid physical training interventions by using digital technologies to remotely deliver home-based exercise sessions should consider (1) infrastructural prerequisites (eg, in the absence of a stable internet coverage the application of digital databases instead of online classes to remotely deliver physical exercise sessions) and (2) use a user-centered and participatory approach when designing and tailoring the intervention to the specific needs of older users (eg, group-based physical training to ensure higher levels of social interaction) [57,65,70,91,92,195]. In addition, from a theoretical point of view and compared with a fully remote implementation, hybrid physical training interventions (ie, with alternating center- and home-based physical exercise sessions) provide the advantage that the regular social interaction between health professional, trainee, and peers during the center-based physical exercise sessions might lead to the development of a social network that allows to more easily overcome barriers or difficulties emerging from the use of digital technologies to remotely deliver the home-based physical exercise sessions. For instance, the possibility of receiving social and technological support, if needed, by the health professional and peers during center visits might foster the implementation and adherence to hybrid physical training interventions as compared with fully remote interventions which are characterized by somewhat looser social interactions. This assumption is supported by the fact that the lack of support is often named as a barrier to the use of digital technologies by older adults without and with cognitive impairment [182,185], although future empirical studies are needed to verify (or refute) our idea that such a lack of technological support can be reduced by hybrid physical training interventions.

Another important point that needs to be considered when providing home-based physical training with and without digital solutions is safety. In general, there is evidence that home-based physical training interventions are safe [196] even when using digital solutions [64] or when conducted in vulnerable cohorts such as adults with cardiac diseases [197,198]. In this context, the findings of a recent systematic review and meta-analysis provide evidence that there is no difference in safety-related measures (eg, dropouts) between home- and center-based physical training [196] buttressing the assumption that home-based physical training is a safe alternative to center-based physical training. However, intuitively we suggest that a higher level of direct supervision (eg, online classes) should be used to further minimize the risk of negative health events in vulnerable groups (eg, older adults with chronic diseases and high risk of falls). However, future research studying the influence of different moderators on safety outcomes (eg, level of supervision, specific setting, and trainees' characteristics such as age and health status) is needed to provide evidence-based and more nuanced recommendations in terms of the safety of remotely delivered and home-based physical training.

Current State of Evidence on Hybrid Physical Training Interventions to Support Healthy Cognitive Aging

Overview

Hybrid physical training is a novel and promising form of delivering physical training to support healthy cognitive aging and thus the evidence of its effectiveness is, as far as we know, relatively scant [64] because only a small quantity of trials has been conducted to study the effects of hybrid physical training approaches on cognitive performance [190,199,200]. The characteristics and findings of these studies will be briefly summarized in the following.

Alternating Hybrid Physical Training

In the RCT of Auerswald et al [190] the effect of a 10-week hybrid physical training in alternating mode (Figure 1A) on different health-related outcomes (ie, including cognition) was investigated in a larger sample of healthy older adults (n=551, included in the final statistical analysis). The participants were randomly allocated to a waitlist control group (CG), an intervention group 1 (IG1) that received physical exercise prescription via print-based material or digital database, or an intervention group 2 (IG2) that received physical exercise prescription via digital database and also used a wearable (ie, physical activity tracker) [190]. The physical exercise prescription for the home-based program was individualized based on the individual fitness level of the participants and follows the recommendations of the World Health Organization for regular physical activity in adults [6,201,202] (eg, balance and flexibility exercise 2 times per week, resistance exercises at 2 nonconsecutive days per week, and endurance exercise for at least 150 minutes with moderate intensity) [190]. In IG1 and IG2, the home-based physical exercises were complemented by once-weekly center-based group meetings in which health education and group-based physical exercise sessions were performed [190]. In IG2, the wearable was used to provide the participants with objective feedback on the regular physical activity level [190]. Although the participants in the IG2 and CG showed better executive functions (ie, faster reaction time in the Simon task) in the posttest compared with the pretest, no significant group differences regarding cognitive performance were observed between CG, IG1, and IG2 [190].

Moon et al [200] conducted a 24-week-long RCT in older adults with one or more modifiable dementia risk factors, but no manifest dementia [200]. The participants (n=140, included in the final statistical analysis) were randomized to a CG (ie, receiving general health education), or 1 of 2 multimodal IGs (eg, including elements such as monitoring and management of metabolic and vascular risk factors, cognitive training and social activity, physical exercise, nutritional guidance, and motivational enhancement) that received 3 times a week a 60-minute session of only supervised center-based physical training or alternating hybrid physical training (Figure 1A). The unsupervised home-based physical exercise sessions consisted of endurance, resistance, flexibility, balance, and finger-and-toe exercises that were delivered via booklets or videos (ie, digital database) [200]. In the first 2 months, the hybrid physical training group performed 1 supervised group- and center-based physical exercise session per week (ie, 2 physical exercise sessions per week at home); whereas in the remaining 4 months, 1 supervised group- and center-based physical exercise session was conducted every 2 weeks (ie, 2 home-based physical exercise sessions in a week with a center visit and 3 home-based physical exercise sessions in a week without a center visit) [200]. Regarding cognitive outcomes, the hybrid physical training group showed (1) a better performance in visuoconstruction, attention, and total scale index score in the Repeatable Battery for the Assessment of Neuropsychological Status, and (2) a better score in the Prospective Retrospective Memory Questionnaire (ie, both as compared with the CG) [200].

Subsequent Hybrid Physical Training With Home-Based Follow-Up

In the randomized controlled pilot study of Wiebking et al [199], which can be classified as subsequent hybrid physical training with home-based follow-up (Figure 1B), a 12-week long intervention (ie, 3 weeks center-based and 9 weeks home-based; 3 exercise sessions per week each lasting 30-40 minutes) was conducted in a small sample (n=21, included in the final statistical analysis) of middle-aged adults with chronic unspecific low-back pain. The participants were randomly allocated to the CG receiving usual care, a unimodal intervention group receiving sensorimotor training (SMT) consisting of stability and resistance exercises, and a multidisciplinary intervention group receiving sensorimotor training supplemented by behavioral therapy (SMT+BT) that includes cognitive distraction during sensorimotor exercises, psychoeducation, and a body scan [199]. The center-based physical exercise sessions were group-based and directly supervised by an exercise professional, whereas the home-based physical exercise sessions were delivered via a digital database (ie, DVD) [199]. Concerning cognitive measures, a faster processing speed (ie, assessed via Trail Making Test A) was observed after the intervention and at the 3-month follow-up only in the SMT+BT group but not in the SMT or the CG group [199].

Interim Summary

Collectively, the findings of the aforementioned studies suggest that hybrid physical training is a promising approach to fostering healthy cognitive aging. However, the limited number of trials that have studied the effect of hybrid physical training on cognitive performance in the aging population does not allow for drawing more nuanced conclusions (eg, which type of hybrid physical training is most suitable for a specific context and setting). Thus, future research is needed to derive more robust and nuanced conclusions on the effectiveness of specific types of hybrid physical training to support healthy cognitive aging. In this context, our classification framework of hybrid physical training interventions provides researchers with an orientation that can help them to (1) structure findings and knowledge and (2) elucidate which type of hybrid physical training is most suitable for the specific context and setting. In prompting the direction of future research, we provide in the next section recommendations for research priorities concerning hybrid physical training and healthy cognitive aging.

Recommendations for Future Research

Considering the facts that (1) hybrid physical training interventions, especially those that use digital solutions to provide home-based physical exercise sessions, have been underused to promote planned and structured forms of physical activity in healthy middle-aged and older adults and adults at higher risk to develop dementia (eg, adults with MCI) [64] and (2) hybrid physical training provides some specific advantages depending on their implementation (see Interim Summary section for a detailed discussion), we recommend that future research should aim to answer the following research questions:

- Do the positive effects of physical training on cognitive health and dementia risk, as seen for traditional physical training intervention approaches, extend to hybrid physical training interventions?
- Is the potential effectiveness of hybrid physical training interventions influenced by their implementation (eg, temporal and intervention-related characteristics)?
- Do hybrid physical training interventions, as compared with traditional physical training approaches, improve measures of adherence?
- Are hybrid physical training interventions using digital technology feasible, safe, and effective in special populations with lower digital health literacy (eg, older adults with MCI)?

In the context of the aforementioned research questions, we propose that future studies should especially focus on, but are not limited to, measures of cognitive performance (eg, global cognition and memory), dementia-related risk factors and biomarkers (eg, blood-based parameters), ability to live independently (eg, activities of daily living, life-space mobility), adherence (eg, attendance and completion adherence [64,203,204]), social interaction (eg, social isolation, social connectedness), and cost use. To get a more comprehensive understanding of the neurobiological mechanisms that drive the positive effects of physical activity on cognitive health and to gain a deeper understanding of how physical training interventions can be effectively tailored to fit the individual needs of healthy middle-aged and older adults, and older adults with existing health conditions (eg, MCI), future studies should (1) use a rigorous study design [205-207] including a transparent reporting of the intervention-related characteristics [34,35,106,208], (2) conduct analysis on multiple levels (ie, level 1: changes on a molecular and cellular level, level 2: functional and structural brain changes, and level 3: socioemotional changes) [36,38,64], and (3) consider potential moderators such as sex or genetic status [209-213].

Conclusions

Hybrid physical training interventions, which consist of both center-based physical exercise sessions and home-based physical exercise sessions, can be a promising option to better tailor physical training-based approaches aiming to promote healthy cognitive aging to the individual needs of a person because they combine the strengths of a center-based approach (eg, supervision and social contact) and a home-based approach (eg, on-demand training), which, in turn, may increase the efficacy of such a form of intervention. To advance research in this direction, this article (1) provides a definition of hybrid physical training, (2) proposes a classification approach of different types of hybrid physical training interventions, (3) discusses the specific advantages and disadvantages of the different types of hybrid physical training interventions, and (4) provides recommendations for future research on hybrid physical training interventions in the context of healthy cognitive aging.

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Authors' Contributions

FH was responsible for the conceptualization, writing the original draft, and visualization. PT, TG, NK, LZ, EDB, LB, and NGM reviewed and edited the original draft. TG and NGM provided supervision, with NGM also contributing resources. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

References

1. Maj M, Sartorius N. Dementia. Chichester, United Kingdom: Wiley; 2000.
2. Arvanitakis Z, Shah RC, Bennett DA. Diagnosis and management of dementia: review. JAMA 2019;322(16):1589-1599 [FREE Full text] [doi: 10.1001/jama.2019.4782] [Medline: 31638686]
3. Wimo A, Seeher K, Cataldi R, Cyhlarova E, Dielemann JL, Frisell O, et al. The worldwide costs of dementia in 2019. Alzheimers Dement 2023;19(7):2865-2873 [FREE Full text] [doi: 10.1002/alz.12901] [Medline: 36617519]
4. Cantarero-Prieto D, Leon PL, Blazquez-Fernandez C, Juan PS, Cobo CS. The economic cost of dementia: a systematic review. Dementia 2019;19(8):2637-2657. [doi: 10.1177/1471301219837776] [Medline: 30909718]
5. Meijer E, Casanova M, Kim H, Llena-Nozal A, Lee J. Economic costs of dementia in 11 countries in Europe: estimates from nationally representative cohorts of a panel study. Lancet Reg Health Eur 2022;20:100445 [FREE Full text] [doi: 10.1016/j.lanepe.2022.100445] [Medline: 35781926]
6. Global status report on physical activity 2022. World Health Organization. 2022. URL: https://www.who.int/publications/i/item/9789240059153 [accessed 2024-06-19]
7. Nichols E, Steinmetz JD, Vollset SE, Fukutaki K, Chalek J, Abd-Allah F, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the global burden of disease study 2019. Lancet Public Health 2022;7(2):e105-e125 [FREE Full text] [doi: 10.1016/S2468-2667(21)00249-8] [Medline: 34998485]
8. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet commission. Lancet 2020;396(10248):413-446. [doi: 10.1016/s0140-6736(20)30367-6] [Medline: 32738937]
9. Kivipelto M, Mangialasche F, Ngandu T. Lifestyle interventions to prevent cognitive impairment, dementia and Alzheimer disease. Nat Rev Neurol 2018;14(11):653-666. [doi: 10.1038/s41582-018-0070-3] [Medline: 30291317]
10. Ringman JM, Cummings JL. Current and emerging pharmacological treatment options for dementia. Behav Neurol 2006;17(1):5-16. [doi: 10.1155/2006/315386]
11. Cummings JL, Morstorf T, Zhong K. Alzheimer’s disease drug-development pipeline: few candidates, frequent failures. Alzheimers Res Ther 2014;6(4):37. [doi: 10.1186/alzrt269] [Medline: 25024750]
12. Alty J, Farrow M, Lawler K. Exercise and dementia prevention. Pract Neurol 2020;20(3):234-240. [doi: 10.1136/practneurol-2019-002335] [Medline: 31964800]
13. Groot C, Hooghiemstra AM, Raijmakers PGHM, van Berckel BNM, Scheltens P, Scherder EJA, et al. The effect of physical activity on cognitive function in patients with dementia: a meta-analysis of randomized control trials. Ageing Res Rev 2016;25:13-23. [doi: 10.1016/j.arr.2015.11.005] [Medline: 26607411]
14. Zou L, Herold F, Cheval B, Wheeler MJ, Pindus DM, Erickson KI, et al. Sedentary behavior and lifespan brain health. Trends Cogn Sci 2024;28(4):369-382. [doi: 10.1016/j.tics.2024.02.003] [Medline: 38431428]
15. De la Rosa A, Olaso-Gonzalez G, Arc-Chagnaud C, Millan F, Salvador-Pascual A, García-Lucerga C, et al. Physical exercise in the prevention and treatment of Alzheimer's disease. J Sport Health Sci 2020;9(5):394-404. [doi: 10.1016/j.jshs.2020.01.004]
16. Richard E, Andrieu S, Solomon A, Mangialasche F, Ahtiluoto S, van Charante EPM, et al. Methodological challenges in designing dementia prevention trials—the European Dementia Prevention Initiative (EDPI). J Neurol Sci 2012;322(1-2):64-70. [doi: 10.1016/j.jns.2012.06.012] [Medline: 22818266]
17. Theobald P, Herold F, Gronwald T, Müller NG. Motoric cognitive risk syndrome—setting the course for dementia prevention? Nervenarzt 2023;94(10):944-950 [FREE Full text] [doi: 10.1007/s00115-023-01487-3] [Medline: 37140606]
18. Mullin DS, Gadd D, Russ TC, Luciano M, Muniz-Terrera G. Motoric cognitive risk syndrome trajectories and incident dementia over 10 years. Cereb Circ Cogn Behav 2023;5:100178. [doi: 10.1016/j.cccb.2023.100178]
19. Verghese J. Motoric cognitive risk syndrome: next steps. Eur J Neurol 2021;28(8):2467-2468. [doi: 10.1111/ene.14949] [Medline: 34057808]
20. Verghese J, Ayers E, Barzilai N, Bennett DA, Buchman AS, Holtzer R, et al. Motoric cognitive risk syndrome: multicenter incidence study. Neurology 2014;83(24):2278-2284 [FREE Full text] [doi: 10.1212/WNL.0000000000001084] [Medline: 25361778]
21. Jessen F, Amariglio RE, van Boxtel M, Breteler M, Ceccaldi M, Chételat G, et al. A conceptual framework for research on subjective cognitive decline in preclinical Alzheimer's disease. Alzheimers Dement 2014;10(6):844-852 [FREE Full text] [doi: 10.1016/j.jalz.2014.01.001] [Medline: 24798886]

22. Jessen F, Amariglio RE, Buckley RF, van der Flier WM, Han Y, Molinuevo JL, et al. The characterisation of subjective cognitive decline. Lancet Neurol 2020;19(3):271-278 [FREE Full text] [doi: 10.1016/S1474-4422(19)30368-0] [Medline: 31958406]
23. Gauthier S, Reisberg B, Zaudig M, Petersen RC, Ritchie K, Broich K, et al. Mild cognitive impairment. Lancet 2006;367(9518):1262-1270. [doi: 10.1016/S0140-6736(06)68542-5]
24. Winblad B, Palmer K, Kivipelto M, Jelic V, Fratiglioni L, Wahlund L, et al. Mild cognitive impairment—beyond controversies, towards a consensus: report of the International Working Group on mild cognitive impairment. J Intern Med 2004;256(3):240-246. [doi: 10.1111/j.1365-2796.2004.01380.x] [Medline: 15324367]
25. Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E. Mild cognitive impairment: clinical characterization and outcome. Arch Neurol 1999;56(3):303-308. [doi: 10.1001/archneur.56.3.303] [Medline: 10190820]
26. Mullin DS, Cockburn A, Welstead M, Luciano M, Russ TC, Muniz - Terrera G. Mechanisms of motoric cognitive risk—hypotheses based on a systematic review and meta - analysis of longitudinal cohort studies of older adults. Alzheimers Dement 2022;18(12):2413-2427 [FREE Full text] [doi: 10.1002/alz.12547] [Medline: 35142038]
27. Verghese J, Annweiler C, Ayers E, Barzilai N, Beauchet O, Bennett DA, et al. Motoric cognitive risk syndrome: multicountry prevalence and dementia risk. Neurology 2014;83(8):718-726 [FREE Full text] [doi: 10.1212/WNL.0000000000000717] [Medline: 25031288]
28. Beauchet O, Sekhon H, Launay CP, Rolland Y, Schott AM, Allali G. Motoric cognitive risk syndrome and incident dementia: results from a population - based prospective and observational cohort study. Eur J Neurol 2019;27(3):468-474. [doi: 10.1111/ene.14093] [Medline: 31571342]
29. Gustavsson A, Norton N, Fast T, Frölich L, Georges J, Holzapfel D, et al. Global estimates on the number of persons across the Alzheimer's disease continuum. Alzheimers Dement 2022;19(2):658-670. [doi: 10.1002/alz.12694] [Medline: 35652476]
30. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Rep 1985;100(2):126-131 [FREE Full text] [Medline: 3920711]
31. Budde H, Schwarz R, Velasques B, Ribeiro P, Holzweg M, Machado S, et al. The need for differentiating between exercise, physical activity, and training. Autoimmun Rev 2016;15(1):110-111. [doi: 10.1016/j.autrev.2015.09.004] [Medline: 26384527]
32. Herold F, Theobald P, Gronwald T, Rapp MA, Müller NG. Going digital—a commentary on the terminology used at the intersection of physical activity and digital health. Eur Rev Aging Phys Act 2022;19(1):17. [doi: 10.1186/s11556-022-00296-y]
33. Herold F, Hamacher D, Schega L, Müller NG. Thinking while moving or moving while thinking—concepts of motor-cognitive training for cognitive performance enhancement. Front Aging Neurosci 2018;10:228. [doi: 10.3389/fnagi.2018.00228]
34. Herold F, Müller P, Gronwald T, Müller NG. Dose–response matters!—a perspective on the exercise prescription in exercise–cognition research. Front Psychol 2019;10:2338 [FREE Full text] [doi: 10.3389/fpsyg.2019.02338] [Medline: 31736815]
35. Herold F, Törpel A, Hamacher D, Budde H, Gronwald T. A discussion on different approaches for prescribing physical interventions—four roads lead to rome, but which one should we choose? J Per Med 2020;10(3):55 [FREE Full text] [doi: 10.3390/jpm10030055] [Medline: 32605044]
36. Erickson KI, Donofry SD, Sewell KR, Brown BM, Stillman CM. Cognitive aging and the promise of physical activity. Annu Rev Clin Psychol 2022;18(1):417-442. [doi: 10.1146/annurev-clinpsy-072720-014213] [Medline: 35044793]
37. Hillman CH, Erickson KI, Kramer AF. Be smart, exercise your heart: exercise effects on brain and cognition. Nat Rev Neurosci 2008;9(1):58-65. [doi: 10.1038/nrn2298] [Medline: 18094706]
38. Stillman CM, Esteban-Cornejo I, Brown B, Bender CM, Erickson KI. Effects of exercise on brain and cognition across age groups and health states. Trends Neurosci 2020;43(7):533-543 [FREE Full text] [doi: 10.1016/j.tins.2020.04.010] [Medline: 32409017]
39. Ludyga S, Gerber M, Pühse U, Looser VN, Kamijo K. Systematic review and meta-analysis investigating moderators of long-term effects of exercise on cognition in healthy individuals. Nat Hum Behav 2020;4(6):603-612 [FREE Full text] [doi: 10.1038/s41562-020-0851-8] [Medline: 32231280]
40. Bherer L, Erickson KI, Liu-Ambrose T. A review of the effects of physical activity and exercise on cognitive and brain functions in older adults. J Aging Res 2013;2013:657508 [FREE Full text] [doi: 10.1155/2013/657508] [Medline: 24102028]
41. Liu-Ambrose T, Barha C, Falck RS. Active body, healthy brain: exercise for healthy cognitive aging. Int Rev Neurobiol 2019;147:95-120. [doi: 10.1016/bs.irn.2019.07.004] [Medline: 31607364]
42. Liu-Ambrose T, Barha CK, Best JR. Physical activity for brain health in older adults. Appl Physiol Nutr Metab 2018;43(11):1105-1112. [doi: 10.1139/apnm-2018-0260] [Medline: 30306793]
43. Falck RS, Davis JC, Best JR, Crockett RA, Liu-Ambrose T. Impact of exercise training on physical and cognitive function among older adults: a systematic review and meta-analysis. Neurobiol Aging 2019;79:119-130. [doi: 10.1016/j.neurobiolaging.2019.03.007]
44. Northey JM, Cherbuin N, Pumpa KL, Smee DJ, Rattray B. Exercise interventions for cognitive function in adults older than 50: a systematic review with meta-analysis. Br J Sports Med 2017;52(3):154-160. [doi: 10.1136/bjsports-2016-096587] [Medline: 28438770]

45. Blondell SJ, Hammersley-Mather R, Veerman JL. Does physical activity prevent cognitive decline and dementia?: a systematic review and meta-analysis of longitudinal studies. BMC Public Health 2014;14(1):510 [FREE Full text] [doi: 10.1186/1471-2458-14-510] [Medline: 24885250]
46. Paillard T. Preventive effects of regular physical exercise against cognitive decline and the risk of dementia with age advancement. Sports Med Open 2015;1(1):20 [FREE Full text] [doi: 10.1186/s40798-015-0016-x] [Medline: 26284161]
47. Veronese N, Soysal P, Barbagallo M, Shenkin SD, Quinn TJ. Commentary on: physical activity and exercise for mild cognitive impairment and dementia: a collaborative international guideline. Aging Clin Exp Res 2024;36(1):99. [doi: 10.1007/s40520-024-02747-1] [Medline: 38652380]
48. Veronese N, Soysal P, Demurtas J, Solmi M, Bruyère O, Christodoulou N, et al. Physical activity and exercise for the prevention and management of mild cognitive impairment and dementia: a collaborative international guideline. Eur Geriatr Med 2023;14(5):925-952 [FREE Full text] [doi: 10.1007/s41999-023-00858-y] [Medline: 37768499]
49. Guthold R, Stevens GA, Riley LM, Bull FC. Worldwide trends in insufficient physical activity from 2001 to 2016: a pooled analysis of 358 population-based surveys with 1·9 million participants. Lancet Glob Health 2018;6(10):e1077-e1086. [doi: 10.1016/s2214-109x(18)30357-7]
50. Hallal PC, Andersen LB, Bull FC, Guthold R, Haskell W, Ekelund U. Global physical activity levels: surveillance progress, pitfalls, and prospects. Lancet 2012;380(9838):247-257. [doi: 10.1016/S0140-6736(12)60646-1]
51. Guthold R, Ono T, Strong KL, Chatterji S, Morabia A. Worldwide variability in physical inactivity: a 51-country survey. Am J Prev Med 2008;34(6):486-494. [doi: 10.1016/j.amepre.2008.02.013] [Medline: 18471584]
52. Gomes M, Figueiredo D, Teixeira L, Poveda V, Paúl C, Santos-Silva A, et al. Physical inactivity among older adults across Europe based on the SHARE database. Age Ageing 2017;46(1):71-77 [FREE Full text] [doi: 10.1093/ageing/afw165] [Medline: 28181637]
53. Falck RS, Landry GJ, Best JR, Davis JC, Chiu BK, Liu-Ambrose T. Cross-sectional relationships of physical activity and sedentary behavior with cognitive function in older adults with probable mild cognitive impairment. Phys Ther 2017;97(10):975-984 [FREE Full text] [doi: 10.1093/ptj/pzx074] [Medline: 29029554]
54. Kim KI, Gollamudi SS, Steinhubl S. Digital technology to enable aging in place. Exp Gerontol 2017;88:25-31. [doi: 10.1016/j.exger.2016.11.013] [Medline: 28025126]
55. Chowdhary N, Barbui C, Anstey KJ, Kivipelto M, Barbera M, Peters R, et al. Reducing the risk of cognitive decline and dementia: WHO recommendations. Front Neurol 2022;12:765584. [doi: 10.3389/fneur.2021.765584]
56. BE MOBILE BE HE@LTHY: A Handbook on How to Implement mAgeing. Geneva: World Health Organization; 2018.
57. Chen C, Ding S, Wang J. Digital health for aging populations. Nat Med 2023;29(7):1623-1630. [doi: 10.1038/s41591-023-02391-8] [Medline: 37464029]
58. Berron D, Glanz W, Clark L, Basche K, Grande X, Güsten J, et al. A remote digital memory composite to detect cognitive impairment in memory clinic samples in unsupervised settings using mobile devices. NPJ Digit Med 2024;7(1):79 [FREE Full text] [doi: 10.1038/s41746-024-00999-9] [Medline: 38532080]
59. Berron D, Ziegler G, Vieweg P, Billette O, Güsten J, Grande X, et al. Feasibility of digital memory assessments in an unsupervised and remote study setting. Front Digit Health 2022;4:892997. [doi: 10.3389/fdgth.2022.892997] [Medline: 35721797]
60. Sabbagh MN, Boada M, Borson S, Doraiswamy PM, Dubois B, Ingram J, et al. Early detection of mild cognitive impairment (MCI) in an at-home setting. J Prev Alzheimers Dis 2020;7(3):171-178. [doi: 10.14283/jpad.2020.22] [Medline: 32463070]
61. Koo BM, Vizer LM. Mobile technology for cognitive assessment of older adults: a scoping review. Innov Aging 2019;3(1):igy038 [FREE Full text] [doi: 10.1093/geroni/igy038] [Medline: 30619948]
62. Daniels K, Bonnechère B. Harnessing digital health interventions to bridge the gap in prevention for older adults. Front Public Health 2024;11:1281923 [FREE Full text] [doi: 10.3389/fpubh.2023.1281923] [Medline: 38259780]
63. Siette J, Adam PJ. Building digital solutions to support brain health prescribing in primary care: where to begin? Alzheimers Dement (N Y) 2024;10(1):e12447 [FREE Full text] [doi: 10.1002/trc2.12447] [Medline: 38356479]
64. Herold F, Theobald P, Gronwald T, Kaushal N, Zou L, de Bruin ED, et al. Alexa, let's train now!—a systematic review and classification approach to digital and home-based physical training interventions aiming to support healthy cognitive aging. J Sport Health Sci 2024;13(1):30-46 [FREE Full text] [doi: 10.1016/j.jshs.2023.01.004] [Medline: 36736727]
65. Di Lorito C, Bosco A, Rai H, Craven M, McNally D, Todd C, et al. A systematic literature review and meta ‐ analysis on digital health interventions for people living with dementia and mild cognitive impairment. Int J Geriatr Psychiatry 2022;37(6):1-25 [FREE Full text] [doi: 10.1002/gps.5730] [Medline: 35588315]
66. Ferguson T, Olds T, Curtis R, Blake H, Crozier AJ, Dankiw K, et al. Effectiveness of wearable activity trackers to increase physical activity and improve health: a systematic review of systematic reviews and meta-analyses. Lancet Digit Health 2022;4(8):e615-e626 [FREE Full text] [doi: 10.1016/S2589-7500(22)00111-X] [Medline: 35868813]
67. Longhini J, Marzaro C, Bargeri S, Palese A, Dell'Isola A, Turolla A, et al. Wearable devices to improve physical activity and reduce sedentary behaviour: an umbrella review. Sports Med Open 2024;10(1):9 [FREE Full text] [doi: 10.1186/s40798-024-00678-9] [Medline: 38219269]
68. Dodds L, Siette J. Challenges, solutions and future directions for public health innovations targeting dementia prevention for rural and remote populations. Australas J Ageing 2022;41(3):466-472. [doi: 10.1111/ajag.13105] [Medline: 35844068]

69. Weden MM, Shih RA, Kabeto MU, Langa KM. Secular trends in dementia and cognitive impairment of U.S. rural and urban older adults. Am J Prev Med 2018;54(2):164-172 [FREE Full text] [doi: 10.1016/j.amepre.2017.10.021] [Medline: 29246677]
70. Wiese LAK, Gibson A, Guest MA, Nelson AR, Weaver R, Gupta A, et al. Global rural health disparities in Alzheimer's disease and related dementias: state of the science. Alzheimers Dement 2023;19(9):4204-4225. [doi: 10.1002/alz.13104] [Medline: 37218539]
71. Glauber R. Rural depopulation and the rural‐urban gap in cognitive functioning among older adults. J Rural Health 2022;38(4):696-704. [doi: 10.1111/jrh.12650] [Medline: 35257439]
72. Thompson WR. Worldwide survey of fitness trends for 2021. ACSM Health Fitness J 2021;25(1):10-19. [doi: 10.1249/fit.0000000000000631]
73. Thompson WR. Worldwide survey of fitness trends for 2022. ACSM Health Fitness J 2022;26(1):11-20. [doi: 10.1249/FIT.0000000000000732]
74. Thompson WR. Worldwide survey of fitness trends for 2023. ACSM Health Fitness J 2023;27(1):9-18. [doi: 10.1249/fit.0000000000000834]
75. Newsome AM, Reed R, Sansone J, Batrakoulis A, McAvoy C, W. Parrott M. 2024 ACSM worldwide fitness trends: future directions of the health and fitness industry. ACSM Health Fitness J 2024;28(1):14-26. [doi: 10.1249/fit.0000000000000933]
76. Ammar A, Boukhris O, Halfpaap N, Labott BK, Langhans C, Herold F, et al. Four weeks of detraining induced by COVID-19 reverse cardiac improvements from eight weeks of fitness-dance training in older adults with mild cognitive impairment. Int J Environ Res Public Health 2021;18(11):5930 [FREE Full text] [doi: 10.3390/ijerph18115930] [Medline: 34073051]
77. Basso JC, Oberlin DJ, Satyal MK, O'Brien CE, Crosta C, Psaras Z, et al. Examining the effect of increased aerobic exercise in moderately fit adults on psychological state and cognitive function. Front Hum Neurosci 2022;16:833149. [doi: 10.3389/fnhum.2022.833149]
78. Tsai CL, Pan CY, Chen FC, Tseng YT. Open- and closed-skill exercise interventions produce different neurocognitive effects on executive functions in the elderly: a 6-month randomized, controlled trial. Front Aging Neurosci 2017;9:294 [FREE Full text] [doi: 10.3389/fnagi.2017.00294] [Medline: 28959200]
79. Eggenberger P, Wolf M, Schumann M, de Bruin ED. Exergame and balance training modulate prefrontal brain activity during walking and enhance executive function in older adults. Front Aging Neurosci 2016;8:66. [doi: 10.3389/fnagi.2016.00066]
80. Eggenberger P, Annaheim S, Kündig KA, Rossi RM, Münzer T, de Bruin ED. Heart rate variability mainly relates to cognitive executive functions and improves through exergame training in older adults: a secondary analysis of a 6-month randomized controlled trial. Front Aging Neurosci 2020;12:197. [doi: 10.3389/fnagi.2020.00197]
81. Schättin A, Arner R, Gennaro F, de Bruin ED. Adaptations of prefrontal brain activity, executive functions, and gait in healthy elderly following exergame and balance training: a randomized-controlled study. Front Aging Neurosci 2016;8:278 [FREE Full text] [doi: 10.3389/fnagi.2016.00278] [Medline: 27932975]
82. Kawabata M, Gan SR, Shen-Hsing AC. Effects of square stepping exercise on cognitive, physical, psychological, and group functioning in sedentary older adults: a center-based hybrid trial. BMC Geriatr 2024;24(1):374. [doi: 10.1186/s12877-024-04904-7] [Medline: 38664613]
83. Justine M, Azizan A, Hassan V, Salleh Z, Manaf H. Barriers to participation in physical activity and exercise among middle-aged and elderly individuals. Singapore Med J 2013;54(10):581-586 [FREE Full text] [doi: 10.11622/smedj.2013203] [Medline: 24154584]
84. Moschny A, Platen P, Klaaßen-Mielke R, Trampisch U, Hinrichs T. Barriers to physical activity in older adults in Germany: a cross-sectional study. Int J Behav Nutr Phys Act 2011;8(1):121 [FREE Full text] [doi: 10.1186/1479-5868-8-121] [Medline: 22047024]
85. Jaarsma EA, Dijkstra PU, Geertzen JHB, Dekker R. Barriers to and facilitators of sports participation for people with physical disabilities: a systematic review. Scand J Med Sci Sports 2014;24(6):871-881. [doi: 10.1111/sms.12218] [Medline: 24730752]
86. Hobson N, Dupuis SL, Giangregorio LM, Middleton LE. Perceived facilitators and barriers to exercise among older adults with mild cognitive impairment and early dementia. J Aging Phys Act 2020;28(2):208-218. [doi: 10.1123/japa.2019-0010] [Medline: 31621645]
87. Leroy V, Gana W, Aïdoud A, N'kodo JA, Balageas AC, Blanc P, et al. Digital health technologies and Alzheimer's disease clinical trials: might decentralized clinical trials increase participation by people with cognitive impairment? Alzheimers Res Ther 2023;15(1):87 [FREE Full text] [doi: 10.1186/s13195-023-01227-4] [Medline: 37106429]
88. Seinsche J, de Bruin ED, Hinrichs T, Giannouli E. Effects of home-based interventions using exergames on physical and cognitive functions in community-dwelling older adults: a PRISMA-P-compliant protocol for a systematic review. Front Public Health 2024;11:1291120. [doi: 10.3389/fpubh.2023.1291120]
89. Seinsche J, de Bruin ED, Saibene E, Rizzo F, Carpinella I, Ferrarin M, et al. Feasibility and effectiveness of a personalized home-based motor-cognitive training program in community-dwelling older adults: protocol for a pragmatic pilot randomized controlled trial. JMIR Res Protoc 2023;12:e49377 [FREE Full text] [doi: 10.2196/49377] [Medline: 37943591]

90. Manser P, Poikonen H, de Bruin ED. Feasibility, usability, and acceptance of "brain-IT"—a newly developed exergame-based training concept for the secondary prevention of mild neurocognitive disorder: a pilot randomized controlled trial. Front Aging Neurosci 2023;15:1163388. [doi: 10.3389/fnagi.2023.1163388]
91. Manser P, Adcock-Omlin M, de Bruin ED. Design considerations for an exergame-based training intervention for older adults with mild neurocognitive disorder: qualitative study including focus groups with experts and health care professionals and individual semistructured in-depth patient interviews. JMIR Serious Games 2023;11:e37616 [FREE Full text] [doi: 10.2196/37616] [Medline: 36602851]
92. Manser P, de Bruin ED. Making the best out of IT: design and development of exergames for older adults with mild neurocognitive disorder—a methodological paper. Front Aging Neurosci 2021;13:734012. [doi: 10.3389/fnagi.2021.734012]
93. Manser P, Michels L, Schmidt A, Barinka F, de Bruin ED. Effectiveness of an individualized exergame-based motor-cognitive training concept targeted to improve cognitive functioning in older adults with mild neurocognitive disorder: study protocol for a randomized controlled trial. JMIR Res Protoc 2023;12:e41173 [FREE Full text] [doi: 10.2196/41173] [Medline: 36745483]
94. Ebert B, Streicher H, Notthoff N. Online exercise during the COVID-19 pandemic and factors promoting or hindering participation in adults: a scoping review. Int J Sport Exerc Psychol 2024:1-32. [doi: 10.1080/1612197x.2024.2314107]
95. Bek J, Groves M, Leventhal D, Poliakoff E. Dance at home for people with Parkinson's during COVID-19 and beyond: participation, perceptions, and prospects. Front Neurol 2021;12:678124 [FREE Full text] [doi: 10.3389/fneur.2021.678124] [Medline: 34140925]
96. Collado-Mateo D, Lavín-Pérez AM, Peñacoba C, Del Coso J, Leyton-Román M, Luque-Casado A, et al. Key factors associated with adherence to physical exercise in patients with chronic diseases and older adults: an umbrella review. Int J Environ Res Public Health 2021;18(4):2023 [FREE Full text] [doi: 10.3390/ijerph18042023] [Medline: 33669679]
97. Ganeshan S, Jackson H, Grandis DJ, Janke D, Murray ML, Valle V, et al. Clinical outcomes and qualitative perceptions of in-person, hybrid, and virtual cardiac rehabilitation. J Cardiopulm Rehabil Prev 2022;42(5):338-346. [doi: 10.1097/HCR.0000000000000688] [Medline: 35420563]
98. Imran HM, Baig M, Erqou S, Taveira TH, Shah NR, Morrison A, et al. Home‐based cardiac rehabilitation alone and hybrid with center‐based cardiac rehabilitation in heart failure: a systematic review and meta‐analysis. J Am Heart Assoc 2019;8(16):e012779 [FREE Full text] [doi: 10.1161/JAHA.119.012779] [Medline: 31423874]
99. Keteyian SJ, Grimshaw C, Brawner CA, Kerrigan DJ, Reasons L, Berry R, et al. A comparison of exercise intensity in hybrid versus standard phase two cardiac rehabilitation. J Cardiopulm Rehabil Prev 2021;41(1):19-22 [FREE Full text] [doi: 10.1097/HCR.0000000000000569] [Medline: 33351540]
100. Hirthammer R, Breitkopf A, Hollmann M, Schifferdecker-Hoch F. The hybrid therapeutic approach for hip and knee osteoarthritis: a pilot study for a novel healthcare concept [Der hybride Therapieansatz bei Hüft- und Kniearthrose: Eine Pilotstudie zu einem neuartigen Versorgungskonzept]. B&G Bewegungstherapie und Gesundheitssport 2021;37(04):172-178. [doi: 10.1055/a-1528-5216]
101. Herold F, Törpel A, Hamacher D, Budde H, Zou L, Strobach T, et al. Causes and consequences of interindividual response variability: a call to apply a more rigorous research design in acute exercise-cognition studies. Front Physiol 2021;12:682891 [FREE Full text] [doi: 10.3389/fphys.2021.682891] [Medline: 34366881]
102. Aranda MP, Kremer IN, Hinton L, Zissimopoulos J, Whitmer RA, Hummel CH, et al. Impact of dementia: health disparities, population trends, care interventions, and economic costs. J Am Geriatr Soc 2021;69(7):1774-1783 [FREE Full text] [doi: 10.1111/jgs.17345] [Medline: 34245588]
103. Brach M, de Bruin ED, Levin O, Hinrichs T, Zijlstra W, Netz Y. Evidence-based yet still challenging! research on physical activity in old age. Eur Rev Aging Phys Act 2023;20(1):7 [FREE Full text] [doi: 10.1186/s11556-023-00318-3] [Medline: 36932320]
104. Breitkopf A, Köppel M, Hirthammer R, Hollmann M, Schifferdecker-Hoch F, Scheer J, et al. Objectives, methodology and content of a new hybrid therapy for people with osteoporosis in different advanced stages [Ziele, Methodik und Inhalte einer neuen hybriden Therapie für Personen mit Osteoporose in unterschiedlich fortgeschrittenen Stadien]. B&G Bewegungstherapie und Gesundheitssport 2021;37(04):190-200. [doi: 10.1055/a-1528-9080]
105. Denton F, Power S, Waddell A, Birkett S, Duncan M, Harwood A, et al. Is it really home-based? a commentary on the necessity for accurate definitions across exercise and physical activity programmes. Int J Environ Res Public Health 2021;18(17):9244 [FREE Full text] [doi: 10.3390/ijerph18179244] [Medline: 34501833]
106. Hecksteden A, Faude O, Meyer T, Donath L. How to construct, conduct and analyze an exercise training study? Front Physiol 2018;9:1007. [doi: 10.3389/fphys.2018.01007]
107. Šlosar L, Voelcker-Rehage C, Paravlić AH, Abazovic E, de Bruin ED, Marusic U. Combining physical and virtual worlds for motor-cognitive training interventions: position paper with guidelines on technology classification in movement-related research. Front Psychol 2022;13:1009052. [doi: 10.3389/fpsyg.2022.1009052]
108. Eynon M, Foad J, Downey J, Bowmer Y, Mills H. Assessing the psychosocial factors associated with adherence to exercise referral schemes: a systematic review. Scand J Med Sci Sports 2019;29(5):638-650. [doi: 10.1111/sms.13403] [Medline: 30742334]

109. Tolks D, Romeike BFM, Ehlers J, Kuhn S, Kleinsorgen C, Huber J, et al. The online inverted classroom model (oICM). a blueprint to adapt the inverted classroom to an online learning setting in medical and health education. MedEdPublish 2020;9:113 [FREE Full text] [doi: 10.15694/mep.2020.000113.1] [Medline: 38073851]
110. Costa RRG, Dorneles JR, Veloso JH, Gonçalves CWP, Neto FR. Synchronous and asynchronous tele-exercise during the coronavirus disease 2019 pandemic: comparisons of implementation and training load in individuals with spinal cord injury. J Telemed Telecare 2023;29(4):308-317 [FREE Full text] [doi: 10.1177/1357633X20982732] [Medline: 33461399]
111. Wilson LS, Maeder AJ. Recent directions in telemedicine: review of trends in research and practice. Healthc Inform Res 2015;21(4):213-222 [FREE Full text] [doi: 10.4258/hir.2015.21.4.213] [Medline: 26618026]
112. Malasanos T, Ramnitz MS. Diabetes clinic at a distance: telemedicine bridges the gap. Diabetes Spectrum 2013;26(4):226-231. [doi: 10.2337/diaspect.26.4.226]
113. Chan S, Li L, Torous J, Gratzer D, Yellowlees PM. Review of use of asynchronous technologies incorporated in mental health care. Curr Psychiatry Rep 2018;20(10):85. [doi: 10.1007/s11920-018-0954-3] [Medline: 30155593]
114. Lemstra M, Bird Y, Nwankwo C, Rogers M, Moraros J. Weight loss intervention adherence and factors promoting adherence: a meta-analysis. Patient Prefer Adherence 2016;10:1547-1559 [FREE Full text] [doi: 10.2147/PPA.S103649] [Medline: 27574404]
115. Driessen EJ, Peeters ME, Bongers BC, Maas HA, Bootsma GP, van Meeteren NL, et al. Effects of prehabilitation and rehabilitation including a home-based component on physical fitness, adherence, treatment tolerance, and recovery in patients with non-small cell lung cancer: a systematic review. Crit Rev Oncol Hematol 2017;114:63-76. [doi: 10.1016/j.critrevonc.2017.03.031] [Medline: 28477748]
116. Lara E, Caballero FF, Rico-Uribe LA, Olaya B, Haro JM, Ayuso-Mateos JL, et al. Are loneliness and social isolation associated with cognitive decline? Int J Geriatr Psychiatry 2019;34(11):1613-1622. [doi: 10.1002/gps.5174] [Medline: 31304639]
117. Luchetti M, Terracciano A, Aschwanden D, Lee JH, Stephan Y, Sutin AR. Loneliness is associated with risk of cognitive impairment in the survey of health, ageing and retirement in Europe. Int J Geriatr Psychiatry 2020;35(7):794-801 [FREE Full text] [doi: 10.1002/gps.5304] [Medline: 32250480]
118. Shankar A, Hamer M, McMunn A, Steptoe A. Social isolation and loneliness: relationships with cognitive function during 4 years of follow-up in the English longitudinal study of ageing. Psychosom Med 2013;75(2):161-170. [doi: 10.1097/PSY.0b013e31827f09cd] [Medline: 23362501]
119. Yin J, Lassale C, Steptoe A, Cadar D. Exploring the bidirectional associations between loneliness and cognitive functioning over 10 years: the English longitudinal study of ageing. Int J Epidemiol 2019;48(6):1937-1948 [FREE Full text] [doi: 10.1093/ije/dyz085] [Medline: 31056641]
120. Lara E, Martín-María N, De la Torre-Luque A, Koyanagi A, Vancampfort D, Izquierdo A, et al. Does loneliness contribute to mild cognitive impairment and dementia? a systematic review and meta-analysis of longitudinal studies. Ageing Res Rev 2019;52:7-16. [doi: 10.1016/j.arr.2019.03.002] [Medline: 30914351]
121. Salinas J, Beiser AS, Samra JK, O'Donnell A, DeCarli CS, Gonzales MM, et al. Association of loneliness with 10-year dementia risk and early markers of vulnerability for neurocognitive decline. Neurology 2022;98(13):e1337-e1348 [FREE Full text] [doi: 10.1212/WNL.0000000000200039] [Medline: 35131906]
122. Shafighi K, Villeneuve S, Rosa Neto P, Badhwar A, Poirier J, Sharma V, et al. Social isolation is linked to classical risk factors of Alzheimer's disease-related dementias. PLoS One 2023;18(2):e0280471 [FREE Full text] [doi: 10.1371/journal.pone.0280471] [Medline: 36724157]
123. Sutin AR, Stephan Y, Luchetti M, Terracciano A. Loneliness and risk of dementia. J Gerontol B Psychol Sci Soc Sci 2020;75(7):1414-1422 [FREE Full text] [doi: 10.1093/geronb/gby112] [Medline: 30365023]
124. Yu J, Lam CLM, Lee TMC. Perceived loneliness among older adults with mild cognitive impairment. Int Psychogeriatr 2016;28(10):1681-1685. [doi: 10.1017/S1041610216000430] [Medline: 27073010]
125. Jenkin CR, Eime RM, van Uffelen JGZ, Westerbeek H. How to re-engage older adults in community sport? reasons for drop-out and re-engagement. Leisure Stud 2021;40(4):441-453. [doi: 10.1080/02614367.2021.1888310]
126. Jenkin CR, Eime RM, Westerbeek H, van Uffelen JGZ. Sport for adults aged 50+ years: participation benefits and barriers. J Aging Phys Act 2018;26(3):363-371. [doi: 10.1123/japa.2017-0092] [Medline: 28952860]
127. Franco MR, Tong A, Howard K, Sherrington C, Ferreira PH, Pinto RZ, et al. Older people's perspectives on participation in physical activity: a systematic review and thematic synthesis of qualitative literature. Br J Sports Med 2015;49(19):1268-1276. [doi: 10.1136/bjsports-2014-094015] [Medline: 25586911]
128. Rhodes RE, Martin AD, Taunton JE, Rhodes EC, Donnelly M, Elliot J. Factors associated with exercise adherence among older adults: an individual perspective. Sports Med 1999;28(6):397-411. [doi: 10.2165/00007256-199928060-00003] [Medline: 10623983]
129. Sommerlad A, Kivimäki M, Larson EB, Röhr S, Shirai K, Singh-Manoux A, et al. Social participation and risk of developing dementia. Nat Aging 2023;3(5):532-545. [doi: 10.1038/s43587-023-00387-0] [Medline: 37202513]
130. Brady S, D'Ambrosio LA, Felts A, Rula EY, Kell KP, Coughlin JF. Reducing isolation and loneliness through membership in a fitness program for older adults: implications for health. J Appl Gerontol 2020;39(3):301-310 [FREE Full text] [doi: 10.1177/0733464818807820] [Medline: 30392420]

131. Sebastião E, Mirda D. Group-based physical activity as a means to reduce social isolation and loneliness among older adults. Aging Clin Exp Res 2021;33(7):2003-2006. [doi: 10.1007/s40520-020-01722-w] [Medline: 33387363]
132. Nagata K, Tsunoda K, Fujii Y, Jindo T, Okura T. Impact of exercising alone and exercising with others on the risk of cognitive impairment among older Japanese adults. Arch Gerontol Geriatr 2023;107:104908. [doi: 10.1016/j.archger.2022.104908] [Medline: 36565607]
133. Mitchell JJ, Hamer M, Blodgett JM, Wannamethee GS, Jefferis BJ. Associations between sporting physical activity and cognition in mid and later-life: evidence from two cohorts. Scand J Med Sci Sports 2023;33(8):1570-1575 [FREE Full text] [doi: 10.1111/sms.14412] [Medline: 37254468]
134. Fujii Y, Seol J, Joho K, Liu J, Inoue T, Nagata K, et al. Associations between exercising in a group and physical and cognitive functions in community-dwelling older adults: a cross-sectional study using data from the Kasama study. J Phys Ther Sci 2021;33(1):15-21 [FREE Full text] [doi: 10.1589/jpts.33.15] [Medline: 33519068]
135. Lam JA, Murray ER, Yu KE, Ramsey M, Nguyen TT, Mishra J, et al. Neurobiology of loneliness: a systematic review. Neuropsychopharmacology 2021;46(11):1873-1887 [FREE Full text] [doi: 10.1038/s41386-021-01058-7] [Medline: 34230607]
136. Dabiri S, Mwendwa DT, Campbell A. Psychological and neurobiological mechanisms involved in the relationship between loneliness and cognitive decline in older adults. Brain Behav Immun 2024;116:10-21. [doi: 10.1016/j.bbi.2023.11.034] [Medline: 38008386]
137. Hawkley LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. Ann Behav Med 2010;40(2):218-227 [FREE Full text] [doi: 10.1007/s12160-010-9210-8] [Medline: 20652462]
138. Maher CA, Olds T, Vandelanotte C, Plotnikoff R, Edney SM, Ryan JC, et al. Gamification in a physical activity app: what gamification features are being used, by whom, and does it make a difference? Games Health J 2022;11(3):193-199. [doi: 10.1089/g4h.2021.0207] [Medline: 35501981]
139. Mazeas A, Duclos M, Pereira B, Chalabaev A. Evaluating the effectiveness of gamification on physical activity: systematic review and meta-analysis of randomized controlled trials. J Med Internet Res 2022;24(1):e26779 [FREE Full text] [doi: 10.2196/26779] [Medline: 34982715]
140. Besnier F, Dupuy EG, Gagnon C, Vincent T, Grégoire CA, Blanchette C, et al. Investigation of the effects of home-based exercise and cognitive training on cognitive and physical functions in cardiac patients: the COVEPICARDIO study protocol of a randomized clinical trial. Front Cardiovasc Med 2021;8:740834 [FREE Full text] [doi: 10.3389/fcvm.2021.740834] [Medline: 34938780]
141. Dupuy EG, Besnier F, Gagnon C, Vincent T, Grégoire CA, Blanchette C, et al. COVEPIC (cognitive and sport virtual epic training) investigating the effects of home-based physical exercise and cognitive training on cognitive and physical functions in community-dwelling older adults: study protocol of a randomized single-blinded clinical trial. Trials 2021;22(1):505 [FREE Full text] [doi: 10.1186/s13063-021-05476-2] [Medline: 34325710]
142. Miyazaki A, Okuyama T, Mori H, Sato K, Kumamoto K, Hiyama A. Effects of two short-term aerobic exercises on cognitive function in healthy older adults during COVID-19 confinement in Japan: a pilot randomized controlled trial. Int J Environ Res Public Health 2022;19(10):6202 [FREE Full text] [doi: 10.3390/ijerph19106202] [Medline: 35627740]
143. Yang L, Gallant SN, Wilkins LK, Dyson B. Cognitive and psychosocial outcomes of self-guided executive function training and low-intensity aerobic exercise in healthy older adults. Front Aging Neurosci 2020;12:576744. [doi: 10.3389/fnagi.2020.576744] [Medline: 33328958]
144. Callisaya ML, Jayakody O, Vaidya A, Srikanth V, Farrow M, Delbaere K. A novel cognitive-motor exercise program delivered via a tablet to improve mobility in older people with cognitive impairment—StandingTall cognition and Mobility. Exp Gerontol 2021;152:111434. [doi: 10.1016/j.exger.2021.111434] [Medline: 34098009]
145. Delbaere K, Valenzuela T, Lord SR, Clemson L, Zijlstra GAR, Close JCT, et al. E-health StandingTall balance exercise for fall prevention in older people: results of a two year randomised controlled trial. BMJ 2021;373:n740 [FREE Full text] [doi: 10.1136/bmj.n740] [Medline: 33824131]
146. de Souto Barreto P, Pothier K, Soriano G, Lussier M, Bherer L, Guyonnet S, et al. A web-based multidomain lifestyle intervention for older adults: the eMIND randomized controlled trial. J Prev Alzheimers Dis 2020;8(2):1-9 [FREE Full text] [doi: 10.14283/jpad.2020.70] [Medline: 33569560]
147. Sedhed J, Johansson H, Andersson N, Åkesson E, Kalbe E, Franzén E, et al. Feasibility of a novel eHealth intervention for Parkinson’s disease targeting motor-cognitive function in the home. BMC Neurol 2024;24(1):114 [FREE Full text] [doi: 10.1186/s12883-024-03614-2] [Medline: 38580913]
148. Putzolu M, Manzini V, Gambaro M, Cosentino C, Bonassi G, Botta A, et al. Home-based exercise training by using a smartphone app in patients with Parkinson’s disease: a feasibility study. Front Neurol 2023;14:1205386 [FREE Full text] [doi: 10.3389/fneur.2023.1205386] [Medline: 37448748]
149. Kruse C, Fohn J, Wilson N, Nunez Patlan E, Zipp S, Mileski M. Utilization barriers and medical outcomes commensurate with the use of telehealth among older adults: systematic review. JMIR Med Inform 2020;8(8):e20359 [FREE Full text] [doi: 10.2196/20359] [Medline: 32784177]

150. Jansons P, Fyfe J, Via JD, Daly RM, Gvozdenko E, Scott D. Barriers and enablers for older adults participating in a home-based pragmatic exercise program delivered and monitored by Amazon Alexa: a qualitative study. BMC Geriatr 2022;22(1):248 [FREE Full text] [doi: 10.1186/s12877-022-02963-2] [Medline: 35337284]
151. Jansons P, Fyfe JJ, Dalla Via J, Daly RM, Scott D. Barriers and enablers associated with participation in a home-based pragmatic exercise snacking program in older adults delivered and monitored by Amazon Alexa: a qualitative study. Aging Clin Exp Res 2023;35(3):561-569 [FREE Full text] [doi: 10.1007/s40520-022-02327-1] [Medline: 36648746]
152. Jansons P, Dalla Via J, Daly RM, Fyfe JJ, Gvozdenko E, Scott D. Delivery of home-based exercise interventions in older adults facilitated by Amazon Alexa: a 12-week feasibility trial. J Nutr Health Aging 2022;26(1):96-102. [doi: 10.1007/s12603-021-1717-0] [Medline: 35067710]
153. Mascret N, Temprado JJ. Acceptance of a mobile telepresence robot, before use, to remotely supervise older adults' adapted physical activity. Int J Environ Res Public Health 2023;20(4):3012. [doi: 10.3390/ijerph20043012] [Medline: 36833706]
154. Mascret N, Vors O, Temprado JJ. Mobile telepresence robot as a new service to remotely supervise older adults' physical activity: effectiveness, acceptance, and perception. Int J of Soc Robotics 2023. [doi: 10.1007/s12369-023-01025-w]
155. Wu X, Nix LC, Brummett AM, Aguillon C, Oltman DJ, Beer JM. The design, development, and evaluation of telepresence interfaces for aging adults: investigating user perceptions of privacy and usability. Int J Human-Computer Stud 2021;156:102695. [doi: 10.1016/j.ijhcs.2021.102695]
156. Salisbury DL, Warry W, Fergen J, Cruikshank K, Soderlund PD, Jacklin K. The MN RIDE pilot: feasibility of a synchronous, remotely delivered, aerobic exercise training program for rural-dwelling adults with subjective cognitive decline. Rural Remote Health 2023;23(4):8351 [FREE Full text] [doi: 10.22605/RRH8351] [Medline: 38086057]
157. Candido Mendes Maranhão D, Daniele de Araújo Silva J, Quintella Farah B, Barros Beltrão Pirauá N, Cappato de Araújo R, Remígio Cavalcante B, et al. Effects of 12-weeks of home-based exercise training on physical and cognitive function of older adults: randomized trial comparing virtual versus minimal supervision in the context of the COVID-19 pandemic in Brazil. Can Geriatr J 2024;27(1):47-55 [FREE Full text] [doi: 10.5770/cgj.27.705] [Medline: 38433880]
158. Menengi Ç KN, Yeldan, Çınar N, Şahiner T. Effectiveness of motor-cognitive dual-task exercise via telerehabilitation in Alzheimer's disease: an online pilot randomized controlled study. Clin Neurol Neurosurg 2022;223:107501. [doi: 10.1016/j.clineuro.2022.107501] [Medline: 36368169]
159. Li F, Harmer P, Fitzgerald K, Winters-Stone K. A cognitively enhanced online Tai Ji Quan training intervention for community-dwelling older adults with mild cognitive impairment: a feasibility trial. BMC Geriatr 2022;22(1):76 [FREE Full text] [doi: 10.1186/s12877-021-02747-0] [Medline: 35078407]
160. Wunsch K, Eckert T, Fiedler J, Woll A. Just-in-time adaptive interventions in mobile physical activity interventions—a synthesis of frameworks and future directions. Eur Health Psychol 2022;22(4):834-842 [FREE Full text]
161. Müller AM, Blandford A, Yardley L. The conceptualization of a just-in-time adaptive intervention (JITAI) for the reduction of sedentary behavior in older adults. mHealth 2017;3:37 [FREE Full text] [doi: 10.21037/mhealth.2017.08.05] [Medline: 29184889]
162. Hardeman W, Houghton J, Lane K, Jones A, Naughton F. A systematic review of just-in-time adaptive interventions (JITAIs) to promote physical activity. Int J Behav Nutr Phys Act 2019;16(1):31 [FREE Full text] [doi: 10.1186/s12966-019-0792-7] [Medline: 30943983]
163. van der Kolk NM, de Vries NM, Kessels RPC, Joosten H, Zwinderman AH, Post B, et al. Effectiveness of home-based and remotely supervised aerobic exercise in Parkinson's disease: a double-blind, randomised controlled trial. Lancet Neurol 2019;18(11):998-1008. [doi: 10.1016/S1474-4422(19)30285-6] [Medline: 31521532]
164. van der Kolk NM, de Vries NM, Penko AL, van der Vlugt M, Mulder AA, Post B, et al. A remotely supervised home-based aerobic exercise programme is feasible for patients with Parkinson's disease: results of a small randomised feasibility trial. J Neurol Neurosurg Psychiatry 2017;89(9):1003-1005. [doi: 10.1136/jnnp-2017-315728] [Medline: 28607121]
165. Anderson-Hanley C, Stark J, Wall KM, VanBrakle M, Michel M, Maloney M, et al. The interactive Physical and Cognitive Exercise System (iPACES™): effects of a 3-month in-home pilot clinical trial for mild cognitive impairment and caregivers. Clin Interv Aging 2018;13:1565-1577 [FREE Full text] [doi: 10.2147/CIA.S160756] [Medline: 30233154]
166. Wall K, Stark J, Schillaci A, Saulnier ET, McLaren E, Striegnitz K, et al. The enhanced interactive Physical and Cognitive Exercise System (iPACES™ v2.0): pilot clinical trial of an in-home iPad-based neuro-exergame for mild cognitive impairment (MCI). J Clin Med 2018;7(9):249. [doi: 10.3390/jcm7090249]
167. Best JR. Exergaming in youth: effects on physical and cognitive health. Z Psychol 2013;221(2):72-78 [FREE Full text] [doi: 10.1027/2151-2604/a000137] [Medline: 25097828]
168. Kappen DL, Mirza-Babaei P, Nacke LE. Older adults' physical activity and exergames: a systematic review. Int J Hum Comput Interact 2019;35(2):140-167. [doi: 10.1080/10447318.2018.1441253]
169. van Santen J, Dröes RM, Holstege M, Henkemans OB, van Rijn A, de Vries R, et al. Effects of exergaming in people with dementia: results of a systematic literature review. J Alzheimers Dis 2018;63(2):741-760 [FREE Full text] [doi: 10.3233/JAD-170667] [Medline: 29689716]
170. ACSM information on exergaming. HealthySD.gov. 2013. URL: http://healthysd.gov/wp-content/uploads/2014/11/exergaming.pdf [accessed 2024-06-19]

171. Adcock M, Fankhauser M, Post J, Lutz K, Zizlsperger L, Luft AR, et al. Effects of an in-home multicomponent exergame training on physical functions, cognition, and brain volume of older adults: a randomized controlled trial. Front Med 2020;6:321. [doi: 10.3389/fmed.2019.00321]
172. Gschwind YJ, Eichberg S, Ejupi A, de Rosario H, Kroll M, Marston HR, et al. ICT-based system to predict and prevent falls (iStoppFalls): results from an international multicenter randomized controlled trial. Eur Rev Aging Phys Act 2015;12(1):10 [FREE Full text] [doi: 10.1186/s11556-015-0155-6] [Medline: 26865874]
173. Gschwind YJ, Schoene D, Lord SR, Ejupi A, Valenzuela T, Aal K, et al. The effect of sensor-based exercise at home on functional performance associated with fall risk in older people—a comparison of two exergame interventions. Eur Rev Aging Phys Act 2015;12(1):11 [FREE Full text] [doi: 10.1186/s11556-015-0156-5] [Medline: 26865875]
174. Schoene D, Lord SR, Delbaere K, Severino C, Davies TA, Smith ST. A randomized controlled pilot study of home-based step training in older people using videogame technology. PLoS ONE 2013;8(3):e57734 [FREE Full text] [doi: 10.1371/journal.pone.0057734] [Medline: 23472104]
175. Schoene D, Valenzuela T, Toson B, Delbaere K, Severino C, Garcia J, et al. Interactive cognitive-motor step training improves cognitive risk factors of falling in older adults—a randomized controlled trial. PLoS ONE 2015;10(12):e0145161 [FREE Full text] [doi: 10.1371/journal.pone.0145161] [Medline: 26673919]
176. Song J, Paul SS, Caetano MJD, Smith S, Dibble LE, Love R, et al. Home-based step training using videogame technology in people with Parkinson's disease: a single-blinded randomised controlled trial. Clin Rehabil 2017;32(3):299-311. [doi: 10.1177/0269215517721593] [Medline: 28745063]
177. Hoang P, Schoene D, Gandevia S, Smith S, Lord SR. Effects of a home-based step training programme on balance, stepping, cognition and functional performance in people with multiple sclerosis—a randomized controlled trial. Mult Scler 2015;22(1):94-103. [doi: 10.1177/1352458515579442] [Medline: 25921035]
178. Sturnieks DL, Hicks C, Smith N, Ratanapongleka M, Menant J, Turner J, et al. Exergame and cognitive training for preventing falls in community-dwelling older people: a randomized controlled trial. Nat Med 2024;30(1):98-105. [doi: 10.1038/s41591-023-02739-0] [Medline: 38228913]
179. Liu‐Ambrose T, Donaldson MG, Ahamed Y, Graf P, Cook WL, Close J, et al. Otago home‐based strength and balance retraining improves executive functioning in older fallers: a randomized controlled trial. J Am Geriatr Soc 2008;56(10):1821-1830. [doi: 10.1111/j.1532-5415.2008.01931.x] [Medline: 18795987]
180. Huang X, Zhang S, Li B, Zhao X, Xu J, Cao T, et al. The feasibility and efficacy of the home-based exercise programs in patients with cognitive impairment: a pilot study. Geriatr Nurs 2022;45:108-117. [doi: 10.1016/j.gerinurse.2022.03.010] [Medline: 35395598]
181. Peixoto C, Matioli MNPDS, Takano SAF, Teixeira MS, Passos Neto CEB, Brucki SMD. Feasibility, safety, and adherence of a remote physical and cognitive exercise protocol for older women. Arq Neuropsiquiatr 2024;82(04):1-9. [doi: 10.1055/s-0044-1785690] [Medline: 38653483]
182. Blok M, van Ingen E, de Boer AH, Slootman M. The use of information and communication technologies by older people with cognitive impairments: from barriers to benefits. Comput Hum Behav 2020;104:106173. [doi: 10.1016/j.chb.2019.106173]
183. Jang-Jaccard J, Nepal S, Alem L, Li J. Barriers for delivering telehealth in rural Australia: a review based on Australian trials and studies. Telemed E Health 2014;20(5):496-504. [doi: 10.1089/tmj.2013.0189] [Medline: 24801522]
184. Whitelaw S, Pellegrini DM, Mamas MA, Cowie M, Van Spall HGC. Barriers and facilitators of the uptake of digital health technology in cardiovascular care: a systematic scoping review. Eur Heart J Digit Health 2021;2(1):62-74 [FREE Full text] [doi: 10.1093/ehjdh/ztab005] [Medline: 34048508]
185. Wilson J, Heinsch M, Betts D, Booth D, Kay-Lambkin F. Barriers and facilitators to the use of e-health by older adults: a scoping review. BMC Public Health 2021;21(1):1556 [FREE Full text] [doi: 10.1186/s12889-021-11623-w] [Medline: 34399716]
186. Turcotte S, Bouchard C, Rousseau J, DeBroux Leduc R, Bier N, Kairy D, et al. Factors influencing older adults' participation in telehealth interventions for primary prevention and health promotion: a rapid review. Australas J Ageing 2023;43(1):11-30. [doi: 10.1111/ajag.13244] [Medline: 38014903]
187. Kampmeijer R, Pavlova M, Tambor M, Golinowska S, Groot W. The use of e-health and m-health tools in health promotion and primary prevention among older adults: a systematic literature review. BMC Health Serv Res 2016;16(S5):290 [FREE Full text] [doi: 10.1186/s12913-016-1522-3] [Medline: 27608677]
188. Salemink K, Strijker D, Bosworth G. Rural development in the digital age: a systematic literature review on unequal ICT availability, adoption, and use in rural areas. J Rural Stud 2017;54:360-371. [doi: 10.1016/j.jrurstud.2015.09.001]
189. Coley N, Andre L, Hoevenaar-Blom MP, Ngandu T, Beishuizen C, Barbera M, et al. Factors predicting engagement of older adults with a coach-supported eHealth intervention promoting lifestyle change and associations between engagement and changes in cardiovascular and dementia risk: secondary analysis of an 18-month multinational randomized controlled trial. J Med Internet Res 2022;24(5):e32006 [FREE Full text] [doi: 10.2196/32006] [Medline: 35385395]
190. Auerswald T, Hendker A, Ratz T, Lippke S, Pischke CR, Peters M, et al. Impact of activity tracker usage in combination with a physical activity intervention on physical and cognitive parameters in healthy adults aged 60+: a randomized controlled trial. Int J Environ Res Public Health 2022;19(7):3785. [doi: 10.3390/ijerph19073785]

191. Sow LC, Liu HH, Wang RY, Wei SH, Wu HK, Yang YR. Feasibility and effectiveness of interactive stepping exercise on community-dwelling older adults: a pilot randomized controlled trial. Geriatr Nurs 2021;42(5):1099-1104. [doi: 10.1016/j.gerinurse.2021.06.021] [Medline: 34274687]
192. Wang RY, Huang YC, Zhou JH, Cheng SJ, Yang YR. Effects of exergame-based dual-task training on executive function and dual-task performance in community-dwelling older people: a randomized-controlled trial. Games Health J 2021;10(5):347-354. [doi: 10.1089/g4h.2021.0057] [Medline: 34491113]
193. Padala KP, Padala PR, Lensing SY, Dennis RA, Bopp MM, Roberson PK, et al. Home-based exercise program improves balance and fear of falling in community-dwelling older adults with mild Alzheimer's disease: a pilot study. J Alzheimers Dis 2017;59(2):565-574. [doi: 10.3233/JAD-170120] [Medline: 28655135]
194. Petersen JD, Larsen EL, la Cour K, von Bülow C, Skouboe M, Christensen JR, et al. Motion-based technology for people with dementia training at home: three-phase pilot study assessing feasibility and efficacy. JMIR Ment Health 2020;7(8):e19495 [FREE Full text] [doi: 10.2196/19495] [Medline: 32845243]
195. van Limburg M, van Gemert-Pijnen JEWC, Nijland N, Ossebaard HC, Hendrix RMG, Seydel ER. Why business modeling is crucial in the development of eHealth technologies. J Med Internet Res 2011;13(4):e124 [FREE Full text] [doi: 10.2196/jmir.1674] [Medline: 22204896]
196. García-Hermoso A, Ramirez-Vélez R, Sáez de Asteasu ML, Martínez-Velilla N, Zambom-Ferraresi F, Valenzuela PL, et al. Safety and effectiveness of long-term exercise interventions in older adults: a systematic review and meta-analysis of randomized controlled trials. Sports Med 2020;50(6):1095-1106. [doi: 10.1007/s40279-020-01259-y]
197. Stefanakis M, Batalik L, Antoniou V, Pepera G. Safety of home-based cardiac rehabilitation: a systematic review. Heart Lung 2022;55:117-126 [FREE Full text] [doi: 10.1016/j.hrtlng.2022.04.016] [Medline: 35533492]
198. Antoniou V, Kapreli E, Davos CH, Batalik L, Pepera G. Safety and long-term outcomes of remote cardiac rehabilitation in coronary heart disease patients: a systematic review. Digit Health 2024;10:20552076241237661. [doi: 10.1177/20552076241237661] [Medline: 38533308]
199. Wiebking C, Lin CI, Wippert PM. Training intervention effects on cognitive performance and neuronal plasticity—a pilot study. Front Neurol 2022;13:773813 [FREE Full text] [doi: 10.3389/fneur.2022.773813] [Medline: 36003302]
200. Moon SY, Hong CH, Jeong JH, Park YK, Na HR, Song H, et al. Facility-based and home-based multidomain interventions including cognitive training, exercise, diet, vascular risk management, and motivation for older adults: a randomized controlled feasibility trial. Aging 2021;13(12):15898-15916 [FREE Full text] [doi: 10.18632/aging.203213] [Medline: 34148030]
201. World Health Organization. WHO Guidelines on Physical Activity and Sedentary Behaviour. Geneva: World Health Organization; 2020.
202. Bull FC, Al-Ansari SS, Biddle S, Borodulin K, Buman MP, Cardon G, et al. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. Br J Sports Med 2020;54(24):1451-1462. [doi: 10.1136/bjsports-2020-102955]
203. Hawley-Hague H, Horne M, Skelton DA, Todd C. Review of how we should define (and measure) adherence in studies examining older adults' participation in exercise classes. BMJ Open 2016;6(6):e011560. [doi: 10.1136/bmjopen-2016-011560] [Medline: 27338884]
204. Rivera-Torres S, Fahey TD, Rivera MA. Adherence to exercise programs in older adults: informative report. Gerontol Geriatr Med 2019;5:233372141882360 [FREE Full text] [doi: 10.1177/2333721418823604] [Medline: 30733977]
205. Dwan K, Li T, Altman DG, Elbourne D. CONSORT 2010 statement: extension to randomised crossover trials. BMJ 2019;366:l4378 [FREE Full text] [doi: 10.1136/bmj.l4378] [Medline: 31366597]
206. Schulz KF, Altman DG, Moher D. CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. BMC Med 2010;8(1):18 [FREE Full text] [doi: 10.1186/1741-7015-8-18] [Medline: 20334633]
207. Boutron I, Altman DG, Moher D, Schulz KF, Ravaud P. CONSORT statement for randomized trials of nonpharmacologic treatments: a 2017 update and a CONSORT extension for nonpharmacologic trial abstracts. Ann Intern Med 2017;167(1):40-47. [doi: 10.7326/M17-0046] [Medline: 28630973]
208. Gronwald T, de Bem Alves AC, Murillo-Rodríguez E, Latini A, Schuette J, Budde H. Standardization of exercise intensity and consideration of a dose-response is essential. commentary on "exercise-linked FNDC5/irisin rescues synaptic plasticity and memory defects in Alzheimer's models", by Lourenco et al., published 2019 in Nature Medicine. J Sport Health Sci 2019;8(4):353-354 [FREE Full text] [doi: 10.1016/j.jshs.2019.03.006] [Medline: 31333889]
209. Barha CK, Falck RS, Skou ST, Liu-Ambrose T. Personalising exercise recommendations for healthy cognition and mobility in aging: time to address sex and gender (part 1). Br J Sports Med 2020;55(6):300-301. [doi: 10.1136/bjsports-2020-102864] [Medline: 33023883]
210. Barha CK, Liu ‐ Ambrose T. Sex differences in exercise efficacy: is midlife a critical window for promoting healthy cognitive aging? FASEB J 2020;34(9):11329-11336. [doi: 10.1096/fj.202000857R] [Medline: 32761860]
211. Barha CK, Davis JC, Falck RS, Nagamatsu LS, Liu-Ambrose T. Sex differences in exercise efficacy to improve cognition: a systematic review and meta-analysis of randomized controlled trials in older humans. Front Neuroendocrinol 2017;46:71-85. [doi: 10.1016/j.yfrne.2017.04.002] [Medline: 28442274]
212. Barha CK, Hsu CL, Ten Brinke L, Liu-Ambrose T. Biological sex: a potential moderator of physical activity efficacy on brain health. Front Aging Neurosci 2019;11:329 [FREE Full text] [doi: 10.3389/fnagi.2019.00329] [Medline: 31866852]

213. Barha CK, Liu-Ambrose T. Exercise and the aging brain: considerations for sex differences. BPL 2018:1-11. [doi: 10.3233/bpl-1867]

Abbreviations

CG: control group
IG1: intervention group 1
IG2: intervention group 2
MCI: mild cognitive impairment
MCR: motoric cognitive risk syndrome
MTR: mobile telepresence robot
RCT: randomized controlled trial
SCD: subjective cognitive decline
SMT: sensorimotor training
SMT+BT: sensorimotor training supplemented by behavioral therapy

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Development and Validation of an Explainable Machine Learning Model for Predicting Myocardial Injury After Noncardiac Surgery in Two Centers in China: Retrospective Study

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Abstract

Background: Myocardial injury after noncardiac surgery (MINS) is an easily overlooked complication but closely related to postoperative cardiovascular adverse outcomes; therefore, the early diagnosis and prediction are particularly important.

Objective: We aimed to develop and validate an explainable machine learning (ML) model for predicting MINS among older patients undergoing noncardiac surgery.

Methods: The retrospective cohort study included older patients who had noncardiac surgery from 1 northern center and 1 southern center in China. The data sets from center 1 were divided into a training set and an internal validation set. The data set from center 2 was used as an external validation set. Before modeling, the least absolute shrinkage and selection operator and recursive feature elimination methods were used to reduce dimensions of data and select key features from all variables. Prediction models were developed based on the extracted features using several ML algorithms, including category boosting, random forest, logistic regression, naïve Bayes, light gradient boosting machine, extreme gradient boosting, support vector machine, and decision tree. Prediction performance was assessed by the area under the receiver operating characteristic (AUROC) curve as the main evaluation metric to select the best algorithms. The model performance was verified by internal and external validation data sets with the best algorithm and compared to the Revised Cardiac Risk Index. The Shapley Additive Explanations (SHAP) method was applied to calculate values for each feature, representing the contribution to the predicted risk of complication, and generate personalized explanations.

Results: A total of 19,463 eligible patients were included; among those, 12,464 patients in center 1 were included as the training set; 4754 patients in center 1 were included as the internal validation set; and 2245 in center 2 were included as the external validation set. The best-performing model for prediction was the CatBoost algorithm, achieving the highest AUROC of 0.805 (95% CI 0.778 - 0.831) in the training set, validating with an AUROC of 0.780 in the internal validation set and 0.70 in external validation set. Additionally, CatBoost demonstrated superior performance compared to the Revised Cardiac Risk Index (AUROC 0.636; *P*<.001). The SHAP values indicated the ranking of the level of importance of each variable, with preoperative serum creatinine concentration, red blood cell distribution width, and age accounting for the top three. The results from the SHAP method can predict events with positive values or nonevents with negative values, providing an explicit explanation of individualized risk predictions.

Conclusions: The ML models can provide a personalized and fairly accurate risk prediction of MINS, and the explainable perspective can help identify potentially modifiable sources of risk at the patient level.

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KEYWORDS

myocardial injury after noncardiac surgery; older patients; machine learning; personalized prediction; myocardial injury; risk prediction; noncardiac surgery

Introduction

Myocardial injury after noncardiac surgery (MINS), a prominent postoperative cardiovascular complication, occurs in approximately 8% to 22% of patients overall [1]. The Vascular Events in Noncardiac Surgery Patients Cohort Evaluation (VISION) study showed that MINS was the second most common cause of short-term mortality among 8 perioperative adverse events [2,3]. MINS is also reportedly an independent predictor of 1-year or long-term mortality [4]. Nevertheless, 90% of the MINS events are unrecognized because most patients are not presenting ischemic symptoms, and a minority of MINS cases are diagnosed by electrocardiogram abnormalities, involving typical chest pain symptoms [5]. Therefore, early prediction and identification of patients at higher risk for MINS is critically important for enhancing the outcomes of these underappreciated complications in older patients.

The most common prediction tool available to identification of high-risk patients is Revised Cardiac Risk Index (RCRI) [6], a universally used screening tool due to ease of use but with poor performance in other validation sets. American College of Surgeons National Surgeons Quality Improvement Program (NSQIP) [7] and Myocardial Infarction or Cardiac Arrest (MICA) surgical risk calculators [8] were subsequently developed with higher accuracy than RCRI, designed to predict more severe outcomes, including death and myocardial infarction, instead of predicting MINS. Another prediction model was derived from the MANAGE cohort [9], using 3 preoperative risk factors and not considering intraoperative factors. ML has been proven more powerful than conventional logistic regression because it can overcome the limitations of statistical methods and even create personalized risk predictions [10]. Recently, two novel ML models were reported to predict the occurrence of MINS. Oh et al [11] developed a machine learning (ML) model and achieved an area under the receiver operating characteristic (AUROC) curve of 0.78 using 12 variables. However, the population heterogeneity and lack of external validation may limit its generalization to older patients. Nolde et al [12] applied single-layer and multiple-layer variables to different models and achieved the highest AUROC of 0.77 and accuracy of 0.70. Despite comprehensive included variables, anesthesiologists and surgeons are unable to distinguish modifiable risk factors and make targeted interventions to improve outcomes.

Currently, no validated and accurate risk prediction tools for MINS are in use. Therefore, the purpose of our research was to develop and validate an ML model that predicts MINS risk based on surgery data available at admission and during the intraoperative period. The model also used Shapley Additive Explanations (SHAP) method to interpret results, allowing for targeted interventions to modify risk factors and support clinical decision-making.

Methods

Patient Cohort

We collected data anonymously from our electronic health record (EHR) system, which was an integrated clinical database containing data on all patients who were admitted to hospitals. The data set was derived from older patients (defined as aged ≥65 years) undergoing noncardiac surgery from January 2017 to August 2019, and the internal validation data set was derived from patients enrolled from July 2020 to July 2021 in center 1 (Chinese People's Liberation Army General Hospital in northern China). We also included patients who had noncardiac surgeries in center 2 (Nanfang Hospital of Southern Medical University in southern China) from January 2021 to October 2021 as an external data set. The uniform exclusion criteria were as follows: excluding patients with the American Society of Anesthesiologists (ASA) grade V, a short operation interval (scheduled for more than 1 surgery within a week), with nongeneral anesthesia, low-risk surgery (eg, outpatient surgery, hysteroscopic surgery, or body surface surgery), and a short surgery duration (≤30 min). Patients undergoing either elective or emergency surgery were eligible for participation.

Ethical Considerations

The study was approved by the Ethics Committee Board of the First Medical Center of Chinese People's Liberation Army (S2019-311-02), and the requirement for informed consent was waived because this was an observational study with minimal risk for patients. This study conforms to the principles outlined in the Transparent Reporting of a multivariable prediction model for Individual Prognosis or Diagnosis (TRIPOD) statement.

Data Processing

Variables from the following categories were collected: demographics, preoperative comorbid conditions and medications, preoperative laboratory results, vital signs, and intraoperative information. For laboratory testing variables with multiple measurements, we used only the last preoperative measurements taken within 1 week before surgery for analysis. A total of 118 variables from the electronic database were extracted and listed in Table S1 in Multimedia Appendix 1. Additional extraction details are displayed in supplementary material 1 in Multimedia Appendix 1. The least absolute shrinkage and selection operator (LASSO) method, which could solve high dimensionality and multicollinearity between variables was used. After the initial screening, recursive feature elimination (RFE), combined with 5-fold cross-validation, was adopted to rescreen and select the best hyperparameters [13]. After final screening, missing values were imputed using multiple imputation [14].

Outcome

The primary end point was the incidence of MINS within the first 30 days after surgery. According to the scientific statement from the American Heart Association [15], MINS was defined as at least 1 postoperative high-sensitivity troponin T of 20 to <65 ng/L with an absolute change ≥5 ng/L or a high-sensitivity troponin T concentration ≥65 ng/L; or at least 1 postoperative measurement of troponin I concentration exceeding the uniform 99th percentile due to a presumed ischemic etiology irrespective of the presence or absence of clinical symptoms and electrocardiographic changes within the first 30 days after noncardiac surgery.

ML Models

Linear and nonlinear ML models were applied, including category boosting (CatBoost) [16], random forest [17], logistic regression [18], naïve Bayes [19], light gradient boosting machine (LightGBM) [20], extreme gradient boosting (XGBoost) [21], support vector machine [22], and decision tree [23,24]. The above algorithms were implemented using the Scikit-learn, LightGBM, XGBoost, and CatBoost Python packages. Each method is described in detail in supplementary material 2 in Multimedia Appendix 1.

Model Performance and Evaluation

Because of the imbalance between the positive and negative events, the random under-sampling technique was used to avoid overfitting by the rationale of eliminating samples from the majority class to make the majority class equal to the minority class, which is a simple but effective way to treat imbalanced data sets. Eight ML models with final indicators were developed to predict outcomes. The AUROC was used as the evaluation standard of the model performance, and classifiers with larger AUROCs were considered to have better prediction efficiency, and the best-performing ML model was chosen by its AUROC. We also calculated the 95% CIs for each model using the advanced bootstrap method. Similarly, the related sensitivity, specificity, and accuracy were assessed in models conducted. Appropriate figures were produced for these metrics in the best fitting model, including a precision-recall curve and calibration curve, to show the average precision and difference between the predicted risk and actual risk. The AUROCs were also calculated in the validation sets and in the RCRI model to compare the efficacy.

Model Interpretation

The SHAP method [24] was used to analyze the importance of features in the model because of the limited interpretability in the ML algorithm. SHAP was used as a scoring metric for feature contributions, through determining the difference between the predicted values with and without each feature for all combinations. The greater the influence a particular value of a sample has on the composition of the model, the farther that point deviates from 0 on the x-axis. Using SHAP values and a summary plot, it is thus possible to determine which features have a significant effect on the prediction and whether this contribution is positive or negative. Moreover, SHAP facilitates individual-level risk prediction and stratification, which is straightforward and understandable by doctors.

Statistical Analysis

For the baseline data analysis, continuous characteristics were evaluated by the Shapiro-Wilk normality test and analyzed by either the 2-tailed *t* test for normally distributed variables or the Mann-Whitney *U* test for skewed data and were reported as means or medians. Categorical variables were compared using the chi-square test or Fisher exact test and were reported as proportions. As this was a retrospective exploratory study, no attempt was made to estimate the sample size of the study; instead, all eligible patients in the database were included to maximize the statistical power. For all analyses, a 2-sided *P* value <.05 was considered statistically significant. All analyses were performed using Python (version 3.6; Python Software Foundation).

Results

Characteristics

In total, we retrospectively enrolled 12,464 patients (median age 69, IQR 67-74 years; n= 6793, 54.5% male) who met the inclusion criteria in center 1 from January 2017 to August 2019 as the training data set. Finally, 884 (7.1%) patients developed postoperative 30-day MINS among 12,464 patients. The flowcharts of patient enrollment in the training data set are shown in Figure 1. In the training data set, patients with postoperative MINS tended to be older; have more chronic conditions, such as hypertension, diabetes mellitus, and cerebrovascular diseases; and have more abnormal laboratory test values. The differences in the demographics and other characteristics between patients with and without MINS are summarized in Table 1. The flowcharts of validation data sets are shown in Figure S1 in Multimedia Appendix 1.

Figure 1. The flowchart of participant selection in the training data set. ASA: American Society of Anesthesiologists.

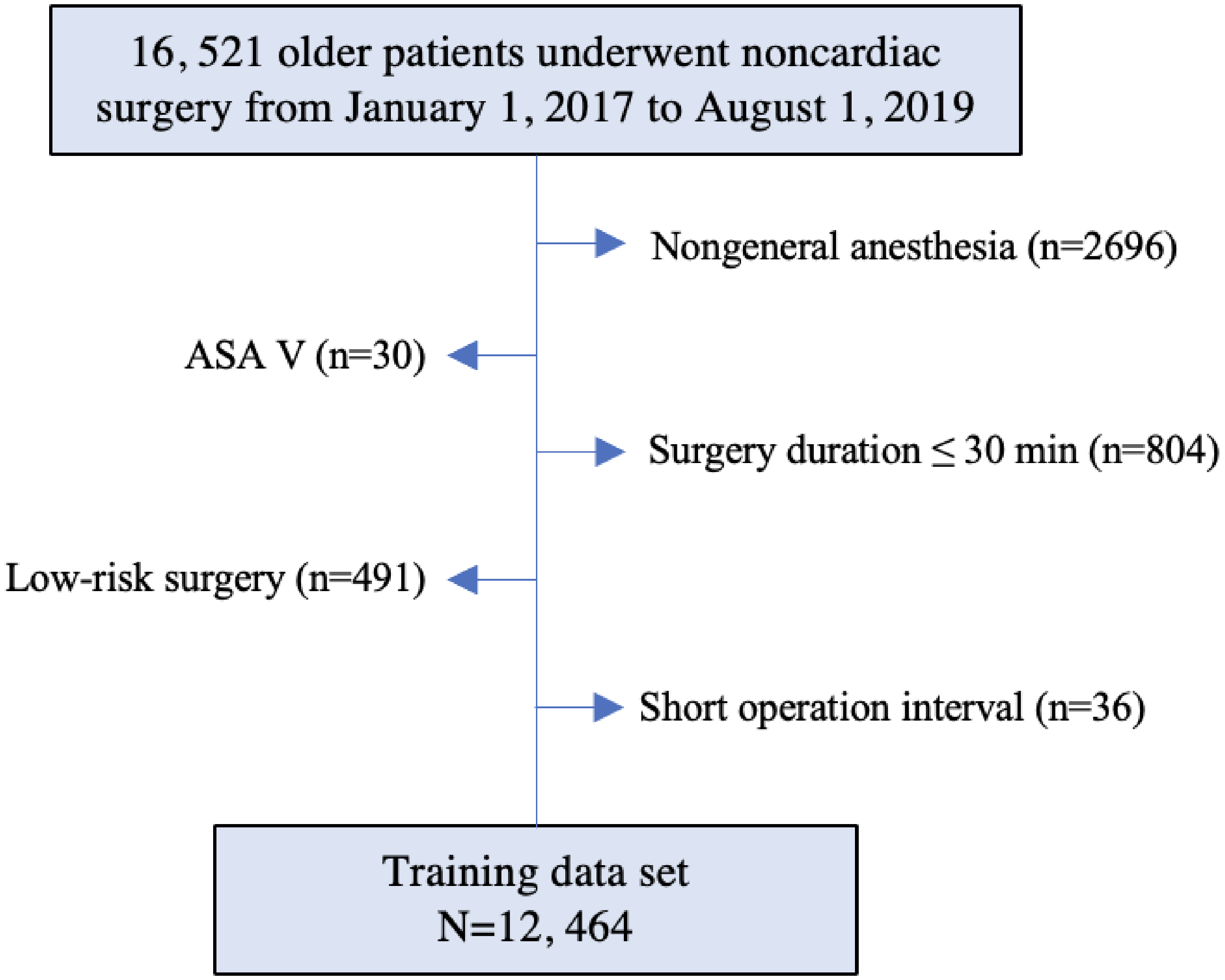


Table . Baseline characteristics of patients with or without myocardial injury after noncardiac surgery (MINS) at center 1 in the training set.

Variable		Non-MINS (n=11,580)	MINS (n=884)	Total (n=12,464)
Age (years), median (IQR)		69 (67-73)	72 (68-78)	69 (67-74)
Hypertension, n (%)		5225 (45.1)	500 (56.6)	5725 (45.9)
Coronary heart disease, n (%)		1282 (11.1)	206 (23.3)	1488 (11.9)
Cerebrovascular disease, n (%)		836 (7.2)	140 (15.8)	976 (7.8)
Renal insufficiency, n (%)		117 (1)	50 (5.7)	167 (1.3)
β-blockers, n (%)		944 (8.2)	140 (15.8)	1084 (8.7)
Diuretics, n (%)		578 (5)	120 (13.6)	698 (5.6)
Anticoagulants, n (%)		845 (7.3)	164 (18.6)	1009 (8.1)
Hemoglobin (g/L), median (IQR)		131 (120-142)	122 (105-136)	131 (120-142)
RBC[a] (10^9), median (IQR)		4.32 (3.96-4.65)	4.04 (3.54-4.45)	4.3 (3.94-4.64)
SCr[b] (umol/L), median (IQR)		71.2 (60.9-82.9)	78.9 (64.8-98.175)	71.6 (61.1-83.7)
RDW[c] (%), median (IQR)		12.8 (12.3-13.4)	13.3 (12.6-14.4)	12.8 (12.3-13.4)
Albumin (g/L), median (IQR)		40.15 (37.8-42.7)	38.2 (34.7-41.1)	40 (37.6-42.6)
Blood glucose (mmol/L), median (IQR)		5.08 (4.62-5.85)	5.46 (4.77-6.63)	5.1 (4.63-5.9)
Lymphocyte count (10^9), median (IQR)		0.3 (0.24-0.36)	0.24 (0.18-0.32)	0.3 (0.24-0.36)
Surgery duration (min), median (IQR)		144 (90-205)	180 (120-260)	145 (93-210)
ASA [d] grade, n (%)				
	I	116 (1)	6 (0.7)	122 (1)
	II	9380 (81)	485 (54.9)	9865 (79.1)
	III	2034 (17.6)	340 (38.5)	2374 (19)
	IV	50 (0.4)	53 (6)	103 (0.8)
Emergency surgery, n (%)		207 (1.8)	76 (8.6)	207 (1.8)
Colloid input (mL), median (IQR)		500 (0-500)	500 (0-1000)	500 (0-500)
Crystalloid input (mL), median (IQR)		1600 (1100-2100)	2000 (1300-2600)	1600 (1100-2100)
Blood loss (mL), median (IQR)		100 (30-200)	150 (50-300)	100 (50-200)
Blood transfusion, n (%)		1044 (9.0)	222 (25.1)	1266 (10.2)
Duration of intraoperative hypotension (min), mean (SD)		16.85 (37.8)	29.91 (57.6)	17.78 (42.3)

[a] RBC: red blood cell.

[b] SCr: serum creatinine.

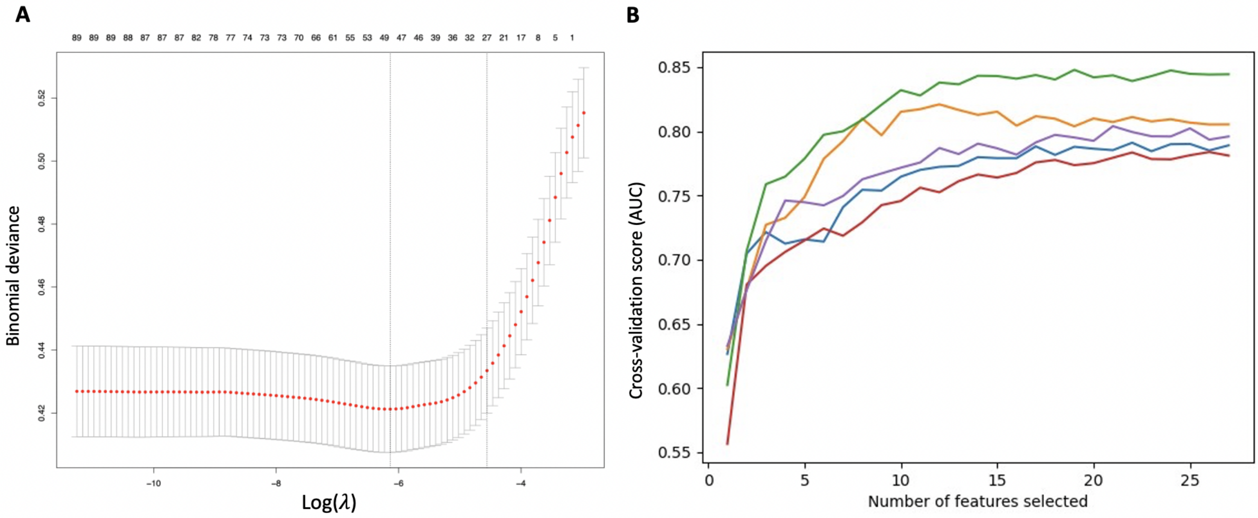
[c] RDW: red blood cell distribution width.

[d] ASA: American Society of Anesthesiologists.

Feature Selection

Through LASSO, we found that the optimal number of features for model prediction was 27 (Figure 2A). The RFE method was used to repeat the model building and feature selecting procedure, finally resulting in 25 features by excluding myocardial infarction history and facility (Figure 2B). The features selected by LASSO and RFE are listed in the supplementary material 1 in Multimedia Appendix 1.

Figure 2. Feature selection by least absolute shrinkage and selection operator (LASSO) and recursive feature elimination (RFE) with 5-fold cross-validation. (A) Through LASSO, the filtered variables were as follows: renal insufficiency, diuretics, cerebrovascular disease, β-blockers, anticoagulants, hypertension, blood transfusion, coronary heart disease, colloid, blood pressure monitoring method, American Society of Anesthesiologists grades, crystalloid, hemoglobin, surgery duration, sodium, age, lymphocyte, anesthesia duration, duration of intraoperative hypotension, red blood cell, glucose, red blood cell distribution width, blood loss, albumin, serum creatinine, facility, and myocardial infarction. (B) Recursive feature elimination with a 5-fold cross-validation method filtered features again and removed 2 parameteres (facility and myocardial infarction), leaving 25 parameters as mentioned above. AUC: area under the curve.

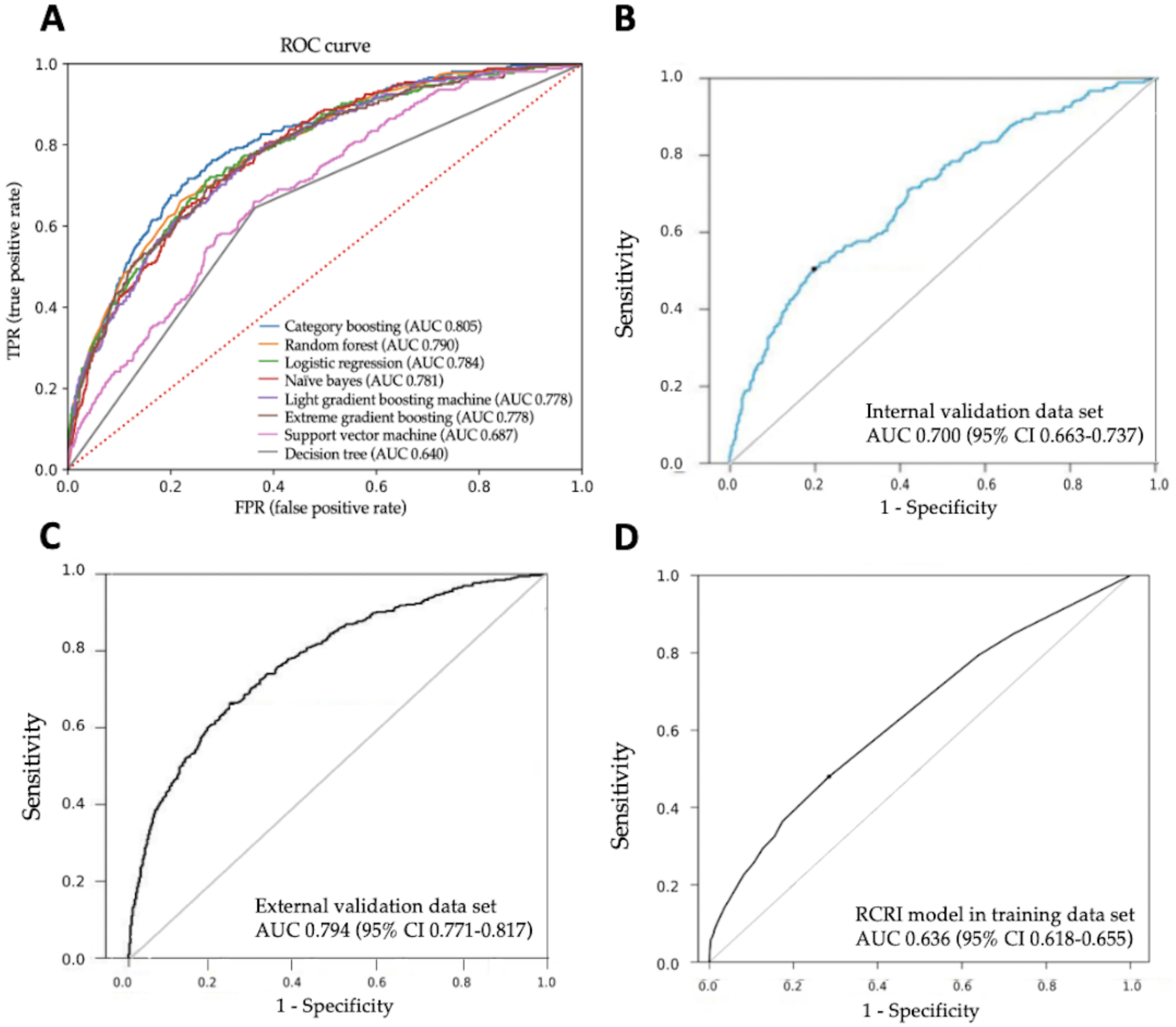


Model Performance and Comparison

The training data set from center 1 was used to develop the forecast models, and MINS was predicted with an AUROC of 0.805 (95% CI 0.778 - 0.831) by the best-performing CatBoost method, compared with the other 7 algorithms. CatBoost revealed a relatively high accuracy (0.730, 95% CI 0.716 - 0.745), sensitivity (0.747, 95% CI 0.694 - 0.797), and specificity (0.729, 95% CI 0.714 - 0.744). The overall AUROC by all algorithms is shown in Figure 3A. The average accuracy, sensitivity, and specificity calculated by all the algorithms are summarized in Table S2 in Multimedia Appendix 1. The model was well calibrated with a Brier score loss of 0.18; its calibration plot is depicted in Figure S2 in Multimedia Appendix 1.

To verify the stability of our model, prediction was validated with an AUROC of 0.794 in the internal validation set of center 1 and 0.70 in the external validation set of center 2, by the method of CatBoost, and their AUROCs are displayed in the Figure 3B and 3C. Incorporating the 6 parameters in the RCRI model into the validation data set, we observed a poor prediction performance, with an AUROC of 0.636, which was inferior to that of our machine learning models (*P*<.001) (Figure 3D).

Figure 3. The receiver operating characteristics curve of different models. (A) Eight different machine learning prediction models for myocardial injury after noncardiac surgery using the training data set from center 1. (B) Model performance in the internal validation data set from center 1. (C) Model performance in the external validation data set from center 2. (D) Performance of 6 indicators from Revised Cardiac Risk Index (RCRI) in the training data set. AUC: area under the curve. ROC: receiver operating characteristic.



Model Interpretation

Assisted by the development of explainable ML models, the SHAP values for the prediction of MINS were calculated. Figure 4A shows the 20 most influential factors ranked by the average absolute SHAP value, and Figure 4B shows their effect values and interpretations. In the graph, the red dots represent high risk, and the blue dots represent low risk. A higher serum creatinine, higher red blood cell distribution count, older age, increased blood loss, higher blood glucose concentration, higher ASA grade, longer duration of intraoperative hypotension, longer surgery duration, greater infusion of crystalloids or colloids, lower red blood cell count, lower lymphocyte count, lower albumin, lower sodium, and lower hemoglobin were associated with a higher predicted probability of postoperative MINS. Invasive arterial pressure monitoring, blood transfusion, preexisting coronary heart disease, and preexisting hypertension also increased the event risk.

In addition, a visualization method [25] was used to make patient-level prediction interpretations of the model. We provided 2 examples to illustrate this in Figure 5. An 81-year-old patient with ASA grade III underwent surgery with a nearly 2.5-hour duration of anesthesia and developed MINS. His preoperative laboratory test values are listed in Figure 5A. The arrows indicate the influence of each feature on prediction; the red arrows suggest an increased risk of the outcome, and the blue arrows suggest a decreased risk. The predicted score of MINS (approximately 3.11) was 30 times higher than the base value predicted by the model (approximately 0.1). Conversely, the second patient, with preoperative normal laboratory measurements, intraoperative blood transfusion, blood loss of 400 mL, and intraoperative short hypotension, did not experience MINS, with a predicted score of −0.72, lower than the base value of 0.1.

Figure 4. The model’s interpretation. (A) Bar summary of the most important 20 features according to the mean Shapley Additive Explanations (SHAP) values. A higher value of a feature has a greater effect on the model’s composition, indicated by how far a point deviates from 0 on the x-axis. (B) Summary of the most impactful features with interpretation. The red dots represent the high-risk value, and the blue dots represent the low-risk value. ASA: American Society of Anesthesiologists; Na: sodium; HGB: hemoglobin; BP: blood pressure; GLU: glucose; RDW: red blood cell distribution width; SCR: serum creatinine.

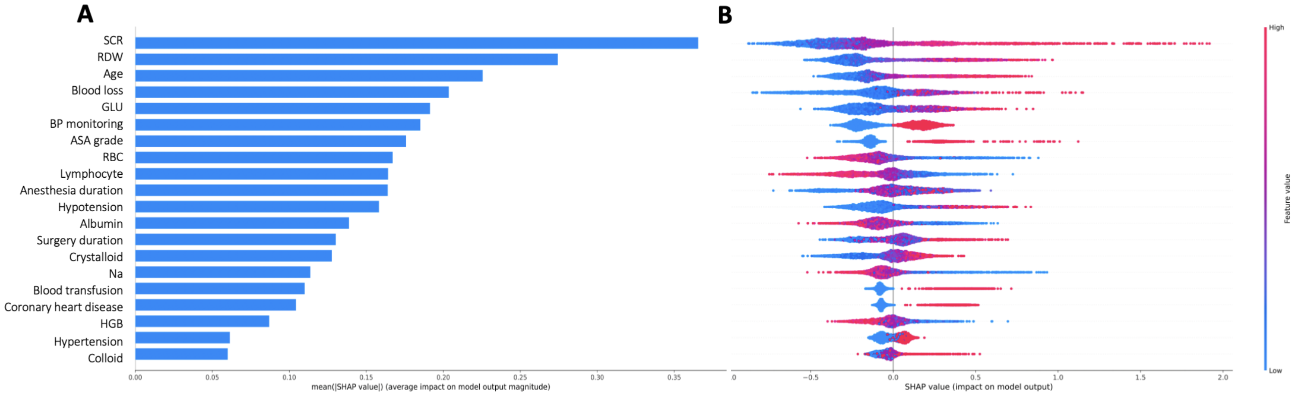
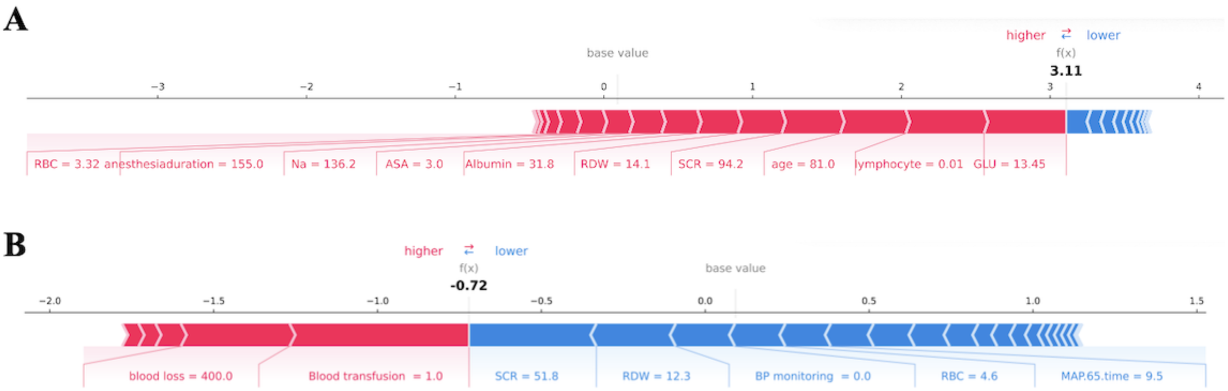


Figure 5. The composition risk of individualized predictions for 2 patients. A blue arrow indicates that a factor reduced the risk of myocardial injury after noncardiac surgery (MINS), whereas a red arrow indicates it increased the risk. (A) An 81-year-old patient with American Society of Anesthesiologists (ASA) grade III underwent surgery with a nearly 2.5-hour duration of anesthesia and developed MINS. (B) A patient with preoperative normal laboratory measurements, with intraoperative blood transfusion, blood loss of 400 mL, and intraoperative short hypotension did not have MINS. ASA: American Society of Anesthesiologists; BP: blood pressure; GLU: glucose; MAP: mean artial pressure; RBC: red blood cell; RDW: red blood cell distribution width; SCR: serum creatinine.



Discussion

Principal Findings

In this cohort study, we used ML approaches with multiple demographic and clinical data from EHR to predict the occurrence of postoperative myocardial injury. The CatBoost algorithm achieved the best predictive performance in the training data set and was validated in both the internal and external data sets, with high sensitivity and specificity, also superior to the classic RCRI model. The SHAP method also provided information on the contribution of each variable toward an event or nonevent, quantifying the association between variables and patient outcomes of a single patient. Our results aim to assist in the accurate and timely identification of older patients at high risk of postoperative myocardial injury, enhancing clinical decision support.

The RCRI is considered a conventional predictive model and has been widely used for more than 20 years [6]. Although it has the merit of simplicity with 6 indicators, its use is limited in clinical practice because of its low discriminative ability and lack of specific and sensitive biomarkers for MINS [26]. In our study population, the RCRI model could only achieve an AUROC of 0.636, significantly lower than our model projections. The NSQIP and MICA surgical risk calculators were validated to better estimate cardiovascular risk compared to the RCRI; however, the NSQIP and MICA scores provided only fair discrimination with a C-statistic of 0.70 for postoperative myocardial infarction and MINS outcomes in another external validation research [27]. Our study did not compare our models with the NSQIP surgical risk calculator and MICA as several key indicators needed to be collected prospectively and were not available in our data. Another prediction model by logistic regression was derived from the MANAGE cohort, using only 3 preoperative risk factors, not accounting for intraoperative factors, which might be important contributors to adverse outcomes [9]. Therefore, neither of these widely used assessment tools performed by logistic regression statistics has yet been shown to have sufficient predictive strength and applicability.

