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Contents

Original Papers

Reviews

Viewpoint

Original Paper

Adapting Chinese Qigong Mind-Body Exercise for Healthy Aging in Older Community-Dwelling Low-income Latino Adults: Pilot Feasibility Study

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Abstract

Background: Research translating the evidence for the benefit of mind-body exercise in older Latinos with limited access to community-based healthy aging programs is sparse.

Objective: This study aimed to evaluate the feasibility of Function Improvement Exercises for Older Sedentary Community-Dwelling Latino Residents (FITxOlder), a Community Health Worker (CHW)-led, mobile technology-facilitated Chinese Qigong mind-body exercise program for healthy aging and to explore its impact on physical and cognitive function and quality of life (QoL) in older community-dwelling low-income Latino adults.

Methods: This study was designed as a Stage 1 feasibility study to develop and pilot-test FITxOlder. In Phase 1 (Stage 1A), a working group of seniors, CHWs, and senior center staff guided the adaptation of Chinese Qigong into a healthy aging program. In Phase 2 (Stage 1B), 49 older Latino adults participated in a 3-arm controlled study to test the feasibility and preliminary effect of CHW-led FITxOlder on physical and cognitive function and QoL measures over 16 weeks.

Results: Although the COVID-19 pandemic disrupted the implementation of the study protocol, we found favorable results regarding participant recruitment, retention, and fidelity of implementation. Notable findings included an 89.3% participant retention, 79.4% of the participants completed at least 70% of the weekly exercise goal, and no report of adverse events. The effects on intervention outcome measures were modest.

Conclusions: FITxOlder is feasible for promoting healthy aging in older Latino adults; future research needs to compare its feasibility with other low-impact exercise programs for healthy aging using a randomized controlled trial.

Trial Registration: ClinicalTrials.gov NCT04284137; https://clinicaltrials.gov/ct2/show/NCT04284137

Introduction

Latinos/Hispanics aged 65 years and older are the fastest-growing racial/ethnic group and the most overrepresented low socioeconomic status population in the United States [1]. Compared to non-Hispanic Whites, older Hispanics have lower levels of physical and mental health, lower quality of life (QoL), and higher levels of impairment when performing activities of daily living (ADL) and other instrumental activities [2]. Aging is also associated with deteriorating health conditions, and 80.1% of Americans aged 65 years and older have 2 or more chronic conditions that further exacerbate ADL impairment and social and cognitive functions [3]. In addition, being a minority, female, and uninsured increases the risk of having multiple chronic conditions [4,5]. For example, Latino females (46.4%) and Black adults (46.7%) aged ≥65 years had the highest prevalence of having ≥4 chronic conditions among the Medicare beneficiaries. Although regular participation in physical activity (PA) is an effective approach to reducing the risk of chronic conditions and promoting healthy aging and independent living [6], the majority of older Americans do not meet the recommended level of PA [1], and over a quarter of older Latino adults do not participate in adequate PA, including leisure-time PA [7]. Ongoing efforts have considered the health conditions, previous PA habits and experiences, cultural preferences, social support, convenience, accessibility, and use of mobile health (mHealth) technologies to promote PA in community-dwelling older adults [8,9], with mixed results [10].

There is increased interest among Americans in mind-body exercises originating from non-Western regions and cultures, and they have been deemed safe, beneficial, and cost-effective therapeutic forms of complementary and alternative medicine (CAM) [11,12]. Chinese Qigong, Tai Chi, and Yoga are commonly known mind-body exercises with roots in ancient Asian culture [13]. Under the broad umbrella of Dao Yin, Qigong and Tai Chi are medical treatment and health preservation practices in traditional Chinese medicine [14], characterized by (1) slow body movements that symbolize the movement or posture of animate objects or natural events with low to moderate physical exertion, (2) coordinated breathing that is consciously or automatically (expertly) controlled, and (3) a state of mental quieting (ie, a meditative state) that is achieved by calming the mind or disassociating from disruptive thoughts [15,16]. Evidence from randomized controlled trials (RCTs) indicates that Qigong and Tai Chi have clinically significant effects on physical and cognitive functions [14,17-19], QoL [20], immunomodulatory or inflammatory responses [21,22], and chronic physical and mental health conditions and disorders [18,19,23] in older adults and populations with chronic conditions. Given the repetitive nature and lower level of physical exertion, Qigong exercises tend to be easier to learn and more appealing to older adults and individuals with chronic health conditions than Tai Chi and Yoga [17,20,24-26]. Qigong can be delivered at a low cost with minimum safety concerns in community locations and homes and thus, are affordable and sustainable [25-27].

While Qigong appears to be an appealing form of PA for older adults, to date, no research exists on the effectiveness of Qigong among low-income Latino adults that have experienced disparities in accessing community-based healthy aging programs [28,29]. Separately, research is limited on evidence-based interventions (EBIs) involving mHealth among older minority adults [30]. Furthermore, indiscriminate cross-cultural adaptation of EBIs may reduce effectiveness and impede sustainability [31,32].

To address this knowledge gap, we evaluated the feasibility of a Qigong healthy aging program in community-dwelling low-income Latino adults with chronic health conditions following the National Institutes of Health's (NIH) Stage Model [33]. As such, the study's primary aim was to assess the feasibility of an adapted Qigong program led by community health workers (CHWs) and facilitated by mHealth. A second aim was to explore the effect of the Qigong program on healthy aging-related outcomes. The study results will be used to plan a large RCT for testing the efficacy of Qigong in promoting healthy aging.

Methods

Study Design

We conducted a 3-arm study to assess the feasibility of a Qigong program for healthy aging, called Function Improvement Exercises for Older Sedentary Community-Dwelling Latino Residents (*FITxOlder*) among low-income Latino participants in the inner-city area of San Antonio, Texas. Designed as an NIH Stage 1 feasibility study [34], the research consisted of 2 phases: Phase 1, a formative study for intervention development (Stage 1A) that was used to develop and adapt *FITxOlder* and create training materials to facilitate the study implementation, and Phase 2, pilot testing of *FITxOlder* (Stage 1B) to evaluate whether the intervention was feasible to implement with and acceptable to the intended study population. The changes in the outcome measures were used to estimate the effect size for designing the healthy aging RCT [34]. The Institutional Review Board of the University of Texas San Antonio approved the study protocol.

Study Setting and Recruitment

The study sites were senior centers that served predominantly Latino, low-income adults who were participants of the congregate meals program. The Phase 1 formative study was conducted at a senior center where all program participants self-identified as Latino, and participation in the working group was voluntary. Participants for the Phase 2 feasibility testing of the pilot intervention were recruited through flyers distributed at 3 senior centers. Interested individuals provided their contact information to senior center staff, then research staff conducted eligibility screening based on established criteria—age ≥60 years, ability to exercise in a standing position, ownership of a cell phone or living with someone with a cell phone, agreement not to participate in other concurrent health programs, and willingness to complete the 3-month study. We did not screen for chronic conditions since over 80% of older adults had ≥3 chronic conditions in a similar congregate meals program in San Antonio [35]. Eligible individuals completed a consent form and signed up for baseline assessment. All recruitment and consent materials were available in Spanish and English.

The recruitment goal was 15-20 participants at each of the 3 sites with ≥25 program participants. The participants received US $30 for completing the baseline assessment and US $40 after completing the posttest.

Description of the Study and Intervention

Phase 1-Formative Study: Intervention Development

We conducted the formative study guided by the principles of community-based participatory research (CBPR) [36] and the framework for the design and adaptation of EBIs in health disparity populations [37]. The Phase 1 goal was to develop a culturally tailored exercise program for healthy aging that would incorporate low-cost mind-body exercises and address PA barriers and facilitators to improve physical and cognitive function and QoL among older low-income Latino adults. A concurrent goal was to develop a healthy aging instructor training program that could be scaled to prepare community-based program instructors for the pilot study in Phase 2.

The initiation of Phase 1 involved convening of a multidisciplinary research team (ie, physical therapy, community nursing, community health, nutrition, and exercise science or psychology) and conducting a state-of-the-art literature review to critically assess current and emerging evidence and identify issues and needs of future research in PA intervention targeting physical and cognitive function and QoL in older adults, focusing on mind-body exercises (see Table S1 Multimedia Appendix 1 for a summary of results). Based on this review, we decided to move forward with 2 forms of Qigong, Five Animal Play or Five Animal Frolics (*Wu Qin Xi* in Chinese) [38] and Eight Pieces of Brocade or Eight-Section Brocade (*Ba Duan Jin* in Chinese) [39]. Five Animal Play consists of 5 sets of choreographed movement routines that symbolize "the courage and robustness of the tiger; serenity and poise of the deer; the steadiness and solidity of the bear; the nimbleness and dexterity of the monkey; and the swiftness and grace of the bird" [40]. The routines combine stretching, balancing, weight-bearing, and eye-hand coordination movements blended with controlled breathing and mental immersion in the "mindset" of each specific animal. Eight Pieces of Brocade consists of 8 sets of primarily stationary movements designed to stretch and strengthen different body parts in conjunction with coordinated breathing and mind-focus.

The subsequent 3-month period involved engaging a 12-member working group of seniors, CHWs, and senior center staff in weekly meetings to co-design *FITxOlder* and provide guidance and feedback to the pilot study protocol. These weekly meetings were held at the senior center and scheduled at the end of the day. English-Spanish bilingual research staff facilitated the meetings. Participating seniors received US $5 for attending each session. At the meetings, research staff presented the goals of the study and discussed the principles of CBPR. Other topics included the historical and cultural background of traditional Chinese medicine and Qigong exercises, symbolism and metaphors in Chinese culture and Qigong exercises, different versions of Five Animal Play and Eight Pieces of Brocade, and research evidence related to the benefits of Qigong exercises. The working group provided input on their understanding of the information presented and experiences of learning and practicing Qigong and their Latino perspective on a traditional Chinese cultural practice. Group discussions compared Qigong to Latino culture and symbolisms, and the participants offered specific suggestions on how to modify Qigong to accommodate their personal and cultural preferences and needs (eg, symbolization of animals, background music, instructor qualifications, safety concerns, challenges in learning complex routines) from a perspective of older Latino adults living in a low-income community. Given the heterogeneity of Latino culture [41], the working group could not offer clear guidance to tailor the symbolism and metaphors in the Qigong culturally. Therefore, we opted to focus on adapting the program delivery process and movement routines to address feedback regarding movement complexity, level of exertion and balance, and safety.

As a result of the CBPR meetings, we decided not to introduce "Qi" or "flow of energy," a concept in traditional Chinese medicine, in the Phase 2 pilot intervention. Although Five Animal Play and Eight Pieces of Brocade*s* are similar mind-body exercises, the former is easier to learn and quite suitable for older adults, and thus, was chosen as the exercise for the study. Working group members also provided input on strategies (eg, using a video model to facilitate independent exercise at home) to promote acceptance, adoption, and sustainability of Qigong for home practice. Finally, the working group provided feedback on the study protocol regarding recruitment, retention, assessment, and safety. During this period, seniors at the senior center, including the working group members, voluntarily participated in learning and practicing the official version of Five Animal Play (OfficialFAP) and Eight Pieces of Brocades every week facilitated by in-person instruction of research staff and CHWs using videos.

Key elements of *FITxOlder* included a video-guided mind-body exercise (ie, Five Animal Play), biweekly group practice sessions, program delivery and social support by trained CHWs, a goal-based home practice program, and facilitation by mHealth technologies to enhance participation and engagement in the *FITxOlder* program. Following social-cognitive theory, *FITxOlder* was designed to increase participants' efficacy to learn and practice Five Animal Play using vicarious experience, goal setting, reinforcement, role modeling, social support, and self-regulation [42]. Expected benefits of the intervention program were improved physical and cognitive function and QoL, which constituted the foundation of healthy aging and independent living [29].

The planned progression of a 12-week *FITxOlder* was guided by the 3 core principles of harmonization (Tiao Shen, Tiao Xi, and Tiao Xin) in Qigong practice [38,43]. Weeks 1-4 focused on harmonizing or tuning one's posture and body movements to symbolize the tiger, bear, monkey, bird, and deer (Tiao Shen). The CHW introduced the Five Animal Play as a form of Chinese body-mind exercise to improve physical and cognitive function. Participants learned to perform the Five Animal Play following a demonstration by CHWs and a display of a study-produced video on a large screen. Weeks 5-8 emphasized harmonizing or tuning the breath with movement routines (Tiao Xi). Participants learned to blend inhaling air with outward or extension movement and exhaling air with inward or flexion

movement. Weeks 9-12 focused on harmonizing or tuning one's mind to reach a state of mental quieting and avoiding disruptive thought by uniting body, breath, and mind into "one" (Tiao Xin). This practice involved mentally immersing oneself into the animal being performed with blended breathing to reach a meditative state [44]. Participants' exercise goals were (1) to attend 2 weekly group sessions and (2) to practice Five Animal Play at home following a 26-minute video, at least once a week in weeks 1-4, 2 times a week in weeks 5-8, and 3 times a week in weeks 9-12.

OfficialFAP [39] begins with an abdominal breathing routine to focus the mind on the body, followed by 5 sets of routines symbolizing 5 animals (2 subroutines per animal). Each set starts and ends with slow controlled breathing. The exercise finishes with an abdominal breathing routine to refocus the mind to an awaking state. Five Animal Play is usually practiced following a model who leads the exercise following a video or audio recording with traditional calming Chinese music in the background. The entire exercise takes approximately 13 minutes to complete [38]. To examine its feasibility and acceptability, we produced 2 versions of English-guided videos demonstrating Five Animal Play based on the working group's suggestions. The videos were 26 minutes total in length, repeating the 13-minute exercise once. Participants could stop the video between the 2 sets to take a break as desired. The first version was the OfficialFAP video, in which Chinese models performed the exercise following translated English voice cues. The second version involved trained CHWs and research staff performing the modified version of Five Animal Play (ModifiedFAP) accompanied by English language action cues. The modifications were made to reduce complexity in 2 subroutines (monkey subroutine 2 and deer subroutine 2) and difficulty of movements requiring one-leg support (weight-bearing) and a high degree of balance. This was done to increase a sense of mastery, reduce the level of physical exertion, and address concerns for safety. The voice cues in both videos were modified to provide detailed movement guidance, emphasize the timing of inhaling and exhaling breath, and offer mental images of the movement (eg, "pick the fruit like a monkey" and "raise arms like a bird").

The final Phase 1 activity involved developing a CHW training program and training 2 English-Spanish bilingual CHWs to deliver the pilot intervention in Phase 2 of the study. The CHW training included (1) the history, cultural background, and health benefits of Qigong, (2) study protocol and human subject protection, (3) instruction and safety in leading exercises with older adults, (4) learning of Five Animal Play, and (5) assignment of home practice. The CHWs received a 2-hour in-person instruction for performing Five Animal Play by a study team member (KP) who had training in traditional Chinese medicine and practiced and taught Qigong exercises to medical students and inpatient and outpatient populations in China over 15 years. The CHWs also practiced the Five Animal Play at home using the video daily for 2 weeks. One CHW was trained to deliver the Five Animal Play without modification, and the other was trained to deliver the ModifiedFAP.

Phase 2-Feasibility Testing of the Pilot Intervention

Phase 2 pilot-tested the feasibility of a 12-week *FITxOlder* exercise program in a 3-arm controlled trial at 3 community centers. Arm 1 participants received *FITxOlder* with in-person instruction and video-guided practice following the OfficialFAP without modifying the movements. At another center, arm 2 participants received *FITxOlder* with in-person instruction and video-guided practice using the ModifiedFAP. The *FITxOlder* delivery (ie, duration, exercise goals, incentive schedule, and support) was identical in both arms 1 and 2. The mHealth component of the intervention included using an Android tablet for playing the Five Animal Play video, text reminders, and telephone calls for support. Arm 3 was a placebo control treatment with a healthy aging program at the third center. Treatment assignment was based on travel distance for each CHW and research staff, with the furthest center assigned to control treatment. All participants received an orientation to the study as part of the baseline assessment, which presented the goals, expectations, safety issues, and study schedule. Instruction in all treatment arms was offered in English since the majority of the participants spoke English. The bilingual CHWs used Spanish to communicate with individual participants who had limited English proficiency or preferred Spanish.

The CHW led the biweekly 60-minute sessions comprising of (1) greet-and-meet, attendance check, and review of activities from the previous week, (2) warm-up, (3) performing Five Animal Play led by CHW while playing the study-produced Five Animal Play video on a big-screen monitor, (4) teaching Five Animal Play with a part-whole method, (5) performing Five Animal Play following Five Animal Play video while the CHW circulated the room and worked with individual participants, (7) cool-down, and (8) closing activities (ie, assigning home exercises for the week, addressing study-related problems, and completing the exercise log and exercise feeling survey). For safety, participants were instructed to perform the exercise to the best of their ability and avoid pain, exhaustion, or unpleasant feelings. The participants could use an assistive device (eg, a walker) for support or sit in a chair at their discretion. Participants were encouraged to ask questions and share their experiences and problem-solving strategies with each other. Each CHW was responsible for developing session lesson plans and documenting the process. Table S2 in Multimedia Appendix 1 presents the layout of the group sessions.

Each intervention participant received a 10-inch Android tablet to play the study-produced Five Animal Play video at home. During the first week, participants were taught how to use the tablets. They also received a study handbook that included exercise goals, weekly exercise logs, adverse event logs, incentive schedule, exercise safety and motivation tips, and study contact information. There were specific instructions on recording their home practice (eg, number of times and problems or issues) in the weekly exercise log.

To increase compliance with home practice expectations, each participant received a text reminder twice per week in their preferred language (English or Spanish). Text messages were sent automatically using Remind, a widely used cloud

communication platform to manage and send text messages to a large audience. Participants who missed an on-site session received a phone call from the CHW, encouraging them to make up the missed session at home. As an incentive, a small trinket worth US $2-$7 was offered upon reaching 70% of the exercise goal (ie, number of biweekly sessions and home practices) during each 4-week period.

Program participants enrolled at the placebo control center received a 12-week evidence-based healthy aging program based on Aging Mastery by the National Council on Aging [45] delivered by the CHWs. Each participant received a workbook and attended weekly instructor-led sessions. Healthy-aging content included exercise, nutrition, finances, advance care planning, community engagement, and healthy relationships. Upon program completion, each participant received a program t-shirt and a US $25 gift card.

Due to the COVID-19 pandemic lockdown, all study sites were closed upon completion of week 4 of the 12-week program on March 15, 2020. As a result of stay-at-home orders and federal COVID-19 guidelines on social distancing, we changed the delivery of the intervention with weekly individual phone calls with participants in the 3 treatment groups aimed at following the original program protocol as closely as possible. Following the original 12-week plan, the CHW called their assigned participants weekly to continue the progression of developing harmonization of breathing (weeks 5-8) and mind (weeks 9-12). Each week, the CHW focused on 1 or 2 routines and answered questions related to the practice of Five Animal Play. The study timeline was extended an additional 4 weeks to offer further reinforcement and support and increase participants' confidence and proficiency in practicing Five Animal Play (weeks 13-16). During these weekly calls, CHWs recorded intervention group participant progress and frequency of home practice. CHWs also called control group participants weekly to review the content of the Aging Mastery curriculum and to answer any questions about the program. During calls with all participants, the CHWs also inquired about each participant's well-being and offered pandemic-related information and support per local, state, and federal guidelines. CHWs made up to 3 calls per week to reach each participant. There was no program activity provided for control participants during weeks 13-16. In addition, due to COVID-19 restrictions, we could not provide the Five Animal Play instruction for control participants after the completion of the study. Textbox 1 shows the objectives and activities for a 16-week revised study protocol of *FITxOlder*.

Textbox 1. FITxOlder Intervention timeline and intervention activities protocol.

Weeks 1 to 4

- Two 60-minute group sessions led by a CHW each week

- Introduction of Five Animal Play to participants and learning choreography of the movement routines

- Practice of Five Animal Play at least one time at home following a video on a tablet

- Weekly text reminder to perform the exercise

Weeks 5 to 8

- Practice of Five Animal Play at least 4 times at home each week following a video on a tablet

- Instruction on blending movements and breathing and support by phone call

- Weekly text reminder to perform the exercise

- Weekly call to the participants by CHW to continue the instruction on integrating movements with breathing and provide social support

Weeks 9 to 12

- Practice of Five Animal Play at least 5 times at home each week following a video on a tablet

- Instruction on blending movements, breathing, and mind into "one" and support by phone call

- Weekly text reminder to perform the exercise

- Weekly call to the participants by CHW to continue the instruction on integrating movements with breathing and mental focus and provide social support

Week 13 to 16

- Practice of Five Animal Play at least 5 times at home each week following a video on a tablet

- Reviewing, reinforcement, and support by phone call

- Weekly text reminder to perform the exercise

- Weekly call to the participants by CHW to review Five Animal Play and provide social support

Note: All study sites were closed at the end of week 4 due to the COVID-19 pandemic.

Study Measures

Primary Aim Measures

Measures of program feasibility included participant recruitment and retention, the fidelity of implementation, and reports of adverse events. Specifically, we defined recruitment success as a minimum of 60% (15 or 25+) enrollment at each study site and 80% retention. The participation target was at least 70% attendance at the biweekly sessions and 70% completion of weekly exercise goals. We also expected to successfully contact at least 50% of the participants through weekly telephone calls. CHWs tracked exercise session attendance and weekly phone calls. Each week participants recorded how many times they practiced the Five Animal Play on their exercise logs. The CHWs collected the practice information at a subsequent meeting or phone call. The CHWs also gathered pertinent information about participants' health conditions and adverse events, as well as explanations for not attending the group session or not reaching the weekly exercise goals. Participants also completed a survey to provide demographics, health history, past experience using tablets, and willingness to participate in future studies.

To assess the reactivity to practicing 2 different versions of Five Animal Play, all participants completed the exercise-induced feeling inventory (EFI) [46] after completing the exercise. The 4 EFI subscales captured feelings of revitalization, tranquility, positive engagement, and physical exhaustion on a 5-point scale from 0 to 4, where 0 stands for "do not feel at all" and 4 stands for "feel very strongly." In terms of formative assessment, the CHWs took notes documenting the participants' progress in learning the routines in their weekly logs, and the research team staff also observed the biweekly sessions.

The original plan was to conduct a structured assessment of participant proficiency in performing the Five Animal Play once every 4 weeks. However, due to the COVID-19 epidemic, we were not able to conduct this participant proficiency assessment. At the conclusion of the study, participants in both intervention and control groups completed the client satisfaction questionnaire-8 (CSQ-8)[47] to assess their satisfaction with the *FITxOlder* program. CSQ-8 scores range from 8 to 32, with higher scores indicating higher levels of satisfaction.

Exploratory Aim Measures

FITxOlder Exploratory aim measures included assessment of physical and cognitive function, QoL, chronic pain, and mindfulness to evaluate the effect of *FITxOlder* on healthy aging (see Table 1). These measures are outcome measures associated with healthy aging and risk for chronic conditions [29,48]. Trained nursing students, research assistants, and CHWs collected the assessment data at baseline and posttest. All questionnaires and surveys were offered in English or Spanish, depending on participant preference. Over the course of 2 weeks, 3 separate attempts were made to reach a participant for the posttest assessments. Given the COVID-19 pandemic restrictions, we modified the data collection protocol and collected data by telephone rather than in person. However, this change precluded our ability to conduct physical function tests. Therefore, participants completed a physical function self-assessment using the basic ADL and intermediate ADL subscale of the functional status questionnaire (FSQ) [49]. We were unable to collect posttest data on the symbol-digits modalities test [50] via telephone. We excluded the data from the Five Facet Mindfulness Questionnaire-Short Form since participants had difficulty comprehending the questions about mindfulness.

Table 1. The description of outcome measures and data collection timepoint.

Outcome measure	Baseline	Posttest
Physical functions: Research staff tested the participants with a battery of physical function tests [51], including the five times sit to stand test, 50-foot fast walk, 6-minute walk for distance, and forward lean reach, and measured the participant's biometrics (height, weight, and blood pressure).	Yes	No
Self-assessment of physical functions: Participants completed the basic activities of daily living (eg, eating and dressing) subscale and intermediate activities of daily living (eg, light exercise, using public transportation, and housework) subscale of the functional status questionnaire.	No	Yes
Cognitive function: Participants completed the symbol-digits modalities test with a time limit of 90 seconds [50].	Yes	No
Quality of life: Participants completed the 12-item health-related quality of life (short-form 12 health survey) to generate a physical component score and a mental component score of quality of life [52].	Yes	Yes
Chronic Pain: Participants completed the 9-item brief pain inventory to measure perceived pain in two domains: pain severity and pain interference with life [53].	Yes	Yes
Mindfulness: Participants completed the 15-item five facet mindfulness questionnaire-short form to measure the deliberate and nonjudgmental attentiveness to present-moment experiences [54].	Yes	No

Data Analysis

Given the study goal and focus of the *FITxOlder* program, the analysis focused on participants who self-identified as Latino (49/56, 87.5%). For the data analysis, we combined data from both the OfficialFAP and ModifiedFAP groups, given there were no discernable group differences across all the measures (ie, retention, attendance in weekly sessions, compliance with

practice goal, reactivity to Five Animal Play during the first 4 weeks, and program satisfaction).

We summarized participant demographic data and other study-related characteristics using means and standard deviations for continuous and categorical variables tabulated as percentages. Depending on the normality of data distribution for continuous variables, we conducted a paired *t* test or

Mann-Whitney U test to assess group differences. Contingency tests were used for categorical variables. We employed descriptive statistics to assess feasibility, retention, and implementation fidelity. General linear modeling was employed to explore the effects of the intervention on outcome variables at posttest, adjusting for baseline and demographic variables. Given that physical functioning was an important study outcome that was not assessed during the posttest, we created a proxy physical function index using a battery of physical function tests. Thus, we adjusted the index of physical function from the baseline to explore the effect of the intervention on the basic ADL and intermediate ADL scores of the FSQ posttest. As previously noted, we excluded the symbol-digits modalities test and Five Facet Mindfulness Questionnaire-Short Form scores in data analysis. Only significant covariate variables were retained in the model. We reported results as the adjusted difference between groups at posttest with CIs and P values. We calculated effect sizes (Cohen d) for the effect of the intervention on the study outcome variables. All analyses were conducted using SPSS software (version 27; IBM).

Results

Overview

Out of 64 study participants who met the study eligibility criteria, 87.5% (56/64; 49/64, 87% Latino; 4/56, 7% Black; and 3/56, 6% other racial/ethnic groups) completed the baseline assessment and were assigned to a treatment group. This included 17 in the OfficialFAP (15 Latinos), 19 in the ModifiedFAP (19 Latinos), and 20 in the control group (15 Latinos). Fifty baseline participants (50/56, 89%; 44/50, 88% Latino) completed the posttest assessment. Among those who did not complete the study, reasons included loss of contact (4/6, 66%), relocation (1/6, 22%), and loss of interest (1/6, 22%). We were able to reach 38% (21/56), 21% (12/56), and 31% (17/56) of the participants on the first, second, and third data collection calls. There were no differences in demographic characteristics between the completers and noncompleters of the study.

There were no differences between 49 Latino participants' demographic characteristics (Table 2). The average age of intervention participants was 74.9 years (SD 6.3), compared to 73.9 years (SD 8.3) among controls. The majority were female and unmarried and reported no use of an assistive device. At study onset, 42.6% (21/49) of the intervention participants reported knowing how to use a tablet computer. Of particular note, nearly all participants expressed willingness to participate in future studies with the study team. Table S3 Multimedia Appendix 1 reports participant health information. The majority had been diagnosed with high blood pressure (28/49, 57%) or high cholesterol (30/49, 61%) or reported physical pain of lower extremity (28/49, 57%). Nearly half (24/49, 49%) reported 2 or more chronic health conditions (ie, high blood pressure, heart trouble, increased anxiety or depression, stomach problem, and vision or hearing problem).

Table 2. Demographic and study-related characteristics of study participants at baseline and posttest.[a]

Variable	Intervention (n=34)	Control (n=15)
Age (years), mean (SD)	74.9 (6.3)	73.9 (8.3)
Sex (female), n (%)	30 (88.2)	12 (80.0)
Education (<high school), n (%)	9 (26.5)	9 (60.0)
Currently working (yes), n (%)	2 (5.9)	2 (13.3)
Marital status (married), n (%)	7 (20.6)	3 (20.0)
Living with someone (yes), n (%)	10 (29.4)	7 (46.7)
Using an assistant device (yes), n (%)	7 (14.2)	1 (7.7)
Language use (Spanish), n (%)	8 (23.5)	8 (53.3)
Knowing how to use a tablet computer (yes), n (%)	24 (42.6)	N/A[b]
Expressing willingness to participate in future studies (yes), n (%)	29 (97.0)	15 (100.0)

[a]One-way F test was used to test the difference between intervention and control groups.

[b]N/A: not applicable.

Attendance and Compliance of Weekly Exercise Goal

Average attendance at the 8 biweekly sessions was 80.1%. Reported practice of Five Animal Play at home ranged from 3 to 4 times a week. The mean percentage of participants who completed at least 70% of the weekly exercise goal was 79.4% (median 100%), ranging from 60.7% to 82.8% (Table 3). The mean percentage of participants who completed the weekly calls with CHW was 61.3% ranging from 56% (median 2 calls) to 69% (median 3 calls) every four weeks from week 5 to week 16.

Table 3. Class attendance, the number of times the exercise was practiced at home, and adherence to the monthly exercise goal.

Activity	Weeks 1-4, n=34	Month 5-8, n=28	Month 9-12, n=26	Month 13-16, n=29
Number of times attended the biweekly group sessions, mean (SD); median	6.41 (1.9); 7	N/A[a]	N/A	N/A
Number of times practiced Five Animal Play at home[b], mean (SD); median	3.0 (1.2); 3	3.1 (1.4); 3	4.0 (1.8); 4	3.4 (1.7); 3
Percent of participants reached 70% of the weekly exercise goal[c], mean (SD); median	79.40% (40.0); 100%	60.70% (49.7); 100%	73.10% (46.5) 100%	82.80% (38.4); 100%
Number of times called by the Community Health Worker, mean (SD); median	N/A	2.74 (1.52); 3	2.24 (1.54); 2	2.38 (1.42); 2.5

[a]N/A: not applicable.

[b]For month 1, the total number of times participants attended the class and the number of times the exercise was practiced at home.

[c]Monthly exercise goal is to complete at least 70% of expected times to practice the exercise for each month.

Reactivity to Five Animal Play

Participant responses related to exercise-induced feelings over the 8 biweekly sessions are presented in Figure 1. The physical exhaustion scores were in the middle range, and revitalization scores were slightly above the mean. The tranquility and positive engagement scores were in the upper range and showed a gradual increase over the 8 sessions.

Figure 1. Subscale scores of the Exercise-induced Feeling Inventory from Group Sessions 1 to 8.
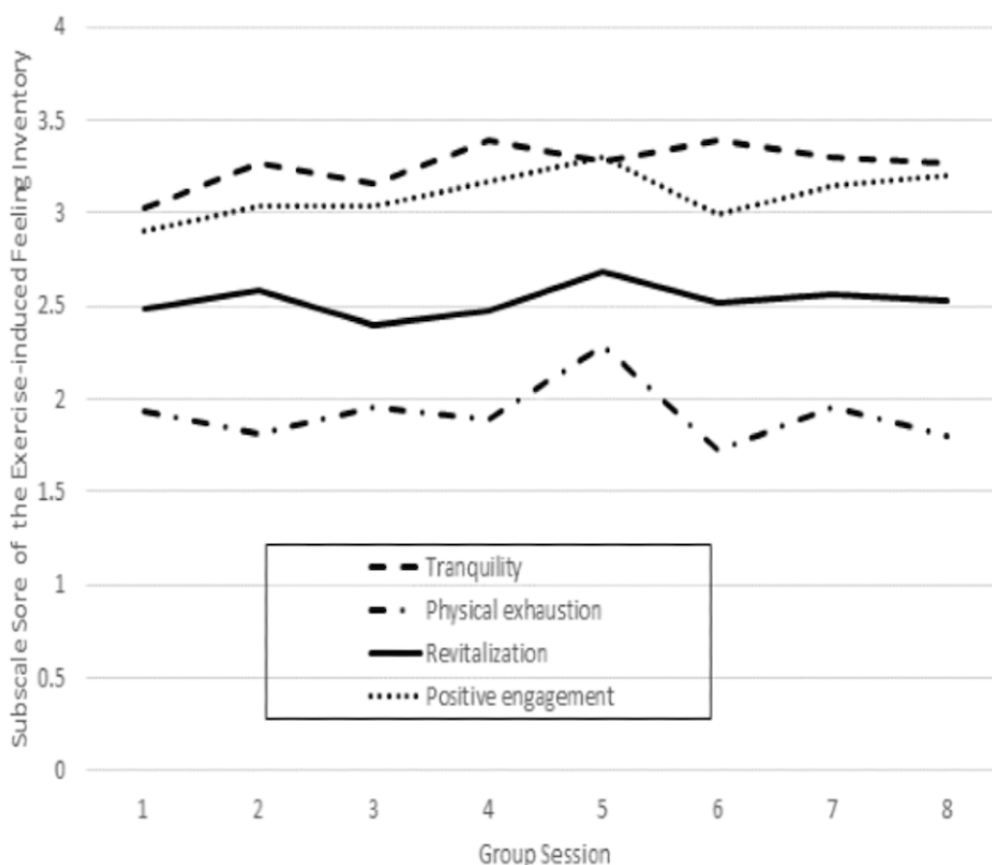
Satisfaction With FITxOlder

Participants in the intervention (mean 30.8, SD 1.7) and control group (mean 30.6, SD 2.1) reported high satisfaction levels with the services and program offered.

Report of Adverse Event

No study-related adverse events were reported by participants based on documentation of the study team. We did not document the level of use of assistive devices during the biweekly sessions and home practices among the participants who reported using an assistive device for mobility and support.

Preliminary Estimates of Change in Outcome Measures for Exploratory Aim

Table 4 presents changes in the outcome measures for the exploratory aim of the study. Compared to the control group, intervention group scores for the short-form 12 health survey

physical component (P=.04) and FSQ basic ADL (P=.02) improved significantly, and BPI pain interference showed a trend of improvement (P=.07). There were no group differences on other measures. The effect size in the change of the outcome measures was small (Cohen d ranged from 0.2 to 0.4)

Table 4. Comparison of difference between the intervention (n=34) and control group (n=15) at the posttest[a].

Outcome measure	Baseline, mean (SD)	Posttest, mean (SD)	Adjusted group difference (SE) at posttest[b]	95% CI for adjusted group difference	P value for adjusted group difference	Cohen d for effect size
SF12[c] physical component						
Intervention	45.6 (9.3)	48.5 (7.8)	4.0 (1.9)	0.1 to 7.8	.04	0.2
Control	41.9 (11.7)	44.1 (9.8)				
SF12 mental component						
Intervention	52.6 (10.5)	53.7 (8.8)	–0.5 (3.0)	–6.5 to 5.5	.89	0.3
Control	56.4 (7.6)	56.9 (6.9)				
FSQ[d] basic activities of daily living[e]						
Intervention	-0.1 (0.9)	11.9 (0.3)	0.7 (0.3)	0.1 to 1.3	.02	N/A[f]
Control	-0.01 (1.1)	11.2 (1.6)				
FSQ intermediate activities of daily living[e]						
Intervention	n/a	19.9 (5.8)	1.3 (1.8)	–2.3 to 4.9	.47	N/A
Control	n/a	17.5 (6.0)				
BPI[g] pain severity						
Intervention	2.5 (2.8)	1.5 (2.1)	0.3 (0.6)	–0.9 to 1.5	.58	0.0
Control	2.4 (2.9)	1.8 (2.4)				
BPI pain interference						
Intervention	1.8 (2.4)	0.9 (1.5)	–1.2 (0.6)	–2.5 to 0.1	.07	0.4
Control	1.9 (2.5)	1.9 (2.8)				

[a]Sample sizes varied for different variables due to missing data.

[b]Adjusted difference in change scores from baseline to posttest between intervention and control group with adjustment to selected covariates.

[c]SF-12: short-form 12 health survey.

[d]FSQ: functional status questionnaire.

[e]Factor score of 5-time sit to stand, 50-foot fast walk, 6-minute walk, and forward reach was used to control the difference at baseline.

[f]N/A: not applicable.

[g]BPI: brief pain inventory.

Discussion

Principal Findings

FITxOlder is a community-based, mHealth-facilitated mind-body exercise program tailored to promote healthy aging among low-income older Latino adults with chronic health conditions. The findings indicate both the feasibility of participant recruitment and retention practices, as well as participants' acceptance and satisfaction with the program. The participants in the intervention group also showed promising favorable responses in regard to measures of QoL and basic ADL.

FITxOlder showed acceptable feasibility of implementation, comparable to or better than published Qigong [55-57] and Tai Chi research [58-61]. An overwhelming majority of participants regularly attended the biweekly group sessions and achieved the weekly exercise goal. This high level of attendance and completion was maintained until COVID-19 hit the study community (weeks 5-8). The successful rate of reaching the study participants for the weekly phone calls (≥50%) was also acceptable considering the ongoing COVID-19 pandemic. We speculate that the acceptance of Five Animal Play is due to older Latinos being prone to seek alternative or nontraditional forms of health care or services partly due to experiences of disparate care and limited access to quality care [62,63].

FITxOlder participants reported positive exercise-induced feelings (eg, revitalization, tranquility, and positive engagement) associated with increased exercise efficacy and future exercise intentionality in older adults participating in low to moderate-intensity exercise programs [64,65]. The scores for physical exhaustion were slightly higher than those reported previously among young and middle-aged adults participating in low-impact aerobics or strength exercise programs and suggested that the Five Animal Play exercise program was equivalent to moderate levels of physical exertion in the older participants [65]. Based on both participant self-report and CHW documentation, importantly, there were no study-related adverse events. Our findings are consistent with other studies that have incorporated Qigong exercises and suggest the relative safety of Qigong practice for older adults with chronic health conditions [26,27]. Furthermore, previous research indicates that simplicity, low to moderate physical exertion demands, safety, and a sense of mastery motivate older adults to participate and continue PA [8,66].

Participants in both the intervention and control groups reported high levels of program satisfaction, which has been associated with high levels of program quality and patient services in medical care, mental health, and community settings [67,68]. Of note, the high level of program satisfaction among control participants indicated the appropriateness and acceptability of the placebo control treatment.

Changes in Outcome Measures

We explored the effect of *FITxOlder* on physical and cognitive function and QoL as part of the feasibility study. Positive changes in the physical component of QoL, physical function, and pain interference were consistent with previous mind-body studies conducted in Western and non-Western older adults [17,26,27]. However, the size of the treatment effect was small. It is possible that the small effect size on physical health outcomes was related to the use of an attention placebo control group [69]. Another possibility is that the potential benefits of Qigong exercise were not fully realized due to the COVID reduction of in-person sessions from 12 weeks to 4 weeks which might have reduced the gain of confidence and proficiency in performing the Five Animal Play [70]. In a prior Qigong study, study participants were able to practice the routines at home after 4 weeks of in-person instruction but continued in-person sessions for the next 6 months [71]. On the other hand, we speculate that the lack of group differences on psychosocial outcomes was due to the weekly CHW phone calls to all participants (both treatment and control) who might have been experiencing social isolation and loneliness due to COVID-19, with the phone calls acting as an important source of attention and social support [72]. A longitudinal study found that individuals who experienced a greater sense of social connection and engagement with others reported a reduced level of pain severity but not pain interference [73].

Comparison With Prior Work

Five Animal Play, one of the earliest forms of mind-body practice in traditional Chinese medicine, is widely practiced in China [40] yet has received limited attention in mind-body research conducted among Western populations [40,74]. Five Animal Play is relatively easy to scale and has much lower demands for space and equipment or instructor qualification and certification than Tai Chi or Yoga. The repetitive play-like routines of Five Animal Play contribute to reduced seriousness or "religiosity" and increases its appeal and acceptance in Western populations without undermining the therapeutic mechanisms of mind-body exercise commonly endorsed by CAM [74. Interventions that utilize simplified forms of Tai Chi, such as "Tai Chi: Moving for Better Balance"[75] and "Qigong/Tai Chi Easy" [71] consisting of repetitive routines of a small number of core Tai Chi or Qigong movements, have demonstrated efficacy and improvement in clinical indicators and QoL for older adults and those with neurodegenerative movement impairments or cancers (including cancer survivors) [44]. Dissemination studies of "Tai Chi: Moving for Better Balance" by lay Tai Chi instructors have demonstrated both acceptable feasibility and acceptability in community-based aging programs serving low-income and immigrant communities in the United States [76,77]. Similarly, we found that CHWs who received brief training could deliver the instruction of Five Animal Play to participants. Similar to previous studies [59,71], the use of study-produced videos allowed the participants to independently practice Five Animal Play from the beginning of the intervention. It was likely that the study videos served as a role model and reinforcement for the continuation of exercise in addition to the text reminders to meet the weekly exercise goal [42]. To our knowledge, this is the first study in which CHWs delivered a Qigong program. Areas for further research include an assessment of promoting participation in healthy aging programs that employ CHWs and incorporate mHealth facilitation.

Strengths and Limitations

The strengths of *FITxOlder* include the CBPR approach and the use of a framework for the cultural adaptation of the evidence-based intervention [37]. The working group provided guidance and input in the adaptation of Five Animal Play and the delivery of the program. As a result, we were able to preemptively address issues and concerns regarding the biomechanics related to movement difficulty and safety (eg, speed, range, and exertion force), pedagogical approach (eg, instruction strategies, cues for breathing and movement, and instructor qualification), and cultural appropriateness (eg, music, animal symbolism, and culture-related analogies). Furthermore, we demonstrated that the program could be delivered by CHWs who have received a brief, focused training, in contrast to the high level of instructor qualifications and certification reported in other Qigong studies [26]. This is key since critiques of community interventions using Tai Chi or Yoga include the limited potential for scale and reproducibility based on high standards for instructor qualification and certification [18,78]. Finally, we used a "transcreation" approach [31] to guide the research team in evaluating scientific evidence and making design decisions. As a result, *FITxOlder* incorporated community-based strategies that fostered increased retention, attendance, and achievement of the exercise goal and increased the likelihood of sustainability. Future studies should compare the acceptability of Five Animal Play with low-impact aerobics,

strength exercises, and other forms of meditative movement in older Latino adults and other vulnerable groups.

The *FITxOlder* intervention also benefited from facilitation by bilingual CHWs and mHealth tools (eg, preloaded Five Animal Play videos on a tablet, text messages, and telephone calls for instruction and support). CHWs can increase culturally appropriate delivery of information and support consistent with the participant's beliefs and values and promote the participant's engagement in community-based health promotion, even in the face of social distance restrictions imposed due to the COVID-19 pandemic [79]. Others also demonstrated that CHWs effectively implemented community-based exercise programs to improve mental health in older Latino adults [80]. The use of mHealth interventions to promote PA in older adults is an emerging field that has demonstrated promising short-term effects and the need for strong social support to engage the participants [30]. Our study findings also suggest that "live-person" social support from CHWs and facilitated by mHealth are critical to engage participants and maintain program participation [30].

The use of an active control was another strength that disentangled placebo effects from social support, attention, and expectancy in mind-body interventions, especially in older adults [69,81]. Some have questioned whether the effectiveness of CAM interventions is the result of a placebo effect due to the power of suggestion and attention experienced by the study participants [82]. We found similar levels of retention and satisfaction among both the intervention and control group participants, lending credence to the differences found in the study outcome measures [81].

Several limitations weakened the internal and external validity of our research. Due to COVID-19 epidemic restrictions, we were unable to assess all study outcomes with one standardized protocol at baseline and posttest. Given that posttest measures were conducted by phone rather than in person, study outcomes should be interpreted with caution. It is possible that posttest measurement by phone may have impacted the validity of the measures. Similarly, we could not examine potential differences between the 2 versions of Five Animal Play due to limited ability to conduct on-site observations after the first 4 weeks of intervention due to COVID-19. When participants transitioned

to home practice, skill acquisition was in an early stage, and we were unable to ascertain the extent to which shortened in-person instruction may have impacted participants' understanding of and ability to practice the movement routines as demonstrated in the study-produced videos.

In contrast, the reported direct instruction time was 12 weeks or longer in published Qigong studies [26,27]. Furthermore, we did not evaluate the level of proficiency of participants performing Five Animal Play at different stages of the learning progression to explore whether the level of skill proficiency was related to program attendance, satisfaction with the program, and changes in the outcome measures at the posttest [26]. For example, we were not able to assess the extent to which participants mastered the techniques of blending breathing with movement and mental quieting, which is essential to Qigong practice [74]. However, some studies found that Qigong interventions with and without a focus on teaching breathing and mental quieting had similar impacts on QoL, cognitive function, depression, and sleep quality in cancer survivors [24,83]. Finally, we did not explore the potential influence of Chinese cultural and Qigong-related beliefs on *FITxOlder* feasibility, acceptability, and outcomes. Of note, we purposefully avoided introducing the concept of "Qi" to participants due to the lack of an informed approach for mixing and matching Chinese and Latino culture-related health beliefs. Further research is needed to understand how culture-related Qigong beliefs influence the feasibility and health effects in non-Chinese participants.

Conclusions

Findings from this research indicated the feasibility and acceptability of CHW-delivery of a traditional Chinese Qigong exercise with the facilitation of mHealth tailored for older low-income Latino adults in a community-based healthy aging program. However, the COVID-19 pandemic required a revision of the intervention protocol and prevented a full test of the feasibility of the *FITxOlder* program and participants' responsiveness in study outcomes. Future research needs to replicate the study and compare the feasibility of Five Animal Play with other low-and-moderate intensity exercise programs with long-term follow-up.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables.
[DOCX File , 107 KB - aging_v4i4e29188_app1.docx]

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Abbreviations

ADL: activities of daily living
BPI: brief pain inventory
CAM: complementary and alternative medicine
CBPR: community-based participatory research
CHW: community health worker
CSQ: client satisfaction questionnaire.
EBI: evidence-based interventions
EFI: exercise-induced feeling inventory
FITxOlder: Function Improvement Exercises for Older Sedentary Community-Dwelling Latino Residents
FSQ: functional status questionnaire
mHealth: mobile health
NIH: National Institutes of Health
PA: physical activity
QoL: quality of life
RCT: randomized controlled trials

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<u>Original Paper</u>

Feasibility of Real-time Behavior Monitoring Via Mobile Technology in Czech Adults Aged 50 Years and Above: 12-Week Study With Ecological Momentary Assessment

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Abstract

Background: Czech older adults have lower rates of physical activity than the average population and lag behind in the use of digital technologies, compared with their peers from other European countries.

Objective: This study aims to assess the feasibility of intensive behavior monitoring through technology in Czech adults aged ≥50 years.

Methods: Participants (N=30; mean age 61.2 years, SD 6.8 years, range 50-74 years; 16/30, 53% male; 7/30, 23% retired) were monitored for 12 weeks while wearing a Fitbit Charge 2 monitor and completed three 8-day bursts of intensive data collection through surveys presented on a custom-made mobile app. Web-based surveys were also completed before and at the end of the 12-week period (along with poststudy focus groups) to evaluate participants' perceptions of their experience in the study.

Results: All 30 participants completed the study. Across the three 8-day bursts, participants completed 1454 out of 1744 (83% compliance rate) surveys administered 3 times per day on a pseudorandom schedule, 451 out of 559 (81% compliance rate) end-of-day surveys, and 736 episodes of self-reported planned physical activity (with 29/736, 3.9% of the reports initiated but returned without data). The overall rating of using the mobile app and Fitbit was above average (74.5 out of 100 on the System Usability Scale). The majority reported that the Fitbit (27/30, 90%) and mobile app (25/30, 83%) were easy to use and rated their experience positively (25/30, 83%). Focus groups revealed that some surveys were missed owing to notifications not being noticed or that participants needed a longer time window for survey completion. Some found wearing the monitor in hot weather or at night uncomfortable, but overall, participants were highly motivated to complete the surveys and be compliant with the study procedures.

Conclusions: The use of a mobile survey app coupled with a wearable device appears feasible for use among Czech older adults. Participants in this study tolerated the intensive assessment schedule well, but lower compliance may be expected in studies of more diverse groups of older adults. Some difficulties were noted with the pairing and synchronization of devices on some types of smartphones, posing challenges for large-scale studies.

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Introduction

Background

With an aging population, there is an increase in the prevalence of chronic conditions, functional limitations, and disability [1]. Although much of the age-related decline in health and functioning can be mitigated through healthy lifestyles [2], the prevalence of unhealthy lifestyle habits remains high globally as well as across the EU member countries. For example, one-third of Czech adults fall short of physical activity (PA) public health recommendations, with individuals aged 40-64 and >65 years being 1.7 and 4 times more likely to have low levels of PA compared with young adults, respectively [3]. Sedentary behavior is also prevalent among Czech adults [4,5], and nearly one-quarter of the Czech population reported experiencing sleep problems [6], suggesting an urgent need for developing effective behavioral interventions to improve the quality of life of Czech older adults.

Traditional intervention (face-to-face) approaches have been successful in promoting healthy behaviors (such as PA or sleep) [7,8] but require substantial resources and have limited public health impact. Advances in digital technology have opened up opportunities for delivering behavioral interventions in a way that is scalable and with potentially greater reach [9]. For example, there is evidence that mobile technologies, along with wearable devices, can be effective in increasing PA and reducing sedentary behavior in both healthy and clinical populations of adults [10-12]. At the same time, dynamic real-time ecological ambulatory methodologies (DREAM) [13] have been advocated for use in surveying behavioral risk factors, psychological states, social context, and various physiological parameters. In combination with digital technology platforms (eg, smartphones or tablets). These methods can also be used for the delivery of ecological momentary interventions delivered *just in time* and in people's natural environments [14,15]. For these methods to be successfully used among older adults, it is critical to first obtain preliminary data on the feasibility of using technology-based methods (such as DREAM).

The evidence of implementing such approaches however comes mainly from the so-called *frontrunner* countries with a high level and fast rate of digital transformation [16]. Studies from countries with relatively low technological penetration (internet and mobile) are rare. Among such countries is the Czech Republic, where the digital gap between younger and older populations grows wider with age [17]. In particular, the penetration of mobile technology remains very low. Only 13% of Czech adults aged between 55 and 74 years report accessing the internet via a mobile phone in national data estimates (compared with a rate of 87% in those aged 18-24 years). The rate of use of mobile internet in the 55-74 years age group is also significantly lower than that in comparable countries such as Slovakia, Poland, and Hungary, where it ranges from 19% to 25% [18].

To date, only a few studies have focused on the feasibility of technology-based ecological momentary assessment (EMA) specifically in older adult populations, and the majority are also from the American context where the penetration of mobile

technology is high. Ramsey et al [19] focused specifically on American older adults with cognitive and emotional difficulties and reported total EMA response rates of 46% and 48% for the two 10-day collection periods, respectively, with 70% of participants completing at least 30% of the surveys. The reasons for nonadherence ranged from being busy during the alarm, not hearing the alarm, to technical difficulties with the questionnaire or the phone. The authors further pointed out that supervised practice with the smartphone as well as more rapid technical assistance appeared to improve adherence rates. This rather low compliance stands in sharp contrast to the compliance rates reported by Fritz et al [20], who focused on community-dwelling older African Americans. The participants completed smartphone questionnaires (and provided saliva samples) 4 times per day for 7 consecutive days, with compliance for the individual variables ranging from 92% to 98%. The high compliance rates may be partially owing to the involvement of older adults in pilot-testing of the EMA interface and including a thorough, 4-step training protocol. Very high compliance (average adherence per person 86.4%) was also noted in a study of American older adults with HIV [21], which used a week-long EMA protocol with 5 prompts per day. Surprisingly, no participants reported difficulties in navigating the smartphone, but 40% reported that the research smartphone interfered with their activities slightly. Nonetheless, a recent study of EMA assessment of PA in American older adults found no evidence of interference with ongoing PA when answering EMA prompts 6 times per day across a 10-day study, with 92% of prompts being completed [22]. In that study, the older adult participants were also compliant with wearing of the ActivePAL activity monitor, with 73% of participants never removing the monitor. The study offered a prorated incentive of up to US $80 (for more than 80% EMA prompts answered).

A recent study by Liu and Lou [23] evaluated an EMA protocol to collect biopsychosocial data from community-dwelling older adults in China, a country with lower rates of mobile technology adoption than the United States. The study lasted one week, and participants completed six assessments per day, consisting of a short survey and a 30-second–long smartphone-based electrocardiogram recording. The total response rate was 91.5%, and younger women (50-59 years) showed the highest compliance (93.3%). The high level of compliance could be partially explained by the fact that while participants received random prompts during the 6 time intervals, they could complete the assessment at any time during these two-hour windows, even before receiving the prompt, as well as by the monetary incentive rewarded upon study completion (approximately US $60). Participants reported little difficulty with the EMA system and app but perceived carrying the research smartphone as inconvenient and the EMA prompts as interfering with their daily activities.

Importantly, all the mentioned EMA feasibility studies used research smartphones and did not make use of participant-owned devices. Although this strategy is useful in low-income populations or populations where smartphone ownership is low, it increases the financial burden for the researcher and might also pose issues for participants who are completely inexperienced with such technology. In addition, as noted by

some older adults in previous studies, carrying an extra device (or two in the case of a connected sensory input device) may be perceived as inconvenient, especially when monitoring for longer periods (weeks or months). It could also be argued that the relatively high adherence rates reported in previous studies with older adults (with over 90% of studies reporting compliance rates above 80%) [24] may partly reflect the reality of carrying a *research-only* device that is novel or new and requires dedicated attention throughout the study. Lower adherence rates may be expected when data are collected through participant-owned smartphones due to the use of the device habitually and for multiple purposes. Nonetheless, such an approach may lead to more ecologically valid estimates of the EMA compliance rates. Together with data from culturally diverse samples (such as from countries with lower or slower rates of adoption of mobile technologies), this would help build more robust evidence of feasibility and more nuanced data on compliance and would generally help expand our knowledge of the dynamic processes (psychological and social) underlying health behaviors and technology use.

Therefore, we were interested in evaluating the feasibility of real-time behavior monitoring using participant-owned devices in a population with relatively low rates of smartphone penetration. In addition, as most previous feasibility studies involved relatively short study protocols (6-10 days), we were interested in evaluating the feasibility of repeated EMA data collection. This approach, sometimes referred to as the measurement burst design [25], is suitable for use in prospective longitudinal or intervention studies, where it is of interest to assess long-term trends along with short-term variability or effects of treatment on variability in outcomes of interest (such as was the case in the study by Ramsey et al [19]).

Objective

This study aims to evaluate an EMA protocol administered repeatedly (in three separate bursts) through participant-owned smartphones and a connected Fitbit monitor to (1) evaluate the feasibility of prospective behavioral monitoring and (2) assess compliance rates and participant experience with intensive psychosocial data collection using a custom-made mobile survey app in adults aged 50 years and older.

Methods

Research Design

Our 12-week observational study used a mixed methods design, with longitudinal data collection via smartphones and fitness trackers to obtain three 8-day measurement bursts of data. Participants also completed web-based questionnaires (pre- and poststudy surveys) and participated in the focus groups. The participants received a prorated incentive of 600 CZK (US $27.41) for the study completion. All participants provided written informed consent before the study, and all study procedures were approved by the Ethics Committee of Masaryk University.

Participants and Study Procedures

Participants (N=30; mean age 61.2 years, SD 6.8 years, range 50-74 years; 16/30, 53% male; 7/30, 23% retired) were recruited from the community (mainly the city of Brno and surrounding areas) through advertisements disseminated in both paper (leaflets) and electronic form (web-based posts on the study website, Facebook, or email advertisements), among organizations serving older adults (eg, libraries, senior clubs, and universities of *third* age) and subsequently through a chain-referral method. The recruited participants were representatives of 3 of the 13 regions in the Czech Republic (Southern Moravia–Brno, Northern Moravia–Ostrava, Opava, Bruntal, and Central Bohemia–Prague). They also represent 3 of the most populous regions (and the 3 largest cities in the Czech Republic–Prague, Brno, and Ostrava). The inclusion criteria were (1) age ≥50 years, (2) ownership of a smartphone with an Android operating system (version 5.0 and higher), (3) ability to connect to the internet (via Wi-Fi or a data plan), and (4) capability of normal PA (ie, having no contraindications to PA diagnosed by a medical doctor).

The participants provided informed consent and completed a web-based baseline questionnaire. Subsequently, they were invited to a personal orientation meeting where the study procedures were explained. At this meeting, participants received a Fitbit Charge 2 monitor, and the Fitbit app along with a survey app developed for the study were installed on their smartphones. The participants received instructions on the use of the monitor and the survey app. Owing to time and schedule constraints, some participants were unable to attend in-person group instruction sessions. Therefore, some participants were instructed in person individually at their time and place of preference (n=10), and some took care of the setup themselves based on email instructions and an instructional video provided by the researchers (n=5). At the end of the study, 3 focus groups took place, with a total of 15 participants (ie, 15/30, 50% of the sample).

Measures

Feasibility and Study Experience

We assessed feasibility (ie, the practicality and ease of implementation of the study methodology) with a number of indicators across key aspects of the study.

Completion of Questionnaires

Two web-based questionnaires were administered as part of this study. The baseline web-based questionnaire (presurvey) collected basic demographic information (age, gender, education, and retirement/occupation) along with self-reported data on health status and medication use. Participants also completed a set of self-reported health behaviors and psychological measures [26-30]. As a measure of mobile health (mHealth) use, participants completed questions about the use of different information communication technology devices, including smartphones (frequency of use and duration). As a measure of smartphone literacy, we asked participants to rate their smartphone skills using a scale developed for the study. The 22-item scale assessed smartphone literacy across 3 areas (technical skills, communication, and security) using a 5-point Likert-type response scale and reflected digital literacy items from other existing tools/studies [31-39]. The internal consistency of the scale was good (Cronbach α=.938). The

postsurvey contained a 10-item System Usability Scale [40] with instructions to rate the overall user experience with the smartphone, Fitbit, and survey mobile app. As additional measures of feasibility, we also included concrete questions on the perceived ease or difficulty of the smartphone/Fitbit/app setup, use, and comprehension of the study instructions. Also included was the same set of self-reported health behavior and psychological measures [26-30] as in the presurvey.

Focus Groups

We organized 2 focus groups with 15 participants each. Each focus group consisted of two 45-minute sections separated by a 15-minute snack break. The topics discussed were three areas: experience in the study, perceptions of future use of Fitbit devices, and the potential of Fitbit and similar devices in providing care (asked only in one of the 2 focus groups where participants were all caregivers). The focus group protocol is included in the Multimedia Appendix 1.

Compliance

We assessed compliance in two key aspects of the study.

The EMA

The EMA protocol was designed to provide snapshots of short-term variability in physical inactivity, sleep, selected psychological indicators, and context. The protocol included three 8-day bursts with 3 pseudorandom surveys, each sent during one of 3 preset time windows (8:00 AM-11:59 AM, 12:00 PM-3:59 PM, 4:00 PM-7:59 PM) and spaced a minimum of 90 minutes apart. Participants also completed an end-of-day report before bedtime (available from 8:00 PM-11:59 PM). In addition, participants were instructed to complete a brief report about any bouts (at least 10 minutes) of planned PA at moderate intensity or higher after each PA episode. This was done either through a self-initiated survey or as part of a *contextual* survey prompted by the server, when incoming Fitbit data indicated a bout of sustained PA lasting at least 10 minutes (with ±2-minute tolerance and threshold for activity set at >100 steps per minute). The custom-made EMA app also operated in an offline mode and sent a notification to signal an EMA prompt/questionnaire. Participants had 45 minutes to complete the questionnaire and were notified about an unfinished questionnaire every 5 minutes during this period with an option to snooze the questionnaire for 20 minutes. After 45 minutes from the initial signal, the questionnaire became inaccessible and was sent to the server (if connected to the internet or later when the connection was established) as it is, even if incomplete. The EMA protocol is described in the supplementary files.

The Fitbit Assessment

Participants wore the Fitbit Charge 2 monitors. Fitbit data were regularly (every 5 minutes) downloaded by a custom-made system from the Fitbit cloud and stored on a secure server where the data from psychosocial daily and momentary surveys were also stored for future analyses. All data gathered in this secure database allowed researchers to view, process, and evaluate the data throughout the study and were available on a web server for researcher access. The server also has an application programming protocol that enables access to data from other systems and scripts. Data retrieved from the Fitbit cloud included sleep parameters, heart rate (beats per minute), step count, and active minute data.

Data Analysis

Descriptive statistics were computed using the statistical software IBM SPSS version 25 to describe the participants and compliance rates with the study protocol. Gender differences were analyzed using independent-sample t tests. Changes in self-reported behaviors and psychological outcomes from baseline to 12 weeks in the web-based pre- and postsurveys were assessed using a paired sample t test. Repeated measures analysis of variance was used to test the difference in PA in and out of assessment bursts. Qualitative data from the focus groups were transcribed verbatim and analyzed using thematic analysis [41].

Results

Sample Characteristics

The sample was balanced by gender (16/30, 53% male vs 14/30, 47% female), and the average age was 61.2 (SD 6.8) years. The majority of the sample was still actively working (22/30, 73%), and a slight majority had college education (56.7%), which is higher than the population average of 24% [42] and expected given that smartphone ownership increases with education level [43]. The participants used smartphones on average for about 3 years and rated their smartphone skills fairly highly (an average of 96 points on a 110-point scale). Most participants stated that they regularly accessed the internet on their smartphone (26/30, 87%) using a combination of Wi-Fi and a data plan (22/30, 73%). The reported use of health or fitness-related mobile apps before the study was relatively low, with 43% (13/30) of participants stating they never use them, 10% (3/30) stating they use them once per week or once per month, and 37% (11/30) stating they use them daily. The descriptive characteristics of the participants are presented in Multimedia Appendix 2, Table S1.

Feasibility and Experience With the Study

All participants completed the pre- and poststudy surveys. Consistent with the observational nature of the study, there were no changes in self-reported parameters assessed in the web-based pre- and postsurveys, although 87% of participants stated that they were paying attention to the steps walked throughout the study.

The overall rating of using the mobile app and Fitbit was above average (74.5 out of 100 on the System Usability Scale) in the poststudy web-based survey. The majority reported that Fitbit (27/30, 90%) and the app (25/30, 83%) were easy to use and rated their experience positively (25/30, 83%). The participants indicated that the survey length and frequency were acceptable, and two-thirds stated that they could envision continuing data collection beyond the 12-week study (Multimedia Appendix 2, Table S2).

In terms of participant experience with the study protocol, focus groups revealed that some surveys were missed owing to notifications not being noticed or that participants would need a longer time window for survey completion. Some participants

mentioned that they would prefer receiving *confirmation of receipt* of the completed surveys and perceived that contextual PA questionnaires were not triggered as they should be (ie, the survey did not always come automatically after an episode of what participants perceived as *moderate* PA). In terms of the Fitbit monitor, participants expressed an interest in knowing how the monitor works/measures activity. Some found wearing the monitor in hot weather or at night uncomfortable, noting technical issues such as the display not being visible in direct sunlight or display disturbing sleep during the night by lighting. Some participants voiced concerns over the imprecision of sleep measurement and wished the Fitbit app (which they were not required to use during the study) were available in the Czech Republic. One of the 3 participants who experienced synchronization issues between their smartphone and the Fitbit monitor noted this issue in the focus group. Overall, participants were, however, highly motivated to complete the surveys and to be compliant with the study procedures.

Regarding the potential of similar mobile technologies and their future use, the focus group participants placed high value on being able to self-monitor their behavior (especially steps and sleep) and receive personalized feedback. They expressed interest in motivational components being incorporated and using these tools as part of personalized interventions. Some mentioned the desire to share their data with their physician and obtain additional insights into their health and habits, although a number of challenges with regard to this were noted, ranging from perceived lack of time on the side of physicians, lack of motivation on both the patient and physician side, or technical issues involved in setting up such a monitoring system.

Compliance

Compliance With Long-term Monitoring Via EMA

All 30 participants completed the study. Across the three 8-day bursts, the participants completed 1568 out of 1906 (82.3% compliance rate) surveys administered 3 times per day at a pseudorandom schedule, 481 out of 613 end-of-day surveys (78.5% compliance rate), and 736 episodes of self-reported planned PA (with 29/736, 3.9% of the reports being initiated but returned without data). The survey completion rates for the three bursts are presented in Multimedia Appendix 2, Table S3.

The average duration of completion for each type of survey is presented in Multimedia Appendix 2, Table S3, along with the total response times for each type of survey and across the three bursts of intensive monitoring (Figures 1 and 2).

Figure 1. Completion rates (%, top row) and survey response times (minutes, bottom two rows) by survey and burst.
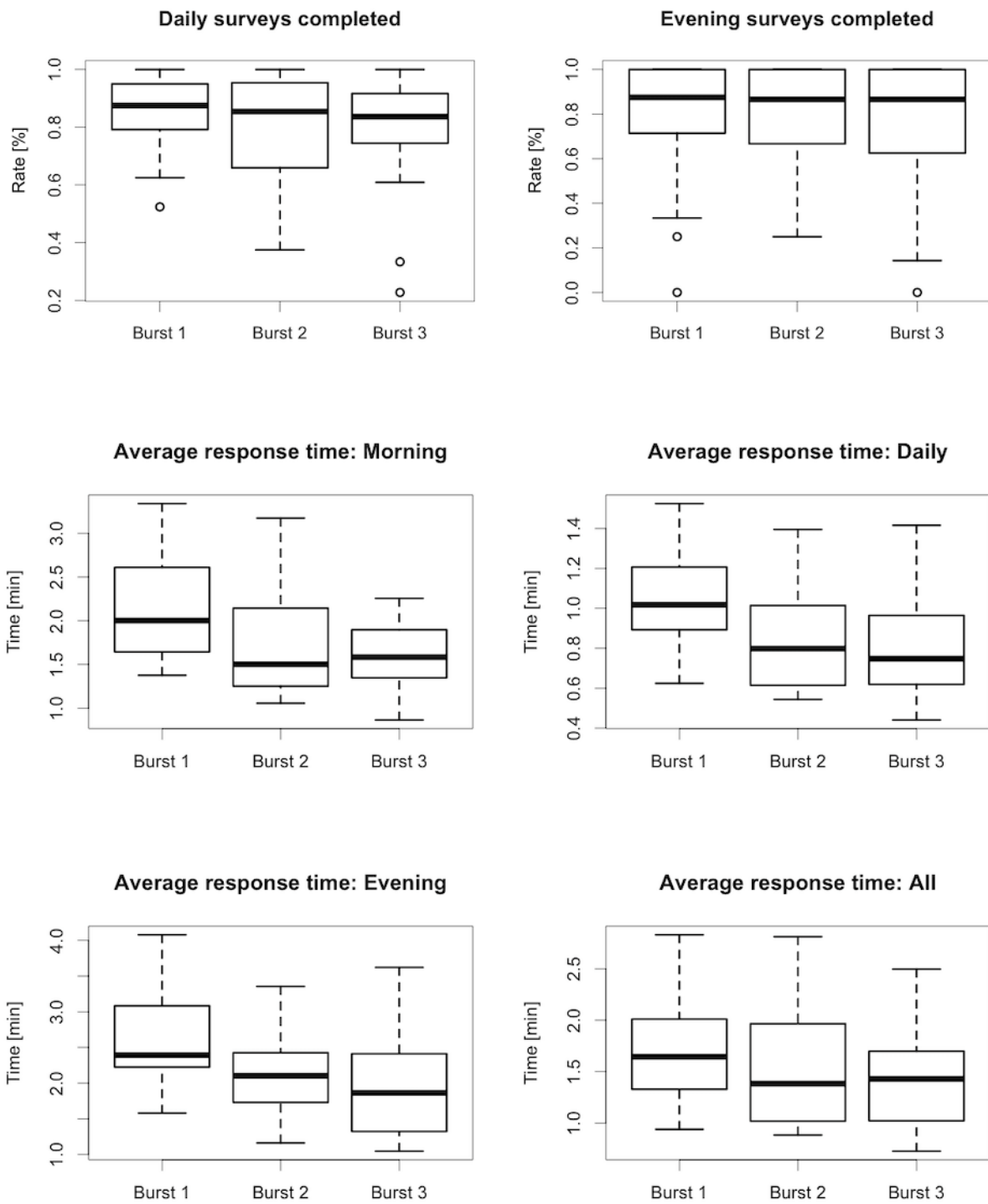
Figure 2. Overall survey response times by survey.
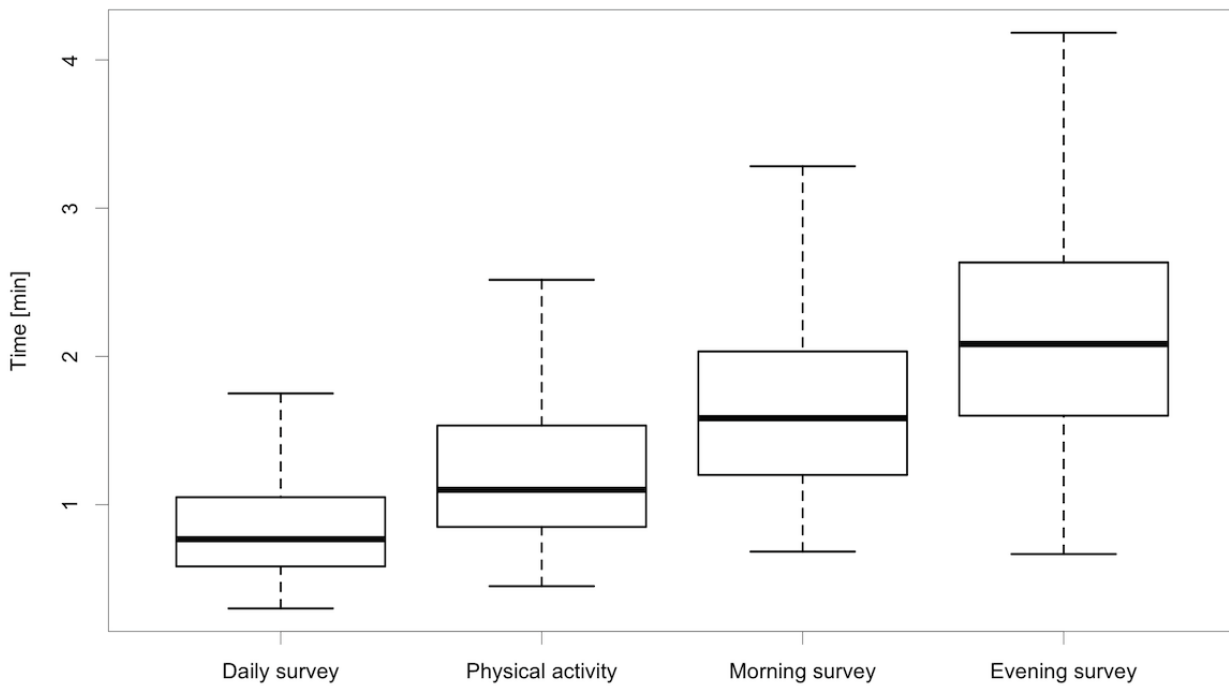
Compliance With Long-term Monitoring Via Fitbit

In terms of Fitbit compliance, upon enrollment, 3 participants had problems with syncing their phones with the Fitbit devices (primarily the lite version of HUAWEI smartphones) and had to use a backup device (computer or tablet) for syncing. On average, participants wore the Fitbit for 20.58 (SD 3.93) hours per day, with 20 participants having no missing days. A total of 3 participants had ≥30 days of Fitbit data missing across the

12 weeks, and this was due to synchronization problems that were not resolved in time and led to loss of data (Multimedia Appendix 2, Table S4).

Analysis of Fitbit data indicated no differences in measured PA between bursts or periods outside of measurement bursts ($F_{4,131}$=0.624; P=.65; Figure 3), but there was substantial within-person variability in PA across the 12-week monitoring period (Figures 3 and 4).

Figure 3. Average moderate intensity physical activity (in minutes) across bursts.
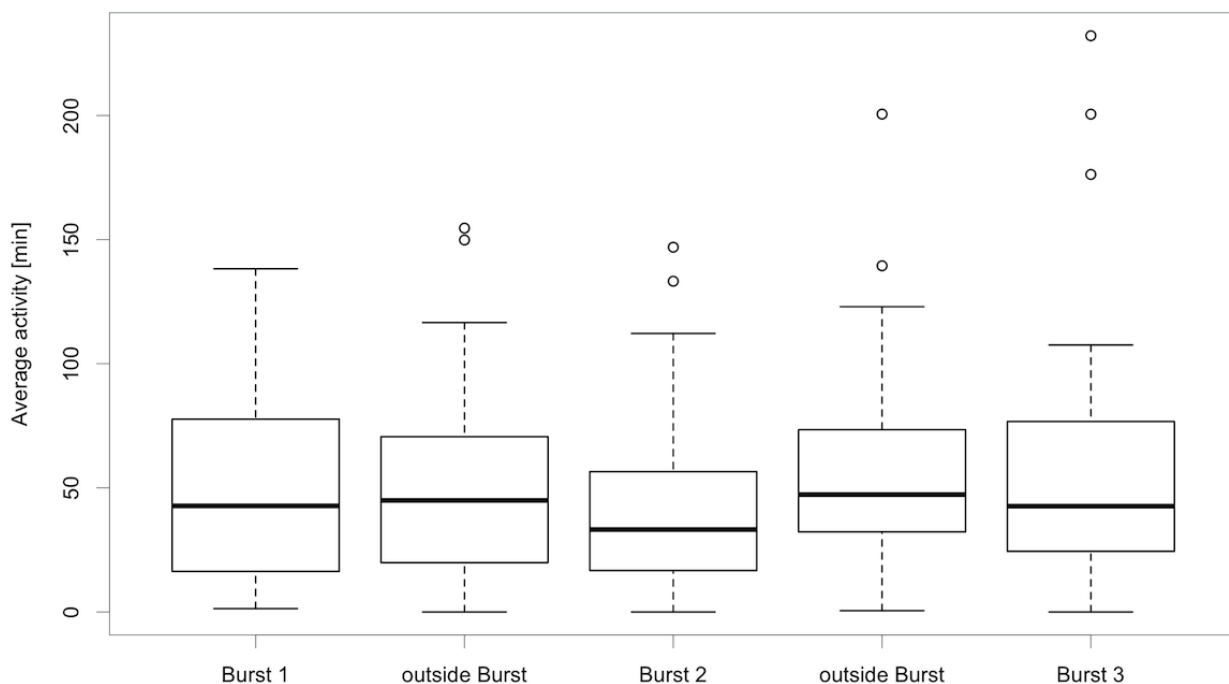
Figure 4. Continuous moderate intensity physical activity (in minutes) across the study. The blue line represents the sample average across the study. The black lines represent person-level variability in physical activity.
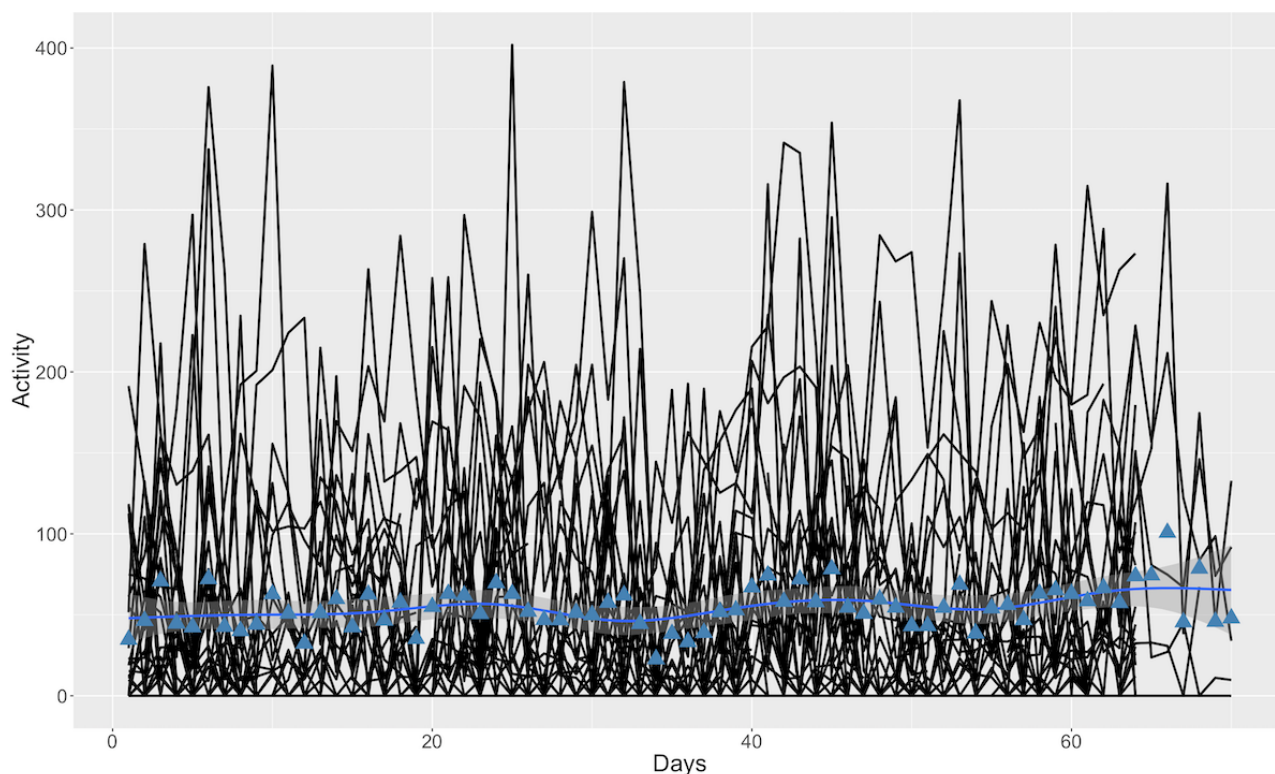
Discussion

Principal Findings

This study demonstrated the feasibility of intensive behavior monitoring via mobile technology in adults aged ≥50 years, in a research design where (unlike in previous studies [22,23]) participants' own smartphones were used. The participants found the system of using a Bluetooth-connected fitness bracelet along with daily surveys presented through an app on their own personal smartphone as easy to use and were not overly bothered by the frequency and length of the surveys. This is encouraging, as it suggests the potential for reducing both financial burden on the side of the researchers as well as participant burden in carrying more than one device. Participants were compliant (79%-82%) with the study protocol across the 12-week study duration with acceptable survey completion rates across all three 8-day measurement bursts. Preliminary analysis of Fitbit data did not suggest meaningful reactivity effects to the monitoring, as overall PA levels appeared stable between burst and out-of-burst periods (Figure 4). These findings demonstrate the feasibility of using similar protocols in the context of longitudinal or intervention studies targeting older adults, even in cultural contexts where overall rates of smartphone ownership and experience with mHealth tools are low.