Recent work has highlighted the strengths of ML algorithms for predicting postoperative complications compared to classic statistical analyses because they can eliminate nonlinear interactions between clinical variables and resolve the imbalance problem. Oh et al [11] developed the prediction model using extreme gradient boosting algorithm and achieved an AUROC of 0.78 through 12 variables. There were 5 variables coinciding in Oh's model and ours: operation duration, age, history of chronic kidney disease, history of coronary artery disease, and intraoperative red blood cell transfusion. Other inconsistent variables were due to medication differences, uncollected variables, and number of events. Furthermore, there were 6811 patients selected from 43,019 patients, and the high exclusion rate (84%) and high incidence of MINS (22%) caused a high risk of selection bias in the study. The potential risk factors in Oh's study may not be generalizable to our data set, which is including older patients. Another ML model was developed by Nolde et al [12], through applying single-layer and multiple-layer variables to different models and achieving the highest AUROC of 0.71. However, the model with optimal prediction efficacy also included information of postoperative vital parameters and oxygenation within 1 - 4 days, making it more challenging for anesthesiologists to identify high-risk patients after procedures immediately. Moreover, despite the presentation of variable importance ranking, anesthesiologists and surgeons are were still unable to distinguish modifiable risk factors and make targeted interventions to improve outcomes.

In our study, we used several ML approaches based on different principles and noticed that the prediction efficacy of each approach did not greatly differ from each other, suggesting the promising performance of all advanced ML algorithms for the relatively small and low-dimension data. Logistic regression, representing the simplest of all classifiers, was chosen to create a reference model against the performance of other machine models. Based on this principle, the CatBoost and random forest demonstrated relatively good prediction results in our data set and CatBoost was chosen for further analysis. We also noticed that the naïve Bayes algorithm provided the highest accuracy but with the disadvantage of worse classification performance. The reason for this result might be due to different models dealing with sample classification in different ways. The accuracy index considered only the percentage of correct classification, whereas the AUROC index reflected the ability of a classification model to discriminate between positive and negative samples, taking into account the set threshold's influence on prediction results. Although similar accuracy can be achieved, the discrimination of being misjudged was not considered while the AUROC index was used as a complementary measure. Based on these points, we conclude that the CatBoost algorithm demonstrates a better predictive effect for MINS due to its highest AUROC, much faster speed, and using default parameters.

In addition, our model not only achieved good predictive effect for MINS but also explored a model-agnostic interpretation technique on how potential variables contribute to adverse outcomes, which was not explored in previous studies. The SHAP values confirmed the importance of variables, reflecting their positive or negative roles. The top important features contributing to adverse cardiovascular complications included preoperative renal dysfunction, inflammatory status, glucose metabolism, anemia, and electrolyte disturbances. The intraoperative hemodynamic and other physiological changes are also important contributors to the occurrence of MINS, including more blood loss, prolonged surgery duration, hypotension, greater infusion of fluids, and blood transfusion [28-34]. The SHAP plot presentats predictions for a single sample in which each feature is a value that increases or decreases the prediction efficacy and its contribution level, providing intuitive explanations for what led to a patient's predicted risk and quantitative prediction at individual levels. For example, in our first sample patient, we recognized that his high preoperative blood glucose concentration played the greatest negative role in the development of complications. Similarly, in the second sample, intraoperative blood transfusion was considered the strongest risk factor for postoperative MINS. Although the complications are unavoidable mainly due to patients' comorbidities and surgical stimuli, some variables are modifiable. Identifying specific patient characteristics that predispose them to at-risk status can prompt early targeted prevention or treatments, such as administering insulin to patients with a high blood glucose concentration or taking measures to reduce intraoperative blood loss, which may improve the prognosis. The individual risk estimates may provide the modifiable factors through the SHAP method, which was clinically meaningful and can be used in multiple surgical scenarios.

Limitations

There are limitations to our study. While the model showed with high accuracy, it was highly dependent on data from EHR. When one indicator was missing, the true risk of adverse outcomes for the patient could not be reflected. Second, the surgical patient data were obtained retrospectively from 2 hospitals, which may have introduced bias, as some potential candidates' data may not be collected in the EHR. Although external validation was conducted in our model, more validation centers are warranted to support the extrapolation and creditability. Third, some variables were excluded before feature selection, especially those laboratory tests not rountinely measured, such as brain natriuretic peptide and C-reactive protein, leading to omission and neglect of important indicators. Lastly, this study only enrolled older Chinese patients who had noncardiac surgeries from 1 northern center and 1 southern center, and whether the results can be extrapolated to other populations remains uncertain.

Conclusions

These findings suggest that the ML technique, combining the preoperative and intraoperative variables for predicting MINS with a model-agnostic interpretation, is a potentially efficient management tool for practitioners to guide their postoperative care planning and management.

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Authors' Contributions

CL, KZ, and XY are the co-authors, contributing equally to methodology, conception, study design, and data curation. BM contributed to data curation and validation. JL, YL, and JC supervised the study. KL contributed to data curation. WM and HL are both corresponding authors and contributed to resources, project administration, writing the manuscript (review and editing), and funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional information.
[DOCX File, 2313 KB - aging_v7i1e54872_app1.docx]

References

1. Botto F, Alonso-Coello P, Chan MTV, et al. Myocardial injury after noncardiac surgery: a large, international, prospective cohort study establishing diagnostic criteria, characteristics, predictors, and 30-day outcomes. Anesthesiology 2014 Mar;120(3):564-578. [doi: 10.1097/ALN.0000000000000113] [Medline: 24534856]
2. Górka J, Polok K, Iwaniec T, et al. Altered preoperative coagulation and fibrinolysis are associated with myocardial injury after non-cardiac surgery. Br J Anaesth 2017 May 1;118(5):713-719. [doi: 10.1093/bja/aex081] [Medline: 28486646]
3. Levy M, Heels-Ansdell D, Hiralal R, et al. Prognostic value of troponin and creatine kinase muscle and brain isoenzyme measurement after noncardiac surgery: a systematic review and meta-analysis. Anesthesiology 2011 Apr;114(4):796-806. [doi: 10.1097/ALN.0b013e31820ad503] [Medline: 21336095]
4. van Waes JAR, Grobben RB, Nathoe HM, et al. One-year mortality, causes of death, and cardiac interventions in patients with postoperative myocardial injury. Anesth Analg 2016 Jul;123(1):29-37. [doi: 10.1213/ANE.0000000000001313] [Medline: 27111647]
5. Devereaux PJ, Szczeklik W. Myocardial injury after non-cardiac surgery: diagnosis and management. Eur Heart J 2020 May 1;41(32):3083-3091. [doi: 10.1093/eurheartj/ehz301] [Medline: 31095334]
6. Lee TH, Marcantonio ER, Mangione CM, et al. Derivation and prospective validation of a simple index for prediction of cardiac risk of major noncardiac surgery. Circulation 1999 Sep 7;100(10):1043-1049. [doi: 10.1161/01.cir.100.10.1043] [Medline: 10477528]
7. Bilimoria KY, Liu Y, Paruch JL, et al. Development and evaluation of the universal ACS NSQIP surgical risk calculator: a decision aid and informed consent tool for patients and surgeons. J Am Coll Surg 2013 Nov;217(5):833-842. [doi: 10.1016/j.jamcollsurg.2013.07.385] [Medline: 24055383]
8. Pereira-Macedo J, Lopes-Fernandes B, Duarte-Gamas L, et al. The Gupta perioperative risk for Myocardial Infarct or Cardiac Arrest (MICA) calculator as an intraoperative neurologic deficit predictor in carotid endarterectomy. J Clin Med 2022 Oct 28;11(21):6367. [doi: 10.3390/jcm11216367] [Medline: 36362595]
9. Serrano AB, Gomez-Rojo M, Ureta E, et al. Preoperative clinical model to predict myocardial injury after non-cardiac surgery: a retrospective analysis from the MANAGE cohort in a Spanish hospital. BMJ Open 2021 Aug 4;11(8):e045052. [doi: 10.1136/bmjopen-2020-045052] [Medline: 34348944]
10. Dong J, Feng T, Thapa-Chhetry B, et al. Machine learning model for early prediction of acute kidney injury (AKI) in pediatric critical care. Crit Care 2021 Aug 10;25(1):288. [doi: 10.1186/s13054-021-03724-0] [Medline: 34376222]
11. Oh AR, Park J, Shin SJ, et al. Prediction model for myocardial injury after non-cardiac surgery using machine learning. Sci Rep 2023 Jan 26;13(1):1475. [doi: 10.1038/s41598-022-26617-w] [Medline: 36702844]
12. Nolde JM, Schlaich MP, Sessler DI, et al. Machine learning to predict myocardial injury and death after non-cardiac surgery. Anaesthesia 2023 Jul;78(7):853-860. [doi: 10.1111/anae.16024] [Medline: 37070957]
13. Lei Y, Li YQ, Jiang W, et al. A gene-expression predictor for efficacy of induction chemotherapy in locoregionally advanced nasopharyngeal carcinoma. J Natl Cancer Inst 2021 Apr 6;113(4):471-480. [doi: 10.1093/jnci/djaa100] [Medline: 33094348]
14. Asch DA, Troxel AB, Stewart WF, et al. Effect of financial incentives to physicians, patients, or both on lipid levels: a randomized clinical trial. JAMA 2015 Nov 10;314(18):1926-1935. [doi: 10.1001/jama.2015.14850] [Medline: 26547464]

15. Ruetzler K, Smilowitz NR, Berger JS, et al. Diagnosis and management of patients with myocardial injury after noncardiac surgery: a scientific statement from the American Heart Association. Circulation 2021 Nov 9;144(19):e287-e305. [doi: 10.1161/CIR.0000000000001024] [Medline: 34601955]
16. Prokhorenkova L, Gusev G, Vorobev A, Dorogush AV, Gulin A. CatBoost: unbiased boosting with categorical features. arXiv. Preprint posted online on Jun 28, 2017. [doi: 10.48550/arXiv.1706.09516]
17. Friesner ID, Feng J, Kalnicki S, Garg M, Ohri N, Hong JC. Machine learning-based prediction of hospitalization during chemoradiotherapy with daily step counts. JAMA Oncol 2024 May 1;10(5):642-647. [doi: 10.1001/jamaoncol.2024.0014] [Medline: 38546697]
18. Ye G, Zhang C, Zhuang Y, et al. An advanced nomogram model using deep learning radiomics and clinical data for predicting occult lymph node metastasis in lung adenocarcinoma. Transl Oncol 2024 Jun;44:101922. [doi: 10.1016/j.tranon.2024.101922] [Medline: 38554572]
19. El Morr C, Jammal M, Bou-Hamad I, et al. Predictive machine learning models for assessing Lebanese university students' depression, anxiety, and stress during COVID-19. J Prim Care Community Health 2024;15:21501319241235588. [doi: 10.1177/21501319241235588] [Medline: 38546161]
20. Fu R, Hao X, Yu J, et al. Machine learning-based prediction of sertraline concentration in patients with depression through therapeutic drug monitoring. Front Pharmacol 2024;15:1289673. [doi: 10.3389/fphar.2024.1289673] [Medline: 38510645]
21. Guo L, Xu X, Niu C, et al. Machine learning-based prediction and experimental validation of heavy metal adsorption capacity of bentonite. Sci Total Environ 2024 May;926(171986):171986. [doi: 10.1016/j.scitotenv.2024.171986]
22. Jia M, Lai J, Li K, et al. Optimizing prediction accuracy for early recurrent lumbar disc herniation with a directional mutation-guided SVM model. Comput Biol Med 2024 May;173:108297. [doi: 10.1016/j.compbiomed.2024.108297] [Medline: 38554662]
23. Valsaraj A, Kalmady SV, Sharma V, et al. Development and validation of echocardiography-based machine-learning models to predict mortality. EBioMedicine 2023 Apr;90:104479. [doi: 10.1016/j.ebiom.2023.104479] [Medline: 36857967]
24. Xue B, Li D, Lu C, et al. Use of machine learning to develop and evaluate models using preoperative and intraoperative data to identify risks of postoperative complications. JAMA Netw Open 2021 Mar 1;4(3):e212240. [doi: 10.1001/jamanetworkopen.2021.2240] [Medline: 33783520]
25. Athanasiou M, Sfrintzeri K, Zarkogianni K, Thanopoulou AC, Nikita KS. An explainable XGBoost–based approach towards assessing the risk of cardiovascular disease in patients with type 2 diabetes mellitus. arXiv. Preprint posted online on Sep 14, 2020. [doi: 10.1109/BIBE50027.2020.00146]
26. Ruzycki SM, Prystajecky M, Driedger MR, Kachra R. Peri-operative cardiac biomarker screening: a narrative review. Anaesthesia 2020 Jan;75 Suppl 1:e165-e173. [doi: 10.1111/anae.14920] [Medline: 31903570]
27. Fronczek J, Polok K, Devereaux PJ, et al. External validation of the revised cardiac risk index and national surgical quality improvement program myocardial infarction and cardiac arrest calculator in noncardiac vascular surgery. Br J Anaesth 2019 Oct;123(4):421-429. [doi: 10.1016/j.bja.2019.05.029] [Medline: 31256916]
28. Punthakee Z, Iglesias PP, Alonso-Coello P, et al. Association of preoperative glucose concentration with myocardial injury and death after non-cardiac surgery (GlucoVISION): a prospective cohort study. Lancet Diabetes Endocrinol 2018 Oct;6(10):790-797. [doi: 10.1016/S2213-8587(18)30205-5] [Medline: 30057170]
29. Koster A, Zittermann A, Börgermann J, Gummert JF. No significant association between the transfusion of small volumes of leukocyte-depleted red blood cells and mortality over 7 years of follow-up in patients undergoing cardiac surgery: a propensity score matched analysis. Anesth Analg 2018 May;126(5):1469-1475. [doi: 10.1213/ANE.0000000000002581] [Medline: 29064873]
30. Durmuş G, Belen E, Can MM. Increased neutrophil to lymphocyte ratio predicts myocardial injury in patients undergoing non-cardiac surgery. Heart Lung 2018;47(3):243-247. [doi: 10.1016/j.hrtlng.2018.01.005] [Medline: 29500104]
31. Smilowitz NR, Redel-Traub G, Hausvater A, et al. Myocardial injury after noncardiac surgery: a systematic review and meta-analysis. Cardiol Rev 2019;27(6):267-273. [doi: 10.1097/CRD.0000000000000254] [Medline: 30985328]
32. Qi W, Zhu J, Wu Q, et al. Maize reas1 mutant stimulates ribosome use efficiency and triggers distinct transcriptional and translational responses. Plant Physiol 2016 Feb;170(2):971-988. [doi: 10.1104/pp.15.01722] [Medline: 26645456]
33. Salmasi V, Maheshwari K, Yang D, et al. Relationship between intraoperative hypotension, defined by either reduction from baseline or absolute thresholds, and acute kidney and myocardial injury after noncardiac surgery: a retrospective cohort analysis. Anesthesiology 2017 Jan;126(1):47-65. [doi: 10.1097/ALN.0000000000001432] [Medline: 27792044]
34. Liu C, Zhang K, Zhang T, et al. Higher preoperative red blood cell distribution width increases the risk of myocardial injury after noncardiac surgery in advanced-age patients: a retrospective cohort study. Clin Interv Aging 2023;18:169-179. [doi: 10.2147/CIA.S392778] [Medline: 36818546]

Abbreviations

ASA: American Society of Anesthesiologists
AUROC: area under the receiver operating characteristic
CatBoost: category boosting

EHR: electronic health record
LASSO: least absolute shrinkage and selection operator
MICA: Myocardial Infarction or Cardiac Arrest
MINS: myocardial injury after noncardiac surgery
ML: machine learning
NSQIP: National Surgeons Quality Improvement Program
RCRI: Revised Cardiac Risk Index
RFE: recursive feature elimination
SHAP: Shapley Additive Explanations
TRIPOD: Transparent Reporting of a multivariable prediction model for Individual Prognosis or Diagnosis

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Expectations and Requirements of Surgical Staff for an AI-Supported Clinical Decision Support System for Older Patients: Qualitative Study

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Abstract

Background: Geriatric comanagement has been shown to improve outcomes of older surgical inpatients. Furthermore, the choice of discharge location, that is, continuity of care, can have a fundamental impact on convalescence. These challenges and demands have led to the SURGE-Ahead project that aims to develop a clinical decision support system (CDSS) for geriatric comanagement in surgical clinics including a decision support for the best continuity of care option, supported by artificial intelligence (AI) algorithms.

Objective: This qualitative study aims to explore the current challenges and demands in surgical geriatric patient care. Based on these challenges, the study explores the attitude of interviewees toward the introduction of an AI-supported CDSS (AI-CDSS) in geriatric patient care in surgery, focusing on technical and general wishes about an AI-CDSS, as well as ethical considerations.

Methods: In this study, 15 personal interviews with physicians, nurses, physiotherapists, and social workers, employed in surgical departments at a university hospital in Southern Germany, were conducted in April 2022. Interviews were conducted in person, transcribed, and coded by 2 researchers (AU, LB) using content and thematic analysis. During the analysis, quotes were sorted into the main categories of geriatric patient care, use of an AI-CDSS, and ethical considerations by 2 authors (AU, LB). The main themes of the interviews were subsequently described in a narrative synthesis, citing key quotes.

Results: In total, 399 quotes were extracted and categorized from the interviews. Most quotes could be assigned to the primary code *challenges in geriatric patient care* (111 quotes), with the most frequent subcode being *medical challenges* (45 quotes). More quotes were assigned to the primary code *chances of an AI-CDSS* (37 quotes), with its most frequent subcode being *holistic patient overview* (16 quotes), then to the primary code *limits of an AI-CDSS* (26 quotes). Regarding the primary code *technical wishes* (37 quotes), most quotes could be assigned to the subcode *intuitive usability* (15 quotes), followed by *mobile availability and easy access* (11 quotes). Regarding the main category *ethical aspects of an AI-CDSS*, most quotes could be assigned to the subcode *critical position* toward *trust in an AI-CDSS* (9 quotes), followed by the subcodes *respecting the patient's will and individual situation* (8 quotes) and *responsibility remaining in the hands of humans* (7 quotes).

Conclusions: Support regarding medical geriatric challenges and responsible handling of AI-based recommendations, as well as necessity for a holistic approach focused on usability, were the most important topics of health care professionals in surgery regarding development of an AI-CDSS for geriatric care. These findings, together with the wish to preserve the patient-caregiver relationship, will help set the focus for the ongoing development of AI-supported CDSS.

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KEYWORDS

traumatology; orthogeriatrics; older adult; elderly; older people; aging; interviews; mHealth; mobile health; mobile application; digital health; digital technology; digital intervention; CDSS; clinical decision support system; artificial intelligence; AI; algorithm; predictive model; predictive analytics; predictive system; practical model; decision support; decision support tool

Introduction

Older adults represent a large proportion of patients in hospitals, and numbers will be increasing [1]. Treatment of these patients can be challenging, due to complex medical conditions including deficits in multiple geriatric domains [2,3]. Therefore, identification of geriatric patients with complex needs is needed and should be followed by comprehensive geriatric assessments to capture needs and resources in multiple domains such as cognition, nutrition, physical functioning, comorbidities, frailty, and others [4].

An additional challenge is determining the best discharge destination for these patients, also referred to as transition of care or continuity of care (COC) [5]. Multiple options exist in most high-resource countries, such as rehabilitation with geriatric or orthopedic specialization, specialized acute geriatric departments or hospitals, short- or long-term care in nursing homes, or ideally a direct discharge home with or without further support [6]. In Germany, social services assist with organizing adequate COC. Ideally, the decision is discussed by physicians, patients, relatives, nurses, therapeutic, and social service staff. Barriers to optimal COC decisions have been observed and include staffing shortages, difficulties to assess the potential of geriatric patients in an acute stress situation, difficulties to communicate with relatives and team members in a structured way, and an insufficient alignment between bed capacity and the demand in the target facilities [5,7,8].

The involvement of geriatric specialists in the treatment of geriatric patients on surgical wards has been shown to improve relevant clinical outcomes [9]. However, a shortage of geriatric specialists prevents the widespread implementation of geriatric comanagement [10]. To address this problem, the SURGE-Ahead project (supporting surgery with geriatric comanagement and artificial intelligence [AI]) aims to develop an AI-enhanced clinical decision support system (AI-CDSS) to support geriatric comanagement and COC decisions in surgical departments without a resident geriatrician [11]. SURGE-Ahead started in July 2021 and is a multidisciplinary project funded by the Federal Ministry of Education and Research. For this purpose, the SURGE-Ahead AI-CDSS system collects patient data from the hospital information system (HIS) including central laboratory parameters, diagnoses, and operation procedures. In addition, relevant scores for comprehensive geriatric assessments domains, such as mobility, cognition including delirium, and medication appropriateness, will be registered, calculated, and presented to the surgical staff. Furthermore, a suggestion for the most suitable COC destination will be given based on decision trees and machine learning algorithms. To develop the algorithm, the ground truth (optimal discharge decision) will be provided by experts for geriatric medicine.

The use of an AI-CDSS in health care delivery raises ethical questions [12-14]. While it could improve communication with patients and contribute to increased quality of the diagnostic and therapeutic process [15,16], it also carries risks such as overlooking patients' individual wishes and needs. Other issues, such as decreased trust in accuracy and usability of the system because of errors, technical problems, or overalerting, may result in the product not being used in everyday clinical practice [12,17]. It has been shown that a cocreation process with end users helps improve the development of targeted new digital health applications [18]. We therefore conducted qualitative expert interviews with different health care professionals to capture current challenges on surgical wards, requirements for an AI-CDSS, and ethical considerations. In detail, we aimed to cover the following 3 main categories:

1. Challenges and need for support in geriatric patient care.
2. Technical and general wishes regarding the development of an AI-CDSS for geriatric patient care in surgery.
3. Expected ethical challenges using an AI-CDSS with respect to the 4 core medico-ethical principles of autonomy, beneficence, maleficence, and justice [19].

Methods

Participants

We included 15 health care professionals involved in the inpatient surgical care of geriatric patients. Three senior physicians, 3 assistant physicians, and 3 nurses from the departments of urology, visceral surgery, and traumatology (all 3 departments are recruitment centers for the SURGE-Ahead project), as well as 2 senior physicians from the emergency department, 2 physiotherapists, and 2 social service workers, all responsible for surgical patients, agreed to participate. None of the interviewees were involved in the SURGE-Ahead project or in the development of the AI-CDSS.

Participants were recruited at Ulm University Medical Center in Southern Germany. The department of orthopedic trauma surgery has been certified as an AltersTraumaZentrum (center for geriatric traumatology) DGU in cooperation with a local geriatric clinic in 2019. This model of care entails medical visits by a geriatrician on trauma wards. Furthermore, a senior surgeon visits the geriatric clinic. Thus, an exchange exists between the 2 hospitals regarding the care for geriatric trauma patients. Currently, this model exists only for orthopedic trauma surgery and not for other surgical departments.

Interviews

An interview guideline with 12 questions corresponding to the 3 main topics was prepared by a multidisciplinary research team consisting of geriatricians, surgeons, public health specialists, and ethicists. The questions were formulated on the basis of a prior literature research, the guidelines for conduct of qualitative interviews [20,21], and professional experience of the researchers. The number of questions was limited to 12 due to the expected short time available to our interview partners. Interviews were conducted in a semistructured way. While the preformulated questions set the focal point, ad hoc questions provided a possibility to clarify statements or focus on particularly important issues mentioned by the interviewees [22,23].

Interviews were conducted in person in April 2022 in German. Potential interview partners were contacted personally or via email. If willing to participate, interviewees received a short information sheet about the SURGE-Ahead project.

Ethical Considerations

Ethical approval was waived by the ethics committee of Ulm University, because no information on personal data, health-related data, or data on sexuality of the interviewees was collected (March 21, 2022). All interviewees declared their consent after being informed about the aim of the study, their rights, potential risks, and data protection. Interviewees did not receive any compensation for participation in the study.

Data Analysis

Interviews were recorded and transcribed by an external transcription service provider (abtipper.de). After transcription, the interviews were anonymized. Transcripts were checked for accuracy against the recordings by 2 authors (AU, LB) to avoid bias. Occurring flaws in transcription were resolved by mutual agreement.

The statements of the interviewees were coded, extracted, and sorted into main categories, primary codes, and subcodes according to usual procedures of qualitative analysis [24] and thematic analysis [25,26] using the software MAXQDA (VERBI GmbH). Total numbers of the extracted categories and codes are presented. Representative quotes that illustrate various themes were translated from German into English by 2 researchers independently (AU, MLF), compared, and then unified into a final version. Based on these representative quotes, a narrative synthesis of the results was written. Finally responses across categories were also stratified according to the most significant hopes and fears of participants [27]. The final manuscript was written based on COREQ (Consolidated Criteria for Reporting Qualitative Research) [28].

Results

Interview Participants

In total, 14 interviews were conducted with 15 professionals. The mean duration of the conducted interviews was 13:51 minutes. The interviewees' professional experience ranged from 2 to 43 years with a median duration of 15 years. Median time of affiliation with the department (8 years) differed between professions. Nursing management had the longest affiliation of 22 years, and senior physicians in the emergency department had the shortest median affiliation of 1.5 years. For details, see Table 1.

Table . Interviewed experts[a].

ID	Profession	Professional experience (years)	Department	Affiliation with the department (years)
1	Social service	32	Social counseling service	2
2	Social service	8	Social counseling service	8
3	Assistant physician	4	Visceral surgery	1
4	Nursing management	43	Urology	40
5	Senior physician	19	Traumatology	19
6	Physiotherapy	22	Physiotherapy surgery	22
7	Senior physician	21	ED[b]	1
8	Physiotherapy	34	Physiotherapy surgery	34
9	Nursing management	37	Traumatology	22
10	Assistant physician	2	Urology	2
11	Senior physician	15	ED	2
12	Assistant physician	6	Traumatology	6
13	Nursing management	8	Visceral surgery	8
14	Senior physician	10	Visceral surgery	9
15	Senior physician	13	Urology	13

[a] Identification numbers (ID) are assigned to the interview partners according to the chronological order of the interviews. In the narrative synthesis of the statements below, these IDs are assigned to the corresponding quotes.

[b] ED: emergency department.

Qualitative Analysis of Interviews

Overview of Themes

Interview data were categorized into three major themes: (1) geriatric patient care, (2) use of an AI-CDSS in geriatric care, and (3) ethical challenges of using an AI-CDSS in geriatric care. Table 2 gives an overview of all extracted main categories (1-3), primary codes, and subcodes. A narrative synthesis of interview statements corresponding with the primary codes and their subcodes is represented thereafter. Key quotes are integrated into the text and additional quotes are listed in Multimedia Appendix 1 (selected quotes for each category).

Table . Main categories (1-3), primary codes, and subcodes emerging from inductive analysis of the interviews.

Main topic, primary codes, and subcodes			Number of quotes
1. Geriatric care			
	Challenges in geriatric patient care		111[a]
		Medical challenge	45
		Discharge management	27
		High workload	20
		Communication	14
		Lack of technical solutions	6
	Solutions for challenges in geriatric patient care		60[a]
		Patient-centered care	22
		Communication (patients, colleagues, and relatives)	21
		Social service	11
		Cooperation with geriatric hospital	6
	Wishes for geriatric patient care		20[a]
		Geriatric expertise	10
		Improved communication and availability of information	7
		Human resources and assistive devices	3
2. Use of an AI-CDSS[b] in geriatric care			
	General wishes for an AI-CDSS[c]		53[a]
		Electronic health record	30
		Work support	22
		No added workload	1
	Chances of an AI-CDSS[c]		37[a]
		Holistic patient overview	16
		Improvement of geriatric patient care	13
		Acceleration of processes	5
		Decision support	3
	Technical wishes for an AI-CDSS		37[a]
		Intuitive usability	15
		Mobile availability and easy access	11
		Automatic transfer of HIS[d] data into AI-CDSS	8
		Other	3
	Limits of an AI-CDSS		26[a]
		Decision-making authority remains with humans	9
		Preservation of individual and personal patient care	9
		Technical affinity and time constraints	7

Main topic, primary codes, and subcodes			Number of quotes
		Information overload	1
3. Ethical aspects of an AI-CDSS in geriatric care			
	Critical assessment of AI-CDSS recommendations		23[a]
		Respecting the patient’s will and individual situation	8
		Beneficence	5
		Data protection	4
		Scientific validation	3
		Loss of professional autonomy	2
		Legal responsibility	1
	Trust in an AI-CDSS		15[a]
		Critical position	9
		Ambivalent position	4
		Rejection	2
	Preserving the patient-caregiver relationship		17[a]
		Responsibility remains in the hands of humans	7
		Inform patients about the use of an AI-CDSS	4
		Preservation of patient-caregiver relationship	3
		Use AI-CDSS without informing patients	3

[a] The total sum of quotes belonging to the subcodes.

[b] AI-CDSS: artificial intelligence–supported clinical decision support system.

[c] In the following section, wishes for and chances of an AI-CDSS are presented together due to their overlapping subcodes.

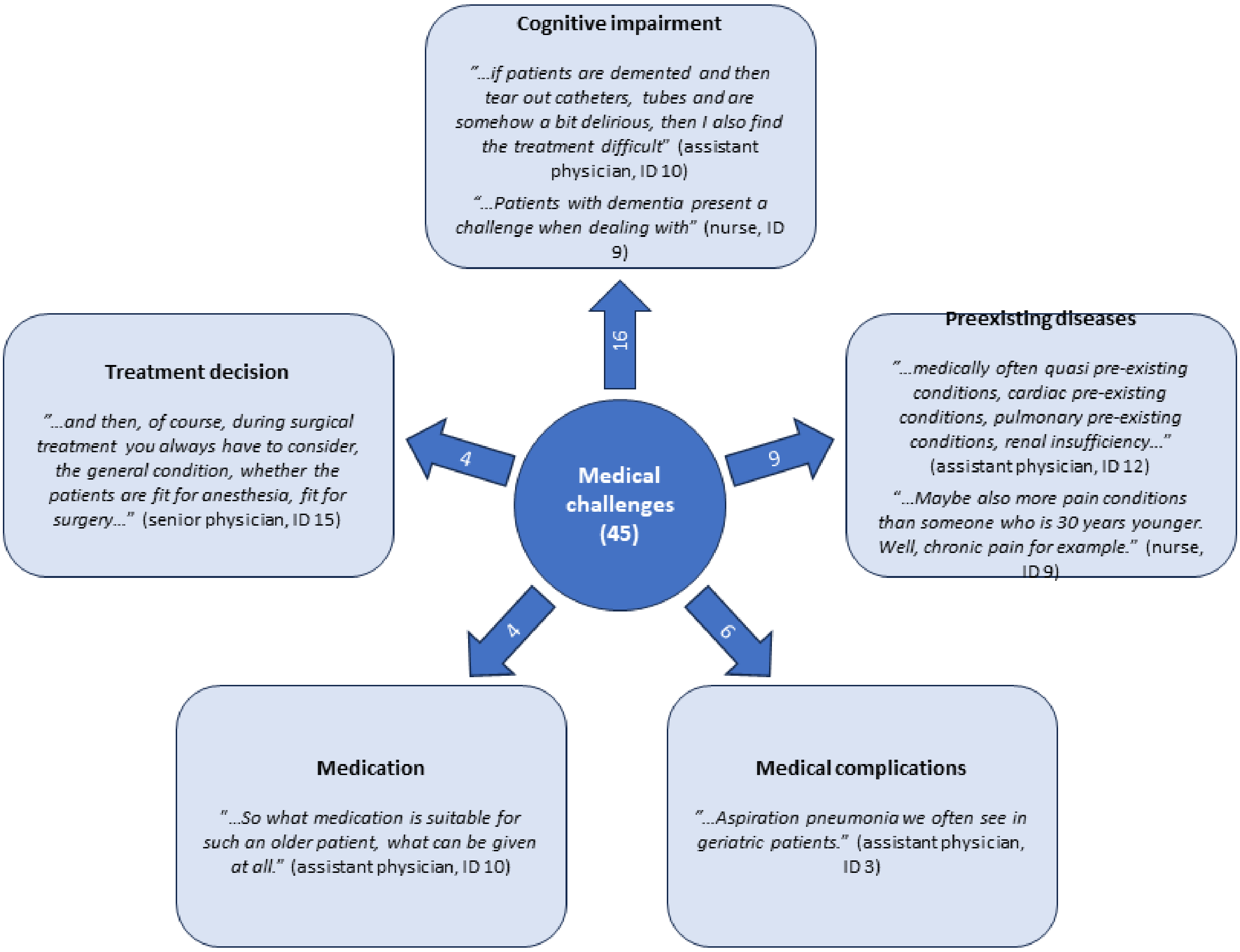
[d] HIS: hospital information system.

Geriatric Care

Challenges

Physicians, nurses, and physiotherapists mentioned multiple medical challenges when caring for geriatric patients on surgical wards such as medical complications, preexisting diseases, and cognitive impairment. Figure 1 shows this primary code and its associated subcodes including key quotes.

Figure 1. Numbers in the inner circle and the outgoing arrows show the number of citations for each subcode and the primary code. Further mentioned challenges were drainages (3 citations), reduced mobility (3 citations), slower regeneration (2 citations), and legal support (1 citation).



Cognitive impairment

”...if patients are demented and then tear out catheters, tubes and are somehow a bit delirious, then I also find the treatment difficult” (assistant physician, ID 10)

“...Patients with dementia present a challenge when dealing with” (nurse, ID 9)

Treatment decision

”...and then, of course, during surgical treatment you always have to consider, the general condition, whether the patients are fit for anesthesia, fit for surgery...” (senior physician, ID 15)

Preexisting diseases

“...medically often quasi pre-existing conditions, cardiac pre-existing conditions, pulmonary pre-existing conditions, renal insufficiency...” (assistant physician, ID 12)

“...Maybe also more pain conditions than someone who is 30 years younger. Well, chronic pain for example.” (nurse, ID 9)

Medication

”...So what medication is suitable for such an older patient, what can be given at all.” (assistant physician, ID 10)

Medical complications

”...Aspiration pneumonia we often see in geriatric patients.” (assistant physician, ID 3)

In addition to medical challenges, discharge management was stressed especially by social service members as highly challenging in clinical routine due to the need to organize the best possible follow-up care for each geriatric patient (Multimedia Appendix 1, quote 1), alongside a high patient turnover and the resulting high workload in acute surgical hospitals. Social service members also stated the lack of a person having the main responsibility for the COC decision as an issue.

> *…each day we have on average 25 to over 30 registrations. And you have to manage that for a start. And that is what is actually almost not possible.* [Social service member, ID 1]

Physicians mentioned that they have difficulties to find the best place for the patient after discharge, because they do not feel properly educated about it (Multimedia Appendix 1, quote 2). Physicians, nurse management, and social service mentioned that staff shortage and high work density can impact the quality of care, which can be aggravated by economic pressure (Multimedia Appendix 1, quotes 3 and 4). Finally, interviewees still relied on telephone, fax, and email as the only technical solutions facilitating geriatric patient care and especially discharge management (Table S1 in Multimedia Appendix 1, quotes 5 and 6).

Solutions

Patient-centered care involving patient contact and diagnostic examinations, for example, in radiology or the laboratory, as well as exchanging ideas with colleagues and experts, are commonly cited strategies in geriatric patient care. While physicians, nurses, and physiotherapists see the social service as a crucial partner for organizing discharge of patients, social service members stated that they find value in involving relatives and having conversations with them. Interviewees also expressed that cooperation with the geriatric hospital is an important aspect in geriatric patient care on surgical wards.

> *…, so you try to find a solution with the social service or, depending on the illness, together with ambulant palliative care (Brückenpflege), together with the relatives to find a solution. Bethesda (acute geriatric hospital) is of course also always a welcome solution.* [Nurse ID 4]

Wishes

The main wish expressed by physicians, nurse management, and social service was an improved cooperation with geriatric experts.

> *…perhaps if we had…people here who are more familiar with geriatric disease patterns. After all, we all rather come from the acute care, acute hospital.*

> *We all don't really have a background in geriatric care, there are other basics involved in our training. So, if you could mix it up a little, it would probably be good for everyone, yes.* [Nurse ID 13]

Nurses, physicians, and social service employees stressed the need for better communication, also across institutions, and timely availability of information (Multimedia Appendix 1, quotes 7 and 8). Further frequent wishes to improve geriatric patient care on surgical wards were improved awareness about drug interactions and side effects especially regarding geriatric patients (assistant physician) and improved management of delirium (senior and assistant physicians). More frequent mobilization of patients through physiotherapy (assistant physicians) and the establishment of a geriatric ward in the department for trauma surgery (senior physician) were mentioned by singular interviewees.

Use of an AI-CDSS

General Wishes for and Chances of an AI-CDSS

All interviewees expressed a desire for an electronic health record (EHR) to gain a holistic picture of the patient's situation, accelerate processes, and reduce resource expenses.

> *…so I see a chance to shorten my time expenditure because I already have a medical history that I can access with a few clicks. Which might otherwise cost me a lot of time.* [Social service ID 2]

Cognition, frailty, mobility, medication, substance abuse, social history, and laboratory values were mentioned as important aspects, which should be integrated in an AI-CDSS (Multimedia Appendix 1, quote 9). Primarily requested by physicians were features that could increase awareness for needs and pitfalls of geriatric patient care but could also give constructive solutions, for example, for drug interactions, delirium management, or discharge management (Multimedia Appendix 1, quotes 10 and 11). The capacity of the AI-CDSS to advance treatment effectiveness through faster evaluation of large amounts of data was mentioned (Multimedia Appendix 1, quote 12). Finally, the application should not increase the existing workload (Multimedia Appendix 1, quote 13).

Technical Wishes for an AI-CDSS

Intuitive usability was mentioned most frequently by all interviewees when asked about technical wishes for an AI-CDSS.

> *So I think it should be intuitive. That's always difficult to define. So it should be a clear program that I can access from anywhere. Maybe not only from fixed PCs, but also from tablets and so on…But it should be kept relatively simple so that everyone can understand it. And can use it without much prior knowledge.* [Assistant physician ID 12]

Mobile and easy access for all involved caregivers were additional desirable features (Multimedia Appendix 1, quote 14). Physicians emphasized the importance of a regular and automatic data transfer from the HIS to the new AI-CDSS to avoid redundancy and additional workload due to the need for double entries (Multimedia Appendix 1, quotes 15 and 16). Some physicians also proposed linking the application with external hospitals for better networking and some suggested incorporating functions such as showing the availability of free beds, for example, in external rehabilitation hospitals (Multimedia Appendix 1, quote 17).

Limits of an AI-CDSS

The main concern expressed by interviewees regarding the use of an AI-CDSS was that the final decision-making authority should always stay with humans. They emphasized that the doctor-patient relationship cannot be replaced by a computer. In addition, some interviewees worried about losing sight of the individual patient's needs when relying on an AI-CDSS:

> *Limitations of course, it is and will remain a human being and not a material in quotation marks. That one does not forget this and that this is still considered and not forgotten, that there is no text-book and no cookie-cutter approach….* [Assistant physician ID 12]

Several interviewees also raised concerns about the implementation of new technology in health care settings, particularly regarding the handling and operation of such systems. One interviewee mentioned that operating an AI-CDSS might be challenging in a busy clinical environment due to the already existing high workload (Multimedia Appendix 1, quotes 18 and 19). One senior physician mentioned that it might be difficult to make decisions about interventions, such as new medications, due to the theoretical risks and complications presented by the system (Multimedia Appendix 1, quote 20). Interestingly, 2 assistant doctors did not see any risks in incorporating such a new technology.

Ethical Aspects of an AI-CDSS

Critical Assessment of AI-CDSS Recommendations

Many interviewees stated that they had no concerns about—and would even appreciate—the use of an AI-CDSS in geriatric patient care as a supporting tool. However, an underlying condition should be informing patients about the use of a CDSS and considering the patient's individual situation. Interviewees stressed that the will of patients or relatives should be at the core of clinical decisions and COC decisions.

> *So, the patient's wishes should be considered. Or, if the patient can no longer decide for themselves, the relatives in any case.* [Nursing ID 9]

In this regard, interviewees mentioned that it might be difficult for an AI-CDSS to capture all facets of geriatric patients (Multimedia Appendix 1, quote 21). One of the respondents described it as "*putting patients in a box*" (physiotherapist, ID 8).

According to the respondents, such a system would require solid scientific validation prior to integration into routine care and adhere to all data protection requirements (Multimedia Appendix 1, quote 22 and 23). Some concerns of the interviewees also raised the question of accountability and reliance on the decisions made by an AI-CDSS. Strong reliance on the technology might lead to a loss of autonomy and professional identity of caregivers. Moreover, the question of professional and legal responsibility for the decisions taken was raised (Multimedia Appendix 1, quote 24).

Trust in an AI-CDSS

The majority of interviewees were unsure whether they would fully trust the AI-CDSS and emphasized the need for medical professionals to critically evaluate all suggestions made by the system.

> *So, I can imagine that it could well be trustworthy and reliable. However, I would not rely on that alone. So would say, it is…a recommendation. So not a strict default. So I think you still have to examine and evaluate the individual case from a human or medical point of view to see whether it really makes sense and whether it is in the best interests of the patient or their relatives. But as a supportive tool, I think it's very good. And then it would also be reliable for me.* [Senior doctor ID 5]

Preserving a Patient-Caregiver Relationship

Regarding the patient-caregiver relationship, most interviewees remarked that it is crucial to openly communicate the use of an AI-CDSS (Multimedia Appendix 1, quote 25) and to emphasize that the main responsibility for clinical decisions remains in the hands of humans. Preservation of the physical and emotional relation between caregivers and patients was also mentioned by interviewees as an important factor for a trusting relation.

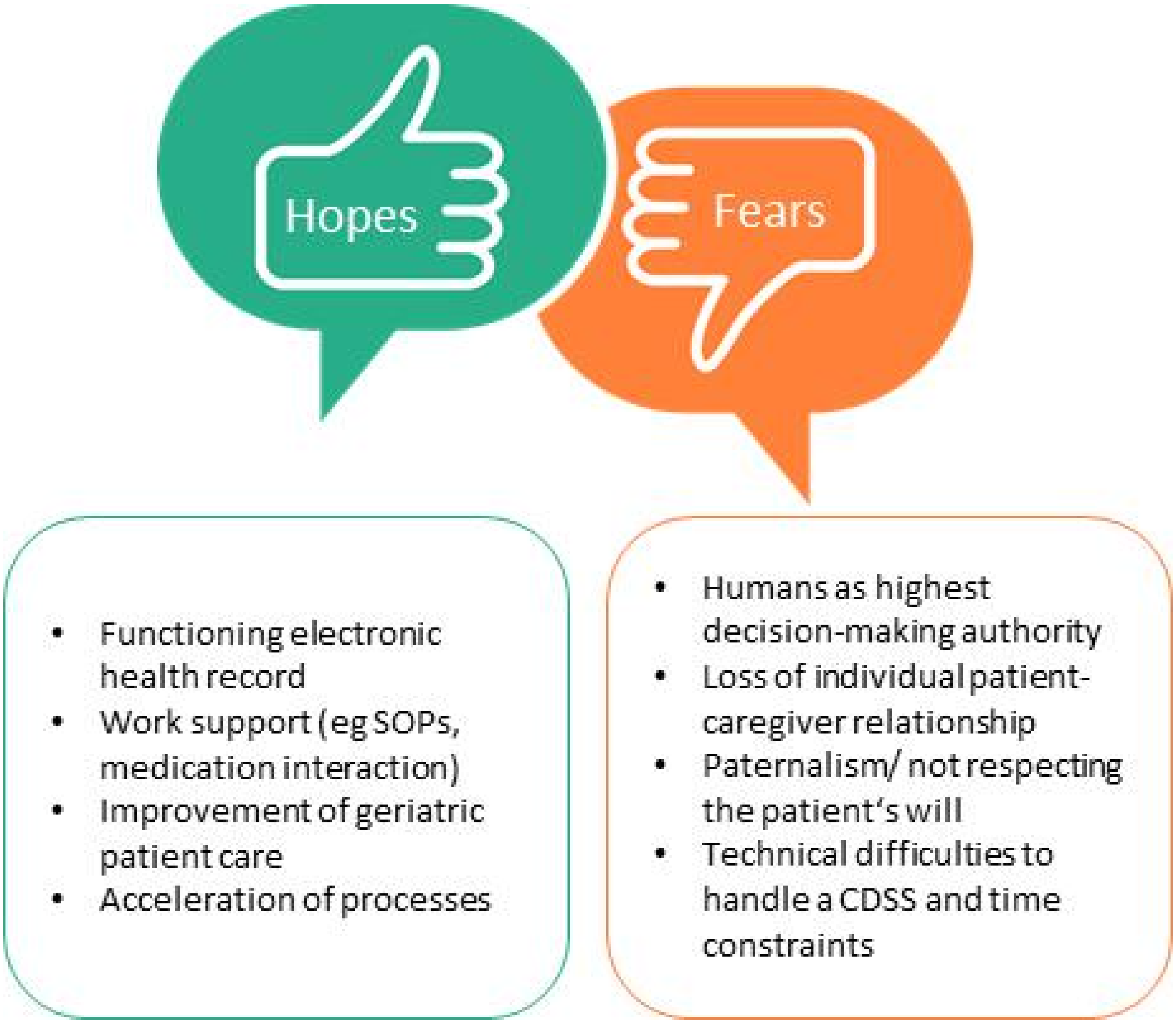
> *…by always clarifying, that the final medical decision always lies with a person or a doctor. I think that is very, very important for the patient, but also for the doctor himself…So I think, the independent decision for medical matters must remain with the doctor. And of course you can't replace the doctor-patient-relationship with a computer, so to speak.…So it must always be clear that the doctor ultimately makes the decision, so to speak, and the machine supports him in making the right one. I would say that the machine processes a complexity of information that the doctor would otherwise not be able to process.* [Senior doctor ID 7]

In contrast, 1 interviewee feared an adverse result for the patient-caregiver relationship if openly communicating about the use of an AI-CDSS and another interviewee proposed not to inform patients about the use of it (Multimedia Appendix 1, quote 26).

Fears and Hopes

In order to summarize all answers and for a quick and clear overview, responses were stratified according to the biggest fears and hopes that could be extracted across all categories and codes as displayed in Figure 2.

Figure 2. Main hopes and fears expressed by interviewees about an AI-CDSS for surgical patient care. CDSS: clinical decision support system; SOP: standard operating procedure.



Discussion

Study Overview

In this qualitative study, we analyzed the status of geriatric care and the expectations for an AI-CDSS supporting patient care by interviewing physicians, nurses, physiotherapists, and social service members. Results were summarized in 3 main categories covering geriatric patient care, the use of an AI-CDSS, and ethical considerations regarding an AI-CDSS. While the biggest hope was that such an application could improve geriatric care including the handling of medical geriatric challenges within a functioning digital service, the loss of individual patient-caregiver relation and a lack of usability were the biggest fears.

AI-CDSS to Support Geriatric Care

Provision of an EHR by an AI-CDSS was the most frequent subcode extracted from the interviews. Currently, health professionals must gather information about patients from different sources (eg, HIS, paper documents, and telephone calls), which is time consuming. One of the biggest advantages of a CDSS could be an overview of relevant individual clinical and social information. However, a higher workload was feared due to the task of entering data. Physicians already spend up to 35% of their time on documentation [29,30]. Because of these shortcomings low acceptance of EHR and CDSS is a common phenomenon in clinical practice [31,32]. Therefore, the involvement of future users in the development of the application [32], ensuring seamless integration with existing clinical information systems, minimizing the need for manual data entry, and designing applications as close as possible to the existing systems have been found to be important for the acceptance of CDSS [17,33].

Interviewees also emphasized how challenging it is to care for geriatric patients due to complex medical conditions and impairments such as cognitive impairment. It has been shown that a multidisciplinary approach is favorable for geriatric patient care and COC decisions [34-37]. Considering the lack of geriatricians [10], geriatric expertise is something the AI-CDSS could provide, and support clinical work, by highlighting relevant issues such as medication interactions or factors increasing the risk for delirium.

The lack of knowledge of optimal COC was considered relevant by all professionals. The discharge destination can have a profound effect on long-term outcomes. A discharge to nursing homes has been associated with lower survival than a discharge home [5]. COC placement suggestions by an AI-CDSS could fill a gap in care for geriatric patients in surgery. Some interviewees even expressed the wish that an AI-CDSS should enable reservation of beds in rehabilitation clinics. For this purpose, new software options for hospitals have already been established and are currently being implemented in several regions in Europe [38].

Organizational and Technical Challenges of an AI-CDSS

Time and resource constraints could inhibit overall feasibility and practicality. Some interviewees were concerned whether all health care professionals will have the technical affinity to operate the AI-CDSS, potentially limiting the acceptance of the system [17]. Acceptance of an AI-CDSS is closely connected to explainability, accountability, and trust [39]. Increasing transparency of AI-systems leads to more trust in these systems and thus increases their acceptance [32]. If medical professionals cannot fully understand the recommendation of an AI-CDSS, it might result in conflicting situations [40]. This becomes evident considering the current legislation stating that even when using an AI-CDSS, medical professionals are responsible for the decisions [41]. However, this might change in the future with a CDSS improving and potentially even outperforming health care professionals [42].

In addition, professional caregivers need to be able to explain the use and functionality of the AI-CDSS to patients and their relatives [40,43,44]. In this context, the concept of digital divide seems important, which describes a decreased ability of older adults to use modern technologies compared with their younger counterparts [45]. However, a recent study could not detect interviewed geriatric patents' reservation toward the use of smart sensors [46].

Ethical Challenges of an AI-CDSS

Regarding the 4 core medico-ethical principles [19], the protection of patient autonomy seemed the most important, which reflects the current consent in medical practice about shared decision-making between patients and clinical professionals [47]. Although an AI-CDSS could support this, the identification of a patient's values, beliefs, and aims is a prerequisite [48-50]. Overreliance on the AI-CDSS might lead to premature and rigid categorization of the patients according to preprogrammed categories, which are not sublime enough to catch intrinsic differences in a patient's individual situation. Interviewees emphasized that all recommendations of an AI-CDSS must be reviewed critically by medical professionals to protect the patient's will and autonomy.

Another central ethical code was the importance of preserving the caregiver-patient relationship—an aspect related to the principle of beneficence [19]. Interviewees demanded that they would not want the AI-CDSS to prejudge a patient. Patient-caregiver relationships were considered important for the recovery and self-efficiency of patients because of associated emotions and their trust-building effect [13]. Research about placebo effects also supports this position [51]. Fear of losing their professional identity was mentioned by some interviewees [52]. The best way to maintain professional identity and a trustful patient-caregiver relationships was seen in an open communication with the patient about the use of a CDSS, followed by informed consent.

Albeit only mentioned by a few participants, data protection and scientific evaluation of a new AI-CDSS are essential regarding the medico-ethical concept of nonmaleficence [53,54]. Especially, data protection seems to be crucial from an ethical perspective to protect sensitive personal patient data from theft, manipulation, or access by third parties [49,55]. In case of geriatric patients, who are often overwhelmed by modern processes of data gathering, storage, and processing, special responsibility falls on the developers of AI-CDSS and clinical professionals collecting the data.

A last aspect of medico-ethical reflection is justice, which was superficially touched upon only during the interviews. It has been argued that developing and maintaining a CDSS is cost-intensive and therefore could be afforded only in high-resource countries with a well-functioning health system and in big hospitals, such as university hospitals [13,56].

Limitations

One limitation of the study was the rather low number of experts and an unproportionate distribution of health care professionals, with a higher representation of physicians. This does not allow for generalization of the results in a wider perspective. However, 15 interviewees should allow to capture about 85% (17/20) of possible topics, a phenomenon called "thematic saturation" [57], and in a smaller sample of interviewees, it is possible to focus on individual perspectives.

In addition, our information sheet did not explain the term AI to the interviewed health care professionals, so the reflections might have depended a lot on the individual knowledge. We, however, did not want to anticipate too much to broaden perspectives. Finally, the unique clinical information system, the status of hospital readiness for IT, and overall clinical structures could make it difficult to compare the findings with those from other hospitals, both nationally and internationally.

Conclusions

An AI-CDSS was mostly considered to be beneficial, especially by providing health care professionals with an easily accessible data platform focused on geriatric needs and supporting geriatric comanagement and COC decisions. The most common concerns focused on maintaining the patient's autonomy and preserving the patient-caregiver relationship, as well as smooth integration into existing workflows without extra tasks. Therefore, careful consideration must mainly be given to address technical demands (intuitive usability and easy access for all caregivers involved) and ethical challenges (maintaining the patient's autonomy, explainability, and supportive character) during the development and implementation of a new AI-CDSS for geriatric patients in surgical departments.

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Authors' Contributions

The study was planned by AU, MLF, CL, TDK, MO, FS, and MD. Participants were recruited by AU. Interviews were conducted by AU and LB. Data analysis was performed by AU, LB, AHA, and MLF. The manuscript was written by AU, MD, and MLF. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Selected quotes for each main category.
[DOCX File, 19 KB - aging_v7i1e57899_app1.docx]

References

1. Hafner T, Kollmeier A, Laubach M, Knobe M, Hildebrand F, Pishnamaz M. Care of geriatric patients with lumbar spine, pelvic, and acetabular fractures before and after certification as a geriatric trauma center DGU®: a retrospective cohort study. Medicina (Kaunas) 2021;57(8):794. [doi: 10.3390/medicina57080794]
2. Lee H, Lee E, Jang IY. Frailty and comprehensive geriatric assessment. J Korean Med Sci 2020;35(3):e16. [doi: 10.3346/jkms.2020.35.e16]
3. Heydari A, Sharifi M, Moghaddam AB. Challenges and barriers to providing care to older adult patients in the intensive care unit: a qualitative research. Open Access Maced J Med Sci 2019 Nov 15;7(21):3682-3690. [doi: 10.3889/oamjms.2019.846] [Medline: 32010399]
4. Ellis G, Gardner M, Tsiachristas A, et al. Comprehensive geriatric assessment for older adults admitted to hospital. Cochrane Database Syst Rev 2017 Sep 12;9(9):CD006211. [doi: 10.1002/14651858.CD006211.pub3] [Medline: 28898390]
5. Gupta S, Perry JA, Kozar R. Transitions of care in geriatric medicine. Clin Geriatr Med 2019 Feb;35(1):45-52. [doi: 10.1016/j.cger.2018.08.005] [Medline: 30390983]
6. Becker C, Rapp K, Rothenbacher D, Schulz C, König HH, Büchele G. Acute care models for hip fracture treatment vs post-acute rehabilitation services in older adults after hip fracture: a comparative claims data analysis from Germany. J Rehabil Med 2020 Feb 27;52(2):jrm00024. [doi: 10.2340/16501977-2630] [Medline: 31748818]
7. Brunn M, Kratz T, Padget M, Clément MC, Smyrl M. Why are there so many hospital beds in Germany? Health Serv Manage Res 2023 Feb;36(1):75-81. [doi: 10.1177/09514848221080691]
8. Song Z, Ferris TG. Baby boomers and beds: a demographic challenge for the ages. J Gen Intern Med 2018 Mar;33(3):367-369. [doi: 10.1007/s11606-017-4257-x] [Medline: 29273896]
9. Rapp K, Becker C, Todd C, et al. The association between orthogeriatric co-management and mortality following hip fracture. Dtsch Arztebl Int 2020 Jan 24;117(4):53-59. [doi: 10.3238/arztebl.2020.0053] [Medline: 32036854]
10. Lester PE, Dharmarajan TS, Weinstein E. The looming geriatrician shortage: ramifications and solutions. J Aging Health 2020 Oct;32(9):1052-1062. [doi: 10.1177/0898264319879325] [Medline: 31583940]
11. Leinert C, Fotteler M, Kocar TD, et al. Supporting SURgery with GEriatric Co-Management and AI (SURGE-Ahead): a study protocol for the development of a digital geriatrician. PLoS One 2023;18(6):e0287230. [doi: 10.1371/journal.pone.0287230] [Medline: 37327245]
12. Amann J, Blasimme A, Vayena E, Frey D, Madai VI, Precise4Q consortium. Explainability for artificial intelligence in healthcare: a multidisciplinary perspective. BMC Med Inform Decis Mak 2020 Nov 30;20(1):310. [doi: 10.1186/s12911-020-01332-6] [Medline: 33256715]
13. Farhud DD, Zokaei S. Ethical issues of artificial intelligence in medicine and healthcare. Iran J Public Health 2021 Nov;50(11):i-v. [doi: 10.18502/ijph.v50i11.7600] [Medline: 35223619]
14. Skuban-Eiseler T, Orzechowski M, Denkinger M, Kocar TD, Leinert C, Steger F. Artificial intelligence-based clinical decision support systems in geriatrics: an ethical analysis. J Am Med Dir Assoc 2023 Sep;24(9):1271-1276. [doi: 10.1016/j.jamda.2023.06.008] [Medline: 37453451]
15. Lagerin A, Törnkvist L, Fastbom J, Lundh L. District nurses' experiences of using a clinical decision support system and an assessment tool at elderly care units in primary health care: a qualitative study. Prim Health Care Res Dev 2021;22:1-7. [doi: 10.1017/S1463423621000530]

16. Rajpurkar P, Chen E, Banerjee O, Topol EJ. AI in health and medicine. Nat Med 2022 Jan;28(1):31-38. [doi: 10.1038/s41591-021-01614-0] [Medline: 35058619]
17. Sutton RT, Pincock D, Baumgart DC, Sadowski DC, Fedorak RN, Kroeker KI. An overview of clinical decision support systems: benefits, risks, and strategies for success. NPJ Digit Med 2020;3(1):17. [doi: 10.1038/s41746-020-0221-y] [Medline: 32047862]
18. Carroll C, Marsden P, Soden P, Naylor E, New J, Dornan T. Involving users in the design and usability evaluation of a clinical decision support system. Comput Methods Programs Biomed 2002 Aug;69(2):123-135. [doi: 10.1016/s0169-2607(02)00036-6] [Medline: 12100792]
19. Beauchamp TL, Childress JF. Principles of Biomedical Ethics, 5th edition: Oxford University Press; 2001.
20. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014 Sep;89(9):1245-1251. [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
21. Orzechowski M, Timmermann C, Woniak K, et al. Access to prenatal testing and ethically informed counselling in Germany, Poland and Russia. J Pers Med 2021 Sep 20;11(9):937. [doi: 10.3390/jpm11090937] [Medline: 34575714]
22. Baumann A, Salloch S, Schildmann J, Vollmann J. Empirische methoden in der medizinethik. Empirical methods in medical ethics. In: Empirische Medizinethik: Konzepte, Methoden Und Ergebnisse. Empirical Medical Ethics: Concepts, Methods and Results: LIT Verlag Münster; 2011:25-44.
23. Kuckartz U. Einführung in Die Computergestützte Analyse Qualitativer Daten. Introduction to Computer-Assisted Analysis of Qualitative Data: VS Verlag für Sozialwissenschaften Wiesbaden; 2010.
24. Mayring P. Einführung in Die Qualitative Sozialforschung Eine Anleitung Zu Qualitativem Denken 5, Überarb Und Neu Ausgestattete Aufl. Introduction to Qualitative Social Research A Guide to Qualitative Thinking: Beltz Verlag; 2016.
25. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs Health Sci 2013 Sep;15(3):398-405. [doi: 10.1111/nhs.12048]
26. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
27. Zink K, Clugston C, Regan L. Hopes and fears: a qualitative analysis of the intern perspective at the start of EM residency. AEM Educ Train 2022 Jun;6(3):e10764. [doi: 10.1002/aet2.10764] [Medline: 35774535]
28. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19(6):349-357. [doi: 10.1093/intqhc/mzm042]
29. Avendano JP, Gallagher DO, Hawes JD, et al. Interfacing with the electronic health record (EHR): a comparative review of modes of documentation. Cureus 2022 Jun;14(6):e26330. [doi: 10.7759/cureus.26330] [Medline: 35911305]
30. Budd J. Burnout related to electronic health record use in primary care. J Prim Care Community Health 2023 Jan;14. [doi: 10.1177/21501319231166921]
31. Horsky J, Schiff GD, Johnston D, Mercincavage L, Bell D, Middleton B. Interface design principles for usable decision support: a targeted review of best practices for clinical prescribing interventions. J Biomed Inform 2012 Dec;45(6):1202-1216. [doi: 10.1016/j.jbi.2012.09.002] [Medline: 22995208]
32. Knop M, Weber S, Mueller M, Niehaves B. Human factors and technological characteristics influencing the interaction of medical professionals with artificial intelligence-enabled clinical decision support systems: literature review. JMIR Hum Factors 2022 Mar 24;9(1):e28639. [doi: 10.2196/28639] [Medline: 35323118]
33. Miller K, Mosby D, Capan M, et al. Interface, information, interaction: a narrative review of design and functional requirements for clinical decision support. J Am Med Inform Assoc 2018 May 1;25(5):585-592. [doi: 10.1093/jamia/ocx118]
34. Baxter R, Shannon R, Murray J, et al. Delivering exceptionally safe transitions of care to older people: a qualitative study of multidisciplinary staff perspectives. BMC Health Serv Res 2020 Aug 24;20(1):780. [doi: 10.1186/s12913-020-05641-4] [Medline: 32831038]
35. Asif M, Cadel L, Kuluski K, Everall AC, Guilcher SJT. Patient and caregiver experiences on care transitions for adults with a hip fracture: a scoping review. Disabil Rehabil 2020 Dec;42(24):3549-3558. [doi: 10.1080/09638288.2019.1595181] [Medline: 31081400]
36. Ellis G, Sevdalis N. Understanding and improving multidisciplinary team working in geriatric medicine. Age Ageing 2019 Jul 1;48(4):498-505. [doi: 10.1093/ageing/afz021] [Medline: 30855656]
37. Wirtz D, Kohlhof H. The geriatric patient: special aspects of peri-operative management. EFORT Open Rev 2019 Jun;4(6):240-247. [doi: 10.1302/2058-5241.4.180087] [Medline: 31210966]
38. Simple and efficientdischarge management. Recare. URL: https://recaresolutions.com/ [accessed 2024-02-10]
39. Amann J, Vetter D, Blomberg SN, et al. To explain or not to explain?—Artificial intelligence explainability in clinical decision support systems. PLOS Digit Health 2022;1(2):e0000016. [doi: 10.1371/journal.pdig.0000016]
40. Grote T, Berens P. On the ethics of algorithmic decision-making in healthcare. J Med Ethics 2020 Mar;46(3):205-211. [doi: 10.1136/medethics-2019-105586] [Medline: 31748206]
41. Prictor M. Where does responsibility lie? Analysing legal and regulatory responses to flawed clinical decision support systems when patients suffer harm. Med Law Rev 2023 Feb 27;31(1):1-24. [doi: 10.1093/medlaw/fwac022] [Medline: 35856156]

42. Tu T, Palepu A, Schaekermann M, et al. Towards conversational diagnostic AI. arXiv. Preprint posted online on Jan 11, 2024 URL: http://arxiv.org/abs/2401.05654 [accessed 2024-12-12] [doi: 10.48550/arXiv.2401.05654]
43. Myskja BK, Steinsbekk KS. Personalized medicine, digital technology and trust: a Kantian account. Med Health Care Philos 2020 Dec;23(4):577-587. [doi: 10.1007/s11019-020-09974-z] [Medline: 32888101]
44. Lorenzini G, Arbelaez Ossa L, Shaw DM, Elger BS. Artificial intelligence and the doctor-patient relationship expanding the paradigm of shared decision making. Bioethics 2023 Jun;37(5):424-429. [doi: 10.1111/bioe.13158] [Medline: 36964989]
45. Seifert A, Cotten SR, Xie B. A double burden of exclusion? Digital and social exclusion of older adults in times of COVID-19. J Gerontol B Psychol Sci Soc Sci 2021 Feb 17;76(3):e99-e103. [doi: 10.1093/geronb/gbaa098] [Medline: 32672332]
46. Orzechowski M, Skuban-Eiseler T, Ajlani A, Lindemann U, Klenk J, Steger F. User perspectives of geriatric German patients on smart sensor technology in healthcare.. Sensors (Basel) 2023 Nov 11;23(22):9124. [doi: 10.3390/s23229124] [Medline: 38005512]
47. Kilbride MK, Joffe S. The new age of patient autonomy: implications for the patient-physician relationship. JAMA 2018 Nov 20;320(19):1973-1974. [doi: 10.1001/jama.2018.14382] [Medline: 30326026]
48. Blanes-Selva V, Doñate-Martínez A, Linklater G, Garcés-Ferrer J, García-Gómez JM. Responsive and minimalist app based on explainable AI to assess palliative care needs during bedside consultations on older patients. Sustainability 2021;13(17):9844. [doi: 10.3390/su13179844]
49. Ho A. Are we ready for artificial intelligence health monitoring in elder care? BMC Geriatr 2020 Sep 21;20(1):358. [doi: 10.1186/s12877-020-01764-9] [Medline: 32957946]
50. Lukkien DRM, Nap HH, Buimer HP, et al. Toward responsible artificial intelligence in long-term care: a scoping review on practical approaches. Gerontologist 2023 Jan 24;63(1):155-168. [doi: 10.1093/geront/gnab180] [Medline: 34871399]
51. Wager TD, Atlas LY. The neuroscience of placebo effects: connecting context, learning and health. Nat Rev Neurosci 2015 Jul;16(7):403-418. [doi: 10.1038/nrn3976] [Medline: 26087681]
52. Lambert SI, Madi M, Sopka S, et al. Author correction: an integrative review on the acceptance of artificial intelligence among healthcare professionals in hospitals. NPJ Digit Med 2023;6(1):125. [doi: 10.1038/s41746-023-00874-z]
53. Bednorz A, Mak JKL, Jylhävä J, Religa D. Use of electronic medical records (EMR) in gerontology: benefits, considerations and a promising future. Clin Interv Aging 2023;18:2171-2183. [doi: 10.2147/CIA.S400887] [Medline: 38152074]
54. Higgins D, Madai VI. From bit to bedside: a practical framework for artificial intelligence product development in healthcare. Adv Intell Syst 2020 Oct;2(10):1-14. [doi: 10.1002/aisy.202000052]
55. Renn BN, Schurr M, Zaslavsky O, Pratap A. Artificial intelligence: an interprofessional perspective on implications for geriatric mental health research and care. Front Psychiatry 2021;12:734909. [doi: 10.3389/fpsyt.2021.734909] [Medline: 34867524]
56. Langhorne P, Ramachandra S. Organised inpatient (stroke unit) care for stroke: network meta-analysis. Cochrane Database Syst Rev 2020 Apr 23;4(4):CD000197. [doi: 10.1002/14651858.CD000197.pub4] [Medline: 32324916]
57. Lowe A, Norris AC, Farris AJ, Babbage DR. Quantifying thematic saturation in qualitative data analysis. Field methods 2018 Aug;30(3):191-207. [doi: 10.1177/1525822X17749386]

Abbreviations

AI: artificial intelligence
AI-CDSS: artificial intelligence–enhanced clinical decision support system
CDSS: clinical decision support system
COC: continuity of care
COREQ: Consolidated Criteria for Reporting Qualitative Research
EHR: electronic health record
HIS: hospital information system

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Corrigenda and Addenda

Correction: Detecting Anomalies in Daily Activity Routines of Older Persons in Single Resident Smart Homes: Proof-of-Concept Study

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Related Article:

Correction of: https://aging.jmir.org/2022/2/e28260

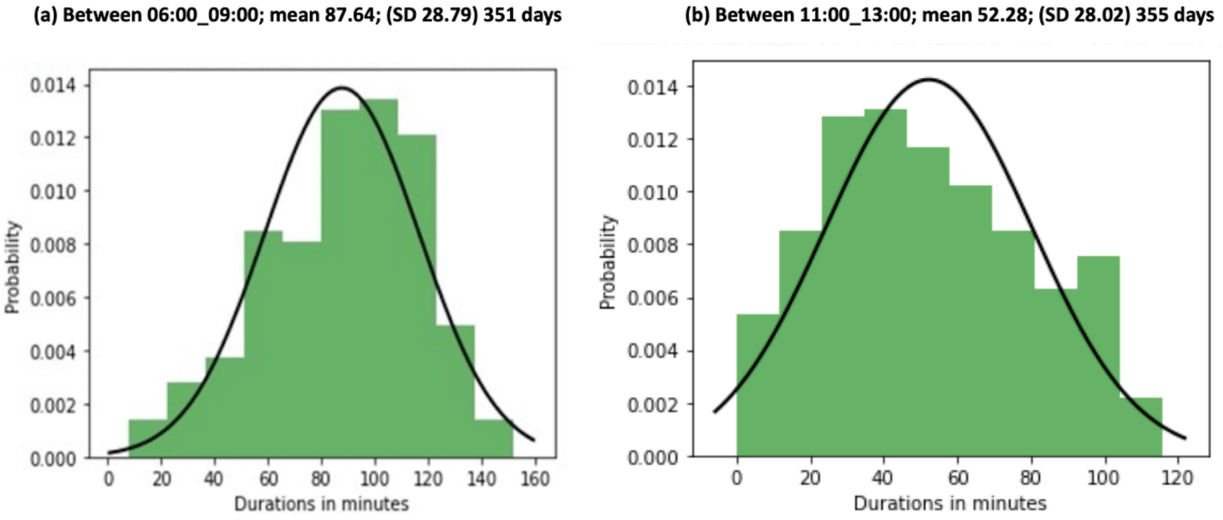
(JMIR Aging 2024;7:e58394) doi:10.2196/58394

In Detecting Anomalies in Daily Activity Routines of Older Persons in Single Resident Smart Homes: Proof-of-Concept Study (JMIR Aging 2022;5(2):e28260), the authors noticed one error.

In the orinally published article, a duplication error occured in Figure 5. The original Figure can be viewed in Multimedia Appendix 1.

Figure 5 has been corrected as follows:

Figure 5. Probability distribution with mean (SD) for 351 days in the kitchen between (a) 6:00 and 9:00 and (b) 11:00 and 13:00 in apartment 1.



(a) Between 06:00_09:00; mean 87.64; (SD 28.79) 351 days

(b) Between 11:00_13:00; mean 52.28; (SD 28.02) 355 days

The correction will appear in the online version of the paper on the JMIR Publications website on April 30, 2024, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

Multimedia Appendix 1
Originally published Figure 5.
[PNG File , 165 KB - aging_v7i1e58394_app1.png]

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Original Paper

Social Media Programs for Outreach and Recruitment Supporting Aging and Alzheimer Disease and Related Dementias Research: Longitudinal Descriptive Study

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Abstract

Background: Social media may be a useful method for research centers to deliver health messages, increase their visibility in the local community, and recruit study participants. Sharing examples of social media–based community outreach and educational programs, and evaluating their outcomes in this setting, is important for understanding whether these efforts have a measurable impact.

Objective: The aim of this study is to describe one center’s social media activities for community education on topics related to aging, memory loss, and Alzheimer disease and related dementias, and provide metrics related to recruitment into clinical research studies.

Methods: Several social media platforms were used, including Facebook, X (formerly Twitter), and YouTube. Objective assessments quantified monthly, based on each platform’s native dashboard, included the number of followers, number of posts, post reach and engagement, post impressions, and video views. The number of participants volunteering for research during this period was additionally tracked using a secure database. Educational material posted to social media most frequently included content developed by center staff, content from partner organizations, and news articles or resources featuring center researchers. Multiple educational programs were developed, including social media series, web-based talks, Twitter chats, and webinars. In more recent years, Facebook content was occasionally boosted to increase visibility in the local geographical region.

Results: Up to 4 years of page metrics demonstrated continuing growth in reaching social media audiences, as indicated by increases over time in the numbers of likes or followers on Facebook and X/Twitter and views of YouTube videos (growth trajectories). While Facebook reach and X/Twitter impression rates were reasonable, Facebook engagement rates were more modest. Months that included boosted Facebook posts resulted in a greater change in page followers and page likes, and higher reach and engagement rates (all $P \leq .002$). Recruitment of participants into center-affiliated research studies increased during this time frame, particularly in response to boosted Facebook posts.

Conclusions: These data demonstrate that social media activities can provide meaningful community educational opportunities focused on Alzheimer disease and related dementias and have a measurable impact on the recruitment of participants into research studies. Additionally, this study highlights the importance of tracking outreach program outcomes for evaluating return on investment.

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KEYWORDS

education; social media; outreach; recruitment; Alzheimer’s disease; Alzheimer disease

Introduction

With the aging of the population, the number of individuals living with dementia globally is expected to triple by 2050 [1]. Disseminating reliable information on topics related to healthy aging and Alzheimer disease and related dementias (ADRD) is particularly important given modifiable lifestyle factors may play a role in dementia risk reduction [2], receiving an early diagnosis requires identifying the signs and symptoms of memory loss, and persons and families affected by dementia may benefit from information about ADRD. Connecting the public with education and resources related to these topics is aligned with national and international initiatives that emphasize the importance of healthy aging, dementia awareness, risk reduction, diagnosis and services, and caregiver support [3,4]. Social media content aimed at older adults may provide a mechanism for sharing resources, research findings, and available services related to healthy aging and ADRD. Social media may also generate increased interest in research participation, in addition to the in-person approaches that have been used for many years.

Research centers specializing in aging and ADRD use several approaches for community outreach, education, and volunteer recruitment for research studies. This includes a variety of in-person events, such as providing educational presentations in the community, hosting resource tables at community events, and organizing conferences in collaboration with community organizations, among others. Centers also use a range of web-based activities including newsletters, websites, and social media platforms such as Facebook, X (formerly Twitter), YouTube, and Instagram. While social media may be a potentially important method of delivering health messaging and recruitment [5], the types of activities used, and the outcomes of social media outreach efforts, are not well understood.

Social media has become a primary source of information for the general public hoping to “seek and share health-related information” [6]. Recent estimates indicate that 73% of middle-aged and 45% of older adults in the United States use social media, with Facebook and YouTube being two of the most common among these age groups [7,8]. This suggests that key age demographics for messaging may be reached through social media, providing a platform for research centers to become trusted web-based sources of information on topics related to healthy aging and memory loss, ADRD, and caregiving in their local communities.

Studies incorporating social media activities into community outreach and recruitment in the context of aging and memory loss have covered a broad range of topics. For example, studies have examined the role of social conversations in providing advice related to cognitive decline [9]; described social media activities in targeted dementia awareness campaigns [10-12]; and evaluated the use of social media advertisements to drive traffic to educational resources [13] or to recruit into aging or ADRD research studies [14-16]. Moreover, prior research has demonstrated the feasibility of using a digital community-engaged research approach (which included a social media component) for reaching individuals from racially diverse backgrounds [17]. More broadly, studies analyzing dementia content on social media have also suggested that these platforms have the potential to deliver health information on this topic, raising awareness and facilitating communication with the public [18-20].

Prior studies in this area have not, to our knowledge, described aging and memory loss educational programs across multiple social media platforms and reported on their impact on research recruitment. To address this gap, this study describes the social media approaches, aimed at community outreach and education related to aging and ADRD, implemented by one research center. Importantly, the objective was not to compare social media to other approaches but to describe the social media activities implemented to date and evaluate the outcomes of these activities using up to 4 years of metrics, including success in reaching members of the community and impact on recruitment.

Methods

Overview

The Johns Hopkins Alzheimer’s Disease Research Center (JHADRC) has used 3 social media platforms over the past 4 years: Facebook, Twitter (rebranded as X in 2023), and YouTube. Each platform was launched with a different set of goals.

Facebook

The primary goal of the *Johns Hopkins Memory & Aging* Facebook page is to provide education and resources, as well as information about community events and research opportunities, related to healthy aging, brain health, memory loss, and dementia. The content primarily targets members of the community and community partners. Content is posted to this page 3-5 times per week. This page was launched in January 2019.

Twitter

The goals of the *Johns Hopkins Memory & Aging* Twitter account are 3-fold. The first goal is consistent with those of the Facebook page: to provide education, resources, and information about community events and research opportunities related to healthy aging, brain health, memory loss, and dementia. This includes promoting the visibility of Johns Hopkins (JH) aging and ADRD researchers, clinicians, and staff. The second goal is to serve as an information hub for local aging and ADRD researchers by sharing academically focused content such as recent research publications, information about social determinants of health for underserved populations (eg, Black Americans, Hispanics, and the LGBTQ+ community), funding and training opportunities, professional development opportunities, and upcoming conferences. Where possible, content is shared (ie, retweeted) through related JH Twitter accounts, such as the Center on Aging and Health and Geriatric Medicine and Gerontology, to expand views of the content. The third goal is to strategically network with community partners engaged in activities related to aging and ADRD. This includes making a concerted effort to share the events, activities, and accomplishments of these groups. Given these 3 broad goals, the target audience includes community audiences and community partners, as well as researchers and health professionals. A communications specialist spends approximately 1-3 hours per weekday identifying, sharing, and retweeting content of relevance to the abovementioned audiences, and approximately 6-8 hours monthly creating original content. This account was launched in July 2020.

Readers should note that the Facebook and Twitter pages are branded with the name *Johns Hopkins Memory & Aging*. This name was selected to be intentionally broad in order to demonstrate relevancy to topics related to aging, memory loss, and ADRD, and to resonate with the general public, particularly the target audience of middle-aged and older adults.

YouTube

The primary goal of the *Johns Hopkins ADRC* YouTube page is to serve as a repository for outreach content, including center-produced resources, recordings of web-based community outreach events, and activities developed in collaboration with the JHADRC's community advisory board, known as the Memory and Aging Community Advisory Board (MACAB). The page primarily targets members of the community, with content uploaded as needed. This page was launched in October 2020.

All social media pages are overseen by members of the JHADRC's Outreach, Recruitment, and Engagement (ORE) Core. The ORE Core worked with the Johns Hopkins Medicine Strategic Marketing and Outreach team to set up the page and get approval for the use of the institutional name. The web-based recruitment materials of the JHADRC were approved by the Johns Hopkins Medicine institutional review board (IRB).

Description of Content

The majority of content shared through the Facebook and Twitter pages highlights topics broadly related to ADRD, consistent with the goals of these pages. This includes educational content related to healthy aging, brain health, and risk factors for memory loss; information about Alzheimer disease and other types of dementia; resources for caregivers; information about clinical research and research findings; social determinants of health; and local events of relevance to these topics (both our own and those of our community partners). During the first year of the COVID-19 pandemic, many posts included COVID-19–related health and support resources.

The shared information includes content developed by JH staff (described below) and content from external sources such as news articles, website pages, infographics, and blog posts from trusted outlets. For example, we frequently share content from the National Institute on Aging, the Alzheimer's Association, our local Alzheimer's Association Chapter, the American Association of Retired Persons (AARP), a website known as MindCrowd, and major news outlets. We also make a concerted effort to share news articles and web-based resources that quote or feature JH staff, researchers, or clinicians, as well as materials that highlight recent research findings from studies that include JH researchers. As noted above, our Twitter page also shares content of relevance to academic audiences and health professionals, such as funding and conference announcements and professional development opportunities.

Internally Developed Social Media Content and Programs

Social Media Series

To date, we have developed 3 educational series consisting of a collection of posts on specific topics, including general information about AD, brain health, and research awareness (see Table 1 for details). Posts within each series are branded with a hashtag, allowing the topic to be indexed and searchable on social media platforms. Although developing a series of posts requires time up-front, the approach provides a library of original content that can be released over several months or more, and are available to be reposted in the future. This also allows for content to undergo IRB review prior to use if needed (eg, Research Awareness Series). Having prepared content on-hand has been particularly helpful given the multiple responsibilities that compete for staff effort.

Table 1. Overview of social media series about aging and ADRD[a].

Series name (social media hashtag)	Goal of content and distribution timeline	Description of content	Posts, n
Alzheimer's awareness series (#JHAlzAwareness)	• Increase awareness of AD[b] • Developed and posted in 2020; some content reposted 2021 and 2022	Two categories of content: (1) education about AD (eg, definitions, prevalence, signs and symptoms, stages, effect on the brain, and importance of research) and (2) risk factors and symptom management (eg, risk factors, risk reduction, genetics, diagnosis, treatments, and caregiving)	31
Brain health series (#JHBrainHealthMatters)	• Share expert recommendations and practical tips from the reports developed by the AARP's[c] Global Council on Brain Health • Developed and posted in 2020; plans to repost some content in future	Content and infographics from Global Council on Brain Health reports: (1) The Brain-Sleep Connection; (2) The Brain-Body Connection; (3) Engage Your Brain; (4) Music on Our Minds; (5) The Brain-Heart Connection; (6) Brain Food; (7) The Real Deal on Brain Health Supplements; (8) Preserving Your Brain Health During Illness or Surgery; (9) Brain Health and Mental Well-Being; and (10) The Brain and Social Connectedness	89 (7-10 posts per topic)
Research awareness series (#JHMemoryResearch)	• Increase awareness of the importance of memory loss research and ongoing research activities to facilitate recruiting participants into JHADRC[d]-affiliated research studies • Developed in 2021, posted 2022-2023	Topics covered: (1) goals of research and different types of research studies (observational, interventions, or clinical trials); (2) examples of research procedures and what's learned (eg, brain imaging and fluid biomarkers); (3) importance of diversity in research; (4) examples of JHADRC-affiliated research studies; (5) benefits of research participation; (6) participant, staff, and researcher spotlights; (7) study recruitment flyers	86

[a] ADRD: Alzheimer disease and related dementias.

[b] AD: Alzheimer disease.

[c] AARP: American Association of Retired Persons.

[d] JHADRC: Johns Hopkins Alzheimer's Disease Research Center.

Web-Based Talks About Memory Loss and Brain Health on Social Media

We have developed brief web-based presentations designed to reach new audiences in the local community. Web-based presentations on the topics of memory loss ("What you should know about memory loss") or brain health ("A brain healthy lifestyle matters for healthy aging") are given by ORE Core Community Outreach Coordinators. Individuals register through Zoom and registrants must attend to receive the content (ie, presentations are not recorded). One week prior to the presentation date, modest funds (US $30-US $150) are used to boost the post on Facebook, targeting middle-aged and older adults in the Greater Baltimore area. These presentations, organized approximately every quarter, have been advertised 11 times to date, at various times of day (eg, noon "lunch & learn"; evening "dinner table discussion"). Typically, more individuals register than actually attend. On average, 19 individuals, representing approximately 25% of those registered, attend each presentation.

Educational Videos Posted to YouTube

A web-based talk series, titled *Memory Matters*, was developed to provide brief research updates on topics related to aging, memory loss, and ADRD. These approximately 15-minute presentations are designed to share recent research findings that may be of particular interest to lay audiences, such as sleep, hearing loss, and physical activity (see the " Growth Trajectories and Page Visibility" section for details). To ensure that the presentations are targeted to a lay audience, presenters are asked to include an overview slide, make their slide content as simple and clear as possible, include a summary slide that recaps main points, conclude with actionable takeaway messages, and share publicly available resources. They also receive a document entitled "Tips and Examples for Effective Science Communication to a Lay Audience." Presenters are given a template for the first and last slide to provide uniformity to the talks within the series. To date, these talks have been given by junior faculty who are given feedback in advance of the video recording by center faculty (CP and MA). Thus, this talk series also provides an opportunity for science communication mentorship to junior investigators, including guidance on effectively communicating complex scientific topics with lay audiences. Talks within this series are branded with the hashtag #JHMemoryMatters. Once recorded and edited, they are posted to YouTube and the JHADRC website and shared through Facebook and Twitter.

A *Community Views* (#CommunityViews) web-based interview series features short (6-7 minutes) one-on-one interviews with members of the community. The goal of these videos is to provide members of the lay community an opportunity to advocate for topics of personal importance to them. Members of the JHADRC ORE Core work with the interviewee to collaboratively develop a set of interview questions, as well as a short set of slides to support the interview content and provide uniformity to the talks within the series. Once recorded and edited, the interviews are posted on YouTube and shared through Facebook and Twitter. To date, the interviews have been with members of the MACAB. Two interviews have been recorded: the first on the importance of educating the youth about dementia and the second on empowering older adults and caregivers to maintain their brain through physical activity and self-care. These programs are ongoing.

Twitter Chats and Webinars

A series of Twitter chats and webinars have been developed to promote the goals of a coalition of stakeholders in the brain health and dementia community. This collaboration consists of 2 research centers internal to Johns Hopkins University (the JHADRC and the Johns Hopkins Alzheimer's Disease Resource Center for Minority Aging Research), as well as external partners including the Global Council on Brain Health convened by the American Association of Retired Persons, the Greater Maryland Chapter of the Alzheimer's Association, and 2 strategically targeted audience stakeholder organizations, both local alumnae chapters of the Delta Sigma Theta Sorority, Inc. Branded as #BrainMatters, the goal has been to develop dialog, engagement, and educational programs for sharing evidence-based information about brain health, health disparities, memory loss, and ADRD at the grassroots level. This approach aligns with the recognized importance of developing equitable community partnerships for reaching individuals from diverse backgrounds [5].

Prior to each scheduled event, the program organizers communicate via email and meet virtually (typically 3-5 times) to make collaborative decisions about program timing, format, content, and invited participants. For Twitter chats, this involves identifying the specific questions to be sequentially asked during the scheduled web-based conversation; questions are answered by both invited guests and the Twitter users at large. For webinars, this involves deciding on the topic and event flow (eg, speaker presentations vs moderated conversations). To date, Twitter chat topics have included (1) brain health, (2) achieving brain health equity, and (3) the state of research on memory loss and dementia, and webinar topics have included (4) dementia caregiving and caregivers and (5) the relationship between community, social connection, and cognitive decline. Event promotion occurs predominantly on Twitter (which allows us to tag guest speakers) and Facebook, and is shared by the coalition's stakeholders. The product of the Twitter chats remains on Twitter indefinitely as a resource to the public, and webinars have been recorded and uploaded to YouTube, thus, generating a marketable product that can also be shared after the event. In 2023, the #BrainMatters leadership made the decision to pivot toward webinars over Twitter chats, as it was determined that this format would better reach the target audiences.

Overarching Strategies

Research Recruitment

When the Facebook and Twitter accounts were first launched, we strategically decided not to emphasize clinical research recruitment (eg, study flyers, information about ongoing studies). Our goal was to first build a modest base of followers and develop a presence as a source of information before discussing research participation. Information about ongoing clinical research studies was not consistently posted until approximately 3 years after the Facebook page was launched. To date, this has been accomplished primarily through our Research Awareness Series (described above and in Table 1).

Diversity and Inclusion

We take care to ensure the visuals we post are representative of individuals from diverse communities. This includes evaluating the pictures posted in association with existing website links, as well as making a concerted effort to ensure that stock photos reflect individuals from diverse racial and ethnic backgrounds.

Boosting Facebook Posts

We have boosted occasional Facebook posts to increase the reach of our content and enhance the local visibility of our efforts, our Facebook page, and our center more broadly. This involves paying Facebook to more prominently display specific posts in users' feeds. To help reach new local audiences who may be interested in our content, boosted posts targeted middle-aged and older adults (eg, 55 years and older) in the Greater Baltimore area (ie, approximately 25- to 50-mile radius of Baltimore, MD) using the Age and Locations fields of Meta Business Suite's Boost Post settings. This strategy relied on Meta's "Audience" settings, which allow users to define who will see their advertised posts by targeting audiences whose profiles match specific characteristics, such as demographics. Each time content is boosted, we make a concerted effort to invite individuals who like the posts to like or follow our Facebook page, to help expand our followership. Boosted content has most frequently included talks on social media, as well as posts from our educational series (eg, the Research Awareness Series) and information about center-organized events (eg, the MACAB's Annual Holistic Health Seminar on Memory Loss). To date, our expenditures have been modest, ranging from US $30 to US $200 per boosted post. In years 2 and 3, we boosted 1 post approximately every other month; from year 4 onwards, we boosted 1 post almost every month.

Measures and Outcomes

In order to track our social media activities, at the start of each new month, members of the ORE Core record metrics from the prior month using data from each platform's native analytics dashboards.

For Facebook, the following metrics were tracked through the Meta Business Suite's Professional Dashboard: number of posts made during the month; the average reach of that month's posts, reflecting the number of people who saw that month's post at least once (calculated as the total [sum] reach of all posts within the month divided by the total number of posts); and the average engagement with that month's posts, reflecting the number of times people engaged with that month's posts through reactions, comments, shares, and clicks (calculated as the total [sum] engagement with that month's posts divided by the total number of posts). Note that all posts within a given month were included in these monthly analytics; therefore, the data reflect both organic and paid reach and engagement. The number of page likes and page followers was additionally recorded. Facebook metrics were missing for 2 months in year 2.

For Twitter, the following metrics were tracked through Twitter's monthly Analytics report: number of Tweets; Tweet impressions, reflecting the number of times that month's Tweets were displayed to users; profile visits; mentions; and new followers. The number of account followers and the number of accounts that we follow were additionally recorded. Two Twitter metrics (the number of account followers and the number of accounts we follow) were missing for 5 months in year 1, 2 months in year 2, and 2 months in year 3.

In this report, we summarize metrics for both Facebook and Twitter. This includes monthly data on the number of likes and followers to assess page growth trajectories (presented in 6-month intervals), which has previously been described as an indicator of success [5]. Monthly metrics were additionally used to calculate average reach rates and average engagement rates for Facebook, and average impression rates for Twitter. These were calculated by dividing each month's average reach, average engagement, or average impressions by that month's total number of page followers, then multiplying the quotient by 100. Annual reach, engagement, and impression rates were calculated for all years (excluding year 1) by averaging over all available months within a year, for year 2 onwards. Year 1 metrics were excluded because they appear inflated due to high engagement from a limited number of followers, as the pages were being established and accruing audiences. Note that the analytics for posts made at the end of the month may be slightly underestimated, given posts may have received continued views after the data were recorded. For videos posted to YouTube, we report the number of views over time.

The number of individuals who expressed interest in participating in research after engaging with our social media activities was tracked through a secure, web-based REDCap database hosted at Johns Hopkins [21,22]. This database is designed to track the outreach activities that result in recruitment, including how an individual learned about our studies, whether they were referred to a center-affiliated research study, and the outcomes of those referrals. Database entries that provide results related to social media come from 2 sources of information. The first reflects individuals who complete an IRB-approved "Participate in Research" webform on the JHADRC website and indicate on that form that they learned about us through social media. The second pertains to entries of individuals who contact us (eg, by phone) to express interest in research after viewing web-based programming, indicating that they learned about our programs through social media while completing their phone screen; these individuals were entered into the database by members of the ORE Core.

Statistical Analysis

The data reported below reflect outcomes and metrics between page launch (as noted by the dates above) and the time of manuscript writing (April 2023). Time-based outcomes (such as growth trajectories and video views) are reported as months since launch, to describe, for example, how long the content or programs have been available. Where relevant, continuous variables are summarized as mean (SD) and categorical data are summarized as n (%). Average annual reach, engagement, and impression rates are calculated as percentages (as described above), with differences between months with versus without boosted posts assessed by Mann-Whitney *U* tests. Analyses were run in SPSS (IBM Corp; version 29.0).

Social media data pertaining to this report are available by qualified investigators upon request to the corresponding author.

Ethical Considerations

The data for this report come from 2 recruitment procedures implemented by the JHADRC, both of which have been approved by the Johns Hopkins Medicine IRB (protocol NA_00045104). First, the JHADRC website includes a section labeled "Participate in Research." This section includes a web form that asks individuals interested in learning more about research to complete an electronic form. The first item on the webform asks that the individual respond "yes" or "no" to the following statement: "I understand that by submitting this form I am providing consent to be contacted about research studies related to aging and memory loss by staff affiliated with the Johns Hopkins Alzheimer's Disease Research Center, and that this information will be stored in a secure database." Second, members of the JHADRC also administer an IRB-approved phone screen, which includes questions similar to those in the web form. The first item on the phone screen includes the following statement "Before we begin, I should point out that the possible risk to your answering questions is that you will be revealing confidential information to us. We promise to keep all such information strictly confidential. You do not have to answer any questions that might make you uncomfortable. Your participation is voluntary. If you do not agree, this will not affect your care, if you are a patient at Johns Hopkins, in any way. If you are not interested, please let me know." The anonymized, group-level demographic data included in this study are based only on outcomes from individuals who responded "yes" to the statement at the beginning of the web form or completed the phone screen and indicated willingness to be contacted about research. Participants were not compensated for completing these optional forms and outcome data are reported in aggregate to protect participant privacy and confidentiality.

Results

Outcomes and Indicators of Success

Growth Trajectories and Page Visibility

Growth trajectories for our Facebook and Twitter pages are shown in Figure 1. Both accounts have demonstrated continued increases in the number of new followers since the account launch, suggesting that it takes years to build a modest audience. The total number of Facebook followers exceeds 500; this includes a clear uptick in the trajectory of Facebook page followers around 24 months when we started boosting occasional Facebook posts. Notably, months that include a boosted Facebook post resulted in a greater change in page followers and page likes (mean change in page followers 13.7, SD 9.2; mean change in page likes 19.0, SD 12.3), compared with months that did not include boosted posts (mean change in page followers 6.2, SD 4.5, *U*=294.5, *P*<.001; mean change in page likes 8.0, SD 5.0, *U*=285.0, *P*=.002), suggesting our efforts to invite individuals to like or follow the page were successful. The total number of Twitter followers exceeds 2000. Additionally, the talks within the *Memory Matters* web-based talk series have received over 3000 views, whereas views of the *Community Views* interviews have been less (Table 2); both of the #BrainMatters webinars hosted to date attracted >100 registrants with >50 individuals attending.

Average annual reach and engagement rates (Facebook) and average annual impression rates (Twitter) for year 2 onward are shown in Table 3. As anticipated, for Facebook, average reach and engagement rates were significantly higher for months that included boosted posts (mean reach rate 136.2%, SD 87%; mean engagement rate 10.7%, SD 6.1%) compared with months that did not include boosted posts (mean reach rate 34.7%, SD 26%, *U*=332.0, *P*<.001; mean engagement rate 5.1%, SD 4.3%, *U*=297.0, *P*<.001).

Figure 1. Growth trajectories in social media followers for Facebook (left; launched January 2019) and Twitter (right; launched July 2020), shown in 6-month intervals.

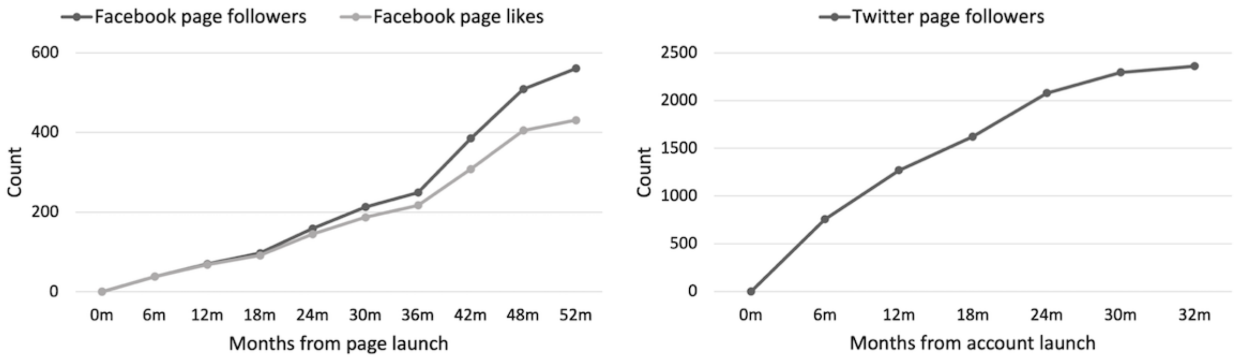

Table 2. Overview of educational videos posted to YouTube, including Memory Matters web-based talk series (#JHMemoryMatters) and Community Views (#CommunityViews) interview series.

Talk title	Months since launch, n	Views to date, n
***Memory Matters* web-based talk series**		
Dementia and cognitive decline: a brief overview	42	658
Vascular risk factors for cognitive decline and dementia	41	430
Changes in sleep and circadian rhythms in aging and memory loss	22	414
Hearing loss and dementia: what’s the connection?	17	1629
The importance of brain donation for Alzheimer’s disease and related disorders	5	90
Physical activity and cognitive health	1	74
***Community Views* interview series**		
Educating the youth about dementia	24	95
Empowering older adults and caregivers	3	35

Table 3. Visibility metrics over time for Facebook and Twitter. Values reflect mean (SD) and ranges.

Year[a]	Facebook				Twitter	
	Average annual reach rate		Average annual engagement rate		Average annual impression rate	
	Mean (SD), %	Range	Mean (SD), %	Range	Mean (SD), %	Range
All years (except year 1)	80.1 (79.1)	8.0-355.3	7.6 (5.8)	1.2-29.2	1260.3 (1076)	559.4-4152.9
Year 2	50.2 (30)	26.7-113.9	8.2 (4.7)	4.1-16.5	1564.9 (1319.6)	559.4-4152.9
Year 3	52.5 (37.7)	13.5-128.9	5.4 (2.7)	2.1-11.2	803.4 (195.6)	573.5-1141.6
Year 4	138.4 (111.4)	11.6-355.3	10 (8.3)	1.4-29.2	—[b]	—
Year 5	62.8 (61)	8.0-122.5	5.7 (5.3)	1.2-12.0	—	—

[a] Metrics exclude each platform's first year of data because these metrics appear inflated due to high engagement from a limited number of followers, as the pages were being established and accruing followers. For Facebook (launched in January 2019), year 2: January 2020-December 2020; year 3: January 2021-December 2021; year 4: January 2022-December 2022; year 5 (partial, n=4 months): January 2023-April 2023. For Twitter (launched in July 2020), year 2: August 2021-July 2021; year 3 (partial, n=8 months): August 2022-March 2023.

[b] Not available.

Research Recruitment Resulting From Social Media Activities

Social media activities have resulted in 89 individuals expressing interest in participating in center-affiliated clinical research studies over the past 2 years, the majority coinciding with boosted social media content (eg, posts from the #JHMemoryResearch series or web-based talks advertised on social media). This includes 76 individuals who indicated that they came to the JHADRC website after viewing social media content, when completing the "Participate in Research" website form (mean age 66.2, SD 10.4 years; 67/76, 88% female; 12/76, 16% self-reporting non-White race or Hispanic/Latino ethnicity). Of these, 46 (61%) have been referred to an ongoing research study, 22 (29%) were not referred, and 8 (11%) have phone screens pending (see Table 4 for additional details). In addition, 13 individuals expressed interest in participating in research after attending a web-based talk advertised on social media (mean age 64.3, SD 4.4 years; 13/13, 100% female; 3/13, 23% self-reporting non-White race). Of these, 12 (92%) have been referred to an ongoing research study; 1 (8%) was not referred (Table 4).

Table 4. Recruitment outcomes: breakdown of participant referrals for those expressing interest in participating in research after learning about the Johns Hopkins Alzheimer's Disease Research Center through social media activities.

	Webform indicates social media as a source for engagement (n=76), n (%)	Attended a social media-advertised web-based talk (n=13), n (%)
Referred to a center-affiliated research study		
Enrolled in a center-affiliated research study	6 (8)	5 (38)
Enrollment pending (referral sent, outcome pending)	26 (34)	6 (46)
Not enrolled (eg, ineligible; study coordinator unable to contact)	9 (12)	1 (8)
Referred to another ADRC or online registries (eg, lives out of state; unable to travel)	5 (7)	0 (0)
Not referred to a center-affiliated research study		
Phone screen pending	8 (11)	0 (0)
Contacted but no longer interested	3 (4)	1 (8)
Unable to contact	19 (25)	0 (0)

Discussion

Principal Findings

This study describes one center's social media strategy for community outreach and recruitment. Four years of page metrics and recruitment data suggest that the content and programs provide educational resources, increase the visibility of the center's activities, and result in the recruitment of participants into center-affiliated research studies.

Given the increased use of social media among middle-aged and older adults, these platforms can serve as one method by which the JHADRC provides reliable education and resources to members of the local community, networks (on the web) with local community organizations, and shares information about the important work (research studies, research findings, events, etc) being done by center-affiliated faculty and staff. Based on these data, it appears that these efforts, including boosting occasional Facebook posts, have increased the visibility of the JHADRC in the local geographic area and have provided opportunities to reach individuals who we may not have encountered through in-person community outreach. Importantly, these activities can be achieved primarily through staff time, with minimal additional cost to center budgets. Using creative digital approaches to serve as a public source of reliable information on topics related to aging, memory loss, and ADRD provides an additional opportunity for centers to meet critical community engagement goals, including building trust and creating better communication with members of the community [23,24].

These findings also demonstrate that social media activities have been a source of participant recruitment. Potential participants (ie, middle-aged and older adults) learned about our research program through social media–advertised talks as well as social media post content, including our Research Awareness Series. This allowed us to increase the number of participant referrals to center-affiliated studies, supporting the promise of social media as a low-cost method of recruiting potential research participants [16,25,26]. Additional follow-up is needed to determine whether these participants have different demographics and retention characteristics than individuals recruited through in-person community outreach or other activities.

Our evidence suggests that innovative social media activities can also provide novel opportunities for the scientific community. For example, although our web-based *Memory Matters* talk series was primarily designed to share recent research findings with the lay community, it simultaneously provided professional development opportunities. Through this series, junior investigators receive mentorship on the principles and importance of science communication, specifically communicating science-related topics with the public [27,28]. Engaging staff and investigators in the development of social media content, such as writing accessible descriptions of their research programs and findings, can also provide science communication opportunities. This highlights an additional possible benefit of social media for centers or programs that may be considering whether to develop a social media presence or those exploring ways in which they might expand their programming.

Moreover, providing education and resources for adults in the local community, including individuals living with cognitive impairment and caregivers, is in alignment with international efforts promoting healthy aging, ADRD education and support, and dementia risk reduction [3,4]. While most of our educational content to date focused on these broad topics, future content could include materials that address ageism and ableism, and promote age-friendly [29] and dementia-friendly [30] activities and resources that ensure inclusive environments, empowerment, and sustained engagement with issues related to age and disease.

Limitations

This study has limitations. First, this is a retrospective account of one center's social media activities and their outcomes, and the number of individuals following the social media pages is still modest. Additional work is needed to understand the long-term impact of these activities on community education, center visibility, and clinical research recruitment, and to evaluate the types of content that lead individuals to express interest in participating in center-affiliated research studies. Second, we do not have data on the demographics of our social media followers to evaluate whether our content reached the target audience or the extent to which we are reaching individuals living with cognitive impairment. However, the recruitment metrics indicate that those expressing interest in participating in research were in the target age range. Social media and internet use is reportedly lower among the oldest-old, as well as individuals with cognitive impairment and poorer subjective health [31-36]; these groups may, therefore, be less likely to engage with these platforms. Third, we did not compare the efficacy of the 3 social media platforms described, although we believe that each allows us to reach unique audiences in different ways. Fourth, the individuals who have expressed interest in research have been predominantly female; additional efforts are needed to understand how to similarly reach males, as well as a greater proportion of individuals from diverse racial and ethnic backgrounds. Fifth, although our reach and impression rates are promising, our Facebook engagement rates are relatively low. Because this metric is an indicator of how, and the degree to which, our audience interacts with our content, these data suggest that much of our social media outreach may be unidirectional (ie, low levels of likes, comments, and content sharing). Future efforts should strive to improve this. Additionally, these measures were collected as monthly averages, which limited our ability to assess the impact of individual posts or specific content types. Furthermore, engagement data were not collected for Twitter. Finally, we describe the efforts of one Alzheimer's Disease Research Center; the extent to which similar approaches generalize to other types of centers or programs remains to be determined.

Although social media may be an effective means for raising awareness about dementia, dispelling stigma, and highlighting positive aspects of clinical research [37], it is only one method within a wide range of strategies needed for engaging communities, individuals with cognitive impairment, and families on topics related to aging and ADRD [5,24]. Social media may supplement in-person community outreach, engagement, and partnerships, the latter of which have been reported to be important for building trust, particularly in minoritized communities [38-40]. It will furthermore be important to continually monitor use trends among target demographics, and evaluate the addition of, or migration to, other emerging platforms. We, nonetheless, hope these activities—or a subset thereof—may serve as an exemplar for other centers or programs, or provide ideas for new initiatives that can be implemented and improved upon.

Conclusions

These data suggest that social media activities may have a measurable impact on the outreach, visibility, and recruitment activities of research centers, including National Institute on Aging–funded ADRCs. They also highlight the importance of tracking the success of outreach programs for evaluating outcomes. These data provide evidence of return on investment and support the continued use of social media for the above-mentioned purposes. Given the public's use of social media as a source of health information [6], this may be an important means by which centers can present themselves as a reliable educational resource, educate the community, and share research findings with community stakeholders. Incorporating additional activities designed to test the efficacy of different approaches for attracting research participants is an important future direction.

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Conflicts of Interest

None declared.

References

1. GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the global burden of disease study 2019. Lancet Public Health 2022;7(2):e105-e125 [FREE Full text] [doi: 10.1016/S2468-2667(21)00249-8] [Medline: 34998485]
2. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 08;396(10248):413-446 [FREE Full text] [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
3. Decade of Healthy Aging: The Platform. URL: https://www.decadeofhealthyageing.org/ [accessed 2024-05-22]
4. Global action plan on the public health response to dementia 2017-2025. World Health Organization. 2017 Dec 07. URL: https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025 [accessed 2024-06-18]
5. Alzheimer's disease and related dementias clinical studies recruitment planning guide. National Institute on Aging. 2019. URL: https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf [accessed 2023-03-09]
6. Chen J, Wang Y. Social media use for health purposes: systematic review. J Med Internet Res 2021;23(5):e17917 [FREE Full text] [doi: 10.2196/17917] [Medline: 33978589]
7. Social media use in 2021. Pew Research Center. 2021. URL: https://www.pewresearch.org/internet/2021/04/07/social-media-use-in-2021/ [accessed 2023-02-21]
8. Share of U.S. adults using social media, including Facebook, is mostly unchanged since 2018. Pew Research Center. 2019. URL: https://www.pewresearch.org/short-reads/2019/04/10/share-of-u-s-adults-using-social-media-including-facebook-is-mostly-unchanged-since-2018/ [accessed 2023-04-10]
9. Lawless M, Augoustinos M, LeCouteur A. Dementia on Facebook: requesting information and advice about dementia risk-prevention on social media. Discourse Context Media 2018;25:44-51. [doi: 10.1016/j.dcm.2018.01.011]
10. Van Asbroeck S, van Boxtel MPJ, Steyaert J, Köhler S, Heger I, de Vugt M, et al. Increasing knowledge on dementia risk reduction in the general population: results of a public awareness campaign. Prev Med 2021 Jun;147:106522 [FREE Full text] [doi: 10.1016/j.ypmed.2021.106522] [Medline: 33744328]
11. Talbot LA, Thomas M, Bauman A, Manera KE, Smith BJ. Impacts of the national your brain matters dementia risk reduction campaign in Australia over 2 years. J Alzheimers Dis 2021;82(3):1219-1228. [doi: 10.3233/JAD-210317] [Medline: 34151804]
12. Friedman DB, Gibson A, Torres W, Irizarry J, Rodriguez J, Tang W, et al. Increasing community awareness about Alzheimer's disease in Puerto Rico through coffee shop education and social media. J Community Health 2016;41(5):1006-1012 [FREE Full text] [doi: 10.1007/s10900-016-0183-9] [Medline: 26983930]
13. Isaacson RS, Seifan A, Haddox CL, Mureb M, Rahman A, Scheyer O, et al. Using social media to disseminate education about Alzheimer’s prevention & treatment: a pilot study on Alzheimer's Universe (www.AlzU.org). J Commun Healthc 2018;11(2):106-113 [FREE Full text] [doi: 10.1080/17538068.2018.1467068] [Medline: 30740140]
14. Cowie JM, Gurney ME. The use of Facebook advertising to recruit healthy elderly people for a clinical trial: baseline metrics. JMIR Res Protoc 2018;7(1):e20 [FREE Full text] [doi: 10.2196/resprot.7918] [Medline: 29367186]
15. Corey KL, McCurry MK, Sethares KA, Bourbonniere M, Hirschman KB, Meghani SH. Utilizing internet-based recruitment and data collection to access different age groups of former family caregivers. Appl Nurs Res 2018;44:82-87 [FREE Full text] [doi: 10.1016/j.apnr.2018.10.005] [Medline: 30389065]
16. Stout SH, Babulal GM, Johnson AM, Williams MM, Roe CM. Recruitment of African American and non-Hispanic White older adults for Alzheimer disease research via traditional and social media: a case study. J Cross Cult Gerontol 2020;35(3):329-339 [FREE Full text] [doi: 10.1007/s10823-020-09405-9] [Medline: 32712751]
17. Mindt MR, Ashford MT, Zhu D, Cham H, Aaronson A, Conti C, et al. The Community Engaged Digital Alzheimer's Research (CEDAR) study: a digital intervention to increase research participation of Black American participants in the brain health registry. J Prev Alzheimers Dis 2023;10(4):847-856 [FREE Full text] [doi: 10.14283/jpad.2023.32] [Medline: 37874107]

18. Cheng TY, Liu L, Woo BK. Analyzing Twitter as a platform for Alzheimer-related dementia awareness: thematic analyses of tweets. JMIR Aging 2018;1(2):e11542 [FREE Full text] [doi: 10.2196/11542] [Medline: 31518232]
19. Robillard JM, Johnson TW, Hennessey C, Beattie BL, Illes J. Aging 2.0: health information about dementia on Twitter. PLoS One 2013;8(7):e69861 [FREE Full text] [doi: 10.1371/journal.pone.0069861] [Medline: 23922827]
20. Tang W, Olscamp K, Choi SK, Friedman DB. Alzheimer's disease in social media: content analysis of youtube videos. Interact J Med Res 2017;6(2):e19 [FREE Full text] [doi: 10.2196/ijmr.8612] [Medline: 29051137]
21. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381 [FREE Full text] [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
22. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, REDCap Consortium. The REDCap consortium: building an international community of software platform partners. J Biomed Inform 2019 Jul;95:103208 [FREE Full text] [doi: 10.1016/j.jbi.2019.103208] [Medline: 31078660]
23. Clinical translational science awards consortium community engagement key function committee task force on the principles of community engagement. In: Principles of Community Engagement, 2nd Edition. Washington, DC: Department of Health and Human Services; 2011.
24. Together we make a difference: national strategy for recruitment and participation in Alzheimer's and related dementias clinical research. National Institutes of Health. 2018. URL: https://www.nia.nih.gov/sites/default/files/2018-10/alzheimers-disease-recruitment-strategy-final.pdf [accessed 2023-03-09]
25. Darko EM, Kleib M, Olson J. Social media use for research participant recruitment: integrative literature review. J Med Internet Res 2022;24(8):e38015 [FREE Full text] [doi: 10.2196/38015] [Medline: 35925655]
26. Darmawan I, Bakker C, Brockman TA, Patten CA, Eder M. The role of social media in enhancing clinical trial recruitment: scoping review. J Med Internet Res 2020;22(10):e22810 [FREE Full text] [doi: 10.2196/22810] [Medline: 33104015]
27. Feliú-Mójer MI. Effective communication, better science. Scientific American. 2015. URL: https://blogs.scientificamerican.com/guest-blog/effective-communication-better-science/ [accessed 2023-05-09]
28. Jucan MS, Jucan CN. The power of science communication. Procedia Soc Behav Sci 2014;149:461-466. [doi: 10.1016/j.sbspro.2014.08.288]
29. van Hoof J, Marston HR. Age-friendly cities and communities: state of the art and future perspectives. Int J Environ Res Public Health 2021;18(4):1644 [FREE Full text] [doi: 10.3390/ijerph18041644] [Medline: 33572181]
30. Shannon K, Bail K, Neville S. Dementia-friendly community initiatives: an integrative review. J Clin Nurs 2019;28(11-12):2035-2045. [doi: 10.1111/jocn.14746] [Medline: 30554458]
31. Huxhold O, Hees E, Webster NJ. Towards bridging the grey digital divide: changes in internet access and its predictors from 2002 to 2014 in Germany. Eur J Ageing 2020;17(3):271-280 [FREE Full text] [doi: 10.1007/s10433-020-00552-z] [Medline: 32904732]
32. Kamin ST, Lang FR. Internet use and cognitive functioning in late adulthood: longitudinal findings from the Survey of Health, Ageing and Retirement in Europe (SHARE). J Gerontol B Psychol Sci Soc Sci 2020;75(3):534-539. [doi: 10.1093/geronb/gby123] [Medline: 30346591]
33. König R, Seifert A, Doh M. Internet use among older Europeans: an analysis based on SHARE data. Univ Access Inf Soc 2018;17(3):621-633. [doi: 10.1007/s10209-018-0609-5]
34. LaMonica HM, English A, Hickie IB, Ip J, Ireland C, West S, et al. Examining internet and eHealth practices and preferences: survey study of Australian older adults with subjective memory complaints, mild cognitive impairment, or dementia. J Med Internet Res 2017;19(10):e358 [FREE Full text] [doi: 10.2196/jmir.7981] [Medline: 29070481]
35. Wan X, Lighthall NR, Paulson D. Subjective markers of successful aging and change in internet use among older adults: the distinctive role of subjective health. Comput Hum Behav 2022;127:107064. [doi: 10.1016/j.chb.2021.107064]
36. Wehrmann H, Michalowsky B, Lepper S, Mohr W, Raedke A, Hoffmann W. Priorities and preferences of people living with dementia or cognitive impairment - a systematic review. Patient Prefer Adherence 2021;15:2793-2807 [FREE Full text] [doi: 10.2147/PPA.S333923] [Medline: 34934309]
37. Hughes TB, Varma VR, Pettigrew C, Albert MS. African Americans and clinical research: evidence concerning barriers and facilitators to participation and recruitment recommendations. Gerontologist 2017;57(2):348-358 [FREE Full text] [doi: 10.1093/geront/gnv118] [Medline: 26553736]
38. Grill JD, Galvin JE. Facilitating Alzheimer disease research recruitment. Alzheimer Dis Assoc Disord 2014;28(1):1-8 [FREE Full text] [doi: 10.1097/WAD.0000000000000016] [Medline: 24322484]
39. Hinton L, Carter K, Reed BR, Beckett L, Lara E, DeCarli C, et al. Recruitment of a community-based cohort for research on diversity and risk of dementia. Alzheimer Dis Assoc Disord 2010;24(3):234-241 [FREE Full text] [doi: 10.1097/WAD.0b013e3181c1ee01] [Medline: 20625273]
40. Watson JL, Ryan L, Silverberg N, Cahan V, Bernard MA. Obstacles and opportunities in Alzheimer's clinical trial recruitment. Health Aff 2014;33(4):574-549 [FREE Full text] [doi: 10.1377/hlthaff.2013.1314] [Medline: 24711317]

Abbreviations

ADRD: Alzheimer disease and related dementias
IRB: institutional review board
JH: Johns Hopkins
JHADRC: Johns Hopkins Alzheimer’s Disease Research Center
MACAB: Memory and Aging Community Advisory Board
ORE: Outreach, Recruitment, and Engagement

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Combating Barriers to the Development of a Patient-Oriented Frailty Website

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Abstract

This viewpoint article, which represents the opinions of the authors, discusses the barriers to developing a patient-oriented frailty website and potential solutions. A patient-oriented frailty website is a health resource where community-dwelling older adults can navigate to and answer a series of health-related questions to receive a frailty score and health summary. This information could then be shared with health care professionals to help with the understanding of health status prior to acute illness, as well as to screen and identify older adult individuals for frailty. Our viewpoints were drawn from 2 discussion sessions that included caregivers and care providers, as well as community-dwelling older adults. We found that barriers to a patient-oriented frailty website include, but are not limited to, its inherent restrictiveness to frail persons, concerns over data privacy, time commitment worries, and the need for health and lifestyle resources in addition to an assessment summary. For each barrier, we discuss potential solutions and caveats to those solutions, including assistance from caregivers, hosting the website on a trusted source, reducing the number of health questions that need to be answered, and providing resources tailored to each users' responses, respectively. In addition to screening and identifying frail older adults, a patient-oriented frailty website will help promote healthy aging in nonfrail adults, encourage aging in place, support real-time monitoring, and enable personalized and preventative care.

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KEYWORDS

frailty; frailty website; patient-oriented assessment; community-dwelling older adults; internet security; privacy; barrier; barriers; development; implementation; patient-oriented; internet; virtual health resource; community dwelling; older adult; older adults; health care professional; caregiver; caregivers; technology; real-time; monitoring; aging; ageing

Introduction

Technological advances, principally computer-aided assessments and electronic health information exchanges, have enormous promise to promote healthy aging. Fortunately, older adults (ie, those aged ≥65 years) are open to using new technologies [1]. Thus, health care is adopting technologies that support real-time monitoring to promote personalized and preventative care [2].

Frailty is an age-related dynamic state characterized by deficits across multiple physiologic systems with increased vulnerability to stressors [3,4]. Consensus guidelines state that early detection of frailty is key to its management [5,6]. To this end, technology-based frailty tools have allowed health care professionals to screen, assess, identify, and develop care plans for frail persons [7-11]. Yet, physician-oriented frailty screening tools are resource intensive.

A patient-oriented frailty website is the next step in frailty care [12]. In Canada, approximately 23% of community-dwelling older adults are frail [13]. Although primary care frailty screening tools used by health care providers show promise in the identification and management of frailty [14], many community-dwelling older adults do not have the ability to undergo in-person frailty screening. Therefore, patient-oriented frailty screening tools in the form of websites and apps should be developed and implemented.

The concept of a patient-oriented frailty website is straightforward. Individuals go to a secure frailty website where they answer a series of health-related questions. The website, in turn, generates a frailty/health summary and score based on the user's responses. In addition to a score, the website could also inform the user of their frailty status and whether they should seek medical counsel. Upon consent, users can share their responses and score with their care provider. In this capacity, a patient-oriented frailty website could identify those that are frail or at an increased risk of becoming frail. The website would be inclusive and encourage *all* older adults, regardless of health status, to participate. For healthy older adults that show no signs of frailty, the website would promote and reinforce their current healthy lifestyle and serve as a baseline. In this way, a frailty website is similar to the standard practice of well-baby visits—periodic examinations that screen for potential developmental health complications [15]. Therefore, well-baby visits and web-based frailty assessments are tools for the prevention and treatment of health issues that occur early and late in life, respectively.

To understand the interest in a patient-oriented frailty website, we conducted a planning project consisting of 2 components. In May 2023, we held a web-based educational symposium on frailty [16]. Experts in frailty spoke on the importance of frailty assessment and identification, approaches to preventing and mitigating frailty, frailty in primary care, and factors common to those who age gracefully beyond the age of 85 years. Recruitment for symposium audience and discussants was done via posters, which were distributed and published in local health authority newsletters, at academic institutions, and at a volunteer recruitment site for health research using REACH BC (the *Ethical Considerations* section provides more details). The audience was Canadian clinicians, researchers, caregivers, and community-dwelling older adults. Before and at the symposium, we invited interested audience members to participate in a discussion session scheduled 2 weeks later; individuals were excluded if they had not seen the symposium. Interested care providers, caregivers, and community-dwelling older adults returned to 1 of 2 discussion sessions. One discussion session included 7 caregivers and care providers, whereas the other session included 6 community-dwelling older adults; sample sizes were determined by best practices [17-19]. In contrast to a traditional qualitative research where findings are summarized then supplemented with participants' quotes, in this viewpoint paper, we summarize the main findings of the discussion groups, highlighting the major barriers to developing a patient-oriented frailty website. To benefit other researchers developing similar health websites, we also provide potential solutions as observed throughout the literature and discuss caveats to those solutions, as summarized in Table 1.

Table . Barriers, their potential solutions, and caveats to those solutions regarding the implementation of a patient-oriented frailty website.

Barriers and solutions	Caveats
Completing a frailty assessment on the web is restrictive to frail persons.	
Caregiver assists or completes assessment on frail person's behalf.	Not all frail older adults will have a caregiver.
Distribute low-tech (ie, paper) frailty assessments.	Requires a set of complex steps a frail person cannot do.
There are privacy and security concerns.	
The website needs to be hosted from a reputable source with clear intent on its use.	It is unknown how users will perceive the trustworthiness of a frailty website.
Users may restrict researchers from health data analyses.	
Implement federated learning.	Federated learning is still relatively novel and may be susceptible to attacks.
Users want to complete the assessment quickly.	
Reduce the number of frailty questions.	Fewer questions may compromise the clinical usefulness of the assessment.
Health care providers need to know how to interpret and apply the information to care for frailty.	
Develop models to treat frailty; implement training for health professionals.	This solution requires significant resources.
Being labeled as frail is counterproductive to combating frailty.	
Educate users on frailty and reframe frailty in a more positive light (eg, well-being).	It is unknown how users will respond to their (potentially negative) scores.
Users want health resources tailored to them in addition to a frailty/health assessment.	
Provide additional resources tailored to users' responses.	Users may be deterred from seeking the expertise of medical professionals.

Ethical Considerations

This planning project received an exemption from the Fraser Health Research Ethics Board as it fell under quality improvement and evaluation studies. Stakeholders provided informed consent prior to the discussion session for review, following the Fraser Health guidelines. All stakeholders had the ability to opt out at any time for any reason and were reminded of this right prior to the start of the discussion session. Both discussion sessions were recorded for the purpose of transcription offline. Videos of the 2 discussions are stored on a secured drive that is both password protected and can only be accessed by approved Fraser Health employees. Stakeholders were compensated CAD $25 (US $18.27) for engaging in the symposium and 1 discussion session.

A Website That Assesses Frailty Is Restrictive to the Frail

The most substantial issue involving the implementation of a patient-oriented frailty website is its restrictiveness. A website targeting a subpopulation assumes that the targeted audience can access the website. On average, internet use among Canadian older adults is 68%, but it is only 41% for those aged ≥80 years [20]. In addition to age, health and frailty status are also related to internet and computer use. For example, 73% of Canadian older adults in excellent or very good health use the internet, whereas 62% of older adults in fair or poor health use the internet [20]. Likewise, another group found that the frailer a person was, the less likely they were to use a computer [21]. Thus, attempting to reach frail older adults through a website is a major hurdle.

A seemingly simple solution to this barrier is targeting caregivers (eg, partners, family members, friends, colleagues, or neighbors) and having caregivers assist or complete the questions on the frail person's behalf. However, this solution only works for those with caregiver support. In one study based in the Netherlands, having a primary caregiver was reported in 32% of older adults who visited the emergency department [22]. This figure may be slightly lower in Canada. It is estimated between 23% [23] and 28% [24] of older Canadian adults have caregivers. Consequently, there is a chance that most frail community-dwelling older adults would not have assistance using a computer, navigating to the frailty website, and answering a series of health-related questions. Clearly, increasing caregiver support is one approach to increasing internet access among frail older adults.

Another solution to combat the restrictiveness of a frailty website is to also provide a paper version to frail older adults. Despite acknowledging the importance and benefits of digital screening tools, older adults have suggested that low-tech alternatives should also be available [25]. It would be convenient to make a paper pamphlet that has the same information and questions as a frailty website. This way, both paper and web-based frailty assessments would be interchangeable, allowing for conversion from one medium (ie, paper) to the other (ie, website) and vice versa. Pamphlets can be widely distributed and made available at family physicians' and nurse practitioners' offices, wellness and health clinics, pharmacies, and even mailed directly to older adults (eg, using Canada Post's Precision Targeter). However, there are concerns regarding this approach as well. Assuming frail community-dwelling older adults obtained access to the frailty pamphlet survey, they would still need to fill it out (accurately), return it, schedule an appointment, and visit a health care professional. Some of these barriers can be mitigated by including a return address with free postage, using free door-to-door shared ride services, or scheduling a telehealth appointment. However, this process requires a series of complicated steps and older adults with mild cognitive impairment will be unable to complete them [26]. Other means of reaching frail persons are needed, but without significant assistance, it is unlikely that these individuals will be screened for proper frailty care.

Older Adults Have Internet Privacy Concerns

Despite a positive attitude toward web-based health services [27], older adults are concerned about privacy, especially when it is unclear by whom or how their medical data will be used [28]. For example, the probability of being identified was the single most important attribute when older adults considered internet privacy, even though sharing their medical data was viewed positively if it was to be used for science and the development of novel care and treatment [29]. The hesitancy of older adults to share their medical data reveals the need for clearly communicating how their information will be used—if they are to be comfortable consenting to its wider use. Similarly, a previous study found that older adults were more willing to share their data (eg, demographics, family relations, economic status, physical and mental illnesses, family history, medication, and health care service use) with family and hospitals compared to researchers or government agencies [30]. Public trust in the government is complex. For example, despite only 19% of Americans trusting the federal government, 70% viewed the US Food and Drug Administration and US Centers for Disease Control and Prevention favorably [31]. Thus, hosting a patient-oriented frailty website on a health authority or a particular branch of government, as opposed to a commercial site, with the clear intent to promote health, may increase the likelihood of the widespread adoption of a web-based frailty assessment tool among older adults. However, more work is needed to fully understand the actual adoption (as opposed to the hypothetical adoption) of a frailty website among older adults and how to securely transfer a user's medical responses to a health authority without compromising privacy if the user consents.

Users' Restriction of Their Data May Limit Health Data Analyses

The reluctance for individuals to share their health data for research purposes is understandable and may dictate the use of a frailty website. Researchers and health authorities may bemoan the decision for users to protect their data, which, in turn, may restrict our understanding of frailty. For example, knowing the frailty status and location of older adults who completed a web-based frailty assessment could reveal concentrated areas of frail older adults, suggesting environmental or societal risk factors and the need for additional services to be deployed to those locations. Realistically, this type of analysis can only be done with a user's location and health data. Still, it is important to remember that the personal health data acquired from any website belongs to the user. It is at the discretion of the user (assuming they have the cognitive faculties to consent in the first place, a topic not discussed in our sessions) whether to share their data.

Hence the success of a frailty website is contingent upon the implementation of a privacy-first approach. A privacy-first approach underscores the users' ownership of their data, using dynamic identifiers and storing data locally (ie, on a smartphone or computer), as opposed to a data-first approach, which prioritizes the retention and distribution of data, typically in a centralized location [32]. However, a happy medium exists where users can keep and protect their data while researchers and health authorities can advance frailty care through modern analysis.

New advances in data analysis [33] have been developed and used to underscore privacy-first approaches. Federated learning, for example, is a machine learning model that aggregates training results from multiple sources to create a consensus model without the need for data to leave a given device or system. A recent study found federated models achieved the same accuracy, precision, and generalizability as standard centralized statistical models using a variety of health data [34]. As a specific example, federated learning was used to predict treatment response in breast cancer patients using data behind a hospital's firewall [35]. Emerging technologies and analyses have made it possible to have a patient-oriented frailty website that both ensures the privacy of the user and allows for analyses that will usher in better frailty care. A caveat to this is that federated learning is relatively new and will take time to implement across health authorities, and it may be prone to specific types of attacks [33].

Users Want to Complete a Frailty Assessment Quickly

A frailty website needs to be efficient and user-friendly [12] while adequately collecting health information that can assess frailty [3,4]. After the user completes a series of health-related questions on a frailty website, the website should produce a score (eg, "Your frailty score is 42/100, consider making an appointment with your doctor" or "Your biological age is 71, 6 years older than your actual age of 65"). One scoring approach could be a multisystem deficit-accumulation frailty index [36,37], which subscribes to the idea of an accumulation of deficits and is scored between 0 and 1, with 0 being no deficits present and 1 being all deficits present and fully expressed (in reliaty, the score seldom exceeds 0.7, a limit of deficit acculation); this approach has acceptable validity, reliability, and diagnostic test accuracy [38]. One benefit of a frailty score derived from a frailty index is that it can be interpreted by nonexperts. However, because the accumulation deficit model subscribes to the idea that frailty is a multisystem state, ideally a frailty website that adopts this approach would require 30 to 40 questions [39] across multiple domains (ie, physical, cognitive, psychological, and social). Research has shown that people are more likely to complete a survey if it takes 15 minutes or less [40]. In the context of a frailty website, completing 30 to 40 questions in 15 minutes would require users to spend 23 to 30 seconds on each question. Therefore, inaccurate responses and the respondent feeling rushed, frustrated, and stressed can be a concern.

In an attempt to make the website user-friendly, the number of questions would have to be reduced, potentially compromising its clinical utility [41]. A frailty index comprising fewer than 30 variables and questions can still be useful. In one study, researchers found that a frailty index constructed using 23 variables was just as accurate as one constructed using 70 variables [42]. An alternative approach to written multiple-choice questions may be a pictorial frailty assessment. The Pictorial Fit-Frail Scale [43] was recently developed for this purpose. It is fast (it took patients 6 minutes to complete) and comprehensive (the assessment covered 14 domains). However, agreement rates among Canadian and UK health care professionals were low (32% agreement for social, 44% agreement for mood, and 59% agreement for function), and it is unclear how patients understood each domain (averages were taken across 146 patients, caregivers, health care professionals, and general public participants) [43]. In contrast to the frailty index with precise grading of frailty, the phenotype model of frailty includes only 5 variables. Yet, the phenotype model requires grip strength and walking speed, measures that cannot be easily tested and may not be safe for many older adults to complete in their own homes. A methodological consensus regarding the definition of a frailty index, the variables that comprise it, and how they are scored has been encouraged [44-46].

Frailty Score Needs to Be Interpretable

In addition to a methodological consensus, output from a patient-oriented frailty website must be sufficient and interpretable for all health care professionals irrespective of location. For example, health care professionals across Canada would need to know what a frailty score of "42/100" means and how to prescribe the appropriate care. Our modern health care system is well designed for treating diseases but not for embracing the unique challenges of frailty among older adults, a population that experiences complex health issues [47].

Fortunately, the development of novel models [48] and guidelines [49] that address frailty in primary care is already underway. Moreover, frailty training would be required for physicians to prescribe appropriate frailty care. A systematic review found that there were limited frailty training programs for health professionals; however, the programs that did exist effectively increased frailty knowledge and competence in frailty assessments [50]. Although this would require significant resources, postponing or reducing frailty would result in a significant reduction in health care costs [51] and would pay for itself.

Being Labeled Frail Is Counterproductive to Combating Frailty

Numerous studies have agreed that there is a stigma around the concept of frailty and being labeled as frail. In one study, community-dwelling older adults reported that frailty was perceived as "approaching the end of their lives, malnourished and highly dependent on care" [52]. This same study also found that older adults are likely to reject the concept of frailty even when an objective measure may define them as frail [52]. Hence, a frailty website that labels a user frail may be counterproductive to the purpose of preventing and managing frailty.

In addition to education, another solution to combat the negative perceptions of frailty is to reframe the concept of frailty in a more positive light, using terminology such as "healthy aging" or "well-being" [52,53] or, within the context of a fit-frail score, "well-being score." It should be noted, however, that positive output from a web-based frailty assessment (eg, a low fit-frail score, or a low biological age relative to chronological age) could also be counterproductive and have the same consequences as a negative output, deterring older adults from seeking medical care. Nevertheless, at least 1 study suggests otherwise. Among older adults who avoided medical care, 36% did so out of fear of a serious illness, and the likelihood of avoidance was greater in those who self-reported a poorer health status [54]. Ultimately, it is unknown how users will respond to negative or positive outputs from a frailty website, and more research is needed to understand the potentially complicated reactions older adults will have after receiving their personalized health score and summary. Regardless, it is of the utmost importance that older adults are comfortable, feel safe, and are motivated (not discouraged) when using a frailty website.

Frailty Websites Should Provide Additional Health Resources

A frailty website should offer resources in addition to a health score and summary. A patient-oriented frailty website that gathers health information can be of great use for health care providers. It should also produce personalized resources based on the user's responses [55,56]. For example, if a community-dwelling older adult is deemed to be at risk of becoming frail and their deficits are primarily in a physical domain (ie, they are slightly overweight, sleep less than 6 hours a night, drink >6 alcoholic drinks a week, and have hypertension but are cognitively normal), the website ought to provide links to resources to meet those care needs. In this scenario, the website could suggest resources such as how to start and maintain an exercise program and provide best sleep hygiene practices in addition to recommending that the user make an appointment with their physician to manage hypertension.

Self-management is a potentially viable, low-cost approach to addressing frailty, but this is a relatively unexplored topic in frailty care [53]. Additionally, caution must be exercised with self-management. For instance, individuals that are provided resources may be lulled into a false sense of security and feel that their health can be managed without regular check-ups by the expertise of trained medical professionals. On the other hand, older adults may be unmotivated to complete a series of health-related questions if a website does not provide any immediate, clear feedback other than a score. There needs to be a happy medium where older adults are motivated to use a frailty website but also supplement the website with a medical expert's opinion. Future studies need to understand where that happy medium exists and incorporate it into frailty website development.

Limitations

This viewpoint paper is not without limitations. One such limitation is the lack of quotes from discussants. While quotes are typically included in qualitative research to strengthen findings, our viewpoint explicitly draws attention to barriers and potential solutions to the development of a patient-oriented frailty website. Further, traditional focus group studies that include theme discovery supplemented with quotes will be needed to better understand and address these barriers. Another limitation is the omission of technological barriers, which have been published elsewhere [12,57]. One important technological barrier is search engine optimization—a process of making modifications to a website to increase its visibility. Well-tuned site optimization strategies increase traffic to health websites, whereas poor search engine optimization can affect older adults' experience in frailty assessment and health interpretation simply due to a missing hyperlink to the website. Finally, the barriers reported here may not generalize to populations outside of Canada. However, some of the barriers reported here also exist for older adults in Switzerland [26] and the United Kingdom [53,56]. Future studies should attempt to recruit samples representing broader geographical regions to promote equity in global health care.

Conclusion

A frailty website that can be used by the community to screen and identify older adults at an increased risk of frailty and health decline is an important step in geriatric care and public health. However, several barriers must be addressed in future research before the development of such websites. While some barriers have potential solutions, they come at a cost (eg, resources required for optimizing frailty models in primary care and patient-oriented frailty assessment training and support). Other potential solutions (eg, caregiver assistance and an accompanying paper-based frailty assessment) have their own challenges. Regardless, addressing these barriers, even partially, is a worthy goal. The early detection and management of frailty can lead to significant inroads to integrated care, benefiting the quality of life of older patients and their caregivers and the health of the aging population.

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Data Availability

Data sharing is not applicable to this article as this is a viewpoint article and represents the experiences and opinions of the authors.

Disclaimer

At no point was artifical intelligence used to aid the writing process.

Authors' Contributions

BG contributed to conceptualization, formal analysis, funding acquisition, investigation, methodology, project administration, resources, supervision, and writing (original draft). SSC contributed to data curation, investigation, project administration, resources, and writing (review and editing). LG is a community patient advisor and contributed to conceptualization, investigation, resources, and writing (review and editing). XS contributed to conceptualization, funding acquisition, team support, methodology, investigation, project management, resources, supervision, and writing (review and editing).

Conflicts of Interest

None declared.

References

1. Mitzner TL, Boron JB, Fausset CB, et al. Older adults talk technology: technology usage and attitudes. Comput Hum Behav 2010 Nov;26(6):1710-1721. [doi: 10.1016/j.chb.2010.06.020]
2. Qi J, Yang P, Min G, Amft O, Dong F, Xu L. Advanced internet of things for personalised healthcare systems: a survey. Pervasive Mob Comput 2017 Oct;41:132-149. [doi: 10.1016/j.pmcj.2017.06.018]
3. Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. Lancet 2013 Mar 2;381(9868):752-762. [doi: 10.1016/S0140-6736(12)62167-9] [Medline: 23395245]
4. Gobbens RJ, Luijkx KG, Wijnen-Sponselee MT, Schols JM. Toward a conceptual definition of frail community dwelling older people. Nurs Outlook 2010 Mar;58(2):76-86. [doi: 10.1016/j.outlook.2009.09.005] [Medline: 20362776]
5. Fallah N, Mitnitski A, Searle SD, Gahbauer EA, Gill TM, Rockwood K. Transitions in frailty status in older adults in relation to mobility: a multistate modeling approach employing a deficit count. J Am Geriatr Soc 2011 Mar;59(3):524-529. [doi: 10.1111/j.1532-5415.2011.03300.x] [Medline: 21391943]
6. Turner G, Clegg A, British Geriatrics Society, Age UK, Royal College of General Practioners. Best practice guidelines for the management of frailty: a British Geriatrics Society, Age UK and Royal College of General Practitioners report. Age Ageing 2014 Nov;43(6):744-747. [doi: 10.1093/ageing/afu138] [Medline: 25336440]
7. Ambagtsheer RC, Beilby J, Dabravolskaj J, Abbasi M, Archibald MM, Dent E. Application of an electronic frailty index in Australian primary care: data quality and feasibility assessment. Aging Clin Exp Res 2019 May;31(5):653-660. [doi: 10.1007/s40520-018-1023-9] [Medline: 30132204]
8. Clegg A, Bates C, Young J, et al. Development and validation of an electronic frailty index using routine primary care electronic health record data. Age Ageing 2016 May;45(3):353-360. [doi: 10.1093/ageing/afw039] [Medline: 26944937]
9. Lawson B, Sampalli T, Wood S, et al. Evaluating the implementation and feasibility of a web-based tool to support timely identification and care for the frail population in primary healthcare settings. Int J Health Policy Manag 2017 Jul 1;6(7):377-382. [doi: 10.15171/ijhpm.2017.32] [Medline: 28812833]
10. Sepehri K, Braley MS, Chinda B, et al. A computerized frailty assessment tool at points-of-care: development of a standalone electronic comprehensive geriatric assessment/frailty index (eFI-CGA). Front Public Health 2020;8:89. [doi: 10.3389/fpubh.2020.00089] [Medline: 32296673]
11. Sepehri K, Low H, Hoang J, Park G, Song X. Promoting early management of frailty in the new normal: an updated software tool in addressing the need of virtual assessment of frailty at points of care. Aging Med (Milton) 2022 Mar;5(1):4-9. [doi: 10.1002/agm2.12198] [Medline: 35309154]
12. Chang R, Low H, McDonald A, Park G, Song X. Web-based software applications for frailty assessment in older adults: a scoping review of current status with insights into future development. BMC Geriatr 2021 Dec 18;21(1):723. [doi: 10.1186/s12877-021-02660-6] [Medline: 34922466]
13. Association of frailty and pre-frailty with increased risk of mortality among older Canadians. Statistics Canada. 2021. URL: https://www150.statcan.gc.ca/n1/pub/82-003-x/2021004/article/00002-eng.htm [accessed 2024-05-02]
14. Garm A, H Park G, Song X. Using an electronic comprehensive geriatric assessment and health coaching to prevent frailty in primary care: the CARES model. Med Clin Rev 2018 Jul 1;3(S1):9. [doi: 10.21767/2471-299X.1000051]
15. Rourke JT, Rourke LL. Well baby visits: screening and health promotion. Can Fam Physician Med Fam Can 1985 May;31:997-1002. [Medline: 21274145]
16. Web-based eFI-CGA. eFI-CGA. URL: https://efi-cga.ca/ [accessed 2024-05-02]
17. Krueger RA, Casey MA. Focus Groups: A Practical Guide for Applied Research, 5th edition: SAGE; 2015.
18. Carey MA, Asbury JE. Focus Group Research: Routledge; 2016.

19. Wilkinson S. Focus group methodology: a review. Int J Soc Res Methodol 1998 Jan;1(3):181-203. [doi: 10.1080/13645579.1998.10846874]
20. Davidson J, Schimmele C. Evolving internet use among Canadian seniors. Statistics Canada. 2019. URL: https://www150.statcan.gc.ca/n1/pub/11f0019m/11f0019m2019015-eng.htm [accessed 2024-05-13]
21. Tong T, Chignell M, Tierney MC, et al. Technology profiles as proxies for measuring functional and frailty status. Procedia Comput Sci 2017;111:77-86. [doi: 10.1016/j.procs.2017.06.013]
22. Zaalberg T, Barten DG, van Heugten CM, et al. Prevalence and risk factors of burden among caregivers of older emergency department patients. Sci Rep 2023 May 4;13(1):7250. [doi: 10.1038/s41598-023-31750-1] [Medline: 37142628]
23. More than half of women provide care to children and care-dependent adults in Canada. Statistics Canada. 2022. URL: https://www150.statcan.gc.ca/n1/daily-quotidien/221108/dq221108b-eng.htm [accessed 2024-05-02]
24. Sinha M. Portrait of caregivers, 2012. Statistics Canada. 2014. URL: https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.htm
25. Gwyther H, van Velsen L, Shaw RL, et al. The use of technology in the context of frailty screening and management interventions: a study of stakeholders' perspectives. BMC Med Inform Decis Mak 2019 Jun 11;19(1):110. [doi: 10.1186/s12911-019-0828-6] [Medline: 31186018]
26. Perneczky R, Pohl C, Sorg C, et al. Complex activities of daily living in mild cognitive impairment: conceptual and diagnostic issues. Age Ageing 2006 May;35(3):240-245. [doi: 10.1093/ageing/afj054] [Medline: 16513677]
27. Ienca M, Schneble C, Kressig RW, Wangmo T. Digital health interventions for healthy ageing: a qualitative user evaluation and ethical assessment. BMC Geriatr 2021 Jul 2;21(1):412. [doi: 10.1186/s12877-021-02338-z] [Medline: 34215209]
28. Li Y. Empirical studies on online information privacy concerns: literature review and an integrative framework. Commun Assoc Inf Syst 2011 May;28:453-469. [doi: 10.17705/1CAIS.02828]
29. Ziefle M, Calero Valdez A. Decisions about medical data disclosure in the Internet: an age perspective. In: Zhou J, Salvendy G, editors. Human Aspects of IT for the Aged Population Applications in Health, Assistance, and Entertainment: Springer International Publishing; 2018:186-201 Lecture Notes in Computer Science; vol 10927. [doi: 10.1007/978-3-319-92037-5]
30. Kim TK, Choi M. Older adults’ willingness to share their personal and health information when adopting healthcare technology and services. Int J Med Inform 2019 Jun;126:86-94. [doi: 10.1016/j.ijmedinf.2019.03.010] [Medline: 31029268]
31. Lee S, Abner G, Hameduddin T. The effects of organizational scandals on the desirability of public organizations as places to work: evidence from the VA waitlist scandal. Am Rev Public Adm 2024;54(1):19-32. [doi: 10.1177/02750740231191524]
32. Fahey RA, Hino A. COVID-19, digital privacy, and the social limits on data-focused public health responses. Int J Inf Manage 2020 Dec;55:102181. [doi: 10.1016/j.ijinfomgt.2020.102181] [Medline: 32836638]
33. Li H, Li C, Wang J, et al. Review on security of federated learning and its application in healthcare. Future Gener Comput Syst 2023 Jul;144:271-290. [doi: 10.1016/j.future.2023.02.021]
34. Sadilek A, Liu L, Nguyen D, et al. Privacy-first health research with federated learning. NPJ Digit Med 2021 Sep 7;4(1):132. [doi: 10.1038/s41746-021-00489-2] [Medline: 34493770]
35. Ogier du Terrail J, Leopold A, Joly C, et al. Federated learning for predicting histological response to neoadjuvant chemotherapy in triple-negative breast cancer. Nat Med 2023 Jan;29(1):135-146. [doi: 10.1038/s41591-022-02155-w] [Medline: 36658418]
36. Rockwood K, Mitnitski A. Frailty in relation to the accumulation of deficits. J Gerontol A Biol Sci Med Sci 2007 Jul;62(7):722-727. [doi: 10.1093/gerona/62.7.722] [Medline: 17634318]
37. Rockwood K, Mitnitski A. Frailty defined by deficit accumulation and geriatric medicine defined by frailty. Clin Geriatr Med 2011 Feb;27(1):17-26. [doi: 10.1016/j.cger.2010.08.008] [Medline: 21093719]
38. Apóstolo J, Cooke R, Bobrowicz-Campos E, et al. Predicting risk and outcomes for frail older adults: an umbrella review of frailty screening tools. JBI Database System Rev Implement Rep 2017 Apr;15(4):1154-1208. [doi: 10.11124/JBISRIR-2016-003018] [Medline: 28398987]
39. Searle SD, Mitnitski A, Gahbauer EA, Gill TM, Rockwood K. A standard procedure for creating a frailty index. BMC Geriatr 2008 Sep 30;8(1):24. [doi: 10.1186/1471-2318-8-24] [Medline: 18826625]
40. Saleh A, Bista K. Examining factors impacting online survey response rates in educational research: perceptions of graduate students. J Multidiscip Eval 2017 Sep 26;13(29):63-74. [doi: 10.56645/jmde.v13i29.487]
41. Muscedere J, Andrew MK, Bagshaw SM, et al. Screening for frailty in Canada’s health care system: a time for action. Can J Aging 2016 Sep;35(3):281-297. [doi: 10.1017/S0714980816000301] [Medline: 27211065]
42. Peña FG, Theou O, Wallace L, et al. Comparison of alternate scoring of variables on the performance of the frailty index. BMC Geriatr 2014 Feb 24;14(1):25. [doi: 10.1186/1471-2318-14-25] [Medline: 24559204]
43. Theou O, Andrew M, Ahip SS, et al. The Pictorial Fit-Frail Scale: developing a visual scale to assess frailty. Can Geriatr J 2019 Jun;22(2):64-74. [doi: 10.5770/cgj.22.357] [Medline: 31258829]
44. Greeley B, Low H, Kelly R, McDermid R, Song X. Preserving the discreteness of deficits during coding leads to a lower frailty index in individuals living in long-term care. Mech Ageing Dev 2023 Sep;214:111851. [doi: 10.1016/j.mad.2023.111851] [Medline: 37453658]

45. Lozano-Montoya I, Correa-Pérez A, Abraha I, et al. Nonpharmacological interventions to treat physical frailty and sarcopenia in older patients: a systematic overview – the SENATOR Project ONTOP series. Clin Interv Aging 2017 Apr;12:721-740. [doi: 10.2147/CIA.S132496] [Medline: 28490866]
46. Welstead M, Jenkins ND, Russ TC, Luciano M, Muniz-Terrera G. A systematic review of frailty trajectories: their shape and influencing factors. Gerontologist 2021 Nov 15;61(8):e463-e475. [doi: 10.1093/geront/gnaa061] [Medline: 32485739]
47. The state of seniors health care in Canada. Canadian Medical Association. 2016. URL: https://www.cma.ca/sites/default/files/2018-11/the-state-of-seniors-health-care-in-canada-september-2016.pdf [accessed 2024-05-13]
48. Sims-Gould J, Elliott J, Tong CE, Giguère A, Mallinson S, Stolee P. A national intervention to support frail older adults in primary care: a protocol for an adapted implementation framework. BMC Geriatr 2021 Aug 4;21(1):453. [doi: 10.1186/s12877-021-02395-4] [Medline: 34348660]
49. Abbasi M, Rolfson D, Khera AS, Dabravolskaj J, Dent E, Xia L. Identification and management of frailty in the primary care setting. CMAJ 2018 Sep 24;190(38):E1134-E1140. [doi: 10.1503/cmaj.171509] [Medline: 30249759]
50. Warren N, Gordon E, Pearson E, et al. A systematic review of frailty education programs for health care professionals. Australas J Ageing 2022 Dec;41(4):e310-e319. [doi: 10.1111/ajag.13096] [Medline: 35801297]
51. Hajek A, Bock JO, Saum KU, et al. Frailty and healthcare costs-longitudinal results of a prospective cohort study. Age Ageing 2018 Mar 1;47(2):233-241. [doi: 10.1093/ageing/afx157] [Medline: 29036424]
52. Frailty: language and perceptions. A report prepared by BritainThinks on behalf of Age UK and the British Geriatrics Society. Age UK. 2015. URL: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_june15_frailty_language_and_perceptions.pdf [accessed 2024-05-13]
53. Ambagtsheer RC, Beilby JJ, Visvanathan R, Dent E, Yu S, Braunack-Mayer AJ. Should we screen for frailty in primary care settings? A fresh perspective on the frailty evidence base: a narrative review. Prev Med 2019 Feb;119:63-69. [doi: 10.1016/j.ypmed.2018.12.020] [Medline: 30594533]
54. Leyva B, Taber JM, Trivedi AN. Medical care avoidance among older adults. J Appl Gerontol 2020 Jan;39(1):74-85. [doi: 10.1177/0733464817747415] [Medline: 29249189]
55. Abdi S, Spann A, Borilovic J, de Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO International Classification of Functioning, Disability and Health Framework (ICF). BMC Geriatr 2019 Jul 22;19(1):195. [doi: 10.1186/s12877-019-1189-9] [Medline: 31331279]
56. MacLeod S, Musich S, Hawkins K, Armstrong DG. The growing need for resources to help older adults manage their financial and healthcare choices. BMC Geriatr 2017 Apr 11;17(1):84. [doi: 10.1186/s12877-017-0477-5] [Medline: 28399818]
57. McDonald AP, Rizzotti R, Rivera JM, D’Arcy RCN, Park G, Song X. Toward improved homecare of frail older adults: a focus group study synthesizing patient and caregiver perspectives. Aging Med (Milton) 2021 Mar;4(1):4-11. [doi: 10.1002/agm2.12144] [Medline: 33738374]

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Original Paper

Automatic Spontaneous Speech Analysis for the Detection of Cognitive Functional Decline in Older Adults: Multilanguage Cross-Sectional Study

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Abstract

Background: The rise in life expectancy is associated with an increase in long-term and gradual cognitive decline. Treatment effectiveness is enhanced at the early stage of the disease. Therefore, there is a need to find low-cost and ecological solutions for mass screening of community-dwelling older adults.

Objective: This work aims to exploit automatic analysis of free speech to identify signs of cognitive function decline.

Methods: A sample of 266 participants older than 65 years were recruited in Italy and Spain and were divided into 3 groups according to their Mini-Mental Status Examination (MMSE) scores. People were asked to tell a story and describe a picture, and voice recordings were used to extract high-level features on different time scales automatically. Based on these features, machine learning algorithms were trained to solve binary and multiclass classification problems by using both mono- and cross-lingual approaches. The algorithms were enriched using Shapley Additive Explanations for model explainability.

Results: In the Italian data set, healthy participants (MMSE score≥27) were automatically discriminated from participants with mildly impaired cognitive function (20≤MMSE score≤26) and from those with moderate to severe impairment of cognitive function (11≤MMSE score≤19) with accuracy of 80% and 86%, respectively. Slightly lower performance was achieved in the Spanish and multilanguage data sets.

Conclusions: This work proposes a transparent and unobtrusive assessment method, which might be included in a mobile app for large-scale monitoring of cognitive functionality in older adults. Voice is confirmed to be an important biomarker of cognitive decline due to its noninvasive and easily accessible nature.

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KEYWORDS

cognitive decline; speech processing; machine learning; multilanguage; Mini-Mental Status Examination

Introduction

According to “The 2021 Ageing Report by the European Commission,” life expectancy has shown a continuous trend over the past years [1]. As life expectancy increases, so does the number of people with dementia worldwide. Dementia is a neurodegenerative disease, which entails a long-term and gradual decrease in cognitive functionality, resulting in the reduction of patients’ autonomy and well-being, as well as worsening of the quality of life of their caregivers. The management of the increased number of older adults at risk of developing severe cognitive decline is a big challenge for health care systems, with the annual global cost expected to rise to US $2 trillion by 2030 [2]. These pathologies start silently up to 20 years before clear cognitive symptoms. However, there is increasing evidence that pharmaceutical interventions may be most effective at milder stages of dementia [3]. Thus, it is fundamental to find strategies that may anticipate the diagnosis [4-6]. Current diagnostic procedures require a thorough examination by medical specialists. The most employed tool for the first screening of cognitive function is the Mini-Mental Status Examination (MMSE). It is based on 30 questions that address short and long-term memory, attention span, concentration, language, and communication skills, as well as the ability to plan and understand instructions [7]. A score of 26 or higher is usually classified as normal. If the score is below 25, the result highlights a possible cognitive impairment, which may be classified as mild (21≤MMSE score≤26) or moderate to severe (MMSE score≤20). Although this test has high sensitivity and specificity (87% and 82%, respectively) [8] and can be quickly administered, its employment is restricted within primary care facilities. Thus, faster, noninvasive, and automatic methods are needed to provide digital biomarkers for large-scale monitoring of cognitive functions in real-life scenarios [9].

In recent years, voice has been one of the most studied digital biomarkers since it allows cheap, noninvasive, ecological, rapid, and remote assessment of several aspects of a patient’s health status, such as the functionality of the respiratory system, cognitive decline, emotions, and heart dysfunctions [7,10-12]. Speech and language capacity is a well-established early indicator of cognitive deficits [13,14]. In the early phase of dementia, participants show alterations in the rhythm, resulting in a higher number of pauses, probably due to word-finding problems (ie, anomia and semantic paraphasia), worsening of verbal fluency [15-17], low speech rates, and decrease in the length of voiced segments [18-20]. Several studies have addressed the possibility of identifying signs of cognitive decline from voice recordings. Martínez-Sánchez and colleagues [21] analyzed the temporal parameters of reading fluency to discriminate between Spanish-speaking asymptomatic participants and those with Alzheimer disease (AD), and they were able to differentiate between patients with AD and healthy controls with an accuracy of 80% based on the speech rate. However, using a reading task introduces the possibility that participants’ fluency is affected by other factors such as educational level or visual impairment. Konig et al [22] demonstrated that it is possible to differentiate between dementia and mild cognitive impairment (MCI) in English-speaking participants based on voice features extracted from different tasks, for example, verbal fluency, picture description, counting down, and free speech, with a classification accuracy of 86%. Toth et al [23] showed that acoustic parameters such as speech rate, hesitation ratio, number of pauses, and articulation rate yield good results in discriminating between Hungarian-speaking participants with MCI and healthy controls. They analyzed a movie recall task and achieved an F_1-score of 78.8%. Calzà et al [2] were able to discriminate between Italian-speaking healthy controls and participants with MCI by using random forest and support vector machine (SVM) with an F_1-score of 75% by employing natural language processing. Finally, Bertini et al [24] achieved high performance (accuracy of 93% and F_1-score of 88.5%) based on acoustic features extracted from spontaneous speech from a corpus of English-speaking participants, that is, Pitt Corpus, by using deep learning techniques. Nevertheless, natural language processing and deep learning require the analysis of raw data, thus having access to the recordings’ information content and endangering the participants’ privacy. Most previous works [2,21-24] aimed to distinguish participants with a proper diagnosis of AD or MCI from healthy participants. However, as far as we know, there are no studies investigating whether machine-learning algorithms based on voice features can identify early signs of functional cognitive decline detected by a decrease in the MMSE score.

In a previous study of our group [25], voice features automatically extracted from recordings of episodic storytelling could discriminate between Italian-speaking participants with normal cognitive functions (MMSE score≥27) and participants with mild cognitive decline (20≤MMSE score≤26) with an accuracy of 73%. Starting from this preliminary study, our study exploits acoustic features automatically extracted from spontaneous speech and machine learning techniques to support the early identification of cognitive function decline, meant as a reduction of the MMSE score. The main novelties involve the extension of a number of features, reduction of the computational time for feature extraction, and the multilanguage approach since both Spanish- and Italian-speaking participants were considered.

Methods

Participants and Data Collection

A sample of older adults were recruited in Italy (Lombardy region) and Spain (Extremadura region). In Italy, participants were recruited based on direct contact with the Geriatric Unit of the Foundation Scientific Institute for Research, Hospitalization and Healthcare (IRCCS) Ca’ Granda Ospedale Maggiore Policlinico (day hospital, ambulatory, and gymnasium). In Spain, people were recruited based on direct contact with professionals working in health care belonging to the Extremadura Health Ecosystem.

The essential requirement for participation was a good knowledge, at least oral, of the language of the country where the audios were recorded. Exclusion criteria were nonnative-speaking participants, clinically unstable participants, terminal illness (life expectancy <6 months), severe hearing or visual deficits, aphasia, and a score on the 30-item Geriatric Depression Scale >9. After providing informed consent to participate in the study, participants were met individually and they underwent the MMSE performed by health care professionals (geriatrician in Italy and neuropsychologist in Spain). Afterward, they were asked to tell 3 stories about their life for 2 minutes each without interruptions (positive, negative, and episodic) and to provide a 2-minute description of the "Cookie-Theft picture" of the Boston Diagnostic Aphasia Examination [26]. For each task, voice signals were recorded in separate .WAV files (16 kHz) by using an ad-hoc toolbox developed in MATLAB (MathWorks), through an external USB microphone. Participants were divided into 3 groups based on the MMSE score:

1. Group 1: MMSE score≥27, that is, healthy participants
2. Group 2: 20≤MMSE score≤26, that is, participants with mild impairment of cognitive function
3. Group 3: 11≤MMSE score≤19, that is, participants with a moderate to severe impairment of cognitive function

The choice of the MMSE score for separation among the groups was employed since the aim was to detect the earliest symptoms of cognitive decline in the prediagnostic phase.

Ethics Approval

This study was approved by the ethics committee of Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico in Italy (ref: 1272018, approval date: March 15, 2018) and by the Comité Ético de Investigaciòn Clìnica de Badajoz in Spain (approval date: April 11, 2018).

Feature Extraction and Statistical Analysis

Data preprocessing and features extraction were performed employing an automatic algorithm implemented in MATLAB [25]. A positive speech polarity was imposed, and voice recordings were standardized. Afterward, the acoustic features described in Table 1 were extracted [20,21,23,27,28]. The features were grouped into 4 macrocategories according to their information content: voice periodicity, shimmer-related, syllabic, and spectral features. Feature extraction was repeated 3 times for voice segments lasting 5 seconds, 10 seconds, and 15 seconds to assess whether different time lengths can capture specific patterns. For each voice segment length, voice features extracted from the 4 audio recordings were substituted by their mean and standard deviation or their median and interquartile range, based on data set distribution, assessed by the Anderson-Darling normality test. Thus, each participant was represented by a single entry in the final data set, and 138 acoustic features (23 features × 3 segments length × 2 statistics) were computed for each entry. A 1-way analysis of variance for independent samples was applied to compare the 3 groups in terms of age. Due to their categorical nature, the Kruskal-Wallis test was applied to compare years of education and MMSE scores among groups. A Pearson chi-squared test was instead used for gender. Finally, generalized linear mixed models were defined in SPSS Statistics (version 28; IBM Corp) to evaluate whether acoustic features were significantly different among groups. Specifically, the mean (or median) values of the 23 acoustic features extracted from the 15-second segments were considered as the target for each model following a gamma regression distribution with a log link to the linear model. If significant differences were found, post hoc analysis with Bonferroni correction was also performed.

Table 1. Overview of the extracted features.

Domain, feature description	Feature code
Voice periodicity	
Unvoiced percentage, that is, percentage of aperiodic parts in the audio segment	F1
Duration of voiced and unvoiced segments, that is, mean, median, 15th and 85th percentiles of the parts of the signal with (voiced) and without (unvoiced) periodic nature	F2-F9
Percentage of voice breaks computed on the number of distances between consecutive pulses longer than 1.25 divided by the pitch floor (70 Hz) [27]	F10
Shimmer	
Shimmer, that is, random cycle-to-cycle temporal changes of the amplitude of the vocal fold vibration [28]	F11
Syllabic and pauses features	
Speech rate, that is, number of syllables per second [21]	F12
Percentage of phonation time, that is, the intrasyllabic and intersyllabic nuclei time <250 ms divided by the total speech time [20,21]	F13
Articulation rate, that is, the number of syllables divided by the phonation time without pause [20,21]	F14
Mean duration of intersyllabic pauses >250 ms [21]	F15
Mean duration of syllables [20,21]	F16
Number and mean duration of pauses of the audio segment [23]	F17-F18
Spectral features	
Mean (SD) of pitch	F19-F20
Standard deviation of third formant (F3-SD)	F21
Speech temporal regularity, that is, temporal structure of the audio segment	F22
Centroid, that is, location of the center of mass of the spectral signal	F23

Feature Selection and Classification

Machine learning algorithms were trained to solve multiclass and binary classification problems (group 1 vs group 2 and group 1 vs group 3) starting from the extracted voice features, which were preliminary normalized.

Classifiers

SVM [29], logistic regression (LR), and CatBoost classifier (CAT) [30] were used. SVM is robust to noise in training data, since SVM decisions are only determined by the support vectors, while CAT represents the state of the art of boosting algorithms based on decision trees, and it has been proven to be very effective with small data sets with a high number of features. LR was investigated due to its simplicity and low computational cost. To achieve robust estimations despite the relatively small number of samples, the performance of each classifier was evaluated using stratified nested 10-fold cross-validation, which leads to the construction of an ensemble model via soft voting starting from each fold, obtaining a macromodel composed of 10 models trained on different subsets of data [31]. The classifier was selected according to the accuracy obtained in validation. Finally, a Kruskal-Wallis test was performed to determine whether there was a statistically significant difference between different classifiers in terms of accuracy.

Parameter Setting

Hyperparameter tuning was performed to limit overfitting with the nonlinear classifier. The following parameters were tuned for CAT through a randomized search method: bagging temperature, tree depth, l2 leaf regularization, and random strength. SVM was employed with a linear kernel and default parameters, and LR was also considered with default parameters. All the experiments were implemented using scikit-learn Python libraries, Catboost library, and Shapley Additive Explanation (SHAP).

Feature Selection

Due to the high dimensionality of the features set, the selection of the most informing features was performed through SHAP [32]. For each fold, starting from the entire set of features, the training was performed iteratively by computing the accuracy and the feature importance via SHAP for that specific iteration. At the end of each iteration, the 2 least significant features were removed until the minimum number of 6 features was reached. Therefore, the best model, that is, the one that achieved the best accuracy, was selected for each fold of the outer loop, and the model parameters were tuned for the identified set of features. As a result, 10 models trained on 10 different folds, each characterized by a different set of parameters and exploiting a different set of features, were obtained. The algorithm related to a single fold of the outer loop is summarized in Textbox 1. Finally, the ranking of the most informing features was implemented by summing up the unweighted mean of the Shapley values obtained at the end of the training of each fold for each feature.

Textbox 1. Algorithm of feature elimination with Shapley Additive Explanations.

```
1: Train algorithm with whole set of features
2: Calculate model performance
3: Calculate feature importance with Shapley Additive Explanations
4: for feature in range (0, total features-6) do
    • Remove the k=2 least significant features
    • Train the model with the remaining features
    • Evaluate machine learning performance based on the scoring function
    • Calculate new features ranking with Shapley Additive Explanations explainer
5: end for
6: Best set is the one with the highest scoring function
```

Results

Characteristics of the Participants

Table 2 shows the characteristics of the recruited participants. A total of 266 participants were recruited: 133 Italian-speaking and 133 Spanish-speaking older adults. In the Italian data set, most participants in all groups were females. In contrast, in the Spanish data set, participants were balanced for gender in group 1 and unbalanced in favor of females in the other 2 groups. Overall, significant differences in terms of age (P=.03 and P=.001 for the Italian and Spanish data sets, respectively), MMSE scores (*P*<.001 for both data sets), and years of education (only for the Italian data set, *P*<.001) were found among the 3 groups, with people with severe impairment of the cognitive function being characterized by an older age in both data sets and by fewer years of education in the Italian data set.

Table 2. Characteristics of the participants.

	Group 1[a]	Group 2[b]	Group 3[c]	*P* value	*P* value group 1 vs group 2	*P* value group 2 vs group 3	*P* value group 1 vs group 3
Italian data set							
Participants, n	45	44	44	N/A[d]	N/A	N/A	N/A
Age (years), mean (SD)	76.5 (4.9)	82.8 (4.6)	84.9 (5.7)	.03	.22	>.99	.02
Gender (female/male)	39/6	33/11	37/7	.40	N/A	N/A	N/A
MMSE[e] (0-30), median (IQR)	30 (1)	24 (3)	16 (5)	<.001	<.001	<.001	<.001
Years of education, median (IQR)	13 (3)	8 (8)	5 (5)	<.001	<.001	.36	<.001
Spanish data set							
Participants, n	43	45	45	N/A	N/A	N/A	N/A
Age (years), mean (SD)	79.9 (7.5)	82.4 (6.9)	85.6 (6.6)	.001	.05	.27	.001
Gender (female/male)	21/22	36/9	27/18	.09	N/A	N/A	N/A
MMSE (0-30), median (IQR)	28 (2)	23 (3)	17 (2)	<.001	<.001	<.001	<.001
Years of education, median (IQR)	6 (5)	5 (4)	7 (4)	.25	N/A	N/A	N/A

[a] Group 1: Mini-Mental Status Examination score≥27.

[b] Group 2: 20≤Mini-Mental Status Examination score≤26.

[c] Group 3: 11≤Mini-Mental Status Examination score≤19.

[d] N/A: not applicable.

[e] MMSE: Mini-Mental Status Examination.

Acoustic Feature Characteristics

Table 3 reports the results of the statistical analysis comparing acoustic features for the Italian and Spanish data sets. Voice periodicity features, particularly those related to unvoiced segments, were found to be significantly different among groups (P<.001 for mean, median, and 85th percentile of duration of unvoiced segments). Indeed, from group 1 up to group 3, a significant increase (P<.001 for mean and 85th percentile and P=.004 for median) in the unvoiced duration was found. Significant differences were found also for some syllabic features such as duration of pauses and syllables, which significantly increased with the decrease in the MMSE score, as expected from literature [20]. The results of the statistical analysis comparing acoustic features for the Italian and Spanish data sets separately are reported in Multimedia Appendix 1 (Tables S1 and S2).

Table 3. Acoustic feature characteristics and significance between the 3 groups for the Italian and Spanish data sets.

Domain, features	Group 1[a] (n=88)	Group 2[b] (n=88)	Group 3[c] (n=89)	*P* value	Group 1 vs group 2	Group 2 vs group 3	Group 1 vs group 3
Voice periodicity, mean (SD)							
Unvoiced (%)	32.7 (10.4)	38.2 (13.5)	44.7 (11.8)	<.001[d]	.004[d]	.003[d]	.001[d]
Duration of voiced segments (s)							
Mean	1.08 (0.36)	1.03 (0.4)	0.98 (0.79)	.24	N/A[e]	N/A	N/A
Median	0.88 (0.32)	0.82 (0.35)	0.8 (0.75)	.33	N/A	N/A	N/A
15th percentile	0.26 (0.1)	0.24 (0.1)	0.22 (0.11)	.003[d]	.24	.29	.002[d]
85th percentile	2.03 (0.71)	1.93 (0.76)	1.77 (1.07)	.08	N/A	N/A	N/A
Duration of unvoiced segments (s)							
Mean	0.5 (0.14)	0.6 (0.2)	0.71 (0.23)	<.001[d]	<.001[d]	<.001[d]	<.001[d]
Median	0.37 (0.12)	0.43 (0.13)	0.49 (0.17)	<.001[d]	.001[d]	<.001[d]	.04[d]
15th percentile	0.15 (0.02)	0.16 (0.03)	0.17 (0.03)	.08	N/A	N/A	N/A
85th percentile	0.91 (0.27)	1.14 (0.46)	1.42 (0.56)	<.001[d]	<.001[d]	<.001[d]	<.001[d]
Voice breaks (%)	34.22 (10)	39.89 (13)	47.17 (11)	<.001[d]	.001[d]	.001[d]	<.001[d]
Shimmer, mean (SD)							
Shimmer	5 (0.56)	5.19 (0.67)	5.05 (0.75)	.17	N/A	N/A	N/A
Syllabic and pauses features, mean (SD)							
Speech rate (syl/s)	3.92 (0.59)	3.52 (0.63)	3.78 (6.76)	.15	N/A	N/A	N/A
Phonation (%)	70 (8)	64 (9)	64 (71)	.06	N/A	N/A	N/A
Articulation rate (syl/s)	5.61 (0.44)	5.54 (0.5)	5.41 (0.46)	.02[d]	.89	.22	.01[d]
Mean intersyllabic duration (s)	0.14 (0.01)	0.15 (0.02)	0.16 (0.02)	<.001[d]	.001[d]	.003[d]	<.001[d]
Mean syllabic duration (s)	0.74 (0.17)	0.91 (0.29)	1.14 (0.37)	<.001[d]	<.001[d]	<.001[d]	<.001[d]
Number of pauses	0.62 (0.19)	0.79 (0.31)	1.01 (0.48)	<.001[d]	<.001[d]	<.001[a]	<.001[d]
Mean duration of pauses (s)	5.09 (1.26)	5.1 (1.42)	5.32 (1.23)	.51	N/A	N/A	N/A
Spectral features, mean (SD)							
Pitch							
Mean	162 (25)	166 (26)	158 (25)	.11	N/A	N/A	N/A
SD	68 (12)	72 (12)	79 (15)	<.001[d]	.10	.004[d]	<.001[d]
F3-SD[f]	466 (46)	490(46)	484.92 (46)	.001[d]	.002[d]	>.99	.02[d]
Speech temporal regularity	1749.5 (66)	1716.4 (67)	1687.8 (85)	<.001[d]	.01[d]	.03[d]	<.001[d]
Centroid	807.8 (154)	776.5 (165)	755.9 (193)	.12	N/A	N/A	N/A

[a] Group 1: Mini-Mental Status Examination score≥27.

[b] Group 2: 20≤Mini-Mental Status Examination score≤26.

[c] Group 3: 11≤Mini-Mental Status Examination score≤19.

[d] Significant at P<.05.

[e] N/A: not applicable.

[f] F3-SD: standard deviation of third formant.

Multiclass Classification

Table 4 reports the results of the multiclass classification in terms of accuracy for 3 data sets: only Italian, only Spanish, and combination of Italian and Spanish participants. Overall, CAT achieved the best scores on the validation sets for the 3 data sets, but its performance considerably worsened when applied to the test sets. From the Kruskal-Wallis test, it can be seen that CAT achieved significantly better performance than LR for all data sets (P=.005, P=.02, and P=.03 for the Italian, Spanish, and Italian&Spanish data sets, respectively). A significant difference was also highlighted between SVM and CAT for the multilanguage data set (P=.01) and between SVM and LR for the Spanish data set (P=.003). Since there was no substantial difference in the accuracy between SVM and CAT, SVM was selected for its simplicity and further metrics, that is, receiver operating characteristic (ROC) curves, confusion matrices, and feature rankings are also reported (Figures 1-2). Overall, ROC curves (Figures 1A, 1C, and 1E) show a better trend for groups 1 and 3, whereas for group 2, the curve almost overlaps the bisector. The macro and micro averages of the areas under the curves achieved a fair score. The confusion matrices in Figures 1B, 1D, and 1F confirm this trend, with group 2 being the most misclassified in all 3 cases. For the Italian data set (Figure 1B), the model mainly misclassifies the participants from group 2 with those belonging to group 3, whereas for the Spanish data set (Figure 1D), participants from group 2 were mainly misclassified with participants from group 1.

The feature rankings obtained from SHAP (Figure 2) show the contribution of the most important features, ranked from the most to the least informing. It can be seen that the most important features changed depending on the considered language. For the Italian data set (Figure 2A), the spectral features (in purple), and those related to voice periodicity (in green) were among the most important features, whereas within the Spanish data set (Figure 2B), features related to syllables and pauses (in blue) and shimmer (in yellow) became more important. For the Italian&Spanish data set, the resulting ranking was a combination of the previous two, as displayed in Figure 2C.

Table 4. Classification accuracies on the validation and test sets for the multiclass classification among the 3 groups (healthy, mild, and severe symptoms) for the 3 data sets.

Data set	CAT[a]	SVM[b]	LR[c]	*P* value	CAT vs SVM	CAT vs LR	SVM vs LR
Italian, mean (SD)							
Validation	0.67 (0.03)	0.64 (0.02)	0.63 (0.03)	.006	.46	.005	.12
Test	0.54 (0.08)	0.57 (0.16)	0.59 (0.13)	N/A[d]	N/A	N/A	N/A
Spanish, mean (SD)							
Validation	0.63 (0.02)	0.64 (0.02)	0.60 (0.02)	.002	.88	.02	.003
Test	0.49 (0.09)	0.53 (0.11)	0.51 (0.15)	N/A	N/A	N/A	N/A
Italian&Spanish, mean (SD)							
Validation	0.61 (0.01)	0.58 (0.02)	0.58 (0.02)	.008	.01	.03	.92
Test	0.53 (0.06)	0.54 (0.08)	0.52 (0.09)	N/A	N/A	N/A	N/A

[a] CAT: CatBoost classifier.

[b] SVM: support vector machine.

[c] LR: logistic regression.

[d] N/A: not applicable.

Figure 1. Receiver operating characteristic curves and confusion matrices obtained with support vector machine for multiclass classification of the (A,B) Italian, (C,D) Spanish, and (E,F) Italian&Spanish data sets, respectively. (A,C,E): The dotted pink line corresponds to the microaveraged receiver operating characteristic curve, while the dotted blue curve corresponds to the macroaveraged one. (B,E,F): Labels 1, 2, and 3 on the x and y axes correspond to the group number.

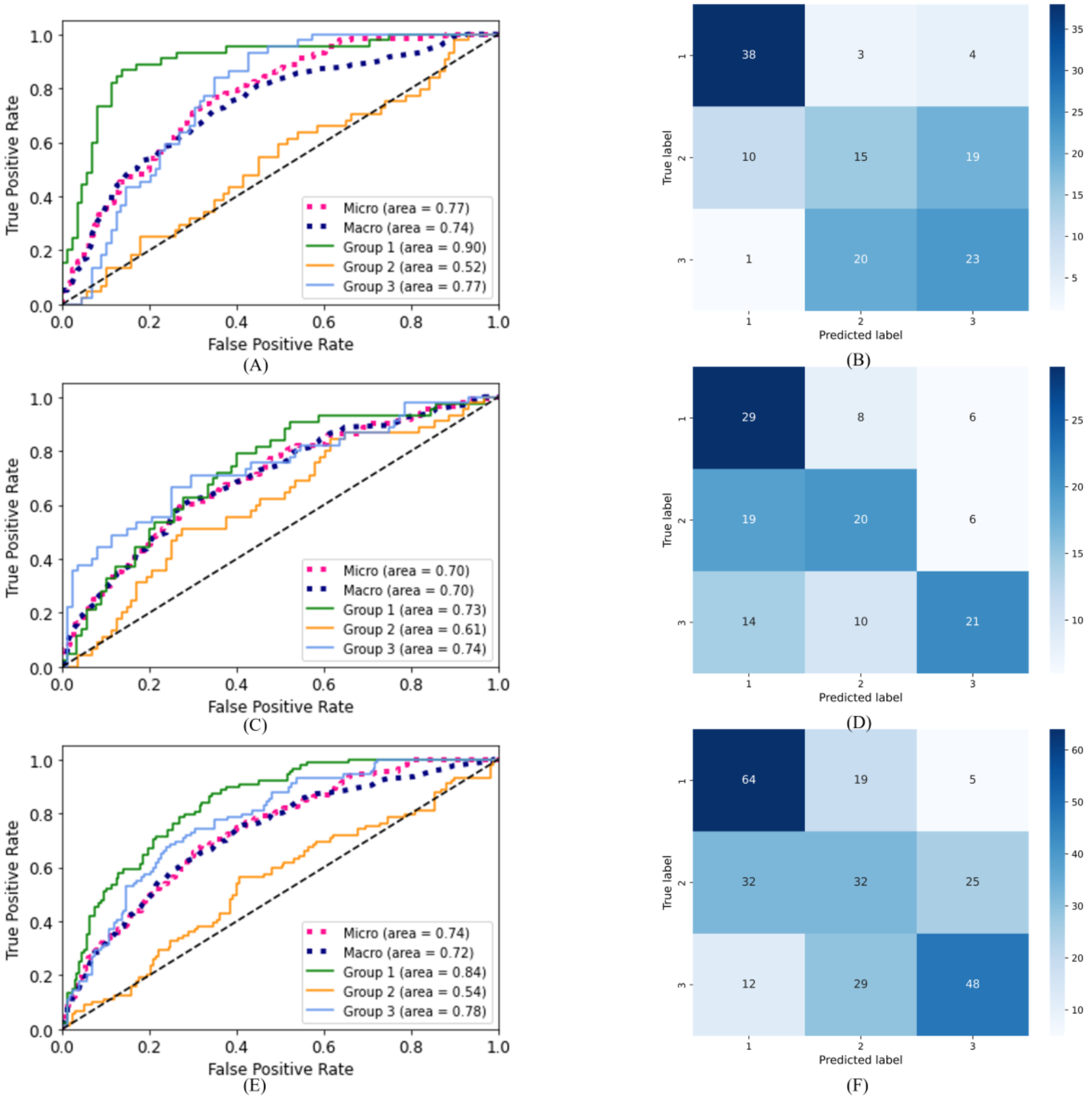
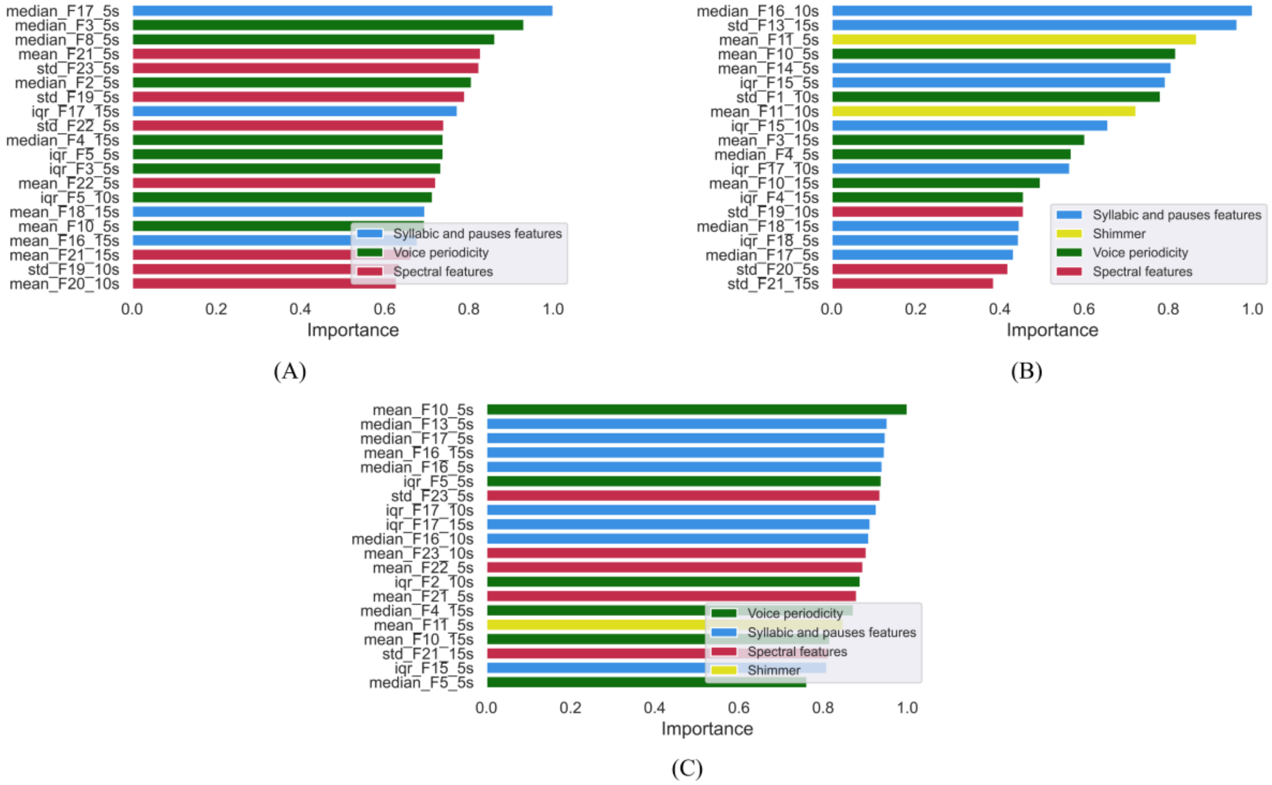


Figure 2. Feature ranking for (A) Italian, (B) Spanish, and (C) Italian&Spanish data sets. Rank is represented from top to bottom from the most contributing to the least important feature.



(A)

(B)

(C)

Binary Classification

Tables 5 and 6 report the performance achieved for the binary classification, respectively, to distinguish group 1 (MMSE≥27) and group 2 (20≤MMSE≤26) and group 1 and group 3 (11≤MMSE≤19). SVM achieved the best scores on the validation sets compared to CAT and LR for the Italian&Spanish data sets in the discrimination between group 1 and group 2. However, the discrimination between group 1 and group 3 achieved a substantial equivalence among the 3 algorithms. As expected, better performance was obtained in the discrimination between healthy participants and those with severe impairment. As for the multiclass scenario, the accuracy of the test sets worsened in all data sets, with the Spanish data set experiencing the largest decrease.

ROC curves, confusion matrices, and feature rankings for the Italian&Spanish data set were shown for SVM, which achieved the best performance, at least in distinguishing group 1 from group 2. Regarding ROC curves, the results were poor for the classification between healthy participants and those with mild impairment, with an area under the curve score of 0.65 (Figure 3A), as it can be noticed also by the confusion matrix in Figure 3B. Fair results were obtained for the ROC curve concerning the distinction between healthy participants and participants with impairment, with an area under the curve score of 0.77 (Figure 4A). Moreover, the confusion matrix (Figure 4B) shows a smaller number of misclassified participants. Feature rankings showed that the most informing features were mainly spectral features and features related to voice periodicity for the classification between healthy participants and participants with mild impairment (Figure 5A). In contrast, features related to syllables and pauses (in blue) were more important for classifying between healthy and older adults with severe impairment (Figure 5B). ROC curves, confusion matrices, and feature rankings related to binary classifications of the Italian&Spanish data sets are reported in Multimedia Appendix 1.

Table 5. Classification accuracies on the validation and test sets for the binary classification of group 1 (Mini-Mental State Examination score≥27) versus group 2 (20≤Mini-Mental State Examination score≤26).

Data set	CAT[a]	SVM[b]	LR[c]	*P* value	CAT vs SVM	CAT vs LR	SVM vs LR
Italian, mean (SD)							
Validation	0.80 (0.02)	0.84 (0.02)	0.79 (0.02)	<.001	.007	.91	.02
Test	0.71 (0.14)	0.80 (0.14)	0.76 (0.16)	N/A[d]	N/A	N/A	N/A
Spanish, mean (SD)							
Validation	0.74 (0.04)	0.79 (0.02)	0.76 (0.03)	.004	.005	.79	.03
Test	0.62 (0.15)	0.59 (0.16)	0.62 (0.17)	N/A	N/A	N/A	N/A
Italian & Spanish, mean (SD)							
Validation	0.74 (0.02)	0.76 (0.01)	0.74 (0.02)	.06	N/A	N/A	N/A
Test	0.64 (0.12)	0.65 (0.11)	0.65 (0.13)	N/A	N/A	N/A	N/A

[a] CAT: CatBoost classifier.

[b] SVM: support vector machine.

[c] LR: logistic regression.

[d] N/A: not applicable.

Table 6. Classification accuracies on the validation and test sets for the binary classification of group 1 (Mini-Mental State Examination score≥27) versus group 3 (11≤Mini-Mental State Examination score≤19) for the 3 data sets.

Data set	CAT[a]	SVM[b]	LR[c]	*P* value	CAT vs SVM	CAT vs LR	SVM vs LR
Italian, mean (SD)							
Validation	0.92 (0.02)	0.93 (0.02)	0.92 (0.02)	.38	N/A[d]	N/A	N/A
Test	0.82 (0.14)	0.86 (0.18)	0.89 (0.14)	N/A	N/A	N/A	N/A
Spanish, mean (SD)							
Validation	0.84 (0.03)	0.83 (0.02)	0.82 (0.03)	.17	N/A	N/A	N/A
Test	0.83 (0.12)	0.73 (0.11)	0.71 (0.15)	N/A	N/A	N/A	N/A
Italian&Spanish, mean (SD)							
Validation	0.85 (0.02)	0.85 (0.01)	0.84 (0.01)	.05	N/A	N/A	N/A
Test	0.79 (0.11)	0.78 (0.05)	0.81 (0.06)	N/A	N/A	N/A	N/A

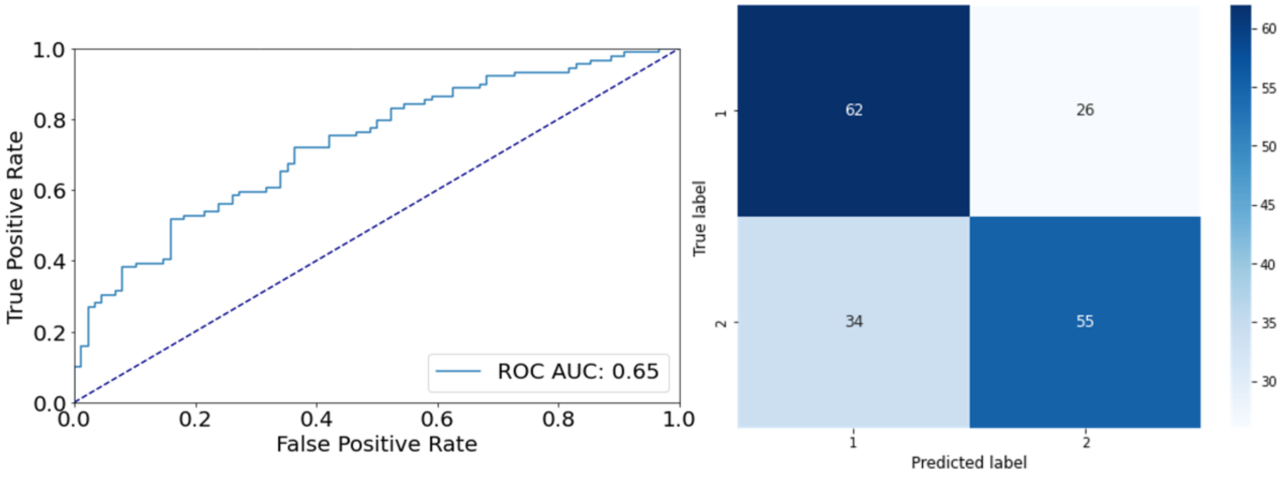
[a] CAT: CatBoost classifier.

[b] SVM: support vector machine.

[c] LR: logistic regression.

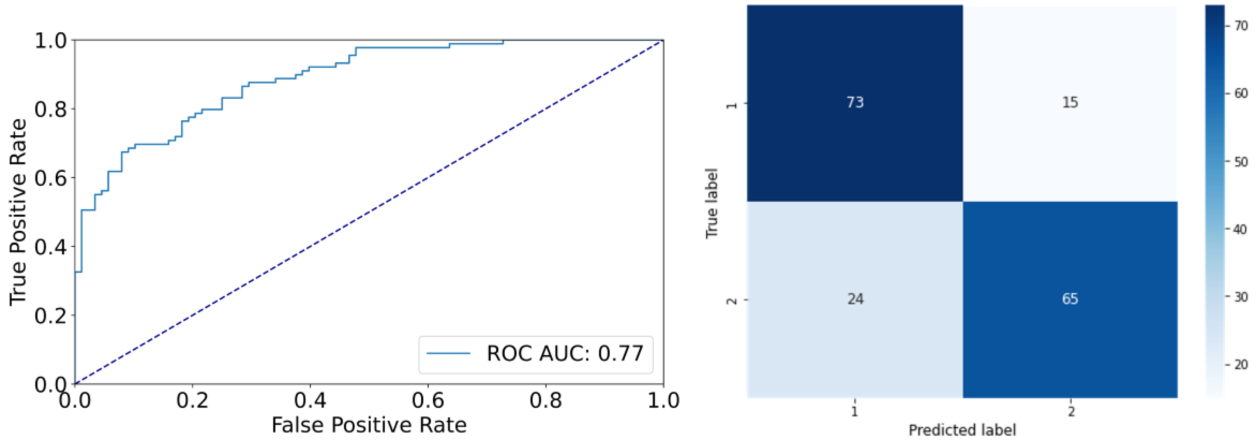
[d] N/A: not applicable.

Figure 3. (A) Receiver operating characteristic curve and (B) confusion matrix for the binary classification of group 1 (Mini-Mental Status Examination score≥27) and group 2 (20≤Mini-Mental Status Examination score≤26) of the Italian&Spanish data set. AUC: area under the curve; ROC: receiver operating characteristic.



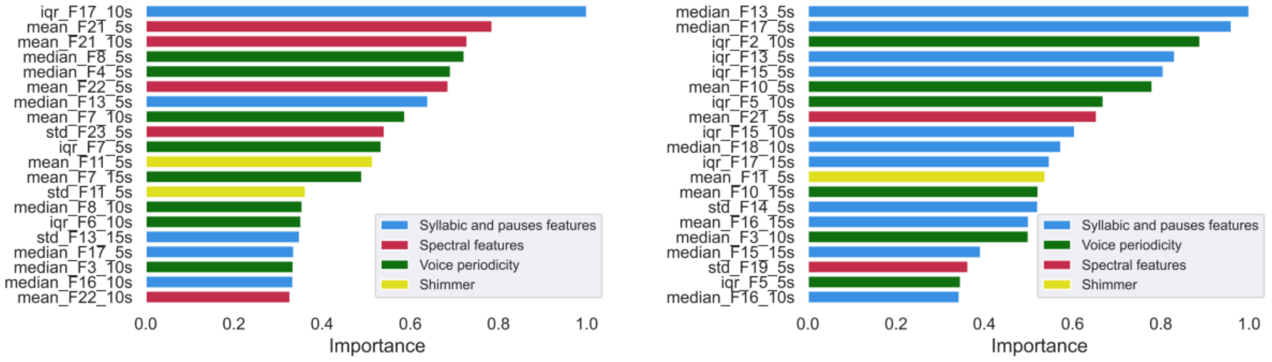
(A) (B)

Figure 4. (A) Receiver operating characteristic curve and (B) confusion matrix for the binary classification between group 1 (Mini-Mental Status Examination score≥27) and group 3 (11≤Mini-Mental Status Examination score≤19) of the Italian&Spanish data set. AUC: area under the curve; ROC: receiver operating characteristic.



(A) (B)

Figure 5. Feature ranking for the binary classifications of the Italian&Spanish data set. (A) Group 1 versus group 2; (B) group 1 versus group 3.



(A) (B)

Discussion

An artificial intelligence–based classification pipeline has been implemented to evaluate the possibility of using voice analysis as a prescreening tool for detecting the impairment of cognitive function in a single and multilanguage approach. Multiclass and binary classification were performed on 3 data sets (Italian, Spanish, and a combination of Italian and Spanish data sets). For the multiclass tasks, the models obtained an accuracy of 57%, 53%, and 54% on the test set with SVM on the Italian, Spanish, and multilanguage data set, respectively. Regarding the binary classification, an accuracy of 80%, 59%, and 65% in the test set was achieved on the Italian, Spanish, and multilanguage data set, respectively, when distinguishing between healthy participants and those with the first symptoms of cognitive decline and an accuracy of 86%, 73%, and 78% for the classification between healthy participants and those with an MMSE score≤19. The ROC curves in the multiclass task underlined how the participants with mild symptoms of cognitive decline are the most misclassified. This outcome aligns with expectations since participants belonging to this group exhibit mild impairment, indicated by an intermediate MMSE score. When having a deeper look into the misclassifications results (confusion matrices in Figure 1B and 1D), we observed that for the Italian data set, the model mainly misclassified participants from group 2 with those belonging to group 3, while for the Spanish data set, participants from group 2 were mainly misclassified with participants belonging to group 1. This result is in line with the results of the statistical analysis for the 2 data sets separately, which are reported in Multimedia Appendix 1 (Tables S1-S2): the statistical analysis highlighted a higher number of significantly different acoustic features between group 1 and group 2 for the Italian data set, while for the Spanish data set, there was a higher prevalence of acoustic features, which significantly differed between group 2 and group 3. A possible confounding factor might be the different distributions between the 2 data sets in terms of years of education, with a difference of 5 years between group 1 and group 2 for the Italian data set and a difference of only 1 year for the Spanish data set (Table 2).

The overall differences in the performance between the 2 languages may be explained by the heterogeneous demographic characteristics between the 2 data sets. Indeed, the distribution of participants in terms of gender, which highly affects acoustic features such as pitch [33], differed between the Italian and Spanish data set. In the Italian one, the distribution was more similar among the 3 groups, with a prevalence of females in each group, whereas for the Spanish data set, there was a prevalence of females in group 2 and group 3 compared to group 1, in which there was a balance between the 2 genders. Furthermore, the overall lower performance obtained on the Spanish data set may be related to the distribution of the MMSE scores among the groups. Indeed, there was a sharper separation among the 3 groups in the Italian data set, with a median MMSE score of 30 in group 1 and a median MMSE score of 24 in group 2, whereas the distribution of the scores in the Spanish data set was shrunk, with more participants being borderline among the groups (see Table 2).

The results highlighted that different sets of features are relevant depending on the considered language and the specific task. Indeed, shimmer was shown to be more relevant in Spanish-speaking participants, suggesting that an amplitude variation is predictive of a decline in cognitive function, whereas spectral features and those related to the voiced and unvoiced parts of speech were more important for predicting cognitive decline in Italian-speaking participants. The feature rankings of the classification tasks obtained with the multilanguage data set showed that the most informing features were a combination of those achieved for the 2 languages, when considered individually. This variability in the ranking of the features may be due to the change in prosody and accents of the languages themselves. Indeed, the Italian language is characterized by a wider spectral range compared with Spanish [34], which might explain why spectral features are predominant in the prediction of cognitive decline for the Italian data set. Nevertheless, these speculations need to be further explored in future studies.

Compared to that achieved by Calzà et al [2], we achieved slightly higher performance in the binary classification for distinguishing participants with mild cognitive decline from healthy participants when only the Italian data set was considered. Indeed, we achieved a test accuracy of 80%, while Calzà and colleagues [2] obtained an F_1-score of 75% on a manually checked corpus. However, there are several differences between these 2 studies. First, they considered not only acoustic features extracted from free speech but also lexical and syntactic features extracted with natural language processing as well as the demographic characteristics of the participants, such as age and years of education, which are considered important indicators of cognitive decline [35]. Conversely, we exploited only acoustic features automatically extracted from free speech, without considering any demographic features, to evaluate the possibility of exploiting this method for longitudinal monitoring. Moreover, in their work, Calzà and colleagues [2] recruited participants with a diagnosis of MCI based on a neuropsychological assessment, while in our work, we focused on the prescreening phase before an eventual diagnosis of MCI, and indeed, our groups were discriminated only based on the MMSE score. In another work [24], Bertini et al achieved instead higher performances, that is, 93% after data augmentation with a 20-fold cross-validation with acoustic features extracted from spontaneous speech from a corpus of English-speaking participants, that is, the Pitt Corpus, by applying deep learning techniques on a graphics processing unit. In their study, patients had a diagnosis of AD with the mean MMSE scores of the healthy control group of approximately 29 versus the AD group characterized by a mean score of 18. The lower performances of our model (accuracy of 86% to discriminate between group 1 and group 3 in the Italian data set) may be due to the use of the MMSE score only to distinguish between groups, which may have resulted in misclassification problems. Toth et al [23] achieved 75% accuracy from a binary classification task on Hungarian-speaking participants to distinguish healthy controls from those with MCI by using leave-one-out cross-validation on a set of 88 participants. Our results slightly outperformed their results on the Italian data set (accuracy of 80%), while we achieved lower performances on the Spanish and the multilanguage data sets (accuracy of 62% and 65%, respectively). However, as in the previous studies [2,24], but differently from our study, Toth and colleagues [23] recruited participants with a diagnosis of MCI based on a neuropsychological assessment. Martínez-Sánchez et al [21] classified dementia among Spanish-speaking participants with an accuracy of 80%. The analysis was conducted to distinguish between 35 patients with AD and 35 healthy participants. They stated that fluency is an important aspect of cognitive decline from spontaneous speech, which was confirmed in our work by Figure 1D since the duration of syllables, phonation percentage, and articulation rate are in the top 5 most important features for the multiclass classification of the Spanish data set.

Our approach is based on acoustic features that can be automatically extracted on-the-fly on short speech segments. The satisfactory accuracy achieved with this approach to distinguish healthy participants from those with mild impairment (80% for the Italian data set) makes our results promising toward the design of a mobile app. Leveraging on this tool, an ecological and transparent mass screening of the early signs of cognitive decline can be performed, for example by analyzing free speech during phone calls. Moreover, since there is no need to store raw data and the information content of the speech is not exploited, this tool would preserve the speaker's privacy.

This work has some limitations. The performance of the models on unseen data, that is, on the test set, worsened overall, probably due to the lack of the generalization power of the model; therefore, there is the need for larger data sets to have more robust classification models. Furthermore, regarding the Spanish data set, another limitation was the lower number of years of education of the recruited participants. Previous studies recruited only participants with more than 6 years of primary education to ensure that participants were fully literate [27]. Another limitation was the use of the MMSE score as the only method to allocate participants into different groups, without collecting information about an eventual diagnosis of MCI or AD, which might have brought to misclassification issues. Furthermore, as reported by Yancheva et al [36], MMSE is affected by a within-participant interrater standard deviation of 3.9 [37,38], which may have resulted in a further wrong group assignment for some participants. Finally, the MMSE test was administered by 2 different professional roles in the 2 recruitment sites—a geriatrician in Italy and a neuropsychologist in Spain, which may have introduced further differences between the 2 data sets.

This work confirmed that it is possible to detect early symptoms of cognitive function decline from the automatic analysis of acoustic features, exploiting a multilanguage approach. Overall, good performances by considering only acoustic features to discriminate between participants with different MMSE scores were achieved. The results obtained on the classification tasks are promising for the development of a screening tool for large-scale monitoring of cognitive function in community-dwelling older adults.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary results for the binary classification tasks of the Italian and Spanish data sets.
[PDF File (Adobe PDF File), 782 KB - aging_v7i1e50537_app1.pdf]

References

1. Directorate-General for Economic and Financial Affairs, Economic Policy Committee. The 2021 ageing report: underlying assumptions and projection methodologies. Economy and Finance (European Commission). URL: https://economy-finance.ec.europa.eu/publications/2021-ageing-report-underlying-assumptions-and-projection-methodologies_en#description [accessed 2023-09-13]
2. Calzà L, Gagliardi G, Rossini Favretti R, Tamburini F. Linguistic features and automatic classifiers for identifying mild cognitive impairment and dementia. Computer Speech & Language 2021 Jan;65:101113. [doi: 10.1016/j.csl.2020.101113]
3. Posner H, Curiel R, Edgar C, Hendrix S, Liu E, Loewenstein DA, et al. Outcomes assessment in clinical trials of Alzheimer's disease and its precursors: readying for short-term and long-term clinical trial needs. Innov Clin Neurosci 2017;14(1-2):22-29 [FREE Full text] [Medline: 28386518]
4. Fraser KC, Lundholm Fors K, Eckerström M, Öhman F, Kokkinakis D. Predicting MCI status from multimodal language data using cascaded classifiers. Front Aging Neurosci 2019;11:205 [FREE Full text] [doi: 10.3389/fnagi.2019.00205] [Medline: 31427959]

5. Laske C, Sohrabi HR, Frost SM, López-de-Ipiña K, Garrard P, Buscema M, et al. Innovative diagnostic tools for early detection of Alzheimer's disease. Alzheimers Dement 2015 May;11(5):561-578. [doi: 10.1016/j.jalz.2014.06.004] [Medline: 25443858]
6. Calzà L, Beltrami D, Gagliardi G, Ghidoni E, Marcello N, Rossini-Favretti R, et al. Should we screen for cognitive decline and dementia? Maturitas 2015 Sep;82(1):28-35. [doi: 10.1016/j.maturitas.2015.05.013] [Medline: 26152814]
7. Robin J, Harrison JE, Kaufman LD, Rudzicz F, Simpson W, Yancheva M. Evaluation of speech-based digital biomarkers: review and recommendations. Digit Biomark 2020;4(3):99-108 [FREE Full text] [doi: 10.1159/000510820] [Medline: 33251474]
8. Anthony JC, LeResche L, Niaz U, von Korff MR, Folstein MF. Limits of the 'Mini-Mental State' as a screening test for dementia and delirium among hospital patients. Psychol Med 1982 May;12(2):397-408. [doi: 10.1017/s0033291700046730] [Medline: 7100362]
9. Piau A, Wild K, Mattek N, Kaye J. Current state of digital biomarker technologies for real-life, home-based monitoring of cognitive function for mild cognitive impairment to mild Alzheimer disease and implications for clinical care: systematic review. J Med Internet Res 2019 Aug 30;21(8):e12785 [FREE Full text] [doi: 10.2196/12785] [Medline: 31471958]
10. Al-Hameed S, Benaissa M, Christensen H, Mirheidari B, Blackburn D, Reuber M. A new diagnostic approach for the identification of patients with neurodegenerative cognitive complaints. PLoS One 2019;14(5):e0217388 [FREE Full text] [doi: 10.1371/journal.pone.0217388] [Medline: 31125389]
11. Pulido MLB, Hernández JBA, Ballester M, González CMT, Mekyska J, Smékal Z. Alzheimer's disease and automatic speech analysis: A review. Expert Systems with Applications 2020 Jul;150:113213. [doi: 10.1016/j.eswa.2020.113213]
12. López-de-Ipiña K, Alonso J, Travieso CM, Solé-Casals J, Egiraun H, Faundez-Zanuy M, et al. On the selection of non-invasive methods based on speech analysis oriented to automatic Alzheimer disease diagnosis. Sensors (Basel) 2013 May 21;13(5):6730-6745 [FREE Full text] [doi: 10.3390/s130506730] [Medline: 23698268]
13. Petti U, Baker S, Korhonen A. A systematic literature review of automatic Alzheimer's disease detection from speech and language. J Am Med Inform Assoc 2020 Nov 01;27(11):1784-1797 [FREE Full text] [doi: 10.1093/jamia/ocaa174] [Medline: 32929494]
14. Haider F, de la Fuente S, Luz S. An assessment of paralinguistic acoustic features for detection of Alzheimer's dementia in spontaneous speech. IEEE J. Sel. Top. Signal Process 2020 Feb;14(2):272-281. [doi: 10.1109/jstsp.2019.2955022]
15. Horley K, Reid A, Burnham D. Emotional prosody perception and production in dementia of the Alzheimer's type. J Speech Lang Hear Res 2010 Oct;53(5):1132-1146. [doi: 10.1044/1092-4388(2010/09-0030)] [Medline: 20643797]
16. Satt A, Sorin A, Toledo-Ronen O, Barkan O, Kompatsiaris I, Kokonozi A, et al. Evaluation of speech-based protocol for detection of early-stage dementia. 2013 Aug Presented at: 14th Annual Conference of the International Speech Communication Association (INTERSPEECH 2013); August 25-29; Lyon, France p. 1692-1696. [doi: 10.21437/interspeech.2013-32]
17. Beltrami D, Gagliardi G, Rossini Favretti R, Ghidoni E, Tamburini F, Calzà L. Speech analysis by natural language processing techniques: a possible tool for very early detection of cognitive decline? Front Aging Neurosci 2018;10:369 [FREE Full text] [doi: 10.3389/fnagi.2018.00369] [Medline: 30483116]
18. Roark B, Mitchell M, Hosom J, Hollingshead K, Kaye J. Spoken language derived measures for detecting mild cognitive impairment. IEEE Trans Audio Speech Lang Process 2011 Sep 01;19(7):2081-2090 [FREE Full text] [doi: 10.1109/TASL.2011.2112351] [Medline: 22199464]
19. Satt A, Hoory R, König A, Aalten P, Robert PH. Speech-based automatic and robust detection of very early dementia. 2014 Sep Presented at: 15th Annual Conference of the International Speech Communication Association (INTERSPEECH 2014); September 14-18; Singapore p. 13140-13144. [doi: 10.21437/Interspeech.2014-544]
20. Themistocleous C, Eckerström M, Kokkinakis D. Voice quality and speech fluency distinguish individuals with Mild Cognitive Impairment from Healthy Controls. PLoS One 2020;15(7):e0236009 [FREE Full text] [doi: 10.1371/journal.pone.0236009] [Medline: 32658934]
21. Martínez-Sánchez F, Meilán JJG, García-Sevilla J, Carro J, Arana JM. Oral reading fluency analysis in patients with Alzheimer disease and asymptomatic control subjects. Neurologia 2013;28(6):325-331 [FREE Full text] [doi: 10.1016/j.nrl.2012.07.012] [Medline: 23046975]
22. Konig A, Satt A, Sorin A, Hoory R, Derreumaux A, David R, et al. Use of speech analyses within a mobile application for the assessment of cognitive impairment in elderly people. Curr Alzheimer Res 2018;15(2):120-129. [doi: 10.2174/1567205014666170829111942] [Medline: 28847279]
23. Toth L, Hoffmann I, Gosztolya G, Vincze V, Szatloczki G, Banreti Z, et al. A speech recognition-based solution for the automatic detection of mild cognitive impairment from spontaneous speech. Curr Alzheimer Res 2018;15(2):130-138 [FREE Full text] [doi: 10.2174/1567205014666171121114930] [Medline: 29165085]
24. Bertini F, Allevi D, Lutero G, Calzà L, Montesi D. An automatic Alzheimer's disease classifier based on spontaneous spoken English. Computer Speech & Language 2022 Mar;72:101298. [doi: 10.1016/j.csl.2021.101298]
25. Ambrosini E, Cid M, de Isla CG, Salamanca P, Borghese NA, Ferrante S, et al. Automatic speech analysis to early detect functional cognitive decline in elderly population. Annu Int Conf IEEE Eng Med Biol Soc 2019 Jul;2019:212-216. [doi: 10.1109/EMBC.2019.8856768] [Medline: 31945880]

26. Giles E, Patterson K, Hodges JR. Performance on the Boston Cookie theft picture description task in patients with early dementia of the Alzheimer's type: Missing information. Aphasiology 1996 May;10(4):395-408. [doi: 10.1080/02687039608248419]
27. Meilan JJG, Martinez-Sanchez F, Carro J, Carcavilla N, Ivanova O. Voice markers of lexical access in mild cognitive impairment and Alzheimer's disease. Curr Alzheimer Res 2018;15(2):111-119. [doi: 10.2174/1567205014666170829112439] [Medline: 28847280]
28. Teixeira JP, Gonçalves A. Algorithm for Jitter and Shimmer measurement in pathologic voices. Procedia Computer Science 2016;100:271-279. [doi: 10.1016/j.procs.2016.09.155]
29. Burges CJ. A tutorial on support vector machines for pattern recognition. Data Mining and Knowledge Discovery 1998;2:1121-1167. [doi: 10.1023/A:1009715923555]
30. Dorogush A, Ershov V, Gulin A. CatBoost: gradient boosting with categorical features support. ArXiv Preprint posted online on October 24, 2018. [doi: 10.48550/arXiv.1810.11363]
31. Krstajic D, Buturovic LJ, Leahy DE, Thomas S. Cross-validation pitfalls when selecting and assessing regression and classification models. J Cheminform 2014 Mar 29;6(1):10 [FREE Full text] [doi: 10.1186/1758-2946-6-10] [Medline: 24678909]
32. Lundberg S, Lee SI. A unified approach to interpreting model predictions. 2017 Presented at: Thirty-first Annual Conference on Neural Information Processing Systems (NIPS); December 4-9; Long Beach, CA p. 4768-4777. [doi: 10.48550/arXiv.1705.07874]
33. Titze IR. Physiologic and acoustic differences between male and female voices. J Acoust Soc Am 1989 Apr;85(4):1699-1707. [doi: 10.1121/1.397959] [Medline: 2708686]
34. Kogan VV, Reiterer SM. Eros, beauty, and phonaesthetic judgements of language sound. we like it flat and fast, but not melodious. comparing phonetic and acoustic features of 16 European languages. Front Hum Neurosci 2021;15:578594 [FREE Full text] [doi: 10.3389/fnhum.2021.578594] [Medline: 33708080]
35. Forbes-McKay KE, Venneri A. Detecting subtle spontaneous language decline in early Alzheimer's disease with a picture description task. Neurol Sci 2005 Oct;26(4):243-254. [doi: 10.1007/s10072-005-0467-9] [Medline: 16193251]
36. Yancheva M, Fraser K, Rudzicz F. Using linguistic features longitudinally to predict clinical scores for Alzheimer's disease and related dementias. 2015 Presented at: SLPAT 2015: 6th Workshop on Speech and Language Processing for Assistive Technologies; September; Dresden, Germany p. 134-139. [doi: 10.18653/v1/w15-5123]
37. Molloy DW, Standish TIM. A guide to the standardized Mini-Mental State Examination. Int Psychogeriatr 1997;9 Suppl 1:87-94; discussion 143. [doi: 10.1017/s1041610297004754] [Medline: 9447431]
38. Molloy DW, Alemayehu E, Roberts R. Reliability of a standardized Mini-Mental State Examination compared with the traditional Mini-Mental State Examination. Am J Psychiatry 1991 Jan;148(1):102-105. [doi: 10.1176/ajp.148.1.102] [Medline: 1984692]

Abbreviations

AD: Alzheimer disease
CAT: CatBoost classifier
IRCCS: Scientific Institute for Research, Hospitalization and Healthcare
LR: logistic regression
MCI: mild cognitive impairment
MMSE: Mini-Mental State Examination
ROC: receiver operating characteristic
SHAP: Shapley Additive Explanations
SVM: support vector machine

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Original Paper

Using Existing Clinical Data to Measure Older Adult Inpatients' Frailty at Admission and Discharge: Hospital Patient Register Study

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Abstract

Background: Frailty is a widespread geriatric syndrome among older adults, including hospitalized older inpatients. Some countries use electronic frailty measurement tools to identify frailty at the primary care level, but this method has rarely been investigated during hospitalization in acute care hospitals. An electronic frailty measurement instrument based on population-based hospital electronic health records could effectively detect frailty, frailty-related problems, and complications as well be a clinical alert. Identifying frailty among older adults using existing patient health data would greatly aid the management and support of frailty identification and could provide a valuable public health instrument without additional costs.

Objective: We aim to explore a data-driven frailty measurement instrument for older adult inpatients using data routinely collected at hospital admission and discharge.

Methods: A retrospective electronic patient register study included inpatients aged ≥65 years admitted to and discharged from a public hospital between 2015 and 2017. A dataset of 53,690 hospitalizations was used to customize this data-driven frailty measurement instrument inspired by the Edmonton Frailty Scale developed by Rolfson et al. A 2-step hierarchical cluster procedure was applied to compute e-Frail-CH (Switzerland) scores at hospital admission and discharge. Prevalence, central tendency, comparative, and validation statistics were computed.

Results: Mean patient age at admission was 78.4 (SD 7.9) years, with more women admitted (28,018/53,690, 52.18%) than men (25,672/53,690, 47.81%). Our 2-step hierarchical clustering approach computed 46,743 inputs of hospital admissions and 47,361 for discharges. Clustering solutions scored from 0.5 to 0.8 on a scale from 0 to 1. Patients considered frail comprised 42.02% (n=19,643) of admissions and 48.23% (n=22,845) of discharges. Within e-Frail-CH's 0-12 range, a score ≥6 indicated frailty. We found a statistically significant mean e-Frail-CH score change between hospital admission (5.3, SD 2.6) and discharge (5.75, SD 2.7; *P*<.001). Sensitivity and specificity cut point values were 0.82 and 0.88, respectively. The area under the receiver operating characteristic curve was 0.85. Comparing the e-Frail-CH instrument to the existing Functional Independence Measure (FIM) instrument, FIM scores indicating severe dependence equated to e-Frail-CH scores of ≥9, with a sensitivity and specificity of 0.97 and 0.88, respectively. The area under the receiver operating characteristic curve was 0.92. There was a strong negative association between e-Frail-CH scores at hospital discharge and FIM scores (r_s=–0.844; *P*<.001).

Conclusions: An electronic frailty measurement instrument was constructed and validated using patient data routinely collected during hospitalization, especially at admission and discharge. The mean e-Frail-CH score was higher at discharge than at admission. The routine calculation of e-Frail-CH scores during hospitalization could provide very useful clinical alerts on the health trajectories of older adults and help select interventions for preventing or mitigating frailty.

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KEYWORDS

frailty; frailty assessment; electronic patient records; functional independence measure; routinely collected data; hospital register; patient records; medical records; clinical data; older adults; cluster analysis; hierarchical clustering

Introduction

Switzerland’s current declared health care policy and its overall national system both aim to support older adults who wish to age healthily in their own homes. Recent statistical trends show increasing numbers of older adults who are multimorbid being hospitalized, thus putting age-related diseases and chronic health conditions at the forefront of the many concerns facing acute health care systems [1,2]. There is growing evidence that frailty syndrome may be a relevant acute hospital care clinical alert to predict complications associated with adverse outcomes [3-6]. Although there is a consensus on the definition of frailty—but perhaps not always on how to measure it—it is widely considered to be a dynamic geriatric condition characterized by an increased vulnerability to external dysfunction, a complex etiology, and intrinsic difficulties distinguishing it from normal aging [7,8]. Frailty is a preclinical state not directly associated with any disease or disability. The scientific literature documents a phenotypical approach to identifying frailty. It uses 3 or more of Fried 5 criteria (unintentional weight loss, exhaustion, low energy expenditure, slowness, and weakness) to recognize prefrailty and the deficit accumulation approach based on Rockwood Clinical Frailty Scale engineering theory [9]. In the phenotypical approach, 3 or more of Fried 5 criteria (unintentional weight loss, exhaustion, low energy expenditure, slowness, and weakness) are used to recognize prefrailty. In Rockwood deficit accumulation approach, frailty is associated with known comorbidities and disabilities, polypharmacy, and the relative risks of adverse drug reactions, rehospitalization, health services use, age-associated sensory deficits, and a lack of social support [9].