Comparison With Prior Work

Reviews of previous research with older adults [10-12] demonstrate that the majority of existing studies included participant samples from mostly frontrunner countries in terms of digital technology adoption, whereas the Czech Republic

represents a population that currently trails behind in their use of mobile technologies to support healthy lifestyles compared with their European counterparts [18,44]. Previous feasibility studies in older adult populations also incorporated short EMA protocols (lasting 6-10 days). One study that collected EMA data in more than one burst (two 10-day periods before and after an intervention for individuals with cognitive and emotional difficulties) showed rapidly lower compliance rates (46%-48% adherence for all surveys) [20] than studies with only one EMA collection period only (86.4%-98%) [20,22,23]. This study used a measurement burst design with three 8-day bursts of EMA data collection, with two-third of the participants indicating they would be willing to continue with the study protocol beyond the 12-week study duration. This may be partly owing to the fact that this study used the participants' own smartphones. Previous studies have shown that a significant number of participants perceived carrying a *research* smartphone as inconvenient and interfering with their daily activities [23,45]. The results of this study show that this might be less of the case when relying on participants' own smartphones. Although an EMA protocol with multiple random prompts during the day might still require participants to pay closer attention to their smartphones than they would on a regular day.

Although compliance was satisfactory overall, in this study, women had slightly higher response rates to the timed daily surveys compared with males (data not shown). The differences did not reach statistical significance but may reflect a commonly reported gender response bias that is reflective of a number of factors, including differences in motivation [46], rather than a survey mode of delivery (ie, smartphone).

Implications

Overall, we conclude that it is feasible to incorporate repeated EMA assessments in larger prospective studies or as a method for evaluating the impact of interventions. Indeed, it was encouraging that many participants expressed an interest in receiving prompts and intervention features as part of the monitoring, boding well for the implementation of *just-in-time* PA interventions in this age group [14,25]. The successful implementation of mobile technologies in lifestyle promotion is critical to increasing the reach and public health impact of behavior modification and health promotion programs. Mobile technologies along with wearable devices have been found to be effective in increasing PA and reducing sedentary behavior, although larger studies with more rigorous methodologies are urgently needed [10-12].

The custom server in our study was built with the capability of accessing data from other systems and scripts via application programming protocol, which opens opportunities for monitoring other behaviors or bodily functions via technology and using these data to develop effective lifestyle or disease management interventions. Such efforts are also under way in the Czech Republic, where the first Czech National eHealth Center was established in 2012 with a focus on telemedicine. Nonetheless, this stands in stark contrast to the rather lukewarm attitude toward embracing such technologies among health care providers in the Czech Republic who remain reluctant to use mHealth technologies with older adults [47]. Participants in our focus groups expressed similar sentiments when discussing the potential of behavior monitoring as part of preventive health care. Clearly, more work is needed to develop sustainable protocols and systems for incorporating mHealth tools within existing health care infrastructures.

From a research standpoint, there are several lessons to be imparted from this study in terms of practical suggestions and the study design. First, researchers must allocate sufficient time to set up the devices and explain the study protocol. In this study, participants were capable of setting up the devices and apps on their own when they were unable to attend the group training sessions. Nonetheless, we recommend that any training session be followed by practice days to ensure sufficient familiarization with mobile apps, devices, and EMA prompts. When using a commercial device such as a fitness bracelet, researchers should be prepared to confront synchronization issues and have appropriate backup plans. In non–English-speaking countries, an additional challenge is presented when used apps are not in the native language of the participants, which is particularly relevant for older adult participants. In this study, we did not require any interaction with the Fitbit app; in fact, participants were asked not to use it. However, many were interested and explored the features on their own and expressed regret that the app was not translated to Czech (the Czech version became available only after this study). Finally, the participants in our study were eager to receive feedback at the end of the study. We provided detailed personalized feedback at the end of the study and informed the participants that they would receive it. However, many were pleasantly surprised at the level of detail and insights available and mentioned that they would have been more compliant and attentive to the data collection if they knew what type of feedback was possible. Researchers may want to provide examples of feedback reports at the beginning of the study as a way to increase motivation to comply with the study protocol.

Limitations and Future Research

This was the first study using intensive behavior monitoring and survey data collection via mobile technology with Czech older adults and the first study to report the feasibility of relying on participants' own smartphones when delivering an EMA study protocol. Although this may currently exclude some older adults who do not own a smartphone, this may be less of an issue in the future, given the rapidly rising numbers of smartphone users and older adults quickly catching up [43]. The sample was small, but there was variability across age, education, weight, and PA status (approximately half of the sample comprised physically active individuals). However, the study's inclusion criteria (smartphone with Android, capable of normal PA) and recruitment strategy may have promoted the participation of younger individuals who are more likely to use technology.

We used an affordable, commercially available fitness tracker that measures PA with acceptable accuracy [48], but the same device was found to be less accurate in the staging of sleep compared with a medical device [49]. Future studies should carefully weigh the advantages and disadvantages of using research grade as opposed to commercial devices, with implications for measurement precision as well as participant interest and burden. Participants in our study enjoyed the feedback provided by the bracelet on its display, but this type of feedback may be undesirable in clinical or randomized controlled trials targeting PA. Using a combination of a research-grade device (for dependent outcome assessment) and a commercial device (as an intervention tool) has been suggested as a possible solution [50].

The system as a whole was rated well by the participants; however, technical difficulties were noted throughout the study. On the side of the participants, there were issues with the compatibility of some of their smartphones with the Fitbit device, resulting in 3 participants having to synchronize their Fitbit through a *third* device (eg, a laptop). Participants missed some surveys due to notifications not being noticed, further highlighting the need to conduct comprehensive pilot-testing and to develop effective training protocols before embarking on a full-scale study. The data provided by this study also served to fine-tune the data collection protocol and improve the robustness of the server/system solution for data integration. Future research and development are also focused on the creation of automatic reports from the server for researchers to obtain information about the current status of all participants (daily, weekly, and monthly) and the status of the ongoing data collection (eg, synchronization status of devices, battery levels, and questionnaire completion rate). Future development will also involve the integration of various streams of data and enhancement of dynamic features, including machine learning, to detect the most appropriate/opportune times to generate EMA prompts and dynamically select the most appropriate items for prompted surveys.

Conclusions

The use of a wearable device coupled with a mobile survey app is feasible for use with older adults, who also indicate a high level of interest in motivational prompting and intervention components. Commercially available tools such as Fitbit devices offer a practical solution for both behavior monitoring and interventions in both small- and large-scale studies. The implementation of intensive measurement protocols, such as in this study, offers unique opportunities for insight into behavior dynamics (both short and long term).

Conflicts of Interest

None declared.

Multimedia Appendix 1
Focus group protocol.
[DOCX File , 127 KB - aging_v4i4e15220_app1.docx]

Multimedia Appendix 2
Ecological momentary assessment protocol.
[DOCX File , 338 KB - aging_v4i4e15220_app2.docx]

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Abbreviations

EMA: ecological momentary assessment
DREAM: dynamic real-time ecological ambulatory methodologies
mHealth: mobile health
PA: physical activity

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Original Paper

Technology Support Challenges and Recommendations for Adapting an Evidence-Based Exercise Program for Remote Delivery to Older Adults: Exploratory Mixed Methods Study

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Abstract

Background: Tele-exercise has emerged as a means for older adults to participate in group exercise during the COVID-19 pandemic. However, little is known about the technology support needs of older adults for accessing tele-exercise.

Objective: This study aims to examine the needs of older adults for transition to tele-exercise, identify barriers to and facilitators of tele-exercise uptake and continued participation, and describe technology support challenges and successes encountered by older adults starting tele-exercise.

Methods: We used an exploratory, sequential mixed methods study design. Participants were older adults with symptomatic knee osteoarthritis (N=44) who started participating in a remotely delivered program called Enhance Fitness. Before the start of the classes, a subsample of the participants (n=10) completed semistructured phone interviews about their technology support needs and the barriers to and facilitators for technology adoption. All of the participants completed the surveys including the Senior Technology Acceptance Model scale and a technology needs assessment. The study team recorded the technology challenges encountered and the attendance rates for 48 sessions delivered over 16 weeks.

Results: Four themes emerged from the interviews: participants desire features in a tele-exercise program that foster accountability, direct access to helpful people who can troubleshoot and provide guidance with technology is important, opportunities to participate in high-value activities motivate willingness to persevere through the technology concerns, and belief in the ability to learn new things supersedes technology-related frustration. Among the participants in the tele-exercise classes (mean age 74, SD 6.3 years; 38/44, 86% female; mean 2.5, SD 0.9 chronic conditions), 71% (31/44) had a computer with a webcam, but 41% (18/44) had little or no experience with videoconferencing. The initial technology orientation sessions lasted on average 19.3 (SD 10.3) minutes, and 24% (11/44) required a follow-up assistance call. During the first 2 weeks of tele-exercise, 47% of participants (21/44) required technical assistance, which decreased to 12% (5/44) during weeks 3 to 16. The median attendance was 100% for the first 6 sessions and 93% for the subsequent 42 sessions.

Conclusions: With appropriate support, older adults can successfully participate in tele-exercise. Recommendations include individualized technology orientation sessions, experiential learning, and availability of standby technical assistance, particularly during the first 2 weeks of classes. Continued development of best practices in this area may allow previously hard-to-reach populations of older adults to participate in health-enhancing, evidence-based exercise programs.

Introduction

Background

Most older adults in the United States live with a chronic disease, such as knee osteoarthritis, with an estimated 62% to 67% reporting multiple chronic conditions [1,2]. Exercise reduces the risk of at least 25 chronic diseases by 20% to 30% and is associated with improved quality of life and physical and cognitive function in older adults [3-5]. Despite the benefits of exercise, participation is low among older adults, with relatively few older adults with chronic conditions meeting the recommendations for exercise [6-8].

Multiple community-based exercise programs, including Enhance Fitness, Fit & Strong!, Active Living Everyday, and Geri-Fit, have been developed to address the strength, balance, and physical fitness of older adults [9]. Benefits from participation in these programs include improvements in physical performance, aerobic endurance, self-efficacy for exercise, self-rated health, and decreased pain [10-12]. Community-based classes have also demonstrated reduced loneliness and social isolation among older adults [13]. To promote participation among older adults, free access to community-based exercise is offered as a benefit through some Medicare Advantage Plans, such as Silver Sneakers and Silver&Fit, and health maintenance organizations, including Kaiser Permanente. However, in March 2020, most community-based programs serving older adults ceased or reduced their capacity, to comply with physical distancing mandates to prevent the spread of COVID-19.

Tele-exercise, including remote delivery of exercise classes through videoconferencing technology, has emerged as a means for community-based programs to resume guided exercise sessions while complying with the physical distancing restrictions during the COVID-19 pandemic [14]. The Gerofit-to-Home program has demonstrated preliminary evidence that older veterans who transition from facility-based to remotely delivered programs retain their physical function [15]. Previous studies have also shown the feasibility and acceptability of videoconference-delivered tai chi and yoga classes for older adults [16-18]. However, all 3 studies used proprietary technology that required specialized equipment installation at the participants' homes. In addition, the technology did not allow the participants to see or interact with other participants in the exercise sessions, thereby reducing the social support asset of group exercise. With increasing ownership of devices with audiovisual capability, such as laptop computers, tablets, and smartphones [19], many older adults have access to videoconferencing technology without the need for proprietary equipment. However, little is known about the technology support needs of older adults to facilitate participation in tele-exercise classes.

Objectives

The adaptation to remote delivery of exercise classes through videoconferencing (referred to as tele-exercise) is needed to meet the needs of older adults abiding by the physical distancing recommendations. In addition, expanding tele-exercise options increases the potential to include older adults who previously had limited access to community-based programs due to rural residence, caregiving responsibilities, transportation, and other challenges [20-22]. Understanding the technology support needs of older adults is critical to foster the success with tele-exercise participation. Therefore, we aim to (1) examine the needs of older adults previously enrolled in community-based exercise for transition to tele-exercise, (2) identify barriers to and facilitators of tele-exercise uptake and continued participation, and (3) describe technology support challenges and successes encountered by older adults starting tele-exercise.

Methods

Methodological Approach and Study Design

We used an exploratory, sequential mixed-methods design in which qualitative data were initially collected and analyzed. This approach allowed for input from older adult participants that was then used to inform the delivery of remote Enhance Fitness and the preparation for technical support before and during the remote classes. The rationale for using a mixed-methods approach was to develop a more comprehensive understanding of the technology needs and barriers related to remote exercise participation among older adults [23]. The qualitative data examined the older adults' perspectives on technology adoption and needs in transitioning from in-person to tele-exercise. The findings then informed the collection of quantitative data that were used to enumerate the technical support needs and determine the extent to which these needs were addressed in the tele-exercise program. Subsequently, the qualitative and quantitative findings were integrated for interpretation [24], wherein we considered the quantitative results in the context of the qualitative findings. The Standards for Reporting Qualitative Research were used to guide the reporting of the study results and methods [25]. All the procedures were approved by the University of Washington Institutional Review Board, and informed consent was obtained from all the participants.

Participants and Recruitment

Participants were recruited from communities in and around Seattle, Washington, using a multimodal approach, including mailing letters and brochures to the UW Medicine patients and posting on social media. Between October 2019 and September 2020, participants were enrolled in a randomized controlled trial (NCT04099394) comparing the combination of group exercise with either a group-based cognitive behavioral skills training program or a group-based health education program. The exercise program, Enhance Fitness, is an evidence-based and nationally disseminated program that involves instructor-led strength, endurance, and balance training for 1 hour, 3 days a week [26,27]. The Centers for Disease Control and Prevention recommend Enhance Fitness for arthritis management and the National Council on Aging recommends it for falls prevention [28,29]. All the participants were English-speaking, community-dwelling older adults (age ≥65 years) with symptomatic knee osteoarthritis and without cognitive impairment. Two-thirds of the participants (n=29) were enrolled in the trial before the COVID-19 pandemic halted all in-person Enhance Fitness exercise classes in Seattle, King County,

Washington [30]. The participant flow diagram is shown in Figure 1. The participants were invited to participate in phone interviews about their technology support needs to transition to tele–Enhance Fitness classes. We used purposeful sampling to ensure interviews were conducted with the participants with a range of technology and computing experience, based on a questionnaire assessing technology ownership and history of technology use. The interviews were conducted until saturation was achieved, that is, until little to no additional information was emerging from conducting additional interviews. After the virtually delivered protocol of tele–Enhance Fitness was developed by the study team (KP and EH in consultation with

NG and Ms Paige Denison, Enhance Fitness National Program Director), guided by the input gathered from the participant interviews and approved by the University of Washington Institutional Review Board, the trial's Data Safety Monitoring Board, and the National Institute on Aging of the National Institutes of Health, the tele–Enhance Fitness classes began in July 2020. An additional 15 participants who did not have prior experience with in-person Enhance Fitness began the tele–Enhance Fitness classes in September 2020. The data reported in this study were collected between October 2019 and January 2021.

Figure 1. Participant flow diagram. EF: Enhance Fitness.
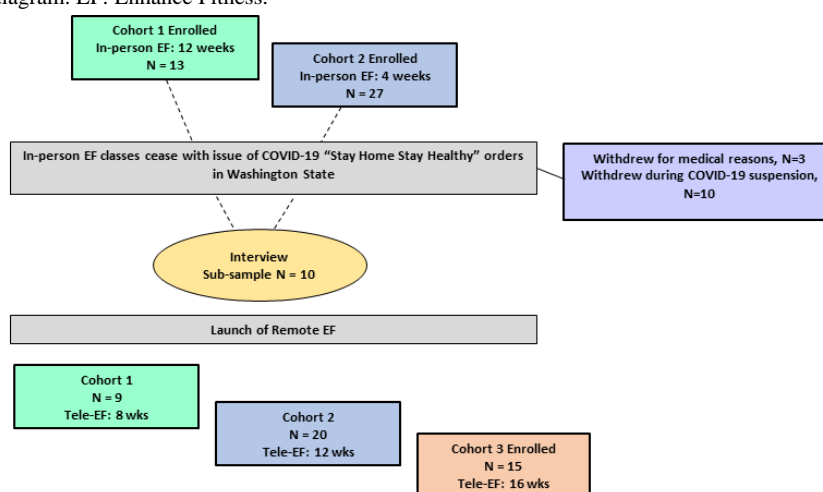
Measures

Qualitative

The participants were interviewed through phone by 1 research team member (interviewer EH) who had prior training and experience in conducting interviews. The interviewer used a semistructured guide with open-ended questions and follow-up probes as needed (refer to Multimedia Appendix 1 for the interview guide). The interviews lasted an average of 27 (SD 9) minutes and included questions on (1) concerns about transitioning from in-person to remote exercise classes, (2) past experience with technology adoption, and (3) barriers to and facilitators of new technology adoption. All the interviews were audio-recorded and transcribed verbatim.

Quantitative

As part of the trial's baseline assessment, the participants completed a series of questionnaires on demographic and health characteristics shown in Table 1. These data were collected through in-person interviews for cohorts 1 and 2, whereas cohort 3 completed the questionnaires on the web using REDCap (Research Electronic Data Capture; Vanderbilt University) electronic capture tools [31]. Physical activity was measured using a thigh-worn activPAL3 microaccelerometer (PAL Technologies) device that assessed the steps per day, averaged over the course of a week before the study interventions began. In addition, before beginning the tele–Enhance Fitness classes, all the participants completed a technology needs assessment and a survey questionnaire on technology use and acceptance.

The technology use assessment adapted questions from the National Health and Aging Trends Study [32] and the Pew Research Center [33]. The 14-item short version of the Senior Technology Acceptance Model (STAM) was also collected, which has demonstrated reliability and validity for measuring (1) attitudinal beliefs, related to positive or negative feelings toward using technology; (2) control beliefs, a reflection of self-efficacy, facilitating conditions, and ease of use; and (3) anxiety in older adults, defined as apprehension about using technology [34]. Finally, as part of the trial protocol, the study team conducted one-on-one technology orientation meetings through Zoom (Zoom Video Communications) with the participants to orient them to the tele–Enhance Fitness program, including guided instruction on videoconferencing. When necessary, the study team provided instructions on accessing and using Zoom, through telephone before the orientation call. The study team systematically recorded the duration of the video call and all the challenges that the participants faced while using technology. Similarly, the study team also recorded the technology challenges encountered when the participants engaged in tele–Enhance Fitness classes and if telephonic assistance was necessary, the length of the call was recorded. Attendance rates were documented for all the classes. The study team members who conducted the orientation meetings and assisted the participants with technology challenges during the tele–Enhance Fitness classes were recent public health graduates from the University of Washington (including EH). These team members were trained in communicating effectively with older adults and were aware of the findings from the qualitative interviews.

Table 1. Participant characteristics.

Characteristic	Total sample (N=44)	Subsample with qualitative interviews (n=10)
Age (years), mean (SD)	74 (6.3)	76.5 (8.1)
Sex, n (%)		
Women	38 (86)	9 (90)
Race and ethnicity, n (%)		
White	38 (86)	9 (90)
Black	3 (7)	1 (10)
Hispanic	1 (2)	0 (0)
Other	2 (5)	0 (0)
Education, n (%)		
High school graduate	1 (2)	0 (0)
Some college or vocational	7 (16)	2 (20)
College graduate	18 (41)	5 (50)
Masters or higher degree	18 (41)	3 (30)
Smoking history, n (%)		
Never smoked	25 (57)	6 (60)
Former smoker	19 (43)	4 (40)
Current smoker	0 (0)	0 (0)
Total number of medical conditions, mean (SD)	2.5 (0.9)	2.6 (1.0)
Steps per day, mean (SD)	4516 (1437)	4201 (1315)
Lives alone, n (%)	24 (55)	6 (60)

Tele–Enhance Fitness Delivery

After the individual technology orientation sessions were completed, the tele–Enhance Fitness classes were delivered 3 days per week for 1 hour over Zoom. The participants were provided with a link to the tele–Enhance Fitness classes through email. The Zoom session opened 5 minutes before the start of the class to allow socialization and opportunities to ask questions to the instructor. The Enhance Fitness-certified instructor led the exercise classes in accordance with the Enhance Fitness guidelines, including instructions for modifications to increase or decrease the level of difficulty. Each 1-hour–long tele–Enhance Fitness class included approximately 5 minutes of warm-up exercise, 20 minutes of aerobic exercise, 20 minutes of strength training, and 10-15 minutes of balance and stretching exercise. A research assistant attended all the web-based classes to provide technical support and monitor the safety and level of effort by the participants.

Data Analysis

Qualitative

The interviews were independently coded by 2 members of the research team (NG and EH). The primary coder (EH) was the same individual who conducted the interviews. She has training in public health and received additional training and supervision from investigators with experience in using qualitative methods. The second coder (NG) has experience in the public health, including training and experience in using qualitative methods.

Thematic analysis followed the guidelines described by Braun and Clark [35] to identify the themes related to older adults' perspectives on technology needs for transitioning to tele-exercise. Both the coders independently read all the transcripts multiple times to identify the codes. Then, they discussed the inconsistencies in the coding until an agreement was reached. After the discussion, the codes were classified into 4 main themes. While reviewing the themes, the research team discussed the meaning behind the themes in relation to the study. The coding and analyses were conducted using Microsoft Word and Microsoft Excel.

Quantitative

Descriptive statistics were computed for all variables. We used the Kruskal-Wallis equality-of-populations rank test (ie, a nonparametric one-way analysis of variance) to determine whether the distribution of STAM subscales varied according to self-rated confidence to go on the web (Table 2). This test was used because the responses to the STAM were skewed. In Table 3, we compute the prevalence and incidence rates of the technology challenges encountered during the initial orientation call and the subsequent tele–Enhance Fitness classes, respectively. Prevalence rate was the number of participants who experienced a given technological challenge during the orientation call divided by the total number of participants (N=44). In contrast, the incidence rate for a specific challenge was calculated by dividing the number of times the challenge occurred by the total number of tele–Enhance Fitness classes attended by the participants. To facilitate interpretation, this

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quantity was then multiplied by 100 to reflect the number of times a challenge was encountered for every 100 people who attended a tele–Enhance Fitness class. Incidence rates are useful to report because they capture not only the single occurrence of a challenge experienced by a participant but also the recurrence of a challenge experienced by a participant (eg, forgetting to join with Zoom audio on a tablet) and account for different rates of tele–Enhance Fitness class attendance across the participants. All the statistical analyses were conducted using Stata SE 15.

Table 2. Senior Technology Acceptance Model (STAM) subscale scores according to self-rated confidence to go on the web.

STAM subscales	Total sample (N=44), median (IQR)	Not at all or only a little confident (n=6), median (IQR)	Somewhat confident (n=17), median (IQR)	Very confident (n=21), median (IQR)	P value
Attitudinal beliefs	8.7 (3)	5.0 (2.3)	8.3 (1.7)	10 (1.3)	<.001
Control beliefs	8.9 (2.5)	6.9 (2.3)	8.8 (1.8)	10 (1)	<.001
Gerontechnology anxiety	3.5 (4)	3.8 (2.5)	5.5 (3)	2 (4)	.046
Health	8.4 (1.6)	8.2 (1.2)	8.4 (1.6)	8 (1.6)	.85

Table 3. Challenges encountered implementing tele–Enhance Fitness at different phases of the program.

Challenges encountered	Initial orientation call (n=42), (setup phase)		First 2 weeks of tele–Enhance Fitness classes		Subsequent 2-month period of tele–Enhance Fitness classes	
	Value, n	Prevalence (%)	Value, n	Rate per 100 persons (Enhance Fitness sessions[a])	Value, n	Rate per 100 persons (Enhance Fitness sessions[a])
Hardware or internet setup issues						
No device camera	1	2	0	0	0	0.0
No device microphone	1	2	0	0	0	0.0
Screen too small	0	0	2	0.9	0	0.0
Internet connectivity issues	0	0	3	1.4	5	0.9
Unable to log into email	2	5	0	0	0	0.0
Allowing Zoom camera access	1	2	0	0	0	0.0
Turning on computer sound	1	2	0	0	0	0.0
Physical setup						
Assembling wide-frame lens	9	21	0	0	0	0
Positioning lens on camera	13	31	1	0.5	0	0
Locating the front camera on device	5	12	0	0	0	0
Tablet or computer camera view	13	31	1	0.5	3	0.5
Room space	7	17	2	0.9	0	0
Backlit image	1	2	1	0.5	0	0
Zoom controls						
Trouble downloading Zoom	2	5	0	0	0	0
Joining or staying on Zoom meeting	0	0	22	10	15	2.6
Joining with Zoom audio	4	10	9	5.1	11	1.9
Using Zoom control buttons (ie, mute)	5	12	3	1.4	3	0.5
Switching to speaker or gallery view	9	21	0	0	1	0.2
Video turned off	0	0	2	0.9	0	0
Technology communication						
Lack of computer or tablet knowledge	2	5	2	0.9	0	0
Lack of understanding of technology terms	5	12	2	0.9	0	0

[a]This incidence rate reflects the number of times a challenge is encountered for every 100 people who take a tele–Enhance Fitness class.

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Results

Study Sample

The participants' characteristics are shown in Table 1. The age distribution ranged from 66-92 (mean age 74, SD 6.3) years and 41% (18/44) of participants were aged ≥75 years. The study sample primarily comprised White women. Most participants had a college or graduate degree and approximately half of them (24/44, 55%) lived alone. Consistent with the epidemiology of the target population, the mean number of medical conditions was 2.5 (SD 0.9) with 67% (29/44) of participants having ≥3 conditions (Table 1). Finally, the participants walked an average of 4516 (SD 1437) steps per day, with 21% (9/44) walking <3000 steps per day. In general, the subsample of participants who were selected for the qualitative interviews had characteristics similar to those of the total study sample (Table 1).

Interview Themes

Overview

We identified 4 themes related to the technology experience and needs for participation in tele-exercise: (1) participants desire features in a tele-exercise program that foster accountability, (2) importance of direct access to helpful people who can troubleshoot and provide guidance with technology, (3) opportunities to participate in high-value activities motivate willingness to persevere through the technology concerns, and (4) belief in the ability to learn new things supersedes technology-related frustration.

Theme 1: Participants Desire Features in a Tele-Exercise Program That Foster Accountability

Participants noted that a key value of community-based (in-person) classes was the accountability inherent in having a scheduled class with the same group of people each week:

> *I think one of the reasons I did well or that I managed with the exercise is I felt obliged to because everybody was doing it.*

> *Having something that is scheduled, do it now three days a week, is going to get me to do it more...I'm probably more likely to do it. Well, actually it's the same as going to the exercise classes at the senior center.*

The opportunity to socialize and *check-in* with other participants enhanced their desire to attend the exercise classes, which they believed should be duplicated with a remotely delivered class:

> *I'm assuming that doing this electronically or however it's going to be done, that there would be a chance to say, "Wait a minute, am I doing this right?"...So that kind of interaction. And ensure the joking and joshing with the other participants, just being friendly and interacting with them.*

In addition, the accountability of a scheduled, live-streamed class versus *on-demand* videos was considered an asset by the participants. Adequate screen size was also noted as important for accountability to enable participants to see others in the class

while also being seen by the instructor. Overall, the participants valued the accountability aspect inherent in the group classes and therefore recommended retaining the accountability features in the tele-exercise classes.

Theme 2: Direct Access to Helpful People Who Can Troubleshoot and Provide Guidance With Technology Is Important

The participants identified attributes of technical assistance critical to the successful transition to web-based exercise classes. One-on-one or small group instruction for the initial setup of technology was identified as key to a successful start. Some people wanted latitude to conduct the technical setup themselves, with guidance, rather than someone else doing it for them. Similarly, there was little consensus on the mode of instructions (ie, printed vs web-based video) with more importance placed on access to a person able to answer questions as they arise during the initial setup:

> *To be accessible without going through a hundred people to get to you to find out what it is I need help with. Your accessibility would be the most important thing to me.*

The temperament of the person providing assistance was also noted as essential, as the participants clearly expressed the importance of avoiding frustration from the person providing technical assistance. Participants also stated a desire for affirmation that their technical challenges were not unique and that they, like other people in a similar situation, were capable of overcoming the challenge:

> *Let me know that I'm not the only one they're happening to. And let me know that I'm not going to lose the marvelous experience because of this problem...I mean, if someone was impatient with me or if something were verbalized like, "You're the only one that has these horrible problems," that would be very discouraging.*

The participants recognized the risk of personal frustration with using technology to access the exercise classes and felt that the attitude and patience of the person providing technical support would help to mitigate their frustration.

Theme 3: Opportunities to Participate in High-Value Activities Motivate Willingness to Persevere Through Technology Concerns

The participants acknowledged concerns about learning and using technology to access exercise classes. Reasons for concern ranged from previous challenges with adopting new technology to the perception that they might take action that resulted in irrevocable loss of software or files on the device. However, the participants stated that the access to guided exercise was sufficiently important to work through the technology-related challenges that arise while joining tele-exercise classes. They noted that the benefit they experienced with the in-person exercise classes motivated them to overcome the technology challenges to participate in the exercise classes again, although remotely:

In other words, I am not adept at computer issues. I think that because I really want to do this...I believe that being able to do this stuff again is going to be so great that I'll be able to get enough help and guidance. So it won't be as tough as I anticipate it might be, but there are things to overcome and there are things to learn and so on.

I'm not eager to, but I will if that's what we need to do...

Overall, the participants were realistic about the likely barriers to initiating a new activity dependent on learning and using technology. Given their past experience with the group exercise classes, they prioritized the benefits of resuming exercise over the barriers of accessing it through technology.

Theme 4: Belief in the Ability to Learn New Things Supersedes Technology-Related Frustration

Some participants reported previous positive experiences with using technology for communication and videoconference activities, particularly since the start of the COVID-19 pandemic. However, overall, the participants acknowledged the likelihood of experiencing frustration in accessing remote exercise classes. Notably, the participants also believed in their ability to learn new technology and overcome challenges:

Learning beforehand instead of learning as we go. I think that would be very helpful. I am a good learner. I still have good intelligence and good ability to pay attention, and so I have good learning skills. That's a very good thing that's still with me.

So since I've been retired, I've tried to figure out things on my own and I'm making some progress on some things, but I tend to have sort of a short, short temper on it. It's like, I can't believe this. Who needs it anyway? And then after a few days, I think well I need to stay up with the modern age. Surely I could do this.

It was important to the participants that they be perceived as capable of adapting to the circumstances, to mirror their own beliefs in their abilities to work with technology. Although technology-related frustration was acknowledged, it was not considered an insurmountable impediment because of their belief in their own abilities and the perceived importance of participating in exercise.

Technology Use and Acceptance

Most participants in the tele–Enhance Fitness classes (40/44, 91%) owned a smartphone and had broadband at home, but approximately one-third did not own a tablet and one-third did not own a computer with a webcam (Table 4). Notably, of those who did not own a computer with a webcam, 69% (31/44) owned a tablet that they could use for tele-exercise (cross-tabulation not shown in Table 4). In addition, 80% (35/44) reported using an app in the last month and 84% (37/44) reported emailing and texting on most days in the last month. In contrast, only 9% (4/44) used a videoconferencing platform on most days in the last month and 41% (18/44) reported either no or rare videoconferencing. Approximately half of the participants (21/44, 48%) were very confident in their ability to use a device to go on the web (Table 4), but 14% (6/44) reported being not at all or only a little confident to go on the web.

Table 2 presents the STAM subscale results for the total sample and is stratified by self-rated confidence to go on the web. Attitudinal and control beliefs were generally high in the total sample, indicating high levels of perceived usefulness of technology in daily life (attitudinal beliefs) and confidence in using technology (control beliefs). In addition, anxiety about using technology (*gerontechnology anxiety*) was generally mild in the overall population; however, there was substantial variation in anxiety scores as the SD was large. In fact, attitudinal and control beliefs and anxiety varied significantly according to self-rated confidence to go on the web (Table 2); the participants with less confidence had lower attitudinal and control belief scores. Notably, the participants who were somewhat confident in their ability to go on the web had the highest levels of anxiety about using technology.

Table 4. Technology ownership and use survey (N=44).

Characteristic	Value, n (%)
Owns a mobile phone	
No	3 (7)
Yes, a cellphone	1 (2)
Yes, a smartphone	40 (91)
Uses home broadband	42 (93)
Owns a computer	
No	4 (9)
Yes, but does not use it	3 (7)
Yes, but it does not have a webcam	6 (14)
Yes, and it has a webcam	31 (71)
Owns a tablet	
No	13 (30)
Yes	30 (68)
Yes, but does not know how to use it	1 (2)
Used an app on cellphone or tablet in the last month	
No	6 (14)
Yes	35 (80)
Not sure	3 (7)
Messaged someone in the last month	
Yes, emailed and texted	40 (91)
Yes, emailed but did not text	3 (7)
Yes, texted but did not email	1 (2)
Frequency of messaging in the last month	
Rarely	1 (2)
Somedays	6 (14)
Most days	37 (84)
Used a videoconference platform in the last month	
No	10 (23)
Yes, but rarely	8 (18)
Yes, on somedays	22 (50)
Yes, on most days	4 (9)
Overall confidence using digital or electronic devices to go on the web	
Not at all confident	1 (2)
Only a little confident	5 (11)
Somewhat confident	17 (39)
Very confident	21 (48)

Technology Support Calls for Tele–Enhance Fitness

Nine participants attended a phone call (mean time of 14 minutes, SD 7 minutes) for guidance on accessing and opening Zoom for the orientation meeting. Subsequently, 42 participants completed the initial technology orientation by videoconference through Zoom. The orientation included an overview of the tele–Enhance Fitness program, orientation to the videoconference platform, and a safety check to confirm the availability of a stable chair of standard height and a clear 5×5 foot space to exercise in. The duration of the orientation ranged from 5 to 45 (mean 19.3, SD 10.3) minutes. A second follow-up Zoom meeting was completed with 2 participants who needed additional training support. These second calls lasted for 10-20

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(mean 15, SD 7.1) minutes. Two participants declined the orientation meeting, citing familiarity with using Zoom from previous experience.

During the first 2 weeks of tele–Enhance Fitness classes, approximately half (21/44, 48%) of the participants required a single telephone call to address the technology challenges encountered while engaging in tele–Enhance Fitness classes. The duration of these support calls ranged from 2 to 15 (mean 6, SD 3.3) minutes. Of the 21 participants who required additional support, only 2 (10%) required a second call during the initial 2-week period. Subsequently, after participating in tele–Enhance Fitness for 2 weeks, 11% (5/44) of participants needed a support call once and 5% (2/44) of participants required assistance 2 or more times. In contrast to the first 2 weeks of classes when there were 24 calls (mean duration 6.5, SD 3.6 minutes), there were 11 calls (mean duration 5.6, SD 3.0 minutes) in the subsequent 2-month period of tele–Enhance Fitness classes. Thus, the need for technology support for older adults participating in tele–Enhance Fitness decreased substantially after the first 2 weeks of classes.

Technology Challenges Encountered

Three participants who did not have sufficient broadband access at home were given cellular-enabled tablets that were sponsored by the study. Table 3 presents the rates of the challenges encountered during the different stages of implementing tele–Enhance Fitness. A common challenge for participants was assembling and placing a clip-on magnifying lens over the webcam, which enabled the exercise instructor to observe the participant's full body when exercising at a safe distance from the device. Other common challenges addressed during the initial technology orientation were navigating the camera's view and learning how to use Zoom functions, including switching from speaker to gallery view. Cluttered room space was addressed by 17% (7/42) of the participants. Finally, limited knowledge of common technology use terms (eg, *scroll up/down* and swipe) hampered communication in 12% (5/42) of participants during the initial orientation. Once tele–Enhance Fitness classes began, difficulty in joining the Zoom meeting and not joining with Zoom audio were common in the first 2 weeks, but the incidence of these challenges decreased by 75% and 59%, respectively, over the subsequent 2-month period.

Attendance

During the first 2 weeks of tele–Enhance Fitness (ie, 6 classes), the median attendance was 100% with an IQR of 83% to 100%. The median attendance for classes during weeks 3 to 16 was 93% (IQR 88%-98%). Interestingly, the overall attendance to tele–Enhance Fitness was better among the participants who did not have prior experience with in-person Enhance Fitness (cohort 3: median 96%, IQR 91%-98%) than among those who did (cohorts 1 and 2: median 92%, IQR 83%-96%).

Discussion

Principal Findings

This study provides insights into the technology support needs of older adults starting with tele-exercise classes. Key findings related to participants' technical support needs, which were identified during the interviews, were incorporated into the technical orientation sessions. Overall, the interviews identified strong interest in technology use, motivated by the opportunity to participate in group exercise and targeted recommendations for a successful transition to tele–Enhance Fitness from the perspective of older adults. The high attendance rates throughout the 16-week tele–Enhance Fitness program, the experience of successfully addressing all technical challenges as they presented, and the diminishing technical challenges after 2 weeks of classes indicate successful transition to tele–Enhance Fitness for older adults.

Previous studies have found relatively positive attitudes among older adults toward technology when it supports desired activities and contains useful features [36,37]. We obtained a similar finding as evidenced by the theme of willingness to persevere through the technology challenges to participate in high-value activities such as exercise. With physical distancing preventing the participation in community-based (in-person) classes, the need to learn videoconference technology is currently relevant for attending livestream exercise classes. This theme also aligns with a key principle of motivational models in adult learning theory, which posits that learning is motivated by the relevance and impact to the learner [38,39]. To date, few studies have considered remote exercise options for older adults, perhaps due to the lower rates of technology use in older adults than in other generations [40]. However, in light of the findings of this study, the perceived challenges of technology adoption should be considered in relation to the value of the end purpose (eg, opportunities to participate in health-enhancing activities) in older adults.

Recommendations for adult education, based on social theories within adult learning theory [41,42], include creating an environment of cooperation and working collaboratively, which aligns with our themes of accountability and desire for direct access to helpful people. The participants articulated that a cooperative environment characterized by minimizing judgment or criticism is critical. This theme is also supported by previous research conducted in rural older adults, where motivation and interest to use technology was dependent on sufficient support and infrastructure [43]. A study of teaching methods for incorporation of technology in daily life for older adults noted the need to account for the learning processes of older adults, including flexible instructors who are able to respond to the unique learning situations and needs of older adults [44]. These findings suggest the need to consider how technical support is designed and delivered in transitioning to remotely delivered exercise classes, including communication skills for technology support providers and awareness of how their responses will impact the older adults they are teaching.

We did not find a consensus on how to provide the initial technology instructions (eg, step-by-step guidance as video instructions or written instructions). Prior work has demonstrated that the preferences for learning vary, depending on previous experience and knowledge, but also for training on specific tasks versus general tasks [45]. As noted in a study examining the approaches to training older adults to use technology, training should include a combination of procedures that include step-by-step guidance, with latitude for attention training,

wherein participants decide on the steps but are given assistance as needed, dependent on individual factors [46]. Adult learning theory posits 2 stipulations: first, that adult learners build on the accumulation of life experience to aid learning, and second, instructions should account for variation in previous experience [38]. Our findings fit within the context of adult learning theory in that they highlight the need for tailored technology orientation sessions in launching remotely delivered exercise programs for older adults. In addition, the interperson variability in technical challenges during orientation and the first 2 weeks of classes lends further evidence for an individualized approach to technical support. This may pose a challenge for programs regarding sufficient funding for ongoing tailored technical support. Therefore, further research is needed to better quantify the return on the investment for tailored technology orientations in engaging and retaining older adults in remotely delivered health promotion programs.

Most participants in the study had access to technology and the internet. Although more than half of the participants (23/44, 52%) were a little or somewhat confident in their ability to go on the web, the scores for anxiety related to using technology were relatively low. However, participants with low confidence to go on the web had lower gerontechnology anxiety scores than those who were somewhat confident going on the web. This may be a reflection of those with little confidence having less experience with technology overall, including situations that they could not manage or overcome. It is worth noting that the STAM questionnaires assess technology acceptance in a general sense [34]. Participants in the study knew that they would need to use technology for a specific purpose (ie, accessing group exercise classes) and one that clearly had value, as indicated by the interviews. The knowledge that technology use would be targeted and specific, rather than technology use in general, may have impacted their acceptance scores on the questionnaire. The overall high scores for attitudinal beliefs align with the interview responses that technology would be useful and effective to access the classes they regarded as valuable. The high scores for control beliefs also align with the participants' responses in the interviews. The control belief questions measure confidence in being skillful at using technology and using technology after being instructed on how to do it. High scores on these questions correspond with the interview themes that opportunities to participate in high-value activities motivate willingness to persevere through the technology concerns and belief in the ability to learn new things supersedes technology-related frustration.

There were relatively few hardware or internet issues after the classes began, in part, because the study staff conducted the one-on-one technology needs assessment before the initial orientation meeting. Orientation to the Zoom features was a key part of the initial instruction, resulting in most participants not requiring additional support thereafter. Overall, the rates of the technical challenges were low at the onset of remote Enhance Fitness classes and declined further after the first 2 weeks of classes. The most common challenges addressed during the orientation session were related to camera adjustments to allow for full body view while exercising at a distance sufficient to see and hear the instructor. During the first 2 weeks of classes,

the most common problem, experienced at a rate of 10%, was joining or staying on the videoconference. By the third week of classes, joining or staying on the videoconference remained the most common challenge but decreased to a rate of less than 3%. We attribute the relatively low rates of technical challenges to (1) a sample of relatively educated older adults including few with previous videoconference experience, (2) the individualized orientation session conducted before the start of classes with the opportunity for individual follow-up orientation sessions as needed, (3) relatively immediate implementation of tele–Enhance Fitness classes after the technology orientation combined with the class structure (ie, 3 days per week) for frequent repetition of the technology procedures, and (4) standby technical assistance before and during the tele–Enhance Fitness classes. Consideration of these factors, which align with adult learning theory principles, may be beneficial in a successful launch of a remote exercise program.

Owing to the limited research to date on adapting an evidence-based exercise program for internet-based delivery to older adults, the mixed-method approach provides advantages at the current stage. Although previous studies have examined technology adoption in older adults and learning strategies for teaching older adults on technology use [44,45], few studies have focused on strategies for supporting older adults to participate in tele-exercise programs. Using the exploratory sequential mixed-method design allowed participant preferences to be incorporated into the technology orientation sessions and then quantified the challenges encountered with and attendance to the exercise classes, an indicator of the success of technology adoption. With the goal of expanding access to tele-exercise classes, an imperative next step is to replicate the study in a larger and more diverse population of older adults, especially regarding technology experience and gerontechnology anxiety. An iterative process will help to refine the best practices in supporting older adults in tele-exercise participation.

Limitations

We acknowledge the limitations of this study. Computer systems and software require frequent updates and occasionally undergo format changes. In this study, we did not examine how these updates or format changes impact perceptions of tele-exercise or the challenges encountered in managing software updates or new technology additions. The study sample consisted predominantly of White, college-educated women with relatively low gerontechnology anxiety and a history of technology use. Therefore, the findings cannot be generalized to all older adults. This study does not allow us to predict how technology barriers will be perceived in more diverse populations. For example, the findings related to the theme of belief in the ability to learn new things may be more relevant to our homogeneous sample of more educated White women and cannot be generalized to all older adults. The current population was originally recruited from community-based senior centers and for the interview sample, had previously participated in the in-person Enhance Fitness classes. Purposeful sampling of Enhance Fitness participants allowed us to capture a range of perspectives from people with varying levels of comfort in using technology to access group exercise classes. We intentionally interviewed older adults who had experience with in-person exercise classes

to understand their needs in transitioning to remote classes. We acknowledge that their perceptions of the benefits of the classes may have enhanced their desire to learn and use technology. However, the high attendance rates in the full sample, including those with and without prior experience with in-person Enhance Fitness, provides some evidence that people without prior in-person Enhance Fitness exercise experience can overcome technology barriers to engage in remote exercise classes, if provided with sufficient support.

Implications and Conclusions

The COVID-19 pandemic has resulted in extreme measures to reduce the spread of the virus, including the cessation of community-based programs for older adults in senior centers and fitness facilities. The loss of access to these programs impacts social opportunities, management of chronic conditions, and fall risk in older adults nationwide. With the availability of vaccines, there is an expectation of returning to community programs in the near future. However, it is too early to predict how long the physical distancing measures will need to be followed, and therefore how long until older adults can safely resume participating in community-based exercise programs. Until that time, remotely delivered programs remain a viable option and, for some, a preferred mode of delivery because of its convenience. On the basis of our findings, with appropriate support and attention, older adults are able to participate in remote exercise using technology. Importantly, these findings are also relevant to the millions of older adults who do not have access to in-person community programs, such as those who are homebound or living in rural areas. With sufficient tailoring of technology and support to meet the needs of diverse populations, continued development of best practices in this area has the potential to allow previously hard-to-reach populations of older adults to participate in health-enhancing, evidence-based exercise programs.

Authors' Contributions

The internet-based delivered protocol of tele–Enhance Fitness was developed by KP and EH in consultation with NG.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Semistructured interview guide.
[DOCX File , 15 KB - aging_v4i4e27645_app1.docx]

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Abbreviations

STAM: Senior Technology Acceptance Model

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Original Paper

Perception and Initial Adoption of Mobile Health Services of Older Adults in London: Mixed Methods Investigation

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Abstract

Background: Advances in mobile technology and public needs have resulted in the emergence of mobile health (mHealth) services. Despite the potential benefits of mHealth apps, older adults face challenges and barriers in adopting them.

Objective: The aims of this study are to understand older adults' perception of mHealth services and to discover the barriers that older adults face in the initial adoption of mHealth apps.

Methods: This paper systematically analyzed main determinants related to mHealth services and investigated them through questionnaires, interviews, and a workshop. Two studies were carried out in London. In study 1, the questionnaires with follow-up interviews were conducted based on the literature review to uncover older adults' perception (including perceived usefulness, perceived ease of use, and perceived behavioral control) of mHealth services. Study 2 was a workshop helping older adults to trial selected mHealth apps. The workshop was conducted by the first author (JP) with assistance from 5 research students. The barriers that older adults faced in the initial adoption period were observed. The interviews and workshop were audiotaped and transcribed. Descriptive statistics and the thematic analysis technique were used for data analysis.

Results: In total, 30 older adults in London completed the questionnaires and interviews in study 1. The results of study 1 show that the lack of obvious advantage, low reliability, scary information, and the risk of privacy leakage would decrease older adults' *perceived usefulness* of mHealth services; the design of app interface would directly affect the *perceived ease of use*; and aging factors, especially the *generation gap*, would create barriers for older users. In total, 12 participants took part in the workshop of study 2, including 8 who took part in study 1. The results of study 2 identified that *access to technology*, *the way of interaction*, *the risk of money loss*, *heavy workload* of using an mHealth app, and *different lifestyle* are influential factors to older adults' adoption of mHealth services.

Conclusions: The perceptions of mHealth services of older adults were investigated; the barriers that older adults may face in the initial adoption stage were identified. On the basis of the synthesis of these results, design suggestions were proposed, including *technical improvement*, *free trial*, *information clarification*, and *participatory design*. They will help inform the design of mHealth services to benefit older adults.

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Introduction

Background

Owing to the development of information and communication technology (ICT), health care service delivery nowadays goes beyond traditional face-to-face interaction. ICT supports health care with electronic communication and system networking capabilities to provide, exchange, and facilitate exchange of health-related information [1]. Mobile health (mHealth) emerged in 2003; Robert Istepanian coined the term to describe the use of *emerging mobile communications and network technologies for health care* [2]. Compared with web-based health services delivered from desktops and laptops, mHealth services have the advantage of interacting with individuals with greater frequency and flexibility, without being limited by time and place [3]. Mobile technologies, especially smartphone-based apps, can improve the efficiency of health care delivery, ultimately make health care more effective [4-6] and help people to better control their chronic conditions [7,8]. However, despite the numerous benefits of mobile health (mHealth) apps, relatively little is known about whether older adults perceive that these apps confer such benefits. Their perspectives toward the use of mobile apps for health-related purposes have not yet been fully investigated [9].

"Living a healthier independent life" is vital for older adults' quality of life [10]. Given that the aging population has become a global issue, making mHealth services more acceptable by older adults is of paramount importance. For instance, the World Health Organization has identified a good practice case study in Singapore's Action Plan for Successful Aging, where a mobile app, *Healthy 365*, was successfully used [11].

Prior Work

Although there has been a steady increase in the number of studies exploring technology adoption or acceptance among older adults, few have focused on mobile technologies, and even fewer have explored the acceptability of mobile technology use for health-related purposes [12]. Studies on mHealth adoption among older people are far less than those on general technology adoption among older people [13-15]. Because of the importance of, and the increased interest in the field, a scoping review protocol was proposed in 2020 to investigate the willingness, perceived barriers, and motivators in adopting mobile apps for health-related interventions among older adults [9].

Published studies on mHealth adoption [16-20] are mostly based on the technology acceptance model (TAM) [21] and its extended variations (ie, TAM2, TAM3, United Theory of Acceptance and Usage of Technology [UTAUT], and UTAUT2). The Health Belief Model (HBM) and the Protection Motivation Theory (PMT) also prove helpful in understanding mHealth adoption. In research on health behavior, eHealth literacy [22], self-efficacy [23], perceived vulnerability, perceived severity, and health consciousness [24] are listed as influential factors in people's adoption of health information technologies. Sun et al [25] integrated several models to find that users' intention to use mHealth services was determined by 5 key factors: performance expectancy, effort expectancy, social influence, facilitating conditions, and threat appraisals.

Deng et al [18] extended the TAM with *trust* and *perceived risks* in studying mHealth adoption in China. Alam et al [19] extended UTAUT to include *perceived reliability* and *price value* to investigate mHealth adoption in Bangladesh. These studies used quantitative methods (eg, survey questionnaires) and recruited patients from local hospitals. Cajita et al [26] investigated the intention to use mHealth in older adults with heart failure, and associated facilitators and barriers [12], using mixed-methods (ie, large survey + small-scale interview). Minimal qualitative research was conducted with *well-old users* [27] who are the largest potential beneficiaries of mHealth services.

Previous research has mainly investigated how older adults use technologies before the objectification phase and usability problems after the conversion phase [28], and few have investigated the initial adoption stage, that is, using only elementary features and limited functions of mobile technologies. Grindrod et al [29] evaluated user perceptions of 4 mobile medication management apps with older adults (those aged ≥50 years) through usability testing and found that most participants *were frustrated by their initial experiences with the apps*."

This paper fills these gaps by exploring older adults' initial adoption of mHealth apps, using qualitative questionnaires combined with interviews and user trial workshops to reveal their perceptions and contextualized experiences. The insights help generate design suggestions to make mHealth services more acceptable to older adults.

Theoretical Framework

mHealth services use ICT. They are relevant to technology adoption theories and can be traced back to the theory of reasoned action (TRA) [30]. On the basis of the TRA, Davis et al [31] developed the TAM in which they suggested that *perceived usefulness* and *perceived ease of use* are the 2 most important individual beliefs about using information technology. Other researchers have extended the TAM and proposed the TAM2 [21] and the TAM3 [32], decomposing *perceived usefulness* and *perceived ease of use*. Ajzen [33] developed the Theory of Planned Behavior (TPB) to extend the TRA and added the new construct of *perceived behavioral control*. Venkatesh et al proposed the UTAUT [34], combining 8 existing theories, and the UTAUT2 [35] emphasized the consumer use context.

As a kind of health behavior, mHealth adoption is also relevant to theories of health behavior, such as the HBM [36] and PMT [37]. The HBM hypothesizes that health-related behavior depends on the combination of perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. The PMT stems from both threat appraisal (perceived vulnerability and perceived severity) and coping appraisal (response efficacy, self-efficacy, and response cost) processes.

The theoretical framework of this study is based on the TRA, TAM, TPB, UTAUT2, HBM, and PMT (column 2 in Table 1).

Eight main constructs (column 1 in Table 1) were extracted by grouping similar factors in these models. These constructs will be further investigated through primary studies in order to gain insights into older adults' perceptions and the initial adoption of mHealth services.

Table 1. Eight main constructs extracted from existing models.

Construct	Definition	Origin from existing models
PU[a]	• An individual's perception that using a particular system would enhance his or her job performance [38].	• Perceived usefulness in TAM[b] • Performance expectation in UTAUT2[c] • Perceived benefits in HBM[d] • Response efficacy in PMT[e]
PEOU[f]	• An individual's perception that using a particular system would be free of effort [38].	• Perceived ease of use in TAM • Effort expectancy in UTAUT2 • Perceived barriers in HBM
PBC[g]	• An individual's perception of how easy or difficult it will be to perform the target behavior [33]. • The perceptions of internal and external constraints on behavior and encompasses self-efficacy, resource facilitating conditions, and technology facilitating conditions [35].	• Perceived behavioral control in TAM • Facilitating conditions in UTAUT2 • Perceived barriers and self-efficacy in HBM • Self-efficacy and perceived cost in PMT
SI[h]	• An individual's perception of the degree to which most people who are important to him or her approve or disapprove of the target behavior [30].	• Subjective norm in TRA[i] • Subjective norm in TPB[j] • Social influence in UTAUT2
HM[k]	• An individual's perception of the fun or pleasure derived from using a technology [35].	• Hedonic motivation in UTAUT2
PV[l]	• An individual's cognitive tradeoff between the perceived benefits of the applications and the monetary cost for using them [39].	• Price value in UTAUT2
HB[m]	• The extent to which an individual tends to perform behaviors automatically because of learning [40]. Habit is a perceptual construct that reflects the results of prior experiences [35].	• Habit in UTAUT2 • Experience in UTAUT2
PHC[n]	• An individual's perception of the risk of acquiring an illness or disease [37] and the seriousness of contracting an illness or disease [36]	• Perceived susceptibility and perceived severity in HBM • Perceived vulnerability and perceived severity in PMT

[a]PU: perceived usefulness.

[b]TAM: technology acceptance model.

[c]UTAUT2: United Theory of Acceptance and Usage of Technology.

[d]HBM: Health Belief Model.

[e]PMT: Protection Motivation Theory.

[f]PEOU: perceived ease of use.

[g]PBC: perceived behavioral control.

[h]SI: social influence.

[i]TRA: theory of reasoned action.

[j]TPB: Theory of Planned Behavior.

[k]HM: hedonic motivation.

[l]PV: price value.

[m]HB: habit and experience.

[n]PHC: perceived health condition.

Methods

Overview

An overview of this study is shown in Figure 1. Study 1 investigated older adults' perception of mHealth devices through questionnaires and interviews based on a literature review. Study 2 observed how older adults initially use mHealth apps to identify the barriers and experiences they have in mHealth adoption.

The research received ethical approval from the Queen Mary University of London (QMERC2016/31). The insights from these 2 studies help generate design suggestions to make mHealth services more acceptable to older adults.

Figure 1. An overview of this research.
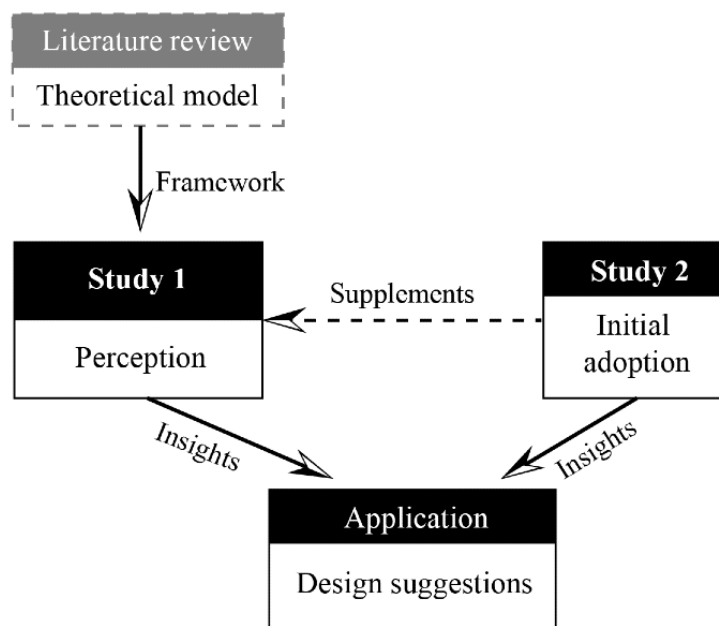
Study 1: Investigation of Perceptions

Study 1 was conducted between January and February 2017 in London. The study comprised a 15-minute questionnaire and a follow-up interview (approximately 30-45 minutes). Conducting face-to-face interviews following questionnaires can not only help to obtain more detailed information from the participants but also help rectify any misunderstanding of the answers. The mHealth service discussed here mainly focused on health-related services that can be accessed by smartphones and tablets, for example, websites and mobile apps.

Existing studies have proved that age plays a moderating role in mHealth adoption [41-43] and factors have different impacts on mHealth adoption intention among different age groups [23]. In Britain, old age can be *any age after 50* years and this definition has been adopted in many human computer interaction studies and initiatives such as age-friendly cities. In this study,

we recruited *well-old users* [27] aged between 50 and 70 years in East London. People with serious disease or impairments and aged ≥70 years were excluded; this was to ensure independent participation in the study (requiring traveling and basic understanding of digital technology).

We targeted 30 samples, as suggested by Corder and Foreman [44]. We included all 32 older adults who contacted us, but 2 of them failed to complete the whole process, so the valid responses were 30. Convenience sampling was used; it is cost-effective and has been widely accepted in information system research [45]. Participants were recruited from the Age UK, Hackney Mobile Centre, and the Queen Mary University of London. The questionnaires and interviews were completed in the classrooms of Age UK East London, Hackney Mobile Centre, or the Senior Common Room of Queen Mary University of London, depending on the time and venue availability. The details of study 1 are shown in Table 2.

Table 2. Details of study 1.

Construct	Content	Research item
Demographic information	• Age, gender, living arrangement, education level, and employment status	• Questions 1-5
PHC[a]	• Perceived health condition	• Question 6
PBC[b]	• Facilitating conditions (access to technology) • Age-related changes in using mobile technology	• Questions 7-8 • Questions 12-17
HE[c]	• Using different devices for health purposes • Using mobile devices for different purposes	• Question 10 • Question 11
PU[d]	• PU of web-based health information • PU of mobile devices on health and well-being • PU of mobile health apps	• Question 9 with interview • Question 18 with interview • Questions 19-31 with interview
PEOU[e]	• Perceived ease of use	• Interview

[a]PHC: perceived health condition.

[b]PBC: perceived behavioral control.

[c]HE: habits and experience.

[d]PU: perceived usefulness.

[e]PEOU: perceived ease of use.

To understand older adults' perceived usefulness of mHealth apps, the participants were asked to rate the usefulness of different features of mHealth apps and to give reasons for low scores. An mHealth app typically offers more than one function; in other words, an mHealth app has multiple features. To understand main features offered by typical mHealth apps, the authors (JP and HD) searched for the term *health* in both the App Store (iOS system) and Google Play Store (Android system) in December 2016, downloaded the top 50 health-related apps in each system, and analyzed the features of each app. For example, Apple Health has features for *fitness and exercises* and *for emergency (providing vital medical information of you in an emergency)*. As a result, 13 features were extracted from the existing health-related apps, and they were evaluated by the older adults participating in study 1.

To understand older adults' *perceived behavioral control* of using mHealth services (eg, mobile apps), the participants were asked to rate how different age-related changes might stop them from using an app, for example, *visual impairment*, *hearing loss*, *decline in memory*, *decline in the ability to understand written and spoken languages*, *decline in the ability to focus attention*, and *decline in movement control* [46]. *Generation*

gap was also added, as we found from our previous pilot study that older adults had difficulties in understanding new terms generated by the younger generation. For example, they were confused by the *menu* or *navigation* of a digital interface.

Study 2: Observation of Initial mHealth Adoption

This study took place as a workshop in March 2017 at the Hackney Mobile Centre in East London, where a Wi-Fi connection was available. mHealth apps were introduced to older adults, and they were helped to start using these apps. At the same time, how they initially used mHealth apps was observed to identify the barriers and experiences that older adults have in mHealth adoption. mHealth apps were selected from the App Store and Google Play Store. After reviewing over 100 mHealth apps, we identified 4 categories beneficial to older adults' health, namely *web-based diagnosis*, *step tracker*, *calories calculator or food diary,* and *health monitor*.

As Google Fit (Android system only) and Apple Health (iOS only) are embedded in most smartphones, they were also included in the trial. An additional 4 pairs of apps, free and available in both Android and iOS systems, were chosen for each category (Table 3).

Table 3. Ten apps introduced in the workshop (in 5 pairs).

Pair 1	Pair 2	Pair 3	Pair 4	Pair 5
Embedded health platforms	Diagnosis on the web	Step tracker	Calories calculator and food diary	Health monitor
Google Fit	Health Tap	Movesum	Lifesum	iCare Health Monitor
Apple Health	Babylon Health	Pacer Health	My Fitness Pal	mySugr Diabetes Diary

Pair 1: Embedded Health Platforms

Google Fit (Android system) and Apple Health (iOS system) apps are often embedded in users' smartphones. They have the basic function of step counting and integrating health information from third-party health apps in the users' phones or wearable devices to track fitness, nutrition, sleep, and weight.

Pair 2: Web-Based Diagnosis

The Health Tap and Babylon Health apps enable users to have online consultations with physicians and health care professionals via SMS text messaging and video messaging. They also help make appointments with general practitioners (GPs) or pharmacies in certain locations. Primary consultancy is free, while more professional and responsive services incur extra costs.

Pair 3: Step Tracker—Movesum and Pacer

The main function is to automatically record the user's steps, distance, active time, and calories burned all day. Movesum motivates people to do exercise by showing what food they have *burned* while Pacer allows people to join different online groups based on common health goals and interests. Both apps use smart notifications to help users reach their daily goals.

Pair 4: Calories Calculator and Food Diary

Unlike the s*tep trackers*, the Lifesum and My Fitness Pal apps import activity information from other apps and focus more on what people eat. Both provide barcode scanners for easy food tracking, recording, and evaluating people's diets. They also give diet or exercise suggestions, but, to obtain personalized suggestions, users need to upgrade to a premium version that requires extra payment.

Pair 5: Health Monitor

The iCare Health Monitor app measures blood pressure, heart rate, vision, hearing, and SpO2breath rate without extra devices. The mySugr Diabetes Diary app includes a blood sugar tracker, carb logger, and a bolus calculator (Europe only). After users put in their meal and medical information, together with activity information from other apps, it will show the estimated glycated hemoglobin level (an objective measure of glycemic control). Users can export their daily, weekly, or monthly medical analysis and report them with a paid version.

The workshop was conducted as an event at the Hackney Mobile Centre. Participants were recruited through the Hackney Mobile Centre's group email contact and poster advertisement. The recruiting criteria were age between 50 and 70 years, using a smartphone, and being interested in mHealth apps. In total, 21 older adults contacted us for participation; however, considering the size of the venue and the number of researchers, we recruited only 57% (12/21). Older adults who took part in study 1 were prioritized; 8 older adults from study 1 participated in the

workshop, and 4 more participants were selected according to the order in which they contacted us. All participants were asked to bring their own smartphones. The workshop lasted 2 hours. All the 10 free mHealth apps were introduced to all participants. They were then invited to decide on which app to be downloaded to their own phones based on their interests.

The first author (JP) organized and conducted the workshop with the assistance of 5 research students. The research students were recruited as volunteers through the university's group email contact with the following criteria: (1) have experience in communicating with older adults, (2) native English speakers, (3) interested in mHealth apps, and (4) have a smartphone that can install at least five of the selected apps. The research students were asked to download and try each selected app the day before the workshop. They were trained by JP 1 hour before the start of the workshop, and all followed the same procedure: each was equipped with a record sheet template to tick the apps tried and to record demographic information, negative and positive perception, reasons for giving up, and willingness to use the app in the next 3 months. Each of the research students and JP took care of 2 older participants, sitting in between them, helping download apps, taking notes, and making audio recordings. After the workshop, JP collected all the notes and audio recordings and discussed with each research student about their observation of the workshop. JP transcribed the notes immediately after the workshop and checked the accuracy of the notes with each research student through email communication.

Descriptive statistics were used to summarize the participants' characteristics and outline the general situation of mHealth adoption among older adults in London. Qualitative data from interviews and workshops were analyzed using the thematic analysis method. The 6-step thematic analysis approach by Braun and Clarke [47] was adopted. A hybrid process of inductive and deductive coding [48] was applied to continually reflect on and refine the themes. Quotes from participants were referenced to support the research statements.

Results

This section reports the outcomes from study 1 and study 2.

Outcomes of Study 1

The 30 participants completed both the questionnaire and the follow-up interview. The sample characteristics of study 1 are shown in Table 4. The participants were asked to rate their own perceived health condition from 1 to 5 points (1 for *poor* and 5 for *excellent*). The average score of all the participants was 3.7 points (SD 1.15 points; minimum=1 point, maximum=5 points); 66% (20/30) of them had a positive perception (scores 4-5) of their own health.

Table 4. The sample characteristics of study 1.

Characteristics	Values, n (%)[a]
Age (years)	
50-54	12 (40)
55-59	6 (20)
60-64	5 (17)
65-70	7 (23)
Gender	
Male	17 (57)
Female	13 (43)
Living arrangement	
Alone	10 (33)
With partner only	6 (20)
With child only	3 (10)
With partner and child	7 (23)
With other relative	1 (3)
Other	3 (10)
Education level	
Postgraduate or higher degree	11 (37)
First Degree	4 (13)
HND[b], HNC[c], or teaching	2 (7)
BTEC[d] or college diploma	7 (23)
Associate level	3 (10)
Lower degree	3 (10)
Employment status	
Retired	7 (23)
Employed part-time	5 (17)
Employed full-time	9 (30)
Unemployed	9 (30)

[a]There were a total of 30 valid samples.

[b]HND: Higher National Diploma.

[c]HNC: Higher National Certificate.

[d]BTEC: Business and Technology Education Council.

Access to Technology

Among all the participants, all (30/30, 100%) had access to the internet, 80% (24/30) had a PC, 47% (14/30) had a cell phone (simple mobile phones), 80% (24/30) had a smartphone, 67% (20/30) had a personal tablet, and 7% (2/30) had smart wristbands. In total, 80% (24/30) of participants had a smart mobile device capable of searching on the web and installing apps.

Using Different Devices for Health Purposes

In total, 13% (4/30) of the participants used an app related to health. The apps used were Fitbit, GoogleFit, Runkeeper, and Apple Health. Their adoption of mHealth apps was rather passive, as they stated:

> I use it because it [is] just there, the information turns out automatically, so I can see it.

> My daughter bought the wristband for me, so I wear it. But rarely check the data on the phone.

We also investigated how frequently the participants used the internet and different devices for health purposes. The results are shown in Figure 2.

Figure 2. Frequency of using the internet and different devices for health purposes by older adults.
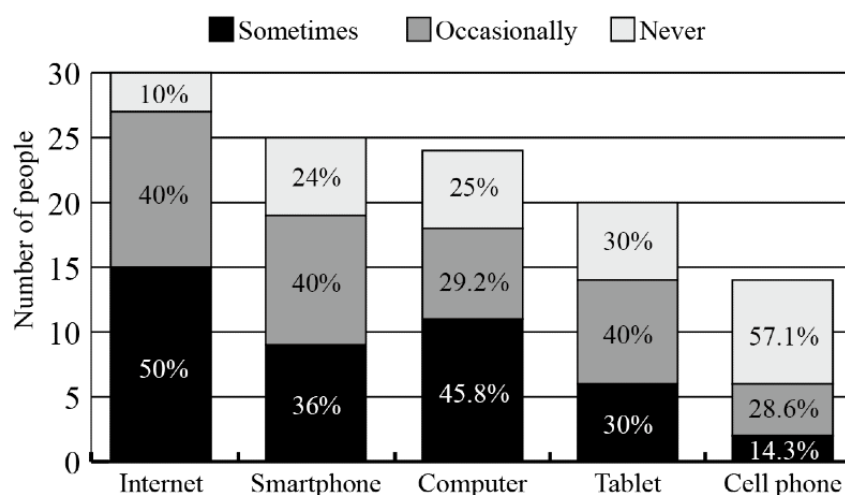
All participants had access to the internet, and 90% (27/30) of them had experience in using the internet for health purposes. Not many people use mHealth apps; smartphones seem to be the first choice for older adults to obtain health information or services on the web. In total, 76% (18/24) of the participants had smartphones and accessed health information or services by their smartphones.

Using Mobile Devices for Different Purposes

Mobile devices are required to adopt mHealth services. Therefore, we investigated how older adults use mobile devices. The results are summarized in Table 5 (excluding people who only have a simple cell phone as their devices may have limited their choices).

Table 5. Frequency of using mobile devices for different purposes.[a]

Purpose of use	Frequency of use[b]		
	Values, Minimum	Values, Maximum	Values, mean (SD)
Creation (eg, taking a photo, filming a video, or editing a file)	2	5	3.5 (0.9)
Traffic and transportation (eg, Google Maps and Citymapper)	1	5	3.3 (1.3)
Social engagement (eg, Facebook or Twitter)	1	5	2.8 (1.6)
Entertainment (eg, playing games, listening to music, and watching videos)	1	5	2.7 (1.5)
Health and fitness (eg, searching information, sport tracking, and health management)	1	4	1.9 (1.1)
Web-based transaction (eg, web-based shopping, banking, and paying bills)	1	4	1.8 (1.2)

[a]The valid sample size is 24.

[b]1=never; 2=less than once a month; 3=every month; 4=every week; 5=every day.

Perceived Usefulness of mHealth Services

As few participants had experience using mHealth apps or wearable health devices, we asked how older adults perceived the usefulness of mobile devices for their health and well-being. The main health-related benefits are seeking information on health issues (70%), making appointments, and maintaining contact with physicians (67%). However, 75% (22/30) of the participants did not think that mobile devices were beneficial to their health or had doubts. As participants said:

> I don't know who put the health information online, maybe someone is just pretending to be a specialist.

> Same symptoms on different people can be result from different reasons and same recipe may have different effect on different people, even physicians cannot give me suggestions before seeing me face to face.

If they had to search for health information on the web, most of the older adults would choose the website of the National Health Service, and some also said that they would search for academic articles to obtain more reliable information.

To understand older adults' perceived usefulness of mHealth services, the participants were asked to evaluate 13 different functions using a scale from 0 to 4 (0 means *this function is not useful at all* and 4 means *this function is very useful*). The most highly valued function was *for emergency* (mean 2.83, SD 1.40) followed by *making an appointment with physicians or hospitals or GPs* (mean 2.79, SD 1.50) and *knowledge about health and health preservation* (mean 2.54, SD 1.39). Some respondents also mentioned that they would try to *communicate with a physician on the web* only if they were unable to go outside. Most of them thought that the mHealth service was not bad but not essential. As one participant noted:

It is a good service, but not necessary to me. I'm satisfied with life without it.

The main reasons for the lower scores (negative perceptions) are summarized in Table 6.

Four main factors that decrease the perceived usefulness of mHealth services were identified:

1. No obvious advantage: compared with older adults' own way of taking care of themselves, the mHealth service did not seem to show sufficient advantages for them.
2. Low reliability: the information or result provided by the mHealth service did not have or show high reliability.
3. Scary information: health information can be difficult to understand or scary to know to some people.
4. Risk of privacy leakage: the concern about privacy has hindered older adults from putting their personal information on their mobile phones or on the internet.

Table 6. Negative perception of mobile health services.

Function	Reasons for giving a low score
Knowledge about health and health preservation information	• "I don't trust it."
Self-assessment or self-diagnosis (eg, check health statues with apps or websites by yourself)	• "I'm not a health professional, I prefer to see a physician." • "Pharmacy is just around the corner, why should I do it myself?" • "I rarely do self-diagnose or assessment, the thinking if there's something wrong with me will make people really sick."
Health measurement (eg, body temperature, blood pressure, blood glucose, and heartbeat)	• "I'm afraid that I can't use it in a right way and that will make the measurement not accurate." • "I don't want to buy all the devices for measurement."
Access to health record or history	• "I don't really understand all the terms, there's no need for me to see it." • "Looking into the bad record makes me feel even worse."
Making an appointment with physicians or hospitals or GPs[a]	• "Calling the GP is easy, using an app for it may make it more complicated."
Helping with healthy diet (eg, healthy recipes, calories calculator, or food diary)	• "It's hard to calculate the calories or sugar in an accurate way." • "I don't think I can keep on with the diary." • "I'm already eating in a quite healthy way."
Information of medicine	• "I can check it on the package."
Fitness and exercises (step counter and exercise guide)	• "I don't need it." • "I'm not an exercise person." • "The number is not accurate."
Communicating with a physician on the web	• "I like seeing people's eyes." • "I feel more comfortable to talk with a physician face to face." • "Physicians cannot see and feel how I am web-based." • "Although you have communication with a physician web-based, he or she will always suggest you to come to the GP." • "You will still have to go to the GP or hospital for some tests."
Communicating with people who have the same health issue	• "I don't want to talk about my disease with strangers." • "Same symptoms on different people can be result from different reasons and same prescription may have different effect on different people. They are not specialist, there's no meaning to discuss with other patients."
Long-term situation management	• "I don't have serious long-term situation." • "My diabetes is under control and I don't think I need an app to deal with it." • "I think going to see the physicians regularly is the best way to control my long-term situation."
Reminder for taking medicine or meeting a physician	• "I don't take medicine." • "My GP will send me a message to remind me of the appointment."
For emergency (eg, calling for help automatically or providing vital medical information of you in an emergency, such as allergies and medical conditions)	• "I don't want my information to be seen by others, what if I lost my phone?"