Routine hospitalization data stored in patients’ electronic health records (EHRs), including social, clinical, medical, and pharmacy data, could be important sources of frailty detection information during hospitalization and for assessing and comparing the different phases of hospitalization, such as in admission and discharge [10,11]. However, EHRs do not currently enable the construction of a standard reference measure of frailty for clinical and research purposes—they require customization. Researchers would require different data types (eg, diagnoses, clinical data, and health service codes) collected over specified periods using specific, discriminating coding methods [10,12]. Indeed, the length of the assessment period during which codes were measured could affect the measure’s accuracy when capturing certain chronic conditions. Another challenge is that coding systems and medical practice can change over time or across geographical regions. Switzerland’s different regional health care systems all use the *ICD-10* (*International Classification of Diseases, Tenth Revision*), as their medical coding system [13]. New billing codes are generated for new health care procedures (in the *ICD-11* [*International Classification of Diseases, Eleventh Revision*]) and services (eg, SARS-CoV-2 vaccination), and numerous codes are withdrawn each year [14]. Therefore, how well the frailty measures routinely collected by health care professionals perform should be evaluated periodically using updated datasets [15]. Developing a frailty measure from patients’ EHRs requires restricting the population to individuals with high rates of data completeness within the system to avoid bias due to missing data [16]. Few studies have explored customizing database-derived frailty measures using EHRs from a hospital register [10,12,16,17]. Measures using EHRs focus on investigating exposure to the risks of a particular outcome (such as syndromes, death, or reoccurrences of a disease) based on the selection of a group of patient characteristics and using a statistical model to explore the effectiveness of interventions and treatments among hospitalized inpatients [18]. However, any model’s usefulness and relevance depend on its accuracy. Few studies have investigated the robustness of frailty measures taken from routinely collected datasets using 2 approaches to frailty simultaneously [10]. Indeed, the Fried phenotypic approach has found a correlation of 0.6-0.7 between hospital EHRs and retrospective medical assurance data; the Rockwood deficit-accumulation approach has found correlation coefficients of 0.2-0.6 [10]. In particular, a recent study by Kim et al [19] showed that a frailty index, estimated using data routinely collected by health care professionals for older adults’ medical assurance claims (equivalent to Medicare claims), performed better than a comorbidity index for predicting disability, mobility impairments, recurrent falls, and days spent in a skilled nursing facility [19]. However, an e-Frailty Index >0.19, a threshold for frailty developed in the United Kingdom, had a positive predictive value of 0.11 (R^2) for death in the next 3 months among primary care patients in that country [19]. Nevertheless, a database-derived measure of frailty might be able to provide a clinical alert of frailty across older adults, although it would be less readily interpretable deterministically for a particular individual. A cutoff point for positive screening can be determined according to percentile distributions (eg, top 5%), to sensitivity and specificity to a state of frailty (eg, 90% sensitivity for detecting a frailty phenotype), or to predefined, clinically relevant thresholds (eg, ≥0.2 according to a deficit accumulation frailty index) after considering clinical contexts (eg, inpatient or preoperative screening) and the resources available for detailed assessments and care management [20].

Few studies to date have used a database-derived frailty measurement score as a clinical alert (ie, change in frailty levels over time) to estimate the effects of an intervention (medical and medication treatment) or hospitalization (length of stay). In addition, frailty measures’ responsiveness to improvements or deteriorations in health status is still under investigation, as is the minimum clinically significant change they can recognize. Most of the research done in North America, Western Europe, and Asia has explored measures of frailty developed from primary care EHRs [10,11,21,22]. The items of clinical knowledge selected for these measures used data relevant to frailty’s overall clinical picture [23]. This paper’s overall aim is to demonstrate that data from hospital registers, which collect clinical and administrative information (for billing), can be used to identify a clinical alert of frailty among patients at the time of their hospital discharge. We hypothesized that the e-CH-frailty (Switzerland) clinical alert would significantly increase hospital discharges compared to the e-CH-frailty scores at hospital admission.

Methods

Study Design

We conducted a register-based study of patients' routinely collected EHR data to customize a database-derived frailty measure. Data came from a large, longitudinal EHR dataset extracted from the register of a multisite public teaching hospital in Switzerland [24]. Once a database-derived frailty measure is developed, the critical next step is validating it against a reference standard, 1D, or multidimensional measure of frailty [20]. Due to the lack of any routine frailty assessment tool within our database, we selected the multidimensional Functional Independence Measure (FIM) [25], recommended by Dodds et al [25], Carlson et al [26], and De Saint-Hubert et al [27], as an alternative means of convergent validation [19,20].

Study Population and Variables

The dataset comprised the Valais Hospitals' sociodemographic, clinical, medical, and drug data. Valais Hospitals is a multisite public hospital in Switzerland serving a population of almost 360,000. It recorded over 40,000 hospitalizations and 650,000 ambulatory visits in 2023, mainly at its 2 primary hospital centers, 1 in each of the canton's 2 distinct linguistic regions [25]. The EHR dataset included all inpatients aged 65 years or older admitted or readmitted between January 1, 2015, and December 31, 2017 (N=53,690). Incomplete records with more than 20% missing health data or records without sociodemographic data were excluded (excluded records numbered 6947, 12.93%). This study did not consider older adult inpatients who were admitted to the emergency department but returned to their homes within 24 hours. These 3 years were selected based on the availability of systematic, well-coded patient data. Without unique patient identifiers, the number of different patients and their readmission rates could not be explored. Per this study's aims, we included the sociodemographic variables of age, gender, prehospital provenance, and discharge destination or death during hospitalization (Table 1). For patients' physical status, we included the variables of general mobility, mobility for changing position, gait, balance disorders, fall risk, exhaustion, independence in upper- and lower-body care, upper- and lower-body dressing or undressing, and bladder continence (Multimedia Appendix 1). Unfortunately, the EHR did not include data on the older adult inpatients' nutritional status for the selected period (January 2015 to December 2017). For their cognitive status, we included the variables of alertness or consciousness, orientation, concentration, verbal expression, capacity and skills to react to the demands of daily life, and ability to learn (Table 2). In addition, we noted the number of comorbidities calculated at each hospitalization (using *ICD-10*) [28].

Table 1. The sociodemographic data used to construct the e-Frail-CH[a] measure (N=53,690).

Variables	Total (%)
Gender, n (%)	
Men	25,672 (47.81)
Women	28,018 (52.18)
Age (years)	
Mean (SD)	78.37 (7.91)
Median (IQR)	78 (72-84)
Minimum-maximum	65-106
Age categories (years), n (%)	
65-74	18,882 (35.17)
≥75	34,808 (64.83)
Admitted from, n (%)	
Home	36,792 (68.52)
Health care setting[b]	16,898 (31.47)
Discharged to, n (%)	
Home	33,738 (62.83)
Health care settings	17,306 (32.23)
Died in hospital	2646 (4.92)
Length of stay	
Mean (SD)	12.26 (16.5)
Median (IQR)	8 (4-15)
Minimum-maximum	1-1316

[a] CH: Switzerland.

[b] Nursing homes, other hospitals, and socioeducational and long-term psychiatric rehabilitation settings.

Table 2. Distributions of the e-Frail-CH[a] instrument's dimensions after cluster analysis (n=46,743 at admission, n=47,361 at discharge).

Dimensions and quality of cluster[b]	Score	Admission conditions	Admissions distribution (%)	Discharge conditions	Discharge distribution (%)	Difference between hospital discharge and admission (*P* value; %)
Cognition						
0.8	0	0+0+0+0	71.9	0+0+0+0	64.9	–7[c]
Good	1	0+0+(1 + 1)	10	0+(1 or 1 or 1)	27.1	17.1
N/A[d]	2	Other	18	Other	8	–10
General health status (*ICD-10*[e]/CHOP[f])						
Allocated manually	0	1 *ICD-10* or 1 CHOP	1 *ICD-10* or 1 CHOP	1 *ICD-10* or 1 CHOP	2.4	N/A
N/A	1	2 *ICD-10* or 2 CHOP	2 *ICD-10* or 2 CHOP	2 *ICD-10* or 2 CHOP	6.2	N/A
N/A	2	>2 *ICD-10* or >2 CHOP	>2 *ICD-10* or >2 CHOP	>2 *ICD-10* or >2 CHOP	91.4	N/A
Functional Independence Measure						
0.7	0	0+0+0+0	49	0+0+0+0	47.3	–1.7 (ns)
Good	1	(0 or 1) + 1+0+0	31.4	One or (1 or 2)+0+0	35.1	3.7
N/A	2	Other	19.7	Other	17.6	–2.1
Social support						
0.5	0	Married and living at home	Married and living at home	Married and living at home	29.9	N/A
Fair to good	1	Single or divorced, or hospital and living at home	Single or divorced, or hospital and living at home	Single or divorced, or hospital and living at home	32.8	N/A
N/A	2	Other	Other	Other	37.3	N/A
Medication						
Allocated manually	0	<5 medications	75.7	75.7	32.5	–43.2[c]
N/A	1	≥5 medications	24.3	24.3	67.5	43.2
Mood						
Allocated manually	0	No mood disorders and no exhaustion	75.7	75.7	77	1.3[c]
N/A	1	Mood disorders or exhaustion in *ICD-10*	24.3	24.3	23	–1.3
Continence						
Allocated manually	0	0+0	84.6	0+0	83.4	–1.2[c]
N/A	1	Other	15.4	Other	16.6	1.2
Self-reported performance						
0.6	0	0+0+0+0+0	45.9	0+0+0+0+0	44.2	–1.7[c]
Good	1	Other	54.1	Other	55.8	1.7

[a] CH: Switzerland.

[b] Divisive coefficients.

[c] *P*<.001; ns=nonsignificant, for Wilcoxon signed rank test, 2-tailed.

[d] N/A: not applicable.

[e] *ICD-10*: *International Classification of Diseases, Tenth Revision*.

[f] CHOP: Swiss classification of surgical procedure.

Variable Selection for the e-Frail-CH Measurement Instrument

Following a literature review on frailty instruments, the authors were inspired by the selection of clinical data and variables reported in the dimensions covered by the Edmonton Frail Scale (EFS; Table 2) [29]. The EFS assessment tool comprises 10 items [29]. Considering this study's retrospective nature, EHR data on the risk of falls replaced a physical assessment of mobility. The EFS has been validated against the comprehensive geriatric assessment tool and was shown to be reliable and feasible for routine use by nongeriatricians [30,31]. Rolfson et al [29] described scores ranging from 0 (not frail) to 17 (severely frail), with scores of 8 or above defining patients as frail [29]. We selected data associated with the clinical features of frailty measured by the EFS to compute a data-driven frailty measure [29]. Using this approach, the clinical variables of frailty were defined as (1) the presence of any of the selected codes (no=not present; yes=present) or (2) the proportion of the codes present (0=not present or good health; 1=sometimes present or moderate health; 2=always present or bad health).

We constructed our instrument using clinical information from the following 9 dimensions of frailty: cognition (0=no errors, 1=minor errors, or 2=other errors), general health status (0=good health, 1=1-2 hospital visits, or 2=more than 2 hospital visits), functional independence (0=0-1 activities of daily living [ADLs] requiring help, 1=2-4 ADLs require help, or 2=5-8 ADLs require help), informal social support (0=always present, 1=sometimes present, or 2=never present), medication use (0=no polypharmacy or adherence problems, or 1=polypharmacy or adherence problems), nutrition (0=no weight loss or 1=substantial weight loss of >10%), mood (0=no depression or 1=depression), continence (0=no urine incontinence or 1=urine incontinence), and self-supported performance (0=able to do heavy work, walk upstairs, or walk 1 km; or 1=not able to do heavy work, walk upstairs, or walk 1 km). Scores of 0-7 were considered "not frail." Scores of 8-9, 10-11, and 12-17 were considered "mild frailty," "moderate frailty," and "severe frailty," respectively [32].

Construction of the Data-Driven Frailty Measure Based on the EHR

The inpatient EHR dataset extracted included each older adult hospitalization between January 1, 2015, and December 31, 2017—3 years selected based on the availability of systematic, well-coded patient data. In addition, variables were selected according to this study's aim and as closely as possible to the EFS, which we used as a reference instrument to create the e-Frail-CH for this study.

Description of the Data

We selected the 8 dimensions of frailty listed in Table 2 (column 1), their indicators (column 2), their aggregated response categories (column 3), and their corresponding codes (column 4). We used them to construct the clusters for each dimension. Columns 5 and 6 present each response category's distribution (as a percentage) within its respective dimension at hospital admission and discharge (when available). Note that the dimension of nutrition was not included in the e-Frail-CH instrument due to high numbers of missing values (92.7% missing at admission and 83.8% missing at discharge). Overall, patients at discharge presented with higher levels of dependency than at admission. In the dimension of functional independence, patients' ability to self-care for their upper body increased (62.11% to 63.42%) between admission and discharge. The same result was noted for mood, with more participants feeling exhaustion at admission than at discharge (18.6% fell to 17.39%), and for an indicator of continence, with more urine drainage devices used at admission than at discharge (9.59% improved to 9.39%). Finally, for the dimension of cognition, the evaluation of patients' states of consciousness found that 97.38% were fully alert at admission, 2.39% were in a state of drowsiness or stupor, and 0.19% were comatose. These proportions were 95.49%, 3.49%, and 0.99% at discharge, respectively. Table 2 presents all these data extracted from the Valais Hospitals' register and used to construct the e-Frail-CH instrument. Almost all the differences between admission and discharge shown in Table 2 (last column) were highly significant ($P<.001$). However, the distributions of only 2 indicators were not significantly different, namely upper body self-care skills and having a urine drainage device.

Data Analysis

In total, 2 experienced data managers (BW and HV) inspected the EHR dataset for extraction errors, missing values, and data consistency. Missing values were not replaced. Data were then imported into SPSS software (version 29, IBM Corp), for analysis. The e-Frail-CH instrument was constructed using hierarchical cluster analysis. This statistical technique involves grouping patients with similar characteristics in the dataset, such as similar diagnosis codes, clinical features, or self-reported performances. After examining the characteristics of each group derived from the hierarchical cluster analysis, a group with 6 or more diagnoses indicative of frailty was identified as the "frailty group." For most of the dimensions of frailty, such as cognition, functional status, social support, and self-reported performance, we created clusters of variables based on an exploratory algorithm that uses the SPSS TwoStep Cluster Analysis procedure—a flexible, adaptable tool for clustering data. This exploratory procedure is designed to reveal natural groupings (or clusters) within a dataset that would not otherwise be apparent. Its algorithm has several advantages over traditional clustering techniques: (1) it can create clusters based on both categorical and continuous variables, (2) the number of clusters can be selected automatically or manually, and (3) it can analyze large data files efficiently. The TwoStep Cluster Analysis procedure handles categorical and continuous variables using a likelihood distance measure that assumes that variables in the cluster model are independent. The number of clusters to be formed is based on the Schwarz-Bayesian information criterion [33]. The higher the coefficient, the better the corresponding algorithm, as this coefficient is akin to a correlation coefficient [34]. Based on a Kolmogorov-Smirnov analysis, all the data included in the cluster analysis showed normal distributions, and the e-Frail-CH scores at admission and discharge were compared using a 2-tailed paired *t* test.

SPSS TwoStep Cluster Analysis Algorithm for the e-Frail-CH Instrument

The 2-step procedure's first step is constructing preclusters to reduce the matrix size and the distances between all the possible pairs of data points. Preclusters are simply clusters of the original cases that are used in place of the raw data in the hierarchical clustering. As a case is read, the algorithm decides, based on a distance measurement, whether the current case should be merged with a previously formed precluster or start a new precluster. In the second step, SPSS uses the standard hierarchical clustering algorithm on the preclusters. This refines the initial estimate by finding the most significant change in distance between the 2 closest clusters in each hierarchical clustering step. Forming clusters hierarchically allows us to explore a range of solutions with different numbers of clusters. At this point, the algorithm can propose a number of clusters, on an experimental basis, using the Schwarz-Bayesian information criterion, but the number of clusters can also be defined in advance. Our top-down, divisive approach groups all the observations into 1 cluster and then splits it recursively as we move down the hierarchy. The divisive coefficient varies from 0 (a poor coefficient) to 1 (a strong coefficient) across the observations [34,35]. Summing all the subcluster scores to create an overall frailty score made our strategy as close as possible to that used in the EFS framework and enabled us to count the score attributed to each of our different subdimensions. The scores of certain dimensions of frailty were defined directly in an affirmative manner, without clustering. This included the dimensions of general health status (defined by the number of *ICD-10* and CHOP [Swiss classification of surgical procedure] surgery intervention codes at discharge), medication (defined by the number of medicines prescribed at admission and discharge), mood (defined by the presence or absence of exhaustion or depression), and continence.

Validity Analysis

We performed a validity analysis to explore the e-Frail-CH instrument's sensitivity, specificity, and cut point accuracy between nonfrail and frail. The sensitivity analysis was constructed using hospital discharge data. We analyzed receiver operating characteristics (ROCs) to reveal the e-Frail-CH instrument's trade-off between sensitivity and specificity [36]. The instrument was structurally validated using the multidimensional FIM as described by Naschitz et al [37] and Stuck et al [19,20,25,37,38]. The FIM instrument includes measures of independence in self-care, including sphincter control, transfers, locomotion, communication, and social cognition. It is an 18-item, 7-level, ordinal scale sensitive to the changes occurring during a comprehensive inpatient medical rehabilitation program. Its total score ranges from 18 (entirely dependent) to 126 points (completely independent), using the levels of assistance individuals need to grade their functional status between the extremes. The instrument can assess a patient's level of disability or a change in their status in response to rehabilitation or a medical intervention. Our sample population's scores were recorded as dependent patients (FIM scores of 18-53), patients with modified independence (54-107), and independent patients (scores from 108 to 126).

Ethical Considerations

The Human Research Ethics Committee of the Canton of Vaud (2018-02196) gave its ethics approval, which enabled the research team to partner with the hospital's data warehouse to access the appropriate dataset. Given the retrospective data source, obtaining consent from the patients concerned was impossible or posed disproportionate difficulties. This study respects the legal requirements for research projects involving data reuse without consent, as set out in Article 34 of Switzerland's Human Research Act. As per Switzerland's Federal Act on Data Protection, which is regulated at the federal and cantonal levels, patients' sensitive personal data, such as their date of birth, address, educational level, and profession, were excluded from the dataset [39]. However, this study's participants had signed a general consent form based on informed consent, in which they agreed that their data could be used for research purposes.

Results

e-Frail-CH Sample

Of the 53,690 hospitalization lines in the dataset, 46,743 and 47,361 met our inclusion criteria for computing 2-step hierarchical clustering for hospital admission and discharge, respectively. About 5.58% (2646/47,361) of the sample died during the hospitalization period selected and thus could not be considered at discharge.

Constructing the e-Frail-CH Admission and Discharge Measurement Instrument

At the beginning of its construction, the e-Frail-CH measurement instrument's 8 basic dimensions were selected based on the available EHR data that closely matched the EFS dimensions (Table 3, column 1). The selected dimensions' clustering quality was computed and assessed using the SPSS TwoStep Cluster Analysis procedure (column 2). Column 3 presents each cluster-construction item's score. In contrast, column 4 indicates the conditions used to attribute different variables to different hospital admission assessment categories, either in an exploratory way or manually, by using the order of the indicators in Table 2. Finally, column 5 presents the relative distributions (as percentages) of each dimension's score at hospital admission. Columns 6 and 7 used the same information for hospital discharge.

The intermediate category for cognition indicators, coded 1, was attributed to patients admitted awake and conscious, displaying full capacity regarding temporal-spatial orientation but a limited ability to acquire knowledge or function in the ADL. The worst state of cognition, coded 2 at hospital admission, corresponded to any other indicator configuration. This clustering solution presented excellent summarizing quality, with a score of 0.8 on a scale from 0 to 1 (Table 2). The dimension of general health status (the same measure at hospital admission and discharge) was not clustered but defined in an affirmative manner based on the number of *ICD-10* and CHOP codes at hospital discharge only. The best health status, coded 0, was given to patients with just 1 *ICD-10* or CHOP code (2.39% of cases); the intermediate score, coded 1, was given to patients with 2 *ICD-10* or 2 CHOP codes (6.21% of cases), while the worst score, coded 2, was given to people with more than 2 *ICD-10* or CHOP codes (91.39% of cases; Table 3).

Table 3. Distribution of frailty scores at admission (n=46,743) and discharge (n=47,361).

e-Frail-CH[a] score	Distribution at hospital admission, n (%)	Distribution at hospital discharge, n (%)	Relative difference in e-Frail-CH distribution from admission to discharge (%)
0 (no frail)	268 (0.57)	226 (0.47)	–0.1
1	1040 (2.22)	782 (1.65)	–0.5
2	5078 (10.86)	2784 (5.87)	–5
3	6871 (14.69)	6710 (14.16)	–0.5
4	7297 (15.61)	7350 (15.51)	–0.1
5	6546 (14)	6664 (14.07)	0.1
6	5438 (11.63)	5766 (12.17)	0.6
7	4373 (9.35)	5249 (11.08)	1.7
8	3436 (7.35)	3900 (8.23)	0.8
9	2670 (5.71)	2677 (5.65)	0
10	1878 (4.01)	2008 (4.23)	0.2
11	1488 (3.18)	2511 (5.30)	2.1
12 (severely frail)	360 (0.77)	734 (1.54)	0.7
Total	46,743 (100)	47,361 (100)	N/A[b]
Missing	6947	6329	N/A

[a] CH: Switzerland.

[b] N/A: not applicable.

Cut Points Between the e-Frail-CH and FIM Scores at Hospital Discharge

Functionally unimpaired patients (with FIM scores ≥107) had optimal e-Frail-CH cutoff scores ≥6, with an excellent sensitivity cut point of 0.82, a specificity cut point of 0.88, and an area under the ROC curve of 0.85. Patients with the lowest FIM scores (18-53, n=272, 0.01%), indicating severe dependence, had optimal e-Frail-CH cutoff scores ≥9, with an excellent sensitivity cut point of 0.97, a specificity cut point of 0.88, and an area under the ROC curve of 0.92.

Prevalence of Frailty Among Admitted and Discharged Patients

Based on the e-Frail-CH instrument and considering equivalent cutoffs based on the FIM score of 6, a total of 42.02% (n=19,643) of older adult patients were considered frail at admission, whereas 48.23% (n=22,845) were frail at discharge. e-Frail-CH scores are constructed by summing an individual's scores for each dimension of frailty at hospital admission and discharge (Table 3). The theoretical score range is 0-12, with 0 meaning no frailty and 12 representing the highest state of frailty. The distribution approached normality for both scales with a slight positive skew. The mean hospital admission score (5.30, SD 2.59) was lower than at discharge (5.75, SD 2.65), indicating deterioration in most cases. The difference between the mean e-Frail-CH admission and discharge scores was significant: $t_{60,651}$=0.45, 95% CI 0.44 to 0.48, *P*<.001).

Association Between the e-Frail-CH and the FIM at Hospital Discharge

A strong negative association was found between e-Frail-CH scores and FIM scores at hospital discharge. Calculating a Spearman rank correlation (r_s) of –0.844 (*P*<.001) showed that they were oriented in opposite directions.

Discussion

Principal Findings

Using routinely collected clinical and medical information, this research study developed a data-driven measurement instrument to compare older adult frailty at admission and discharge from Valais Hospitals' multiple acute care sites. Frailty was measured using a cumulative approach, incorporating 8 dimensions of inpatients' diagnostic, health, and clinical characteristics. These characteristics were very similar to those in prior studies measuring the prevalence of frailty based on accumulations of *ICD-10* diseases [28,40]. They were also similar to those in the studies by Hilmer et al [32] and Liang et al [28], which concluded that frailty appears to be a good predictor of adverse health outcomes and should be used as a health indicator in acute clinical practice to help formulate care and discharge plans and improve shared decision-making [32,41,42].

To transform frailty into a health indicator, we used hierarchical cluster analysis, a statistical technique that groups together individuals in a dataset whose measured characteristics are similar. These characteristics could be diagnosis codes or social, clinical, and medical data reported during a specified period [43,44]. However, hierarchical cluster analysis can require significant computing power for large datasets and yield different clusters in different datasets. Inspired by the components of EFS and Hilmer et al [32], this study tried to overcome the latter limitation by conducting its cluster analysis on a subset of a large hospital's overall clinical dataset and developing a model to predict patients' membership of different frailty groups [29]. Although our approach identified frail older adult individuals without requiring a dataset with a reference standard frailty measure, how the number of groups in the cluster analysis (anything other than a single, large frailty group) should be determined is open to interpretation. Frail older adult individuals will likely not all be classified into 1 group. For example, frail patients with cancer and frail patients with heart disease may be classified into different groups despite similar levels of frailty [40]. Our e-Frail-CH measurement instrument used information available within patients' EHRs to identify their varying degrees of frailty. The 2-step hierarchical clustering strategy demonstrated robust results, with divisive coefficients between 0.5 and 0.8 fitting well with the results reported in similar studies [45,46]. e-Frail-CH's high sensitivity, specificity, and areas under the ROC curve confirmed the instrument's robustness. The EHR dataset included more than 45,000 valid hospitalizations or rehospitalizations used to construct the e-Frail-CH measurement instrument's clusters. This should be considered an extremely big set of routinely collected data, especially when compared to the smaller samples used in the studies by Horn et al [47] and Pronk et al [47,48].

The summing of preclustered components enabled us to develop a clinical frailty score for older adults at acute hospital admission and discharge. Routinely identifying potentially frail older adult inpatients opens the way to targeted needs assessments and clinical alerts, better integrated care coordination, and coordinated planning to deliver necessary interventions during older adults' health care trajectories and follow-up [18,20].

Our innovative approach aligns with a recent investigation in Spain by Orfila et al [40], who created and validated an electronic frailty score based on hospitalized patients' clinical EHR data [40]. This study has the advantages of being inexpensive and transferable to other health care settings, especially in Switzerland. However, e-Frail-CH is not a clinical diagnostic tool—it is a population risk stratification tool that identifies groups of people likely to live with varying degrees of frailty. It cannot categorize specific individuals. Consequently, longitudinal assessments should take place to support the diagnosis when e-Frail-CH identifies an individual with potentially severe or moderate frailty. This study showed a 0.45-point mean increase in the frailty score between hospital admission and discharge. Although this value is essential for research purposes, the magnitude of such an e-Frail-CH score change might have clinical implications for individuals.

The e-Frail-CH instrument can be used as a clinical alert instrument in longitudinal retrospective studies and tested as a continuous variable. However, although it is suitable for acute care settings, the e-Frail-CH instrument's screening effectiveness should be tested and compared against instruments screening for frailty in specific diseases or among preoperative patients. On the other hand, the EFS, the inspiration for our frailty scale, has recognized good psychometric properties [29,49,50]. The e-Frail-CH measurement instrument provides new insights into the potential for data-driven frailty assessments and comparisons of patient frailty during acute hospital trajectories [51,52]. Frailty remains complex, often undetected or confounded with other geriatric conditions or comorbidities [53]. To respond positively to frailty and its challenges, acute health care institutions need to be prepared for it: they should attempt tertiary preventive measures to take care of people exhibiting frailty and, where possible, report frailty scores for optimal hospital care planning. This could lead to targeted assessments and person-centered care plans being developed as the condition progresses to severe frailty. Alternatively, e-Frail-CH could guide optimized integrated care planning to help reverse emerging frailty among at-risk older adults [47,54]. Other investigations on data-driven electronic frailty indicators [8,39,55] corroborate our ideas about the e-Frail-CH measurement instrument. However, our investigation of frailty at acute hospital admission and discharge presents the added value of allowing an evaluation of changing frailty scores between these 2 critical points in a care trajectory. Additionally, e-Frail-CH enables patients who are frail to be distinguished from fit ones. Recent clinical guidelines recommend that inpatients be screened for frailty using a validated clinical alert instrument appropriate to the clinical setting, whether it is data-driven or not [53].

Strengths and Limitations

One of this study's main strengths was its innovative use of hospital register data-driven frailty detection or clinical alert indicator in acute care. To the best of our knowledge, few studies have investigated frailty using hospital registers. Another strength was using an approach that hierarchically clustered existing data to show frailty at hospital admission and discharge. Using an existing large-scale dataset and coding from patients' EHRs was a crucial advantage because we did not have to solicit busy clinicians or patients who are frail and already weakened by multiple health conditions.

Nevertheless, this study had some limitations, notably its retrospective design and use of routinely collected hospital admission and discharge data. However, this could be considered a strength based on the clinical relevance of data in real-life hospital trajectories. As a result, we were unable to include data on patient nutrition due to that variable's absence in the database for the selected period; nutrition is an essential dimension in assessing frailty [29]. Additionally, we could not control for potential data assessment errors made by health care staff during admission and discharge hospitalization. We could not suggest that our CH-e-frailty indicator was in a causal relationship with hospitalization trajectories, merely that it might serve as a clinical alert that could be communicated to other health care professionals (such as in a discharge letter) taking over responsibilities for older inpatients. Without a unique, encrypted patient identifier, we were unable to track inpatients who might have undergone multiple hospitalizations from 2015 to 2017, including some who died during their stay. The absence of data on patients' functional status preadmission meant that we could not assess changes to that status during hospitalization or the influence of improving or deteriorating functional and cognitive impairments. Furthermore, using the FIM as an instrument for making comparisons should be carried out cautiously as it does not measure frailty directly but rather the level of disability. Further research should be conducted to reveal the profiles of older adult inpatients at risk of frailty. This means we must be careful about the external validity of our results and their interpretations. Finally, our findings should be considered with care because it was impossible to detect rehospitalizations, which may be a confounding factor in measuring frailty during hospital trajectories.

Conclusion

The e-Frail-CH measurement instrument developed in this study could be applied widely across Switzerland to make the most of the routinely collected data on older adult inpatients in its acute care hospitals. This study demonstrated that patients' EHRs contain easily extractable data that can be used to identify frail inpatients and to compare measures of frailty at admission and discharge. Furthermore, by using the e-Frail-CH measurement instrument, frailty could easily be identified using broader sociodemographic data and patients' EHRs. Introducing a routine estimation of potential frailty among older adults via automated e-Frail-CH measurements could be a valuable way of identifying at-risk patients or clinical indicator and managing their frailty along their health trajectories. Further research could be carried out by using the e-Frail-CH measurement instrument score as both a long-term outcome and a patient-reported outcome [56].

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Data Availability

As part of the Data Use Agreement, the authors are not allowed to provide raw data. Upon a reasonable request, the corresponding author will provide the statistical programming code used to generate results.

Authors' Contributions

BW, FP and HV had the original idea. BW, FP, AvG, and HV provided conceptual and methodological expertise to study design, data analysis, and interpretation. BW, FP, AvG, and HV were major contributors to writing this paper. All the authors read, edited, and approved the final paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Description and distribution of the variables included in the e-Frail-CH frailty indicator. CH: Switzerland.
[DOCX File , 29 KB - aging_v7i1e54839_app1.docx]

References

1. Ghazalbash S, Zargoush M, Mowbray F, Costa A. Impact of multimorbidity and frailty on adverse outcomes among older delayed discharge patients: implications for healthcare policy. Health Policy 2022;126(3):197-206. [doi: 10.1016/j.healthpol.2022.01.004] [Medline: 35063325]
2. Vetrano DL, Palmer K, Marengoni A, Marzetti E, Lattanzio F, Roller-Wirnsberger R, Joint Action ADVANTAGE WP4 Group. Frailty and multimorbidity: a systematic review and meta-analysis. J Gerontol A Biol Sci Med Sci 2019;74(5):659-666. [doi: 10.1093/gerona/gly110] [Medline: 29726918]
3. Gobbens RJJ, van Assen MA, Luijkx KG, Wijnen-Sponselee MT, Schols JM. Determinants of frailty. J Am Med Dir Assoc 2010;11(5):356-364. [doi: 10.1016/j.jamda.2009.11.008] [Medline: 20511103]
4. Henry RK, Reeves RA, Wackym PA, Ahmed OH, Hanft SJ, Kwong KM. Frailty as a predictor of postoperative complications following skull base surgery. Laryngoscope 2021;131(9):1977-1984. [doi: 10.1002/lary.29485] [Medline: 33645657]
5. Han B, Li Q, Chen X. Effects of the frailty phenotype on post-operative complications in older surgical patients: a systematic review and meta-analysis. BMC Geriatr 2019;19(1):141 [FREE Full text] [doi: 10.1186/s12877-019-1153-8] [Medline: 31126245]
6. Tavares JPDA, Nunes LANV, Grácio JCG. Hospitalized older adult: predictors of functional decline. Rev Lat Am Enfermagem 2021;29:e3399 [FREE Full text] [doi: 10.1590/1518-8345.3612.3399] [Medline: 33439951]
7. Fried LP, Ferrucci L, Darer J, Williamson JD, Anderson G. Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. J Gerontol A Biol Sci Med Sci 2004;59(3):M255-M263. [doi: 10.1093/gerona/59.3.m255] [Medline: 15031310]

8. Fried LP, Tangen CM, Walston J, Newman AB, Hirsch C, Gottdiener J, Cardiovascular Health Study Collaborative Research Group. Frailty in older adults: evidence for a phenotype. J Gerontol A Biol Sci Med Sci 2001;56(3):146-156. [doi: 10.1093/gerona/56.3.m146] [Medline: 11253156]
9. Rockwood K, Mitnitski A. Frailty in relation to the accumulation of deficits. J Gerontol A Biol Sci Med Sci 2007;62(7):722-727. [doi: 10.1093/gerona/62.7.722] [Medline: 17634318]
10. Pogam MAL, Seematter-Bagnoud L, Niemi T, Assouline D, Gross N, Trächsel B, et al. Development and validation of a knowledge-based score to predict Fried's frailty phenotype across multiple settings using one-year hospital discharge data: the electronic frailty score. EClinicalMedicine 2022;44:101260 [FREE Full text] [doi: 10.1016/j.eclinm.2021.101260] [Medline: 35059615]
11. Lansbury LN, Roberts HC, Clift E, Herklots A, Robinson N, Sayer AA. Use of the electronic frailty index to identify vulnerable patients: a pilot study in primary care. Br J Gen Pract 2017;67(664):e751-e756 [FREE Full text] [doi: 10.3399/bjgp17X693089] [Medline: 28947622]
12. Kim DH. Measuring frailty in health care databases for clinical care and research. Ann Geriatr Med Res 2020;24(2):62-74 [FREE Full text] [doi: 10.4235/agmr.20.0002] [Medline: 32743326]
13. World-Health-Organization. International Statistical Classification of Diseases and Related Health Problems (ICD). 2021. URL: https://www.who.int/standards/classifications/classification-of-diseases [accessed 2021-01-20]
14. Chan E, Small SS, Wickham ME, Cheng V, Balka E, Hohl CM. The utility of different data standards to document adverse drug event symptoms and diagnoses: mixed methods study. J Med Internet Res 2021;23(12):e27188 [FREE Full text] [doi: 10.2196/27188] [Medline: 34890351]
15. Luo J, Liao X, Zou C, Zhao Q, Yao Y, Fang X, et al. Identifying frail patients by using electronic health records in primary care: current status and future directions. Front Public Health 2022;10:901068 [FREE Full text] [doi: 10.3389/fpubh.2022.901068] [Medline: 35812471]
16. Gilbert T, Neuburger J, Kraindler J, Keeble E, Smith P, Ariti C, et al. Development and validation of a hospital frailty risk score focusing on older people in acute care settings using electronic hospital records: an observational study. Lancet 2018;391(10132):1775-1782 [FREE Full text] [doi: 10.1016/S0140-6736(18)30668-8] [Medline: 29706364]
17. Shashikumar SA, Huang K, Konetzka RT, Joynt Maddox KE. Claims-based frailty indices: a systematic review. Med Care 2020;58(9):815-825. [doi: 10.1097/MLR.0000000000001359] [Medline: 32520767]
18. Martini C, Barla A, Odone F, Verri A, Cella A, Rollandi GA, et al. Data-driven continuous assessment of frailty in older people. Front Digit Humanit 2018;5. [doi: 10.3389/fdigh.2018.00006]
19. Kim DH, Glynn RJ, Avorn J, Lipsitz LA, Rockwood K, Pawar A, et al. Validation of a claims-based frailty index against physical performance and adverse health outcomes in the health and retirement study. J Gerontol A Biol Sci Med Sci 2019;74(8):1271-1276 [FREE Full text] [doi: 10.1093/gerona/gly197] [Medline: 30165612]
20. Broad A, Carter B, Mckelvie S, Hewitt J. The convergent validity of the electronic frailty index (eFI) with the clinical frailty scale (CFS). Geriatrics (Basel) 2020;5(4):88 [FREE Full text] [doi: 10.3390/geriatrics5040088] [Medline: 33182222]
21. Clegg A, Bates C, Young J, Ryan R, Nichols L, Ann Teale E, et al. Development and validation of an electronic frailty index using routine primary care electronic health record data. Age Ageing 2016;45(3):353-360 [FREE Full text] [doi: 10.1093/ageing/afw039] [Medline: 26944937]
22. Mak JKL, Hägg S, Eriksdotter M, Annetorp M, Kuja-Halkola R, Kananen L, et al. Development of an electronic frailty index for hospitalized older adults in Sweden. J Gerontol A Biol Sci Med Sci 2022;77(11):2311-2319 [FREE Full text] [doi: 10.1093/gerona/glac069] [Medline: 35303746]
23. Eckart A, Hauser SI, Haubitz S, Struja T, Kutz A, Koch D, et al. Validation of the hospital frailty risk score in a tertiary care hospital in Switzerland: results of a prospective, observational study. BMJ Open 2019;9(1):e026923 [FREE Full text] [doi: 10.1136/bmjopen-2018-026923] [Medline: 30647051]
24. Taushanov Z, Verloo H, Wernli B, Di Giovanni S, von Gunten A, Pereira F. Transforming a patient registry into a customized data set for the advanced statistical analysis of health risk factors and for medication-related hospitalization research: retrospective hospital patient registry study. JMIR Med Inform 2021;9(5):e24205 [FREE Full text] [doi: 10.2196/24205] [Medline: 33973865]
25. Dodds TA, Martin DP, Stolov WC, Deyo RA. A validation of the functional independence measurement and its performance among rehabilitation inpatients. Arch Phys Med Rehabil 1993;74(5):531-536. [doi: 10.1016/0003-9993(93)90119-u] [Medline: 8489365]
26. Carlson JE, Zocchi KA, Bettencourt DM, Gambrel ML, Freeman JL, Zhang D, et al. Measuring frailty in the hospitalized elderly: concept of functional homeostasis. Am J Phys Med Rehabil 1998;77(3):252-257. [doi: 10.1097/00002060-199805000-00012] [Medline: 9635561]
27. De Saint-Hubert M, Schoevaerdts D, Cornette P, D'Hoore W, Boland B, Swine C. Predicting functional adverse outcomes in hospitalized older patients: a systematic review of screening tools. J Nutr Health Aging 2010;14(5):394-399 [FREE Full text] [doi: 10.1007/s12603-010-0086-x] [Medline: 20424808]
28. Liang YD, Xie Y, Du M, Shi J, Yang J, Wang H. Development and validation of an electronic frailty index using routine electronic health records: an observational study from a general hospital in China. Front Med (Lausanne) 2021;8:731445 [FREE Full text] [doi: 10.3389/fmed.2021.731445] [Medline: 34650997]

29. Rolfson DB, Majumdar SR, Tsuyuki RT, Tahir A, Rockwood K. Validity and reliability of the Edmonton Frail Scale. Age Ageing 2006;35(5):526-529 [FREE Full text] [doi: 10.1093/ageing/afl041] [Medline: 16757522]
30. Pilotto A, Custodero C, Maggi S, Polidori MC, Veronese N, Ferrucci L. A multidimensional approach to frailty in older people. Ageing Res Rev 2020;60:101047 [FREE Full text] [doi: 10.1016/j.arr.2020.101047] [Medline: 32171786]
31. Lee H, Lee E, Jang IY. Frailty and comprehensive geriatric assessment. J Korean Med Sci 2020;35(3):e16 [FREE Full text] [doi: 10.3346/jkms.2020.35.e16] [Medline: 31950775]
32. Hilmer SN, Perera V, Mitchell S, Murnion BP, Dent J, Bajorek B, et al. The assessment of frailty in older people in acute care. Australas J Ageing 2009;28(4):182-188. [doi: 10.1111/j.1741-6612.2009.00367.x] [Medline: 19951339]
33. Shek DTL, Ma CMS. Longitudinal data analyses using linear mixed models in SPSS: concepts, procedures and illustrations. Sci World J 2011;11:42-76 [FREE Full text] [doi: 10.1100/tsw.2011.2] [Medline: 21218263]
34. Roux M. Basic procedures in hierarchical cluster analysis. In: Devillers J, Karcher W, editors. Applied Multivariate Analysis in SAR and Environmental Studies. Dordrecht: Springer Netherlands; 1991:115-135.
35. Baker FB, Hubert LJ. Measuring the power of hierarchical cluster analysis. J Am Stat Assoc 1975;70(349):31-38. [doi: 10.1080/01621459.1975.10480256]
36. Kamarudin AN, Cox T, Kolamunnage-Dona R. Time-dependent ROC curve analysis in medical research: current methods and applications. BMC Med Res Methodol 2017;17(1):53 [FREE Full text] [doi: 10.1186/s12874-017-0332-6] [Medline: 28388943]
37. Naschitz JE, Zaigraykin N, Badarny M, Zalyesov O. Combined frailty - functional independence measure instrument. J Clinical Research Notes 2023;4(1). [doi: 10.31579/2690-8816/092]
38. Stuck AK, Mangold JM, Wittwer R, Limacher A, Bischoff-Ferrari HA. Ability of 3 frailty measures to predict short-term outcomes in older patients admitted for post-acute inpatient Rehabilitation. J Am Med Dir Assoc 2022;23(5):880-884 [FREE Full text] [doi: 10.1016/j.jamda.2021.09.029] [Medline: 34687605]
39. Swiss-Federal-Council, Federal Act on Data Protection (FADP). Federal Act of 19 June 1992. Bern: T.F.A.o.t.S. Confederation; 1992.
40. Orfila F, Carrasco-Ribelles LA, Abellana R, Roso-Llorach A, Cegri F, Reyes C, et al. Validation of an electronic frailty index with electronic health records: eFRAGICAP index. BMC Geriatr 2022;22(1):404 [FREE Full text] [doi: 10.1186/s12877-022-03090-8] [Medline: 35525922]
41. Theou O, Squires E, Mallery K, Lee JS, Fay S, Goldstein J, et al. What do we know about frailty in the acute care setting? A scoping review. BMC Geriatr 2018;18(1):139 [FREE Full text] [doi: 10.1186/s12877-018-0823-2] [Medline: 29898673]
42. Hao Q, Zhou L, Dong B, Yang M, Dong B, Weil Y. The role of frailty in predicting mortality and readmission in older adults in acute care wards: a prospective study. Sci Rep 2019;9(1):1207 [FREE Full text] [doi: 10.1038/s41598-018-38072-7] [Medline: 30718784]
43. Wartelle A, Mourad-Chehade F, Yalaoui F, Chrusciel J, Laplanche D, Sanchez S. Clustering of a health dataset using diagnosis co-occurrences. Appl Sci 2021;11(5):2373. [doi: 10.3390/app11052373]
44. Tangianu F, Gnerre P, Colombo F, Frediani R, Pinna G, Berti F, et al. Could clustering of comorbidities be useful for better defining the internal medicine patients' complexity? Ital J Med 2018;12(2):137-144. [doi: 10.4081/itjm.2018.940]
45. Lewis ET, Williamson M, Lewis LP, Ní Chróinín D, Dent E, Ticehurst M, et al. The feasibility of deriving the electronic frailty index from Australian general practice records. Clin Interv Aging 2022;17:1589-1598 [FREE Full text] [doi: 10.2147/CIA.S384691] [Medline: 36353269]
46. Drubbel I, Numans ME, Kranenburg G, Bleijenberg N, de Wit NJ, Schuurmans MJ. Screening for frailty in primary care: a systematic review of the psychometric properties of the frailty index in community-dwelling older people. BMC Geriatr 2014;14:27 [FREE Full text] [doi: 10.1186/1471-2318-14-27] [Medline: 24597624]
47. Horn ME, Reinke EK, Mather RC, O'Donnell JD, George SZ. Electronic health record-integrated approach for collection of patient-reported outcome measures: a retrospective evaluation. BMC Health Serv Res 2021;21(1):626 [FREE Full text] [doi: 10.1186/s12913-021-06626-7] [Medline: 34193125]
48. Pronk Y, Pilot P, Brinkman JM, van Heerwaarden RJ, van der Weegen W. Response rate and costs for automated patient-reported outcomes collection alone compared to combined automated and manual collection. J Patient Rep Outcomes 2019;3(1):31 [FREE Full text] [doi: 10.1186/s41687-019-0121-6] [Medline: 31155689]
49. Kojima G, Liljas AEM, Iliffe S. Frailty syndrome: implications and challenges for health care policy. Risk Manag Healthc Policy 2019;12:23-30 [FREE Full text] [doi: 10.2147/RMHP.S168750] [Medline: 30858741]
50. Rose M, Yang A, Welz M, Masik A, Staples M. Novel modification of the reported Edmonton Frail Scale. Australas J Ageing 2018;37(4):305-308. [doi: 10.1111/ajag.12533] [Medline: 29635729]
51. Rezaei-Shahsavarloo Z, Atashzadeh-Shoorideh F, Gobbens RJJ, Ebadi A, Ghaedamini Harouni G. The impact of interventions on management of frailty in hospitalized frail older adults: a systematic review and meta-analysis. BMC Geriatr 2020;20(1):526 [FREE Full text] [doi: 10.1186/s12877-020-01935-8] [Medline: 33272208]
52. Wong CW. Frailty assessment: clinical application in the hospital setting. Hong Kong Med J 2018 Dec 11;24(6):623-628. [doi: 10.12809/hkmj187572]

53. Dent E, Morley J, Cruz-Jentoft A, Woodhouse L, Rodríguez-Mañas L, Fried L, et al. Physical frailty: ICFSR international clinical practice guidelines for identification and management. J Nutr Health Aging 2019;23(9):771-787 [FREE Full text] [doi: 10.1007/s12603-019-1273-z] [Medline: 31641726]
54. van Dam CS, Labuschagne HA, van Keulen K, Kramers C, Kleipool EE, Hoogendijk EO, et al. Polypharmacy, comorbidity and frailty: a complex interplay in older patients at the emergency department. Eur Geriatr Med 2022 Aug;13(4):849-857 [FREE Full text] [doi: 10.1007/s41999-022-00664-y] [Medline: 35723840]
55. Engvig A, Maglanoc LA, Doan NT, Westlye LT, Alzheimer’s Disease Neuroimaging Initiative. Data-driven health deficit assessment improves a frailty index's prediction of current cognitive status and future conversion to dementia: results from ADNI. Geroscience 2023 Feb;45(1):591-611 [FREE Full text] [doi: 10.1007/s11357-022-00669-2] [Medline: 36260263]
56. Long SO, Hope SV. What patient-reported outcome measures may be suitable for research involving older adults with frailty? A scoping review. Eur Geriatr Med 2024;15(3):629-644. [doi: 10.1007/s41999-024-00964-5] [Medline: 38532081]

Abbreviations

ADL: activity of daily living
CH: Switzerland
CHOP: Swiss classification of surgical procedure
EFS: Edmonton Frail Scale
EHR: electronic health record
FIM: Functional Independence Measure
***ICD-10*:** *International Classification of Diseases, Tenth Revision*
***ICD-11*:** *International Classification of Diseases, Eleventh Revision*
ROC: receiver operating characteristic

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Enhancing Frailty Assessments for Transcatheter Aortic Valve Replacement Patients Using Structured and Unstructured Data: Real-World Evidence Study

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Abstract

Background: Transcatheter aortic valve replacement (TAVR) is a commonly used treatment for severe aortic stenosis. As degenerative aortic stenosis is primarily a disease afflicting older adults, a frailty assessment is essential to patient selection and optimal periprocedural outcomes.

Objective: This study aimed to enhance frailty assessments of TAVR candidates by integrating real-world structured and unstructured data.

Methods: This study analyzed data from 14,000 patients between January 2018 and December 2019 to assess frailty in TAVR patients at the University of Florida. Frailty was identified using the Fried criteria, which includes weight loss, exhaustion, walking speed, grip strength, and physical activity. Latent Dirichlet allocation for topic modeling and Extreme Gradient Boosting for frailty prediction were applied to unstructured clinical notes and structured electronic health record (EHR) data. We also used least absolute shrinkage and selection operator regression for feature selection. Model performance was rigorously evaluated using nested cross-validation, ensuring the generalizability of the findings.

Results: Model performance was significantly improved by combining unstructured clinical notes with structured EHR data, achieving an area under the receiver operating characteristic curve of 0.82 (SD 0.07), which surpassed the EHR-only model's area under the receiver operating characteristic curve of 0.64 (SD 0.08). The Shapley Additive Explanations analysis found that congestive heart failure management, back problems, and atrial fibrillation were the top frailty predictors. Additionally, the latent Dirichlet allocation topic modeling identified 7 key topics, highlighting the role of specific medical treatments in predicting frailty.

Conclusions: Integrating unstructured clinical notes and structured EHR data led to a notable enhancement in predicting frailty. This method shows great potential for standardizing frailty assessments using real-world data and improving patient selection for TAVR.

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KEYWORDS

transcatheter aortic valve replacement; frailty; cardiology; machine learning; TAVR; minimally invasive surgery; cardiac surgery; real-world data; topic modeling; clinical notes; electronic health record; EHR

Introduction

Degenerative severe aortic stenosis is estimated to affect 3.4% of the older population [1]. It results in reduced cardiac output, which reduces activity tolerance and often restricts the ability to perform activities of daily living [2,3]. This stage is associated with high short-term mortality [4]. The most common treatment that helps many patients resume an active lifestyle is transcatheter aortic valve replacement (TAVR), a less invasive procedure than open-heart surgery that replaces the diseased or damaged aortic valve [5]. Unfortunately, about 25% to 35% of patients either die or achieve no functional, morbidity, or mortality benefit from TAVR [6,7]. To optimize patient selection and postsurgical outcomes, accurate tools to acquire personalized, pertinent health data for TAVR candidates can provide valuable insights for patients and their clinicians to make informed decisions in presurgical clinics [6,8].

The American College of Cardiology's guidelines [9], along with various clinical studies [8,10,11], have identified frailty as a risk factor for post-TAVR mortality and morbidity. In a systematic review, Sepehri et al [12] demonstrated the relationship between frailty and adverse postsurgical outcomes in the cardiac population. In addition, research in health economics has shown that frail patients undergoing cardiac procedures incur higher hospitalization costs than nonfrail patients [13]. Given the clinical and economic implications of the TAVR procedure, there is a need to standardize the frailty assessment. This can aid in formulating strategies to enhance post-TAVR outcomes in frail patients. Such strategies may include partnering with geriatricians, opting for monitored anesthesia care, and employing 2 surgeons for complicated procedures, among several others [14].

Existing risk scores, such as the Society of Thoracic Surgeons score and the European System for Cardiac Operative Risk Evaluation, are commonly used for patients referred for cardiac surgery. These scores are useful, but they are stratified into lower-risk patient groups referred for cardiac surgery and do not meet the specific needs of TAVR patients [15-17]. The current methods of assessing frailty in patients undergoing TAVR have significant limitations. A wide variety of tests and instruments are used across studies, many of which have not been robustly evaluated for this specific patient population [15,18]. For example, some studies use subjective methods such as the eyeball test, which relies on visual assessments to gauge frailty but lacks standardization and objective criteria [15]. Other instruments like the Katz Index of Independence in Activities of Daily Living [19] and the Kansas City Cardiomyopathy Questionnaire [20] are often employed in TAVR clinics to assess functional dependency in older individuals, focusing on daily living activities like feeding, bathing, and dressing. While these assessments are valuable in evaluating different aspects of frailty, they vary significantly in their focus and methodology, leading to inconsistencies in frailty classification among TAVR patients. Additionally, they are not specific to the TAVR population. The Fried frailty phenotype [21] and the Rockwood Frailty Index [22] are well-established and validated frailty assessments. However, these assessments require a detailed physical examination, patient interviews [21], and the completion of surveys [22], which may be time consuming and resource intensive. For example, the Fried frailty phenotype assessment takes 15 - 20 minutes [23], and the Rockwood Frailty Index requires answering a 70-item questionnaire [22], which can burden health care providers and patients, hindering the adoption of frailty assessments and raising concerns about their feasibility, particularly in high-volume and resource-limited settings.

The goal of this study is to create a novel method that utilizes both structured and unstructured real-world data, along with machine learning (ML) techniques, to construct a frailty index that is specific to patients with aortic stenosis who are scheduled to undergo a TAVR procedure.

Methods

Ethical Considerations

This retrospective study utilized perioperative data collected from January 2018 to December 2019, as part of a federal study (R01 AG055337, CP) approved by the institutional review board of the University of Florida, with a waiver for Health Insurance Portability and Accountability Act compliance and an honest broker for medical record retrieval. The research adhered to the Declaration of Helsinki and followed all the institutional protocols. Participants provided written informed consent at the time of data collection.

Study Population

The study extracted data on 14,000 patients from a deidentified historical database. A specific subset, the TAVR cohort, was identified using the Current Procedural Terminology code 33361, which narrowed the focus to 131 patients. All these patients had aortic stenosis as one of their symptoms.

Frailty Phenotype and Target Variables

A person is classified as frail if they meet 3 or more of the following conditions: (1) unintentional weight loss of 10 pounds or more over the past 6 months; (2) a sense of persistent exhaustion, characterized by a moderate feeling that normal activities were strenuous over the past week or a moderate inability to initiate activities; (3) a reduced pace in walking, as assessed by a nurse; (4) diminished grip strength, determined by a gender-specific T-score below −2.5, based on the highest grip strength recorded across 3 attempts using a Jamar hydraulic hand dynamometer (Model J00105, Lafayette Instrument Europe); and (5) a self-reported decrease in physical activity, gauged by the Duke Activity Status Index [24]. The scoring range is from 0 to 5; individuals meeting fewer than 3 of these criteria are considered nonfrail. This frailty assessment is documented in electronic health records (EHRs) to assist in planning perioperative care. In the preoperative anesthesia clinic, both the nursing staff and anesthesia professionals undergo training to perform frailty assessments, guided by published criteria [21,25], alongside documenting educational background and conducting cognitive evaluations.

Topic Modeling

Latent Dirichlet allocation (LDA) is a statistical model used in the field of natural language processing to uncover the hidden thematic structure in extensive collections of documents. We used LDA to generate 150 topics on clinical notes collected 60 days before surgery. A total of 543,520 clinical notes from 18,513 patients were collected. We removed preoperative evaluation notes that documented the results of the Fried frailty phenotype score to avoid information contamination. During data preprocessing, we found that some clinical notes contained similar information about the patients. To overcome this issue, we calculated the similarity between clinical notes that share the same NOTE_KEY using cosine distance and removed the notes with a similarity score greater than 80%. Special characters were removed, and all uppercase letters were converted to lowercase. Three types of words from the clinical notes were removed: (1) high-frequency words that were not closely related to medical symptoms, (2) words with a frequency less than 30, and (3) common stop words. We further performed stemming to reduce the words to their root form to simplify and standardize the vocabulary. After the data preprocessing, a total of 170,731 notes from 18,012 patients were included. Topic modeling was based on 50,000 randomly selected clinical notes. Topics of the remaining clinical notes were predicted and aggregated to the individual level to represent if the patients had a mention of a certain topic.

Structured EHR Data

Preoperative attributes extracted from structured EHR data encompassed patient details available up to 6 months prior to their frailty evaluation. These included sociodemographic data (like age, gender, race, and years of education), medical history and severity (such as cancer history and the American Society of Anesthesiologists [ASA] physical status classification [26]), along with the latest biochemical markers typically recorded in preoperative settings (eg, hemoglobin and hematocrit levels).

Sociodemographic attributes captured information such as the patient's age at frailty evaluation, gender, race, marital and employment status, and educational attainment. We divided age into 3 categories: under 70 years, between 70 and 79 years, and over 80 years. Education level was quantified by the total years of formal education [27], with each year of progression counted and repetitions not contributing to the total. For instance, completion of high school was marked as 12 years, a bachelor's degree as 16 years, and so on. Medical history and acuity features included various medical conditions, the ASA physical status score, and the type of clinical encounter.

Medical conditions were binary indicators based on whether a patient had certain conditions, with the *International Classification of Diseases and Related Health Problems, Tenth Revision*, diagnosis codes condensed into Clinical Classifications Software categories for a more clinically relevant summarization. Conditions appearing in at least 10% of a broader cohort were selected as features for the ML models. The ASA score, ranging from 1 to 5, assessed patient health, with scores 1-2 indicating low-risk or mild systemic disease, and scores 3 and above signaling serious systemic illness.

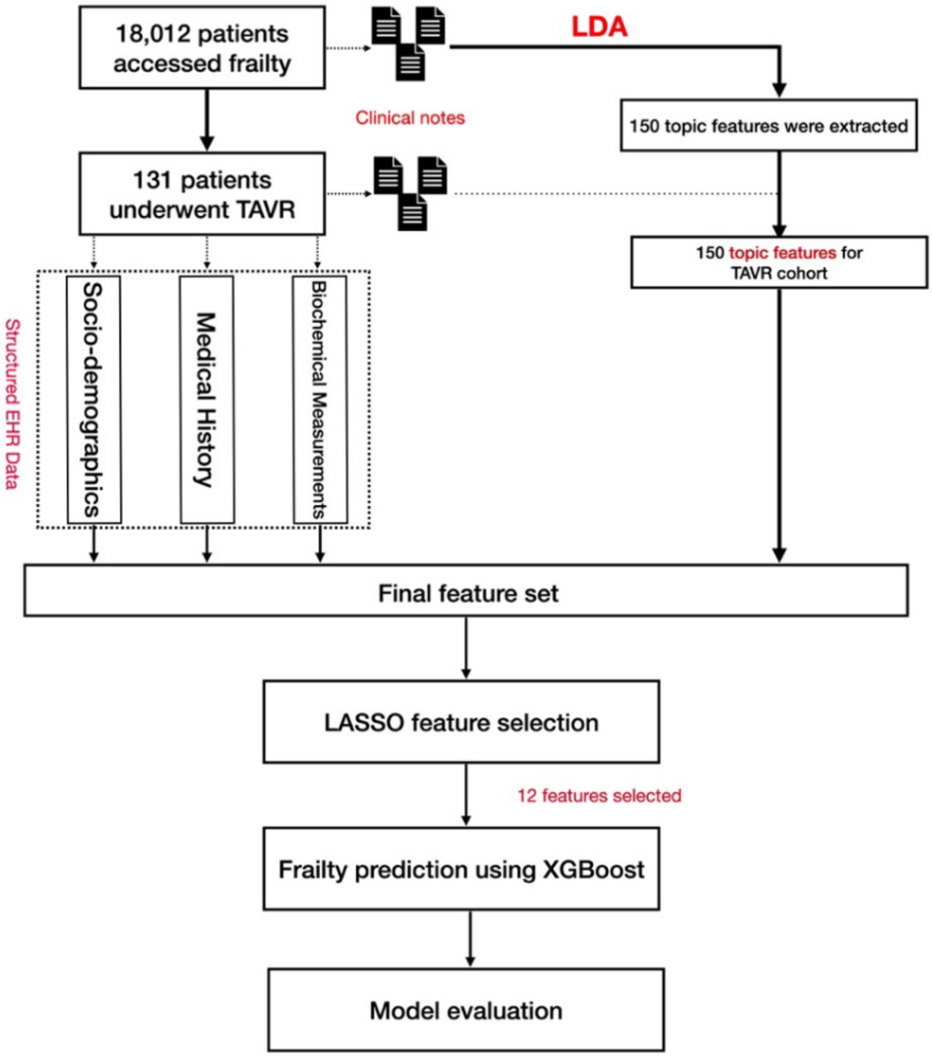
Biochemical features included hematocrit, hemoglobin, and platelet count, with hemoglobin and hematocrit levels recommended for evaluation in older patients (65 years and above) undergoing significant surgery or those with a history of severe anemia undergoing minor surgery.

Integration of Topic Features and Structured EHR Features

We manually reviewed topics generated from topic modeling and removed those that were not related to medical findings, resulting in 121 topic features in total. TAVR patients without clinical notes were removed (n=34), resulting in 97/131 patients in the training and evaluating ML models. Table S1 in Multimedia Appendix 1 compares the demographics between patients who were removed due to the absence of clinical notes and those who were used for modeling. After combining features generated from topic modeling and those from structured EHR data, we performed least absolute shrinkage and selection operator (LASSO) regression to reduce the feature space. Different parameters for regularization strength were examined, and the one that achieved the highest area under the receiver operating characteristic curve (AUC) for predicting frailty was selected for feature selection. We further applied Extreme Gradient Boosting (XGBoost) on features selected from LASSO to predict frailty. XGBoost is an ensemble learning method that uses decision tree frameworks. It creates models to improve the efficacy of preceding trees by diminishing errors through gradient descent. The resulting frailty index from XGBoost is a continuous score between 0 and 1, representing the probability of a patient being predicted as frail; high scores indicate a greater likelihood of frailty in TAVR patients.

To assess the additive value of topic features derived from clinical notes, we also evaluated the performance of XGBoost on predicting frailty using only features from structured EHR data. We used the k-nearest neighbor imputation technique to impute missing values in numerical features with the mean value from the k-nearest neighbors (k=5) found in the training dataset. Missing values in categorical features were imputed as a new label (unknown). Numerical features were scaled to 0-1, and categorical features were encoded before training the ML model. Figure 1 illustrates the overview of the analytic pipeline.

Figure 1. Overview of the analytic pipeline. EHR: electronic health record; LASSO: least absolute shrinkage and selection operator; LDA: latent Dirichlet allocation; TAVR: transcatheter aortic valve replacement; XGBoost: Extreme Gradient Boosting.



Model Performance and Evaluation

We employed a 5×5 nested cross-validation technique to evaluate our ML models. This technique consisted of 5 outer and 5 inner folds. During each outer fold, we set aside one-fifth of the patient records as an independent testing set, while the remaining four-fifths formed the training set. This outer training subset was then split into 5 inner folds for further validation. Each inner fold served as a stand-alone validation set, while the other 4 acted as the training set for the inner loop. The inner loop was responsible for training the models and fine-tuning the hyperparameters, taking a methodical approach in searching for the model's ideal hyperparameter settings. Meanwhile, the outer loop estimated errors and evaluated generalization capabilities. To optimize hyperparameters, we utilized a grid search strategy to systematically explore various combinations of predefined hyperparameters to train our models. We calculated and reported the mean and SD for metrics like AUC, accuracy, sensitivity, and specificity across the 5 outer folds. This thorough approach boosts confidence in the models' generalizability and scalability.

Model Interpretation and Feature Ranking

We used the Shapley Additive Explanations (SHAP) method to explain how our trained ML models work. SHAP is a widely used model-agnostic explanatory approach that helps in understanding the outputs of ML models. We created a SHAP summary plot to demonstrate the importance of features and their impact on the outcome. This impact is shown through a sign and magnitude: the SHAP value's sign indicates the direction of the feature's impact on the outcome (eg, a positive SHAP value indicates that the feature in question increases the likelihood of frailty), while its magnitude reflects the feature's predictive influence.

Statistical Analysis

Categorical features between the frail and nonfrail cohorts were compared using a χ^2 test for features with expected cell counts greater than 5 and a Fisher exact test for features with expected cell count less than or equal to 5 (ie, race). Age differences between the frail and nonfrail cohorts were compared using a Wilcoxon rank sum test. The significance level was set at *P*<.05.

Results

Table 1 compares patient characteristics between frail and nonfrail patients who underwent TAVR. The most significant difference observed was that frail patients were older and had lower hematocrit and hemoglobin levels compared to nonfrail patients. However, there were no significant differences in other characteristics such as gender, race, marital status, education, ASA score, or employment status.

Table . Comparison of patient characteristics between frail and nonfrail TAVR[a] patients.

Features	Frail (n=46)	Nonfrail (n=51)	*P* value
Age (years), mean (SD)	80.22 (7.45)	77.31 (6.05)	.04
Hematocrit (%), mean (SD)	36.16 (5.38)	39.93 (4.99)	<.001
Hemoglobin (g/DL), mean (SD)	12.14 (1.89)	13.4 (1.78)	.002
Platelet count (platelets/mL), mean (SD)	199.95 (86.34)	202.12 (51.91)	.88
Gender, n (%)			.69
Female (n=37)	19 (51.4)	18 (48.6)	
Male (n=60)	27 (45)	33 (55)	
Race, n (%)			.54
White (n=93)	43 (46.2)	50 (53.8)	
Others (n=4)	3 (75)	1 (25)	
Marital status, n (%)			.32
Married (n=65)	28 (43.1)	37 (56.9)	
Others (n=32)	18 (56.3)	14 (43.7)	
Years of education, n (%)			.41
Greater than 12 (n=58)	25 (43.1)	33 (56.9)	
Less than or equal to 12 (n=49)	21 (53.8)	28 (46.2)	
ASA[b] physical status score, n (%)			.47
Less than or equal to 3 (n=21)	8 (38.1)	13 (61.9)	
Greater than 3 (n=76)	38 (50)	38 (50)	
Employment status, n (%)			.79
Retired (n=76)	35 (46.1)	41 (53.9)	
Not retired (n=21)	11 (52.4)	10 (47.6)	

[a] TAVR: transcatheter aortic valve replacement.

[b] ASA: American Society of Anesthesiologists.

Table S2 in Multimedia Appendix 1 shows the number of features selected by LASSO alongside corresponding performance metrics across different regularization parameter values. Lower regularization parameter values (ie, inversed regularization strength) correspond to increased penalization of coefficient magnitudes and reduced features retained in the final model. Specifically, an inversed regularization strength of 0.25 imposed the highest penalty, leading to the smallest feature selection. Comparatively, an inversed regularization strength of 0.5 resulted in 12 selected features and achieved the highest AUC (0.67) and accuracy (0.65).

Table S3 in Multimedia Appendix 1 and Figure 2 show the performance of the ML models in identifying frailty. Results showed significant enhancement in the predictive performance when topic features derived from clinical notes were integrated with structured EHR data, compared to when only structured EHR data were used. Specifically, the combined topic + EHR model demonstrated a superior AUC of 0.82 (SD 0.07), indicating a robust ability to distinguish between frail and nonfrail individuals. This was a notable improvement over the EHR-only model, which achieved an AUC of 0.64 (SD 0.08).

Figure 3 shows the rank of features in predicting the frailty phenotype based on their SHAP values. Notably, the treatment and management of congestive heart failure (CHF) with carvedilol, spondylosis, intervertebral disc disorders, and other back problems and the treatment and management of atrial fibrillation (AFib) were found to have the strongest influence. These features exhibited high SHAP values, suggesting they strongly predict the frailty phenotype. Other significant factors included musculoskeletal symptoms, anemia, and age ≥80 years.

Figure 2. Receiver operating characteristic curves of frailty prediction using structured EHR data only and an integration of structured EHR data and topic features. Structured EHR features included sociodemographics, medical history and severity, and biochemical measurements. Topics features included features derived from clinical notes using latent Dirichlet allocation. The final features used were the ones selected from least absolute shrinkage and selection operator logistic regression. AUC: area under the receiver operating characteristic curve; EHR: electronic health record.

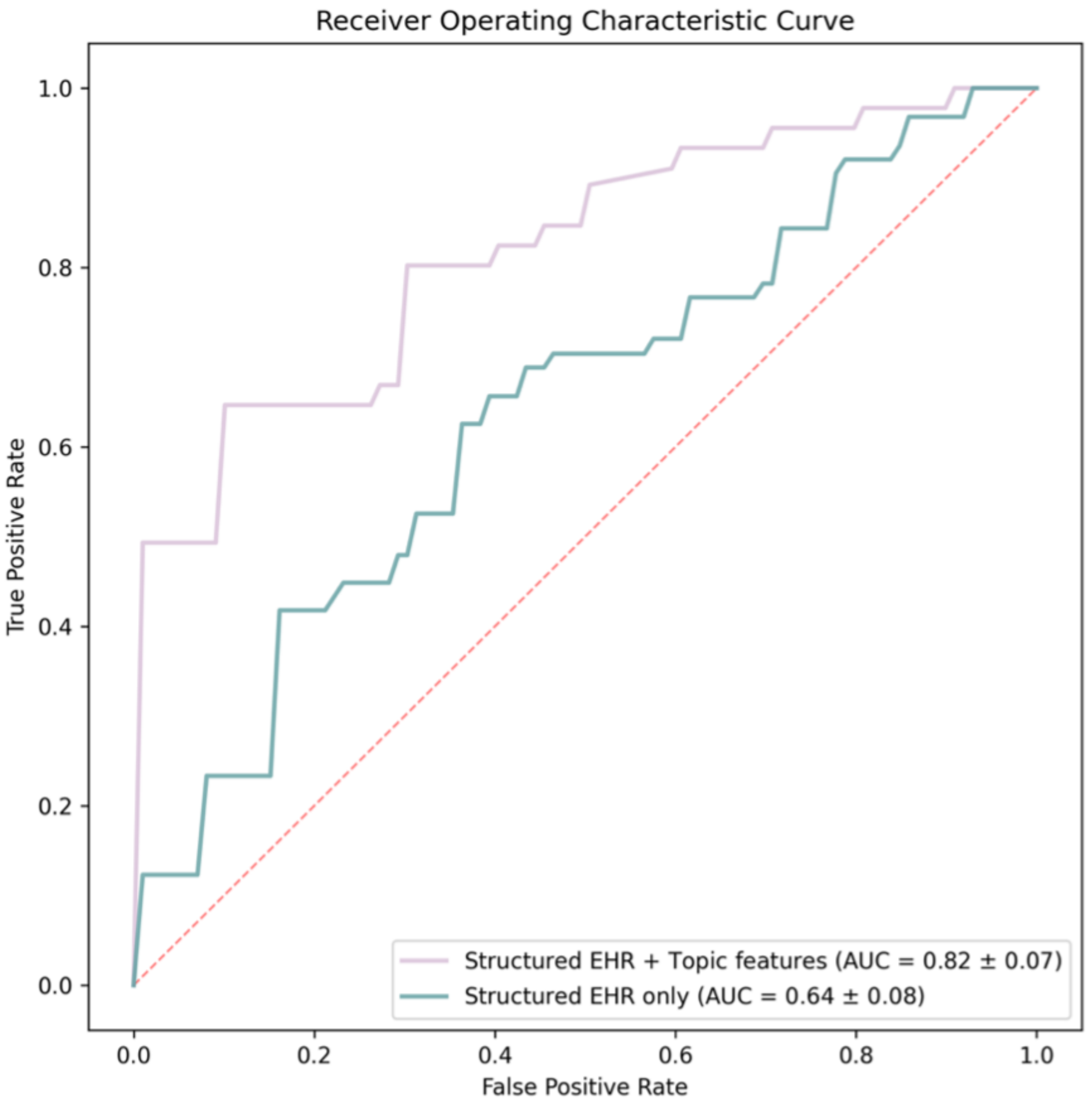


Figure 3. The rank of features in predicting the frailty phenotype. SHAP values greater than 0 (towards the right) contributed to predicting frailty, whereas SHAP values less than 0 contributed to predicting nonfrailty. For diagnosis and topic features, red dots indicate the presence, while blue dots indicate the absence of the condition. Red dots in “Years of education” represent patients with less than 12 years of education. Red dots in “Age >= 80” represent patients aged over 80 years old. SHAP: Shapley Additive Explanations.

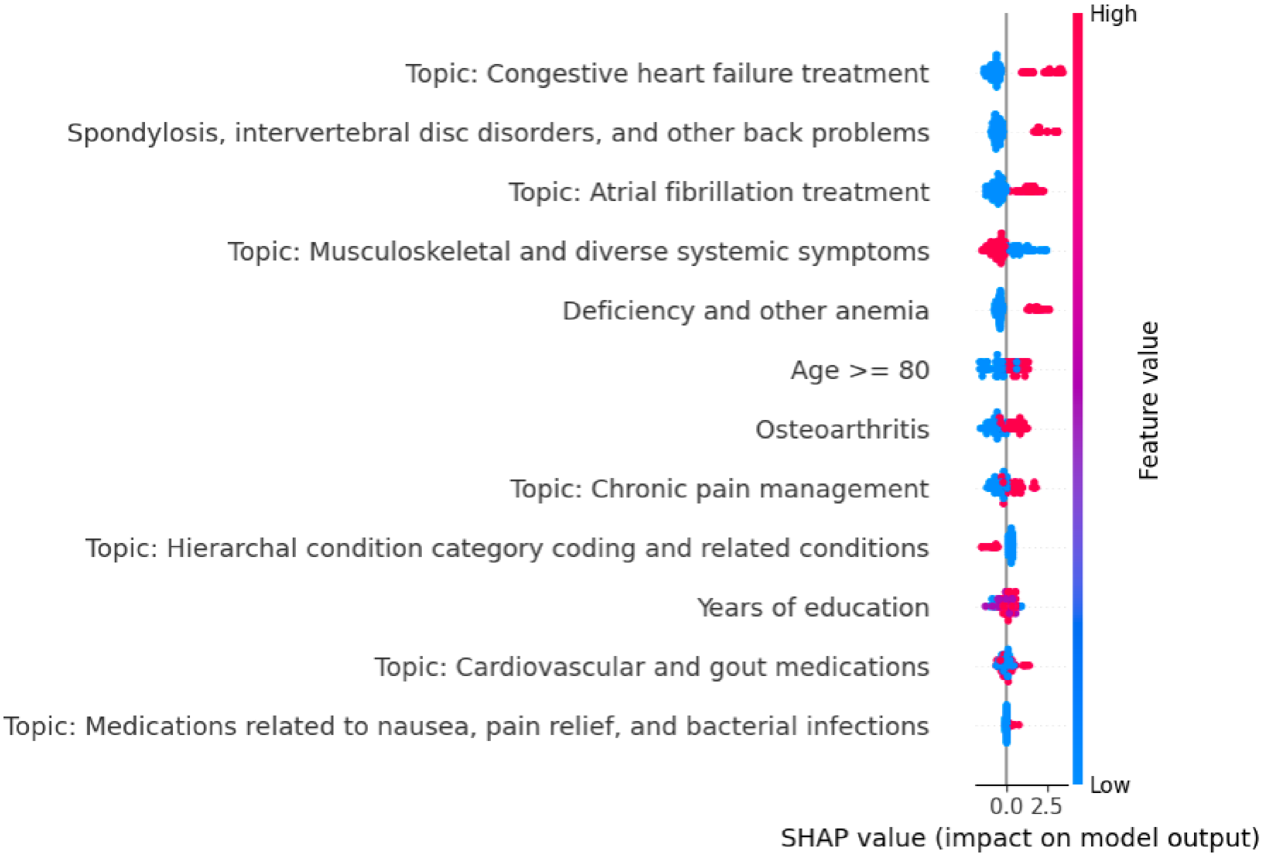


Table 2 presents 7 topics identified through LDA of clinical notes and further selected by LASSO. Of these, 5 topics related to the treatment and management of specific medical comorbidities in the cohort. The LDA algorithm identified underlying topics by clustering co-occurring terms across the clinical corpus. Each topic’s top 10 weighted terms indicated which terms appeared most prominently within a given cluster. Higher term weights represented stronger associations between the term and the topic. For instance, the medications “Carvedilol” (term weight 0.097) and “Coreg” (term weight 0.094) had the highest weights within the first topic. Based on the prominence of these cardioprotective drugs, the topics were interpreted as medical treatment and management of CHF.

Table . Topics selected by least absolute shrinkage and selection operator regression for predicting the frailty phenotype in transcatheter aortic valve replacement patients, along with the top associated terms (stemmed) and their respective weights. The topics and terms listed are critical factors identified by the least absolute shrinkage and selection operator model that contribute to the prediction of frailty. The weights indicate the strength and direction of each term’s association with the frailty phenotype, providing insights into the underlying factors influencing patient outcomes.

Topics	Details
Topic: Congestive heart failure treatment	0.097*“carvedilol”+0.094*“coreg”+0.056*“chf”+0.056*“lasix”+0.034*“bumex”+0.034*“spironolacton”+0.032*“cardiomyopathi”+0.029*“meal”+0.029*“bp”+0.027*“aldacton”
Topic: Atrial fibrillation treatment	0.168*“eliqui”+0.071*“fib”+0.069*“apixaban”+0.052*“xarelto”+0.047*“diltiazem”+0.035*“rate”+0.029*“stop”+0.028*“sotalol”+0.027*“hold”+0.025*“cardiovers”
Topic: Musculoskeletal and diverse systemic symptoms	0.058*“movement”+0.044*“swell”+0.041*“joint”+0.039*“musculoskelet”+0.033*“respiratori”+0.029*“extra”+0.026*“mucou”+0.026*“jaundic”+0.025*“psychiatr”+0.025*“rate”
Topic: Chronic pain management	0.197*“everi”+0.131*“tramadol”+0.091*“ultram”+0.080*“acetaminophen”+0.051*“nightli”+0.045*“ointment”+0.043*“appli”+0.038*“norco”+0.034*“bactroban”+0.032*“mupirocin”
Topic: Hierarchal condition category coding and related conditions	0.498*“hcc”+0.412*“code”+0.020*“mellitu”+0.014*“problem”+0.011*“anemia”+0.010*“list”+0.004*“neuropathi”+0.004*“pvd”+0.003*“coronari”+0.002*“defici”
Topic: Cardiovascular and gout medications	0.105*“tartrat”+0.102*“lopressor”+0.065*“gout”+0.064*“allopurinol”+0.057*“atorvastatin”+0.049*“zyloprim”+0.047*“lipitor”+0.042*“male”+0.042*“nightli”+0.036*“physic”
Topic: Medications related to nausea, pain relief, and bacterial infections	0.210*“everi”+0.073*“zofran”+0.060*“ondansetron”+0.043*“acetaminophen”+0.038*“amoxicillin”+0.034*“releas”+0.027*“odt”+0.027*“keflex”+0.025*“augmentin”+0.024*“delay”

Discussion

Principal Findings

This study developed a frailty index using ML techniques by combining structured and unstructured real-world data. Incorporating the features obtained from unstructured clinical notes and structured EHR data significantly improved the model’s performance in identifying frailty. SHAP revealed that cardiovascular conditions, specifically CHF and AFib, as well as musculoskeletal disorders, were the primary factors that predict frailty among patients. This is consistent with the mainstream of clinical evidence [28-30]. The prominence of age as a predictor supports the well-established association between advancing age and increased vulnerability to frailty and limited quality of life improvement post TAVR [31]. The impact of years of formal education on frailty prediction was relatively lower (ranked 10th in importance), indicating that while socioeconomic factors contribute to health outcomes, clinical characteristics are more determinative in the context of frailty. This clinical ML application can easily be integrated into pre-TAVR settings to guide perioperative management, heart team discussions, and resource utilization. Our model provides actionable and semiquantitative insights and can potentially highlight targets for optimization (eg, anemia). In addition, the data processing and derivation pipeline we practically demonstrate allows ML model retraining to accommodate updates in practice and interinstitutional context differences.

Structured real-world data that contain rich historical and current information across various domains (eg, diagnoses, procedures, demographics) have been leveraged to predict frailty. Segal et al [32] constructed ML models using medical claims data to predict the Fried frailty phenotype, achieving an AUC of 0.76 with a gradient boosting machines algorithm. Similarly, Le Pogam et al's [33] exploration using inpatient discharge data obtained an AUC of 0.71, while Bai et al [34] harnessed structured EHR data to predict preoperative frailty, achieving an AUC of 0.74 using XGBoost. Notably, a considerable amount of information contained within EHRs exists as unstructured text. Recent advancements in ML and natural language processing have enabled researchers to harness this valuable resource, which traditionally posed substantial challenges for manual analysis. For instance, Shao et al [35] used topic modeling to extract frailty-related topics from clinical notes and defined frailty using the number of frailty-related topics present. This frailty index was associated with a 2-fold increased risk of the composite outcome combining 1-year hospitalization and mortality. Further, Chen et al [36] and Martin et al [37] developed deep learning models to predict sentences indicating geriatric syndromes or actionable frailty aspects and achieved an F_1-score of 0.61 and a scaled Brier score of 0.52. Despite these advances, a gap remains in the literature concerning the integration of structured and unstructured real-world data for frailty prediction. Moreover, the development of frailty indices tailored to preoperative contexts, especially for TAVR patients, remains unexplored.

Our results demonstrated that clinical notes serve as a complement to structured EHR data in predicting preoperative frailty. Incorporating features extracted from clinical notes significantly improved the model's performance over using only structured EHR data, with the integrated model using only 12 features achieving an AUC of 0.82 compared to 0.64 for the EHR-only model in the test set. This performance is superior to the one-size-fits-all statistical models such as the Society of Thoracic Surgeons score, which has an AUC of 0.64-0.7 in risk stratifying patients [38-40].

Identifying the key topics and associated terms provides actionable insights into understanding and managing frailty-associated factors. For instance, knowing that the patient has heart failure requiring cardiac medications and contributing to frailty may trigger putting the patient on a more intensive pre- and post-TAVR optimization pathway, such as right heart catheterization, to optimize heart failure therapy preprocedures. Similar approaches can be applied to other cardiovascular conditions or musculoskeletal disorders that are partially correctable with focused pre- or postprocedural conditioning. The topic of CHF treatment and management, with high-weight terms like "Carvedilol," can highlight high systemic vascular resistance hemodynamic phenotypes, systolic heart failure, or arrhythmia requiring beta blockade. Similarly, the topic focusing on AFib management, with terms like "Eliquis" and "Apixaban," highlights the need to evaluate and manage arrhythmias, which are risk factors for stroke and also are associated with obesity, hypoventilation, and chronically low physical and cardiopulmonary conditioning. The specificity of terms and their weights in each topic provides a framework for health care professionals to identify and prioritize areas of concern in pre-TAVR patients, ensuring a comprehensive and tailored approach to frailty assessment. Identifying "high-risk candidates" is crucial in determining a patient's readiness for TAVR and optimizing postprocedural outcomes by addressing the multifaceted aspects of frailty and medical complexity in this vulnerable patient population [41,42]. A considerable advantage to using ML models is that they are translatable to new TAVR techniques, adaptable to clinical settings and automated facilitating implementation, and updatable to accommodate shifts in populations and practices.

Compared to the traditional frailty measurements, a key advantage of our developed method is its applicability to newly admitted patients with severe aortic stenosis being considered for TAVR. The model can process a patient's available information, including both structured EHR data and unstructured clinical notes, to generate a frailty index score once the patient is admitted. This assessment provides an objective measure of a patient's frailty status, which has the potential to enhance the clinical shared decision-making between physicians and the patient. By offering an early and timely indication of a patient's frailty status, this approach allows for a more informed discussion about the risks and benefits of TAVR, potential alternative treatments, and the need for additional preoperative interventions and postoperative care plans, ultimately improving the care of TAVR patients.

This study, while insightful, acknowledges specific limitations. It utilizes retrospective EHR data, a method that provides a valuable foundation for analysis despite its inherent limitations, such as the potential for minor reporting inconsistencies, recall variations, and lead time considerations. The study's focus on frailty, although a topic of ongoing discussion due to its varied definitions and intersection with medical complexity, enriches the discourse by offering a nuanced view of its implications. Additionally, while our ML approach effectively integrates structured and unstructured real-world data to predict frailty, it does not extensively address potential confounding factors such as comorbidities, medications, or socioeconomic status. This focus on predictive modeling, rather than causal analysis, may limit the ability to fully account for these variables. Furthermore, this study has not undergone external validation; however, this aspect is mitigated by the rigorous internal review processes, which reduce the risk of overfitting and ensure the model's preliminary reliability. Rather than significantly limiting, these considerations underscore the study's contribution to ongoing research and its potential as a springboard for further investigation and external validation efforts.

Conclusion

This study demonstrates the effectiveness of combining unstructured clinical notes with structured EHR data to assess frailty in TAVR patients. This approach can potentially improve risk stratification for TAVR, adding insight into targets for perioperative optimization and potentially improving TAVR outcomes. Future efforts should integrate these models into clinical settings to improve TAVR planning and patient care, emphasizing continuous medical education and innovation.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary material.
[DOCX File, 16 KB - aging_v7i1e58980_app1.docx]

References

1. Osnabrugge RLJ, Mylotte D, Head SJ, et al. Aortic stenosis in the elderly: disease prevalence and number of candidates for transcatheter aortic valve replacement: a meta-analysis and modeling study. J Am Coll Cardiol 2013 Sep 10;62(11):1002-1012. [doi: 10.1016/j.jacc.2013.05.015] [Medline: 23727214]
2. Kim DH, Afilalo J, Shi SM, et al. Evaluation of changes in functional status in the year after aortic valve replacement. JAMA Intern Med 2019 Mar 1;179(3):383-391. [doi: 10.1001/jamainternmed.2018.6738] [Medline: 30715097]
3. Carabello BA, Paulus WJ. Aortic stenosis. Lancet 2009 Mar 14;373(9667):956-966. [doi: 10.1016/S0140-6736(09)60211-7] [Medline: 19232707]
4. Bevan GH, Zidar DA, Josephson RA, Al-Kindi SG. Mortality due to aortic dtenosis in the United States, 2008-2017. JAMA 2019 Jun 11;321(22):2236-2238. [doi: 10.1001/jama.2019.6292] [Medline: 31184728]
5. Makkar RR, Thourani VH, Mack MJ, et al. Five-year outcomes of transcatheter or surgical aortic-valve replacement. N Engl J Med 2020 Jan 29;382(9):799-809. [doi: 10.1056/NEJMoa1910555] [Medline: 31995682]
6. Puri R, Iung B, Cohen DJ, Rodés-Cabau J. TAVI or no TAVI: identifying patients unlikely to benefit from transcatheter aortic valve implantation. Eur Heart J 2016 Jul 21;37(28):2217-2225. [doi: 10.1093/eurheartj/ehv756] [Medline: 26819226]
7. Arnold SV. Calculating risk for poor outcomes after transcatheter aortic valve replacement. J Clin Outcomes Manag 2019 May;26(3):125-129. [Medline: 31427851]
8. Li Z, Dawson E, Moodie J, et al. Measurement and prognosis of frail patients undergoing transcatheter aortic valve implantation: a systematic review and meta-analysis. BMJ Open 2021 Mar 4;11(3):e040459. [doi: 10.1136/bmjopen-2020-040459] [Medline: 33664067]
9. Otto CM, Kumbhani DJ, Alexander KP, et al. 2017 ACC Expert Consensus Decision Pathway for transcatheter aortic valve replacement in the management of adults with aortic stenosis: a report of the American College of Cardiology Task Force on Clinical Expert Consensus Documents. J Am Coll Cardiol 2017 Mar 14;69(10):1313-1346. [doi: 10.1016/j.jacc.2016.12.006] [Medline: 28063810]
10. Kim DH, Kim CA, Placide S, Lipsitz LA, Marcantonio ER. Preoperative frailty assessment and outcomes at 6 months or later in older adults undergoing cardiac surgical procedures: a systematic review. Ann Intern Med 2016 Nov 1;165(9):650-660. [doi: 10.7326/M16-0652] [Medline: 27548070]
11. Afilalo J, Lauck S, Kim DH, et al. Frailty in older adults undergoing aortic valve replacement: the FRAILTY-AVR study. J Am Coll Cardiol 2017 Aug 8;70(6):689-700. [doi: 10.1016/j.jacc.2017.06.024] [Medline: 28693934]
12. Sepehri A, Beggs T, Hassan A, et al. The impact of frailty on outcomes after cardiac surgery: a systematic review. J Thorac Cardiovasc Surg 2014 Dec;148(6):3110-3117. [doi: 10.1016/j.jtcvs.2014.07.087] [Medline: 25199821]
13. Goldfarb M, Bendayan M, Rudski LG, et al. Cost of cardiac surgery in frail compared with nonfrail older adults. Can J Cardiol 2017 Aug;33(8):1020-1026. [doi: 10.1016/j.cjca.2017.03.019] [Medline: 28754387]
14. van Steenbergen GJ, van Veghel D, Schulz DN, et al. Better survival after transcatheter aortic valve replacement by process improvements. Neth Heart J 2021 Apr;29(4):193-200. [doi: 10.1007/s12471-020-01526-7] [Medline: 33284420]
15. Hinterbuchner L, Strohmer B, Hammerer M, Prinz E, Hoppe UC, Schernthaner C. Frailty scoring in transcatheter aortic valve replacement patients. Eur J Cardiovasc Nurs 2016 Oct;15(6):384-397. [doi: 10.1177/1474515115596640] [Medline: 26216870]

16. Shroyer ALW, Coombs LP, Peterson ED, et al. The Society of Thoracic Surgeons: 30-day operative mortality and morbidity risk models. Ann Thorac Surg 2003 Jun;75(6):1856-1864. [doi: 10.1016/s0003-4975(03)00179-6] [Medline: 12822628]
17. Nashef SAM, Sharples LD, Roques F, Lockowandt U. EuroSCORE II and the art and science of risk modelling. Eur J Cardiothorac Surg 2013 Apr;43(4):695-696. [doi: 10.1093/ejcts/ezs468] [Medline: 22922694]
18. Morley JE, Vellas B, van Kan GA, et al. Frailty consensus: a call to action. J Am Med Dir Assoc 2013 Jun;14(6):392-397. [doi: 10.1016/j.jamda.2013.03.022] [Medline: 23764209]
19. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. JAMA 1963 Sep 21;185:914-919. [doi: 10.1001/jama.1963.03060120024016] [Medline: 14044222]
20. Spertus JA, Jones PG. Development and validation of a short version of the Kansas City Cardiomyopathy Questionnaire. Circ Cardiovasc Qual Outcomes 2015 Sep;8(5):469-476. [doi: 10.1161/CIRCOUTCOMES.115.001958] [Medline: 26307129]
21. Fried LP, Tangen CM, Walston J, et al. Frailty in older adults: evidence for a phenotype. J Gerontol A Biol Sci Med Sci 2001 Mar;56(3):M146-M156. [doi: 10.1093/gerona/56.3.m146] [Medline: 11253156]
22. Rockwood K, Mitnitski A. Frailty in relation to the accumulation of deficits. J Gerontol A Biol Sci Med Sci 2007 Jul;62(7):722-727. [doi: 10.1093/gerona/62.7.722] [Medline: 17634318]
23. Kim H, Higgins PA, Canaday DH, Burant CJ, Hornick TR. Frailty assessment in the geriatric outpatient clinic. Geriatr Gerontol Int 2014 Jan;14(1):78-83. [doi: 10.1111/ggi.12057] [Medline: 23530477]
24. Hlatky MA, Boineau RE, Higginbotham MB, et al. A brief self-administered questionnaire to determine functional capacity (the Duke Activity Status Index). Am J Cardiol 1989 Sep 15;64(10):651-654. [doi: 10.1016/0002-9149(89)90496-7] [Medline: 2782256]
25. Amini S, Crowley S, Hizel L, et al. Feasibility and rationale for incorporating frailty and cognitive screening protocols in a preoperative anesthesia clinic. Anesth Analg 2019 Sep;129(3):830-838. [doi: 10.1213/ANE.0000000000004190] [Medline: 31425227]
26. Horvath B, Kloesel B, Todd MM, Cole DJ, Prielipp RC. The evolution, current value, and future of the American Society of Anesthesiologists physical status classification system. Anesthesiology 2021 Nov 1;135(5):904-919. [doi: 10.1097/ALN.0000000000003947] [Medline: 34491303]
27. Price C, Cole DJ. Adding ‘Formal Years of Education’ to patients’ preoperative screening. ASA Monitor 2023 May 1;87(5):1-4. [doi: 10.1097/01.ASM.0000935232.57361.7f]
28. Damluji AA, Rodriguez G, Noel T, et al. Sarcopenia and health-related quality of life in older adults after transcatheter aortic valve replacement. Am Heart J 2020 Jun;224:171-181. [doi: 10.1016/j.ahj.2020.03.021] [Medline: 32416332]
29. Krishnan A, Suarez-Pierre A, Zhou X, et al. Comparing frailty markers in predicting poor outcomes after transcatheter aortic valve replacement. Innovations (Phila) 2019 Feb;14(1):43-54. [doi: 10.1177/1556984519827698] [Medline: 30848712]
30. Zahid S, Din MTU, Khan MZ, et al. Trends, predictors, and outcomes of 30-day readmission with heart failure after transcatheter aortic valve replacement: insights from the US nationwide readmission database. J Am Heart Assoc 2022 Aug 16;11(16):e024890. [doi: 10.1161/JAHA.121.024890] [Medline: 35929464]
31. Attinger-Toller A, Ferrari E, Tueller D, et al. Age-related outcomes after transcatheter aortic valve replacement: insights from the SwissTAVI Registry. JACC Cardiovasc Interv 2021 May 10;14(9):952-960. [doi: 10.1016/j.jcin.2021.02.031] [Medline: 33865734]
32. Segal JB, Chang HY, Du Y, Walston JD, Carlson MC, Varadhan R. Development of a claims-based frailty indicator anchored to a well-established frailty phenotype. Med Care 2017 Jul;55(7):716-722. [doi: 10.1097/MLR.0000000000000729] [Medline: 28437320]
33. Le Pogam MA, Seematter-Bagnoud L, Niemi T, et al. Development and validation of a knowledge-based score to predict Fried’s frailty phenotype across multiple settings using one-year hospital discharge data: the electronic frailty score. E Clin Med 2022 Jan 10;44:101260. [doi: 10.1016/j.eclinm.2021.101260] [Medline: 35059615]
34. Bai C, Al-Ani M, Amini S, et al. Developing and validating an electronic health record-based frailty index in pre-operative settings using machine learning. J Intell Inf Syst 2023 Oct 14;62(2):339-354. [doi: 10.1007/s10844-023-00818-9]
35. Shao Y, Mohanty AF, Ahmed A, et al. Identification and use of frailty indicators from text to examine associations with clinical outcomes among patients with heart failure. AMIA Annu Symp Proc 2017 Feb 10;2016:1110-1118. [Medline: 28269908]
36. Chen T, Dredze M, Weiner JP, Kharrazi H. Identifying vulnerable older adult populations by contextualizing geriatric syndrome information in clinical notes of electronic health records. J Am Med Inform Assoc 2019 Aug 1;26(8-9):787-795. [doi: 10.1093/jamia/ocz093] [Medline: 31265063]
37. Martin JA, Crane-Droesch A, Lapite FC, et al. Development and validation of a prediction model for actionable aspects of frailty in the text of clinicians’ encounter notes. J Am Med Inform Assoc 2021 Dec 28;29(1):109-119. [doi: 10.1093/jamia/ocab248] [Medline: 34791302]
38. Reiff C, Gurevich S, Bertog S, Sorajja P, Kelly R, Garcia S. Validation of STS/ACC TVT-TAVR score in veterans undergoing transcatheter aortic valve replacement. J Invasive Cardiol 2018 Dec;30(12):447-451. [Medline: 30218556]

39. D’Ascenzo F, Capodanno D, Tarantini G, et al. Usefulness and validation of the survival post TAVI score for survival after transcatheter aortic valve implantation for aortic stenosis. Am J Cardiol 2014 Dec 15;114(12):1867-1874. [doi: 10.1016/j.amjcard.2014.09.031] [Medline: 25438915]
40. Al-Azizi K, Shih E, DiMaio JM, et al. Assessment of TVT and STS risk score performances in patients undergoing transcatheter aortic valve replacement. J Soc Cardiovasc Angiogr Interv 2023 Apr 21;2(3):100600. [doi: 10.1016/j.jscai.2023.100600] [Medline: 39130722]
41. Rogers T, Thourani VH, Waksman R. Transcatheter aortic valve replacement in intermediate- and low-risk patients. J Am Heart Assoc 2018 May 12;7(10):e007147. [doi: 10.1161/JAHA.117.007147] [Medline: 29754127]
42. Reyes M, Reardon MJ. Transcatheter valve replacement: risk levels and contemporary outcomes. Methodist Debakey Cardiovasc J 2017;13(3):126-131. [doi: 10.14797/mdcj-13-3-126] [Medline: 29743997]

Abbreviations

AFib: atrial fibrillation
ASA: American Society of Anesthesiologists
AUC: area under the receiver operating characteristic curve
CHF: congestive heart failure
EHR: electronic health record
LASSO: least absolute shrinkage and selection operator
LDA: latent Dirichlet allocation
ML: machine learning
SHAP: Shapley Additive Explanations
TAVR: transcatheter aortic valve replacement
XGBoost: Extreme Gradient Boosting

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Determinants of Visual Impairment Among Chinese Middle-Aged and Older Adults: Risk Prediction Model Using Machine Learning Algorithms

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Abstract

Background: Visual impairment (VI) is a prevalent global health issue, affecting over 2.2 billion people worldwide, with nearly half of the Chinese population aged 60 years and older being affected. Early detection of high-risk VI is essential for preventing irreversible vision loss among Chinese middle-aged and older adults. While machine learning (ML) algorithms exhibit significant predictive advantages, their application in predicting VI risk among the general middle-aged and older adult population in China remains limited.

Objective: This study aimed to predict VI and identify its determinants using ML algorithms.

Methods: We used 19,047 participants from 4 waves of the China Health and Retirement Longitudinal Study (CHARLS) that were conducted between 2011 and 2018. To envisage the prevalence of VI, we generated a geographical distribution map. Additionally, we constructed a model using indicators of a self-reported questionnaire, a physical examination, and blood biomarkers as predictors. Multiple ML algorithms, including gradient boosting machine, distributed random forest, the generalized linear model, deep learning, and stacked ensemble, were used for prediction. We plotted receiver operating characteristic and calibration curves to assess the predictive performance. Variable importance analysis was used to identify key predictors.

Results: Among all participants, 33.9% (6449/19,047) had VI. Qinghai, Chongqing, Anhui, and Sichuan showed the highest VI rates, while Beijing and Xinjiang had the lowest. The generalized linear model, gradient boosting machine, and stacked ensemble achieved acceptable area under curve values of 0.706, 0.710, and 0.715, respectively, with the stacked ensemble performing best. Key predictors included hearing impairment, self-expectation of health status, pain, age, hand grip strength, depression, night sleep duration, high-density lipoprotein cholesterol, and arthritis or rheumatism.

Conclusions: Nearly one-third of middle-aged and older adults in China had VI. The prevalence of VI shows regional variations, but there are no distinct east-west or north-south distribution differences. ML algorithms demonstrate accurate predictive capabilities for VI. The combination of prediction models and variable importance analysis provides valuable insights for the early identification and intervention of VI among Chinese middle-aged and older adults.

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KEYWORDS

visual impairment; China; middle-aged and elderly adults; machine learning; prediction model

Introduction

Visual impairment (VI) represents a significant global public health challenge. Over the period from 1990 to 2019, the burden index of VI has escalated for individuals aged 50 - 74 years and individuals aged 75 years and older, shifting from the 20th and 16th positions to the 19th and 15th positions, respectively [1]. The global increase in VI prevalence is primarily attributed to cataracts and uncorrected refractive errors, accounting for 55% of blindness cases and 77% of VI cases among adults aged 50 years and older in 2015 [2]. This trend is further exacerbated by population growth and aging [2]. According to the National Bureau of Statistics of China's January 2022 report, adults aged 60 years and older accounted for 18.9% of the total population by the end of 2021.

Meanwhile, adults aged 65 years and older exceeded 200 million, representing 14.2% of the total population [3]. It is projected that during the "14th Five-Year Plan" period, the total number of adults aged 60 years and older will surpass 300 million, accounting for over 20% of the population, indicating a transition into the moderate aging phase. By around 2035, China is anticipated to enter the severe aging phase [3]. Older adults with VI are at a heightened risk of falls [4], potentially leading to fractures and severe outcomes such as cerebral hemorrhage. Furthermore, VI can hinder social engagement among older adults, possibly giving rise to more profound mental health issues, including depression and anxiety [5]. As the population ages, the prevalence of VI is expected to increase dramatically. However, half of all VI cases are estimated to be preventable or treatable [6]. Hence, bolstering screening efforts and enhancing risk prediction for VI is paramount in stemming the tide of this growing concern.

In response to the crises posed by VI and to improve public visual health, the China National Health Commission has released the 14th Five-Year National Eye Health Plan (2021 - 2025). The plan focuses on enhancing eye health information platforms and promoting the harmonious integration of big data, artificial intelligence, and ophthalmology services to advance the early detection of eye diseases [7]. Through the development of machine learning (ML) prediction models for VI, the precise determination of VI risk and identification of influencing risk factors can be achieved. ML could offer new insights for early detection and timely intervention of retinopathy, as well as for the integrated management of ocular health in older adults, ultimately enhancing the overall eye health status of the population.

Artificial intelligence has experienced swift progress in recent years, resulting in extensive use of diverse ML algorithms in clinical research [8,9]. Compared with traditional statistical methods, ML algorithms can handle more complex nonlinear relationships, interactions, and multiple covariances, significantly improving the predictive ability of artificial intelligence models [10,11].

Despite the advantages of ML algorithms, there is an absence of the use of ML algorithms to predict the risk of VI in the general middle-aged and older adult population in China. Previous studies on predicting VI have focused on various topics, including examining trends in the incidence of VI among populations [12,13]; assessing the risk of VI in specific groups, such as those with congenital cytomegalovirus infection [14-16]; and further predicting the risk of developing particular types of VI [17]. However, these studies have not focused on predicting the individual risk of VI among the general population. In current research on predicting individual risk of VI among the general population, three studies [18-20] based on traditional statistical methods and two studies [21,22] based on ML algorithms have achieved good predictive performance. Among these, two studies [20,21] lacked Chinese populations, with the studied populations being mainly from the United States and Singapore; one focused on Chinese children [22]; one was a single-center study [18]; and one [19] had a small sample size of 133 participants. To date, no research has yet been conducted on using ML algorithms to predict VI in Chinese middle-aged and older adults. Therefore, our objective was to develop an individual risk prediction model for VI, which could be used to assess the risk of VI among China's general middle-aged and older population. Additionally, we aimed to identify key predictors of VI. Our findings could be used to provide personalized intervention guidance for health care professionals, aiming to reduce and delay the onset of retinal diseases among middle-aged and older adults.

Methods

Analytic Sample

The data used in our study originate from the China Health and Retirement Longitudinal Study (CHARLS), a longitudinal survey that represents a nationally diverse cohort of Chinese adults aged 45 years and older. This survey strives to establish a comprehensive public database documenting Chinese adults' social, economic, and health statuses, thereby bolstering scientific investigations conducted by the National Development Institute of Peking University. The CHARLS project executed a nationwide baseline survey between 2011 and 2012, with subsequent follow-up visits occurring biennially [23]. The CHARLS baseline survey encompassed 450 villages and neighborhoods spread across 150 counties in China. The sampling process encompassed multiple levels, including counties, villages, households, and individuals, culminating in interviews with 10,257 households and broadly reflecting the general Chinese middle-aged and older adult populace. We used 25,538 observations from 4 waves of surveys between 2011 and 2018. Excluding ages younger than 45 years (n=4079) and missing information on self-reported vision conditions (n=2457), 19,047 participants were included in this study. More details of the sampling process are shown in Figure S1A in Multimedia Appendix 1.

Predictors of VI

Drawing on existing literature and expert insights, 42 predictors were used for ML algorithm training. The predictors were categorized as follows: self-reported questionnaire, physical examination, and blood biomarkers. The self-reported questionnaire included (1) demographic factors (gender, age, and region), [24] (2) lifestyle (night sleep duration, smoking, and drinking), (3) health status factors (pain, weight change, health status during childhood, and self-expectations of health status), [25] (4) disease factors (depression, hearing impairment, hypertension, dyslipidemia, diabetes, liver disease, heart disease, stroke, kidney disease, stomach or other digestive disease, memory-related disease, arthritis or rheumatism, menopause, and prostatic diseases), (5) living environment factors (house structure, heating energy, cooking energy, and room temperature), and (6) socioeconomic factors (standard of living and education level). Measurement parameters included (1) physical examination data ([26] hand grip strength, waist, and BMI) and (2) blood biomarker data (white blood cell, platelets, glycated hemoglobin, glucose, total cholesterol, triglycerides, high-density lipoprotein cholesterol, and low-density lipoprotein cholesterol). The characteristics of the predictor distribution in the study are displayed in Table S1 in Multimedia Appendix 1.

Measurement of VI

Vision encompasses both far and near eyesight. VI in our study was assessed using the following questions from the CHARLS questionnaire: (1) “How well do you see things in the distance? For example, can you recognize a friend across the road (even with glasses on)? Is it excellent, very good, good, fair, or bad?” and (2) “How well do you see things close up? For example, can you read a newspaper with your glasses on? Is it excellent, very good, good, fair, or bad?” Respondents who answered “not good” to any of the questions were categorized as having a VI, while those who answered “excellent” to “fair” were considered to have no VI [27].

Statistical Analysis

We used R (version 4.3.1), developed by the R Core Team of the R Foundation for Statistical Computing, for statistical analysis and model development. The summary of continuous variables involved the use of the median and IQR (25th and 75th percentiles), and categorical variables were summarized by providing the count (n) and proportion (%) for each category. We used the R H2O package to construct various ML predictive models for a dichotomous outcome of VI [28]. H2O supports a wide range of ML models, including deep learning (DL), gradient boosting machine (GBM), distributed random forest (DRF), and more. In our study, we chose the generalized linear model (GLM) as our benchmark model, representing logistic regression. The study process is shown in Figure S1B in Multimedia Appendix 1. As per the No Free Lunch Theorem [29], no algorithm can outperform a linear enumeration of the search space or a purely random search algorithm. Thus, we split the dataset into training (n=14,286) and testing (n=4761) datasets at a 75:25 ratio. The training dataset was used to develop various models, including a GLM with regularization to prevent overfitting and enhance the model’s predictive accuracy. GBM uses decision trees as weak learners and boosts their predictions iteratively [30]. DRF incorporates both DRF and extremely randomized tree approaches to ensure diversity and robustness in the ensemble [31]. The DL model consists of a fully connected multilayer artificial neural network trained with backpropagation to capture complex nonlinear relationships [32,33]. A stacked ensemble combines the predictions of these individual models as input features for the ensemble’s meta-learner. The meta-learner then outputs a final prediction based on the learned weights of each base model’s contribution, enhancing overall prediction performance [34]. The random forest algorithm was used to impute missing values, while the continuous variables were normalized. In this study, the ratio of positive to negative outcomes in the target variable was 1:2, indicating an imbalanced dataset. To address data imbalance, random oversampling of the minority class was initially used [35]. Furthermore, to mitigate overfitting and enhance model generalization [36], external 5-fold cross-validation was implemented. However, the model’s performance did not show improvement compared with the no-resampling, blending mode. Therefore, we trained the stacked combinations using the no-resampling and blending mode, plotted the receiver operating characteristic (ROC) curves, and constructed the confusion matrix. We used the area under the curve (AUC) to evaluate the best model, with an acceptable AUC of 0.7 - 0.8, a good AUC of 0.8 - 0.9, and an excellent AUC of >0.9 [37]. We calibrated the probabilities predicted by the models to the actual occurrence level in the testing dataset using a logistic function and calculated the Brier score to assess the reliability of the prediction of VI [38]. The Brier score takes values from 0 to 1, and at a predicted probability of 50%, the Brier score is 0.25 [39]. A model score between 0 and 0.25 indicates a correct prediction, and a score closer to 0 indicates better model effectiveness. Additionally, we used models with acceptable AUCs for variable importance analysis. This enabled us to quantitatively assess the contribution of each feature towards model predictions, thereby allowing us to evaluate and compare the significance of various features.

Ethical Considerations

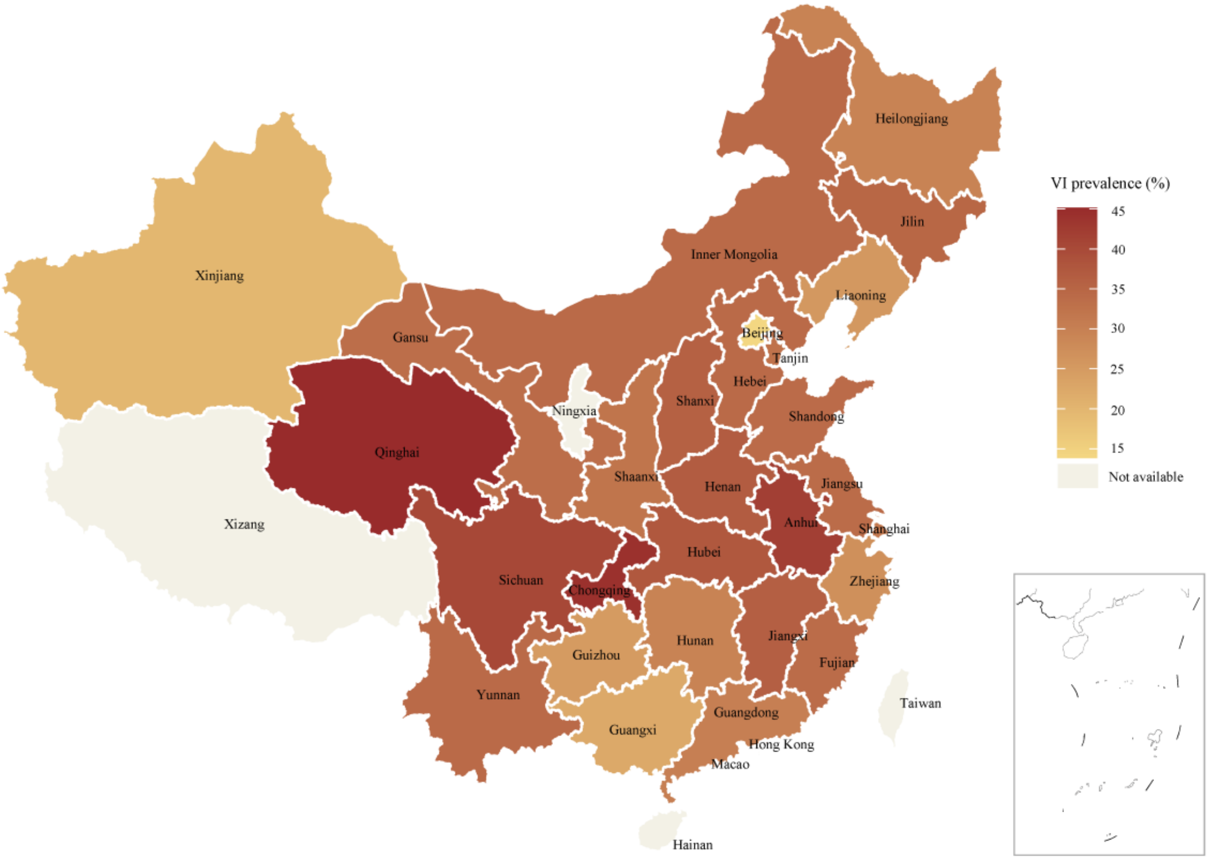
The Peking University Institutional Review Board (IRB) granted ethical approval for all waves of the CHARLS. The IRB approval number for the self-reported questionnaire (including physical examination measurements) was IRB00001052-11015; the IRB approval number for the biomarker collection was IRB00001052-11014.

Results

Geographical Distribution of VI

Figure 1 presents the prevalence of VI by province in China, based on data from the 4 waves of the CHARLS conducted between 2011 and 2018. Qinghai, Chongqing, Anhui, and Sichuan provinces reported a high prevalence of VI, with rates exceeding 40% (69/153, 45.1%; 117/265, 44.2%; 390/930, 41.9%; and 654/1619, 40.4%, respectively). In contrast, Xinjiang and Beijing had a low prevalence of VI, with rates below 20% (23/116, 19.8% and 14/101, 13.8%, respectively). The remaining provinces, municipalities, and autonomous regions exhibited a moderate prevalence of VI, ranging from 20% to 40%. Additional information regarding the prevalence of VI in each province is presented in Table S2 in Multimedia Appendix 1.

Figure 1. The prevalence of VI by province in China from the China Health and Retirement Longitudinal Study (2011 - 2018) 4 waves. VI: visual impairment.



Characteristics of the Study Participants

A total of 33.9% (6449/19,047) of participants reported VI, divided between the training dataset (n=4837) and the testing dataset (n=1612). Among the cases of VI, 58.8% (3795/6449) were female, and 41.2% (2654/6449) were male. The age group with the highest prevalence of VI was 55 - 65 years, accounting for 39.1% (2520/6449), followed by those aged 65 years or older at 31.4% (2025/6449) and 45 - 55 years at 29.5% (1904/6449). The selected characteristics of the study participants are shown in Table 1. The full characteristics of the predictor distribution in the study are shown in Table S1 in Multimedia Appendix 1.

Table . Selected characteristics of study participants among Chinese adults older than 45 years as drawn from the China Health and Retirement Longitudinal Study (2011 - 2018; N=19,047).

Characteristic		Overall (N=19,047), n (%)	Non-VI[a] (n=12,598), n (%)	VI (n=6449), n (%)	*P* value[b]
Sex					<.001
	Female	9927 (52.1)	6132 (48.7)	3795 (58.8)	
	Male	9120 (47.9)	6466 (51.3)	2654 (41.2)	
Age (years)					<.001
	45 - 55	7279 (38.2)	5375 (42.7)	1904 (29.5)	
	55 - 65	6794 (35.7)	4274 (33.9)	2520 (39.1)	
	≥65	4974 (26.1)	2949 (23.4)	2025 (31.4)	
Region					<.001
	East	6995 (36.7)	4486 (35.6)	2509 (38.9)	
	Central	6315 (33.2)	4355 (34.6)	1960 (30.4)	
	West	5737 (30.1)	3757 (29.8)	1980 (30.7)	
Education level					<.001
	Less than elementary school	8368 (43.9)	4869 (38.6)	3499 (54.3)	
	Elementary school	4113 (21.6)	2805 (22.3)	1308 (20.3)	
	Middle school	3971 (20.8)	2909 (23.1)	1062 (16.5)	
	High school or above	2595 (13.6)	2015 (16.0)	580 (9.0)	
Standard of living					<.001
	Poor	2260 (11.9)	1182 (9.4)	1078 (16.7)	
	Relatively poor	5824 (30.6)	3768 (29.9)	2056 (31.9)	
	Average	10,420 (54.7)	7257 (57.6)	3163 (49.0)	
	Relatively high	507 (2.7)	365 (2.9)	142 (2.2)	
	Very high	36 (0.2)	26 (0.2)	10 (0.2)	

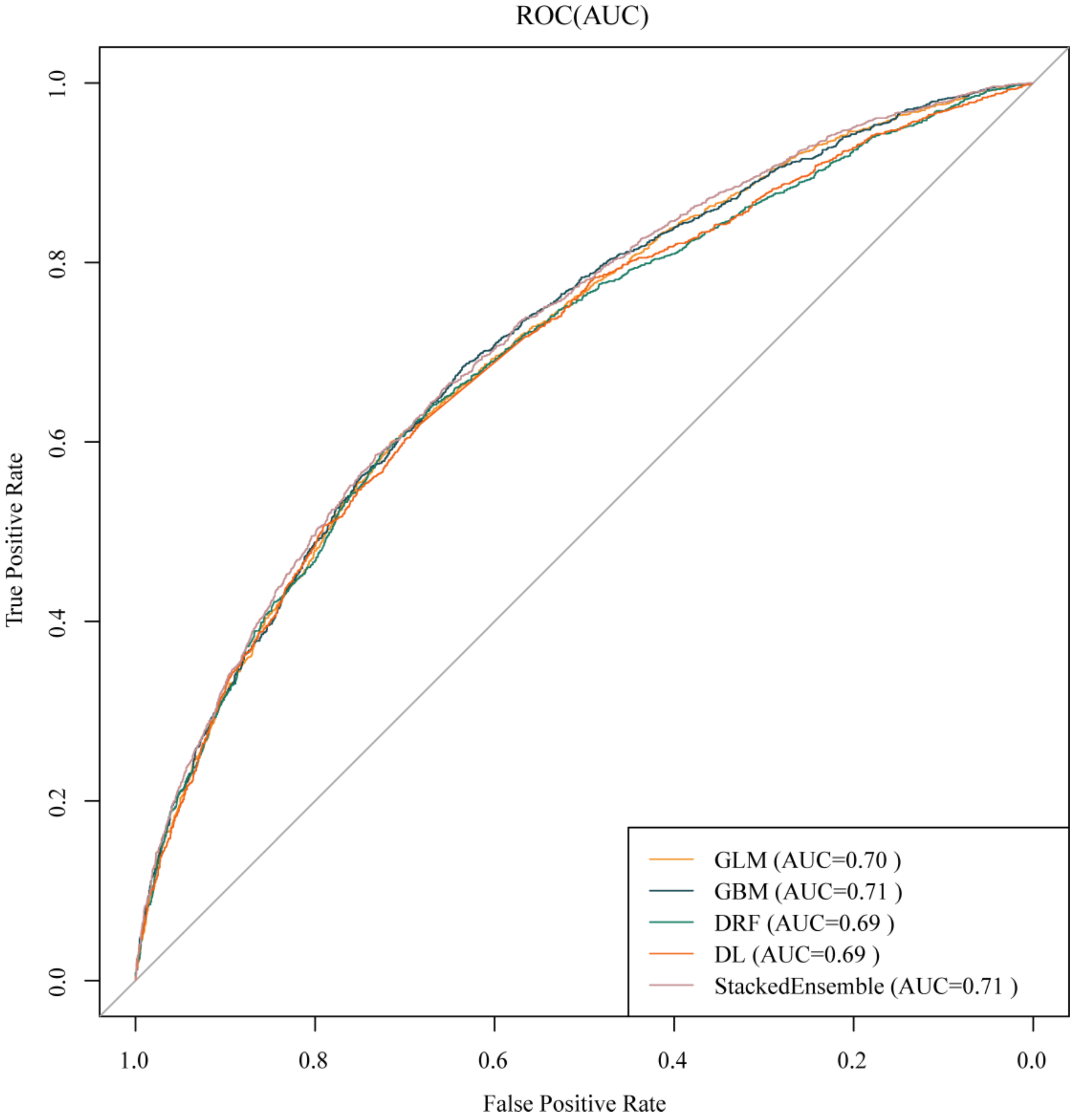
[a] VI: visual impairment.

[b] Pearson χ^2 test.

VI Prediction

We applied the trained models to the testing dataset. The distribution of predictor variables between the testing and training datasets is detailed in Table S3 in Multimedia Appendix 1. The results indicate that the ensemble model demonstrates superior predictive performance compared with individual ML models. Three algorithms, namely the GLM, GBM, and stacked ensemble model (GBM-XGBoost-GLM-DL-DRF), achieved acceptable AUC values 0.706, 0.710, and 0.715, respectively. The ensemble model exhibited the best performance. However, the DRF and DL models did not meet the acceptable AUC threshold of 0.70, achieving an AUC of 0.698. Detailed evaluation metrics for all models on the testing dataset are provided in Table S4 in Multimedia Appendix 1. Figure 2 depicts the ROC curves for all the models. The hyperparameters used in model training are summarized in Table S5 in Multimedia Appendix 1. ROC curves of all VI prediction models on the training dataset are shown in Figure S2 in Multimedia Appendix 1.

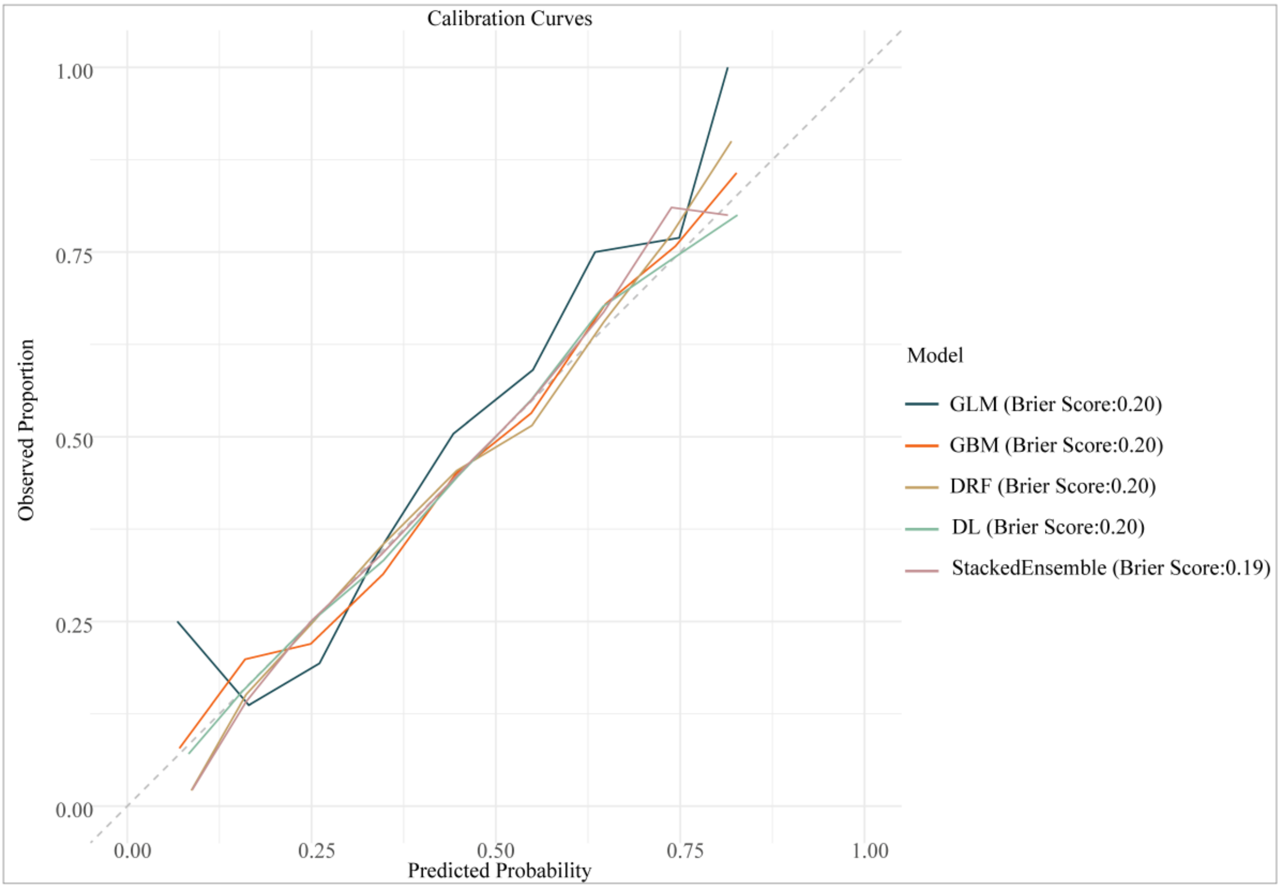
Figure 2. Receiver operating characteristic curves of all visual impairment prediction models on the testing dataset. AUC: area under the curve; DL: deep learning; DRF: distributed random forest; GBM: gradient boosting machine; GLM: generalized linear model; ROC: receiver operating characteristic; StackedEnsemble: GBM-XGBoost-GLM-DL-DRF.



Assessing the Efficacy of ML Models for VI Prediction

Figure 3 presents the calibration curves of all the models on the testing dataset. These curves illustrate the agreement between each model’s predicted probabilities and VI’s observed probabilities in the testing data. The results indicated that all models accurately predicted VI, as evidenced by their Brier scores being less than 0.25.

Figure 3. The calibration curves of all visual impairment prediction models on the testing dataset. DL: deep learning; DRF: distributed random forest; GBM: gradient boosting machine; GLM: generalized linear model; StackedEnsemble: GBM-XGBoost-GLM-DL-DRF.



Determinants of VI

Table 2 presents the importance of predictors for VI in models with acceptable AUCs. The top 10 important predictors for VI were identified by the GLM, including hearing impairment, pain, depression, hand grip strength, standard of living, education level, age, self-expectation of health status, night sleep duration, and arthritis or rheumatism. For GBM, the top predictors for VI were hearing impairment, self-expectation of health status, pain, age, hand grip strength, depression, night sleep duration, hemoglobin, high-density lipoprotein cholesterol, and arthritis or rheumatism. Notably, hearing impairment, self-expectation of health status, pain, age, hand grip strength, depression, night sleep duration, and arthritis or rheumatism have emerged as common predictors for these models.

Table . Variable importance analysis was performed by the generalized linear model (GLM) and gradient boosting machine (GBM), sorted in descending order.

Rank	GLM	GBM
1	Hearing impairment	Hearing impairment
2	Pain	Self-expectations of health status
3	Depression	Pain
4	Hand grip strength	Age
5	Standard of living	Hand grip strength
6	Education level	Depression
7	Age	Night sleep duration
8	Self-expectations of health status	Hemoglobin
9	Night sleep duration	High-density lipoprotein cholesterol
10	Arthritis or rheumatism	Arthritis or rheumatism

Discussion

Principal Results

To our knowledge, this study is the first attempt to predict the risk of VI among middle-aged and older adults in China using ML algorithms. The findings indicated that ML algorithms could accurately identify individuals at risk of VI among this demographic. Our results also showed that ensemble algorithms proved superior to individual ML models. Furthermore, we calculated the prevalence of VI and presented it through regional visualization. The results indicated the existence of regional disparities in the prevalence of VI among Chinese middle-aged and older adults, with varying rates across provinces. However, it is worth noting that we did not find any significant north-south or east-west directional differences in prevalence. Based on these results, gaining a more intuitive understanding of the regional distribution of VI is possible. Additionally, our prediction model can be leveraged to develop a risk assessment tool for early detection of VI. Predictors' importance could help guide personalized early interventions for middle-aged and older individuals at risk of VI.

Comparison With Prior Work

Our study showed that GBM outperformed logistic regression in predicting VI among middle-aged and older Chinese adults. Previous ML studies on VI prediction have predominantly relied on single algorithms without comparing the predictive performance across multiple algorithms. In contrast, our work used various ML algorithms for VI prediction and assessed their comparative effectiveness. Furthermore, our findings highlighted the superior performance of ensemble algorithms over individual learning models despite an accuracy of 0.625. This is due to the imbalanced nature of our dataset, where accuracy may not fully reflect the model's ability to predict VI. We chose AUC as the primary metric and found that the ensemble model had the highest AUC, indicating its overall superior ability to rank positive and negative samples.

The calibration curves showed satisfactory calibration but moderate discrimination, indicating the models' ability to assess the overall risk for VI in the population effectively. This finding has significant implications for designing resource allocation strategies in clinical and public health settings. While the models' discriminatory power was not exceptional, they could be used as supplementary tools in broader clinical or public health assessment frameworks, providing valuable insights for early screening of VI risk. Nevertheless, we acknowledged and considered the limitations of these models when applying them in practice. Consequently, our research contributed significantly to future investigations of ML algorithms for VI prediction by providing a comprehensive evaluation of multiple algorithms and emphasizing the advantages of ensemble methods. Additionally, our work offers technical guidance for the primary prevention of VI by identifying the most effective predictive models.

Our study has the following strengths compared with previous ML models for VI prediction. First, our model is more adept at identifying potentially modifiable risk factors. Unlike prior studies that primarily relied on image or video data as predictors [21,22], our approach incorporates easily accessible everyday information, such as lifestyle factors like night sleep duration. Second, our predictive model holds greater representativeness and general applicability for the middle-aged and older adult Chinese population. Previous domestic studies on VI prediction tended to focus on specific disease groups (stroke patients) or particular types of VI (anterior retinal VI) [14,15]. Our study, based on a national sample, includes individuals from the middle-aged and older adult demographics, and our results pertain to general types of VI.

We found that the important predictors of VI included hearing impairment, self-expectation of health status, pain, age, hand grip strength, depression, night sleep duration, high-density lipoprotein cholesterol, and arthritis or rheumatism. This finding aligns with those documented in prior research [24,25,40-42]. Significantly, our study newly highlighted the crucial role of hearing impairment, self-expectation of health status, and pain in predicting VI. Although hearing impairment does not directly affect vision, its underlying causes may be associated with ocular or neurological disorders. For instance, neurofibromatosis occurring near the inner ear and optic nerve can potentially lead to concurrent hearing and VI [43]. The eyes and ears share a common neuroectodermal origin and exhibit similar genetic networks [44]. When pathogenic mutations occur in these shared genes, they can concurrently affect the functions of both the eyes and ears, leading to dual sensory loss. For instance, defects in the development of inner ear hair cells and photoreceptor cells may underlie the pathogenesis of Usher syndrome, the most prevalent syndromic form of retinitis pigmentosa [45]. In addition, self-expectation of health status reveals one's attitudes towards personal health. High expectations often lead to proactive health behaviors, such as regular ophthalmologic check-ups for vision issues. In contrast, lower expectations, possibly due to comorbid chronic conditions [25], may cause psychological stress affecting vision [46]. For example, depression is more prevalent in patients with VI [47]. Additionally, pain serves as a vital physiological indicator, revealing certain discomforts or underlying ailments in the body. Prolonged pain can keep an individual in a constant state of stress, disrupting the normal functions of the immune and endocrine systems, thereby indirectly impacting vision. Our findings enhance comprehension of the mechanisms underlying the development of VI, enabling early identification of high-risk groups and the implementation of targeted interventions for these individuals. Moreover, our findings provide a valuable reference for selecting variables in constructing VI prediction models. Nevertheless, to ensure the accuracy and credibility of our findings, further studies are required to validate these associations.

Limitations

This study has several limitations that should be acknowledged. First, the assessment of VI relied on self-reported data, which may be subject to recall bias or subjectivity in responses. The qualitative nature of the VI assessment responses lacks the numerical precision of a quantitative evaluation, potentially affecting the accuracy of the outcome variable. Second, while environmental and lifestyle factors were considered, VI is also influenced by genetic factors, which were not included in the model due to the absence of such information in the database. Incorporating genetic data could potentially enhance the model's predictive performance. Finally, the data were sourced from the CHARLS, which only represents the Chinese population aged 45 years and older. Consequently, the model's generalizability to other age groups or populations outside of China remains uncertain. Further validation studies are necessary to evaluate the model's effectiveness in diverse populations across different countries and age ranges.

Conclusions

The prevalence of VI was notably high among middle-aged and older Chinese adults, displaying regional disparities but no significant variances between north-south or east-west regions. Our study is the first to use ML algorithms in predicting VI among China's general middle-aged and older population. The findings demonstrate that ML algorithms can accurately predict VI among this demographic. Ensemble algorithms outperform individual learning models in predicting VI. Variable importance analysis highlighted the importance of considering factors such as hearing impairment and individuals' self-expectation of health status when predicting VI risk. By incorporating these predictors, our study facilitates the early identification of individuals at high risk for VI, enabling timely interventions and preventive measures to mitigate the development and progression of VI.

Acknowledgments

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Authors' Contributions

XX and LM conceived and designed the study. LM and XX cleaned the data and built the models and codes. LM wrote the first draft and edited the manuscript. LM and XX contributed to data cleaning. HS, HZ, and XX contributed to data validation and supervision. YZ, LL, MS, HS, HZ, and XX contributed to data interpretation and manuscript revision. All authors contributed to the preparation of the manuscript and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary tables and figures containing further data on participant characteristics, visual impairment prevalence, predictive factors, model performance, hyperparameters, the sampling and study processes, and receiver operating characteristic curves of prediction models on the training dataset.

[DOCX File, 440 KB - aging_v7i1e59810_app1.docx]

References

1. GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet 2020 Oct 17;396(10258):1204-1222. [doi: 10.1016/S0140-6736(20)30925-9] [Medline: 33069326]
2. Flaxman SR, Bourne RRA, Resnikoff S, et al. Global causes of blindness and distance vision impairment 1990–2020: a systematic review and meta-analysis. Lancet Glob Health 2017 Dec;5(12):e1221-e1234. [doi: 10.1016/S2214-109X(17)30393-5]
3. NHC: China made solid progress in elderly care over past decade. The State Council of the People's Republic of China. 2022 Sep 20. URL: https://english.www.gov.cn/statecouncil/ministries/202209/20/content_WS6329c182c6d0a757729e0446.html [accessed 2023-11-22]
4. Jin H, Zhou Y, Stagg BC, Ehrlich JR. Association between vision impairment and increased prevalence of falls in older US adults. J Am Geriatr Soc 2024 May;72(5):1373-1383. [doi: 10.1111/jgs.18879] [Medline: 38514075]
5. Almidani L, Miller R, Varadaraj V, Mihailovic A, Swenor BK, Ramulu PY. Vision impairment and psychosocial function in US adults. JAMA Ophthalmol 2024 Apr 1;142(4):283-291. [doi: 10.1001/jamaophthalmol.2023.6943] [Medline: 38386343]
6. Blindness and vision impairment. World Health Organization. 2023. URL: https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment [accessed 2023-11-29]
7. Circular of the National Health Commission on the issuance of the "14th five-year plan" for National Eye Health (2021-2025) [Article in Chinese]. Central People's Government of the People's Republic of China. 2022. URL: https://www.gov.cn/zhengce/zhengceku/2022-01/17/content_5668951.htm [accessed 2023-11-28]

8. Farah L, Borget I, Martelli N, Vallee A. Suitability of the current health technology assessment of innovative artificial intelligence-based medical devices: scoping literature review. J Med Internet Res 2024 May 13;26:e51514. [doi: 10.2196/51514] [Medline: 38739911]
9. Alexander N, Aftandilian C, Guo LL, et al. Perspective toward machine learning implementation in pediatric medicine: mixed methods study. JMIR Med Inform 2022 Nov 17;10(11):e40039. [doi: 10.2196/40039] [Medline: 36394938]
10. Rajula HSR, Verlato G, Manchia M, Antonucci N, Fanos V. Comparison of conventional statistical methods with machine learning in medicine: diagnosis, drug development, and treatment. Medicina (Kaunas) 2020 Sep 8;56(9):455. [doi: 10.3390/medicina56090455]
11. Xi Y, Wang H, Sun N. Machine learning outperforms traditional logistic regression and offers new possibilities for cardiovascular risk prediction: a study involving 143,043 Chinese patients with hypertension. Front Cardiovasc Med 2022;9:1025705. [doi: 10.3389/fcvm.2022.1025705] [Medline: 36451926]
12. GBD 2019 Blindness and Vision Impairment Collaborators, Vision Loss Expert Group of the Global Burden of Disease Study. Trends in prevalence of blindness and distance and near vision impairment over 30 years: an analysis for the Global Burden of Disease Study. Lancet Glob Health 2021 Feb;9(2):e130-e143. [doi: 10.1016/S2214-109X(20)30425-3] [Medline: 33275950]
13. Fricke TR, Jong M, Naidoo KS, et al. Global prevalence of visual impairment associated with myopic macular degeneration and temporal trends from 2000 through 2050: systematic review, meta-analysis and modelling. Br J Ophthalmol 2018 Jul;102(7):855-862. [doi: 10.1136/bjophthalmol-2017-311266] [Medline: 29699985]
14. Hsia Y, Lin YY, Wang BS, Su CY, Lai YH, Hsieh YT. Prediction of visual impairment in epiretinal membrane and feature analysis: a deep learning approach using optical coherence tomography. Asia Pac J Ophthalmol (Phila) 2023;12(1):21-28. [doi: 10.1097/APO.0000000000000576] [Medline: 36706331]
15. Xu J, Wu Z, Nurnberger A, Sabel BA. Interhemispheric cortical network connectivity reorganization predicts vision impairment in stroke. Annu Int Conf IEEE Eng Med Biol Soc 2021 Nov:836-840. [doi: 10.1109/EMBC46164.2021.9630628] [Medline: 34891420]
16. Jin HD, Demmler-Harrison GJ, Miller J, et al. Cortical visual impairment in congenital cytomegalovirus infection. J Pediatr Ophthalmol Strabismus 2019 May 22;56(3):194-202. [doi: 10.3928/01913913-20190311-01] [Medline: 31116869]
17. Liu TYA, Ling C, Hahn L, Jones CK, Boon CJ, Singh MS. Prediction of visual impairment in retinitis pigmentosa using deep learning and multimodal fundus images. Br J Ophthalmol 2023 Oct;107(10):1484-1489. [doi: 10.1136/bjo-2021-320897] [Medline: 35896367]
18. Zhao Y, Wang A. Development and validation of a risk prediction model for visual impairment in older adults. Int J Nurs Sci 2023 Jul;10(3):383-390. [doi: 10.1016/j.ijnss.2023.06.010] [Medline: 37545769]
19. Zhao Y, Yu R, Sun C, et al. Nomogram model predicts the risk of visual impairment in diabetic retinopathy: a retrospective study. BMC Ophthalmol 2022 Dec 8;22(1):36482340. [doi: 10.1186/s12886-022-02710-6]
20. Burkemper B, Torres M, Jiang X, McKean-Cowdin R, Varma R. Factors associated with visual impairment in Chinese American adults: the Chinese American eye study. Ophthalmic Epidemiol 2019 Oct;26(5):329-335. [doi: 10.1080/09286586.2019.1622737] [Medline: 31146615]
21. Tham YC, Anees A, Zhang L, et al. Referral for disease-related visual impairment using retinal photograph-based deep learning: a proof-of-concept, model development study. Lancet Digit Health 2021 Jan;3(1):e29-e40. [doi: 10.1016/S2589-7500(20)30271-5] [Medline: 33735066]
22. Chen W, Li R, Yu Q, et al. Early detection of visual impairment in young children using a smartphone-based deep learning system. Nat Med 2023 Feb;29(2):493-503. [doi: 10.1038/s41591-022-02180-9] [Medline: 36702948]
23. Zhao Y, Hu Y, Smith JP, Strauss J, Yang G. Cohort profile: the China Health and Retirement Longitudinal Study (CHARLS). Int J Epidemiol 2014 Feb;43(1):61-68. [doi: 10.1093/ije/dys203] [Medline: 23243115]
24. Sun M, Bo Q, Lu B, Sun X, Zhou M. The association of sleep duration with vision impairment in middle-aged and elderly adults: evidence from the China Health and Retirement Longitudinal Study. Front Med (Lausanne) 2021;8:778117. [doi: 10.3389/fmed.2021.778117] [Medline: 35004745]
25. Gu Y, Cheng H, Liu X, Dong X, Congdon N, Ma X. Prevalence of self-reported chronic conditions and poor health among older adults with and without vision impairment in China: a nationally representative cross-sectional survey. BMJ Open Ophthalmol 2023 Mar;8(1):e001211. [doi: 10.1136/bmjophth-2022-001211] [Medline: 37278435]
26. Shang X, Wu G, Wang W, et al. Associations of vision impairment and eye diseases with frailty in community-dwelling older adults: a nationwide longitudinal study in China. Br J Ophthalmol 2022 Dec 19;108(2):310-316. [doi: 10.1136/bjo-2022-322048] [Medline: 36535748]
27. Shang X, Zhu Z, Wang W, He M. Associations of vision impairment and eye diseases with memory decline over 4 years in China and the United States. Am J Ophthalmol 2021 Aug;228:16-26. [doi: 10.1016/j.ajo.2021.03.021] [Medline: 33773983]
28. Convergence of the world’s best predictive and generative AI for private, protected data. H2O.ai. URL: https://h2o.ai/ [accessed 2024-07-01]
29. Wolpert DH, Macready WG. No free lunch theorems for optimization. IEEE Trans Evol Computat 1997 Apr;1(1):67-82. [doi: 10.1109/4235.585893]

30. Ke G, Meng Q, Finley T, et al. LightGBM: a highly efficient gradient boosting decision tree. Presented at: 31st Conference on Neural Information Processing Systems (NIPS 2017); Dec 4-9, 2017; Long Beach, CA.
31. Rigatti SJ. Random forest. J Insur Med 2017;47(1):31-39. [doi: 10.17849/insm-47-01-31-39.1] [Medline: 28836909]
32. López OAM, López AM, Crossa J. Fundamentals of artificial neural networks and deep learning. In: Multivariate Statistical Machine Learning Methods for Genomic Prediction: Springer International Publishing; 2022:379-425.
33. Jang HJ, Cho KO. Applications of deep learning for the analysis of medical data. Arch Pharm Res 2019 Jun;42(6):492-504. [doi: 10.1007/s12272-019-01162-9] [Medline: 31140082]
34. Dey R, Mathur R. Ensemble learning method using stacking with base learner, a comparison. Presented at: International Conference on Data Analytics and Insights (ICDAI 2023); May 11-13, 2023; Kolkata, India. [doi: 10.1007/978-981-99-3878-0_14]
35. Longadge R, Dongre S. Class imbalance problem in data mining review. arXiv. Preprint posted online on May 8, 2013. [doi: 10.48550/arXiv.1305.1707]
36. Atabaki-Pasdar N, Ohlsson M, Viñuela A, et al. Predicting and elucidating the etiology of fatty liver disease: a machine learning modeling and validation study in the IMI DIRECT cohorts. PLoS Med 2020 Jun;17(6):e1003149. [doi: 10.1371/journal.pmed.1003149] [Medline: 32559194]
37. Mandrekar JN. Receiver operating characteristic curve in diagnostic test assessment. J Thorac Oncol 2010 Sep;5(9):1315-1316. [doi: 10.1097/JTO.0b013e3181ec173d] [Medline: 20736804]
38. Alba AC, Agoritsas T, Walsh M, et al. Discrimination and calibration of clinical prediction models: users' guides to the medical literature. JAMA 2017 Oct 10;318(14):1377-1384. [doi: 10.1001/jama.2017.12126] [Medline: 29049590]
39. Brier GW. Verification of forecasts expressed in terms of probability. Mon Wea Rev 1950 Jan;78(1):1-3. [doi: 10.1175/1520-0493(1950)078<0001:VOFEIT>2.0.CO;2]
40. Wong PWF, Lau JKP, Choy BNK, et al. Sociodemographic, behavioral, and medical risk factors associated with visual impairment among older adults: a community-based pilot survey in Southern District of Hong Kong. BMC Ophthalmol 2020 Sep 18;20(1):372. [doi: 10.1186/s12886-020-01644-1] [Medline: 32948134]
41. Shang X, Wu G, Wang W, et al. Associations of vision impairment and eye diseases with frailty in community-dwelling older adults: a nationwide longitudinal study in China. Br J Ophthalmol 2024 Jan 29;108(2):310-316. [doi: 10.1136/bjo-2022-322048] [Medline: 36535748]
42. Sun R, Huang D, Liu Z, et al. Prevalence, causes, and risk factors of presenting visual impairment and presenting blindness in adults presenting to an examination center in Suzhou, China. J Ophthalmol 2022;2022:2885738. [doi: 10.1155/2022/2885738] [Medline: 36583116]
43. Alshoabi SA. Neurofibromatosis type-2 presenting with vision impairment. Pak J Med Sci 2023;39(2):611-615. [doi: 10.12669/pjms.39.2.6813] [Medline: 36950434]
44. Thiery A, Buzzi AL, Streit A. Cell fate decisions during the development of the peripheral nervous system in the vertebrate head. Curr Top Dev Biol 2020;139:127-167. [doi: 10.1016/bs.ctdb.2020.04.002] [Medline: 32450959]
45. Fuster-García C, García-Bohórquez B, Rodríguez-Muñoz A, et al. Usher syndrome: genetics of a human ciliopathy. Int J Mol Sci 2021 Jun 23;22(13):6723. [doi: 10.3390/ijms22136723] [Medline: 34201633]
46. Zhang Q, Cao GY, Yao SS, et al. Self-reported vision impairment, vision correction, and depressive symptoms among middle-aged and older Chinese: findings from the China Health and Retirement Longitudinal Study. Int J Geriatr Psychiatry 2021 Jan;36(1):86-95. [doi: 10.1002/gps.5398] [Medline: 32783270]
47. Virgili G, Parravano M, Petri D, et al. The association between vision impairment and depression: a systematic review of population-based studies. J Clin Med 2022 Apr 25;11(9):2412. [doi: 10.3390/jcm11092412] [Medline: 35566537]

Abbreviations

AUC: area under the curve
CHARLS: China Health and Retirement Longitudinal Study
DL: deep learning
DRF: distributed random forest
GBM: gradient boosting machine
GLM: generalized linear model
IRB: Institutional Review Board
ML: machine learning
ROC: receiver operating characteristic
VI: visual impairment

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Developing Independent Living Support for Older Adults Using Internet of Things and AI-Based Systems: Co-Design Study

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Abstract

Background: The number of older people with unmet health care and support needs is increasing substantially due to the challenges facing health care systems worldwide. There are potentially great benefits to using the Internet of Things coupled with artificial intelligence to support independent living and the measurement of health risks, thus improving quality of life for the older adult population. Taking a co-design approach has the potential to ensure that these technological solutions are developed to address specific user needs and requirements.

Objective: The aim of this study was to investigate stakeholders' perceptions of independent living and technology solutions, identify stakeholders' suggestions on how technology could assist older adults to live independently, and explore the acceptability and usefulness of a prototype Internet of Things solution called the NEX system to support independent living for an older adult population.

Methods: The development of the NEX system was carried out in 3 key phases with a strong focus on diverse stakeholder involvement. The initial predesign exploratory phase recruited 17 stakeholders, including older adults and family caregivers, using fictitious personas and scenarios to explore initial perceptions of independent living and technology solutions. The subsequent co-design and testing phase expanded this to include a comprehensive web-based survey completed by 380 stakeholders, encompassing older adults, family caregivers, health care professionals, and home care support staff. This phase also included prototype testing at home by 7 older adults to assess technology needs, requirements, and the initial acceptability of the system. Finally, in the postdesign phase, workshops were held between academic and industry partners to analyze data collected from the earlier stages and to discuss recommendations for the future development of the system.

Results: The predesign phase revealed 3 broad themes: loneliness and technology, aging and technology, and adopting and using technology. The co-design phase highlighted key areas where technology could assist older adults to live independently: home security, falls and loneliness, remote monitoring by family members, and communication with clients. Prototype testing revealed that the acceptability aspects of the prototype varied across technology types. Ambient sensors and voice-activated assistants were described as the most acceptable technology by participants. Last, the postdesign analysis process highlighted that ambient sensors have the potential for automatic detection of activities of daily living, resulting in key recommendations for future developments and deployments in this area.

Conclusions: This study demonstrates the significance of incorporating diverse stakeholder perspectives in developing solutions that support independent living. Additionally, it emphasizes the advantages of prototype testing in home environments, offering crucial insights into the real-world experiences of users interacting with technological solutions.

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KEYWORDS

independent living; gerontology; geriatric; older adult; elderly; aging; Internet of Things; IoT; wearable electronic device; medical device; daily living activities; quality of life; QoL; artificial intelligence; AI; algorithm; predictive model; predictive analytics; predictive system; practical model

Introduction

The world is witnessing a rapidly aging population. Population aging can be seen as one of the greatest successes of public health, as a longer life brings opportunities, not only for older people and their families, but also for societies as a whole [1]. The extent of these opportunities and contributions however depends heavily on one factor: healthy and positive aging [1]. Therefore, mechanisms that support healthy and positive aging are essential to ensure older people can enjoy physical and mental health and well-being to their full potential. Globally, health care policies including Ireland's "Sláintecare" [2] are focusing on extending the ability of older people to continue to live independently at home. This entails maintaining quality of life as well as working to reduce the costs of an older person's care. This presents a grand challenge to ensure that older adults receive adequate and individualized care and support to maintain their health, well-being, and safety whilst living independently [3].

The Internet of Things (IoT) and artificial intelligence (AI) offer significant benefits for supporting older adults in living independently, through enhanced health monitoring, improved home safety, and increased social connection, which in turn can improve health-related quality of life [4,5]. In this context, IoT refers to a network of physical devices that communicate and exchange data, while AI-based systems use algorithms and machine learning to process and analyze this data. Wearable IoT devices like smartwatches and fitness trackers monitor vital signs such as heart rate, blood pressure, and blood glucose levels, providing critical data to health care providers [6-8]. Smart home devices and AI-powered digital assistants can also mitigate risks by detecting hazards like fires and intruders, as well as alleviating loneliness and managing chronic conditions such as diabetes and hypertension [9-11]. Previous system-based approaches such as The HABITAT system [12] aim to support the independence of older adults by integrating technologies like radio frequency identification, wearable electronics, wireless sensor networks, and AI to enhance daily living environments. However, the deployment of these technologies comes with challenges, notably privacy and security risks that could expose older adults to cybercrimes and unauthorized access to sensitive health data [13,14]. Addressing these concerns is crucial to ensure the safe and accepted use of IoT technologies in this population.

The NEX system is an advanced IoT platform designed to support the independent living of older adults by monitoring their daily activities unobtrusively. It integrates various technologies such as smartwatches, voice-activated assistants, contact sensors, and smart plugs to gather comprehensive data on users' activities and environments. This system uses AI and machine learning algorithms to analyze this data, enabling the detection and prediction of changes in the routines of older adults, known as activities of daily living (ADLs). The objective is to offer prompt and customized support to improve the quality of life and safety of older adults living at home. By unobtrusively monitoring for changes in routine behavior, such as a notable decrease in daily step count, the NEX system enables caregivers to respond quickly and provide necessary interventions. To address privacy and security concerns related to these technologies, the NEX system was designed to be highly customizable, giving users autonomy over the components they chose to use. Users were fully informed about the data each technology component collected and its purpose.

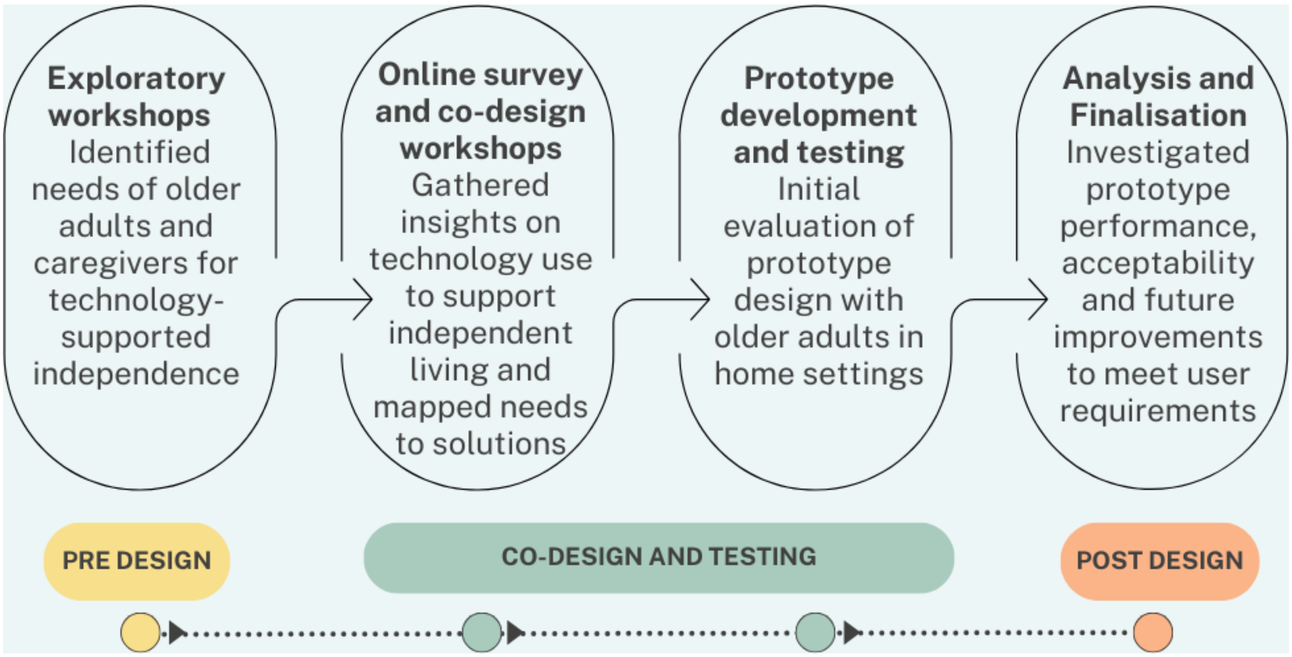
Despite the mounting evidence of the role of technology in supporting older adults to live independently at home [4,15,16], evidence in the literature suggests that end user's acceptability and usability of technology are often neglected [17] and the literature calls for a shift in emphasis from focusing on product design to the user perspective. Co-design is essential in developing technology for older adults, as it engages end users directly in the design process to ensure that solutions align with their specific needs and preferences and enhances the relevance, usability, and acceptance of technology [18]. This research describes the comprehensive co-design approach used in the development of the NEX system, which integrates the perspectives and insights of multiple stakeholders [19]. By involving a diverse array of stakeholders including older adults, caregivers, and health care professionals, the project ensures that the system addresses the real-world needs and preferences of its end users. This participatory approach enhances the relevance and usability of the system in order to foster greater acceptance and effectiveness. Furthermore, the development process includes rigorous prototype testing in the homes of older adults, providing authentic insights into how the system functions in everyday home-based settings. This iterative process, characterized by real-world testing and stakeholder involvement, is fundamental to creating effective and sustainable health technology solutions.

Methods

Overview

A user-centered design approach [20] was used to identify user needs and requirements. This co-design approach focuses on partnering with end users to design technology with them and not for them. This paper describes the use of a generative co-design framework for health care innovation [21] to inform the design of the NEX system. Figure 1 illustrates the adapted framework used to co-design the NEX system.

Figure 1. Co-design framework for the NEX system.



Recruitment and Participant Profile

The recruitment process for the study involved multiple phases, starting with exploratory workshops aimed at older adults and family caregivers, who were recruited through Dublin City University Age Friendly network, social media, and local newspaper advertisements. The study's co-design phase further expanded recruitment through a web-based survey targeting older adults, family caregivers, and health and social care professionals. This survey was advertised through social media and local council Age Friendly coordinators throughout Ireland. The final phase of recruitment occurred during the prototype development, where participants were those who had engaged in the web-based survey and expressed interest in further research participation. To ensure diverse participant recruitment a range of strategies were used ranging from web-based recruitment to recruiting and hosting one of the workshops at an older adults' club in Dublin's inner city. The recruitment for workshop and focus group activities ceased when thematic saturation was reached, indicating that sufficient data to robustly inform the design process was collected. Participants in the predesign and co-design workshops received a €20 (US $22) One4All voucher as compensation for their time and effort. Those who participated in the 10-week prototype testing phase were compensated with a €60 (US $66) One4All voucher.

The research engaged diverse participant groups across different phases. In the exploratory workshops, 17 participants including 15 older adults aged 60 years and older and 2 family caregivers participated. In the web-based survey, 380 respondents participated, comprising 235 older adults, 77 family caregivers, 47 health care professionals, and 21 homecare support staff. The majority were female (304/380, 80%) and well-educated with 58% (n=220) having completed tertiary education. The mean age of the cohort was 62.5 years (SD 11.5 years). Twenty-nine individuals including 15 older adults, 4 family caregivers, 4 health care professionals, and 6 home support workers participated in web-based workshops to discuss the utility and concerns regarding the various technology solutions proposed as part of the co-design phase. Lastly, 7 healthy older adults, aged 63 to 87 years, participated in a 10-week prototype testing of a system in their own homes. This sample size is based on population sizes from other published prototype testing studies in this area [22]. This group consisted of 5 women and 2 men, all living alone across Ireland, predominantly in urban areas. Living independently was a requirement for testing the prototype version of the system to ensure that most of the sensor data collected was attributable solely to the participant, not co-inhabitants. Due to COVID-19 restrictions limiting the movement of older adults, participants in the prototype testing self-installed the system with remote assistance from technical support over the phone. Future research will explore solutions for older adults living with caregivers or family. All described their health as "very good" or "excellent," with most having chronic conditions. They were all regular smartphone users, and all had home broadband.

Ethical Considerations

Ethical approval for the study was granted by the Dublin City University (DCU) Research Ethics Committee. The study adhered to strict data protection and ethical guidelines throughout its phases, from exploratory workshops to prototype testing. Participants' contributions, whether in workshops or web-based surveys, were conducted with a focus on confidentiality and informed consent. Participation was voluntary, and oral and written information was provided to participants regarding the purpose of the study and how their data would be used in the research. The academic partners completed a data sharing agreement and conducted a data protection impact assessment to guarantee the protection and responsible use of participant data. While the industry partners had access to participants' names and home addresses for technology installation purposes, they were restricted from accessing any health assessment data or any other personal information. To further ensure data security, all study-related data were securely stored on a designated drive at DCU. Ethical approval for conducting the predesign and co-design phases of this research was obtained from the DCU Research Ethics Committee under the reference DCUREC2019223, and for the prototype testing under the reference DCUREC2020180.

Data Collection

Data collection methods varied across the study's phases. In the predesign phase, exploratory workshops were conducted with potential end users (n=17), including older adults and family caregivers, to identify their needs and explore how technology could support their independence. These workshops were audio recorded and later transcribed to facilitate the exploration of the real-world needs and scenarios of users, setting a solid foundation for future technology design. Moving into the co-design and testing phase, a web-based survey (n=380 responses) was developed and disseminated using LimeSurvey platform to gain broader insights into older adults' and stakeholders' attitudes toward using technology for independent living. A user needs mapping exercise followed, linking these identified needs to potential technological solutions. Co-design workshops (n=29 participants) involving older adults, family caregivers, health care professionals, and home support workers facilitated in-depth discussions on these solutions, gathering feedback on their utility and acceptability. This phase also included the development of a prototype system that integrated various technologies, all tailored to the specific needs identified earlier.

The proposed prototype design consisted of contact sensors on entry and exit doors to the home and contact sensors on drawers and cupboards in the kitchen to detect activity around the house; smart plugs for kitchen appliances; 6-in-1 sensors to detect motion within rooms in the home alongside temperature and humidity; a Sony mWatch (smart watch device) as an alert system (call for assistance) and for measurement of sleep duration and step count; and an Amazon Echo Show 8 voice-activated assistant for entertainment or leisure use and reminder functionality. The prototype was subsequently tested in a real-world environment, with older adults (n=7) testing the prototype in their home environments for a period of 10 weeks. Participants also completed a process evaluation interview with a researcher via Zoom providing critical feedback on usability, acceptability, and technical performance, aiding in further refinement. In the postdesign phase, the feedback and data collected from the testing were analyzed to extract key insights, which were instrumental in refining the technology and finalizing the design, ensuring it aligned with the users' needs and requirements effectively.

Data Analysis

Quantitative survey responses were analyzed using descriptive statistics in SPSS (IBM Corp). Thematic analysis, as outlined by Braun and Clarke [23], is a qualitative research method used to systematically identify and analyze patterns or themes within data. This approach was applied to workshop and interview transcripts to uncover key themes and insights using NVIVO (Lumivero) qualitative data analysis software. The findings from this analysis were integral to the iterative design process, guiding the development of prototypes and informing the final design and functionality of the NEX system.

Results

Exploratory Workshop

Three broad themes emerged from the thematic analysis of the transcripts from the exploratory workshops based on the aims: loneliness and technology, aging and technology, and adopting and using technology (Table 1).

Table . Key themes from predesign workshops.

Theme	Key findings	Participant quotes
Loneliness and technology	Loneliness is a significant issue for older adults, particularly postretirement, and may lead to mental health concerns. Technology can potentially mitigate some aspects of loneliness by providing means of communication and maintaining social connections.	*If you could have some kind of a system, it is probably technology that could link a person who is isolated at home with some kind of community group or something.* [Family caregiver 01]
Aging and technology	Participants recognized technology's role in supporting independent living for older adults. They discussed the challenges associated with aging, such as the risk of falling, and how technology can offer solutions for home safety and security.	*And also I suppose falling, maybe if there is a stairs in the house, at the top of the stairs, an alert that would come on, say if you were at the top of the stairs, be careful or something. It happened to me, that is why I am conscious of it.* [Older adult 01]
Adopting and using technology	Adoption and ongoing use of technology are hindered by a lack of familiarity and reluctance to use new devices. Participants expressed the need for gradual introduction of technology, appropriate training, and the importance of nonstigmatizing technology that adapts to their changing needs.	*I have a friend, she is older and she has the tablet she won't even open it, even to do a text, it is easy, I will sit and show you. She is very intelligent and that but she has no interest.* [Older adult 02]

Web-Based Survey and Web-Based Workshops

Web-Based Survey

The findings from the survey responses are reported elsewhere [19]. In brief, there was a high level of willingness reported across all groups (202/235, 86% older adults; 71/77, 91% family caregivers; 45/47, 96% health care professionals; and 16/21, 76% homecare staff) to use technology in the future to support older adults to live independently. Additionally, the analysis highlighted that key areas identified by older adult stakeholders where technology could assist in living independently were: home security (77/235, 33%), falls (69/235, 30%), reduced mobility (55/235, 23%), and loneliness (54/235, 23%). Thematic analysis of free text responses for other stakeholder groups highlighted that there were differences in which technology could best assist with independent living. The key areas that were identified were: remote monitoring of family members (family caregivers), communication with clients (health care professionals), and falls (homecare workers). The main disadvantages were considered to be the ability of some older adults to use the technologies, limited access to broadband, impaired cognition limiting the ability to use the technology, and the ability to interpret the data. Older adults perceived the main advantages of the technologies presented to be security or safety potential, the use of these devices to provide independence, and the ability to monitor their own health. Older adults reported the financial investment required and privacy concerns over data collected as the main disadvantages of these devices.

Web-Based Workshops

Participants of the web-based workshops discussed the potential value and concerns related to technology solutions identified by the technology partners. The findings are summarized in Table 2.

Table . Summary of technology types and participant value and concerns from the NEX web-based workshops.

Technology	Value for older adults	Concerns for older adults	Value for other stakeholders	Concerns for other stakeholders
Voice-activated assistant	Communication, entertainment, and activity	Dependency, privacy/intrusion, and data security	Reminders, social connections, entertainment, emergency calls, and promotes confidence	Dependence, disembodied voice, annoying accent, and issues for those with speech impediments
Ambient sensors	Confidence, falls prevention, security, and information for objective assessment	Intrusion/tracking and false alarms	Fall prevention, home security, emergency response activation, clinical benefits, person-centered monitoring, and value for caregivers	Maintenance, false alarms, complex data interpretation, and additional services required for monitoring
Wearables	Emergency response, falls detection, monitoring, and sleep	Stigma and forgetting to wear	Fall detection, reassurance, rehabilitation, and goal setting	Stigma, limited range (geofencing), cumbersome, aesthetically unpleasing, interferes with daily activities, and may forget to wear
Overall system	Reassurance and fosters independence	Trust issues, readiness, and burden on family	Favorable perception and substantial monitoring and information	Ability to adapt to different contexts and tailoring system to individual needs and preferences

Prototype Testing

Overview

In the prototype testing, participants interacted with 4 types of technology: a wearable device (Sony mWatch), a voice-activated assistant (Amazon Echo 8), ambient sensors (Aeotec door and window sensor 6), and smart plugs (Samsung SmartThings smart plugs) installed in their home environment for a 10-week period. At the end of the testing phase, participants completed an evaluation interview. Although the small participant group size made it difficult to generalize the acceptability results, there appeared to be clear trends in the feedback from the prototype testing. The most salient findings from the thematic analysis of transcribed interviews in relation to users' experiences of the prototype are outlined in Table 3 below.

Table . A summary of user experiences from prototype testing.

Technology	User feedback	Participant quotes
Wearable device	Participants were generally disappointed with the watch due to its large, chunky, and masculine design. They found it less attractive compared with other smartwatches like Fitbit, noted issues with its functionality including lack of step history, and frequent need for recharging.	• *I didn't like the watch, I didn't like the style, it wasn't a bit feminine.* [Participant 01] • *I've seen watches that would give you yesterday's and today's steps but there was no history on this watch.* [Participant 04]
Voice-activated assistant	The response was mixed: some participants appreciated the device for its ability to provide companionship, access to music, and international radio stations. However, others viewed it as gimmicky and raised privacy concerns related to data sharing with Amazon.	• *I felt it was a bit of company, to have a voice coming back at you…you could have a conversation with it...I just think it's a wonderful piece of equipment. I live on my own.* [Participant 01] • *If I was lonely, it was quite nice to have someone to talk to and who wouldn't get cross with you.* [Participant 03]
Ambient sensors and Smart plugs	Participants quickly adapted to these technologies, noting a high level of comfort with their presence. Participants appreciated the sensors for their nonintrusive nature and the sense of security they provided, with minimal behavior modification observed.	• *I forgot all about them, except occasionally I might notice the green light flashing if I opened the door.* [Participant 01] • *… great to be able to know what state people are in and what they are doing without necessarily a camera being on them.* [Participant 03]

Post Design Analysis

To consider the implications of the co-design process on the final NEX system design, discussion workshops between the NEX team members (academic and industry project partners) were conducted. A public and patient involvement panel which was established at the outset of the project was also consulted at each stage of design to give expert opinion and advice on how to consider the findings at each iterative phase. The discussion workshops were based on (1) the findings of the pre- and co-design phases, and (2) an investigation of the technical performance of the system during prototype testing (Table 4).

Table . Key findings and recommendations from post design analysis phase.

Aspect	Key issues identified	Recommendations for future deployments
Participant experience	One participant withdrew due to the self-installation process.	Install the NEX system in participant's homes by a technical expert.
Device use	Sony mWatch was found to be unsatisfactory.	Discontinue Sony mWatch and switch to an alternative wearable for data collection.
System performance	Battery life issues, configuration of sensors, system crashes, and missing data.	Implement automatic system data checks to reduce data losses.
Sensor configuration	Issues with battery life, participant-led installation, and devices turned off.	Review and use next-generation devices with longer battery life.
Data integrity	Missing data attributed to device and installation issues.	Use only pretested Smart Plugs and improve ground truth data collection.
Technical analysis	Front-end usability issues and back-end issues like memory use.	Deploy a larger range of sensors and smart plugs, and collect more frequent ground truth data.
ADL[a] detection	Need for improved accuracy in ADL detection.	Deploy a broader range of sensors and smart plugs alongside more frequent ground truth data collection to enhance ADL detection accuracy.

[a] ADL: activities of daily living.

Discussion

Principal Findings

The results of this research have implications for researchers, practitioners, and digital health organizations who are aiming to design and implement technology-based solutions for health care. The co-design process used in this research facilitated the consideration of the needs and requirements of the proposed NEX system through a dynamic design process and design tool selection in response to a range of stakeholder perspectives.

Barriers and Facilitators to Co-Designing Technology to Support Independent Living

In the development of the NEX system, a structured co-design methodology was used, incorporating a series of distinct phases that gathered and integrated insights from a diverse group of stakeholders. Initially, exploratory workshops and web-based surveys provided a broad array of perspectives from older adults, caregivers, health care professionals, and home care staff. These early phases captured essential needs and expectations, which were then analyzed in subsequent co-design sessions focused on refining the prototype. Discussion workshops between researchers and industry partners with input from a public and patient involvement panel were crucial for consolidating the findings from each phase. This process ensured that diverse insights were synthesized into a cohesive design strategy.

A systematic review [18] on co-designing technology for aging in place emphasizes the significant benefits of involving stakeholders in developing technological solutions for older adults, such as enhanced acceptance and adoption. However, the review also identifies that a lack of knowledge among participants can lead to unrealistic expectations, which may impede the design process. This knowledge gap poses a substantial barrier, particularly when co-designing with older adults who may not be familiar with the functionalities of smart devices. The challenge of addressing gaps in understanding the capabilities and benefits of technology was actively addressed during the NEX system's co-design process. Due to COVID-19 constraints, at the early co-design stages (web-based focus groups and surveys) participants were not able to interact with some of the proposed technological solutions. To overcome this, technology images, descriptions of technology use, and demonstration videos were developed to showcase each of the potential technology solutions and their functionality. The images and text descriptions were embedded in the survey to assist with responses relating to the usefulness of technology and the demonstration videos were played via web-based focus groups to aid discussions.

Technology Acceptability and Usability

The exploratory workshops and web-based surveys from the predesign phase underscored the critical importance of using technology to enhance the safety and security of older adults living independently. Interestingly, in the prototype testing, of all of the different technology types that make up the NEX system, ambient sensors were the most widely accepted technology among participants. Additionally, ambient sensors collected the most valuable data to assist with automated identification of ADL [24] which has been implicated as an important approach for supporting continued autonomous living for older adults in the future [25]. A smartwatch was also incorporated into the prototype design to address these needs with features like step count motivation for promoting a healthy lifestyle and emergency response capabilities for safety. However, the smartwatch was not well-received mainly due to its aesthetic features (interfered with clothing) and some technical issues with the GPS emergency response feature, rendering it less effective. Participants did appreciate the step count feature of the smartwatch. These findings prompted further exploration of alternative solutions for safety and security in the home environment for future iterations of the NEX system. Moore et al [26] note that older adults generally enjoy wearable devices that monitor steps, track location, log activities, measure health metrics, and offer automatic emergency contact features. However, continued use of devices requires more than just useful features; it necessitates a support system that motivates users, encourages social interaction, and adjusts to their preferences.

Consistent with the observations of Moore et al [26], the NEX system prototype testing revealed that research participants initially demonstrated high levels of engagement with new technology, but their engagement and potential interest can lessen over time [27]. This has been evidenced by others [28,29] who have investigated motivation among long-term users of assistive technologies. As part of the NEX project, the authors explored the intentions of older adults to adopt and use smart home technologies using the Theoretical Domains Framework, the results of which are reported elsewhere [30]. This work highlighted that unless methods to increase intrinsic motivation are considered in the design of such systems, long-term adherence is unlikely to be achieved. This is an important point of consideration for future research to promote consistent engagement by participants for the collection of data to support their well-being.

Recommendations for Future Deployments

The results of the post design phase highlight the iterative nature of technology development in the context of IoT systems for older adults, emphasizing the need for continuous refinement and user-centered design to address practical challenges effectively. The withdrawal of a participant due to challenges with the self-installation process underscores the importance of user-friendly setup procedures. The recommendation for future deployments to include installation by a technical expert will ensure that participants are not burdened by technical complexities. Participants from the predesign phase also discussed the need for training and support to develop the digital literacy skills required to adopt technology to support independent living. Jiménez et al [31] outline the benefits of an iterative training approach for supporting older adults in the development of these skills. This approach involves a continuous process of training and support, allowing older adults to gradually build their digital literacy skills and confidence in using technology. This approach was subsequently implemented as part of the action research cycle which explored the feasibility and acceptability of NEX in a larger population of community-dwelling older adults. Another key observation from the prototype testing was the need for improved accuracy in detecting ADLs which is a critical aspect of the system's functionality. The recommendation to deploy a broader range of sensors and collect more frequent ground truth data reflects an ongoing commitment to enhancing the precision and effectiveness of the system in real-world applications. Ghayvat et al [22] suggest larger numbers of sensor placements (approximately 30) for effective detection of ADLs in the homes of older adults however the acceptability of the placement of this number of sensors in the home environments of older adults needs to be explored further.

Limitations

As for many other research projects, the COVID-19 pandemic and subsequent restrictions on movement limited the way the research teams could engage with participants and may have had implications for both co-design and prototype testing in this study. For aspects of the co-design process, focus groups were conducted via the web using Zoom as it was not possible to meet in person due to national COVID-19 guidelines. It is possible that richer discussions and opinions on how individual technology types may support independent living might have been achieved during in-person focus groups. Additionally, the prototype testing of NEX occurred during a time when restrictions on movement were in place and therefore the technician could not install the prototype in the homes of participants. Although participants self-installed the technology with the remote support of a technician, there were instances where technology failed (due to battery life) and data was lost, impacting the assessment of the technical performance of NEX. However, these adapted research approaches did facilitate the progression of this research during difficult circumstances.

Conclusion

The co-design process described by the authors enabled the project team to use an agile approach and consider a range of stakeholders' opinions in the design of this system. Although COVID-19 restrictions prevented face-to-face co-design research activities, the research team adapted research methods to facilitate web-based data collection and remote real-life testing. In terms of the research methodology, the authors presented an approach for a comprehensive co-design process involving older adults experiencing technology to support independent living over a sustained period in their own homes rather than conducting experiments and analyzing results based on limited exposure and assessment. The findings from this co-design process highlight that early participant engagement in the design process is necessary to ensure that the system meets the needs of stakeholders, which in turn supports technology adoption and cultivates motivation to use technology. An appreciation of the role of co-design and stakeholder opinions in terms of user needs and requirements by industry partners and clear and frequent communication channels were key attributes of a successful academic-industry collaboration in the area of digital health innovation.

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Conflicts of Interest

None declared.

References

1. Ageing and health. World Health Organization. 2022. URL: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health [accessed 2023-08-15]
2. Sláintecare. Government of Ireland. 2018. URL: https://www.gov.ie/en/campaigns/slaintecare-implementation-strategy/ [accessed 2023-08-15]
3. Lewis C, Buffel T. Aging in place and the places of aging: a longitudinal study. J Aging Stud 2020 Sep;54:100870. [doi: 10.1016/j.jaging.2020.100870] [Medline: 32972616]
4. Tun SYY, Madanian S, Mirza F. Internet of things (IoT) applications for elderly care: a reflective review. Aging Clin Exp Res 2021 Apr;33(4):855-867. [doi: 10.1007/s40520-020-01545-9] [Medline: 32277435]
5. Wang S, Bolling K, Mao W, et al. Technology to support aging in place: older adults' perspectives. Healthcare 2019 Apr 10;7(2):60. [doi: 10.3390/healthcare7020060] [Medline: 30974780]
6. Carek AM, Conant J, Joshi A, Kang H, Inan OT. SeismoWatch: wearable cuffless blood pressure monitoring using pulse transit time. Proc ACM Interact Mob Wearable Ubiquitous Technol 2017 Sep;1(3):40. [doi: 10.1145/3130905] [Medline: 30556049]
7. Rachim VP, Chung WY. Wearable-band type visible-near infrared optical biosensor for non-invasive blood glucose monitoring. Sens Actuat B Chem 2019 May;286:173-180. [doi: 10.1016/j.snb.2019.01.121]
8. Xiao N, Yu W, Han X. Wearable heart rate monitoring intelligent sports bracelet based on Internet of Things. Meas Lond 2020 Nov;164:108102. [doi: 10.1016/j.measurement.2020.108102]
9. Corbett CF, Wright PJ, Jones K, Parmer M. Voice-activated virtual home assistant use and social isolation and loneliness among older adults: mini review. Front Public Health 2021;9:742012. [doi: 10.3389/fpubh.2021.742012] [Medline: 34708017]
10. Dahmen J, Cook DJ, Wang X, Honglei W. Smart secure homes: a survey of smart home technologies that sense, assess, and respond to security threats. J Reliab Intell Environ 2017 Aug;3(2):83-98. [doi: 10.1007/s40860-017-0035-0] [Medline: 28966906]
11. Facchinetti G, Petrucci G, Albanesi B, De Marinis MG, Piredda M. Can smart home technologies help older adults manage their chronic condition? A systematic literature review. Int J Environ Res Public Health 2023 Jan 10;20(2):1205. [doi: 10.3390/ijerph20021205] [Medline: 36673957]

12. Borelli E, Paolini G, Antoniazzi F, et al. HABITAT: an IoT solution for independent elderly. Sensors (Basel) 2019 Mar 12;19(5):1258. [doi: 10.3390/s19051258] [Medline: 30871107]
13. Jo TH, Ma JH, Cha SH. Elderly perception on the Internet of Things-based integrated smart-home system. Sensors (Basel) 2021;21(4):1284. [doi: 10.3390/s21041284] [Medline: 33670237]
14. Wei W, Gong X, Li J, Tian K, Xing K. A study on community older people's willingness to use smart home-an extended technology acceptance model with intergenerational relationships. Front Public Health 2023;11:1139667. [doi: 10.3389/fpubh.2023.1139667] [Medline: 37346111]
15. Baig MM, Afifi S, GholamHosseini H, Mirza F. A systematic review of wearable sensors and IoT-based monitoring applications for older adults - a focus on ageing population and independent living. J Med Syst 2019 Jun 15;43(8):233. [doi: 10.1007/s10916-019-1365-7] [Medline: 31203472]
16. Stavropoulos TG, Papastergiou A, Mpaltadoros L, Nikolopoulos S, Kompatsiaris I. IoT wearable sensors and devices in elderly care: a literature review. Sensors (Basel) 2020 May 16;20(10):2826. [doi: 10.3390/s20102826] [Medline: 32429331]
17. Al-Shaqi R, Mourshed M, Rezgui Y. Progress in ambient assisted systems for independent living by the elderly. Springerplus 2016;5(1):624. [doi: 10.1186/s40064-016-2272-8] [Medline: 27330890]
18. Sumner J, Chong LS, Bundele A, Wei Lim Y. Co-designing technology for aging in place: a systematic review. Gerontol 2021 Sep 13;61(7):e395-e409. [doi: 10.1093/geront/gnaa064] [Medline: 32506136]
19. Murphy C, Timon C, Heffernan E, Hopper L, Gallagher P, Hussey P. Technology to support independent living at home: online survey of user needs and requirements. Age Ageing 2022 Oct 25;51. [doi: 10.1093/ageing/afac218.053]
20. Pedrozo Campos Antunes T, Souza Bulle de Oliveira A, Hudec R, et al. Assistive technology for communication of older adults: a systematic review. Aging Ment Health 2019 Apr 3;23(4):417-427. [doi: 10.1080/13607863.2018.1426718]
21. Bird M, McGillion M, Chambers EM, et al. A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework. Res Involv Engagem 2021 Mar 1;7(1):12. [doi: 10.1186/s40900-021-00252-7] [Medline: 33648588]
22. Ghayvat H, Awais M, Pandya S, et al. Smart aging system: uncovering the hidden wellness parameter for well-being monitoring and anomaly detection. Sensors (Basel) 2019 Feb 13;19(4):766. [doi: 10.3390/s19040766] [Medline: 30781852]
23. Braun V, Clarke V. Thematic Analysis: A Practical Guide: SAGE Publications Ltd; 2021.
24. Timon CM, Hussey P, Lee H, Murphy C, Vardan Rai H, Smeaton AF. Automatically detecting activities of daily living from in-home sensors as indicators of routine behaviour in an older population. D Health 2023;9:20552076231184084. [doi: 10.1177/20552076231184084] [Medline: 37485328]
25. Camp N, Lewis M, Hunter K, et al. Technology used to recognize activities of daily living in community-dwelling older adults. Int J Environ Res Public Health 2020 Dec 28;18(1):163. [doi: 10.3390/ijerph18010163] [Medline: 33379319]
26. Moore K, O'Shea E, Kenny L, et al. Older adults' experiences with using wearable devices: qualitative systematic review and meta-synthesis. JMIR Mhealth Uhealth 2021 Jun 3;9(6):e23832. [doi: 10.2196/23832] [Medline: 34081020]
27. Ollevier A, Aguiar G, Palomino M, Simpelaere IS. How can technology support ageing in place in healthy older adults? A systematic review. Pub Health Rev 2020 Nov 23;41(1):26. [doi: 10.1186/s40985-020-00143-4] [Medline: 33292707]
28. Jeno LM, Vandvik V, Eliassen S, Grytnes JA. Testing the novelty effect of an m-learning tool on internalization and achievement: a self-determination theory approach. Comput Educ 2019 Jan;128:398-413. [doi: 10.1016/j.compedu.2018.10.008]
29. Shin G, Feng Y, Jarrahi MH, Gafinowitz N. Beyond novelty effect: a mixed-methods exploration into the motivation for long-term activity tracker use. JAMIA Open 2019 Apr;2(1):62-72. [doi: 10.1093/jamiaopen/ooy048] [Medline: 31984346]
30. Kilcullen S, Heffernan E, Hussey P, et al. A Theoretical Domains Framework (TDF) approach to the qualitative analysis of older adults' intentions to adopt assistive smart home technology. Gerontechnology 2022 Jan 1;21(1):1-14. [doi: 10.4017/gt.2022.21.1.591.12]
31. Jiménez FN, Brazier JF, Davoodi NM, Florence LC, Thomas KS, Gadbois EA. A technology training program to alleviate social isolation and loneliness among homebound older adults: a community case study. Front Public Health 2021;9:750609 [FREE Full text]

Abbreviations

ADL: activities of daily living
AI: artificial intelligence
DCU: Dublin City University
IoT: Internet of Things

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Positive Emotional Responses to Socially Assistive Robots in People With Dementia: Pilot Study

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Abstract

Background: Interventions and care that can evoke positive emotions and reduce apathy or agitation are important for people with dementia. In recent years, socially assistive robots used for better dementia care have been found to be feasible. However, the immediate responses of people with dementia when they are given multiple sensory modalities from socially assistive robots have not yet been sufficiently elucidated.

Objective: This study aimed to quantitatively examine the immediate emotional responses of people with dementia to stimuli presented by socially assistive robots using facial expression analysis in order to determine whether they elicited positive emotions.

Methods: This pilot study adopted a single-arm interventional design. Socially assistive robots were presented to nursing home residents in a three-step procedure: (1) the robot was placed in front of participants (visual stimulus), (2) the robot was manipulated to produce sound (visual and auditory stimuli), and (3) participants held the robot in their hands (visual, auditory, and tactile stimuli). Expression intensity values for “happy,” “sad,” “angry,” “surprised,” “scared,” and “disgusted” were calculated continuously using facial expression analysis with FaceReader. Additionally, self-reported feelings were assessed using a 5-point Likert scale. In addition to the comparison between the subjective and objective emotional assessments, expression intensity values were compared across the aforementioned 3 stimuli patterns within each session. Finally, the expression intensity value for “happy” was compared between the different types of robots.

Results: A total of 29 participants (mean age 88.7, SD 6.2 years; n=27 female; Japanese version of Mini-Mental State Examination mean score 18.2, SD 5.1) were recruited. The expression intensity value for “happy” was the largest in both the subjective and objective assessments and increased significantly when all sensory modalities (visual, auditory, and tactile) were presented (median expression intensity 0.21, IQR 0.09-0.35) compared to the other 2 patterns (visual alone: median expression intensity 0.10, IQR 0.03-0.22*;* *P*<.001; visual and auditory: median expression intensity 0.10, IQR 0.04-0.23; *P*<.001). The comparison of different types of robots revealed a significant increase when all stimuli were presented by doll-type and animal-type robots, but not humanoid-type robots.

Conclusions: By quantifying the emotional responses of people with dementia, this study highlighted that socially assistive robots may be more effective in eliciting positive emotions when multiple sensory stimuli, including tactile stimuli, are involved. More studies, including randomized controlled trials, are required to further explore the effectiveness of using socially assistive robots in dementia care.

Trial Registration: UMIN Clinical Trials Registry UMIN000046256; https://tinyurl.com/yw37auan

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KEYWORDS

dementia care; robotics; emotion; facial expression; expression intensity; long-term care; sensory modality; gerontology; gerontechnology

Introduction

The number of people with dementia is increasing globally, and it is estimated that it will reach 152 million by 2050 [1]. The provision of adequate social care for people with dementia is a major public health concern in many countries. The neurodegenerative nature of dementia affects memory, cognitive function, and more, resulting in a range of noncognitive symptoms, including changes in behavior, emotion, and social functioning. The most frequent changes include agitation, depression, and apathy. These emotional changes are reported as the most challenging aspect of dementia care by many caregivers [2]. On the other hand, positive emotions such as joy or comfort are relatively preserved until the terminal stage of the disease [3,4]. Previous studies suggest that the arousal of positive emotions may enhance cognitive function, presumably through amygdala activation; therefore, stimuli with a positive valence may enhance the effect of the rehabilitative approach for patients with dementia [3,5]. Considering these facts, interventions and caregiver involvement that can evoke positive emotions and suppress negative psychological responses are important strategies that should be actively implemented in long-term care for people with dementia to maintain residual functions and alleviate the burden of care.

As examples of emotion-related interventions, music therapy [6,7] and occupational therapy [8,9] have been shown to be effective in terms of emotional control. However, due to the rapid increase in the number of people with dementia and the shortage of dementia caregivers [1,10,11], there is a lack of staffing power to provide such nondrug therapies broadly and equally. In recent years, clinical applications of socially assistive robots have been used to provide high-quality emotional support and companionship [12-14]. Socially assistive robots are machines designed to provide assistance in the caregiving process through social rather than physical means and are equipped with a social interface to enable interaction with the user [15-17]. One systematic review and meta-analysis, as well as one scoping review, found that Paro, a baby seal–shaped socially assistive robot, has significant effects on agitation and depression [12,18], while another systematic review and meta-analysis concluded that there is little evidence that people with dementia derive benefits from socially assistive robots for cognition or neuropsychiatric symptoms when considering various types of robots, although they are feasible and acceptable [11]. On the other hand, one small between-groups comparison study reported that a certain type of socially assistive robot showed a negative effect in participants with cognitive decline, based on an examination of immediate neurophysiological changes [19].

When using socially assistive robots in clinical practice, one important aspect to consider is the immediate response of persons with dementia. In general, when confronted with a new robot or technology, a relatively positive immediate response known as the novelty effect [20] tends to be observed. In contrast, in people with cognitive decline, the immediate response to robots is reported to be somewhat stressful rather than positive [19]. These findings suggest that people with dementia, or those with memory and other cognitive impairments, may have a different immediate response compared to the general public. For example, people with dementia have a reduced ability to process multiple sensory stimuli [21]; therefore, they might have difficulty accepting and integrating multiple unfamiliar stimuli (eg, shapes, lights, sounds, and touch) provided simultaneously by the robot in the first interaction. Since they are prone to mental stress when they do not understand a situation [22], these stimuli from the robots could cause a tense or negative response. Nonetheless, no studies have verified how socially assistive robots are perceived by people with dementia from the perspective of having to process multiple sensory modalities. Moreover, an immediate response from the person with dementia is crucial in clinical settings because it helps care providers confirm the effectiveness of the robot on the spot and make precise decisions about whether to continue using the robot. Therefore, it is beneficial for clinical applications to focus on understanding the immediate responses of people with dementia when they are given multiple sensory modalities from socially assistive robots.

For an objective and better understanding of these issues, the signs of emotional responses should be quantified using appropriate techniques. Given that verbal skills tend to be impaired in people with dementia [23,24], it is important to use not only self-reported outcomes but also objective measures that can be obtained with minimal burden. For example, in the field of psychology, facial expression is considered a differentiated indicator of inner emotions [25,26]. According to recent reports, analysis of facial imaging using facial expression analysis software is able to quantify facial expressions and estimate emotions with good validity [27,28]. Applying these technologies to the investigation of the use of socially assistive robots among people with dementia will enable detailed and empirical verification of their effects, such as responses to the different sensory stimuli mentioned above, which are difficult to detect with subjective scales.

In this context, this study aimed to quantitatively evaluate the psychological and emotional reactions evoked in people with dementia to stimuli derived from socially assistive robots using facial expression analysis of facial video clips. In particular, we investigated how immediate responses changed as the modalities of sensory stimulation provided by the robot increased. Furthermore, from the perspective of eliciting positive emotions, which are beneficial to dementia care, this study also examined the differences in the emotion of joy elicited by the different types of robots.

Methods

Ethical Considerations

The study protocol was approved by the institutional ethics committee of the National Center for Geriatrics and Gerontology (1539) and prospectively registered in the UMIN Clinical Trial Registry (UMIN000046256). All participants with a Clinical Dementia Rating (CDR) scale [29] score of 0 or 1 provided informed consent themselves in accordance with the Declaration of Helsinki. For those who were considered to have an insufficient capacity to consent due to cognitive decline equivalent to CDR 2 and 3, informed consent was obtained from their family members, and the procedures were explained to the participants in plain language to obtain their approval. To comply with ethical principles, all data collected were anonymized and stored in a locked file or on a password-protected computer.

Study Design and Setting

This pilot study was conducted as a single-arm, self-controlled, interventional study. Two local nursing care facilities that had no previous experience implementing socially assistive robots were selected as the experiment sites.

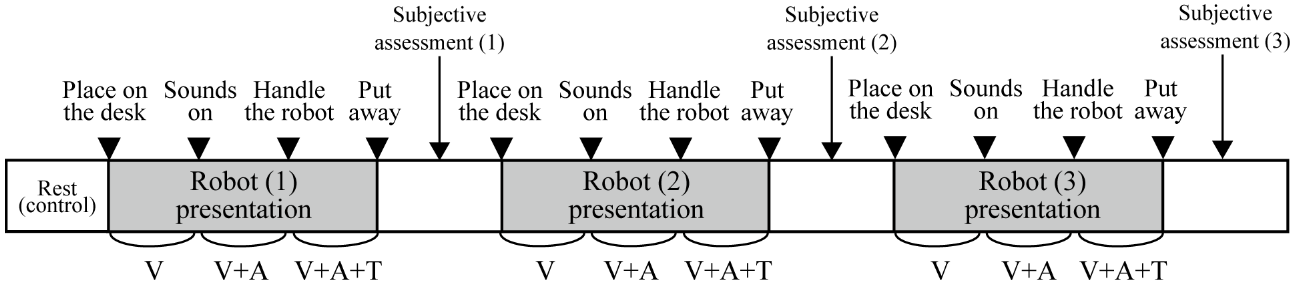
Participants

Participants were recruited among the residents of the 2 nursing homes. The inclusion criteria were as follows: a significant decline in cognitive function interfering with independence in the performance of everyday activities, the ability to maintain a sitting position for 15 minutes or more, the ability to communicate using simple words, and the ability to follow 2-step instructions. These criteria were first assessed by nursing home staff members through assessments performed as part of daily nursing care procedures. Regarding cognitive decline, candidates either had a previous formal diagnosis of dementia from their physician or received a diagnosis from one of the researchers (EO, a physician); they also had confirmed evidence that cognitive decline was present and that the decline was not due to delirium or other mental disorders. Ultimately, all the participants met the diagnostic criteria for dementia in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*). Those with unstable physical or mental conditions or evident higher cognitive dysfunction due to causes other than dementia were excluded.

Procedures

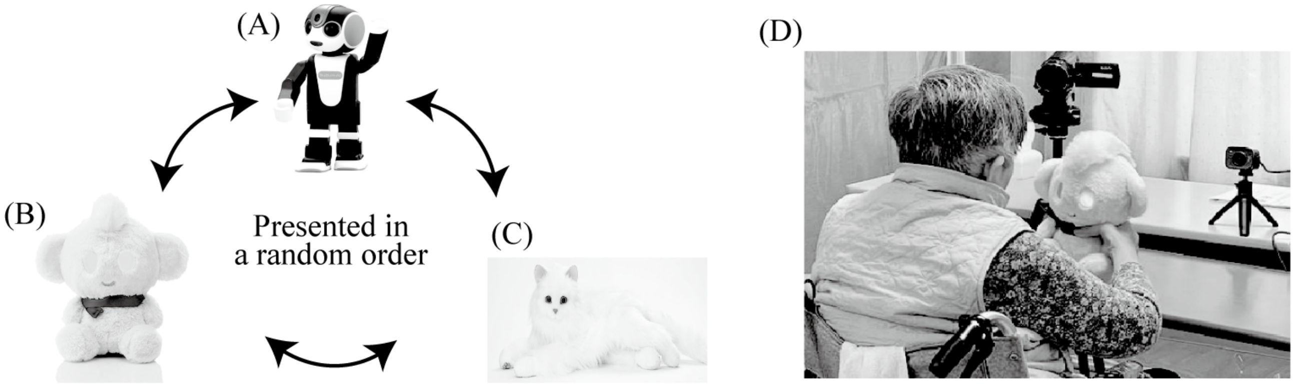
The participants were taken to a private room or a place with minimum environmental noise, and their faces were recorded in a resting state for 30 seconds. This was referenced as the control image for calibrating the facial expression analysis (to be described below). Next, the socially assistive robots were presented to the participant by a familiar staff member in 1 session using a predetermined 3-step procedure. The staff explained in advance that they wanted the participants to share how they felt after experiencing the robots. In the first step, the robot was placed on a desk in front of the participant (visual stimulus). In the second step, the robot was manipulated to produce a gentle voice or meow (visual and auditory stimuli). In the third step, the participant was encouraged to touch the robot (visual, auditory, and tactile stimuli) and was able to handle it freely, including petting and holding. The 3 patterns of sensory stimulus produced by the robots were presented for approximately 30 seconds in the context of assessing the participant's immediate responses unless the participant refused (Figure 1).

Figure 1. The flow of robot presentation to the participant. V: visual stimulus only; V+A: visual and auditory stimuli; V+A+T: visual, auditory, and tactile stimuli.



Each participant was presented with 3 types of commercially available robot with typical characteristics—a humanoid-type robot capable of voice communication (RoBoHoN; Sharp Corp), a doll-type robot with the appearance of a stuffed toy and a voice recognition and reproduction system (Chapit; RayTron Inc), and an animal-type (cat-shaped) robot that can meow, move its tail, and recognize sound (Amaenbou-Nekochan; Digirect Co, Ltd)—resulting in 3 sessions per participant. The order of presentation, which was determined in advance using a random number table, differed for each participant (Figure 2).

Figure 2. Socially assistive robots used in this study. Each participant was presented with these 3 types of robots with typical characteristics, resulting in 3 sessions per participant. The order of presentation was determined in advance using a random number table. (**A**) Humanoid-type, (**B**) doll-type, and (**C**) animal-type robots; (**D**) video recording while the participant is touching the robot.



Assessments of Emotional Responses

Subjective Assessment

At the end of each robot presentation session, the degree of subjective feelings (happy, sad, angry, surprised, scared, and disgusted) was recorded using a 5-point Likert scale (1: not at all; 2: very little; 3: so-so; 4: somewhat; 5: very much). The participants were shown a scale with words corresponding to each of the 5 points of the scale and were asked to select the point that best described their current feelings. This was assessed a total of 3 times (ie, once at the end of each robot presentation).

Video Recording and Facial Expression Analysis

For the study procedures, a video camera (Logicool StreamCam; Logitech Inc) was configured on a desk to capture the participants' faces from the front. In case this camera's view was blocked by arm movements or the robot, another camera (Handycam HDR-CX470, Sony Corp) was fixed on a tripod positioned 30 degrees diagonally in front of the participant.

The videos were recorded continuously during the session in full HD (1920 × 1080 pixels) at 60 frames per second. To optimize the sensitivity and accuracy of the facial expression analysis, we segmented the video clips such that each clip contained 1 sensory stimulation pattern (visual only; visual and auditory; or visual, auditory, and tactile), and then cropped them to a suitable resolution that focused on the facial region. If necessary, the brightness of the video clips was minimally adjusted.

We used commercially available software for quantifying facial expressions (FaceReader; version 7; Noldus Information Technology Inc). This software was developed based on a quantitative evaluation method called the Facial Action Coding System [30], which describes visually identifiable facial muscle movements as "action units," identifies the intensity of a basic emotional state, and outputs time-series data sets comprising expression intensity values from 0 to 1 for each of the 7 facial expression elements (ie, neutral, happy, sad, angry, surprised, scared, and disgusted) on a continuous scale with high accuracy [27,31,32]. This method is advantageous in that it can quantitatively evaluate facial expressions conveniently with good reproducibility, unlike subjective evaluations, as discussed previously [33]. The software provides 5 face models (General, General61, Children, East Asians, and Elderly) that correspond to the data sets used in the algorithm training. We used the East Asian face model according to the software specifications.

Additionally, we used the calibration function provided by the software to minimize person-specific biases due to facial wrinkles or light effects. The reference manual of FaceReader explains that this function removes biases in the 7 facial expression elements but does not increase the intensity. For each participant, the resting facial image in the first part of recording was used as the calibration image for all the video clips of the participant. In cases where certain facial expression elements were detected in the neutral control image, those expression elements were corrected in the images to be analyzed. The degree of successful face recognition was evaluated for every video clip, and the session was excluded from further analysis if both images from the 2 cameras had a low proportion of successful frames (<20%), with reference to previous studies [32,34].

Clinical Assessments

In addition to basic characteristics, overall cognitive function was assessed using the Japanese version of the Mini-Mental State Examination (MMSE-J) [35] and the Japanese version of the Montreal Cognitive Assessment (MoCA-J) [36]. The Barthel index was used to assess performance on 10 basic activities of daily living (ADL), which tend to deteriorate in people with dementia. The total score ranges from 0 (worst; all dependent) to 100 (best; all independent). The Dementia Behavior Disturbance Scale (DBDS) [37,38] was used to assess the severity of neuropsychiatric symptoms. The scale evaluates a total of 28 items on a 5-point scale from 0 (not at all) to 4 (always) in terms of the frequency of the behavioral disturbances typically seen in persons with dementia, such as wandering, agitation, and aggression, and is scored from 0 (best) to 112 (worst). The questionnaire format allowed caregivers to answer the questions easily. Finally, to assess hearing disability, which may affect the response to auditory stimulation, 10 items from the Questionnaire on Hearing [39] were surveyed to score the severity of hearing loss in daily life. These 10 questions set up specific situations of hearing speech or environmental sounds in daily life and were to be answered on a 5-point scale from 1 (always able to hear) to 5 (never able to hear). The total score ranges from 10 (best) to 50 (worst).

The MMSE-J and MoCA-J were administered by skilled occupational therapists on different days. The Barthel index, DBDS, and the Questionnaire on Hearing were scored by nursing home staff members who were sufficiently familiar with the participants.

Statistical Analyses

The averages of the emotions expressed in response to the robot (ie, happy, sad, angry, surprised, scared, and disgusted) were compared to each other using the nonparametric Wilcoxon signed-rank test, with the *P* values multiplied by the number of tests according to the Bonferroni method. The correlations between subjective and objective emotional assessments were also examined using Spearman correlation coefficients. The average expression intensity values during the 30 seconds for each sensory stimulus obtained by facial expression analysis were compared for all 3 patterns (visual only; visual and auditory; or visual, auditory, and tactile) using the Friedman test with the Wilcoxon signed-rank test as a post hoc test. The average of the 3 robot presentation sessions was used in this part of the analysis. Additionally, focusing on positive emotions, the expression intensity values for “happy” were compared between the different types of robots using the Friedman test with the Wilcoxon signed-rank test as a post hoc test. Statistical analyses were performed using STATA/SE (version 13.1; StataCorp). Any *P* value less than .05 was considered statistically significant.

Results

Table 1 presents the demographic characteristics of the participants. Eleven participants (38%) had been diagnosed with Alzheimer disease by their physician, 5 (17%) had dementia with Lewy bodies, and 13 (45%) met the criteria for major neurocognitive disorder in the *DSM-5*, but the etiology was not specified. All the participants had cognitive decline when compared with the cutoff value of 26 on the MoCA-J [36].

Table . Overall participant characteristics (N=29).

Characteristics		Values
Age (years), mean (SD; range)		88.7 (6.2; 71-98)
Gender, n		
	Male	2
	Female	27
Type of disease, n		
	Alzheimer disease[a]	11
	Dementia with Lewy bodies[b]	5
	Not specified	13
Years of education, mean (SD; range)		9.7 (2.2; 6-13)
MMSE-J[c], mean score (SD; range)		18.2 (5.1; 11-28)
MoCA-J[d], mean score (SD; range)		11.8 (4.9; 2-24)
Barthel index, mean score (SD; range)		66.0 (24.8; 10-95)
10 items from the Questionnaire on Hearing, mean score (SD; range)		26.6 (8.6; 14-50)
DBDS[e], mean score (SD; range)		13.4 (9.6; 0-40)

[a] A total of 4 patients were taking medication for dementia.

[b] A total of 2 patients were taking medication for dementia.

[c] MMSE-J: Japanese version of Mini-Mental State Examination.

[d] MoCA-J: Japanese version of Montreal Cognitive Assessment.

[e] DBDS: Dementia Behavior Disturbance Scale.

The average subjective emotional assessments (5-point Likert scale) and objective expression intensity values for the expression elements across all of 3 types of robots are shown in Table 2. Facial analysis failed to detect any action units or emotional elements in 1 of the 29 participants. Also, 1 video clip was excluded from the analyses because of a low proportion of successful frames (participant 13; doll-type robot; visual, auditory, and tactile stimuli presented). After excluding these video clips, the overall percentage of the video frames analyzable by the software was 81.4%. Among the self-reported emotions, “happy” was significantly the most common (happy vs surprised: *P*=.01; happy vs sad, angry, scared and disgusted: *P*<.001), and facial analysis–detected emotions showed the same trend in that the values of “happy” were significantly the most common among the 6 emotional elements assessed (happy vs all others: *P*<.001). Additionally, the correlations between subjective and objective emotional assessments were significant for “happy,” “sad,” and “surprised,” though the correlation coefficients were interpreted as slight or low. Taking the value of “happy” as an example, as shown in Figure 3, there were cases where the objective value was detected as high even when the subjective feelings were reported as low.

Table . The relationship between subjective and objective emotional assessments.

	Subjective (5-point Likert scale; n=29)		Objective (expression intensity values; n=28)		ρ	*P* value
	Mean (SD)	Range	Mean (SD)	Range		
Happy	3.6 (1.0)	1-5	0.18 (0.16)	0-0.73	0.21	<.001
Sad	2.1 (0.8)	1-5	0.07 (0.09)	0-0.61	0.14	.03
Angry	1.9 (0.8)	1-4	0.07 (0.11)	0-0.77	0.06	.31
Surprised	3.1 (1.1)	1-5	0.09 (0.11)	0-0.62	0.29	<.001
Scared	1.9 (0.7)	1-5	0.03 (0.05)	0-0.36	0.05	.42
Disgusted	2.0 (1.0)	1-5	0.05 (0.06)	0-0.34	0.08	.21
Neutral	N/A[a]	N/A	0.46 (0.13)	0.14-0.85	N/A	N/A

[a] N/A: not applicable.

Figure 3. Comparison of the objective expression intensity for “happy” at each grade of subjective emotional assessment (5-point Likert scale). Error bars indicate SDs, the lines within the boxes indicate medians, and the dots indicate outliers that were more than a quarter of the range × 1.5 away from the first or third quartile.

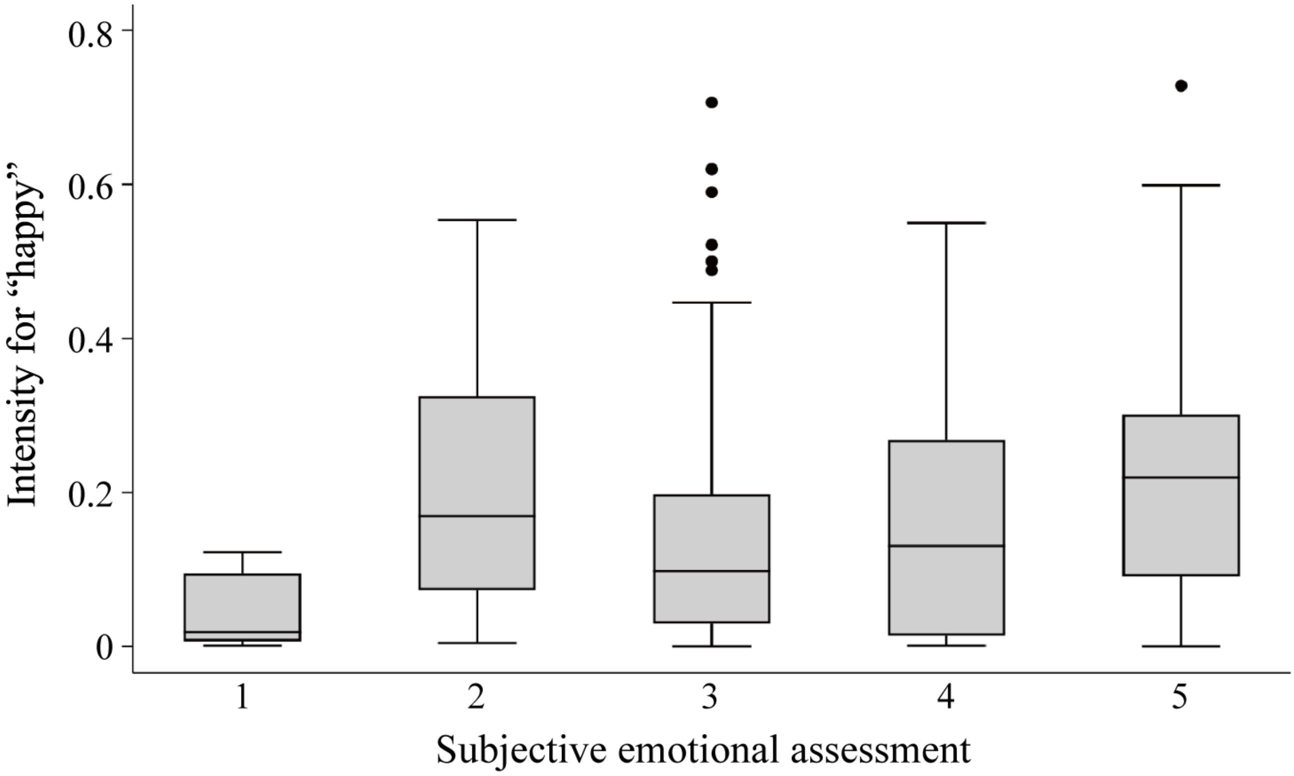
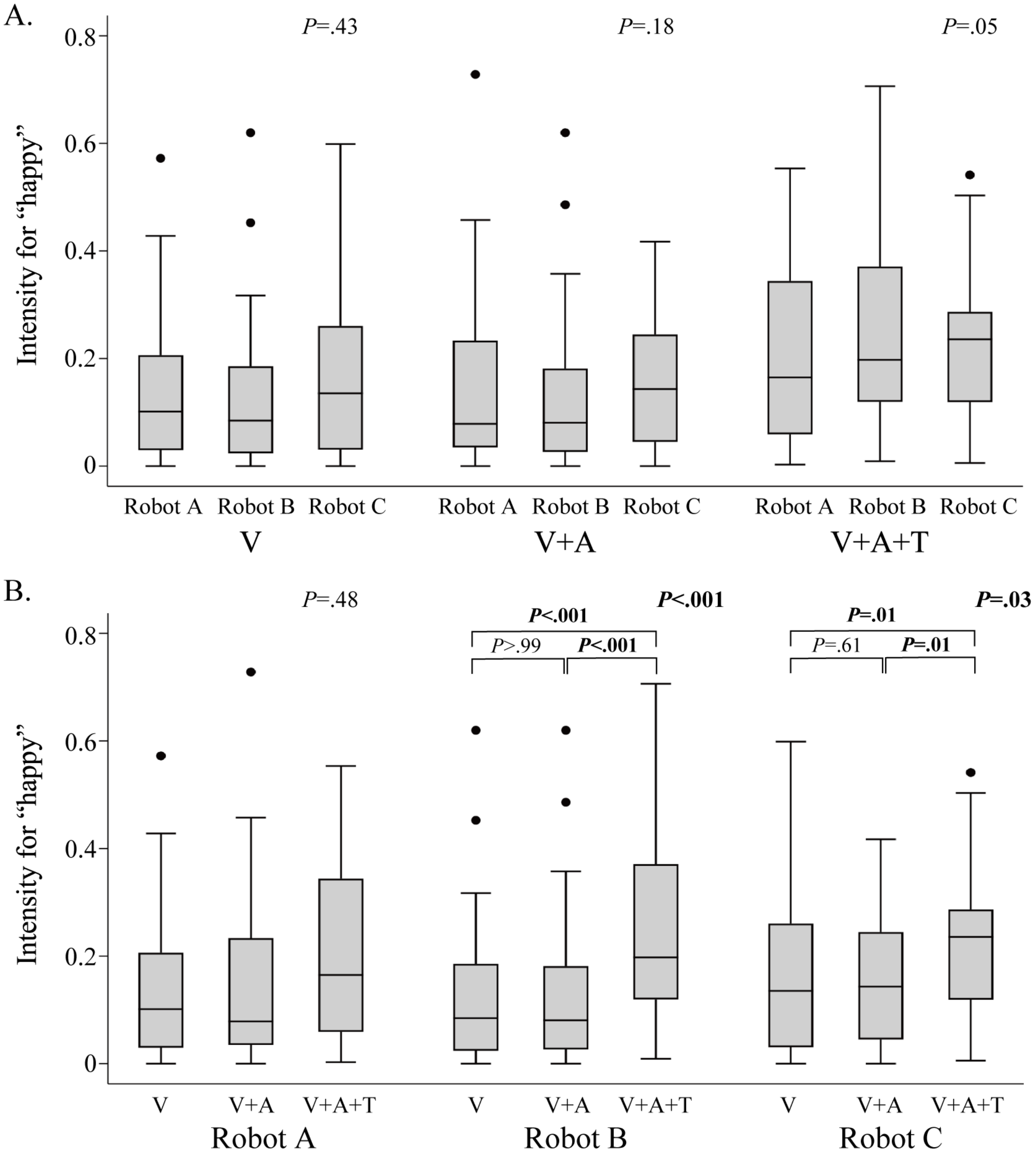


Figure 4 shows a comparison of 3 different patterns of sensory stimuli among all participants. There were significant differences in the values for “neutral” (*P*<.001), “happy” (*P*<.001), “sad” (*P*=.001), “scared” (*P*=.04), and “disgusted” (*P*<.001) among the 3 patterns. Post hoc analyses revealed that the values for “happy” significantly increased in the pattern with visual, auditory, and tactile stimuli (median score 0.21, IQR 0.09-0.35) compared to the patterns with visual stimulus only (median score 0.10, IQR 0.03-0.22; *P*<.001) and with both visual and auditory stimuli (median score 0.10, IQR 0.04-0.23; *P*<.001). The values for “sad” (with visual, auditory, and tactile stimuli: median score 0.05, IQR 0.01-0.11) and “disgusted” (with visual, auditory, and tactile stimuli: median score 0.04, IQR 0.02-0.10) exhibited the same trend, though both of these values were significantly smaller than those for “happy” (*P*<.001). In contrast, the values for “neutral” and “scared” significantly decreased in the pattern with visual, auditory, and tactile stimuli compared with the other 2 patterns. However, the intensity of each emotional element did not change linearly over time.

Figure 4. Comparison of all the expression intensities under the 3 different patterns of sensory stimulation. Error bars indicate SDs, the lines within the boxes indicate medians, and the dots indicate outliers that are more than a quarter range × 1.5 away from the first or third quartile. The values in the upper right of each group represent the overall *P* values in the Friedman test. The values above the boxplots for the nonresponder group represent the *P* values in the post hoc test (the Wilcoxon signed-rank test). *P* values less than .05 are denoted in bold. V: visual stimulus only; V+A: visual and auditory stimuli; V+A+T: visual, auditory, and tactile stimuli.

When comparing the expression intensity values for "happy" between the different types of robots for the same participants and the same sensory stimuli, no statistical differences were found, as depicted in Figure 5A. When comparing the expression intensity values for "happy" between the different sensory stimuli for the same robot type, no statistically significant differences were found for robot A (humanoid-type*;* *P*=.48), while robot B (doll-type*;* *P*<.001) and robot C (animal-type*;* *P*=.03) had large, significant values in the pattern with visual, auditory, and tactile stimuli compared with the other 2 patterns, as shown in Figure 5B.

Figure 5. Comparison of the expression intensity for "happy" between the different types of robots. (A) Comparison between 3 types of robots with the same pattern of sensory stimulation. (B) Comparison within each robot type using the 3 different patterns of sensory stimulation. Error bars indicate SDs, the lines within the boxes indicate medians, and the dots indicate outliers that are more than a quarter of the range × 1.5 away from the first or third quartile. The values in the upper right of each group represent the overall *P* values from the Friedman test. The values above the boxplots for robots B and C represent the *P* values from the post hoc test (the Wilcoxon signed-rank test). *P* values less than .05 are denoted in bold.



Discussion

Principal Results

This study aimed to quantitatively evaluate the psychological and emotional responses of people with dementia to complex sensory stimuli provided by socially assistive robots. To summarize, the values for “happy” were found to be the largest in the overall response to the robots among the emotional elements in both the self-recorded assessment and objective facial expression analysis. However, correlations between the subjective and objective emotional assessments were found to be relatively low or insignificant. When comparing the 3 different patterns of sensory stimulation, there was a significant increase in some of the expression intensity values when all stimuli (visual, auditory, and tactile) were presented. In the comparison between different types of robots, focusing on “happy,” there was a significant increase when all stimuli were presented by a doll-type robot and by an animal-type robot but not by a humanoid-type robot.

The emotional responses revealed by the objective facial expression analysis showed the same trend as the participants’ subjective assessment, with happy emotions having the largest values in both assessments. This result suggests that the facial expression analysis system can successfully detect the expressions that emerge in people with dementia, which is consistent with a previous study [40].

However, considering that the facial expression intensity was detected as relatively high in some cases where the subjective rating was moderate, the facial expression analysis may be able to capture emotions that are not sufficiently represented by a subjective 5-point Likert scale. In fact, a previous study supports the appropriateness of facial expression analysis as a nonverbal pain assessment for people with dementia when they lack the ability to self-report [41]. Therefore, facial expression analysis may also be useful as an accurate nonverbal assessment of emotions for people with dementia.

Although some studies have already demonstrated positive responses in people with dementia when presented with socially assistive robots [42,43], this study is the first to objectively and quantitatively describe emotional responses using facial expression analysis. Additionally, these results are inconsistent with those of Goda et al [19], who found that a 5-minute talk session with a socially assistive robot caused stress in people with dementia. In contrast to this study, the socially assistive robot’s interaction in the study by Goda et al [19] was mainly through verbal communication; thus, it was inferred that these stimuli were burdensome for people with dementia, who tend to have a decline in verbal communication skills. The positive expressions shown in this study are considered to have been observed as responses to sensory stimuli and not verbal stimuli.