[a]GP: general practitioner.

Perceived Ease of Use of mHealth Apps

To understand what really affects older adults' perceived ease of use of apps, the participants were asked the following questions:

> *What is "ease of use" of an app to you?*
>
> *Which of these two apps you use is "easier to use" and why?*

The factors identified were *clarity of the language*, *text size*, *knowing where (which icon or button) to press*, *knowing what the icon or button means*, *finding what I need easily*, *knowing how to use without learning*, and *having no problem to do what I want.*

Perceived Behavioral Control of Using a Mobile App

In the questionnaire, participants ranked how aging factors might stop using an app. The higher the score, the greater the influence. The results are presented in Table 7.

Table 7. How aging factors influence older adults' adoption of mobile apps.[a]

Aging factors	Influence[b]		
	Values, Minimum	Values, Maximum	Values, mean (SD)
Generation gap (having difficulty to understand the new terms generated by the younger generation)	0	4	1.7 (1.3)
Visual impairment	0	4	1.5 (1.4)
Decline in memory	0	4	1.5 (1.3)
Decline in the ability to understand written and spoken languages	0	4	1.2 (1.5)
Decline in the ability to focus attention	0	4	1.1 (1.3)
Hearing loss	0	4	0.9 (1.0)
Decline in movement control (eg, typing or clicking)	0	4	0.9 (1.1)

[a]The valid sample size is 30.

[b]0=no influence; 1=small influence; 2=some influence; 3=big influence; 4=great influence.

Generation gap has the most influence on older adults' adoption of mobile apps. Visual impairments have the second biggest influence, followed by Decline in memory.

Outcomes of Study 2

The workshop (study 2) was conducted in March 2017, a month after the completion of study 1. In total, 12 participants (5/12, 42% males and 7/12, 58% females), aged between 50 and 70 years (minimum 52, maximum 66; mean 56.8, SD 4.5) participated in the workshop. Table 8 shows the sample characteristics of study 2.

Table 8. The sample characteristics of study 2.[a]

Characteristics	Values, n (%)
Age (years)	
50-54	2 (16)
55-59	5 (42)
60-64	4 (33)
65-70	1 (8)
Gender	
Male	5 (42)
Female	7 (58)
Living arrangement	
Alone	2 (16)
With partner only	6 (50)
With child only	3 (25)
With partner and child	1 (8)
With other relative	0 (0)
Other	0 (0)
Education level	
Postgraduate or higher degree	0 (0)
First degree	1 (8)
HND[b], HNC[c], or teaching	2 (16)
BTEC[d] or college diploma	5 (42)
A-level	4 (33)
Lower degree	0 (0)
Employment status	
Retired	7 (58)
Employed part-time	3 (25)
Employed full-time	0 (0)
Unemployed	2 (16)

[a]The valid sample size is 12.

[b]HND: Higher National Diploma.

[c]HNC: Higher National Certificate.

[d]BTEC: Business and Technology Education Council.

Barriers to the Initial Adoption of mHealth Apps

Embedded health platforms proved the easiest for participants to try because of the lack of need for downloading; 1 participant abandoned the tests when downloading a new app; there was not enough storage space in her phone. She said:

> It says there's not enough space. I have to delete old apps to install new apps. But I am not sure if I really want this one [the app introduced in the workshop]

In total, 2 participants withdrew from the tests during installation. When the app asked for access to their location or photos, they gave up, worrying about the security of their personal data:

> Why they want to access my camera? I don't want to share my location. It's unsafe. I'd rather not use it.

A total of 2 participants decided to quit the tests during the registration process. Almost all health-related apps require registration, which often requires personal information such as age, gender, and weight. Participants felt that their privacy was invaded, especially when they had no idea what these apps could do for them. One participant complained:

> It asked for too much. You need to be cautious when putting personal information online. . .never know who is on the other side of the app. Of course, if it can really benefit my health, I'll take that. But for

now, I just want to have a try, I don't know if it is what I want.

The physical barriers to mHealth adoption are illustrated in Figure 3 based on these observations. First, older adults must have access to a mobile device with adequate space for app installation. Second, the internet must be available (meaning that people are willing to pay for using mHealth apps and are comfortable with connecting their devices to the internet). Third, people will choose an mHealth app to download and then install the app. Registrations are often required after the installation of an mHealth app.

Figure 3. Barriers to adopting mobile health apps.
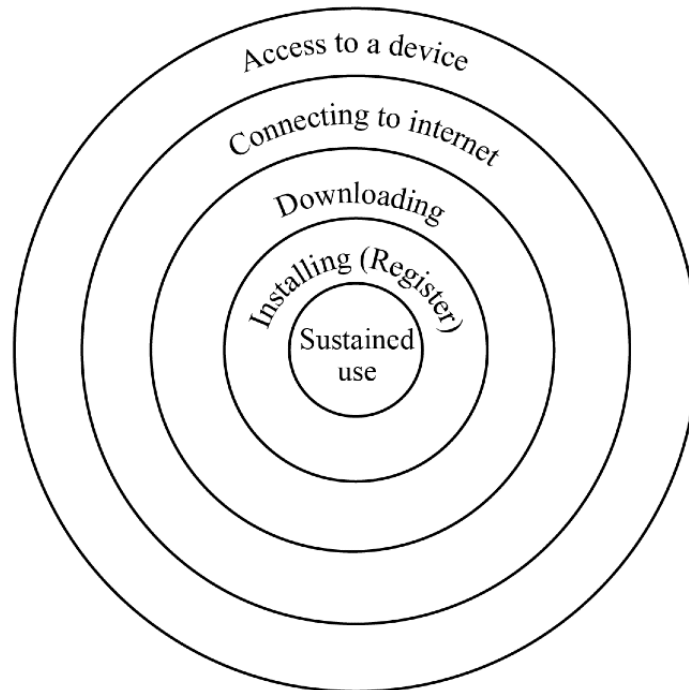
Feedback From Initial Experience

In total, 58% (7/12) of participants installed one or more mHealth apps in the workshop. The feedback on their initial experience is summarized in Table 9.

From the participants' feedback, factors influencing older adults' initial experience of using mHealth apps were identified as follows.

Table 9. Participants' feedback regarding their initial experience of mobile health apps.[a]

App categories	People who tried, n (%)	Feedback
Embedded health platform	9 (75)	• "I'm not really using it, I just notice my steps when the notification from the app shows up."
Diagnose on the web	4 (33)	• "It keeps asking me to put in personal information before I can find out if I really want this." • "If I… will it cost my money?" • "It's useless; it still asked me to see a physician." • "There's no response." • "It requires very good internet connection". • "I won't do a face chat without Wi-Fi."
Step tracker	3 (25)	• "It (Pacer) doesn't have much difference with Google fit" • "I'm not eating junk food, showing me how much junk food I have burnt is useless."
Calories calculator and food diary	6 (50)	• "It keeps asking me to put in personal information before I can find out if I really want this." • "I don't have patience to calculate my calories every day." "Scanning bar codes for recording calories is cool, but many self-made food still need to be calculated by myself." • "If the calculation is not accurate, it isn't helpful to me."
Health monitor	7 (58)	• "The way to use it is amazing!" • "I don't want to buy any extra device unless it's really accurate and not very expensive."

[a]The valid sample size is 12.

Access to Technology

Access to technology can not only stop people from adopting an mHealth app, but also affect their experience in using it. For example, when web-based consultancy was introduced, 1 participant mentioned the following:

> I don't have Wi-Fi connection at home, and I won't do a face chat without Wi-Fi. Otherwise, I'll pay very expensive Internet fees. So actually, this function is not useful to me.

Some participants had an unnerving experience in the self-diagnosis process. Long waiting for system responses often frustrates people when the responses come slowly owing to the unstable connection of the internet or low speed:

> It doesn't respond.
>
> My phone is stuck. What's wrong with it?
>
> What should I do now?...Should I keep waiting?

The Way of Interaction

A one-way interaction may fail to attract older adults' attention and thus has little impact on their health. This was observed most obviously in the *embedded health platform* and *Step Tracker*. Before this workshop, the participants who used the platforms were unaware that they were using an mHealth app. As one participant noted:

> I'm not really using it. I just notice my steps when the notification from the app shows up

Without connection with other health-related apps, the platforms mostly work as a *Step Tracker*. People who tried this type of app in the workshop did not show much enthusiasm. One participant said:

> I can find that I walk more or less steps than yesterday by using this app. I see it [the numbers], but I do care about it.

iCare Health Monitor, an app used to measure blood pressure, heart rate, vision, hearing, SpO2, and breathing rate was the most welcomed app in the workshop; 7 (58%) participants tried this app and were surprised to be able to measure their blood pressure using a phone camera. Although they were told that the measurements might not be very accurate, all of them intended to use this app in the next 3 months.

Risk of Money Loss

The participants were not ready to pay for a mobile health service that they did not understand. Many participants kept asking questions such as:

> Is it free?
>
> If I...will it cost my money?

This was observed in *web-based diagnosis* apps. With these apps, users can perform a self-diagnosis step-by-step or consult a physician or therapist and receive medical advice quickly; 33% (4/12) of participants tried an app in this category. Although they had been told that *Talking to a qualified physician on demand via a video consultation or phone call* will cost money while *Texting your medical questions to a physician to receive a quick, personal response* is free, they were reluctant

to use this free function, worrying about wasting money by misuse.

Heavy Workload

Excessive workload prevents older adults from using mHealth services. This was the case for the *calories calculator and food diary*. These apps require users to enter a large amount of information every day to obtain accurate results. One participant noted:

> This will work only if I put accurate data into it. It's difficult to count calories of what I eat. It's impossible for me to do that every meal.

Similar feelings were experienced when the participant tried mySugr Diabetes Diary.

Different Lifestyle

Different lifestyles lead to different needs. As many older adults eat relatively healthy food, showing *how much junk food have been burnt* (Movesum) was not appealing for them.

While online communities were becoming popular among older adults, joining an online group (Pacer) was not very attractive when they had no idea of using the same app. Few participants checked this function.

The barcode scanner in the *calories calculator and food diary* is designed to reduce the user's workload of inputting information. However, it can only recognize information on limited packages such as fast food. This design is not in accordance with the lifestyles of older adults who often cook by themselves. One participant said:

> I seldom eat fast food. I always cook at home. To get an accurate number of calories, I need to weigh how much the raw material I used in the meal by myself. The scanner won't help much.

Discussion

Principal Findings

This paper has uncovered older adults' perceptions and initial adoption of mHealth services using qualitative data collected from questionnaires, interviews, and workshops in East London.

Study 1 found that the lack of obvious advantage, low reliability, scary information, and risk of privacy leakage will decrease the *perceived usefulness* of mHealth services; the design of app interface will directly affect the *perceived ease of use*; aging factors, especially the *generation gap*, will make mHealth difficult for older adults to use.

Study 2 identified the barriers that older adults face during their initial adoption of mHealth apps (Figure 3). Access to technology, the way of interaction, the risk of money loss, heavy workload to use an mHealth app, and the different lifestyles of older adults have a great influence on older adults' adoption of mHealth services.

On the basis of the results of the 2 studies, the implications for the design are summarized in Textbox 1. These suggestions can help design practitioners develop more acceptable mHealth services for a wider population.

Textbox 1. Implications for designing mobile health apps.

Technical improvement

- Reducing the size of the app

- Improving data security

- Improving the accuracy of information

- Providing quick and easy ways of inputting data, especially when similar data are required frequently

Free trial

- Providing a free and quick trial of the main service instead of asking for personal information before people know the function of the app

Information clarification

- Clarifying what is free and what is paid service

- Making security visible. For example, showing who have access to the data, and explaining why the app needs access to users' photos or locations

- Providing instruction of the next step, especially when processing takes long

- Avoiding information that scares people

Participatory design

- Involving older people in the design process when designing apps that are expected to be adopted by them. Treating them as active consumers of technology [11,49]

- Involving health care professionals in the health information design. The information should be easy for older people to understand

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Implications for Design

The implications fall into 4 categories, that is, technical improvement, free trial, information clarification, and participatory design. The specific suggestions are presented in Textbox 1.

Taking traditional or other existing health care services into consideration and offering (added) advantages.

Research Contributions

Compared with prior studies, the value of this study lies in its 3 contributions. As for *theoretical contribution*, this study systematically analyzed several main determinants from theoretical models, such as the theory of reasoned action, technology acceptance model, Theory of Planned Behavior, UTAUT2, Health Belief Model, and Protection Motivation Theory, and investigates them through primary research. Some factors were redefined or decomposed according to our results.

Perceived usefulness has been used to predict mHealth adoption [16-18,20]. In this paper, *perceived relative advantage* is found to be a better substitute for explaining older adults' initial adoption of mHealth services. This is in line with the *related advantage* in the diffusion of innovation theory [50]. mHealth services should not only be good but also have more *relative advantage* than traditional health care services. Older adults' *perceived usefulness* of mHealth services is associated with lifestyle compatibility and information quality. An mHealth service is perceived to be *useful* only when it is compatible with the lifestyle of older adults. This is in accordance with the *compatibility* factor in the diffusion of innovation theory, which indicates how consistent the innovation is with the values, experiences, and needs of potential adopters [50]. Information

should not only be *easy to understand* but should also avoid frightening older people.

Perceived behavioral control in this paper is investigated through the access to technology and age-related ability decline. *Access to technology* affects older adults' initial adoption of mHealth apps. Many older adults do not often upgrade their mobile devices or internet services, and their *out-of-date* facilities constrain them from downloading new apps (Figure 3). Age-related ability decline influences older people's adoption of mobile apps. This is consistent with the findings from previous studies [42,43]. Our study also suggests that *generation gap* creates understanding barriers (Table 8), which has not been addressed by published studies.

Ease of use is thought to be perceived firstly from the interface of an App, such as the text and icons (study 1). However, heavy workloads for registration and inputting information often put older people off before they start (study 2).

Perceived reliability is positively correlated with the intention to use mHealth services [19]. However, it seems that *the accuracy of the information* is less important in the workshop than what people said in the questionnaire and interview sessions. A novel and easy interaction (eg, using a phone camera to measure blood pressure) can motivate people to start.

mHealth apps generate new security and privacy concerns [51]. Evidence has shown that *perceived risk*, including performance risk, legal concern, and privacy risk, may significantly decrease older people's intention to use mHealth apps [52]. In our study, the risk of using mHealth apps perceived by the participants was mostly due to privacy leakage (study 1) and unexpected money loss (study 2).

In the *methodological contribution,* the hands-on trial (study 2) illustrates concerns and frustrations when older people *bodily experienced* mHealth apps and provides deeper insights into key issues of initial adoption. The entire study is digitized (access to internet, smartphones, tablets, downloading apps, and initial trial), and goes beyond common technology use among older adults in general.

In the *practical contribution*, we not only investigated perceptions and barriers but also proposed suggestions to design potential barriers. The design implications and specific suggestions are based on the findings of our studies (shown in Textbox 1) to support the better design of mHealth services. Our suggestions share some commonality with [53] which proposed to face cultural resistance and concerns, improve engagement of users in design (see the *participatory design* suggestion in Textbox 1), and build or increase users' trust (see *free trial* and *information clarification* in Textbox 1). Our more detailed suggestions will help designers tackle these barriers more effectively.

Limitations and Future Work

This study has several limitations. This research was conducted in East London, and the sampling was not representative of the United Kingdom older population or older adults in general. Participants from different countries and regions could have various perceptions and face different barriers to mHealth services. Gender balance could also have an impact on the results. We tried to balance the participants' gender, but in reality, study 1 had more male participants (17/30, 57%) and study 2 had more female participants (7/12, 58%). Our participants were relatively well educated, and around 60% were younger *well-old users* (aged 50-60 years). This is because of our recruitment methods and criteria. However, they may be *early adopters* of mHealth services in the future. The workshop participants had limited experience of using mHealth services, which is common among older populations (and given the sampling, the situation of a general older population may be worse). We focused on the initial adoption of mHealth, regardless of the users' prior experience. It is useful to observe 5 users' withdrawing from the trial because of the various barriers encountered during the process. Seven users still provide good insights into major usability problems [54,55], and we have been able to learn from both successful and *failed* user-testing.

In our study, eHealth literacy, hedonic motivation, price value, and social influence have not been fully investigated. Future research should address these issues in detail. For future work, more participants with experience using mHealth apps will be recruited to find the motivations in addition to the barriers. Our research was conducted before the COVID-19 pandemic, and health service systems have been largely challenged by the pandemic; significantly more people have experienced remote or web-based health consultation since 2020, which might motivate older adults to accept mHealth if barriers are addressed and trustworthiness is ensured.

Conflicts of Interest

None declared.

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Abbreviations

GP: general practitioner
HBM: Health Belief Model
HM: hedonic motivation
ICT: information and communication technology
PBC: perceived behavioral control

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PEOU: perceived ease of use
PHC: perceived healthy condition
PMT: Protection Motivation Theory
PU: perceived usefulness
PV: price value
SI: social influence
TAM: technology acceptance model
TPB: Theory of Planned Behavior
TRA: theory of reasoned action
UTAUT: United Theory of Acceptance and Usage of Technology

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Original Paper

Evaluation of Family Caregivers' Use of Their Adult Care Recipient's Patient Portal From the 2019 Health Information National Trends Survey: Secondary Analysis

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Abstract

Background: Patient engagement is critical for realizing the value of telehealth modalities such as the patient portal. Family caregiver engagement may also be critical for facilitating the use of the patient portal among adult patients, including older adults.

Objective: This study aims to analyze the 2019 Health Information National Trends Survey to characterize family caregivers' use of their care recipient's patient portal in terms of sociodemographic, health, and caregiving characteristics and caregivers' use of their own portal.

Methods: We conducted a secondary analysis of cross-sectional data from the National Cancer Institute's Health Information National Trends Survey 5 Cycle 3. This survey was administered to 5438 US adults between January and May 2019. We analyzed data from 320 respondents who were identified as family caregivers. We created measures to reflect family caregivers' use of their care recipient's and their own portal, caregiver demographic and caregiving characteristics, and care recipient health characteristics.

Results: Over half of the caregivers (179/320, 55.9%) reported using their own portal at least once, whereas only one-third (105/320, 32.8%) reported using their care recipient's record in the previous 12 months. Caregivers using their own portal were significantly more likely to use their care recipient's portal (odds ratio 11.18; $P<.001$).

Conclusions: Policies should enable patients to designate family caregivers who can access their patient portal. Providers could screen caregivers for challenges in their caregiving responsibilities that may be addressed through the portal so they can better support their adult relatives. Interventions to support family caregivers, especially older caregivers, in using their own portal may facilitate their use of their care recipient's portal.

Introduction

Background

Telehealth (ie, synchronous or asynchronous distribution of health services and information via electronic information or telecommunication) can fill gaps in health care delivery, including increasing access to services, reducing patient and family burdens (eg, transportation), and alleviating the impacts of provider shortages [1]. This is particularly the case among older adults who may experience greater barriers to access because of transportation and mobility challenges, with

implications for continuity of care and ability to age in place [2]. However, there is a need to build evidence of patient engagement with telehealth modalities, such as the patient portal, to contribute to its value in care delivery for patients and their family caregivers [1].

Family caregivers are increasingly involved in health care and medical responsibilities, including communicating with clinicians, supporting medical decision-making, and assisting adult care recipients with following clinician recommendations [3,4]. Despite being responsible for communicating with their care recipient's health care providers, few family caregivers use their care recipient's patient portal [5]. Studies report that about 40% to 50% of patients use their patient portal [6,7] and that only 25% to 35% of caregivers, including family members and nonrelatives, use the portal for their caregiving responsibilities [5,8]. Two of the major challenges caregivers report include unmet information needs regarding their care recipient's health conditions and difficulties in communicating with their care recipient's provider; these challenges can have implications for caregiver distress and burden [9]. Providing caregivers with access to their care recipient's patient portal can support caregivers in their responsibilities of communicating with their care recipient's clinicians and retrieving important information about their care recipient's health care needs, with the potential for enabling effective patient care [9,10]. In particular, for those supporting adults, family caregivers' inclusion in the patient portal can support aging in place or their relative's ability to live in their own home or community independently by facilitating remote communication and ensuring provision of clinical advice, medication refills, and viewing of laboratory results and referrals without making the care recipient susceptible to potential barriers such as transportation or mobility [11,12].

Previous studies characterizing the use of the patient portal suggest that low engagement with the patient portal for certain populations, such as older adults, could be attributed to technology barriers or to the possibility that family caregivers are using the patient portal on their behalf [6,7]. Although some caregivers have formal proxy access to their care recipient's portal (with estimates at less than 5%), some literature suggests that 25% to 50% of proxies informally use their care recipient's portal [13-15]. By offering caregivers log-in credentials for informal proxy access, patients may share more health information than intended or desired [16]. Furthermore, only two-thirds of surveyed American hospitals were found to provide the option of granting proxy access, and the process of doing so was often time consuming and challenging [17]. In addition, proxy access tools may not provide patients with the flexibility to choose which information should be shared with caregivers [15,18]. In general, studies suggest low use of the patient portal among family caregivers despite the potential benefits for adult care recipients, including aging in place, early detection of health needs, and continuity of care [2,5,16,19,20]. Prior work has demonstrated opportunities for patient portal use to aid family caregivers, including formally designating caregivers on patients' medical records, supporting caregivers in their caregiving roles via training and access to behavioral health services, supporting caregivers in health care tasks, and

expanding portal functionality to address caregivers' unique needs [21]. Further, little research has examined how caregivers' use of their own patient portal is related to their use of their care recipient's patient portal [22]. Family caregivers who use their own patient portal may be more likely to use their care recipient's patient portal, whereas those who do not use their own patient portal may have concerns about using the technology or may have concerns about using their own patient portal that translates to similar concerns about using their care recipient's portal. Caregivers might also be more likely to access their care recipient's patient portal if they anticipate a specific need, for instance, to obtain important laboratory test results or communicate with a provider about an upcoming surgery [14].

Objectives

Unless family caregivers are effectively integrated into telehealth modalities such as the patient portal, there is potential to exacerbate disparities in access to telehealth and subsequent impacts on health, for example, among older adults, adults with limited computer or internet access, and racial and ethnic minority adults who may face sociocultural barriers to effective care independently via telehealth [23]. Family caregivers may be critical for ensuring effective and equitable health care delivery via telehealth modalities, including the patient portal. The purpose of this study is to characterize family caregivers' use of their care recipient's patient portal in terms of caregivers' use of their own patient portal, to better inform the development of policies and design technologies that support family caregivers in managing their own health and the health and health care of their care recipient.

Methods

Data Source

We used data from the National Cancer Institute's publicly available Health Information National Trends Survey (HINTS). The nationally representative survey routinely collects information about the American public's use of cancer-related information and seeks to understand how adults aged ≥18 years use different types of health communication to obtain health information for themselves and for their relatives. We performed a secondary analysis of data from the HINTS 5 Cycle 3, administered to 5438 US adults between January and May 2019 [24].

Study Sample

We restricted our sample to respondents who were family caregivers. First, we excluded observations (n=197) with missing responses to the question: Are you currently caring for or making health care decisions for someone with a medical, behavioral, disability, or other condition? We excluded noncaregivers (n=4413); respondents who provided professional support or had missing information about whether they provided professional caregiving support (n=122); caregivers of multiple adult care recipients and sandwich generation caregivers (ie, supporting both a child or children and at least one adult care recipient; n=10); and caregivers of friends or nonrelatives (n=18) to focus on family members specifically. We also excluded caregivers of children (n=221) as the policy landscape for

caregivers of children (often parents or guardians) is different from the policies governing caregiver access to the medical records of adult relatives. Finally, we excluded observations with missing data in any of our measures of interest described below (n=137), resulting in our final analytic sample of (N=320) family caregivers.

Measures

Our outcome of interest was caregiver use of their care recipient's medical record, based on the question: How many times did you access your care recipient's web-based medical record in the last 12 months? Respondents indicated the number of times they accessed the record from options: none, 1-2 times, 3-5 times, 6-9 times, and 10 or more times. From this, we created an indicator variable reflecting "No use (0)" or "Use (1)."

We assessed caregiver use of their own patient portal based on the question: How many times did you access your web-based medical record in the last 12 months? Possible responses included: 0, 1-2 times, 3-5 times, 6-9 times, and 10 or more times. From this, we created an indicator variable reflecting "No use (0)" or "Use (1)," which reflected using the portal more than once. Other covariates included caregiver demographic characteristics (age in years, self-reported sex [male or female], race and ethnicity [White, non-Hispanic; Black, non-Hispanic; Hispanic; and other, non-Hispanic], education [high school or less, some college, and college graduate], and United States Department of Agriculture metropolitan indicator [nonmetro vs metro]), caregiver physical health conditions (diagnoses of cancer, diabetes, heart condition, lung disease, or multiple conditions), caregiver mental health condition (diagnosis of depression), caregiving experiences (relationship to care recipient [spouse or partner, adult child, and other relative]), hours spent caregiving per week (less than 20 and 20 or more), and care recipient's health conditions (physical, cognitive, or both).

To better understand the variation in caregivers' use of their own medical record, which may give us insight into caregivers' familiarity with different uses of the portal and their subsequent engagement with their care recipient's portal, we evaluated caregivers' reported uses of their patient portals and reasons for not using their records. Measures indicating reasons for using

the record included medication refills, correcting inaccurate information in the record, securely messaging health care providers or staff, adding health information such as side effects to share with provider, downloading health information to a personal device such as a phone, and using information to make a decision about treatment. Measures indicating reasons for not using the record included preference to speak with the provider directly, not having a way to access the website, concerns about the privacy or security of the website, difficulties logging in, discomfort or insufficient experience with computers, having multiple portals, and not having a need to use the patient portal.

Statistical Analysis

We summarized descriptive statistics to characterize the sample and then conducted a multivariable logistic regression to estimate the relationship between our outcome of interest (caregiver use [any vs none] of the care recipient's patient portal) and covariates (caregiver use of own patient portal, demographic, health, and caregiving characteristics). Finally, we summarized the uses of the portal among caregivers who reported accessing their portal and reasons for not using the portal, among those who reported not accessing their patient portal.

Results

Overview

The final sample included 320 family caregivers. The average age of respondents was 57.8 years (SD 13.6), with nearly half of the respondents aged ≥60 years (Table 1). Our sample was predominantly female (190/320, 59.4%) and White, non-Hispanic (206/320, 64.4%). Nearly half of our sample reported having high blood pressure or hypertension (142/320, 44.4%), and over one-quarter (83/320, 25.9%) reported having depression. Over half of our sample (165/320, 51.6%) provided care to a parent, and almost one-third (97/320, 30.3%) support a spouse or partner. All respondents supported their care recipient with a physical condition (eg, diabetes, cancer, and aging-related conditions) and 57.5% (184/320) supported their care recipient with a cognitive condition (eg, dementia) with over one-third (112/320, 35%) of the respondents reporting spending 20 or more hours per week toward caregiving.

Table 1. Family caregiver demographic and health characteristics and caregiving experiences (N=320).

Demographic characteristics	Values
Age (years)	
Value, mean (SD)	57.8 (13.6)
Age group, n (%)	
18-59	164 (51.3)
≥60	156 (48.8)
Sex, n (%)	
Male	130 (40.6)
Female	190 (59.4)
Race and ethnicity, n (%)	
White, not Hispanic	206 (64.4)
Black, not Hispanic	37 (11.6)
Hispanic	46 (14.4)
Other, not Hispanic	31 (9.7)
Education, n (%)	
High school or less	48 (15)
Some college	86 (26.9)
College graduate	186 (58.1)
USDA[a] rural-urban classification, n (%)	
Nonmetro	29 (9.1)
Metro	291 (90.9)
Income, n (%; US $)	
Below 50,000	102 (31.9)
50,000-99,000	108 (33.8)
100,000 or higher	110 (34.4)
Health conditions, n (%)	
Cancer diagnosis	50 (15.6)
Depression diagnosis	83 (25.9)
Diabetes diagnosis	63 (19.7)
Heart condition diagnosis	27 (8.4)
High blood pressure or hypertension diagnosis	142 (44.4)
Lung disease diagnosis	39 (12.2)
Caregiving experiences, n (%)	
Relationship with the care recipient	
Spouse or partner	97 (30.3)
Adult child	165 (51.6)
Other relative	58 (18.1)
Hours per week spent caregiving	
<20 hours	208 (65)
≥20 hours	112 (35)
Care recipient's conditions	
Physical[b]	320 (100)

Demographic characteristics	Values
Cognitive	184 (57.5)
Use of own patient portal, n (%)	179 (55.9)
Use of care recipient's patient portal, n (%)	105 (32.8)

[a]USDA: United States Department of Agriculture.

[b]Physical condition may include having any of the following conditions: cancer, orthopedic, musculoskeletal, another chronic condition (eg, diabetes), an acute condition, aging, or other.

Over half of respondents (179/320, 55.9%) reported using their own patient portal at least once, whereas 32.8% (105/320) reported using their care recipient's portal at least once. We summarize respondents' device ownership and engagement with different health technologies in Multimedia Appendix 1.

Caregiver Use of Care Recipient's Patient Portal

Family caregivers who use their own patient portal were significantly more likely to use their care recipient's portal (odds ratio [OR] 11.18, 95% CI 5.51-22.69; $P<.001$; Table 2). Being female (OR 2.58, 95% CI 1.40-4.75; $P=.002$) was associated with a significantly higher likelihood of using their care recipient's portal, whereas older caregivers (aged ≥60 years) were less likely to use their care recipient's portal (OR 0.55, 95% CI 0.30-1.00; $P=.05$) and not having a diagnosis of depression (OR 2.24, 95% CI 1.13-4.46; $P=.02$) was associated with a significantly higher likelihood of using their care recipient's portal. In addition, caregivers supporting a parent (OR 0.31, 95% CI 0.15-0.64; $P=.002$) and caregivers supporting another relative (OR 0.31, 95% CI 0.12-0.78; $P=.01$) were significantly less likely to use their care recipient's portal when compared with caregivers supporting a spouse or partner.

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Table 2. Odds ratios for family caregivers' use of their care recipient's patient portal in the last 12 months (N=320).

Characteristics	Odds ratio (SE; 95% CI)	P value
Caregiver use of own web-based medical record	11.18 (4.04; 5.51–22.69)	<.001
Demographic characteristics		
Age (years)		
18-59	Reference	N/A[a]
≥60	0.55 (0.17; 0.30–1.00)	.05
Sex		
Male	Reference	N/A
Female	2.58 (0.80; 1.40–4.75)	.002
Race and ethnicity		
White, not Hispanic	Reference	N/A
Black, not Hispanic	0.60 (0.28; 0.24–1.52)	.28
Hispanic	0.86 (0.37; 0.37–1.99)	.73
Other, not Hispanic	0.53 (0.28; 0.19–1.47)	.22
Education		
High school or less	Reference	N/A
Some college	0.53 (0.27; 0.20–1.44)	.21
College graduate	0.88 (0.40; 0.36–2.13)	.78
USDA[b] rural-urban classification		
Nonmetro	Reference	N/A
Metro	0.89 (0.50; 0.30–2.68)	.83
Health conditions		
Cancer diagnosis		
Yes	Reference	N/A
No	1.13 (0.46; 0.51–2.51)	.76
Depression		
Yes	Reference	N/A
No	2.24 (0.79; 1.13–4.46)	.02
Diabetes		
Yes	Reference	N/A
No	1.06 (0.39; 0.52–2.18)	.87
Heart condition		
Yes	Reference	N/A
No	0.86 (0.45; 0.31–2.42)	.78
Lung disease		
Yes	Reference	N/A
No	0.85 (0.36; 0.37–1.95)	.70
High blood pressure		
Yes	Reference	N/A
No	0.84 (0.26; 0.46–1.53)	.57
Caregiving experiences		
Relationship to care recipient		

Characteristics	Odds ratio (SE; 95% CI)	P value
Spouse or partner	Reference	N/A
Adult child	0.31 (0.11; 0.15–0.64)	.002
Other relative	0.31 (0.15; 0.12–0.78)	.01
Hours per week spent caregiving		
<20 hours	Reference	N/A
≥20 hours	0.97 (0.32; 0.51–1.86)	.94
Care recipient's conditions		
Cognitive	1.05 (0.32; 0.58–1.89)	.88

[a]N/A: not applicable (for reference groups).

[b]USDA: United States Department of Agriculture.

Caregivers' Reported Reasons for Using or Not Using the Patient Portal

Caregivers who reported using the portal (n=179) most commonly reported using their own portal to look up test results (148/179, 82.7%), securely message their health care provider and staff (108/179, 60.3%), and request medication refills (96/179, 53.6%; Table 3). Among those who reported never using their own portal (n=141), the most common reasons included preferring to speak directly with their provider (99/141, 70.2%), not having a need to use the portal (76/141, 53.9%), not having a patient portal (38/141, 26.9%), and privacy and security concerns (36/141, 25.5%; Table 3).

Table 3. Caregivers' reported uses of their own patient portal (n=179) and reasons for not accessing their own patient portal (n=141)[a].

	Values, n (%)
Caregivers' reported uses of their own patient portal (n=179)	
Request correction of inaccurate information	13 (7.3)
Download health information to computer or device	52 (29.1)
Add health information to share with provider	58 (32.4)
Help make decisions about treatment	70 (39.1)
Request medication refill	96 (53.6)
Securely message health care provider and staff	108 (60.3)
Look up test results	148 (82.7)
Caregivers' reported reasons for not accessing their own web-based medical record (n=141)	
Have multiple web-based medical records	18 (12.8)
Not comfortable or experienced with computers	25 (17.7)
Do not have a way to access the website	27 (19.2)
Difficulties logging into website	34 (24.1)
Privacy and security concerns	36 (25.5)
Do not have a web-based medical record	38 (26.9)
Did not have a need to use web-based medical record	76 (53.9)
Prefer to speak directly with provider	99 (70.2)

[a]Participants could indicate multiple reasons.

Discussion

Principal Findings

About one-third of the family caregivers in this study used their care recipient's patient portal. Compared with family caregivers who do not use their patient portal, those who do are significantly more likely to use their care recipient's portal. Consistent with previous findings, this study also suggests that family caregivers of a parent or another relative are significantly less likely to use their care recipient's portal compared with caregivers of a spouse or partner [5,19]. Female caregivers are more likely to use their relative's portal is less surprising, given that females are more likely to be caregivers. However, future research should study whether there are different uses of the patient portal across gender identities and the impacts of those uses on distress and ability to carry out caregiving

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responsibilities. However, older caregivers are less likely to use their care recipient's patient portal compared with caregivers aged <60 years. Caregivers who access their portal reports include looking up laboratory results and communicating with their provider, whereas those who do not access the portal report reasons such as concerns about their preference to speak directly with their provider or not having a need to use the portal.

Comparison With Prior Work

Our study aligns with previous research, suggesting that family caregivers may be using their care recipient's patient portal on behalf of or with their care recipient [6,7]. However, engaging family caregivers in using their own portal may be critical for increasing the likelihood that they will use their care recipient's portal either with or on behalf of their care recipient. This may be especially the case for older caregivers who may hesitate to use their own portal and be more likely to be a spouse or partner of their care recipient. Higher caregiver intensity (in terms of hours spent caregiving) is associated with a slightly lower likelihood of using their care recipient's portal may be reflective of the burden associated with caregiving and its impact on caregivers' time available to engage with the patient portal [25]. However, engaging with the patient portal could also reduce caregiver distress and burden, potentially alleviating challenges with communication and unmet information needs. This may be the case even among caregivers who do not perceive the need to use the portal. Achieving value in telehealth, particularly in terms of patient engagement, may require attention to family caregiver engagement [1,10].

Addressing family caregiver engagement with telehealth modalities will require the development of formal and standardized policies supporting family caregivers' access to their care recipient's patient portal [26]. Policies need to be developed to designate family caregivers who can use a patient's medical record and determine the circumstances under which they can use it [27]. Policies also need to specify when patients should express their preferences for family caregiver designation (eg, upon enrollment with a physician) and how they can change their preferences or customize the types of information that are shown to family caregivers.

As evidence supports the role of family caregivers in promoting positive patient health outcomes, policies can also incentivize providers to support family caregivers in their health care responsibilities in various ways [28,29]. For instance, this could include training family caregivers on effective use of the patient portal to facilitate timely communication with providers about patient needs and concerns, refill medications, and fix inaccuracies in the record, among other possibilities. There may be opportunities to develop shared portal platforms for family caregivers and their care recipients, which could also offer resources and support for family caregivers. For instance, a shared portal could screen family caregivers for distress when they access their care recipient's portal. Policy makers and payers must recognize family caregivers as integral components of value in telehealth. Subsequently, health care providers can encourage patients and their caregivers (or caregivers during their own health care visits) to use the patient portal as an

approach to supporting caregivers so that they can better support their care recipients.

Given that some of the most common reasons for family caregivers not accessing their own patient portal included a preference for speaking directly with their provider and not having a patient portal or perceiving a need to use it, providers should also discuss the benefits and barriers to portal use among patients who identify as family caregivers and demonstrate its potential for web-based communication, which could be a fruitful alternative to direct face-to-face or telephone-based communication. These caregivers may benefit from information about the portal and its potential benefits for supporting them in managing their own health conditions and the needs of their relatives. More than one-fifth of caregivers reported that they did not perceive a need for the portal, highlighting the possibility that these caregivers, as patients themselves, may not see value in the patient portal or may not have health conditions that require the use of the portal. However, given the considerable research on caregiver distress associated with negative mental, physical, and psychosocial health outcomes, it may be valuable for providers to screen caregivers for distress or at least encourage their use of their own patient portal to keep track of their health and communicate with their providers about health concerns that may be related to caregiving responsibilities [30,31]. Doing so would also require discussions about the privacy and security of the portal, including potential uses of health information. Future research should continue soliciting insights from caregivers and patients about their concerns and preferences related to privacy and security of health information on the patient portal. For example, caregivers may view information that patients do not want them to know about; discussions involving clinicians, patients, and caregivers should be comprehensive in identifying preferences related to the amount and nature of information shared with caregivers and the instances during which information can be observed by caregivers.

Our finding that caregivers with depression were less likely to use their care recipient's portal was in contrast with other recent research that finds the opposite relationship [32]. Although it is possible that the use of the care recipient's patient portal is a way of gathering information if the depression is related to caregiving or that using the portal actually facilitates social engagement by enabling the caregiver to communicate with information or with the health care system, it is also possible that the use of a care recipient's patient portal could actually exacerbate depression or anxiety—an area requiring further study.

Limitations

There are some limitations to our study. First, HINTS is a cross-sectional survey that limits the determination of causality. Second, our sample was limited to the representation of rural respondents, which could bias our estimates of the relationship between geographic residence and caregiver use of the care recipient's patient portal. This could be attributed to complexities in accessing mailing addresses for rural households to disseminate the survey and requires further study, as rural communities are particularly susceptible to disparities in digital

access and may face additional barriers to accessing their care recipient's patient portal [24]. Finally, the HINTS survey sample was limited, particularly in the representation of racial and ethnic minority groups. Racial and ethnic minority family caregivers may have different concerns about the patient portal or different reasons for using it. For instance, research suggests that Black and Hispanic caregivers, on average, spend more hours caregiving and are more likely to co-reside with their care recipient when compared with White, non-Hispanic caregivers [33]. As a result, these caregivers may not perceive the need to use their care recipient's patient portal, may not have enough time to use their own, or may have different concerns about communicating via technology that need to be studied further.

Conclusions

Our analysis suggests that family caregivers who use their own patient portals are more likely to use their care recipient's patient portal. This suggests, first, that family caregivers may use the portal for older adults and other populations that have been previously described as having lower engagement with their patient portal. However, it also suggests that there is a need for policies and technology designs to facilitate family caregiver use of their own patient portal and encourage their use of their care recipient's portal. Family caregivers' engagement with their care recipient's portal could be critical to achieving value from telehealth, supporting caregivers in their caregiving responsibilities, and supporting effective patient care.

Acknowledgments

Authors' Contributions

Study concept and design; data, analysis, and interpretation of data; and preparation of the manuscript were carried out by MR and BI.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Family caregivers' technology ownership and engagement (n=294).
[DOCX File , 28 KB - aging_v4i4e29074_app1.docx]

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Abbreviations

HINTS: Health Information National Trends Survey
OR: odds ratio

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Review

Factors Influencing Implementation of eHealth Technologies to Support Informal Dementia Care: Umbrella Review

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Abstract

Background: The worldwide increase in community-dwelling people with dementia underscores the need for innovative eHealth technologies that aim to provide support to both patients and their informal caregivers in the home setting. However, sustainable implementation of eHealth technologies within this target group can be difficult.

Objective: The goal of this study was to gain a thorough understanding of why it is often difficult to implement eHealth technologies in practice, even though numerous technologies are designed to support people with dementia and their informal caregivers at home. In particular, our study aimed to (1) provide an overview of technologies that have been used and studied in the context of informal dementia care and (2) explore factors influencing the implementation of these technologies.

Methods: Following an umbrella review design, five different databases were searched (PubMed, PsycINFO, Medline, Scopus, and Cochrane) for (systematic) reviews. Among 2205 reviews retrieved, 21 were included in our analysis based on our screening and selection procedure. A combination of deductive and inductive thematic analyses was performed, using the Nonadoption, Abandonment, Scale-Up, Spread, and Sustainability (NASSS) framework for organizing the findings.

Results: We identified technologies designed to be used "by informal caregivers," "by people with dementia," and "with people with dementia." Within those groups, most of the represented technologies included, respectively: (i) devices for in-home monitoring of lifestyle, health, and safety; (ii) technologies for supporting memory, orientation, and day structure; and (iii) technologies to facilitate communication between the informal caregiver and person with dementia. Most of the identified factors influencing implementation related to the condition of dementia, characteristics of the technology, expected/perceived value of users, and characteristics of the informal caregiver. Considerably less information has been reported on factors related to the implementing organization and technology supplier, wider institutional and sociocultural context of policy and regulations, and continued adaptation of technology over time.

Conclusions: Our study offers a comprehensive overview of eHealth technologies in the context of informal dementia care and contributes to gaining a better understanding of a broad range of factors influencing their implementation. Our results uncovered a knowledge gap regarding success factors for implementation related to the organizational and broader context and continuous adaptation over the long term. Although future research is needed, the current findings can help researchers and stakeholders in improving the development and implementation of eHealth technologies to support informal dementia care.

KEYWORDS

Introduction

Background

Dementia affects more than 50 million people worldwide [1] and this number is expected to triple by 2050 [2]. To reduce the tension between an increasing demand for care and the growing shortage in residential care capacity [3], many countries have shifted their attention toward deinstitutionalization and to support people with dementia to live at home for as long as possible [4,5]. Although extended independent living is preferred by most people with dementia [6], this also puts more pressure on their informal caregivers [7] such as spouses, children, or other relatives providing unpaid care at home. The volume of informal care has already been relatively large in most European countries, making up most of the care received by those aged 50 years or older [8,9]. Informal caregivers of people with dementia can feel heavily burdened by their care responsibilities, often resulting in stress-related symptoms such as anxiety [10], mood, or sleep disorders [11]. The strain on informal caregivers and people with dementia has become even more present in light of the COVID-19 pandemic as routine professional care services were postponed or decreased [12], inevitably causing a greater reliance on home care as one pillar of the health care system [13].

The increasing need for support of both patients and their informal caregivers in the home setting has led to innovative solutions, including those from the field of eHealth technology [14]. In the Netherlands, the National Dementia Strategy 2021-2030 [15] promotes the utilization and further development of eHealth technologies to support both patients and caregivers. The goals of these technologies within dementia care are diverse. A systematic review performed by Ienca et al [16] distinguished several purposes of (smart) technologies for dementia care, including assistance for activities of daily living, cognitive and emotional assistance, health and behavioral monitoring, fostering social interaction, and remote communication and emergency systems. In this review, we consider eHealth as "the use of technology to support health, well-being, and healthcare" [17]. This rather inclusive and broad definition covers all (intelligent) assistive technologies and technology-based interventions that can be used to support people with dementia and their informal caregivers in the home setting.

Despite their promising potential and position within recent policy, the use of eHealth technologies in dementia care is unfortunately still limited [18]. Low adoption rates may signal problems during implementation. In fact, the sustainable implementation of eHealth technologies aimed at providing support in home-based settings is frequently unsuccessful in daily practice [19,20], resulting in these technologies falling into the "valley of death" [21] after the research projects have ended. This raises a question about what exactly facilitates or hinders the successful implementation of a broad range of eHealth technologies in the informal dementia care context, which so far has been given little attention in research [14].

A previous scoping review performed by Guisado-Fernández et al [22] investigated factors influencing the adoption of "smart health technologies" [22] for people with dementia and their informal caregivers. Their review identified attitudinal aspects, ethical issues, design-related issues, and dementia-related challenges as playing key roles. Another review by Christie et al [14] focused on the implementation of digital interventions for informal caregivers of people with dementia. Several determinants were identified, including perceived data security, psychological characteristics of caregivers, care policy, or financial constraints. Both studies illustrate simultaneously that knowledge about factors influencing the implementation of eHealth technologies in informal dementia care is currently fragmented across different studies in the literature. Previous reviews tended to either focus primarily on a specific part or outcome of implementation (eg, adoption or acceptance) [22,23] or zoomed in on a specific type of technology [14,24]. This makes it difficult to obtain a complete overview of supportive eHealth technologies in the context of informal dementia care and what factors facilitate or impede their implementation.

To the best of our knowledge, no review yet exists that aims to summarize the influential factors across the whole spectrum of implementation and related to a broad range of technologies studied in the specific context of informal dementia care. For such a review to deliver beneficial and complete results, we consider the guidance of a holistic view on implementation as essential. Numerous implementation frameworks exist that view implementation as a postdesign phase [25-27], although it is currently recommended to target aspects of implementation at an early stage of development [17]. By contrast, the Nonadoption, Abandonment, Scale-Up, Spread, and Sustainability (NASSS) framework [28] considers the implementation process in a multilevel and comprehensive fashion, which encompasses the influences on the adoption, nonadoption, abandonment, spread, scale-up, and sustainability of eHealth technologies. This evidence-based and theory-informed framework includes both adoption and acceptance from the viewpoint of the stakeholders but also considers aspects of implementation that relate to the wider context [28]. Because of its holistic view on implementation, the NASSS framework was used as a general guide in our study.

Aims of the Study

The aim of this review was to gain a more complete understanding of why it is often difficult to implement and integrate eHealth technologies in everyday life despite the numerous technologies that have been studied and designed to support people with dementia and their informal caregivers at home. In particular, the complementary study aims were to (1) provide an overview of the types of technologies that have been used and studied in the context of informal dementia care and (2) explore the factors influencing the implementation of those technologies.

The findings of this review are expected to be useful in determining directions for future research, and to help

researchers and stakeholders in improving the development and implementation of eHealth technologies to support informal dementia care.

Methods

Approach

We used an umbrella review design to create an overview of the state of the art of technology for supporting informal dementia care and to identify determinants for its implementation. The methodology of an umbrella review can best be described as a systematic review of reviews, meaning that reviews are used as the analytical unit of the umbrella review [29]. Umbrella reviews are particularly fitting in a broad field of work and aim to provide a summary of the highest-quality studies into the state of the art of a certain domain. With this approach, gaps in the literature are highlighted and principal findings are presented in a tabular and concise manner that can be used in practice [29].

Search Strategy

A systematic literature search of five databases (PubMed, PsycINFO, Medline, Scopus, and Cochrane) was performed in June 2020. The aims of the search were to identify reviews that describe (i) technologies that are in use or have been studied to support informal dementia care and (ii) information related to the implementation of those technologies. The search string included terms pertaining to four main categories of keywords: (i) eHealth, (ii) Implementation, (iii) Informal Care, and (iv) Dementia. To build the search string, thesaurus and nonthesaurus terms were used. The search string was then adapted to each database and approved by a library consultant at the University of Twente. In general, the four categories were separated by AND, and the single terms inside of each category were separated by OR. The complete search string and database adaptations can be found in Multimedia Appendix 1.

Inclusion and Exclusion Criteria

Included studies needed to be reviews containing information related to the implementation of eHealth technologies for people with dementia and/or their informal caregivers. Studies in English, German, Dutch, Italian, and Portuguese languages were searched. Nonreview articles such as primary studies, randomized controlled trials, books, dissertations, and grey literature were excluded, as recommended for umbrella reviews [30]. Studies that also included non-eHealth interventions or other types of diseases were excluded. Furthermore, studies published before 2010 were excluded as it was believed that these would not add relevant information since those technologies are likely to have become outdated.

Data Extraction

During title and abstract screening, each paper was independently evaluated by at least two reviewers (SB, MS, or CW) and conflicts were solved through discussion. For full-text screening, the same procedure was followed, but consensus was reached through unanimity. Studies that fit all inclusion criteria were examined using a data extraction form on Covidence. The form was used to extract data about study details (eg, title, year, author, type of review, number of included studies), information about included technologies (eg, technology types, purposes, and primary user groups), and any statements related to implementation, including potential barriers and facilitators. Each paper was randomly assigned to at least two of the three reviewers (SB, CW, MS) who performed the data extraction independently from each other. Subsequently, completed data extraction forms for each paper were reviewed and adapted until consensus among all reviewers was reached.

Data Analysis

A qualitative thematic analysis was performed on the extracted data using Atlas.Ti9.

The NASSS framework was used to categorize the data. This framework consists of seven domains and can be used to evaluate the success of implementation of a health technology retrospectively and prospectively. Relevant fragments were selected and categorized into (1) one of the seven domains of the NASSS framework or (2) classified as miscellaneous information. Subsequently, selected fragments were further categorized inductively into overarching themes. To minimize single-researcher bias, the coded papers were checked independently by a second researcher. The final coding scheme was developed and defined based on consensus among the three researchers (SB, CW, MS).

Results

Characteristics of the Included Studies

Figure 1 illustrates the process of inclusion and exclusion of papers. The search strategy (available in Multimedia Appendix 1) produced 3109 results. After removing 904 duplicates and 2061 papers that were determined to be irrelevant according to our inclusion and exclusion criteria during title and abstract screening, 144 articles were considered for full-text screening. Finally, 21 papers were included for this review. Reasons for exclusions are detailed in Figure 1.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flow diagram of the study selection process.
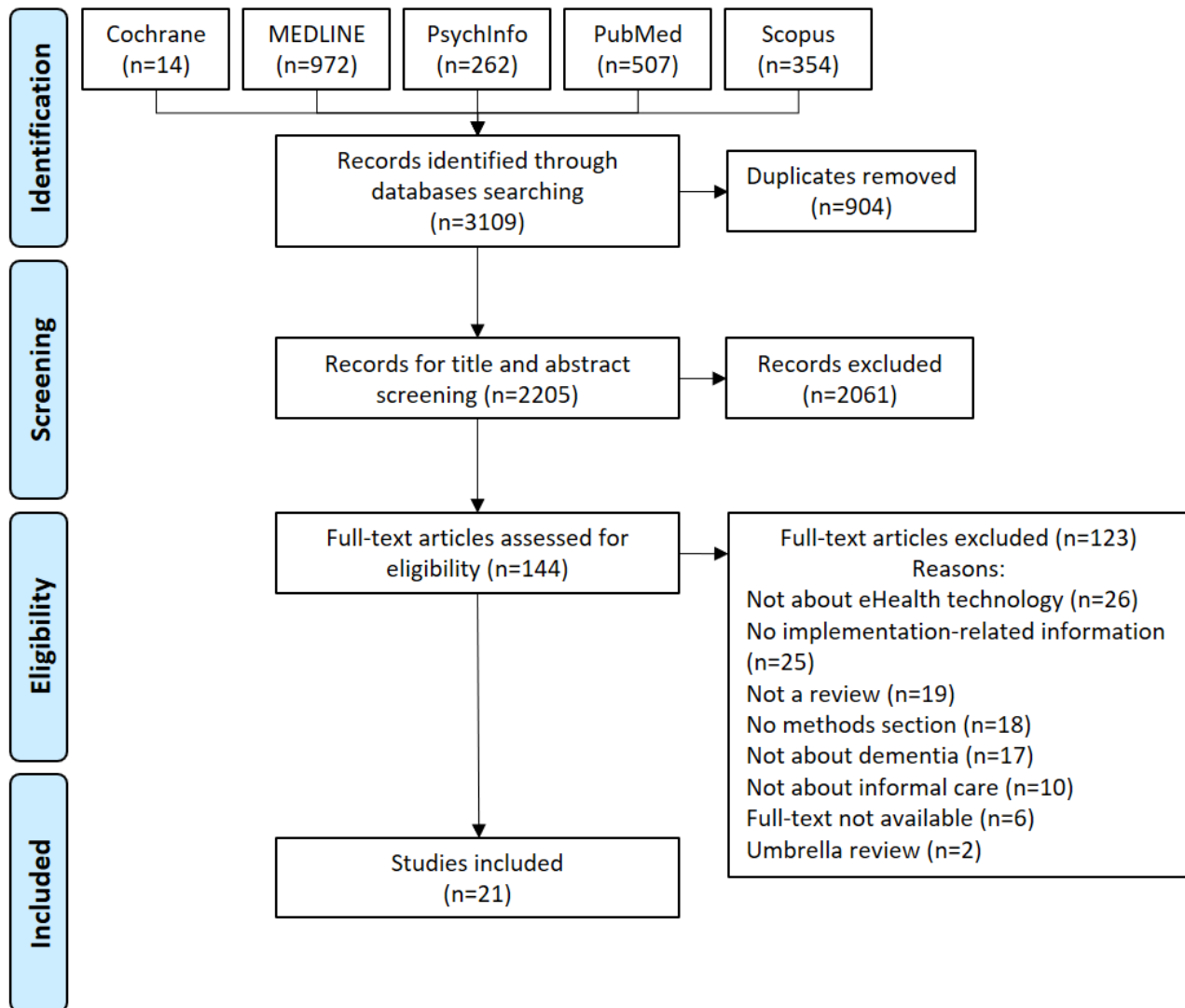
Table 1 summarizes details about the included studies such as author, year, title, type of review, and number of studies included per review. The studies were published between 2014 and 2020 and the majority were systematic reviews. The quality of the included studies was evaluated according to the Critical Appraisal Checklist for Systematic Reviews and Research Syntheses checklist [30], which ranged from 55% to 100% (for further details see Multimedia Appendix 2).

The included studies varied in their usage of implementation-related terminology and focus. For instance, 43% (9/21) of the included studies did explicitly use the term "implementation" in the text. Those that did not often used terminology related to certain subcomponents of implementation such as adoption, effectiveness, acceptability, or acceptance instead. Furthermore, although all studies contained information related to implementation, only 5 out of 21 reviews exclusively acknowledged implementation, or certain subcomponents of it, as the main focus of the study.

Table 1. Characteristics of the included studies.

Reference	Year	Title	Type of review	Number of included studies	Quality appraisal (%)
Armstrong and Alliance [31]	2019	Virtual support groups for informal caregivers of individuals with dementia: a scoping review	Scoping	25	100
Brando et al [32]	2017	The application of technologies in dementia diagnosis and intervention: A literature review	Literature	30	75
Christie et al [14]	2018	A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia	Systematic	46	95
Guisado-Fernández et al [22]	2019	Factors influencing the adoption of smart health technologies for people with dementia and their informal caregivers: scoping review and design framework	Scoping	109	100
Holthe et al [23]	2018	Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: A systematic literature review	Systematic	29	95
Hopwood et al [24]	2018	Internet-based interventions aimed at supporting family caregivers of people with dementia: systematic review	Systematic	40	80
Hung et al [33]	2020	Using touchscreen tablets to support social connections and reduce responsive behaviors among people with dementia in care settings: A scoping review	Scoping	17	86
Klimova et al [34]	2019	E-learning as valuable caregivers' support for people with dementia–A systematic review	Systematic	6	55
McKechnie et al [35]	2014	Effectiveness of computer-mediated interventions for informal carers of people with dementia—A systematic review	Systematic	14	100
Novitzky et al [36]	2015	A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia	Literature	173	93
Rathnayake et al [37]	2019	mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review	Integrative	7	93
Ruggiano et al [38]	2018	Rural dementia caregivers and technology: what is the evidence?	Systematic	30	100
Sanders and Scott [39]	2020	Literature review: Technological interventions and their impact on quality of life for people living with dementia	Literature	38	100
Sriram et al [40]	2019	Informal carers' experience of assistive technology use in dementia care at home: A systematic review	Systematic	56	100
Suijkerbuijk et al [18]	2019	Active involvement of people with dementia: a systematic review of studies developing supportive technologies	Systematic	49	75
Thordardottir et al [41]	2019	Acceptance and use of innovative assistive technologies among people with cognitive impairment and their caregivers: a systematic review	Systematic	30	100
Tyack and Camic [42]	2017	Touchscreen interventions and the well-being of people with dementia and caregivers: A systematic review	Systematic	16	85
Van Boekel et al [43]	2019	Perspectives of stakeholders on technology use in the care of community-living older adults with dementia: a systematic literature review	Systematic	46	90
Vermeer et al [44]	2019	What do we require from surveillance technology? A review of the needs of people with dementia and informal caregivers	Scoping	28	93

Reference	Year	Title	Type of review	Number of included studies	Quality appraisal (%)
Waller et al [45]	2017	Computer and telephone delivered interventions to support caregivers of people with dementia: a systematic review of research output and quality	Systematic	34	100
Yousaf et al [46]	2019	Mobile-health applications for the efficient delivery of healthcare facility to people with dementia (people with dementia) and support to their carers: a survey	Literature	17	93

Characteristics of Technologies to Support Informal Dementia Care

Overview

The following sections summarize the types of eHealth technologies that aim to support informal dementia care (either directly or indirectly) that have been studied in the included literature. More specifically, we present an overview of primary user groups and the purpose of identified technologies.

Primary User Groups of Identified Technologies

Based on the included reviews, we identified supportive technologies that aim to be used by different primary user groups, characterized by different levels of involvement of informal caregivers (from high to low). Based on Gibson et al [47], we arranged the technologies into three overall groups. Most of the identified technologies are designed to be used "by informal caregivers," (mentioned in 17 out of 21 reviews), while fewer are meant to be used "by people with dementia" (mentioned in 9 out of 21 reviews) and "with people with dementia" (PwD and informal caregivers jointly; mentioned in 8 out of 21 reviews). This result also highlights that most of the

technologies identified in this review entail high involvement of the informal caregivers.

Purposes of Identified Technologies Per User Group

As shown in Figure 2, overarching purposes of supportive technologies were identified within the different primary user groups.

Technologies used by informal caregivers were typically those operated without the active involvement of people with dementia, which were primarily specifically designed to support (in)formal caregivers. Within this user group, most of the included technologies were used for the purpose of in-home monitoring of lifestyle, health, and safety of people with dementia using wearable and nonwearable sensors, and internet-based interventions providing professional (psychological) support to caregivers (both represented within 38% of all reviews). The third largest type of technology, represented within 33% of the reviews, was outdoor GPS location identification to reduce risks by alerting caregivers. Lastly, internet-based platforms for electronic learning and information were identified in 24% of all reviews.

Figure 2. Purposes of technologies identified per primary user group. Percentages refer to the number of reviews mentioning a certain type and purpose of technology. One single review could mention different types and purposes of technologies.
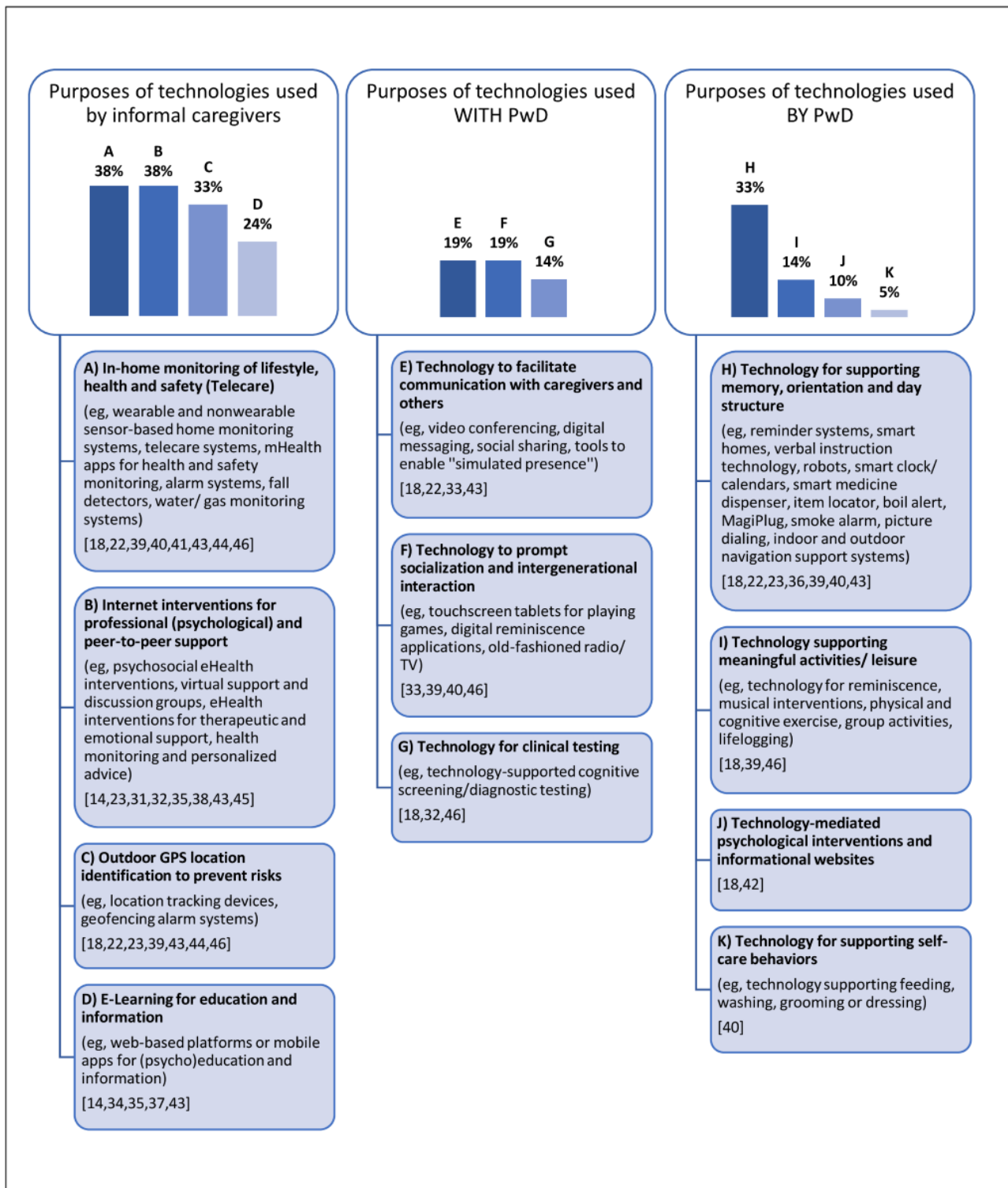
Technologies used with people with dementia usually included those that require active involvement of people with dementia and caregivers, and/or establish a communication channel between people with dementia and their caregivers. Within this user group, most of the included technologies (represented within 19% of the reviews) were collaborative devices designed to facilitate communication between people with dementia and their informal caregivers or relevant others (eg, video conferencing). This type of technology also included tools to enable simulated communication or the "simulated presence" [33] of informal caregivers. Furthermore, we identified technologies to prompt socialization and intergenerational interaction such as touchscreen tablets for playing games or digital reminiscence applications in 19% of the reviews. Lastly, in a minority of reviews (14%), we identified technology for clinical testing.

Technologies that can be used independently by people with dementia usually included supportive devices that make

everyday living easier, thereby indirectly creating relief for informal caregivers as well. Most of the represented technologies within the user group of people with dementia (highlighted in 33% of the reviews) included technology for supporting memory, orientation, and day structure such as reminder systems or smart medicine dispensers. Technologies supporting meaningful activities and leisure such as reminiscence or musical interventions were represented within 14% of the reviews. Finally, technology-mediated psychological interventions and informational websites (represented within 10% of the reviews) and technology supporting self-care behaviors such as feeding or washing were the least identified among all reviews.

Factors Influencing Implementation

Overview

The following section presents identified factors (ie, potential barriers and facilitators) influencing the implementation of technologies to support informal dementia care. Implementation-related information collected across the reviews was grouped within the seven domains of the NASSS framework: condition, technology, value proposition, adopters, organization, wider system, and embedding and adaptation over time [28]. These domains refer respectively to the context of the specific health condition in which the technology is applied, characteristics of the technology, added value of the technology, factors related to adopters, characteristics of the implementing organization, and wider institutional and sociocultural context of policy and regulations. The last domain refers to the relation between the first six domains and the adaptation over time of the technology [28]. Textbox 1 presents an overview of identified factors influencing the implementation of technology to support informal dementia care, sorted by the corresponding NASSS framework domains and subdomains.

Textbox 1. Factors influencing implementation of technologies to support informal dementia care, structured according to the Nonadoption, Abandonment, Scale-Up, Spread, and Sustainability (NASSS) framework domains and subdomains. Factors that fall beyond the subdomains within "Condition" of the NASSS Framework are reported under "Miscellaneous".

---

1. Condition

Nature of condition or illness

- Deterioration of functional and cognitive resources [22]

- Increasing level of suspicion [22]

- Advantages and challenges of involving people with dementia in early-stage development [18,22,36,40,48]

- Timing and pace of technology introduction [14,18,22,39,40,43,44]

- Adaptation of technology along the disease progression [14,31,42,44]

Comorbidities, sociocultural influences

- Technology vs condition denial [22]

Miscellaneous

- Fear of breaking or losing the technology [43]

- Partnership between participant and researcher [18]

2. Technology

Material features

- Unobtrusive and familiar design (including physical appearance, simplicity, and usability) [22,23,36,39,42,44]

- Stigmatizing design [23,36,43]

Knowledge needed to use

- Technology literacy and access [14,22,24,31,36,41,44]

3. Value proposition

Demand-side value

- Perception of immediate advantage [41]

- Mismatch between expected and perceived benefits [22,41]

- Different or competing values of informal caregivers and patients [43]

- Lack of expected value through lack of personalization [36,40]

4. Adopters

Patients

- Reported within the domain "Condition" above

Informal caregivers

- Characteristics of informal caregiver that hinder or foster implementation (including motivation, digital literacy, training/education, attitude toward technology, perceived competence, ethnicity/culture, caregiving workload) [14,22,23,39-41,45]

- Expected or perceived technology burden (including privacy concerns, the fear of being replaced by machines, routine disturbance) [14,22,36,41]

5. Organization

Capacity to innovate

- Capacity for long-term technical user support [14,22,43]

Readiness for this technology

- Staff insecurity toward technology [14]

Nature of adoption/funding decision

- Resources for public relations [14]

XSL•FO

RenderX

Extent of change needed to routines

- Staff availability, replacement, and training [14]

6. Wider system

Political, policy

- Preference of health insurance companies for more classically delivered solutions [14]
- Local care policies [14]

Regulatory/legal

- Privacy and ethical issues [14,36]
- Interoperability issues [36]

7. Embedding and adaptation over time

Organizational resilience

- Monitoring intervention fidelity and active facilitation of the service uptake [14]

Challenges Related to the Condition

A high number of factors influencing the implementation of technology to support informal dementia care were found to be related to the condition of dementia. Among those factors, the *deterioration of functional and cognitive resources,* associated with progression of the disease, were reported to complicate the process of acquiring the new knowledge needed to use new technologies [22]. In addition, an *increasing level of suspicion* toward new things, the general disapproval of supportive technologies that remind patients of their own condition (especially for those in *condition denial* [22]), and the patients' *fear of breaking or losing expensive equipment* [43] could act as additional barriers to implementation, related to the condition of dementia.

Furthermore, the *advantages and challenges of involving people with dementia in early-stage technology development* and the consequences for uptake were widely addressed in the reviews [14,18,22,36,40]. In terms of advantages, involving and codesigning with people with dementia promotes the realization that technologies are accessible and meaningful to them, and helps to make their needs explicit to the eyes of the developers [18], which in turn prevents technology abandonment and rejection [36]. However, involving people with dementia in the early stages of development when there is no concrete or physical prototype yet available creates challenges. For instance, people with dementia might experience difficulties in retrospection or anticipation of hypothetical/abstract scenarios [18], which are skills that are especially required in predesign phases. Using low-fi prototypes and letting people with dementia interact with them [18] could be one potential solution, although it would still require a certain degree of hypothetical thinking to imagine using the technology in everyday life situations [18]. Coherently, the reviews report that the extent of involvement by people with dementia in the development phase was moderate [18]: people with dementia were usually involved as informants, and most of the time during the postdesign evaluative stage [18]. In other stages, different stakeholders such as informal caregivers or experts were preferably involved [18].

Additionally, *the timing and pace of technology introduction* was widely considered as crucial [14,18,22,39,40,43,44]. Even though people with early-stage dementia have fewer difficulties in learning new things [18,39], they might not always see a benefit in using supportive technologies if introduced too early, as they often find themselves in denial about the severity of their condition or their need for help [22]. By contrast, when technologies are introduced at a later stage, it might be more difficult for people with dementia to adapt to them [43]. The pace of technology introduction is closely related to the feeling of familiarity with the device. A sudden introduction of technology could lead to rejection, especially in the case of wearable devices, where people with dementia could remove them if they seem unfamiliar, whereas caregivers often think their loved ones are going to accept technologies easily [44]. A more gradual introduction, making the technology almost invisible to the user [22], could potentially facilitate the adoption process and continuity of use.

Furthermore, certain technologies seem to be more suitable for different stages of disease progression, and it is important that they match the users' level of skills [42]. Disregarding the stage of dementia has been reported as a barrier to uptake, even when it comes to technologies such as virtual support groups for caregivers [31]. Therefore, it might be particularly useful to create supportive technologies that are able to *adapt to the disease progression* [14,31,42,44]. In particular, the content of interventions needs to be fitting and up to date [14].

Lastly, to maintain and improve the involvement of people with dementia and prevent early dropout, establishing a proper *partnership between the participants and researchers* and keeping participants thoroughly informed about the research development are recommended [18].

Technology

Technology-related aspects influencing uptake largely centered around an *unobtrusive and familiar design*. In particular, technologies designed to be used by people with dementia should be intuitive and familiar and, if desired, mimic old technologies that people with dementia might already be

acquainted with, thus eliciting recognition rather than recall [22]. They should have a uniform and coherent design in terms of fonts, colors, and the shape and size of buttons, and have a nonthreatening look [22]. The type of technology and its usability also plays an important role in the adoption/implementation process [23]. For instance, touchscreen technologies seem to be well-tolerated and, if well-designed, people with early-stage dementia require minimal training to use them [42]. Technologies to be used by people with dementia need to be especially simplified in design and appearance; even technologies that tell the time need to be as simple as possible, according to Sanders and Scott [39].

Furthermore, a *stigmatizing design* should be prevented as it often leads to rejection [36,43] by people with dementia and their caregivers. Devices can be stigmatizing both in terms of appearance, such as creating a "handicapped look," and in terms of the signals they emit in public settings that might be embarrassing [36]. Devices should therefore match the user's identity to be adopted and not be perceived as stigmatizing [23].

In addition to having *access* to an internet connection [24], *technology literacy* (ie, knowledge needed to use technology) was recognized as a determinant for implementation [14,22,24,31,36,41]. Hopwood et al [24] raised the matter of the "digital divide," referring to the gap between those who can use internet-based technologies and those who cannot. Although younger caregivers may not have problems using digital technology, caregivers of people with dementia such as partners or spouses are more likely to be older themselves and might experience more difficulties [24]. Disregarding the digital divide often starts in an early stage of development, as a certain level of technology literacy is often an inclusion criterion to participate in research studies [24]. Reducing the complexity of digital technologies, supporting access with potential input from health professionals, and helping to understand the potential benefits that might come from using technology may aid in bridging the divide [22,24,41].

Value Proposition

For successful implementation of technology in informal dementia care, it must be clear for whom and how the technology generates value. In the included studies, only implementation-related factors related to the demand-side value (ie, the value to the user) were considered, whereas factors related to the supply-side value (eg, business cases and models, chances of return on investment, potential risks for investors) were largely underrepresented.

Thordardottir et al [41] highlighted the importance of how the benefits of a technology are communicated to people with dementia and their caregivers. The authors suggest that the *perception of an immediate advantage* is a key element of acceptance and value creation, which helps to prevent the abandonment of technology after a short period of usage, even when it comes to more obtrusive technologies.

Furthermore, the review of Guisado-Fernández et al [22] found that it was rather common for people with dementia and their informal caregivers to have unrealistic expectations of what supportive technologies might accomplish for them. Such a

mismatch between expected and perceived benefits [41] can hinder technology adoption. Thordardottir et al [41] underline the importance of a correct matching between expectations of people with dementia and their caregivers before implementation and the actual benefits of the technology following the initial use. A mismatch in this regard can impede successful implementation as consequence of the users' disappointment [41].

Moreover, although the expected or perceived benefits are usually in line with the original purpose of the technology, informal caregivers and people with dementia often perceive different features as valuable [43]. Insight into *different or competing values of informal caregivers and patients* is important to prevent contradictory perspectives from becoming a barrier to continue using a technology [43].

Lastly, as mentioned by Novitzky et al [36] and Guisado-Fernández et al [22], users often consider that a certain technology is not meant for them. This issue can occur when introducing "off-the-shelf" technologies, which lack *personalization* both toward people with dementia and their caregivers [40]. As Sriram et al [40] describe, many technologies needed to be customized to the individual situations of the carers and people with dementia, and abandonment was frequent when this was not the case.

Adopters

We found a broad range of factors influencing implementation relating to the adopters/primary users of technology to support informal dementia care. Factors related to people with dementia themselves and the context of their specific condition are summarized in the subsection ''Challenges Related to the Condition'' above. We thus here report on identified factors related to the informal caregiver.

The largest group of factors that facilitate or impede implementation centered around *personal characteristics of the informal caregiver*. Among these, their motivation, digital literacy, and training and education were found to be important factors [14,23,39-41]. Their attitude toward technology may influence whether they begin to use technologies or interventions, and their perceived competence influences whether or not they continue to use the technology [22,45]. Relating to digital interventions, ethnicity and culture were frequently mentioned as influencing factors, suggesting a potential benefit to tailoring interventions to specific minorities before implementing them [14,40]. Furthermore, caregiving workload has been identified as an important factor regarding adherence to digital technologies: the busier informal caregivers were, the less usage took place [14].

Finally, factors related to *expected or perceived technology burden* such as privacy concerns of informal caregivers about using technology to document personal issues [14], the fear of being replaced by machines [22,36,41], and routine disturbance [22] have been reported to hinder implementation.