Regarding the relationship between the type of sensory stimulus and emotional responses, the expression intensity values for “happy,” “sad,” and “disgusted” significantly increased with increasing sensory stimuli. Particularly, happy emotions were revealed to be elicited most strongly in persons with dementia when different varieties of sensory stimuli were presented. With respect to the values for “sad” and “disgusted,” we consider it natural that participants became somewhat careful or timid toward unknown experiences when interacting closely with robots. However, these emotional elements in automated analysis should be interpreted with caution, as they can occasionally include other negative emotions, such as fear [44], especially when accompanied by facial movements around the lips or jaws [31]. Nevertheless, the values for these negative emotions remain small compared to the value for “happy,” showing that positive emotions were dominant when visual, auditory, and tactile sensory stimuli were offered.

Notably, this increase in positive emotional responses may include changes over time, because the sensory stimuli were added over time in this study. Given the procedures in this study, the results could have been influenced by the novelty effect [20], which is derived from curiosity toward a new experience. However, the intensity of each emotional element did not change linearly when sensory stimuli were added over time. Moreover, the addition of an auditory stimulus did not significantly increase the expression intensity value, whereas the addition of a tactile stimulus did. These findings suggest the importance of adding tactile stimuli to visual and auditory stimuli. This is plausible considering that tactile information connects through several pathways to the insular cortex, which evokes emotional responses [45,46]. The finding that tactile stimuli evoked positive feelings is supported by previous studies that showed that haptic or tangible input was effective in helping people with dementia understand and adapt to their surroundings [47,48]. Regarding auditory stimuli, the results of the Questionnaire on Hearing did not indicate that the participants had very good hearing, suggesting that the effects of auditory stimuli on emotion elicitation may have been relatively small. Since hearing loss is associated with the risk of developing dementia [49], and a high percentage of people with dementia actually have hearing loss [50,51], this issue may also be of great clinical importance.

Furthermore, it is noteworthy that a significant increase in expression intensity values for “happy” with increased sensory stimuli was observed for doll-type robots and animal-type robots, but not for humanoid-type robots. One of the distinctive characteristics of the doll-type and animal robots used in this study was that they were covered by soft, fur-like materials. The importance of soft materials is commonly discussed in the field of soft robotics for medical use or human assistance [52,53]. Softness is considered effective not only in terms of safety for the human body but also in terms of the imitation of reality or the creation of familiarity [54] and emotional processing [55]. However, the emotional effects of various tactile sensations in people with dementia have not yet been studied; consequently, given the findings of this study, the effectiveness of soft tactile stimuli in dementia care may be worth exploring in future research.

Limitations

This study has a few limitations. First, it included a small number of participants and a single experimental group. Changes in facial expressions were reliably detected by using the participants’ resting states as controls. However, another study design, such as a randomized controlled trial, is required to confirm these effects more clearly. Second, the generalizability of our findings may be limited, as most of the participants in this study were female. Previous studies report that there are gender differences in emotional responses to some types of sounds [56], emotion expression [57], and emotion regulation [58], although gender and facial expression have been reported to have no significant correlation [40]. Further research with male participants will be needed to reveal possible gender differences in responses toward social robots. Third, since there is no prior literature that has identified a minimum detectable change or a minimal clinically important difference for expression intensity, the clinical significance of the changes in expression intensity values demonstrated in this study needs to be explored further. Finally, this study only investigated the immediate responses to socially assistive robots, with patients allowed to interact with each robot for only 1.5 minutes in total. However, in real clinical settings, people with dementia might express more diverse patterns of responses, using these robots as they would like. Moreover, any enthusiasm resulting from the novelty effect may diminish over time. Thus, further investigation is required to reveal the long-term emotional effects of socially assistive robots on people with dementia, including variability in positive responses over several hours or days of use and the effects of these robots on their neuropsychiatric symptoms.

Conclusions

This study quantitatively examined the emotional reactions of people with dementia to socially assistive robots. The expression intensity values, especially the values for “happy,” significantly increased with multiple sensory stimuli, including visual, auditory, and tactile stimuli. Therefore, this study shows that socially assistive robots may be more effective in arousing positive emotions when multiple sensory stimuli are involved. Further studies, including randomized controlled trials, are required to further explore the effectiveness of and the optimal methods for using socially assistive robots in dementia care.

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EO, AO, KK, KM, and SH conceptualized and designed the study. EO collected and analyzed data and drafted the manuscript. MK participated in data collection, data interpretation, and manuscript editing. AO, KK, YO, and SU participated in data interpretation and manuscript editing. IK participated in data interpretation and critical revisions of the manuscript. All authors have read and approved the final manuscript. This study was supported by the Japan Health Research Promotion Bureau Research Fund for Young Investigators (JH2021-Y-11). We sincerely thank the staff of Wakyokai Nagomi-no-Sato and Jinshikai Ruminasu Obu (nursing homes for older people) and the Wellness Valley Promotion Office (Obu City) for their cooperation. We also thank Naho Hashimoto, Ai Sugiyama, Michiko Chiso, and Ayumi Ogura for their technical support.

Conflicts of Interest

None declared.

References

1. GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. Lancet Public Health 2022 Feb;7(2):e105-e125. [doi: 10.1016/S2468-2667(21)00249-8] [Medline: 34998485]
2. Teng E, Marshall GA, Cummings JL. Neuropsychiatric features of dementia. In: Boeve BF, Miller BL, editors. The Behavioral Neurology of Dementia: Cambridge University Press; 2009:85-100. [doi: 10.1017/CBO9780511581410]
3. Nashiro K, Sakaki M, Mather M. Age differences in brain activity during emotion processing: reflections of age-related decline or increased emotion regulation? Gerontology 2012 Feb;58(2):156-163. [doi: 10.1159/000328465] [Medline: 21691052]
4. Chaudhary S, Zhornitsky S, Chao HH, van Dyck CH, Li CS. Emotion processing dysfunction in Alzheimer's disease: an overview of behavioral findings, systems neural correlates, and underlying neural biology. Am J Alzheimers Dis Other Demen 2022 Jan;37:15333175221082834. [doi: 10.1177/15333175221082834] [Medline: 35357236]
5. Broster LS, Blonder LX, Jiang Y. Does emotional memory enhancement assist the memory-impaired? Front Aging Neurosci 2012 Mar;4:2. [doi: 10.3389/fnagi.2012.00002] [Medline: 22479245]
6. van der Steen JT, Smaling HJ, van der Wouden JC, Bruinsma MS, Scholten RJ, Vink AC. Music-based therapeutic interventions for people with dementia. Cochrane Database Syst Rev 2018 Jul 23;7(7):CD003477. [doi: 10.1002/14651858.CD003477.pub4] [Medline: 30033623]
7. Sihvonen AJ, Särkämö T, Leo V, Tervaniemi M, Altenmüller E, Soinila S. Music-based interventions in neurological rehabilitation. Lancet Neurol 2017 Aug;16(8):648-660. [doi: 10.1016/S1474-4422(17)30168-0] [Medline: 28663005]
8. Dooley NR, Hinojosa J. Improving quality of life for persons with Alzheimer’s disease and their family caregivers: brief occupational therapy intervention. Am J Occup Ther 2004 Sep;58(5):561-569. [doi: 10.5014/ajot.58.5.561] [Medline: 15481783]
9. Gitlin LN, Winter L, Burke J, Chernett N, Dennis MP, Hauck WW. Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. Am J Geriatr Psychiatry 2008 Mar;16(3):229-239. [doi: 10.1097/JGP.0b013e318160da72] [Medline: 18310553]

10. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. World Alzheimer report 2015: the global impact of dementia, an analysis of prevalence, incidence, cost and trends. : Alzheimer's Disease International; 2015 URL: https://www.alzint.org/u/WorldAlzheimerReport2015.pdf [accessed 2024-03-29]
11. Yu C, Sommerlad A, Sakure L, Livingston G. Socially assistive robots for people with dementia: systematic review and meta-analysis of feasibility, acceptability and the effect on cognition, neuropsychiatric symptoms and quality of life. Ageing Res Rev 2022 Jun;78:101633. [doi: 10.1016/j.arr.2022.101633] [Medline: 35462001]
12. Leng M, Liu P, Zhang P, et al. Pet robot intervention for people with dementia: a systematic review and meta-analysis of randomized controlled trials. Psychiatry Res 2019 Jan;271:516-525. [doi: 10.1016/j.psychres.2018.12.032] [Medline: 30553098]
13. Takayanagi K, Kirita T, Shibata T. Comparison of verbal and emotional responses of elderly people with mild/moderate dementia and those with severe dementia in responses to seal robot, PARO. Front Aging Neurosci 2014 Sep;6:257. [doi: 10.3389/fnagi.2014.00257] [Medline: 25309434]
14. Banks MR, Willoughby LM, Banks WA. Animal-assisted therapy and loneliness in nursing homes: use of robotic versus living dogs. J Am Med Dir Assoc 2008 Mar;9(3):173-177. [doi: 10.1016/j.jamda.2007.11.007] [Medline: 18294600]
15. Feil-Seifer D, Mataric MJ. Defining socially assistive robotics. Presented at: 9th International Conference on Rehabilitation Robotics, 2005. ICORR 2005; Jun 28 to Jul 1, 2005; Chicago, IL p. 465-468. [doi: 10.1109/ICORR.2005.1501143]
16. Kachouie R, Sedighadeli S, Khosla R, Chu MT. Socially assistive robots in elderly care: a mixed-method systematic literature review. Int J Human-Comp Interac 2014 May 4;30(5):369-393. [doi: 10.1080/10447318.2013.873278]
17. Matarić MJ. Socially assistive robotics: human augmentation versus automation. Sci Robot 2017 Mar 15;2(4):eaam5410. [doi: 10.1126/scirobotics.aam5410] [Medline: 33157869]
18. Hung L, Liu C, Woldum E, et al. The benefits of and barriers to using a social robot PARO in care settings: a scoping review. BMC Geriatr 2019 Aug 23;19(1):232. [doi: 10.1186/s12877-019-1244-6] [Medline: 31443636]
19. Goda A, Shimura T, Murata S, Kodama T, Nakano H, Ohsugi H. Psychological and neurophysiological effects of robot assisted activity in elderly people with cognitive decline. Gerontol Geriatr Med 2020 Jan;6:2333721420969601. [doi: 10.1177/2333721420969601] [Medline: 33241078]
20. Smedegaard CV. Why a proper investigation of novelty effects within SHRI should begin by addressing the scientific plurality of the field. Front Robot AI 2022 May;9:741478. [doi: 10.3389/frobt.2022.741478] [Medline: 35719207]
21. Tun PA, McCoy S, Wingfield A. Aging, hearing acuity, and the attentional costs of effortful listening. Psychol Aging 2009 Sep;24(3):761-766. [doi: 10.1037/a0014802] [Medline: 19739934]
22. Sharp BK. Stress as experienced by people with dementia: an interpretative phenomenological analysis. Dementia (London) 2019 May;18(4):1427-1445. [doi: 10.1177/1471301217713877] [Medline: 28599594]
23. Welland RJ, Lubinski R, Higginbotham DJ. Discourse comprehension test performance of elders with dementia of the Alzheimer type. J Speech Lang Hear Res 2002 Dec;45(6):1175-1187. [doi: 10.1044/1092-4388(2002/095)] [Medline: 12546486]
24. Ripich DN, Carpenter BD, Ziol EW. Conversational cohesion patterns in men and women with Alzheimer's disease: a longitudinal study. Int J Lang Commun Disord 2000 Jan;35(1):49-64. [doi: 10.1080/136828200247241] [Medline: 10824224]
25. Ellgring H. Facial expression as a behavioral indicator of emotional states. Pharmacopsychiatry 1989 Feb;22(Suppl 1):23-28. [doi: 10.1055/s-2007-1014620] [Medline: 2654968]
26. Ekman P, Cordaro D. What is meant by calling emotions basic. Emotion Review 2011 Oct;3(4):364-370. [doi: 10.1177/1754073911410740]
27. Lewinski P, den Uyl TM, Butler C. Automated facial coding: validation of basic emotions and FACS AUs in Facereader. J Neurosci, Psy, and Econo 2014 Dec;7(4):227-236. [doi: 10.1037/npe0000028]
28. Kulke L, Feyerabend D, Schacht A. A comparison of the affectiva iMotions facial expression analysis software with EMG for identifying facial expressions of emotion. Front Psychol 2020 Feb;11:329. [doi: 10.3389/fpsyg.2020.00329] [Medline: 32184749]
29. Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. Br J Psychiatry 1982 Jun;140:566-572. [doi: 10.1192/bjp.140.6.566] [Medline: 7104545]
30. Ekman P, Friesen WV. Measuring facial movement. J Nonverbal Behav 1976;1(1):56-75. [doi: 10.1007/BF01115465]
31. Skiendziel T, Rösch AG, Schultheiss OC. Assessing the convergent validity between the automated emotion recognition software Noldus Facereader 7 And Facial Action Coding System scoring. PLoS One 2019 Oct;14(10):e0223905. [doi: 10.1371/journal.pone.0223905] [Medline: 31622426]
32. Cohen AS, Morrison SC, Callaway DA. Computerized facial analysis for understanding constricted/blunted affect: initial feasibility, reliability, and validity data. Schizophr Res 2013 Aug;148(1-3):111-116. [doi: 10.1016/j.schres.2013.05.003] [Medline: 23726720]
33. Obayashi Y, Uehara S, Kokuwa R, Otaka Y. Quantitative evaluation of facial expression in a patient with minimally conscious state after severe traumatic brain injury. J Head Trauma Rehabil 2021 Sep;36(5):E337-E344. [doi: 10.1097/HTR.0000000000000666] [Medline: 33741824]
34. Owada K, Kojima M, Yassin W, et al. Computer-analyzed facial expression as a surrogate marker for autism spectrum social core symptoms. PLoS One 2018 Jan;13(1):e0190442. [doi: 10.1371/journal.pone.0190442] [Medline: 29293598]

35. Sugishita M, Hemmi I, Takeuchi T. Reexamination of the validity and reliability of the Japanese version of the Mini-Mental State Examination (MMSE-J). Japanese J Cognit Neurosci 2016;18(3+4):168-183. [doi: 10.11253/ninchishinkeikagaku.18.168]
36. Fujiwara Y, Suzuki H, Yasunaga M, et al. Brief screening tool for mild cognitive impairment in older Japanese: validation of the Japanese version of the Montreal Cognitive Assessment. Geriatr Gerontol Int 2010 Jul;10(3):225-232. [doi: 10.1111/j.1447-0594.2010.00585.x] [Medline: 20141536]
37. Baumgarten M, Becker R, Gauthier S. Validity and reliability of the Dementia Behavior Disturbance Scale. J Am Geriatr Soc 1990 Mar;38(3):221-226. [doi: 10.1111/j.1532-5415.1990.tb03495.x] [Medline: 2313003]
38. Mizoguchi T, Iijima S, Eto F, Ishizuka A, Orimo H. Reliability and validity of a Japanese version of the Dementia Behavior Disturbance Scale. Nihon Ronen Igakkai Zasshi 1993 Oct;30(10):835-840. [doi: 10.3143/geriatrics.30.835] [Medline: 8301854]
39. Suzuki K, Okamoto M, Suzuki M, et al. A study on the application of “the Questionnaire on Hearing 2002” as a tool for subjective validation of hearing aid fitting. Audiology Japan 2009 Jan;52(6):588-595. [doi: 10.4295/audiology.52.588]
40. Liu Y, Wang Z, Yu G. The effectiveness of facial expression recognition in detecting emotional responses to sound interventions in older adults with dementia. Front Psychol 2021;12:707809. [doi: 10.3389/fpsyg.2021.707809] [Medline: 34512466]
41. Atee M, Hoti K, Parsons R, Hughes JD. A novel pain assessment tool incorporating automated facial analysis: interrater reliability in advanced dementia. Clin Interv Aging 2018 Jul;13:1245-1258. [doi: 10.2147/CIA.S168024] [Medline: 30038491]
42. Liang A, Piroth I, Robinson H, et al. A pilot randomized trial of a companion robot for people with dementia living in the community. J Am Med Dir Assoc 2017 Oct 1;18(10):871-878. [doi: 10.1016/j.jamda.2017.05.019] [Medline: 28668664]
43. Inoue T, Nihei M, Narita T, et al. Field-based development of an information support robot for persons with dementia. Technol Disabil 2012 Dec;24(4):263-271. [doi: 10.3233/TAD-120357]
44. Sato W, Hyniewska S, Minemoto K, Yoshikawa S. Facial expressions of basic emotions in Japanese laypeople. Front Psychol 2019 Feb;10:259. [doi: 10.3389/fpsyg.2019.00259] [Medline: 30809180]
45. Koelsch S, Cheung VKM, Jentschke S, Haynes JD. Neocortical substrates of feelings evoked with music in the ACC, insula, and somatosensory cortex. Sci Rep 2021 May 12;11(1):10119. [doi: 10.1038/s41598-021-89405-y] [Medline: 33980876]
46. Olausson H, Lamarre Y, Backlund H, et al. Unmyelinated tactile afferents signal touch and project to insular cortex. Nat Neurosci 2002 Sep;5(9):900-904. [doi: 10.1038/nn896] [Medline: 12145636]
47. Dixon E, Lazar A. The role of sensory changes in everyday technology use by people with mild to moderate dementia. ASSETS 2020 Oct;2020:41. [doi: 10.1145/3373625.3417000] [Medline: 34308427]
48. Che Me R, Biamonti A, Mohd Saad MR. Conceptual design of haptic-feedback navigation device for individuals with Alzheimer's disease. Stud Health Technol Inform 2015;217:195-203. [doi: 10.3233/978-1-61499-566-1-195] [Medline: 26294473]
49. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020 Aug 8;396(10248):413-446. [doi: 10.1016/S0140-6736(20)30367-6] [Medline: 32738937]
50. Mamo SK, Nirmalasari O, Nieman CL, et al. Hearing care intervention for persons with dementia: a pilot study. Am J Geriatr Psychiatry 2017 Jan;25(1):91-101. [doi: 10.1016/j.jagp.2016.08.019] [Medline: 27890543]
51. Nguyen MF, Bonnefoy M, Adrait A, et al. Efficacy of hearing aids on the cognitive status of patients with Alzheimer’s disease and hearing loss: a multicenter controlled randomized trial. J Alzheimers Dis 2017 Apr;58(1):123-137. [doi: 10.3233/JAD-160793] [Medline: 28387664]
52. Kim S, Laschi C, Trimmer B. Soft robotics: a bioinspired evolution in robotics. Trends Biotechnol 2013 May;31(5):287-294. [doi: 10.1016/j.tibtech.2013.03.002] [Medline: 23582470]
53. Trimmer B. Soft robots. Curr Biol 2013 Aug 5;23(15):R639-R641. [doi: 10.1016/j.cub.2013.04.070] [Medline: 23928077]
54. Cabibihan JJ, Joshi D, Srinivasa YM, Chan MA, Muruganantham A. Illusory sense of human touch from a warm and soft artificial hand. IEEE Trans Neural Syst Rehabil Eng 2015 May;23(3):517-527. [doi: 10.1109/TNSRE.2014.2360533] [Medline: 25291795]
55. Kress IU, Minati L, Ferraro S, Critchley HD. Direct skin-to-skin versus indirect touch modulates neural responses to stroking versus tapping. Neuroreport 2011 Sep 14;22(13):646-651. [doi: 10.1097/WNR.0b013e328349d166] [Medline: 21817928]
56. Meng Q, Hu X, Kang J, Wu Y. On the effectiveness of facial expression recognition for evaluation of urban sound perception. Sci Total Environ 2020 Mar 25;710:135484. [doi: 10.1016/j.scitotenv.2019.135484] [Medline: 31780160]
57. Safdar S, Friedlmeier W, Matsumoto D, et al. Variations of emotional display rules within and across cultures: a comparison between Canada, USA, and Japan. Can J Behav Sci 2009;41(1):1-10. [doi: 10.1037/a0014387]
58. Masumoto K, Taishi N, Shiozaki M. Age and gender differences in relationships among emotion regulation, mood, and mental health. Gerontol Geriatr Med 2016;2:2333721416637022. [doi: 10.1177/2333721416637022] [Medline: 28138490]

Abbreviations

ADL: activities of daily living

CDR: Clinical Dementia Rating
DBDS: Dementia Behavior Disturbance Scale
***DSM-5*:** *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*
MMSE-J: Japanese version of Mini-Mental State Examination
MoCA-J: Japanese version of Montreal Cognitive Assessment

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Assessing the Quality of ChatGPT Responses to Dementia Caregivers' Questions: Qualitative Analysis

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Abstract

Background: Artificial intelligence (AI) such as ChatGPT by OpenAI holds great promise to improve the quality of life of patients with dementia and their caregivers by providing high-quality responses to their questions about typical dementia behaviors. So far, however, evidence on the quality of such ChatGPT responses is limited. A few recent publications have investigated the quality of ChatGPT responses in other health conditions. Our study is the first to assess ChatGPT using real-world questions asked by dementia caregivers themselves.

Objectives: This pilot study examines the potential of ChatGPT-3.5 to provide high-quality information that may enhance dementia care and patient-caregiver education.

Methods: Our interprofessional team used a formal rating scale (scoring range: 0-5; the higher the score, the better the quality) to evaluate ChatGPT responses to real-world questions posed by dementia caregivers. We selected 60 posts by dementia caregivers from Reddit, a popular social media platform. These posts were verified by 3 interdisciplinary dementia clinicians as representing dementia caregivers' desire for information in the areas of memory loss and confusion, aggression, and driving. Word count for posts in the memory loss and confusion category ranged from 71 to 531 (mean 218; median 188), aggression posts ranged from 58 to 602 words (mean 254; median 200), and driving posts ranged from 93 to 550 words (mean 272; median 276).

Results: ChatGPT's response quality scores ranged from 3 to 5. Of the 60 responses, 26 (43%) received 5 points, 21 (35%) received 4 points, and 13 (22%) received 3 points, suggesting high quality. ChatGPT obtained consistently high scores in synthesizing information to provide follow-up recommendations (n=58, 96%), with the lowest scores in the area of comprehensiveness (n=38, 63%).

Conclusions: ChatGPT provided high-quality responses to complex questions posted by dementia caregivers, but it did have limitations. ChatGPT was unable to anticipate future problems that a human professional might recognize and address in a clinical encounter. At other times, ChatGPT recommended a strategy that the caregiver had already explicitly tried. This pilot study indicates the potential of AI to provide high-quality information to enhance dementia care and patient-caregiver education in tandem with information provided by licensed health care professionals. Evaluating the quality of responses is necessary to ensure that caregivers can make informed decisions. ChatGPT has the potential to transform health care practice by shaping how caregivers receive health information.

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KEYWORDS

Alzheimer's disease; information technology; social media; neurology; dementia; Alzheimer disease; caregiver; ChatGPT

Introduction

Older adults have responded to the COVID-19 pandemic by increasing their internet-enabled behaviors, which include expanding their medical care to the use of web-based platforms [1]. Indeed the internet has become the most common source of information among dementia caregivers [2], and with recent advances in artificial intelligence (AI), caregivers will increasingly use AI to obtain information about health [3,4]. ChatGPT by OpenAI [5], an innovative, dialogue-based large language model that responds to complex natural language inquiries, holds great promise to improve the quality of life of patients with dementia and their caregivers by providing high-quality responses to meet their needs for information [4]. On the other hand, several studies have highlighted the limitations of generative AI models in health care, citing the lack of trust and reliability as some of the primary challenges [6,7]. Although there have been studies on the quality of ChatGPT responses to common questions about heart disease [8], cirrhosis [9], and bariatric surgery [10], to our knowledge, no studies have examined the quality of ChatGPT responses to real-world questions posed by dementia caregivers. We have addressed this gap by examining the quality of ChatGPT-3.5 responses to complex questions posted by dementia caregivers on social media.

Methods

Overview

From January to May 2023, a total of 60 social media posts representing dementia caregivers' needs for information in 3 areas (memory loss and confusion, aggression, and driving; 20 posts per area) were selected from Reddit, a popular social media platform. These topics were chosen because they are common clinical themes that are often complex and difficult to navigate with potential safety implications. Four seed posts were used in each area to discover the additional 16 posts. Posts were excluded if the poster's main question did not fall into the 3 aforementioned areas as verified by dementia clinicians or if the poster declared they were "venting" and/or no specific question was asked. Posts that were unclear on whether the person had a dementia diagnosis were excluded to avoid assessing posts that were not clearly dementia related. Word count for posts in the memory loss and confusion category ranged from 71 to 531 (mean 218; median 188), aggression posts ranged from 58 to 602 (mean 254; median 200), and driving posts ranged from 93 to 550 (mean 272; median 276). Of the 60 posts, the caregiver described the person with dementia as their parent (n=34, 56%), grandparent (n=22, 36%), uncle (n=2, 3%), or spouse (n=1, 1.6%). One post did not report relationship. The gender of the person with dementia was described as female in 57% (n=34) of posts and as male in 42% (n=25) of posts. One post did not report gender.

Three clinicians, each having more than 15 years of experience with patients with dementia and their caregivers, but from diverse disciplines (pharmacy, neuropsychology, and social work), assessed ChatGPT responses to the 60 posts using an adapted rating scale based on Hurtz et al's [11] levels of cognitive complexity pertaining to clinical decision-making (Table 1). Responses received 1 point for each of the following characteristics: *factuality*, *interpretation*, *application*, *synthesis*, and *comprehensiveness*, with a scoring range of 0-5 for each response, where higher scores indicate higher quality. Table S1 in Multimedia Appendix 1 presents examples of posts for each topic area, ChatGPT responses, and clinician ratings for each response category.

Table . Description of rating scale categories used to measure the quality of ChatGPT responses.

Characteristic	Description
Factuality	Response did not contain inaccurate or false information.
Interpretation	Response adequately interpreted the poster's main need, correctly disregarded nonpriority details, and did not recommend strategies that the poster had already tried.
Application	Response suggested tangible actions (eg, educational information, a change the caregiver could make, and communication strategies such as validation and redirection).
Synthesis	Response contained follow-up recommendations as needed (referrals to help beyond the caregiver-patient dyad, such as support groups, health care professionals, or other community resources).
Comprehensiveness	Response had strong depth, breadth; response was thorough and complete.

Although the results reported in this paper were based on raters' consensus scores, we acknowledge the potential benefits of expanding on ChatGPT responses that originally received different scores. Initially, 1 rater gave a point for comprehensiveness when the majority of suggestions they would provide clinically were conveyed in ChatGPT's response, but another rater did not give the point if they felt it was missing anything at all. It was agreed upon during consensus that if the majority of recommendations were provided, ChatGPT responses would receive full credit for *comprehensiveness*.

Ethical Considerations

This study was approved by the institutional review boards of The University of Texas at Austin (STUDY00003358) and the University of Pittsburgh (STUDY20020007).

Results

ChatGPT responses in the memory loss and confusion category ranged from 89 to 276 words (mean 170; median 165), 91 to 372 words in the aggression category (mean 221; median 234), and 65 to 359 words in the driving category (mean 175; median 130). At least 2 clinicians agreed on the ratings for all ChatGPT responses, with any disagreements resolved by discussion. ChatGPT scores ranged from 3 to 5. Overall, of the 60 responses, 26 (43%) received 5 points, 21 (35%) received 4 points, and 13 (21.7%) received 3 points (Table 2), suggesting high quality. There were no responses that scored a 0, 1, or 2; there were no fabricated responses; and no responses were considered harmful to posters. ChatGPT received the lowest ratings in *comprehensiveness*, followed by *interpretation*, and the highest ratings in *synthesis*, with only 2 out of 60 posts failing to receive the point (Table 3).

Table . Rating scale results by topic.

Score	Memory loss and confusion (n=20), n (%)	Aggression (n=20), n (%)	Driving (n=20), n (%)	Total (N=60), n (%)
3	6 (30)	3 (15)	4 (20)	13 (22)
4	7 (35)	6 (30)	8 (40)	21 (35)
5	7 (35)	11 (55)	8 (40)	26 (43)

Table . Number of ChatGPT points for each topic.

Characteristic	Memory loss and confusion (n=20), n (%)	Aggression (n=20), n (%)	Driving (n=20), n (%)	Total (N=60), n (%)
Factuality	17 (85)	19 (95)	20 (100)	56 (93)
Interpretation	17 (85)	17 (85)	13 (65)	47 (78)
Application	20 (100)	17 (85)	17 (85)	54 (90)
Synthesis	18 (90)	20 (100)	20 (100)	58 (96)
Comprehensiveness	9 (45)	15 (75)	14 (70)	38 (63)

Discussion

Principal Findings

In this study, ChatGPT responses to complex, real-world questions posted by dementia caregivers were assessed by dementia clinicians using a clinical decision-making rating scale. ChatGPT was found to produce high-quality responses, suggesting the potential of online chatbots to be a useful source of health information for dementia caregivers. The majority of responses contained factual information (n=56, 93%), with 78% (n=47) of responses correctly interpreting the poster's main need. The majority (n=54, 90%) of ChatGPT responses contained tangible actions the caregiver could apply to their situation. In only 2 instances, follow-up referrals were not suggested when reviewers felt recommendations were needed.

ChatGPT also had limitations, primarily in the areas of *interpretation* and *comprehensiveness*. In 22% (n=13) of posts, ChatGPT recommended strategies that posters had already explicitly tried, or missed subtleties that affected the accuracy of recommendations, such as failing to recognize that a person placed in a "home" meant a nursing home facility and not a traditional home. In another instance, ChatGPT recommended considering short-term hospitalization, but the poster already disclosed the person with dementia was currently hospitalized. In 37% (n=22) of posts, ChatGPT's response did not include information that dementia clinicians felt was important or was unable to anticipate future problems that a human clinician might choose to address in response to the same post. For example, if ChatGPT recommended a driving test, it did not suggest what to do if the patient in question refused to take the driving test. The data suggest that ChatGPT has strengths in providing objectively correct information (*factuality*, *application*, and *synthesis*) but is less successful in contextualizing the information it provides (*interpretation* and *comprehensiveness*).

Limitations

Study limitations included potential sample bias and small sample size. Very few posters in this study identified as a spousal caregiver (n=1, 1.6%) even though national studies report that 60% of dementia caregivers are a spouse or partner [12]. In selecting social media posts for inclusion, we included only those in which it was clear that the individual had a diagnosis of dementia. Historically, racial and ethnic minority groups are less likely to seek or receive a dementia diagnosis; thus, our sample may have been skewed for race and ethnicity. Posts were from one specific platform, which risked including caregivers with a certain level of technology access and literacy. This study did not evaluate differences in ChatGPT responses at multiple time points, so no conclusions can be made regarding reproducibility. Raters were aware that responses were generated by ChatGPT, which could have influenced stricter grading. Although our 5-point scale graded specific aspects of ChatGPT responses, it might have had a ceiling effect.

Conclusions

This study contributes to the currently small but rapidly growing literature on AI's potential to assist patient-caregiver education by providing high-quality information. Our study illustrates that ChatGPT-3.5 can provide high-quality responses to most questions in the areas of memory loss and confusion, aggression, and driving. Future research should examine family caregivers' receptiveness to using ChatGPT, as well as the usefulness of the responses from the perspective of family caregivers. Validated rating scales to assess the quality of ChatGPT responses are still in progress; the field would benefit from a reliable, validated method to evaluate the quality of AI responses to health care questions. We encourage future studies to expand on our findings and investigate how ChatGPT might be used in tandem with information provided by licensed health care professionals.

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Conflicts of Interest

TS was employed by The University of Texas at Austin during the submission of this work but has since changed positions and is employed by Otsuka America Pharmaceutical, Inc.

Multimedia Appendix 1
Scoring of responses generated from ChatGPT.
[DOCX File, 20 KB - aging_v7i1e53019_app1.docx]

References

1. Benge JF, Aguirre A, Scullin MK, et al. Internet-enabled behaviors in older adults during the pandemic: patterns of use, psychosocial impacts, and plans for continued utilization. Work Aging Retire 2024 Jan;10(1):6-13. [doi: 10.1093/workar/waac026] [Medline: 38196827]
2. Allen F, Cain R, Meyer C. Seeking relational information sources in the digital age: a study into information source preferences amongst family and friends of those with dementia. Dementia (London) 2020 Apr;19(3):766-785. [doi: 10.1177/1471301218786568] [Medline: 29999410]
3. Xie B, Tao C, Li J, Hilsabeck RC, Aguirre A. Artificial intelligence for caregivers of persons with Alzheimer's disease and related dementias: systematic literature review. JMIR Med Inform 2020 Aug 20;8(8):e18189. [doi: 10.2196/18189] [Medline: 32663146]
4. Lindeman DA, Kim KK, Gladstone C, Apesoa-Varano EC. Technology and caregiving: emerging interventions and directions for research. Gerontologist 2020 Feb 14;60(Suppl 1):S41-S49. [doi: 10.1093/geront/gnz178] [Medline: 32057082]
5. ChatGPT. OpenAI. 2023. URL: https://openai.com/chatgpt [accessed 2023-09-21]
6. Zhang P, Kamel Boulos MN. Generative AI in medicine and healthcare: promises, opportunities and challenges. Future Internet 2023 Aug;15(9):286. [doi: 10.3390/fi15090286]
7. De Angelis L, Baglivo F, Arzilli G, et al. ChatGPT and the rise of large language models: the new AI-driven infodemic threat in public health. Front Public Health 2023;11:1166120. [doi: 10.3389/fpubh.2023.1166120] [Medline: 37181697]
8. Sarraju A, Bruemmer D, Van Iterson E, Cho L, Rodriguez F, Laffin L. Appropriateness of cardiovascular disease prevention recommendations obtained from a popular online chat-based artificial intelligence model. JAMA 2023 Mar 14;329(10):842-844. [doi: 10.1001/jama.2023.1044] [Medline: 36735264]
9. Yeo YH, Samaan JS, Ng WH, et al. Assessing the performance of ChatGPT in answering questions regarding cirrhosis and hepatocellular carcinoma. Clin Mol Hepatol 2023 Jul;29(3):721-732. [doi: 10.3350/cmh.2023.0089] [Medline: 36946005]
10. Samaan JS, Yeo YH, Rajeev N, et al. Assessing the accuracy of responses by the language model ChatGPT to questions regarding bariatric surgery. Obes Surg 2023 Jun;33(6):1790-1796. [doi: 10.1007/s11695-023-06603-5] [Medline: 37106269]
11. Hurtz GM, Chinn RN, Barnhill GC, Hertz NR. Measuring clinical decision making: do key features problems measure higher level cognitive processes? Eval Health Prof 2012 Dec;35(4):396-415. [doi: 10.1177/0163278712446639] [Medline: 22605792]
12. 2023 Alzheimer's disease facts and figures. Alzheimers Dement 2023 Apr;19(4):1598-1695. [doi: 10.1002/alz.13016] [Medline: 36918389]

Abbreviations

AI: artificial intelligence

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Original Paper

Promoting Personalized Reminiscence Among Cognitively Intact Older Adults Through an AI-Driven Interactive Multimodal Photo Album: Development and Usability Study

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Abstract

Background: Reminiscence, a therapy that uses stimulating materials such as old photos and videos to stimulate long-term memory, can improve the emotional well-being and life satisfaction of older adults, including those who are cognitively intact. However, providing personalized reminiscence therapy can be challenging for caregivers and family members.

Objective: This study aimed to achieve three objectives: (1) design and develop the GoodTimes app, an interactive multimodal photo album that uses artificial intelligence (AI) to engage users in personalized conversations and storytelling about their pictures, encompassing family, friends, and special moments; (2) examine the app's functionalities in various scenarios using use-case studies and assess the app's usability and user experience through the user study; and (3) investigate the app's potential as a supplementary tool for reminiscence therapy among cognitively intact older adults, aiming to enhance their psychological well-being by facilitating the recollection of past experiences.

Methods: We used state-of-the-art AI technologies, including image recognition, natural language processing, knowledge graph, logic, and machine learning, to develop GoodTimes. First, we constructed a comprehensive knowledge graph that models the information required for effective communication, including photos, people, locations, time, and stories related to the photos. Next, we developed a voice assistant that interacts with users by leveraging the knowledge graph and machine learning techniques. Then, we created various use cases to examine the functions of the system in different scenarios. Finally, to evaluate GoodTimes' usability, we conducted a study with older adults (N=13; age range 58-84, mean 65.8 years). The study period started from January to March 2023.

Results: The use-case tests demonstrated the performance of GoodTimes in handling a variety of scenarios, highlighting its versatility and adaptability. For the user study, the feedback from our participants was highly positive, with 92% (12/13) reporting a positive experience conversing with GoodTimes. All participants mentioned that the app invoked pleasant memories and aided in recollecting loved ones, resulting in a sense of happiness for the majority (11/13, 85%). Additionally, a significant majority found GoodTimes to be helpful (11/13, 85%) and user-friendly (12/13, 92%). Most participants (9/13, 69%) expressed a desire to use the app frequently, although some (4/13, 31%) indicated a need for technical support to navigate the system effectively.

Conclusions: Our AI-based interactive photo album, GoodTimes, was able to engage users in browsing their photos and conversing about them. Preliminary evidence supports GoodTimes’ usability and benefits cognitively intact older adults. Future work is needed to explore its potential positive effects among older adults with cognitive impairment.

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KEYWORDS

aging; knowledge graph; machine learning; reminiscence; voice assistant

Introduction

As the proportion of older individuals rapidly grows, an increasing number of older individuals are becoming concerned about their physical and mental well-being [1]. Steptoe et al [2] found that a decline in health is associated with a negative psychological state. In addition, aging is closely associated with various psychosocial stress factors, such as loneliness, personal losses, and lower socioeconomic status [3]. These factors may increase the risk of developing mental health disorders. In recent years, increasing evidence suggests that psychological well-being could be a potential asset for healthy aging [4].

Reminiscence therapy stands as a profound approach, rooted in a deep understanding of cognitive and emotional processes, designed to elevate the psychological well-being of older adults. This therapy transcends the mere recall of life histories, encompassing both oral and written narratives, in a multisensory journey that engages sight, sound, taste, touch, and smell [5-7]. It extends beyond a mere collection of activities, encompassing the contemplation of photographs, immersion in music, and the sharing of narratives about pivotal life events [5-8]. The underlying success of reminiscence therapy lies in its capacity to stimulate long-term memory, playing a pivotal role in fostering overall well-being, an attribute particularly invaluable for those grappling with short-term memory challenges [9]. As individuals review and discuss evocative materials, including vintage videos, cherished photographs, or sentimental household artifacts, they embark on a path to not only retrieve memories but also enhance their self-esteem, nurture interpersonal skills, and enrich their psychosocial well-being [4,10]. This is rooted in the therapy’s ability to harness the profound impact of these sensory stimuli. Significantly, the American Psychological Association recognizes the therapeutic potential of reminiscence therapy, attesting to its ability to ameliorate mental health conditions, elevate mood, and mitigate agitation, especially among individuals coping with Alzheimer disease or dementia [5].

Research by Tam et al [4] indicates that reminiscence intervention not only produces positive effects among older adults with dementia but also benefits cognitively intact older adults. For instance, it reduces the depressive symptoms of cognitively intact older adults, significantly improves their life satisfaction, and promotes their self-esteem, psychological well-being, and happiness.

Reminiscence interventions, whether administered within health care facilities such as hospitals, assisted living communities, or nursing homes, or within the familial cocoon of private homes, are bolstered by the skillful orchestration of trained professionals and caregivers [5,7,11]. In health care settings, psychologists, social workers, and specialists in geriatric care often take the helm in conducting these interventions, drawing upon a wealth of materials that hold personal significance for older adults. The tailored application of these materials, including photos, videos, and cherished objects, becomes a key facet in rekindling memory and reminiscence. These interventions can be adjusted to individual or group settings, finely attuned to the unique needs and preferences of older adults [5,11,12]. In private residences, reminiscence interventions are executed with dedication by family members, caregivers, or volunteers [5]. They use similar materials as those found within health care facilities, including familial photographs and cherished keepsakes, as a conduit to memory stimulation and the initiation of reminiscing. Nevertheless, conducting these interventions at home can be challenging due to a shortage of human resources [11]. Caregivers and family members, juggling numerous responsibilities, may find their time and resources stretched thin, underscoring the need for innovative approaches, such as the one proposed in this study, to bridge this gap.

To overcome the challenges of limited resources and specialized training in performing reminiscence interventions, flexible and effective computer-based interventions are highly beneficial [13-15]. We designed, developed, and tested GoodTimes, a personalized interactive multimodal photo album mobile app for cognitively intact older adults. It can be used on smartphones and tablets, providing older adults with on-the-go access to their photos as well as those provided by family members. This intelligent digital photo album allows users to browse and query photos in various orders, including chronological order, by location, by event, or by specific family members. To enhance the reminiscing experience, a voice assistant (VA) interacts with the user, providing information about the picture, such as the family members in the picture, the special moment, and the location. The VA also asks questions, answers user questions, and responds to user comments, creating a setting where special memories can be remembered and enjoyed. To ensure the user’s comfort and avoid any distress, the VA will not mention anything about depression or other challenges that older adults may be facing. Older adults can use the app independently, but it is also beneficial for families, caregivers, and assisted living staff to share the mobile app with the older adult they care for. Overall, GoodTimes is a convenient and effective tool that can be used anytime, anywhere, with or without caregiver support, for cognitively intact older adults. This user study indicates that after using this app, users reported engaging in enjoyable conversations with the app.

Methods

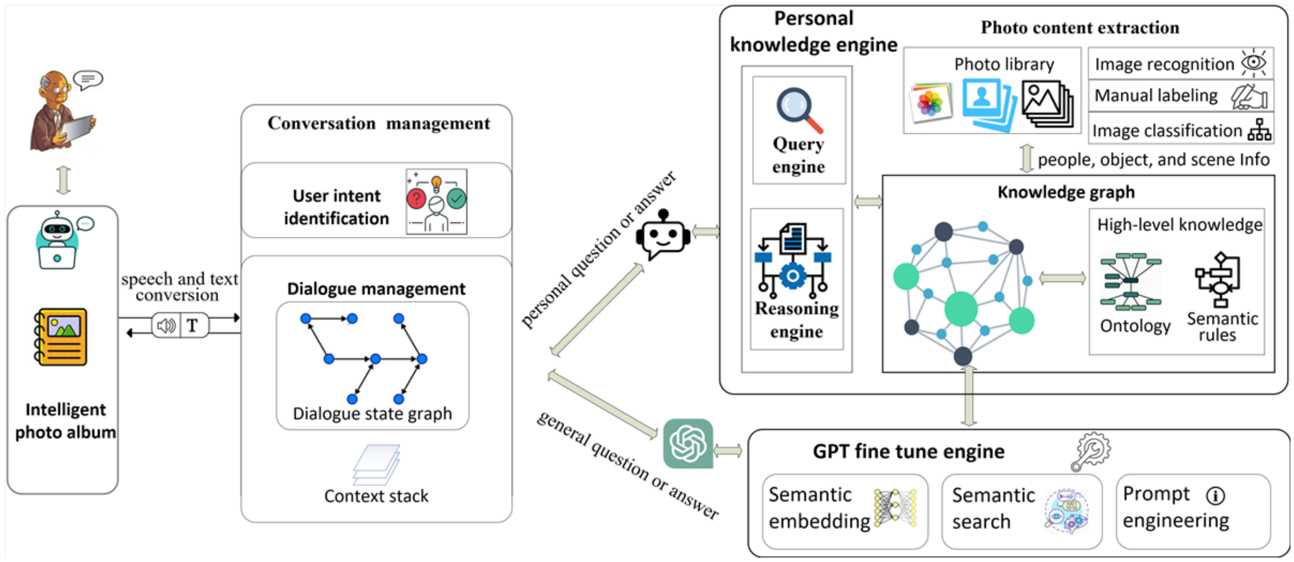
Ethics Approval

This study was reviewed and approved by the institutional review board of NDSU. The IRB Protocol number is IRB0004419.

Overview

GoodTimes is built on artificial intelligence (AI) technologies, including image recognition, natural language processing, knowledge graph, logic, and machine learning, to provide an interactive and personalized experience for older adults. The system architecture is illustrated in Figure 1. The app can be accessed through smartphones and tablets, and users can interact with it using their voice or fingers. The VA, which uses automatic speech recognition and natural language understanding technologies, converts the user's voice into a text request. The conversation management module then processes the user's request through 2 steps: user intent identification and dialogue management (DM). First, the user intent identification matches the user's text request with predefined intents and dialogue states to create an input frame. Then, the DM module executes the dialogue policy based on the dialogue state graph and updates the dialogue state.

Figure 1. System Architecture.



There are 2 types of communication requests: personal requests, which involve questions and answers related to the user's personal information, and general requests, which do not necessarily involve personal information. Examples of personal questions include "Who is in the photo?" and "What is the story behind this photo?" General requests include knowledge not necessarily related to the user's personal information, for example, a commonplace or a piece of widely known artwork. For instance, the AI may provide an answer about art collections in the Louvre Museum in Paris.

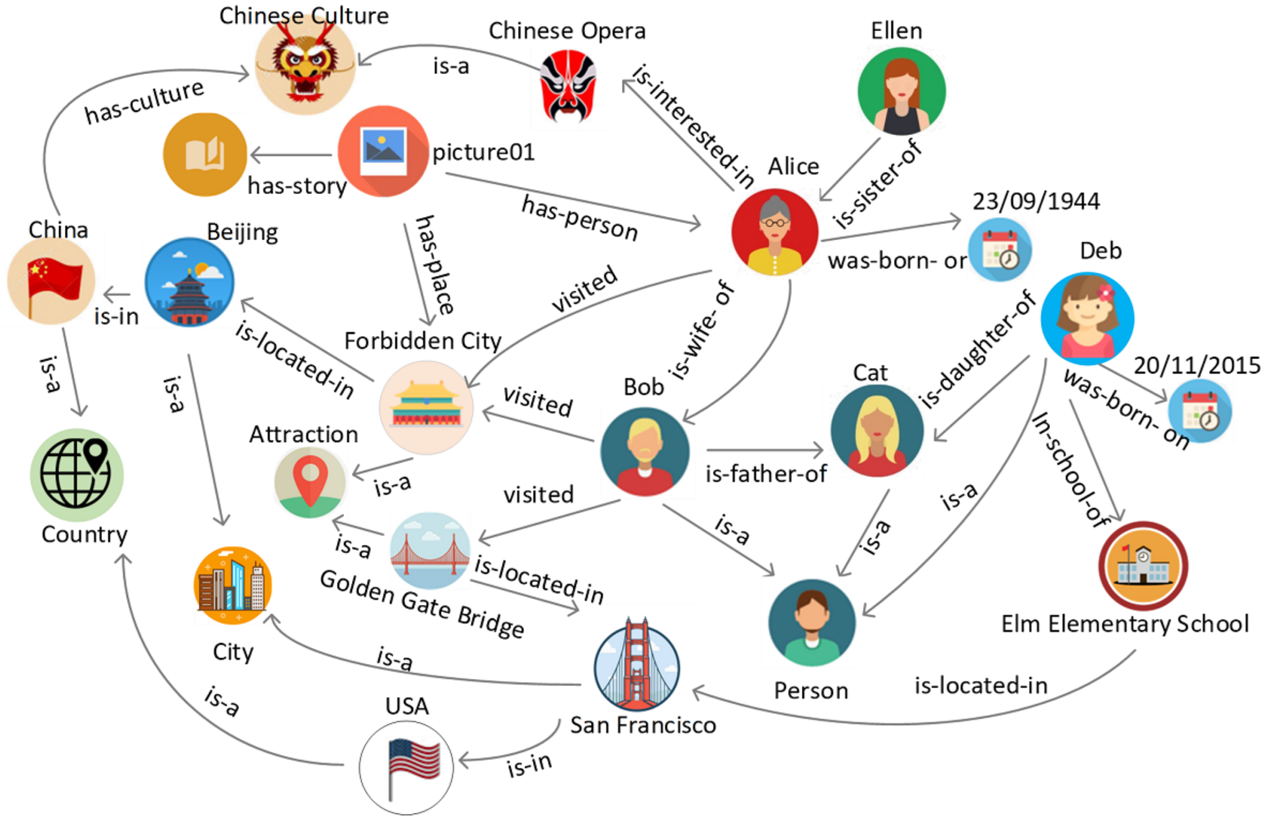
To handle general requests, we fine-tuned a Generative Pre-Trained Transformer (GPT; OpenAI) [16], a powerful neural language model. For personal requests, we have designed our own personal knowledge engine to provide tailored responses. Backend services of our personal knowledge engine are requested based on the user's intent, and these services are supported by a semantics-based query engine and reasoning engine. These engines work over a knowledge graph, which is the brain of the system. The knowledge graph contains facts, relationships, and rules about photos, people, places, time, and stories. The search and reasoning engines link the dialogue with a specific photo, user profile, and context to enable personalized services. Finally, the DM module generates responses using the speech act and content selected based on the input frame.

The system maintains a library of photos that can be uploaded by the older adult user's family members and caregivers. Metadata of a photo, such as people, animals, location, time, and special events, are also saved in the knowledge. Family members get involved in uploading, sharing, and explaining the photos, promoting collaboration, and having fun. Involving family members in the photo album can improve their relationship, help family members learn more about older adults, and facilitate reminiscence interventions for older adults, with or without caregiver support.

Constructing an Open Personal Knowledge Graph

The "brain" of the system is a comprehensive knowledge graph [17] that contains knowledge about the user and the photos. All the knowledge is represented as a graph in which data is modeled as nodes (vertices) and links (edges) between them. Nodes in our knowledge graph are normally a person, place, location, or thing, and links are how they are connected or related. Figure 2 shows an example knowledge graph about an older adult, Bob. In this graph, Bob, Alice, Cat, Person, Attraction, and Golden Gate Bridge are nodes. They are connected by many different relationships. For example, Alice is Bob's wife, and Bob is the father of Cat. Alice, Bob, and Cat are persons. Bob visited the Golden Gate Bridge, which is an attraction. This example graph shows many things and relationships about Bob. It is used by the system to explain the story of the picture, including the people inside the picture, their relationships, where they visited, etc.

Figure 2. An example of a personal knowledge graph of user Bob.



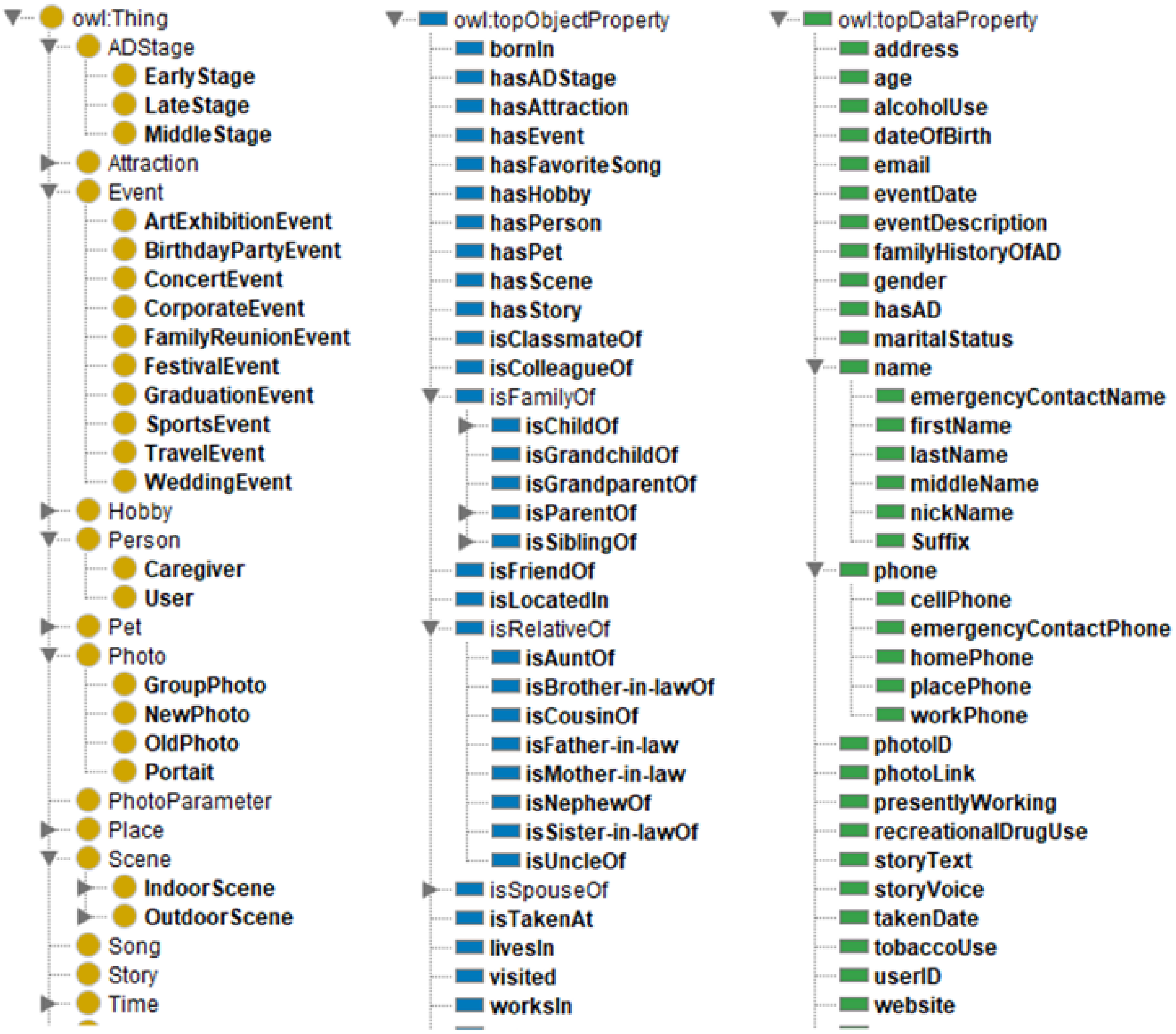
Graphs are used to model knowledge because they can encode real-world knowledge as “things” (not “strings”) and their interrelationships. This enables the system to communicate with users by analyzing what the words in a sentence actually mean rather than simply analyzing strings of characters. In addition, structuring knowledge in the form of graphs allows knowledge to evolve over time. New “things,” relationships, and external knowledge can be easily added or linked to the existing graph. In our system, we extend the core knowledge graph with external knowledge graphs, such as Wikidata [18,19], to extend our knowledge. Furthermore, reasoning and navigation can be performed over knowledge graphs.

Knowledge Graph Construction

First, we built a high-level ontology working as the schema of the knowledge graphs. Then, we create a knowledge graph by instantiating the ontology with detailed instances retrieved from uploaded photos (with metadata) and user surveys and external knowledge graphs, such as Wikidata. Using ontology would allow logical inference for retrieving implicit knowledge rather than only allowing queries requesting explicit knowledge. We proposed a “Who-What-When-Where” model as the foundation of this album ontology. “Who” represents the person in or not in the photo but related. “What” points to the story related to a photo. “When” specifies the time when the photo was taken, which can be a date, a social occasion, or a historical monument. “Where” describes the place where the photo is taken. Figure 3 shows a major part of the ontology. This ontology is instantiated with instances through photo metadata extraction, tagging extraction, image recognition, and social media extraction.

The ontology serves as schema-level knowledge used to instantiate instances or individuals, thereby creating a comprehensive knowledge graph. Instance information is collected through various means, such as automatically extracting metadata from photos or through manual input or voice-based question and answer. Through these processes, a detailed knowledge graph like the one shown in Figure 2 can be generated.

Figure 3. Part of the photo album ontology.



- owl:Thing
  - ADStage
    - EarlyStage
    - LateStage
    - MiddleStage
  - Attraction
  - Event
    - ArtExhibitionEvent
    - BirthdayPartyEvent
    - ConcertEvent
    - CorporateEvent
    - FamilyReunionEvent
    - FestivalEvent
    - GraduationEvent
    - SportsEvent
    - TravelEvent
    - WeddingEvent
  - Hobby
  - Person
    - Caregiver
    - User
  - Pet
  - Photo
    - GroupPhoto
    - NewPhoto
    - OldPhoto
    - Portait
  - PhotoParameter
  - Place
  - Scene
    - IndoorScene
    - OutdoorScene
  - Song
  - Story
  - Time

- owl:topObjectProperty
  - bornIn
  - hasADStage
  - hasAttraction
  - hasEvent
  - hasFavoriteSong
  - hasHobby
  - hasPerson
  - hasPet
  - hasScene
  - hasStory
  - isClassmateOf
  - isColleagueOf
  - isFamilyOf
    - isChildOf
    - isGrandchildOf
    - isGrandparentOf
    - isParentOf
    - isSiblingOf
  - isFriendOf
  - isLocatedIn
  - isRelativeOf
    - isAuntOf
    - isBrother-in-lawOf
    - isCousinOf
    - isFather-in-law
    - isMother-in-law
    - isNephewOf
    - isSister-in-lawOf
    - isUncleOf
  - isSpouseOf
  - isTakenAt
  - livesIn
  - visited
  - worksIn

- owl:topDataProperty
  - address
  - age
  - alcoholUse
  - dateOfBirth
  - email
  - eventDate
  - eventDescription
  - familyHistoryOfAD
  - gender
  - hasAD
  - maritalStatus
  - name
    - emergencyContactName
    - firstName
    - lastName
    - middleName
    - nickName
    - Suffix
  - phone
    - cellPhone
    - emergencyContactPhone
    - homePhone
    - placePhone
    - workPhone
  - photoID
  - photoLink
  - presentlyWorking
  - recreationalDrugUse
  - storyText
  - storyVoice
  - takenDate
  - tobaccoUse
  - userID
  - website

Semantic Rule Definition

In order to facilitate logical inference and gain new insights from the knowledge graph, we have established a set of rules and used logical reasoning over the ontology. We provide a few examples of these rules below, noting that some are specified within the ontology itself, while others are created separately using Semantic Web Rule Language [20-22]. For clarity, we present all rules using the same first-order logic [22] format.

Relatives:

If x is the husband of y, then y is the wife of x, and vice versa:

$$\forall x,y\ Husband(x,y) \Leftrightarrow Wife(y,x)$$

If x is the mother or father of y, then x is also the parent of y, and vice versa:

$$\forall x,y\ (Mother(x,y) \vee Father(x,y)) \Leftrightarrow Parent(x,y)$$

If z is the parent of both x and y, and x is not the same as y, then x and y are siblings:

$$\forall x,y,z\ (Parent(z,x) \wedge Parent(z,y) \wedge x \neq y) \Rightarrow Sibling(x,y)$$

If x is the parent of y, and y is the parent of z, then x is the grandparent of z:

$$\forall x,y,z\ (Parent(x,y) \wedge Parent(y,z)) \Rightarrow Grandparent(x,z)$$

Social Relations:

…

Time:

$$\forall x,y,z\ Time(x) \wedge Time(y) \wedge Time(z) \wedge Before(x,y) \wedge Before(y,z) \Rightarrow Before(x,z)$$

$$\forall x,y\ Time(x) \wedge Time(y) \wedge Before(x,y) \Rightarrow After(y,x)$$

…

Location:

…

Photo co-occurrence Relations:

//Person p visited location l at time t, and took a photo ph

$$\forall p,l,t,ph\ (Person(p) \wedge Location(l) \wedge Time(t) \wedge Photo(ph) \wedge PersonInPhoto(p, ph) \wedge PhotoTakenAtLocation(ph, l) \wedge PhotoTakenTime(ph, t)) \Rightarrow Visited(p, l, t, ph)$$

//Person p1 and p2 visited location l at time t together

$$\forall p1,p2,l,t,ph\ \ Person(p1) \wedge Person(p2) \wedge Visited(p1,l,t,ph) \wedge Visited(p2,l,t,ph) \Rightarrow VisitedTogether(p1,p2,l,t)$$

Dialogue Management

The photo album's VA is a machine learning-based system that enables users to engage with it through natural conversation. The VA is capable of understanding user intents from free text, answering questions, and asking questions for a specific purpose. To promote reminiscence intervention, GoodTimes guides users in recalling their memories by asking them photo-related questions and responding based on their answers. The VA facilitates personalized questions during the dialogue flow and can route natural conversations with users. A photo album with a VA can help older adults feel more connected to their past and present, providing them with a sense of familiarity and comfort, which is especially important for older adult users. Our dialogue flow management includes the following key points to facilitate engaging interactive conversation: VA-driven conversation, intent recognition, context management, personalization, and empathy incorporation.

VA-Driven Conversation

In our app, the VA initiates and guides the conversation. The conversation between the VA and the user begins with a friendly greeting or prompt, followed by a series of questions that revolve around the "Who-What-When-Where" themes but are not limited to them. These questions are designed to elicit specific information about the photos from the user and jog their memory. We use techniques including contextual prompts, confirmation prompts, and error handling to let the VA control the dialogue flow.

The VA provides prompts or suggestions to the user based on the current context of the conversation. For example, if the user talks about a specific photo, the VA can suggest related topics or questions to keep the conversation flowing smoothly. The VA uses confirmation prompts to confirm the user's intent or response to a question. This is useful when the VA needs to verify information before moving on to the next question or action. When the user provides incorrect or invalid input, the VA will provide appropriate responses, including rephrasing a question or prompt, asking for clarification, or providing an explanation of what the VA is looking for. By using these techniques, the VA can guide the conversation in a way that ensures the user provides the necessary information while keeping the conversation under control.

Intent Recognition

There are 2 ways to identify the user's intent. One is to fine-tune a GPT to let it specify the intent or use our designed intent identification model (IIM). In our implementation, we used our own IIM as the main method, as GPT is more expensive. In our IIM, the VA uses the natural language processing algorithm, part of speech tagging [23], to break down a sentence or phrase into its constituent parts, such as nouns, verbs, and adjectives. Then, it uses named entity recognition [24] to extract important information such as the user's intent, entities (relevant keywords or phrases), and context from these components. We use machine learning algorithms (eg, our previous proposed algorithm [25]) to analyze the user's input and match it with the most relevant intent. To train the model, we provide sample user inputs and assign them to specific intents. The VA then uses these examples to learn patterns in the data and improve its ability to recognize user intent over time.

Context Management

The VA also keeps track of the conversation's context, including previous statements made by the user and the VA's responses. This helps to ensure that the VA's responses are relevant to the current conversation. Context management in the VA of the interactive photo album is critical to providing a seamless and personalized user experience. VA uses a context stack to manage the context of the conversation. For example, suppose the user is looking at a photo of a trip to Paris taken in front of the Louvre Museum. In that case, the VA can use this information to provide related suggestions or ask follow-up questions, such as "Did you see Leonardo da Vinci's Mona Lisa in Louvre?" These questions are generated by prompting GPT using our knowledge graph and previous conversation history as context. The VA also needs to be able to handle changes in context, such as if the user switches to talking about a different topic. In such cases, the VA must recognize the change in context and adjust its responses accordingly. Overall, effective context management is crucial to creating a personalized and engaging experience for users interacting with the VA in the interactive photo album.

Personalization

The VA personalizes the conversation by considering multiple factors, including the user's preferences, personal profile such as name, age preferences, and conversation history. The very basic form of personalization is addressing the user by name to make the conversation more personal and engaging. In addition, the VA will use knowledge in the knowledge graph to address people or things in the photo. For example, the VA will use the information stored in the knowledge graph to refer to people or things depicted in the photos. For instance, if the user's mother is shown in the photo, the VA may address her as "your mother, Susan," as her name is known from the knowledge graph. Similarly, if the user's pet dog is in the photo, the VA may refer to the dog by its name, "Buddy." Additionally, suppose the knowledge graph indicates that the user has a close relationship with a particular person. In that case, the VA can refer to them with a personal term, such as "your dear friend, John." This personalization can enhance the user's experience and create a more natural and engaging conversation. Also, the VA uses the conversation history to tailor the conversation. For example, if the user has previously shown a preference for a particular type of photo or event, the VA can use this information to recommend similar photos or events.

Empathy Incorporation

The VA incorporates empathy into dialogue to create a more natural and engaging conversation. This involves understanding and responding to the user's emotional state, using appropriate tone and language, and showing concern for the user's needs and feelings. Older adults and people with Alzheimer disease may have difficulty understanding complex sentences or abstract concepts [26]. Our VA uses simple, clear language to make sure they understand what the VA is saying. The VA always tries to be patient and understanding when asking older adults about photos. The VA gives positive feedback when the user answers questions correctly or remembers important information. If they provide incorrect answers, the VA will gently correct them and provide additional context or information. It is also important to repeat questions if they are not answered correctly, as older adults may need more time to process and remember information. Asking related questions, such as about memories of a trip shown in the photo or the hobbies of a person in the photo, can also be helpful in stimulating memories and encouraging conversation. Overall, we try to create a comfortable and positive environment for older adults to share their memories and stories.

Conversation Using Knowledge Graph

The knowledge graph is the source of information for conversing with users and is stored in Neo4j [27-29], a graph database that the VA uses to ask and answer questions about photos. Cypher [27-29], Neo4j's query language, is used by the VA to navigate the graph and generate questions and responses. Natural language queries and answers from users are converted into Cypher queries. For example, if a user asks, "Who is in this photo?" the VA can convert this into a Cypher query that retrieves all people in the photo. To generate photo-related questions, Cypher first locates a specific photo node based on certain criteria. Relevant properties are then extracted from this node to generate a question, with the property value serving as the standard answer. Cypher can also query for a relationship linked to this node, creating a directional triple consisting of the photo node, a relationship, and another node. The knowledge graph uses directional triples (node-relationship-node) to express semantic data as subject-predicate-object. For more complex questions with multiple bindings, Cypher enables searching for nearby nodes and relationships by limiting the number of hops and specific relationships.

To keep the conversation engaging, the VA can ask follow-up questions related to the previous topic. For instance, if the previous query was about Mary, the VA might ask, "Do you remember Mary's hobby?" by using the previous query result (ie, Mary) as the subject or object of a new triple. The new question is generated based on this triple, with the other node or relationship serving as the question and the remaining element in the triple as the standard answer. In addition, GPT [30,31] is used to generate related questions and content, which will be discussed further later on.

GPT as a Complement

GPT is the state-of-the-art large language model used for various natural language processing tasks, including "question answering." One of the main advantages of GPT is its large amount of pretrained knowledge, which enables it to understand and generate natural language text with high accuracy. However, the cost of using GPT could be prohibitive for some applications, including our system. Despite this limitation, we still benefited from GPT's capabilities by using it to provide complementary functions. For example, we used GPT to help identify user intent if our IIM was not confident about its result. Moreover, GPT was used to enhance the conversational experience by generating follow-up questions and responses. For instance, if a user asks a question about a particular topic, GPT can generate related questions or statements that may help the user explore the topic further.

To ensure that the responses generated by GPT are relevant and accurate, we provided appropriate context for the conversation. One way to achieve this is by leveraging our local knowledge graph and conversation history as a source of relevant information. By converting the knowledge graph database into a triple format (subject, predicate, and object), we could index the triple file using semantic embeddings, which represent text data in a continuous vector space. This allows for efficient comparison and retrieval of similar text items while preserving semantic relationships between words and phrases. To generate embeddings, we used the pre-trained embedding model "Bidirectional Encoder Representations from Transformers" [32], resulting in a single vector embedding. These embeddings were then used in semantic search, enabling efficient and cost-effective searching. When a user query was received, we converted it into semantic embeddings and matched them with the embeddings of the knowledge graph using cosine similarity. This helped us identify the most relevant or related information sources in our knowledge graph that are related to the user's query. Once we had identified the most similar embeddings in our local knowledge base, we used them as context or query input for the GPT model. This context provides GPT with relevant information from our local knowledge base, allowing it to generate relevant responses. In summary, while GPT may not be used extensively in our system due to its cost, it can still provide valuable complementary functions that enhance the user experience and help us better understand the user's intent.

Prototype System

We have implemented GoodTimes as an Android-based app using a mobile app development framework called Flutter [33]. The app includes a VA that uses Google's Dialogflow [34] to understand natural language. When the VA identifies what the user wants, it uses Google Cloud Functions to interact with a backend server built with Spring Boot [35]. This server connects to a Neo4j database that stores information in the form of a knowledge graph. We used *LangChain* (Harrison Chase) [36], a Python package, to integrate OpenAI's GPT language models with the knowledge graph. Specifically, we used the GPT-3.5 Turbo model and defined the GPT language model using the LLMPredictor class and the input prompt format using the

PromptHelper class. The user has the option to interact with the app using either voice commands or touch input.

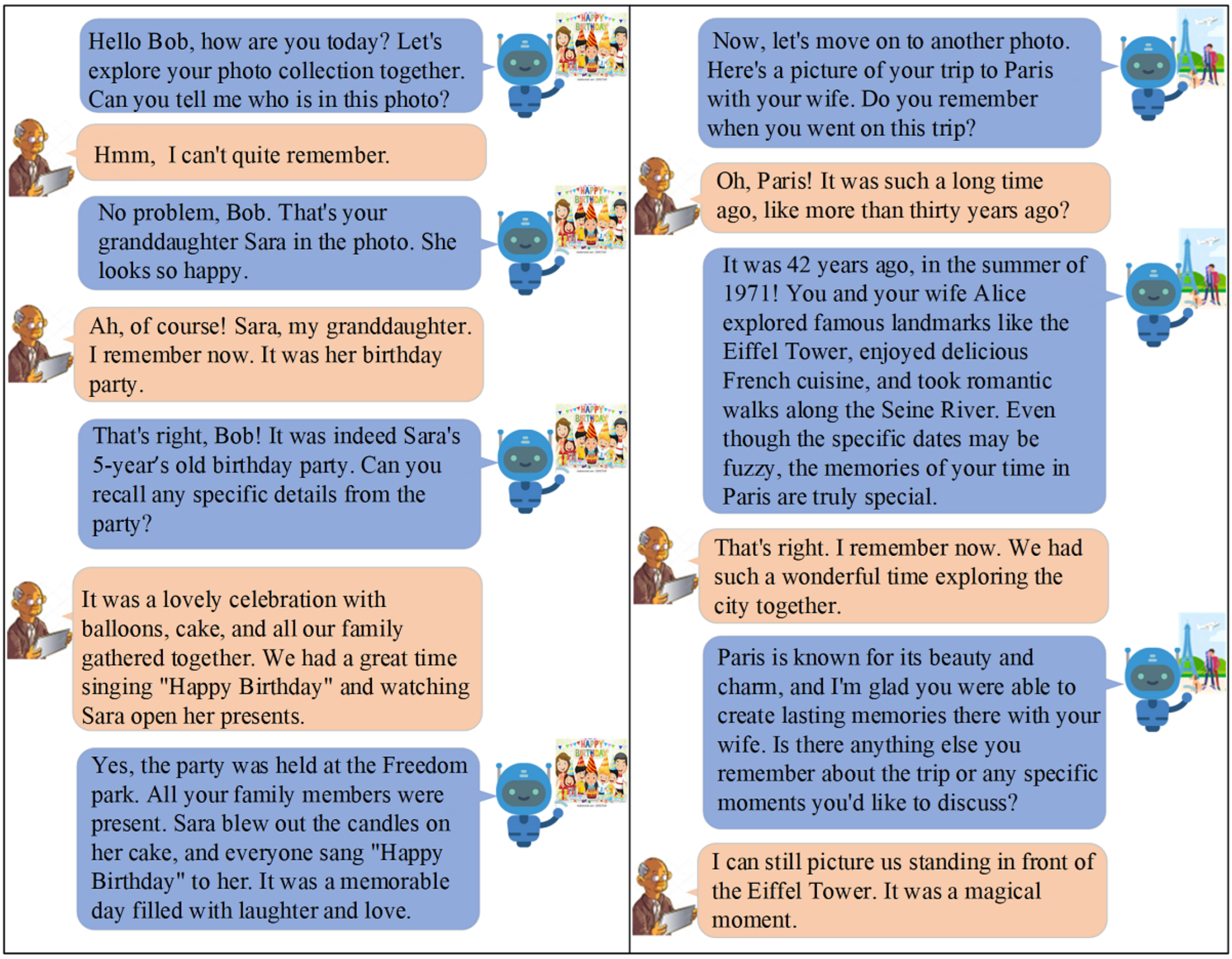
Use-Case Study

We conducted a use-case study to evaluate the functionality of our interactive photo album app before deploying it to real users. This involved identifying and analyzing specific scenarios in which the app could be used, such as browsing photos, sharing them with friends and family, and asking questions related or unrelated to the photo. By examining how the app was used in these scenarios, we were able to identify areas for improvement to make it more user-friendly. The creation of fictional users for the use cases involved careful consideration of relevant characteristics and demographics aligned with this study's objectives. Factors taken into account included age, gender, cultural background, language proficiency, cognitive and physical abilities, technological familiarity, and more. This iterative process allowed for refinement based on the specific goals and requirements of our research or design project.

Let us consider a fictional character, Bob, who is 79 years old and has memory challenges that affect his ability to remember things. As part of our use case, we presented Bob with a collection of photos encompassing significant moments such as his granddaughter Sara's birthday party, his memorable trip to Paris with his wife, and heartwarming memories with his beloved pet dog, Lucy.

Figure 4 exemplifies the interaction between Bob and the VA, showcasing their communication regarding photos in the album. This particular example demonstrates the VA's capability to engage with Bob and help him remember significant moments. In the conversation, Bob and the VA discuss a photo from Sara's birthday party. Initially, Bob is unsure of the people in the photo. The VA kindly reminds him that it is Sara in the picture, which prompts Bob's memory. The VA provides additional information about the event, refreshing Bob's memory and filling in the gaps. The VA also helps Bob recall his trip to Paris. This interaction highlights the VA's ability to serve as a helpful reminder and facilitator of memory recall. By engaging in conversations and providing contextual information, the VA helps Bob reminisce about important occasions and people in his life. This feature demonstrates the valuable role the VA plays in aiding individuals with memory challenges by providing gentle reminders and support.

Figure 4. An example case of communication between the voice assistant (VA) and a user.



Hello Bob, how are you today? Let's explore your photo collection together. Can you tell me who is in this photo?

Hmm, I can't quite remember.

No problem, Bob. That's your granddaughter Sara in the photo. She looks so happy.

Ah, of course! Sara, my granddaughter. I remember now. It was her birthday party.

That's right, Bob! It was indeed Sara's 5-year's old birthday party. Can you recall any specific details from the party?

It was a lovely celebration with balloons, cake, and all our family gathered together. We had a great time singing "Happy Birthday" and watching Sara open her presents.

Yes, the party was held at the Freedom park. All your family members were present. Sara blew out the candles on her cake, and everyone sang "Happy Birthday" to her. It was a memorable day filled with laughter and love.

Now, let's move on to another photo. Here's a picture of your trip to Paris with your wife. Do you remember when you went on this trip?

Oh, Paris! It was such a long time ago, like more than thirty years ago?

It was 42 years ago, in the summer of 1971! You and your wife Alice explored famous landmarks like the Eiffel Tower, enjoyed delicious French cuisine, and took romantic walks along the Seine River. Even though the specific dates may be fuzzy, the memories of your time in Paris are truly special.

That's right. I remember now. We had such a wonderful time exploring the city together.

Paris is known for its beauty and charm, and I'm glad you were able to create lasting memories there with your wife. Is there anything else you remember about the trip or any specific moments you'd like to discuss?

I can still picture us standing in front of the Eiffel Tower. It was a magical moment.

In addition to the previously mentioned use cases, we conducted evaluations on 12 additional scenarios for our app. The diverse range of use cases demonstrated the app's potential as a valuable tool for helping older adults cherish their memories and enhance their overall well-being.

User Study

We conducted a user study to evaluate the usability and features of the GoodTimes app. Participants were recruited through convenience sampling using various digital communication channels, such as phone calls, social media, and email. To accommodate participants' preferences, the study sessions were conducted in person at locations including their homes, local coffee shops, or parks. These sessions were conducted individually, allowing for personalized interaction and feedback.

At the beginning of each session, participants were provided with an overview of the study objectives and the app's key features. Written consent was obtained from each participant, following the approved study protocol by the institutional review board of North Dakota State University. A video demonstration was presented, and participants were given approximately 30 minutes of hands-on practice with the app. A researcher was present to address any questions during the session. Following the interaction, participants completed a set of questionnaires to provide feedback on their experience, which took approximately 15 minutes to complete. This approach enabled us to gather comprehensive insights into the app's usability and user experience.

The questionnaire consists of 2 main parts. The first part focused on participants' experiences with the app's features, including their interactions with the intelligent agent and their emotional responses to the digital photo gallery. They rated their experiences with 5 statements on a Likert scale ranging from "strongly agree" to "strongly disagree." The survey included questions developed by the research team based on previous research and expert opinions.

The second part focused on the overall usability of the app, and open-ended questions were used to identify areas for improvement. In this part, we used a subset of the System Usability Scale (SUS) to assess the app's usability. The SUS is a widely recognized and validated instrument for evaluating the usability of interactive systems. We selected 5 relevant SUS questions out of a total of 10 and included them in our survey.

In our evaluation of the app's usability and user experience, we used statistical analyses to objectively understand participant feedback. Specifically, we used a 1-sample 2-tailed *t* test, a parametric test used to determine if the sample mean significantly differs from a known or hypothesized population mean. Given that our data was interval in nature and derived from Likert-scale responses, the 1-sample *t* test was particularly apt. The hypothesized population mean in our context was the neutral point on our scale, allowing us to discern whether participants' responses significantly leaned toward agreement or disagreement.

Results

Participants

The user study included a total of 15 participants, with 13 of them completing the survey. Out of the 12 studies conducted, 11 were in-person sessions, while 1 was conducted on the web through Zoom (Zoom Video Communications) as per the participant's preference. The participant demographics are summarized in Table 1. Among the participants, 8 fell in the age range of 55-64 years, 2 were in the age range of 65-74 years, and 3 were in the age range of 75-84 years. In terms of gender distribution, there were 8 male participants and 5 female participants. Regarding education, 3 participants held a PhD degree, 4 participants had a master's degree, 3 participants had a bachelor's degree, 1 participant had a college degree, and 2 participants had completed high school.

Table 1. Demographic information of the participants.

Variable	Participants, n (%)
Age (years)	
55-64	8 (62)
65-74	2 (15)
75-84	3 (23)
≥85	0 (0)
Gender	
Man	8 (62)
Woman	5 (38)
Highest educational degree	
PhD	3 (23)
Master's	4 (31)
Bachelor's	3 (23)
College degree	1 (8)
High school	2 (15)
Less than high school	0 (0)

Evaluation Outcomes

In order to evaluate the GoodTimes app, we conducted a user study with 13 older adult participants to collect feedback on their experiences with the app and its usability. Table 2 encapsulates participants' feedback on their conversational experiences with the VA. The outcomes revealed an overwhelmingly positive response to their interaction experience with the VA. A significant majority of participants (12 out of 13) endorsed the efficacy and relevance of the VA in their conversations. Specifically, 8 participants were in strong agreement that the VA disseminated pertinent information, while the remaining 5 concurred with this sentiment. Furthermore, a compelling majority (11 out of 13) expressed strong affirmation regarding the VA's accuracy in sharing memory-related information. In terms of the VA's language clarity and appropriateness, 12 participants were either in strong agreement or in agreement, indicating near-universal approval.

The *P* value, a measure of statistical significance, provides robust statistical validation of these findings. For instance, the statement "The VA provided relevant information" had a *P* value of <.001, suggesting that the observed results are extremely unlikely to have occurred by chance alone. Similarly, the almost identical *P* values for "The VA provided correct information" and "The VA's language is appropriate and easy to understand" (both *P*<.001) underscore the authenticity and significance of these findings. A *P* value below the typical threshold of .05 indicates a significant difference from the expected neutral response. This provides strong evidence that participants genuinely felt the statements were accurate descriptors of their experiences.

Table 3 depicts a profound capacity to foster positive emotions and reminisce among the study participants. It was noteworthy that every participant either agreed or strongly agreed that the app invoked cherished memories. Moreover, a substantial majority signaled their agreement or strong agreement with the app's efficacy in reviving memories of dear ones, such as friends and family. Impressively, a significant 11 out of 13 participants articulated that the app augmented their happiness.

In Table 3, *P* values offer compelling evidence of these perceptions. For the statement "Brings a lot of Good Memories," a *P* value of <.001 indicates an exceptionally significant result, suggesting the overwhelmingly positive feedback was not a mere coincidence. The sentiment "accelerates thinking about friends and family" also received a *P* value of <.001, reinforcing the strong affirmation of the app's ability to stir memories of loved ones. Furthermore, the feedback "Makes me happy" also manifested a *P* value of <.001, emphasizing that a significant number of participants derived joy from the app's use. These *P* values, being well below the conventional .05 threshold, bolster the claim of the app's potent capability to enhance emotional health through memory stimulation.

During the usability assessment phase of our survey, we gauged the app's interface using standardized usability prompts. Table 4 depicts an overview of the results on app usability. The results elucidated a prevailing sentiment of approval among respondents concerning the app's usability. Notably, a significant desire was expressed to engage with the system regularly, as indicated by a *P* value of .005, which suggests this sentiment was not merely by chance. Additionally, the system's helpfulness and its design simplicity garnered significant endorsement, as evidenced by the compellingly low *P* values of <.001, respectively. This denotes a genuine appreciation for the system's functionality and design among users.

Table 2. Participants' feedback on their conversational experience with the voice assistant (VA).

Statement	Strongly agree, n	Agree, n	Neutral, n	Disagree, n	Strongly disagree, n	Mean (SD)	2-tailed *t* (*df*)	*P* value
Conversation was pleasant	8	3	1	1	0	4.3846 (0.9608)	5.1959 (12)	<.001
Conversation was fluent and natural	4	7	1	1	0	4.0769 (0.8623)	4.5029 (12)	<.001
The VA provided relevant information	8	5	0	0	0	4.6154 (0.5064)	11.5016 (12)	<.001
The VA provided correct information	11	2	0	0	0	4.8462 (0.3755)	17.7272 (12)	<.001
The VA's language is appropriate and easy to understand	11	2	0	0	0	4.8462 (0.3755)	17.7272 (12)	<.001

Table 3. Participants' feedback on their emotional response to app usage.

Statement	Strongly agree, n	Agree, n	Neutral, n	Disagree, n	Strongly disagree, n	Mean (SD)	2-tailed *t* (*df*)	*P* value
Brings a lot of Good Memories	10	3	0	0	0	4.7690 (0.4385)	14.5455 (12)	<.001
Accelerates thinking about friends and family	10	2	1	0	0	4.6920 (0.6304)	9.6773 (12)	<.001
Makes me happy	5	6	1	1	0	4.1538 (0.8987)	4.6290 (12)	<.001

Table 4. Overview of results on the app's usability.

Statement	Strongly agree, n	Agree, n	Neutral, n	Disagree, n	Strongly disagree, n	Mean (SD)	2-tailed *t* (*df*)	*P* value
I would like to use this system frequently	0	9	3	1	0	3.6154 (0.6504)	3.4115 (12)	.005
I think the system is very helpful	4	7	1	1	0	4.0769 (0.8623)	4.5029 (12)	<.001
I think the system design is very simple and easy to use	4	8	1	0	0	4.2308 (0.5991)	7.4073 (12)	<.001
I feel very confident about using the system	4	4	3	2	0	3.7692 (1.0919)	2.5400 (12)	.03
I think that I would need the support of a technical person to be able to use this system	1	3	2	6	1	2.7692 (1.1658)	0.7138 (12)	.49

Another commendable finding was the respondents' confidence in using the app without external technical assistance. This was statistically supported by a *P* value of .03, reflecting a valid level of user self-assurance. However, the topic of needing technical support to operate the system did receive varied responses. Interestingly, the statement "I think that I would need the support of a technical person to be able to use this system" had a *P* value of .49, indicating that this sentiment was not statistically significant and could likely be attributed to random variability.

Discussion

Principal Results

We designed, developed, and tested an interactive photo album app called GoodTimes that uses AI technology to engage in conversations with users and tell stories about pictures, including family, friends, and special moments. The app was developed using state-of-the-art AI technologies, including image recognition, natural language processing, knowledge graph, logic, and machine learning. We constructed a comprehensive knowledge graph that models the information required for effective communication, including photos, people, locations, time, and stories related to the photos. We then developed a VA that interacts with users by leveraging the knowledge graph and machine learning techniques.

In order to evaluate the GoodTimes app, we conducted a use-case study to verify its various functions in different real-life scenarios. Additionally, we conducted a user study with 13 older adult participants to collect feedback on their experiences with the app and its usability. We found that the feedback from our participants was highly positive, with 92% (12/13) reporting a positive experience conversing with GoodTimes. All participants mentioned that the app invoked pleasant memories and aided in recollecting loved ones, resulting in a sense of happiness for the majority (11/13, 85%). Additionally, a significant majority found GoodTimes to be helpful (11/13, 85%) and user-friendly (12/13, 92%). Most participants (9/13, 69%) expressed a desire to use the app frequently, although some (4/13, 31%) indicated a need for technical support to navigate the system effectively.

Limitations

Our research has some limitations that we aim to address in future work. First, we plan to increase family members' active involvement in the process of using the app by making it easy and enjoyable for them to upload pictures and record their voices. Additionally, the findings may not be generalizable to both cognitively impaired and cognitively intact older adults due to the small convenience sample used in this study.

To better understand the potential of our app as a supplementary tool for reminiscence therapy, we plan to deploy the app to their homes or assisted living environments, allowing them to use it for an extended period of time. By doing so, we can observe the app's impact over time and gain valuable insights into how it can provide emotional and mental stimulation to improve their quality of life.

Comparison With Previous Work

Previous research has shown that reminiscence therapy, which involves the use of photos and videos to stimulate long-term memory, can improve the emotional well-being of older adults [5,37]. However, providing personalized reminiscence therapy can be challenging for caregivers and family members.

Various studies have investigated technology as a means of supporting reminiscence therapy for older adults. For instance, Chen et al [38] developed an app that used a lifelogging device to capture photos and videos and presented them in a timeline format, resulting in improved quality of life and cognitive function for participants. However, this approach is limited to recent events and can be inconvenient for users to wear many devices. Additionally, the mashup process requires significant caregiver involvement.

Another study by Tsao et al [39] developed an augmented reality app that allows users to interact with virtual versions of their memories. The app was found to increase participants' sense of control and satisfaction with their lives. The study by Schoneveld [40] developed an AR photo album prototype to facilitate communication between a person with dementia and their caregiver, family member, or friend, aiming to evoke more details and elements of memory and contribute to additional discussion material. The prototype has shown positive results in low- and high-fidelity prototype testing with experts and proxy testers. Another study [41] created digital reminiscence and music therapies using prompts such as photos, videos, and music. The study focused on the rural population, which has reduced access to dementia care services.

Compared with these studies, our GoodTimes app uses AI technology to engage in conversations with users and tell stories about pictures, including friends, family members, and special moments. This personalized approach aims to provide a more engaging and emotionally supportive experience for older adults, requiring minimum efforts from caregivers. This study's results showed that the app was well-received by participants, who found it helpful, easy to use, and enjoyable. In conclusion, while previous research has shown the benefits of reminiscence therapy for older adults, our GoodTimes app adds a new dimension to the field by using AI technology to provide a personalized and engaging reminiscence therapy experience.

Conclusions

In conclusion, this study demonstrated the potential of the GoodTimes app to provide personalized reminiscence therapy to older adults, improving their emotional well-being. The use-case study and user study results showed that the app was well-received by participants and provided a helpful, easy-to-use, and enjoyable experience. Although this study has some limitations, such as the need for a larger sample size and a longer evaluation period, we plan to address these limitations in future work. Our GoodTimes app adds a new dimension to the field of reminiscence therapy by using AI technology to provide a personalized and engaging experience. Overall, we believe that the GoodTimes app has the potential to positively impact the lives of older adults and their families.

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Conflicts of Interest

None declared.

References

1. Tardif S, Simard M. Cognitive stimulation programs in healthy elderly: a review. Int J Alzheimers Dis 2011;2011:378934. [doi: 10.4061/2011/378934] [Medline: 21876829]
2. Steptoe A, Deaton A, Stone AA. Subjective wellbeing, health, and ageing. Lancet 2015;385(9968):640-648 [FREE Full text] [doi: 10.1016/S0140-6736(13)61489-0] [Medline: 25468152]
3. Adams KB, Moon H. Subthreshold depression: characteristics and risk factors among vulnerable elders. Aging Ment Health 2009;13(5):682-692 [FREE Full text] [doi: 10.1080/13607860902774501] [Medline: 19882406]
4. Tam W, Poon SN, Mahendran R, Kua EH, Wu XV. The effectiveness of reminiscence-based intervention on improving psychological well-being in cognitively intact older adults: a systematic review and meta-analysis. Int J Nurs Stud 2021;114:103847 [FREE Full text] [doi: 10.1016/j.ijnurstu.2020.103847] [Medline: 33352435]
5. Woods B, O'Philbin L, Farrell EM, Spector AE, Orrell M. Reminiscence therapy for dementia. Cochrane Database Syst Rev 2018;3(3):CD001120 [FREE Full text] [doi: 10.1002/14651858.CD001120.pub3] [Medline: 29493789]
6. Redulla R. Reminiscence therapy for dementia. Issues Ment Health Nurs 2020;41(3):265-266. [doi: 10.1080/01612840.2019.1654572] [Medline: 31714840]
7. Cuevas PEG, Davidson PM, Mejilla JL, Rodney TW. Reminiscence therapy for older adults with alzheimer's disease: a literature review. Int J Ment Health Nurs 2020;29(3):364-371 [FREE Full text] [doi: 10.1111/inm.12692] [Medline: 31984570]
8. Subramaniam P, Woods B. Digital life storybooks for people with dementia living in care homes: an evaluation. Clin Interv Aging 2016;11:1263-1276 [FREE Full text] [doi: 10.2147/CIA.S111097] [Medline: 27698556]
9. Melendez JC, Torres M, Redondo R, Mayordomo T, Sales A. Effectiveness of follow-up reminiscence therapy on autobiographical memory in pathological ageing. Int J Psychol 2017;52(4):283-290 [FREE Full text] [doi: 10.1002/ijop.12217] [Medline: 26377350]
10. Xu L, Li S, Yan R, Ni Y, Wang Y, Li Y. Effects of reminiscence therapy on psychological outcome among older adults without obvious cognitive impairment: a systematic review and meta-analysis. Front Psychiatry 2023;14:1139700 [FREE Full text] [doi: 10.3389/fpsyt.2023.1139700] [Medline: 37065888]
11. Woods RT, Orrell M, Bruce E, Edwards RT, Hoare Z, Hounsome B, et al. REMCARE: pragmatic multi-centre randomised trial of reminiscence groups for people with dementia and their family carers: effectiveness and economic analysis. PLoS One 2016;11(4):e0152843 [FREE Full text] [doi: 10.1371/journal.pone.0152843] [Medline: 27093052]
12. Elias SMS, Neville C, Scott T. The effectiveness of group reminiscence therapy for loneliness, anxiety and depression in older adults in long-term care: a systematic review. Geriatr Nurs 2015;36(5):372-380 [FREE Full text] [doi: 10.1016/j.gerinurse.2015.05.004] [Medline: 26099638]

13. Astell AJ, Smith SK, Potter S, Preston-Jones E. Computer interactive reminiscence and conversation aid groups-delivering cognitive stimulation with technology. Alzheimers Dement (N Y) 2018;4:481-487 [FREE Full text] [doi: 10.1016/j.trci.2018.08.003] [Medline: 30258977]
14. Samuelsson C, Ekström A. Digital communication support in interaction involving people with dementia. Logoped Phoniatr Vocol 2019;44(1):41-50 [FREE Full text] [doi: 10.1080/14015439.2019.1554856] [Medline: 30739510]
15. Lazar A, Thompson H, Demiris G. A systematic review of the use of technology for reminiscence therapy. Health Educ Behav 2014;41(1 Suppl):51S-61S [FREE Full text] [doi: 10.1177/1090198114537067] [Medline: 25274711]
16. Liu J, Shen D, Zhang Y, Dolan B, Carin L, Chen W. What makes good in-context examples for GPT-3? ArXiv. Preprint posted online on January 17 2021 2021. [doi: 10.18653/v1/2022.deelio-1.10]
17. Song Y, Li A, Tu H, Chen K, Li C. A novel encoder-decoder knowledge graph completion model for robot brain. Front Neurorobot 2021;15:674428 [FREE Full text] [doi: 10.3389/fnbot.2021.674428] [Medline: 34045950]
18. Fensel D, Şimşek U, Angele K, Huaman E, Kärle E, Panasiuk O, et al, editors. Introduction: what is a knowledge graph? In: Knowledge Graphs: Methodology, Tools and Selected Use Cases. Cham: Springer International Publishing; 2020:1-10.
19. Malyshev S, Krötzsch M, González L, Gonsior J, Bielefeldt A. Getting the most out of wikidata: semantic technology usage in Wikipedia's knowledge graph. In: The Semantic Web – ISWC 2018. Cham: Springer International Publishing; 2018 Presented at: 17th International Semantic Web Conference; October 8-12, 2018; Monterey, CA, USA p. 376-394 URL: https://link.springer.com/chapter/10.1007/978-3-030-00668-6_23#citeas [doi: 10.1007/978-3-030-00668-6_23]
20. Pauwels P, Zhang S, Lee YC. Semantic web technologies in AEC industry: a literature overview. Autom Constr 2017;73:145-165 [FREE Full text] [doi: 10.1016/j.autcon.2016.10.003]
21. Yarushkina NG, Moshkin VS, Filippov AA. Development of a knowledge base based on context analysis of external information resources. 2018 Presented at: IV International Conference on "Information Technology and Nanotechnology" (ITNT-2018); April 24-27, 2018; Samara, 151 Molodogvardeyskaya St URL: https://api.semanticscholar.org/CorpusID:53364866 [doi: 10.18287/1613-0073-2018-2212-328-337]
22. de Farias TM, Roxin A, Nicolle C. SWRL rule-selection methodology for ontology interoperability. Data Knowl Eng 2016;105:53-72 [FREE Full text] [doi: 10.1016/j.datak.2015.09.001]
23. Chiche A, Yitagesu B. Part of speech tagging: a systematic review of deep learning and machine learning approaches. J Big Data 2022;9(1):10 [FREE Full text] [doi: 10.1186/s40537-022-00561-y]
24. Li J, Sun A, Han J, Li C. A survey on deep learning for named entity recognition. IEEE Trans Knowl Data Eng 2022;34(1):50-70 [FREE Full text] [doi: 10.1109/tkde.2020.2981314]
25. Wang X, Liang T, Li J, Roy S, Pandey V, Du Y, et al. Artificial intelligence-empowered chatbot for effective COVID-19 information delivery to older adults. Int J E-Health Med Commun 2021;12(6):1-18 [FREE Full text] [doi: 10.4018/IJEHMC.293285]
26. Banovic S, Zunic LJ, Sinanovic O. Communication difficulties as a result of dementia. Mater Sociomed 2018;30(3):221-224 [FREE Full text] [doi: 10.5455/msm.2018.30.221-224] [Medline: 30515063]
27. Vukotic A, Watt N, Abedrabbo T, Fox D, Partner J. Neo4j in Action. Shelter Island: Manning; 2015.
28. Lal M. Neo4j Graph Data Modeling: Design Efficient and Flexible Databases by Optimizing the Power of Neo4j. Birmingham, UK: Packt Publishing; 2015.
29. Needham M, Hodler AE. Graph Algorithms: Practical Examples in Apache Spark and Neo4j. Beijing: O'Reilly Media; 2019.
30. Lee P, Bubeck S, Petro J. Benefits, limits, and risks of GPT-4 as an AI chatbot for medicine. N Engl J Med 2023;388(13):1233-1239 [FREE Full text] [doi: 10.1056/NEJMsr2214184] [Medline: 36988602]
31. Nori H, King N, McKinney SM, Carignan D, Horvitz E. Capabilities of GPT-4 on medical challenge problems. ArXiv. Preprint posted online on April 12 2023 2023.
32. Alsentzer E, Murphy JR, Boag W, Weng WH, Jin D, Naumann T, et al. Publicly available clinical BERT embeddings. ArXiv. Preprint posted online on June 20 2019 2019. [doi: 10.1090/mbk/121/79]
33. Singh A, Bhadani R. Mobile Deep Learning with TensorFlow Lite, ML Kit and Flutter: Build Scalable Real-world Projects to Implement End-to-end Neural Networks on Android and IOS. Birmingham: Packt Publishing; 2020.
34. Patil J, Shewale A, Bhushan E, Fernandes A, Khartadkar R. A voice based assistant using Google dialogflow and machine learning. Int J Sci Res Sci Technol 2021;8(3):6-17 [FREE Full text] [doi: 10.32628/ijsrst218311]
35. Walls C. Simon and Schuster. In: Spring Boot in Action. Shelter Island, NY: Manning Publications; 2015.
36. Chase H. LangChain. 2022. URL: https://github.com/langchain-ai/langchain [accessed 2023-12-19]
37. Piper AM, Weibel N, Hollan JD. Designing audio-enhanced paper photos for older adult emotional wellbeing in communication therapy. Int J Hum Comput Stud 2014;72(8-9):629-639 [FREE Full text] [doi: 10.1016/j.ijhcs.2014.01.002]
38. Chen YW, Chen Y, Peng Y, Leu WJ. Reminiscence processes using mashups dedicated to the design of lifelogging system. Adv Res 2015;3(4):382-390 [FREE Full text] [doi: 10.9734/air/2015/11588]
39. Tsao YC, Shu CC, Lan TS. Development of a reminiscence therapy system for the elderly using the integration of virtual reality and augmented reality. Sustainability 2019;11(17):4792 [FREE Full text] [doi: 10.3390/su11174792]
40. Schoneveld J. Augmented reality photo album for people with dementia. University of Twente Student Theses. 2020. URL: http://essay.utwente.nl/83143/ [accessed 2023-12-19]

41. Imtiaz D, Khan A, Seelye A. A mobile multimedia reminiscence therapy application to reduce behavioral and psychological symptoms in persons with alzheimer's. J Healthc Eng 2018;2018:1536316 [FREE Full text] [doi: 10.1155/2018/1536316] [Medline: 29755713]

Abbreviations

AI: artificial intelligence
DM: dialogue management
GPT: Generative Pre-trained Transformer
IIM: intent identification model
SUS: System Usability Scale
VA: voice assistant

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Original Paper

Detection of Mild Cognitive Impairment From Non-Semantic, Acoustic Voice Features: The Framingham Heart Study

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Abstract

Background: With the aging global population and the rising burden of Alzheimer disease and related dementias (ADRDs), there is a growing focus on identifying mild cognitive impairment (MCI) to enable timely interventions that could potentially slow down the onset of clinical dementia. The production of speech by an individual is a cognitively complex task that engages various cognitive domains. The ease of audio data collection highlights the potential cost-effectiveness and noninvasive nature of using human speech as a tool for cognitive assessment.

Objective: This study aimed to construct a machine learning pipeline that incorporates speaker diarization, feature extraction, feature selection, and classification to identify a set of acoustic features derived from voice recordings that exhibit strong MCI detection capability.

Methods: The study included 100 MCI cases and 100 cognitively normal controls matched for age, sex, and education from the Framingham Heart Study. Participants' spoken responses on neuropsychological tests were recorded, and the recorded audio was processed to identify segments of each participant's voice from recordings that included voices of both testers and participants. A comprehensive set of 6385 acoustic features was then extracted from these voice segments using OpenSMILE and Praat software. Subsequently, a random forest model was constructed to classify cognitive status using the features that exhibited significant differences between the MCI and cognitively normal groups. The MCI detection performance of various audio lengths was further examined.

Results: An optimal subset of 29 features was identified that resulted in an area under the receiver operating characteristic curve of 0.87, with a 95% CI of 0.81-0.94. The most important acoustic feature for MCI classification was the number of filled pauses (importance score=0.09, *P*=3.10E–08). There was no substantial difference in the performance of the model trained on the acoustic features derived from different lengths of voice recordings.

Conclusions: This study showcases the potential of monitoring changes to nonsemantic and acoustic features of speech as a way of early ADRD detection and motivates future opportunities for using human speech as a measure of brain health.

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KEYWORDS

early detection; Alzheimer disease and related dementias; mild cognitive impairment; digital voice; machine learning; smartphone; mobile phone

Introduction

Alzheimer disease and related dementias (ADRDs) constitute a significant public health issue, impacting an estimated 6.2 million individuals in the United States, with projections indicating the number of cases to grow to 12.7 million and 150 million globally by 2050 [1,2]. Emerging evidence suggests that the functional, psychological, pathological, and physiological alterations associated with ADRD may manifest many years prior to the clinical onset of cognitive dysfunction [3-6]. This increasing awareness has sparked interest in early detection and monitoring of ADRD, with the goal of implementing timely preventive and therapeutic strategies to slow the progression of the disease. As effective as they are in identifying individuals at high risk of ADRD, conventional diagnostic methods, such as cerebrospinal fluid biomarkers and neuroimaging, face accessibility limitations primarily due to their high costs [7] and high subject burden. This limits their applicability to other groups, particularly populations in lower-resourced settings, in effectively monitoring the dynamic progression of the disease. Therefore, there is an urgent need for an effective detection method that has a much broader and more inclusive reach for the early detection of ADRD.

Producing speech is a cognitively complex task that engages various cognitive domains [8], and the ease of audio data collection underscores the potential cost-effectiveness and noninvasiveness that using human speech-based features may offer to facilitate early identification of cognitive impairment, including mild cognitive impairment (MCI). Studies have indicated that language deficits may manifest in the prodromal stages of cognitive impairment, often years before the clinical diagnosis of dementia [9,10]. Speech, however, is far richer in characterizing cognition than just language. Audio recordings can yield a variety of attributes, encompassing both acoustic and linguistic features. Acoustic features, given their language independence, have the potential for broader global applicability. Previous studies from the Framingham Heart Study (FHS) demonstrated significant associations between acoustic features extracted from voice recordings and 2 primary clinical indices of neurodegeneration: neuropsychological (NP) test performance [11] and brain volumes [12]. Moreover, acoustic-based models can be readily deployed on devices such as hand-held recorders, smartphones, tablets, and other internet-connected mobile devices, enabling widespread usage. These characteristics enable voice as a potential digital biomarker for early cognitive impairment monitoring and detection of MCI.

While the use of speech recordings as a novel measure of cognition is still in the early stages of validation, most of the previous studies have relied on a limited set of acoustic features [13-16], potentially constraining the enhancement of early detection capabilities for ADRD. For instance, some studies have concentrated on Mel-frequency cepstral coefficients [13,15], while others have explored a narrow range of temporal and spectral features (such as duration of utterance, number and length of pauses, and F0) [14,16]. There has been a notable absence of exploration into diverse categories of features, including energy, spectral, cepstral, and voicing-related features. Although deep learning has been used to investigate these features, its complexity often compromises interpretability. Therefore, there is a need for research to use more interpretable methods for exploring a richer set of acoustic features for the detection of MCI. Furthermore, the question of whether extensive voice recordings are necessary to achieve better cognitive assessment performance has not been thoroughly investigated. These issues have significant implications for the widespread, real-world application of speech as a digital data modality for cognitive assessment.

Therefore, the aims of this study were to explore the utility of acoustic features derived from human speech for the identification of MCI and to assess the impact of the duration of voice recordings on the predictive performance of MCI identification.

Methods

Study Population

Initiated in 1948, FHS is a community-based, longitudinal cohort study. This study initially included 605 FHS participants with at least one audio recording who were aged 60 years or older at the time of the NP exam visit where the recordings were collected. Then, a case-control data set was created consisting of 100 MCI cases and 100 cognitively normal (CN) controls and matched on age, sex, and education to control for potential confounders and ensure the reliability of the study results. MCI cases were identified through a clinical review conducted by a panel including at least one neurologist and one neuropsychologist based on criteria from the *DSM-IV* (*Diagnostic and Statistical Manual of Mental Disorders* [Fourth Edition]) and the National Institute of Neurological Disorders and Stroke–Alzheimer Disease and Related Disorders [17]. The details of the cognitive status determination can be found in previous studies [15]. The participants were stratified into 6 age groups, with each group spanning a 5-year interval from 60 to 89 years (eg, 60-64, 65-69, 70-74, 75-79, 80-84, and 85-89 years). Additionally, there was a separate category for individuals aged 90 years and older. Study participants were also stratified into 4 education groups: high school nongraduates, high school graduates, individuals with some college education, and college graduates. Subsequently, controls were selected from the data set who matched the cases based on age, sex, and education. The earliest collected voice recording from each participant was included in this analysis.

Ethical Considerations

The procedures and protocols of the FHS were approved by the institutional review board of the Boston University Medical Campus (FHS is H-32132), and written informed consent was obtained from all participants.

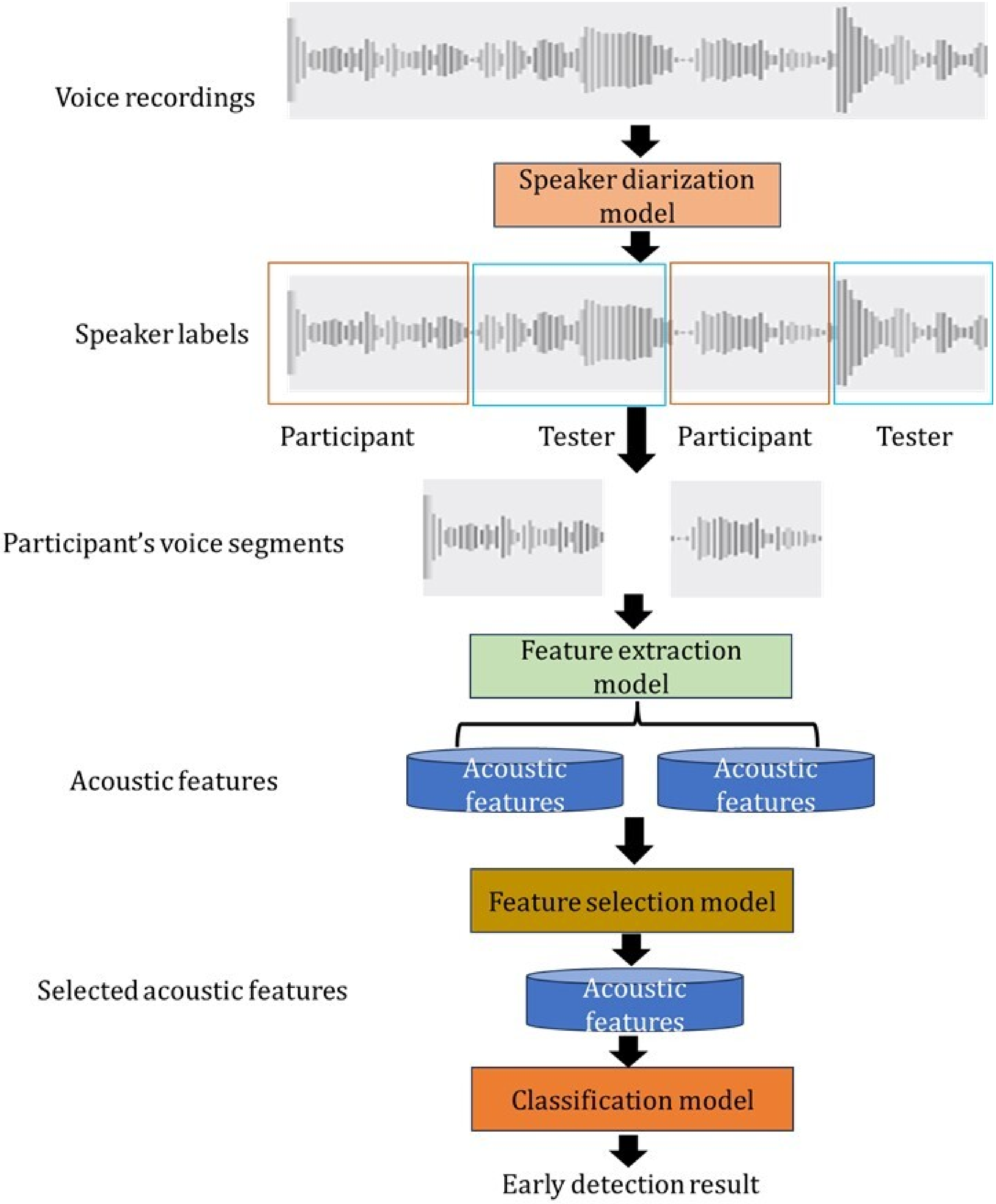
Voice Recordings

FHS has been monitoring cognitive status since 1976, which includes comprehensive NP testing [18]. Since 2005, FHS has digitally recorded all responses to NP test questions that required a voice response, which encompasses the spoken interactions between the tester and the participant. These recordings have been stored in the .wav format and downsampled to 16 kHz. This study included digital voice recordings between September 2005 and March 2020.

Machine Learning Pipeline

This study developed a machine learning pipeline that incorporated speaker diarization, feature extraction, feature selection, and classification to identify a set of acoustic features that exhibited strong MCI detection capability (Figure 1).

Figure 1. The machine learning pipeline for MCI detection from voice recordings.



Speaker Diarization

To accurately analyze the speech of the participants, it is crucial to distinguish between the participant and the tester and to determine “who spoke when” [19]. This process is known as speaker diarization, which involves segmenting the voice recordings based on the speaker's identity. In this study, the open-source speaker diarization package, pyannote, was used to automatically segment each recording into hypothesized utterances from the tester and the participant [20,21]. Since the NP administration testing process in FHS is standardized, the segmented dominant speaker, based on the duration of the voice recording, was labeled as the participant's speech in this study. These participant segments were combined for subsequent analysis.

Feature Extraction

To extract relevant information from the voice recordings, OpenSMILE software (version 2.1.3; audEERING) [22] and Praat software (University of Amsterdam) [23] were used, which facilitated the extraction of a comprehensive set of 6376 features [24] and 9 features, respectively. The OpenSMILE feature set used in this study consisted of 65 low-level descriptors (LLDs). These descriptors included energy, spectral, cepstral, and voicing-related features. Each recording was divided into segments of 20 milliseconds using a sliding window approach with a shifting size of 10 milliseconds [25,26]. The LLDs were extracted from each segment. By allowing for overlaps between successive windows, we were able to facilitate the conservation of information continuity and enable a more precise capture of the signal's dynamics [25,26]. First-order delta regression coefficients were calculated for all LLDs. A comprehensive set of functionals, such as mean, maximum, minimum, SD of segment length, and linear regression slope, were applied to extract statistical characteristics from the LLDs and deltas over the full recordings [27-29]. This process provided a concise representation of the acoustic features across the entire recording. As a result of this summarization process, each recording was represented by a set of 6376 features from OpenSMILE, capturing essential information about the acoustic properties of the audio data. The details of the feature generation process can be found in a prior study [30]. The Praat script was used to generate 9 features on syllable nuclei and fill pauses in the voice recordings [31].

Feature Selection

First, *z* scores were computed for each feature, and those with an absolute *z* score greater than 2 were removed as they were considered as outliers. Then, *t* tests (2-tailed) were used to determine whether there was a significant difference in each feature between the MCI and CN groups. Features that exhibited a significant difference below a *P* value threshold of .002 were then selected to be included in the model.

Classification Model

A random forest model was built using a final set of 29 selected features, and the performance of the model was evaluated using 10-fold cross-validation. To evaluate the MCI detection performance of the model, the area under the receiver operating characteristic curve (AUC), along with the 95% CI, for the random forest algorithm was obtained. The importance of each feature was computed using an impurity-based approach [32].

Comparison of Performance Across Different Audio Recording Lengths

To investigate the impact of the length of the audio recordings on the MCI classification performance, the first 5, 10, 15, and 30 minutes of the whole recording for each participant were extracted. Subsequently, the same processing steps were applied to each extracted audio segment, including speaker diarization, feature extraction, and the construction of the MCI classification model.

Results

Cohort Descriptive

The study sample included 200 participants, of whom 100 were diagnosed with MCI and the other 100 were classified as CN. In the overall sample, the average age was 74 (SD 6) years, and 46% (92/200) were female, with the sex distribution (females versus males) equal in both MCI and CN groups. Education in the overall sample was distributed as follows: 18 participants (18/200, 9%) did not graduate from high school, 54 participants (54/200, 27%) were high school graduates, 66 participants (66/200, 33%) had completed some college, and 62 participants (62/200, 31%) held at least a college degree.

Feature Selection and Detection Performance

Table 1 presents the 29 acoustic features significantly associated with cognitive status, selected using a *P* value threshold of .002. The table also displays the importance scores of these features for the classification of MCI, with higher values indicating greater importance. The most important acoustic feature for MCI classification was the number of filled pauses, with an importance score of 0.09. The optimal model was achieved when including these 29 acoustic features that were based on using a *z* score cutoff of 2 and a *P* value threshold of .002 (AUC 0.87, 95% CI 0.81-0.94; Figure 2).

Table 1. The optimal acoustic feature set for mild cognitive impairment detection.

Feature	Description	Importance[a]	*P* value[b]
nrFP	Number of filled pauses	0.09	<.001
tFP	Total time of filled pauses	0.08	<.001
mfcc_sma[11]_meanFallingSlope	Mean of the falling slope of the second MFCC[c]	0.06	.001
pcm_fftMag_spectralHarmonicity_sma_risetime	Rise time of the signal for magnitude of psychoacoustic harmonicity	0.05	.001
mfcc_sma[14]_risetime	Rising time of the second MFCC	0.05	.001
pcm_fftMag_spectralRollOff90.0_sma_de_minPos	Absolute position of the minimum value of the deltas of magnitude of the spectral roll-off point 90%	0.05	<.001
mfcc_sma_de[9]_upleveltime25	Percentage of time over 25% of the range of variation of the deltas of the ninth MFCC	0.05	<.001
audSpec_Rfilt_sma[25]_quartile1	First quartile of the RASTA-style filtered auditory spectrum, band 25	0.04	.002
mfcc_sma[1]_segLenStddev	Standard deviation of the segment lengths of the first MFCC	0.04	.002
audSpec_Rfilt_sma_de[5]_iqr2-3	Interquartile 2-3 of the deltas of the RASTA-style filtered auditory spectrum, band 5	0.04	<.001
pcm_fftMag_fband250-650_sma_de_stddev	Standard deviation of the delta of magnitude of the frequency band 250-650 Hz	0.04	.002
mfcc_sma_de[2]_lpc1	Linear prediction coefficient as one of the deltas of the second MFCC	0.04	.002
pcm_fftMag_fband250-650_sma_de_rqmean	Root-quadratic mean of the deltas of magnitude of the frequency band 250-650 Hz	0.04	.002
audSpec_Rfilt_sma[7]_upleveltime75	Percentage of time over 75% of the range of variation of the RASTA-style filtered auditory spectrum, band 7	0.03	.001
mfcc_sma[2]_maxSegLen	Maximum of the segment lengths of the second MFCC	0.03	.002
audSpec_Rfilt_sma_de[5]_upleveltime75	Percentage of time over 75% of the range of variation of the deltas of the RASTA-style filtered auditory spectrum, band 5	0.03	.002
audSpec_Rfilt_sma_de[5]_upleveltime90	Percentage of time over 90% of the range of variation of the deltas of the RASTA-style filtered auditory spectrum, band 5	0.03	.002
audSpec_Rfilt_sma_de[7]_upleveltime75	Percentage of time over 75% of the range of variation of the deltas of the RASTA-style filtered auditory spectrum, band 7	0.03	.002
audSpec_Rfilt_sma_de[15]_lpc0	Linear prediction coefficient zero of the delta of the RASTA-style filtered auditory spectrum, band 15	0.03	.002
audSpec_Rfilt_sma_de[15]_lpc1	Linear prediction coefficient one of the deltas of the RASTA-style filtered auditory spectrum, band 15	0.03	<.001
audSpec_Rfilt_sma_de[15]_lpc2	Linear prediction coefficient 2 of the delta of the RASTA-style filtered auditory spectrum, band 15	0.03	<.001
audSpec_Rfilt_sma[18]_qregc1	Quadratic regression coefficient 1 of the RASTA-style filtered auditory spectrum, band 19	0.03	<.001
audSpec_Rfilt_sma[18]_qregc2	Quadratic regression coefficient 2 of the RASTA-style filtered auditory spectrum, band 19	0.03	<.001
audSpec_Rfilt_sma_de[15]_lpc3	Linear prediction coefficient 3 of the delta of the RASTA-style filtered auditory spectrum, band 15	0.02	<.001

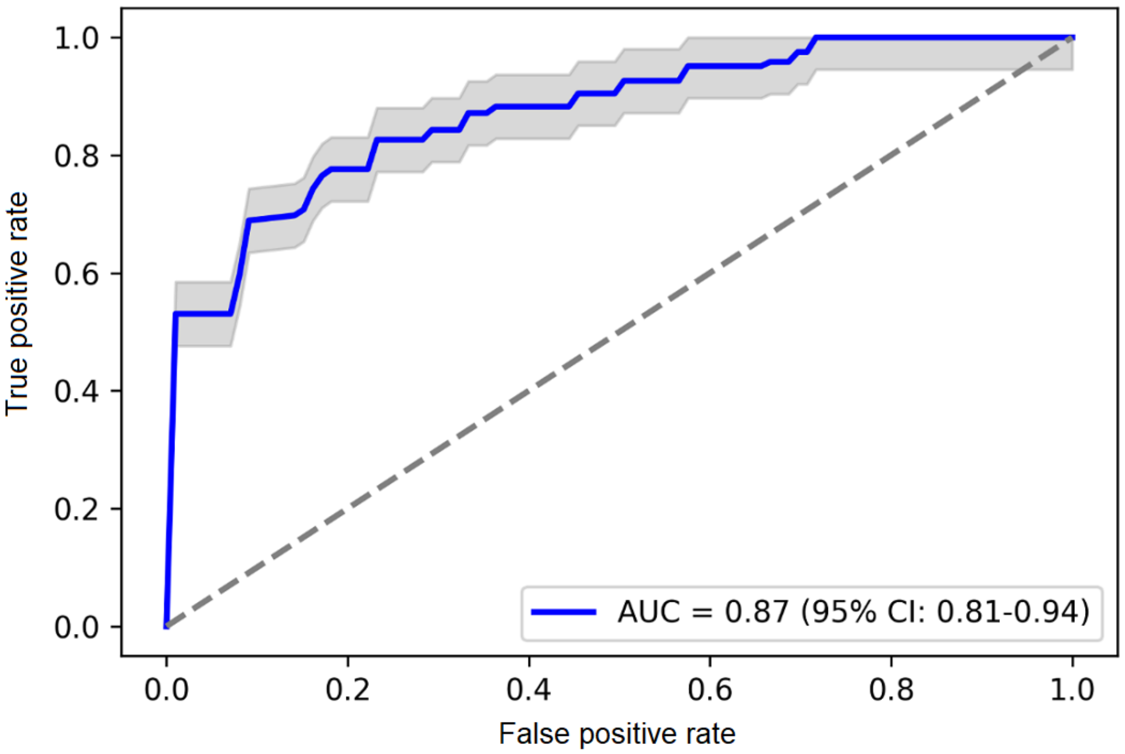
Feature	Description	Importance[a]	*P* value[b]
audspec_lengthL1norm_sma_peakRangeAbs	Absolute peak range of the sum of the auditory spectrum	0.02	.002
pcm_fftMag_spectralRollOff25.0_sma_pctlrange0-1	Outlier robust signal range “max-min” represented by the range of the 1% and the 99% percentile from the magnitude of the spectral roll-off point 25%	0.01	<.001
mfcc_sma_de[4]_peakMeanRel	Relative peak mean of the delta of the fourth MFCC	0.01	<.001
pcm_fftMag_spectralRollOff75.0_sma_quartile1	First quartile of magnitude of the spectral roll-off point 75%	0.00	<.001
pcm_fftMag_spectralRollOff75.0_sma_quartile3	Third quartile of magnitude of the spectral roll-off point 75%	0.00	<.001

[a] Importance was the impurity-based importance score of each acoustic feature that was computed as the mean of accumulation of the impurity decrease within each tree of the random forest.

[b] The *P* value was calculated using a *t* test (2-tailed) for each acoustic feature. Only the acoustic features with a *P* value less than .002 were included in the model.

[c] MFCC: Mel-frequency cepstral coefficient.

Figure 2. Receiver operating characteristic (ROC) curve of the random forest model for MCI classification. The mean ROC is depicted by the blue line, while the shaded gray area surrounding the curve represents confidence intervals, offering insights into the associated uncertainty of the curve.



Comparison of Performance Across Different Audio Recording Lengths

In addition to the optimal model based on whole recordings (1+ hour), we further examined the MCI detection performance of various audio recording lengths. In the case of 5-minute audio segments, we identified 21 acoustic features that exhibited significant associations with cognitive status (eg, $P<.002$). The random forest model constructed using these 21 features achieved an AUC of 0.79 (95% CI 0.73-0.86). Similarly, for the 10-minute audio segments, we identified 25 significant acoustic features and achieved an AUC of 0.81 (95% CI 0.75-0.87). When using 15-minute audio segments, 17 acoustic features were found to be significantly associated with cognitive status, leading to an AUC of 0.80 (95% CI 0.75-0.86) from the random forest model. Lastly, in the case of 30-minute audio segments, 17 acoustic features were significantly associated with cognitive status, and the random forest model achieved an AUC of 0.82 (95% CI 0.76-0.89). The accuracy, sensitivity, and specificity of these models were presented in Multimedia Appendix 1. These metrics were computed based on the means and SDs obtained using 10-fold cross-validation.

Discussion

Principal Findings

This study developed a machine learning pipeline to optimize the detection capability of acoustic features for MCI. We identified 29 acoustic features from 200 FHS participants' voice recordings collected at their NP exams, which yielded an AUC of 87% in classifying those with normal cognition versus MCI. Our findings highlight the significant potential of acoustic-based features of human speech as an easily collectible and accurate data modality for early ADRD detection.

Detecting ADRD early in the disease course and implementing timely interventions to slow its progression continue to be the primary strategies for addressing this condition. The method developed in this study using acoustic features for MCI monitoring aligns well with this goal. Specifically, despite recent FDA approvals for aducanumab and lecanemab as disease-modifying treatments for ADRD, concerns have emerged about the inclusivity of the trial population and the equitable distribution of benefits to all potential beneficiaries [33]. The acoustic feature-based machine learning approach in this study addresses the limited early detection capability of traditional NP tests for asymptomatic individuals, as well as the challenges associated with the cost and time-consuming nature of cerebrospinal fluid and blood-based biomarkers [34]. Speech data collection presents a noninvasive and accessible approach for cognitive health monitoring. This motivates potential future applications where passive voice collection tools, like hearing aids, could be used to gather such data. The use of nonsemantic, acoustic features of speech offers practical advantages from the perspective of data privacy and security. Unlike linguistic features, which may raise concerns around individual privacy and confidentiality, acoustic features can be derived without the need for direct access to sensitive personal information. The analysis based on acoustic features reduces privacy concerns and ensures that confidential data remain protected or unidentifiable during the cognitive monitoring process.

Studies examining discourse patterns in participants with ADRD have consistently observed difficulties in word retrieval, less efficient speech, and a notable increase in both the frequency and duration of pauses when their speech is compared to that of healthy adults [35,36]. Notably, in this study, among the features considered crucial for model performance, those related to filled pauses, such as the number of filled pauses and the total time of filled pauses, played a significant role. Filled pauses, such as "um" or "er," are nonlexical vocalizations. In individuals with dementia, pauses in speech are frequently longer and more frequent, which may indicate challenges with semantic and lexical decision-making, cognitive load, and familiarity with topics [36,37]. This study further highlights that pausing in the speech of individuals with dementia is often considered a dysfluency, serving as a behavioral hallmark that may signify difficulties in social interactions [38]. Our findings are also consistent with previous studies that have examined acoustic-based speech markers in older adults and found good predictive accuracy in identifying those with MCI as compared to being CN [39,40]. Other studies have also found temporal parameters, including prosodic rate and spectrum features, such as Mel-frequency cepstral coefficients, to predict those with MCI or early ADRD [41,42]. These findings offer a research target for further understanding speech issues and mechanisms related to cognitive health. By integrating acoustic analysis into routine clinical assessments, we can potentially enhance current diagnostic tools. This integration provides clinicians with additional quantitative data to support their diagnostic decisions and monitoring of disease progression. Furthermore, the acoustic features identified in this study hold promise for their potential application in large-scale screening programs aimed at identifying individuals at risk of developing MCI. Such screening tools, leveraging these features, could offer a cost-effective and scalable approach, enabling a broader population reach and early intervention strategies. Thus, these findings not only contribute to our scientific understanding but also have practical implications for improving early detection of cognitive impairment.

A unique contribution of our study that has not been well-examined in previous studies is the impact of the speech recording duration on the model performance. Although the full recording yielded the highest AUC (87%), we did not observe substantial differences in model performance based on varying voice recording lengths (eg, 5, 10, 15, and 30 minutes). This finding holds important implications for future studies that involve collecting voice recordings from participants, suggesting that achieving good predictive performance may not require collecting lengthy audio data. It underscores the potential to minimize participant burden and time spent collecting data, while preserving the data's analytical quality. Other strengths of this study include using a community-based sample within a controlled environment for the voice recordings taken during the NP exams. Furthermore, this study uses highly interpretable methods throughout, from feature selection to predictive model construction, achieving good MCI prediction capability. This sets a benchmark for future research attempting more complex analytical approaches. In the future, we can compare complex machine learning methods to fully investigate how to balance the relationship between interpretability and predictive performance.

Important limitations, however, include the inability to account for or investigate the impact of other conditions or risk factors, such as depression [43], that may influence speech patterns within the analysis. Due to the lack of available data on depression at the time of voice recording data collection in FHS, we did not investigate the relationship between depression, cognition, and acoustic features in this study. Future research will be essential to delve into this relationship using more comprehensive cohort data sets. Additionally, our sample consisted mostly of individuals who were White or of European descent, which could potentially limit the generalizability of our findings to other demographic groups. We also recognize that cognition and MCI are not static entities and that individuals with MCI can be considered to be CN at a later point in time [44]. Therefore, it may be possible that some participants were misclassified in terms of their cognitive status in our sample. For example, we acknowledge that the use of the National Institute of Aging–Alzheimer Association (NIA-AA) criteria

[45] offers advantages over the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association and *DSM-IV* criteria, which were used in this study, to ascertain individuals with MCI since it can provide a more comprehensive and inclusive approach, incorporating multiple pathological features. Additionally, the NIA-AA criteria use objective biomarkers and imaging techniques, enhancing diagnostic accuracy and reproducibility. The voice data used in this study were collected in quiet environments, which to some extent limits the widespread applicability of the study results in different environments, such as in-home settings.

To address these limitations, we plan to expand our research in several ways. First, we aim to include more diverse populations in future studies to assess whether the same acoustic features or different ones yield similar results in distinguishing MCI from normal cognition across various demographic groups. Future research should consider using cohorts with biomarker evidence of neurocognitive disorders for further validation of the findings. Additionally, we will explore the inclusion of other medical conditions or factors that may impact model performance, broadening our understanding of how speech patterns can be indicative of cognitive health. Specifically, we recognize that emotions may confound the relationship between speech patterns and cognition. Exploring the detection capability of MCI using voice collected in more real-life environments is another direction for future research. Finally, as we continue to advance in the development of speech-based screening and diagnostic tools, it is crucial to proactively address privacy and data security concerns. While our focus in this paper is primarily on the technical aspects of acoustic feature analysis for cognitive assessment, we recognize the importance of considering the broader societal implications of deploying such technologies in open source or free-market contexts. Safeguards must be implemented to ensure that individuals' privacy rights are respected and that their data are used responsibly and ethically.

Conclusions

This study demonstrated the potential for accurate identification of MCI using nonsemantic, acoustic speech features. Our research benefits from a well-defined sample and comprehensive speech data collected during NP exams, which have been rigorously analyzed.

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Data Availability

The data sets generated during and/or analyzed during this study are available in the Framingham Heart Study [46].

Conflicts of Interest

RA reports conflicts including Signant Health, NovoNordisk, and the Davos Alzheimer's Collaborative.

Multimedia Appendix 1
Performance of models for MCI prediction using different audio length segments.
[DOCX File , 13 KB - aging_v7i1e55126_app1.docx]

References

1. 2021 Alzheimer's disease facts and figures. Alzheimers Dement 2021;17(3):327-406. [doi: 10.1002/alz.12328] [Medline: 33756057]
2. Gustavsson A, Norton N, Fast T, Frölich L, Georges J, Holzapfel D, et al. Global estimates on the number of persons across the Alzheimer's disease continuum. Alzheimers Dement 2023;19(2):658-670. [doi: 10.1002/alz.12694] [Medline: 35652476]
3. Desai AK, Grossberg GT. Diagnosis and treatment of Alzheimer's disease. Neurology 2005;64(12 Suppl 3):S34-S39. [doi: 10.1212/wnl.64.12_suppl_3.s34] [Medline: 15994222]
4. Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, et al. Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease. Alzheimers Dement 2011;7(3):280-292. [doi: 10.1016/j.jalz.2011.03.003] [Medline: 21514248]
5. Tarawneh R, Holtzman DM. The clinical problem of symptomatic Alzheimer disease and mild cognitive impairment. Cold Spring Harb Perspect Med 2012;2(5):a006148 [FREE Full text] [doi: 10.1101/cshperspect.a006148] [Medline: 22553492]

6. Leifer BP. Early diagnosis of Alzheimer's disease: clinical and economic benefits. J Am Geriatr Soc 2003;51(5 Suppl Dementia):S281-S288. [doi: 10.1046/j.1532-5415.5153.x] [Medline: 12801384]
7. Laske C, Sohrabi HR, Frost SM, López-de-Ipiña K, Garrard P, Buscema M, et al. Innovative diagnostic tools for early detection of Alzheimer's disease. Alzheimers Dement 2015;11(5):561-578. [doi: 10.1016/j.jalz.2014.06.004] [Medline: 25443858]
8. Robinson P. The cognitive hypothesis, task design, and adult task-based language learning. Stud Second Lang Acquis 2003;21(2):45-105.
9. Cuetos F, Arango-Lasprilla JC, Uribe C, Valencia C, Lopera F. Linguistic changes in verbal expression: a preclinical marker of Alzheimer's disease. J Int Neuropsychol Soc 2007;13(3):433-439. [doi: 10.1017/S1355617707070609] [Medline: 17445292]
10. Deramecourt V, Lebert F, Debachy B, Mackowiak-Cordoliani MA, Bombois S, Kerdraon O, et al. Prediction of pathology in primary progressive language and speech disorders. Neurology 2010;74(1):42-49. [doi: 10.1212/WNL.0b013e3181c7198e] [Medline: 19940270]
11. Ding H, Mandapati A, Karjadi C, Ang TFA, Lu S, Miao X, et al. Association between acoustic features and neuropsychological test performance in the Framingham heart study: observational study. J Med Internet Res 2022;24(12):e42886 [FREE Full text] [doi: 10.2196/42886] [Medline: 36548029]
12. Ding H, Hamel AP, Karjadi C, Ang TFA, Lu S, Thomas RJ, et al. Association between acoustic features and brain volumes: the Framingham heart study. Front Dement 2023;2:1214940 [FREE Full text] [doi: 10.3389/frdem.2023.1214940] [Medline: 38911669]
13. Nagumo R, Zhang Y, Ogawa Y, Hosokawa M, Abe K, Ukeda T, et al. Automatic detection of cognitive impairments through acoustic analysis of speech. Curr Alzheimer Res 2020;17(1):60-68 [FREE Full text] [doi: 10.2174/1567205017666200213094513] [Medline: 32053074]
14. Meghanani A, Anoop C, Ramakrishnan A. An exploration of log-mel spectrogram and MFCC features for Alzheimer's dementia recognition from spontaneous speech. 2021 Presented at: 2021 IEEE Spoken Language Technology Workshop (SLT); January 19, 2021; Shenzhen, China. [doi: 10.1109/slt48900.2021.9383491]
15. Xue C, Karjadi C, Paschalidis IC, Au R, Kolachalama VB. Detection of dementia on voice recordings using deep learning: a Framingham heart study. Alzheimers Res Ther 2021;13(1):146 [FREE Full text] [doi: 10.1186/s13195-021-00888-3] [Medline: 34465384]
16. Vincze V, Szatlóczki G, Tóth L, Gosztolya G, Pákáski M, Hoffmann I, et al. Telltale silence: temporal speech parameters discriminate between prodromal dementia and mild Alzheimer's disease. Clin Linguist Phon 2021;35(8):727-742. [doi: 10.1080/02699206.2020.1827043] [Medline: 32993390]
17. McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA work group under the auspices of department of health and human services task force on Alzheimer's disease. Neurology 1984;34(7):939-944. [doi: 10.1212/wnl.34.7.939] [Medline: 6610841]
18. Hinterberger M, Fischer P, Zehetmayer S. Incidence of dementia over three decades in the Framingham heart study. N Engl J Med 2016;375(1):93. [doi: 10.1056/NEJMc1604823] [Medline: 27406364]
19. Anguera Miro X, Bozonnet S, Evans N, Fredouille C, Friedland G, Vinyals O. Speaker Diarization: A Review of Recent Research. : IEEE; 2012 Presented at: IEEE Transactions on Audio, Speech, and Language Processing; 2012 Jan 23; Canada p. 356-370. [doi: 10.1109/tasl.2011.2125954]
20. Bredin H, Laurent A. End-to-end speaker segmentation for overlap-aware resegmentation. arXiv:210404045 2021. [doi: 10.21437/interspeech.2021-560]
21. Bredin H, Yin R, Coria J, Gelly G, Korshunov P, Lavechin M. Pyannote.audio: neural building blocks for speaker diarization. : IEEE; 2020 Presented at: ICASSP 2020 - 2020 IEEE International Conference on Acoustics, Speech and Signal Processing (ICASSP); 2020 May 04; Barcelona, Spain. [doi: 10.1109/icassp40776.2020.9052974]
22. Eyben F, Wöllmer M, Schuller B. Opensmile: the munich versatile and fast open-source audio feature extractor. 2010 Presented at: Proceedings of the 18th ACM International Conference on Multimedia; October 25, 2010; United States p. 1459-1462. [doi: 10.1145/1873951.1874246]
23. Boersma P. Praat: doing phonetics by computer. 2011. URL: http://www.praat.org/ [accessed 2024-07-19]
24. Schuller B, Steidl S, Batliner A, Vinciarelli A, Scherer K, Ringeval F. The INTERSPEECH 2013 computational paralinguistics challenge: social signals, conflict, emotion, autism. 2013 Presented at: Proceedings INTERSPEECH 2013, 14th Annual Conference of the International Speech Communication Association; August 10, 2013; Lyon, France. [doi: 10.21437/interspeech.2013-56]
25. Dumpala SH, Rodriguez S, Rempel S, Sajjadian M, Uher R, Oore S. Detecting depression with a temporal context of speaker embeddings. 2022 Presented at: Proc AAAI SAS; January 10, 2022; Canada.
26. Luz S, Haider F, de la Fuente Garcia S, Fromm D, MacWhinney B. Alzheimer's dementia recognition through spontaneous speech. Front Comput Sci 2021;3:780169 [FREE Full text] [doi: 10.3389/fcomp.2021.780169] [Medline: 35291512]
27. Beccaria F, Gagliardi G, Kokkinakis D. Extraction and classification of acoustic features from Italian speaking children with autism spectrum disorders. : ELRA; 2022 Presented at: Proceedings of the LREC 2022 Workshop on Resources and

Processing of Linguistic, Para-linguistic and Extra-linguistic Data from People with Various Forms of Cognitive/Psychiatric/Developmental Impairments (RaPID-4 2022); June 25, 2022; Italy p. 22-30.
28. Sümer, Beyan C, Ruth F, Kramer O, Trautwein U, Kasneci E. Estimating presentation competence using multimodal nonverbal behavioral cues. arXiv:210502636 2021.
29. Sidorov M, Ultes S, Schmitt A. Automatic recognition of personality traits: a multimodal approach. 2014 Presented at: Proceedings of the 2014 Workshop on Mapping Personality Traits Challenge and Workshop; 2014 Nov 12; United States p. 11-15. [doi: 10.1145/2668024.2668028]
30. Weninger F, Eyben F, Schuller BW, Mortillaro M, Scherer KR. On the acoustics of emotion in audio: what speech, music, and sound have in common. Front Psychol 2013;4:292 [FREE Full text] [doi: 10.3389/fpsyg.2013.00292] [Medline: 23750144]
31. de Jong NH, Pacilly J, Heeren W. PRAAT scripts to measure speed fluency and breakdown fluency in speech automatically. Assess Educ Principles Policy Pract 2021;28(4):456-476. [doi: 10.1080/0969594x.2021.1951162]
32. Breiman L. Random forests. Mach Learn 2001;45:5-32. [doi: 10.1007/978-0-387-30164-8_695]
33. Manly JJ, Glymour MM. What the aducanumab approval reveals about Alzheimer disease research. JAMA Neurol 2021;78(11):1305-1306. [doi: 10.1001/jamaneurol.2021.3404] [Medline: 34605885]
34. Dokholyan NV, Mohs RC, Bateman RJ. Challenges and progress in research, diagnostics, and therapeutics in Alzheimer's disease and related dementias. Alzheimers Dement (N Y) 2022;8(1):e12330 [FREE Full text] [doi: 10.1002/trc2.12330] [Medline: 35910674]
35. König A, Satt A, Sorin A, Hoory R, Toledo-Ronen O, Derreumaux A, et al. Automatic speech analysis for the assessment of patients with predementia and Alzheimer's disease. Alzheimers Dement (Amst) 2015;1(1):112-124 [FREE Full text] [doi: 10.1016/j.dadm.2014.11.012] [Medline: 27239498]
36. Pistono A, Pariente J, Bézy C, Lemesle B, Le Men J, Jucla M. What happens when nothing happens? An investigation of pauses as a compensatory mechanism in early Alzheimer's disease. Neuropsychologia 2019;124:133-143 [FREE Full text] [doi: 10.1016/j.neuropsychologia.2018.12.018] [Medline: 30593773]
37. Merlo S, Mansur LL. Descriptive discourse: topic familiarity and disfluencies. J Commun Disord 2004;37(6):489-503. [doi: 10.1016/j.jcomdis.2004.03.002] [Medline: 15450437]
38. Davis BH, Maclagan M. Examining pauses in Alzheimer's discourse. Am J Alzheimers Dis Other Dement 2009;24(2):141-154 [FREE Full text] [doi: 10.1177/1533317508328138] [Medline: 19150969]
39. Kato S, Homma A, Sakuma T. Easy screening for mild Alzheimer's disease and mild cognitive impairment from elderly speech. Curr Alzheimer Res 2018;15(2):104-110. [doi: 10.2174/1567205014666171120144343] [Medline: 29165082]
40. Themistocleous C, Eckerström M, Kokkinakis D. Identification of mild cognitive impairment from speech in Swedish using deep sequential neural networks. Front Neurol 2018;9:975 [FREE Full text] [doi: 10.3389/fneur.2018.00975] [Medline: 30498472]
41. Toth L, Hoffmann I, Gosztolya G, Vincze V, Szatloczki G, Banreti Z, et al. A speech recognition-based solution for the automatic detection of mild cognitive impairment from spontaneous speech. Curr Alzheimer Res 2018;15(2):130-138 [FREE Full text] [doi: 10.2174/1567205014666171121114930] [Medline: 29165085]
42. López-de-Ipiña K, Alonso J, Travieso C, Solé-Casals J, Egiraun H, Faundez-Zanuy M, et al. On the selection of non-invasive methods based on speech analysis oriented to automatic Alzheimer disease diagnosis. Sensors (Basel) 2013;13(5):6730-6745 [FREE Full text] [doi: 10.3390/s130506730] [Medline: 23698268]
43. Cannizzaro M, Harel B, Reilly N, Chappell P, Snyder PJ. Voice acoustical measurement of the severity of major depression. Brain Cogn 2004;56(1):30-35. [doi: 10.1016/j.bandc.2004.05.003] [Medline: 15380873]
44. Koepsell TD, Monsell SE. Reversion from mild cognitive impairment to normal or near-normal cognition: risk factors and prognosis. Neurology 2012;79(15):1591-1598 [FREE Full text] [doi: 10.1212/WNL.0b013e31826e26b7] [Medline: 23019264]
45. Jack CR, Albert MS, Knopman DS, McKhann GM, Sperling RA, Carrillo MC, et al. Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease. Alzheimers Dement 2011;7(3):257-262 [FREE Full text] [doi: 10.1016/j.jalz.2011.03.004] [Medline: 21514247]
46. Framingham Heart Study For Researchers. 2024. URL: https://www.framinghamheartstudy.org/fhs-for-researchers/ [accessed 2024-04-22]

Abbreviations

ADRD: Alzheimer disease and related dementias
AUC: area under the receiver operating characteristic curve
CN: cognitively normal
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)
FHS: Framingham Heart Study
LLD: low-level descriptor
MCI: mild cognitive impairment

NIA-AA: National Institute of Aging–Alzheimer Association
NP: neuropsychological

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Original Paper

Investigating Acoustic and Psycholinguistic Predictors of Cognitive Impairment in Older Adults: Modeling Study

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Abstract

Background: About one-third of older adults aged 65 years and older often have mild cognitive impairment or dementia. Acoustic and psycho-linguistic features derived from conversation may be of great diagnostic value because speech involves verbal memory and cognitive and neuromuscular processes. The relative decline in these processes, however, may not be linear and remains understudied.

Objective: This study aims to establish associations between cognitive abilities and various attributes of speech and natural language production. To date, the majority of research has been cross-sectional, relying mostly on data from structured interactions and restricted to textual versus acoustic analyses.

Methods: In a sample of 71 older (mean age 83.3, SD 7.0 years) community-dwelling adults who completed qualitative interviews and cognitive testing, we investigated the performance of both acoustic and psycholinguistic features associated with cognitive deficits contemporaneously and at a 1-2 years follow up (mean follow-up time 512.3, SD 84.5 days).

Results: Combined acoustic and psycholinguistic features achieved high performance (F_1-scores 0.73-0.86) and sensitivity (up to 0.90) in estimating cognitive deficits across multiple domains. Performance remained high when acoustic and psycholinguistic features were used to predict follow-up cognitive performance. The psycholinguistic features that were most successful at classifying high cognitive impairment reflected vocabulary richness, the quantity of speech produced, and the fragmentation of speech, whereas the analogous top-ranked acoustic features reflected breathing and nonverbal vocalizations such as giggles or laughter.

Conclusions: These results suggest that both acoustic and psycholinguistic features extracted from qualitative interviews may be reliable markers of cognitive deficits in late life.

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KEYWORDS

acoustic; psycholinguistic; speech; speech marker; speech markers; cognitive impairment; CI; mild cognitive impairment; MCI; cognitive disability; cognitive restriction; cognitive limitation; machine learning; ML; artificial intelligence; AI; algorithm; algorithms; predictive model; predictive models; predictive analytics; predictive system; practical model; practical models; early warning; early detection; NLP; natural language processing; Alzheimer; dementia; neurological decline; neurocognition; neurocognitive disorder

Introduction

It is estimated that approximately one-third of adults aged 65 years and older in the United States have mild cognitive impairment (MCI) or dementia [1]. Given the high prevalence of MCI and dementia, better methods are needed for earlier identification. Biomarkers associated with future cognitive decline can be evident decades before the deficits are clinically detected [2]. By the time cognitive changes are evident to the patient or their families, functional difficulties may be more advanced, and potential interventions to reduce decline may be less effective.

Language abilities remain largely preserved in typical aging, despite gradual declines in other cognitive functions such as processing speed. The decline in language abilities may serve as a key indicator of atypical or pathological aging such as MCI and dementia [3-5]. Prior studies have reported speech and language declines across disease progression from early MCI to moderate-stage Alzheimer disease [6-8]. Mueller et al [8] found that subtle declines in speech fluency and semantic content are apparent even prior to the onset of clinically diagnosed MCI. Therefore, developing techniques to identify early changes in language functioning may enhance the detection of subtle cognitive decline associated with pathological cognitive aging.

Natural language processing (NLP) has emerged as a promising approach for identifying early signs of pathological cognitive decline [9]. NLP includes a variety of techniques to capture and quantify linguistic or semantic aspects of speech (eg, syntactic complexity, idea density, and semantic content) and is often combined with machine learning (ML) to automate classification based on latent patterns in data. Asgari et al [10] used linguistic features derived from audio recordings of unstructured conversations with 41 older adults and were able to differentiate cognitively intact individuals from participants with MCI with 84% classification accuracy. Studies using intermittent audio recordings of older adults without cognitive impairment in real-world settings over 4 days found that several linguistic features were associated with performance on standardized measures of working memory [11,12]. In a longitudinal analysis of data from the Framingham Heart Study, linguistic variables derived from written responses to a picture description task (the cookie theft task), improved the predictive accuracy of conversion from cognitively normal to Alzheimer disease over nonlinguistic markers [13]. Though transcripts have been the current standard of understanding language, audio features remain underresearched in psychiatry. Another possibility is that audio feature files are difficult to share due to privacy controls, and therefore, are more difficult to access. Acoustic features of speech (eg, volume) have been evaluated to a lesser extent than linguistic features [14-16]. To date, few studies evaluated the relative predictive performance of acoustic versus psycholinguistic-derived features, and none, to our knowledge, have evaluated performance in predicting future cognitive deficits.

This study aimed to explore and identify acoustic and psycholinguistic features associated with cognitive abilities on neuropsychological measures, both contemporaneously and at follow-up assessments, among older adults recruited from an independent living facility. Our work is unique from prior research in several ways. First, we use both acoustic and psycholinguistic features from speech derived from a semistructured interview rather than using standardized tasks. Second, all participants underwent a research-based neuropsychological assessment comprising multiple cognitive domains (eg, global cognitive ability as measured by a screening instrument, verbal memory, and phonemic and semantic fluency). Third, we collected follow-up neuropsychological data to evaluate the stability of prediction. Finally, we used ML techniques to develop predictive algorithms to identify acoustic and psycholinguistic features associated with cognitive impairment and change, using sociodemographic features alone as a comparison. We hypothesized that both acoustic and psycholinguistic features derived from the recordings of semistructured interviews would predict baseline and follow-up cognitive deficits, exceeding the predictive accuracy of sociodemographic characteristics (eg, age). We explored the contribution of individual features to these predictions and the relative performance of acoustic and psycholinguistic feature-based models across cognitive domains.

Methods

Participants and Procedures

This is a secondary analysis of interview transcripts from a sample that was previously described [17,18]. The original study goals were to examine predictors of cognitive and functional decline in a community-dwelling sample of older adults; thus, the lower age limit was set at 65 years in order to be representative of older adult populations that are at risk for cognitive decline. There was no upper age limit for inclusion in this study [17]. Participants were recruited from the independent living sector of a continuing care senior housing community in San Diego County. Enrollment criteria were (1) English-speaking individuals aged 65 years or older, (2) ability to complete study assessments and engage in a qualitative interview, and (3) no known diagnosis of dementia or any other disabling illness. For the study, we excluded individuals with medical or neurological conditions that would impede their ability to complete the assessments. However, we did not exclude those with major depressive disorders, as our sample primarily consists of healthy older adults living independently. This study protocol was approved by the Human Research Protections Program of the University of California, San Diego, and written informed consent was obtained from all study participants.

In-person interviews by a trained professional were conducted between April 2018 and January 2020. The interviewer and other staff were trained to administer neuropsychological tests according to standardized procedures by a licensed neuropsychologist (EWT), who was continuously available to answer scoring questions for the duration of the study. A comprehensive battery of neuropsychological assessments was planned, but the follow-up neuropsychological assessments were modified due to the COVID-19 pandemic. The neuropsychological tests included in these analyses were limited to those that were suitable for remote assessment (via telephone or videoconference). Of the 71 individuals who had completed interviews and assessments at baseline, 55 individuals had follow-up assessments (46 assessments were recorded at ~12 months, 6 assessments at ~18 months, and 3 assessments at ~24 months) with a mean follow-up interval of 1.4 years (512.3, SD 84.5 days). Of those, 37 assessments had all included measures available. Participants who did not complete a follow-up assessment had either moved out of the facility, moved to a higher level of care (eg, a nursing facility), declined further participation, or died.

Sociodemographic and Clinical Neuropsychological Measures

Overview

The sociodemographic data collected included age, sex, marital status, and racial or ethnic background (Tables 1 and 2). Trained staff also administered a neuropsychological battery [19] to assess different cognitive domains. Information on the psychometric properties of the battery constituents can be found in Section S1 in Multimedia Appendix 1.

Table 1. Demographic characteristics of the sample at baseline (N=71).

	Value	Percentage impaired
Sociodemographics		
Age (in years at the time of visit)		N/A[a]
Mean (SD)	83.3 (7.0)	
Range	67-98	
Education (in years)		N/A
Mean (SD)	15.9 (2.3)	
Range	12-20	
Marital status (single), n (%)	45 (63)	N/A
Race (White), n (%)	65 (91)	N/A
Sex (female), n (%)	47 (66)	N/A
Clinical measures		
MoCA[b]		39.44
Mean (SD)	23.8 (3.7)	
Range	13-29	
HVLT[c] total recall		22.39
Mean (SD)	21.3 (5.3)	
Range	9-31	
HVLT delayed recall		28.36
Mean (SD)	6.2 (3.5)	
Range	0-12	
HVLT retention		31.34
Mean (SD)	67.5 (31.8)	
Range	0-122	
FAS[d]		29.41
Mean (SD)	35.3 (11.3)	
Range	16-61	
Animals[e]		30.88
Mean (SD)	16.6 (5.4)	
Range	8-32	
Overall deficit		71.83
Depression PHQ-9[f]		N/A
Mean (SD)	3.2 (3.8)	
Range	0-15	

[a] N/A: not applicable.

[b] MoCA: Montreal Cognitive Assessment.

[c] HVLT: Hopkins Verbal Learning Test-Revised.

[d] F-A-S verbal fluency test.

[e] Verbal processing speed (animals).

[f] PHQ-9: 9-item Physical Health Questionnaire.

Table 2. Demographic characteristics of the sample at follow-up (N=55).

	Value	Percentage impaired
Sociodemographics		
Age (in years at the time of visit)		N/A[a]
Mean (SD)	84.1 (7.5)	
Range	68-100	
Education (in years)		N/A
Mean (SD)	16.3 (2.2)	
Range	12-20	
Marital status (single), n (%)	42 (93)	N/A
Race (White), n (%)	40 (89)	N/A
Sex (female), n (%)	30 (67)	N/A
Clinical measures		
MoCA[b]		35.14
Mean (SD)	24.3 (4.3)	
Range	6-29	
HVLT[c] total recall		42.22
Mean (SD)	19.6 (6.6)	
Range	5-31	
HVLT delayed recall		42.22
Mean (SD)	5.7 (3.7)	
Range	0-12	
HVLT retention		42.22
Mean (SD)	63.2 (34.1)	
Range	0-100	
FAS[d]		29.55
Mean (SD)	35.0 (9.3)	
Range	18-53	
Animals[e]		43.18
Mean (SD)	16.1 (5.0)	
Range	5-27	
Overall deficit		78.26
Depression PHQ-9[f]		N/A
Mean (SD)	3.5 (4.0)	
Range	0-17	

[a] Not applicable.

[b] MoCA: Montreal Cognitive Assessment.

[c] HVLT: Hopkins Verbal Learning Test-Revised.

[d] F-A-S verbal fluency test.

[e] Verbal processing speed (animals).

[f] PHQ 9: 9-item Physical Health Questionnaire.

The Montreal Cognitive Assessment

The Montreal Cognitive Assessment (MoCA) [20] is a brief cognitive screening test to identify and stage dementia and includes items measuring attention, working memory, orientation, and short-term memory.

Hopkins Verbal Learning Test-Revised

The Hopkins Verbal Learning Test-Revised (HVLT) [21,22] is a list-learning and memory test that includes total recall (ie, total recalled words over 3 learning trials), a delayed recall trial, and a recognition trial.

Delis-Kaplan Executive Function System Verbal Fluency

This subtest [23] includes tests of verbal processing speed requiring the participant to name as many animals as possible in 1 minute and to name as many words starting with the letters F, A, and S in 1 minute.

Deficits Scores

For HVLT and Verbal Fluency tests, normative data from respective test manuals were used to convert raw scores to age-corrected T-scores. Each of the T-scores was converted into binary deficit scores. Deficits were defined as scores <23 on the MoCA or T-scores <40 on the remaining tests (reflecting >1 SD below the mean).

Overall Deficit

A composite binary variable was constructed by combining the MoCA, HVLT, and Verbal Fluency tests (0=no deficit, 1=deficit on any test).

Acoustic Features

This study used a standardized procedure for qualitative interview processing as outlined by previous research [24,25]. Acoustic files (digital speech standard) were obtained following testing and converted to .wav format using NCH Switch Audio Converter (NCH Software). The audio files included the interviewer’s speech; however, we note that although multiple staff members were involved in administering the battery of neuropsychological assessments, the interviews were conducted by the same person and included a common set of questions, see Section S2 in Multimedia Appendix 1 for details. To reduce the number of parameters, we used the feature set “eGeMAPSv02,” which is based upon the Geneva minimalistic acoustic parameter set for voice research and affective computing, which identifies a basic set of acoustic features commonly used in clinical speech analysis [26]. A total of 88 Geneva minimalistic acoustic parameter set acoustic features are identified in the Python openSMILE library, which has been previously validated for this purpose [27-29]. These features were then extracted from the entirety of the interview using openSMILE audio processing software (audEERING GmbH). Notable among these were features of spectral slope (alphaRatioUV, slope UV 500-1500 HZ) and balance or shape or flux (Mel-frequency cepstral coefficient). F0 in the context of acoustic features generally refers to the fundamental frequency or the lowest resonating frequency produced by the vocal tract, while F1, F2, and F3 refer to higher resonating frequencies seen as successive peaks in the frequency spectrum. These are also referred to as formants. More details on the acoustic features can be found in Section S3 in Multimedia Appendix 1.

Psycholinguistic Features

Linguistic features were extracted from the transcripts for each sample, drawing from established methodologies such as those detailed in Yamada et al [30] and other relevant literature [31]. In addition, we also explored the use of other higher-level psycholinguistic elements to assess language attributes, like readability, coherence, and references to forgetfulness and recollection. The interviews were transcribed using third-party services and were subsequently reviewed and verified manually.

In total, 86 distinct features were extracted to represent various linguistic traits: text statistics that denote parts of speech, vocabulary richness, grammatical complexity gauged by the nesting of phrases (Yngve depth) [32], verbal overlap between sentences (measured through cosine similarity [33,34]), sentiment analysis, readability metrics [35], and other features based on sentence embeddings generated by advanced language models such as the Bidirectional Encoder Representations from Transformers (BERT) [36]. Detailed interpretations of these features can be found in Table S1 in Multimedia Appendix 1.

Data Analysis

After incorporating sociodemographic variables, like age, gender, education, race (categorized as White, Black, or Other), and ethnicity (distinguished as Hispanic or non-Hispanic), the total feature set for classification encompassed 178 distinct features.

Predicting baseline and future cognitive deficits often uses traditional regression techniques such as linear regression analysis or mixed linear modeling. However, due to observed limitations in model fit with our data set, a classification approach was deemed more appropriate. Target variables were dichotomized using cutoffs based on literature recommendations. This adaptation not only improved model accuracy but also aligned with clinical standards, specifically diagnostic cutoffs like scores below 23 on the MoCA [37] or T-scores 1 SD below the mean [38].

Owing to the limited understanding of the audio feature space in the context of psychiatry and the sparse body of work on psycho-linguistic features, 6 diverse ML models were separately explored to determine their performance. This was done in part to characterize the problem space: a high-performing support vector machine model or k-nearest neighbor might suggest distinct regions or clusters in the feature space, which could be pursued for future investigation. The models were retrained for the follow-up assignments, in order to identify potential lead-lag effects. To address the risk of overfitting, the feature space was reduced to the top 10 using the Gini impurity index [39,40] and the performance results (ie, F_1-score, sensitivity, and specificity) were reported using leave-one-out cross-validation.

The following ML algorithms were used in the investigation: k-nearest neighbor, support vector machine, random forest, neural network, and naïve Bayes classifiers. Importantly, gender was considered alongside acoustic features in the ML analysis due to its potential impact on various acoustic properties, including pitch, which could represent a confounding variable. The hyperparameters applied across these models are exhaustively detailed in Table S2 in Multimedia Appendix 1.

The relative contribution of the features across domains was assessed by calculating the correlation between sociodemographic, acoustic, and psycholinguistic features with both raw scores and dichotomized deficits on neuropsychological subscales. Subsequently, the maximum correlation value for each feature with either the raw scores or deficit scores was determined, and the features were prioritized based on these values. The principal 25 features were then depicted in a heat map to facilitate the examination of their interrelationships. In addition, biclustering techniques [41] were used to delve deeper into the feature interdependencies. The emergent correlation matrix was visualized through a heat map, providing a comprehensive synopsis of the variable associations.

Ethical Considerations

The study procedures and data analyses were reviewed and approved by the University of California San Diego Human Research Protections Program (Institutional Review Board #170466). The participants provided written informed consent to participate in this study. All data were anonymized, by use of a manual review of each transcript to remove any proper names, addresses, or potentially identifying information. All participants whose data are presented here provided additional consent to the use of information extracted from audio recordings for research purposes. Participants were compensated US $75 for participation in the study, which included the clinical and neurocognitive tests and qualitative interviews detailed in this manuscript.

Results

Sample Characteristics

The sample's age ranged from 67 to 98 years at the initial visit, with a mean age of 83.3 (SD 7.0) years (Table 1). Most participants were single (n=45, 63%), White (n=65, 91%), and female (n=47, 66%), and had a high level of education (mean 15.9, SD 2.3 years). Cognitive functioning varied among participants, as indicated by MoCA scores ranging from 13 to 29. Depression scores were low (mean 9-item Patient Health Questionnaire score of 3.2, SD 3.8), rendering the sample inadequate for investigating the intersection of cognitive impairment with depression. The average time to the follow-up visit was 1.4 years (mean 512.3, SD 84.5 days) postbaseline (refer to Table 2). Attrition was primarily due to a lack of interest (n=27, 21%), transfer to more intensive care (n=11, 9%), participant deaths (n=11, 9%), and medical issues (n=3, 2%). A minority (n=3, 2%) reportedly withdrew due to cognitive decline. The reasons for the decrease in participation were not further analyzed.

Classification Performance Using Acoustic and Psycholinguistic Features

The initial assessment focused on the effectiveness of various feature groups in distinguishing individuals with cognitive impairment from those without at baseline. To this end, F_1-scores were used due to their balanced consideration of precision and recall, which is critical in the context of an uneven class distribution. Table 3 shows F_1 performance scores, sensitivity, and specificity for various feature groups. Assuming a threshold of 0.75 for F_1-scores (see Section S4, Multimedia Appendix 1 for the choice), acoustic and psycholinguistic features were acceptable and generally higher than F_1-scores of sociodemographic features. Given the limited performance, sociodemographic features (gender, age, race, years of education) were best at predicting HVLT total recall (or learning) deficits compared to other deficits. Acoustic features were the best predictors of animal naming and overall deficits, and the psycholinguistic features performed best for HVLT total recall. The performance for MoCA and HVLT retention was comparable for both acoustic (F_1 of 0.76 and 0.71, respectively) and psycholinguistic feature (F_1 of 0.78 and 0.70, respectively) sets. Acoustic features performed better than psycholinguistic features in HVLT delayed recall (F_1 of 0.72 vs 0.67), animal naming (F_1 of 0.80 vs 0.70), and letter fluency (F_1 of 0.78 vs 0.73), while psycholinguistic features performed better than acoustic in HVLT total recall (learning; F_1 of 0.82 vs 0.77). As expected, the combined set (acoustic, linguistic, and sociodemographic features) performed the best among all individual feature sets. Gender did not play a factor among the top 10 features for any target in the baseline or the follow-up visit.

Table 3. Performance of features (by categories) for classification of deficits in baseline visit using top 10 features.

Target	Sample size	Sociodemographic top model, F_1 (sensitivity, specificity)	Acoustic[a] top model, F_1 (sensitivity, specificity)	Psycholinguistic top model, F_1 (sensitivity, specificity)	Combined[b] top model, F_1 (sensitivity, specificity)
MoCA[c]	71	ANN[d] logistic, 0.62 (0.39, 0.79)	NB[e], 0.76 (0.71, 0.79)	ANN logistic, 0.78 (0.64, 0.88)	NB, 0.80 (0.79, 0.81)
HVLT[f] total recall T deficit score	67	NB, 0.74 (0.27, 0.90)	NB, 0.77 (0.67, 0.79)	NB, 0.82 (0.60, 0.88)	NB, 0.85 (0.73, 0.88)
HVLT delayed recall T deficit score	67	NB, 0.60 (0.05, 0.92)	ANN ReLu, 0.72 (0.42, 0.85)	ANN ReLu, 0.67 (0.32, 0.83)	NB, 0.74 (0.74, 0.73)
HVLT retention T deficit score	67	NB, 0.64 (0.14, 0.98)	NB, 0.71 (0.62, 0.74)	ANN tanh, 0.70 (0.48, 0.80)	NB, 0.73 (0.90, 0.63)
Animals T deficit score[g]	68	ANN tanh, 0.61 (0.29, 0.77)	NB, 0.80 (0.81, 0.79)	NB, 0.70 (0.57, 0.74)	NB, 0.80 (0.71, 0.83)
FAS T deficit score[h]	68	Random forest, 0.65 (0.30, 0.81)	NB, 0.78 (0.85, 0.73)	SVM[i], 0.73 (0.40, 0.90)	NB, 0.76 (0.75, 0.75)
Overall deficit score	71	ANN ReLu, 0.69 (0.76, 0.50)	NB, 0.81 (0.84, 0.70)	NB, 0.81 (0.76, 0.90)	NB, 0.86 (0.84, 0.90)

[a] Incudes gender as a feature.

[b] Combined: acoustic, psycholinguistic, and sociodemographic features.

[c] MoCA: Montreal Cognitive Assessment.

[d] ANN: artificial neural network.

[e] NB: naïve Bayes.

[f] HVLT: Hopkins Verbal Learning Test.

[g] Animals T-score (D-KEFS Norms).

[h] FAS total T-score (D-KEFS Norms).

[i] SVM: support vector machine.

Using baseline features to determine cognitive status at subsequent follow-up visits (Table 4), it was observed that the predictive capacity of these features remained consistent across tests (for instance, an F_1-score of 0.87 was noted for MoCA using all features). This observation was in line with the initial analysis, where psycholinguistic features outperformed acoustic features, which in turn were more predictive than sociodemographic variables. There was also an improvement in the performance of sociodemographic features (F_1-scores; Table 4) and sensitivity (of >0.5 in most cases, Table 4), but they continued to underperform compared with the acoustic and psycholinguistic features. MoCA (F_1=0.87, sensitivity=0.85, specificity=0.88) and letter fluency (F_1=0.91, sensitivity=1.00, specificity=0.87) were the best predicted cognitive tests for a year in the future. Among the ML models used, the naïve Bayes classifier generally performed better than other models for most classification targets (Table S3, Multimedia Appendix 1). In addition, we performed a 10-fold cross-validation; the results aligned closely with leave-one-out cross-validation for best-performing models and are reported in Table S4 in Multimedia Appendix 1.

Table 4. Performance of features (by categories) for classification of deficits in follow-up visits using top 10 features.

Target	Sample Size	Sociodemographic top model, F_1 (sensitivity, specificity)	Acoustic[a] top model, F_1 (sensitivity, specificity)	Psycholinguistic top model, F_1 (sensitivity, specificity)	Combined[b] top model, F_1 (sensitivity, specificity)
MoCA[c]	37	ANN[d] logistic, 0.72 (0.54, 0.83)	NB[e], 0.79 (0.92, 0.71)	NB, 0.87 (0.85, 0.88)	ANN tanh, 0.87 (0.85, 0.88)
HVLT[f] total recall T deficit score	45	Random forest, 0.64 (0.58, 0.69)	NB, 0.71 (0.74, 0.69)	NB, 0.69 (0.63, 0.73)	ANN ReLu, 0.76 (0.79, 0.73)
HVLT delayed recall T deficit score	45	NB, 0.71 (0.58, 0.81)	NB, 0.69 (0.68, 0.69)	NB, 0.82 (0.79, 0.85)	NB, 0.87 (0.84, 0.88)
HVLT retention T deficit score	45	ANN logistic, 0.71 (0.63, 0.77)	NB, 0.69 (0.68, 0.69)	NB, 0.76 (0.68, 0.81)	NB, 0.82 (0.84, 0.81)
Animals T deficit score[g]	44	Random forest, 0.66 (0.58, 0.72)	NB, 0.77 (0.84, 0.72)	NB, 0.70 (0.63, 0.76)	NB, 0.82 (0.79, 0.84)
FAS T deficit score[h]	44	ANN tanh, 0.70 (0.46, 0.81)	NB, 0.84 (0.77, 0.87)	NB, 0.89 (1.00, 0.84)	NB, 0.91 (1.00, 0.87)
Overall deficit score	46	ANN tanh, 0.81 (0.94, 0.40)	Random Forest, 0.78 (0.86, 0.50)	ANN Logistic, 0.80 (0.89, 0.50)	NB, 0.89 (0.92, 0.80)

[a] Incudes gender as feature.

[b] Combined: acoustic, psycholinguistic, and sociodemographic features.

[c] MoCA: Montreal Cognitive Assessment.

[d] ANN: artificial neural network.

[e] NB: naïve Bayes.

[f] HVLT: Hopkins Verbal Learning Test.

[g] Animals T-Score (D-KEFS Norms).

[h] FAS Total T-Score (D-KEFS Norms).

Ranking and Proportion of Acoustic and Psycholinguistic Features and Demographics

Overall, acoustic features performed best in classifying animal fluency, letter fluency, and HVLT total recall (learning), while psycholinguistic features performed best in classifying MoCA and HVLT retention (Table 5). The prominence of acoustic features in deficit prediction prompted us to establish age correlates of acoustic features (Table S5, Multimedia Appendix 1). Few sociodemographic features were present in the top 10 features. Among acoustic features, the most predictive included ones corresponding to nonverbal vocalizations of energy and its distribution across frequencies (formants) in absolute ranges of 500-1500 Hz (slopeUV), as well as in terms of individual physiology (Mel-frequency cepstral coefficient), and jitter. Variation in loudness was also an important acoustic feature in identifying cognitive deficits. Among the psycholinguistic features, the amount of speech produced (number of transcribed characters and words, number of utterances) along with vocabulary richness (vocabulary type token ratio, interview readability), proportion of nouns (noun to verb ratio, verb frequency, pronoun, and particle frequency), repetition (cosine similarity), and sentiment were important correlates of cognitive deficits.

Table 5. Contribution profile of deficits based on top contributing features at the baseline visit. MoCA[a] scores are dominated by psycholinguistic predictors. HVLT[b] total and delayed recall, animal naming, and FAS[c] are all predominantly determined by acoustic features. Sociodemographic features play a minor role in HVLT total recall and the overall deficit.

Cognitive assessment target	Acoustic (%)	Psycholinguistic (%)	Sociodemographic (%)
MOCA	10	90	0
HVLT total recall	80	10	10
HVLT delayed recall	70	30	0
HVLT retention	40	60	0
Animals	70	30	0
FAS	70	30	0
Overall deficit	20	70	10

[a] MoCA: Montreal Cognitive Assessment.

[b] HVLT: Hopkins Verbal Learning Test-Revised.

[c] F-A-S verbal fluency test.

Clustering and Heat Map of Features and Targets

The raw scores of HVLT and MoCA tasks were clustered in a subtree, while all deficits were in a separate subtree. The clustering suggested that animal naming deficits very closely resembled the derived overall deficit.

Our analysis indicated that the set of top contributing features across all targets was clustered into 4 subtrees. The cluster labeled A (Figure 1) was comprised of psycholinguistic features representing vocabulary richness and other metrics of vocabulary use including type token ratio, noun-verb ratio, interview readability, and sentiment. These features correlated positively with task scores and negatively with deficits. The cluster labeled B in Figure 1 predominantly contains psycholinguistic features representing increased speech production. Included in this cluster were features corresponding to particle, verb, and pronoun use, increased utterances, transcribed characters, and words. The cluster labeled C also predominantly includes psycholinguistic properties features and contains features that represent speech fragmentation. This includes features that punctuate language (interjections) and repetition (cosine similarity), and also present were acoustic features representing variation in loudness (slopeUV500-1500, loudness) or the control of glottis closure. These features correlated positively with deficits and negatively with raw cognitive scores. In contrast to clusters A, B, and C, the cluster labeled D was comprised of almost all acoustic features representing spectral balance and tilt.

Figure 1. Heat map and results of biclustering of top 25 features by correlation. Along the x-axis, the acoustic features are in green, psycholinguistic features in pink, and sociodemographic are in black. Along the y-axis, the task scores are in brown and the deficits in blue. Four clusters of features are evident, (A) and (B) being predominantly psycholinguistic and (D) predominantly acoustic. (A) Lexical richness and positive sentiment: the group of features reflect vocabulary richness (interview readability, vocabulary type token ratio, noun to verb ratio) and sentiment that relates positively with the cognition scores and negatively with deficits. (B) Reversal of concreteness and greater speech production: comprises mostly of psycholinguistic features that suggest replacement of nouns by descriptive phrases (pronoun frequency, particle frequency, verb frequency, number of utterances, number of transcribed characters and words, yngve depth) but one acoustic feature is also included (mean alpha ratio UV simple moving average). These features correlate positively with some deficits and negatively with others and show a certain homogeneity, the cluster associates with increased language output. (C) Speech fragmentation: the cluster seems to encode speech fragmentation through interjection (interjection frequency), repetition (cosine similarity) and loudness variation (norm of loudness standard deviation), and audio features for spectral balance in absolute frequency terms (mean slope UV 500-1500 Hz and F1 bandwidth) correlating negatively with cognition scores and positively with the deficits. (D) Nonverbal vocalizations: acoustic features representing spectral balance or shape or dynamics in individual vocal tract and glottis physiology (mean and SD of mel-frequency cepstral coefficients, jitter) and age, that corelates negatively with the cognition scores but positively with deficits and can encode nonverbal emotions. HVLT: Hopkins Verbal Learning Test-Revised; MoCA: Montreal Cognitive Assessment.

Discussion

Principal Findings

A manual review of the cognitive measures of participants along the timeline revealed abrupt changes that were not always monotonic (strictly decreasing) as might be expected. In fact, MoCA has been shown to significantly improve in the second administration [42]. These effects combined with the noise in the testing, as well as the within-subject fluctuations, make regression over short intervals difficult. Furthermore, individuals transferred to higher care facilities, who may have shown greater declines, were not included in this analysis. The research and medical team agreed that modeling individual decline over 1.4 years might not be feasible. Posing it as a classification problem by dichotomization, however, allowed us to model age-related changes at a very broad level with a modest degree of success.

This work is among the first to evaluate both acoustic and psycholinguistic features in a longitudinal study of cognitive performance in an older adult sample. We found that both acoustic and psycholinguistic features provided a reasonably strong classification of overall cognitive impairment, verbal memory, and verbal fluency tasks at both baseline and follow-up assessments. While using psycholinguistic features and sociodemographic features alone, the classification of cognitive impairment was similar to previous approaches [13]. Combining the acoustic and psycholinguistic features, however, enhanced the classification performance. We found that baseline acoustic and psycholinguistic features predicted future performance on the same cognitive tasks at a mean follow-up of 1.4 years. Comparing the relative accuracy of acoustic versus psycholinguistic features, there was a slight disadvantage of acoustic features compared to psycholinguistic features using the F_1-score metric in the follow-up. Features clustered by type and varied across cognitive tasks, suggesting that different features may be useful for detecting different aspects of cognitive impairment. Since the actual performance scores (F_1-scores) were in the 0.7-0.8 range, separation boundaries were expected to be fuzzy. Overall, our findings add to the growing body of literature indicating that linguistic and acoustic analysis of speech samples may aid in the detection of cognitive deficits in aging.

Our findings are consistent with prior research that has investigated psycholinguistic markers of cognitive aging. A change, generally a reduction, in noun production, has long been identified as an early indicator of cognitive decline by several studies [43-45]. Nouns and verbs are the most common categories in the English language, and their use often declines in early dementia [46]. Word-finding difficulties foreshadow progressive aphasias and other degenerative dementias [47,48]. In our heat map–based analysis of the baseline data, we found that lexical richness related negatively to deficits and positively to cognitive performance. The reduced access to nouns due to a decline in semantic networks may initially result in longer phrases that describe the nouns, thus resulting in increased language production in social settings [49,50]. This may also be related to as "reversal of concreteness effect" [51-53]. This phenomenon is reflected in the features that represent an increase in the frequency of pronouns, particles, and verbs (eg, the inability to recall the word "fork" could result in saying "that thing you eat with," such that a noun is replaced by several other parts of speech) and increase in utterances, words and characters, and even coverbal gestures [54]. Grammatically, this would cause an increase in the depth of the parse tree, the Yngve depth [32], as a single word gets replaced by a phrase. Written grammatical complexity, however, decreases over longer timeframes, as suggested by a study spanning the lifetime of a novelist with Alzheimer disease [55]. Notably, we did not predict decline per se but rather future cognitive ability. Eyigoz et al [13] demonstrated the predictive value of linguistic features over a 7-year period in reference to conversion to Alzheimer disease. It is possible that our mean follow-up period of 1.4 years was too short to result in a significant number of individuals becoming impaired.

Our study adds to the comparatively smaller body of literature on acoustic features in cognitive aging. Exploring these features is important given that not all are detectable with the human ear, despite some evidence that they may covary with age and cognitive ability. Acoustic features relating to the Mel-frequency cepstral coefficient may have embedded within them artifacts of age-related decline [56,57] leading to the poorer representation of nonverbal vocalizations, possibly through the expression of emotions through glottis control, for example, laughter or giggle [58]. Some top predicting acoustic features were also associated with variation in loudness [59] or the glottis closing slowly or insufficiently due to aging [60]. Such nonverbal vocalizations are not correlated with grammar [61,62], so they are undetected by NLP extraction tools. Some, such as laughter or giggle, are produced in glottal or subglottal structures spontaneously and are in the annotation category, while others such as breathing, correlate with pauses in prosodic hierarchy [63]. Aging is also reflected in jitter [64] due to vocal fold atrophy [65]. Overall, it was notable that our best models combined acoustic and psycholinguistic features, and that our heat map suggested that different cognitive domains were predicted by unique feature sets that clustered with acoustic features or psycholinguistic. As such, future research should evaluate the dynamics of within-person change in acoustic and linguistic features as they may predict changes in cognitive performance in a range of cognitive tasks over time.

It is possible that the decline manifests itself in fits and bursts due to the noise in the measurement of cognitive tasks and within-individual fluctuations: the changes are small over the interval of 1.4 years compared to the overall value. Furthermore, individuals who were transferred to a higher level of care may have a greater decline but could not be included in this analysis. Hence, our data does not allow for the prediction of various cognitive scores on an individual basis. However, if the scores are dichotomized and aggregated, the predictions about the cognitive status change can achieve performance that is suitable for screening purposes. Future studies with larger samples and longer periods of follow-up would allow for finer-grained prediction of cognitive decline in specific domains.

One study [66] has documented extensively the performances of a variety of BERT-based transformers on this task. We found that most of these models under-performed our combined models, and only one approached a comparable performance ($\mathrm{BERT}_{\mathrm{Large}}$-LR; F_1-scores of 87%). This, in our opinion, can be attributed to our rich feature set that included acoustic features that potentially convey important information about the physical health of the participants. The use of large language models (such as ChatGPT) was avoided due to two concerns: (1) the models are criticized for opaqueness to feature interpretation, which was our focus, and (2) patient privacy concerns. At the time of our research, the available generative large language models did not meet our specific needs in terms of local deployment capabilities and data sensitivity [67] (ie, ChatGPT and Claude could not be run locally). We are excited to note that with the introduction of open-source models, such as Llama 3, which offers robust performance while being feasible for local deployment, we plan to bridge this gap.

Limitations

There are some limitations in this study. The sample was relatively homogenous, with high socioeconomic status, primarily White, and highly educated, relative to the broader older adult population. The acoustic recordings were roughly 1.5-2 hours in length, and thus the minimum length of speech data needed for these analyses is unknown. The current interview length may not be practical for clinical deployment. These analyses include acoustic features extracted from the entire interview; the fraction of the interviewer's speech was small and there were fixed questions. Although the same interviewer conducted the interview with the same set of prompts, it is reasonable to expect that some bias was introduced in the acoustic features of the interviewee resulting in some loss of performance of ML models. Other limitations include that drop out was significant and longitudinal prediction may be affected by this; as well, there was a variable follow-up duration. We also had planned a broader neuropsychological battery with nonverbal domains, but the transfer to a remote assessment paradigm due to the COVID-19 pandemic prevented this. In addition to impacting the shift to remote assessments, the COVID-19 pandemic may have impacted aspects of daily life that may influence cognitive ability (eg, access to physical activity), therefore, the findings should be interpreted in this light.

Finally, while we did perform leave-one-out cross-validation, we lacked an independent sample with which to validate these features or establish confidence intervals. Model fits were evaluated based solely on F_1-score comparisons. Constrained by the mentioned limitations, the study should be considered exploratory.

Conclusions

Despite these limitations, our study raised questions that warrant future investigation. We were unable to ascertain if the features most indicative of cognitive impairments are also predictive of those likely to experience decline in the near future. Furthermore, the mapping between the acoustic features and cognitive domains remains unclear. The value of adding acoustic and psycholinguistic features to assessments and the duration of speech needed to discriminate cognitive impairments could be contrasted to the relative importance beyond that associated with cognitive screening data. Although our semistructured interview was broad, it would be useful to understand both the impact of the nature of the prompts and topics covered, as well as the minimum duration of speech sample required, to achieve the desired accuracy in predicting cognitive deficits. The generalizability of acoustic and psycholinguistic features, especially beyond English-speaking and primarily well-educated White groups, requires confirmation across different languages and racial or ethnic backgrounds. Overall, our results suggest a potential role for acoustic and psycholinguistic data in cognitive assessment; the next step is to determine the timing and connection to brain changes that occur with pathological aging processes such as in dementia.

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Data Availability

The datasets generated during or analyzed during this study are not publicly available due to privacy concerns, including Health Insurance Portability and Accountability Act regulations, but the code for generating custom features of machine learning model parameters is available from the corresponding author upon reasonable request.

Authors' Contributions

VDB designed and implemented the artificial intelligence-based (natural language processing and machine learning) approaches, performed data analysis, interpreted results, prepared the first draft of the manuscript, incorporated feedback, and edited and contributed to drafts of the manuscript. JMR proposed the research questions, helped with data analysis and interpretation, provided feedback, edited, and contributed to drafts of the manuscript. EWT proposed the research questions, helped with data analysis and interpretation, provided feedback, edited, and contributed to drafts of the manuscript. EEL oversaw the study, proposed the research questions, helped with data analysis and interpretation, provided feedback, edited, and contributed to drafts of the manuscript. RPF wrote sections of the first draft, helped with data analysis and interpretation, provided feedback, edited, and contributed to drafts of the manuscript. EB oversaw the study, proposed the research questions, implemented the natural language processing–based approaches, helped with data analysis and interpretation, provided feedback, edited, and contributed to drafts of the manuscript. CAD oversaw the study, proposed the research questions, helped with data analysis and interpretation, provided feedback, edited, and contributed to drafts of the manuscript. All authors contributed to the manuscript revision and read and approved the submitted version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary Material.
[DOCX File , 4944 KB - aging_v7i1e54655_app1.docx]

References

1. Manly JJ, Jones RN, Langa KM, Ryan LH, Levine DA, McCammon R, et al. Estimating the prevalence of dementia and mild cognitive impairment in the US: the 2016 health and retirement study harmonized cognitive assessment protocol project. JAMA Neurol 2022;79(12):1242-1249 [FREE Full text] [doi: 10.1001/jamaneurol.2022.3543] [Medline: 36279130]
2. Jack CR, Knopman DS, Jagust WJ, Petersen RC, Weiner MW, Aisen PS, et al. Update on hypothetical model of Alzheimer's disease biomarkers. Lancet Neurol 2013;12(2):207. [doi: 10.1016/j.jalz.2013.04.248]
3. Boschi V, Catricalà E, Consonni M, Chesi C, Moro A, Cappa SF. Connected speech in neurodegenerative language disorders: a review. Front Psychol 2017;8:269 [FREE Full text] [doi: 10.3389/fpsyg.2017.00269] [Medline: 28321196]

4. Bondi MW, Edmonds EC, Jak AJ, Clark LR, Delano-Wood L, McDonald CR, et al. Neuropsychological criteria for mild cognitive impairment improves diagnostic precision, biomarker associations, and progression rates. J Alzheimers Dis 2014;42(1):275-289 [FREE Full text] [doi: 10.3233/JAD-140276] [Medline: 24844687]
5. Taler V, Phillips NA. Language performance in Alzheimer's disease and mild cognitive impairment: a comparative review. J Clin Exp Neuropsychol 2008;30(5):501-556. [doi: 10.1080/13803390701550128] [Medline: 18569251]
6. Ahmed S, de Jager CA, Haigh AM, Garrard P. Semantic processing in connected speech at a uniformly early stage of autopsy-confirmed Alzheimer's disease. Neuropsychology 2013;27(1):79-85. [doi: 10.1037/a0031288] [Medline: 23356598]
7. Ahmed S, Haigh AMF, de Jager CA, Garrard P. Connected speech as a marker of disease progression in autopsy-proven Alzheimer's disease. Brain 2013;136(Pt 12):3727-3737 [FREE Full text] [doi: 10.1093/brain/awt269] [Medline: 24142144]
8. Mueller KD, Hermann B, Mecollari J, Turkstra LS. Connected speech and language in mild cognitive impairment and Alzheimer's disease: a review of picture description tasks. J Clin Exp Neuropsychol 2018;40(9):917-939 [FREE Full text] [doi: 10.1080/13803395.2018.1446513] [Medline: 29669461]
9. Clarke N, Foltz P, Garrard P. How to do things with (thousands of) words: computational approaches to discourse analysis in Alzheimer's disease. Cortex 2020;129:446-463. [doi: 10.1016/j.cortex.2020.05.001] [Medline: 32622173]
10. Asgari M, Kaye J, Dodge H. Predicting mild cognitive impairment from spontaneous spoken utterances. Alzheimers Dement (N Y) 2017;3(2):219-228 [FREE Full text] [doi: 10.1016/j.trci.2017.01.006] [Medline: 29067328]
11. Ferrario A, Luo M, Polsinelli AJ, Moseley SA, Mehl MR, Yordanova K, et al. Predicting working memory in healthy older adults using real-life language and social context information: a machine learning approach. JMIR Aging 2022;5(1):e28333 [FREE Full text] [doi: 10.2196/28333] [Medline: 35258457]
12. Polsinelli AJ, Moseley SA, Grilli MD, Glisky EL, Mehl MR. Natural, everyday language use provides a window into the integrity of older adults' executive functioning. J Gerontol B Psychol Sci Soc Sci 2020;75(9):e215-e220. [doi: 10.1093/geronb/gbaa055] [Medline: 32310293]
13. Eyigoz E, Mathur S, Santamaria M, Cecchi G, Naylor M. Linguistic markers predict onset of Alzheimer's disease. EClinicalMedicine 2020;28:100583 [FREE Full text] [doi: 10.1016/j.eclinm.2020.100583] [Medline: 33294808]
14. Shah Z, Sawalha J, Tasnim M, Qi SA, Stroulia E, Greiner R. Learning language and acoustic models for identifying Alzheimer’s dementia from speech. Front Comput Sci 2021;3:624659. [doi: 10.3389/fcomp.2021.624659]
15. Koo J, Lee JH, Pyo J, Jo Y, Lee K. Exploiting multi-modal features from pre-trained networks for Alzheimer's dementia recognition. 2020 Presented at: Interspeech; October, 2020; Shanghai, China. [doi: 10.21437/Interspeech.2020-3153]
16. Balagopalan A, Eyre B, Rudzicz F, Novikova J. To BERT or not to BERT: comparing speech and language-based approaches for Alzheimer's disease detection. 2020 Presented at: Interspeech; October, 2020; Shanghai, China. [doi: 10.21437/interspeech.2020-2557]
17. Jeste DV, Glorioso D, Lee EE, Daly R, Graham S, Liu J, et al. Study of independent living residents of a continuing care senior housing community: sociodemographic and clinical associations of cognitive, physical, and mental health. Am J Geriatr Psychiatry 2019;27(9):895-907 [FREE Full text] [doi: 10.1016/j.jagp.2019.04.002] [Medline: 31078382]
18. Paredes AM, Lee EE, Chik L, Gupta S, Palmer BW, Palinkas LA, et al. Qualitative study of loneliness in a senior housing community: the importance of wisdom and other coping strategies. Aging Ment Health 2021;25(3):559-566 [FREE Full text] [doi: 10.1080/13607863.2019.1699022] [Medline: 31918561]
19. Van Patten R, Lee EE, Graham SA, Depp CA, Kim HC, Jeste DV, et al. The utility of the timed up-and-go test in predicting cognitive performance: a cross-sectional study of independent living adults in a retirement community. J Appl Gerontol 2020;39(10):1163-1168 [FREE Full text] [doi: 10.1177/0733464819872636] [Medline: 32924758]
20. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The montreal cognitive assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc 2005;53(4):695-699. [doi: 10.1111/j.1532-5415.2005.53221.x] [Medline: 15817019]
21. Brandt J. The hopkins verbal learning test: development of a new memory test with six equivalent forms. Clin Neuropsychol 1991;5(2):125-142. [doi: 10.1080/13854049108403297]
22. Benedict RH, Schretlen D, Groninger L, Brandt J. Hopkins verbal learning test—revised: normative data and analysis of inter-form and test-retest reliability. Clin Neuropsychol 2010;12(1):43-55. [doi: 10.1076/clin.12.1.43.1726]
23. Delis DC, Kaplan E, Kramer JH. Delis-kaplan executive function system. Assessment 2001:796-801. [doi: 10.1037/t15082-000]
24. Badal VD, Nebeker C, Shinkawa K, Yamada Y, Rentscher KE, Kim HC, et al. Do words matter? Detecting social isolation and loneliness in older adults using natural language processing. Front Psychiatry 2021;12:728732 [FREE Full text] [doi: 10.3389/fpsyt.2021.728732] [Medline: 34867518]
25. Badal VD, Graham SA, Depp CA, Shinkawa K, Yamada Y, Palinkas LA, et al. Prediction of loneliness in older adults using natural language processing: exploring sex differences in speech. Am J Geriatr Psychiatry 2021;29(8):853-866 [FREE Full text] [doi: 10.1016/j.jagp.2020.09.009] [Medline: 33039266]
26. Eyben F, Scherer KR, Schuller BW, Sundberg J, Andre E, Busso C, et al. The Geneva minimalistic acoustic parameter set (GeMAPS) for voice research and affective computing. IEEE Trans Affective Comput 2016;7(2):190-202. [doi: 10.1109/taffc.2015.2457417]

27. Eyben F, Wöllmer M, Schuller B. OpenEAR—introducing the Munich open-source emotion and affect recognition toolkit. : IEEE; 2009 Presented at: 3rd International Conference on Affective Computing and Intelligent Interaction and Workshops; September 10, 2009; Amsterdam, Netherlands. [doi: 10.1109/acii.2009.5349350]
28. Schuller B, Eyben F, Rigoll G. Fast and robust meter and tempo recognition for the automatic discrimination of ballroom dance styles. : IEEE; 2007 Presented at: IEEE International Conference on Acoustics, Speech and Signal Processing—ICASSP '07; April 15, 2007; HI, USA. [doi: 10.1109/icassp.2007.366655]
29. Schuller B, Steidl S, Batliner A. The Interspeech 2009 Emotion Challenge. Brighton, UK: Interspeech; 2009.
30. Yamada Y, Shinkawa K, Shimmei K. Atypical repetition in daily conversation on different days for detecting Alzheimer disease: evaluation of phone-call data from regular monitoring service. JMIR Ment Health 2020;7(1):e16790 [FREE Full text] [doi: 10.2196/16790] [Medline: 31934870]
31. Badal VD, Nebeker C, Shinkawa K, Yamada Y, Rentscher KE, Kim HC, et al. Do words matter? Detecting social isolation and loneliness in older adults using natural language processing. Front Psychiatry 2021;12:728732 [FREE Full text] [doi: 10.3389/fpsyt.2021.728732] [Medline: 34867518]
32. Yngve VH. A model and an hypothesis for language structure. Pro American Phil Soc 1960;104(5):444-466 [FREE Full text]
33. Wang J, Dong Y. Measurement of text similarity: a survey. Information 2020;11(9):421. [doi: 10.3390/info11090421]
34. Guo K. Testing and validating the cosine similarity measure for textual analysis. SSRN J 2022:41. [doi: 10.2139/ssrn.4258463]
35. Crossley S, Heintz A, Choi JS, Batchelor J, Karimi M, Malatinszky A. A large-scaled corpus for assessing text readability. Behav Res Methods 2023;55(2):491-507 [FREE Full text] [doi: 10.3758/s13428-022-01802-x] [Medline: 35297016]
36. Devlin J, Chang MW, Lee K, Toutanova K. BERT: pre-training of deep bidirectional transformers for language understanding. arXiv Preprint posted online on October 11, 2018. [doi: 10.48550/arXiv.1810.04805]
37. Carson N, Leach L, Murphy KJ. A re-examination of Montreal Cognitive Assessment (MoCA) cutoff scores. Int J Geriatr Psychiatry 2018 Feb;33(2):379-388. [doi: 10.1002/gps.4756] [Medline: 28731508]
38. Busse A, Hensel A, Gühne U, Angermeyer MC, Riedel-Heller SG. Mild cognitive impairment: long-term course of four clinical subtypes. Neurology 2006;67(12):2176-2185. [doi: 10.1212/01.wnl.0000249117.23318.e1] [Medline: 17190940]
39. Tyagi N. Understanding the Gini index and information gain in decision trees. URL: https://medium.com/analytics-steps/understanding-the-gini-index-and-information-gain-in-decision-trees-ab4720518ba8 [accessed 2020-07-01]
40. Brown SD, Myles AJ. GINI Index. ScienceDirect. 2009. URL: https://www.sciencedirect.com/topics/mathematics/gini-index [accessed 2024-08-06]
41. Zhao H, Liew AWC, Wang DZ, Yan H. Biclustering analysis for pattern discovery: current techniques, comparative studies and applications. Curr Bioinf 2012;7(1):43-55. [doi: 10.2174/157489312799304413]
42. Cooley SA, Heaps JM, Bolzenius JD, Salminen LE, Baker LM, Scott SE, et al. Longitudinal change in performance on the Montreal cognitive assessment in older adults. Clin Neuropsychol 2015;29(6):824-835 [FREE Full text] [doi: 10.1080/13854046.2015.1087596] [Medline: 26373627]
43. Bird H, Ralph MAL, Patterson K, Hodges JR. The rise and fall of frequency and imageability: noun and verb production in semantic dementia. Brain Lang 2000;73(1):17-49. [doi: 10.1006/brln.2000.2293] [Medline: 10872636]
44. De Jager C, Blackwell AD, Budge MM, Sahakian BJ. Predicting cognitive decline in healthy older adults. Am J Geriatr Psychiatry 2005;13(8):735-740. [doi: 10.1176/appi.ajgp.13.8.735] [Medline: 16085791]
45. Cao L, Han K, Lin L, Hing J, Ooi V, Huang N, et al. Reversal of the concreteness effect can be detected in the natural speech of older adults with amnestic, but not non-amnestic, mild cognitive impairment. Alzheimers Dement (Amst) 2024;16(2):e12588 [FREE Full text] [doi: 10.1002/dad2.12588] [Medline: 38638800]
46. Almor A, Aronoff JM, MacDonald MC, Gonnerman LM, Kempler D, Hintiryan H, et al. A common mechanism in verb and noun naming deficits in Alzheimer's patients. Brain Lang 2009;111(1):8-19 [FREE Full text] [doi: 10.1016/j.bandl.2009.07.009] [Medline: 19699513]
47. Rohrer JD, Knight WD, Warren JE, Fox NC, Rossor MN, Warren JD. Word-finding difficulty: a clinical analysis of the progressive aphasias. Brain 2008;131(Pt 1):8-38 [FREE Full text] [doi: 10.1093/brain/awm251] [Medline: 17947337]
48. Mesulam MM. Primary progressive aphasia—a language-based dementia. N Engl J Med 2003;349(16):1535-1542. [doi: 10.1056/NEJMra022435] [Medline: 14561797]
49. Dodge HH, Mattek N, Gregor M, Bowman M, Seelye A, Ybarra O, et al. Social markers of mild cognitive impairment: proportion of word counts in free conversational speech. Curr Alzheimer Res 2015;12(6):513-519 [FREE Full text] [doi: 10.2174/1567205012666150530201917] [Medline: 26027814]
50. Appell J, Kertesz A, Fisman M. A study of language functioning in Alzheimer patients. Brain Lang 1982;17(1):73-91. [doi: 10.1016/0093-934x(82)90006-2] [Medline: 7139272]
51. Papagno C, Capasso R, Miceli G. Reversed concreteness effect for nouns in a subject with semantic dementia. Neuropsychologia 2009;47(4):1138-1148. [doi: 10.1016/j.neuropsychologia.2009.01.019] [Medline: 19350708]
52. Jessen F, Heun R, Erb M, Granath DO, Klose U, Papassotiropoulos A, et al. The concreteness effect: evidence for dual coding and context availability. Brain Lang 2000;74(1):103-112. [doi: 10.1006/brln.2000.2340] [Medline: 10924219]
53. Crutch SJ, Warrington EK. Abstract and concrete concepts have structurally different representational frameworks. Brain 2005;128(Pt 3):615-627. [doi: 10.1093/brain/awh349] [Medline: 15548554]

54. Carlomagno S, Pandolfi M, Marini A, Di Iasi G, Cristilli C. Coverbal gestures in Alzheimer's type dementia. Cortex 2005;41(4):535-546. [doi: 10.1016/s0010-9452(08)70193-x] [Medline: 16042029]
55. Pakhomov S, Chacon D, Wicklund M, Gundel J. Computerized assessment of syntactic complexity in Alzheimer's disease: a case study of Iris Murdoch's writing. Behav Res Methods 2011;43(1):136-144. [doi: 10.3758/s13428-010-0037-9] [Medline: 21287110]
56. Yang Q, Xu F, Ling Z, Li X, Li Y, Fang D. Selecting and analyzing speech features for the screening of mild cognitive impairment. : IEEE; 2021 Presented at: 43rd Annual International Conference of the IEEE Engineering in Medicine & Biology Society (EMBC); November 04, 2021; Hefei, China. [doi: 10.1109/embc46164.2021.9630752]
57. Fu Z, Haider F, Luz S. Predicting mini-mental status examination scores through paralinguistic acoustic features of spontaneous speech. : IEEE; 2020 Presented at: 42nd Annual International Conference of the IEEE Engineering in Medicine & Biology Society (EMBC); July 20, 2020; QC, Canada. [doi: 10.1109/embc44109.2020.9175379]
58. Kamiloğlu RG, Boateng G, Balabanova A, Cao C, Sauter DA. Superior communication of positive emotions through nonverbal vocalisations compared to speech prosody. J Nonverbal Behav 2021;45(4):419-454 [FREE Full text] [doi: 10.1007/s10919-021-00375-1] [Medline: 34744232]
59. Sundberg J, Nordenberg M. Effects of vocal loudness variation on spectrum balance as reflected by the alpha measure of long-term-average spectra of speech. J Acoust Soc Am 2006;120(1):453-457. [doi: 10.1121/1.2208451] [Medline: 16875241]
60. da Silva PT, Master S, Andreoni S, Pontes P, Ramos LR. Acoustic and long-term average spectrum measures to detect vocal aging in women. J Voice 2011;25(4):411-419. [doi: 10.1016/j.jvoice.2010.04.002] [Medline: 20817474]
61. Pell M, Rothermich K, Liu P, Paulmann S, Sethi S, Rigoulot S. Preferential decoding of emotion from human non-linguistic vocalizations versus speech prosody. Biol Psychol 2015;111:14-25. [doi: 10.1016/j.biopsycho.2015.08.008] [Medline: 26307467]
62. Scott SK, Sauter D, McGettigan C. Brain mechanisms for processing perceived emotional vocalizations in humans. Handb Behav Neurosci 2010:187-197. [doi: 10.1016/b978-0-12-374593-4.00019-x]
63. Trouvain J. Laughing, breathing, clicking-the prosody of nonverbal vocalisations. 2014 Presented at: Proceedings of Speech Prosody; 2014; Germany. [doi: 10.21437/speechprosody.2014-108]
64. Wilcox KA, Horii Y. Age and changes in vocal jitter. J Gerontol 1980;35(2):194-198. [doi: 10.1093/geronj/35.2.194] [Medline: 7410776]
65. Kaneko M, Hirano S, Tateya I, Kishimoto Y, Hiwatashi N, Fujiu-Kurachi M, et al. Multidimensional analysis on the effect of vocal function exercises on aged vocal fold atrophy. J Voice 2015;29(5):638-644 [FREE Full text] [doi: 10.1016/j.jvoice.2014.10.017] [Medline: 25944293]
66. Roshanzamir A, Aghajan H, Baghshah MS. Transformer-based deep neural network language models for Alzheimer's disease risk assessment from targeted speech. BMC Med Inform Decis Mak 2021;21(1):92 [FREE Full text] [doi: 10.1186/s12911-021-01456-3] [Medline: 33750385]
67. Wu S, Koo M, Blum L, Black A, Kao L, Fei Z, et al. Benchmarking open-source large language models, GPT-4 and claude 2 on multiple-choice questions in nephrology. NEJM AI 2024;1(2):AIdbp2300092. [doi: 10.1056/aidbp2300092]

Abbreviations

BERT: Bidirectional Encoder Representations from Transformers
HVTL: Hopkins Verbal Learning Test-Revised
MCI: mild cognitive impairment
ML: machine learning
MoCA: Montreal Cognitive Assessment
NLP: natural language processing

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Extracting Critical Information from Unstructured Clinicians' Notes Data to Identify Dementia Severity Using a Rule-Based Approach: Feasibility Study

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Abstract

Background: The severity of Alzheimer disease and related dementias (ADRD) is rarely documented in structured data fields in electronic health records (EHRs). Although this information is important for clinical monitoring and decision-making, it is often undocumented or "hidden" in unstructured text fields and not readily available for clinicians to act upon.

Objective: We aimed to assess the feasibility and potential bias in using keywords and rule-based matching for obtaining information about the severity of ADRD from EHR data.

Methods: We used EHR data from a large academic health care system that included patients with a primary discharge diagnosis of ADRD based on *ICD-9* (*International Classification of Diseases, Ninth Revision*) and *ICD-10* (*International Statistical Classification of Diseases, Tenth Revision*) codes between 2014 and 2019. We first assessed the presence of ADRD severity information and then the severity of ADRD in the EHR. Clinicians' notes were used to determine the severity of ADRD based on two criteria: (1) scores from the Mini Mental State Examination and Montreal Cognitive Assessment and (2) explicit terms for ADRD severity (eg, "mild dementia" and "advanced Alzheimer disease"). We compiled a list of common ADRD symptoms, cognitive test names, and disease severity terms, refining it iteratively based on previous literature and clinical expertise. Subsequently, we used rule-based matching in Python using standard open-source data analysis libraries to identify the context in which specific words or phrases were mentioned. We estimated the prevalence of documented ADRD severity and assessed the performance of our rule-based algorithm.

Results: We included 9115 eligible patients with over 65,000 notes from the providers. Overall, 22.93% (2090/9115) of patients were documented with mild ADRD, 20.87% (1902/9115) were documented with moderate or severe ADRD, and 56.20% (5123/9115) did not have any documentation of the severity of their ADRD. For the task of determining the presence of any ADRD severity information, our algorithm achieved an accuracy of >95%, specificity of >95%, sensitivity of >90%, and an F_1-score of >83%. For the specific task of identifying the actual severity of ADRD, the algorithm performed well with an accuracy of >91%, specificity of >80%, sensitivity of >88%, and F_1-score of >92%. Comparing patients with mild ADRD to those with more advanced ADRD, the latter group tended to contain older, more likely female, and Black patients, and having received their diagnoses in primary care or in-hospital settings. Relative to patients with undocumented ADRD severity, those with documented ADRD severity had a similar distribution in terms of sex, race, and rural or urban residence.

Conclusions: Our study demonstrates the feasibility of using a rule-based matching algorithm to identify ADRD severity from unstructured EHR report data. However, it is essential to acknowledge potential biases arising from differences in documentation practices across various health care systems.

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KEYWORDS

electronic health record; EHR; electric medical record; EMR; patient record; health record; personal health record; PHR; unstructured data; rule based analysis; artificial intelligence; AI; large language model; LLM; natural language processing; NLP; deep learning; Alzheimer's disease and related dementias; AD; ADRD; Alzheimer's disease; dementia; geriatric syndromes

Introduction

More than 6 million Americans aged 65 years and older are currently living with Alzheimer disease and related dementias (ADRD), constituting about 11% of the total American population aged 65 years and older [1]. This number is projected to double by 2060, reaching 13.8 million individuals affected by ADRD [1]. Despite the absence of a cure, timely identification of ADRD can significantly improve the quality of life of patients and better prepare their families with essential support resources [2]. Early identification of ADRD will also allow health care professionals and policy makers to develop adequate care programs for both patients and their families. Furthermore, the recent US Food and Drug Administration approval for ADRD treatment, lecanemab-irmb, has demonstrated promising advancements in the pharmacological management of the disease [3]. However, it is important to note that most of these treatments are only targeted at patients with mild cognitive impairment or early-stage dementia. Therefore, identifying ADRD at an early stage of the disease has become even more critical.

Early identification of ADRD poses significant challenges [4,5]. Even among patients with diagnosed ADRD, determining disease severity remains complex from a clinical perspective. Information regarding the presence and severity of ADRD is often limited to structured fields of electronic health records (EHRs) and is more likely to be stored within unstructured EHR sections, such as clinical reports. Moreover, wide variability exists in documentation practices and data structures across different health care systems, specialties, and even among clinicians within the same clinic [6]. Over the past decade, there has been a substantial increase in leveraging information contained in the EHR to improve diagnostic precision [7]. In this context, natural language processing (NLP) has emerged as a promising approach to extract relevant information from EHR data, bridging the gap between structured and unstructured clinical information.

In recent years, EHR data and NLP have been used in various ways to improve ADRD care, such as identifying corelated symptoms [8] and common description of cognitive impairment used by clinicians [9], establishing consensus on cognitive test scores [10], phenotyping of cognitive status [11], and predicting the onset of cognitive decline [12]. However, while structured EHR data have traditionally been used in previous research, they fall short of adequately documenting the severity of ADRD [13]. To address this gap, the unstructured component of EHR becomes critical for capturing essential symptoms and severity indicators related to ADRD [11]. The extent to which unstructured EHR data can be used to determine the severity of ADRD remains largely unknown.

In this study, we assess the feasibility and potential bias of a rule-based matching algorithm for extracting information on ADRD severity in patients with a primary discharge diagnosis of ADRD. Specifically, we develop an algorithm that acquires cognitive test scores and identifies distinct mentions of the presence and severity of ADRD from the primary discharge diagnosis. As each health care system may encode clinical information in the EHR differently, we propose a general framework that health care systems can adopt to tailor their needs and reduce irrelevant “noise” in the EHR—any unwanted irrelevant information.

Methods

Data Sources and Study Population

This is a retrospective cohort study that used data from Duke University Health System. Due to the sensitive nature of the data, qualified researchers trained in human subject confidentiality protocols may send requests to access the data that support the findings of this study to the corresponding author.

EHR data were extracted using Duke Enterprise Data Unified Content Explorer, a data extraction system based on Epic (Maestro Care) that identifies patient cohorts and provides access to clinical data stored in the organizational data warehouse [14]. According to previous research, we identified patients with ADRD as those who had at least one clinical encounter at Duke University Health System with at least one principal discharge diagnosis of ADRD based on *ICD-9* (*International Classification of Diseases, Ninth Revision*) or *ICD-10* (*International Statistical Classification of Diseases,Tenth Revision*) codes [9,15,16]. The list of *ICD-9/10* codes was based on an established algorithm from previous literature [10,17]. A total of 9115 patients aged 40 years or older, diagnosed with ADRD between January 1, 2014, and December 31, 2019, were included, totaling 65,576 patient records.

Data Management

As most of the content present in a patient record is not directly related to the severity of ADRD, we used a keyword list that contains common ADRD terminologies to flag patient records and sections of the record that include words directly related to ADRD. The initial list was generated based on previous work [9] and was further modified to include synonyms and additional keywords corresponding to *ICD-9/10* codes related to ADRD. An expert panel of clinicians provided input on the list through an iterative process. The final list (Table S1 in Multimedia Appendix 1) included 38 unique ADRD keywords, consisting of terminologies used by clinicians at Duke University Health System to document ADRD-related information in patient records. This step helped us extract the context in which these words and phrases were mentioned to reduce noise (ie, text not related to the severity of ADRD).

NLP Algorithms

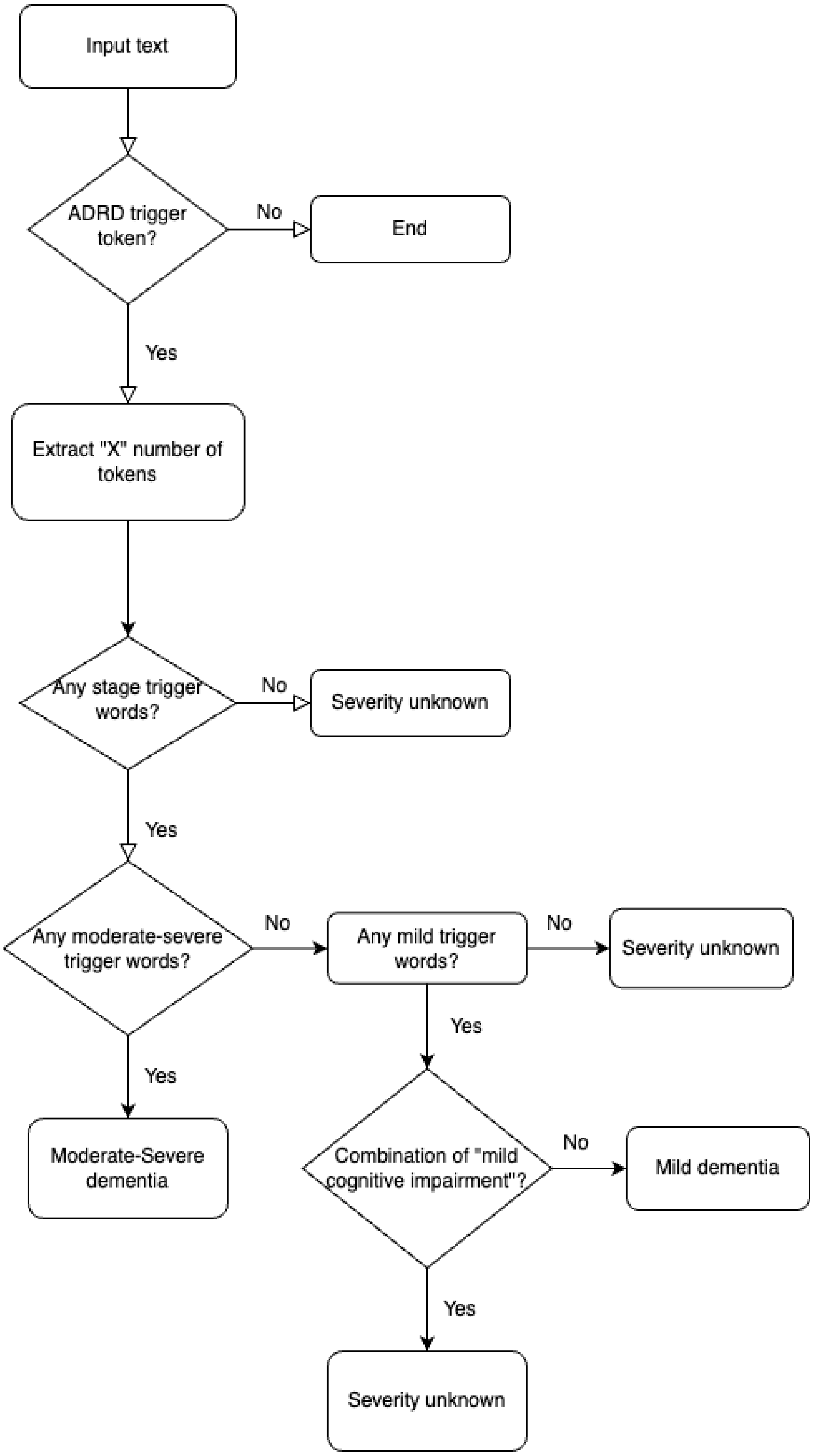
Unstructured EHR data, characterized by its absence of standardized writing patterns, often manifests inconsistencies in both quality and content. This includes the presence of spelling errors, typographical inaccuracies, formatting inconsistencies, uncommon abbreviations, and other customary challenges inherent in note-taking practices [18]. In response to these challenges, progress in NLP capabilities has helped to filter out important and relevant information from EHR data automatically. This can be done through a rule- or learning-based approach. Previous research has suggested that learning-based methods struggle with interpretability [19] and require a considerable amount of labeled text data, which can hinder scalability. Therefore, in our study, we used a rule-based approach, allowing us to interpret our results clearly and quantify the scope of our algorithm.

Specifically, our algorithm worked by sequentially narrowing down the target tokens (parts of the sentence) to extract information pertaining to ADRD textual mentions (ie, ADRD Text) and cognitive scores (ie, ADRD Cognitive Score). Then the algorithm determined the severity of ADRD based on either the direct mention of keywords pertaining to ADRD severity, or cognitive test scores. We categorized the severity of ADRD into three categories that include (1) mild, (2) moderate-to-severe (ie, advanced stage of ADRD), and (3) no severity indicated. Keywords corresponding to each severity stage are included in Table S2 in Multimedia Appendix 1. In the absence of any direct mention of the severity keywords in patient records, the severity of ADRD was defined based on cognitive test scores (Table S3 in Multimedia Appendix 1). Separate lists of keywords for the severity and cognitive scores were generated to aid the NLP algorithm. For patients whose records contained multiple severity levels from the same source (eg, all from cognitive scores), the more severe ADRD was assigned to the patient. As patients are likely to progress from mild to more advanced dementia over time, the more severe disease information was more likely to be the most updated information. In cases where there were discrepancies between the severity indicated by the explicit keywords and the cognitive scores, we defined the severity of ADRD based on the keywords, as providers may characterize the severity of the condition of the patients comprehensively based on additional assessments besides cognitive tests.

ADRD Text

We used the Python package spaCy’s pattern-matching function to identify occurrences of words listed in the ADRD keyword list (ie, trigger words). Once a word was identified, we assigned it a positional value of 0. We then extracted 5 tokens before and after the identified word (–5,5), creating a variable with 11 tokens, including the trigger word. The decision to extract this specific number of tokens was based on language constraints and observations from chart reviews, which revealed that most keywords related to the severity of ADRD appeared near the trigger words (eg, “mild dementia”). Next, we performed another pattern search using the severity keywords listed in Table S2 in Multimedia Appendix 1, but this time only on the previously extracted 11 tokens. If a match was confirmed, we extracted the keyword defining the severity of ADRD. The extracted keyword was then assigned a severity category based on the Montreal Cognitive Assessment (MoCA) and Mini Mental State Examination (MMSE) score ranges as outlined in Table S3 in Multimedia Appendix 1. The flowchart for this method is illustrated in Figure 1.

Figure 1. Flowchart to determine the severity of Alzheimer disease and related dementias based on Alzheimer disease and related dementias trigger words. ADRD: Alzheimer disease and related dementias.



ADRD Cognitive Score

Based on previous literature and input from clinicians, we focused on the cognitive scores from MMSE and MoCA to define the severity of ADRD [16,20]. These 2 cognitive tests were widely used in clinical practice with established cutoffs to determine the severity of cognitive impairment [16,20]. Through chart review and consultation with clinicians, we observed the following patterns for reporting the scores in patient records. For MMSE, the scores were reported either as variations of “AB/30” or “AB”. For MoCA, the scores were reported as variations of “AB/30,” “AB,” or a special case, “score AB,” where A $\in$ (0,3), B $\in$ (0,9). Some exemplars are present in Table 1. For each patient record, a pattern-matching search was performed to identify occurrences of MoCA and MMSE trigger words. Once a keyword was identified, it was assigned a positional value of 0, and 10 tokens before and after the word were extracted together (–10,10) into a variable. We then used regular expression (Regex) to extract only the numerical score value from the variables with extracted tokens.

The above method was used for all the cases mentioned above, with MoCA scores including a special case, due to a slight deviation in terms of extracted tokens, belonging to (0,50) as seen in Figure 2.

Table 1. Examples of potential causes of misclassification and representative phrases.