Organization

This section describes factors influencing implementation related to the implementing organization, namely the technology

provider. Although these were among the least addressed factors within the included reviews, several factors could be identified.

Primarily, when distributing new technologies, the organization's *capacity for long-term technical user support* plays a key role for sustainable implementation. Providers should have the capacity to deliver guidance to people with dementia and their caregivers on how to use the technology, allow sufficient time to practice, and provide face-to-face home assistance in case of technical glitches [22]. Software and content should be updated regularly. Related to this, the literature stresses the importance of sufficient *staff availability, replacement when staff leaves,* and regular *staff training* [14]. Certain staff characteristics such as *insecurity about technological or ethical issues* have also been reported to impede implementation [14]. Lastly, the lack of sufficient *resources for public relations*, which is a situation that mostly impacts smaller organizations, has been described as a barrier to sustainable implementation [14].

Wider System

As described by the NASSS framework [28], the wider institutional and sociocultural context is often key to explaining an organization's failure or success in moving from a demonstration project to a fully spread and sustainable technology. Based on the reviews, we identified a limited number of factors that mainly relate to the context of policy and (legal) regulations.

In particular, the effect of *local care policies* has been described as an important factor [14]. In recent years, policy developments have increasingly recognized the possible benefits of innovative eHealth technologies. However, the constrained ability of health insurance authorities to support innovation and their *preference for more classically delivered care* have been identified as significant barriers to implementation [14].

Furthermore, the literature discussed certain *privacy and ethical issues* that can pose a barrier to implementation [14]. Novitzky et al [36] reported that caregivers of people with dementia are increasingly concerned about the ethical responsibility and legal liability for any possible misuse of a technology that is used in the home setting. For instance, Vermeer et al [44], who reviewed the literature on surveillance technologies in home-based dementia care, posed the question of who is authorized to know the location of the person with dementia and when the use of these types of technologies would or should result in legal issues.

Lastly, it has been reported that sustainable implementation of supportive technologies requires them to be developed in a way to ensure that they are *interoperable* with future systems [44].

Embedding and Adaptation Over Time

We found that aspects within this last domain were strongly underrepresented, with only one review reporting on aspects related to the continued evolution and adaptation of technology over time. In particular, the review of Christie et al [14] mentions some of the suggested long-term implementation strategies such as reconciling community and organizational characteristics, streamlining processes for *monitoring intervention fidelity*, and *active facilitation of the service uptake* [14].

Identified Gaps

Table 2 presents an overview of the number of reviews describing factors related to implementation of technology supporting informal dementia care per the domains of the NASSS framework. Most of the reviews described factors relating to the technology and the condition of dementia, followed by reviews describing factors related to adopters (informal caregivers) and the technology value proposition. Factors relating to the implementing organization, the wider system, and embedding and adaptation of technology over time were the least represented. In conclusion, the most identified factors provide information about how the condition of dementia, the technology itself, its expected and perceived value (demand side), and the informal caregiver might influence successful implementation, whereas considerably less has been reported on factors relating to the implementing organization, the wider institutional and sociocultural of context of policy and regulations, and the continuing adaptation of technology over time.

Table 2. Number of reviews identified per domain of the Nonadoption, Abandonment, Scale-Up, Spread, and Sustainability (NASSS) framework (N=21)[a].

NASSS framework domain	Number of reviews
Condition (people with dementia)	11
Technology	11
Adopters	8
Value proposition	5
Organization	3
Wider system	2
Embedding and adaptation over time	1

[a]Based on the information provided in a review, one single review could fall within multiple NASSS domains simultaneously. To prevent overlap between categories, factors related to people with dementia and their specific condition have been grouped under "Condition"; factors related to the informal caregiver are represented within the "Adopters" domain.

Discussion

Principal Results

Our study aimed at gaining a more complete understanding of why it is often difficult to implement eHealth technologies that have been specifically designed to support people with dementia and their informal caregivers in everyday life. According to Bauer and colleagues [49], the main goals of implementation science should be (1) identifying barriers and facilitators to the uptake of innovations and (2) developing and applying strategies to promote the successful implementation of innovations. Our umbrella review integrates knowledge that has been fragmented across different reviews until now by (1) providing an overview of the types of technologies that have been used and studied in the context of informal dementia care, and (2) exploring the factors influencing the implementation of those technologies.

Our review found that regardless of the difficulties that come with implementing supportive technologies, a broad range of existing or to-be-developed technologies are studied in the context of informal dementia care. Similar to Gibson et al [47], we generally identified technologies that aim to be used by different primary user groups, characterized by varying levels of involvement of informal caregivers, ranging from technologies used by informal caregivers to technologies used between caregivers and people with dementia to technologies used by people with dementia. It was possible to identify a certain degree of overlap between the categorization by user groups that emerged in our study and the structure of the NASSS framework, specifically with respect to how certain determinants of implementation refer to the patients (Condition and Adopters) and others to the caregivers (Adopters). However, we find the distinction between the domain of Condition and the subdomain "Patients" (embedded in the Adopter domain) to be less practical.

One of the largest groups of technologies found in our review were monitoring devices, including in-home monitoring of health and safety, and outdoor location identification of people with dementia, showing that this technology domain has developed rapidly and is seen as promising. We found that privacy and ethical issues were frequently mentioned as a barrier in relation to this type of technology; however, ways to overcome this barrier have mostly been unaddressed. In a previous study among potential users, we found that artificial intelligence–driven monitoring systems particularly require introduction in a way that prevents caregivers from feeling undervalued [50]. We have published a set of requirements that can benefit the development and introduction of in-home monitoring technologies aimed at supporting home-based dementia care [50].

An important finding of our study was the uneven distribution of references identified within the 7 domains of the NASSS framework. Although most reviews contained information on how the condition of dementia, the technology itself, its expected and perceived value, and the informal caregiver might influence successful implementation, considerably less has been reported on factors related to the implementing organization, wider institutional and sociocultural context, and continued adaptation of technology over time.

Interestingly, two included reviews came to a similar observation. The review from Christie et al [14], which focused on digital interventions for caregivers of people with dementia, found contextual factors related to implementing organizations and the wider context to be underrepresented in the included studies. Similarly, the implementation factors identified by Thordardottir et al [41] often related to a "micro level" (the individual user), whereas factors on the "meso level" (organizational processes) and "macro level" (national policy context) were less frequently found.

An additional blind spot that emerged from our study was the lack of information on factors related to the supply-side value, which was surprising as business modeling is crucial for the success of an eHealth technology and can serve on a strategic level to guide sustainable implementation [51].

Overall, there seems to be a mismatch between the focus of research performed on supportive technologies for people with dementia and their informal caregivers, and existing implementation frameworks. In our view, this might indicate (1) a misconception or partial mental model of implementation within researchers in the context of informal dementia care or (2) a lower interest in research about the wider contextual factors. In fact, researchers probably prefer to focus more on concrete, well-known, and measurable aspects of implementation instead of focusing more on abstract concepts. Nevertheless, these results could constitute a possible explanation to implementation failures that are very diffused in this (and other) contexts [52].

The identified mismatch between theory and research practice was also visible in the fact that most of the included reviews did not generally identify the use of implementation frameworks in their included studies nor did they employ such a framework to systematize the results. However, the latter could be explained by the fact that many of the reviews did not focus on implementation "as a whole" but rather focused on specific subcomponents of implementation such as acceptance or adoption. One review we included produced an ad hoc framework to guide the design of "smart health technology" [22]. Interestingly, this DemDesCon framework [22] also covers considerations to be made at the user, social, and development levels.

Strengths and Limitations

To the best of our knowledge, this review is the first of its kind to explore factors influencing the implementation of eHealth technologies to support informal dementia care at this level of abstraction. By analyzing reviews (that included 840 studies in total) instead of primary studies, we were able to (indirectly) include a large knowledge base. According to the methodology employed, our results could lay the grounds to provide practical insights for decision making in the context of implementation of eHealth to support informal dementia care [30]. An additional strength of this review also lies in the rigor of the data extraction and analysis, with multiple researchers independently screening and analyzing the information.

However, some limitations must be considered. First, our results specifically refer to the context of informal dementia care and therefore are not necessarily generalizable to other implementation contexts. Second, due to the employed umbrella review design, we had to rely on the way review authors have summarized their findings. The level of detail provided within the included reviews varied; not all reviews provided a detailed description of the types and purposes of their included technologies, with some only providing a shorter summary. Lastly, although the authors kept close track of recent literature, due to technical time for finalization and publication of the manuscript, papers that would have otherwise been included might have been overlooked.

Future Research

Our results suggest that more research is needed to understand how implementing organizations, the wider institutional and sociocultural context, and business modeling influence the successful implementation of technologies to support people with dementia and their caregivers, as many of the included reviews failed to address these aspects. In addition, future implementation research within this target group should increase its focus on continued adaptation and embedding of technology over time. As eHealth technologies to support informal dementia care develop rapidly, it seems essential for implementers not to fall behind the technological progress or eventual changes in context and care standards.

Lastly, our review provides an overview of factors influencing implementation, but it does not differentiate between different types of technologies in this regard. Future research should investigate what is needed for successful implementation of specific kinds of technologies to support people with dementia and their informal caregivers at home.

Practical Recommendations

To help future developers in creating and successfully implementing meaningful technologies for both informal caregivers and people with dementia, we generally recommend use of the NASSS framework in combination with a holistic and iterative development approach, which views implementation not as a postdesign phase but rather intertwined with development right from the start. In light of our results, the CeHRes Roadmap [17,53]—a toolkit to guide holistic eHealth development—seems especially suitable in several ways. First, this roadmap pays special attention to the characteristics of and interrelation between relevant stakeholders, the (wider) context, and the technology. Second,

it incorporates evidence-based methods from participatory development and human-centered design. Third, it focuses on cocreation of a business model even before a prototype of a technology is being made. In this way, possible implementation barriers such as those identified in our study can be addressed and accounted for at an early stage of development.

In addition, we present a synthesis of our most important results in the form of checklist (see Multimedia Appendix 3) aimed at promoting reflections and providing insights for readers interested in the field of technologies to support informal dementia care. The present checklist is intended for researchers, policymakers, practitioners, experts, and any other stakeholder interested in technologies for informal dementia care who want to gain specific insights on the implementation process and determinants. Specifically, readers are provided with (i) a concise overview of relevant aspects and domains of implementation identified in this review in light of the NASSS framework and (ii) best practices and recommendations. The first step to use this simple tool is to define the technology (or type of technology) that needs to be implemented, and its primary user group. Readers can make use of Figure 2 to navigate the different options. By filtering the most and least important domains, researchers can concentrate on the most relevant aspects. Moreover, the reader can rate their relevance, the extent to which they were addressed in design or implementation, and make use of the practical insights that directly derive from our review and CeHRes Roadmap [17,53].

Conclusions

The increasing number of community-dwelling people with dementia worldwide underscores the need for innovative eHealth solutions that can provide support to both patients and their caregivers in the home setting. However, sustainable implementation of supportive technologies within this target group can be difficult. Our umbrella review has provided a comprehensive overview of eHealth technologies studied in the context of informal dementia care and contributes to a better understanding of a broad range of factors influencing their implementation. These findings can help researchers and stakeholders improve the development and implementation of eHealth technologies to support informal dementia care. More research is needed to identify the specific factors determining successful implementation related to the wider institutional and sociocultural context, the implementing organization and technology supplier, and continued adaptation and embedding of technology over time.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search string.
[DOCX File , 17 KB - aging_v4i4e30841_app1.docx]

Multimedia Appendix 2
Quality of the included studies.
[DOCX File , 20 KB - aging_v4i4e30841_app2.docx]

Multimedia Appendix 3
Implementation of eHealth in the Informal Dementia Care setting: Practical Recommendations Checklist.
[DOCX File , 23 KB - aging_v4i4e30841_app3.docx]

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Abbreviations

NASSS: Nonadoption, Abandonment, Scale-Up, Spread, and Sustainability
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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<u>Original Paper</u>

An App-Based Mindfulness-Based Self-compassion Program to Support Caregivers of People With Dementia: Participatory Feasibility Study

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Abstract

Background: The number of persons with dementia is steadily growing, as is the number of individuals supporting persons with dementia. Primary caregivers of persons with dementia are most often family members or spouses of the persons with dementia, and they are more likely to experience increased stress and other negative effects than individuals who are not primary caregivers. Although in-person support groups have been shown to help buffer the negative impacts of caregiving, some caregivers live in isolated or rural communities and are unable to make the burdensome commitment of traveling to cities. Using an interdisciplinary approach, we developed a mobile smartphone support app designed for primary caregivers of persons with dementia, with the goal of reducing caregiver burden and easing stress. The app features a 12-week intervention, largely rooted in mindfulness-based self-compassion (MBSC), because MBSC has been linked to minimizing stress, depression, and anxiety.

Objective: The primary objectives of our program are twofold: to explore the feasibility of a 12-week mobile support program and to conduct an initial efficacy evaluation of changes in perceived caregiver burden, coping styles, and emotional well-being of caregivers before and after the program.

Methods: Our feasibility study used a 2-phase participatory pretest and posttest design, focusing on acceptability, demand, practicality, implementation, and efficacy. At phase I, we recruited 57 primary caregivers of persons with dementia (mean age 76.3, SD 12.9 years), comprising spouses (21/57, 37%), children (21/57, 37%), and friends or relatives (15/57, 26%) of persons with dementia, of whom 29 (51%) completed all measures at both pre- and postprogram. The content of the program featured a series of MBSC podcasts. Our primary outcome measure was caregiver burden, with secondary outcome measures including coping styles and emotional well-being. Daily ecological momentary assessments enabled us to ask participants, "How are you feeling today?" Phase II of our study involved semistructured follow-up interviews with most participants (n=21) who completed phase I.

Results: Our findings suggest that our app or program meets the feasibility criteria examined. Notably, participants generally accepted the program and believed it could be a useful resource. Emotional well-being increased significantly (P=.04), and emotion-based coping significantly decreased (P=.01). Participants generally considered the app or program to be a helpful resource.

Conclusions: Although there were no significant changes in caregiver burden, we were encouraged by the increased emotional well-being of our participants following the completion of our program. We also conclude that our app or program demonstrated feasibility (ie, acceptability, practicality, implementation, and efficacy) and can provide a much-needed resource for primary caregivers of persons with dementia. In the subsequent version of the program, we will respond to participant feedback by incorporating web-based weekly sessions and incorporating an outcome measure of self-compassion.

KEYWORDS

Introduction

Background

Dementia is a growing health concern that currently affects approximately 47 million people worldwide [1]. More than half of persons with dementia live in their own homes, supported primarily by family caregivers [2,3]. Family caregivers can face considerable stress when caring for a person with dementia at home [4,5], resulting in higher levels of depression and anxiety [6,7], social isolation [8], lower levels of subjective well-being [6-9] and worse physical outcomes for these individuals compared with caregivers of people without dementia [6-10]. One meta-analysis demonstrated caregivers of persons with dementia to be more stressed than nondementia caregivers and to experience more serious depressive symptoms and physical problems [6], whereas another found overall prevalence rates for depression and anxiety among primary caregivers of persons with dementia to be 34% and 44%, respectively, both figures being considerably higher than nondementia caregivers [11].

Although stress can often be alleviated through conventional education and counseling programs [12-14], participation in face-to-face interventions is not always feasible [15-17]. Caregiving responsibilities, the caregiver's own health issues, the personal and economic burden of long travel distances to programs, and inclement weather can all pose major obstacles to program participation [16]. The COVID-19 pandemic has heightened awareness of the need to support caregivers of persons with dementia who were already at risk for social isolation before widespread precautionary restrictions were imposed [18].

To improve access to programs for caregivers who are not able to attend in person, the delivery of psychoeducational support programs through a mobile app is a promising, scalable solution. The ubiquitous nature of smartphones provides unprecedented opportunities for both content delivery and data collection. A systematic review [19] of mobile app-based health promotion programs, such as diet, physical activity, and lifestyle support, found better health outcomes for mobile app users compared with nonusers.

Although extensive research has focused on developing programs to alleviate burden in primary caregivers of persons with dementia [20,21], access to these programs remains limited and fragmented for many family caregivers [17-22]. Improving caregiver access to interventions may be enhanced through the judicious use of technology. A 2018 systematic review [15] of 8 randomized controlled trials of internet-based interventions for primary caregivers of persons with dementia concluded that the use of technology to teach people new coping skills to moderate stress can improve mental health, although marked methodological diversity prevented robust pooling of results.

For primary caregivers of persons with dementia, mindfulness-based interventions [23-27] have been shown to be more effective than traditional education and support. Self-compassion, a specific form of mindfulness training [28], is an approach to dealing with challenging or difficult situations that foster emotionally positive, understanding, and nonjudgmental attitudes toward oneself [29,30]. A systematic review [31] found that higher self-compassion in older adults was associated with lower levels of depression and anxiety and higher levels of well-being. The feasibility and effectiveness of delivering self-compassion programs on the internet has been demonstrated in several studies [32,33], but the proposed investigation is one of the first that we have identified to evaluate a mobile self-compassion program for primary caregivers of persons with dementia.

Objectives

The overall objectives of this project are to: (1) explore the feasibility of a 12-week mobile support program, and (2) conduct an initial efficacy evaluation of changes in perceived caregiver burden, coping styles, and emotional well-being of caregivers before and after the program.

Methods

Design and Rationale

This feasibility study used a 2-phase participatory pretest and posttest design. Feasibility studies, which are considered particularly relevant to real-world settings, help to determine whether an intervention is appropriate for further testing and to identify the modifications in the research methods and protocols required [34]. Areas of focus for feasibility studies can include acceptability, demand, practicality, implementation, and

efficacy. Acceptability refers to the extent to which a program is judged as suitable, satisfying, or attractive to participants, whereas demand can be demonstrated by interest or likelihood of use. Implementation is defined as the extent to which a new program can be successfully delivered to the intended audience [34]. Practicality refers to factors such as efficiency, speed, or quality of implementation and the ability of participants to undertake intervention activities [34]. A focus on limited efficacy involves the evaluation of whether the program shows promise of being successful, as examined by measuring the intended effects of the program on key intermediate variables [34].

Ethics approval for this study was obtained from the University of Saskatchewan (Behavioral Ethics Research Board #1014). Phase 1 involved the co-design of a mindfulness-based self-compassion (MBSC) intervention developed specifically for primary caregivers of persons with dementia. Our interdisciplinary team comprised researchers from the disciplines of nursing, nutrition, and computer science, as well as community representatives. Community advisors included one staff member from the Alzheimer Society of Saskatchewan (ASOS) and 2 patient family advisors (TH and BW). The advisory members helped to ensure all facets of the project

reflected the values and interests of primary caregivers of persons with dementia and contributed to the ecological validity of the project [35]. Two certified MBSC consultants (JS and CG) with extensive experience working with primary caregivers of persons with dementia in the community participated in all team meetings, so that the MBSC content developed addressed the stated needs and preferences of the advisory members. This interdisciplinary approach drew upon complementary expertise and multiple perspectives to create an ecologically relevant program.

On the basis of caregivers' lived experiences and preferences, the expertise of our self-compassion consultants and our review of the literature, the content for a 12-week MBSC and support program was co-designed within a 6-month time frame, incorporating existing web-based caregiver support resources developed by the ASOS or other reputable advocacy agencies (eg, Alzheimer's Association), as appropriate. MBSC consultants developed the original material for this program in the form of 14 podcasts, 12 meditations, and 4 body-based practices. Table 1 describes the co-designed content categories and provides examples of the activities associated with each session.

Table 1. Co-designed app content.

Topics	Links to existing resources	Content example
Communication and dealing with difficult emotions	• Difficult situations (eg, repetition and memory loss; wandering, paranoia) • Difficult emotions (eg, guilt, anger, frustration)	Podcast "Who should Practice Mindfulness and Self-Compassion?"
Coping with stress, anxiety, and depression; Change and transition	• Reducing caregiver stress • Coping • Overwhelm • Rumination • Emotional regulation • YouTube video clip	Cognitive behavioral practice "Thought stopping"
Relationships, intimacy, and sexuality	• Role changes, support, relationship dynamics, protection, loss, dealing with limited supports, boundaries	Meditation "Opening the Heart Space"
Grief and loss	• Ambiguous loss and grief • Anticipatory grief • Loss of roles, relationships, independence, and history • Changes in identity and personality	Meditations "Three Minute Breathing Space"
Caregiver fatigue and stress	• Fatigue and exhaustion • Stress • Depletion • Caregiver burden • Respite • Time for self-care and guilt	Podcast "Introduction to Loving Kindness Practice"
Positive ways to cope with caregiver fatigue and burn-out	• Safety • Insomnia and interrupted sleep • Nutrition and activity	Body scan practice
More positive ways to cope with caregiver fatigue and burn-out	• Developing resilience • Gratitude • Self-care	Podcast "The Power of Gratitude"

The program was delivered using the Ethica platform co-designed and codeveloped by the coauthor NO and Ethica Data Services. The Ethica platform is designed to aid in the creation, delivery, and data collection of smartphone-based apps [36,37]. A computer science student (JN) customized functionalities on the Ethica system to reflect the co-designed program.

Daily ecological momentary assessments (EMAs) sampled participants' responses to the question "How are you feeling today?" The program offered a range of MBSC tools (including bespoke audio and video recordings and links to external resources such as relevant YouTube videos) with varying lengths between 1 and 20 minutes that caregivers could incorporate into their lives in ways that worked best for them [38]. Coping cards (eg, *Talk to yourself like you would to someone you love*) were developed to allow participants to access positive messages about coping and center them in a mindful and self-compassionate mindset.

Phase 2 consisted of a pre- and posttest design using validated instruments delivered through the app and qualitative data from postprogram individual interviews. The target sample size was 40 individuals. Information on demographic characteristics and current participation in support groups was collected after informed consent was obtained at enrollment. The Ethica app was installed on participants' smartphones, and they received proper instruction on the use and privacy guarantees of the technology, including how to temporarily pause data collection. The duration of use data was gathered through the Ethica app use functionality. At the conclusion of 12 weeks or at termination of the program, participants were offered the opportunity to participate in individual telephone or Zoom interviews focusing on the experience of using the app.

Participants

Caregivers were recruited by the ASOS using direct contact and social media, by linking the research team with ASOS caregiver programs in the province, and through media coverage and broadcast interviews. The eligibility criteria for this study included self-identification as a primary caregiver of a community-dwelling family member who has memory loss consistent with dementia, aged ≥18 years, able to read and speak English, and access to a smartphone. Participants received a CAD $100 (US $80.4) gift card to a grocery store of their choice to offset the data plan costs associated with using their personal devices during this study.

Instruments

Caregiver burden, the primary outcome, was measured using the Burden Scale for Family Caregiving (BSFC) [39] at baseline and 1 week after the conclusion of the program through the Ethica app. The BSFC is a widely used 28-item questionnaire developed to identify individual caregiver service needs, predict caregiver health in research studies, and evaluate the effectiveness of programs [40,41]. The degree of subjective burden was expressed as the level of disagreement with the statements. Furthermore, 12 of the 28 items were inversely presented to minimize the potential for response bias. The completion of the BSFC takes approximately 5-10 minutes. The

possible scores ranged from 0 to 84. The BSFC cumulative score is assigned to three levels of subjective burden categories specific to caregivers of persons with dementia: none to mild (0-35), moderate (36-45), and severe (46-84) [42]. Standardization with 1911 subjects established the average BSFC score for caregivers of persons with dementia as 41.9 (SD 14.8); Cronbach α was .92, and test-retest reliability was 0.94 [39].

The secondary outcomes included changes in coping style and emotional well-being. Short questionnaires were delivered daily via the app to the participants on a rotating basis. One 2-item scale from the Brief-COPE instrument [43,44] was delivered every day. The Brief-COPE is a validated, 28-item measure of different coping styles comprising 14 2-item scales [43,44]. Coping styles refer to an individual's response to a psychological stressor, which is often related to a negative event [43]. These styles include self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Total scores were calculated for each scale, allowing us to detect whether changes in coping style occurred over the duration of the program [44]. These scales can be grouped into emotion-focused, problem-focused, and dysfunctional coping styles. Emotion-focused coping styles aim to reduce, alleviate, and/or minimize the unpleasant feelings associated with the stressor and are especially valuable in situations in which the person has little control [44], as can often occur in caring for a person with dementia.

In addition to the Brief-COPE, the World Health Organization (WHO)-5 Well-Being Scale was completed weekly. The WHO-5 is a short, commonly used, psychometrically sound measure of positive emotional well-being with a single cumulative score, where 100 represents the best possible quality of life [45].

Qualitative Data

This paper summarizes data from field notes kept by research assistants during enrollment and program delivery, as well as interview data related specifically to the technical aspects of the app in terms of acceptability, practicality, and implementation for the 72% (21/29) of participants included in the quantitative analyses who also completed the final interviews.

Data Analysis

Pearson correlations were used to assess the relationships between raw scores on the BFSC and personal characteristics (continuous variables), WHO-5 scores, and the three Brief-COPE (emotion-focused, problem-focused, and dysfunctional coping styles) summary scores. Descriptive analyses were performed to detect differences in scores at baseline and at the end of the program on the key variables of interest (ie, burden, coping styles, and well-being). Wilcoxon signed-rank tests were used to compare baseline and final scores on the BSFC, the WHO-5, and the three (ie, emotion-focused, problem-focused, and dysfunctional coping styles) summary scores on the Brief-COPE. A *P* value of <.05 was considered as statistically significant. All statistical analyses were conducted

using the SPSS version 27 (IBM Inc). Content analysis [46] using a deductive approach allowed for the targeted analysis of qualitative data related to acceptability, practicality, and implementation.

Results

Participants

A total of 77 participants were enrolled in the study, although 16 did not open the app. One of these individuals indicated: *"I'm past tired now without reading stuff first to download [the app]...even simple instructions are too much."* Three participants withdrew after several weeks because of busy personal schedules or other priorities and another was found not to own a smartphone.

A total of 53 participants (48/53, 91% female) with a mean age of 58.0 (SD 13.6) years were recruited into the study between September 2019 and March 2020. The persons with dementia for whom participants were caring included spouses (19/53, 36%), parents (17/53, 32%), and other friends or relatives (17/53, 32%) with a mean age of 77.6 (SD 12.0) years. Complete baseline and final data sets (BFSC, WHO-5, and Brief-COPE) were available for 51% (29/57) of participants who completed all questionnaires at both baseline and the end of the program and were included in the data analysis below. Demographic characteristics of excluded participants were compared using 2-tailed *t* tests (age) and chi-square analyses (participant sex, care recipient sex, and age), and no significant differences were detected.

Table 2 displays the demographic and personal characteristics of the participants. The participants were mostly female (26/29, 90%), with excellent or very good health (18/29, 62%) with a mean age of 59.6 (SD 11.3; range 28-79) years. Most participants cared for a spouse or parent (22/29, 76%). The mean age of care recipients was 78.9 (SD 10.1) years.

Table 2. Demographic and personal characteristics (N=29).

Characteristics	Value, n (%)
Gender	
Female	26 (90)
Male	3 (10)
Relation to persons with dementia	
Spouse	11 (38)
Child	11 (38)
Other relative	6 (21)
Friend	1 (3)
Currently work for pay	
Yes	11 (38)
No	18 (62)
Have one or more family members available for support	
Yes	24 (83)
No	5 (17)
Duration of caregiving for persons with dementia	
2 years or less	13 (45)
3-6 years	7 (24)
7 years or more	9 (31)
Participant self-rated health	
Excellent	4 (14)
Very good	14 (48)
Good	9 (31)
Fair	2 (17)
Poor	0 (0)
Rating of persons with dementia health	
Excellent	0 (0)
Very good	4 (14)
Good	5 (17)
Fair	16 (55)
Poor	4 (14)
Persons with dementia behaviors reported	
Memory loss	28 (97)
Refusing help	16 (55)
Repetitive behaviors	15 (52)
Sleep disturbances	13 (45)
Paranoia	10 (34)
Hoarding	8 (28)
Aggression	6 (21)
Wandering	6 (21)
Other	10 (34)
Total number of behaviors reported	
1-3	13 (45)

Characteristics	Value, n (%)
4 or more	16 (55)

Acceptability, Practicality, and Implementation of the App

Understanding the acceptability, practicality, and implementation of using an app to deliver a psychoeducational program targeted at caregivers of persons with dementia was central to this study, especially because of the wide variation in possible caregiver ages and comfort with technology. Participants generally found the app easy to use and user-friendly, although several required additional assistance from the research assistant to address navigation problems early in the program. One participant noted:

> I'm not a very techy person, so I was really nervous about it at first...But anyway, once I got that it was fine.

Many participants noted the convenience of having the content available on their phones:

> I liked that it was on my phone. I liked that I could access it at my convenience. And I do use my phone pretty much like my right hand all the time.

The availability of multiple types of content was very appealing to many participants:

> It's got a variety of different things in one place. I like that. It's like a one stop shop.

The incorporation of EMAs has received numerous favorable comments:

> The most useful part was the, "How are you feeling," survey, every day. It made me sit down and think about the last few hours, and was how stressed I really was, or maybe I wasn't as stressed as I thought I was. And I've come to look forward to that, so I actually have a minute to sit down and say, "Well how was just the last bit?" I found that really, really helpful.

Incorporation of appropriate YouTube videos was appreciated by most participants, but several participants did not like the automatic redirection to alternate videos that were not part of the program. Several commented that they wished that the program could also be available on their computers to improve readability.

Over the 12 weeks of the program, participants' mean hours of app use were 15.60 (SD 28.83) hours with a median time of 5.31 hours (IQR 3.0-11.1).

Outcome Measures

As there was minimal variability in the BFSC, WHO-5, and Brief-COPE subscale scores obtained midprogram and at the end of the program, this study compared only baseline and the final scores obtained on these instruments.

At baseline, the median BFSC score was 45 (IQR 35.5-50; range 31-61). Most participants were categorized as having either no to mild burden (12/29, 41%) or moderate burden (16/29, 55%), with 3% (1/29) reporting severe burden. Table 2 displays the demographic characteristics of the participants according to burden categories. BFSC scores were negatively correlated with emotional well-being ($r=-0.40$; $P=.03$) and positively correlated with the use of avoidance-based coping ($r=0.57$; $P=.001$) and the number of behaviors exhibited by the persons with dementia ($r=0.42$; $P=.02$). There were no correlations between BFSC scores and caregiver age ($r=-0.17$; $P=.39$), duration of providing care ($r=0.30$; $P=.11$); age of persons with dementia ($r=0.10$; $P=.60$), emotion-focused coping ($r=0.08$; $P=.70$), and problem-focused coping ($r=0.07$; $P=.73$).

Table 3 displays the frequencies of the coping strategies reported by the participants at baseline. Emotion-focused coping strategies, particularly acceptance, were most frequently used by participants at baseline. The two acceptance items, "I've been accepting the reality of the fact that it has happened" and "I've been learning to live with it," were used by 52% (15/29) and 45% (13/29), respectively. Almost half (14/29, 48%) also reported frequent use of the problem-focused coping strategy, "I've been thinking hard about what steps to take." Two avoidance and dysfunctional coping strategies were reported by about one-third of participants: "I've been blaming myself for things that happened" (11/29, 38%) and "I've been turning to work or other activities to take my mind off things" (9/29, 31%). There was minimal endorsement of other avoidance and dysfunctional coping strategies.

Table 3. Frequencies of reported baseline coping strategies (N=29).

Coping strategy	Frequency of use, n (%)			
	Not at all	A little bit	Medium amount	A lot
Emotion-based coping strategies				
I have been trying to see it in a different light, to make it seem more positive.	2 (7)	11 (38)	11 (38)	5 (17)
I have been getting comfort and understanding from someone.	3 (10)	10 (34)	5 (17)	11 (38)
I have been looking for something good in what is happening.	7 (24)	8 (28)	9 (31)	5 (17)
I have been making jokes about it.	16 (55)	7 (24)	3 (10)	3 (10)
I have been accepting the reality of the fact that it has happened.	4 (14)	2 (7)	9 (31)	15 (52)
I have been trying to find comfort in my religion or spiritual beliefs.	11 (38)	4 (14)	3 (10)	11 (38)
I have been learning to live with it.	0 (0)	3 (10)	13 (45)	13 (45)
I have been praying or meditating.	9 (31)	4 (14)	5 (17)	11 (38)
I have been making fun of the situation.	21 (72)	7 (24)	0 (0)	1 (3)
Problem-based coping strategies				
I have been concentrating my efforts on doing something about the situation I am in.	2 (7)	9 (31)	9 (31)	9 (31)
I have been getting emotional support from others.	5 (17)	13 (45)	8 (28)	3 (10)
I have been taking action to try to make the situation better.	0 (0)	10 (34)	11 (38)	8 (28)
I have been getting help and advice from other people.	3 (10)	15 (52)	10 (34)	1 (3)
I have been trying to come up with a strategy about what to do.	3 (10)	10 (34)	5 (17)	11 (38)
I have been trying to get advice or help from other people about what to do.	3 (10)	18 (62)	6 (21)	2 (7)
I have been thinking hard about what steps to take.	1 (3)	6 (21)	8 (28)	14 (48)
Avoidance and dysfunctional coping strategies				
I have been turning to work or other activities to take my mind off things.	6 (21)	7 (24)	7 (24)	9 (31)
I have been saying to myself "this isn't real."	17 (59)	8 (28)	2 (7)	2 (7)
I have been using alcohol or other drugs to make myself feel better.	21 (72)	3 (10)	4 (14)	1 (3)
I have been giving up trying to deal with it.	16 (55)	8 (28)	2 (7)	3 (10)
I have been refusing to believe that it has happened.	21 (72)	4 (14)	4 (14)	0 (0)
I have been saying things to let my unpleasant feelings escape.	9 (31)	11 (38)	6 (21)	3 (10)
I have been using alcohol or other drugs to help me get through it.	22 (76)	5 (17)	2 (7)	0 (0)
I have been criticizing myself.	2 (7)	11 (38)	10 (34)	6 (21)
I have been giving up the attempt to cope.	17 (59)	11 (38)	0 (0)	1 (3)
I have been doing something to think about it less, such as going to movies, watching television, reading, daydreaming, sleeping, or shopping.	2 (7)	11 (38)	11 (38)	5 (17)
I have been expressing my negative feelings.	3 (10)	15 (52)	9 (31)	2 (7)
I have been blaming myself for things that happened.	9 (31)	4 (14)	5 (17)	11 (38)

Table 4 displays the demographic characteristics of the participants according to burden categories. BFSC scores were negatively correlated with emotional well-being ($r=-0.40$; $P=.03$) and positively correlated with the use of avoidance-based coping ($r=0.57$; $P=.001$) and the number of behaviors exhibited by the persons with dementia ($r=0.42$; $P=.02$). There were no correlations between BFSC scores and caregiver age ($r=-0.17$; $P=.39$), duration of providing care ($r=0.30$; $P=.11$); age of persons with dementia ($r=0.10$; $P=.60$), emotion-focused coping ($r=0.08$; $P=.70$), and problem-focused coping ($r=0.07$; $P=.73$).

Table 4. Burden ratings and participant and care recipient characteristics (N=29).

Characteristics	None to mild burden (0-41; n=12), n (%)	Moderate to severe burden (≥42; n=17), n (%)
Relationship to persons with dementia		
Spouse	7 (64)	4 (36)
Parent	2 (18)	9 (82)
Other	3 (43)	4 (57)
Currently work for pay		
Yes	3 (27)	8 (73)
No	9 (50)	9 (50)
Caregiver self-rated health		
Excellent or very good	9 (50)	9 (50)
Good, fair, or poor	3 (27)	8 (73)
Persons with dementia health		
Excellent, very good, or good	6 (67)	3 (33)
Fair or poor	6 (30)	14 (70)

Table 5 compares the baseline and end-of-program scores for the outcome measures. No significant change was detectable in the moderate level of caregiver burden reported by the participants following this intervention. A statistically significant (P=.04) increase in emotional well-being as measured by the WHO-5 was noted. No differences were evident in the Brief-COPE scores for problem-based or avoidance and dysfunctional coping, but the decrease in emotion-focused coping was statistically significant (P=.01).

Table 5. Comparison of baseline and end-of-program scores.

Outcome	Baseline median (IQR)	End median (IQR)	WS-R[a] (Z score)	P value
Burden scale	45 (35.5-50)	42 (35-48)	−0.56	.57
WHO-5[b]	52 (28-72)	52 (32-80)	−2.09	.04[c]
Brief-COPE emotion-based coping	18 (15-22)	15 (13-18.5)	−2.49	.01[c]
Brief-COPE problem-based coping	18 (15-22)	18 (15-21.5)	−0.45	.66
Brief-COPE avoidance and dysfunctional coping	21 (18-15.5)	21 (17.5-26.5)	−0.55	.59

[a]Wilcoxon signed rank.

[b]WHO-5: World Health Organization-5.

[c]Difference statistically significant at P<.05.

Discussion

Principal Findings

This study examined 4 aspects of feasibility (acceptability, practicality, implementation, and efficacy) in relation to a co-designed web-based support program for primary caregivers of persons with dementia delivered via an app on a smartphone. Our deployment results revealed that participants valued the *one-stop shop* approach of having a range of MBSC practices (acceptability) available on their personal smartphones (practicality) that could be used to support them in their caregiving challenges. A few technical problems were experienced, and the app was considered easy to use (implementation). This is especially important in studies such as this, where participants are anticipated to lack the high comfort and smartphone skills (ie, digital literacy) of digital-native generations [47].

The interdisciplinary collaboration between health care researchers and computer scientists afforded a unique opportunity to capitalize on the expertise of multiple disciplines and to deploy a program in a reasonably short window. Although each discipline has its own unique body of knowledge and jargon, ongoing discussions between team members allowed all the voices to be heard in a respectful manner, to achieve consensus on key aspects of the project, and to undertake a study that no one team member could have achieved without such a collaboration.

The participatory, co-design approach to this project ensured that the perspectives of key stakeholders such as primary caregivers of persons with dementia and the Alzheimer's Society were incorporated into content and program development, which we consider a strength of our project. The value of co-designed programs has been amply demonstrated in the literature, notably in the field of technological support for chronic diseases and/or ailments, given the purposes of our research [48,49]. Despite

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some challenges that can stem from co-designed programs (eg, time issues can interfere with a fully democratic process [49]), they remain the gold standard for program development in the field of integrated care [50]. The advantages of co-designed support apps such as ours include knowledge cocreation across technical solutions, lived experience, and medical expertise [48] and the reduction of social health inequalities [50]. For caregivers of functionally dependent adults like many of the primary caregivers of persons with dementia in our research, co-designed support apps have shown value by enabling caregivers to identify their needs and tailoring the support program accordingly [49]. Moreover, inclusivity and feasibility are enhanced through co-designed programs because users and/or stakeholders can provide insight into important considerations, including appropriate digital literacy levels and respect for the help-seeking process of users [50].

By incorporating perspectives of primary caregivers of persons with dementia and members of the Alzheimer's Society in the development process of our support program, we adhered to the guiding principle of integrated care [50]. In addition, by collecting feedback from the primary caregivers of persons with dementia in the form of semistructured interviews post program completion, the co-design approach will be built into future iterations of the program or app design. Overall, participants and invested stakeholders (eg, members of the Alzheimer's Society) shaped this version of our program and offered suggestions to improve it moving forward. It is our view that committing to a user-centered support program promotes optimization of the final product, at least in part, through the enhanced acceptance, usability, and feasibility of its users.

The content and data collection instruments were successfully delivered via the smartphone as planned, but only 51% (29/57) of participants completed all questionnaires. Although data collection using smartphones offers the advantages of ecological validity and real-time data, missing data in these types of studies is a well-recognized problem [47]. The participant burden of completing the data collection protocol, which involved multiple administrations of 3 questionnaires throughout the 12-week program, likely contributed to missing data in this sample of caregivers and was noted by some of the participants. Future studies with primary caregivers of persons with dementia delivering programs via smartphones should consider whether interviewer-administered data collection can be integrated into studies.

Evaluation of the short-term efficacy of this intervention to support primary caregivers of persons with dementia yielded mixed results. During this feasibility study, participants chose their own level of engagement with the content of the program, and the hours spent on the content varied widely, as did the content that was accessed by participants. As this study sought to establish the feasibility of delivering this program via smartphones, the duration of the program and follow-up period were relatively constrained.

No change in caregiver burden scores was detectable immediately following the program, which may be attributable to several factors. As caregiver burden is influenced by diverse factors [51], including the cognitive function of persons with dementia, hours spent caregiving, the caregiver's level of social support, and previous caregiver experience, any positive impact of beginning to incorporate an MBSC approach may have been overshadowed by these other factors. We encourage future researchers to examine whether some of these exogenous factors may impede the efficacy of MBSC programming. In addition, the relatively short duration of the program may have contributed to the lack of change in burden.

As there was no significant reduction in caregiver burden, our primary outcome measure, from baseline to post intervention (P=.57), we conducted a post hoc reliable change index analysis in an effort to detect individual changes. The results of the reliable change index showed that 7 participants had a statistically significant reduced burden, whereas 1 participant had a significantly increased burden from baseline to post intervention.

No differences were detected in problem-based or avoidance-dysfunctional coping styles, but there was an unexpected decrease in emotion-based coping. We suspect that a variety of factors contributed to this decrease in emotion-based coping following our intervention. For instance, diminished health of persons whom our participants were caring for might have made it more difficult for caregivers to engage in emotion-focused coping behaviors that make light of the situation, like "I've been making jokes about it." Some of our participants noted in the follow-up interviews that the health of their loved ones deteriorated significantly over the course of the 8-week program, which could have been partly responsible for the unexpected decrease in emotion-based coping approaches. The introduction to MBSC approaches in this study could potentially strengthen cognitive restructuring as a coping strategy but has not been identified as affecting the degree to which people use problem solving or avoidance and dysfunctional coping [52].

Emotional well-being of participants showed a small, but statistically significant improvement, although this failed to meet the 10% change in scores recommended to signify a *clinically* significant difference. Around 48.3% (14/29) of participants scored lower than 50 on the WHO-5 and met the criteria for screening for depression, highlighting that caregivers are at risk for adverse emotional sequelae.

Strengths and Limitations

Our study enabled primary caregivers of persons with dementia to access resources from the convenience of their smartphones that they may not otherwise have been able to use, especially considering that some of the content was developed specifically for this project (eg, MBSC podcasts). Although it is possible that some of the primary caregivers of persons with dementia could attend in-person support groups where similar content could be available, others cited their geographic isolation in remote communities or rural settings as a barrier to doing so, and that having the material so readily available to them was particularly helpful, as was the user-friendly nature of our app and content. In addition, with current COVID-19 restrictions, in-person support group meetings may be less prevalent in various locations.

One potential shortcoming of our research is rooted in the nature of feasibility studies, as not all possible outcomes can be measured. To reduce the burden on respondents, we did not measure changes in MBSC, which have typically been evaluated using the Self-Compassion Scale (SCS) [53]. However, given that there might be a connection between MBSC and reduced caregiver burden, we recommend future programs including the SCS or perhaps its short-form.

Because of missing data, only half of the questionnaires could be included in the final analyses, although we found no differences in the demographic characteristics of those who completed all questionnaires and those who did not.

The experimental nature of our study ensured that we assessed measures pre- and postintervention. However, a control group was not included in our study, which can be considered a limitation. The rationale behind our decision to not include a control group was to ensure that participants were not deceived, particularly given their vulnerable status as primary caregivers of persons with dementia, and also to better assess the feasibility of our program by enrolling all participants in it. Ultimately, we wanted to know if the core elements of our program were well received by participants, although we acknowledge that it might be advisable for future iterations to include a control group. In addition, a 1-month postintervention follow-up assessment is recommended to researchers to examine whether intervention effects can withstand the test of time. In this study, we interviewed participants approximately 1 month after they completed the program to collect their thoughts on its acceptability, implementation, and feasibility, although quantitatively assessing primary outcome measures would be advantageous.

An additional limitation is that the vast majority of participants were female (26/29, 90%), meaning that although the program was received favorably overall, its generalizability is somewhat unknown. For instance, the male primary caregiver of persons with dementia might reject our program initially or they might not find it effective. However, there was male representation among our patient family advisors (ie, TH), though perhaps future iterations of the program should be informed by a more equal representation of males and females across varying age groups.

Future Directions

Our program as currently structured has value and utility for primary caregivers of persons with dementia, as evidenced by our results and in postintervention interviews with our participants. However, we acknowledge ways that our program could be improved in future iterations, starting with usability. Specifically, some participants expressed that they felt burdened by certain inclusions (eg, daily EMAs), whereas others valued these inclusions. Accordingly, we recommend that future

versions have optional EMAs, for example, where participants can choose the number of daily EMAs (eg, maximum of 2/day, minimum of 2/week, for instance). We also encourage researchers to use a version of our program to include a measure of MBSC—specifically, the SCS—at each time point, as a way to determine whether mindful self-compassion levels increase following the MBSC intervention.

Other considerations for future iterations of our program include weekly web-based meetings among small groups of participants via breakout rooms, to enhance a sense of community and/or support that was lacking in the current version. These breakout rooms could be moderated by an *expert* in the field from the research team to ensure that participants' questions were addressed or answered. In addition, a postintervention focus group *wrap up* session could be delivered virtually, where the primary caregivers of persons with dementia could connect with the experts and one another. Finally, as communicated by participants, more coping cards and a clearer layout of each week's content should be introduced.

As noted in a thematic literature analysis by Rampioni et al [54], collaboration between researchers, technology developers, patients, and caregivers remains a significant challenge in developing technologies appropriate to support dementia. Our future directions include sustaining the interdisciplinary, community-involved team we have developed and potentially expanding the team to include additional disciplines such as psychiatry and social work.

Conclusions

Our study is one of the first to co-design and deliver an MBSC program for caregivers of persons with dementia using a smartphone. We believe that the findings of this study have demonstrated the feasibility and demand for this type of web-based program and identified the key challenges to be addressed in future studies. Specifically, it is our view that an MBSC program for primary caregivers of persons with dementia, like the one presented in this study, can be particularly helpful for individuals in rural or isolated communities, with limited access to support groups. In addition, this feasibility study has helped identify key outcome variables that were left out of this version (eg, self-compassion), while also enabling us to address intervention elements that can be altered (eg, daily EMAs) or incorporated in the next installment of our intervention (eg, web-based breakout groups to develop both a sense of community among primary caregivers of persons with dementia lacking in the current iteration and to enable participants to ask questions as they progress through the intervention). Our findings will inform the development of future iterations of the MBSC program and will contribute to the evidence on strategies to better support caregivers of persons with dementia.

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Conflicts of Interest

None declared.

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Abbreviations

ASOS: Alzheimer Society of Saskatchewan
BSFC: Burden Scale for Family Caregiving
EMA: ecological momentary assessment
MBSC: mindfulness-based self-compassion
SCS: Self-Compassion Scale
WHO: World Health Organization

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Original Paper

Dementia Caregiver Experiences and Recommendations for Using the Behavioral and Environmental Sensing and Intervention System at Home: Usability and Acceptability Study

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Abstract

Background: Caregiver burden associated with dementia-related agitation is one of the most common reasons for a community-dwelling person living with dementia to transition to a care facility. The Behavioral and Environmental Sensing and Intervention (BESI) for the Dementia Caregiver Empowerment system uses sensing technology, smartwatches, tablets, and data analytics to detect and predict agitation in persons living with dementia and to provide just-in-time notifications and dyad-specific intervention recommendations to caregivers. The BESI system has shown that there is a valid relationship between dementia-related agitation and environmental factors and that caregivers prefer a home-based monitoring system.

Objective: The aim of this study is to obtain input from caregivers of persons living with dementia on the value, usability, and acceptability of the BESI system in the home setting and obtain their insights and recommendations for the next stage of system development.

Methods: A descriptive qualitative design with thematic analysis was used to analyze 10 semistructured interviews with caregivers. The interviews comprised 16 questions, with an 80% (128/160) response rate.

Results: Postdeployment caregiver feedback about the BESI system and the overall experience were generally positive. Caregivers acknowledged the acceptability of the system by noting the ease of use and saw the system as a fit for them. Functionality issues such as timeliness in agitation notification and simplicity in the selection of agitation descriptors on the tablet interface were identified, and caregivers indicated a desire for more word options to describe agitation behaviors. Agitation intervention suggestions were well received by the caregivers, and the resulting decrease in the number and severity of agitation events helped confirm that the BESI system has good value and acceptability. Thematic analysis suggested several subjective experiences and yielded the themes of usefulness and helpfulness.

Conclusions: This study determined preferences for assessing caregiver strain and burden, explored caregiver acceptance of the technology system (in-home sensors, actigraph or smart watch technology, and tablet devices), discerned caregiver insights on the burden and stress of caring for persons living with dementia experiencing agitation in dementia, and solicited caregiver

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input and recommendations for system changes. The themes of usefulness and helpfulness support the use of caregiver knowledge and experience to inform further development of the technology.

Introduction

Background

Caregiver burden associated with dementia-related agitation is one of the most common reasons for a community-dwelling person living with dementia to transition to a care facility. Agitation is a highly prevalent behavior and is one of the most persistent neuropsychiatric symptoms associated with dementia [1,2]. Several studies have examined the use of technology for the detection and prediction of agitation in dementia [3]. A review of smart health technologies for persons living with dementia and their caregivers found that most technologies address activities of daily living but not behavioral changes and fail to involve the end user's experience in the development of products [3]. A review of home-based monitoring systems for early agitation detection that promotes the use of behavioral interventions calls to attention the fact that research must involve caregivers and persons living with dementia and be flexible enough to meet the need for individualization of the systems [4]. Management of disruptive behaviors for caregivers of persons living with dementia was identified in 8 of 118 mobile apps. In a discussion with 4 caregivers, only 2 apps were preferred as helpful, specific intervention strategies [5].

A design framework to guide smart health technology development in caregivers of persons living with dementia was based on a review of factors influencing the adoption of technology, including ethical issues, and identified challenges for both cognitive and physical decline [3]. Challenges of mobile app users in protecting privacy were identified within the theme of helplessness related to the overwhelming nature of the digital world [6]. In-home monitoring of persons living with dementia was studied for unobtrusive preferences in both formal and informal caregivers. Both felt potential benefits in more proactive responses to the needs of persons living with dementia [7]. The COVID-19 pandemic brought increased urgency in the development of remote monitoring systems, which are applicable to our focus on agitation with dementia.

The Behavioral and Environmental Sensing and Intervention System

The Behavioral and Environmental Sensing and Intervention (BESI) for Dementia Caregiver Empowerment system (Figure 1) for persons living with dementia and caregivers living together (dyads) at home uses sensing technology, smartwatches, tablets, and data analytics to detect and predict agitation in persons living with dementia [8]. The BESI project was a 3-phase study completed over 6 years with the goal of understanding the environmental and interpersonal factors that influence persons living with dementia agitation, caregiver stress, and the impact of agitation on the caregiver. The unit of study in the BESI project was the dyad. The BESI system was deployed in the dyads' homes for 30- or 60-day trials. The 60-day trials included just-in-time notifications and dyad-specific intervention recommendations to caregivers that were based on the clinical assessment completed at intake, interviews with the dyad, and demographic information. This innovative system was designed to provide caregivers with a potential early warning for episodes of agitation and provided an opportunity for caregiver awareness and intervention before behavioral distress occurred, thus reducing caregiver burden and improving quality of life.

We conducted predeployment interviews with each dyad to assess the history of agitation, other neuropsychiatric symptoms, cognition, sleep, burden, self-efficacy, quality of life, depression, dementia staging, and functional assessment using standardized assessment tools. Postdeployment interviews were conducted on system value, usability, and acceptability. The BESI system showed that there is a valid relationship between dementia-related agitation and environmental factors and that caregivers prefer a home-based monitoring system [9].

In our follow-up study, implementing a Caregiver-Personalized Automated Non-Pharmacological Intervention System (CANIS) for dementia-associated agitation, we sought additional input from caregivers for a narrative of their experiences months after the completion of the BESI study. The interviews included open-ended response questions at the end of each category. The primary aim was to use information from caregiver interviews to inform technological preferences and assess insights and impact on caregiver mood and burden.

Figure 1. The Behavioral and Environmental Sensing and Intervention (BESI) system. The components of the system are (a) BESI environmental sensing nodes deployed in houses with people living with dementia, (b) a wearable sensor used to monitor behaviors of people living with dementia, and (c) tablet and wearable applications for caregiver interfacing, such as delivering agitation intervention suggestions.
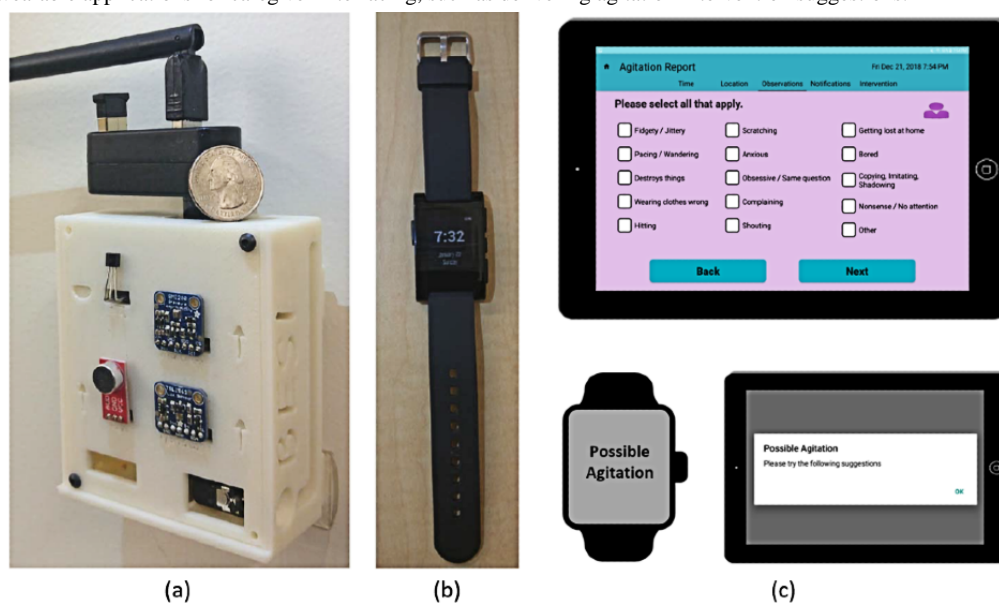
Context and Objectives of the Study

Following the completion of the BESI study, we embarked on the CANIS study to help further the process of automating the personalized interventions developed with BESI. As part of BESI, phase 3, we evaluated several dementia-related interventions and suggestions and categorized them as intellectual stimulation or interpersonal communication. The intervention categories were accompanied by appropriate suggestions for interventions. For example, dementia-related suggestions in the interpersonal communications category could be *ask yes or no questions if possible* or *offer distracting activity during personal hygiene care, for example, hand them a washcloth to clean their face*. Our team linked the intervention categories to the individual responses of the clinical assessment tools in CANIS to create interventions and suggestions for each dyad that were customized to their needs.

The aim of this study is to determine preferences for assessing caregiver strain and burden, explore caregiver acceptance of the technology system (in-home sensors, actigraph or smart watch technology, and tablet devices), discern caregiver insights on the burden and stress of caring for persons living with dementia experiencing agitation in dementia, and study caregiver input and recommendations for system changes.

Methods

Recruitment

The study was conducted in southeastern United States. We mailed letters to caregivers who participated in BESI phases 2 and 3 to determine their interest in participating in CANIS. Only 4 responded to the letter, with 2 declining to participate and 2 who became our first interviewees. Our institutional review board subsequently granted permission to contact previous caregivers in their preferred method of communication (letters, phone calls, SMS text messages, or emails), as established in the BESI study. We obtained 10 agreements for interviews with

these previous participants in the BESI study. Of these 10, 4 of the responding dyads had participated in phase 2 only, 4 in phase 3 only, and 2 dyads had participated in both the phases. Thus, 6 of the 10 original dyads from phase 2 and all 6 dyads from phase 3 participated in CANIS.

Procedure

Written informed consent was obtained from all the participants. All 10 semistructured interviews, which were recorded, were conducted by 1 researcher (MSA). The research coordinator transcribed all 10 interviews. Of the 10 dyad participants, interviews for 7 were completed in person and for 3 were conducted over the phone. The interviews lasted approximately 75-100 minutes. These CANIS participants were invited to receive feedback from the initial BESI phase 2 caregivers, and 9 of the 10 caregivers agreed to this. The caregiver who declined chose to participate in the other semistructured interview questions that asked for thoughts and feelings in interactions with the BESI system. Participants were offered an honorarium of US $50. The study was approved by the health system's Institutional Review Board (CANIS: IRB-19-517#).

Data Analysis

Analysis began with the first author (MSA) reading and reviewing personal interview notes and transcriptions, repeating the review of each interview multiple times to determine the general nature of the material. Next, words and phrases related to similar ideas or constructs were identified. These findings were then coded, grouped into categories, and related to the group of interviews. Feedback topics were categorized, and the second author (AB) reviewed the material with back-and-forth discussions of categories and codes leading to condensation, subcategories, and subthemes. This process continued until the 2 authors agreed upon the findings [10-12] and determined the themes.

The Progressively Lowered Stress Threshold model [13,14] was applied conceptually to understand the impact of agitation

in dementia. The Progressively Lowered Stress Threshold model demonstrates that increasing stress over time leads to outbursts and that changing the environment can help reduce stress and behavioral outbursts. Thus, recommendations for dementia agitation interventions need to be individualized to the dyad to be the most effective [13-15]. Gaining information about BESI system usability was essential in order to offer individualized recommendations.

Efforts to engage caregivers in the development of the system were made throughout the BESI study. One of the initial steps in the BESI study was to engage with caregivers in defining descriptive words for agitation and involved research team members attending multiple Alzheimer association support group meetings [15]. An original list of agitation descriptors from the Cohen-Mansfield Agitation Index [16,17] was shown to support group members in eliciting other word suggestions. The goal was to allow each dyad to capture its own unique descriptors of its experiences of agitation. In the early phases 1 and 2 of BESI, participant-oriented design decisions included the preferred method of communicating (email, SMS text message, or phone), more concise assessments of both members of the dyad, and determining of the layout of the home before the placement of sensors [8]. This study focused on caregiver input months after the initial participation. Although persons living with dementia were not interviewed here, they were involved throughout intake, assessment, and postdeployment in the BESI study. Most caregivers chose not to have the persons living with dementia present during the interviews. The research team has worked together for over 6 years and has consistently involved end users in developing and responding to changes in the technology. The importance of these follow-up interviews for thematic analysis is essential for guiding further understanding.

Assessment Scales

An extended battery of standardized assessment scales was administered during the first home visit in the BESI study [8]. Geriatric clinicians, both a geriatric psychiatrist and 2 advanced practice nurses, administered all the tests. Assessments were selected for both the caregivers and the persons living with dementia. The goal of reducing burden or depression accompanied the technology goal of identifying early agitation to reduce problematic behavior escalation. In Multimedia Appendix 1, the assessment scales are listed by those measuring caregiver status and those measuring the status of the person living with dementia. Depression, sleep, confidence in caregiving, burden and strain, and caregiver distress were assessed as being related to caregivers [18-20,22,23]. Cognition and functional levels, neuropsychiatric symptomatology, agitation, depression, quality of life, and sleep quality were specific to persons living with dementia [17,21,23-29].

Automated intervention suggestions were piloted in the last 5 dyads in phase 3. The clinical team identified unique intervention recommendations based on the completed assessment scales and intake interviews. The suggested interventions were sent in response to system detection of an agitation event, even if the caregiver did not confirm the agitation. Notifications were sent to the caregivers on their smartwatches in all phase 3 deployments during the second 30 days. For deployment 1, the notification text asked, "Is this agitation," and the caregiver's response was "yes" or "no." In the remaining deployments (ie, 2-6), the notification merely stated *Upcoming Agitation*.

Qualitative Analysis

Interview transcriptions and personal interview notes were read and reviewed multiple times to determine the general nature and themes of the responses. *Meaning units* from prior BESI caregiver interviews guided the process. Meaning units were defined as categories of subjective opinions about participating in the research and asked for agreement or disagreement with those opinions. We then asked the participants for additional thoughts, allowing open-ended responses. Words and phrases were classified based on their relationships with similar ideas. Inductive analysis [10] led to the condensation of the transcripts into positive or negative responses. These findings were grouped into categories and related back to caregiver interviews. Researchers used an inductive approach in these interviews to seek insight and reflection on the initial themes. As the data were analyzed, themes consistent with caregivers' subjective experiences were clarified. The authors reviewed the material and discussed the findings until they were in agreement. The interviews in this study sought reflections on the cascade of responses regarding caregivers' subjective experiences, which are categorized in Textbox 1.

Positive and negative responses were reviewed to interpret the data. Whether the response was positive or negative, discussions between the first 2 authors determined whether the agreement was related to the interview question. Quotations from participants were studied and discussed back and forth to determine their thematic relevance.

Example quotes and meaning units of the subjective experiences of BESI phase 2 caregivers were shown to the phase 3 caregiver group. They were then asked, "Do you agree with this finding?" (with *yes* indicating a positive response) and "Do you have any additional thoughts on this?"

Understanding how caregivers felt about participating in the research was important in evaluating their acceptance of the technology and its presence in their homes. First, caregivers were asked to think back to their time of participation and recall whether they had negative or positive experiences. In total, 9 caregivers responded with positive comments, such as, "it made me stop and think; I try to view each day as a learning opportunity" and "anything that keeps everything quiet, calm or happy."

Of these, 3 other positive responses mentioned the support of the team, and 2 addressed the future—*someone will benefit*. The 1 negative comment noted, "It was complicated to keep up with it all." A range of experiences from *no difficulty* to *no help* was reported.

Textbox 1. Categorization of the caregivers' subjective experiences.

Categorization of the caregivers' subjective experiences

1. No difficulty: covers a variety of brief responses regarding the use of Behavioral and Environmental Sensing and Intervention (BESI) technology or their impact on the behavior of persons living with dementia. This includes using the tablet, BESI application, in-home sensors, and smartwatches.

2. Functionality: describes the targeted actions required to record data in the BESI application or smartwatches; ease of use.

3. Recommendations: specific information about how the BESI system as a whole could be improved to make caregiving tasks easier or better customized to their needs.

4. Future capability: includes input on ways to maximize the usefulness of the BESI technology as a future product for caregivers of persons living with dementia.

5. Esthetics: most often, references to having in-home sensors mounted on their walls, including having sensors falling from walls and even damaging paint and wallpaper.

6. Intrusiveness: describes unusual behaviors in persons living with dementia related to having sensors in their homes.

7. No help: describes caregiver feelings about the BESI system being of no use in reducing the intensity or improving the challenging nature of caregiving.

In this study, we shared qualitative quotes from our earlier work [31], seeking input and asking caregivers if they agreed or disagreed with the statements. Interviewers then offered open-ended questions to gain additional thoughts and insights. Table 1 presents an example of coding in the thematic analysis of caregiver responses to the subjective experience.

Table 1. Caregiver-Personalized Automated Non-Pharmacological Intervention System (CANIS) example of coding in the thematic analysis of caregiver responses to the subjective experience.

Feedback topic	Phase 2 BESI[a] qualitative quotes	Meaning units	Caregiver follow-up interviews: "Do you agree with this statement?"		Condensation	Subtheme	Theme
			Yes	No			
Incorporation and impact of all the aspects of the BESI technology on the behavior of persons living with dementia	"They were not a bother to use."	No difficulty	8	1	Positive; because of functionality	Agreeability; ease of use	Usefulness
Caregiver perceptions of actions necessary to record data with the BESI technology	"If we were out, I sometimes did not remember exact time of agitation occurrence...At times I would forget to make a(n) entry upon return."	Functionality	7	2	Negative; because of difficulty with functionality and burdensome	Burden; frustration; and negative ease of use	Usefulness
Customization of the BESI system to better serve caregiver needs	"Not much, maybe to be able to add to the choice on the Daily report page."	Recommendations	8	2	Positive; because of functionality, ease of use, recommendations, and give "own thoughts"	Personalization; future potential	Helpfulness
Ways to maximize usefulness of the BESI technology as a future product for caregivers of persons living with dementia	"Ability to measure over time their attitude and activities that set off the agitation."	Future capability	9	0	Positive; because of recommendations on functionality	Personalization; future potential	Helpfulness

[a]BESI: Behavioral and Environmental Sensing and Intervention.

Results

Demographics

Descriptive statistics and demographic information for the 10 unique caregivers interviewed and information about the person living with dementia in each dyad are presented in Table 2. Caregivers were mostly female (n=8) and were well-educated, 6 had bachelor's degrees, and the other 4 had high school diplomas. The mean age was 65.80 years (SD 15.1 years; R=45). All caregivers were White despite efforts to recruit a diverse population. Days between deployment and the time of the CANIS interview indicate the most recent data collection in an earlier phase of the BESI study and ranged from 253 to 1076 days.

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Table 2. Demographics and description of Caregiver-Personalized Automated Non-Pharmacological Intervention System (CANIS) dyads.

Caregiver characteristic	Deployment phase and dyad ID											
	Phase 2 (P2)						Phase 3 predeployment (P3 pre)					
	D1[a]	D3[a]	D4	D6	D9	D10	D1[a]	D2	D3[a]	D4	D5	D6
Age (years)	73	78	82	56	70	43	79	77	74	60	80	37
Sex	Male	Female	Female	Female	Female	Female	Female	Male	Male	Female	Female	Female
Education level	BS[b]	BS	BS	BS	BS	HS[c]	BS	HS	BS	BS	HS	HS
Days between deployment and interview	—[d]	—	1029	1036	806	780	1076	456	1164	356	253	313
Assessments												
NPI-Q[e] Symptom Severity	10	18	9	3	20	18	23	13	10	23	10	26
NPI-Q Caregiver Distress	11	27	14	3	24	24	31	11	15	23	48	37
CMAI-C[f] frequency	35	69	45	60	92	69	119	54	46.5	86	50	100
CMAI-C behaviors	2	10	8	13	18	15	13	11	6	16	7	17
Cornell Scale for Depression in Dementia	5	15	6	4	15	21	23	20.5	7	12	11	15
Center for Epidemiologic Studies Depression Scale	4	26	13	19	33	10	18	4	6	14	13	40
Quality of Life-Alzheimer Disease	37	26	27	36	33	25	27	30	39	29	28	18
Pittsburg Sleep Quality Index	2	3	4	6	8	7	13	1	7	4	5	16.5
RSSE[g]-respite	54	50	66	98	24	30	20	56	83	100	40	0
RSSE-behavior	100	50	52.5	60	82	90	63	84	100	50	70	68
RSSE-thoughts	90	92	72.5	95	28	81.6	91	76	93	87.5	55	56.3
Zarit	21	18	20	16	35	14	13	9	23	15	24	34
Barthel	85	95	75	85	90	60	75	75	75	40	70	75
Caregiver Strain Index-CANIS only	—	—	5	6	9	10	7	8	8	12	8	12

[a]Identical dyads.

[b]BS: bachelor's degree.

[c]HS: high school.

[d]Dyad participated in both phase 2 and phase 3, thus more recent measures were used.

[e]NPI-Q: Neuropsychiatric Inventory Questionnaire.

[f]CMAI-C: Cohen Mansfield Agitation Inventory-Community form.

[g]RSSE: Revised Scale for Caregiving Self-Efficacy.

Insights Into Caregivers per Assessment Scales

Caregiver assessments by the clinical team offered other insights into the aspects of the dyad. Caregiver burden and strain caused by agitation in the person living with dementia significantly contributed to transitions to care facilities. In the CANIS study, 2 persons living with dementia had moved to assisted living facilities since their participation in the BESI study. Both caregivers remained active in visiting and supporting the person living with dementia. In total, 1 person living with dementia died. The extended time from the BESI study to follow-up interviews in the CANIS study may have contributed to the evolution of placement or decline.

Caregivers reported agitation in the person living with dementia as a criterion for study participation and also mentioned it in the measures of the Cohen-Mansfield Agitation Inventory [23] and Neuropsychiatric Index [19]. All persons living with dementia scored positive for dementia with the Modified Mini Mental State Examination measure of cognitive function (mean 48.9, SD 28.42; R=83.00), where a score <79 indicates cognitive impairment. Functional Assessment Staging is another measure

of cognition with scores ranging from normal to Alzheimer disease; all persons living with dementia scored ≥4, indicating mild dementia, (mean 6.7, SD 2.98; R=8.00).

Caregiver scores on the Zarit Burden Scale [20] showed a mean of 19.43 (SD 8.05; R=26; maximum score=48), with higher scores indicating greater burden. Of them, 1 caregiver rated burden as rare, 2 rated it as moderate, and 9 rated it as mild to moderate. None of the participants rated the burden as severe. Burden was not excessive in these caregivers.

The Caregiver Strain Index (CSI) [21] has recently been used in research on older adults. This scale was introduced in the CANIS study. We asked caregivers for their preference or if they found one more helpful or appropriate, as burden and strain are often major concerns in caregiving. In a large national study of older adults in caregiving roles [31], caregivers of persons living with dementia in the last 12 months of life had double the amount of strain, as measured by 2 national surveys. There was no clear preference for assessment in these caregivers, as the Burden (Zarit) scale was preferred by 5 caregivers and the CSI scale was preferred by 4 caregivers. For the CSI, a score of 7 or higher indicates a high level of caregiver strain (mean 8.5, SD 4.95; R=7). Caregivers rated a score of >7 7 times, indicating a greater burden than was measured with the Zarit scale, despite no clear stated preference between the scales. The CSI asks for responses as yes (score=2), sometimes (score=1), or no (score=0) and is summed. The Zarit is also summed but offers more choices as to whether burden occurs never (score=0), rarely (score=1), sometimes (score=2), quite frequently (score=3), or nearly always (score=4). A caregiver explained that there was no preference stating the following:

> The first one (CSI) had questions that made me reflect that I am perhaps guilty about the issue. Although I can still answer it.

Others preferred the Zarit because it offered *more flexibility* with the larger range of responses or because it was *deeper and more relevant*. It is essential that burden and strain are addressed in dementia caregivers, whichever valid tool is selected.

Depression in caregivers was assessed using the Center for Epidemiological Studies Depression Scale [24]. Higher scores indicate more symptoms. The maximum level of depressive symptoms is 60. The mean depression score was 14.1 (SD 9.85; R=36); only 3 scored >25 to 40. The caregivers did not indicate that they were significantly depressed.

The Cornell Depression Scale [25] rates depression in persons living with dementia by caregiver observation of severity; ratings are unable to evaluate, absent (score=0), mild to intermittent (score=1), and severe (score=2). Scores >12 indicate probable depression in the person living with dementia. In total, 7 persons living with dementia scored >12. These persons living with dementia severity scored X=13.93, SD 6.28, and R=19. Caregivers perceived the person living with dementia to be depressed.

The presence of a burden and even mild depression in caregivers could impact their responses. Overall, the assessment scores did not reveal excess burden or depression in caregivers, even though they felt differently about the persons living with

dementia. We assessed the quality of life of the persons living with dementia using the Quality of Life-Alzheimer Disease scale [26]. This instrument is based on caregiver input (X=29.10, SD 5.21; R=21). The scores indicate good ratings for the group.

Caregiver measures for confidence in 3 aspects of caregiving were measured using the Revised Scale for Caregiving Self-Efficacy [19]. Higher scores indicate greater confidence. The mean for the Revised Scale for Caregiving Self-Efficacy for obtaining respite was 51.70 (SD 34.53; R=100), for responding to disruptive behaviors was 71.95 (SD 16.54; R=50.00), and for controlling upsetting thoughts about caregiving was 73.59 (SD 21.42; R=67.00). Caregivers demonstrated high confidence, especially in the latter 2 categories. Obtaining respite was a midpoint mean and was supported by 8 caregivers spending up to 24 hours/day with the person living with dementia and the remaining 2 spending more than 12 hours/day. The opportunity to obtain respite is challenging in these time commitments of caregiving. Sleep, as measured by the Pittsburg Sleep Quality Index [21], was X=7.15, SD 4.55, and R=15.50, where scores >5 indicate poor sleep quality. Half of the caregivers rated the sleep quality of the person living with dementia as >5. Sleep difficulties and decreased confidence in obtaining respite may demonstrate the burden of caregiving. Impaired sleep quality is a known cause of additional stress for caregivers of persons living with dementia [2].

Caregivers expressed strain and burden, saying, "It's just like nothing helps" and expounding on the particular difficulty with agitation and participating in the study, "That's part of the burden. You have a to deal with the agitation, then recording it." It is difficult to see changes in persons being cared for while losing social connections and privacy and often experiencing financial and physical changes [20,21], especially with functional changes in persons living with dementia at the end of life [22] or with disease progression.

Agitation in the person living with dementia, as measured by caregivers with the Cohen-Mansfield Agitation Inventory for frequency (X=72.15, SD 25.67; R=74.00; maximum 203) and behavior occurrence (X=12.40, SD 4.27; R=12.00; maximum 29), was in lower quantities. Neuropsychiatric symptom severity (X=15.64, SD 7.56; R=23.00; maximum 36) was mild to moderate, and distress experienced by the caregiver because of the symptoms (X=23.00, SD 13.23; R=45.00; maximum 60) was mild. Agitation can create a burden even if symptoms are not severe or very frequent [1], and it is one of the most significant symptoms of dementia leading to institutionalization [1].

Themes

Analysis of caregiver interviews in the CANIS study regarding participation in research with the BESI system revealed themes of usefulness and helpfulness with subthemes of agreeability and ease of use. The theme of usefulness was derived from both positive feelings about the ease of use of the BESI system, including receiving automated intervention suggestions and negative feelings about the difficulties with functionality of the developing system, as indicated by burden and frustration. Caregiving burden and stress were demonstrated in caregivers

giving lengthy feedback, deemed helpful by researchers, in the potential for the system but feeling that their input was negative.

The interviews comprised 16 questions. With the 10 caregivers, out of a possible 160 responses, there were 128 (80%) responses, which were transcribed. Overall, participating for 30-60 days in the BESI study was perceived positively. Caregivers expressed the desire to "give more information" and were future-oriented; "People are getting an idea of what I am going through." Positively coded feedback supported the subthemes of agreeability and ease of use with caregivers' sense of commitment to the technology.

The theme of helpfulness related to feedback on the potential of the system and was demonstrated by commitment to completing the surveys and allowing multiple interviews many months after the initial intake visit. Numerous detailed future recommendations from caregivers revealed their helpfulness in participating in the next phase of the system's development and in their belief that the system would be beneficial. The future potential to detect agitation and give a *heads up* before it became a behavior difficulty spoke of the helpfulness that caregivers ascribed to the system.

Agreeability with receiving agitation notifications on the smartwatch and with consistent support for the research team was demonstrated. Future potential of the developing system was emphasized, and it supports users' acceptance of the technology. Ease of use in the overall acceptability of and confidence in handling the technology was evident:

> They [sensors] were not a bother to me.
>
> I was actually called to fix things myself.

The themes of usefulness and helpfulness were supported by caregiver feedback, participation, and future recommendations.

Caregiver Acceptance of the BESI Technology System

Caregiver responses to previous caregiver quotes were largely positive. Positive responses applied to sensors "not being a bother" in the home, recommendations of being able to make changes such as "to put my own thoughts in," and to future capability, with all caregivers agreeing that the system would be of benefit. Ease of use was evident both in the negative—"It was a nuisance to run over to the table...every time I thought something was worthy"—and the positive—"it was good"—feedback regarding receiving notifications on the smartwatch about possible agitation.