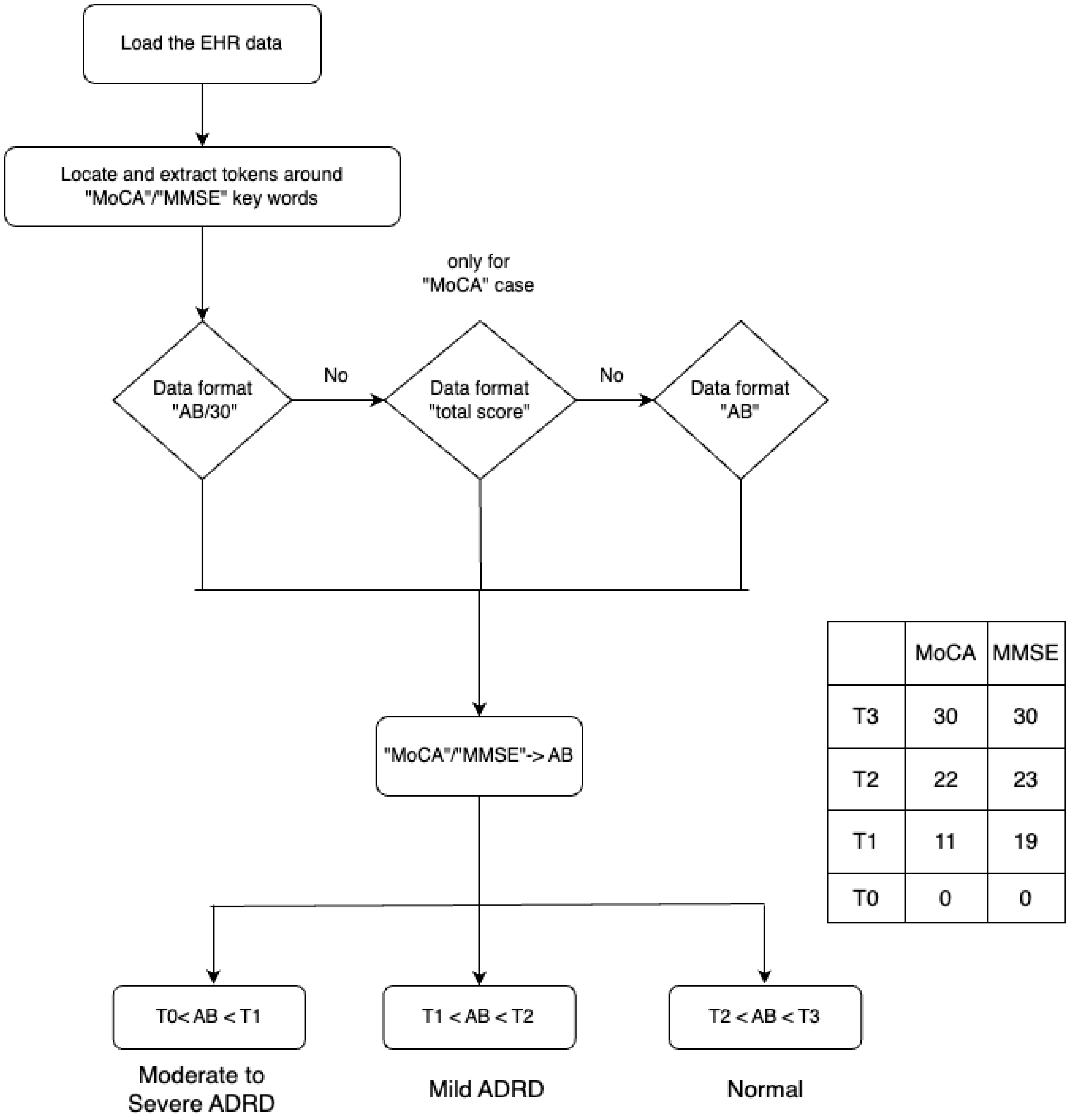
Category and cause of error	Sample sentence	Explanation
ADRD[a] text		
Incorrect textual representation	• Patient demonstrates decreased function secondary to deceased activity tolerance; cognitive deficits; medical status limitations • [‘contrast. \r\n\r\n indication: dementia \r\n\r\n findings: \r\n no’, ‘ -- -- -- -- -- -- ’]	• Token delimiter missing
Lack of contextual relationship between texts	• Lost 2 points for recalling only 1 out of 3 words after 3 minutes. Her neuropsychological testing concluded that she had evidence of a “mild cognitive disorder, nos.” • Mini-cognitive total scoring 1-2 recall and normal cdt: negative for cognitive impairment • Vascular dementia with a superimposed severe delirium	• Presence of “mild” and “cognitive” words in close vicinity • Failure to identify negative context. • Presence of “dementia” and “severe” in close vicinity.
ADRD cognitive score		
Particular pattern of reporting MoCA[b] score	• MoCA XX/XX/20XX trails 1 cube 1 clock 2 naming 3 digit span 1 letter a 1 serial 7s 3 sentence repetition 2 fluency 1 abstraction 2 orientation 6 memory 0 education level 0 total score 23	• Consistent pattern has been addressed in the algorithm.
Complex score reporting format	• Montreal Cognitive Assessment by on 8/22 (scored 19/30, normal is 26-30/30)	• Multiple scores in AB/30 format.
Human error	• MMSE[c] 36/50	• Out of bounds for MMSE score and spelled wrong.

[a] ADRD: Alzheimer disease and related dementias.

[b] MoCA: Montreal Cognitive Assessment

[c] MMSE: Mini Mental State Examination.

Figure 2. Flowchart to determine Alzheimer disease and related dementias (ADRD) stage based on cognitive test score. EHR: electronic health record; MMSE: Mini Mental State Examination; MoCA: Montreal Cognitive Assessment.



	MoCA	MMSE
T3	30	30
T2	22	23
T1	11	19
T0	0	0

Sampling, Testing, and Analysis

The rule-based algorithm was fine-tuned on a set of 200 patient records. To test the performance of the algorithm, we generated 2 additional sample files with 200 records each. The index of the first record was chosen using a random number generator to avoid bias. The annotation and validation were done at the level of each patient visit record. A certified clinician reviewed each EHR and determined the severity of ADRD. This manual annotation method served as our gold standard. All discrepancies were reviewed manually by both the data scientist and the clinician and were discussed on a case-by-case basis for resolution. Table 1 was also reviewed by 2 additional team members: 1 data scientist and 1 clinical scientist. We assessed the model performance by comparing the results generated from the algorithm against the gold standard based on the following parameters: F_1-score (ie, the predictive power of the algorithm), accuracy (ie, correct classification), sensitivity, and specificity. In addition, we compared patient characteristics between patients with and without documented dementia severity using Mann - Whitney U and Pearson chi - square tests for continuous and categorical variables, respectively. Among patients with documented severity of dementia, we further compared patient characteristics between those with mild ADRD and those with moderate-to-severe ADRD.

Ethical Considerations

This study was approved by the DUHS Institutional Review Board (Pro00104990).

Results

A total of 9115 eligible patients were included in the study with over 65,000 records. The median age of the patient population was 78 (IQR 70-84) years. Approximately 60% (5547/9115) of the patients were female, 22.9% (2087/9115) were non-Hispanic Black, and about half were diagnosed by an ADRD specialist (neurologists, neuropsychiatrists, geriatricians, etc). On average, each record contained 931.15 words.

Among all included patients, less than half (3992/9115, 43.8%) had documented information on the stage of their dementia in the EHR. Specifically, about 35% (3190/9115) of the records (3172/9115, 34.8%) included explicit terms that indicated dementia severity, whereas about one-third of the notes (n=2977, 32.7%) included scores from cognitive tests that indicated the severity of patients' dementia. We found no differences between patients with and without their dementia severity documented with regard to sex (*P*=.45) and race (*P*=.31). However, patients who were older at the time of diagnosis (*P*=.01) and those who were diagnosed at an ADRD specialty clinic or an in-hospital setting (*P*<.001) were more likely to have the severity of their dementia documented in the EHR.

Among those with documented dementia severity, less than 25% (n=920, 23.0%) were determined only based on cognitive scores. In our data, approximately half of these patients (n=1902, 47.7%) were documented to have moderate-to-severe ADRD. Compared with patients with mild ADRD, patients with moderate-to-severe ADRD were more likely to be older.

Table 1 shows potential causes of misclassification and representative phrases from the data sets used. Common causes of these challenges include (1) incorrect textual representation, (2) lack of contextual relationship between texts, (3) either particular or complex patterns of documenting cognitive scores, and (4) human data entry error.

Table 2 presents the performance of our algorithm across 3 sets of data. Overall, the algorithm can identify the presence of information on ADRD severity with high levels of accuracy (F_1-score=0.94, accuracy=0.97, sensitivity=0.94, and specificity=0.98) for training data (set 1). The overall accuracy across the 4 matrices in the 2 testing data sets (sets 2 and 3) was greater than 0.91, except for the F_1-score for set 3. To evaluate the performance of identifying the severity of ADRD, we defined a binary metric with "moderate-to-severe" diagnosis being positive and "mild" being negative. The ability of the algorithm to identify ADRD severity is comparable, if not better than identifying the presence of ADRD severity (F_1-score=0.94, accuracy=0.96, sensitivity=0.88, and specificity=1.0) for training data (set 1). The algorithm had accuracy greater than 0.91 with sensitivity of 1.00 in 2 testing data. The specificity for the 2 testing sets was greater than 0.80.

Table 2. Evaluation of ADRD[a] stage labeling algorithm for patient stage identification and severity of the diagnosis from unstructured EHR data.

Category	Set 1		Set 2		Set 3	
	ADRD information	ADRD severity	ADRD information	ADRD severity	ADRD information	ADRD severity
TP[b]	50	16	21	11	26	15
FP[c]	3	1	3	2	8	0
FN[d]	3	2	1	0	3	0
TN[e]	144	28	171	8	163	11
Accuracy	0.97	0.96	0.98	0.91	0.95	1.0
Sensitivity	0.94	0.88	0.95	1.0	0.90	1.0
Specificity	0.98	1.0	0.98	0.8	0.95	1.0
F_1-score	0.94	0.94	0.91	0.92	0.83	1

[a] ADRD: Alzheimer disease and related dementias.

[b] TP: True positive.

[c] FP: False positive.

[d] FN: False negative.

[e] TN: True negative.

Discussion

Principal Findings

In this study, we developed and successfully implemented a rule-based algorithm to identify the severity of ADRD from unstructured EHR data. We detailed the steps to be taken for extracting the relevant information from EHR data and highlighted the challenges associated with it due to heterogeneity in textual representation. We find a lack of access to specialty facilities may impede timely diagnosis and the possibility of treatment at early stages of ADRD progression. As the severity of dementia is critical for health care providers to prescribe appropriate treatment and link resources to patients and their caregivers, our 2-pronged approach to search for relevant information presents a parsimonious yet effective way to make the disease severity information readily available across disciplines and care settings.

Similar to previous research [21-24], we developed the algorithm using a rule-based approach. Starting with an initial list of keywords or phrases based on previous work and contextual clinical knowledge, the list is refined iteratively to identify the target information. This step is followed by sampling the reports from the data set and dividing them into training and testing sets for gold-standard comparison and evaluation. Previous research applied a rule-based approach to identify caregiver availability [21], a record of mild cognitive impairment or Alzheimer disease [22], documentation of cognitive tests [23], and social determinants of health for patients with ADRD [24]. Unlike previous work, where either the rule definition step specific to the medical system [21], included *ICD* (*International Classification of Diseases*) codes [22], or had additional biomarker and cognitive tests information [23]. In comparison, our method shows robustness by using common occurring keywords and points toward the need for defining a minimum number of umbrella rules that have the potential to be generalizable for the entire data set and have better performance. Our developed algorithm is independent of the health care systems and provides clinicians with the flexibility to either use it without any modification or adapt it to their needs. A recent systematic review paper has suggested that rule-based NLP algorithms had similar performance compared with those using more sophisticated methods when the information is scarce in the EHR [25]. In our case, information on the severity of ADRD was presented using a few words, in less than half of the data. To evaluate the performance of our algorithm, we divided the tests into two categories that are (1) identifying the "presence of information on ADRD severity" and (2) "severity of ADRD." We found our algorithm to be highly accurate in extracting documented information on ADRD severity from the EHR. The performance on sensitivity and specificity also indicates that our algorithm was able to correctly extract stage information where present and reduce false positive results. Taken together, these results support the clinical use of our simplified and generalizable approach to identify the severity of ADRD. Furthermore, compared with previous work, our algorithm showed an improved average F_1-score in identifying the ADRD severity of the condition of the patient [26]. The better performance of our algorithm compared with previous work could be attributed to the use of unstructured EHR data instead of structured EHR and defining clear umbrella rules by identifying recurring patterns in our data set for ADRD severity categorization.

The performance of our algorithm is slightly diminished in identifying the severity of dementia from the records. Upon inspection of the wrongly labeled cases, it can be attributed to (1) the test scores not reflecting the correct severity compared with the clinician's evaluation, (2) lack of contextual understanding of the sentence, and (3) noise in EHR note (irrelevant information), also noted in previous work [21]. A majority of the abovementioned issues were mitigated by defining subrules [27]. However, any further inclusion would have come at the cost of reduced performance and the need for increased clinician oversight, which limits its generalizability.

Although the rule-based algorithm worked considerably well in most of the cases, it is limited by the patterns and rules defined by the developer. For cases where the token default token delimiter, in our case "space," is changed or missing, the algorithm fails to extract information. One approach to solve this could be to have an alternative copy of the algorithm that includes other common delimiters (eg, ";" "," ":") to identify word tokens. In our evaluation, we only found a few outliers not following the default way of describing texts with "space" as the delimiter. The urge to include all the stray cases would lead to the hard coding of the algorithm and give rise to new challenges with considerable false positive results, making it difficult to comb through. With the development of large language models (LLMs), 1 potential solution might be to use LLM to shape the EHR data in the same format, such as converting all patient records to have equal spacing, removing random commas, etc, without changing textual content and then follow a rule-based approach as presented in this study. Our design philosophy has been to keep the algorithm general while including common patterns. One possible criticism of our study could be dichotomizing the severity of ADRD. The rationale for dichotomizing the severity of ADRD into mild versus moderate-to-severe dementia is related to clinical decision-making. Given that there are several types of ADRD, such as Alzheimer disease, vascular dementia, and Lewy body dementia, to name a few, the differential treatment and care plans are limited as a considerable number of patients have mixed dementia, and the gold standard for a definitive differential diagnosis is still based on autopsy studies. Therefore, for this study, we only focused on a dichotomized version of the severity of ADRD. Future studies should further investigate a more comprehensive classification of ADRD severity and possibly include other tests for diagnosis of ADRD outside MoCA and MMSE.

Overall, we demonstrate the ability of our rule-based algorithm to identify the severity of ADRD, where present, in the EHR and narrow it down to the location of occurrence in the EHR. This not only allows us to comb through valuable unstructured data with ease, but the sequential nature of the algorithm provides us with contextual data that has a high probability of containing information about the severity of dementia. The extracted data can be used in future work to train a machine learning (ML) model with rich and high-quality data. We expect to enhance our method to further identify and predict the progression of ADRD over time. As the performance of an ML model depends on the quality of the data set, following a segmented approach of using a rule-based algorithm for extracting relevant paragraphs from the EHR can be used first to enrich the data set and reduce noise (ie, nonrelevant information from the EHR) followed by model training on the data. Previous research has found that combining structured and unstructured data might be a viable approach to classify patients. With structured data containing useful demographic information and unstructured data containing contextual, patient, and clinical notes, the path forward could be to leverage the qualities of both kinds of data [28] for the use of EHR.

Previous studies that used traditional ML models, such as logistic regression and support vector machine, often include only the structured EHR data due to the limited requirement for data management [6,12,13]. In recent years, increasing numbers of studies have applied deep learning approaches to classify patients for a given condition [6,29,30]. One of the strengths of the deep learning approach is its ability to incorporate relationships between words and a large amount of data in the analysis, which fits the need for using both structured and unstructured data together. Despite its strength, a common criticism against the implementation of deep learning approaches in clinical settings is the lack of interpretability [19]. The use of an interpretable rule-based approach has enabled us to highlight potential biases and pitfalls to be considered when using black-box deep learning models. One potential solution is to use rule-based pattern matching to highlight the trigger words and related neighborhood of words for added context and classify or label the patient record using deep learning techniques [31,32]. With the improvements in LLMs and their enhanced contextual and semantic understanding of texts, our rule-based method can be coupled with a pretrained LLM in pre- or postprocessing of the extracted texts [33]. Care must be taken while using LLMs due to the generative nature of text predictions in avoiding alteration of textual information and being limited to standardizing textual information. The proposed approach needs to be thoroughly evaluated through data privacy and model uncertainty lens before adoption.

We also found that the percentage of patients with missing information on the severity of ADRD is very high. Given the added significance of such information in recent times due to newly approved treatment, it is critical in current clinical practice to improve documentation of the severity of dementia to promote high-quality care. In addition, despite the missing information, our relatively simple algorithm approach has been successful in making previously inaccessible and hard-to-find information readily available to clinicians for a large number of patients. These patients would have otherwise not had this information available to their care team without our very practical approach.

Our study has a few limitations due to the algorithm of our choice and design decisions. First, as mentioned earlier, the rules have to be manually defined and fine-tuned based on a training set. This process, although simple in complexity, can be challenging as EHR can be very different based on health care systems. As the rules are manually defined, it has room for human error. On the other hand, this approach gives the researchers the flexibility to adapt the algorithm structure easily to their health care systems and needs to be fine-tuned. Second, rule-based algorithm matching studies are limited by a lack of contextual understanding between text groups and fail to recognize connotations in sentences. For example, the presence of a negative test result may confuse the algorithm pattern identification process unless explicitly included in the algorithm definition. Third, our approach has been able to only include rules for patterns that are common throughout the data set, such as for the ADRD Cognitive Score function, we include every score defined in the format of AB/30, AB, and a special type of definition as mentioned before. Therefore, we might have missed out on some of the cases straying away from the common patterns. For our instance, attempts to include every unique case led to the results being very irrelevant as it started capturing a lot of unimportant information and the algorithm became very rigid. Fourth, the study determines dementia severity based on cognitive test scores and trigger words for ADRD and does not include medical prescriptions being used by the patient which can be a future direction to make our approach holistic.

Finally, even though we have attempted to keep our method generalizable, the data were extracted from 1 health care system, and the developed rules may not directly apply to data from other health care systems. We have described in detail the steps taken in designing the algorithm with the aim of serving as a baseline approach for research in identifying ADRD severity from unstructured EHR data. The algorithm does the job well for the criteria chosen, and the choice of criteria to include can be a decision of the study designer.

Conclusion

Rule-based algorithms can provide an interpretable approach to process unstructured EHR data. This study demonstrates the value of unstructured EHR data in providing critical information about ADRD severity from patient records. Pattern-matching rule-based algorithms can be tuned and adapted to health care systems and study-specific needs. The proposed algorithm can serve as a baseline or initial point to shift through pages of EHR reports to identify the most relevant sections or regions. However, it is important to clearly identify the assumptions made, and their limitations while defining the rules. Differences in documentation may also introduce bias in the algorithm as it is fine-tuned. Overall, rule-based algorithms are powerful in handling unstructured EHR data while being transparent and interpretable.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Description of the electronic health record data set.

[DOC File , 133 KB - aging_v7i1e57926_app1.doc]

References

1. NA. 2021 Alzheimer's disease facts and figures. Alzheimers Dement 2021;17(3):327-406. [doi: 10.1002/alz.12328] [Medline: 33756057]
2. PAD 20/20 Work Group on Community-Based Detection of Cognitive Decline Dementia. Improving community health-care systems' early detection of cognitive decline and dementia. Alzheimers Dement 2022;18(11):2375-2381. [doi: 10.1002/alz.12837] [Medline: 36314503]
3. US Food and Drug Administration. FDA converts novel Alzheimer’s disease treatment to traditional approval. URL: https://www.fda.gov/news-events/press-announcements/fda-converts-novel-alzheimers-disease-treatment-traditional-approval [accessed 2024-08-06]
4. Ford E, Carroll JA, Smith HE, Scott D, Cassell JA. Extracting information from the text of electronic medical records to improve case detection: a systematic review. J Am Med Inform Assoc 2016;23(5):1007-1015 [FREE Full text] [doi: 10.1093/jamia/ocv180] [Medline: 26911811]
5. McCoy TH, Han L, Pellegrini AM, Tanzi RE, Berretta S, Perlis RH. Stratifying risk for dementia onset using large-scale electronic health record data: a retrospective cohort study. Alzheimers Dement 2020;16(3):531-540 [FREE Full text] [doi: 10.1016/j.jalz.2019.09.084] [Medline: 31859230]
6. Wu J, Roy J, Stewart WF. Prediction modeling using EHR data: challenges, strategies, and a comparison of machine learning approaches. Med Care 2010;48(6 Suppl):S106-S113. [doi: 10.1097/MLR.0b013e3181de9e17] [Medline: 20473190]
7. Johnson AE, Pollard TJ, Shen L, Lehman LH, Feng M, Ghassemi M, et al. MIMIC-III, a freely accessible critical care database. Sci Data 2016;3:160035 [FREE Full text] [doi: 10.1038/sdata.2016.35] [Medline: 27219127]
8. Anzaldi LJ, Davison A, Boyd CM, Leff B, Kharrazi H. Comparing clinician descriptions of frailty and geriatric syndromes using electronic health records: a retrospective cohort study. BMC Geriatr 2017;17(1):248 [FREE Full text] [doi: 10.1186/s12877-017-0645-7] [Medline: 29070036]
9. Gilmore-Bykovskyi A, Block LM, Walljasper L, Hill N, Gleason C, Shah MN. Unstructured clinical documentation reflecting cognitive and behavioral dysfunction: toward an EHR-based phenotype for cognitive impairment. J Am Med Inform Assoc 2018;25(9):1206-1212 [FREE Full text] [doi: 10.1093/jamia/ocy070] [Medline: 29947805]
10. Harding BN, Floyd JS, Scherrer JF, Salas J, Morley JE, Farr SA, et al. Methods to identify dementia in the electronic health record: comparing cognitive test scores with dementia algorithms. Healthc (Amst) 2020;8(2):100430 [FREE Full text] [doi: 10.1016/j.hjdsi.2020.100430] [Medline: 32553526]
11. Kharrazi H, Anzaldi LJ, Hernandez L, Davison A, Boyd CM, Leff B, et al. The value of unstructured electronic health record data in geriatric syndrome case identification. J Am Geriatr Soc 2018;66(8):1499-1507. [doi: 10.1111/jgs.15411] [Medline: 29972595]
12. Hane CA, Nori VS, Crown WH, Sanghavi DM, Bleicher P. Predicting onset of dementia using clinical notes and machine learning: case-control study. JMIR Med Inform 2020;8(6):e17819 [FREE Full text] [doi: 10.2196/17819] [Medline: 32490841]
13. Ferrão JC, Janela F, Oliveira MD, Martins HMG. Using structured EHR data and SVM to support ICD-9-CM coding. 2013 Presented at: 2013 IEEE International Conference on Healthcare Informatics; 2013 September 09-11; Philadelphia, PA p. 511-516.
14. Horvath MM, Winfield S, Evans S, Slopek S, Shang H, Ferranti J. The DEDUCE guided query tool: providing simplified access to clinical data for research and quality improvement. J Biomed Inform 2011;44(2):266-276 [FREE Full text] [doi: 10.1016/j.jbi.2010.11.008] [Medline: 21130181]
15. Shao Y, Zeng QT, Chen KK, Shutes-David A, Thielke SM, Tsuang DW. Detection of probable dementia cases in undiagnosed patients using structured and unstructured electronic health records. BMC Med Inform Decis Mak 2019;19(1):128 [FREE Full text] [doi: 10.1186/s12911-019-0846-4] [Medline: 31288818]
16. Halpern R, Seare J, Tong J, Hartry A, Olaoye A, Aigbogun MS. Using electronic health records to estimate the prevalence of agitation in Alzheimer disease/dementia. Int J Geriatr Psychiatry 2019;34(3):420-431. [doi: 10.1002/gps.5030] [Medline: 30430642]
17. Taylor DH, Fillenbaum GG, Ezell ME. The accuracy of medicare claims data in identifying Alzheimer's disease. J Clin Epidemiol 2002;55(9):929-937. [doi: 10.1016/s0895-4356(02)00452-3] [Medline: 12393082]
18. Tayefi M, Ngo P, Chomutare T, Dalianis H, Salvi E, Budrionis A, et al. Challenges and opportunities beyond structured data in analysis of electronic health records. WIREs Computational Stats 2021 Feb 14;13(6):e1549. [doi: 10.1002/wics.1549]
19. Seinen TM, Fridgeirsson EA, Ioannou S, Jeannetot D, John LH, Kors JA, et al. Use of unstructured text in prognostic clinical prediction models: a systematic review. J Am Med Inform Assoc 2022;29(7):1292-1302. [doi: 10.1093/jamia/ocac058] [Medline: 35475536]
20. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc 2005;53(4):695-699. [doi: 10.1111/j.1532-5415.2005.53221.x] [Medline: 15817019]

21. Mahmoudi E, Wu W, Najarian C, Aikens J, Bynum J, Vydiswaran VGV. Identifying caregiver availability using medical notes with rule-based natural language processing: retrospective cohort study. JMIR Aging 2022;5(3):e40241. [doi: 10.2196/40241] [Medline: 35998328]
22. Aguilar BJ, Miller D, Jasuja G, Li X, Shishova E, O'Connor MK, et al. Rule-based identification of individuals with mild cognitive impairment or Alzheimer's disease using clinical notes from the United States veterans affairs healthcare system. Neurol Ther 2023;12(6):2067-2078 [FREE Full text] [doi: 10.1007/s40120-023-00540-2] [Medline: 37747662]
23. Chen Z, Zhang H, Yang X, Wu S, He X, Xu J, et al. Assess the documentation of cognitive tests and biomarkers in electronic health records via natural language processing for Alzheimer's disease and related dementias. Int J Med Inform 2023;170:104973. [doi: 10.1016/j.ijmedinf.2022.104973] [Medline: 36577203]
24. Wu W, Holkeboer KJ, Kolawole TO, Carbone L, Mahmoudi E. Natural language processing to identify social determinants of health in Alzheimer's disease and related dementia from electronic health records. Health Serv Res 2023;58(6):1292-1302 [FREE Full text] [doi: 10.1111/1475-6773.14210] [Medline: 37534741]
25. Patra BG, Sharma MM, Vekaria V, Adekkanattu P, Patterson OV, Glicksberg B, et al. Extracting social determinants of health from electronic health records using natural language processing: a systematic review. J Am Med Inform Assoc 2021;28(12):2716-2727 [FREE Full text] [doi: 10.1093/jamia/ocab170] [Medline: 34613399]
26. Vyas A, Aisopos F, Vidal M, Garrard P, Paliouras G. Calibrating Mini-Mental State Examination scores to predict misdiagnosed dementia patients. Applied Sciences 2021;11(17):8055. [doi: 10.3390/app11178055]
27. Oh IY, Schindler SE, Ghoshal N, Lai AM, Payne PRO, Gupta A. Extraction of clinical phenotypes for Alzheimer's disease dementia from clinical notes using natural language processing. JAMIA Open 2023;6(1):ooad014 [FREE Full text] [doi: 10.1093/jamiaopen/ooad014] [Medline: 36844369]
28. Bayramli I, Castro V, Barak-Corren Y, Madsen EM, Nock MK, Smoller JW, et al. Predictive structured-unstructured interactions in EHR models: a case study of suicide prediction. NPJ Digit Med 2022;5(1):15 [FREE Full text] [doi: 10.1038/s41746-022-00558-0] [Medline: 35087182]
29. Luo X, Gandhi P, Zhang Z, Shao W, Han Z, Chandrasekaran V, et al. Applying interpretable deep learning models to identify chronic cough patients using EHR data. Comput Methods Programs Biomed 2021;210:106395. [doi: 10.1016/j.cmpb.2021.106395] [Medline: 34525412]
30. Magdamo CG, Hong ZM, Noori A, Sheu Y, Deodhar M, Ye EM, et al. Active deep learning to detect cognitive concerns in electronic health records. Alzheimer's & Dementia 2021;17(S11). [doi: 10.1002/alz.055362]
31. Magdamo CG, Hong ZM, Noori A, Sheu Y, Deodhar M, Ye EM, et al. Active deep learning to detect cognitive concerns in electronic health records. Alzheimers Dement 2021;17(S11):e055362. [doi: 10.1002/alz.055362]
32. Noori A, Magdamo C, Liu X, Tyagi T, Li Z, Kondepudi A, et al. Development and evaluation of a natural language processing annotation tool to facilitate phenotyping of cognitive status in electronic health records: diagnostic study. J Med Internet Res 2022;24(8):e40384 [FREE Full text] [doi: 10.2196/40384] [Medline: 36040790]
33. Goel A, Gueta A, Gilon O, Liu C, Erell S, Nguyen LH, et al. LLMs Accelerate Annotation for Medical Information Extraction. In: LLMs accelerate annotation for medical information extraction.: Proceedings of Machine Learning Research; 2023 Presented at: Machine Learning for Health (ML4H); 10th December, 2023; New Orleans, United States p. 82-100 URL: https://proceedings.mlr.press/v225/goel23a/goel23a.pdf

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Abbreviations

ADRD: Alzheimer disease and related dementias
EHR: electronic health record
***ICD*:** *International Classification of Diseases*
***ICD-9*:** *International Classification of Diseases, Ninth Revision*
***ICD-10*:** *International Statistical Classification of Diseases, Tenth Revision*
LLM: large language model
ML: machine learning
MMSE: Mini Mental State Examination
MoCA: Montreal Cognitive Assessment
NLP: natural language processing

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Review

Machine Learning Driven by Magnetic Resonance Imaging for the Classification of Alzheimer Disease Progression: Systematic Review and Meta-Analysis

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Abstract

Background: To diagnose Alzheimer disease (AD), individuals are classified according to the severity of their cognitive impairment. There are currently no specific causes or conditions for this disease.

Objective: The purpose of this systematic review and meta-analysis was to assess AD prevalence across different stages using machine learning (ML) approaches comprehensively.

Methods: The selection of papers was conducted in 3 phases, as per PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) 2020 guidelines: identification, screening, and final inclusion. The final analysis included 24 papers that met the criteria. The selection of ML approaches for AD diagnosis was rigorously based on their relevance to the investigation. The prevalence of patients with AD at 2, 3, 4, and 6 stages was illustrated through the use of forest plots.

Results: The prevalence rate for both cognitively normal (CN) and AD across 6 studies was 49.28% (95% CI 46.12%-52.45%; *P*=.32). The prevalence estimate for the 3 stages of cognitive impairment (CN, mild cognitive impairment, and AD) is 29.75% (95% CI 25.11%-34.84%, *P*<.001). Among 5 studies with 14,839 participants, the analysis of 4 stages (nondemented, moderately demented, mildly demented, and AD) found an overall prevalence of 13.13% (95% CI 3.75%-36.66%; *P*<.001). In addition, 4 studies involving 3819 participants estimated the prevalence of 6 stages (CN, significant memory concern, early mild cognitive impairment, mild cognitive impairment, late mild cognitive impairment, and AD), yielding a prevalence of 23.75% (95% CI 12.22%-41.12%; *P*<.001).

Conclusions: The significant heterogeneity observed across studies reveals that demographic and setting characteristics are responsible for the impact on AD prevalence estimates. This study shows how ML approaches can be used to describe AD prevalence across different stages, which provides valuable insights for future research.

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KEYWORDS

Alzheimer disease; ML-based diagnosis; machine learning; prevalence; cognitive impairment; classification; biomarkers; imaging modalities; MRI; magnetic resonance imaging; systematic review; meta-analysis

Introduction

The progression of Alzheimer disease (AD) affects memory, thinking, and behavioral functions over time [1]. Not only the individuals affected by the condition but also their families and caregivers, who have to cope with it daily. AD has become a major health concern worldwide because of the aging population in the last 3 decades [2,3]. The majority of cases of AD occur among older individuals, and increasing evidence suggests that a combination of genetic, lifestyle, and environmental factors is behind it [3,4]. The progression of the disease causes a slow deterioration of memory and cognitive abilities.

AD is represented by different stages of progression such as cognitively normal (CN) [5], significant memory concern (SMC) [6], early mild cognitive impairment (EMCI) [7], mild cognitive impairment (MCI) [8], and late mild cognitive impairment (LMCI) [7,8]. Biomarkers could help detect individuals at risk of AD before symptoms occur. Cerebrospinal fluid (CSF) testing is considered the most reliable marker of progression of AD. Brain neuroimaging like computerized tomography (CT), magnetic resonance imaging (MRI), and positron emission tomography (PET), blood tests, and genetic testing are attracting increasing attention as important markers of this pathology [1,9,10]. CSF biomarkers such as β-amyloid 42 and tau and phosphor tau are key indicators of AD [11]. An MRI or CT scan can reveal structural changes associated with AD, while a PET scan can reveal amyloid plaques and tau tangles in the brain [12]. The early diagnosis of AD can be aided by the identification of novel biomarkers, the identification of hidden data patterns, and the generation of hypotheses [13-16]. Machine learning (ML)–based predictive models can help us detect early signs of AD, improve diagnostic accuracy, and enable timely interventions [16,17].

ML applications in medicine have received significant attention for their potential in disease detection and diagnosis [18]. ML models have been proposed in existing literature to improve diagnostic accuracy for early detection of AD [19-21]. It is said that ML algorithms aid in forecasting outcomes for patients with AD, diagnosing illnesses, and tailoring treatments [15]. ML models have been reported to be able to predict patient readmissions, which allows health care providers to allocate resources more efficiently and improve patient outcomes [15,22]. In addition, deep learning (DL) algorithms can examine medical images, like CT scans or MRIs, to aid in identifying abnormalities [23-25]. The application of DL techniques to conventional MRI could reduce patient burden, risk, and cost when extracting biomarker information [26,27].

DL-based neural networks contribute significantly to AD detection [28,29]. Hierarchical representations can be learned by neural networks and achieve promising results in AD, especially when applied to neuroimaging data [30,31]. Their role includes assisting in the discovery of new AD biomarkers and analyzing large datasets to identify patterns and correlations that are indicative of AD progression [32]. Convolutional neural networks (CNNs) are used in the analysis of AD image data in the form of MRI [33], PET [34], and CT scans [35]. CNNs can automatically extract relevant features from complex imaging data and learn hierarchical representations of subtle AD patterns.

Advanced techniques like Gradient-Weighted Class Activation Mapping after CNN model training highlight important regions of the input MRI brain image [36,37]. The brain areas in these regions are responsible for influencing the model's AD prediction. These techniques bridge the gap between accuracy and interpretability in AD detection. Moreover, recurrent neural networks are capable of analyzing temporal data, such as longitudinal studies examining cognitive decline over time [38]. Predicting cognitive decline trajectories and future outcomes is possible through the capture of sequential dependencies in data [38,39]. Multimodal data integration can enhance the accuracy of AD detection models, resulting in a more comprehensive view of the patient's condition [40].

The role of ML models in the early diagnosis of AD has not been determined through extensive review of ML algorithms and meta-analysis. The accuracy and efficiency of AD diagnosis can be enhanced by using advanced algorithms and models as well as careful feature selection and extraction. However, the level of reliability of these techniques is a significant factor. The objective of this study is to address the knowledge gap by conducting a systematic review and meta-analysis of ML applications for AD detection, which aim to establish their role in improving diagnostic accuracy and patient outcomes. The main contribution of this study is (1) assessing the role of image feature selection methods in achieving competitive accuracy in AD classification modeling, (2) examining the ML methods that can be used to detect AD with the help of magnetic resonance image modeling, and (3) identifying the best ML classifier based on accuracy metrics.

Methods

This study was conducted by identifying, selecting, and analyzing relevant studies, which included a literature search, screening document inclusion criteria, and tools for risk bias assessment.

Search Strategy

A systematic search was carried out using libraries such as PubMed (MEDLINE), Scopus, and Web of Science. The search followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) 2020 guidelines to maintain transparency, authenticity, and completeness of details of reporting [41]. The PRISMA checklist of this paper can be found in Multimedia Appendix 1. This search was carried out over the last 15 years and was centered on published studies specific to early-stage AD detection and classification (between January 2010 and March 2024). Limiting our review to the last 15 years of publication allowed us to focus on papers reflective of current trends in research.

The search strategy used the following keywords: "Alzheimer's disease," "machine learning," "early detection," "diagnostic accuracy," "diagnosis," "predictive models," "biomarkers," "deep learning," "diagnostic accuracy," "feature selection," "AD biomarkers," and "ML models." The search strategy was ("machine learning" OR "artificial intelligence" OR "classification") AND "Alzheimer's disease" AND "MRI" AND "diagnosis" AND "classification."

Inclusion and Exclusion Criteria

Full-text papers in the English language were considered. We have included in this study only published papers in peer-reviewed journals. The majority of the papers analyzed were centered on MRI data combined with ML models in AD diagnosis. Selected studies included patients diagnosed with early-stage AD and healthy controls. The papers published with a title or abstract containing at least 1 abovementioned keyword were considered for inclusion.

Papers written in a language other than English were excluded. We excluded studies that were not specifically conducted in the context of AD diagnosis using MRI and were not primarily focused on ML models. Papers published before 2010 were not considered. Studies in which ML in MRI was not explicitly linked to clinical diagnosis, medical training, or initiatives to improve AD diagnosis were excluded. This review excluded studies using PET and CT scans because the primary focus was on ML in MRI, which is specifically linked to clinical diagnosis, medical training, and initiatives to enhance AD diagnosis. The selection process excluded review papers, conference proceedings, and gray literature reports.

Paper Screening

Multiple stages were involved in the paper selection process. The results of the systematic search were documented in a spreadsheet using the above strategy. The selected papers were equally distributed among the authors, and each paper was screened by examining titles and abstracts to identify potentially relevant publications. The selected papers were then reviewed comprehensively according to predefined inclusion and exclusion criteria in the subsequent phase. To facilitate synthesis, relevant information was extracted and organized in a tabular format, covering study design, datasets, performance metrics, model validation, and feature selection. As a result, a summary of each study’s main findings to discern trends, patterns, and common themes was done.

Quality and Publication Bias

The Newcastle-Ottawa Scale [42] was used to assess the study quality based on different factors such as selection, comparability, and outcome, providing a structured approach to gauge the risk of bias. In terms of quality, scores ranged from very poor (0-3) to moderate (4-6) to excellent (7-9). The papers meeting the score (Newcastle-Ottawa Scale≥7) were only considered for final review. Two authors (GB and NC) independently assessed the quality, and any discrepancies were resolved through discussion or consultation with a third author (FA).

Statistical Analysis

The statistical tests Egger regression [43] and Begg rank correlation [44] were used to address the potential bias of publications. To assess the strength of our findings against potential biases or variations in study characteristics, sensitivity analyses were performed. Lower methodological quality or different study designs were excluded. To identify the effect size measures and quantify the strength or magnitude of the relationship between variables or the magnitude of differences between AD groups, we applied the “PLOGIT” function to the logit transformation of the proportion [45]. The logit transformation is commonly used when dealing with proportions or probabilities, especially when they are bounded between 0 and 1. An inverse variance method has been applied that specifies the method for pooling effect sizes. There were 2 types of models considered in the meta-analysis: fixed effects and random effects. Using the fixed effects model when we observed a low level of heterogeneity, the test is not statistically significant.

The random effects model (REM) was considered for the heterogeneity test with statistical significance [46]. By calculating T^2, the amount of heterogeneity between the true effect sizes of different studies was quantified. An estimation method using a restricted maximum likelihood estimator that maximizes the likelihood function while accounting for other parameters of the model was used [47]. I^2 and Cochran Q statistic tests were conducted to assess the heterogeneity among the effect sizes of individual studies [48,49]. The measures of heterogeneity (T^2 and I^2) indicate the variability in AD prevalence estimates across the studies [50].

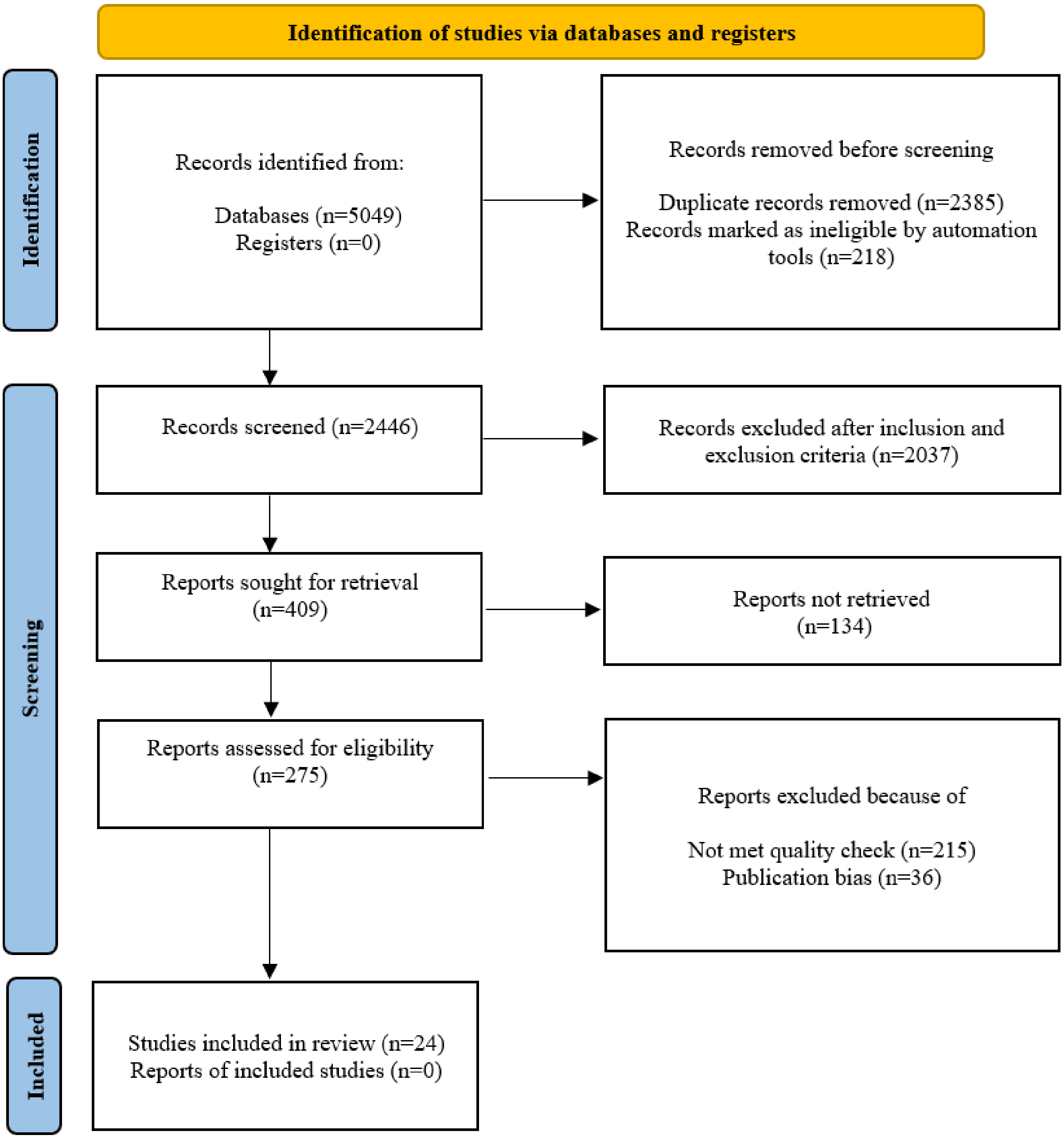
The prevalence of patients with AD across different subgroups within the overall population was also investigated. Subgroup analysis enables the identification of factors that can influence prevalence estimates and provide insight into the sources of heterogeneity [51]. A subgroup-specific meta-analysis model was used to calculate the pooled prevalence estimates for each subgroup, followed by a comparison of the prevalence estimates across subgroups to assess whether there were any significant differences. Data were subgrouped into 4 category-based AD classifications namely, 2-group classification, 3-group classification, 4-group classification, and 6-group classification. The 2-group classification involved individuals either without dementia (nondemented, ND) or with dementia (demented, AD). The 3-group classification includes CN, MCI, and AD. The 4-group classification comprises ND, mildly demented (MD), moderately demented (MoD), and AD. Meanwhile, the 6-group classification involves CN, SMC, EMCI, MCI, LMCI, and AD. Each subgroup data was recorded separately into a Microsoft Excel spreadsheet, which was further supplied as input to R software (version 4.3.3; R Foundation for Statistical Computing). For prevalence and summary meta-analysis, we used the “meta prop” functions available in the *meta* package.

Results

Search Outcomes

During the identification phase, 5049 records were obtained from 3 major scientific databases using the given search strategy. Following the removal of duplicates (n=2355) and the assessment of ineligibility using tools (n=218), 2446 records were included in the screening stage. The inclusion and exclusion criteria determined that 2037 records were ineligible. We further screened 409 records, with 134 being excluded due to lack of full-text availability. In total, 251 records from the remaining 275 were excluded due to low-quality scores and publication bias. A total of 24 papers were included in the final analysis. Details on the procedures for selecting papers are summarized in Figure 1.

Figure 1. Paper screening procedure flowchart.



Data Sources

The data collected for this study were collected from various geographical locations and may have included memory clinics and neurology departments, suggesting a focus on cognitive impairment and related conditions. Table 1 displays the distribution of AD imaging sample data along with data sources.

Table 1. Participants' data collected from different sources.

Data source	AD[a], n/N (%)	Reference
ADNI[b]	33/204 (16.17)	[52]
Tianjin First Central Hospital, China	27/56 (48.21)	[53]
ADNI and AIBL[c]	1673/3335 (50.16)	[54]
OASIS[d] 3	1077/3979 (27.06)	[55]
ADNI	70/210 (30)	[56]
ADNI	193/818 (23.59)	[57]
ADNI	3200/6400 (50)	[58]
ADNI	186/805 (23.10)	[59]
Kaggle	3200/6400 (50)	[60]
ADNI	231/432 (50)	[61]
Kaggle	3200/6400 (50)	[62]
Shanghai Pudong New Area People's Hospital	55/119 (46.21)	[63]
ADNI	268/1048 (25.57)	[64]
ADNI and NACC[e]	1170/4644 (25.19)	[65]
Kaggle and ADNI	390/1310 (29.77)	[66]
ADNI	584/1421 (41.1)	[67]
ADNI	25/138 (18.11)	[68]
OASIS 1	78/150 (52)	[69]
Kaggle	3200/6400 (50)	[70]
Memory clinic of the neurology department in Nanfang Hospital	44/180 (24.44)	[71]
ADNI	118/245 (48.16)	[72]
ADNI	24/142 (16.90)	[73]
ADNI	1077/3979 (27.06)	[74]
ADNI	260/560 (46.42)	[75]

[a] AD: Alzheimer disease.

[b] ADNI: Alzheimer's Disease Neuroimaging Initiative.

[c] AIBL: Australian Imaging Biomarkers and Lifestyle Flagship Study of Ageing.

[d] OASIS: Open Access Series of Imaging Studies.

[e] NACC: National Alzheimer's Coordinating Center.

The analyzed studies collected image data from various sources such as Alzheimer's Disease Neuroimaging Initiative (ADNI) [76], Open Access Series of Imaging Studies (OASIS) [77], Australian Imaging Biomarkers and Lifestyle Flagship Study of Ageing [78], and public domains like Kaggle [79]. ADNI datasets were used more often for image collection [52,54,56-59,61,64-68,72-75,80]. The purpose of ADNI is to develop biomarkers for early detection and AD tracks through a multicenter study involving clinical imaging, genetics, and biochemistry. The studies that use ADNI datasets aim to detect AD at its prime stage. One study jointly applied 2 image datasets from ADNI and Australian Imaging Biomarkers and Lifestyle Flagship Study of Ageing [54].

OASIS brains aim to make it possible for anyone to access neuroimaging datasets of the brain through an initiative known as Open Access to Neuroimaging Datasets. Through this project, researchers can access and use a variety of brain imaging data for free. This resource assists neuroscience researchers in advancing their research by providing a comprehensive collection of brain imaging datasets. Cross-sectional OASIS 1 data were used by researchers for hypothesis-driven analysis, neuroanatomical atlases, and segmentation algorithms [69]. In another study, OASIS-3 was integrated with longitudinal neuroimaging, clinical, cognitive, and biomarker data [55]. The use of public datasets or participation in Kaggle competitions related to AD research helps as a platform for data science competitions and datasets [70]. Three studies collected data from 3 hospitals in China [53,63,71]. The findings indicate that a diverse dataset from multiple sources, such as clinical settings and publicly available datasets, could provide a comprehensive basis for AD research and analysis.

Study Characteristics

AD Stages

Table 2 presents a summary of various studies, which includes authors, publication year, AD stages, preprocessing techniques, classifiers, validation methods, and the best-performing model. Four studies have examined the progression of AD over 6 stages to gain a better understanding of how diseases develop and change [52,54,68,73]. Seven studies examined 4 groups of AD stages analyzing neurobiological mechanisms behind cognitive decline or exploring nonpharmacological treatments [55,58-60,64,66,70]. Similarly, 7 works associated with 3-stage classification studies involved patients with CN, MCI, and AD [56,57,62,65,67,71,74]. These studies were mainly focused on the early detection of dementia with subtle differences in biomarkers and cognitive performance. Moreover, the ML models used in the study predicted AD progress in estimating the transition from MCI to dementia. Finally, 6 studies associated a binary or 2-stage classification of AD with ML models to identify biomarkers that predict treatment response or disease progression [53,61,63,69,72,75]. This enables more effective targeted therapies and biomarker-driven clinical trials to be developed.

Table 2. Machine learning models and their characteristics.

	Author	Year	AD[a] stages	Image preprocessing methods	ML[b] models incorporated	Validation	Diagnosis accuracy (%)	Best model
1	Alorf and Khan [52]	2022	6	Normalization and smoothing	GLMICA[c]	K-fold (10)	84.03	BC-GCN[d]
2	Chen et al [53]	2017	2	Diffusivity and kurtosis mapping and ROI[e]	SVM[f]	K-fold (10)	96.23	SVM with DKI[g]
3	Mofrad et al [54]	2021	6	LME[h] for ROI extraction	SVC[i]	K-fold (15)	69-75	SVC
4	EL-Geneedy et al [55]	2023	4	Image normalization	DenseNet121[j], ResNet50[k], VGG16[l], EfficientNetB7, and InceptionV3	K-fold (10)	99.68	Customized CNN[m] model
5	Hazarika et al [56]	2022	3	Histogram-based approach	20 Different DL[n] models	K-fold (10)	90.22	DenseNet121
6	Khan et al [57]	2022	3	SMOTE[o]	16 Different ML models	K-fold (10)	90.24	SVM with DKI
7	Sorour et al [58]	2024	4	Image normalization and labeling	CNN, LSTM[p], SVM, and VGG16	K-fold (10)	99.92	CNN-LSTM
8	Abdelaziz et al [59]	2021	4	Interpolation	CNN	K-fold (10)	98.22	CNN
9	Sharma et al [60]	2022	4	VGG16	Neural network with VGG16 feature extractor	K-fold (10)	90.4	VGG16
10	Nguyen et al [61]	2022	2	Augmentation	3D-ResNet, XGB[q]	K-fold (5)	96.20	XGB
11	Saleh et al [62]	2023	3	CNN feature extraction	DenseNet121, 169, and 201	K-fold (10)	96.05	DenseNet201
12	Yang et al [63]	2022	2	Recursive feature elimination	Recursive random forest (RF)	K-fold (10)	97	RF
13	El-Sappagh et al [64]	2021	4	SMOTE	SVM, KNN[r], DT[s], NB[t], RF	K-fold (10)	87.76	RF
14	Liu et al [65]	2022	3	Unified segmentation	3D CNN	Holdout and external validation	85.12	3D CNN
15	Elgammal et al [66]	2022	4	Generalization	KNN	Multifractal geometry	99.4	KNN
16	Das et al [67]	2021	3	Skull stripping, intensity normalization, corpus callosum segmentation	SVM	K-fold (100)	90	SVM
17	Chelladurai et al [68]	2023	6	Gray-level co-occurrence matrix	RF, XGB, DT, SVM, MLP[u]	Evaluation metrics	99.44	MLP
18	Battineni et al [69]	2021	2	Outliers' detection	RF, GNB[v], LR[w], SVM, gradient boosting, and Ada boosting	K-fold (10)	97.58	Gradient boosting
19	Sharma et al [70]	2022	4	Normalization and augmentation	SVM, XGB, GNB	Not mentioned	89.89	SVM

	Author	Year	AD[a] stages	Image preprocessing methods	ML[b] models incorporated	Validation	Diagnosis accuracy (%)	Best model
20	Long et al [71]	2023	3	MRMR[x] algorithm in combination with the SFC[y] method	SVM, ANN[z]	K-fold (10)	80.36	SVM
21	Wang et al [72]	2023	2	Deep features extraction	CNN	K-fold (5)	98.86	CNN
22	Tajammal et al [73]	2023	6	Augmentation	VGG16, ResNet18, Alex Net, Inception V1, Custom CNN	Not mentioned	96.2	Custom CNN
23	Golovanevsky et al [74]	2022	3	Unified hyperparameter tuning	Multimodal	K-fold (3)	96.88	Multimodal AD diagnosis framework
24	Li and Yang [75]	2021	2	Transfer learning	SVM, VGG Net[aa], ResNet	K-fold (5)	95	VGG Net, ResNet

[a] AD: Alzheimer disease.

[b] ML: machine learning.

[c] GLMICA: generalized linear model incorporating covariates analysis.

[d] BC-GCN: brain connectivity–based graph convolutional network.

[e] ROI: region of interest.

[f] SVM: support vector machine.

[g] DKI: diffusion kurtosis imaging.

[h] LME: linear mixed-effects model.

[i] SVC: support vector classifier.

[j] DenseNet: dense convolutional network.

[k] ResNet: residual network.

[l] VGG: Visual Geometry Group.

[m] CNN: convolutional neural network.

[n] DL: deep learning.

[o] SMOTE: Synthetic Minority Oversampling Technique.

[p] LSTM: long short-term memory.

[q] XGB: extreme gradient boosting.

[r] KNN: k-nearest neighbor.

[s] DT: decision tree.

[t] NB: Naïve Bayes.

[u] MLP: multilayer perceptron.

[v] GNB: Gaussian Naive Bayes.

[w] LR: logistic regression.

[x] MRMR: minimum redundancy maximum relevance.

[y] SFC: sparse functional connectivity.

[z] ANN: artificial neural network.

[aa] VGG Net: Visual Geometry Group network.

Feature Engineering Techniques

Feature engineering plays an important contribution in brain image analysis [81]. Various feature techniques were discussed to tackle challenges in AD classification, such as class imbalance, feature extraction, robustness, and generalization. ConvNet or CNN was designed for processing grid-like data, such as images, using convolutional layers to learn spatial hierarchies of features automatically [62]. Visual Geometry Group (VGG16) uses 3×3 convolution filters to construct a 16-layer CNN architecture and is known for its simplicity and high performance in image classification tasks [60]. Models like multilayer perceptron, Dense Net, Efficient Net, and residual network in AD classification lie in their ability to effectively handle deep neural networks for feature extraction and classification, which is crucial in analyzing complex brain magnetic resonance images for AD detection. Support vector machine (SVM) is a supervised learning algorithm used for AD classification, and it constructs hyperplanes in a high-dimensional space to separate different classes. In contrast, diffusion kurtosis imaging (DKI) is an MRI procedure that captures non-Gaussian diffusion, giving insight into tissue microstructure and facilitating better brain mapping. These techniques range from basic normalization [55,58,70], outlier detection [69], interpolation [59], and transfer learning [75] to more advanced methods such as data augmentation [61,70,73], feature extraction using DL models like VGG16 [60], deep feature extraction [72], ConvNet [62], and statistical modeling for region of interest extraction [54]. Another paper extracted features related to corpus callosum atrophy for AD diagnosis [67]. A single study investigated texture analysis in brain images using the Gabor and gray-level co-occurrence matrix [52]. For feature selection and analysis of functional connectivity patterns, another investigation used the minimum redundancy maximum relevance algorithm alongside the sparse functional connectivity method [55]. Unified hyperparameter tuning was applied to optimize model parameters across algorithms and settings [58].

Classifiers

Supervised models like SVM were used by several studies for classification tasks due to their effectiveness in handling high-dimensional magnetic resonance image data and nonlinear relationships [53,54,58,64,67-69,71,75]. The generalized linear model incorporating covariates analysis was used by Alorf and Khan [52] to assess a model's performance and generalization ability by ensuring that all data points are used during both training and validation, reducing overfitting risk and allowing more reliable model performance estimates. The authors demonstrated that MRI data can be fine-tuned to capture subtle differences in brain morphology associated with AD by using pretrained models [55].

Similarly, to learn discriminative patterns, other models like logistic regression (LR), decision tree, Gaussian Naive Bayes, and k-nearest neighbor (KNN) largely contribute to the MRI-based AD classification. The combination of these multimodal classifiers was adopted among 6 works to leverage AD early diagnosis [63,64,66,68-70]. Alternatively, CNN-based DL models have the capability of autonomous learning and represent complex patterns in magnetic resonance images. In this review were identified 2 studies that used dense convolutional network (DenseNet) [55,62] and Inception [55,73]. In total, 4 studies applied residual network [55,61,73,75], 5 studies used VGG [55,58,60,73,75], and 1 study the EfficientNet [55]. The multimodeling approaches (comparison of 16 and 20 classifiers) of CNN models were incorporated in 2 works [56,57]. Long short-term memory, another DL framework largely used in the context of MRI classification, can be used to analyze sequential data, such as time-series MRI scans, to detect temporal changes in brain structures characteristic of AD progression [58]. One study used a different approach, the multimodal neural networks for analyzing data from multiple sources or modalities [74]. Ensemble learning techniques like extreme gradient boosting (XGB), gradient boosting, and Ada boosting combine weak learners to create a more powerful classification. MRI data in 4 studies were successfully handled by the XGB classifier, which captured nonlinear relationships between features and predicted AD status accurately [61,68-70].

Validation Techniques

K-fold cross-validation is a common method used by most studies, where the dataset is divided into K subsets, and the model is trained and tested for K times. Testing was conducted on each subset, while the remaining ones served as training. This method can be used to assess model performance and generalization across different subsets of data. The K-fold has been used in most studies with varying values of K including 3 [74], 5 [61,72,75], 10 [52,53,55-60,62-64,69,71,72], 15 [54], and 100 [67], indicating that the total partitioning of data varies depending on the level of validation. It is important to take into account the differences between different methods of validation. A recent study used a holdout technique and external validation, dividing the dataset into training and testing sets and performing an additional test on completely new, from-scratch datasets [65]. A unique approach to data analysis that uses multifractal geometries has been introduced by Elgammal et al [66] and is likely to involve characterizing complex patterns in data using fractal-based techniques. The findings above show that many validation methods need to be considered. Therefore, adaptable methodologies are necessary when it comes to datasets and objectives. On the other hand, there are a few mentions of specific evaluation metrics [68]. The use of K-fold cross-validation remains common, but the inclusion of alternative methods such as holdout and multifractal geometry suggests a willingness to explore new approaches to evaluating model performance and ensuring the robustness of ML and data analysis tasks.

Prevalence-Based Participant Pooling

There was no evidence of publication bias with Eggers (P=.49) or Begg (P=.38) tests. Figures 2-5 present the forest plot with the prevalences of participants with AD for 2, 3, 4, and 6 AD stage subgroups, respectively. Six studies with 1562 participants were identified among disease diagnoses with 2 stages including CN and AD [53,61,63,69,72,75]. The overall pooled prevalence of the REM reported 49.28% (95% CI 46.12%-52.45%; I^2=15%; P=.32). Studies do not differ significantly in their estimates of prevalence, and the test of heterogeneity does not reveal substantial differences between them. Seven studies were identified with a total sample of 17,588 patients with AD with 3-stage AD classification including CN, MCI, and AD [56,57,62,65,67,71,73]. The overall prevalence of AD diagnosis is estimated at 29.75% (95% CI 25.11%-34.84%; I^2=97%; P<.001). Each study provides an estimate of the AD prevalence among their respective populations with 95% CI. For example, Hazarika et al [56] found AD prevalence at 33.33% (95% CI 27%-40.15%). This indicates that if we were to combine the results of all the studies, this would be the estimated AD prevalence. I^2=97% indicates that a large proportion of the total variation in prevalence estimates is due to true differences between study populations rather than random error. The significant P value (<.01) for the test of heterogeneity indicates that there is substantial variability in AD diagnostic prevalence estimates among the studies.

Figure 2. A forest plot AD diagnosis prevalence (%) among 2-stage classification using random effects model [53,61,63,69,72,75]. AD: Alzheimer disease.

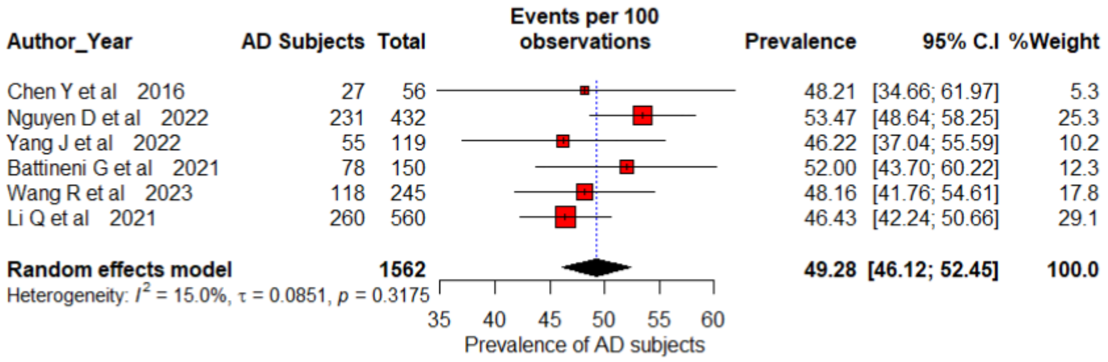


Figure 3. A forest plot AD diagnosis prevalence (%) among 3-stage classification using random effects model [56,57,62,65,67,71,74]. AD: Alzheimer disease.

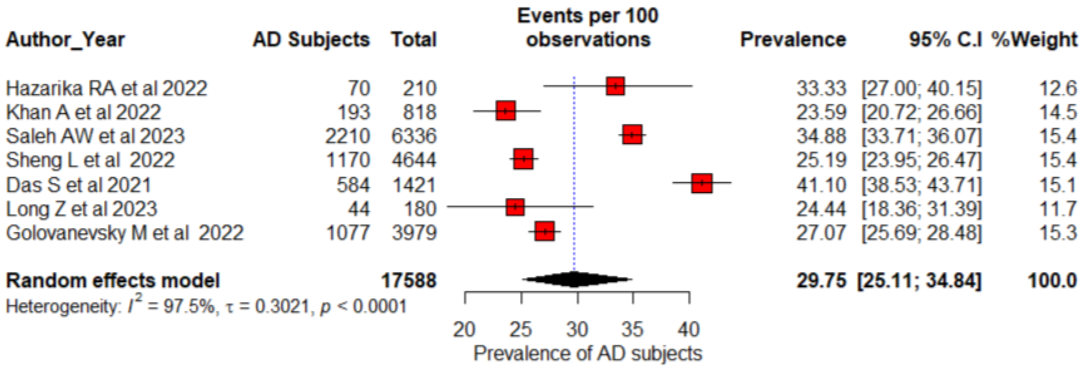


Figure 4. A forest plot AD diagnosis prevalence (%) among 4-stage classification using random effects model [55,59,64,66,70]. AD: Alzheimer disease.

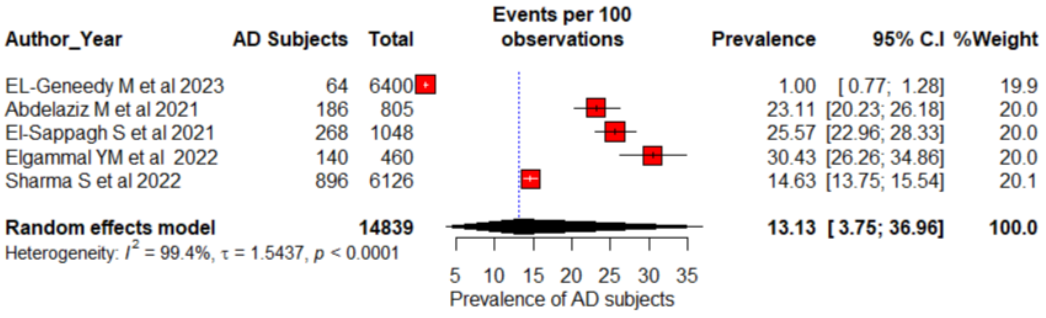
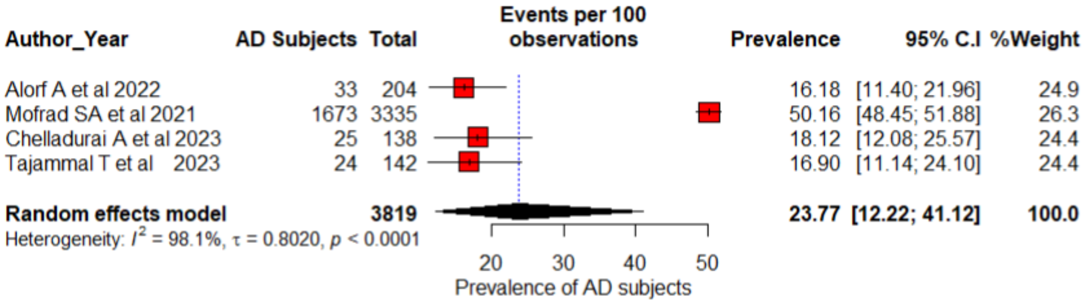


Figure 5. A forest plot AD diagnosis prevalence (%) among 6-stage classification using random effects model [52,54,68,73]. AD: Alzheimer disease.



Five studies with 14,839 participants were included for the meta-analysis of 4-stage AD classifications as ND, MoD, MD, and overt AD [55,59,64,66,70]. This systematic review included 7 studies, but we excluded 2 studies [58,60] because they used the same dataset with 6400 ADNI participants. Overall prevalence estimation with REMs is 13.13% (95% CI 3.75%-36.96%; I^2=99%; P<.001). There is significant heterogeneity in the studies based on the high I^2 and significant P value and a considerable variation in the prevalence of AD across these studies, according to these estimates. Different research studies have found prevalence estimates ranging from 1% [55] to 30.43% [66]. The CIs indicate the degree of uncertainty in these estimates. As a result of the high degree of heterogeneity observed in the study, the true prevalence of AD may vary significantly between populations and settings. Four studies with 3819 were considered for the calculation of the overall prevalence of AD diagnosis of 6 stages such as CN, SMC, EMCI, MCI, LMCI, and AD [52,54,68,73]. The estimated prevalence for each study is ranging from 16.18% [52] to 50.16% [54]. The overall estimate of prevalence from the REM stands at 23.77% (95% CI 12.22%-41.12%; I^2=0.8020; P<.001). One study has a substantially greater estimated proportion of AD prevalence diagnosis than the other studies [54]. Compared to others, it reported the highest prevalence of 50.16% (95% CI 48.45%-51.88%) but does not differ weights (26.3%) significantly from other studies.

Meta-analysis through forest plots provides a comprehensive way of understanding meta-analysis results. It can be argued, however, that forest plots can only display CIs by assuming a fixed significant threshold (P<.05). It causes a replication crisis when hypothesis tests are conducted using P values. Based on P value functions, drapery plots were proposed to resolve this problem [82]. Using a drapery plot, an average effect and a confidence curve can be identified. The x-axis shows the effect size metric, and the y-axis shows the assumed P value. Multimedia Appendix 2 presents the drapery plots. There is a red curve showing the overall REM, which shows the P values for various effect sizes. Compared to the CI of pooled effects, the shaded area represents the prediction range. The prediction range is noticeably wider than the CI for the pooled effect. It indicates that the overall pooled effect does not fully capture the variability or uncertainty across different effect sizes.

Discussion

Principal Findings

In this work, we conducted a systematic review and meta-analysis based on the prevalence of patients with AD among different disease progression stages. For the systematic review, 24 studies were selected, among 22 selected for the meta-analysis. Due to their association with the same dataset of ADNI and similar sample size of patients with AD, these 2 studies avoid bias in the analysis [58,60]. The studies included in this review have explored the ML applications for AD diagnosis and intended to provide an understanding of AD progression, potentially with a focus on biomarker identification.

Different preprocessing techniques used to extract relevant features including cortical thickness [83], hippocampal volume [84], and brain activity patterns [85] from magnetic resonance images associated with AD were examined. According to the research objectives and AD stages being investigated, each study applied specific image preprocessing techniques. The progression of AD has been evaluated across multiple stages in our work. An accuracy range of 69%-75% is achieved with linear mixed-effects models that account for region of interest features with interparticipant variability of hierarchical structures [54]. Using image normalization, 1 study classified AD stages with different labeling with 84.03% accuracy by ensuring consistency in intensity and spatial properties [52,86]. Combining DL models with imaging techniques like MRI and PET has shown that structural and functional changes in the brain associated with AD can be detected [87,88]. Water molecules' diffusion properties in brain tissue can be measured using diffusivity and kurtosis mapping. The results provided insight into microstructural changes for a maximum accuracy of 96.23% [53]. By conducting magnetic resonance image normalization, the authors proposed an MRI-based DL technique for 99.68% accurate AD detection [55]. Magnetic resonance images were investigated for pixel intensity distributions to detect AD abnormalities [56].

These techniques encompass diverse methodologies ranging from normalization and smoothing to advanced mapping and feature extraction methods [89-91]. Several approaches have demonstrated high accuracy in identifying AD features, including image normalization, histogram-based approaches, and diffusion mapping [92-95]. Techniques like recursive feature elimination and outlier detection showcase promising results, emphasizing the importance of feature selection and data quality assessment in enhancing classification performance [57,63]. A similar study analyzed and segmented different tissue types within MRI scans using unified segmentation. A magnetic resonance image of the brain was segmented simultaneously into different tissue types with 85.12% accuracy [65,96]. KNN-trained data can be used to classify AD with 99.4% accuracy using the generalization method [66]. Moreover, the use of advanced DL architectures such as VGG16 [60] and ConvNet [62] for feature extraction underscores the significance of leveraging sophisticated computational tools in AD research. Augmentation methods, interpolation, and transfer learning also emerge as valuable strategies for improving classification accuracy and robustness [73-75].

By integrating statistical and ML algorithms with preprocessing techniques, AD diagnosis research further enhances its interdisciplinary nature. The CNN-long short-term memory model had an accuracy of 99.92%, followed by the multimodal AD diagnosis framework model with a precision of 96.88%. The accuracy of a customized CNN model was 99.68%, SVM with DKI was 96.23%, XGB was 96.20%, and multilayer perceptron was 99.44%. In addition, DenseNet121, CNN, DenseNet201, random forest, and gradient boosting achieved accuracy levels between 90% and 97%. While some models demonstrated higher accuracy, such as 3D CNN and SVM, others demonstrated lower accuracy, 85.12% and 80.36%, respectively.

Many ML modeling techniques have been explored, including SVM, LR, and DenseNet. Ensemble methods like gradient boosting and Ada boosting have highlighted the importance of aggregating multiple models to improve predictive accuracy and robustness, especially when dealing with complex neurological disorders like AD [69,97]. The identification of specific best-performing models further underscores the importance of optimization of methods and model selection to improve diagnostic accuracy. The use of SVM along with DKI or DenseNet201 in different studies illustrates the researchers' tailored approach to leveraging each algorithm's and feature representation's strengths [98-100]. AD diagnosis is a nuanced process, where the choice of ML model can have a significant impact on model reliability and efficacy.

Data from magnetic resonance images have been analyzed using various ML models and validation techniques. To ensure robustness and generalization, the common technique used is K-fold cross-validation. Additionally, some authors have applied specific DL models along with traditional ML techniques, reflecting the diversity of approaches for modeling and validation [72,73]. Different mechanisms and approaches are used in each of these models to detect AD using magnetic resonance images. We have observed that SVM classifiers are largely used for 2-stage classification such as CN and AD [53,54,67,71]. Similarly, LR classifiers were used in other studies to assess MRI-based AD status interpretation and predictive factors for disease risk assessment. Based on learned discriminative patterns from magnetic resonance images, these models, as well as others mentioned, produce accurate AD detection predictions. Additionally, KNN can be used to identify magnetic resonance images with feature vectors similar to those associated with AD helping to detect patterns.

The meta-analysis shows that there is a great deal of variation between studies when it comes to estimating AD prevalence. The reason for this is probably because the study involved a wide range of diagnostic criteria and populations, not just prevalence rates. The prevalence estimates are diverse due to some studies focusing on specific AD stages while others cover a wider spectrum. The significant P values and I^2 statistics show that the diagnosis of AD is highly heterogeneous and requires a nuanced understanding of its epidemiology. The challenges associated with synthesizing prevalence data from disparate sources are revealed by this analysis. The prevalence of AD is subject to complex and variable research, which leads to wider CIs in some studies. Even after trying to use REMs to account for this heterogeneity, significant variation persists, suggesting that variables like demographics, study design, and diagnostic methodology may play a significant role. The provision of more reliable estimates requires the adoption of standardized protocols and collaboration in future research efforts, which stresses the importance of rigorous methodology and careful interpretation of results.

Comparison With Existing Reviews

There have been a few systematic reviews and meta-analyses about the importance of ML models in AD diagnosis. Table 3 summarizes the comparison between our work and the reviews that have already been published. In our analysis, we concentrated on using ML for AD diagnosis, while other studies were focused on using it for dementia forecasting [101]. In a similar study [102], the authors explored the effectiveness of both ML and DL models in AD diagnosis. In this study, the authors did not examine multistage AD cases but only the binary classification of AD. A single study [103] conducted a meta-analysis based on Wilcoxon signed rank tests and discussed multiple imaging modalities, including MRI, PET, and CSF. Despite this, there is a lack of discussion about feature selection techniques and their potential impact on ML accuracy. A prevalence-based meta-analysis on MRI-centered AD discussions is presented in our study along with an in-depth description of subcategories of AD. Our study stands out because it covers all aspects of ML in AD diagnosis, including imaging modalities and stages of AD. We reviewed and analyzed various imaging modalities, talked about feature selection methods, and delved deeper into AD subcategories in our research.

Table 3. Comparison of this review with existing systematic reviews.

Study	Systematic review	Meta-analysis	Imaging modalities	Feature selection	Alzheimer disease stages
[101]	✓		✓		4
[102]	✓		✓		2
[103]	✓	✓	✓		6
Our study	✓	✓	✓	✓	6

Future Directions and Study Limitations

Data from open-access libraries such as ADNI, Kaggle, and others were used in studies, as evidenced by the analysis of datasets. Prospective validation studies should be carried out in the future to assess the accuracy of ML models for AD diagnosis across diverse populations and clinical settings. The incorporation of multimodal data, including imaging, genetics, and clinical information, into ML models can improve their accuracy and robustness in diagnosing AD and distinguishing it from other brain disorders [89]. To enhance their clinical utility and acceptability, ML models must be interpretable and explainable. It may be possible to use these models to predict the onset and AD progression based on longitudinal studies that track individuals over time [14,101]. Future research must incorporate ML models into diagnostic workflows and assess their influence on patient outcomes and health care delivery.

Despite its comprehensiveness, this study is characterized by some shortcomings. The availability and quality of data are essential for the effectiveness of ML approaches. The outcome of the meta-analysis may have been influenced by the limitations in access to complete datasets with different levels of quality. The potential for publication bias, in which studies with positive findings are more likely to be published, may lead to an overestimation of the effectiveness of ML approaches for diagnosing AD. The included studies may have experienced heterogeneity due to variations in study designs, patient populations, imaging modalities, and ML algorithms, making it difficult to draw definitive conclusions. Despite our best efforts to conduct a thorough review, some relevant studies may have been mistakenly excluded, potentially creating gaps in the analysis. The generalizability of ML models for AD diagnosis may be limited by their development and validation on specific datasets.

Conclusions

A summary comparison of current literature on ML approaches in AD diagnosis, along with a systematic review and meta-analysis, helps to understand the prevalence of disease at different stages. Our analysis of 24 relevant papers shows a significant difference in AD prevalence estimates, as individuals progress from CN to MCI and ultimately to overt AD. We observed a pooled prevalence of 49.28% during the CN to AD transition. This was followed by 29.75% for CN, MCI, and AD, 13.13% for CN, MoD, MD, and AD, and 23.75% for CN, SMC, EMCI, MCI, LMCI, and AD. Our analysis reveals the importance of adjusting diagnostic and management strategies to minimize the impact of demographic and setting characteristics on AD prevalence estimates. Due to the heterogeneity observed across studies, it is necessary to consider various factors to accurately estimate the prevalence of AD. Our study is different from other studies by comparing it to existing systematic reviews and meta-analyses, which provide an original contribution to the topic under evaluation. Unlike previous studies that have focused on imaging modalities and AD stages, our study has comprehensively analyzed ML in AD diagnosis. Multiple imaging modalities were reviewed and analyzed, feature selection techniques were discussed, and AD subcategories were explored, focusing particularly on MRIs. Although none of the biomarkers currently available can provide a precise diagnosis of AD, using ML approaches to identify prevalence patterns across disease stages will lead to progress in AD diagnosis.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) checklist.

[PDF File (Adobe PDF File), 57 KB - aging_v7i1e59370_app1.pdf]

Multimedia Appendix 2

Drapery plots.

[DOCX File , 62 KB - aging_v7i1e59370_app2.docx]

References

1. Hodson R. Alzheimer's disease. Nature 2018;559(7715):S1. [doi: 10.1038/d41586-018-05717-6] [Medline: 30046078]
2. Jucker M, Walker LC. Alzheimer's disease: from immunotherapy to immunoprevention. Cell 2023;186(20):4260-4270 [FREE Full text] [doi: 10.1016/j.cell.2023.08.021] [Medline: 37729908]
3. Weller J, Budson A. Current understanding of Alzheimer's disease diagnosis and treatment. F1000Res 2018;7:1161 [FREE Full text] [doi: 10.12688/f1000research.14506.1] [Medline: 30135715]
4. Beata BK, Wojciech J, Johannes K, Piotr L, Barbara M. Alzheimer's disease—biochemical and psychological background for diagnosis and treatment. Int J Mol Sci 2023;24(2):1059 [FREE Full text] [doi: 10.3390/ijms24021059] [Medline: 36674580]
5. Subramanyam Rallabandi VP, Seetharaman K. Classification of cognitively normal controls, mild cognitive impairment and Alzheimer’s disease using transfer learning approach. Biomed Signal Process Control 2023;79:104092. [doi: 10.1016/j.bspc.2022.104092]
6. Swinford CG, Risacher SL, Charil A, Schwarz AJ, Saykin AJ. Memory concerns in the early Alzheimer's disease prodrome: regional association with tau deposition. Alzheimers Dement (Amst) 2018;10(1):322-331 [FREE Full text] [doi: 10.1016/j.dadm.2018.03.001] [Medline: 29780876]
7. Lin SY, Lin PC, Lin Y, Lee Y, Wang C, Peng S, et al. The clinical course of early and late mild cognitive impairment. Front Neurol 2022;13:685636 [FREE Full text] [doi: 10.3389/fneur.2022.685636] [Medline: 35651352]
8. Ilardi CR, Chieffi S, Iachini T, Iavarone A. Neuropsychology of posteromedial parietal cortex and conversion factors from mild cognitive impairment to Alzheimer's disease: systematic search and state-of-the-art review. Aging Clin Exp Res 2022;34(2):289-307 [FREE Full text] [doi: 10.1007/s40520-021-01930-y] [Medline: 34232485]
9. Ogbodo JO, Agbo CP, Njoku UO, Ogugofor MO, Egba SI, Ihim SA, et al. Alzheimer's disease: pathogenesis and therapeutic interventions. Curr Aging Sci 2022;15(1):2-25. [doi: 10.2174/1874609814666210302085232] [Medline: 33653258]
10. Dubois B, von Arnim CAF, Burnie N, Bozeat S, Cummings J. Biomarkers in Alzheimer's disease: role in early and differential diagnosis and recognition of atypical variants. Alzheimers Res Ther 2023;15(1):175 [FREE Full text] [doi: 10.1186/s13195-023-01314-6] [Medline: 37833762]
11. Gunes S, Aizawa Y, Sugashi T, Sugimoto M, Rodrigues PP. Biomarkers for Alzheimer's disease in the current state: a narrative review. Int J Mol Sci 2022;23(9):4962 [FREE Full text] [doi: 10.3390/ijms23094962] [Medline: 35563350]
12. Shaw LM, Arias J, Blennow K, Galasko D, Molinuevo JL, Salloway S, et al. Appropriate use criteria for lumbar puncture and cerebrospinal fluid testing in the diagnosis of Alzheimer's disease. Alzheimers Dement 2018;14(11):1505-1521 [FREE Full text] [doi: 10.1016/j.jalz.2018.07.220] [Medline: 30316776]
13. Ahsan MM, Luna SA, Siddique Z. Machine-learning-based disease diagnosis: a comprehensive review. Healthcare (Basel) 2022;10(3):541 [FREE Full text] [doi: 10.3390/healthcare10030541] [Medline: 35327018]
14. Kumar S, Oh I, Schindler S, Lai A, Payne P, Gupta AM. Machine learning for modeling the progression of Alzheimer disease dementia using clinical data: a systematic literature review. JAMIA Open 2021;4(3):ooab052 [FREE Full text] [doi: 10.1093/jamiaopen/ooab052] [Medline: 34350389]
15. Chang CH, Lin CH, Lane HY. Machine learning and novel biomarkers for the diagnosis of Alzheimer's disease. Int J Mol Sci 2021;22(5):2761 [FREE Full text] [doi: 10.3390/ijms22052761] [Medline: 33803217]
16. Wang N, Chen J, Xiao H, Wu L, Jiang H, Zhou Y. Application of artificial neural network model in diagnosis of Alzheimer's disease. BMC Neurol 2019;19(1):154 [FREE Full text] [doi: 10.1186/s12883-019-1377-4] [Medline: 31286894]
17. Świetlik D, Białowąs J. Application of artificial neural networks to identify Alzheimer's disease using cerebral perfusion SPECT data. Int J Environ Res Public Health 2019;16(7):1303 [FREE Full text] [doi: 10.3390/ijerph16071303] [Medline: 30979022]
18. Rahmani AM, Yousefpoor E, Yousefpoor MS, Mehmood Z, Haider A, Hosseinzadeh M, et al. Machine learning (ML) in medicine: review, applications, and challenges. Mathematics 2021;9(22):2970. [doi: 10.3390/math9222970]
19. Borchert RJ, Azevedo T, Badhwar AP, Bernal J, Betts M, Bruffaerts R, et al. Artificial intelligence for diagnostic and prognostic neuroimaging in dementia: a systematic review. Alzheimers Dement 2023;19(12):5885-5904. [doi: 10.1002/alz.13412] [Medline: 37563912]
20. Hansson O, Blennow K, Zetterberg H, Dage J. Blood biomarkers for Alzheimer's disease in clinical practice and trials. Nat Aging 2023;3(5):506-519 [FREE Full text] [doi: 10.1038/s43587-023-00403-3] [Medline: 37202517]
21. Skolariki K, Exarchos TP, Vlamos P. Computational models for biomarker discovery. Adv Exp Med Biol 2023;1424:289-295. [doi: 10.1007/978-3-031-31982-2_33] [Medline: 37486506]
22. Qiu S, Miller MI, Joshi PS, Lee JC, Xue C, Ni Y, et al. Multimodal deep learning for Alzheimer's disease dementia assessment. Nat Commun 2022;13(1):3404 [FREE Full text] [doi: 10.1038/s41467-022-31037-5] [Medline: 35725739]
23. Amiri Z, Heidari A, Navimipour NJ, Unal M, Mousavi A. Adventures in data analysis: a systematic review of deep learning techniques for pattern recognition in cyber-physical-social systems. Multimed Tools Appl 2023;83(8):22909-22973. [doi: 10.1007/s11042-023-16382-x]
24. Klang E. Deep learning and medical imaging. J Thorac Dis 2018;10(3):1325-1328 [FREE Full text] [doi: 10.21037/jtd.2018.02.76] [Medline: 29708147]

25. Li M, Jiang Y, Zhang Y, Zhu H. Medical image analysis using deep learning algorithms. Front Public Health 2023;11:1273253 [FREE Full text] [doi: 10.3389/fpubh.2023.1273253] [Medline: 38026291]
26. Vrahatis AG, Skolariki K, Krokidis MG, Lazaros K, Exarchos TP, Vlamos P. Revolutionizing the early detection of Alzheimer's disease through non-invasive biomarkers: the role of artificial intelligence and deep learning. Sensors (Basel) 2023;23(9):4184 [FREE Full text] [doi: 10.3390/s23094184] [Medline: 37177386]
27. Feng X, Provenzano FA, Small SA. A deep learning MRI approach outperforms other biomarkers of prodromal Alzheimer's disease. Alzheimers Res Ther 2022;14(1):45 [FREE Full text] [doi: 10.1186/s13195-022-00985-x] [Medline: 35351193]
28. Saleem TJ, Zahra SR, Wu F, Alwakeel A, Alwakeel M, Jeribi F, et al. Deep learning-based diagnosis of Alzheimer's disease. J Pers Med 2022;12(5):815 [FREE Full text] [doi: 10.3390/jpm12050815] [Medline: 35629237]
29. Alsubaie MG, Luo S, Shaukat K. Alzheimer's disease detection using deep learning on neuroimaging: a systematic review. Mach Learn Knowl Extr 2024;6(1):464-505. [doi: 10.3390/make6010024]
30. Basaia S, Agosta F, Wagner L, Canu E, Magnani G, Santangelo R, et al. Automated classification of Alzheimer's disease and mild cognitive impairment using a single MRI and deep neural networks. Neuroimage Clin 2019;21:101645 [FREE Full text] [doi: 10.1016/j.nicl.2018.101645] [Medline: 30584016]
31. Liu J, Li M, Luo Y, Yang S, Li W, Bi Y. Alzheimer's disease detection using depthwise separable convolutional neural networks. Comput Methods Programs Biomed 2021;203:106032. [doi: 10.1016/j.cmpb.2021.106032] [Medline: 33713959]
32. Abdelwahab MM, Al-Karawi KA, Semary HE. Deep learning-based prediction of Alzheimer's disease using microarray gene expression data. Biomedicines 2023;11(12):3304 [FREE Full text] [doi: 10.3390/biomedicines11123304] [Medline: 38137524]
33. Ebrahimi A, Luo S, Alzheimer's Disease Neuroimaging Initiative. Convolutional neural networks for Alzheimer's disease detection on MRI images. J Med Imaging 2021;8(02):024503. [doi: 10.1117/1.jmi.8.2.024503]
34. Liu M, Cheng D, Yan W. Classification of Alzheimer's disease by combination of convolutional and recurrent neural networks using FDG-PET images. Front Neuroinform 2018;12:35 [FREE Full text] [doi: 10.3389/fninf.2018.00035] [Medline: 29970996]
35. Lien WC, Yeh CH, Chang CY, Chang C, Wang W, Chen C, et al. Convolutional neural networks to classify Alzheimer's disease severity based on SPECT images: a comparative study. J Clin Med 2023;12(6):2218 [FREE Full text] [doi: 10.3390/jcm12062218] [Medline: 36983226]
36. Guluwadi S, Mohamed MM, Mahesh TR, Vinoth KV. Enhancing brain tumor detection in MRI images through explainable AI using Grad-CAM with Resnet 50. BMC Med Imaging 2024;24(1):107 [FREE Full text] [doi: 10.1186/s12880-024-01292-7] [Medline: 38734629]
37. Yang C, Rangarajan A, Ranka S. Visual explanations from deep 3D convolutional neural networks for Alzheimer's disease classification. AMIA Annu Symp Proc 2018;2018:1571-1580. [Medline: 30815203]
38. Cui R, Liu M, Alzheimer's Disease Neuroimaging Initiative. RNN-based longitudinal analysis for diagnosis of Alzheimer's disease. Comput Med Imaging Graph 2019;73:1-10. [doi: 10.1016/j.compmedimag.2019.01.005] [Medline: 30763637]
39. Giorgio J, Landau SM, Jagust WJ, Tino P, Kourtzi Z. Modelling prognostic trajectories of cognitive decline due to Alzheimer's disease. Neuroimage Clin 2020;26:102199 [FREE Full text] [doi: 10.1016/j.nicl.2020.102199] [Medline: 32106025]
40. Chen Y, Wang L, Ding B, Shi J, Wen T, Huang J, et al. Automated Alzheimer's disease classification using deep learning models with soft-NMS and improved ResNet50 integration. J Radiat Res Appl Sci 2024;17(1):100782. [doi: 10.1016/j.jrras.2023.100782]
41. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71 [FREE Full text] [doi: 10.1136/bmj.n71] [Medline: 33782057]
42. Lo CKL, Mertz D, Loeb M. Newcastle-Ottawa Scale: comparing reviewers' to authors' assessments. BMC Med Res Methodol 2014;14:45. [doi: 10.1186/1471-2288-14-45] [Medline: 24690082]
43. Lin L, Chu H. Quantifying publication bias in meta-analysis. Biometrics 2018;74(3):785-794 [FREE Full text] [doi: 10.1111/biom.12817] [Medline: 29141096]
44. Gjerdevik M, Heuch I. Improving the error rates of the Begg and Mazumdar test for publication bias in fixed effects meta-analysis. BMC Med Res Methodol 2014;14(1):109. [doi: 10.1186/1471-2288-14-109] [Medline: 25245217]
45. Data Analysis in the Geosciences. URL: http://stratigrafia.org/8370/rtips/proportions.html [accessed 2024-03-27]
46. Bollen KA, Brand JE. A general panel model with random and fixed effects: a structural equations approach. Soc Forces 2010;89(1):1-34 [FREE Full text] [doi: 10.1353/sof.2010.0072] [Medline: 21769157]
47. Nusrang M, Annas S, Heinonen J, Clarke J. Performa restricted maximum likelihood and maximum likelihood estimators on small area estimation. J Phys Conf Ser 2018;1028:012234 [FREE Full text] [doi: 10.1088/1742-6596/1028/1/012234]
48. von Hippel PT. The heterogeneity statistic I(2) can be biased in small meta-analyses. BMC Med Res Methodol 2015;15(1):35 [FREE Full text] [doi: 10.1186/s12874-015-0024-z] [Medline: 25880989]
49. Thorlund K, Imberger G, Johnston BC, Walsh M, Awad T, Thabane L, et al. Evolution of heterogeneity (I2) estimates and their 95% confidence intervals in large meta-analyses. PLoS One 2012;7(7):e39471 [FREE Full text] [doi: 10.1371/journal.pone.0039471] [Medline: 22848355]
50. Aslam M. Cochran's Q test for analyzing categorical data under uncertainty. J Big Data 2023;10(1):1-10. [doi: 10.1186/s40537-023-00823-3]

51. Barendregt JJ, Doi SA, Lee YY, Norman RE, Vos T. Meta-analysis of prevalence. J Epidemiol Community Health 2013;67(11):974-978. [doi: 10.1136/jech-2013-203104] [Medline: 23963506]
52. Alorf A, Khan MUG. Multi-label classification of Alzheimer's disease stages from resting-state fMRI-based correlation connectivity data and deep learning. Comput Biol Med 2022;151(Pt A):106240 [FREE Full text] [doi: 10.1016/j.compbiomed.2022.106240] [Medline: 36423532]
53. Chen Y, Sha M, Zhao X, Ma J, Ni H, Gao W, et al. Automated detection of pathologic white matter alterations in Alzheimer's disease using combined diffusivity and kurtosis method. Psychiatry Res Neuroimaging 2017;264:35-45 [FREE Full text] [doi: 10.1016/j.pscychresns.2017.04.004] [Medline: 28448817]
54. Mofrad SA, Lundervold A, Lundervold AS. A predictive framework based on brain volume trajectories enabling early detection of Alzheimer's disease. Comput Med Imaging Graph 2021;90:101910 [FREE Full text] [doi: 10.1016/j.compmedimag.2021.101910] [Medline: 33862355]
55. EL-Geneedy M, Moustafa HED, Khalifa F, Khater H, AbdElhalim E. An MRI-based deep learning approach for accurate detection of Alzheimer's disease. Alexandria Eng J 2023;63:211-221. [doi: 10.1016/j.aej.2022.07.062]
56. Hazarika RA, Kandar D, Maji AK. An experimental analysis of different deep learning based models for Alzheimer's disease classification using brain magnetic resonance images. J King Saud Univ - Comput Inf Sci 2022;34(10):8576-8598. [doi: 10.1016/j.jksuci.2021.09.003]
57. Khan A, Zubair S. Development of a three tiered cognitive hybrid machine learning algorithm for effective diagnosis of Alzheimer's disease. J King Saud Univ - Comput Inf Sci 2022;34(10):8000-8018. [doi: 10.1016/j.jksuci.2022.07.016]
58. Sorour SE, El-Mageed AAA, Albarrak KM, Alnaim AK, Wafa AA, El-Shafeiy E. Classification of Alzheimer's disease using MRI data based on deep learning techniques. J King Saud Univ - Comput Inf Sci 2024;36(2):101940. [doi: 10.1016/j.jksuci.2024.101940]
59. Abdelaziz M, Wang T, Elazab A. Alzheimer's disease diagnosis framework from incomplete multimodal data using convolutional neural networks. J Biomed Inform 2021;121:103863 [FREE Full text] [doi: 10.1016/j.jbi.2021.103863] [Medline: 34229061]
60. Sharma S, Guleria K, Tiwari S, Kumar S. A deep learning based convolutional neural network model with VGG16 feature extractor for the detection of Alzheimer disease using MRI scans. Meas Sens 2022;24:100506. [doi: 10.1016/j.measen.2022.100506]
61. Nguyen D, Nguyen H, Ong H, Le H, Ha H, Duc NT, et al. Ensemble learning using traditional machine learning and deep neural network for diagnosis of Alzheimer's disease. IBRO Neurosci Rep 2022;13:255-263 [FREE Full text] [doi: 10.1016/j.ibneur.2022.08.010] [Medline: 36590098]
62. Saleh AW, Gupta G, Khan SB, Alkhaldi NA, Verma A. An Alzheimer's disease classification model using transfer learning Densenet with embedded healthcare decision support system. Decis Anal J 2023;9:100348. [doi: 10.1016/j.dajour.2023.100348]
63. Yang J, Sui H, Jiao R, Zhang M, Zhao X, Wang L, et al. Random-forest-algorithm-based applications of the basic characteristics and serum and imaging biomarkers to diagnose mild cognitive impairment. Curr Alzheimer Res 2022;19(1):76-83 [FREE Full text] [doi: 10.2174/1567205019666220128120927] [Medline: 35088670]
64. El-Sappagh S, Alonso JM, Islam SMR, Sultan AM, Kwak KS. A multilayer multimodal detection and prediction model based on explainable artificial intelligence for Alzheimer's disease. Sci Rep 2021;11(1):2660 [FREE Full text] [doi: 10.1038/s41598-021-82098-3] [Medline: 33514817]
65. Liu S, Masurkar AV, Rusinek H, Chen J, Zhang B, Zhu W, et al. Generalizable deep learning model for early Alzheimer's disease detection from structural MRIs. Sci Rep 2022;12(1):17106 [FREE Full text] [doi: 10.1038/s41598-022-20674-x] [Medline: 36253382]
66. Elgammal YM, Zahran MA, Abdelsalam MM. A new strategy for the early detection of Alzheimer disease stages using multifractal geometry analysis based on K-Nearest Neighbor algorithm. Sci Rep 2022;12(1):22381 [FREE Full text] [doi: 10.1038/s41598-022-26958-6] [Medline: 36572791]
67. Das S, Panigrahi P, Chakrabarti S. Corpus callosum atrophy in detection of mild and moderate Alzheimer's disease using brain magnetic resonance image processing and machine learning techniques. J Alzheimers Dis Rep 2021;5(1):771-788. [doi: 10.3233/adr-210314]
68. Chelladurai A, Narayan DL, Divakarachari PB, Loganathan U. fMRI-based Alzheimer's disease detection using the SAS method with multi-layer perceptron network. Brain Sci 2023;13(6):893 [FREE Full text] [doi: 10.3390/brainsci13060893] [Medline: 37371371]
69. Battineni G, Hossain MA, Chintalapudi N, Traini E, Dhulipalla VR, Ramasamy M, et al. Improved Alzheimer's disease detection by MRI using multimodal machine learning algorithms. Diagnostics (Basel) 2021;11(11):2103 [FREE Full text] [doi: 10.3390/diagnostics11112103] [Medline: 34829450]
70. Sharma S, Gupta S, Gupta D, Altameem A, Saudagar AKJ, Poonia RC, et al. HTLML: hybrid AI based model for detection of Alzheimer's disease. Diagnostics (Basel) 2022;12(8):1833. [doi: 10.3390/diagnostics12081833] [Medline: 36010183]
71. Long Z, Li J, Fan J, Li B, Du Y, Qiu S, et al. Identifying Alzheimer's disease and mild cognitive impairment with atlas-based multi-modal metrics. Front Aging Neurosci 2023;15:1212275 [FREE Full text] [doi: 10.3389/fnagi.2023.1212275] [Medline: 37719872]

72. Wang R, He Q, Han C, Wang H, Shi L, Che Y. A deep learning framework for identifying Alzheimer's disease using fMRI-based brain network. Front Neurosci 2023;17:1177424 [FREE Full text] [doi: 10.3389/fnins.2023.1177424] [Medline: 37614342]
73. Tajammal T, Khurshid SK, Jaleel A, Qayyum Wahla S, Ziar RA. Deep learning-based ensembling technique to classify Alzheimer's disease stages using functional MRI. J Healthc Eng 2023;2023:6961346 [FREE Full text] [doi: 10.1155/2023/6961346] [Medline: 37953911]
74. Golovanevsky M, Eickhoff C, Singh R. Multimodal attention-based deep learning for Alzheimer's disease diagnosis. J Am Med Inform Assoc 2022;29(12):2014-2022 [FREE Full text] [doi: 10.1093/jamia/ocac168] [Medline: 36149257]
75. Li Q, Yang MQ. Comparison of machine learning approaches for enhancing Alzheimer's disease classification. PeerJ 2021;9:e10549. [doi: 10.7717/peerj.10549] [Medline: 33665002]
76. About ADNI. Alzheimer’s Disease Neuroimaging Initiative. URL: https://adni.loni.usc.edu/about/ [accessed 2024-03-15]
77. Marcus DS, Wang TH, Parker J, Csernansky JG, Morris JC, Buckner RL. Open Access Series of Imaging Studies (OASIS): cross-sectional MRI data in young, middle aged, nondemented, and demented older adults. J Cogn Neurosci 2007;19(9):1498-1507. [doi: 10.1162/jocn.2007.19.9.1498] [Medline: 17714011]
78. The AIBL Study. URL: https://aibl.org.au/ [accessed 2024-03-15]
79. Alzheimer's MRI brain scan images (augmented). Kaggle. URL: https://www.kaggle.com/datasets/vencerlanz09/alzheimers-mri-brain-scan-images-augmented [accessed 2024-03-15]
80. Crystal O, Maralani PJ, Black S, Fischer C, Moody AR, Khademi A. Detecting conversion from mild cognitive impairment to Alzheimer's disease using FLAIR MRI biomarkers. Neuroimage Clin 2023;40:103533 [FREE Full text] [doi: 10.1016/j.nicl.2023.103533] [Medline: 37952286]
81. Opfer R, Suppa P, Kepp T, Spies L, Schippling S, Huppertz H. Atlas based brain volumetry: how to distinguish regional volume changes due to biological or physiological effects from inherent noise of the methodology. Magn Reson Imaging 2016;34(4):455-461. [doi: 10.1016/j.mri.2015.12.031] [Medline: 26723849]
82. Infanger D, Schmidt-Trucksäss A. P value functions: an underused method to present research results and to promote quantitative reasoning. Stat Med 2019;38(21):4189-4197. [doi: 10.1002/sim.8293] [Medline: 31270842]
83. Pettigrew C, Soldan A, Zhu Y, Wang M, Brown T, Miller M, et al. Cognitive reserve and cortical thickness in preclinical Alzheimer's disease. Brain Imaging Behav 2017;11(2):357-367 [FREE Full text] [doi: 10.1007/s11682-016-9581-y] [Medline: 27544202]
84. Li A, Li F, Elahifasaee F, Liu M, Zhang L. Hippocampal shape and asymmetry analysis by cascaded convolutional neural networks for Alzheimer's disease diagnosis. Brain Imaging Behav 2021;15(5):2330-2339. [doi: 10.1007/s11682-020-00427-y] [Medline: 33398778]
85. Horikawa T, Tamaki M, Miyawaki Y, Kamitani Y. Neural decoding of visual imagery during sleep. Science 2013;340(6132):639-642. [doi: 10.1126/science.1234330] [Medline: 23558170]
86. Zou M, Zhou Q, Li R, Hu M, Qian L, Yang Z, et al. Image quality using synthetic brain MRI: an age-stratified study. Acta Radiol 2023;64(5):2010-2023. [doi: 10.1177/02841851231152098] [Medline: 36775871]
87. Arafa DA, Moustafa HED, Ali HA, Ali-Eldin AMT, Saraya SF. A deep learning framework for early diagnosis of Alzheimer’s disease on MRI images. Multimed Tools Appl 2023;83(2):3767-3799. [doi: 10.1007/s11042-023-15738-7]
88. Amini M, Pedram MM, Moradi A, Jamshidi M, Ouchani M. GC-CNNnet: diagnosis of Alzheimer's disease with PET images using genetic and convolutional neural network. Comput Intell Neurosci 2022;2022:7413081 [FREE Full text] [doi: 10.1155/2022/7413081] [Medline: 35983158]
89. Salvi M, Loh HW, Seoni S, Barua PD, García S, Molinari F, et al. Multi-modality approaches for medical support systems: a systematic review of the last decade. Inf Fusion 2024;103:102134. [doi: 10.1016/j.inffus.2023.102134]
90. Catalino MP, Yao S, Green DL, Laws ER, Golby AJ, Tie Y. Mapping cognitive and emotional networks in neurosurgical patients using resting-state functional magnetic resonance imaging. Neurosurg Focus 2020;48(2):E9 [FREE Full text] [doi: 10.3171/2019.11.FOCUS19773] [Medline: 32006946]
91. Frost MA, Esposito F, Goebel R. Improved correspondence of resting-state networks after macroanatomical alignment. Hum Brain Mapp 2014;35(2):673-682 [FREE Full text] [doi: 10.1002/hbm.22191] [Medline: 23161519]
92. Tang X, Qin Y, Zhu W, Michael MMH. Surface-based vertexwise analysis of morphometry and microstructural integrity for white matter tracts in diffusion tensor imaging: with application to the corpus callosum in Alzheimer's disease. Hum Brain Mapp 2017;38(4):1875-1893 [FREE Full text] [doi: 10.1002/hbm.23491] [Medline: 28083895]
93. Katabathula S, Wang Q, Xu R. Predict Alzheimer's disease using hippocampus MRI data: a lightweight 3D deep convolutional network model with visual and global shape representations. Alzheimers Res Ther 2021;13(1):104 [FREE Full text] [doi: 10.1186/s13195-021-00837-0] [Medline: 34030743]
94. Shaikh T, Ali R. Automated atrophy assessment for Alzheimer's disease diagnosis from brain MRI images. Magn Reson Imaging 2019;62:167-173. [doi: 10.1016/j.mri.2019.06.019] [Medline: 31279772]
95. Zhang T, Wu S, Zhang X, Dai Y, Wang A, Zhang H, et al. Spatial normalization and quantification approaches of PET imaging for neurological disorders. Eur J Nucl Med Mol Imaging 2022;49(11):3809-3829. [doi: 10.1007/s00259-022-05809-6] [Medline: 35624219]

96. Ashburner J, Friston KJ. Unified segmentation. Neuroimage 2005;26(3):839-851. [doi: 10.1016/j.neuroimage.2005.02.018] [Medline: 15955494]
97. Shojaie M, Cabrerizo M, DeKosky ST, Vaillancourt DE, Loewenstein D, Duara R, et al. A transfer learning approach based on gradient boosting machine for diagnosis of Alzheimer's disease. Front Aging Neurosci 2022;14:966883. [doi: 10.3389/fnagi.2022.966883] [Medline: 36275004]
98. Atik C, Kut RA, Yilmaz R, Birant D. Support vector machine chains with a novel tournament voting. Electronics 2023;12(11):2485. [doi: 10.3390/electronics12112485]
99. Oliveira M, Wilming R, Clark B, Budding C, Eitel F, Ritter K, et al. Benchmarking the influence of pre-training on explanation performance in MR image classification. Front Artif Intell 2024;7:1330919 [FREE Full text] [doi: 10.3389/frai.2024.1330919] [Medline: 38469161]
100. Amaya-Tejera N, Gamarra M, Vélez JI, Zurek E. A distance-based kernel for classification via Support Vector Machines. Front Artif Intell 2024;7:1287875 [FREE Full text] [doi: 10.3389/frai.2024.1287875] [Medline: 38469159]
101. Javeed A, Dallora AL, Berglund JS, Ali A, Ali L, Anderberg P. Machine learning for dementia prediction: a systematic review and future research directions. J Med Syst 2023;47(1):17 [FREE Full text] [doi: 10.1007/s10916-023-01906-7] [Medline: 36720727]
102. Arya AD, Verma SS, Chakarabarti P, Chakrabarti T, Elngar AA, Kamali AM, et al. A systematic review on machine learning and deep learning techniques in the effective diagnosis of Alzheimer's disease. Brain Inform 2023 Jul 14;10(1):17 [FREE Full text] [doi: 10.1186/s40708-023-00195-7] [Medline: 37450224]
103. Odusami M, Maskeliūnas R, Damaševičius R, Misra S. Machine learning with multimodal neuroimaging data to classify stages of Alzheimer's disease: a systematic review and meta-analysis. Cogn Neurodyn 2024;18(3):775-794 [FREE Full text] [doi: 10.1007/s11571-023-09993-5] [Medline: 38826669]

Abbreviations

AD: Alzheimer disease
ADNI: Alzheimer’s Disease Neuroimaging Initiative
CN: cognitively normal
CNN: convolutional neural network
CSF: cerebrospinal fluid
CT: computerized tomography
DenseNet: dense convolutional network
DKI: diffusion kurtosis imaging
DL: deep learning
EMCI: early mild cognitive impairment
KNN: k-nearest neighbor
LMCI: late mild cognitive impairment
LR: logistic regression
MCI: mild cognitive impairment
MD: mildly demented
ML: machine learning
MoD: moderately demented
MRI: magnetic resonance imaging
ND: nondemented
OASIS: Open Access Series of Imaging Studies
PET: positron emission tomography
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis
REM: random effects model
SMC: significant memory concern
SVM: support vector machine
VGG: Visual Geometry Group
XGB: extreme gradient boosting

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