Agreeability was evident with responders demonstrating acceptance of receiving the notifications indicating possible agitation. When asked, "When we sent notifications on your smartwatch asking about agitation, how did it affect you?"—70% (7/10) of the respondents replied that it was "no problem" or "it didn't." In contrast, 1 response was negative—"after a while, it was irritating since it was too late." As to whether it increased their awareness of the situation, "yes" and "no" were answered equally, with 1 caregiver adding that it confirmed the agitation. Later in the study, automated suggestions or possible interventions were delivered at the end of each week. Moreover, 4 phase 2 participants did not receive any notifications, and thus did not respond to this question.

Another 2 caregivers from phase 3 said they "hardly remembered them." In total, 3 caregivers felt they were "no help" and only 1 found them helpful. This first attempt to deliver individualized interventions did not have a significant impact and was not useful or helpful at the time. Later, in these interviews, 70% (7/10) of respondents indicated positive feelings about the automated intervention suggestions with comments including:

> It just made me more aware of what was going on and made me think: Do I need to do anything?
>
> It was good,...would be helpful.
>
> Something that could say "heads up, do something" would be nice.

The usefulness and helpfulness of the technology were also affirmed in interviews with 90% (9/10) of the caregivers agreeing on the future capability of the BESI system. Most caregivers did not notice a change in agitation frequency over the course of deployment. Moreover, 1 caregiver offered additional thoughts about the unique characteristics of agitation in a person living with dementia:

> I always had problems with word agitation. I used that word, but (the person living with dementia) was not overly demonstrative. After living with __ for 50 years, I knew something was going on. There would be little tells that __ was upset about something, there were never any bouts of throwing, screaming, or stamping feet. It was all very low-key and difficult to say if there was something going on here. A bad situation would look like absolute refusal to do anything, just a total shutdown.

Caregiver opinions on the use of the BESI tablet app were mostly positive about the process of individualizing the word lists on the tablet for agitation descriptors in the persons living with dementia. The pilot implementation of sending suggestions or recommendations near a possible agitation event was also generally received positively with feedback indicating feelings of usefulness for the future for these suggestions and satisfaction with the technology indications. Although interventions were not deemed timely enough to prevent agitation during the study, lower numbers of agitation events suggests that the *heads up* on the wrist device may have alerted the caregivers before behaviors were evident [8].

Caregiver Insights on the Burden and Stress of Caring for Persons Living With Dementia and Agitation

In total, 2 caregivers indicated difficulty with the technology, noting it was burdensome to "remember exact time of the agitation" if they had been out. However, the functionality of the system did not require them to document any agitation if they were out of the home. This may speak of their commitment to their efforts and the project. Multiple recommendations to improve the system included agreement with the recommendations—"to be able to add to the choice on the Daily report page"—by 70% (7/10) of caregivers. Additional comments by 4 caregivers included "maybe better words...to describe what [the person living with dementia] did," referring

to the words describing agitation available for quick selection on the tablet.

Caregivers were involved in the development of the technology throughout; however, limited recall in the CANIS interviews may indicate the stress and burden of the caregiving process despite feeling supported by the research team. Few mobile apps are available to support caregivers of persons living with dementia with behavioral difficulties [5]. Developing technologies must be adapted to the needs of caregivers.

Burden was also expressed in dealing with the system with physical manifestations of the stress of caregiving and in the acceptance that the disease is progressive, "That's part of the burden. You have to deal with the agitation, then recording it." No help in the cascade of caregiver feelings was described with the example of a caregiver saying, "I don't know anything to help caregiving tasks." The open-ended responses to the *no help* example were supported with statements such as:

> *It's just like nothing helps. You are just in it with the two of you and you need to determine your own ways of dealing with things.*

The burden of caregiving was especially evident in 3 caregivers who agreed that caregiving was too difficult for them to imagine anything being of help. Moreover, 6 caregivers disagreed with the *no help* comment, stating that they felt more positive and useful even with physical manifestations, while in the caregiver role:

> *The stress level [of caregiving] was such that atopic dermatitis kicked in, I think it is difficult to express there is not hope.*
>
> *You come to assist, but nothing will fix it.*

In seeking additional understanding of the home situation, we asked if anything happened to them during the study. We received only 2 responses, and both addressed physical stressors and family stress. Further inquiry into their situations revealed that many had taken actions, including 2 caregivers choosing placement (although one found it more stressful because of making daily visits), 2 adding services in the home, 3 improving their social involvement, and 3 changing their environment—2 within the home setting and 1 relocated, leaving the caregiver role to another family member. These significant changes indicate proactive decisions and changes within the dyads.

Seeking information about caregiving since they completed the study, we asked, "What intervention and prevention strategies have you found most helpful in recent caregiving?" In response, 60% (6/10) of the caregivers gave strategies including:

> *Telling people to walk away and pick your battles*
>
> *I tried to identify a trigger like nothing being in the house to eat*

Finally, we were interested in whether any complementary or alternative therapies had been tried for either the caregiver or the person living with dementia. In total, 3 had done so. Massage therapy for the person living with dementia was mentioned twice. Aromatherapy, meditation, and light therapy were administered. These caregivers continued to try new techniques to help improve their caregiving situation. Proactive caregivers demonstrated the ability to take action to improve their situation. Quality of life assessments support the positive behaviors demonstrated by caregivers.

Caregiver Recommendations for System Changes

The interviews addressed system usability. Ease of use applied to multiple facets of the technology system:

Overall *acceptability* was demonstrated in confidence in handling the technology—"They were not a bother to me. I was actually called to fix things myself." Acceptability was shown in using the system as a tablet, rather than having "the app on the phone...would not make it easier while out." In total, 70% (7/10) of the caregivers found it was not intrusive. They had no problems with notifications on the smartwatch or with receiving the automated intervention suggestions. The esthetics of the sensors on the walls in the home were not a problem for most but caregivers noted:

> *It needs to be considered better...knocking them off the wall due to being curious of what they are or malfunctioning of equipment such as "his watch kept messing up."*

Functionality issues increased burden at times. Difficulty using the system yielded concerns with functionality:

> *It was a nuisance to run over to the tablet and be putting in information every time I thought something was worthy.*

Functionality was also identified with caregivers as an area to focus on:

> *Maybe better words would be good to describe what he did, since I do not think a lot of them fit him.*

Difficulties with the developing technology have caused some frustration. Wall sensors were an esthetic problem for 60% (6/10) of the caregivers, with 1 caregiver noting "...units need to be smaller, less intrusive..." Frustration at the rudimentary look of the mounted sensors and the method of attaching it was reported. For example, 1 caregiver noted "times when the sensors did not work" and 2 caregivers found the equipment to be intrusive. Our engineer support team and nurse coordinator were available to address these issues and were received very positively in all surveys. However, frustration persisted in the current situation. Caregivers provided good suggestions for the next steps, even with these frustrations indicating negative ease of use:

> *We ran in to one of the sensors and it fell off, but when we set it back up we did not know if it was still working. There should be some sort of indicator that says if it is working.*

Future Recommendations

The caregivers offered recommendations during the interviews. In total, 70% (7/10) of the caregivers agreed that they would like to add to the choices on the daily report completed on the tablet, and 1 wanted to be able to give their own insights:

> *A place to put an explanation of what we thought was causing the agitation.*

Practical feedback included [making sensors] less intrusive and industrial looking

Innovative recommendations pointed to the user insights and lessons learned and their feelings of usefulness in assisting in the development of the technology system. All caregivers who provided future recommendations (n=9) agreed that the ability to measure what set off the agitation would be helpful. As noted in the cascade of subjective thoughts (phase 2 in the BESI study), when asked about the future ability to measure over time attitude and activities that set off the agitation of the person living with dementia, all 10 caregivers agreed, noting:

Yes, that would be good (with caregivers recommending) on a scale like day 1 to 30 to track progress, or a way to see the trend of behavior over time, and finally, a trendline that says this behavior is becoming more prevalent. Something that would give me a heads up...like something's developing here, you need to be watching for it.

Other insights for future development included:

Not just this specific thing is happening, and you need to do something about it. But we see something coming over the horizon, tell me about that, and I know the equipment only worked in the home, but maybe a way to gauge external stressors when we are out. We noticed when she watched the news at night that would stress her out. Maybe a reporting mechanism that says what happened.

Discussion

Principal Findings

This study evaluated the participation in developing technology that addresses issues important to caregivers of persons living with dementia. We sought caregiver experiences based on mood, burden, personal reflections, and recommendations. Caregiver feedback highlighted the themes of *usefulness* and *helpfulness,* supported by the subthemes of *agreeability* and *ease of use.* The CANIS study helped to further our understanding of the BESI system. We elicited new information from caregivers, including the potential burden with participation, and obtained feedback about the technology.

New efforts to offer technology focusing on caregivers and older adults find that with in-home monitoring [29] or with older adults aged ≥55 years, searching for mental health resources for others [32], there is frustration or difficulty with the resources available [24]. However, they respond positively to the potential of technology to offer proactive approaches [22]. Even younger adults are frustrated with technical glitches and difficulty navigating an app for mental health support [33].

Most caregivers felt that the technology components were *not a bother*, addressing the ease of use of the BESI system. Ease of use proffers that there is functionality in using the BESI system for the early detection of dementia-related agitation. Ease of use is key to new technology, helping with uptake. Thus, if a technology is helpful but not easy to use, there is more resistance or a lack of acceptance. In this study, the importance of the clarity of words used in describing agitation was

identified, with caregivers seeking simpler words and more choices. Usefulness was evident in their acceptability and agreeability and confidence in dealing with new technology.

The functionality of the system reflects that the BESI system can detect agitation events and that it is accurate at detecting early agitation [8]. Functionality also addressed caregiver feelings responsible for entering information in the tablet app even if they were away from the home, especially as this was not a requirement of the study. Caregivers saw the potential in the technology and offered recommendations to improve functionality and ease of use. Timeliness, as an element of functionality, is of utmost importance in the delivery of agitation notices in time to intervene. Notifications occurring in the middle of an agitation episode were not useful. Simplicity in using the system is also important, and issues noted include sensors falling off walls, button presses, or having to scroll for the page needed on the app.

In addition, 30% (3/10) of the caregivers wanted to record more of their impressions—"I thought a place to put an explanation of what we thought was causing the agitation." This highlighted the theme of helpfulness and could be an added component in future development of the BESI system. Some studies involve caregiver journals and diaries [34,35] for caregivers to record their thoughts. Web-based caregiver forums are beneficial to caregivers [36]. Our focus was on the technology, the acceptance of the technology by the caregiver and person living with dementia, and the potential help it will provide with further development by providing journaling capabilities or other formats of web-based caregiver support within the BESI tablet app.

Future expansion of the process of automating personalized interventions developed with BESI is also needed. Caregivers agreed that the ability to measure what set off the agitation would be helpful. Most caregivers indicated potential, indicating that a proactive mindset would be helpful. Recent work with formal and informal caregivers in the use of unobtrusive monitoring in the home brought forth themes of prevention and proactive measures as helpful [7]. Future potential of the technology could include addressing stress, strain, and the burden of caregiving. Even with the increasing number of technologies available for use for older adults [2], behavioral disturbances or agitation are rarely addressed specifically, but the need for this is supported by this study. Helplessness was identified in a study of mHealth apps related to the vast amount of digitally available information [5]. Strategies were used to choose simplicity of look and ease of use over the level of information available on the apps [5]. The importance of user involvement in the development of technologies is essential in providing appropriate systems that empower users in negotiation of information for health care challenges for themselves or those for whom they care.

The well-received intervention suggestions and decreased number of agitations confirmed that BESI has good value and acceptability. The system's future capability was supported by noting the potential usefulness of a system in offering timely notifications of an impending agitation episode. The importance of assisting family caregivers with nonpharmacological support

for managing behavioral symptoms in dementia has been prioritized for future research [37]. Persons living with dementia in different disease stages with agitation behaviors responded differently to the proposed intervention. The interventions with positive ratings varied between dyads, highlighting the need for personalized dementia-related interventions in CANIS.

The caregivers were able to be present almost all the time. They demonstrated personal investment in the care that the person living with dementia received. Their willingness to participate in, work with researchers, and use technology 24 hours a day for 30-60 days was a significant commitment. Many were not necessarily technologically proficient caregivers, but they wanted to be useful. None of the caregivers implied that the research should not continue to be refined.

Caregiver feedback postdeployment about the BESI system and their overall experience was generally positive, indicating caregiver acceptance of the technology system (in-home sensors, actigraphy or smart watch technology, and tablet app). Caregiver acceptance of developing technology was consistently demonstrated by tolerance, commitment, and their efforts to offer recommendations related to ease of use, functionality, and future capability. Many offered specific suggestions and recommendations, including interest in a journaling format that could inform the next phase of BESI system development.

Finally, assessment of caregiver depression, burden, and caregiver insights into depression and quality of life for the person living with dementia supports the need for caregiver help and support when handling dementia-related agitation. The abovementioned themes support the positive process of involving caregiver knowledge and experience to inform further development of a potentially helpful technology. Using the Progressively Lowered Stress Threshold model as a framework provides a tool to help caregivers better understand agitation triggers and their effects on persons living with dementia as the disease progresses. With more disease burden, smaller triggers will be more important to identify, thus helping to reduce stress in the environment and prevent serious agitation.

Limitations

Although this study provides several valuable insights, several limitations must also be noted. First, although it was positive to have half of the previous dyads participate in this extended study, the sample size is small and offers limited generalizability. Because interviews occurred a long time after the start of phases 2 and 3 participation (mean 506.47 days, SD 424.52; R=49), some noted that they forgot information or were unable to recall details. It may be that opinions and reactions would have been different if all caregivers were interviewed sooner after their deployment experience.

The agitation detection system used to notify caregivers is based on monitoring the behaviors of the person living with dementia using wearable and environmental sensors. Thus, the agitation detection system may miss subtle agitated behaviors, such as when the person living with dementia stays still and refuses care. The detection system also learns the agitated behaviors of persons living with dementia based on the caregivers' observations and reports. A late report of agitation by the caregiver, which can be caused by the need for immediate attention and intervention required to stop agitation from escalating, may cause delayed detection and notification of the reported agitation. The system can be tuned to notify caregivers of agitation earlier, but this may cause more false alarms.

Finally, although the purpose of delivering interventions in this pilot study was received positively, the process needs refinement and enhanced timeliness. For example, the system only provides an agitation intervention suggestion list to caregivers via a tablet device. Some caregivers may find the checking-on-tablet inconvenient and may prefer that the intervention list be sent to their mobile phone if they have the habit of carrying the phone with them.

Conclusions

Dementia caregivers dealing with agitation demonstrated acceptance of this developing technology by their initial participation in 30- and 60-day or 60-day deployments and allowing follow-up interviews months afterward. The caregivers consistently demonstrated tolerance, commitment to using the technology, and offered extensive feedback on ways to improve the system. The themes of usefulness and helpfulness were discerned and support the use of caregiver knowledge and experience to inform further development of the technology. Ease of use and acceptability were the subthemes revealed in the analysis. The importance of caregiver involvement in the development and implementation of new systems is essential to provide useful and acceptable technologies. Future development of technologies such as this is especially needed to support caregivers in dealing with behavioral disturbances caused by dementia. These developments could help to reduce the significant stress and burden that caregivers of persons living with dementia live with.

Conflicts of Interest

None declared.

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Multimedia Appendix 1

Assessment tool descriptions for creating individualized recommendations for both caregivers and persons living with dementia.
[PDF File (Adobe PDF File), 545 KB - aging_v4i4e30353_app1.pdf]

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Abbreviations

BESI: Behavioral and Environmental Sensing and Intervention
CANIS: Caregiver-Personalized Automated Non-Pharmacological Intervention System
CSI: Caregiver Strain Index

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Original Paper

Internet-Based Psychotherapy Intervention for Depression Among Older Adults Receiving Home Care: Qualitative Study of Participants' Experiences

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Abstract

Background: Depression is common among homebound older adults. Internet-based cognitive behavioral therapy (iCBT) is a promising but understudied approach for treating depression among older adults with disabilities.

Objective: This study aims to understand the experiences of homebound older adults who participated in a pilot feasibility trial of an iCBT for depression.

Methods: The participants included 21 homebound older adults who participated in a generic iCBT program that was not specifically designed for older adults and 8 home care workers who assisted in the iCBT program. Informants completed semistructured individual interviews, which were transcribed verbatim and analyzed using methods informed by grounded theory. A hierarchical code structure of themes and subthemes was developed after an iterative process of constant comparisons and questionings of the initial codes. The data analysis was conducted by using dedoose, a web app for mixed methods research.

Results: Three themes and various subthemes emerged related to participants' experience of the iCBT intervention, as follows: intervention impact, which involved subthemes related to participants' perceived impact of the intervention; challenges and difficulties, which involved subthemes on the challenges and difficulties that participants experienced in the intervention; and facilitators, which involved subthemes on the factors that facilitated intervention use and engagement.

Conclusions: iCBT is a promising intervention for homebound older adults experiencing depression. Home care workers reported improved relationships with their clients and that the program did not add a burden to their duties. Future programs should involve accessible technical features and age-adapted content to improve user experience, uptake, and adherence.

Trial Registration: ClinicalTrials.gov NCT04267289; https://clinicaltrials.gov/ct2/show/NCT04267289

Introduction

Background

Homebound older adults receive services and support from home care workers (HCWs) to help them maintain community living [1]. Up to half of these older adults experience clinically significant depressive symptoms, and 14% of them meet the diagnostic criteria for current major depression [2]. Untreated and undertreated depression, even when the symptoms are mild, can lead to various adverse health events and decrease life expectancy [3,4]. Psychotherapy interventions based on the principles of cognitive behavioral therapy (CBT) are an evidence-based approach for treating depression in older adults

[5]. The side effects of antidepressants, compounded by comorbid conditions and potential interactions with other medications, make psychotherapy a safe alternative [6]. However, office-based psychotherapy treatment is often out of reach for homebound older adults owing to access barriers, such as stigma, provider shortage, cost, and transportation [7].

In recent years, internet-based psychotherapy has received increased attention as a promising alternative to face-to-face treatment. Internet-based CBT (iCBT) delivers prerecorded CBT lessons via dedicated websites or apps. It allows patients to engage in therapy on demand and provides a nonstigmatizing and accessible treatment option. A recent systematic review suggested that iCBT is as effective as face-to-face CBT for depression in mixed-age samples [8]. An emerging body of research also suggests that iCBT is acceptable and potentially effective in reducing depressive symptoms in later life [9]. In addition, a recent randomized controlled trial reported no significant age-related differences in iCBT effectiveness [10].

Most iCBT programs are self-directed, with or without therapist support. When available, therapist support is typically no more than 10 minutes per week per patient [11]. With proper clinical supervision, a layperson or peer can also facilitate iCBT uptake in place of a trained therapist [12]. Guided iCBT, whether by a therapist or by a layperson, may be more efficacious than self-guided iCBT because it provides more opportunities for addressing technological challenges and personalized feedback [13].

However, older adults, especially those with chronic conditions or disabilities, are often excluded from iCBT trials [14]. The few studies that have included them frequently required participants to have computer literacy and access to the internet or a computer [9]. As a result, it is unclear whether previous findings can be extended to homebound older adults who tend to be older, more cognitively and physically impaired, and less familiar with technology [15].

To address this knowledge gap, we conducted an open trial that explored the acceptability and preliminary effects of an existing iCBT program in a sample of homebound older adults, with optional support from their regular HCWs [16]. Our quantitative evaluation found that iCBT was acceptable and associated with a significant reduction in depressive symptoms in the study sample, who were overwhelmingly low income and had low computer literacy. Despite these encouraging findings, the overall completion rate was 23%, which is much lower than the 55%-97% rates reported in previous iCBT trials with older adults [9]. Adherence and symptom improvement have a dose-response relationship [17]. The low completion rate is a cause for concern and warrants further investigation.

Objective

In this study, we focused on qualitative data from interviews to understand participants' experiences with iCBT. Qualitative research can provide valuable insights into treatment mechanisms, strengths, and weaknesses, enhance understanding of how interventions are delivered, and guide future treatment innovation [18]. Qualitative analysis is particularly needed on this subject, given the minimal research involving homebound older adults in technology-based psychotherapy. We also analyzed interviews with HCWs to understand their roles in iCBT uptake. We discussed the themes that emerged from the qualitative analysis and recommendations for designing internet-based psychotherapy for depression in homebound older adults.

Methods

Participants and Procedures

The trial methodology and procedures have been described previously [16]. The study was registered at ClinicalTrials.gov as NCT04267289. All participants provided written informed consent. Briefly, 26 homebound older adults, recruited from community advertisements and referrals, agreed to participate in the study and started the treatment program. To qualify for the study, older adults needed to be ≥60 years, to be able to read and speak English, to have elevated depressive symptoms at screening (≥5 on the Patient Health Questionnaire-9), and to have received home care (ie, paid help from an HCW) for more than 1 month at screening and expect continued care for at least 3 months. The exclusion criteria included current engagement in psychotherapy, current suicidal ideation, a diagnosis of psychotic disorder, cognitive impairment [19], or a terminal illness diagnosis.

Participants had 3 months to use a commercially available iCBT program called Beating the Blues (BTB). We used an American-specific version of BTB, an iCBT program that was developed in the United Kingdom. Randomized controlled trials of BTB support its clinical effectiveness in treating both major and minor depression in both younger and older adults [20-22]. BTB included didactic content (in the form of lessons), in-session practices, and homework assignments designed to impart cognitive (eg, guided discovery, thought records) and behavioral (eg, activity scheduling, problem-solving) skills. The program has 8 sessions, each consisting of 3-5 modules. The program recommends that users complete a module in one sitting position. Most of the modules took study team members, who were able-bodied and computer literate, about 15-20 minutes to complete, although several more extended modules took about 30 minutes.

Users engage in BTB via a secure and dedicated website compatible with different devices (eg, laptop computers, tablets, and mobile phones). Each user's progress is saved immediately on the server, allowing them to pick up where they left off from either the same or a different device. Device ownership was not a requirement for participation. For participants without a reliable device (19/26, 73%), we provided each with a Samsung tablet (Galaxy Tab A 10.1 with 4G Long-Term Evolution) and free internet access for the program's duration. We used ManageEngine's mobile device management software to uniformly configure and manage all the study team's tablets. Tablet configurations allowed access to only the BTB website. Most drop-down menu options on the home screen were disabled to prevent accidental contact. We also provided a stylus pen to each participant when the touchscreen failed to respond to finger tapping.

The BTB lessons and materials were entirely web-based. We designed a client workbook and printed it out for each participant. The workbook contained general information about the study, unique user credentials for the BTB website, the study team's contact information, technology troubleshooting frequently asked questions, a list of all BTB modules with extra space for taking notes, and homework printouts.

When possible, older adult participants were paired with one of their current HCWs to assist with the BTB (13/26, 50%). All HCWs completed a mandatory 2-hour, asynchronous, web-based training course that consisted of an introduction to the study, the role of HCWs in the study, light CBT training, psychoeducation, and safety planning around suicidal ideation. Each HCW received a certificate of completion. In cases where consistent assistance from the same HCW was not feasible (13/26, 50%), participants chose to either work on the iCBT program on their own (7/13, 54%) or receive assistance from a research assistant (RA; 6/13, 46%). RAs were students working on their master's degrees of social work. They did not receive specialized CBT training and were told to limit their assistance to program navigation and technology troubleshooting.

In addition, all the participants received a short tutorial on using the program. For participants using their own devices, we helped them create a bookmark and shortcut to the BTB website. We also set all browser settings to *remember* user credentials, yet another strategy to reduce user frustration related to technology. Furthermore, we conducted brief check-in calls to each participant approximately once a week, each lasting 2-5 minutes, to monitor symptoms and identify issues requiring immediate intervention. Finally, the participants were told to call the study team for technological issues requiring immediate assistance from the study team.

Data

All participants, including older adults (n=26) and HCWs (n=13), completed a baseline assessment. We conducted a posttest and semistructured qualitative interview with 21 older adults and 8 HCWs. About half of the older adult participants belonged to the HCW-guided group (n=11), and the rest were split between the RA-guided (n=5) and the self-guided (n=5) groups. Table 1 presents the demographic characteristics of the participants. Further details of the original study sample are available elsewhere [16].

Interviews with older adults were conducted at their homes and recorded using a digital voice recorder. Older adults responded to questions that asked about their program experiences, including probing questions regarding their likes, dislikes, difficulties, perceived impact, and HCW involvement, if applicable. HCWs separately participated in interviews over the phone through BlueJeans, a video conferencing software. HCWs shared their program experiences, perceived impact on client-worker relationships and workload, and web-based training experiences. All interview recordings were transcribed verbatim using a third-party transcription service. The duration of the interviews was 25 minutes. These interviews were the primary data sources for this study. Several members of the study team had close interactions with the participants through home visits and check-in calls. These encounters and observations provided rich contextual data, which were not systematically analyzed, but considered in the coding and interpretation of the interview data.

Table 1. Demographics of study participants, including homebound older adults and home care workers (N=29).

Sociodemographic characteristics	Older adults (n=21)	Home care workers (n=8)
Age (years), mean (SD)	76 (9.1)	48 (10.4)
Sex, n (%)		
Female	17 (81)	7 (87)
Male	4 (19)	1 (13)
Race and ethnicity, n (%)		
White, non-Hispanic	16 (76)	4 (50)
Black or African American, non-Hispanic	4 (19)	2 (25)
Hispanic or Latinx	1 (5)	1 (13)
Asian or Pacific Islander, non-Hispanic	0 (0)	1 (13)
Education, n (%)		
High school or less	4 (19)	2 (25)
Some college	8 (38)	2 (25)
AA[a] or BA[b]	4 (19)	4 (50)
Graduate degree	5 (24)	0 (0)
Household income (US $), n (%)		
0-20,000	14 (67)	3 (38)
20,001-50,000	6 (29)	3 (38)
>50,000	1 (5)	2 (25)
Marital status, n (%)		
Married	1 (5)	5 (63)
Widowed	6 (29)	0 (0)
Divorced or separated	11 (52)	2 (25)
Never married	3 (14)	1 (13)
Lived alone	18 (86)	1 (13)
Technology use and competency, n (%)		
Ever used a computer	12 (57)	—[c]
Ever used a tablet	6 (29)	—
Years worked in home care, mean (SD)	N/A[d]	12.7 (7.7)

[a]AA: Associate of Arts.

[b]BA: Bachelor of Arts.

[c]Not available (ie, not assessed).

[d]N/A: not applicable.

Data Analysis

The qualitative data were analyzed using grounded theory [23]. Our analytic process involved line-by-line open coding and refinement through an iterative process of constant comparisons and questionings. The codes were examined within the same participant and across different participants to ensure consistency and reduce redundancy. XX performed open coding and worked with YS. to refine and merge codes and create a hierarchical code structure of themes and subthemes. We conducted data analysis using dedoose, a web app for mixed methods research.

Results

Overview

During the iterative coding process, we found that older adults' narratives were congruent with those from HCWs. Therefore, we combined their experiences and reported them on the same thematic map (Figure 1). Themes related to participants' experience fell under the following three categories: (1) intervention impact, which involved subthemes related to participants' perceived impact of the intervention, and these subthemes shed light on the intervention mechanisms; (2) challenges and difficulties, which involved subthemes on the

challenges and difficulties experienced by participants in the intervention, and these challenges were the likely culprit of low program adherence and completion, and (3) facilitators, which

involved subthemes on the factors that facilitated intervention use and engagement.

Figure 1. Thematic map depicting themes and subthemes.
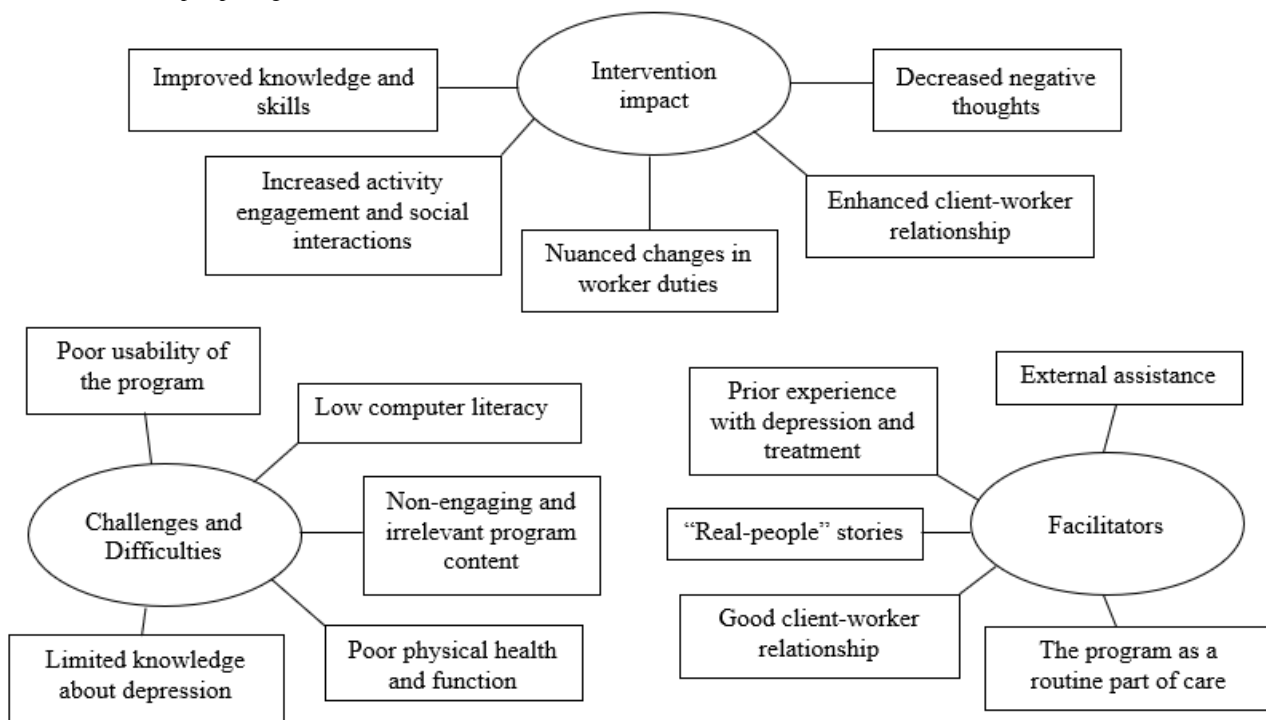
Intervention Impact

Improved Knowledge and Skills

Participants, including older adults and HCWs, reported improved awareness and knowledge of depression. Several older adults shared that they did not know that they were depressed but after the program they were able to identify their symptoms as typical signs of depression. Participants also reported that they learned skills related to goal setting, problem-solving, and sleep management. HCWs also reported that they applied the skills learned through the program to their own lives and with other clients:

> *I have got depression. I didn't even know it was depression, like staying in my room and not going out, or I was invited over for dinner and not going. I would give excuses....It helped me to identify what it is.* [71-year-old adult, HCW-guided, completed 5 sessions]

Increased activity engagement and social interactions. Another impact of intervention was related to behavioral activation. Older adults reported that they were more active or more motivated to engage in various activities, such as personal care, social events, community activities, and volunteering. They also reported initiating or engaging in more social interactions, which helped to improve their mood:

> *Most of the time, I'm always up in my room. I don't really go downstairs. It made me get out to learn how to mingle more with people, and then I found out I kind of like doing that. And then they started a little class, I actually started participating in the Bible*

study class, and I met more people, more friends. So that, to me, was a big help right there. [71-year-old adult, HCW-guided, completed 8 sessions]

Decreased Negative Thoughts

Participants reported less negative thinking and more positive thinking. Although some reported having a more positive outlook in general without elaboration, some discussed the process of challenging thoughts in detail. For example:

> *Helped me to understand...this situation wasn't my personal failing. Because I've heard that throughout my life. It's still difficult to say, but I'm born out of wedlock...I think I was always, and my mother too, was like, we brought shame to our family....And so, my mother had a nickname for me, which in Spanish it's like an ugly, old hag, ever since I was a child...you're programmed to think everything is your fault when it isn't. So...I would think, "This happened because I'm an ugly, old hag, and I'm corrupt, and I'm contaminated in some way." But you have to challenge that...I think the program reminded me that this wasn't my fault....* [60-year-old adult, HCW-guided, completed 8 sessions]

Enhanced client-worker relationship. A prominent theme in the narratives of participants involved in the HCW-guided group was the closer relationship between the older adult and the HCW. HCWs reported *bonded* or *grew closer* with their clients, which made it easier to understand their needs and to care for them. Older adults' reports echo those from HCWs:

I think it sort of helped the relationship become more of a friendship because in the course of doing all these exercises, he would tell me about his personal life, so I got to know him better...I think we had a better working relationship. It enhanced his trust in me, and we probably developed a greater respect for each other as people. [HCW]

Nuanced changes in worker duties. Most HCWs reported little change in their overall workload and did not perceive the program as an extra burden. For some HCW-client pairs, doing the program gave them activities to do together:

Before the program, we [sometimes] watched TV....This gave us something to do together. [HCW]

Challenges and Difficulties

Overview

Poor usability of program. The most robust theme related to challenges and difficulties involved program usability, including web interface and program content. Most participants, including the HCWs, reported experiencing many glitches such as being stuck on a page, receiving error messages, and trouble playing video content at times. Trouble entering text as required was the most frequently reported difficulty. Participants pointed out a few accessibility issues, including small font, low volume of some video content, and small navigation buttons. In addition to the website's poor usability, many participants also reported some of the lessons that were confusing, repetitive, and challenging to understand. They also overwhelmingly reported that the modules were too long, and they were often unable to finish a module in one sitting:

Well, I got frustrated with it quite a bit. There were several things that I found frustrating. One of them was when you're supposed to fill out something, and it says to enter in the line, and the line is like, so small that you can hardly see it. And then it's always giving me this message, "Oops, you forgot something." And it does that over and over and over....It gets stuck. And you have to go back and start over. It's a buggy program. [80-year-old adult, self-guided, completed 7 sessions]

Low Computer Literacy

Another salient challenge was a generally low level of computer literacy among homebound older adults, including those who owned a computer. One participant said, "I'm just computer illiterate, mostly" (72-year-old adult, HCW-guided, completed 1 session).

Nonengaging and Irrelevant Program Content

The study participants perceived some aspects of the program as irrelevant to older adults. The case stories in BTB did not depict the common problems and challenges faced by older adults, such as physical and cognitive decline, loneliness and isolation, and loss of independence. As a result, several older adults reported that they could not relate to the characters or had trouble applying the lessons to their life situations. Several participants also thought that the program was not very interesting, which dampened their motivation to continue with the program:

It *wasn't about older people. Well, they might consider themselves older, but some of them were still working. They'd lost a husband or wife, or something....There just weren't a whole of a lot of things that pertained to people who were very old.* [94-year-old adult, RA-guided, completed 5 sessions]

Well, it just didn't create any intense curiosity or, "Where's this going? How is it going to help?" It was just kind of [laughter] pedestrian or boring. [79-year-old adult, HCW-guided, completed 3 sessions]

Poor physical health and function. Participants experienced adverse health events, such as a visit to the emergency room and an overnight hospital stay. Some reported fatigue and malaise, which made it difficult for them to participate in the program:

I'm exhausted. I have difficulty trying to prepare myself for the next day, the next week. [88-year-old adult, HCW-guided, completed 1 session]

Limited Knowledge of Depression

The final subtheme of challenges is limited knowledge of depression among participants, particularly among those who dropped out within 4 sessions. A few participants identified feelings of anger and shared a lack of motivation, but did not identify them as depression symptoms. Depression denial was common in the baseline clinical interviews. There was also a sentiment that they were *too old to change*. In 1 case, this sentiment made it difficult for the participant to set up a goal, and she dropped out of the program after the first session:

The project itself is an antithesis for me because I can feel anger. I can feel regret. I can feel all kinds of things, but I cannot define depression as a thing. Sometimes, I can feel remorse for something, or I can feel sorry for myself, but I don't think I do that much. [83-year-old adult, self-guided, completed 4 sessions]

Facilitators

External Assistance

The most salient subtheme of facilitators was external assistance, including HCW assistance and support from the research team, such as workbook printouts, stylus pens, and especially help with technology:

Then I'd call [RA]. And then she would fix it; sometimes, she even had to come. But sometimes, she could do it from afar, which I thought was great. [74-year-old adult, HCW-guided, completed 8 sessions]

Prior Experience with Depression and Treatment

Most participants who completed 7 or 8 sessions spontaneously reported experience with depression and some familiarity with psychotherapy treatments, which helped them better relate to and complete the iCBT lessons:

I mean, I'm familiar with goal setting, I've done that before, and how you break down the things into individual chores and all that. [80-year-old adult, self-guided, completed 7 sessions]

Real People Stories

Many participants liked the characters in the program that told real-life stories. Unknown to the participants, the characters were actors. Nevertheless, it appears that using real-life examples made the program more relatable and engaging. Most participants identified with a character named Rosa, an older woman grieving over losing her husband:

I enjoyed the six or seven people that you tracked through the different modules...I liked listening to what the folks had to say about how they started and the progress through the whole program, and then identify how they were able to use the specific part of the program. I liked it a lot. [74-year-old adult, HCW-guided, completed 8 sessions]

Good Client-Worker Relationship

Participants in the HCW-assisted group tended to have a better relationship with their HCWs before the study, which improved their experiences with the iCBT program:

Me and my client have actually known each other for a long time already. I already knew a lot about her as it was. So, this was everything that she was telling in the program, I already knew...and about her depression and everything. [HCW]

This program is a routine part of care. HCWs who assisted clients with a high adherence to BTB commonly reported making the program a routine part of care. They intentionally adjusted their routine to allocate time for completing the program and integrated homework assignments into the shared activities they did with the clients:

One of the exercises of that week would be exercise while we were out shopping. So, we just incorporated it into our time. [HCW]

We were able to set everything around the time that I was scheduled to be with her, and we made that part [the iCBT program] a part of our care. [HCW]

In addition to the 3 main themes, we analyzed the roles of HCWs separately and explored why HCW involvement was undesirable for some older adults. We organized the subthemes related to HCW roles based on the efficiency model of support, a model for understanding the provision of human support in the context of behavioral intervention technologies [24]. The premise of this model is that human support increases the adherence and effectiveness of technology-based psychotherapy. The provision of human support should consider failure points and reasons why people might fail to benefit from technology-based psychotherapy. These failure points include usability (ease of use), engagement (motivation), fit (meeting user's needs), knowledge (how to use a tool within intervention), and implementation (how to apply tools learned into users' lives). We used the failure point classification to organize the subthemes associated with HCW roles (Table 2).

Table 2. Home care worker (HCW) assistance subthemes and representative quotes.

Subthemes	Description	Representative quotes
Usability and fit	Help clients with technology, including the tablet and the program web interface. Specific activities were turning the tablet on and off, logging on, navigating the program (eg, going backward/forward), entering text, reading out loud to clients with vision impairment, solving tech related problems (eg, frozen screen)	"I sat through her segment with her...moving the program along....Actually, I kind of somewhat helped her with the whole program because she needed help to do it. She couldn't do it by herself." [HCW]
Engagement	Help with engagement through encouraging conservations, nudge and reminders, and hold clients accountable	"She would double-check to make sure that I was doing it....She also encouraged me to do the modules [laughter]...." [74-year-old adult, HCW-guided, completed 8 sessions]
Knowledge	Help clients better understand the lessons, explain and clarify the content, discuss and review lessons, and help them complete the in-session exercises	"If I didn't quite understand something, he would explain it more fully....A lot of times, I wouldn't remember, but he could always refer to things." [72-year-old adult, HCW-guided, completed 8 sessions]
Implementation	Help clients apply the lessons by assisting them complete the homework assignments and continue to practice the skills and techniques during their interactions, even after program completion	"I helped her with her goals of the week. I know some of the goals that she has that were maybe going out into the community or maybe she wanted to get up and do a certain exercise or she wanted to do certain things." [HCW]
Personal autonomy and privacy	Older adults in the self-guided and research assistant–guided group shared reasons for not wanting to involve their HCW in the internet-based cognitive behavioral therapy program. The strongest theme was the concept of personal autonomy and privacy—the desire to keep somethings private and maintain independence as much as possible	"I don't want anybody helping me. I am too independent [laughter]". [80-year-old adult, self-guided, completed 7 sessions]
Competency	Another common reason for not wanting to involve HCWs is concern over HCWs' competency. There was some concern among several older adults that their HCWs did not possess the professional knowledge to make a difference in their experience	"It's not like she's really a professional like you are. But she had some rudimentary exposure with this program, and she knew how and what to help me with. She was a help but still didn't make the program any more meaningful to me or helpful." [79-year-old adult, HCW-guided, completed 3 sessions]

Discussion

Principal Findings

This study analyzed data from individual interviews with homebound older adults and HCWs who participated in a pilot feasibility trial of iCBT with optional support from lay workers. In our study, homebound older adults tended to be older, more functionally impaired, more socioeconomically disadvantaged, and less tech-savvy than older adults from previous iCBT trials [12]. This study complemented a previous quantitative evaluation of the iCBT program [16] by providing insights into intervention mechanisms, barriers, and facilitators of iCBT uptake in this high-need and hard-to-reach population. Taken together, the qualitative and quantitative findings suggest that iCBT, even a program initially designed for those who are able-bodied and computer literate, is acceptable and can benefit older adults with diverse socioeconomic backgrounds and abilities. Study participants reported that the program improved their knowledge and skills, increased engagement in social activities and interactions, and decreased negative thinking patterns. These changes closely align with the CBT theory and the mechanisms of change in CBT treatment [25]. In addition, participants in the HCW-guided iCBT group, including older adults and HCWs, reported enhanced client-worker relationships with more closeness, trust, and respect. The enhanced relationship made it easier for workers to understand clients' needs and care for them. We found a consensus from the HCWs

that assisting clients with iCBT did not change their workload or work nature. These findings suggest that adding HCW support to iCBT is feasible and can bring benefits beyond symptom reduction.

However, participants' experience was also marked with difficulties using the program because the interface was not optimized for older adults with diverse abilities and a generally low level of computer literacy among the study population. While learning a new technology can empower and increase a sense of self-efficacy for some older adults [26], technological challenges may cause feelings of disempowerment, aggravating symptoms of stress and anxiety for others [27]. These challenges are common when interacting with a multicomponent complex interface, such as an iCBT program, even among those with moderate to high computer literacy [28].

Overall, the challenges and difficulties experienced by our participants are consistent with those reported by older adults who used MoodTech, an iCBT program with a peer support component specifically designed for older adults with symptoms of depression [28]. Textual data from a pilot trial of MoodTech showed that older adult participants, all of whom were college-educated and owned a computer, reported various difficulties in working with the program interface, particularly those associated with entering and saving text entry. Similarly, text entry was the most frequently reported difficulty and a significant source of frustration with iCBT among homebound older adults in our study, who were less educated and computer

savvy than MoodTech users. These difficulties led to confusion, frustration, and self-doubt and fueled the participants' insecurities in life [28]. Another shared challenge among our study participants and MoodTech users involved the length and pace of iCBT. In both studies, participants reported being overwhelmed by the amount of work involved. The convergence in findings across different iCBT programs (one tailored for older adults and the other being nonage specific) and study populations (one involving college-educated and computer literate older adults and the other involving frail homebound older adults with limited computer literacy) suggests that technological challenges and perceived user burden are common, and that existing iCBT programs need to be further optimized to improve user experience.

A unique barrier to iCBT engagement in our study was the perceived lack of relevance in program content, which contributed to low adherence and engagement. MoodTech was developed explicitly for older adults aged 65 years or above, whereas BTB was not designed for a specific age group. Although general iCBT programs can help treat depression among older adults [29], our qualitative analysis suggests that age adaptations can improve user experience and lead to better adherence, engagement, and clinical effectiveness.

Whether from an HCW or from a member of the study team, receiving external assistance was crucial for a positive user experience and treatment adherence in our study population. External assistance improved the fit between the demands of the program and the capabilities of users. HCWs also frequently provided reminders, encouragement, clarifications, and assistance with homework assignments and skills application. These findings echo those of a qualitative study of patients' experience of an iCBT program with a face-to-face component, which suggested that in-person meetings compensated for the insufficient tailoring of iCBT to the user's needs and provided opportunities for individualized discussions about feelings, lessons, and challenges [30].

Implications for iCBT Design

This study provides several takeaways for designing internet-based psychotherapy programs for older adults with diverse physical, cognitive, and technological abilities. Our findings align with those of other studies that emphasize the importance of a user-friendly program interface [28]. The initial impression of computer interfaces, which is dependent on how easy it is for users to achieve simple tasks, strongly influences users' attitudes toward their intentions to use a technology [31]. Future interface design must involve careful consideration of accessibility features, including but not limited to button size and spacing, font size, color contrast, and voice-over narration and its volume, and use plain language accessible to those with low health literacy. Moreover, features requiring user input, such as text entry, should be tested with potential end-users to improve usability. Particular attention should be given to text entry, a feature that commonly causes problems for users. Potential remedies include making text entry options and including alternative ways of soliciting user input, such as asking them to write down their responses in a paper workbook accompanying the web-based program. Using voice input and handwriting input features on digital devices is another potential remedy. For example, we showed participants how to enter text using voice typing and handwriting on the tablets. Several participants opted to use voice input, and some went to handwriting. Those who could use either voice or handwriting input commented on how useful it was to bypass finger typing.

One of the most important implications for the future design of iCBT for older adults involves age-appropriate case stories. Although programs without age-appropriate stories can improve depressive symptoms in older adults, age-appropriate case stories may be more effective at engaging users and imparting skills, and as a result, augment treatment effectiveness. Using age-appropriate case stories may be particularly important for individuals with mild cognitive impairment and impaired cognitive flexibility. Examples of age-appropriate case stories, based on participants' input, include (1) challenges of adaptation to late-onset disabilities, (2) significant life events and transitions (eg, widowhood and change in living arrangements); (3) loneliness and social isolation; (4) family relations (eg, caregiving, multigenerational households, family conflict, and estranged children); (5) financial constraints and housing stability; and (6) early life trauma (eg, childhood sexual abuse). The case-story design should also consider the tremendous diversity of older adults. Old age spans several decades and includes people from several generations. Including stories that reflect this diversity can make the program more relatable and appealing to people from different birth cohorts.

In addition, given that limited knowledge on geriatric depression among older adults is common and can prevent them from engaging in treatment, strong psychoeducation is an essential component in iCBT to educate older adults on depression and address agism and mental illness stigma. When designing psychoeducation, age-related differences in the experience of depressive symptoms should be considered. Older adults are less likely to endorse affective symptoms and identify more strongly with cognitive, somatic, and behavioral symptoms [32]. Those who identify more strongly with nonaffective symptoms also find it more difficult to accept that they may have depression, and as a result, may be less motivated to engage in iCBT. For example, a few participants in our study endorsed anger and irritability but failed to realize that these could be symptoms of depression; none of these participants completed more than 3 sessions. Psychoeducation for older adults, therefore, should educate them about the nonaffective symptoms of depression and commonly held misconceptions.

In terms of program content, excessive repetition may cause confusion, rather than clarification. One way to determine whether repetition might be excessive is to test the program with a few potential end-users with varying cognitive ability levels. Relatedly, shorter individual modules spanning several months may reduce user fatigue and improve adherence.

Beyond program design, external assistance may be required for older adults with moderate to severe impairments in vision, hearing, cognition, and manual dexterity and is desirable for those with limited computer literacy. Our findings suggest that having laypersons as external support is feasible and may

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improve user experience by resolving technological challenges and clarifying program content.

Limitations

This study was limited to a small sample size for each of the 3 treatment subgroups, making it more difficult to compare participants' experiences across subgroups. Moreover, older adult interviewees were primarily female, non-Hispanic White people, and nonmarried individuals. Older men, ethnic minorities, particularly Hispanics and Asians, and married individuals were underrepresented. In addition, our findings were based primarily on individual interviews with study participants. Other data sources, such as text entry, notes in the client workbook, and in vivo observations, were unavailable, but could have provided additional insights to inform future interventions.

Conclusions

iCBT is a promising intervention approach for reducing the burden of depression among homebound older adults. Participants reported decreased negative thoughts and improved knowledge and skills, consistent with the goals of the program.

Those with HCWs also reported enhanced client-worker relationships. Of note, HCWs did not find that adding the program to their regular duties increased their burden, suggesting that adding HCW support to self-guided iCBT is feasible. However, homebound older adults, especially those who started iCBT without external assistance, had many difficulties related to poor usability of the program, nonengaging content, physical limitations, and low computer literacy. These findings suggest that external assistance may be an essential component of iCBT for older adults with diverse abilities. Future research should further investigate sources of support already present in older adults' environments (eg, family caregivers, HCWs, or a nonhuman assistant like Amazon Alexa) and compare the added benefits of support from different sources on iCBT completion and effectiveness. Our study findings also suggest that adaptations to existing iCBT programs are needed to improve user experience, uptake, and adherence. Future work should further investigate the themes and user preferences exposed through our qualitative work to provide a more detailed articulation of desirable adaptations to program features and session content.

Conflicts of Interest

None declared.

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Abbreviations

BTB: Beating the Blues
CBT: cognitive behavioral therapy
HCW: home care worker
iCBT: internet-based cognitive behavioral therapy
RA: research assistant

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Original Paper

Patient-Reported Outcomes in a Nationally Representative Sample of Older Internet Users: Cross-sectional Survey

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Abstract

Background: The rapid diffusion of the internet has decreased consumer reliance on health care providers for health information and facilitated the patients' ability to be an agent in control of their own health. However, empirical evidence is limited regarding the effects of health-related internet use among older adults, which is complicated by the proliferation of online health and medical sources of questionable scientific accuracy.

Objective: We explore the effects of health-related internet use, education, and eHealth literacy on medical encounters and patient-reported outcomes. Patient-reported outcomes are categorized into two dimensions: (1) self-reported health problem and (2) affective distress (feeling worried and anxious) due to information obtained. We were particularly interested in whether education and eHealth literacy moderate the association between perceived strain in medical encounters and patient-reported outcomes.

Methods: Our study sample consisted of online panel members who have used the internet as a resource for health information, randomly drawn from one of the largest probability-based online research panels. This paper specifically reports results obtained from older panel members (age≥60 years: n=194). First, we examined descriptive statistics and bivariate associations (Pearson correlations and independent samples t tests). We used hierarchical ordinary least squares regression analyses by running separate regressions for each patient-reported outcome. In model 1, we entered the main effects. In model 2, technology and medical encounter variables were included. Model 3 added the statistical interaction terms.

Results: Age (β=–.17; P=.02), gender (β=–.22; P=.01), and medical satisfaction (β=–.28; P=.01) were significant predictors of self-reported health problems. Affective distress was positively predicted by gender (β=.13; P=.05) and satisfaction with medical encounters (β=.34; P<.001) but negatively predicted by education (β=–.18; P=.03) and eHealth literacy (β=–.32; P=.01). The association between experiencing a health problem in relation to health-related internet use and perception of strained medical encounters was greater among respondents with lower levels of education (β=–.55; P=.04). There was also a significant interaction between education and eHealth literacy in predicting the level of affective distress (β=–.60; P=.05), which indicated that higher levels of education predicted lower averages of feeling anxiety and worry despite lower eHealth literacy. Older women reported higher averages of affective distress (β=.13; P=.05), while older men reported higher averages of experiencing a self-reported health problem (β=–.22; P=.01).

Conclusions: This study provides evidence for the effect of health-related internet use on patient-reported outcomes with implications for medical encounters. The results could be used to guide educational and eHealth literacy interventions for older individuals.

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Introduction

Internet in the Health Care Landscape

Rapid diffusion of information and communication technologies along with the self-care/self-help movement has increased the use of the internet for health information while decreasing consumer reliance on health care providers. Health professionals increasingly interact with health care consumers who want to relinquish their dependent role [1]. Most individuals consult the internet to find information for at least one health topic before visiting their health care provider, making it one of the most common online activities [2-6]. Historically, health care providers used to be the information source for their patients, which ensured patient acceptance of the health care provider's informational authority and their compliance with the treatment plan decided for them. The internet has transformed the landscape of health communication and information. As the use of the internet as a source of information has substantially increased, a more participatory model of care has increasingly become prominent in US medical care, which has led to changes in the structure of the traditional paternalistic health care paradigm [6,7]. In the age of expanding digital information technologies, the internet, as an important source of health information, has transformed the ways that consumers use health information, interact with their physicians, and receive health care services [8].

Health-Related Internet Use and Older Adults

Health care providers increasingly interact with older adults who gather health information from the internet. Although older adults are more likely to prefer health care providers as their trusted source of health information, the internet presents convenient options to obtain health and medical information, making it one of the major reasons for internet use [9-14]. In fact, aging adults in the United States represent the fastest growing group of internet users who view online information as a resource to support their health and well-being [9-11,15,16]. The Pew Research Center reports that almost 70% of computer-connected seniors use the internet [17]. The societal focus on successful aging strategies and increased quality of life in later life has provided an impetus to empower older adults as health care consumers. Health information gathering is among the major motivations for using the internet among aging baby boomers who have more experience with information and communication technologies compared to previous cohorts of older adults [3,9,11,18]. Technology acts as a buffer against health challenges in later life by increasing access to informational resources that allows older adults to be proactive in shaping their health outcomes [9-14,17,19]. With these developments, more research attention is focusing on how digital health information influences doctor-patient interactions and health outcomes among older internet users [6,8,9,20-23].

Concerns for Information Quality and Medical Encounters

The internet presents new multiple options for older adults to gather information to support their health care [10,24,25]. eHealth technologies associated with health management, promotion, and disease prevention continue to grow with new smartphone and iPad apps, mobile health tools, and social media. Although there is a generally favorable perspective toward use of the internet to acquire health information [21], the ease of access to inaccurate information on the web or the misinterpretation of the information poses potential risks to health and well-being. Despite the fact that aging baby boomers are better educated and more technology savvy than previous cohorts, inaccurate information on the internet represents a major challenge to an informed use of information technology among older adults [9,11,13,26-31]. Older adults are of particular concern as they are likely to have lower eHealth literacy than younger adults despite their increased needs for health information [26]. Research reports that just over 10% of US adults have adequate eHealth literacy [16]. This percentage is only about 3% among older adults [32-40]. The presence of questionable information sources on the internet, which ranges from personal blogs to non–peer-reviewed medical advice and commercial websites, hinders the proactive and informed use of the internet for health information [41]. Despite these challenges, older adults' use of the internet for health purposes and their ability to evaluate online information and, consequently, possible negative health outcomes remain an understudied area of research that is further complicated by the rapid proliferation of web sources of questionable scientific accuracy and trustworthiness [9,11,13,23-28,30,31].

Prior research has shown that individuals with higher levels of education and eHealth literacy levels are better able to engage in an assessment of information quality and to deploy the information appropriate in the management of their health [3,6,20,22,25,28,33,34,42-45]. Even though the internet can be an efficient tool to inform oneself, users' limited skills to make quality and credibility assessments of online health information limits health care providers' endorsement of the internet as a beneficial informational resource for their patients [46,47]. Although concerns about most patients' inability to appraise online health information and access inaccurate information due to their limited eHealth literacy have been noted, researchers have mostly focused on positive effects of internet use on the relationship between patients and their physicians [41].

Internet use for health-related information is also associated with challenges in the doctor-patient relationship, when a health consumer believes that online information is as good as information provided by their provider [43,48-50]. Researchers found that trust in information sources affect patients' attitudes and behaviors, and their satisfaction with interactional and communicational aspects of the clinical encounters [51]. Medical directives may come from providers, but health consumers' choices are influenced by a wide range of alternative sources

of information on the internet [24,48,52,53]. Information retrieval from noncredible internet sources may particularly hinder a patients' ability to form effective collaboration with their health care provider [11,16,21,54-56], which increases the importance of eHealth literacy skills. Insufficient eHealth literacy particularly presents challenges for older health consumers in an increasingly digitized society that places primary responsibility on individuals for their health care, a phenomenon to which some scholars have referred to as a "perfect storm" [57].

Distrust in the doctor's opinion, diagnosis, or treatment and subsequently nonadherence with the treatment plan may occur when patients find information that is not aligned with the doctor's approach [6,32,49,50,57-59]. Furthermore, a health care provider may also feel that the patient does not trust their knowledge and expertise or may feel that the internet information is being used to test the health care provider's knowledge [1,6,23,35,36,57]. Chung [7] found that patients who experienced poor health perceived health providers' reactions to their use of online information to be negative. About 40% of physicians think that internet use may harm the quality of the physician-patient relationship, given the vast amount and varying quality of information [49].

Health-related internet use might also be a source of frustration as "online information can add a new interpretive role to physicians' responsibilities during consultations" [6], increasing the amount of time and labor with misinformed patients, particularly if they have more questions or request additional treatments or medications [1,6,7,23,32,47,49,60,61]. If a health care provider dismisses information, a patient may feel frustrated and concerned that their use of the internet poses a barrier to achieving satisfactory doctor-patient interactions [7,24,36,49,59]. Consequently, internet use for health information may have an effect on medical encounters that is not always for the better [1,6,23,32,36,49,54,56,62,63]. Thus, there has been growing recognition that eHealth literacy should be taken into account to achieve an effective doctor-patient communication and health care partnership [11].

Theoretical Approaches

The Transaction Model of eHealth Literacy (TMeHL) informs the theoretical approach of our paper [27]. The transactional aspects of eHealth literacy refers to the communicative skills of an online information user in exchanging information with medical professionals [27]. TMeHL posits that interpersonal dynamics in social contexts drive the transactional process of communication [3]. People who possess eHealth literacy are likely to develop competences and skills, which improve their ability to communicate with their physicians, such as the ability to ask informed questions and better understand new information, which in turn are likely to result in more satisfaction in patient interactions with physicians [3,30,41]. Therefore, effective health information exchange is dependent on the interpersonal dynamics between the patient and provider. Individuals with higher eHealth literacy are better able to make appropriate assessments of information quality and credibility, and to deploy this information as a resource in the management of their health [27,28]. Accordingly, this perspective considers

education and eHealth literacy to be essential intrapersonal resources to engage with online health information effectively that would contribute to the quality of health care interactions.

A related theoretical framework of the paper is the Transactional Model of Communication (TMC). The TMC posits that the interactions among communicators may include varying levels of noise that can interfere with the process of communication [27]. Importantly, noise may hinder a patient's ability to appropriately consume and apply eHealth information or participate in successful exchanges of information with health providers particularly for those who have low levels of eHealth literacy [27]. The factors that induce *noise* within the context of medical encounters can include use of various questionable sources of information on the internet, ranging from personal blogs to non–peer-reviewed medical advice on commercial websites.

Theoretical underpinnings of the TMeHL and TMC suggest that eHealth literacy promotes a positive eHealth experience when interacting with medical professionals. eHealth literacy assists internet users to sort through online health-related information that may result in improved interactions with health care professionals [27,30]. eHealth literacy may also negate the detrimental effects produced from noise in eHealth contextual factors (eg, health and medical information of questionable accuracy on the internet) [27]. Seçkin et al [30] also identified communication with health providers as a core component of eHealth literacy, a dimension they refer to as interactional literacy. A consumer of online health information resources must possess an eHealth literacy skill set to support positive eHealth experiences and patient-provider interactions while reducing noise that may impact the transaction [27]. Paige et al [27] also pointed to a need for research to explore how eHealth literacy may serve as a moderator to buffer the negative effects of personal or relational impediments or barriers in medical encounters that limit the effective use of information technology in the management of patient health. Thus, research increasingly points to the need to examine the moderating role of the eHealth literacy on patient-physician dynamics, including interpersonal tensions and strain that might stem from consuming either too much or irrelevant information or locating erroneous information from noncredible websites [3,27,41]. Although research over the last decade has examined technological or personal barriers that impact eHealth literacy, this research has delivered limited understanding of the communicational and transactional processes, which are highly salient to a positive patient experience during medical encounters [27]. Research on eHealth literacy is infrequently framed in a way that demonstrates its transactional nature, which continues to limit our full comprehension of eHealth literacy in the digital age [27]. Moreover, in contrast to the rapidly growing literature focused on positive aspects of using online health information, little research has examined adverse outcomes of health-related internet use [21,61,63].

Research Goals and Objectives

The previously discussed issues led us to examine the effects of education and eHealth literacy separately as independent predictors and as joint moderators in our paper, which captures

the transactional nature of eHealth literacy within the context of medical encounters for older individuals' subjectively reported health-related outcomes. This paper seeks to connect eHealth literacy with interactional dynamics of medical encounters that affects patients' experience of medical encounters and subjective health outcomes.

eHealth literacy encompasses both patient information appraisal behavior (behavioral eHealth literacy) and communicational skills used by the patient when interacting with their health care providers (interactional eHealth literacy), which supports a successful acquisition of health information and meaningful patient-physician interactions [27,30]. Prior research shows that internet users with less education tend to have lower scores on health literacy measures, a trend that adversely affects satisfaction with doctor-patient interactions [64]. Seckin et al [30] also reported significant differences in eHealth literacy among internet users based on their educational attainment. Building on previous research, we suggest that education and eHealth literacy are intrapersonal resources that facilitate the exchange of information between self-informed patients and health care professionals [27]. One of the contributions of this paper to the literature lies in its ability to capture the transactional importance of eHealth literacy, which is important for fostering collaboration between a health care provider and patient-consumer.

We specifically examined whether eHealth literacy predicts patient-reported negative outcomes, whether education moderates the association between eHealth literacy and negative outcomes, and whether both eHealth literacy and education moderate the association between the perception of strain in the health care provider-patient relationship and negative patient-reported outcomes. It is important to understand these relationships because the consequences for using low-quality, misleading, or false information could endanger health [19]. To our knowledge, no prior research has examined whether education and eHealth literacy moderate the effect of perceived strain in medical encounters on patient-reported outcomes among older internet users [58].

Methods

Sample

Respondents were randomly sampled from the online probability-based research panel developed by Knowledge Networks (KN). KN used an address-based sampling frame derived from the US Postal Service Delivery Sequence File, which covers 97% of US households, thereby maximizing sample representativeness. Analyses are representative of the larger US population because all KN panel households were selected randomly with a known probability of selection, and our study respondents were further randomly selected from the larger panel. KN sent a recruitment email invitation to 1315 randomly selected panel members who were asked whether they sought health-related information on the internet. We obtained a 66% (n=870) response rate Of those who responded to the recruitment email, 710 cases qualified for the study by confirming their use of the internet to the screening question

and completed the online survey. This paper specifically focuses on the internet users who were 60 years or older (n=194).

Measures

Patient-reported outcomes included the extent to which study participants have ever experienced a health problem (self-reported health problem) as a result of using the internet information and felt worried or anxious (affective distress) because of gathering health or medical information from the internet. Responses ranged from 1 (strongly disagree) to 5 (strongly agree). We examined these patient-reported outcomes individually by performing item-based analyses.

Health-related internet use was measured with eight items (Multimedia Appendix 1) such as whether respondents "seek information on the internet to self-diagnose" and whether they "use information from the internet to make treatment decisions." Response options ranged from 1 (never) to 5 (always). An index score was created by computing the average score of the eight items (full sample: mean 1.86, SD 0.63; older adult subsample: mean 1.79, SD 0.65). The Cronbach alpha reliability coefficient for the composite scale is .83 in the full sample and .90 in the older adults subsample.

Patient nonadherence was measured by whether respondents "doubt diagnosis or treatment of a health care provider if it conflicts with information on the internet," "change their willingness to accept a health care provider's treatment after reading information on the internet," and "change a health care provider's treatment after reading information on the internet." Response options ranged from 1 (never) to 5 (always). An index score was created by computing the average score of the three items (full sample: mean 4.67, SD 1.72; older adult subsample: mean 1.71, SD 0.63). The Cronbach alpha reliability coefficient for the composite scale is .71 in the full sample and .73 in the older adults subsample.

Satisfaction with health care provider-patient relationship (referred to as medical satisfaction in tables) was assessed by asking respondents to indicate the extent of their agreement with statements such as "information on the internet helps me to communicate more effectively with health providers during appointments" and "I receive more information from health providers as a result of gathering information from the internet." Responses ranged from 1 (strongly disagree) to 5 (strongly agree). An index score was created by computing the average score of the six items (full sample: mean 3.16, SD 0.61; older adult subsample: mean 3.17, SD 0.57). The Cronbach alpha reliability coefficient for the composite scale is .86 in the full sample and .91 in the older adults subsample. A complete list of items is provided in Multimedia Appendix 1.

Respondents were also asked a single item about perceived strain in health care provider and patient relationship with the statement "interactions with health providers have become strained as a result of bringing in health or medical information from the internet to my appointments" (1, strongly disagree, to 5, strongly agree). Item-based analyses examined whether differential patterns of associations were obtained for perceived strain on this item instead of reverse coding it and including in the composite scale for medical satisfaction, which ensured

detailed results were obtained for dissatisfaction with medical encounters.

eHealth literacy was measured with the 19-item eHealth Literacy Scale (e-HLS) instrument [30], as this instrument reflects skills associated with evaluating, communicating, and using information to make informed decisions when it comes to health care such as whether respondents check for credentials and institutional affiliations of those who provide information on websites (Multimedia Appendix 1). Responses ranged from 1 (never) to 5 (always). An index score was created by computing the average score of the 19 items (full sample: mean 2.51, SD 0.77; older adult subsample: mean 2.53, SD 0.81). The Cronbach alpha reliability coefficient for the composite scale is .93 in the full sample and the older adults subsample. The responses to the e-HLS items were recoded into two groups for independent samples t test analyses to represent low health literacy and average to high health literacy. Respondents who indicated 1 (never) and 2 (rarely) on a five-point Likert scale for each item on the e-HLS instrument were coded as the low eHealth literacy group using SPSS (IBM Corp) procedures for recoding data. Respondents who indicated sometimes to always (3=sometimes, 4=often, and 5=always) on e-HLS items were coded as the average to high eHealth literacy group.

Sociodemographic covariates included the following: age was measured as a continuous variable; sex was coded as male (0) and female (1); race/ethnicity was coded as Caucasian (0) and minority (1); education was coded as high school or less (1), some college or associate degree (2), college degree (3), and postgraduate degree (4); income was collapsed into four groups: US $29,999 or less (1); US $30,000-$59,999 (2); US $60,000-$99,999 (3); and US $100,000 and above (4); marital status was coded as married (0) and unmarried (1).

Statistical Analysis

First, descriptive and bivariate analyses (correlational analyses and t tests) were performed. Regression diagnostics were conducted on the residuals to make sure the underlying assumptions of multiple regression analysis (ie, homoscedasticity) were met. Hierarchical ordinary least squares regression models examined the associations among variables and their relative predictive strengths. Model 1 in each table represents the main effects for sociodemographic characteristics. Model 2 was adjusted for technology and medical encounter variables. The interaction terms (eHealth literacy × strain,

eHealth literacy × education, and education × strain) were entered in the final step (model 3). This analytical approach allowed examination of the changes in the relative effect of each covariate on the outcome variables. Parallel regression models for each patient-reported outcome were performed.

Results

The complete study sample included respondents aged 18-93 years (mean 48.8, SD 16.4). Respondents 60 years and older (the focus of this paper) represented about 27% (194/710) of the total sample (mean 68.7, SD 7.4). About 40% (73/194, 37.6%) of the older respondents had a college degree or higher, and just over half of the respondents (99/194, 51.1%) reported an income level of US $60,000 or more. Women accounted for more than half of the sample (107/194, 55.2%). About 60% were married (121/194, 62.4%), and just over 80% (160/194, 82.5%) were Caucasian. Descriptive statistics of the study variables in the older sample of health-related internet users is provided in Table 1.

As shown in Table 2, we also examined independent samples t tests to investigate the effect of eHealth literacy levels on study covariates. Older adults with higher levels of eHealth literacy reported lower averages for perceived strain in medical encounters (t_{194}=2.92; P=.01). They also reported lower averages for affective distress (t_{194}=2.11; P=.04) and more satisfaction with medical encounters (t_{194}=4.70; P<.001). There are also significant differences in the averages for nonadherence (t_{194}=5.06; P<.001) and self-reported health problems in relation to internet use (t_{194}=1.93; P=.05).

Correlational analyses indicated that education is positively associated with eHealth literacy (r=0.27; P<.001) but negatively associated with strain in medical encounters (r=0.16; P=.03). eHealth literacy has a positive association with satisfaction with medical encounters (r=0.40; P<.001) but a negative association with perceived strain (r=–0.18; P=.01). We also found that affective distress is negatively related to education (r=–0.21; P=.01) and eHealth literacy (r=–0.16; P=.03) but positively related to health-related internet use (r=0.17; P=.02) and strained medical encounters (r=0.17; P=.01). Experiencing a self-reported health problem is positively associated with health-related internet use (r=0.16; P=.02) and nonadherence (r=0.17; P=.04).

Table 1. Descriptive statistics (N=194).

Research variables	Participants, mean (SD)
Health-related internet use (range 1-5)	1.79 (0.65)
eHealth literacy (range 1-5)	2.53 (0.81)
Medical satisfaction (range 1-5)	3.17 (0.57)
Perceived strain (range 1-5)	2.40 (0.77)
Nonadherence (range 1-5)	1.71 (0.63)
Self-reported health problem (range 1-5)	1.04 (0.26)
Affective distress (range 1-5)	2.34 (0.80)

Table 2. Covariates stratified by eHealth literacy level (N=194).

Covariates	Low eHealth literacy, mean (SD)	Average to high eHealth literacy, mean (SD)	T test (df)	P value
Medical satisfaction	3.09 (0.58)	3.51 (0.66)	4.70 (194)	.001
Perceived strain	1.56 (0.50)	1.36 (0.48)	2.92 (194)	.01
Nonadherence	1.50 (0.52)	1.90 (0.64)	5.06 (194)	.001
Self-reported health problem	1.30 (0.46)	1.75 (0.50)	1.93 (194)	.05
Affective distress	2.45 (0.72)	2.22 (0.85)	2.11 (194)	.04

Next, we present regression models for patient-reported outcomes in Tables 3 and 4. We provide both standardized (β) and unstandardized regression coefficients (b). As Table 3 shows, affective distress was positively predicted by gender (β=.13; P=.05) and satisfaction with medical encounters (β=.34; P<.001). Perception of strain in medical encounters was positively associated with affective distress (β=.20; P=.01) in model 2, which became nonsignificant in model 3, probably because its main effect was partially out when the interaction terms were included. Similarly, education and eHealth literacy were negative predictors of affective distress in model 2 before including the interaction terms (β=–.18, P=.03 and β=–.32, P=.01, respectively). There was also a significant interaction between education and eHealth literacy in predicting affective distress (β=–.60; P=.05), which indicated that higher levels of education predicted lower averages of feeling anxiety and worry despite lower levels of eHealth literacy among older internet users.

As shown in Table 4, age (β=–.17; P=.02), gender (β=–.22; P=.01), health-related internet use (β=.29; P=.03), and medical satisfaction (β=–.28; P=.01) were significant predictors of experiencing a health problem associated with the use of information found on the internet. There was also a significant interaction between education and perception of strain in medical encounters in predicting self-reported health problems. The association was greater among respondents with lower levels of education (β=–.55; P=.04), which indicated that the association between experiencing a health problem in relation to health-related internet use and perception of strained medical encounters was greater among respondents with lower levels of education. The regression models explained 23% of the variance in affective distress and 18% of the variance for self-reported health problems.

Table 3. Regression analyses predicting affective distress (N=194).

Covariates	Affective distress								
	Model 1[a]			Model 2[b]			Model 3[c]		
	b	β	P value	b	β	P value	b	β	P value
Age	–0.01	–0.07	.41	–0.01	–.07	.36	–0.01	–0.08	.23
Sex	0.13	0.08	.24	0.20	.12	.08	0.21	0.13	.05
Race	–0.01	–0.00	.91	0.03	.01	.92	0.05	0.02	.81
Education	–0.20	–0.29	<.001	–0.12	–.18	.03	0.40	0.59	.10
Income	0.16	0.21	.02	0.14	.19	.03	0.12	0.16	.08
Marital status	–0.12	–0.07	.62	–0.19	–.11	.26	–0.19	–0.11	.29
Health-related internet use				0.02	.02	.89	0.03	0.02	.88
eHealth literacy				–0.31	–.32	.01	–0.25	–0.26	.42
Medical satisfaction				0.40	.33	.001	0.41	0.34	.001
Perceived strain				0.20	.20	.01	0.11	0.11	.40
Nonadherence				0.04	.02	.77	0.03	0.02	.74
Education × strain							–0.09	–0.34	.15
eHealth literacy × strain							0.08	0.27	.43
eHealth literacy × education							–0.12	–0.60	.05

[a]R^2 for model 1 was 0.09 (adjusted R^2=0.06).

[b]R^2 for model 2 was 0.22 (adjusted R^2=0.16).

[c]R^2 for model 3 was 0.23 (adjusted R^2=0.17).

Table 4. Regression analyses predicting self-reported health problems (N=194).

Covariates	Self-reported health problem								
	Model 1[a]			Model 2[b]			Model 3[c]		
	b	β	*P* value	b	β	*P* value	b	β	*P* value
Age	–0.01	–0.17	.02	–0.01	–.16	.02	–0.01	–.17	.02
Sex	–0.10	–0.20	.01	–0.12	–.22	.01	–0.11	–.22	.01
Race	–0.06	0.19	.17	–0.08	–.11	.10	–0.07	–.10	.12
Education	–0.02	–0.10	.22	–0.03	–.14	.11	0.10	.48	.21
Income	–0.00	–0.01	.89	0.01	.02	.74	–0.00	–.02	.89
Marital status	–0.04	–0.06	.13	–0.02	–.03	.25	–0.01	–.01	.34
Health-related internet use				0.13	.30	.03	0.12	.29	.03
eHealth literacy				0.02	.05	.62	0.02	.02	.95
Medical satisfaction				–0.11	–.27	.01	–0.11	–.28	.01
Perceived strain				0.04	.12	.34	0.10	.31	.32
Nonadherence				0.01	.02	.70	0.01	.03	.68
Education × strain							–0.05	–.55	.04
eHealth literacy × strain							0.01	.14	.68
eHealth literacy × education							–0.01	–.15	.67

[a]R^2 for model 1 was 0.08 (adjusted R^2=0.05).

[b]R^2 for model 2 was 0.16 (adjusted R^2=0.11).

[c]R^2 for model 3 was 0.18 (adjusted R^2=0.11).

Discussion

Principal Findings

In this study, we provide the empirical evidence of the importance of education and eHealth literacy and their implications for health-related outcomes within the context of transactional importance of medical encounters in older demographics. Our findings highlight the role of education as a significant moderator of the effects of inadequate eHealth literacy and strained medical encounters on patient-reported outcomes. Specifically, older internet users with lower levels of eHealth literacy but higher educational levels reported feeling less worried and anxious because of what they read on the internet. For example, the significant interaction between educational level and perceived strain in medical encounters suggested that the effect of lower education on likelihood of experiencing a health problem, associated with information use obtained from the internet, is greater under conditions of greater strain in medical encounters.

Gender is a significant predictor of patient-reported outcomes. Older women reported lower averages on experiencing a health problem but higher averages on affective distress because of using the information obtained from online sources. These associations could be attributed to their gender-associated caretaker roles and responsibilities that encourage women to be more discerning health information consumers while increasing their exposure to potentially inaccurate information that may increase their distress level as women tend to be more frequent users of the internet for health-related information [16,65-68].

In contrast, older men reported higher averages on experiencing a health problem as consequence of using the internet information but less affective distress. These different gender-based outcomes need further exploration to have a more comprehensive grasp of the nature of the effect of health information–related use of the internet on subjective health outcomes.

Nonadherence with medical professionals was not a significant predictor of patient-reported outcomes. As Seckin et al [51] noted, prior to the 1980s, the passive patient was expected to accede to their physician's authority by conforming to their physician's stipulated treatment and advice. Socialization of older cohorts into medical paternalism, which promoted a *doctor knows best* approach for health care increased the tendency of older adults to show compliance with medical professional authority, which offers a potential explanation for this specific nonsignificant association in the older sample [1,26].

Satisfaction with medical encounters is a negative predictor of likelihood of experiencing a health problem associated with internet information. Respondents who were more satisfied with their patient-physician relationship may feel less need to consult online sources of information, which may or may not be credible, thereby lowering their risks with incorrect information or misinterpretation of correct information. Alternatively, even if they consult the internet for supplementary information, they might be less likely to implement the information or follow the advice found online because of their trust in their health care provider's approach to their care provision. Interestingly, satisfaction with medical encounters is positively associated

with affective distress, which might reflect increased information or attention received from health care providers when a patient feels distressed because of the content of the information they came across on the internet. It is also important to note that perception of strain in doctor-patient relationships was a significant predictor of affective distress. Perception of strain in medical interactions, as discussed earlier in the paper, may discourage people from discussing online information with their health care providers, which in turn may increase their distress level, particularly when a patient does not possess adequate health literacy skills to evaluate the information [32].

Limitations

This paper captures limited dimensions of patient-reported outcomes. Individuals with chronic health issues or serious diseases may use the internet in more targeted ways than those who browse the internet for general health purposes, which in turn may result in differential health outcomes and perceptions of how medical encounters are affected by use of the internet sources. Future evaluations of health-related internet use should focus on older adults with specific chronic conditions to elucidate its role in health management. Furthermore, the analyses relied on self-reports and reflected on the cross-sectional nature of these associations. A longitudinal design to elucidate the pathways through which health-related internet use influences health outcomes will provide more detailed information [21,69,70]. Thus, future work should consider the specific mechanisms such as behavioral pathways (eg, specific self-care behavior) that potentially link eHealth information consumerism to health outcomes. Using a mixed-methods approach will also help to unpack health providers and consumers' perspectives. Inclusion of unaccounted variables, such as trust in health care providers or trust in the

internet, would have probably increased the explanatory power of the statistical models used in this study.

Despite these limitations, this study makes an important contribution to research on health-related internet use among older adults by illustrating the empirical links of education and eHealth literacy to patient-reported outcomes [25,71]. There has been a research lag in examining whether, to what extent, and how eHealth literacy influences patient-reported outcomes in the general population, particularly among older adults [9,23,34,69]. This paper captures the role of eHealth literacy among older internet users. The results highlight the need to foster positive experiences in medical interactions and underlie the importance of informed consumerism of online information among older adults in the age of eHealth information technology.

Conclusion

The findings have implications for health care providers to guide patients to reliable and accurate health resources on the internet. Older health consumers will be able to make more informed choices and better decisions about their health if health professionals help to empower them in finding credible and trustworthy online sources [9,33,34,43,47,48,69,72]. Given older adults' substantial health needs, their ability to find credible online information is critical in furthering a research agenda on technology use among older adults [2,23,73-75]. Empowerment of older adults as proactive health information consumers necessitates addressing their eHealth literacy needs and improving their health literacy skills through educational or intervention programs, which in turn will help to offset potential undesirable outcomes due to misinformation or inaccurate information use [1,14,24,36,76].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Measures.
[DOCX File , 17 KB - aging_v4i4e16006_app1.docx]

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Abbreviations

e-HLS: eHealth Literacy Scale
KN: Knowledge Networks
TMC: Transactional Model of Communication
TMeHL: Transaction Model of eHealth Literacy

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Original Paper

Clinicians and Older Adults' Perceptions of the Utility of Patient-Generated Health Data in Caring for Older Adults: Exploratory Mixed Methods Study

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Abstract

Background: Many people are motivated to self-track their health and optimize their well-being through mobile health apps and wearable devices. The diversity and complexity of these systems have evolved over time, resulting in a large amount of data referred to as patient-generated health data (PGHD), which has recently emerged as a useful set of data elements in health care systems around the world. Despite the increased interest in PGHD, clinicians and older adults' perceptions of PGHD are poorly understood. In particular, although some clinician barriers to using PGHD have been identified, such as concerns about data quality, ease of use, reliability, privacy, and regulatory issues, little is known from the perspectives of older adults.

Objective: This study aims to explore the similarities and differences in the perceptions of older adults and clinicians with regard to how various types of PGHD can be used to care for older adults.

Methods: A mixed methods study was conducted to explore clinicians and older adults' perceptions of PGHD. Focus groups were conducted with older adults and health care providers from the Greater Toronto area and the Kitchener-Waterloo region. The participants were asked to discuss their perceptions of PGHD, including facilitators and barriers. A questionnaire aimed at exploring the perceived usefulness of a range of different PGHD was also embedded in the study design. Focus group interviews were transcribed for thematic analysis, whereas the questionnaire results were analyzed using descriptive statistics.

Results: Of the 9 participants, 4 (44%) were clinicians (average age 38.3 years, SD 7 years), and 5 (56%) were older adults (average age 81.0 years, SD 9.1 years). Four main themes were identified from the focus group interviews: influence of PGHD on patient-provider trust, reliability of PGHD, meaningful use of PGHD and PGHD-based decision support systems, and perceived clinical benefits and intrusiveness of PGHD. The questionnaire results were significantly correlated with the frequency of PGHD mentioned in the focus group interviews ($r=0.42$; $P=.03$) and demonstrated that older adults and clinicians perceived blood glucose, step count, physical activity, sleep, blood pressure, and stress level as the most useful data for managing health and delivering high-quality care.

Conclusions: This embedded mixed methods study generated several important findings about older adults and clinicians' perceptions and perceived usefulness of a range of PGHD. Owing to the exploratory nature of this study, further research is needed to understand the concerns about data privacy, potential negative impact on the trust between older adults and clinicians, data quality and quantity, and usability of PGHD-related technologies for older adults.

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KEYWORDS

mobile health; mHealth; older adults; wearables; patient generated health data; chronic disease management; home care; self-care; activities of daily living; sleep

Introduction

Background

A recent national survey reported that Canadians aged ≥55 years have the highest rate of self-tracking of health data at 62.9%, whereas 38.73% track the data digitally using mobile health (mHealth) apps, consumer wearable devices, and smart medical devices [1]. Many individuals are motivated to track their health data, including physical activity and sleep quality, and optimize their well-being [2]. The diversity and complexity of the collected data has evolved over time with the advancement of sensors. Self-tracking of health data began with a collection of simple measurements such as weight, step counts, hours slept, and exercise logs, and has now demonstrated successful tracking of qualitative and subjective assessments such as mood and emotion [2]. The added complexity of self-tracked health data demonstrates the level of motivation and interest of the general population and the desire to improve one's health and well-being.

Self-tracking of health data results in a large amount of data, often referred to as patient-generated health data (PGHD). PGHD is defined as "data created, recorded, gathered, or inferred by or from patients or their designees to help address a health concern" [3]. The key characteristic of PGHD is that its management and sharing are directed by patients. Similar concepts about collecting data from patients in natural settings exist, such as patient-reported outcome measures (PROMs) and ecological momentary assessment (EMA). PROMs are standardized data collection methods that are initiated by health care providers with the aim of evaluating the effectiveness of care [4]. PGHD differs from PROMs in its use of consumer technologies and in that the collection and sharing are patient-directed. EMA is a research-driven data collection method that allows participants to report occurrences of phenomena of research interest, such as symptoms, behaviors, or cognitive processes [5]. As with PROMs, EMAs are not patient-driven, and their purpose is to provide data for research.

Patients, health care providers, researchers, private industry, and governments share a similar vision of future health care where PGHD plays an important and significant role [6-10]. In the United Kingdom, PGHD is envisioned as one of the foundations for improving the quality of care and decreasing health care costs under the *Personalised Health and Care 2020* policy [9]. The plan to integrate PGHD into health care practice has also been shared by the US government, where PGHD will provide a holistic and longitudinal view of the patient's health [11]. Although PGHD and related health monitoring systems can help older adults age in place, the way such technologies are used for geriatric care can decrease their effectiveness and even cause confusion or intimidation for older adults [12-14]. Although the increased interest in using PGHD is evident from a strong commitment by governments, successful adoption and

implementation of required health information systems hinge on buy-in from care providers and users.

Despite the increased interest in PGHD, little is known about the opinions of clinicians and patients on PGHD. Common barriers to the use of PGHD by clinicians include unfamiliarity with the data, insufficient expertise in interpreting the data, and concerns about data completeness, reliability, and relevance [15]. Furthermore, the lack of time for any task outside of routine clinical practice, technical challenges including incompatibility between PGHD and electronic medical record systems, and uncertainty around privacy regulations hamper clinicians' willingness to adopt PGHD [16-18]. Although these factors hinder clinicians from using PGHD, little is known about the opinions of older patients and the common barriers to adopting PGHD. Understanding the factors associated with the use of PGHD by older adults can inform policy makers, health care providers, software developers, and other stakeholders about PGHD and provide useful guidance.

Research Objective

This study aims to explore the similarities and differences in the perceptions of older adults and clinicians' with regard to how various types of PGHD can be used to care for older adults. We compared their attitudes toward different types of PGHD. This study extends the current literature by investigating the opinions of older adults and health care providers on the key factors that facilitate or hinder the use of PGHD.

Methods

Study Design

An embedded mixed methods design was used with the one-phase QUAN (qual) approach to explore the study objective. To introduce the topic of PGHD to the participants and set the scope of the focus group, we presented a case study that described an older patient being asked to collect PGHD to manage multiple chronic conditions [19]. The quantitative data collection was nested within the overall research design and performed after reviewing the case study through a questionnaire that was developed specifically for this study. Focus group interviews were conducted immediately following the completion of the questionnaire to probe the perceived barriers and key factors in using PGHD.

Research ethics approval for this study was received from the University of Waterloo Office of Research Ethics (ORE #40803). All participants provided written informed consent.

Procedures

The Data Rating Questionnaire (Multimedia Appendix 1) was administered to measure participants' perceived usefulness of PGHD. Demographic information and information regarding previous experience with mHealth apps and wearable technologies that generate PGHD were also collected. Two semistructured focus group interviews were conducted at the

University of Waterloo and at the conference room of a health care organization. A set of questions was prepared and used by the interviewer as a guide to probe the participants' perceived factors that facilitate and hinder the use of PGHD (Multimedia Appendix 2). The discussions were audio-recorded for analysis.

Recruitment

Convenience sampling and snowball recruitment strategy were used to recruit 5 older adults and 4 clinicians. They were recruited from the Greater Toronto Area and the Waterloo-Wellington region in Ontario, Canada. An invitation email was sent to local clinicians and a research support group comprising over 60 older adults. Recruitment started in October 2019, and focus group interviews were conducted in December 2019.

Data Collection and Analysis

Case Study

The case study described a 77-year-old man newly diagnosed with congestive heart failure with pre-existing type 2 diabetes, hypertension, and hyperlipidemia (Multimedia Appendix 3). The case study highlights the new responsibility given to the patient to collect and monitor a plethora of PGHD, including weight, blood pressure, blood glucose level, dietary intake, and medication log, using a variety of digital tools and a traditional paper journal. Participants reviewed the case study and were encouraged to ask questions about the types of PGHD presented and the role of information technology in collecting PGHD. The case study was used as an anchor for the focus group as some participants were unfamiliar with the topic.

Data Rating Questionnaire

A 26-item, 5-point Likert scale questionnaire (Multimedia Appendix 1) was developed based on the outlined definition of PGHD from the office of the national coordinator for health information technology of the US government [20] and from literature review [21]. The questionnaire categorized PGHD types based on the mode of data collection as either passively collected or actively collected. Passively collected data were generated without user input and included step count, sleep quality, and location information. Actively collected data were manually captured by patients on demand. Participants were asked to rate the perceived usefulness of each PGHD type based on the case study.

Focus Group Interviews

Two 30-minute focus group interviews were conducted and audio-recorded. We interviewed 6 and 3 participants in the first and second sessions, respectively. The first group comprised 5 older adults and 1 physiotherapist, whereas the second group comprised 2 nurses and 1 family physician. The composition of each session was based on geographic and logistical convenience, and the division between clinicians and older adults was unintentional.

Analysis

Descriptive statistics were performed to analyze demographic information and previous experience with mHealth apps, wearable devices, collecting PGHD, and Data Rating Questionnaire results. There were some missing data as some participants did not provide answers, and they were excluded from all quantitative analyses.

Focus group interviews were transcribed and read in their entirety. A constant comparative analysis strategy was used to code and categorize them into themes [22]. This inductive approach involved an iterative cycle of comparing the data with existing codes and themes, providing the researchers with a sense of frequency of the theme. This approach allowed researchers to investigate other aspects of the themes, including their extensiveness, intensity, internal consistency, and perceived importance [22]. The number of times each PGHD concept was mentioned was tallied regardless of who mentioned them (eg, if one participant mentioned a particular concept three times, it was counted as 3). All quantitative analyses were performed using R Studio, and qualitative analyses were performed using NVivo 12 (QSR International).

Results

Participant Characteristics

Of the 9 participants, 4 (44%) identified themselves as clinicians, including 1 primary care physician, 2 registered nurses, and 1 registered physiotherapist. The mean age of the clinicians was 38.3 (SD 7) years, and 3 of them were women. The remaining 56% (5/9) of the participants identified themselves as health care users. The mean age of this group was 81.0 (SD 9.1) years, and 4 of the 5 older adults were women (Table 1).

Table 1. Participant characteristics (N=9).

Participants	Age (years)	Sex
Older adults		
Participant 1	82	Female
Participant 2	78	Female
Participant 3	94	Male
Participant 4	78	Female
Participant 5	69	Female
Clinicians		
C1-physiotherapist	47	Female
C2-primary care physician	39	Female
C3-registered nurse	30	Male
C4-registered nurse or educator	37	Female

Participant Exposure to PGHD

Of the 4 clinicians asked about their previous use of mHealth apps, 3 (75%) reported having used them to track dietary intake and calories, to monitor weight changes, and to improve exercise and training. These 3 clinicians also used a wearable device. Wearable devices were used to monitor step counts, physical activity levels, exercise intensity, sleep quality, and heart rate. Of the 5 older adults, 3 (60%) used either an mHealth app or a wearable device to monitor step counts only despite understanding that their wearable device offered monitoring of other PGHD.

Thematic Analysis

Theme 1: Influence of PGHD on Patient-Provider Trust

Older adults and clinicians had conflicting views on the impact of PGHD on patient compliance. Older adults felt that monitoring PGHD increased the transparency of their (lack of) engagement in healthy behaviors. Older adults understood that increased transparency encouraged and motivated compliance, although this was not explicitly stated.

Participants stated:

...he just sits in that chair and watching TV and he can say "Oh I walk" but you didn't. from here to the washroom to the kitchen; that's not enough. [Participant #1]

...[clinicians will] see whether they have done this. And that goes for the exercise programs too and not just say it but follow through. [Participant #3]

I think the device would help the clinician know when somebody is sneaking a candy bar or somebody says that they go for a walk everyday, but they really only go twice a week. [Clinician #1]

Clinicians expressed concerns about the increased transparency via PGHD and how it could lead to noncompliance with the use of the system and selective disclosure of PGHD by patients. Clinicians also perceived that older adults were afraid of the negative impact noncompliance would have on the

patient-provider relationship and, in turn, on the quality of care they received from their providers:

The biggest one I have seen as a doctor is the fact that you've not been following your diet or your exercise plan so I'm not going to show you because now you know. [Clinician #2]

So, [patients] are like, okay I'm not going to, I'm just going to skip it this day, because having no data is better than showing that I wasn't following directions or doing it properly. [Clinician #3]

...the perception of, you know, how much they want to help me, because of things like, you know, well I can only help if you help yourself and then the perception of, well you don't want to help yourself, so how could that impact that relationship with the provider. [Clinician #3]

Not all older adults agreed with the suspected tendency toward selective disclosure of PGHD. Two older adults expressed that they were less likely to share PGHD when they were noncompliant and inclined to share only compliant information. However, one participant was comfortable sharing their PGHD regardless of compliance:

...if you're underperforming, you're a little more likely not to want to tell everything that you do [Participant #2]

But if I walk every day in the good weather—not this weather—I want him to know about it and I wouldn't tell him I did if I didn't do it. [Participant #3]

I would tell him. If I walk only 5000 or 6000 I will tell him too. [Participant #1]

Older adults and clinicians generally agreed on the benefit that increased transparency arising from PGHD sharing has on the care they provide or receive. Ultimately, clinicians viewed noncompliance with PGHD collection as an issue they could help prevent by gaining buy-in from patients. Patients also raised the need for additional education, which might improve the understanding of the need for PGHD.

Theme 2: Reliability of PGHD

The clinicians recognized the issue of accuracy of PGHD from mHealth apps and wearable devices and understood that they might not be perfect. Despite the inaccuracies, the perceived clinical value outweighed the alternative of having no data. However, the clinicians' concerns about the reliability of PGHD stemmed from the perceived lack of trust in the patients' ability to capture or share the data reliably:

> *You have to assume that the patient is wearing it for the majority of the time.* [Clinician #1]

> *Not remembering to do it...I was told I was supposed to track this and I've forgotten so many times.* [Clinician #3]

Older adults and clinicians perceived that the lack of clinical knowledge by patients leads to a collection of irrelevant PGHD and decreases the usefulness of the information. In contrast, older adults viewed education on self-management as a key component in understanding the importance of PGHD:

> *I guess it depends on who is looking at the data and if the person entering it can also appreciate or have some clinical background, because then they can say, okay I'll use it and I'll enter it, because it has usefulness for my clinical provider.* [Clinician #3]

> *...they really there to teach him, make sure that he understands what—he needs to understand that he needs to take his blood pressure medication everyday and they need to monitor that and see whether it's working.* [Participant #4]

Gaming mHealth apps and wearable devices used by patients to collect favorable data were viewed as a threat to the reliability of PGHD. Clinicians acknowledged that this issue was not unique to PGHD and that it could happen to any self-reported information:

> *And how accurate is the data when it comes, so like if you learn to game the system, you can choose to, you know...in the case of like blood sugars, you know, take it later on, so that way it looks like it's a better reading than it actually is.* [Clinician #3]

> *Shake your hand as though you're walking.* [Clinician #2]

> *They could be lying about writing down their values, right, or they could be lying about the weight that they measure at their home scale or whatever, right.* [Clinician #4]

Clinicians emphasized the threat to the reliability of PGHD through the manipulation of mHealth and wearable systems. This was because clinicians were aware of the advancement in sensor technology that enabled some previously actively collected PGHD to be passively collected, such as blood glucose levels. Passive data collection increased the trust clinicians put in the quality of the data as it prevented data manipulation by patients:

> *Like blood glucose right now, like right now it's under actively sensed data...because I guess you would have to do like a finger prick and then we do reading and*

then enter it in, but now there is technology that exists where you, you know, you attach, and all you have to do is put the device. [Clinician #3]

> *I mean after having worked with patients and now having parents that are dealing with chronic conditions themselves, I really hope that at some point a lot of that data collection is passive.* [Clinician #2]

Overall, the reliability and accuracy of PGHD were disproportionately perceived as an issue by clinicians compared with older adults. Clinicians also alluded to old age as a potential challenge as the older generation is not as fluent with mHealth, wearable technology, and other devices that collect PGHD.

Theme 3: Meaningful Use of PGHD and Decision Support Systems

The uncertainty around the meaningful use of PGHD was expressed by both older adults and clinicians. Older adults were reluctant to share their PGHD with their clinicians as they were uncertain of the use of PGHD by their clinicians and the skill levels of their clinicians to use them:

> *That's the thing; check up are they really doing this?* [Participant #4]

> *...he is not going to absorb it any more than we would.* [Participant #3]

A large amount of data was viewed as a major hindrance to the use of PGHD by both older adults and clinicians. Older adults felt *overwhelmed* when trying to review and understand the data. Older adults felt discouraged from sharing the data as they perceived that reviewing PGHD was a time-consuming task and felt that clinicians would not have enough time:

> *And you want to know what's important for you and I think people can do these things but you have to do it in little steps too. This is kind of overwhelming, the whole thing.* [Participant #2]

> *...the doctor is just simply too busy, he'll never look at all this information that we're talking about here. He won't have the time.* [Participant #4]

However, clinicians did not express lack of skills as a barrier to PGHD use. Instead, clinicians reiterated the issue of the volume of PGHD and acknowledged the lack of time to review and discuss PGHD before or during consultations:

> *...as a provider, like I wouldn't want to be the one going through like excel sheets of data.* [Clinician #2]

> *If I'm looking at all of the data that's available across like 20 different measures, how long do I have for a consult even, or how long do I have allocated for a meeting for this patient.* [Clinician #3]

Despite the issues of information overload and lack of time, clinicians saw clinical value in collecting more PGHD. Clinicians envisioned that PGHD could provide additional information when investigating the effectiveness of treatments, such as newly prescribed medications or behavioral changes:

> *I would say if it wasn't a technological or a financial cost constraint to have, at least the passive data stuff all included and made available to the clinician,*

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because then you can correlate things like, all right well...you know, they had a blood pressure issue, right. What were they doing at the time, what was your physical activity at the time or did they get a good night's sleep before, you may not see that directly, but having that data wouldn't hurt. [Clinician #3]

...from a clinician perspective, but when you asked about the clinician versus patients, I think it'd be nice to have all this data. [Clinician #2]

Clinicians had an extensive view on decision support systems as an essential part of operationalizing PGHD in the clinical context. A decision support system was perceived as a tool that could highlight the most relevant information and reduce the time taken to interpret the data. It was also viewed as an early warning system for patients with deteriorating health:

From the provider perspective, how is the data presented to me, is it a whole set of charts and numbers I have to go find and find trends? Or is it, is there a dashboard that comes up that easily [find] trends for you, because then I can look at it, I'm going, oh okay, I see a positive trend, here's what I can, it's actionable like you said, I can do something with it and provide guidance. If it's just a whole bunch numbers and I have to see well how close is it and how much time will that take, then I may be less, I may be more hesitant to ask for this data or use this data. [Clinician #3]

...with maybe mental health issues or support issues, like depression, with their consent I think that would be great...if suddenly their social media usage or their call, texting has dropped then, you know, it should set off an alarm. [Clinician #2]

Older adults perceived PGHD to be difficult to use as the volume of data would be too large, and it would be time-consuming to gain an understanding of their health and the effectiveness of care. Clinicians expressed the significance of a decision support system to act on the PGHD.

Theme 4: Perceived Clinical Benefits and Intrusiveness of PGHD

The monitoring aspect of PGHD disturbed the older adults to varying degrees. One older participant repeatedly expressed emotionally charged negativity toward PGHD collection and sharing of the data with clinicians. This was further perceived as a threat to autonomy. Clinicians acknowledged the tension between the clinical benefits and the intrusiveness of PGHD systems and felt that clinicians were accountable for gaining buy-in from patients:

It just seems to me very intrusive. Every little thing, every little step you take and so on...you get to a point where "I don't want so much of you in my life." I like the act that my doctor doesn't overdo it. You thought about not wearing it and then you don't get all the information. [Participant #2]

And I guess I'm afraid I'm going to be told "You shouldn't be doing this, you shouldn't be doing this, you shouldn't be doing that." That's hard to live with. [Participant #2]

...gaining that buy-in and helping people understand that this data is going to help them in the long run. [Clinician #2]

Clinicians also had heightened sensitivity to PGHD which might intrude patient privacy. One clinician perceived the monitoring of social media use for tracking mental health and GPS information for Alzheimer and dementia patients to be intrusive. The internal conflict between the clinical benefits and intrusiveness of PGHD was evident for one clinician:

Social media uses and communication felt a little intrusive...Yeah, the social media and the communication, I can see how that's useful. [Clinician #2]

When asked about the current regulations for patient privacy and confidentiality, clinicians viewed them as a necessary barrier and even as a facilitator for integrating PGHD into existing health information systems safely and securely:

...talking now between patient and provider, like that definitely needs to be given the most security that we can...so if you want to take information from a wearable device and throw it to an EMR or a hospital system, there's sometimes a lot of challenges in being able to do that. [Clinician #2]

the privacy laws are necessary...I would say it's a, it's definitely a barrier what between like healthcare provider sharing, So yeah, it is a, it's a necessary barrier - [Clinician #3]

Perceived Usefulness of PGHD

When the frequency of the different types of PGHD mentioned in the focus groups was examined, it was noted that clinicians engaged in more diverse types of PGHD more frequently than older adults. Table 2 summarizes the PGHD asked in the Data Rating Questionnaire and the frequency of mention. Blood glucose level, step count, physical activity, sleep, and blood pressure were most frequently discussed.

Table 2. Frequency of patient-generated health data (PGHD) mentioned in focus group interviews.

PGHD	Frequency (how often was a concept mentioned?)		
	Clinicians (n=45), n (%)	Older adults (n=24), n (%)	Total (n-69), n (%)
Blood glucose	6 (13)	3 (13)	9 (13)
Step count	3 (7)	4 (17)	7 (10)
Physical activity	5 (11)	2 (8)	7 (10)
Sleep	3 (7)	4 (17)	7 (10)
Blood pressure	2 (4)	4 (17)	6 (9)
Gait	4 (9)	—[a]	4 (6)
Heart rate	2 (4)	2 (8)	4 (6)
Communication activity	3 (7)	—	3 (4)
Social media use	3 (7)	—	3 (4)
Stress level	—	3 (13)	3 (4)
Dietary intake	2 (4)	1 (4)	3 (4)
Body temperature	2 (4)	—	2 (3)
Body weight	1 (2)	1 (4)	2 (3)
GPS	1 (2)	—	1 (1)
Air quality	1 (2)	—	1 (1)
Ambient light	1 (2)	—	1 (1)
Air pressure	1 (2)	—	1 (1)
Body fat percentage	1 (2)	—	1 (1)
Mood	—	1 (4)	1 (1)
Typing pattern	1 (2)	—	1 (1)
Wound pictures	1 (2)	—	1 (1)
Sedentariness	—	—	—
EDA[b]	—	—	—
PEF[c]	—	—	—
Inhaler use	—	—	—

[a]Not mentioned.

[b]EDA: electrodermal activity.

[c]PEF: peak expiratory flow.

Stress level as PGHD was discussed only by older adults, and it was portrayed as having significant importance for overall well-being. Older adults also made a distinction between acute and chronic stresses:

> *If you have high stress and you have, what we would call a bad day, that affects your whole being, your whole body, and your mind more.* [Participant #3]

> *We get to this stage and many people have lost their spouse and it seems to take a really long—well, it never goes away. But to deal with stress is a high component.* [Participant #2]

The Data Rating Questionnaire results showed that, on average, participants rated the usefulness of PGHD at 3.35, which is between moderately useful and very useful. The five most frequently mentioned types of PGHD (blood glucose, step count, physical activity, sleep, and blood pressure) had a higher average score of 3.83. The questionnaire results were significantly correlated with the frequency of PGHD mentioned in the focus group interviews (r=0.42; P=.03). Table 3 presents the average ratings of all PGHD for older adults and clinicians. Figure 1 shows the overall distribution of ratings for each PGHD type.

Clinicians tended to rate PGHD higher than older adults (mean 3.55 vs 3.18). The actively collected PGHD was rated significantly higher than the passively collected PGHD (mean 3.80 vs 3.05). Clinicians perceived passively collected PGHD as more trustworthy, as it prevented data manipulation by patients. However, the clinician ratings for actively and passively collected PGHD were similar.

Table 3. Average rating of patient-generated health data (PGHD) by older adults and clinicians[a].

| PGHD	Rating (1=not at all useful and 5=extremely useful), mean (SD)		
	Older adults	Clinicians	Both older adults and clinicians
Passively collected PGHD			
Step count	2.8 (1.10)	4 (1.41)	3.33 (1.32)
Gait	2.75 (0.96)	3.25 (1.50)	3.00 (1.20)
Physical activity	3.8 (0.45)	4.5 (1.00)	4.11 (0.78)
Sleep	2.9 (1.34)	3.38 (1.70)	4.44 (1.43)
Heart rate	4 (0.71)	5 (0.00)	3.63 (0.73)
Sedentariness	3.75 (1.26)	3.5 (1.29)	3.56 (1.19)
Body temperature	3.2 (1.64)	4 (1.15)	4.00 (1.42)
EDA[b]	3.6 (1.52)	4.5 (0.58)	3.11 (1.22)
GPS	2.8 (1.64)	3.5 (1.29)	2.67 (1.45)
Air quality	2.8 (1.64)	2.5 (1.91)	2.56 (1.66)
Ambient light	2.8 (1.79)	2.25 (1.89)	1.75 (1.74)
Air pressure	2 (1.41)	1.5 (0.58)	2.38 (1.66)
Communication activity	2.25 (1.50)	2.5 (1.73)	1.71 (1.51)
Social media use	1.67 (1.15)	1.75 (0.50)	2.38 (0.76)
Typing pattern	1.75 (0.96)	3 (1.83)	3.11 (1.51)
Actively collected PGHD			
Body weight	4.2 (0.45)	4.75 (0.50)	4.44 (0.53)
Body fat percentage	4.2 (0.45)	4.5 (1.00)	4.33 (0.71)
Blood glucose	4.4 (0.55)	5 (0.00)	4.67 (0.50)
Blood pressure	4.2 (0.45)	4.75 (0.50)	4.44 (0.53)
PEF[c]	3.75 (0.50)	3.5 (1.73)	3.63 (1.19)
Inhaler use	3.2 (1.30)	1.75 (1.50)	2.56 (1.51)
Wound pictures	2.25 (1.50)	2 (0.82)	2.13 (1.13)
ECG[d]	4 (1.00)	5 (0.00)	4.44 (0.88)
Mood	2.4 (1.14)	3.75 (0.50)	3.00 (1.12)
Dietary intake	4 (0.71)	4.75 (0.50)	4.33 (0.71)

[a]Older adults: mean 3.18 (SD 0.82); clinicians: mean 3.56 (SD 1.12); both: mean 3.35 (SD 0.90).

[b]EDA: electrodermal activity.

[c]PEF: peak expiratory flow.

[d]ECG: electrocardiogram.

Figure 1. Bar graph showing the distribution of the Data Rating Questionnaire answers. ECG: electrocardiogram; EDA: electrodermal activity; PEF: peak expiratory flow; PGHD: patient-generated health data.
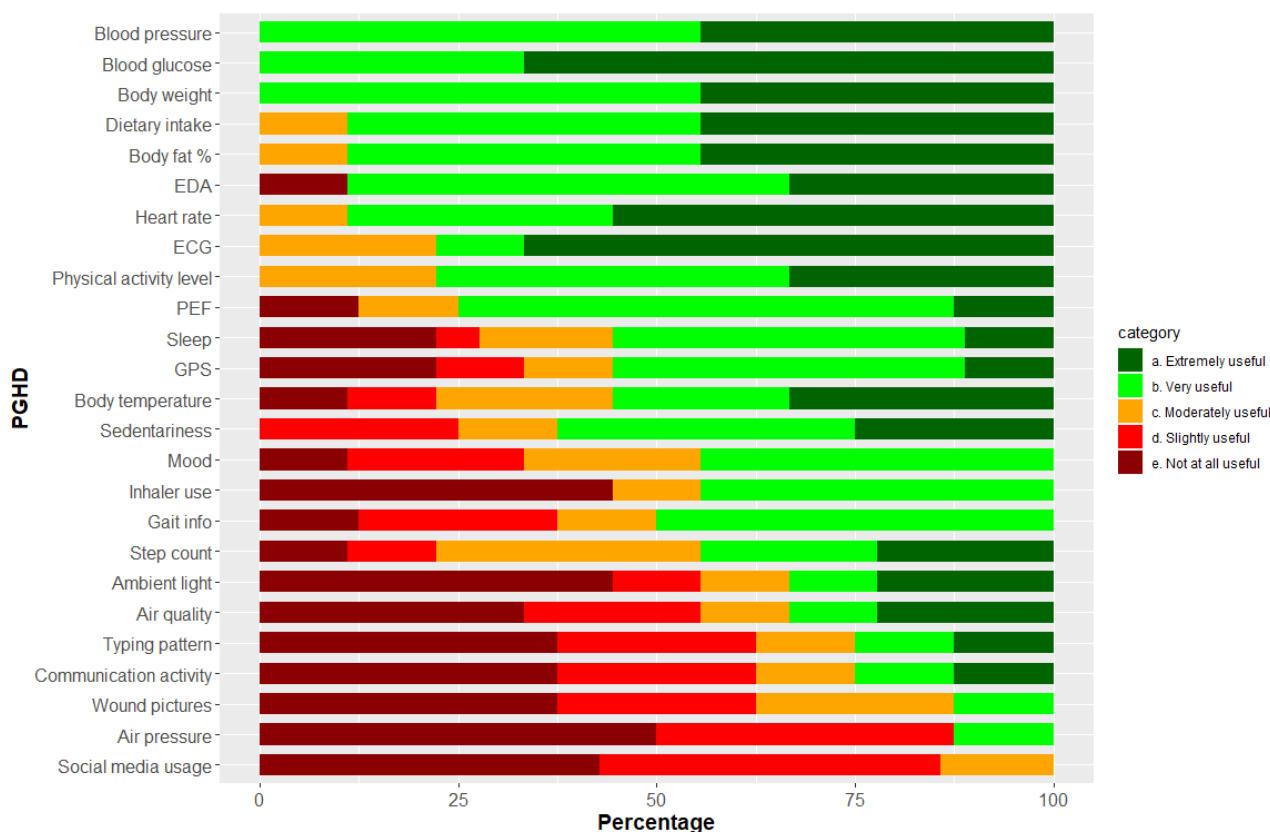
Discussion

Principal Findings

This study aimed to explore the perceptions of older adults and clinicians regarding PGHD and its perceived usefulness. The embedded mixed methods design allowed us to investigate the viewpoints of participants qualitatively and added specificity by quantitatively measuring the perceived usefulness of different types of PGHD. This approach augmented the findings from the focus group interviews with quantitative results by examining an additional aspect of PGHD while testing for the convergence of results from the two data sources.

Overall, we identified four major themes that older adults and clinicians perceived as influencing the use and sharing of PGHD. Participants perceived the objective nature of PGHD as asserting transparency in the patient-provider relationship. From the clinicians' experience, patients tended to react negatively to the added transparency by stopping the collection of PGHD, selectively disclosing favorable data, and gaming the system. This view was reiterated by the patients. In general, people seek positive social interactions, and the patient-provider relationship is not an exception [23]. Patients display a natural tendency to *please the doctor*, and the older adults expressed fear and anxiety about the capacity of PGHD to highlight noncompliance with the care plan. As a result, it was perceived to have a negative impact on the patient-provider relationship. This finding expanded a recent interview study that called for the exploration of the unintended consequences of PGHD, which might include

a feeling of failure or inadequacy on the part of health care consumers [24]. However, our findings directly contradicted those of previous studies [25]. Previously, PGHD was mainly viewed as a facilitator to enhance the patient-provider relationship with evidence for engaging patients in their care and increasing timely communication [26]. The difference in findings may be because the previous study focused on the effectiveness of PGHD from the perspective of system implementation and evaluation with limited insight into patient perception. In addition, our study sample showed contradicting views on their comfort level about disclosing noncompliant PGHD. This indicates the need for careful consideration of user preferences for data sharing and the need for flexibility in system design.

The accuracy, reliability, and validity of mHealth and wearable device-based PGHD have been previously identified as a common barrier for clinical use [15]. Our analyses identified poor reliability of data as a barrier, but the root cause for concern was the perceived lack of patient self-efficacy to carry out PGHD collection rather than the technical inaccuracies of the tools. Clinicians also voiced concerns about the perceived lack of understanding of the clinical relevance of PGHD collected by patients. Inadequate confidence in mHealth and wearable systems was identified where clinicians expressed the issue of inaccurate self-reported data. This theme highlighted the overall need for training and uncertainty about who is accountable for training the users. The need for patient training on collecting and recording PGHD has been a recurring theme in the literature [25]. Proper education may alleviate this issue, but the

responsibility for educating patients is unclear when PGHD tracking is patient-initiated rather than clinician-initiated. Transferring the responsibility of educating patients about the proper use of PGHD systems to clinicians may not be an efficient use of resources as the lack of expertise in PGHD is a commonly reported barrier for clinicians [15]. This highlights the need for technical support for patients from health care organizations and recommends a higher standard for user-friendly interfaces for older adults.

Both clinicians and older adults discussed the uncertainty about the efficient ways of interpreting PGHD. Older adults had concerns about how the data are used by clinicians to benefit the care they receive. Clinicians voiced their lack of expertise in managing PGHD to extract relevant information. This was perceived as the main barrier for realizing the added clinical value of PGHD. As a result, a decision support system was viewed as an essential component of PGHD systems. This is in line with the recommendation that prioritizes a decision support system that can readily summarize PGHD and present the most relevant information as a key to integrating PGHD into electronic health records (EHRs) [27]. The need for a decision support system also extends to the patients' use of PGHD. This can help them extract the most relevant and helpful information easily. However, only a handful of mHealth and wearable device systems have integrated decision support that can guide users to effectively turn information into meaningful actions [26,28]. Future studies should investigate the types of decision support that can be effectively delivered via mHealth.

Protecting patient privacy and confidentiality goes beyond complying with the minimum requirements imposed by regulations. Some older adults perceived the monitoring of PGHD as intrusive and perceived it as a threat to their autonomy. A similar sentiment was shared by clinicians, and sensitivity was particularly displayed toward GPS information, communication tracking, and social media use. Although concerned about its intrusiveness, clinicians saw the clinical benefits and the role of privacy regulations in enabling the collection of such information safely and securely. Furthermore, clinicians perceived that privacy regulations could facilitate the safe and secure integration of PGHD into health information systems. This view of the clinicians contradicts findings from the literature, indicating that many stakeholders view privacy concerns as a hindrance to the successful use of PGHD in clinical settings [15,16,25]. For example, patients were often unsure of privacy and confidentiality standards and regulations [25]. PGHD was sometimes shared with clinicians in noncompliant ways, further hindering its use by clinicians [16]. Privacy regulations are localized, and each jurisdiction faces unique challenges. Knowledge and expertise in health care exist for the integration of EHR systems, and parallels can be drawn with the integration of PGHD into EHR. Future studies should investigate possible solutions.

Older adults and clinicians tended to discuss the familiar types of PGHD, which were rated higher and as being more useful than other unfamiliar types of PGHD. The diversity of the PGHD discussed differed significantly. Clinicians ventured more frequently into discussions of PGHD types that were new to them than older adults and explored how they might add

clinical value. This result was different from that of a previous study that tracked a range of PGHD collected by health care consumers and providers [24]. They found that health care consumers tracked a larger number of PGHD, and that clinicians focused on PGHD-related to their clinical specialty. The authors of this study did not share detailed information on the health care consumers, but we suspect that the difference may be due to differences in the study population. This was indicated when the most commonly tracked PGHD were wellness-focused, such as dietary intake, physical activity, and heart rate, whereas more clinical PGHD, such as blood pressure and blood glucose, were less frequently mentioned.

Clinicians carried out more extensive and detailed discussions on the clinical use of a range of PGHD than older adults. A significantly higher average PGHD rating by clinicians supports this finding. Clinicians indicated enhanced trustworthiness of passively collected data over actively collected data, as passive collection prevents patients from incorrect reporting. However, passively collected data were not rated as more useful by clinicians. This may be because the most highly rated PGHD, including blood glucose, blood pressure, body weight, and dietary intake, were actively collected. This represents a mismatch between state-of-the-art mHealth technology and the needs of patients and clinicians. Our participants explicitly mentioned that further advancement of sensor technology should lead to the expansion of passively collected data such as blood pressure and blood test results. This finding provides evidence for medical technology developers regarding clinicians' data needs.

Limitations

This study had several limitations. The small number of participants in the focus group interviews limited the concepts from reaching saturation. This limitation was partly alleviated as more than 80% of all themes are usually discovered within two to three focus group sessions [29], and partly through the collection of quantitative data to augment the qualitative results. Only young clinicians were interested in participating in the study. Owing to this convenience sampling, the absence of older clinicians is a limitation of this study. The composition of the focus group sessions, comprising older adults and clinicians, was uneven. This may have influenced the dynamics of the discussions to be narrower in scope, as one group of participants may have not been able to express their opinions freely. Even within each group, participants were likely to simply confirm other participants' opinions (ie, confirmation bias). The analyses of the study results were conducted by a single reviewer, which may have introduced bias and personal views in the coding process and theme synthesis. Our older adult participants were members of a research support group, and as a result, there may have been a representative bias. Limited information about the topic was provided before the focus group, and some participants were unfamiliar with the topic of PGHD. Although the lack of understanding of PGHD may have limited the breadth and depth of discussion, this was done intentionally to capture the true perceptions of older adults and clinicians. Finally, the Data Rating Questionnaire was not piloted before the study.

Conclusions

This embedded mixed methods study generated several important findings about older adult and clinician perceptions and perceived usefulness of a range of PGHD. The increasing popularity and adoption of consumer wearable devices and mHealth apps, especially among older adults, will continue to lead to an increasing demand for better integration of PGHD into health care systems. The volume and complexity of PGHD will also continue to increase with the advancement of sensor technologies, and the borderline between consumer and medical devices has already started to blur. PGHD presents new opportunities to improve the care clinicians provide and increase the efficiency of the health care system. Such momentous opportunities have been recognized by governments around the world, and foundational work has begun in many countries. Nevertheless, there is a need for more evidence to identify obstacles for health care users, providers, organizations, and decision makers. Greater insight into these barriers can inform users, providers, developers, and other stakeholders of the priorities for the effective integration of PGHD into health care. In particular, concerns about data privacy, potential negative impact on the trust between older adults and clinicians, data quality and quantity, and usability of PGHD-related technologies will need to be investigated and addressed further.

Authors' Contributions

BK and JL conceived and designed the study. BK conducted data collection and analysis under the supervision of JL. BK and PG prepared the manuscript. PS and JL provided oversight throughout the study and proofread the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data rating questionnaire.
[DOCX File , 19 KB - aging_v4i4e29788_app1.docx]

Multimedia Appendix 2
Group discussion guide.
[DOCX File , 18 KB - aging_v4i4e29788_app2.docx]

Multimedia Appendix 3
A case study of a 77-year-old man newly diagnosed with congestive heart failure with pre-existing type 2 diabetes, hypertension, and hyperlipidemia.
[DOCX File , 14 KB - aging_v4i4e29788_app3.docx]

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Abbreviations

EHR: electronic health record
EMA: ecological momentary assessment
mHealth: mobile health
PGHD: patient-generated health data
PROM: patient-reported outcome measure

Original Paper

Developing a Management Guide (the DemPower App) for Couples Where One Partner Has Dementia: Nonrandomized Feasibility Study

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Abstract

Background: Promoting the health and well-being of couples where one partner has dementia is an overlooked area of care practice. Most postdiagnostic services currently lack a couple-centered approach and have a limited focus on the couple relationship. To help address this situation, we developed a tablet-based self-management guide (DemPower) focused on helping couples enhance their well-being and relationship quality.

Objective: The aim of this study is to investigate the feasibility and acceptability of the DemPower app.

Methods: A nonrandomized feasibility design was used to evaluate the DemPower intervention over 3 months among couples where a partner had a diagnosis of dementia. The study recruited 25 couples in the United Kingdom and 19 couples in Sweden. Outcome measures were obtained at baseline and postintervention. The study process and interventions were evaluated at various stages.

Results: The study was completed by 48% (21/44) of couples where one partner had dementia, of whom 86% (18/21) of couples accessed all parts of the DemPower app. Each couple spent an average of 8 hours (SD 3.35 hours) using the app during the study period. In total, 90% (19/21) of couples reported that all sections of DemPower were useful in addressing various aspects of daily life and helped to focus on how they interacted in their relationship. Of the 4 core subjects on which the DemPower app was structured, home and neighborhood received the highest number of visits. Couples used activity sections more often than the core subject pages. The perception of DemPower's utility varied with each couple's lived experience of dementia, geographic location, relationship dynamics, and opportunities for social interaction. A 5.2-point increase in the dementia quality of life score for people with dementia and a marginal increase in the Mutuality scale (+1.23 points) for caregiver spouses were found. Design and navigational challenges were reported in the DemPower app.

Conclusions: The findings suggest that the DemPower app is a useful resource for couples where one partner has dementia and that the implementation of the app requires the support of memory clinics to reach couples at early diagnosis.

Trial Registration: ISRCTN Registry ISRCTN10122979; http://www.isrctn.com/ISRCTN10122979

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Introduction

Background

The progressive nature of dementia, with its symptoms of cognitive decline, poses challenges to relationships. Couples where one partner has dementia adapt to the transition from an interdependent relationship toward a relationship of caregiver-care receiver roles [1-4]. This transition can negatively affect a couple's relationship, where the couple relationship is secondary to the care relationship. When the sense of couplehood is reduced, the risks of cognitive and functional decline increase [5] alongside the psychosocial dissatisfaction of both partners [6] and the need for special accommodations [7,8]. Extensive research has shown that the sense of couplehood is a crucial factor for well-being in everyday life among couples where one partner is diagnosed with dementia and for the prevention of negative consequences [9-11]. However, there is currently a gap in knowledge about how to support couples' relationships and everyday lives in their own homes.

eHealth and Self-management in Dementia

Interventions in dementia are often problem-based and target cognitive function, strain, and burden [1,2,12,13], and there is limited evidence of resource-oriented approaches. Self-management is a common feature in the treatment of chronic conditions. An increasing number of self-management eHealth services that consist of websites, applications, and monitoring are available for chronic conditions such as diabetes, chronic obstructive pulmonary disease, and heart failure [14]. There are also a small number of eHealth resources for informal caregivers of people with dementia [15]. The generic approach to self-management is often based on people's perceived problems of a condition and deals with the management of symptoms [16]. This differs from the self-management approach that can be applied to dementia, where the focus is on managing challenges in everyday life from the perspective of quality of life, the abilities of people with dementia, and couples where one partner has dementia, and not solely on the condition and symptoms [17,18]. Bearing in mind this gap in positive, resource-oriented interventions for people with dementia and their partners, a couple self-management guide in the form of an app named DemPower was developed. The development of the guide was underpinned by salutogenic, resource-oriented, and strength-based approaches. The theoretical underpinning is discussed in detail in the protocol and DemPower development studies [17,19].

This study titled Living Life and Doing Things Together—work program 6 is part of the 5-year Economic Social Research Council and the National Institute for Health Research Neighborhoods and Dementia study (2014-2019) [20]. The study was funded in the United Kingdom under action point 12 of the first Prime Minister's Challenge on Dementia [21] and was based in Manchester (United Kingdom) and Sweden.

A user-centered participatory design [22,23] guided the development of the DemPower app in the following 3 phases. Phase 1 involved a comprehensive literature review of couplehood and well-being in dementia, which informed a draft framework of themes identified as potential targets for the self-management guide [1,2]. Phase 2 explored the draft framework with 5 couples in Sweden, where a partner had a diagnosis of dementia. In this phase, the predetermined themes were presented to the couples to confirm or reject their relevance. Phase 3 authenticated the findings within expert groups of people with dementia and caregivers in Sweden and the United Kingdom. This phase enabled testing the empirical validity of the themes as sensitizing concepts, the transferability of findings to a UK context, and conversion into an app (for more information on the development phase, refer to the studies by Bielsten et al [17] and Lasrado et al [19]).

Aims and Objectives

The overall aim of this study is to investigate the feasibility and acceptability of the DemPower app among couples living together at home, where one partner had dementia. The key objectives are to (1) evaluate the usability and acceptability of DemPower, (2) determine recruitment and completion rates, and (3) assess the suitability of the outcome measures for calculating the sample size of a full randomized controlled trial (RCT).

Methods

The DemPower App

The DemPower app is a self-management resource guide intended for couples where one partner has a dementia diagnosis, and they live together at home. The app is structured around 4 themes with corresponding sections and suggestions for activities under each section (Table 1). The contents are storyboarded and converted into animated videos and films of couples who share their approaches to everyday life and situations. The home page of the app lists the core themes, navigational buttons are available at the bottom of the screen, and a help menu is available at the top of each screen throughout the app. Screenshots are shown in Figure 1. DemPower is a multimedia app with text, audio, and video sources. The app design focuses on making the interface simple and easy to access. User-centered and participatory approaches [24,25] informed the overall app design and concept.

The DemPower app focuses on enhancing couple relationships and managing everyday life. The couple participants were encouraged to complete all 4 themes or those parts they found relevant to their situation. The app guides the participants through introductory animated videos that describe the contents

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of each section, followed by videos of couples sharing their experiences. The aim of these videos was to provide participating couples with opportunities for reflection and active participation in the process by engaging in suggested activities. It takes between 10 minutes and 20 minutes to complete a section depending on the nature of the activities (Table 1). The app was installed on Samsung tablets, which were given to participating couples and which they could retain on completion of the study. The couples were encouraged to complete all parts of the app within the 3-month intervention period.

Participants were encouraged to contact the researchers (RL, TB, and RD) if they needed support and when they had completed all or the chosen sections under each theme. The researchers (RL, TB, and RD) were tasked with contacting participants every month by phone or email to ensure continued participation and to follow up on their progress. We also encouraged participants to make appointments if additional training or home visits were needed to address any challenges.

Table 1. DemPower content.

Themes	Activities
1. Home and neighborhood	
1.1. The meaning of home	Take pictures
1.2. Inside	Use checklist to identify required changes or use SCIE app
1.3. Outside	Walk together, take pictures, and discuss
1.4. Couplehood	Describe positive relationship experiences, listen to music, and express emotions
2. Meaningful activities and relationships	
2.1. Physical exercise	Watch video, exercise, and keep a log
2.2. Doing things together at home and outside	List tasks to do together, choose one and engage
2.3. Individual activities	List individual activities and schedule time
2.4. Adapting activity to capability	Revisit the task list and discuss how to adapt
2.5. Mental exercise	Games
3. Meeting, sharing, and caring in your neighborhood	
3.1. Socializing with friends and family	Schedule meeting appointments, keep visitor log, and share communication sheet with family and friends
3.2. Meeting others who live with dementia	Visit social groups or dementia cafés
3.3. Informing each other and others	Share your experience with neighbors and discuss your experience
4. Managing communication and emotions	
4.1. Being a comfort and a friend	Discuss your approaches to comforting each other
4.2. Living as usual and keeping the routine	Plan a routine and display the routine
4.3. Stress	Listen to stress management audio and follow instructions
4.4. Conflicts	List strategies helpful for conflict management
4.5. Future and planning	Use the future planning checklist
4.6 Communication	Examine the listed strategies and add to it

Figure 1. DemPower screenshots.
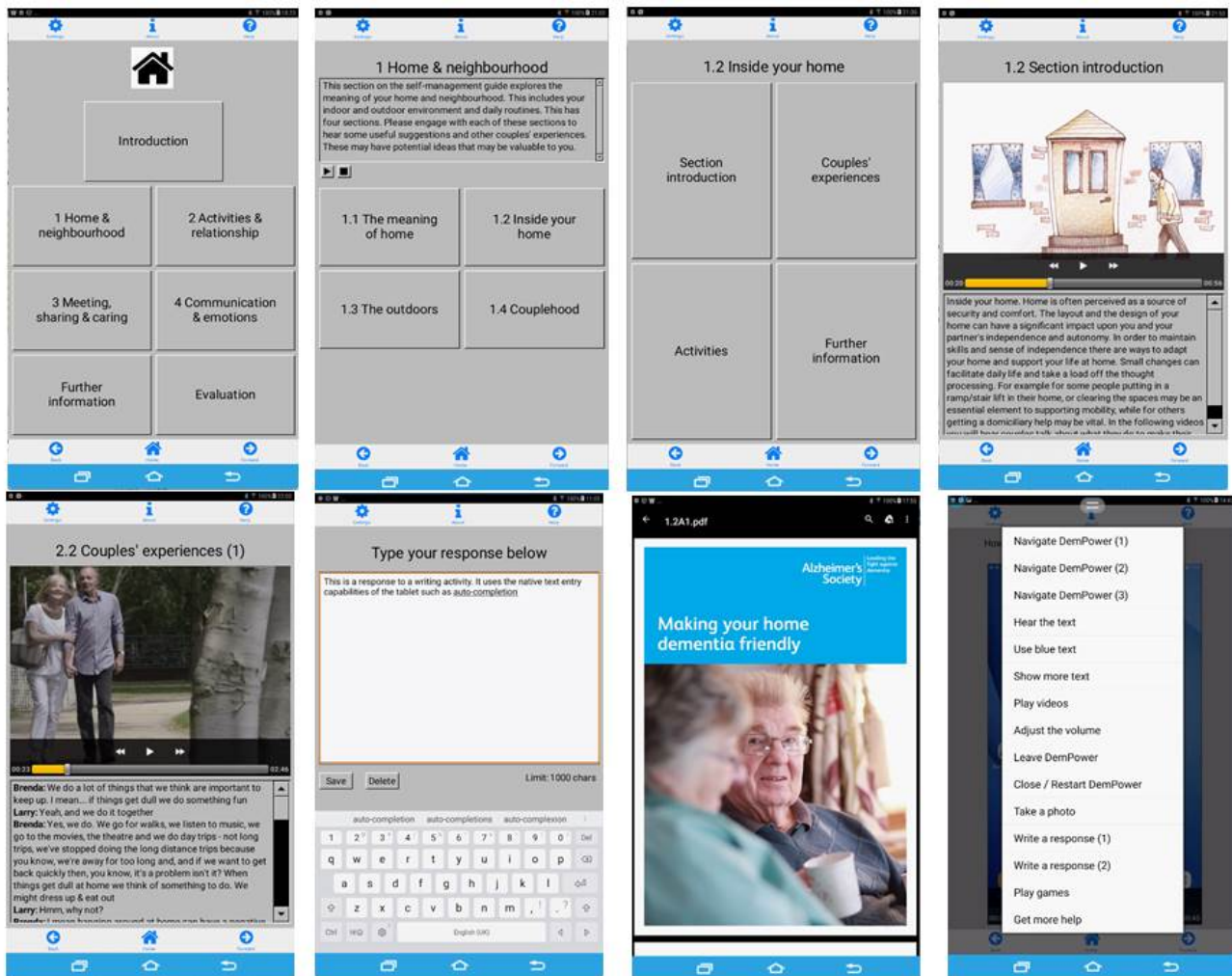
The Study Design

A prospective, nonrandomized feasibility design was used to facilitate the assessment of study processes and to explore the usability and acceptability of the DemPower intervention. The study was approved by the National Health Service Research Ethics Committee (17/NW/0431) in the United Kingdom and the Regional Ethical Review Board in Sweden (Dnr: 2017 2017/281-31). The study was registered under the International Standard Randomized Controlled Trial registry (ISRCTN10122979).

Setting and Participants

This was a multisite study based in North West England, the United Kingdom, and Linköping and Norrköping in Sweden. The participants in the United Kingdom were recruited via the Join Dementia Research (JDR) network at dementia cafés and through advertisements over a period of 12 months. The staff at these organizations disseminated the study information and obtained the initial expressions of interest. A researcher (RL) presented the study to groups at dementia cafés, and potential participants who learned about the study through posters contacted the researcher (RL) directly. In Sweden, memory clinics were the primary source of recruitment, and nurses approached potential participants at clinic appointments over a period of 12 months. A researcher (TB) then followed up with the potential participants over a further 6-month period, and recruitment in Sweden took 18 months. The researchers followed the process consent procedure [26] in both countries and obtained informed consent.

The detailed inclusion and exclusion criteria for recruitment are listed in Textbox 1 [19]. The participant characteristics were not limited to types of dementia, comorbidities, sexual orientation, age, profession, or social, cultural, or religious beliefs.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria

- Couples in which a partner or spouse has a diagnosis of dementia in the early to moderate stages. The stage will be identified either by a clinical team during referral or through self-report .

- The couples live together in their own homes (not residential care).

- Both partners understand and speak English (in the United Kingdom) or Swedish (in Sweden) .

- Couples have lived in a long-term relationship for 2 or more years.

Exclusion criteria

- Couples in which one or both partners are blind and might find it difficult to interact with DemPower.

- Any partner who has become completely immobile or bedbound and may not be able to engage with suggested activities .

- Both partners have a diagnosis of dementia.

- Both partners in a couple in which one or both lack capacity or may have fluctuating capacity.

Primary Outcome Measures

The primary outcome measure was intended to evaluate the usability and acceptability of DemPower and assess recruitment capability, sample size, and completion rates to determine whether a fully integrated clinical and economic RCT could be conducted.

DemPower Feasibility

The acceptability and suitability of DemPower was explored during the study and at the end of the study using a set of questionnaires adapted from Bowen et al [27], Craig et al [28], and Judge et al [29]. The System Usability Scale questionnaire on a 5-point Likert scale [30] was used to obtain participants' perceptions of usefulness. Usage data were gathered from tablets at the end of the study. The app recorded a screen identifier (Multimedia Appendix 1) and timestamp every time the user moved to a new screen. Other measures can be deduced from the raw data.

Recruitment Capability

This study was informed by the recommendation of Aron et al [31] for assessing critical parameters such as recruitment and retention rate. Researchers (RL, TB, and RD) maintained a detailed record of the total number of target population accessed,

recruited, and retained. Additional notes were maintained on the role of local organizations and colleagues, the time taken for recruitment, the number of contacts, visits, the challenges encountered, reasons for withdrawal from the study, and factors that influenced recruitment and study completion rates.

Secondary Outcome Measures

We aimed to explore the acceptability and relevance of the secondary outcome measures used in the study to inform the selection of outcome measures in a full RCT to assess the effectiveness of the intervention. The outcomes of quality of life, self-efficacy, interconnectedness, and mutuality were measured using validated tools for both partners at baseline and postintervention. All outcome measures used in this study are listed in Table 2 [19]. The tools ranged from 1 to 15 items, with 3- to 5-point Likert scales and response options. Participants who chose to engage with only parts of the app completed postintervention outcome measures and end-of-study evaluation at a point when they felt they had finished the app. Where support was required, researchers (RL, TB, and RD) explained the questions and filled in the forms if participants were struggling to write or mark their responses using a pen and paper. Participants also commented on the ease of use of these tools.

Table 2. Outcome measures.

Outcomes	Tools	Description	Answered by
Quality of life	Quality of life in Alzheimer's disease [32]	• 13-item tool • Addresses mood, cognitive and functional ability, activities of daily life, and quality of relationships with family and friends • A 4-point Likert scale ranging from "poor" (1p[a]) to "excellent" (4p) with a maximum score of 52	Both spouses or partners individually
Caregiver-related quality of life	Carer Quality of life [33]	• A 7-item tool • Addresses 5 negative and 2 positive dimensions of providing informal care • A 3-point Likert scale from "a lot" (0p) to "no" (2p) for the negative dimensions and reversed scale for positive dimensions. The higher the score, the better the care situation.	Partner or spouse caregiver
Self-efficacy	General self-efficacy scale [34]	• A 10-item tool • Assesses coping skills and adaptation to situations • Has a 4-choice response ranging from "not at all true" (1p) to "exactly true" (4p); Scores are summarized to a total score, and a higher score indicates a higher sense of self-efficacy.	Both spouses or partners individually
Interconnectedness	The Inclusion of Other in Self Scale [31]	• A single item pictorial measure of closeness • Assesses people's sense of being interconnected to each other	Both spouses or partners individually
Mutuality	Mutuality Scale [35]	• A 15-item Mutuality Scale • Includes 4 dimensions—love and affection, shared values, reciprocity, and shared pleasurable activities • Rated on a 4-point Likert scale between 0 "not at all" to 4 "a great deal"	Both spouses or partners individually
Health and social care service use	Service use questionnaire	• The service use questionnaire was adapted from current service use questionnaires held by the investigators. It is to be refined after consultation with the study service user group. • Covers key health and social care services • Assesses the range of services used and the frequency of use • The measure is to be administered by the researcher at baseline and at the end of follow-up assessments.	Both spouses or partners individually
Health status	5-level EuroQoL-5 dimension version [36]	• Has a 5-dimensional structure (mobility, self-care, usual activities, pain or discomfort, and anxiety or depression) • Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems • Allows estimation of quality-adjusted life years	Both spouses or partners individually
Quality of life	Dementia quality of life [37]	• A condition-specific measure of health-related quality of life for people with dementia • A 28-item tool • Can be completed with the person with dementia or a main caregiver • The measures cover 5 domains: daily activities and looking after yourself, health and well-being, cognitive functioning, social relationships, and self-concept • Preference weights are available to allow estimation of quality-adjusted life years	Partner or spouse with dementia

[a]Scoring instructions for QOL-AD: points are assigned to each item as follows—poor=1, fair=2, good=3, excellent=4. The total score is the sum of all 13 items.

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Process Evaluation

The process evaluation was informed by the Medical Research Council's guidance on complex interventions [28] and questions specific to the feasibility designs discussed by Bowen et al [27] and Orsmond and Cohn [38]. The relevance and significance of the DemPower intervention, its contents, design, and user interface were explored by the participants during the course of the study and at the end of the study using a questionnaire, usage data, and issue logs. This questionnaire included both close-ended and open-ended questions (refer to the protocol study by Lasrado et al [19] for the questionnaire) and was administered via an interview at home visits. The assessment of study procedures, recruitment and resource capability, and the relevance and feasibility of outcome measures were explored through a detailed analysis of researchers' field notes and the end-of-study evaluation questionnaire presented to the participants.

Data Management and Analysis

Data were analyzed using Stata software (version 14; StataCorp), and descriptive statistics were reported, such as measures of central tendency (mean and median) and spread (SD, IQR, and range). Responses to open-ended questions were processed using NVivo (version 11; QSR International) and analyzed thematically using the deductive approach. The outcome data were analyzed to determine whether there was sufficient change and variation in the measures, and these were checked for floor and ceiling effects. Recruitment and attrition rates were analyzed to assess the recruitment capability.

Results

## Recruitment and Participant Characteristics

A total of 44 couples (United Kingdom, n=25; Sweden, n=19) were recruited at both sites between October 2017 and November 2018. The overall study completion rate was 48% (95% CI 33%-63%; United Kingdom: 9/25, 36%; Sweden: 12/19, 63%). Figure 2 outlines participant flow through the various stages of the study.

In the United Kingdom, 43.5% (81/186) of people with dementia and their caregiver spouses met the eligibility criteria and were identified via JDR, dementia cafés, and advertisements. A total of 50 (25 couples) participants consented to participate, representing a consent rate of 27% (95% CI 21%-34%). A total of 5 couples withdrew consent before the intervention, 6 during the study, and an additional 2 at follow-up. The recorded reasons for attrition were bereavement, declining mental capacity, both partners had dementia, challenging use of technology, lack of motivation, and ill health. In Sweden (Linköping and Norrköping), memory clinic nurses identified potential participants, and 44 met the eligibility criteria and 38 consented to participate. The total number of people screened for the study by the memory clinic nurses is unknown, as many nurses were involved, and records were not maintained. A total of 12 couples completed the intervention and the end of the study assessments. The reasons for attrition were disinterest among people with dementia, being unwell, and coming to terms with a recent diagnosis and one of the caregiver spouses wished to withdraw after they had viewed parts of the videos that discussed advanced stages of dementia, which they found distressing.

The demographic data from both sites revealed that 68% (13/19) of the participants with dementia in Sweden were over 71 years of age in comparison with 52% (13/25) in the United Kingdom. Swedish couples were potentially in a relationship for a longer duration than couples in the United Kingdom. A greater proportion of the participants from Sweden had a graduate education. The difference in education indicates potential socioeconomic differences in both countries. The gender differences in the study among people with dementia and caregiver spouses were more equal in the United Kingdom. In Sweden, 68% (13/19) of participants with dementia were men. It is also interesting to note that 36% (9/25) of participants with dementia in the United Kingdom had a mixed diagnosis, and another 36% (9/25) had Alzheimer disease. In Sweden, no participants had a mixed diagnosis; most (11/19, 58%) had Alzheimer disease and a more recent diagnosis (14/19, 74%; <2 years of diagnosis). In Sweden, people with more subtle or complex symptoms are referred to memory clinics and more likely to receive follow-up care, as primary care is limited in resources and competences [39]. Detailed demographics for both sites are presented in Table 3.

Figure 2. CONSORT (Consolidated Standards of Reporting Trials) flow diagram of participants. The number of people screened in Sweden was unavailable because of a lack of data from memory clinics. CS: caregiver spouse; JDR: Join Dementia Research; PwD: person living with dementia; UK: United Kingdom.
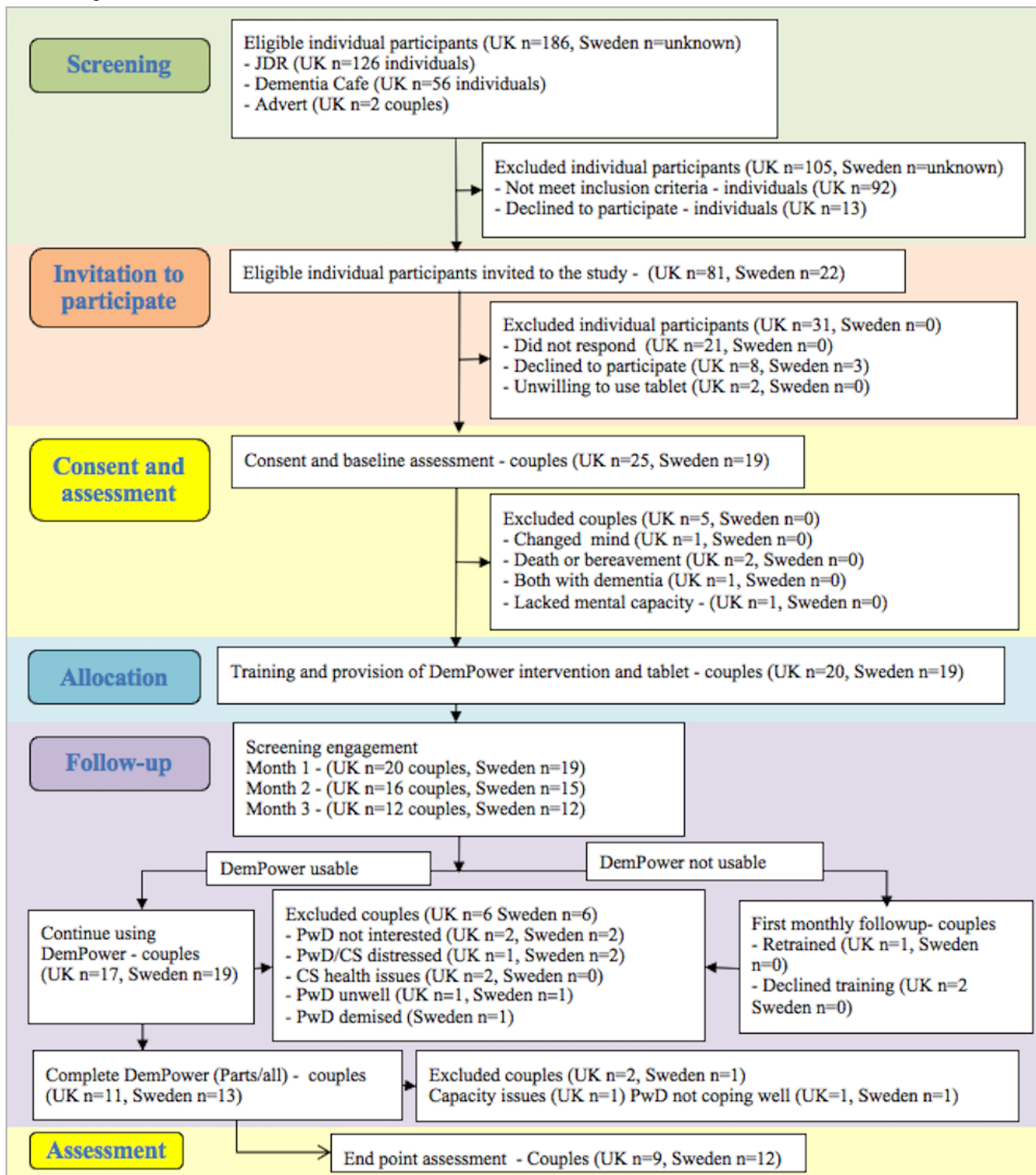
Table 3. Demographic characteristics of participants enrolled in the study[a].

Characteristics	Persons with dementia, n (%)		Spouses (caregivers), n (%)	
	United Kingdom (n=24)	Sweden (n=19)	United Kingdom (n=24)	Sweden (n=19)
Age (years)				
51-60	3 (13)	1 (5)	2 (8)	1 (5)
61-70	8 (33)	5 (26)	11 (46)	7 (37)
71-80	11 (46)	7 (37)	10 (42)	10 (53)
81-90	2 (8)	6 (32)	1 (4)	1 (5)
Gender				
Male	13 (54)	13 (68)	11 (46)	6 (32)
Female	11 (46)	6 (32)	13 (54)	13 (68)
Education				
Secondary	12 (50)	3 (16)	10 (42)	3 (16)
Advanced or upper secondary	4 (17)	4 (21)	3 (13)	5 (26)
Graduate	6 (25)	10 (53)	9 (38)	9 (47)
Postgraduate	2 (8)	2 (11)	2 (8)	2 (11)
Employment status				
Employed	4 (17)	0 (0)	8 (33)	3 (16)
Retired	20 (83)	19 (100)	16 (67)	16 (84)
Length of relationship (years)				
11-20	1 (4)	1 (5)	1 (4)	1 (6)
21-30	5 (21)	1 (5)	5 (21)	0 (0)
31-40	4 (17)	5 (26)	4 (17)	5 (28)
41-50	11 (46)	5 (26)	11 (46)	5 (28)
51-60	3 (13)	6 (32)	3 (13)	6 (33)
61-70	0 (0)	1 (5)	0 (0)	1 (6)
Type of diagnosis				
Alzheimer disease	9 (38)	11 (58)	N/A[b]	N/A
Frontal temporal	0 (0)	1 (5)	N/A	N/A
Lewy body	0 (0)	2 (11)	N/A	N/A
Mild cognitive impairment	2 (8)	0 (0)	N/A	N/A
Parkinson disease	0 (0)	1 (5)	N/A	N/A
Vascular	3 (13)	0 (0)	N/A	N/A
Mixed	9 (38)	0 (0)	N/A	N/A
Unspecified	1 (4)	4 (21)	N/A	N/A
Years since diagnosis				
<1	2 (8)	8 (42)	N/A	N/A
1-2	4 (17)	6 (32)	N/A	N/A
2-3	7 (29)	4 (21)	N/A	N/A
3-5	10 (42)	1 (5)	N/A	N/A
>5	1 (4)	0 (0)	N/A	N/A

[a]Variable-specific column percentages do not always sum to 100 because of rounding. One UK couple did not provide demographic information. One Swedish caregiver did not provide information on relationship length.

[b]N/A: not applicable.

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DemPower Usability

Of the 21 couples who completed the study, only 86% (18/21) had accessed all sections of DemPower, and the average usage per couple was 8 hours (SD 3.35 hours) during the 3-month study period. Of the 4 themes, home and neighborhood averaged 250 visits; activities and relationships averaged 174 visits; meeting, sharing, and caring averaged 160 visits; and communication and emotions averaged 122 visits. The sections on home and neighborhood were in the first part of the app, which might explain the greater number of visits (Multimedia Appendix 2). However, the participant feedback detailed below highlights the role of this section in facilitating discussion and strategies for everyday life and associated challenges. Over the course of the study, participants visited suggested activity pages more frequently (mean 95) than the core content pages that had section-specific introductory videos (mean 71) or videos of couples (mean 69), for example, couples taking pictures, doing physical exercise, talking to each other, walking, and listening to music, and there was a home adaptation checklist.

DemPower Acceptability

The theme-specific and end-of-study evaluation revealed that 90% (19/21) of couples acknowledged that all sections of DemPower were useful in addressing various aspects of daily life (Multimedia Appendix 3; for the evaluation questionnaire, see the protocol paper [19]). However, 24% (Sweden: 4/12, 33%; Manchester: 1/9, 11%) stated that the sections on mental activity (3/21, 14%), physical activity (2/21, 10%), managing stress (2/21, 10%), adapting activity (2/21, 10%), and meeting others with dementia (2/21, 10%) were less useful. As reasons for this, 2 couples gave their involvement in activities and their own exercise regime, and others said that they had their own strategies for addressing stress and that the suggested activities were less suitable.

A detailed analysis of couples' perspectives on the meaning and usefulness of various parts of the DemPower app revealed that most couples found the sections on the home useful (13/21, 62% stated a great deal; 7/21, 33% stated somewhat). These sections helped them explore what home means to them, the need for adaptation, and how to adapt their home to meet changing needs. Parts of DemPower helped most couples focus on what they could do rather than what they could not do (18/21, 86%) and to recognize the importance of continued living as usual (20/20, 100%; a Swedish couple did not answer questions on themes 2, 3, and 4), and the app helped couples focus on how they interacted in their relationship and become more aware of the way they addressed everyday tasks (19/21, 90%):

> *It has made me think more about why we are doing things and making changes. It is food for thought.* [MC16]

More than half (11/20, 55%) of the couples indicated that DemPower helped them to recognize the need to maintain a social life, and 85% (17/20) of couples reported feeling encouraged and happy about meeting people. However, 60% (Sweden: 9/11, 82%; United Kingdom: 3/9, 33%) felt that sharing their experiences of dementia was hurtful and considered the activity burdensome rather than helpful. Recognizing the importance of a planned routine (20/20, 100%) and instructions

for managing everyday communication (18/19, 95%) were found to be useful by most couples. A number of participants felt that the app helped somewhat and a great deal to address conflict situations (17/20, 85%), to practice relaxation (18/20, 90%), and to think about financial and legal (15/20, 75%) and care needs (17/20, 85%).

In total, 19% (4/21) of couples found information about support devices (locators, ID phone, and sensor lights) and contacts to discuss support needs irrelevant. All 4 couples were within 2-3 years of their diagnosis. In addition, 32% (6/19) of couples indicated that the information on counseling services was not very helpful as they lacked clarity on referral pathways.

Reminiscing about memorable moments (21/21, 100%), listening to music (19/21, 90%), and meeting people with dementia (15/17, 88%) rated high as suggested activities. These were followed by taking photos (18/21, 86%), physical exercise (15/19, 79%), and communication strategies (18/19, 95%). A few couples (4/19, 21%) said that the suggested exercises did not provide options to match different strength levels, and some felt encouraged to take further steps to maintain physical fitness. Activities that encouraged couples to plan for the future were rated as somewhat useful, indicating that the couples preferred to focus on the present:

> *Exercises too simple, would be good to get to choose some harder ones.* [SC13]
>
> *Bought a gym-card.* [SC20]

A total of 33% (7/21) of couples in the United Kingdom who rated the app positively also said that the app would be more relevant to people with limited knowledge and access to resources, those who are isolated and do not attend support or social groups, and those who are at the initial stages of diagnosis. Some (United Kingdom, n=3; Sweden, n=1) couples in the early stages of dementia found the content relevant to advanced dementia somewhat distressing and said that the app seemed more relevant for people at later stages of dementia. Those at a more progressive stage said that it was challenging for people with dementia to feel encouraged and focused (United Kingdom, n=2; Sweden, n=1), and they would have made better use of the app if they had received it earlier. A total of 2 people with dementia (United Kingdom, n=1; Sweden, n=1) and a caregiver spouse (United Kingdom, n=1) who expressed feelings of distress were offered support, and the distress protocol was followed. The development of the protocol was informed by current research and best practice evidence [40].

Design and User Interface

Most participants at both sites said that the layout and overall design were simple, easy to use, visual, and helpful and had comprehensive information. A total of 8 (42%) participants found that using the same couples to narrate the story in various parts of the app helped them follow the storyline and coping methods. Some participants found having the same structure in all the sections of DemPower useful and liked the idea of being able to use it as and when they wished. A total of 13 couples (62%; United Kingdom, n=8; Sweden, n=5) used the help manual (paper and video) from time to time to guide them through the app:

Since using the app, we have done things that we wouldn't have done before. [MC15 and MC16, eg, exercises, music, and word-search game]

Some of the limitations raised by the participants included navigation concerns, confusion around indexing, lack of colors, and pointers to indicate where they were in their last session. Caregiver spouses often reported taking a leading role in initiating app usage and navigation, whereas partners with dementia used the activity sections more and at times returned to watching videos. A person with dementia from Sweden, who withdrew from the study because of the spouse caregiver's lack of interest, used the app in a group session at a day care center

with the help of a facilitator. This highlights the joint commitment and interest required from both partners to achieve relationship-focused outcomes.

The utility scale data (Table 4) revealed that couples in the United Kingdom liked to use the app more frequently than their Swedish counterparts. However, Swedish couples found the app easier to use and were more confident when using it. Participants in Sweden contacted the researcher more frequently via SMS text messages, phone, and emails than participants in the United Kingdom. This could potentially influence the usability of apps. There were mixed responses to how quickly participants could learn to use the app at both sites.

Table 4. Utility scale.

Characteristics	Sweden (13 couples)			United Kingdom (9 couples)		
	Codes 1 and 2 (disagree), n	Code 3 (neutral), n	Codes 4 and 5 (agree), n	Codes 1 and 2 (disagree), n	Code 3 (neutral), n	Codes 4 and 5 (agree), n
Like to use system frequently	3	7	3	2	3	4
System unnecessarily complex	10	2	1	4	3	2
System easy to use	0	2	11	2	3	4
Technical support required	8	3	2	6	1	1
Well integrated system functions	2	4	7	1	3	4
Inconsistency in the system	10	2	1	4	1	1
Quickly learn to use the system	1	7	5	3	1	4
Very cumbersome system	12	1	0	6	0	1
Confident using the system	0	3	10	3	1	4
Needed to learn a lot before use	11	2	0	6	1	1

Outcome Measures

A total of 43 couples completed baseline measures, and 21 completed most follow-up measures (19 carers completed the Alzheimer's disease quality of life [ADQoL] measure). Mean, SD, and mean change scores between baseline and follow-up are reported in Tables 5 and 6.

A 5.2-point increase, on average, was observed in the dementia quality of life (DEMQoL; measurement of health-related quality of life for people with dementia) score for participants with dementia, indicating a clinically significant change [41], particularly in the domains of social relationships and emotional well-being. There was a small increase, on average, in the Mutuality scale (+1.23 points) for caregiver spouses but no change in any of the other outcome measures. A comparison of these results with evaluation data suggests that DemPower had a positive effect on the couple relationship in terms of how they felt, expressed themselves, listened to others' experiences, and used some of the suggested strategies. During the evaluation, participants said that it was helpful to have the flexibility to choose sections relevant to their situation and that using the app while on vacation or when having a dull moment was helpful

to focus on their relationship and the practicalities of everyday life.

The degree of change (ie, the mean relative to the SD/range) on the ADQoL scale was equivalent to that on the DEMQoL scale. Otherwise, the degree of change is much smaller. Although the domains explored in ADQoL and DEMQoL are similar, DEMQoL considers more detailed items under the rubrics' emotional well-being and social relationships. Some of the individual, postintervention differences in the secondary outcome measures for people with dementia were large; for example, a 23-point decrease on the Mutuality scale or a 37-point increase on the DEMQoL. Such differences are not the norm but, in a sample of this size, can unduly influence the mean. There was some evidence of a ceiling effect in response to the inclusion of other in the self (IOS) scale. This was unsurprising given the narrow range and sensitivity of its measures. There was weaker evidence of a ceiling effect on the Mutuality scale. There was weak evidence of ceiling effects for caregiver spouses on self-efficacy, IOS, and ADQoL scales. Some couples felt that the mutuality questionnaire was too personal, and a few others found the IOS and self-efficacy scales difficult to understand.

Table 5. Outcome measures of people with dementia.

Outcome measures	Baseline (n=43)	Baseline (who also completed follow-up; n=21)	Follow-up (n=21)	Change (follow-up-baseline; n=21)
Mutuality score				
Values, mean (SD)	48.31 (10.83)	50.57 (9.63)	49.81 (10.27)	−0.76 (6.71)
Values, median (IQR)	51.0 (43.9 to 57.0)	54 (44 to 58)	53 (45 to 58)	0 (−3 to 1)
Values, range	3 to 60	26 to 60	26 to 60	−23 to 15
Self-efficacy				
Values, mean (SD)	28.48 (6.41)	30.04 (6.75)	30.89 (5.90)	0.85 (3.25)
Values, median (IQR)	30 (25 to 32)	30.0 (27.8 to 34.0)	31 (29 to 34)	1 (−1 to 3)
Values, range	11 to 40	14 to 40	15 to 40	−4.8 to 7
Inclusion of other in the self				
Values, mean (SD)	5.79 (1.61)	6.43 (0.93)	6.19 (1.21)	−0.24 (1.00)
Values, median (IQR)	6 (5 to 7)	7 (6 to 7)	7 (5 to 7)	0 (0 to 0)
Values, range	1 to 7	4 to 7	3 to 7	−2 to 1
Alzheimer disease quality of life				
Values, mean (SD)	36.92 (7.16)	38.19 (7.38)	40.33 (6.16)	2.14 (4.87)
Values, median (IQR)	37.0 (32.0 to 41.2)	38 (33 to 43)	42 (37 to 44)	2 (−1 to 5)
Values, range	18 to 50	25 to 50	28 to 50	−8 to 12
Dementia quality of life				
Values, mean (SD)	85.46 (15.98)	88.67 (16.84)	93.86 (11.09)	5.19 (11.77)
Values, median (IQR)	88 (73 to 98)	93 (79 to 103)	97.0 (85.0 to 99.1)	2 (−2 to 11)
Values, range	45 to 112	48 to 112	73 to 112	−12 to 37
Carer quality of life	N/A[a]	N/A	N/A	N/A

[a]N/A: not applicable.

Table 6. Outcome measures of caregiver spouse.

Outcome measures	Baseline (n=43)	Baseline (who also completed follow-up; n=21)	Follow-up (n=21)	Change (follow-up-baseline; n=20)
Mutuality score				
Values, mean (SD)	41.61 (11.13)	42.42 (11.13)	43.66 (12.16)	1.23 (4.38)
Values, median (IQR)	44 (35 to 48)	44 (37 to 48)	46 (41 to 53)	1 (−1 to 4)
Values, range	16 to 59	19 to 59	18 to 59	−10 to 9
Self-efficacy				
Values, mean (SD)	31.95 (3.75)	33.10 (3.94)	33.10 (3.13)	0.00 (3.02)
Values, median (IQR)	32 (29 to 35)	33 (30 to 36)	33 (31 to 35)	−1 (−1 to 1)
Values, range	26 to 40	27 to 40	28 to 39	−5 to 8
Inclusion of other in the self				
Values, mean (SD)	5.53 (1.59)	5.81 (1.33)	5.86 (1.11)	0.05 (0.59)
Values, median (IQR)	6 (5 to 7)	6 (5 to 7)	6 (5 to 7)	0 (0 to 0)
Values, range	1 to 7	2 to 7	3 to 7	−1 to 1
Alzheimer disease quality of life				
Values, mean (SD)	40.40 (5.12)	41.58 (4.63)	41.63 (5.85)	0.05 (3.81)
Values, median (IQR)	41 (38 to 44)	41 (39 to 46)	42 (36 to 46)	−1 (−2 to 2)
Values, range	27 to 49	34 to 49	30 to 51	−7 to 8
Dementia quality of life	N/A[a]	N/A	N/A	N/A
Carer quality of life				
Values, mean (SD)	7.60 (3.31)	7.48 (3.92)	7.52 (3.46)	0.05 (1.72)
Values, median (IQR)	7 (5 to 10)	6 (5 to 11)	7 (5 to 11)	0 (−1 to 2)
Values, range	1 to 14	1 to 14	3 to 13	−4 to 3

[a]N/A: not applicable.

Most people with dementia and caregiver spouses were able to complete the outcome questionnaires without much assistance. Some couples said that it was easier to respond to "yes" or "no" type questions rather than having to rate on a specific scale, whereas some couples experienced difficulty in interpreting the IOS and found the Mutuality scale too personal. A few people with dementia and caregiver spouses had difficulty completing the self-efficacy questionnaire, and the researcher had to explain the questions. The spousal caregivers said that the carer quality of life questionnaire items were irrelevant, as most people with dementia were able to execute daily tasks independently.

Discussion

Principal Findings

The feasibility and acceptability of the DemPower app was explored at various stages of the study by investigating participants' opinions of the content, design, and delivery. The DemPower app is a self-management guide intended to support both persons with dementia and their partners in their efforts to enhance well-being and relationship quality. The results show that the topic areas addressed in the app were meaningful and relevant to everyday life situations, although their utility varied with couples' trajectory through dementia and their general well-being. Evidence confirms that recognizing a person with

dementia and the family caregiver's position in their aging trajectory is essential in understanding how people make use of the support and perceive its effectiveness [42-44]. The videos of couples sharing their experiences and the active prompts in DemPower were reported to have encouraged couples to reflect on their own approaches to everyday activities, discuss their relationship, recognize both positive and challenging aspects of their life together in the context of dementia, and share experiences with each other. DemPower further challenged their own perceptions of dementia and their everyday choices. This might indicate the change observed in the DEMQoL scores for people with dementia and the marginal increase in the Mutuality scale for spouse caregivers. These results reveal that the self-management approach, concepts, videos, and suggested strategies for couples as a dyad are promising. This is consistent with the findings of a recent systematic review that found that a caregiver's emotional withdrawal can negatively affect the behavior of a person with dementia [45], which reaffirms our approach of actively involving both partners in couple-focused self-management.

Usability and Acceptability of DemPower

Examining the cultural adaptability of DemPower in both countries revealed that relationship dynamics, perception and acceptance of the condition, varied opportunities for social

interaction, and geographic location informed the couples' usage. For example, couples in the United Kingdom had better access to dementia cafés and activity-based groups such as reading, walking, choir, and art groups. Although not all couples welcomed the idea of attending groups, those who responded to the suggested activity said that their misconceptions were challenged and that they enjoyed the group, made friends, and continued attending the group activities. Couples had limited opportunities for socializing in groups in Sweden, and more so in rural locations in that country. Most Swedish couples moved between their summer and winter homes, which means that activities changed according to their location. However, the couples said that the videos on DemPower helped them learn about other couples' experiences, mutual interactions, and to feel that they were not alone in the way they experienced the situation. Most couples said that they would consider using DemPower in the future.

The use of technology and availability of DemPower on a handheld device provided couples with easy access to resources and suggestions that were relevant to everyday life situations, regardless of their location. All couples in both countries said that they were comfortable using a tablet device; however, navigational challenges in the DemPower app and lack of motivation in a few people with dementia have been reported. Both partners engaged actively in individual and couple-focused activities and watched videos, regardless of design-related challenges. Increasing evidence suggests that technology-based interventions in dementia that encourage active involvement contribute to better quality of life and quality of relationships [46,47]. The parts of the app that discussed advanced dementia were reported as distressing for some couples, and these parts were likely to discourage these couples from using the app. However, some studies have emphasized the need to address the future to create a sense of normalcy and deal with fears [48]. Other research into sensitive topic areas has highlighted participant distress; however, no research has discussed any long-term impact or continued distress caused by research participation [49]. The core contents of DemPower were carefully considered, informed by current evidence, and in consultation with people with dementia and their partners [17,50]. However, the presentation and design of DemPower needed further consideration to facilitate participant preparedness and to allow participants to select topics that were relevant to the participants' stage of dementia and at the time of their choosing.

Recruitment and Completion Rates

The study obtained tremendous support in the recruitment of participants from organizations in both the United Kingdom and Sweden. The JDR network in the United Kingdom screened most of the potential participants there, but this organization was independent of the clinical care team. The Swedish memory clinic nurses approached potential participants during their clinic appointments. It is likely that the signposting of study by the care team might have influenced the recruitment and retention rates in Sweden and introduced selection bias to a certain extent. For example, the memory clinics in Sweden usually follow up with persons with dementia with more complex symptoms up to 6 months after diagnosis. The differences in the type of

dementia, age, education, gender, and the length of time since the diagnosis in this study highlight the need to carefully consider these variables in the design of a future trial.

Planned strategies that address any unforeseen delays in intervention delivery, being mindful of motivational issues in both partners, promoting interest in the use of technology, and maintaining continuity in researcher-participant contact are some of the recommendations for a future trial. To detect a 4-point change in the DEMQoL, assuming an SD of 15 points, a correlation of 0.6 between baseline and follow-up scores, and an 80% retention rate at follow-up, 354 couples would need to be randomized for a definitive RCT to achieve 80% power (480 couples for 90% power) [41]. Memory clinics in Sweden and dementia advisers in primary care and third-sector organizations in the United Kingdom are most likely to be the point of delivery in the future.

Suitability of the Outcome Measures

Outcome measures, such as quality of life, self-efficacy, and relationship-focused tools, could be considered to evaluate the changes and the impact the app has on the everyday lives of couples. It is important for these outcome measures to reflect what is important to people living with dementia [44] and consider the core outcome set for evaluating community-based interventions for people with dementia [51]. In view of the study results, measures of social well-being, relationship quality, positive feelings, and strength-based perspectives need particular focus in the future. The wider literature acknowledges the relevance of these domains and their potential to capture the experiences of people with dementia and family caregivers [51,52]. The measures also need to be mindful of the intrusive nature of the questions, especially those that assess relationship quality and emotional well-being, to determine whether self-administration or the interview method is ideal. Although the study found that it was feasible to use interviewing strategies to obtain responses to open-ended questions in the evaluation and administering outcome measures, the method limited the exploration of new themes arising from the responses. Hence, the use of both a questionnaire and in-depth interviews to assess outcomes and perform evaluations at various stages of the study is important for future consideration.

Conclusions

The findings suggest that the DemPower app is a meaningful resource for addressing various aspects of daily life and interactions in couple relationships where one partner has dementia. However, whether DemPower is more relevant for people with a recent diagnosis of dementia needs to be explored. The design and organization of app contents must be revised before further implementation and testing of the app. A larger sample size, longer follow-up periods, and various control groups (including couple groups rather than individual couples) need to be considered to test the effectiveness of the app. Important outcomes for the couples in this study were to be able to continue as usual, focus on strengths, on social well-being, and mutual relationship quality. These factors need to be considered when identifying relevant outcome measures for future trials.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix 1
Usage log lookup.
[PNG File , 60 KB - aging_v4i4e16824_app1.png]

Multimedia Appendix 2
Number of visits per screen.
[PNG File , 169 KB - aging_v4i4e16824_app2.png]

Multimedia Appendix 3
Evaluation data summary.
[XLSX File (Microsoft Excel File), 93 KB - aging_v4i4e16824_app3.xlsx]

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Abbreviations

ADQoL: Alzheimer's disease quality of life
DEMQoL: dementia quality of life
IOS: inclusion of other in the self
JDR: Join Dementia Research
RCT: randomized controlled trial

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<u>Original Paper</u>

Personalized Visual Mapping Assistive Technology to Improve Functional Ability in Persons With Dementia: Feasibility Cohort Study

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Abstract

Background: Mobile health (mHealth) apps using novel visual mapping assistive technology can allow users to develop personalized maps that aid people living with cognitive impairment in the recall of steps needed to independently complete activities of daily living (ADLs), such as bathing, toileting, and dressing.

Objective: This study aims to determine the feasibility and preliminary impact of an mHealth assistive technology app providing guidance to aid individuals living with cognitive impairment in the recall of steps to independently complete ADLs.

Methods: A total of 14 Veterans (mean age 65 SD 9.5 years; 14/14, 100% male; 10/14, 71.4% Black) and 8 non-Veterans (mean age 78, SD 10.3 years; 5/8, 62.5% male; 8/8, 100% Black) were recruited and enrolled from the Department of Veterans Affairs (VA) and non-VA cognitive care clinics. A visual mapping software program, MapHabit, was used to generate a series of personalized visual map templates focused on ADLs created within the MapHabit app. The visual maps were accessed through a tablet device. A 19-item exit questionnaire was administered to the participants to assess perceived improvement in their functional ability after using the MapHabit system for 3 months.

Results: A total of 13 (93%) VA clinic participants and 8 (100%) non-VA clinic participants completed the 3-month study. Baseline cognitive testing indicated impaired to significantly impaired cognitive function. After 3 months of using the MapHabit system, VA clinic participants reported perceived improvement in social engagement (P=.01) and performance of ADLs (P=.05) compared to the baseline, whereas non-VA clinic participants reported improvements in the performance of ADLs (P=.02), mood (P=.04), social engagement (P=.02), and memory (P=.02). All study participants reported they would recommend the MapHabit system to a colleague, and 85% (11/14) of VA and 100% (8/8) of non-VA clinic participants reported a willingness to participate in a future study.

Conclusions: Older VA and non-VA clinic participants with cognitive impairment were willing to use an mHealth app to assist with the completion of ADLs, and they reported positive preliminary effects. A larger study is warranted to assess the efficacy in the setting of a randomized controlled trial.

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Introduction

More than 16 million family members provide unpaid care to a person with Alzheimer disease or other dementias [1]. A recent report estimated that 18.6 billion hours of unpaid care are provided annually, totaling to a value of US $244 billion [1]. In the future, an increase for in-home or institutional care and unpaid assistance by family and friends will be needed as the numbers of those with Alzheimer disease and other forms of cognitive impairment continue to grow. Maintenance of functional ability has been linked to improved quality of life among persons with dementia, and strategies that promote functional ability and independence are of high priority in dementia care research [2,3].

Two recent developments have converged in an attempt to effectively address this challenge. First, developments in the field of assistive technology, including the use of smart devices (eg, tablets, phones, and wearables) have provided ways to enhance the ability of caregivers—both family and professional—to assist individuals with dementia and memory impairment to successfully perform activities of daily living (ADLs), such as bathing, toileting, and dressing [4]. Importantly, there is cumulating evidence that technology adoption is being progressively embraced both among dementia care recipients and their caregivers, findings that bode well for the potential effectiveness of assistive technology interventions [5-7]. Second, developments in the field of neuroscience have shown that there are at least two systems important for memory: the declarative memory system, which is important for conscious recollection of facts and events in our lives, and a more recently recognized procedural, or habit system, that can underlie the development and maintenance of nonconscious habits, motor skills, and other forms of nonconscious procedural learning, often called implicit memory [8]. The present report takes advantage of these two developments in assistive technology and habit memory development and explores the possibility of their use in enhancing the quality of life and functional ability of individuals living with dementia.

MapHabit is a novel mobile health (mHealth) assistive technology app that allows users and/or caregivers to develop personalized maps that aid people living with cognitive impairment in the recall of steps needed to complete the above-described ADLs [4,9]. With repeated use of these maps, people with impaired memory can develop a habit of consulting their visual maps routinely and independently of their caregivers.

In this paper, we describe the results from feasibility studies conducted in two clinical samples to determine whether people with cognitive impairment were willing to use the MapHabit system and whether there is evidence of potential benefit to inform a larger, more definitive study.

Methods

Study Setting and Ethical Approval

Participants for the feasibility study were recruited from two outpatient clinical programs: a Department of Veterans Affairs (VA) clinic and a non-VA academic health system clinic, focused on serving the needs of older adults with cognitive impairment. The protocol for each clinical cohort was approved by the Emory University Institutional Review Board, and all participants provided written informed consent. The protocols differed primarily based upon the requirement to recruit a care recipient–caregiver dyad in the non-VA clinic population. This provided the opportunity to assess the impact of assistive technology on two separate groups with similar levels of impairment belonging to two different US health systems. Data were analyzed separately for each cohort in order to comply with data information security protocols established by the VA. Here, we present data based on the outcomes assessed among participants living with cognitive impairment in each study group.

Intervention

A visual mapping software program was used to generate a series of visual map templates created by an assistive technology company, MapHabit, Inc. Participants accessed the software and visual maps through a mobile tablet device. Visual maps consisted of pictures and keywords in a step-by-step sequence to guide and assist participants with memory impairment in organizing and successfully accomplishing ADLs [4]. Participants were encouraged to self-select visual maps based on personal preferences and needs, and they could add images from their own environment to personalize the selected templates. Snapshots of the MapHabit system are presented in Figure 1. Visual maps involving ADL performance were commonly selected, with those pertaining to medication, bathing, and dressing being the most popular. After a staff member conducted initial training and development of selected ADL maps, participants were given an iPad to access and use the MapHabit system.

Figure 1. Screenshots of the MapHabit system app on mobile and tablet devices.

Measures

Demographic characteristics included age, sex, self-reported race and ethnicity, and the presence of a caregiver. Baseline cognition was assessed using the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), a brief, individually administered test measuring attention, language, visuospatial or constructional abilities, and immediate and delayed memory. The RBANS consists of 12 subtests, which yield 5 index scores of the measures described above, and a *total scale score* [10]. A 19-item overall exit questionnaire was administered to assess whether any change (positive or negative) occurred as a result of using the MapHabit system for 3 months. The questionnaire is provided in Multimedia Appendix 1. Questions were grouped to assess the various domains of ADL independence (questions #2, #3, #4, and #5 in the exit questionnaire), mood (questions #1, #7, #8, #9, #10, and #11), social engagement (questions #6, #13, #16, and #17), quality of life (questions #14 and #15), and self-reported memory impairment (question #12). The remaining questions of the measurement tool assessed the participants' overall satisfaction with the MapHabit system. The questionnaire was administered orally to the participants, using a Likert scale with a self-rating format (5=much better, 4=better, 3=not much change, 2=worse, or 1=much worse). A 2-item yes/no questionnaire assessed participants' overall user experience with the system.

Statistical Analysis

Baseline characteristics for each clinical sample were analyzed using descriptive statistics. Exit interview responses were compared using the Wilcoxon signed rank test to assess any differences from an expected result of "not much change"—that is, a score of 3 on the Likert scale for the exit questionnaire. Analyses were conducted using the RStudio statistical package (version 1.1.463).

Results

In all, 14 VA clinic (mean age 65 SD 9.5 years; 14/14, 100% male; 10/14, 71% Black) and 8 non-VA clinic (mean age 78, SD 10.3 years; 5/8, 62.5% male; 8/8, 100% Black) participants were enrolled in the study (Table 1). Following the 3-month intervention, 13 of the 14 (93%) VA clinic participants and all 8 (100%) non-VA clinic participants completed the study. Baseline cognition measured by the RBANS indicated impaired to significantly impaired cognitive function, on average, across all 5 indices of neuropsychological function [6]. Immediate memory scores indicated impaired ability to remember information immediately after it was presented. Visuospatial or construction scores indicated impaired ability to perceive spatial relations and to construct a spatially accurate copy of a drawing. Language scores indicated impaired ability to respond verbally to either naming or retrieving learned material. Attention scores indicated impaired capacity to remember and manipulate both visually and orally presented information in short-term memory. Delayed memory scores indicated impaired anterograde memory. Total scale scores were calculated by summing the abovementioned 5 index scores.

After 3 months of using the MapHabit system, analysis of the overall exit questionnaire responses showed that both VA and non-VA clinic participants reported perceived improvement in

social engagement (*P*=.01 and *P*=.02, respectively) and performance of ADLs (*P*=.05 and *P*=.02, respectively) compared to the baseline (Figure 2). Non-VA clinic participants also reported perceived improvement in mood (*P*=.04) and memory (*P*=.02; Figure 2). There was no significant perceived change in quality of life for either group (*P*=.09). Many participants reported using a particular map daily, such as to guide teeth-brushing, toileting, or showering. All VA and non-VA clinic participants reported they would recommend the MapHabit system to a colleague, and 85% (11/14) of VA and 100% (8/8) non-VA clinic participants reported a willingness to participate in a future study.

Table 1. Baseline characteristics of the Veterans Affairs (VA) and non-VA clinic participants.

Characteristic	VA cognitive clinic (n=14)	Non-VA cognitive clinic (n=8)
Age (years), mean (SD)	65 (9.5)	78 (10.3)
Gender, n (%)		
Female	0 (0)	3 (37.5)
Male	14 (100)	5 (62.5)
Race, n (%)		
White	4 (28.6)	0 (0)
Black or African American	10 (71.4)	8 (100)
Other	0 (0)	0 (0)
Are you of Hispanic or Latino origin, n (%)		
Yes	1 (7.1)	0 (0)
No	13 (92.9)	8 (100)
Marital status, n (%)		
Single	3 (21.4)	0 (0.0)
Married	9 (64.4)	5 (62.5)
Divorced	1 (7.1)	0 (0)
Widowed	0 (0)	3 (37.5)
Unknown	1 (7.1)	0 (0)
Baseline RBANS[a], mean (SD)		
Immediate memory score	70.50 (18.7)	56.75 (20.6)
Visuospatial score	67.36 (10.6)	70.12 (19.4)
Language score	85.57 (14.2)	71.00 (21.9)
Attention score	74.64 (11.9)	69.62 (10.3)
Delayed memory score	62.00 (18.6)	52.12 (20.4)
Total scale score	63.07 (13.3)	58.00 (15.6)

[a]RBANS: Repeatable Battery for the Assessment of Neuropsychological Status.

Figure 2. Exit interview responses from study participants 3 months after using personalized visual maps. Non-VA: non–Veterans Affairs clinic participants; VA: Veterans Affairs clinic participants.
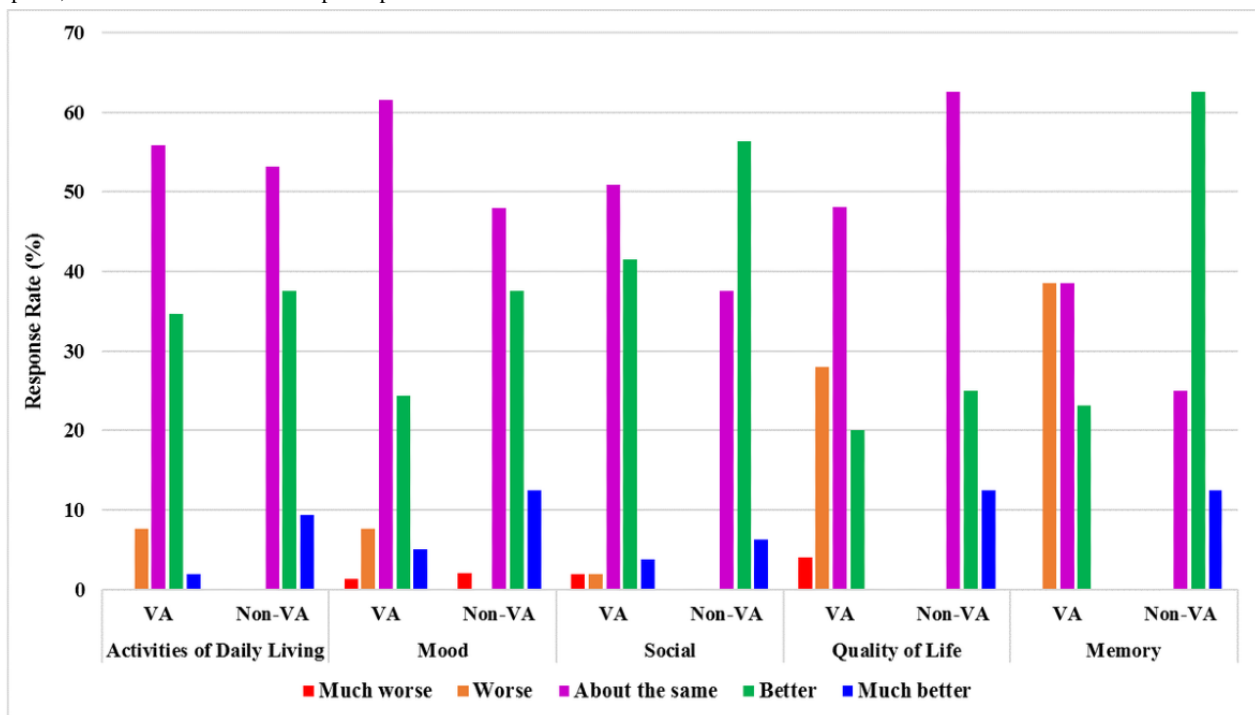
Discussion

Principal Findings

The findings from the present studies indicate that the use of visual mapping, specifically the MapHabit system as an assistive technology, is feasible for individuals with memory impairment. Participants reported a positive experience in using the MapHabit system as an assistive technology, adding they would recommend it, and they would again engage with the MapHabit system if the opportunity arose in the future. Furthermore, our study findings suggest that use of the MapHabit system for 3 months may result in perceived improvement in social engagement and performance of ADLs.

Although it has been previously speculated that the use of technology is not widely accepted by older adults, the present results suggest otherwise. Similarly, a study investigating the feasibility of personalized technology use in individuals with mild cognitive impairment found that technology adoption was excellent among both care recipients and their caregivers [5]. Both the present MapHabit system and technology used in the previous study in a senior living community population [5] are personalized, which may suggest that personalization, wherein users are engaged in the selection of activities, serves as a facilitator in technology use among diverse populations of older adults.

Regarding the potential benefit of technology to users' independence, a recent systematic review of the literature assessing assistive technology use among older adults found that both users and caregivers reported these technologies assisted caregivers by reducing the time, level of assistance, and energy expended on caregiving, as well as anxiety and fear, task difficulty, and safety risk. Previous research has suggested that these improvements were associated with increased

independence of the user and reduced need for physical assistance with ADLs [11]. In our studies, both VA and non-VA clinic participants reported perceived improvement in performance of ADLs, echoing the finding that the use of assistive technologies may decrease caregiver burden by promoting increased independence in ADLs by the user.

Limitations

These studies are not without limitations. As feasibility studies, they were not designed to determine efficacy or definitive evaluation across all outcomes of interest. The outcomes were self-reported; however, patient-reported outcomes are likely the most relevant for determining the initial feasibility of an assistive technology in this population. Although these were not long-term studies, assistive technology appears to be a feasible delivery method for visual maps, and participants were willing to use the technology for at least 3 months. A larger, randomized controlled trial evaluating the visual MapHabit system in individuals living with memory impairment is warranted with a longer follow-up, to determine sustainability.

Conclusions

Novel findings from this study suggest that the assistive technology MapHabit system is a feasible delivery method for personalized visual maps that can aid people living with cognitive impairment in the recall of steps needed to complete ADLs with greater independence. Strong endorsement from two diverse clinical samples of older adults with cognitive impairment (eg, Black vs White, VA vs non-VA, and male vs female) suggests a potential broad appeal of personalized visual mapping as an assistive technology. Based on research priorities aimed at new strategies to promote ADL independence in individuals with cognitive impairment, the next step entails a definitive study to assess efficacy of personalized visual mapping.

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Conflicts of Interest

An in-kind donation of the MapHabit system was made by MapHabit, Inc. SZ and MG are current employees of MapHabit, Inc. SL served on the Advisory Board of MapHabit, Inc. The researchers do not hold a direct financial interest in the sponsors, or the product being studied.

Multimedia Appendix 1
Exit interview questionnaire for caregivers or study participants.
[DOCX File , 17 KB - aging_v4i4e28165_app1.docx]

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Abbreviations

ADLs: activities of daily living
mHealth: mobile health
RBANS: Repeatable Battery for the Assessment of Neuropsychological Status.
VA: Department of Veterans Affairs

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<u>Original Paper</u>

The Association of Delayed Care With Depression Among US Middle-Aged and Older Adults During the COVID-19 Pandemic: Cross-sectional Analysis

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Abstract

Background: During the COVID-19 pandemic, the depression level among US adults has significantly increased. Age disparity in depression during the pandemic has been reported in recent studies. Delay or avoidance of medical care is one of the collateral damages associated with the COVID-19 pandemic, and it can lead to increased morbidity and mortality.

Objective: This study aimed to assess the prevalence of depression and delayed care among US middle-aged adults and older adults during the pandemic, as well as investigate the association of delayed care with depression among those 2 age groups.

Methods: This cross-sectional study used data from the 2020 Health and Retirement Study (HRS) COVID-19 Project (Early, Version 1.0). Univariate analyses, bivariate analyses, and binary logistic regression were applied. US adults older than 46 years were included. Depression was measured by the Composite International Diagnostic Interview-Short Form (CIDI-SF). Delayed care was measured by the following 4 items: delayed surgery, delayed seeing a doctor, delayed dental care, and other delayed care.

Results: A total of 3246 participants were identified. More than half of the participants were older than 65 years (n=1890, 58.2%), and 274 (8.8%) participants had depression during the pandemic. Delayed dental care was positively associated with depression among both middle-aged adults (OR 2.05, 95% CI 1.04-4.03; *P*=.04) and older adults (OR 3.08, 95% CI 1.07-8.87; *P*=.04). Delayed surgery was positively associated with depression among older adults (OR 3.69, 95% CI 1.06-12.90; *P*=.04). Self-reported pain was positively related to depression among both age groups. Middle-aged adults who reported higher education levels (some college or above) or worse self-reported health had a higher likelihood of having depression. While perceived more loneliness was positively associated with depression among older adults, financial difficulty was positively associated with depression among middle-aged adults.

Conclusions: This study found that depression was prevalent among middle-aged and older adults during the pandemic. The study highlighted the collateral damage of the COVID-19 pandemic by identifying the association of delayed surgery and dental care with depression during the pandemic. Although surgery and dental care cannot be delivered by telehealth, telehealth services can still be provided to address patients' concerns on delayed surgery and dental care. Moreover, the implementation of telemental health services is needed to address mental health symptoms among US middle-aged and older adults during the pandemic. Future research that uses more comprehensive measurements for delayed care is needed to decipher the path through which delayed care is associated with depression.

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Introduction

COVID-19 Outbreak

Since first recognized in December 2019, COVID-19 has posed significant challenges for public health, research, and medical communities [1,2]. On March 11, 2020, the World Health Organization announced that COVID-19 can be characterized as a pandemic [3]. During the pandemic, most states in the United States have taken nonpharmaceutical pandemic control measures, including imposing mandatory stay-at-home orders; closing or limiting capacity at nonessential businesses, restaurants, and bars; closing schools; limiting large gatherings; requiring quarantines; and requiring masks [4,5].

Depression During the Pandemic

Comparing national representative data collected before and during the pandemic, prior studies have demonstrated that the depression level among US adults significantly increased during the pandemic [6,7]. Daly et al used Patient Health Questionnaire-2 (PHQ-2) and found that the rate of US adults with depression was 5.7% higher during the pandemic compared to the rate in 2017-2018 [6]. Ettman et al applied Patient Health Questionnaire-9 (PHQ-9) and reported that the prevalence of depressive symptoms among US adults was 3-fold higher during the pandemic compared to before the pandemic [7]. Even without the comparison, recent studies used different depression measurements and reported high levels of depression among US adults during the pandemic [8-11]. The worsened depression level among US adults might be related to the nonpharmaceutical measures taken to control the pandemic. Those measures had significant social and economic consequences that might in return harm health [4]. For example, school closure caused disrupted educational development, social distancing caused lack of access to social support systems, and business closure caused unemployment [4]. In fact, job insecurity, unemployment, loneliness, and social support were cited as factors associated with depression among US adults during the pandemic [7,8,12-14].

Age Disparity in Depression

Age disparity in depression during the pandemic was reported in recent studies [15-18]. While older age is associated with a higher risk of COVID-19 infection and worse outcomes [19,20], younger age is a risk factor for a higher level of depression during the pandemic [15-18]. Previous studies found that loneliness, COVID-19–specific worries, job insecurity, resilience, and social support were significantly related to depression levels among young US adults aged 18 to 35 years during the pandemic [8,12,13]. Studies examining the factors associated with depression among middle-aged and older adults during the pandemic were not found. However, previous studies indicated that while depression in middle-aged adults might be related to lifecycle gains and losses, marriage, employment, and economic well-being [21], depression in older adults is often linked to coexisting medical conditions or cognitive impairment [22].

Delayed Care and Depression During the Pandemic

Delay or avoidance of medical care is one of the collateral damages caused by the COVID-19 pandemic, and it can lead to increased morbidity and mortality [23,24]. A nationwide survey conducted among US adults from June 24 to 30, 2020, indicated that approximately 40.9% of US adults reported avoidance of medical care during the pandemic because of COVID-19 concerns [25]. A recent study found a significant association between depression and delayed medical care among US adults amidst the pandemic [26]. Delayed medical care also might lead to untreated or undertreated pain [27,28] that was found to be associated with significantly higher depression levels compared to the time when pain was treated [29].

Aim

While depression and its associated factors among young adults during the pandemic have been well studied [8,12,13], studies focusing on the prevalence of depression and its linked factors among middle-aged and older adults during the pandemic are scarce. Moreover, as a population that is more likely to have medical conditions [30], older adults were disproportionally impacted by delayed care during the pandemic because their existing medical conditions might have been untreated or undertreated [27,28]. Because depression in older adults is often related to their coexisting medical conditions or cognitive impairment [22], the pandemic might pose a threat to older adults' mental health status through increased delayed care. Previous studies have not investigated the association of delayed care with depression among US middle-aged and older adults during the pandemic. Using national representative survey data, this study aimed to (1) assess the prevalence of depression and delayed care among US middle-aged adults (46-64 years old) and older adults (≥65 years old) during the COVID-19 pandemic and (2) investigate the association of delayed care with depression among these 2 age groups during the pandemic. In line with the Medicare-eligible age for older adults, 65 years was used as a cutoff to differentiate older adults from middle-aged adults [31].

Methods

Data Description

This study used the 2020 Health and Retirement Study (HRS) COVID-19 Project (Early, Version 1.0) data that are part of the HRS, which is sponsored by the National Institute on Aging (grant number NIA U01AG009740) and is conducted by the University of Michigan [32]. The HRS is a national longitudinal study collecting data on economy, health, marital status, and family status, as well as support systems among older Americans [32]. The HRS sampled at the household level and built the sample over time [33]. Since the first wave of the HRS in 1992, a new cohort of individuals aged 51 to 56 years has been added every 6 years (eg, in 1998, 2004, 2010, and 2016) [34]. If the person meeting the age eligibility was coupled, their spouse or partner was also included in the sample [33]. The COVID-19 sample was randomly selected from households who were originally assigned to enhanced face-to face interviewing (EFTF) and then split into the following 2 random samples: EFTF1 and EFTF2. The sample included US adults who were older than

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55 years by 2020 (community dwelling and noninstitutionalized) and their spouse or partner [35]. Telephone interviews were conducted to collect the data due to social contact restriction during the pandemic [32]. The data collection started on June 11, 2020, for EFTF1 and on September 24, 2020, for EFTF2. The current data were originally released in November 2020 and updated in February 2021 [32]. While data collection for both samples is still under way, the current data include 3266 respondents from the EFTE1 sample, with a response rate of 62% [32]. The HRS data set was approved for use without seeking institutional review board approval by the first author's institution.

Approaches

Dependent Variable

The outcome variable was depression, and it was measured by Composite International Diagnostic Interview-Short Form (CIDI-SF) [36,37]. In CIDI-SF, participants were asked 2 series of stem questions, with one containing questions about having 2 weeks of dysphoria (series A) and the other containing questions about having 2 weeks of anhedonia (series B) as follows: (A1) During the last 12 months, was there ever a time when you felt sad, blue, or depressed for 2 weeks or more in a row? (A2) Thinking of the 2-week period during the last 12 months when these feelings were worst, did the feelings of being sad, blue, or depressed usually last all day long, most of the day, about half the day, or less than half the day? (A3) Thinking of the 2-week period during the last 12 months when you felt sad, blue, or depressed, did you feel this way every day, almost every day, or less often than that? (B1) During the last 12 months, was there ever a time lasting 2 weeks or more when you lost interest in most things like hobbies, work, or activities that usually give you pleasure? (B2) Thinking of the 2-week period during the last 12 months when you had the most complete loss of interest in things, did the loss of interest usually last all day long, most of the day, about half the day, or less than half the day? (B3) Thinking of the 2-week period during the last 12 months when you lost interest in most things, did you feel this way every day, almost every day, or less often than that?

Participants are considered to meet the diagnostic requirement for major depression (MD) if they report 2 weeks of the aforementioned symptoms in ether series (A or B) lasting at least most of the day and at least almost every day. In this study, 291 participants were identified as meeting the requirement.

Seven additional questions (yes or no) on symptoms are asked to participants who meet the diagnostic requirements as follows: losing interest, feeling tired, change in weight, trouble with sleep, trouble concentrating, feeling down, and thoughts about death (0=no, 1=yes). In this study, an MD score was obtained by summing up the above 7 items (range 0-7). Participants who reported three or more symptoms (MD score ≥3) are classified as MD probable cases. The final outcome variable "probable MD" was generated by integrating the 2 series of stem questions and 7 additional symptom questions, where "no" represented that participants did not have probable MD (not meeting the diagnostic stem requirement or having an MD score <3) and

"yes" represented that participants had probable MD. Depression was analyzed as a binary variable (0=no, 1=yes).

Independent Variables

Four types of delayed care were independent variables. Participants were asked "Since March 2020, was there any time when you needed medical or dental care, but delayed getting it, or did not get it at all?" For participants who reported delayed care, another question was asked about the type of care that was delayed, including surgery, seeing the doctor, filling a prescription, and dental care. Combining both questions, 4 dummy variables were generated for delayed surgery, delayed seeing a doctor, delayed dental care, and delayed other care (0=no, 1=yes). Participants who reported delayed care were also asked the reasons for not getting care (could not afford it; could not get an appointment; the clinic/hospital/doctor's office cancelled, closed, or suggested rescheduling; decided it could wait; was afraid to go; and other reasons).

Covariates

Demographic Characteristics

Demographic characteristics were included and analyzed as binary variables as follows: gender (0=male, 1=female), education (0=high school graduate or below, 1=some college or above), race (0=White/Caucasian, 1=Black/African American, 2=other), and ethnicity (0=non-Hispanic, 1=Hispanic).

Health Status

Self-reported health status, physical chronic conditions, self-reported pain, and pain medication use were included. Self-reported health status was measured with a 5-point scale in the survey (1=poor, 2=fair, 3=good, 4=very good, and 5=excellent) and was analyzed as a continuous variable. For physical chronic conditions, participants were asked whether a doctor had ever told them that they have the following medical conditions: high blood pressure or hypertension, diabetes or high blood sugar, cancer or a malignant tumor (excluding minor skin cancer), chronic lung disease, heart problems (ie, heart attack, coronary heart disease, angina, or congestive heart failure), stroke, arthritis or rheumatism, and high blood cholesterol levels. Participants responded yes or no to each condition (0=no, 1=yes). The final variable for physical chronic conditions was obtained by adding up responses for 8 conditions, and it was analyzed as a continuous variable. Self-reported pain was analyzed as a continuous variable that ranged from 0 to 3 (0=not troubled by pain at all, 1=mild pain, 2=moderate pain, 3=severe pain). Self-reported health status (range 1-5), physical chronic condition (range 0-8), and self-reported pain (range 0-3) were analyzed as continuous variables. Regarding pain medication use, participants who responded that they had taken over-the-counter pain medications or opioids (Vicodin, oxycodone [OxyContin], codeine, and morphine) for the treatment of pain were considered as using pain medications. Pain medication use was analyzed as a binary variable (0=no, 1=yes).

Pandemic Stressors

Pandemic stressors included perceived less often in-person contact, perceived more loneliness, having anyone known die

from COVID-19, financial difficulty, and COVID concern, as these stressors have been reported in recent studies as factors associated with depression during the pandemic [7,10,13,14,38]. Perceived less often in-person contact and perceived more loneliness were analyzed as binary variables (0=no, 1=yes). Participants were asked "Has anyone you know died from COVID-19?" (0=no, 1=yes). To measure financial difficulty, participants were asked "How difficult is it for (you/your family) to meet monthly payments on (your/your family's) bills?" with 5-point responses (1=not difficult at all, 5=completely difficult). For COVID-19 concern, participants were asked "Overall, on a scale from 1 to 10, where 1 is the least concerned and 10 is the most concerned, how concerned are you about the coronavirus pandemic?" Financial difficulty (range 1-5) and COVID-19 concern (range 1-10) were analyzed as continuous variables.

Statistical Analysis

Univariate analyses were conducted to describe demographic characteristics, health status, pandemic stressors, and delayed care, as well as depression among participants. Bivariate analyses were used to examine the age difference for all variables between middle-aged adults (46-64 years old) and older adults (≥65 years old), and the unadjusted relationship between depression and all variables. Lastly, binary logistic regression was applied to examine the factors associated with depression, and especially investigate the association of delayed care with depression. All statistical analyses were conducted using Stata/SE 15.1 (StataCorp).

Results

Description of Demographic Characteristics, Health Status, Pandemic Stressors, and Delayed Care

According to Table 1, slightly more than half of the participants were older than 65 years (n=1890, 58.2%), were female (n=1137, 56.8%), had an education level of some college or above (n=1134, 56.6%), and were White (n=1146, 57.5%). Moreover, 26.1% (n=520) of participants were African American. The majority of participants were non-Hispanic (n=1583, 79.2%). In terms of the health status, participants reported a moderate health status (mean 3.08, range 1-5). The average number of physical chronic conditions among participants was more than two (mean 2.42, range 0-8). Participants reported a low level of pain (mean 0.78, range 0-3), and 68.6% (n=2214) of participants reported using over-the-counter medication or opioids for pain relief. Regarding pandemic stressors, 26.1% (n=542) of participants reported that they felt lonelier during the pandemic. Moreover, 38.9% (n=813) of participants perceived that they had less often in-person contact with others outside of the household during the pandemic, and 19.8% (n=641) of participants had someone they knew die from COVID-19. Participants reported a low level of financial difficulty (mean 1.76, range 1-5) and a high level of COVID concern (mean 7.78, range 1-10). Only few participants (n=135, 4.2%) had experienced delayed surgery since March 2020. Furthermore, 17.4% (n=560) of participants experienced delay seeing a doctor, and 21.8% (n=704) of participants experienced delayed dental care. Only 6.8% (n=220) of participants experienced delayed other care besides surgery, seeing a doctor, and dental care. Table 1 shows that middle-aged and older adults had significant differences in gender (*P*=.02), race (*P*=.002), physical chronic conditions (*P*<.001), self-reported pain (*P*=.049), pain medication use (*P*=.043), having anyone they know die from COVID (*P*<.001), financial difficulty (*P*<.001), COVID concern (*P*=.02), and delayed care (surgery, *P*=.02; seeing a doctor, *P*<.001; dental care, *P*<.001; and other care, *P*<.001).

Table 1. Demographic characteristics, health status, pandemic stressors, and delayed care by age.

Characteristic	All (N=3246[a])	Age 30-64 years (n=1356, 41.8%)	Age ≥65 years (n=1890, 58.2%)	P value[b]
Demographics				
Gender, n (%)				.02
Male	866 (43.2)	540 (41.3)	326 (46.9)	
Female	1137 (56.8)	768 (58.7)	369 (53.1)	
Education, n (%)				.96
High school graduate or below	869 (43.4)	568 (43.4)	301 (43.3)	
Some college or above	1134 (56.6)	740 (56.6)	394 (56.7)	
Race, n (%)				.002
White/Caucasian	1146 (57.5)	719 (55.3)	427 (61.8)	
Black/African American	520 (26.1)	344 (26.4)	176 (25.5)	
Other	326 (16.4)	238 (18.3)	88 (12.7)	
Ethnicity, n (%)				.84
Non-Hispanic	1583 (79.2)	1036 (79.3)	547 (78.9)	
Hispanic	416 (20.8)	270 (20.7)	146 (21.1)	
Health status				
Self-reported health status (range 1-5), mean (SD)	3.08 (1.01)	3.09 (1.04)	3.08 (1.01)	.64
Physical chronic conditions (range 0-8), mean (SD)	2.42 (1.53)	1.95 (1.46)	2.75 (1.49)	<.001
Self-reported pain (range 0-3), mean (SD)	0.78 (1.03)	0.82 (1.06)	0.75 (1.01)	.049
Pain medication use, n (%)				.043
No	1014 (31.4)	398 (29.3)	616 (32.8)	
Yes	2214 (68.6)	953 (70.7)	1261 (67.2)	
Pandemic stressors				
Perceived more loneliness, n (%)				.80
No	1537 (73.9)	558 (73.6)	979 (74.1)	
Yes	542 (26.1)	200 (26.4)	342 (25.9)	
Perceived less in-person contact, n (%)				.91
No	1276 (61.1)	463 (60.9)	813 (61.2)	
Yes	813 (38.9)	297 (39.1)	516 (38.8)	
Anyone they know died from COVID, n (%)				<.001
No	2593 (80.2)	1022 (75.5)	1571 (83.5)	
Yes	641 (19.8)	331 (24.5)	310 (16.5)	
Financial difficulty (range 1-5), mean (SD)	1.76 (0.94)	1.98 (1.01)	1.63 (0.87)	<.001
COVID concern (range 1-10), mean (SD)	7.78 (2.66)	7.65 (2.71)	7.87 (2.62)	.02
Delayed care				
Delayed surgery, n (%)				.02
No	3091 (95.8)	1281 (94.8)	1810 (96.5)	
Yes	135 (4.2)	70 (5.2)	65 (3.5)	
Delayed seeing a doctor, n (%)				<.001
No	2665 (82.6)	1053 (77.9)	1612 (86.1)	
Yes	560 (17.4)	299 (22.1)	261 (13.9)	
Delayed dental care, n (%)				<.001

Characteristic	All (N=3246[a])	Age 30-64 years (n=1356, 41.8%)	Age ≥65 years (n=1890, 58.2%)	P value[b]
No	2526 (78.2)	999 (73.8)	1527 (81.4)	
Yes	704 (21.8)	354 (26.2)	350 (18.6)	
Delayed other care, n (%)				<.001
No	3009 (93.2)	1236 (91.3)	1773 (94.6)	
Yes	220 (6.8)	118 (8.7)	102 (5.4)	

[a]The total sample size of the study may not be the same as the total sample size of the survey due to missing values.

[b]We performed the *t* test for continuous variables and the χ^2 test for categorical variables.

Reasons for Delayed Care

As shown in Table 2, the clinic/hospital/doctor's office cancelled, closed, or suggested rescheduling was the most common reason for delayed care (n=423, 43.8%). Moreover, around 10% of participants delayed care because they could not afford it (n=92, 9.5%), could not get an appointment (n=97, 10.0%), or were afraid to go (n=88, 9.1%). Slightly more than 13% of participants reported that they decided to wait (n=133, 13.8%), and the same percentage of participants delayed care for other reasons (n=133, 13.8%). The 2 age groups showed a significant difference in the reasons for delayed care (P=.002). More middle-aged adults reported that they delayed care because they could not afford it or they were afraid to go, while more older adults reported reasons, including the clinic/hospital/doctor's office cancelled, closed, or suggested rescheduling, could not get an appointment, decided to wait, or other reasons.

Table 2. Reasons for delayed care.

| Characteristic	All (N=968[a]), n (%)	Age 30-64 years, n (%)	Age ≥65 years, n (%)	P value
Could not afford it	92 (9.5)	62 (12.8)	30 (6.2)	.002
Could not get an appointment	97 (10.0)	57 (11.8)	40 (8.3)	.002
The clinic/hospital/doctor's office cancelled, closed, or suggested rescheduling	423 (43.8)	200 (41.3)	223 (46.7)	.002
Decided it could wait	133 (13.8)	62 (12.8)	71 (14.7)	.002
Afraid to go	88 (9.1)	45 (9.3)	43 (8.9)	.002
Other reasons	133 (13.8)	58 (12.0)	75 (15.6)	.002

[a]The total sample size of the study may not be the same as the total sample size of the survey due to missing values.

Depression Among US Middle-Aged and Older Adults During the Pandemic

As shown in Figure 1, for the first series of CIDI-SF stem questions (series A), 510 participants reported that they felt sad, blue, or depressed for 2 weeks or more in a row during the last 12 months. Of those participants, 254 reported that when these feelings were the worst, the feelings lasted for most of the day or all day long. Of the 254 participants, 217 reported that they had the feelings every day or almost every day. Among the 217 participants, 207 reported scores higher than 3 on the 7 symptom questions. For the second series of CIDI-SF stem questions (series B), 273 participants reported that they lost interest in most things like hobbies, work, or activities that usually give them pleasure for 2 weeks or more in a row during the last 12 months. Of those participants, 117 reported that when they completely lost interest in most things, the feelings lasted for most of the day or all day long. Of the 117 participants, 74 reported that they had the feelings every day or almost every day. Among the 74 participants, 67 reported scores higher than 3 on the 7 symptom questions. Totally, 274 (8.8%) participants were identified as having MD. Table 3 shows that participants with MD and participants without MD had significant differences in age (P<.001), gender (P<.001), self-reported health status (P<.001), physical chronic conditions (P<.001), self-reported pain (P<.001), pain medication use (P<.001), perceived less in-person contact with others (P=.001), financial difficulty (P<.001), COVID concern (P=.009), and delayed care (surgery, P<.001; seeing a doctor, P<.001; dental care, P<.001; and other care, P<.001). The unadjusted bivariate analysis indicated that participants with depression tended to be middle-aged and female, had worse self-reported health status, had more physical chronic conditions, perceived more loneliness, perceived less in-person contact with others, had financial difficulty, had a higher COVID concern score, had delayed care (surgery, seeing a doctor, dental care, and other care), and reported worse pain and pain medication use.

Figure 1. Depression among US middle-aged and older adults during the pandemic: Composite International Diagnostic Interview-Short Form (CIDI-SF).
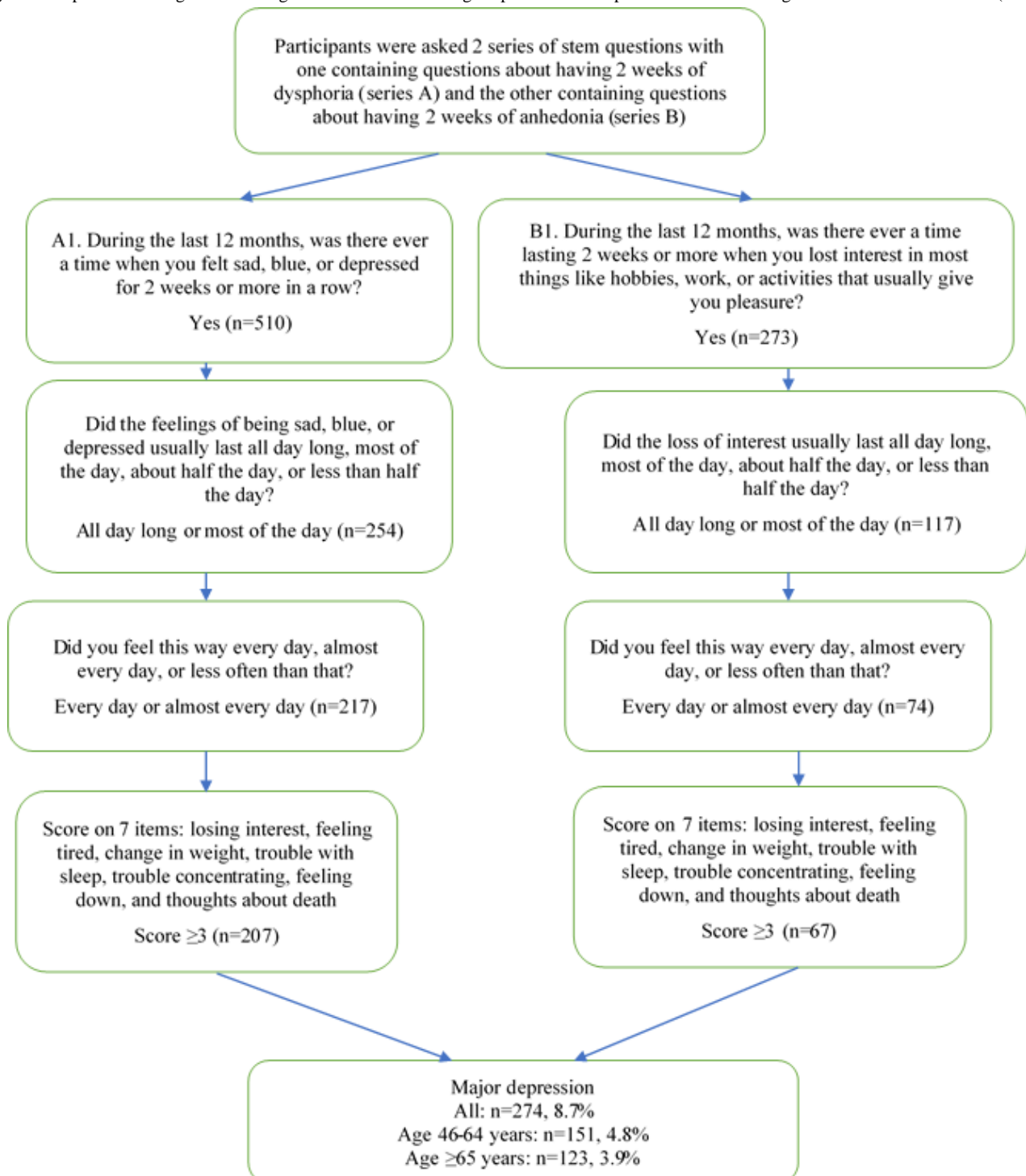
Table 3. Demographic characteristics, health status, pandemic stressors, and delayed care by depression.

Characteristics	All (N=3246[a])	Participants without major depression (n=2840, 91.2%)	Participants with major depression (n=274, 8.8%)	P value[b]
Demographics				
Age, n (%)				<.001
30-64 years	1356 (41.8)	1179 (41.5)	151 (55.1)	
≥65 years	1890 (58.2)	1661 (58.5)	123 (44.9)	
Gender, n (%)				<.001
Male	866 (43.2)	774 (43.9)	62 (31.0)	
Female	1137 (56.8)	990 (56.1)	138 (69.0)	
Education, n (%)				.97
High school graduate or below	869 (43.4)	759 (43.0)	88 (44.0)	
Some college or above	1134 (56.6)	1005 (57.0)	112 (56.0)	
Race, n (%)				.98
White/Caucasian	1146 (57.5)	1011 (57.6)	114 (57.3)	
Black/African American	520 (26.1)	456 (26.0)	53 (26.6)	
Other	326 (16.4)	287 (16.4)	32 (16.1)	
Ethnicity, n (%)				.38
Non-Hispanic	1583 (79.2)	1386 (78.7)	162 (81.4)	
Hispanic	416 (20.8)	375 (21.3)	37 (18.6)	
Health status				
Self-reported health status (range 1-5), mean (SD)	3.08 (1.01)	3.17 (1.98)	2.48 (1.05)	<.001
Physical chronic conditions (range 0-8), mean (SD)	2.42 (1.53)	2.35 (1.50)	3.04 (1.64)	<.001
Self-reported pain (range 0-3), mean (SD)	0.78 (1.03)	0.70 (0.98)	1.49 (1.18)	<.001
Pain medication use, n (%)				<.001
No	1014 (31.4)	913 (32.3)	57 (20.9)	
Yes	2214 (68.6)	1913 (67.7)	216 (79.1)	
Pandemic stressors				
Perceived more loneliness, n (%)				<.001
No	1537 (73.9)	1424 (75.5)	79 (52.7)	
Yes	542 (26.1)	462 (24.5)	71 (47.3)	
Perceived less in-person contact, n (%)				.001
No	1276 (61.1)	1173 (61.8)	72 (48.3)	
Yes	813 (38.9)	724 (38.2)	77 (51.7)	
Anyone they know died from COVID, n (%)				.85
No	2593 (80.2)	2262 (80.0)	217 (79.5)	
Yes	641 (19.8)	567 (20.0)	56 (20.5)	
Financial difficulty (range 1-5), mean (SD)	1.76 (0.93)	1.72 (0.90)	2.21 (1.21)	<.001
COVID concern (range 1-10), mean (SD)	7.86 (2.59)	7.82 (2.59)	8.25 (2.50)	.009
Delayed care				
Delayed surgery, n (%)				<.001
No	3091 (95.8)	2723 (96.4)	241 (89.3)	
Yes	135 (4.2)	103 (3.6)	29 (10.7)	
Delayed seeing a doctor, n (%)				<.001

Characteristics	All (N=3246[a])	Participants without major depression (n=2840, 91.2%)	Participants with major depression (n=274, 8.8%)	P value[b]
No	2665 (82.6)	2369 (83.9)	174 (64.2)	
Yes	560 (17.4)	455 (16.1)	97 (35.8)	
Delayed dental care, n (%)				<.001
No	2526 (78.2)	2233 (79.0)	172 (63.5)	
Yes	704 (21.8)	595 (21.0)	99 (36.5)	
Delayed other care, n (%)				<.001
No	3009 (93.2)	2657 (94.0)	223 (82.3)	
Yes	220 (6.8)	170 (6.0)	48 (17.7)	

[a]The total sample size of the study may not be the same as the total sample size of the survey due to missing values.

[b]We performed the *t* test for continuous variables and the χ^2 test for categorical variables.

Factors Associated With Depression Among Middle-Aged and Older Adults

Table 4 shows that after controlling demographics, health status, and pandemic stressors, delayed dental care was positively associated with depression among both middle-aged adults (odds ratio [OR] 2.05, 95% CI 1.04-4.03; *P*=.04) and older adults (OR 3.08, 95% CI 1.07-8.87; *P*=.04). The results indicated that participants who reported delayed dental care had a higher log OR of having depression compared to those who did not. Moreover, delayed surgery was positively associated with depression among older adults (OR 3.69, 95% CI 1.06-12.90; *P*=.04).

Other factors associated with depression are also reported in Table 4. Self-reported pain was positively related to depression among both middle-aged adults (OR 1.74, 95% CI 1.28-2.37; *P*<.001) and older adults (OR 1.98, 95% CI 1.22-3.21; *P*=.005). Middle-aged adults who reported higher education levels (some college or above) (OR 2.98, 95% CI 1.06-4.11; *P*=.03) or worse self-reported health (OR 0.68, 95% CI 0.47-0.98; *P*=.04) had a higher likelihood of having depression. While perceived more loneliness was positively associated with depression among older adults (OR 3.58, 95% CI 1.24-10.29; *P*=.02), financial difficulty was positively associated with depression among middle-aged adults (OR 1.78, 95% CI 1.33-2.37; *P*<.001).

Table 4. Binary logistic regression for the association of delayed care with depression on controlling covariates between the age groups.

Characteristic	Depression			
	Age 46-64 years[a]		Age ≥65 years[b]	
	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Demographics				
Gender: female (reference: male)	1.43 (0.74-2.76)	.28	2.27 (0.87-5.93)	.10
Education: some college or above (reference: high school graduate or below)	2.98 (1.06-4.11)	.03	0.69 (0.28-1.71)	.42
Race: Black/African American (reference: White/Caucasian)	1.02 (0.48-2.19)	.96	0.81 (0.25-2.57)	.72
Race: other (reference: White/Caucasian)	1.20 (0.48-3.01)	.69	0.86 (0.15-5.05)	.87
Ethnicity: Hispanic (reference: non-Hispanic)	0.73 (0.30-1.78)	.49	0.92 (0.24-3.58)	.90
Health status				
Self-reported health status	0.68 (0.47-0.98)	.04	0.82 (0.49-1.40)	.47
Physical chronic condition	1.10 (0.88-1.37)	.40	0.89 (0.64-1.23)	.49
Self-reported pain	1.74 (1.28-2.37)	<.001	1.98 (1.22-3.21)	.005
Pain medication use: yes (reference: no)	1.34 (0.54-3.33)	.53	0.41 (0.16-1.06)	.07
Pandemic stressors				
Perceived more loneliness: yes (reference: no)	1.00 (0.48-2.10)	.99	3.58 (1.24-10.29)	.02
Perceived less in-person contact: yes (reference: no)	1.15 (0.55-2.37)	.71	1.20 (0.39-3.67)	.75
Anyone they know died from COVID: yes (reference: no)	0.55 (0.24-1.25)	.16	1.13 (0.40-3.19)	.82
Financial difficulty	1.78 (1.33-2.37)	<.001	0.92 (0.64-1.41)	.70
COVID concern	0.94 (0.84-1.06)	.31	0.97 (0.80-1.18)	.77
Delayed care				
Delayed surgery: yes (reference: no)	0.40 (0.12-1.31)	.13	3.69 (1.06-12.90)	.04
Delayed seeing a doctor: yes (reference: no)	1.24 (0.60-2.57)	.57	1.78 (0.62-5.09)	.29
Delayed dental care: yes (reference: no)	2.05 (1.04-4.03)	.04	3.08 (1.07-8.87)	.04
Delayed other care: yes (reference: no)	2.02 (0.88-4.64)	.10	0.38 (0.07-2.12)	.27

[a]The number of observations was 697, log likelihood was −158.90, LR chi-square (19) was 95.88 (*P*<.001), and pseudo R-square was 0.2318.

[b]The number of observations was 437, log likelihood was −89.89, LR chi-square (19) was 44.01 (*P*<.001), and pseudo R-square was 0.1966.

Discussion

Principal Results and Comparison to Prior Work

This study used national representative survey data from the HRS and aimed to (1) assess the prevalence of depression and delayed care among US middle-aged and older adults during the COVID-19 pandemic and (2) examine factors associated with depression among those 2 age groups during the pandemic, and particularly investigate the association of delayed care with depression. This study is the first to examine and compare the association of delayed care with depression among middle-aged and older adults in the United States during the COVID-19 pandemic.

Depression and Delayed Care

For the first aim, this study found that 274 (8.7%) participants reported symptoms for depression. Using different measures for depression, previous studies have reported high depression levels among US adults during the pandemic [8-11]. Two studies compared 2 nationally representative surveys of US adults, and both concluded that depression levels measured by the PHQ (PHQ-2 or PHQ-9) were higher during the pandemic than in 2017-2018 [6,7].

This study also found that about 17% of participants delayed seeing a doctor and about 20% of participants had delayed dental care, while few participants had delayed surgery and other medical care. Although statistics of delayed care among the same sample before the pandemic are not available, a recent study reported that emergency department visits significantly declined after the declaration of the COVID-19 national emergency [24]. A web-based survey in June 2020 reported that 40.9% of US adults delayed medical care since the pandemic, with 12% delaying emergency care and 31.5% delaying routine care [25]. The most common reason for delayed care in this study was that the clinic/hospital/doctor's office cancelled, closed, or suggested rescheduling. A previous study also suggested that the increased delayed care might be associated

with the social distancing policy or participants' concerns about COVID-19 [23].

Association of Delayed Care With Depression

With regard to the second aim, delayed dental care was positively associated with depression in both middle-aged and older adults. This relationship was not documented in previous studies. Considering the positive relationship between untreated or undertreated pain and depression, delayed dental care might be linked to depression through pain caused by dental issues. A previous study also reported that dental pain was positively associated with depression [39]. Another study also suggested that having an oral health condition was positively linked to depression among adults [40]. Moreover, delayed surgery was positively related to depression among older adults but not middle-aged adults. Only a single previous study examined the association between delayed care and depression during the pandemic [26]. Recent studies indicated that untreated or undertreated pain from delayed medical care might be prevalent during the pandemic [27,28]. Meanwhile, a previous study reported that patients experienced higher levels of depression during a 3-month wait time for pain treatment than when their pain was treated [29]. Given the strong link between depression and pain, Kaiser pointed out that delayed surgery that would reduce pain and suffering during the pandemic might make patients' conditions worse and increase depression [41]. Compared to middle-aged adults, older adults reported more chronic physical conditions, which might explain the higher demand on surgery among older adults and the insignificant relationship between delayed surgery and depression among middle-aged adults.

Other Factors Associated With Depression

This study also found that self-reported pain was positively linked to depression among both age groups. The positive relationship between pain and depression was also frequently reported in previous literature [42-45]. Patients with pain might experience undertreatment of pain or untreated pain during the pandemic [27,28], which was found to be associated with significantly higher depression levels compared to when the pain was treated [29]. In addition, education, self-reported health status, and financial difficulty were significantly associated with depression only among middle-aged adults, while perceived more loneliness was significantly related to depression only among older adults. Middle-aged adults with higher educational levels (some college or above) were more likely to have depression in this study, which is not consistent with previous studies that reported a negative relationship between educational levels and depression [46,47]. This inconsistent finding implies that middle-aged adults with higher education might be impacted by the pandemic disproportionally, though the path is not known yet. Middle-aged adults reporting worse health were more likely to have depression, which is consistent with previous studies [48-50]. Moreover, middle-aged adults with higher levels of financial difficulty had a higher risk of depression, which is in line with previous studies that were conducted among general US adults during the pandemic [9,51,52]. While younger adults

or middle-aged adults might lose their jobs during the pandemic and face financial difficulty because of unemployment, older adults aged 65 years or over are less likely to be in the labor force and therefore less likely to be impacted financially by the pandemic [53]. The study also found that older adults who perceived more loneliness during the pandemic were more likely to get depressed. This is consistent with previous studies, which indicated that perceived loneliness was positively associated with depression among older adults during the pandemic [54-56]. Although such a relationship was also documented by studies conducted among general adults [57] and younger adults aged 22 to 29 years [58], this study did not find a significant relationship between perceived more loneliness and depression among middle-aged adults.

Limitations

There were several limitations in this study. First, the cross-sectional design of this study was not able to examine the causal effect of delayed care on depression during the pandemic. Second, delayed care was simply measured by 4 yes-or-no questions, and the details of delayed care, such as the urgency of the care needed and how long the care was delayed, were not known. More comprehensive measurements for delayed care are needed in a future study to examine the path through which delayed care is associated with depression. Third, the data collection for this study happened during fall and summer 2020, while the peak of COVID cases/deaths occurred during winter 2020-2021 (November 2020 to January 2021) [59]. Therefore, the delayed care during the pandemic might have been underestimated.

Implications for Practice and Research

While previous studies focused on examining depression among younger adults or general adults during the pandemic [7,9-14,38,52], this study found that depression was also prevalent among middle-aged and older adults during the pandemic. Delayed surgery was positively associated with depression among older adults, and delayed dental care was significantly associated with depression among both middle-aged and older adults. Despite the limitations, this study has several implications for future practice and research. First, literature regarding the association of delayed care with depression during the pandemic is limited, and future research that uses more comprehensive measurements for delayed care is needed to decode the path through which delayed care is associated with depression. Second, this study highlighted the collateral damage of the COVID-19 pandemic by identifying the association of delayed surgery and dental care with depression during the pandemic, which provides evidence for the assessment of the indirect effect of the COVID-19 pandemic on non-COVID–related health [23]. Third, although surgery and dental care cannot be delivered by telehealth, telehealth services can still be provided to address patients' concerns on delayed surgery and dental care. Moreover, the implementation of telemental health services is needed to address mental health symptoms among US middle-aged and older adults during the pandemic [26].

Authors' Contributions

YL contributed to the study conception and design, data analysis and interpretation, manuscript preparation, manuscript review, and manuscript editing.

Conflicts of Interest

None declared.

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Abbreviations

CIDI-SF: Composite International Diagnostic Interview-Short Form
EFTF: enhanced face-to face interviewing
HRS: Health and Retirement Study
MD: major depression
PHQ: Patient Health Questionnaire

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Review

Implementation of Unobtrusive Sensing Systems for Older Adult Care: Scoping Review

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Abstract

Background: The continuous growth of the older adult population will have implications for the organization of health and social care. Potentially, in-home monitoring unobtrusive sensing systems (USSs) can be used to support formal or informal caregivers of older adults, as they can monitor deviant physical and physiological behavior changes. Most existing USSs are not specific to older adult care. Hence, to facilitate the implementation of existing USSs in older adult care, it is important to know which USSs would be more suitable for older adults.

Objective: This scoping review aims to examine the literature to identify current USSs for monitoring human activities and behaviors and assess their implementation readiness for older adult care.

Methods: We conducted a structured search in the *Scopus*, *Web of Science*, and *ACM Digital Library* databases. Predefined inclusion criteria included studies on unobtrusive sensor-based technology; experimental in nature; aimed at monitoring human social, emotional, physical, and physiological behavior; having the potential to be scalable in in-home care; and having at least 5 adults as participants. Using these criteria, we screened studies by title, abstract, and full text. A deductive thematic analysis based on the Proctor implementation framework along with an additional outcome of *external validity* was applied to the included studies to identify the factors contributing to successful implementation. Finally, the identified factors were used to report the implementation readiness of the included studies for older adult care.

Results: In this review, 52 studies were included. Deductive analysis using the implementation framework by Proctor resulted in six factors that can contribute to the successful implementation of USSs in older adult care: study settings, age of participants, activities monitored, sensor setup, sensing technology used, and usefulness of USSs. These factors were associated with the implementation outcomes as follows: study settings and age of participants contributed to external validity, sensor setup contributed to acceptability, usefulness of USSs contributed to adoption, activities monitored contributed to appropriateness, and sensing technology used contributed to implementation cost. Furthermore, the implementation assessment of the included 52 studies showed that none of the studies addressed all the identified factors. This assessment was useful in highlighting studies that have addressed multiple factors; thus, these studies represent a step ahead in the implementation process.

Conclusions: This review is the first to scope state-of-the-art USSs suitable for older adult care. Although the included 52 USS studies fulfilled the basic criteria to be suitable for older adult care, systems leveraging radio frequency technology in a no-contact sensor setup for monitoring life risk or health wellness activities are more suitable for older adult care. Finally, this review has extended the discussion about *unobtrusiveness* as *a property of systems that cannot be measured in binary because it varies greatly with user perception and context*.

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Introduction

Background

The older adult population has been increasing at an alarming rate over the past few years. According to the United Nations World Population Prospect Report, the population of people aged ≥65 years will approximately double, rising from 9% in 2019 to 16% in 2050. Consequently, by 2050, 1 in 4 persons will be aged ≥65 years in Europe and Northern America [1]. This anticipated growth of the older adult population will have a direct impact on the economy, employment, social care, and health care services worldwide [2,3]. With increasing age, older adults become more prone to fatal diseases, mandating continuous care by formal (trained professionals) or informal (family, friends, and relatives) caregivers. Most older adults prefer to stay in their own homes, which increases the burden on informal caregivers [4]. Owing to this, detrimental effects on the physical, emotional, and social well-being of caregivers have been observed [5,6]. Thus, to provide continuous care without burdening informal caregivers and adhering to the needs of older adults, intelligent in-home monitoring technological solutions are proposed and demanded [7-9].

Many in-home monitoring technological solutions that can recognize various physical and physiological human activities have been designed and evaluated. The most common human activity recognition (HAR) solutions include (1) wearable sensing systems (eg, smartwatches, smart clothing, and mobile phones), (2) vision-based systems (eg, surveillance cameras and Kinect), and (3) radio frequency (RF)–based sensing systems (eg, Wi-Fi, radar, and wireless sensors embedded in daily-use objects). The aforementioned solutions have the potential to assist caregivers, but most of them are not favorable for older adult care. *Wearable sensing systems* have acceptability issues because wearing monitoring devices all the time leads to feelings of stigmatization in older adults [10]. Wearables also have feasibility issues when used by older adults with cognitive impairments as they might forget to wear them [11]. *Vision-based systems* require users to be in their line of sight (LOS) and are consequently prone to privacy and ethical issues [12]. *RF-based systems* overcome the disadvantages of wearables and vision-based systems [13]. Potentially, RF systems could be considered more privacy aware than vision-based systems, as the raw data are not easily interpretable by humans and require complex data processing. Most importantly, they are *unobtrusive*, such that the user does not have to wear the device (device-free sensing) for continuous monitoring and can operate in a non-LOS (NLOS) region, thus making them more suitable for older adult care [4].

With the advancement in technology, the meaning of *unobtrusive* has evolved. Initially, wearables were labeled *unobtrusive* as they are noninvasive to the human body [14]. Currently, the possibility of using sensing systems far away from the human body (device free) for HAR is being explored and such systems are now referred to as unobtrusive systems [15]. This shift in the interpretation of *unobtrusive* as per convenience is because of the lack of a consensus definition or framework for unobtrusiveness. To eliminate the existing biases regarding the meaning of *unobtrusive*, the dictionary meaning was used in this paper. According to the dictionary, unobtrusive means "not noticeable or seeming to fit in well with the things around or something that does not draw attention" [16,17]. Evolving from this meaning, a sensor-based technology that does not draw the user's attention or demand their direct involvement, while blending well with the surroundings, can be termed as an unobtrusive sensing technology (UST). The systems that leverage such technologies were considered as unobtrusive sensing systems (USSs) and included in this study. For example, in a study by Adib et al [15], radio wave sensors were used as a UST to determine the physiological activities (heart rate [HR] and breathing rate [BR]) of healthy human subjects. Similarly, Wi-Fi channel state information used to detect physical activities such as walking, sitting on a chair, and falling can be considered as UST [18]. In line with the aforementioned definition and the conceptual framework for obtrusiveness by Hensel et al [19], wearables, smartphones, camera-based systems, and any systems that require direct human contact are categorized as obtrusive sensing systems. It should be noted that unobtrusiveness does not account for the privacy and sustainability aspects (specifically for this study).

In the past few years, the focus of sensing research has shifted toward unobtrusive sensing specifically to support older adults, patients, and disabled persons. As a result, intelligent state-of-the-art USSs are being developed with the aim of supporting independent living by leveraging different USTs (RF identification, infrared [IR], and channel state information) for HAR and health monitoring. The European technology readiness level (TRL) scale can be used to measure the maturity and hence implementation possibilities of state-of-the-art USTs [20]. A few of the available USTs were translated to commercial products, such as AbiSensor [21] (TRL 7/9), or some are in real-life demonstration phases, such as the Gator Tech smart house, MavHome prototype, etc (TRL 5/7) [22,23], and can thus be seen as an initiative to use USSs in older adult care. Finally, most of the advanced technologies are still in the exploratory and validation phases. For example, radar-based systems were developed for monitoring activities of daily life and vital signs but tested in controlled laboratory settings with young adults (TRL 2/4) [15,24-29]. The available state-of-the-art UST research or prototype (TRL 2/4) can also be used to support older adult care, given their effective implementation process. In this regard, this study aims to bring forward exploratory technologies and systems in TRL 2/4, as they are not widely adopted by current health care organizations or older adult homes despite their possible benefits.

Ideally, a successful implementation process incorporates the user's needs and perspectives (accounts for acceptability) [30], evaluates the technical maturity of systems (accounts for reliability) [31], and undertakes challenges faced by prospective industries or organizations (accounts for feasibility) [32,33].

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Thus, with the development of UST, parallel research on its effective implementation is required [34]. To facilitate the implementation process in health care, frameworks such as NASSS (nonadoption, abandonment, scale-up, spread, sustainability) are popular and effective [35]. It can be used to preassess the technology for implementation after its development. However, to make the development implementation aware, the psychometric and pragmatic implementation constructs or outcomes that serve as preconditions for achieving intended results or changes should be considered from the development phase itself [36]. For this, basic frameworks such as the one by Proctor et al [37] can be used. This framework uses eight distinct implementation outcomes—acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability—encompassing the implementation process, success, and outcomes; hence, it could be used to make early-stage technologies, such as UST, implementation aware.

Objectives

Along with the development of new technologies, existing state-of-the-art technologies could be made implementable to facilitate and accelerate the process of using USSs in older adult care. To achieve this, a consolidated overview of existing research on USSs followed by an evaluation of their implementation readiness is required. Therefore, first, this study aims to identify existing research or validation phase studies using USSs and their underlying technologies for monitoring physical, physiological, and emotional behavior changes or activities of human adults that are suitable for older adult care through a scoping review. Second, the study aims to evaluate them for implementation readiness using the framework by Proctor et al [37] for facilitating and accelerating their use in older adult care. In addition to the framework by Proctor et al [37], *external validity* was added as a relevant outcome, considering the novelty and technical nature of USSs [38].

Methods

Overview

As the technology is developing rapidly, a time-bound scoping review was conducted [39]. The review followed the five stages of the methodological framework for scoping reviews by Arksey and O'Malley [40]. These stages were (1) identifying the research question (Introduction section); (2) identifying relevant studies (*Identifying Relevant Studies* section); (3) selection of relevant studies (*Selection of Relevant Studies* section); (4) charting the data obtained from selected literature (*Data Extraction* section); and (5) collating, summarizing, and reporting the results (*Results* section). Two researchers were involved in the review process. The primary researcher (NS) was responsible for title, abstract, and full-text screening of the identified literature, followed by data extraction and manuscript writing. To ensure the quality of the review, the second reviewer (JKB) carried out 25% of full-text screening, followed by writing and evaluating parts of the *Results* sections.

Identifying Relevant Studies

This review required technical literature with its application in social science. Therefore, three electronically available databases, Scopus, Web of Science, and ACM Digital Library, including papers from both engineering and social science fields, were explored. A search string for identifying existing USSs was formed. The search string was finalized after discussion with an information specialist from the Faculty of Behavioral, Management, and Social Sciences at the University of Twente. The search string was divided into five sets: type of system, type of technology, type of user, type of behavior or activity, and type of observation. The keywords used are presented in Table 1.

Table 1. Keywords for the search string.

Sets of keywords	Search words
Type of systems	*Unobtrusive*, *Nonintrusive*, *Non-wearable*, *Contactless*, *Wireless*
Type of technology	*Sensing technology*
Type of users	*Human adults* (this by default includes older adults)
Type of activity or behavior	*Social*, *Emotional*, *Physical*, *Physiological*
Type of observation	*Recognition*, *Detection*, *Monitoring*, *Tracking*

We found a total of 3157 research articles by using a search string composed of these keywords (Scopus: 1171; Web of Science: 1524; and ACM Digital Library: 462). The search strings are provided in Multimedia Appendix 1. The search included the title, keywords, and abstracts from January 2011 to March 2020 (last decade). The time span was limited, as we aimed to identify state-of-the-art USTs (time-bound scoping review). No other search limitations were imposed.

Selection of Relevant Studies

The title, abstract, and full-text screening was conducted using the web-based software platform Covidence [41]. To systematically report the process of identified articles, the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidelines extension for scoping reviews were used [42]. For the title, abstract, and full-text screening, the inclusion and exclusion criteria were defined considering the use of USSs in older adult care. Textbox 1 details the inclusion and exclusion criteria.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria

- Sensor-based technology but unobtrusive in nature

- Experimental studies demonstrating practical application of technology (including laboratory or field testing)

- Studies with the aim of monitoring, detecting, recognizing, or tracking human social, emotional, physical, and physiological behavior

- Studies that can be applied in in-home care or showing or possible applications in health care (such as monitoring vital signs)

- Studies with human adults as participants (≥18 years)

Exclusion criteria

- Wearables, smart phone–based systems, and camera-based systems (labeled as *Obtrusive systems* in Figure 1)

- Review papers and qualitative studies (labeled as *qualitative studies* in Figure 1)

- Studies suggesting only algorithmic, hardware improvements and papers with different aims then desired (labeled as *Different Context* in Figure 1)

- Sensor-based technology that are used in a wide range of domains such as environment monitoring, driver behavior monitoring, etc (labeled as *Different Context* in Figure 1)

- Studies on infants and animals (labeled as *Wrong target group* in Figure 1)

First, from 3157 papers, 382 duplicate papers were removed, and the remaining 2775 unique papers were used for title screening. Using the aforementioned inclusion and exclusion criteria in title screening, 2263 studies were excluded, and 512 studies were selected for the abstract screening step where another 330 articles were excluded, resulting in 182 studies for full-text screening. Among the excluded 330 studies, most studies (n=203) used obtrusive sensing (mobile based or vision based) systems and 95 studies had different contexts than the aim of this review. For full-text screening of 182 studies, two additional inclusion and exclusion criteria were added by discussing with all the authors. These criteria aimed to filter studies with inadequate evidence for upscaling them in older adult care. The additional inclusion and exclusion criteria are detailed in Textbox 2.

Textbox 2. Additional inclusion and exclusion criteria.

Inclusion criteria

- The performance of a system should be scalable and competent with state-of-the-art systems, that is, the accuracy or equivalent measure of the proposed system should be more than 80%.

- Number of participants should be greater or at least equal to 5 (N≥5).

Exclusion criteria

- Papers having low performance (or accuracies or other equivalent measure; labeled as *Unscalable* in Figure 1).

- Papers that have tested the systems with less than 5 participants (labeled as *N<5* in Figure 1).

Finally, out of 182 research articles, 52 articles were found relevant and were added in this scoping review upon agreement between reviewers NS (reviewed all 182 studies independently) and JKB (reviewed 46 studies independently). Studies with discrepancies were discussed until a consensus was reached. Interreviewer reliability was calculated using the Cohen κ coefficient. The Cohen κ for 25% of full-text articles was 0.81, which indicates almost perfect agreement between reviewers [43]. Among the excluded 130 studies, most were in the category of obtrusive systems followed by different contexts (both labeled as *Others* in Figure 1), participants less than five, and unscalable systems. Figure 1 (PRISMA flow diagram) illustrates the step-by-step flow of information through different phases of study selection. All of the aforementioned steps were continuously discussed and reported by the primary researcher with the research committee.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) flow diagram.
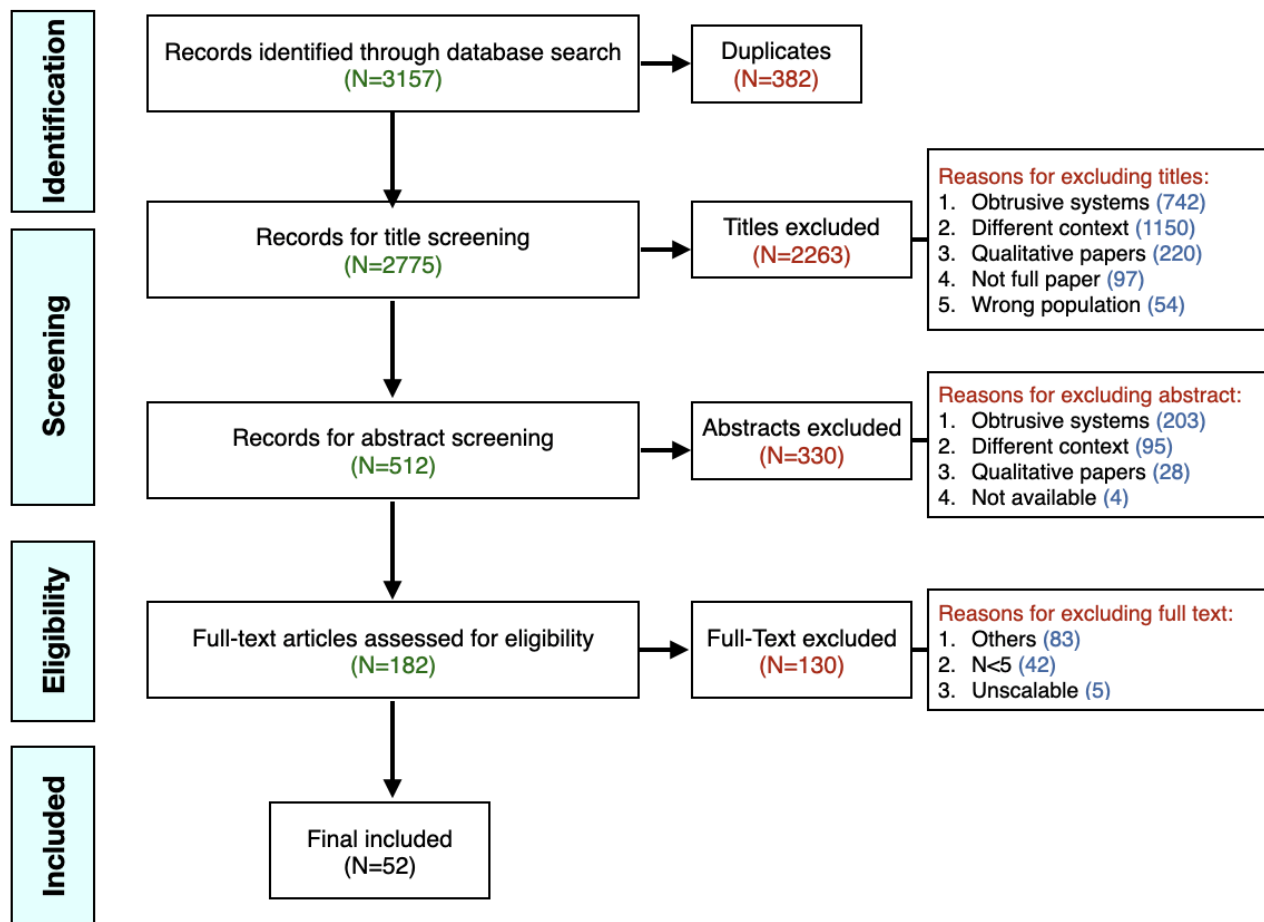
Data Extraction

Descriptive analysis was used to chart the key information of the 52 USS studies, including general study description elements: study aim, study design, study settings, participant information, and the main results. In addition to general study description elements, technological description elements, including activity or behaviors monitored, sensor used, and data analysis methods, were also added. The obtained information is presented in Multimedia Appendix 2 [11,15,18,24-29,44-86].

The implementation outcomes defined in the framework by Proctor et al [37] were used to evaluate the implementation readiness of 52 identified USSs for older adult care (RQ2). The eight conceptually distinct implementation outcomes—acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration or coverage, and sustainability—are helpful in understanding and conceptualizing

the implementation process, success, and outcome. Considering that USSs are still in the developing stage, implementation outcomes that belong to early- to midstage implementation (acceptability, adoption, appropriateness, and implementation cost) were used [37]. Furthermore, an additional outcome, external validity, which can contribute to the early implementation stage was added [38]. These outcomes were translated according to the older adult care context (Textbox 3). Next, a deductive thematic analysis [87] based on the translation of the framework by Proctor et al [37] was performed on the 52 studies to identify factors (or themes) that can contribute to the successful implementation of USSs. Furthermore, textual analysis was performed within the identified themes to identify the subthemes. These key factors are elaborated as key themes in the *Results* section. Finally, the included studies were assessed on the basis of identified factors for implementation readiness. The Atlas.ti software (8.4.5) was used for deductive and textual analyses [88].

Textbox 3. Implementation outcomes and their translation for older adult care.

External validity

- Meaning: it is the extent to which the results of a study can be generalized to and across other situations, people, stimuli, and times [38,89].

- Translation: for older adult care, a study should provide valid results in older adult homes and with older adults. Therefore, studies that were performed in appropriate settings (real-life settings) and with the intended age group of participants (older adults) have checked external validity [90].

Acceptability

- Meaning: the perception among stakeholders that an intervention is agreeable or fit with user's expectations [37,91].

- Translation: for older adult care, the acceptance of any new technology is related to ease with which it can be integrated in their lifestyle, hence they require systems which provide them freedom without continuously bothering them [14,90]. Therefore, sensors which provide user freedom to roam around without wearing it or staying in the line of sight might have more chances of acceptance by older adults.

Adoption

- Meaning: the intention, initial decision, or action to try to use a new intervention [37,91].

- Translation: the process of adoption begins with the intention of research. In this review, more than 50% of included studies discussed the advantages of their USS for older adult care. This indicates the intention or possibility to use their intervention for older adult care.

Appropriateness

- Meaning: the perceived fit or relevance of the intervention in a particular setting or for a particular target audience or problem [37,91].

- Translation: in older adult care, activities monitored are of interest and value from the perspective of stakeholders such as formal or informal caregivers, older adults, and involved organizations (such as older adult homes and participating companies). Therefore, studies that monitor activities relevant to older adult care are more appropriate [9].

Implementation cost

- Meaning: it encapsulates cost of intervention, implementation strategy, and the location of service delivery [37,91].

- Translation: the cost of implementation involves the cost of systems, efforts, and time required to install the systems. Thus, to implement USSs in older adult care, studies using technologies that require minimum cost for deployment, maintenance can be considered [4].

Results

Overview

An overview of the included 52 studies is provided in Multimedia Appendix 2. From this, it can be observed that most of the research in the field of USSs was conducted in the last 5 years (44/52, 85% of studies were from 2015 to 2019). Moreover, the geographical locations of these existing research studies show that most of the studies were conducted in Asia (20 studies), followed by North America (19 studies), Europe (12 studies), and Australia (1 study).

From deductive thematic analysis based on implementation outcomes by Proctor et al [37], 6 key factors that can contribute to successful implementation were identified: *sensor setup, study settings, age of participants, type of activities monitored, sensing technology used, and usefulness of unobtrusive systems*. The implementation outcomes were associated with these factors as follows: study settings and age of participants contribute to external validity, sensor setup contributes to acceptability,

usefulness of USSs contributes to adoption, activities monitored contribute to appropriateness, and sensing technology used contributes to implementation cost. The detailed explanation of factors, the associated implementation outcome, and the corresponding subthemes identified by textual analysis is elaborated in the *Key themes: Factors contributing to implementation* section. Finally, the results of the assessment of the identified studies for implementation readiness are presented.

Key Themes: Factors Contributing to Implementation

Theme 1: Sensor Setup

Overview

The sensor setup can be referred to as an arrangement of sensors in the user's surroundings. The studies included in this review were unobtrusive in nature. Within unobtrusive sensing, two broad patterns in the sensor setup were identified: (1) *no-contact sensor setup* and (2) *indirect contact sensor setup.* Table 2 lists the identified studies into these categories.

Table 2. Sensor setup.

Sensor setup: arrangement of sensors or sensing units	Included studies
No-contact sensor setup	
One or a couple of sensors or sensing units placed at a reasonable distance from the user (~3-9 m) and operates in NLOS[a] scenarios	[15,18,24-26,28,29,44,45,53,60,68,72,77,78,80,82]
One or a couple of sensors or sensing units placed close to the user (approximately 0.5-3 m) and evaluated in only LOS[b] or close proximity scenarios	[11,27,50-52,56-59,62,64,65,69,71,75,76,79,81,83,85,86]
Sensors or sensing units placed in surroundings objects such as on doors, fridge, walls, among others	[46,48,55]
Indirect contact sensor setup	
One or a couple of sensors or sensing units embedded in daily-use objects such as mattress, chair, floor tiles, among others. Require user to be in indirect contact with respective objects	[47,49,54,61,63,66,67,70,73,74,84]

[a]NLOS: non–line of sight.

[b]LOS: line of sight.

No-Contact Sensor Setup

It can be seen as a single sensing unit consisting of either a single sensor or an assembly of heterogeneous sensors capable of gathering a subject's intended activity data from a distance. Within the no-contact sensing system, three patterns based on the number of sensors and the distance of operation were observed:

1. Sensor setups with only one or a couple of sensors or sensing units placed at a distance between 3 and 9 m and can operate in NLOS: systems that have this type of sensor setup are potentially unobtrusive because of their larger coverage and easy deployment as the device is compact in nature. Such systems can be placed in the corner of a house or room (almost unnoticeable), and desirable results can still be obtained. For example, the FMCW (frequency modulated continuous wave) radar was used to track an individual's walking gestures beyond the wall or at approximately 9 m [44]. Among the 52 included studies, 17 were identified in this category.

2. Sensor setups with only one or a couple of sensors or sensing units but tested for smaller distances 0.5-3 m in LOS or close proximity: this category includes studies that were tested at a limited distance with the possibility of scaling up by evaluating them at larger distances. For example, a contactless sleep-sensing system was developed to continuously track sleep quality using commercial off-the-shelf radar modules [69]. The system was placed at a distance of 0.5 m from the user in the experiments. More experiments at larger distances or modifications in this system can be carried out to upscale the system. A total of 21 such studies were found.

3. Sensor setup with a number of sensors or sensing units mounted on surrounding objects at multiple locations and works only when the user is in LOS: this type of sensor setup enables close and accurate monitoring of individuals when in the LOS of the sensors. Higher accuracy makes these systems more reliable, but unobtrusiveness is compromised as they have to be mounted on multiple locations in close proximity to the user. They might face implementation challenges as they require planning according to the house structure or permanent and prominent changes to the environment. For example, a sensing environment was created by placing 15 different sensors across the house of an older adult. These sensors were placed on different day-to-day appliances, such as pressure sensors on doors and motion sensors on walls [46]. Most such studies include wearables as a part of systems and were omitted from the review. Only three studies were included in this category.

Indirect Contact Sensor Setup

In these types of setups, a couple of sensors or sensing units are embedded inside the furniture or any other daily-use object. They require indirect contact (users to use them) to obtain the intended activity data. For example, a smart mattress in a study [67] with sensors was developed to measure the BR and HR of the person sleeping on it. The sensors were placed inside to make the system more esthetic and user friendly. Such a system can have disadvantages when daily cleaning is required, such as in older adult care homes [50]. They are also unobtrusive, but the degree of unobtrusiveness varies with user needs and context. In this review, 11 such studies were identified.

Sensor Setup Contributes to Implementation Outcome Acceptability

Acceptability of technology in case of older adult care is understood as the ease with which technology can be used or integrated in the day-to-day lives of older adults [4,92]. Therefore, systems that allow device-free monitoring might be more acceptable for older adult care as they can be integrated in their lives without disturbing them. Within device-free sensing, no-contact and indirect contact sensor setup were found (Table 2). Both can be acceptable, depending on the needs of older adults, use cases, among others. For example, when an older adult is sitting and watching television, a cushion that can record vital signs can be helpful; however, when they are walking, the cushion will not be helpful. In this case, a sensing system that has a no-contact sensor setup is more feasible. Within this also, it is desirable to be able to monitor at the maximum possible distances, so that only a few sensor units

are sufficient for a house. Many of the included studies have tested up to the range of approximately 9 m, such as in the study by Hsu et al [53], where the walking of older adults is monitored to reflect various health issues or injuries. This study, along with external validity, conducted an acceptability study with the same participants, which showed a high rate of acceptance. This indicates that sensing systems with no-contact sensor setup tested in the range of approximately 3-9 and NLOS scenarios might be more acceptable for older adult care. However, no study other than the one by Hsu et al [53] reported conduction of acceptability testing.

Theme 2: Study Settings

Overview

The study settings encompass the type of environment used for conducting the experiments. Usually, sensor-based studies are conducted in empty rooms or laboratory setups (to observe the basic behavior of the sensors), rooms with some furniture (to validate the sensor in comparatively realistic situations), and in actual or simulated home settings (to evaluate the sensor in real-life situations). As per the observed pattern in the included studies, studies are categorized as (1) *laboratory setting with basic furniture* (including office environments and corridors) and (2) *real-life setting* (including simulation home, actual homes or apartments, and hospitals). In Table 3, studies are arranged on the basis of these two categories.

Table 3. Study settings.

Study settings	Included studies
Laboratory setting	[15,24-29,44,45,50,51,58,61,62,64,65,71,74-79,82,85,86]
Real-life settings	[11,18,25,46-49,52,53,55,57,59,60,68,69,72,80,81]
No information given	[54,56,63,66,67,70,73,83,84]

Laboratory Settings

For HAR, it is common to test the proposed systems or technology in a controlled environment before moving toward more realistic scenarios. These controlled environments are called laboratory settings. In this study, researchers tested the system with a specific experimental paradigm in a less complicated environment using healthy human participants. From such experiments, basic observations about the system or probability of using technology in HAR can be drawn, but it does not make the system compatible for implementation in real-life scenarios. For example, a high accuracy of vital signs was achieved when monitored in a controlled environment (ie, participants sitting silently very close to the device in an empty room), but as soon as the settings were changed (ie, basic furniture was introduced or distance or angle between device and participant is changed), the accuracies were negatively affected [80]. It has been observed that 50% (26/52 studies) of the studies included in this review used laboratory settings to evaluate their systems.

Real-life Settings

This represents the settings that are the actual use cases for the system. Specifically, in the case of device-free sensing because of the multipath propagation (the propagation of radio signals by using more than one or direct LOS path), testing in more realistic scenarios is required. Most of these systems are dependent on machine learning algorithms for data analysis,

which requires a large quantity and variety of data to produce accurate results. Thus, testing the systems with more participants and in different settings increase the robustness and reliability of the system. For example, participants' houses were used to test the radar system for monitoring sleep [52,59,69]. Using real-life settings for the evaluation of systems brings them a step closer to the implementation process. Here, 17 such studies were found.

Furthermore, it was observed that most studies that have used an indirect contact sensor setup have not provided information on study settings. This is because they require the user to use them to monitor them and are less, or not at all, affected by surroundings, unlike radio signals (device-free sensing). Of the 52 studies, 9 did not provide information on the study settings.

Theme 3: Age of Participants

Overview

This review includes USSs that were tested with adults (age: 18 years or older), including both early adults (18 years<age<55 years) and older adults (age>55 years). Among 52 studies, 2 tested older adults, 8 tested both older adults and young adults, and 21 tested their systems with early adult populations. The remaining 21 studies did not provide any information on the age of participants except mentioning that *experiments were done with adults*. Table 4 categorizes the studies based on the age groups of the participants.

Table 4. Age group of the participants.

Age group of the participants (years)	Included studies
>55	[46,50]
18-55	[15,25-29,45,52,54,57,58,63,65-67,73,75,77,79,84,86]
18-55 and >55	[44,47,53,59,72,76,78,85]
Adults >18 (exact information on age is missing)	[11,18,24,48,49,51,55,56,60-62,64,68-71,74,80-83]

Study Settings and Age of Participants Together Contribute to Implementation Outcome External Validity

External validity is a step ahead of validity in a laboratory setting. Specific to older adult care, the technology or system needs to be validated in older adult homes with older adults. Therefore, studies that have tested their systems with older adults and older adult homes can be assessed as studies with external validity.

Table 5. Activities monitored.

Type of activities	Included studies
Physiological activities	[27,29,45,47,51,54,61,67,70,76,81,84]
Physical activities	[11,15,18,24,26,28,44,48,49,53,55-57,62,64,66,68,74,75,77-79,82,86]
Both physiological and physical activities	[25]
Behavior from physiological activities	[60,65,80,85]
Behavior from physical activities	[46,50,52,58,59,63,71,72,83]
Behavior from both	[69,73]

Physiological States or Activities

Within the HAR, vital signs are the most researched physiological states. By daily monitoring of vital signs, chronic illnesses (cardiovascular and respiratory disorders) can be diagnosed early [93]. This is important from the viewpoint of older adult care. Various diseases occur with age, and if they are diagnosed early, prevention can be taken on time, hence improving the quality of life of older adults. By using the USS, HR and BR were monitored. In addition, BCG signals and blood pressure were also monitored [84]. In this review, 12 studies were identified that monitored only physiological states, whereas some studies monitored behaviors from physiological states, such as vital signs to monitor cognitive load, emotional state, and sleeping behavior [60,65,80,85]. Interestingly, it can be observed that most systems used for monitoring physiological states were of an indirect contact sensing setup. This is because physiological activities such as HR and BR are movements in the range of millimeters, which is difficult to capture with wireless signals. In this review, seven studies also monitored HR and BR using a no-contact sensing setup.

Physical Activities

Physical activities are defined as bodily movements produced by skeletal muscles that result in energy expenditure, for example, activities of daily living (ADL; eg, walking, sitting, and eating) [92]. Similar to physiological activities, a decline in physical activity also indicates cognitive impairments and other disorders. Using USSs to monitor ADLs, various emergency situations, such as falls, can be easily tracked. Among the 52 included studies, 24 recognized or monitored physical activities, whereas nine used physical activity to monitor behaviors such as sleep, water drinking, seizure, and cognitive impairment.

Theme 4: Activities Monitored

Overview

As per the included studies, two major types of activities or behaviors were measured, detected, monitored, or recognized using USSs: (1) physiological states (or activities) and (2) physical activities. Only a few studies have extended work in monitoring behaviors from activities, for example, measuring sleep quality using HR and BR. Table 5 lists the studies in these two categories.

Combination of Physical and Physiological Activities

By monitoring both these activities, more crucial and accurate behaviors can be predicted. For example, in sleep scenarios, measuring vital signs and tracking the body posture can result in a more accurate diagnosis of sleep disorders. In this review, one study explored monitoring both activities [25], whereas two studies simultaneously monitored vital signs and body movements to estimate sleep quality (behavior) [69,73].

Activities Monitoring Contributes to Implementation Outcome Appropriateness

In this review, the included studies monitored diverse behaviors or activities. For older adult care, it is important to monitor activities that are relevant to various stakeholders. For example, a system that can unobtrusively detect what a person is typing on a keyboard is of no use for older adult care, whereas systems that can unobtrusively monitor falls, personal hygiene, and sleep patterns are more useful for older adult care [9].

Theme 5: Sensing Technology Used

Overview

The sensing technology used in USSs can consist of different types of heterogeneous sensors. The type of sensing technology used determines the different sensor setups. Usually, for a *no-contact sensor setup*, electromagnetic or acoustic spectra are commonly used because they require a medium in which the impact of the event can be propagated. For *the indirect contact sensing setup,* various physical sensors (eg, biomedical, physical, and optical) that can transfer or translate the impact of activity can be used. Table 6 describes the sensing technology used in the included 52 studies.

Table 6. Sensing technology used.

Sensing technology used	Included studies
Electromagnetic spectrum	
Passive infrared	[46,64,83]
Radio frequency	
Radar	[15,24-29,44,45,52,53,55,65,69,75,81,85]
P2P[a]	[11,18,51,57-60,62,68,71,77-80,82,86]
Acoustic spectrum	[76]
Other technologies	
Biomedical sensors	[63,73]
Force sensors	[49,54,61,72]
Thermal sensors	[50,72]
Optical sensors	[47,67,70,84]
Capacitive sensors	[56,74]
Electrostatic sensors	[66]

[a]P2P: point-to-point.

Electromagnetic Spectrum

This technology consists of sensors that can monitor the environment and participants from a distance. Most of these systems are based on the electromagnetic spectrum (especially IR and radio waves). They can be further classified into IR- and RF-based technology:

- IR technology: it is used for short-ranged solutions (0.5-3 m) as a radar or a point-to-point (P2P) solution. Passive IR sensors are mostly used for HAR [46,64,83]. These sensors measure the IR light radiated by the objects. In this review, three studies that used passive IR were found.

- RF technology: this technology enables long-range solutions (3-9 m) and provides a higher resolution for more precise detection of small-scale human activities. This is because more fine-grained information can be collected with higher frequencies. Within RF technology, radar and P2P systems are often used. A radar system consists of one transmitter and at least one receiver at approximately the same location, making the system centralized. Often, the transmitter transmits a signal (an impulse or modulated wave), and the receiver collects different reflections of this signal. Among 52 studies, 17 such studies were found [15,18,24-29,44,45,52,53,65,69,75,81,85]. Alternatively, a P2P system can be used where the transmitters and receivers are separated in space, and thus decentralized. This review recognizes 16 studies that used P2P systems [11,18,51,57-60,62,68,71,77-80,86]. Radar-based solutions are often based on the LOS between the radar and the event or activity, whereas P2P systems are often based on the multipath propagation of a signal and are hence affected by the environment. The advantage of using a P2P system is that it can be used in NLOS environments (such as through-the-wall or behind-obstacle situations), whereas radar-based systems are often bound to direct LOS. However, radar-based systems often require less space (as

they are located in a single location) and can function more easily at higher frequencies (such as mmWave), resulting in a higher resolution for HAR. Another important aspect of RF technology is the difference between higher and lower frequencies, which are frequencies in the range of RF identification and Wi-Fi (around 2.4-5 GHz), and mmWave (over 20 GHz). Here, it can be seen that for vital sign monitoring (often while sleeping or sitting still), it is more common to use higher frequencies [27,29,80], as they are more suitable for distinguishing fine-grained movements such as heartbeats. For larger activities (such as ADLs), it is more common to use lower frequencies [57] because they are more robust (can travel further) and less susceptible to noise. However, it is important to note that these are not mutually exclusive: lower frequencies (around 5-7 GHz) can still be used to monitor vital signs [26,45,60], whereas higher frequencies may still be used for general HAR or ADL.

Acoustic Spectrum

Acoustic waves are another way to enable truly contactless sensing. Differentiation can be made between audible acoustic waves (sound), ultrasound, and infrasound. Ultrasound is often used for distance estimation (radar-based methods). A study [76] used off-the-shelf audio speakers capable of generating up to 23 kHz (giving a limited range [18-23 kHz] to sweep over before it becomes audible to humans or requires more expensive and specialized equipment) for respiratory rate monitoring [76]. Conversely, audible sound can be captured by regular microphones, which can consist of environmental sounds (footsteps or door slamming) or vocal parameters (eg, pitch or volume). Once the actual voice is used (words and sentences), it becomes more privacy intrusive; therefore, such studies were omitted from this review.

Other Technologies

In this review, various studies have used different types of physical sensors such as biomedical, physical, thermal, optical, capacitive, and electrostatic sensors for HAR. Although physical sensors require contact with the subject for sensing the activities, they were made unobtrusive in the included studies by placing onto or embedding them into the infrastructure and/or objects in the environment.

- Force sensors require a physical force to register the impact on the environment (eg, vibrations for an accelerometer, applying pressure to a pressure plate, and introducing mechanical or physical stress to the stress sensor). These sensors are often placed in the environment to make them unobtrusive. Examples include pressure plates under the floor [49], geophones [54], or accelerometers on doors or windows to detect open and close events.
- Biomedical sensors require contact with the user, as they measure biological and/or chemical processes in the human body (eg, electrocardiogram and ballistocardiograph [84]). Contact is often achieved by including them in objects that participants hold close to themselves, for example, a blanket [73], pillow, or mattress [63].
- Thermal sensors change their resistance with changes in temperature, and thus can be used to monitor temperature or temperature changes. These are usually combined in heterogeneous sensor boxes [72]. In addition, the radiated temperature can be sensed by creating a thermophilic sensor, which measures the temperature difference between two points [50].
- Optical sensors work with visible light or UV emissions (luminescence sensors). An interesting application of optical sensors is in fiber-optic sensors. Light refracts and reflects differently based on the properties of the fiber (bending, temperature, and acceleration) and can therefore be used in many settings. In this review, a study [67] used a fiber-optic sensor under a mattress to measure human vital signs, whereas another study [70] used one in a headrest.
- Capacitive sensors measure changes in capacitance through capacitive coupling. In this review, one study [74] used this method by applying an electrode to the floor (transmitter) and ceiling (receiver) to measure human height. In addition, electrostatic fields exist between differently charged objects or when an object is charged differently with respect to its environment. This is often the case with the human body, as friction between the body and clothing causes the body to become electrically charged. One study [56] used an electrode on a tripod to measure the effect of capacitive coupling. Another study [66] used a piezoelectric polymer known to emit electric fields when stress is applied. This polymer was applied to the floor and used to detect different floor-impact activities (such as walking with one or more people).

Sensing Technology Used Contributes to Implementation Outcome Implementation Cost

Implementation cost is one of the key factors affecting the implementation process. It involves the cost of systems, efforts, and time required to install the systems [38]. Thus, to implement USSs in older adult care, studies using technologies that require

minimum costs for development, deployment, and maintenance can be considered [14,94]. Technologies based on the electromagnetic spectrum require more extensive research for development, resulting in a higher cost for research and development compared with physical sensors (eg, force, biomedical, and thermal sensors). These sensors are more widely available and range in price but are often cheaper than RF-based technologies. However, these sensors are often limited in range and require multiple sensors to register events throughout a whole house setup (eg, sensors on doors or walls [46,72] or modified beds or blankets for all older adults in a care home [61,73]), and some sensors also require permanent and/or prominent structural changes to the environment (eg, implementing smart tiles [66] or adding sensors to the ceiling [46,74]), which adds additional costs to the actual implementation compared with RF-based technologies, which are often isolated boxes that offer a larger (whole house) coverage with a minimum amount of sensors [68]. For wide-scale adoption in older adult care, it is recommended to look for a solution by weighing the costs of development and deployment.

Theme 6: Usefulness of Unobtrusive Systems in Older Adult Care

Overview

The usefulness of unobtrusive sensing for HAR was obtained from the textual analysis of the included studies, especially in the context of older adult care. Out of 52 studies, 28 indicated or discussed the possible use or requirement of such a system in older adult care. These studies enlisted the various advantages of USSs for the older adults and their caregivers. From the perspective of the older adults, the included studies highlight that USSs are comfortable [18], do not require technical competency [25], are privacy aware, require less (to no) attention and compliance [72,75], are affordable [50], and can operate in NLOS situations [66,68]. From the perspective of caregivers, USSs are ubiquitous in nature [57], enable continuous monitoring [46], are easy to integrate [50], are prone to noisy environments [48], provide security [18], and are safe to use with older adults [47]. These systems are more reliable and promising for older adults affected with medical conditions such as cognitive impairment (dementia) because physicians have to rely on the caregiver's narratives for diagnosing such conditions. For example, a study [46] aimed to detect mild cognitive impairment through an unobtrusive sensing approach to avoid delay in recognition of cognitive impairments, as it can result in severe and/or permanent damage. Similarly, another study [71] demonstrated seizure detection via wireless sensing to ensure timely intervention by caregivers to reduce the risk of injury.

In addition to these extraordinary situations, USSs are also advantageous in monitoring a wide range of general physical activities and physiological behaviors to facilitate older adult care. For example, emotion detection by methods such as FMCW radar, as demonstrated by Zhao et al [85], can help in identifying early symptoms of anxiety or depression. Accidental falls are considered as the leading cause of death in the older adult population. They not only cause physical injury but also

affect physiological health. Owing to the fear of falling, most older adults limit their daily life activities, thereby impacting their quality of life. Studies [74,75] have used various USSs to ensure security by providing immediate assistance. Similarly, sleep monitoring studies [11,50,53,59,60,69,84] intended to measure the quality of sleep to promote good health by predicting sleep disorders and chronic heart diseases.

Usefulness of Unobtrusive Systems in Older Adult Care Contributes to Implementation Outcome Adoption

Adoption is intention, initial decision, or action to try a new technology. For older adult care, it can be seen as the intention of studies to use their systems in older adult care. Only a few of the included studies were specifically developed for older adult care. Other than these, most studies showed the intention or discussed the possible advantage of using their system for older adult care. Thus, such studies have more chances of adoption for upscaling in older adult care.

Implementation Readiness of Identified USS Studies for Older Adult Care

The six identified factors (or themes) corresponding to the early-to midstage implementation outcomes of the framework by Proctor et al [37] were used to evaluate the implementation readiness of USSs for older adult care. They were associated with the aforementioned factors as follows: study settings and age of participants contribute to external validity, sensor setup contributes to acceptability, usefulness of USSs contributes to adoption, activities monitored contribute to appropriateness, and sensing technology used contributes to implementation cost (Table 7). On the basis of this association, the implementation readiness of the included 52 studies was checked. Among the 52 studies, studies fulfilling the associated factors were presented in the column *studies fulfilling associated factors* of Table 7. These studies can be seen as more implementation-ready than others.

Table 7. Implementation readiness of unobtrusive sensing system studies for older adult care.

Implementation outcomes	Identified factors and themes contributing to implementation outcomes	Studies fulfilling associated factors or themes
External validity	• Study settings: studies tested in real-life settings (preferably older adult homes or at least in simulated homes) • Age of participant: studies performed with older adults (Age group: 55 years or older)	• [46,47,53,59,72]
Acceptability	• Sensor setup: studies with no-contact sensing setups (sensors placed at a reasonable distance, approximately 3-9 m from the user)	• [15,18,24-26,28,29,44,45,53,60,68,72,77,78,80,82]
Adoption	• Usefulness of USSs[a]: studies that showed the possible use of their system for older adult care	• [11,15,25-29,45,46,49,50,52,53,59,60,63,64,66-68,70,72-78]
Appropriateness	• Activities monitored: studies monitoring activities relevant to older adult care such as life risk activities (fall) and health wellness activities (sleep)	• Fall: [11,18,25,26,44,49,57,64,66,75,77,78] • Sleep: [46,50,52,59-61,63,69,73,80,81,83]
Implementation cost	• Sensing technology used: studies that require minimal permanent or prominent structural changes to the environment, are easy to adapt, and offer large coverage	• [18,26,44,50,57,58,60,68,77,80,82]

[a]USS: unobtrusive sensing system.

It can be observed that none of the studies have considered all the factors contributing to successful implementation for use in older adult care. Although all the included studies have the potential to be used in older adult care, currently only a few studies are implementation-ready (considering some trade-offs), and most of them require improvements and tailoring to older adult care scenarios. Out of 52 studies, only five studies [46,47,53,59,72] checked external validity of their systems in real-life settings with older adults, 17 studies [15,18,24-26,28,29,44,45,53,60,68,72,77,78,80,82] used a no-contact sensor setup that can be suitable for monitoring older adults without restricting their freedom, 28 studies [11,15,25-29,45,46,49,50,52,53,59,60,63,64,66-68,70,72-78] acknowledged possible use of their system for older adult care, 24 studies (monitoring falls [11,18,25,26,44,49,57,64,66,75,77,78] and sleep [46,50,52,59-61,63,69,73,80,81,83])

monitored activities or behavior relevant to older adult care, and 11 studies [18,26,44,50,57,58,60,68,77,80,82] used technology that requires minimal structural changes or are less expensive while implementing. As all the included studies are unobtrusive and have good accuracy, they can still be improved on the some or the other aforementioned factors for better implementation results. The study by Adib et al [44] can be considered as acceptable, appropriate, and implementation cost friendly, but it is not externally validated and was not designed considering older adult care. Similarly, for other studies, some weigh high on one outcome and less on another. Although all the identified factors are important, a trade-off depending on the use case can be made. In addition, note that for each implementation outcome, there can be more factors that can contribute to it. However, in this study, one factor was associated

for each implementation outcome, which became obvious during deductive analysis.

Discussion

Principal Findings

This scoping review first identified 52 state-of-the-art USSs that have the potential to be used in older adult care. The deductive thematic analysis of these 52 studies helped to identify the six key factors: usefulness of USSs, types of activities monitored by USSs, type of sensing technology used to monitor activities, sensor setup used for implementing the technology, settings in which studies were tested, and the age of participants in the study. These factors in association with implementation outcomes defined by Proctor et al [37] were used to evaluate the included studies for implementation readiness. The results of this evaluation reflect that most of the included studies are at the lower end of the TRL (2/3), with only a few studies demonstrating a sufficient level of implementation readiness, thus demanding technical and behavioral research in both the pre– and post–technology implementation stages.

Furthermore, this review largely depends on the interpretation of the word *unobtrusiveness*, which is regarded as the property of sensing systems determined by the degree of attention required by the user. As per the conceptual framework developed by Hensel et al [19], the degree of attention or noticeability is categorized in eight broad dimensions which on adherence might lead to the desired *Unobtrusive* sensing system: physical, usability, privacy, functional, human interaction, self-concept, routine, and sustainability dimension [19]. Therefore, in this *Discussion* section, we aim to extend the discussion on the implications of the identified key factors in implementation readiness and unobtrusiveness by taking inspiration from the framework by Hensel et al [19].

Sensor Setup

The sensor setup contributes to the acceptability outcome such that no-contact (NLOS) sensor setup working in the range of approximately 3-9 m or an indirect contact sensor setup can have more chances of acceptance. This is in line with the physical dimension of the conceptual framework by Hensel et al [19], which also advocates that a system is unobtrusive when it can be physically integrated into the user's surroundings without clashing with their esthetic sensibilities. Although the degree of physical dimension may vary or a trade-off with other dimensions can be noticed, it can be accommodated by accounting user needs. For example, DeepBreath is a radar-based device for monitoring the BR by placing it near the participant's bed in their house [81]. A similar BR device called VitalMon uses geophone sensors embedded inside the mattress [54]. Here, VitalMon is comparatively more esthetic (satisfies the physical dimension), whereas DeepBreath can work even if the user is out of the bed (satisfying the functional dimension). Similarly, for fall detection, many systems were designed and developed: SenseFall [65] used multiple sensors assembled in a box mounted on the ceiling to identify falls from other ADLs, WiVit [57] used Wi-Fi channel state information to monitor ADLs (including fall), and another system by Minvielle et al [66] embedded sensors in the floor. From the perspective of the physical dimension, the systems by Minvielle et al [66] and SenseFall are more esthetic as users cannot see anything, whereas WiVit uses at least one transmitter and receiver placed in the surroundings, requiring less structural modifications in the house.

Study Settings and Age of Participants

For successful implementation of USSs in older adult care, the external validity of the system must be evaluated in real life or intended deployment settings with the intended age group of users. In this case, USSs should be tested preferably in the homes of older adults who usually live independently (or alone) and are vulnerable or are in the need of formal or informal care. By doing so, the functional dimension of the conceptual framework, which accounts for reliability and effectiveness, can also be satisfied. In this review, only a few studies extended the study setting from a laboratory to an in-home field study setting with seniors. For example, one study [61], monitored BR in adults (≤55 years) while they were sleeping. Upon checking the external validity of this system, it can be used for monitoring BR in older adults, as changes in BR can indicate various serious medical conditions. Although the focus of this review is limited to supporting the independent living of older adults, in real-life scenarios, various possibilities such as visits by caregivers and relatives can be anticipated. For such scenarios, one study [81] proposed an identity-matching module that used independent component analysis to identify the breathing of multiple persons, one study [58] considered leveraging the concept of Fresnel zones to determine the impact of multiple people in the surroundings, one study [54] used the Degenerate Unmixing Estimation Technique blind source algorithm to separate the heartbeat signals of multiple participants, and one study [52] demonstrated an RF-based sleep sensor to accurately monitor the sleep patterns of multiple users by combining location tracking with temporal analysis of breathing signals. Similarly, advanced data analysis can be used to separate signals from multiple persons present in the house for RF-based monitoring or no-contact sensor setup. Conversely, while using an indirect contact sensor setup, the sensing units can be embedded inside the belongings of the target user.

Activities Monitored

A major step in developing technology for older adult care is to select the right or desired behavior or activity for monitoring. The system will be more acceptable if it measures the behaviors that are in line with the needs of stakeholders and are part of the daily routine of the older adults. From the results of a qualitative study among formal or informal caregivers of persons with dementia, it can be concluded that sensing technology should be used to monitor the risk of falls, personal hygiene, nocturnal restlessness, and eating and drinking patterns [9]. In accordance with the routine dimension of the conceptual framework, if the system is unobtrusive, it will not impact the daily routine while using such monitoring devices. Among the 52 studies, 23 (44%) focused on monitoring fall and sleep behaviors, whereas others monitored activities that can later be tailored to the older adult use case. For example, in one study [15], a human body part tracking or identification system was developed using Wi-Fi. This system can be tailored as an

information provider to informal caregivers to count visitors. Similarly, other included USS studies can also contribute to older adult care after context or requirement assessment.

Sensing Technology Used

The review reports the use of various technologies by leveraging a no-contact sensor setup to make the system unobtrusive. Among all the studies, RF-based technologies (P2P and radar) were used prominently, with more than 50% (31/52) of the studies being in that category. Within RF-based solutions, the split is quite even between radar-based and P2P-based solutions. However, other unobtrusive technologies can also be considered, which require no immediate or purposeful interaction from the participant. These sensors often need to be attached to the environment itself, such as sensor boxes [72] or smart tiles [25], or in very close proximity to the user (as an object), such as mattresses [67] and sheets [73]. Although these technologies appear promising, their development and deployment costs largely affect their implementation. Considering the conceptual framework, the sustainability dimension (affordability) and privacy dimension should be considered to make the technology unobtrusive [19]. In addition, it can be observed that researchers have succeeded in wide-range and high-resolution monitoring of human activities, enabling recognition of very small human gestures, such as tapping and picking [80], and micromovements, such as chest displacement to monitor vital signs. From the perspective of older adult care, a wide-range (or ubiquitous) and high-resolution monitoring solution can help in predicting subtle behavioral changes such as agitated behavior shown by persons with dementia without troubling them.

Usefulness of USSs

To adopt any new technology or system, it is important to show its perceived usefulness for the relevant users. Some studies included in this review stated that their technology was designed for older adult care and thus also explained its usefulness for the same, for example, one study [46] (aimed to detect seizures), explained the adverse effect of delay in seizure detection. However, most of the included studies were on TRL 2/3 with the goal of evaluating the experimental proof of concept (explored the validity and reliability of the sensing technology in a controlled laboratory setting); hence, usefulness was not studied as a research goal. By discussing the possible use of their systems in older adult care, the intention, consideration, and initiation of the use of USSs in older adult care was shown. However, this limited knowledge of these systems has also impacted the evaluation of the effectiveness of these USSs in measuring health outcomes.

Limitations

The review aims to enhance the implementation of the USS, specifically in older adult care. Therefore, this review has a limited scope, focusing on emerging unobtrusive technologies for older adult care from January 2011 to March 2020. Furthermore, as there is no clear consensus on the definition of unobtrusiveness, a dictionary meaning in combination with available literature was used to derive the definition of USS and UST. This variation in the understanding of *unobtrusiveness*

might impact the number of identified records. The process of including studies was performed by 2 researchers (NS and JKB), but analysis of key themes obtained from the final included studies through deductive analysis was performed by 1 researcher (NS) only, which might introduce bias and impact the results and hence conclusion. However, the identified themes and their association with implementation outcomes were thoroughly discussed with other authors. Finally, although no search limitation for the type of language was used, only studies written in English were considered for final inclusion. Therefore, there is a possibility that some relevant work that was not in English is missing from the review.

Challenges

During the review process, a number of challenges concerning implementation were encountered: (1) more than half of the included studies were not primarily designed or tested in older adult care scenarios and are early-stage experiments in laboratory settings; (2) none of the studies, except one [53], included acceptability studies along with experimental studies, and therefore, no clear picture on what users think about the systems or acceptability can be drawn; (3) the studies that targeted their systems for older adult care also require more careful consideration of factors such as testing them in older adult homes, using sensor setup that is more acceptable for older adults, or including acceptability studies; (4) for older adult care, cost is the main factor, but none of the studies provided much information on the cost associated with the system or while deploying it; and (5) the extracted geographical information indicates that most of these studies took place in nations where the required infrastructure for normalizing the use of advanced technology (such as availability of device or technology, etc) is possible. This imposes an additional challenge to normalize the use of USSs in nations where such infrastructure is not common or less idea about their cultural acceptability can be drawn.

Other than these, challenges concerning technology have also been identified. It is worth highlighting the major challenges that RF solutions can encounter in the future. One of these challenges is RF pollution: as more technologies move toward RF sensing, the amount of interference on the frequency bands increases. Two prominent bands (the 2.4 and 5 GHz) are already filled with household appliances, such as laptops and smartphones. Common ways to deal with this are multiple receivers to increase coverage or apply modulation to different transmitters and receivers to differentiate. In addition, although it is likely that RF-based sensing is a more privacy-aware solution than video-based solutions, there is an additional risk for privacy, which is the ability of RF to penetrate through walls. Although this can be used as an advantage, it also increases the privacy risk for others (eg, neighbors or guests), leading to ethical challenges. Although it is assumed that the system will be developed to promote independent living of older adults (ie, they will be staying alone mostly), there is a chance that there might be some visits from their caregivers or relatives. In addition, it is possible that RF-based systems can penetrate neighboring walls and collect data outside the household. However, these concerns can be rectified by using additional

data-transferring security measures and adapting the transmitting power.

In addition, other ethical challenges involve the storage and access of collected data. Data can be stored locally for analysis through artificial intelligence algorithms (eg, neural networks), and only in emergency situations (eg, the patient falls or is feeling very unwell), a flag can be sent to the (informal) caregivers. This would be more challenging for (real-time) distant monitoring, as the actual (aggregated) data would need to be submitted. However, technologies exist that could make this as safe as possible, but there is an ongoing ethical concern about whom the data belong to.

Future Research and Recommendations

The review shows that diverse unobtrusive technologies were explored for HAR, but most of them are still in the early stages of development, making it difficult to report implementation readiness for older adult care. Therefore, it is strongly recommended that future HAR studies intending to implement technology in older adult care should consider including implementation constructs as given by Proctor et al [37], or frameworks such as those by Greenhalgh et al [95] in advance for successful implementation. These frameworks can guide researchers in prioritizing factors (most of them identified in this review) crucial for older adult care or specific scenarios.

Challenges arise when exploring how to provide effective, safe, and meaningful personalized care while using technology. Therefore, a holistic approach must be applied that focuses on the fit between users, context, and technology. As such, it is relevant to start with user requirements, explore and identify how older adults want to live, what social and technical skills they need to be engaged in society, and use supporting technology, which then leads to the identification of values stakeholders want to achieve with products and services. Therefore, we recommend applying a holistic participatory development approach that combines value-based user-centered design, business modeling, and persuasive and positive technology. This roadmap has been applied in dementia care to develop and evaluate sensor technology and social support [96-98].

Along with using a holistic participatory development approach while developing technologies for older adult care, it is recommended to evaluate the technology or system in terms of development and implementation costs. Importantly, the developed system should be checked for external validity in older adult homes. Furthermore, RF-based solutions fit well for older adult care because of high resolution in HAR monitoring and the ease of deployment. Thus, in the future, more such solutions can be developed and implemented specifically for older adult care. In addition, experimental studies should consider adding acceptability studies as part of the research project. In this way, more meaningful insights on the perceived usefulness of the technology can be obtained from users (and perhaps other stakeholders). This results in a better adaptation to the proposed technologies. These identified factors provide the basic steps for initializing implementation from the development phase. Finally, as discussed, the importance of unobtrusiveness in eHealth, more work in defining or developing frameworks for unobtrusiveness, is desired in the future.

Conclusions

This review is the first to explore state-of-the-art USSs suitable for older adult care. This has opened the possibilities of using existing USSs in older adult care. It shows the promising future of using RF-based technology as the USSs for HAR and its feasibility for older adult care. The assessment of identified USSs on implementation readiness is not only reflected in where improvements are required but can also be seen as guidelines for the future development of technologies.

The review also reports the points enhancing the possibility of implementation: (1) 52 unobtrusive systems that do not require direct contact with users were identified; (2) a trend in using USSs (specifically RF technology and radar-based systems) for HAR was observed, as 85% (44/52) of studies were conducted in the last 5 years; (3) among the included studies, 24 studies monitored activities or behaviors that are desired for older adult care; and (4) as for most of the studies, the primary focus was not older adult care, but they concluded or introduced how their systems can contribute to this sector. Overall, the findings of this review are intended to boost the use of USSs to provide better and on-time care to older adults and support caregivers.

All the studies included in the review are unobtrusive, but the definition of unobtrusiveness differs: some systems are very unobtrusive in physical appearance, but less unobtrusive in their implementation. The primary observation can be summed up as follows: *Unobtrusiveness or obtrusiveness is not binary; a system can have varied degrees of unobtrusiveness depending on user perspective and context*. Moreover, unobtrusive is not a quantifiable variable, but rather a qualifiable one, thus requiring a uniform and appropriate framework or instrument for informed assessment. Hence, for better understanding and fair comparisons of unobtrusiveness, a valid and reliable instrument that can be tailored to context and user attitude is required.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search string for databases.

[DOCX File , 13 KB - aging_v4i4e27862_app1.docx]

Multimedia Appendix 2

Overview of the included studies.

[PDF File (Adobe PDF File), 218 KB - aging_v4i4e27862_app2.pdf]

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Abbreviations

ADL: activities of daily living
BR: breathing rate
FMCW: frequency modulated continuous wave
HAR: human activity recognition
HR: heart rate
IR: infrared
LOS: line of sight
NASSS: nonadoption, abandonment, scale-up, spread, sustainability
NLOS: non–line of sight
P2P: point-to-point
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis
RF: radio frequency
TRL: technology readiness level
USS: unobtrusive sensing system
UST: unobtrusive sensing technology

Viewpoint

Falls Detection and Prevention Systems in Home Care for Older Adults: Myth or Reality?

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Abstract

There is an exponential increase in the range of digital products and devices promoting aging in place, in particular, devices aiming at preventing or detecting falls. However, their deployment is still limited and only few studies have been carried out in population-based settings owing to the technological challenges that remain to be overcome and the barriers that are specific to the users themselves, such as the generational digital divide and acceptability factors specific to the older adult population. To date, scarce studies consider these factors. To capitalize technological progress, the future step should be to better consider these factors and to deploy, in a broader and more ecological way, these technologies designed for older adults receiving home care to assess their effectiveness in real life.

KEYWORDS

The Era of Fall Detection and Prevention Devices for Older Adults Living at Home

These recent years have witnessed a considerable evolution of new technologies such as wearable sensors and connected applications aimed at promoting home life for older adults by providing them support in their daily activities. A frequent purpose of these technologies is the detection of falls, as falls are one of the main causes of institutionalization and functional decline [1,2]. Indeed, it has been shown that falls without severe injury multiply the risk of institutionalization by 3 while falls with severe injury multiply this risk by 10 [3]. Different types of sensors and systems for the prevention and detection of falls are currently being developed. This progress has been made possible by the development of remote data collection techniques with wireless communication technologies such as Bluetooth or Zigbee and the integration of these sensors in different contexts in research and at home, as they are smaller, less expensive, and thus more accessible to users [4].

Indeed, many wearable sensors in the Internet of Things' paradigm have been developed with the aim of preventing and detecting falls at home [5-7]. These technologies are mostly based on monitoring and alarm systems, which are used to prevent, detect, and alert caregivers in case of fall [7]. Some provide reactive assistance to the person when a fall occurs, limiting the complications when the older adult is lying on the floor for a long time because he/she is unable to get up without help. This is typically the case of devices designed to activate an alarm when a fall occurs [8]. Other technologies such as *exergames*, *Wii Fit*, or the *Kinect* devices [9,10] act proactively

by proposing preventive actions for older adults, such as home exercise programs of muscular strength and balance training. According to several studies, such home-based exercise programs could significantly reduce the risk of falls [11,12]. As a consequence, these technologies could reduce the costs and consequences of falls and increase user acceptance by providing regular information and notifications on the evolution of the user's performance and health status, thereby encouraging older adults to use them [7].

Most tools aimed at preventing or detecting falls are based on monitoring of an individual's motor activity by using one or several sensors [13-15]. Sensors play an essential role as they are the basic elements of data acquisition systems. These electronic devices make it possible to transform the nature of an observed physical value into an exploitable digital one. There is a huge variety of sensors: those allowing the collection of data on the physiological state of a person (eg, temperature, heart and respiratory rate, blood pressure, electrocardiogram, glycemia), those allowing the measurement of movements (eg, accelerometers, gyroscopes, magnetometers), or those detecting the geolocation of the person (eg, global positioning system). There are also ambient measurement sensors (audio and video) providing information on the environment in which the individual is. For fall detection specifically, the most frequently used measures are acceleration, angular velocity, and magnetic fields to identify body movements [13].

There are 2 types of sensors that allow the detection and prevention of falls: wearable and nonwearable ones. Wearable systems require placing sensors on the person; it may be a watch, a pendant, or a wearable camera usually attached to clothes or around the wrist [16,17]. Nonwearable systems involve sensors positioned in the person's usual environment and use a variety of measurements such as pressure sensors [18] and ambient sensors, including visual (fixed cameras, *Kinect* sensors) [19] and acoustic (microphones) [20,21] sensors. Even though they may be perceived as more constraining for the user, wearable sensors are more effective than nonwearable ones in detecting falls because of the following reasons: first, because they can detect changes in acceleration, planes of motion, or impact with high accuracy [22]; and second, because they are not limited to a specific monitoring area in the individual's environment [23]. To date, the most technologically and ergonomic advanced technologies are those combining several types of sensors. The data collected are multimodal (physiological, actimetric, mechanical) and thus allow more thorough analysis for both prevention and detection of falls [9,10,23-32].

Different types of connections are possible, such as wearable sensors connected to an app via a smartphone. The "SmartStep" system, for instance, uses sensors integrated into the shoe sole, which record the users' motion. "SmartStep" is a connected electronic device, which includes a 3D accelerometer, a 3D gyroscope, pressure sensors, and Bluetooth connectivity. The system is wirelessly connected to an Android phone app, allowing both recording and visualization of data. This device has shown excellent accuracy in recognizing several daily living actions such as walking and running and has shown higher efficiency than wrist-worn devices [24,25]. Similarly, a fall detector worn in a waist belt, based on an Attitude and Heading

Reference system and a barometric sensor, has been developed. This system has shown maximum sensitivity (100%) for fall detection in several studies [23,27]. Another fall detection system has been developed in an indoor environment, consisting of a belt with an accelerometer connected to a data concentrator with a wireless connection based on the Ensemble-Random Forest machine learning algorithm. This device has shown a rate of success of more than 94% for accuracy, sensitivity, and specificity in the detection of 3 types of falls (forward, backward, and sideways fall) and several actions of daily life such as walking, climbing stairs, and sitting [29]. In this line of devices integrating data from different sensors worn directly on the individual, the Bio Immersive Risk Detection System is currently being developed. It is a particularly innovative system as, in addition to the ambient, physiological, and motor sensors, the system includes a wearable camera with real-time transfer via an Android app and automatic analysis of the images to detect several risk situations, including falls and the risk of falling [30,31].

Other detection systems combine both wearable and nonwearable sensors based on the Internet of Things. For instance, there is a smart and connected home health monitoring system [26] comprising several sensors placed on household objects and sensors worn directly on the individual (belt, key ring, or pendant) with an alarm button, an interface, and software for data collection. Sensors can be attached to strategic household objects to provide information on the user's activity or health status; for example, the pillbox (indicating adequate/inadequate medication intake) and the refrigerator door (indicating food consumption). The sensor worn by the user is used to record different movements such as walking and, especially, falling. The data processing is based on deep learning methods and hidden Markov models. The alarm button can be activated at any time by the user to alert an emergency response team. Finally, the physiological data from the different sensors are gathered on the same software platform. This system showed 99% sensitivity and 98% specificity for fall detection. Another study reported a prototype monitoring system for fall detection called "Tagcare" based on Doppler frequency recorded from a sensor worn on the person and sensors placed in the environment. The "Tagcare" system has shown high accuracy (98%) in detecting sudden movements and falls [32].

Regarding devices specifically designed for fall prevention, most are based on ambient and contextual sensors, connected to the Internet of Things, and rely on the analysis of the user's gait and balance measures collected through different tests and physical exercises [9,10]. In a pilot study, Williams et al (2010) proposed a game console (Wii) consisting of a balance tray (like a bathroom weight scale) in which pressure sensors are integrated to monitor changes in the person's balance, weight, and gravity while performing a recreational activity [10]. Another study reports a *Kinect* device, allowing the detection of the posture of a person with a combined system comprising a color camera coupled with an infrared emitter and its detector [28]. Although still in progress, this type of device highlights the relevance of using gait and specifically, cadence variability, while walking as predictors of falls and functional decline [28].

As may be seen, a large variety of technological solutions aiming at supporting older adults' home life is now available and the recent results regarding fall prevention are particularly promising. Nevertheless, important challenges and barriers to a wider adoption of these devices remain [5].

Technological Challenges

Falls refer to "the act of falling to the ground independently of one's will. It is associated with sensory, neuromuscular, and/or osteoarticular deficiencies" [33]. Although falls in older adults are widely studied in the scientific literature, from a technical point of view, the act of falling is complex to analyze and model [34]. There are 3 types of falls: the "soft" fall, when the person holds on to a piece of furniture; the "heavy" fall, corresponding to a rapid loss of verticality associated with an impact; and the "syncopal" fall, when the person slips after losing consciousness. In addition, a distinction should be made between an effective accidental fall situation and a risk of fall. The accidental fall situation has been widely studied and its occurrence can be determined with an accuracy of 200 to 600 ms before the onset of the fall whereas the risk of falling depends on individual-specific data (physiological or environmental) and requires more sophisticated analyses.

An additional difficulty in the study of falls is that occurrence depends on the clinical context. Although falls are far less frequent in healthy individuals than in a population of frail older adults with pathological conditions, it is more difficult to detect falls in these populations. Indeed, a study from the Cambridge City over-75s Cohort on 110 older participants (over 90 years of age) considered at risk of falls equipped with an emergency call system has shown that 80% of them forgot to press the alarm button after a fall [35]. Therefore, with aging, monitoring technology solutions based on a "passive" interaction, that is, which do not require any intervention of the user, are more adapted for falls and risk of falls detection [6].

The detection systems approach has some limitations. Since falls generally follow a specific pattern (prefall, fall, and postfall) and are characterized by significant variations in movement, most approaches consider this sequence by using temporal models and by calculating the person's movement. Many detection systems have been based on a thresholding technique, which uses a fixed threshold to detect movement variations (via wearable sensors) to distinguish falls from nonfall situations [13,22]. One of the limitations of this method is that a fixed threshold value cannot be representative of the different types of falls. Moreover, in most cases, the threshold is determined by the lowest peaks of simulated falls assessed in healthy individuals. Thus, the thresholding is quite empirical, generating numerous false positives, particularly in ecological contexts. A solution has been to turn to machine learning methods applied to measurements collected from various sensors (motion and ambient) and thus using multisensor and multimodal fusions. Using data from multiple sources ensures greater device reliability, increased robustness toward environmental interference, and improved measurement accuracy.

In addition to the difficulties inherent to fall analysis, other difficulties are related to the sensors and the Internet of Things. The first concerns the extraction of high quality and reliable data depending on both the sensors used and their sensitivities. For example, a nonoptimal placement of the sensors on the individual or on a household object would directly alter the quality of the recording or lead to errors during the reception of the signal. Connected objects are also subject to artifacts and may be interfered by the individual's movements when they are worn on the body [36]. The second challenge concerns the collection and processing of remote data. Indeed, quality internet bandwidth cannot be ensured continuously, and the greater or lesser speed of data transmission can lead to misinterpretations and data loss [5]. Therefore, it is necessary to use backup systems and more reliable networks such as *Sigfox* to retrieve data stored in a device (eg, a smartphone) and transfer it to another device [37]. However, some information can be transmitted because there are specific conditions of security and protection of personal data. Connected devices are also limited by storage capacities and battery issues of the objects used [38,39]. Further, most technologies aiming at promoting home support are based on artificial intelligence techniques such as deep learning to proactively detect events. Deep machine learning requires a very big data volume to ensure model accuracy. Collecting such an amount of data requires a lot of time and is very costly. Finally, another potential limitation is that the data extracted from the sensors cannot be directly used by the older adult, a family caregiver, or by the clinician. Indeed, in most cases, artificial intelligence requires considerable analysis, that is, a kind of "preprocessing" so that the raw data collected by the sensors (which are data sources that did not exist before) can be transformed into meaningful, reliable, and exploitable information for the users [5]. Taken together, these limitations explain the scarce deployment of such devices in the general population or in clinical routine. Advances in digital science progressively allow finding alternatives or solutions addressing each of the technical issues previously mentioned [5]. Yet, if such technical improvements are undeniably necessary, they may not be sufficient. More research in the field of new technologies should be dedicated to social and human factors since real needs, representations, and knowledge and skills of the older adult population actually play a critical role in the effective use of the device.

Barriers to Adopting New Technologies Among Older Adults: Between the Digital Divide and Levers of Acceptability

Despite technological advances, there are many barriers that make connected objects poorly operational for the majority of the older adult population. One of these obstacles is related to the intergenerational digital divide, which refers to an inequality in the use of and access to technology between generations, highlighting the exclusion of certain people or social groups because of their physical, social, psychological, or economic characteristics, which make them unable to access the digital world and the resources that it makes available [40]. In France, 1 out of 2 people older than 75 years does not have an internet

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connection at home compared to only 2% of the population in the 15-29 years age group [41]. This technological divide between the different generations may increase in the next decades owing to the exponential advance of a digitally oriented world and the nonmeeting of real needs, skills, and attitudes of older users with the opportunities provided by the current digital offer. This situation generates often stereotyped conceptions of agism in terms of interfaces, contents, and functionalities, often proving unsuitable to cover the heterogeneity of the needs and capacities of older people [42].

Another potential barrier is the social stigma generated by the exponential offer of innovative technologies (eg, home automation, fall detectors, robotics) called as "gerontechnologies" [43]. Paradoxically, the use of these new technologies to help older adults stay at home can be perceived by the general population as a new form of dependency. Indeed, in our modern societies, old age is often associated with dependence and illness. These age-related stereotypes are manifestations of "agism" with negative consequences on the mental and physical health of older adults, and as a consequence, on their access to new technologies. Biased and often stereotypical views of aging lead designers to produce solutions, which are not very accessible or inclusive for older users and contribute to the perception of older people as incompetent and unable to understand and use new technologies [44]. For example, a shared belief among the general population is that older people are not physically capable of using new technologies. However, the problem is mainly due to size (eg, small text fonts, buttons), contrast, brightness and other physical features. This problem can be solved by designing specific user interfaces for older people. Indeed, various age-related physical or sensory limitations can be counteracted with a suitable design and an optimal combination of hardware and support. Another belief is that older people lack the basic knowledge required for using new technologies. Indeed, the specific language used to describe computer objects and functions (eg, file, browser, link, desktop, download, scrollbar, cursor) is very unfamiliar to older adults. Once again, this problem could be solved by using easy and adapted language to facilitate the understanding of how the device works and how to use it [45]. Several qualitative studies using focus group methodology reveal that older adults have limited knowledge of technologies, which could be offered to them, and experience a negative stigma toward them by the simple fact that they use technological tools in their daily lives [42,46,47]. Thus, the use of technologies for home life may contribute to creating a new stereotype in the older adults who become "technologically assisted persons," who use assistive technologies, nourishing the stigma of aging and dependence [48,49]. In turn, this vision can cause older adults to reject new technologies and thus accentuate the digital divide already prevalent in our societies [40].

Regarding "human factors" more specifically, a systematic review conducted by Hawley-Hague et al [7] reports specific intrinsic and extrinsic acceptability factors for the adoption of fall prevention and detection systems. The first intrinsic factor concerns privacy, more particularly for the systems involving automatic activation of video after a fall. To ensure the acceptability of such technologies using video recording, one

solution is to use image blurring, especially in the most private areas of the home such as the bedroom or the bathroom [50,51]. Another question is whether it is appropriate to ask the older adults to set the thresholds for the activation of the video monitoring system or to turn off the video recording in the case of false alarms. At least, it should be clearly specified to the older adults what situations are likely to activate the video recording [50,52,53]. Autonomy and feeling of control may also be determining factors in the use of fall-specific technologies. To a certain extent, these technologies allow users with the loss of autonomy recovering a feeling of independence for some actions (eg, using stairs, mopping the floor in slippery areas), which are considered to be risky with advancing age and thus, regaining confidence in their functional abilities while being secured by the connected system [52,54,55]. The third factor is the perceived need by the user himself/herself for fall prevention and detection systems. This factor is influenced by the older person's self-perceived physical, cognitive, and emotional condition, and self-esteem [48,50,51,53,54,56,57]. Faced with a society increasingly turned toward the use of new technologies, some older adults feel excluded. They fear being "overtaken," being "out of the game," or "unable" of appropriating and using new technology. This feeling may lead older adults to develop "technophobia," which is an exacerbated fear of using technology and a concern about its effects on society [58,59]. In this respect, the image of one's own aging will be an essential issue [48]. Aging persons with a positive view of themselves will be more enthusiastic about using new technology because they will perceive an opportunity to develop new skills and new experiences in their life. On the contrary, a person who has a negative image of his/her age will tend to feel "incapable" of acquiring the skills to use new technologies and will be reluctant to use it, even if their use is simplified. The life trajectory of the individual can also be a factor influencing the use of technologies and the level of anxiety associated with their use [35,48,58]. This factor refers to the experience the person has developed throughout his/her life, both personally and professionally, which will contribute to the representations of his/her own general skills acquired in this field. For example, a person who has used in his/her former occupation tools considered as "technical" may feel more armed to apprehend new technologies and may see an opportunity to capitalize his/her previous experience. This experiential factor can be favorable or unfavorable to the discovery and use of connected devices. Other factors such as anticipation of difficulties in one's home life, the physical environment, and the type of technology may play a role in the perceived need and requirements of the technology [56]. Finally, it is important to highlight the older adults' entourage, which is often intergenerational and often plays the role of a mediator between the technology and the older adult. In some cases, the entourage not only facilitates but also encourages, valorizes, gives meaning to the use of new technology, and provides a form of positive "social pressure," whereas in some families where digital devices are less present and enhanced, the entourage may rather be an impeding factor [56].

Among the extrinsic factors, usability, feedback, and cost are the most important to consider in the use of fall-specific technologies [7]. Usability and usage factors refer to the

individual's perception of the object utility. This principle applies at any age of life when it is a question of appropriating a new tool of any kind [60]. The notion of utility is generally linked to a value judgment since there is no "universal" or "intrinsic" utility to an object. Similarly, the appreciation of the usefulness (or uselessness) of the object taps into individual representations, which depend on the relationship that the person has with his/her physical and social environment [61]. In the older adult population, the notion of usefulness can be linked to a specific need, for example, fighting against social isolation [62], but it is also often associated with the notion of immediacy. Indeed, the utility representation of an object depends on its capacity to address a specific and immediate need. Unfortunately, to date, very few studies consider the usefulness of technologies appreciated from the point of view of the user, in particular, when it comes to older adult users [63]. Once the tool is acquired, abandonment and poor adherence remain one of the major pitfalls [64,65]. Motivational and commitment factors depend on the ease of use of the technology, which underlines the importance of giving feedback to the user [5,61,65-67]. If the object is perceived as useful and easy to use, the person will be motivated to repeat the experience. An experience of "success" will enhance the person's image as well as the acquired skills [66]. The connected object will not be perceived as a simple data collection system but rather as a motivational and self-engagement system [5]. Lastly, from the perspective of the older adult user, cost is an important consideration. Therefore, to guarantee a wide and egalitarian application for the whole older adult population, cost issues are very important to consider, as there is an increasing impoverishment in adults aged 65 years and older [51].

Conclusion

This opinion paper allows drawing perspectives regarding the use of new technologies for the prevention and detection of falls

among older adults and in particular, it underlines that this issue encompasses a complexity, which goes far beyond the technological challenges. Even though there is a growing interest in optimizing the accessibility of older adults to new technologies, scarce research takes into account the diversity of factors participating directly or indirectly in the digital divide and the factors of acceptability specific to the older adult population, which are decisive in the adoption of these tools. To extend this reflection, further work should consist of conducting systematic and scoping reviews addressing more specific questions by focusing, for instance, on clinical trials assessing the impact of fall detection tools and systems in frail older adults or by focusing on ergonomic studies having considered acceptability factors. To promote active and independent aging at home, it is important to encourage the use of certain assistive and preventive technologies, conveying positive messages about their benefits and ensuring that these technologies are easy-to-use, reliable, effective, and adapted to the older adults' needs to motivate their adoption [7]. Both technological and human barriers appeal for more multidisciplinary and collaborative work between the different actors and stakeholders, that is, users, family caregivers, clinicians, and researchers from digital science, clinical sciences, and humanities who may be the key to accelerating this research.

Finally, although efforts are being made to improve the feasibility and acceptability of digital devices outside of a laboratory setting, few studies have assessed their efficacy in the "real life" of older adults selected from the general population. After the first step of development of a wide range of devices relatively accessible in terms of use and cost, evaluating such devices in large samples of older adults in ecological contexts is the second necessary step to take if we want these tools to be not just technological prototypes but operational allies really effective in promoting active aging and improving the quality of life of older adults experiencing frailty or loss of autonomy.

Conflicts of Interest

None declared.

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